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# The role of multilevel policy initiatives in promoting the earlier diagnosis of cancer – what can we learn from the Detect Cancer Early Programme in Scotland?

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# Abstract

**Background:** Early cancer detection and early diagnosis have a key role in multilevel policy initiatives aiming to improve cancer outcomes. In Scotland, the Detect Cancer Early (DCE) Programme was launched in 2012 with the aim to increase the proportion of lung, breast and bowel cancers diagnosed at Stage I by 25%. Initiatives such as DCE are complex, with many interacting components, and influenced by the context. It is important to investigate such initiatives to ensure accountability, to learn from their experience, and inform other strategies. This PhD aimed to investigate the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer, using the DCE Programme as a case study. Objectives were: 1) to understand the international landscape of multilevel policy initiatives promoting earlier cancer diagnosis; 2) to evaluate DCE's first three years (2012-2015); 3) to compare DCE with other initiatives; and 4) to provide recommendations for policy.

**Methods:** Three studies were carried out: 1) a systematic review (Study 1) synthesising characteristics of multilevel policy initiatives promoting the earlier diagnosis of cancer, their target populations, outcomes and stakeholder views; 2) development and refinement of a mixed-methods, theory-based evaluation (Study 2), carried out through documentary analysis and stakeholder interviews, guided by the Medical Research Council Framework for Process Evaluation of Complex Interventions, complexity theory/systems thinking, and theory-based evaluation in order to elicit programme theory, implementation assumptions and mechanisms of impact; 3) an evaluation of the DCE programme (Study 3); its outcomes (through secondary analyses of data) and processes (whether assumptions and mechanisms were confirmed by stakeholders, barriers and facilitators, and unanticipated outcomes) through stakeholder interviews and an online questionnaire.

**Results:** Study 1: eighteen initiatives from 10 countries were included and grouped as strategies to improve public cancer awareness and/or knowledge, professional education, referral pathways based on cancer symptoms or combinations of these strategies. Most of them targeted patients suspected of having cancer based on high-risk symptom criteria. Very few of them reported on high-level outcomes such as survival (inconclusive results), mortality (one study; higher mortality associated with low use of urgent referral pathways) and tumour staging (some positive results). Other outcomes included positive changes in knowledge/awareness (but limited impact on

behaviour) and reduced diagnostic intervals. Views on initiatives were often positive. Study 2: 160 documents were analysed and a logic model was developed; nine stakeholders were interviewed – this resulted in a refined logic model, development of a textual programme theory and outcomes chains, and elicited assumptions and mechanisms to be examined in the evaluation. Study 3: a) outcome evaluation: DCE objectives were often aspirational, with limited outcome measures and data availability – DCE's key aim was not met, although there were improvements in tumour staging; there was increase in awareness of cancer symptoms and signs, in consultations due to breast symptoms and in requests for bowel screening kits, but barriers to help-seeking persisted; b) process evaluation: 25 stakeholders were interviewed and 53 completed the questionnaire. There was support for an early detection initiative, and most agreed that DCE was part of their role. Increasing diagnostic resources was challenging when there was no staff available to recruit. Communication challenges influenced engagement and sense of ownership. Demand drove action but resulted in frustration, especially when strategies attracted the worried well seeking reassurance. Targets negatively influenced engagement when they were perceived to be unachievable and to have limited clinical relevance. Several barriers and facilitators were described, in addition to unanticipated outcomes. By being a government initiative, DCE brought early cancer detection to the centre of attention, but also generated conflict due to short timescales (not conducive to long-term changes).

**Discussion:** Multilevel policy initiatives give prominence to earlier diagnosis of cancer. There are mixed findings on their benefits, and the ability to measure impact is affected by variation in outcome measures, data availability, and the short-term aspect of government initiatives. In Scotland, the aspirational nature of objectives and limited definition of outcome measures hindered outcome assessment, while the process evaluation highlighted support for DCE, provided that communication is efficient, efforts are acknowledged, structural barriers are recognised and stakeholders are able to see that they can make a difference. Recommendations for policy refer to data quality, relevance and availability; setting measurable objectives; targeting populations at risk; communication and dissemination; and considering contextual influencers. Results show that much can be learned from available initiatives promoting the earlier diagnosis of cancer.

# Lay Summary

Cancer affects us all in different ways. In Scotland, it is estimated that one in two people will have cancer sometime in their lives. However, more people are now surviving cancer than in the past. This is mostly because of better treatment and because cancers are being found earlier. Cancer found earlier is more likely to be successfully treated. In different countries, governments have developed programmes to promote earlier cancer diagnosis. It is important that these programmes are well understood and evaluated, so we know what works and who is benefitting from them.

This project aimed to understand these government initiatives worldwide, evaluate a specific programme in Scotland (the Detect Cancer Early Programme or DCE), compare these initiatives, and prepare recommendations for future programmes. This was done by identifying and summarising the findings of programmes in the UK and elsewhere and developing and carrying out an evaluation of the DCE Programme.

I found eighteen government programmes in ten countries, all of which aimed to find cancer early. Commonly used approaches were to 1) increase public knowledge/awareness of cancer, of cancer screening, cancer symptoms and signs; 2) educate health care professionals; and/or 3) create faster care routes so patients with certain symptoms do not need to wait too long for a diagnosis. It was difficult to summarise the impact of these eighteen programmes as they were describing different types of results. Positive results included increase in public awareness of cancer symptoms and signs (although it was harder to see change in attitudes), and patients waiting less to receive a cancer diagnosis after being in contact with a health care professional.

Before I evaluated DCE, I had to spend some time learning more about it. I read and analysed 160 government documents and interviewed nine people who were deeply involved in the programme. Then, I created a description of the programme in text and figures, often called “programme theory”: it includes assumptions about how the programme is expected to work and descriptions of how programme activities will end up with an early cancer diagnosis (these descriptions are called “mechanisms”). The DCE evaluation then checked if the programme’s official objectives were met (checking published and unpublished reports describing impact), if the programme

activities were carried out as planned, and if the assumptions and mechanisms identified previously were confirmed (through interviews and an online questionnaire).

I found that most of DCE objectives were aspirational and hard to measure. The programme's main aim was to have more cancers diagnosed in earlier stages: this was only partially met. There was increase in awareness of cancer symptoms and signs, in consultations with GPs because of breast symptoms, and in requests for bowel screening test kits. From the interviews and online survey, I learned that most professionals were in favour of having an early diagnosis programme, and believed it was part of their jobs to be involved. However, the programme increased the amount of work they had to do, and often it was hard to cope because NHS resources were limited. The increase in workload caused frustration when professionals could not see that they were making a difference/finding cancer early. Professionals said that sometimes communication between them and DCE could have been better, and that they not always had time to prepare for programme activities. DCE created some targets that were not approved by some professionals as it was not possible to achieve them. Although the programme helped to bring early cancer detection to the centre of attention, professionals believed that the government was expecting changes to happen too quickly.

Overall, my studies found that government initiatives have an important role in promoting early cancer diagnosis, but it is hard to calculate exactly how much difference they can make. Using my findings and discussing them with other professionals, I developed recommendations for the government about collecting better data, using objectives that can be measured, focusing on groups that are more likely to develop cancer, improving communication with professionals, and understanding external issues that may affect the programme's ability to make a difference (for example, having enough NHS staff or equipment). The results from this project show that a lot can be learned from early diagnosis initiatives. I hope that my recommendations are useful not only for the Scottish Government, but also for other governments and policy makers working on similar programmes.

# Declaration

I declare that this thesis has been composed solely by myself and that the work has not been submitted, in whole or in part, for any other degree or professional qualification.

Natalia Monteiro Calanzani

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# Acknowledgements

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# Contents

# List of Figures

# List of Tables

# List of Boxes

# Abbreviations

| | |
|---|---|
| 2WW | 2-week wait |
| A&E | Accident and Emergency |
| ACE | Accelerate, Coordinate, Evaluate |
| B2B | Business-to-business |
| BA | Before-and-after |
| BCOC | Be Clear on Cancer |
| BCW | Behaviour Change Wheel |
| CAM | Cancer Awareness Measure |
| CDC | Centers for Disease Control and Prevention |
| CDS | Clinical Decision Support |
| CI | Confidence Interval |
| CMO | Context, Mechanisms, and Outcomes |
| COM-B | Capability, Opportunity and Motivation - Behaviour |
| CPPs | Cancer Patient Pathways |
| CRC | Colorectal Cancer |
| CRUK | Cancer Research UK |
| CT | Computed Tomography |
| CWTs | Cancer Waiting Times |
| DCE | Detect Cancer Early |
| DAPs | Diagnostic Assessment Pathways |
| EBUS | Endobronchial Ultrasound |
| FIT | Faecal Immunochemical Test |
| FOBt | Faecal Occult Blood Test |
| GPs | General practitioners |
| HEAT | Health, Efficiency, Access and Treatment |
| ICBP | International Cancer Benchmarking Partnership |
| ISD | Information Services Division |
| IT | Information Technology |
| MCN | Managed Clinical Networks |
| MDT | Multidisciplinary Team |
| MMR | Mixed Methods Research |
| MRC | Medical Research Council |
| NAEDI | National Awareness and Early Diagnosis Initiative |
| NCWTG | National Cancer Waiting Times Group |

| | |
|---|---|
| NHS | National Health Service |
| NICE | National Institute of Clinical Excellence |
| NMSC | Non-Melanoma Skin Cancers |
| NOSCAN | North of Scotland Cancer Network |
| NRAC | NHSScotland Resource Allocation Committee |
| NSS-CPP | Cancer patient pathway for non-specific symptoms and signs |
| PPV | Positive Predictive Value |
| qFIT | quantitative Faecal Immunochemical Test |
| QOF | Quality and Outcomes Framework |
| QPIs | Quality Performance Indicators |
| RACs | Rapid Access Clinics |
| SCAN | South East of Scotland Cancer Network |
| SCPs | Standardised Care Pathways |
| SCT | Scottish Cancer Taskforce |
| sGMS | Scottish General Medical Services |
| SIMD | Scottish Index of Multiple Deprivation |
| SPIRE | Scottish Primary Care Information Resource |
| TDF | Theoretical Domains Framework |
| TNM | Tumour, Node, Metastasis |
| UK | United Kingdom |
| UoE | University of Edinburgh |
| UREG | Usher Research Ethics Group |
| US | United States |
| WHO | World Health Organization |
| WOSCAN | West of Scotland Cancer Network |

# Chapter 1 Introduction

## 1.1 Overview

This chapter describes the background to this PhD project, its overall aims and objectives. Furthermore, it outlines the thesis structure and the contents of each thesis chapter.

## 1.2 Background to the study

This PhD project was developed in late 2014 when I was working as a Research Fellow at the University of Edinburgh (UoE). Dr Christine Campbell and Prof David Weller were my supervisors in a study aiming to improve bowel screening uptake in Scotland (1, 2). I was interested in undertaking a PhD, and they asked me to prepare brief research proposals for discussion. The evaluation of the Detect Cancer Early (DCE) Programme was one of these proposals. With their guidance, I refined the proposal to share with DCE management at the Scottish Government, which approved and funded it in 2015. Although this PhD is broader than the evaluation, it includes components outlined in the funded proposal.

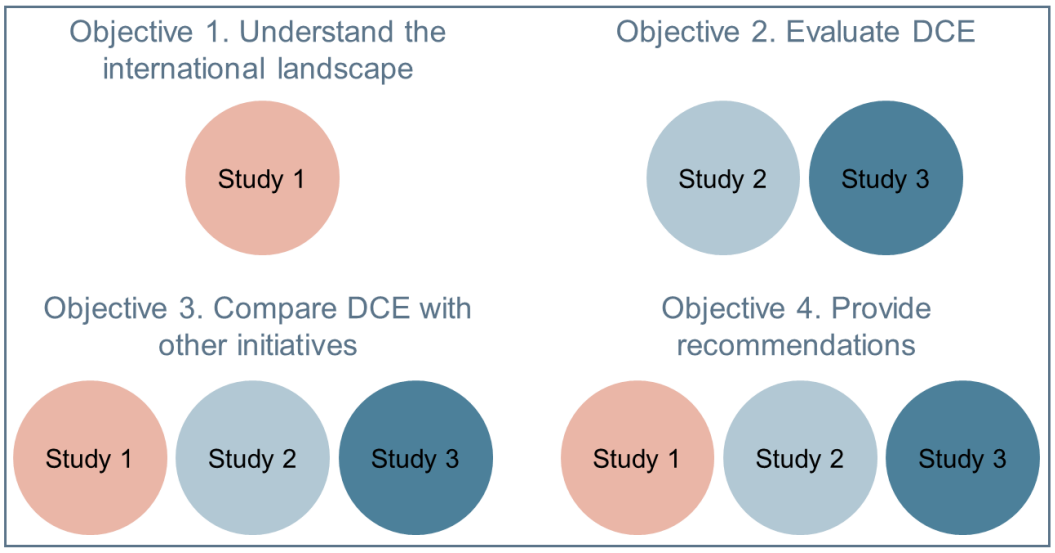
## 1.3 Overall study aims and objectives

This PhD project aimed to investigate the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer, using the DCE Programme in Scotland as a case study. It had four objectives:

1. To understand the international landscape of multilevel policy initiatives promoting earlier cancer diagnosis
2. To evaluate the first three years of the DCE programme (2012-2015 – the initially planned duration), assessing its processes and outcomes
3. To compare DCE with other initiatives promoting earlier cancer diagnosis
4. To provide recommendations to inform policy in this area

Objective 1 was addressed through a systematic review of initiatives promoting the earlier diagnosis of cancer (Study 1). Objective 2 was addressed through a theory-based evaluation of the DCE programme comprising: evaluation development and refinement (Study 2); and process and outcome evaluations (Study 3). All three studies addressed Objectives 3 and 4 (Figure 1.1).

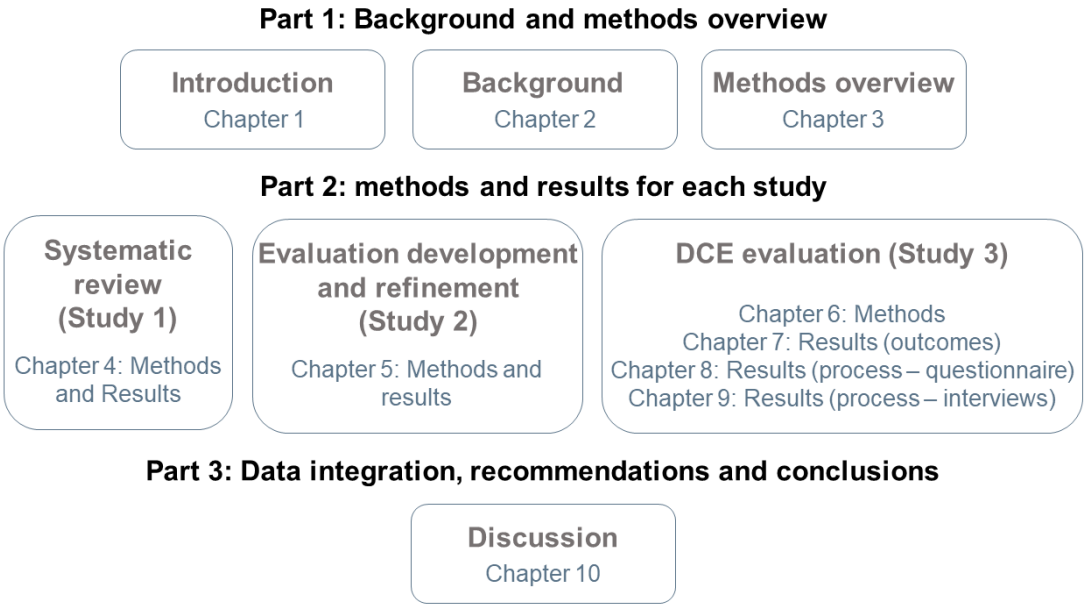
**Figure 1.1** Studies and objectives




## 1.4 How this thesis is structured

This thesis comprised a cyclical process of understanding the literature to inform methods, acquiring data, reassessing and refining methods for other studies, and continuing with data collection. Hence, fieldwork did not have a fully linear strategy. The thesis structure is illustrated in Figure 1.2.

**Figure 1.2.** The thesis structure



Chapter 1 (this Chapter) describes how this study originated, introduces its objectives and overall structure.

Chapter 2 focuses on describing why multilevel policy initiatives promoting early diagnosis of cancer are important; this is done by describing the cancer burden worldwide and in Scotland, and the role of early cancer detection in cancer survival. The DCE programme and the policy context in Scotland are also outlined.

Chapter 3 gives an overview of the methods adopted in this PhD research project (i.e. use of a theory-based evaluation and mixed-methods research). It also provides the rationale for carrying out a systematic review and evaluating the DCE programme, and outlines the relationships between the three studies in this PhD project.

Chapter 4 comprises the methods and the results of the systematic review investigating the landscape of multilevel policy initiatives promoting the earlier diagnosis of cancer (Study 1).

Chapter 5 describes the methods and results of the development and refinement of the DCE evaluation (Study 2) and outlines how Study 2 outputs informed the DCE evaluation.

Chapter 6 describes the methods adopted for the evaluation of DCE outcomes and process (Study 3).

Chapter 7 comprises the results of the outcome evaluation of the DCE programme.

Chapter 8 describes the results of a questionnaire survey carried out as part of the process evaluation, while Chapter 9 focuses on the second component of the process evaluation: semi-structured interviews with stakeholders.

Finally, Chapter 10 integrates data from the three studies, provides recommendations for policy and research, and concludes this thesis.

# Chapter 2 Cancer burden and policies

## 2.1 Overview

In order to understand the need for initiatives promoting the earlier diagnosis of cancer, it is necessary to recognise the burden of cancer, and the role of early detection in cancer survival (including its benefits and limitations). The way the population perceives symptoms and acts upon them also provides opportunities and challenges when aiming for early detection. Finally, we need to acknowledge the role of context in cancer outcomes. This Chapter approaches these issues, then introduces the cancer policy landscape in the United Kingdom (UK) (focusing on Scotland) and the DCE programme. A brief description of the Scottish health system is also provided.

## 2.2 Cancer and early detection

### 2.2.1 Cancer burden and aetiology

Cancer is one of the leading causes of morbidity and mortality worldwide. In 2018, there were over 18 million new cancer cases and over 9.5 million cancer deaths (3). Cancer is the second leading cause of death, with lung, breast and colorectal cancers being the most common cancer sites (4).

Cancer causes are diverse and include several genetic loci (i.e. fixed locations of genes or markers), chronic infections, reproductive and hormonal factors, occupational/environmental factors (such as exposure to ultraviolet radiation), naturally occurring chemical carcinogens and lifestyle factors (such as tobacco consumption, alcohol drinking, diet, obesity, and lack of exercise) (5). It has been estimated that four in ten cancers can be attributed to modifiable risk factors (6, 7), and therefore could be prevented through lifestyle changes.

Cancer will remain an important public health problem in the upcoming decades due to population growth, population ageing (as cancer is more common at an older age, mainly due to accumulation of cancer risk factors), and increased prevalence in lifestyle behaviours that increase cancer risk (4, 5, 8). This is also the case for Scotland (Box 2.1).

**Box 2.1.** Cancer burden in Scotland

It is estimated that more than two out of five people in Scotland will get cancer in their lifetime (9). In 2017, there were 32,234 cancer diagnoses (10) and 16,105 deaths due to cancer (not including non-melanoma skin cancers) – NMSC) (11).

| Summary statistics for all cancers in Scotland | Males | Females | Persons |
|---|---|---|---|
| Number of new cases diagnosed in 2017 | 15,867 | 16,367 | 32,234 |
| Number of deaths recorded in 2017 | 8,327 | 7,778 | 16,105 |

**Source: adapted from ISD Scotland (12)**

Most cancer cases are diagnosed among those aged 60 and older (76% of cases in 2017) (10). If all cancers were combined (malignant neoplasms (ICD-10 C00-C97)), cancer would have been the main cause of death in Scotland in 2018 (13). Lung cancer was the lead cause of cancer death among males and females, followed by breast and prostate (the second leading causes for women and men respectively) and colorectal cancer (14).

Lung cancer rates in Scotland (both incidence and prevalence) are amongst the highest in the world and are higher in Scotland compared to other UK countries. This may be due to higher smoking prevalence (15). Scotland also has the highest age-standardised cancer mortality rates in the UK. Cancer mortality rates in Scotland are 15% higher than the UK average (16, 17).

From the perspective of public health and government policy, it is important to consider different strategies to minimise the increasing cancer burden. The World Health Organization (WHO) recommends the implementation of national cancer control programmes with defined strategies for the "prevention, early detection, diagnosis, treatment and palliation of cancer" (18, 19). In 2015, 87% of all its 177 member states reported having national cancer control policies, strategies or action plans (68% reported that these plans were operational) (20).

### 2.2.2 Improvements in cancer survival

Due to improvements in early detection and treatment, more people are surviving cancer worldwide (21). In 2018, 43.8 million people were estimated to be living with cancer within 5 years of diagnosis (3). Official statistics show that survival has also improved in Scotland. Five-year standardised relative cancer survival has increased when comparing the periods of diagnosis 1987-1991 and 2007-2011 (22). Cancer survival is better for cancers detected through screening and cancers for which treatment has improved over time. Survival is lower for patients with cancers often presented at later stages (i.e. pancreas, lung and stomach) and higher for cancers often presented at earlier stages (e.g. malignant melanoma) (22). Lung cancer has an estimated five-year age standardised relative survival of 9.5% for men and 12.0%

for women. Breast cancer relative survival is 82.8% for women, while colorectal cancer survival is similar for men (59.9%) and women (59.8%) (22).

Nonetheless, the improvements in survival are not evenly distributed worldwide. This is partly due to inequalities in access to diagnostics and treatment within and between countries (23). In Europe, the EUROCARE research programme reported that England and Denmark have poorer survival rates compared to other Western European countries (24-30). Scotland was reported to have the worse age-standardised relative survival and age and case mix-standardised relative survival across all the UK countries for all cancers combined at 5 years after diagnosis (31).

There are recognised challenges regarding cross-national comparisons such as methodological limitations and variations in data collected (32-34), but these do not explain the observed variations in survival outcomes, especially when it comes to the UK. Issues such as longer diagnostic intervals, access to treatment, limited investment in healthcare and suboptimal care are likely to be better explanatory factors (35, 36). EUROCARE results describing poorer 1-year survival outcomes (37), and studies showing higher number of deaths close to diagnosis (38) also help to explain worse survival in England and Denmark.

The International Cancer Benchmarking Partnership (ICBP) was established in 2009 to better understand international variation in cancer survival to inform policymaking (39, 40). Led by the UK Department of Health, it involves collaborations with Australia, Canada, Denmark, Norway, Sweden, and the UK (39). ICBP has compared population-based data and has also reported that Denmark and the UK (England, Northern Ireland and Wales) have poorer survival rates, especially regarding 1-year survival and for patients aged 65 or older (26).

## 2.3 The role of early detection in cancer survival

There are many opportunities to optimise cancer care throughout a cancer trajectory (i.e. the cancer care continuum). According to Taplin and Rodgers, there are seven types of care in the cancer continuum: risk assessment, primary prevention, detection, diagnosis, primary treatment, survivorship and surveillance, and end-of-life-care (41). Among these, (early) detection and diagnosis have a prominent role in policies and initiatives aiming to improve cancer outcomes (42). They are also key components in

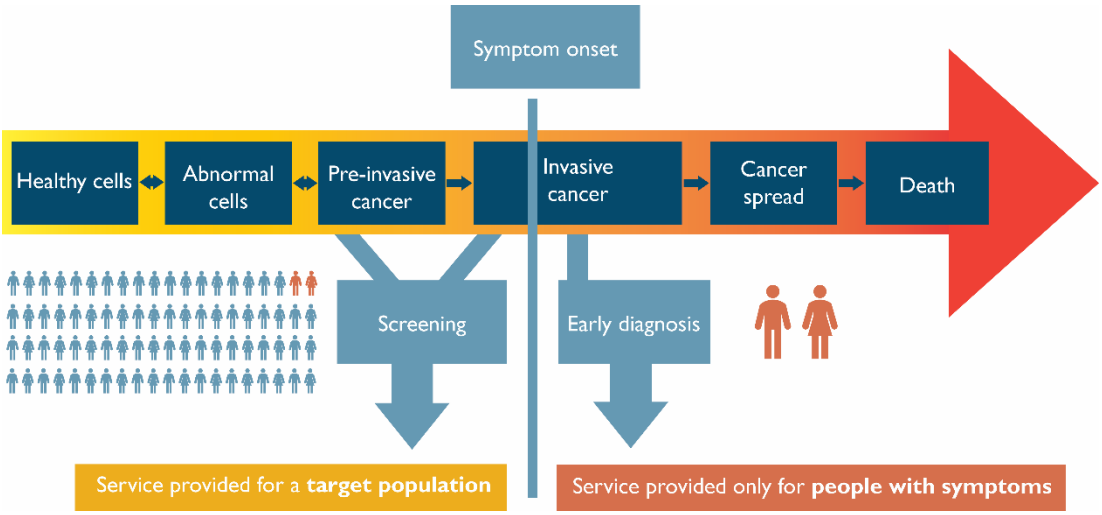
evidence-based models investigating pathways to diagnosis and cancer survival (described later in this Chapter).

The focus on early detection can be explained by the relationship between tumour staging and prognosis (43). There is evidence of the impact of tumour staging on survival for breast (29, 44), lung (30) and colorectal cancers (45). Furthermore, successful treatments, less invasive/aggressive treatments and low treatment costs are more likely when cancers are detected in earlier stages (46).

The WHO defines early detection as diagnosing cancer at an earlier stage (e.g. in a specific organ and not yet invading any surrounding tissue) (19). There are many different classification systems for staging; the TNM system is widely used and refers to the extent of the primary tumour (T), the extent of involvement of lymph nodes (N), and metastasis (M). Numbers are added after each letter to give more details about the cancer. TNM combinations can be grouped into different stages, from Stage I (the least advanced) to Stage IV (the most advanced) (47).

The WHO describes two early detection strategies: 1) systematic screening of asymptomatic individuals that identify precancerous lesions or cancer in its earlier stages; and 2) early diagnosis of symptomatic patients (19) (Figure 2.1). Throughout this thesis, "earlier diagnosis of cancer" and "early detection" are used as synonyms; and both terms can refer to either symptomatic or asymptomatic patients.

**Figure 2.1.** Early detection according to the WHO




***Source: adapted from the World Health Organization 2017 (19)***

Both screening and early diagnosis have limitations; these are discussed below.

### 2.3.1 Cancer screening: benefits and limitations

Screening has been shown to reduce mortality for breast, cervical and colorectal cancers in randomised controlled trials and/or observational studies (46, 48-52). Evidence for prostate cancer is less strong, with some evidence in reduction in disease-specific mortality in a recent systematic review (53) and a less recent trial (54), and no significant differences on other trials (55-57). Screening for lung cancer has been shown to have benefits in trials (58-60), and the European Union has recently developed recommendations for implementation of lung cancer screening, suggesting the use of a risk stratification approach (61).

It is worth noting that screening can cause physical and psychological harm (48, 50) (Box 2.2). Several criteria need to be met before a screening programme is implemented; seminal screening principles developed in the late 1960s (62) have been updated over the years by others (46, 63-65). Implicit in these principles is the need to avoid overdiagnosis and overtreatment.

**Box 2.2.** Screening risks

- **Physical Risks:** Improvements in mortality are considered at a population level. At an individual level, most people being screened will not have cancer. Hence, everyone is exposed to the same risks (such as x-ray exposure or invasive procedures), but only a few will benefit. Furthermore, those who receive a false positive result may undergo unnecessary investigations (48).
- **Risk of Psychological Harm:** These refer to anxiety prior to/after tests and distress after receiving results. False positive results can cause psychological harm. Evidence quantifying psychological costs of screening is limited. It is worth noting that screening can also have psychological benefits such as reducing worry (48).
- **Overdiagnosis:** Not all diagnosed cancers will progress, and it is not always easy to know when this is the case. Invasive treatment of a non-progressive abnormality is described as overtreatment, and it can have a detrimental impact on the patient's health and quality of life (48, 50, 66).

Since cancers can be identified before symptoms are present, screening can be beneficial to early detection. Scotland and other UK countries have organised screening programmes for breast, bowel and cervical cancers, with some variations regarding eligibility criteria. In Scotland, over three out of five cancers (62.5%) diagnosed through bowel screening were diagnosed at the earliest stages (Duke's A and B, the staging system used for colorectal cancer in Scotland) (67). More than half (55.5%) of invasive breast cancers found through screening in 2015/2016 in Scotland

were smaller than 15mm in size and were therefore unlikely to be detected during physical examination (68).

Increased screening participation is required for benefits to be accrued (69). Screening will miss some cancers, and interval cancers (i.e. diagnosed between screening rounds) are possible (70, 71). In England, 6% of cancers were diagnosed through screening in 2012-2013 (72). The first National Cancer Diagnosis Audit in Scotland showed a similar proportion for a sample of the Scottish population in 2014 (73). Hence, early diagnosis of symptomatic patients is very important.

### 2.3.2 Early diagnosis: benefits and limitations

According to the WHO, early diagnosis has three steps: 1) awareness of cancer symptoms and accessing care; 2) clinical evaluation, diagnosis and staging; and 3) access to treatment (19). Hence, early diagnosis is dependent on patient, health system (such as infrastructure and resources) (46) and professional factors.

In the UK, where primary care is the first point of contact for patients, most cancers are diagnosed after a patient presents to primary care and undergoes diagnostic investigations (74). This is also the case for other countries with similar health systems such as Denmark (75). Hence, the role of primary care in early diagnosis has been increasingly recognised (37, 76-79). In Scotland, the most recent data on routes to diagnosis report that less than half of patients diagnosed with cancer (38%) were referred without having primary care-led investigations. Almost two out of three patients (62.9%) who were diagnosed with cancer first presented in the GP surgery with symptoms related to the diagnosis (73).

Cancer symptomatology is a core issue when trying to understand early diagnosis challenges. Cancer is a heterogeneous disease, with diverse symptomatology according to tumour type and location (74). Red flag or alarm symptoms have been identified for some cancers and urgent referral pathways have been implemented in different countries, including Denmark, England and Scotland (80-82). However, alarm symptoms typically have low positive predictive values (PPVs) in primary care; and most people presenting with them will not have cancer (74, 83). Importantly, alarm symptoms may only be present when the disease is advanced. If the “window of opportunity” for a successful treatment occurs before symptomatic presentation, then early diagnosis of patients presenting with symptoms may provide little benefit (84).

Furthermore, not all cancers have alarm symptoms. Cancers may have non-specific or vague symptoms common to other health conditions (77, 85). However, symptoms may still suggest cancer and may need to be investigated further. Patients without alarm symptoms may miss the opportunity to access potentially beneficial rapid diagnostic pathways (77).

General practitioners (GPs) only see a few cancer cases in a year among thousands of consultations (74, 79). More than one consultation may be necessary before proceeding with exams or referring for more complex diagnostic investigations (74). There is also the need to balance the risks of missing cancers against using potentially unnecessary, invasive and harmful examinations, over diagnosing or overtreating patients. Additionally, diagnostic resources may be urgently needed by other patients (and unnecessary use can potentially delay care to those who need it the most) (86).

Recognising these challenges, a variety of diagnostic pathways for patients presenting with symptoms have been pioneered in Denmark and are being tested in England. These include the development of diagnostic centres and GPs having direct access to diagnostics (85, 87, 88). Furthermore, Cancer Decision Support (CDS) tools for professionals have been developed in the UK (89-92). Safety netting is also being adopted to help avoid missing cancer in patients with vague symptoms (93). This refers to a strategy to deal with uncertainty regarding diagnosis; information is shared with patients so they know what to expect, feel empowered, know what to look for and how to seek help (94).

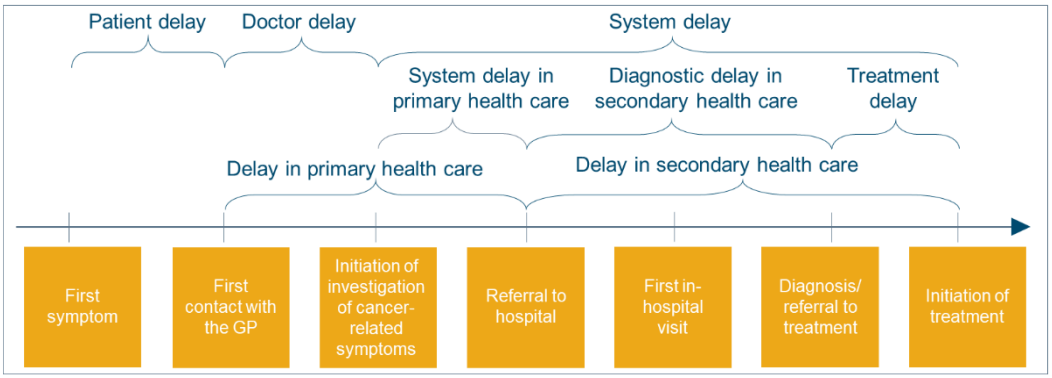
#### 2.3.2.1 The role of longer intervals in the diagnostic pathway

While early detection can improve cancer survival, longer time intervals in presenting to a health care professional, diagnosing and/or treating cancer may result in cancer being detected in its later stages (which is detrimental to cancer survival). Shorter time to diagnosis (and treatment) has been associated with better outcomes for patients with breast, bowel, head and neck, testicular cancers and melanoma, while evidence is insufficient (or equivocal) for several other tumour types (95). More high-quality studies are recommended to better elucidate the role of time to diagnosis in cancer outcomes (95).

Acknowledging the potential impact of longer intervals, Olesen and colleagues developed an evidence-based model approaching “delays” in the diagnostic pathway (80). The model was developed for a context in which the GP is a gatekeeper of

services/referral to specialists and has limited access to diagnostics. The model describes the pathway from first symptom to treatment and three types of delay to diagnosis: patient delay, doctor delay and system delay. Patient delay is influenced by how long it takes for the patient to interpret their symptoms/signs and see the doctor; doctor delay will depend on whether s/he considers the likelihood of a cancer diagnosis, and system delay is dependent on the speed and efficiency of the pathway after investigations commence or the patient is referred, until treatment begins (or a cancer diagnosis is rejected) (80) (Figure 2.2).

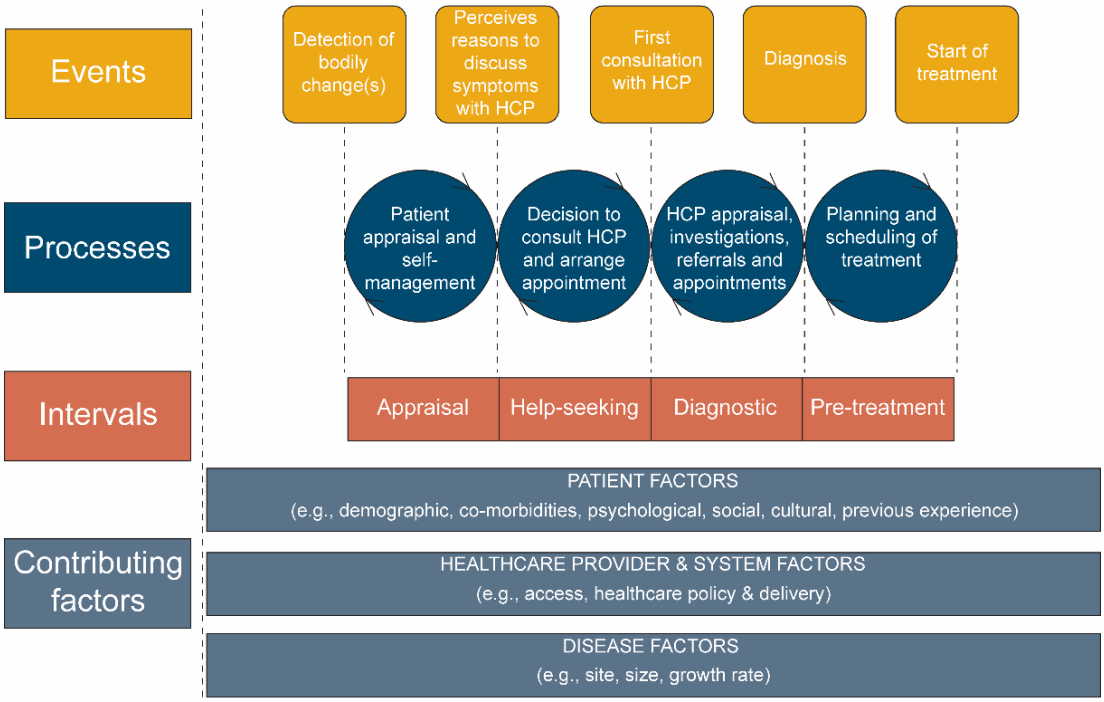
**Figure 2.2**. Model emphasising delays in diagnosis and treatment




***Source: Adapted from Olesen et al 2009 (80)***

Walter and colleagues also developed a model after reviewing the use of the Andersen Model of total patient delay (96) in studies assessing cancer diagnosis (97, 98). Their “model of pathways to treatment” incorporates psychological theories and the role of decision-making processes and symptom appraisal in patient intervals. Walter and colleagues used the term “intervals” instead of “delay” as they believed the latter was value laden. The model describes events, processes, outline intervals and their contributing factors (97) (Figure 2.3).

**Figure 2.3.** Model of pathways to treatment




***Source: adapted from Walter et al 2012 (97)***

Both models are frequently used/referred to in early diagnosis research, and have informed the development of international consensus on ways to improve design and reporting in the field, including the Aarhus Statement (99). Inconsistencies when defining and measuring time points and intervals prior to diagnosis; limited guidance on how to measure these; limited evidence on adopted theoretical frameworks underpinning definitions and measurements; and no transparency nor precision when adopting methods and instruments were some of the issues approached by the Aarhus Statement (99).

## 2.3.3 Factors influencing early detection

Evidence shows that many conditions/contextual factors need to be in place to allow for early cancer detection. These include health system characteristics, and population behaviour and society. Social deprivation also has an important role in cancer outcomes. These factors are described below.

### **2.3.3.1** Health system characteristics

Early detection strategies are dependent on resource availability (such as finance, equipment and specialist staff). Furthermore, they are influenced by access to care and available information about screening programmes, cancer symptoms and signs

(19, 46). Not all countries have sufficient resources to have systematic, organised screening programmes, and community strategies may be implemented instead (18). Furthermore, provision of information is needed so people know what to look for and can make an informed choice about what they wish to do (100, 101), considering both potential benefits and harms.

Although health system characteristics can influence early diagnosis, evidence is limited on which factors are most important (102). Brown and colleagues investigated the role of a range of healthcare system factors in cancer outcomes, including financing, the GP gatekeeping role, and direct access to secondary care. They found that it was not possible to show a causal relationship between system factors and cancer outcomes, although issues such as centralisation of services, free movement of patients between different providers and access to secondary care were found to influence patient and professional behaviour (and potentially early detection) (102). Other studies have found mixed evidence on the role of gatekeeping referrals to specialists in longer diagnostic intervals (103-105).

#### **2.3.3.2** Help-seeking behaviour and society

The fields of Health Psychology, Sociology and Medical Anthropology are important contributors to early diagnosis research, and provide useful evidence on how symptoms are perceived, and how/why patients seek help.

*Health Psychology*

Health Psychology explores and explains issues regarding bodily sensations, symptom appraisal and health seeking behaviour. A range of theories, models and frameworks have been developed over time. These include the Health Belief Model (developed to explain why people did not take part in screening, then expanded to cover how people respond to symptoms and diagnoses), the Theory of Planned Behaviour (developed to explain the relationships between attitudes, intentions and resulting behaviours), the Transtheoretical Model and Stages of Change (integrated theories of psychotherapy and behaviour change associated with preventive behaviours), Social Cognitive Theory (postulates that the individual and the environment influence and interact with each other and result in both individual and societal changes), and the Health Behaviour Framework (a synthesis of several of the models above, while also considering contextual issues) (106).

Furthermore, psychological constructs such as fatalism and cancer fear are widely used in early diagnosis research. Fatalism refers not only to the perception that events are beyond individual control, but also to the assumption that the outcome will be negative (e.g. if it is cancer, it will be fatal). Fatalism can be a barrier to receiving information about cancer, to early detection and to treatment (107, 108). Cancer fear, on the other hand, can be a motivator as screening/test results can provide reassurance (48), but can also hinder help-seeking behaviour due to fears about a positive result, or about having to undergo unpleasant tests (109).

*Sociology and Medical Anthropology*

Sociology and Medical Anthropology explore how experience, cultural and social contexts influence and shape the way people interpret bodily sensations, configurate them into symptoms and act upon them. Sensations are described as embodied experiences that are transformed into symptoms. While sensations are felt, symptoms are socially and historically constructed and require cognitive interpretation (110). These acts of recognising socially, cultural and cognitively constructed cancer symptoms (and seeking help) are described as being much more complex than what is believed by biomedical approaches (111).

Furthermore, facing illness may be perceived as a threat to one's sense of self, social identity and relationships, a barrier to fulfilling obligations, potential risk of marginalisation, and social exclusion. Power relations between the doctor and the patient and the way the health system is structured may also influence the patient's decision to seek help (111).

For people dealing with multimorbidities and a range of challenging social circumstances, it can be more difficult to be sensitive to sensations and symptoms that may indicate cancer among so many "noises" that require their attention on a daily basis (112). Moreover, studies report on the challenges of deciding to seek help when trying to be a "good citizen" as this means not only taking care of one's health, but also not wasting public resources nor the doctor's time (113).

Similar to issues raised by Walter and colleagues (97) the term "delay" is not seen favourably as it is seen as normative and not necessarily corresponding to how patients understand their own behaviour (111).

#### **2.3.3.3** Social and health inequalities

Health inequalities are a result of a “toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics” (114, 115). Inequalities in health are not the same as variations in health as the former are systematic, socially produced (which means that they are not natural nor biological and can be modified) and, importantly, unfair (116).

The reduction of health inequalities can have social and economic benefits such as reduction of years of life lost, of productivity losses, of years of illness and disability, and of costs for treating poor health (117). The WHO’s Commission on Social Determinants of Health argues that different actors in a system need to be involved (i.e. governments, communities, businesses and international organisations) in order to reduce inequalities (114, 115).

Social deprivation has a strong and persistent impact on health inequalities in Scotland, although age, ethnicity and gender also play an important role (15). Deprivation refers to a combination of domains (income, employment, health, education, housing, access to services and crime) that cover multiple dimensions. An Index (SIMD or Scottish Index of Multiple Deprivation) identifies geographical areas of poverty and inequality (118). Deprivation levels vary widely across Scotland, even within small local areas. The West of Scotland is more deprived than other regions, especially in Glasgow and its surrounding areas (15).

In Scotland, populations living in less deprived areas have both better life expectancy and heathy life expectancy than those living in more deprived areas (15). Furthermore, those living in the most deprived areas are more likely to have poorer access to primary care and poorer health outcomes and have higher levels of multi-morbidity (119).

Available evidence also describes the role of deprivation on cancer outcomes (120, 121). In Scotland, both cancer incidence and overall cancer death rates are higher amongst the most deprived (although effects vary by cancer type) (15, 122). Those living in more deprived areas are a third more likely to have a cancer diagnosed (compared to those in less deprived areas), with some variations across tumour types (10). The three main cancer types (breast, bowel and lung combined) are most often diagnosed at advanced stages (30.3% of cases at Stage IV) among the most

deprived, while the highest proportion of these cancers (29.5%) are diagnosed at Stage II, closely followed by Stage I (28.1%) among the least deprived (123).

The increased prevalence of risk factors in deprived populations may help to explain this discrepancy. Smoking rates, obesity rates (especially among women) and type 2 diabetes rates are much higher in the most deprived areas. Furthermore, uptake for breast and bowel screening is lower amongst the most deprived (15, 124).

### 2.3.4 Other factors influencing cancer survival

Detecting cancer in its earlier stages does not guarantee improved survival. Cancer survival is influenced by other factors such as tumour biology, tumour location, and patient characteristics. Some tumours are more aggressive than others, and aggressive tumours are associated with poorer prognosis. Very short diagnostic intervals can be associated with poorer outcomes if a tumour develops very aggressively (125). This has been described as the “waiting time paradox”; i.e. patients with quicker presentation, diagnosis and treatment having worse outcomes than patients with longer diagnostic intervals because of aggressive tumours (95).

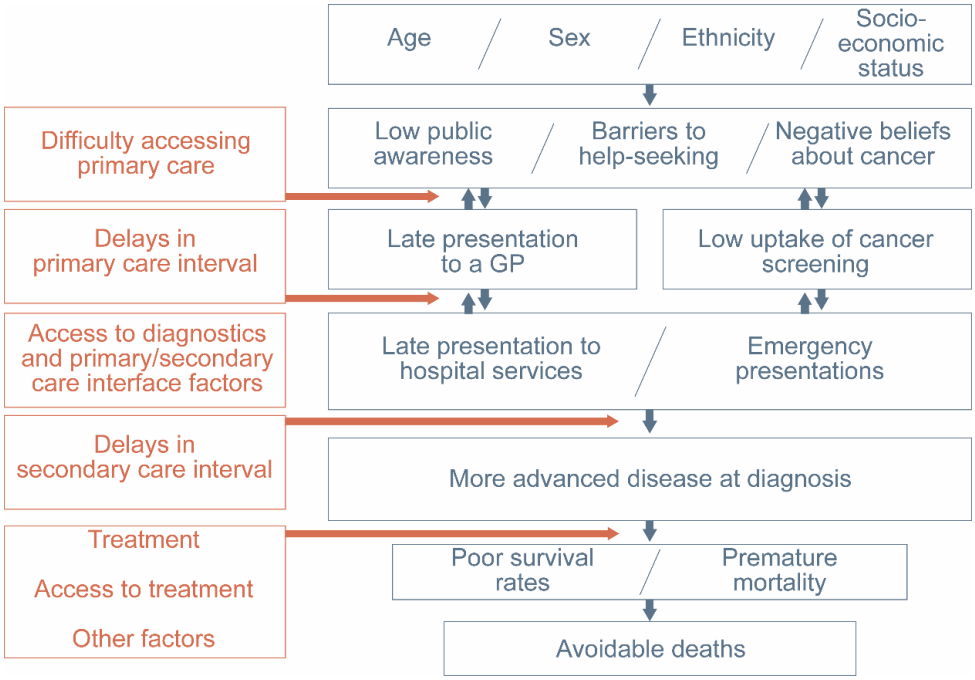
Tumour location can also influence survival; for example, studies have shown that patients with right-sided metastatic colorectal tumours have worse prognosis (126) and pancreatic cancers of the body and tail have poorer survival compared to head lesions (127). Tumour location also influences survival outcomes for primary brain tumours such as glioma (128).

Patient characteristics also influence cancer mortality and survival; these include co-morbidities (which are associated with poorer prognosis), general health, health related behaviours (such as smoking tobacco, drinking alcohol and sedentarism), and age (as older people often have poorer survival) (120). Poorer general health and limited social support are both associated with poorer cancer survival (129). As described above, socioeconomic deprivation (which is an area-level as opposed to an individual-level indicator) is another important factor.

Cognisant of the multiple factors influencing cancer survival, a multilevel early detection initiative in England (the National Awareness and Early Diagnosis Initiative or NAEDI) developed and updated a comprehensive evidence-based hypothesis of factors influencing cancer survival and premature mortality (130). Patient characteristics such as sex, age and socio-economic status are described as having

an impact on awareness of cancer symptoms and signs, help-seeking behaviours and cancer beliefs. Difficulties in accessing primary care may interact with these factors and influence late presentation in primary care or poor screening uptake. Challenges in accessing diagnostics and problems in the primary and secondary care interface can lead to late presentation in hospital, and patients with advanced cancer may be unnecessarily diagnosed in emergency hospital departments. Further delays in secondary care may lead to cancer being diagnosed at later stages. In these scenarios, treatment is likely to provide worse chances of survival. Outcomes may deteriorate further if there are additional delays in treatment. Excess cancer deaths in these scenarios are described as avoidable deaths (130) (Figure 2.4). From a public health perspective, it is important that these deaths are avoided.

**Figure 2.4.** Updated NAEDI model: factors influencing cancer survival



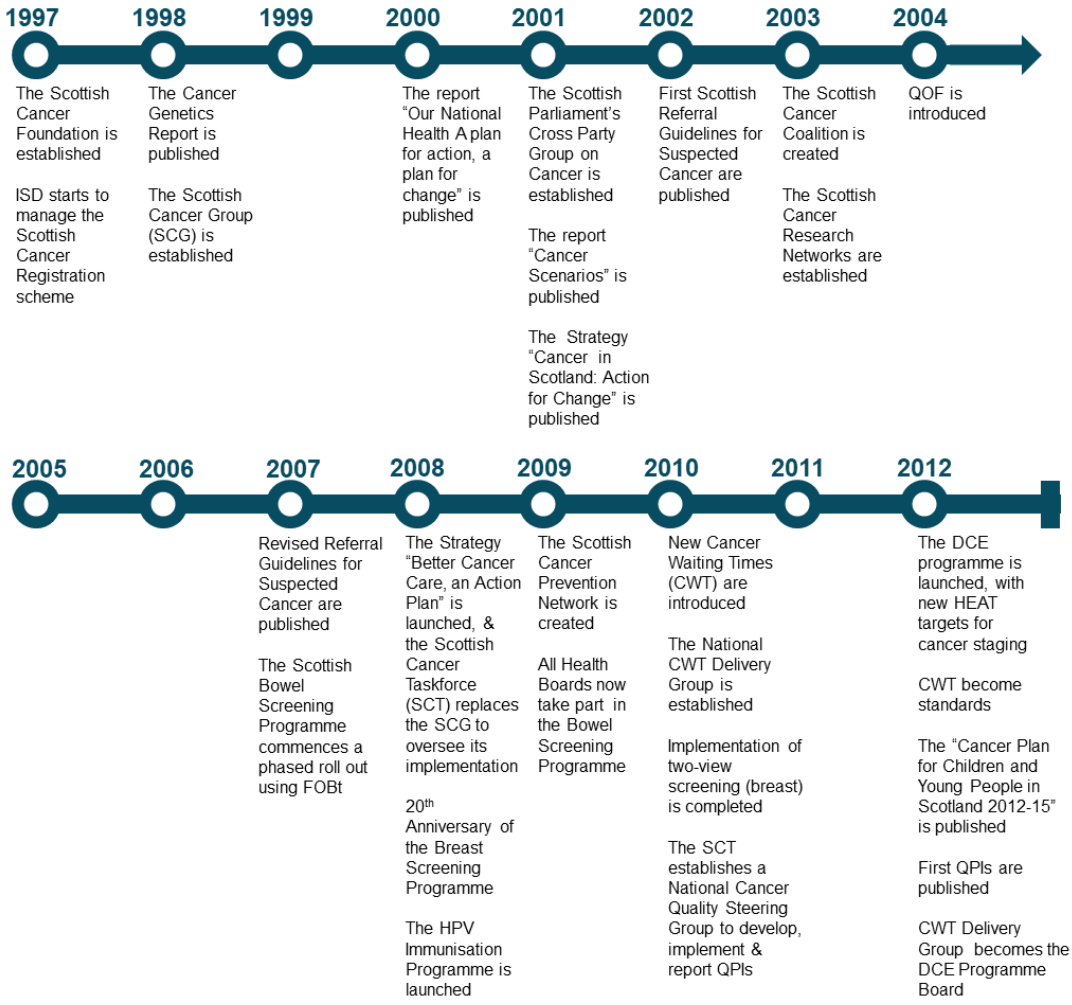

***Source: Adapted from Hiom 2015 (130)***

## 2.4 The policy context

### 2.4.1 Cancer policies prior to the DCE programme

The first comprehensive cancer report in the UK (covering England and Wales) was published in 1995 (131). Known as the Calman-Hine Report, it provided a policy framework for commissioning cancer care and service delivery (132), and was followed by Cancer Plans in England (133, 134) and developments in Scotland. These included the creation of the Scottish Cancer Group (SCG) in 1998 to provide "leadership, direction, advice and guidance for cancer services" (135) (Figure 2.5).

**Figure 2.5.** Policy developments in cancer in Scotland until 2012




***Abbreviations: ISD: Information Services Division; SCG: Scottish Cancer Group; QOF: Quality and Outcomes Framework; FOBt: Faecal Occult Blood Test; SCT: Scottish Cancer Taskforce; HPV: Human Papillomavirus; CWT: Cancer Waiting Times; QPIs: Quality Performance Indicators; HEAT: Health Improvement, Efficiency; Access to treatment and Treatment. Source: DCE policy documents***

In 2001 the Scottish Government published: "Cancer in Scotland: Action for Change". The SCG was involved in developing and implementing this Cancer Strategy, which focused on prevention, diagnosis and treatment (135). It addressed developments in screening (including a colorectal screening pilot); proposed to eliminate delays in investigation, diagnosis and treatment; and committed to creating urgent referrals for breast cancer and establishing a maximum waiting time of two months for urgent referral to treatment for all cancers. There was also a plan to develop referral guidelines for urgent referrals. The strategy acknowledged the increase in workload for radiology and pathology, and issues with shortage of staff, delays in imaging and the need to ensure sufficient diagnostic capacity. It proposed the establishment of regional cancer networks to oversee the patient journey (135).

In 2008 “Better Cancer Care: An action Plan” was published. Similar to the previous strategy, it focused on prevention, early diagnosis, genetic/molecular testing for cancer, referral and diagnosis, and treatment. A Scottish Cancer Taskforce was established to oversee the implementation of this plan. The strategy supported the roll-out of the Scottish Bowel Screening Programme and looked at ways to encourage bowel and cervical screening uptake. It proposed to work with different stakeholders to promote public awareness of cancer symptoms and encourage patients to seek help early. There were plans to work with different Health Boards in Scotland to redesign referrals and investigation pathways. Furthermore, a primary care cancer lead would be nominated within each Board (136). This strategy paved the way for the development of a national early detection initiative; i.e. the DCE Programme.

### 2.4.2 The DCE Programme

In March 2011, it was announced that the Scottish Government would invest £30 million in a 3-year “Detect Cancer Early Initiative”; and the commitment was reiterated in a political manifesto (137). A draft Implementation Plan was finalised in June 2011 and circulated to territorial Health Boards, different departments at the Scottish Government, cancer charities and other non-governmental organisations (138). A refined implementation plan was finalised in December 2011.

Preparatory work was carried out before DCE launch. Different groups were created to coordinate and ensure the management of the programme. The already established National Cancer Waiting Times Delivery Group was “refreshed” into the “Detect Cancer Early Programme Board” (138). Desk research and insight gathering

via focus groups were carried out in order to inform social marketing campaigns (Diane Primrose, personal communication).

DCE was officially launched in February 2012 by the Cabinet Secretary for Health and Wellbeing (139). The programme aimed to improve overall 5-year survival for people in Scotland diagnosed with cancer, and created a new HEAT (Health, Efficiency, Access and Treatment) target to measure this. The target used tumour staging as a proxy for cancer survival and referred to an *increase in the proportion of cancers diagnosed at Stage I by 25%*. The DCE implementation plan outlined eight official programme objectives (Figure 2.6).

**Figure 2.6.** DCE's aim and objectives

| | | |
|---|---|---|
| **1.** To increase the proportion of people with Stage I disease at diagnosis by 25% (as a proxy indicator of survival outcome) and to use performance against a HEAT target as a lever for whole systems approach to improvement | **2.** To improve informed consent and participation in national screening programmes to help detect cancer earlier and improve survival rates | **3.** To raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier |
| **4.** To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access | **DCE's main aim:** Improve overall 5-year survival for people in Scotland diagnosed with cancer | **5.** To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part |
| **6.** To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early disease requiring treatment | **7.** To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral, and survival | **8.** To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit |

***Source: created with data from the DCE Implementation Plan 2011 (138)***

In its first three years, DCE focused on lung, breast and colorectal cancers as these were the three main causes of cancer death in Scotland (138). The implementation plan emphasised that DCE was "a fundamental shift" in the way that the Scottish Government engaged with the National Health Service (NHS) regarding a new cancer target; as a "whole systems level of support" was introduced instead of the traditional focus on secondary care (138).

DCE required collaboration with primary and secondary care professionals, directors of Public Health, cancer charities and official providers of health intelligence data. It had four main strategies (Figure 2.7).

**Figure 2.7.** DCE's main strategies

| | |
|---|---|
| **Public Awareness and Behaviour Influencing** | Social marketing campaigns, public relations, field marketing and partnership. Social marketing campaigns targeted barriers to help-seeking, bowel screening, breast screening, breast cancer symptoms, and lung cancer symptoms |
| **Primary Care Symptom Management and Referral** | Training of primary care professionals and knowledge sharing; updating already existing referral guidelines for suspected cancer; and plans to develop general practice profiles with cancer outcomes to be used for consultation and benchmarking |
| **Secondary Care and Diagnostic Capacity** | Through distribution of funds to territorial Health Boards to be invested in diagnostic capacity |
| **Performance management and monitoring** | Development of a new HEAT target (25% increase in breast, lung and bowel cancers diagnosed at stage 1); financial reimbursement to primary practices decreasing the proportion of non-responders to bowel screening (new sGMS QOF rewards) ; and assessment of already existing CWT targets |

***Source: created with data from the DCE Implementation Plan 2011 (138). Abbreviations: HEAT; Health, Efficiency, Access and Treatment; sGMS: Scottish General Medical Services; QOF: Quality and Outcomes Framework; CWT: Cancer Waiting Times***

Additionally, small projects in collaboration with cancer charities, Health Boards and Scottish universities were fully or partly funded by DCE (Nicola Barnstaple, personal communication). A thorough description of each DCE strategy is available in the final report prepared for the Scottish Government (see Chapter 10 for reference to report).

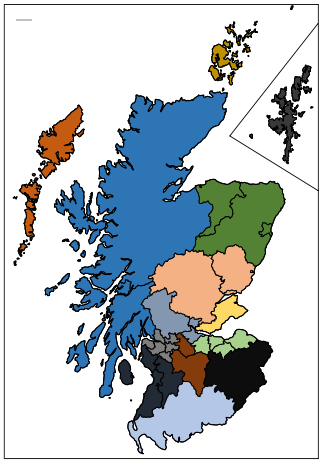
### 2.4.3 The Scottish health system: an overview

In the UK, universal health coverage is provided through the NHS. Services are free at the point of use according to need, and funding is obtained from general taxation (140). Health was devolved to the Scottish Parliament in 1999. There are differences in service provision compared to England such as choices regarding the level of funding and other benefits such as free prescriptions (available in Scotland but not in England) (140, 141).

Scotland (NHSScotland) has 14 territorial Health Boards to deliver care services through public health, primary, secondary and tertiary care (140). Population, cancer incidence and mortality vary across these Boards (Box 2.3). There are seven special

Health Boards to cover other services (e.g. ambulances, health improvement and health education) and one Public Health body (141). NHS Boards are accountable to the Scottish Parliament and subject to frequent reviews, in addition to specific targets and standards they should aim for. About 75% of the annual budget for health and wellbeing (which corresponds to over a third of the Scottish Government budget) is allocated to Health Boards. A specific formula (NHSScotland Resource Allocation Committee (NRAC)) determines these allocations based on population characteristics (140). Managed Clinical Networks (MCN) have been set up to coordinate work in primary, secondary and tertiary care across Health Boards (140); these include three Cancer Networks for the North (NOSCAN), South East (SCAN) and West of Scotland (WOSCAN).

**Box 2.3.** Territorial Health Boards and population estimates (absolute numbers)




| Territorial Health Board | Pop. Estimates mid- 2018 | Cancer incidence (2017) | Cancer mortality (2017) |
|---|---|---|---|
| Ayrshire & Arran | 369,670 | 2,433 | 1,220 |
| Borders | 115,270 | 894 | 406 |
| Dumfries and Galloway | 148,790 | 983 | 515 |
| Fife | 371,910 | 2,213 | 1,181 |
| Forth Valley | 306,070 | 1,893 | 861 |
| Grampian | 584,550 | 3,271 | 1,575 |
| Greater Glasgow & Clyde | 1,174,980 | 6,835 | 3,511 |
| Highland | 321,800 | 2,002 | 1,019 |
| Lanarkshire | 659,200 | 3,951 | 2,000 |
| Lothian | 897,770 | 4,654 | 2,183 |
| Orkney | 22,190 | 115 | 81 |
| Shetland | 22,990 | 137 | 62 |
| Tayside | 416,080 | 2,672 | 1,395 |
| Western Isles | 26,830 | 181 | 96 |
| Total | 5,438,100 | 32,234 | 16,105 |

***Notes: Mortality includes all persons, all ages, exclude NMSC. Highland include Argyll. Cancer incidence refers to absolute numbers. Sources: (10, 11, 142, 143)***

Current challenges include integration of health and social care (which require involvement from 32 local authorities or councils in Scotland), alongside demanding issues from an ageing population, limited resources, and limited workforce (140).

Furthermore, a new General Medical Services (GMS) contract was implemented in April 2018 (144). The new contract refocuses the GP role as expert medical generalists and emphasises holistic, person-centred care. It also introduced a new funding formula that aimed to better reflect practice workload. Other system changes included embedding GP clusters (professional groupings of general practices) in

order to improve quality of care and abolishing the Quality and Outcomes Framework (QOF) (due to concerns such as its effectiveness over time and its non-holistic, disease-specific approach) (144).

## 2.5 Summary of Chapter 2

This Chapter describes how cancer represents an important public health problem worldwide. In Scotland, if all cancers were combined, cancer would be the main cause of death. Cancer survival has been improving, mainly due to developments in early detection and treatment. Indeed, early cancer detection is a key component of cancer control initiatives, as recommended by the World Health Organization.

Early cancer detection comprises systematic screening of asymptomatic individuals and early diagnosis of symptomatic patients. Tumours identified in earlier stages are more likely to be successfully treated; shorter diagnostic intervals have also been found to be beneficial for some tumour types.

Most patients are still diagnosed with cancer through symptomatic presentation; primary care has a key role in promoting early diagnosis. Early diagnosis challenges include heterogeneous symptomatology (not all cancers have red flag symptoms – even if they do, the positive predictive values are often low, and symptoms may indicate late stage disease), risk of overdiagnosis and overtreatment, and limited diagnostic resources. Other factors influencing early diagnosis include health system characteristics, population behaviour and society, and socioeconomic inequalities. In Scotland, socioeconomic deprivation has a key role in cancer incidence, mortality and survival. Importantly, early diagnosis does not guarantee improved cancer survival; characteristics such as tumour biology, tumour location, patient characteristics (such as co-morbidities, age and health-related behaviour), and social deprivation also play an important role.

Recognising the multiple factors influencing early detection and cancer survival, multilevel policy initiatives aiming to promote early detection have been implemented in a range of countries, including Scotland. The DCE Programme was launched in 2012 with the aim to increase the proportion of cancers diagnosed at Stage I by 25% (a proxy for cancer survival). The Programme had four strategies (public awareness and behaviour influencing; primary care symptom management and referral; secondary care and diagnostic capacity; and performance management and monitoring) and eight official objectives.

Despite the importance of such multi-level policy initiatives, no attempts had been made to synthesise their components, target populations and outcomes worldwide. Furthermore, no system-level evaluation of the DCE Programme had been carried out. This PhD research project investigated the role of these initiatives further, carrying out a systematic review and evaluating the DCE Programme. The next Chapter gives an overview of the methods adopted to do so.

# Chapter 3 Methods overview

## 3.1 Overview

This Chapter describes the rationale for each of the studies in this PhD project, the theoretical underpinnings for the DCE evaluation (Study 2 and Study 3) and how studies connect to each other. From the outset, I was aware that DCE was a system-level, government programme with multiple components, stakeholders and outcomes, and that I should investigate appropriate ways to evaluate it, while bearing in mind its political nature. These thoughts led to investigating evaluation theories and complexity theory, and evaluation guidance. Furthermore, I was aware that a PhD with multiple components and objectives was likely to require the adoption of mixed methods. Therefore, this Chapter also describes key issues I had to consider when adopting this approach. Finally, this Chapter gives an overview of methods adopted in this PhD project, and of how Studies 1-3 connect with each other.

## 3.2 Justification for the studies in this PhD

### 3.2.1 Why carry out a systematic review?

At the time of this study, to my knowledge no other reviews had comprehensively synthesised multilevel policy initiatives promoting the earlier diagnosis of cancer worldwide; outlining their characteristics, components, target populations and overall outcomes. González-Robledo et al analysed databases and documents to describe breast cancer early detection initiatives in Latin America; and outlined that such initiatives operated through regulation, design and implementation of early diagnosis programmes, care provided by public and private services, and the development of guidelines for early detection (145). Palmer described a range of UK policies and government initiatives promoting early cancer diagnosis (146). Brown et al explored how healthcare system characteristics in six different countries contributed towards cancer outcomes (not focusing specifically on early diagnosis); approached the issue of complexity; and the importance of understanding the context (102). Hence, this review had the potential to bridge an important gap in the early diagnosis literature, in addition to being necessary in order to answer the PhD research questions.

### 3.2.2 Why evaluate DCE?

Government initiatives are publicly funded; and as such should be evaluated to check if they benefit the population they plan to benefit, and for the purposes of transparency

and accountability (147). Furthermore, considering the burden of cancer worldwide, understanding early detection initiatives worldwide is particularly important. A thorough understanding of a national initiative, alongside synthesised evidence from several initiatives worldwide can provide a more nuanced understanding of the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer.

No system-level evaluation of the DCE programme had been planned prior to this PhD project. Reports on HEAT targets and screening participation were published by ISD Scotland, and DCE had internal documents/grey literature with discrete reports on different programme components. There was an unmet need to synthesise the evidence and develop a comprehensive evaluation of the DCE programme. In order to choose the best way to do so, it was important to immerse myself in the field of evaluation research. The next section discusses the theoretical underpinnings for the DCE evaluation.

## 3.2.3 Theoretical underpinnings for the DCE evaluation

### 3.2.3.1 Theory-based evaluation

I was particularly interested in theory-driven or theory-based evaluation; this approach had already been outlined in the funded evaluation proposal as it had successfully been adopted to evaluate other health policy initiatives (148-150). As opposed to a "black box evaluation" that only focuses on inputs and outputs in a programme (i.e. a simple outcome evaluation), a theory-based evaluation seeks information about the underlying mechanism/conditions that help to generate changes (i.e. the processes happening between inputs and outputs) (151). A theory-based evaluation is based on the premise that programmes are "theory incarnate", with implicit or explicit assumptions on how they are supposed to work (152). It seeks information on whether an intervention is effective and also why it is effective (153), investigating assumptions underlying a programme in terms of activities and expected outcomes (154, 155). It is method-neutral and open to different research designs (156), and often needs a combination of qualitative and quantitative methods as it encompasses several different elements (154).

The term "theory-driven evaluation" was made popular by Chen and Rossi (152) in their seminal paper (157), although in the early 1970s, Carol Weiss had already emphasised that "there is some kind of theory implicit in almost every program" (158). Weiss proposed the term "theory-based evaluation". Its aim is to examine whether,

and to which extent, assumptions about a programme will hold, where they break down and which theories underlying a programme are supported by evidence (159). Realistic evaluation is also a type of theory-based evaluation; it investigates “what works, for whom and in what circumstances”. A programme is described as having three key ingredients: context (C), mechanism (M) and outcome (O) – known as the CMO configuration. The evaluator identifies, articulates, tests and refines CMO configurations (152). Realistic evaluation has been adopted to evaluate public health programmes (148, 149, 160).

A theory-based evaluation is informed by programme theory. Definitions of what comprises programme theory vary between authors and overlap with each other. Rossi describes programme theory as having three interrelated components: programme impact theory, service utilisation plan, and the programme’s organisational plan. Programme impact theory refers to assumptions about the changes caused by the programme and the expected improvements. The service utilisation plan describes how and why the target population will engage with the programme until the receipt of services is sufficient to generate the changes described by the programme impact theory. Finally, the organisational plan outlines the roles and activities of a programme and the resources needed for service provision (161).

Weiss’ definition of a programme theory was adopted in the DCE evaluation, i.e. *implicit or explicit assumptions about why planned activities would lead to desirable outcomes* (155). Weiss also proposed the separation between implementation theory and programme theory. While implementation theory concentrates on how a programme is carried out, programme theory focuses on the mechanisms intervening between service delivery and outcomes (162). Mechanisms are not the programme activities, but the response generated by activities. One example would be increased knowledge (mechanism) generated by contraceptive counselling (activity) which results in reduced pregnancy rates (outcomes) (162). Weiss states that most evaluations describing themselves as theory-based only assess implementation theory. She developed the term “theories of change evaluation” for evaluations assessing both implementation theory and programme theory (162). Theories of change are widely used to evaluate public health interventions (163, 164).

*Representing programme theory*

Programme theory is usually demonstrated in graphic representations, with one of the most prominent being the logic model (161). Rossi et al described the logic model as having four components: inputs (i.e. resources and constraints; this is where his proposed organisation plan is shown); activities (services provided); outputs (where components of his proposed service utilisation plan are shown); and outcomes (which can be initial, intermediate or long-term) (161).

A logic model was chosen to describe the DCE programme in order to facilitate the identification of evaluation questions, help to recognise important programme issues and avoid overlooking critical issues (158, 161, 165). Furthermore, logic model development has been found to be useful to highlight weak links, conflicts and contradictions, identify different understandings regarding a programme, and shed light on possible unanticipated outcomes (166). Finally, the use of logic models has been advocated by governmental and non-governmental agencies in the United States (US) and the UK (167-169), and evaluation frameworks published by the Medical Research Council in the UK (166).

*Theory-based evaluation components*

When adopting a theory-based evaluation, it is important to understand both programme processes and outcomes. Therefore, it was necessary to design both a process and an outcome evaluation. While the process evaluation investigated what happened and how it happened (i.e. the “how and what” in an evaluation) (170), the outcome evaluation assessed whether the DCE programme met its objectives/generated its intended results. An outcome evaluation can also be called an impact evaluation (161), or as seen before in this chapter, a “black box” evaluation when carried out on its own (151).

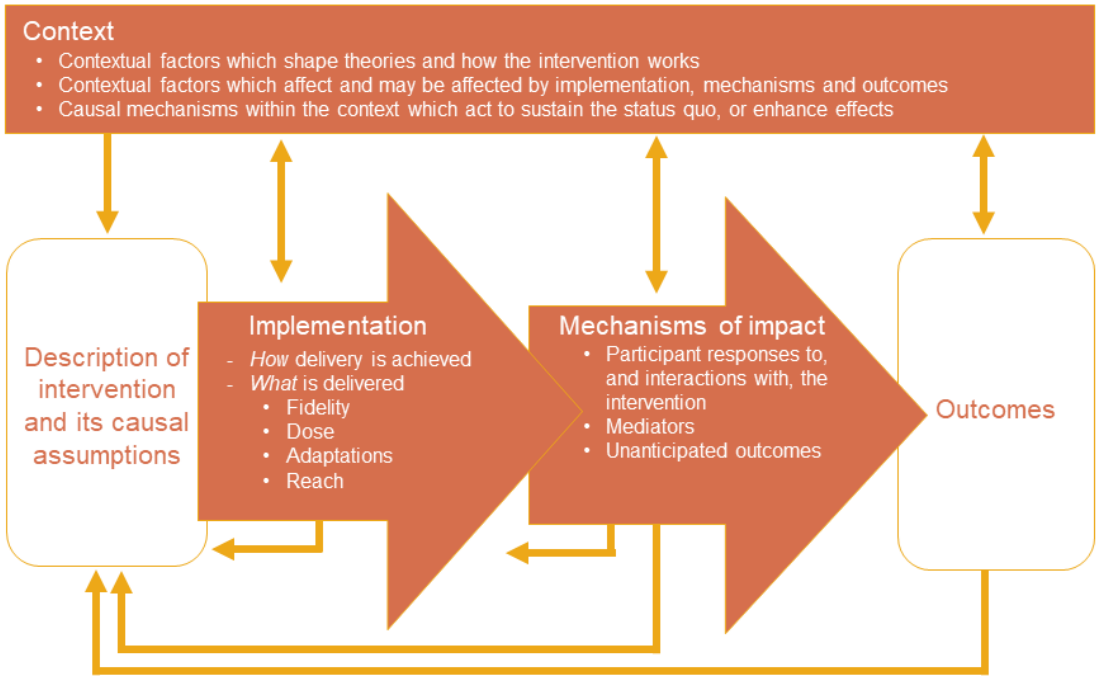
A process evaluation alongside an assessment of programme outcomes can help to distinguish between programme failure or theory failure (155, 158). In other words, a programme may have been unsuccessful due to poor implementation or poor theory. Even if implementation was successful, an inadequate theory will not result in the desired changes/outcomes. Edward Suchman gave a simple example to illustrate this almost 50 years ago: “the operation was a success, but the patient died" (171).

*Process evaluation*

Specific guidance on process evaluation published by the UK Medical Research Council (MRC) (166) was used to inform the DCE evaluation. The MRC guidance recommends that process evaluation should focus on investigating implementation (how intervention is delivered, and the quality and quantity of what was carried out), mechanisms of impact (how the intervention generates change) and contextual issues (how they influence both implementation and outcomes) (166).

The MRC guidance was a good fit with theory-based evaluation, in addition to providing a comprehensive description of different components of a process evaluation (and the bidirectional relationships between them) in a clear framework (Figure 3.1). Furthermore, it provided advice when planning, designing, analysing and reporting data from a process evaluation; described a range of theories, models and frameworks suitable to guide each evaluation component; and provided a checklist for reviewers appraising a process evaluation which was used to inform the DCE evaluation (completed checklist is available in Appendix 1) (166). Finally, the MRC is a well-established, recognised UK organisation that funds high quality research, disseminates best practice, and produces widely adopted guidance (172).

**Figure 3.1.** The MRC Framework for process evaluation of complex interventions




***Source: adapted from Moore et al 2014 (166)***

In addition to being necessary in a theory-based evaluation, there were other reasons for carrying out a process evaluation. My supervisors and I wished to generate new, helpful evidence to inform policy and to contribute to new knowledge in early detection and evaluation research. Hence, it was important to understand not only whether DCE objectives were met, but also to what extent, and why this was the case; while also adopting robust theories and frameworks. We were particularly interested in lessons that could be learned from the programme to inform DCE and other early detection initiatives. Furthermore, analysis of cancer survival needs a long timeframe (173); DCE was rolled out nationally as a policy as opposed to a scientific experiment, and we were aware that demonstrating causal relationships would be challenging (see next section). Hence, an outcome evaluation on its own was not perceived to be as useful as a more comprehensive evaluation.

We also expected that a system-level evaluation assessing both processes and outcomes would shed light on outcomes which could be beneficial or even harmful and were not part of official programme outcomes (i.e. “unanticipated outcomes”). Finally, we expected that a process evaluation would generate useful implementation data for those wishing to successfully adopt similar programmes elsewhere (166).

*Outcome evaluation*

Randomised designs (in which outcomes are compared across randomised groups that either received or did not receive an intervention) are considered the “gold standard” in research as the potential for selection bias is reduced, there is control for unmeasured confounding (168, 172), and it is possible to make direct inferences regarding causality (174). However, experimental designs are often not feasible, practical or cost-effective (168). It may not be possible to have a control group when an intervention is delivered to everyone (168, 172, 175). If it takes a long time for outcomes to be observed, adequate follow-up may not be possible (168, 172, 175).

The ability to make reliable estimates when evaluating public health interventions is limited (172) as studies without a random allocation do not control for unmeasured or poorly measured confounders (175). Nonetheless, quasi-experimental (comparisons between groups without random assignments such as case-control studies) and observational designs (such as before-and-after studies, time-series analysis, cross-sectional surveys and case studies) are often adopted in public health interventions (168) and to evaluate nationwide programmes, including in early diagnosis research in the UK (150, 176-178). Natural experiments are also common (179). Natural

experiments refer to programmes, interventions or policies which are not carried out for the purposes of research, but whose outcomes are evaluated (by assessing exposure and outcomes) in order to make causal inferences (180).

Before deciding on which design to adopt in the DCE outcome evaluation, it was important to consider issues such as appropriateness, feasibility, the study aims and how evaluation results would be used (168). MRC guidance on developing and evaluating complex interventions recommended caution on selecting outcome measures (highlighting that subjective measures were less reliable), on deciding on length of follow-up (to ensure that time was sufficient to observe changes), and on using proxy outcomes (172). Prioritisation of outcomes according to their importance and investigating unanticipated outcomes were described as important requirements (166, 172). In order to make such decisions, it was important to better understand the DCE programme, and a study was designed to do so (Study 2).

#### 3.2.3.2 The role of complexity theory

The adopted MRC Framework for process evaluation of complex interventions highlights the importance of the context when carrying out an evaluation. The role of contextual issues and the challenges in promoting early cancer diagnosis were highlighted in Chapter 2. In this Chapter, challenges in demonstrating causality when evaluating public health programmes were outlined. Complexity theory is helpful to understand these issues.

Complexity theory does not have a single origin nor a single definition (181). It has been used to describe interventions (172), but also to describe social systems (181, 182). The MRC describes five characteristics that make an intervention complex: the number of interacting components within each group, the number and difficulty of required behaviours (in terms of intervention receipt and delivery), number of groups or levels targeted, number and variability of outcomes, and how much flexibility or tailoring is allowed (172). Funnell and Rogers, building upon a range of authors, describe not only complex, but also simple and complicated interventions, with different characteristics regarding what they look like and how they work. Furthermore, they highlighted that “few, if any” interventions can be characterised as simple. The most likely scenario is that some intervention components are simple, others complicated, and others complex (165) (Table 3.1).

**Table 3.1.** Simple, complex and complicated aspects of an intervention

| Categories | What interventions look like | How interventions work |
|---|---|---|
| Simple aspects | • Standardised activities<br>• Implemented by one organisation | • The same way everywhere |
| Complicated aspects | • Multiple components<br>• Implemented by multiple organisations in ways that can be predicted | • Variation according to different situations, different people or implementation environments |
| Complex aspects | • Not standardised and changing, adaptive and emergent<br>• Implemented by multiple organisations with emergent and unpredictable roles | • Generalisations decay quickly<br>• Results sensitive to both initial conditions and the context |

***Source: Adapted from Funnell and Rogers 2011 (165)***

Other authors have criticised the term "complex interventions" due to the likelihood that the complexity lies in the context in which the intervention was introduced and with which it interacts (183). Hawe recommends that interventions are seen as "events in systems", and that the focus should be in understanding the context, settings, strategies and relationships (183). Understanding complexity as a system implies that different programmes, even if not complex, may benefit from being evaluated from a complexity standpoint (181).

The terms complexity theory (181), complex adaptive systems (182), complex systems, systems science (184), systems thinking (183, 185) or complexity science (183) have been used to describe this broad, multidisciplinary area. A widely accepted definition of complex systems refers to systems with many heterogeneous components that interact with each other, producing an emergent effect which is distinct from the effect of each component on its own. This effect persists and adapts according to different circumstances (184). An important implication is that the system needs to be understood as a whole instead of its separate components (181).

Peters defines systems thinking as an approach aiming to understand connections between "the whole, its parts, and the interactions within and between levels", all "within some notion of a whole entity". Explicit theories, models and tools developed to address complex problems are used (185). These include system archetypes (patterns of behaviour in a system that help to understand interactions in a story) and causal diagrams (description of how elements of a problem relate to each other) (185). Box 3.1 summarises key characteristics of complex systems highlighted by a range of authors.

**Box 3.1.** Characteristics of complex systems

- Interactions in a complex system are non-linear; changes in one component may have a minor or a large impact overall (181, 183). There is uncertainty regarding the type/timing of impact (181). Longer time frames are needed to be able to investigate changes (183)
- Different actors may have different views about whether something worked or not, and may value different outcomes (181)
- Interventions/programmes interact with other interventions/programmes in a complex system (181) as it has "fuzzy boundaries" (182). Hence, it is difficult to identify the specific effects of a single intervention (181). It is also difficult to understand agents and systems without understanding the agents and systems with which they interact (182)
- The agents and the system are adaptive, and changes of behaviour occur over time (182)
- Complex systems have heterogeneous actors, are usually multilevel, dynamic, and full of interactions between actors within the system. Hence, holistic methods are recommended in order to examine the whole system and identify underlying mechanisms (184)

Complex systems are common in public health (184), and I believed that the adoption of a complexity lens/perspective would be beneficial for the DCE evaluation. Hence, I sought to better understand how to adopt this perspective.

In practical terms, there was limited consensus on how to incorporate complexity theory in an evaluation (181), although several general recommendations were available. These were synthesised in order to inform the DCE evaluation (Box 3.2).

**Box 3.2.** Recommendations for using complexity theory/systems thinking in an evaluation

- Develop a view of the system and its interactions over time; try to see the big picture and the pre-intervention context in order to identify emergent changing processes (181, 186)
- Adopt mixed methods (181, 186)
- Adopt approaches that allow for the investigation of interactions (e.g. theory-based evaluation approaches such as theories of change and pragmatism) and consider different levels; also allow for multiple theories to be used in multiple levels (181). Sole reliance on individual level-theories is not deemed appropriate as changes should not be understood as an aggregation of individual level results (186)
- Investigate multiple levels (181, 186), but bear in mind the practicalities of doing so. Case studies and other approaches may be an alternative (181)
- Bear in mind that it is not the form, but the function of an intervention that needs to be standardised (183)

Adopting longer timeframes and starting evaluation during programme development and implementation were also recommended (181). The latter was also recommended by MRC guidance on developing and evaluation complex interventions (172). This was not possible for the DCE programme, and implications are approached in Chapter 10.

#### 3.2.3.3 Evaluation as a political activity

As DCE was a government programme, it was important to understand the implications of this for the evaluation.

Carol Weiss is one of the key evaluation theorists emphasising that evaluation research is a political activity. According to her, a programme is brought by political procedures, evaluations inform decision-making processes, and have an inherent political stance. They indicate that a programme is important, suggest that it had a chance to be successful, and give it legitimacy (187). Furthermore, the acceptance of programme goals indicate that these goals are desirable and may imply that other elements are not as important. As key goals may not highlight concerns from other stakeholders or programme recipients, Weiss argues that "evaluation tends to accept the world as it is" (187). Evidence from evaluation can serve as a warning if conditions are not improving, can become ammunition (in a positive or negative way) and can occasionally provide evidence for action. Furthermore, sometimes it can generate enlightenment, i.e. a cumulative effect of new ideas and data becoming part of organisational and policymaking discourse (187, 188).

Pawson and Tilley argue that the very act of engaging in an evaluation constitutes a political statement. Social problems are "politically coloured" (i.e. views on what a problem is can vary). Evaluations are "petty political" as relevant social/historical or political structures are treated as given. Similar to Weiss' views, they state that evaluation often aims to reduce a problem instead of a generating a more radical, fundamental structural change (152). Pawson adds that outcome measurement (or its "crueller term" performance measurement) is deeply politicised (189). Furthermore, he highlights that policymaking is complex, and that programmes do not "stand in pristine purity" waiting to be evaluated. Programme theories are borrowed from other programmes, adaptations and changes are likely to occur over time, and it is difficult to know where one government programme begins and another one ends (189).

These considerations made me reflect upon challenges in evaluating DCE and its components, and upon the need to ensure the evaluation was carried out independently. Furthermore, they indicated the likelihood of facing challenges when trying to disseminate results or using them to inform policy.

Available evidence indicates that well-designed evaluations provide no guarantee that results will be used by policymakers. Results may be suppressed, ignored or discredited. Policymakers may have beliefs regarding what works that do not match the results described by an evaluation (190).

Weiss argues that policymakers are faced with “four I’s” any time new research data arrives: ideology, interests, institutional norms and practices, and prior information (191). Ideology is defined as basic values; it is difficult for good evidence to be supported if it goes against the values of policymakers (e.g. supporting abortion policy). Interests refer to self-interest (individual or organisational), due to opportunities such as career advancement, votes or larger budgets. Institutional norms and practices influence how policymakers receive and absorb information. They also influence decision-making, and drastic changes in organisational processes and rules may not be seen favourably. Finally, information refers to the amount of information the policymakers already receive from several sources, how they deal with it, and how they add new information to what they already know. If the new information challenges previous beliefs, it needs to be very strong to have any effect (191).

I took these considerations into account when designing the evaluation and engaged with stakeholders from the earlier stages of the DCE evaluation. The issue is further approached in Chapters 5 and 6.

Furthermore, an independent steering group with specialists in evaluation, public policy, primary care and research, and a lay representative was formed in 2016 (full names are available in the Acknowledgements page). In addition to helping to ensure transparency, the steering group also provided expert advice to the DCE evaluation in a range of areas. Having a steering group/advisory team was recommended by the adopted MRC guidance (166) and CDC evaluation guidance (168). Furthermore, the MRC guidance highlighted that junior researchers often lead complex evaluations and emphasised the importance of having an expert advisory team to provide support. This was also the case in the DCE evaluation.

## 3.3 Research paradigms and mixed-methods

### 3.3.1 Research paradigms

As this project included diverse studies, it was important to investigate the use of mixed methods in research. When doing so, I became aware of discussions about research paradigms. A paradigm refers to suppositions about the world that give a “philosophical and conceptual framework” for studying that world (192). Guba and Lincoln state that paradigms are defined by beliefs related to ontology, epistemology and methodology. Ontology refers to the “form and nature of reality”, i.e. whether the

world exists independently of the way it is perceived or whether reality is a human construction (193). Epistemology refers to knowledge, and the relationship between the researcher and the research participant (i.e. whether it is possible or not to maintain an objective separation between both) (194). Finally, methodology refers to how the researcher carries out an investigation (i.e. using qualitative or quantitative methods) and is influenced by both ontology and epistemology (193).

Thomas Kuhn pioneered the use of the term paradigm in science (195, 196). Kuhn argued that through scientific revolutions, assumptions and prevailing paradigms that are used to guide research are replaced with new ones (197, 198), but there is often a misunderstanding between the new and old (or "competing") paradigms as their proponents view the world and do research differently (196). As proponents of different paradigms often disagree with the problems that must be solved, or on the standards of what constitutes science, communication is challenging (196). Kuhn's views on paradigms have had a strong influence on social research (197), especially on discussions regarding the benefits of one paradigm over another. Discussions were particularly salient between positivism (the dominant paradigm in scientific enquiry – it assumes that human behaviour can be observed and measured, and that an existing single objective reality can be tested) (199) and constructivism (that postulates that reality is a social construct, and systems and classifications are a result of "historical, social and political processes") (200).

Closely associated with discussions about competing paradigms were heated debates about "the merits and assumptions of quantitative and qualitative research", often described as the "paradigm wars" (201). While quantitative research methods are typically used in studies adopting a positivistic/post-positivistic approach, qualitative methods have been typically based upon constructive or other interpretive paradigms. A crucial implication of linking methods with paradigms is that mixing them in research is deemed inappropriate by some theorists (201). Nonetheless, this view is disputed by others, who believe that there is a confusion between paradigm and method (192, 202), and that focusing on differences is counterproductive in terms of advancing science (202, 203). Others argue that such discussions wrongly imply that methodological challenges in research can be solved by making a choice between different paradigms (197).

Onwuegbuzie and Leech state that the conflict between the use of qualitative and quantitative methods is often present between methodological purists, who not only advocate the use of a single method, but also the superiority of one over the other (202). They advocate the adoption of pragmatism, as methods are then not necessarily linked to a paradigm (202). Michael Patton, a key name in evaluation, believes that “paradigmatic blindness” locks researchers into unconscious biases and may affect their ability to be flexible and adaptable (which he describes as crucial in evaluation research). He favours “methodological appropriateness” over “methodological orthodoxy”, or pragmatism over choosing a side in the paradigmatic debate (204).

Over time, pragmatism became the preferred choice for many researchers because it helped to avoid a “forced choice” between paradigms (205), and allowed answering questions beyond discussions about ontology, epistemology and methodology (206, 207).

As I became aware of these discussions, I investigated pragmatism further. Pragmatism has been proposed as a research paradigm (195, 198, 207), but also as a useful philosophical or practical approach to research (201, 202, 208, 209). As a philosophical tradition (210), pragmatism originated in the late 1800s in the US with the philosopher and logician Charles Peirce. Other prominent classic pragmatists include William James and John Dewey (211). Deweyan pragmatism is the most often approach described in evaluation research. For pragmatists, human inquiry requires both “imagination and interpretation, intentions and values” and empirical experience (208). Knowledge is relative, and causal relationships are transient and difficult to identify (205). Individuals engage with the environment and transform it; these experiences produce knowledge and reconstruct reality, which is both constructed and real. The environment is always changing, and this requires adaptations from individuals. While inquiry helps to deal with uncertainty, it does not result in absolute truths as these are transient, and generated through experience with the world (210).

These definitions reinforced the compatibility of pragmatism with mixed methods research; they also showed that pragmatism was a good fit for an evaluation study incorporating complexity and systems thinking. Pragmatism’s ability to accommodate different perspectives was particularly appealing in order to investigate both processes and outcomes in the DCE evaluation. Even before investigating research

paradigms, my research questions already guided me towards using mixed methods. In other words, pragmatism was underpinning this PhD project even before I realised this was the case. Furthermore, pragmatism is well established in both mixed-methods and evaluation research (170, 202, 205, 207, 210, 212).

Importantly, irrespective of divergences regarding paradigmatic choices, there is consensus regarding the need to be aware of one's theoretical views and assumptions and to report these, as they may influence how research is conducted and data are interpreted (193, 195, 199, 208). The concern is also shared in the field of evaluation research, (204, 213) as evaluation is often "laden with values"(213).

### 3.3.2 Mixed methods research

Mixed methods research (MMR) can be broadly defined as rigorously collecting and analysing both qualitative and quantitative data, mixing or integrating them, prioritising either both or one type of data, carrying out these steps either in a single study or in multiple components in a study, describing underpinning philosophical worldviews and theories, and combining procedures into research designs that will guide a study (195). This definition highlights the importance of valuing the benefits of both types of data, and the need to combine or integrate these, as "something unique and creative will occur" (214). There is growing consensus that integration is a key requirement when doing MMR (215, 216).

Well-established evaluation guidance, core evaluation books and peer-reviewed publications have confirmed the usefulness of using mixed methods in evaluation. MMR has been recommended in the field of evaluation for over 40 years (195). Furthermore, it is suggested by key names in evaluation research (161, 165, 170), and endorsed by the MRC guidance adopted for the DCE evaluation (166). MMR was also consistent with the questions I was trying to address (i.e. seeking to understand not only "what happened", but also "how" and "why" it happened). The DCE evaluation (Studies 2 and 3) required both exploring perspectives and testing hypotheses, adopting both deductive and inductive approaches, obtaining both in-depth insights and broader views regarding processes and outcomes. Likewise, the systematic review (Study 1) required assessing both qualitative and quantitative data in order to understand the characteristics of earlier diagnosis initiatives worldwide, allow for comparisons with the DCE evaluation and provide recommendations for policy.

Hence, a single method would not have been enough for answering my PhD research questions.

After compatibility with mixed methods was confirmed, there was the need to understand how to appropriately carry out MMR. Key issues to consider were *benefits and limitations of using MMR*, *purpose of using MMR*, *design*, *sampling*, *data collection*, *data validity and quality*. These issues are described next.

#### 3.3.2.1 Benefits and limitations of using MMR

The available literature highlighted a range of benefits and limitations of using MMR (192, 195, 206, 216-218); these were synthesised in Box 3.3. I considered that the benefits outweighed the limitations, and that it was still worthwhile (and necessary) to use MMR.

**Box 3.3.** Benefits and limitations of using MMR

**Benefits**

- Qualitative and quantitative methods help to overcome each other's weaknesses (e.g. bias) and can increase robustness of results; they add meaning to each other, and provide new insights; and encourage both inductive and deductive thinking
- Results from MMR can generate more complex and contextual understanding of phenomena; reveal new relationships and patterns; and help to answer questions that a single method would not be able to answer, and provide stronger evidence for conclusions
- MMR can help to produce more complete knowledge to inform theory and practice
- In evaluation research, MMR can shed light on processes and help with a detailed contextual analysis; and help to give meaning to complex constructs (e.g. engagement)

**Limitations**

- Requires skills and knowledge in each method, and in MMR
- Requires time and resources
- There may be the need to convince others about its usefulness
- It is an evolving area, many issues are yet to be solved in terms of paradigms, data analysis and interpretation of conflicting results
- In evaluation research, there is the risk of choosing MMR because it is popular, without considering whether the approach best responds the evaluation questions; and research findings can be confusing if the evaluator mixes different paradigms uncritically

***Source: synthesised from a range of authors (192, 195, 206, 216-218)***

#### 3.3.2.2 Purpose of using MMR

In addition to the need to justify the usefulness of adopting MMR, the literature also highlights the need for a methodological purpose of doing so. Greene et al developed a framework on the rationale for conducting MMR, highlighting five purposes: triangulation (to seek convergence/corroboration of results – this can increase validity and reduce bias), complementarity (to elaborate, illustrate or clarify results – this can enhance interpretations, meanings and validity), development (using results from one method to inform the other – this can increase validity), initiation (looking for paradoxes, contradictions and new ways of organising results – this can enhance

inquiry as different views are considered), and expansion (to extend breadth of research) (219).

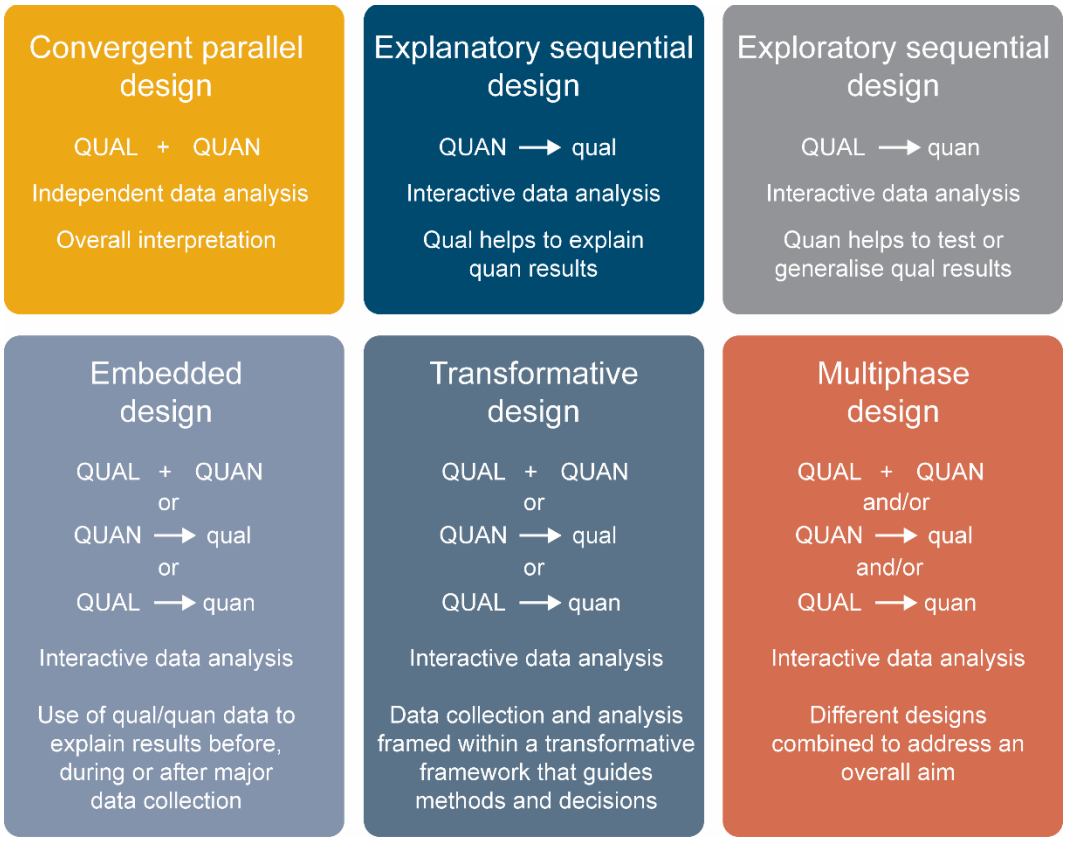
The purposes of development, complementarity and triangulation were relevant to this PhD project. Study 1 (systematic review) aimed to use MRR for complementarity. Study 2 (evaluation development and refinement) was designed mainly for the purpose of development (i.e. to inform the DCE evaluation), although it was expected that results from initial interviews would also complement those from final interviews. The purposes of adopting a theory-based evaluation investigating processes and outcomes were complementarity and triangulation. Finally, there was the need to have both the review and the evaluation for the purposes of complementarity.

#### **3.3.2.3** Study design

The next step was to choose the study design for the PhD project. Study design typologies for MMR have been proposed by different authors. Johnson and Onwuegbuzie describe a mixed-method design matrix which approaches issues of paradigm emphasis (i.e. whether qualitative and quantitative methods have equal status) and time order decision (i.e. whether methods are used in a concurrent or sequential manner) (206). Morse argues that the research design is informed by the research question. A deductive research project would have a quantitative theoretical drive (which would be indicated by using uppercase letters - QUAN), while an inductive, descriptive or interpretative question would have a qualitative theoretical drive (i.e. QUAL). In both cases, when using mixed methods, additional strategies to answer the question would be shown using a lower-case letter (i.e. either qual or quan). If strategies are used concurrently, a + sign is used. If one strategy follows the other (i.e. sequentially), an arrow is used (195).

Creswell and Plano-Clarke describe six designs which could be adopted as frameworks in MMR. These were synthesised in Figure 3.2, using the typologies described above.

**Figure 3.2.** Frameworks described by Creswell and Plano-Clark




***Source: created by synthesising data from Creswell & Plano-Clark 2011 (195)***

After obtaining a better understanding of all possible options and discussing them with my supervisors, I have adopted a variant of a multiphase design, using both parallel (concurrent) and sequential designs. My supervisors and I agreed that a multiphase design was the most appropriate option in order to address the PhD project overarching aim (i.e. to understand the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer). Furthermore, the approach also allowed for each phase to address specific research questions (important in a project with multiple study components). A multiphase design is often used in programme evaluation, and pragmatism is recommended when methods are used concurrently (195).

#### 3.3.2.4 Sampling

In MMR, decisions about sampling designs can affect the researcher's ability to interpret overall results, make inferences, generalise or transfer findings to different populations and contexts (220, 221). Furthermore, inadequate sample size in one component may lead to limited analysis of another component (especially when these are connected/inform one another) (220).

The first step for this PhD project regarding sampling was to acknowledge core differences in sampling procedures between qualitative and quantitative research (195) (Box 3.4).

**Box 3.4.** Sampling in qualitative and quantitative research

**Qualitative research:** Purposive sampling is used to obtain in-depth, rich insights about social phenomena (199, 204, 220). There is no unique rule for defining sample size (222). Due to the complexity of the data, costs and the time it takes to obtain them, samples sizes are often small (199). Grounded theory recommends the use of theoretical sampling; i.e. participants continue to be sampled and data are analysed until saturation. Green and Thorogood state that sample size should be defined based on the study aims, and add that little new information is expected after 20 interviews within a group with similar characteristics (200). Patton recommends answering several questions to define sample size (regarding research purpose, what is useful and what is feasible) (204).

**Quantitative research:** Probabilistic samples are often used with the aim to obtain a representative sample of the population of interest. However, non-probabilistic samples are used for practical reasons, or when the researcher is interested in certain characteristics which are not common in a larger population (195). Random selection helps to ensure that everyone from a specific population has the same chances of being selected, reducing selection bias and helping to generalise results (195, 220). Sample sizes are often (but not always) large so statistical tests can be carried out (195).

The second step was to acknowledge that in MMR, sampling designs are dependent on the purpose and time orientation of the study (220, 223) (Table 3.2). Therefore, before deciding on sampling design, I checked whether my chosen purpose and time orientation were compatible.

**Table 3.2.** Matrix crossing purpose and time orientation

| Purpose of MMR | Time orientation | |
|---|---|---|
| | Concurrent design | Sequential design |
| Triangulation | Yes | No |
| Complementarity | Yes | Yes |
| Development | No | Yes |
| Initiation | Yes | Yes |
| Expansion | No | Yes |

***Source: Adapted from Collins 2010 and Onwuegbuzie & Collins 2007 (220, 223)***

For example, sequential designs are not appropriate for triangulation (as findings from the first approach are likely to influence and bias findings from the second approach) and concurrent designs are not appropriate for development (as studies occurring at the same time cannot inform each other appropriately) (220, 223). These checks were made for the PhD in order to ensure compatibility between designs and purposes.

Then, it was necessary to select a sampling design based on time orientation and relationship between the qualitative and quantitative samples. Four types of

relationship were described: identical (same sample members in the qualitative and quantitative components); parallel (different samples are drawn from the same population of interest); nested (sample for one component is a subset of the sample from another component); and multilevel (one or more samples extracted from different populations) (223). For triangulation purposes, identical or parallel samples are acceptable. For development purposes, parallel, nested, and multilevel combinations are accepted (223). I was interested in parallel samples for the evaluation, in order to reach different groups within DCE stakeholders, while also allowing for triangulation and complementarity.

Finally, I decided to prioritise purposive sampling for qualitative data collection (to obtain important insights into a phenomenon), and probabilistic sampling for quantitative data collection in order to allow for generalisation of results (unless this was not feasible and alternative arrangements had to be made).

#### 3.3.2.5 Data collection

It is recommended that data collection procedures are reported in detail when carrying out MMR. If adopting a multiphase design, it is important to identify the single objective that binds all the study phases together (195). This was clear for the DCE study, as all studies were required to understand the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer. There are several references to *binding aims* in this thesis; these refer to aims connecting different PhD studies/components.

#### 3.3.2.6 Data integration

In MMR, data integration refers to relating different components to the extent that findings are then “greater than the sum of parts” (224). Data integration has been described as being understudied in MMR (224, 225).

Creswell and Plano-Clark’s recommendations for integration are dependent on the study design. Those adopting a multiphase design should analyse data for each component separately, then merge and connect findings in order to meet the key research question (195). They suggest the adoption of merged data analysis (using side by side comparison, joint displays or data transformation merged analysis) for those using concurrent designs, and give advice on connected data analysis for those using sequential designs (195). These recommendations were adopted for this PhD project; independent data analysis was followed by merged data analysis using joint displays of data. Furthermore, informed by a recent book focusing on data integration (226), descriptive and narrative accounts merging results were also prepared.

#### 3.3.2.7 Data validity and quality

The final issues to consider when adopting MMR refer to credibility, trustworthiness or validity (227). As in most discussions in MMR, this area is still in its early stages of development (195). There are debates over whether it is appropriate to apply quantitative criteria to qualitative data and vice versa, and criticisms over attempts to "impose" validity concepts which some believe only make sense for quantitative research (228, 229). Some argue that a "pervasive post-positivism" is prevalent in MMR, with qualitative analysis becoming subordinate to quantitative studies (230).

Creswell and Plano-Clark list several potential threats to validity (such as giving more weight to one type of data, not relating different study phases to each other, developing instruments without sound psychometric properties, not discussing the mixed methods research questions, among many others) and suggest strategies to deal with these threats (195). O'Cathain and colleagues developed quality criteria to be used as guidelines for those using MMR (GRAMMS) (231). These comprised describing why MMR is being used in relation to the research question; outlining the adopted design in terms of priority, aim and sequencing; approaching sampling, data collection and analysis for each method; explaining where integration occurs, how this is done and who has done it; describing limitations of mixing methods; and describing new insights obtained with MMR (231). These issues have been addressed in this thesis.

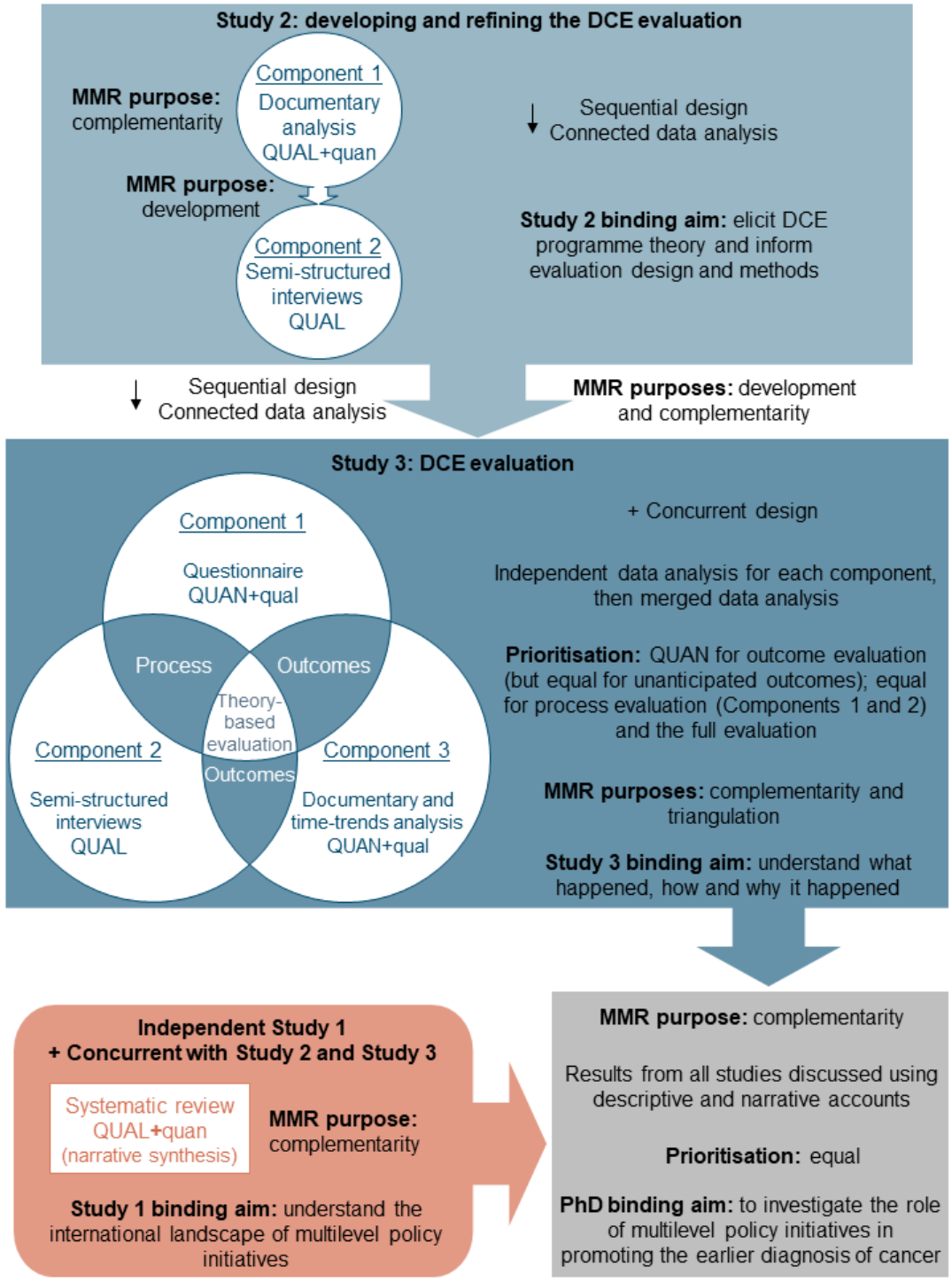
## 3.4 PhD studies and relationships between them

In line with guidance, a procedural diagram was developed to communicate the complexity of using MMR (195). The diagram describes: 1) the aim that binds study components; 2) the purpose of using mixed methods; 3) the adopted designs; and 4) data analysis and integration methods (Figure 3.3).

The systematic review (Study 1) had one component and a qualitative theoretical drive. Qualitative and quantitative results were summarised using narrative synthesis. Study 1 was carried out independently from, and concurrently with, Study 2 and 3.

Evaluation development and refinement (Study 2) had a qualitative theoretical drive; its two components were linked by a sequential design. Documentary analysis informed qualitative interviews (connected data analysis; purpose: development). Studies 2 and 3 were linked through a sequential design (connected data analysis; purposes: development and complementarity).

**Figure 3.3.** Procedural mixed-methods diagram




***Abbreviations: QUAL/qual – qualitative; QUAN/quan – quantitative; uppercase indicates prioritisation; + indicates a concurrent design; ↑ indicates a sequential design***

DCE evaluation (Study 3) components were organised in a concurrent design. Each component was first analysed independently followed by merged data analysis. I was the one responsible for data integration. Component 1 (C1) had a quantitative

theoretical drive; component 2 (C2) was solely qualitative. Together, they comprised the process evaluation (purposes: triangulation and complementarity). Qualitative and quantitative methods had equal priorities, and results were merged through a synthesis (narrative), joint displays and summary tables. Component 3 (C3) comprised the outcome evaluation and was carried out through qualitative (narrative) and quantitative synthesis of outcomes. Results were presented prioritising its quantitative component. The DCE evaluation had three components for the purposes of complementarity and triangulation. Qualitative and quantitative methods had equal priority, and results were merged in a narrative description and tables.

Finally, Study 1 and Study 3 were mixed for the purposes of complementarity in order to address the PhD binding aims. I integrated the results using a narrative description. Qualitative and quantitative results were equally prioritised.

## 3.5 Summary of Chapter 3

This Chapter described the rationale for the methods adopted in this PhD project. Methods for each study are comprehensively described in Chapters 4-6.

A theory-based evaluation was chosen for the DCE programme. Despite having a common premise, different authors described this approach in different ways. I expected that with a better understanding of the DCE programme (Study 2 – evaluation development and refinement), I would be able to make a more informed decision about how to operationalise evaluation components. Choices were made to adopt the MRC framework for process evaluation of complex interventions, and to be underpinned by complexity theory and systems thinking.

This PhD project was underpinned by pragmatism (209) and adopted a variant of a multiphase mixed-methods design (195), with components adopting sequential and concurrent designs. It was informed by overall mixed-methods guidance proposed by Creswell and Plano-Clark, and purposes of mixed-methods research and theoretical prioritisation requirements described in the literature (195, 219, 232). Guidance on sampling (220, 223) and quality in MMR was followed (231).

This Chapter is the last one of the first part of this thesis (Background and methods overview). The next Chapter describes the methods and results of the systematic review investigating the characteristics of multilevel policy initiatives promoting the earlier diagnosis of cancer.

# Chapter 4 Systematic review (Study 1)

## 4.1 Overview

This Chapter describes the methods and results for the systematic review investigating multilevel policy initiatives promoting the earlier diagnosis of cancer. The review aimed to address Objectives, 1, 3 and 4 in this thesis.

## 4.2 Review methods

### 4.2.1 Aim and objectives

The systematic review aimed to identify, describe and categorise evidence on multilevel policy initiatives aiming to promote the earlier diagnosis of cancer among the adult population. It had four research questions:

1. What are the key components of these initiatives?
2. Who are the target populations and what are their characteristics?
3. What are the reported overall outcomes of these initiatives?
4. Where reported, what are the perspectives of participants (patients, professionals and policy makers) on these initiatives?

If data were available, I also aimed to describe contextual issues that helped to shed light on how/why the initiatives' aims were (or not) met.

Based on the theories underpinning this PhD, I was aware that the initiatives were likely to be complex. Hence, guidance on reviewing complex interventions was consulted (233, 234). Furthermore, the review protocol was guided by the PRISMA P-checklist (235), registered at PROSPERO (CRD42016047233) and published by BMJ Open (236) (Appendix 3). The review was also informed by PRISMA reporting guidelines (237), the Cochrane Handbook (238) and the Centre for Reviews and Dissemination guidance (239).

### 4.2.2 Inclusion and exclusion criteria

Study selection criteria are summarised in Table 4.1 and described in text. Importantly, DCE met inclusion criteria but was already being comprehensively evaluated. Hence, for the purposes of the review, only publications found using the review search strategy were included. This was to avoid data repetition, and to ensure that other strategies could be properly described.

**Table 4.1.** Inclusion and exclusion criteria

| | Inclusion criteria | Exclusion criteria |
|---|---|---|
| Design and publication types | • Experimental and non-experimental studies<br>  ○ Studies using quantitative, qualitative or mixed methods<br>  ○ Protocols, editorials, commentaries, short reports, viewpoints, and letters to the editor<br>  ○ Reviews/overviews and systematic reviews reporting on a number of components from a single national strategy/initiative<br>  ○ Conference abstracts when full-text about initiatives is also available | • Reviews and systematic reviews reporting on more than one national initiative<br>• Conference abstracts when full-text about initiatives is not available<br>• Published guidelines/recommendations from Professional Bodies which are not part of a government initiative<br>• Publications without full-text in English |
| Population and setting | • Adults (aged 18 or older)<br>• Patients/member of the public with or without medical conditions<br>• Health care professionals<br>• Health institutions/settings<br>• High-income countries (World Bank) | • Children (aged 17 or younger)<br>• Professionals working in an administrative capacity (even if within a health system)<br>• Low- and middle-income countries (World Bank) |
| Interventions | • Initiatives aiming to promote early diagnosis<br>AND<br>• Initiatives addressing the patient/member of the public and at least two more levels of contextual influence (see Taplin et al)<br>AND<br>• National level initiatives or equivalent (i.e. State or Provincial level depending on health system structure and autonomy) | • Initiatives aiming to support the entire cancer trajectory or to reduce cancer disparities (in which early diagnosis is only a component)<br>• Initiatives focusing on primary prevention, surveillance programmes, genetic counselling, cancer recurrence or screening programmes<br>• Cost-effectiveness studies<br>• Initiatives addressing the patient/public only<br>• Small, localised research studies and purely academic research studies/projects |
| Comparators and outcomes | • Any comparators (studies without comparators are also eligible for inclusion)<br>• High-level outcomes (national or equivalent) related to the initiatives' main aims (e.g. improve awareness, diagnose cancer earlier)<br>• Overall views/experiences about initiatives | • Local, setting-specific outcomes<br>• Outcomes for a single cancer type (when strategies targeted more than one type) |

#### 4.2.2.1 Study designs and publication types

The review included quantitative (experimental and observational), qualitative and mixed-methods studies. Study protocols, editorials, commentaries, short reports, viewpoints, letters to the editor, theses, government reports and other policy documents were also eligible for inclusion as it was expected that they would have relevant information on initiatives. It was important to be inclusive regarding study designs and publication types (even including editorials, commentaries and short reports) in order to identify background information about initiatives. As the review aimed to understand the international landscape (as opposed to being focused on the effectiveness of interventions), background information was particularly important. From experience (and prior to carrying out the review), my supervisors and I were aware that these publication types were often used to introduce initiatives. This was the case for at least two well-known initiatives in England, for example (42, 240). Furthermore, we also expected that references in these short publications would guide us towards government reports and other publications with relevant information on eligible initiatives.

Conference abstracts were only eligible for inclusion if full-text articles were also available. Reviews/overviews were eligible if they were about a single initiative; otherwise they were excluded, and their references checked in order to identify additional relevant initiatives and publications. Published guidelines which were not part of a government initiative were not eligible for inclusion.

#### 4.2.2.2 Study population and setting

Initiatives aiming to promote earlier cancer diagnosis for the adult population (aged 18 and over) were included. All cancer types were eligible for inclusion. Early cancer diagnosis initiatives aiming at healthy participants or patients with any underlying medical conditions were eligible for inclusion. Initiatives targeting health care professionals, health care providers, institutions and governments were also eligible for inclusion. Initiatives carried out solely with professionals working on an administrative capacity were excluded.

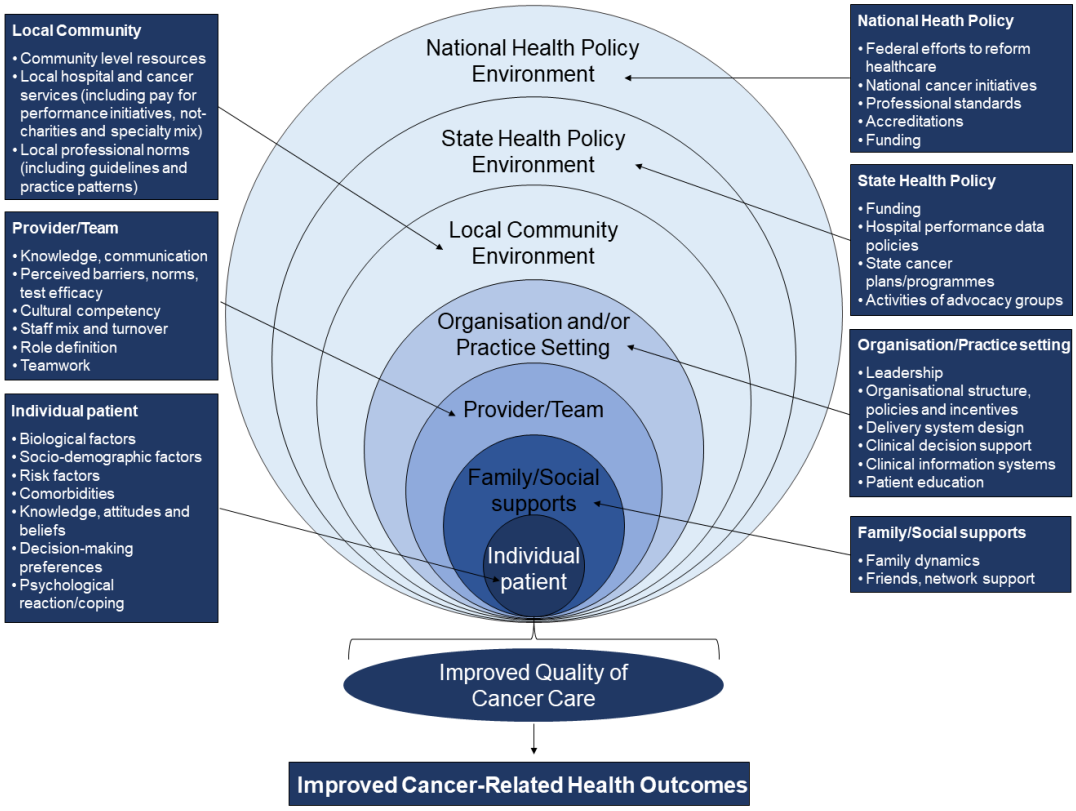
Only initiatives carried out in high-income countries as classified by the World Bank (241) were included. Low- and middle-income countries were excluded as it would have been challenging (and likely unfeasible) to compare review results with DCE activities in Scotland in order to answer the PhD research questions.

#### 4.2.2.3 Interventions

Interventions were defined as any "specified strategy or set of strategies designed to change the knowledge, perceptions, skills, and/or behaviour of individuals, groups, or organizations, with the aim of improving patients' health outcomes" (242).

National initiatives with the explicit aim of promoting earlier cancer diagnosis at a health system-level were included. Acknowledging a model of multiple levels of contextual influence in the cancer care continuum described in the literature (242), initiatives were only included if they addressed the patient (individual level) in addition to at least two more levels (Figure 4.1).

**Figure 4.1**. Multiple levels of contextual influence




***Source: adapted from Taplin and Rodgers 2012 (242)***

Interventions were also required to have involvement from governments (at State or National Level). Local research studies within an organisation and purely academic research studies were excluded.

I expected that initiatives would be about campaigns to increase knowledge/awareness of cancer, training for professionals, and development of pathways to cancer diagnosis and treatment. Initiatives focusing solely on primary cancer prevention, surveillance, genetic susceptibility of cancer, aiming to avoid cancer recurrence, or cost effectiveness studies were excluded. Publications solely describing cancer screening programmes were excluded as they referred to a different, extensive body of literature.

#### 4.2.2.4 Comparators

I expected that many included studies would not have comparators, as the review had a broader aim and included policy initiatives described in qualitative, quantitative and mixed-methods studies. Available comparators were likely to be: 1) indicators before (baseline) and after (one or more time points) at an individual and other levels; or 2) those in receipt versus those either not in receipt of any initiative or in receipt of a different initiative.

#### 4.2.2.5 Outcomes

The review aimed to *synthesise* initiatives and their characteristics rather than assess all available outcomes for each initiative, as I was aware that these analyses would not be feasible in a single review. Outcome data were reported on overall, high-level outcomes. Local outcomes reported for local, small studies were not described. Likewise, outcomes from pilot studies, needs assessment and development of initiatives were not reported. Finally, if more than one publication reported on the same outcomes for the same initiative, data were extracted from the most recently published publication (to avoid duplication and inaccuracies). Core publications for each initiative were identified (from which data were extracted), and all other relevant, additional publications with local outcomes were listed in Appendix 4.

I expected that high-level quantitative outcomes would include measures of knowledge/awareness of cancer, cancer symptoms or cancer screening, mortality, cancer survival and proxy measures such as cancer staging. Qualitative outcomes would include views or experiences from professionals regarding implementation, feasibility and acceptability of initiatives, patient and public views on the impact of the initiatives and the importance of outcomes (233). Qualitative findings were also likely to describe the context in which initiatives were implemented (233).

Finally, I was aware that some studies eligible for inclusion would be reporting on ongoing initiatives (for which outcome data would not yet be available) or would only describe components of eligible initiatives.

### 4.2.3 Search strategy

A search strategy was developed by listing keywords considered to be relevant based on my knowledge of available literature on cancer and early diagnosis (complemented by my supervisors' knowledge) and by examining search strategies from publications in the area (95, 243). It was then refined after discussions with Marshall Dozier, a Senior Academic Liaison Librarian at the UoE. Finally, it was tested to ensure it was identifying relevant publications, and not missing any initiatives that I was aware were likely to be included (such as 2-week wait in England, and different referral pathways in Denmark). It was challenging to define specific keywords based on the exploratory research questions as there was the risk of missing relevant studies. Furthermore, I expected that national health initiatives would not always be described as such. A decision was made to have a broad search strategy and to prioritise sensitivity over precision (238). The Medline search strategy is described in Table 4.2. Other search strategies are available in Appendix 5. Government, charity websites and data repositories for randomised controlled trials and studies funded by the European Commission were also checked (Table 4.3).

**Table 4.2.** Medline Search Strategy

| | Search Terms |
|---|---|
| 1 | government or policy$ or policies or national or regional or multi-level$ or system-level or whole-system$ or NAEDI or "Detect Cancer Early" or "National Awareness and Early Diagnosis Initiative" or "Find Cancer Early" or "Be Cancer Aware" or "Be Clear on Cancer" or initiative$ or program$ or campaign$ or strateg$ or engagement or awareness.mp |
| 2 | health$ adj2 (care or service$ or system$ or seek$ or provi$).mp |
| 3 | surviv$.mp |
| 4 | delay$ adj4 (diagnos$ or present$ or treat$ or consult$ or patient$ or doctor$ or system$ or refer$ or therap$ or care or detect$).mp |
| 5 | time adj4 (diagnos$ or present$ or treat$ or refer$ or care or detect$).mp |
| 6 | late adj4 (diagnos$ or treat$ or refer$ or present$ or detect$).mp |
| 7 | earl$ adj4 (diagnos$ or present$ or treat$ or refer$ or therap$ or detect$).mp |
| 8 | 3 or 4 or 5 or 6 or 7 |
| 9 | Cancer$ or neoplas$ or tumour or tumor or malign$ or oncolog$.mp |
| 10 | Randomi$ or RCT or intervention or trial or cross-sectional or survey$ or questionnaire$ or train$ or "natural experiment" or interview$ or "focus group$" or "case study" or observation$ or time-series or "time series" or CBA or "controlled before and after" or "controlled before-after" or prospective or retrospective or cohort or case-control or cross-over or "case series" or case-reports or "case reports" or feasibility or pilot or narrative or qualitative or quantitative or mixed-methods or "mixed methods" or evaluat$ or assess$ or attitude$ or view$ or perception$ or perspective$ or "discourse analysis" or "content analysis" or "thematic analysis" or "narrative analysis" or phenomenolog$ or "purposive sampl$" or ethnograph$ or "theoretical sampl$" or "grounded theory".mp |
| 11 | 1 and 2 and 8 and 9 and 10 |
| 12 | 11 not (child$ or pediatric$ or paediatric$ or adolesc$ or teenag$).ti |
| 13 | 12 not (palliative or terminal or "end of life" or end-of-life or "advance directive$" or hospice$).ti |
| 14 | 13 not (biomarker$ or molecul$).ti. |
| 15 | limit 14 to (english language and humans and yr="2005 -Current") |

[a] ***".mp" searches automatically for subject heading (MeSH) fields***

**Table 4.3.** Electronic data sources

| Search platform/provider | Databases | |
|---|---|---|
| Cochrane Library (single search) | • Cochrane Database of Systematic Reviews (CDSR)<br>• Cochrane Central Register of Controlled Trials (CENTRAL)<br>• Database of Abstracts of Reviews of Effects (DARE) | • Health Technology Assessment Database (HTA)<br>• NHS Economic Evaluation Database |
| Ovid (searching each database independently) | • Embase Classic + Embase<br>• MEDLINE(R) and MEDLINE(R) In-Process & Other Non-Indexed Citations | • PsycInfo<br>• PsycARTICLES full-text |
| Web of Science Core Collection (single search) | • Scielo<br>• Science and Social Sciences<br>• Conference Proceedings in Science and Social Science & Humanities | |
| ProQuest (single search) | • ProQuest Dissertations & Theses Global<br>• Applied Social Sciences Index and Abstracts (ASSIA) | • International Bibliography of the Social Sciences (IBSS)<br>• PAIS International |
| EBSCOhost (single search) | • Cinahl Plus<br>SocINDEX with full-text | |
| Other sources of data | • *United Kingdom:* UK Department of Health Publications and Statistics; The Knowledge Network (NHS e-library); UK Clinical Research Network; Healthcare Management Information Consortium (HMIC) database<br>• *United States:* Centers for Disease Control and Prevention<br>• International Agency for Research on Cancer<br>• European Commission's Community Research and Development Information Service (CORDIS)<br>• OECD iLibrary<br>• *Charities worldwide:* Cancer Research UK, Marie Curie, Macmillan Cancer Care, The King's Fund, The Nuffield Trust, National Cancer Research Institute, World Cancer Research Fund International, American Lung Association, American Cancer Society, Cancer Research Institute, National Cancer Institute, Cancer Council Australia, Canadian Cancer Society, Danish Cancer Society, Cancer Society of New Zealand, German Cancer Aid, Irish Cancer Society, Dutch Cancer Society, Norwegian Cancer Society, Portuguese Cancer League,, Asociación Española Contra el Cáncer, Swedish Cancer Society, Nordic Cancer Union, German Cancer Society<br>• *Theses*: EThOS - Electronic Theses Online Service; Dart-Europe<br>• *Clinical Trials*: U.S. National Institutes of Health's Clinical Trials Database; WHO International Clinical Trials Registry Platform Search Portal; UK Clinical Trials Gateway<br>• *Grey literature*: Open Sigle | |

In addition to electronic sources, I checked the reference lists of all included publications. Finally, the list of included studies was checked by me and my supervisors to assess whether any relevant studies known to them were missing.

Studies published prior to 2005 were excluded (as this was when the WHO approved its resolution on Cancer Prevention and Control) (244). Only publications in English were included.

### 4.2.4 Data management, selection and extraction

Citations and abstracts were exported into EndNote X7 for Windows. After removing duplicates, studies were screened through the following procedures: 1) I screened all the titles and abstracts against the inclusion criteria, while one of my supervisors screened a random selection (30%) of the excluded studies at this step; 2) One of my supervisors and I independently screened the full-text of studies included in step 1; and 3) One of my supervisors and I carefully independently reassessed the full text of all studies included in step 2 (to ensure they had relevant information to be extracted – publications without this were excluded from the analysis). The study selection process was recorded in SPSS v.23 (245) for Windows and a PRISMA flow diagram (237) was developed. Disagreements were solved by consensus.

Other sources of data and references of included studies were searched by me. A list of potentially eligible initiatives was shared with one of my supervisors for discussion regarding eligibility. Likewise, disagreements were solved by consensus.

A data extraction template was created (Appendix 6) to record information on the initiatives' characteristics and key components, target populations and outcomes, in addition to study design, setting, location, and participants' views. Data extraction was carried out by me and a postgraduate student at the UoE. The data extraction form was piloted with three randomly selected included studies. Forms were compared in order to reduce bias and ensure data extraction was being done in a consistent manner. Then, I extracted data from 50% of the included initiatives and a Master of Public Health (MPH) student extracted data from the remaining 50%. This student (Ms Orjola Shahaj) was recruited in order to ensure that quality assessment was carried out by independent reviewers and data extraction was completed in a timely manner. Orjola had experience working in systematic reviews and had just completed a Cochrane review as part of her studies. Initiatives were randomly selected for data extraction (initiative names were written in paper, folded, and picked up from a box).

All data extraction forms were checked again (by me) against original sources of data prior to data synthesis.

### 4.2.5 Quality assessment

As it was expected that the included studies would vary in terms of design, and most of them would be observational (125), more than one tool was used to assess quality. Study quality was not part of the inclusion criteria; as there were concerns about missing relevant studies describing eligible initiatives if doing so.

Quantitative studies were analysed using the McMaster Critical Review Form for Quantitative Studies (246). This tool had multiple choice questions regarding the study purpose, literature, design, sample, outcomes, intervention, results, conclusions and implications. It also had open-ended questions regarding bias, validity and reliability, allowing for the assessment to be carried out for different observational designs (246). Initially I had considered using the method of scoring descriptive studies developed by Mitchell and colleagues as it had been used in reviews investigating factors associated with delays in cancer diagnoses (247, 248). However, the McMaster Form was used instead as it allowed for a comprehensive description of study limitations, in addition to approaching risk of bias.

Qualitative studies were assessed using the quality assessment tool from Hawker and colleagues (249). The original tool had nine items; one of them was divided into two so issues regarding ethics and bias could be assessed separately. I had already successfully applied this adaptation in a previous systematic review assessing a range of qualitative studies (250). Each item allowed for four possible answer options (“good”, “fair”, “poor” and “very poor”). Editorials, commentaries, and viewpoints were also assessed using this tool.

Letters to the editor, conference abstracts, government reports and cancer plans were not assessed for quality as I did not identify any appropriate tools to do so. Potential methodological issues and implications for the review findings were discussed in a narrative format (Chapter 10). Reviews and systematic reviews were assessed using the validated Oxman and Guyatt’s 10-item checklist (Overview Quality Assessment Questionnaire) (251, 252). Initial considerations to use AMSTAR (253-256) were abandoned as it did not perform well with non-systematic reviews during piloting.

Mixed-methods studies were assessed using the tools for qualitative and quantitative studies. No summed quality scores were calculated due to recognised problems when doing so (257, 258). Quality assessment results were prepared for all included studies eligible for quality assessment and for each study separately.

Each study was independently assessed by me and a second reviewer (a visiting medical student from the Netherlands or the MPH student who also did 50% of the data extraction) with disagreements solved by consensus. Interrater reliability was calculated using both percentage agreement and Cohen's kappa scores in order to control for agreement by chance (259, 260). Cohen's kappa was calculated using SPSS v.23 (245). Unweighted Cohen's kappa was used for nominal data and weighted kappa was used for ordinal data (i.e. giving greater emphasis to large differences between reviewer ratings compared to small differences) (261). Landis and Koch guidelines were used to assess strength of agreement for kappa scores (<0.00 poor; 0.00-0.20 slight; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 substantial; and 0.81-1.00 almost perfect agreement) (262). Confidence intervals (CIs) for weighted kappa scores were calculated using the formula ($k - 1.96 \times SE_k$ to $k + 1.96 \times SE_{k;}$ - with SE representing standard errors and k representing the kappa scores) (260).

### 4.2.6 Data synthesis

Narrative synthesis was chosen instead of meta-analysis for several reasons. Firstly, heterogeneity was expected in the composition and intensity of initiatives, populations and contexts (234, 263). Narrative synthesis is often used when there is heterogeneity (239, 263). The method relies on using words and text to "tell a story" of findings (264). Secondly, narrative synthesis is useful in reviews that do not focus on the effectiveness of interventions (263) and is a good fit for complex interventions (233). Finally, narrative synthesis is effective to synthesise both qualitative and quantitative evidence (265) and to describe different study contexts and designs (266). Guidelines for using narrative synthesis (264) were followed.

Findings were described in diagrams, text and tables, focusing on key features of initiatives (including contextual issues such as drivers and influencers, described policies and source of funding); key components (such as referral guidelines); and target populations. Findings were categorised according to Taplin et al's model of multi-level influences on the cancer care continuum (242), and the updated NAEDI's

hypothesis of factors influencing cancer survival and premature mortality (shown in Figure 2.4) (130). A general overview of included initiatives was prepared, followed by findings corresponding to each of the four review questions. For feasibility purposes and to ensure reporting of high-level data, any detailed information about included initiatives was only provided in Appendices.

## 4.3 Review results

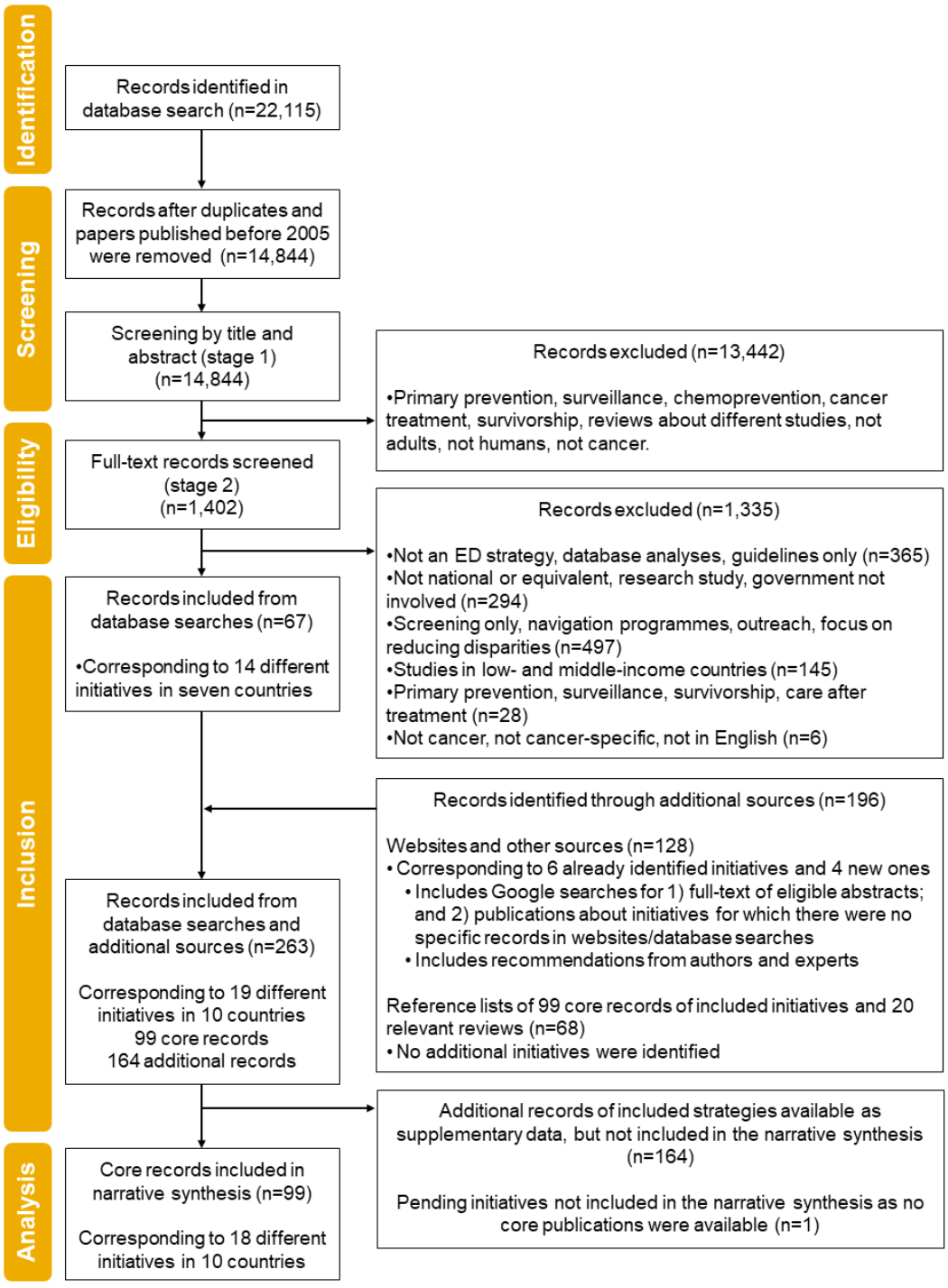
### 4.3.1 Study selection

Database searches were carried out on the 13th September 2016, while website searches were carried out in April and May 2017. Exact dates and hits in each database/website are available (Appendix 8).

A total of 22,115 records were identified in databases, these were reduced to 14,844 after removing duplicates and studies which had been published before 2005. A total of 13,442 records were excluded in stage 1 (title and abstract screening), and 1,335 in stage 2 (full-text screening), resulting in 67 records included from the database searches.

Additional searches (websites and other sources and reference lists of included records) resulted in further 196 included records. Overall, 263 records corresponding to 19 initiatives in ten countries met inclusion criteria (Figure 4.2). Data were extracted from 99 core publications describing 18 initiatives; a list of the remaining 164 records is available (Appendix 4). There were no core publications for “Be Cancer Aware”, a cancer awareness programme in Northern Ireland which met criteria for inclusion (267).

**Figure 4.2.** PRISMA flowchart




About a third of core publications (n=32) were peer-reviewed publications; these were independently assessed for quality. The remaining core publications consisted of reports (n=45), official government correspondence (n=9), official Cancer Plan or Cancer Strategy (n=7), theses (n=3), news pieces (n=2) and a power point presentation (n=1).

## 4.3.2 Quality assessment

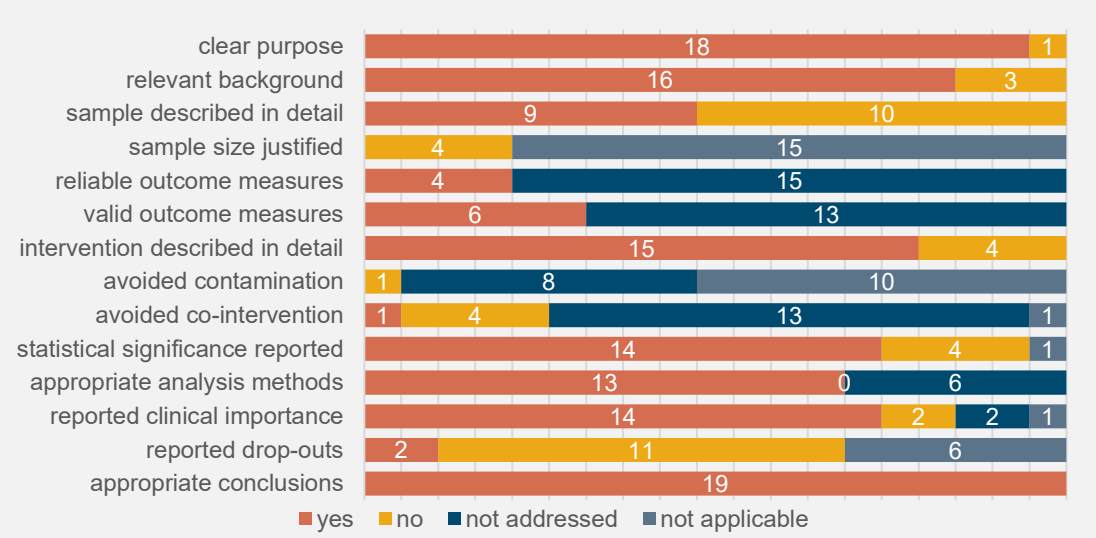
Fifteen publications were assessed using the McMaster Critical Review Form for Quantitative Studies, nine using the tool for qualitative studies; four using both tools and four using the OACC tool for reviews. Tables describing quality assessment for each publication and results for the interrater reliability assessment are available (Appendix 7).

Percentage agreement across raters varied from 30.8% (question 10 in the tool for qualitative studies – importance of findings to policy and practice) to 100% (several questions in each tool). There were wide variations in agreement across questions and quality assessment tools (especially for tools assessing qualitative and quantitative studies). Disagreements between raters were common and solved by consensus. This variation was influenced by challenges in using tools for studies with a range of designs, even though tools were piloted to assess suitability and reduce variability. Low percentage agreement for several items indicated low interrater reliability. Similarly, there was wide variation regarding strength of agreement across different tools (measured using Cohen's kappa). Strength of agreement varied from slight agreement to almost perfect agreement. Fair (k=0.21-0.40) strength of agreement was often reported for the quantitative tool (strength was often higher for other tools); this also indicated low interrater reliability.

### 4.3.2.1 Quantitative studies or mixed-methods studies with a quantitative component

Key study limitations referred to the sample not being described in detail (n=10), no mention of validity (n=13) or reliability (n=15) for outcome measures, not addressing potential contamination (n=8) nor co-interventions (n=13) (Figure 4.3). Key issues in terms of bias, validity and reliability referred to study design (i.e. observational studies without a control group - there were four case-controls and no trials), limited information on the socio-demographic characteristics of cohorts and providing only brief descriptions of adopted methods.

**Figure 4.3.** Quality assessment: quantitative studies (n=19)

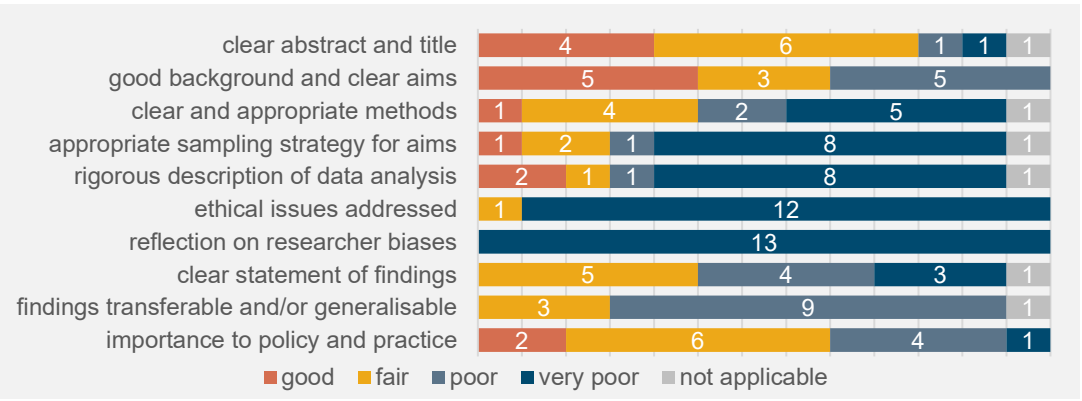



***When the sample size was not justified, but the whole population of interest was included in the study, the question was deemed not applicable. When there was no control group, contamination was deemed not applicable. When there was no justification for the methods used; the issue was deemed not addressed. The question about drop-outs was not applicable depending on the study design.***

#### 4.3.2.2 Qualitative studies or mixed-methods studies with a qualitative component

More than half of the studies (n=7) had either a very poor or poor description of methods, nine did not mention sampling, nine had either poor or very poor description of data analysis, all but one did not address ethical issues, no studies discussed potential biases between researchers and participants, and seven had either poor or very poor statements of findings (Figure 4.4). There were challenges in using the tool for editorials/commentary papers, and it is likely that the large number of poor/not applicable ratings was influenced by this.

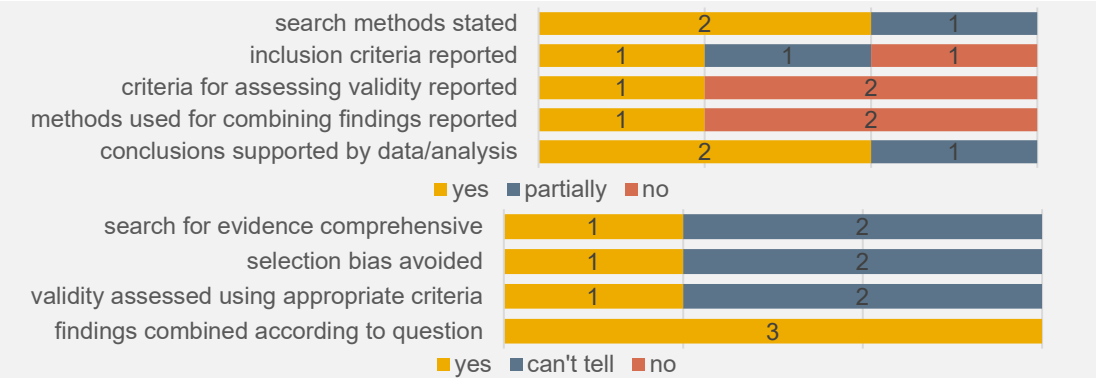
**Figure 4.4.** Quality assessment: qualitative studies (n=13)



#### 4.3.2.3 Reviews

All included reviews referred to the same initiative (2-week wait in England) (268-270); two publications were assessed together as they referred to the same review (270). In terms of rated scientific quality, one review had “minimal flaws” (score 7/7), while two had “mid-range extensive to major flaws” (score 2/7). For the latter two, it was not possible to tell if the search for evidence was reasonably comprehensive nor if bias in the selection of studies was avoided. Furthermore, there was no reporting of the criteria to assess study validity. Finally, both reviews did not mention the methods used to combine findings (Figure 4.5).

**Figure 4.5.** Quality assessment: reviews (n=3)




## 4.3.3 Characteristics of included initiatives

#### 4.3.3.1 Country where initiative was implemented

Most strategies were based in Europe (n=13) and North America (n=3). The UK had the highest number of strategies (n=5). Three initiatives were carried out in Spain, two in the United States, two in Denmark and one in each of the remaining countries (Australia, Canada, Norway, Qatar, Republic of Ireland and Sweden).

#### 4.3.3.2 Study designs

There were no randomised controlled trials; all quantitative studies or studies with a quantitative component were observational studies. Before-and-after (BA) or pre-post studies and cross-sectional studies (often descriptive studies of a specific population or online/paper questionnaire surveys) were the most commonly adopted observational designs. When comparators were used in BA studies, they were often time-period controls or geographical controls. Most qualitative studies or studies with a qualitative component adopted interviews or focus groups to collect data. Other designs included systematic reviews and PhD theses (Table 4.4).

**Table 4.4.** Study designs adopted by included studies

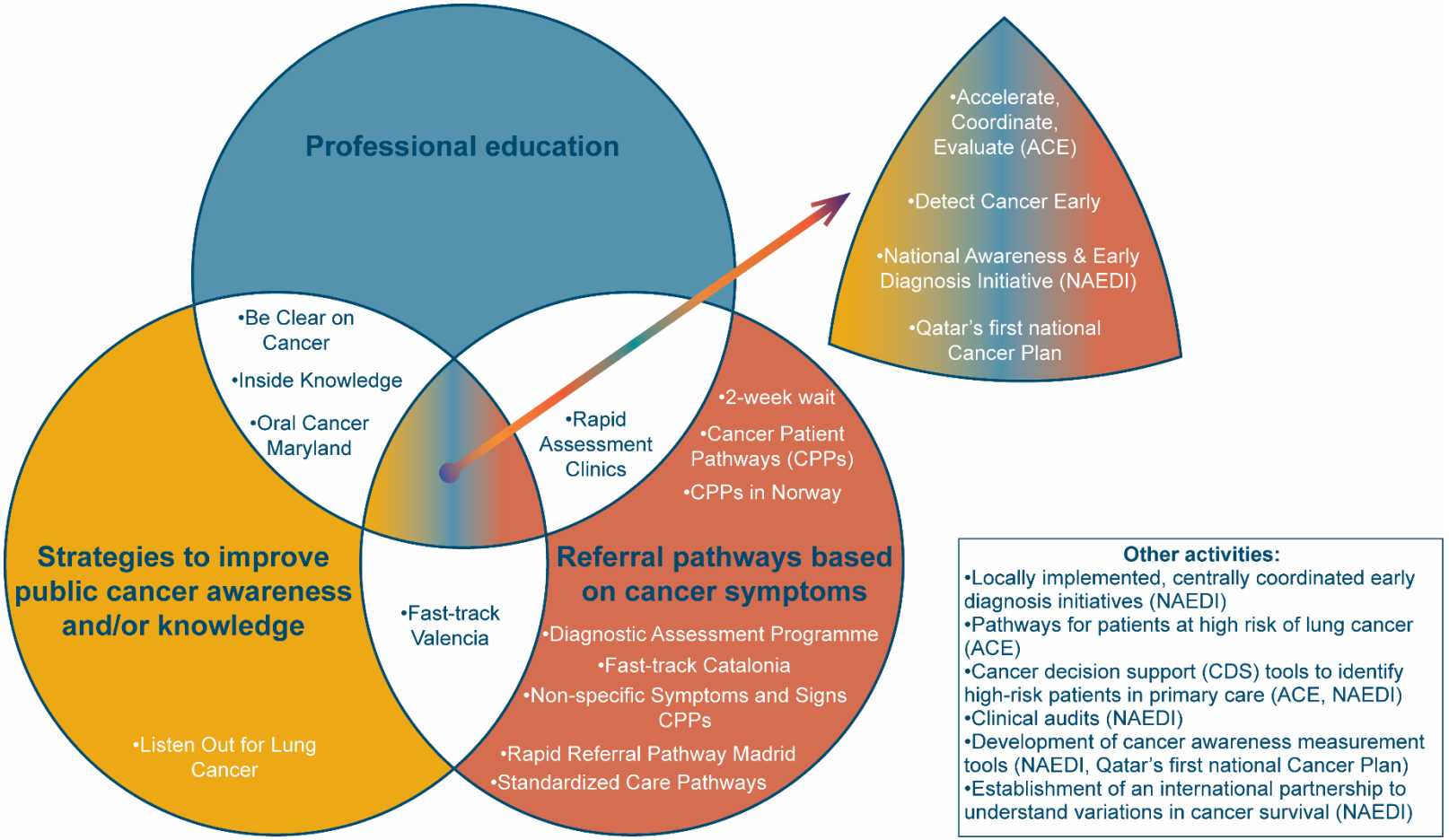
| | Quantitative | | | | Qualitative | | | Other |
|---|---|---|---|---|---|---|---|---|
| | Cohort | Before-and-after / pre-post | Cross-sectional | Other | Interviews | Focus groups | Other | |
| 2 week-wait (2WW) | ◆ | ◆ | ◆ | ◆ | | | | ◆ |
| Accelerate, Coordinate, Evaluate (ACE) | ◆ | | ◆ | | ◆ | | | |
| Be Clear on Cancer (BCOC) | | ◆* | | | | | | |
| Cancer Patient Pathways (CPPs) | ◆ | ◆ | ◆ | | | | | ◆ |
| Detect Cancer Early (DCE) | | ◆ | ◆ | | | | | |
| Diagnostic Assessment Pathways (DAPs) | ◆ | | | | | | | |
| Fast-track Catalonia | ◆ | | | | ◆ | | | |
| Fast-track Valencia | | | ◆ | | | | | |
| Inside Knowledge | | ◆ | ◆ | | | ◆ | | |
| Listen out for lung cancer | | ◆ | ◆ | | ◆ | ◆ | | |
| National Awareness and Early Diagnosis Initiative (NAEDI) | | ◆* | ◆ | ◆ | ◆ | ◆ | | |
| Non-specific symptoms and signs (NSS) CPPs | | | ◆ | | | | | ◆ |
| Norwegian CPPs | | | | | | | ◆ | |
| Oral Cancer Maryland | | ◆ | ◆ | | | ◆ | | |
| Rapid Assessment Clinic (RAC) | | | ◆ | | | | | |
| Qatar's first national Cancer Plan | | | | | | | | |
| Rapid Referral Pathway Madrid | ◆ | | | | | | | |
| Standardised care pathways (SCPs) | | | | | | | | |

**** Indicates that geographical or time-defined controls were often (but not always) used. Notes: Other quantitative design includes time series analysis (2WW), case-control study (NAEDI) and impact and outcome evaluation studies (NAEDI). Other qualitative design comprised theoretical and analytical analysis of online data drawing upon critical discourse analysis (CPPs in Norway). Other design includes PhD theses (CPPs and NSS-CPPs), systematic and non-systematic reviews (2WW), review of waiting times standards (which included stakeholder engagement) and guideline development (2WW).***

#### 4.3.3.3 Types of strategy

The 18 included initiatives were categorised into: strategies to improve cancer awareness and/or knowledge among the public; professional education strategies; referral pathways based on cancer symptoms; or combinations of these strategies (Figure 4.6). Half of the initiatives comprised at least two of these strategies. Three initiatives not only comprised all three strategies; but also developed other activities.

**Figure 4.6.** Types of strategy



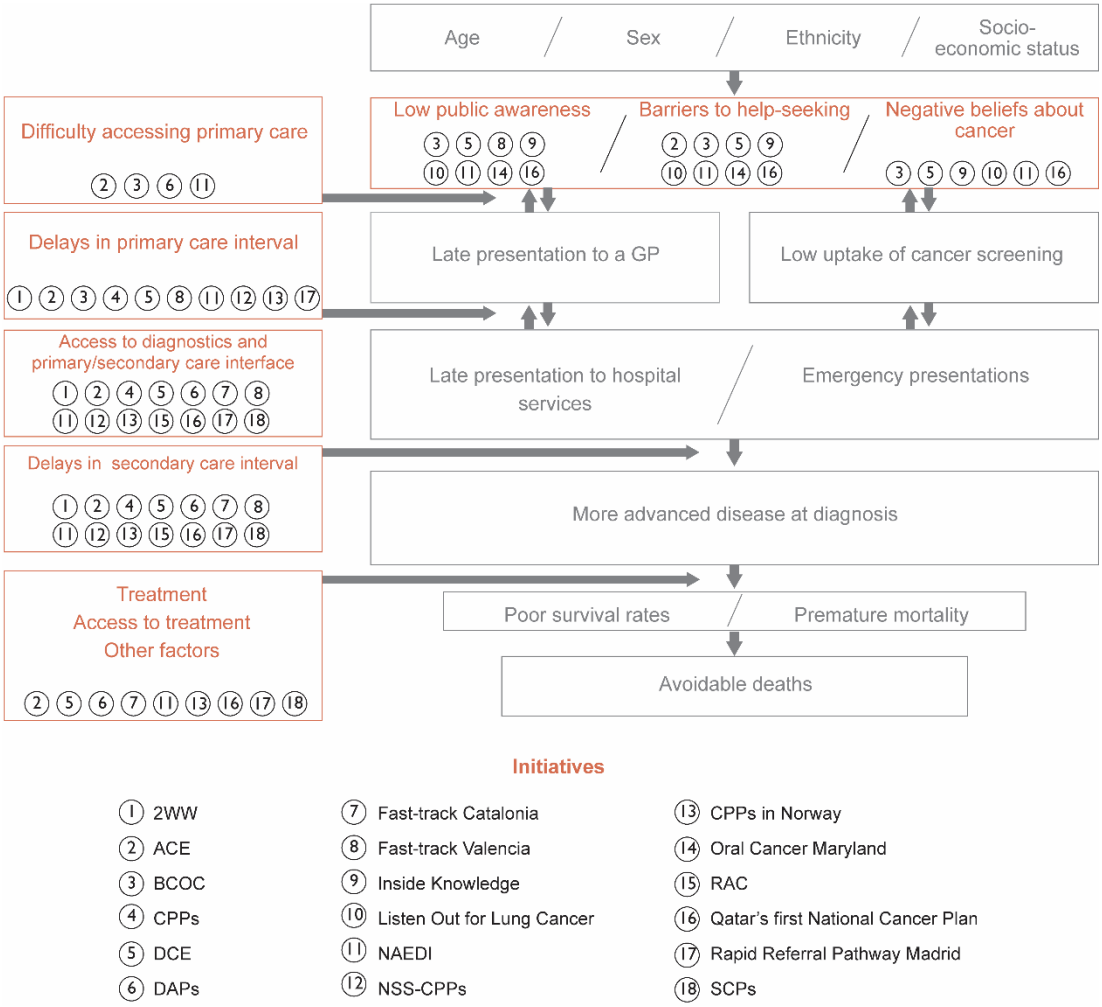
Initiatives are not fully independent: BCOC was created under the auspices of NAEDI before becoming an independent strategy (271). One of the ACE projects initially received NAEDI funding (272). The NSS-CPP was developed to complement the pre-existing Danish CPPs (273). More recent strategies (such as ACE and Qatar's first national Cancer Plan) often referred to established initiatives in other countries (especially in England and Denmark).

#### 4.3.3.4 Placing initiatives into theoretical and evidence-based frameworks/models

All initiatives addressed the individual level of contextual influence described by Taplin and colleagues (242) (part of the inclusion criteria). The least often addressed level was family/social supports (n=6). All other levels were consistently addressed, except for the National Health Policy Environment as initiatives in Spain, Australia, Canada and the United States (except for Inside Knowledge) took place at State/Provincial level only.

When considering NAEDI's updated hypothesis of factors influencing cancer survival and premature mortality (130), most initiatives targeted factors associated with health systems such as access to diagnostics (n=14), delays in the secondary care interval (n=14), and delays in primary care interval (n=10). Difficulty accessing primary care was the least often targeted factor (n=4). Regarding patient factors, low public awareness (n=8) and barriers to help-seeking (n=8) were targeted more often than negative beliefs about cancer (n=6). (Figure 4.7)

**Figure 4.7**. Initiatives according to the updated NAEDI model




***Source: Adapted from Hiom 2015 (130)***

#### 4.3.3.5 Drivers, rationale and aims of the included initiatives

Most of the included strategies were driven by the high burden of cancer incidence and mortality and the need to improve cancer survival (this could be to improve performance either within a country in order to reduce disparities or when compared to other countries with better cancer outcomes) (Appendix 9). In contrast, Standardised Care Pathways (SCPs) were implemented in Sweden, a country with good cancer survival and good quality of cancer services, in order to improve patient satisfaction (274). In Qatar, the burden of cancer will be an issue in the future, as the country's population is still considerably young (275).

There was wide recognition of the role of late diagnosis in cancer survival and poorer cancer outcomes (and this was often described as a rationale for the developed

strategies); some strategies also acknowledged the role of other factors in cancer survival. A few also recognised the psychological impact of longer diagnostic intervals. The limitations of screening and the fact that most cancers are diagnosed through symptomatic presentation were also reported; and at times used as a justification for the need to involve and better support a range of primary care professionals in early diagnosis. The need to change a perceived low awareness of screening and cancer symptoms and signs (which was reported to vary across different population groups) was provided as a rationale for awareness raising initiatives. Comprehensive information on drivers and rationale for each initiative is available in Appendix 9.

The initiatives aimed to improve cancer survival and promote early cancer diagnosis mainly through promoting/encouraging early presentation and reducing diagnostic intervals in the health system. Some initiatives also explicitly aimed to improve patient satisfaction and quality of care (through the development of more efficient pathways, improvement of communication between health care professionals and between professionals and patients). (Table 4.5).

**Table 4.5.** Aims and core references for included initiatives

| Initiative and country | Aims and core references |
|---|---|
| 2WW<br>England, UK | Improve prompt access to specialist services as part of a larger strategy to improve cancer outcomes (81, 268-270, 276-285) |
| ACE<br>England, UK | Address the NHS outcome of "preventing people from dying prematurely"; improve overall patient experience along the diagnostic pathway; and accelerate changes by adding to the knowledge base. Each ACE component/cluster had a specific aim (72, 88, 240, 272, 286-291) |
| BCOC<br>England and Wales, UK | Support earlier diagnosis of cancer and improve survival rates by: 1) highlighting cancer signs and symptoms to increase public awareness; and 2) encourage prompt health seeking (176, 177, 292-306) |
| CPPs<br>Denmark | Increase cancer survival rates through reducing system delay (reducing waiting time and ensuring earlier/faster diagnosis), improving the health status of cancer patients and increasing satisfaction (by ensuring fast treatment, continuity of care and reducing distress) (80, 179, 307-310) |
| DCE<br>Scotland, UK | Key aim: improve overall 5-year cancer survival. Objectives included: increase the proportion of cancer diagnosed at Stage I; improve informed consent and screening participation; raise public awareness of screening, cancer symptoms and signs; promote early referral or investigation; ensure there is sufficient screening, diagnostic and treatment capacity; strengthen data collection (138, 311-317) |
| DAPs<br>Ontario, Canada | Improve care quality and patient experience through shorter waiting times and improved care coordination (318, 319) |
| Fast-track Catalonia<br>Catalonia, Spain | Reduce the time passed between a well-founded suspicion of cancer and the start of initial treatment (320) |

| Initiative and country | Aims and core references |
|---|---|
| Fast-track Valencia Valencia, Spain | Improve communication between primary and specialised care, helping primary care to decide which patients should be urgently evaluated by a hospital specialist in order to reduce time to diagnosis (321) |
| Inside Knowledge US | Inform women and healthcare providers about the signs, symptoms, risk factors, and prevention strategies related to gynaecological cancers, and increase knowledge of HPV and the HPV vaccine. Align care with evidence-based recommendations (322-330) |
| Listen out for lung cancer New South Wales, Australia | Assess behaviour and knowledge regarding lung cancer (campaign development only) (331) |
| NAEDI England and Wales, UK | Improve cancer survival and reduce premature mortality by reducing the number and proportion of cancers diagnosed and treated at a late stage; improve outcomes for patients; provide leadership and support to activities and research that promote early diagnosis; and assemble existing and new evidence linking awareness, early diagnosis and poor survival. NAEDI components had specific aims (42, 130, 150, 332-340) |
| NSS-CPPs Denmark | Account for the fact that: 1) patients with cancer in its earlier stages present very differently in general practice; and 2) a single focus on alarm symptoms or red flags may not be sufficient (85, 273, 341) |
| Norwegian CPPs Norway | Provide an organised, coherent and predictable pathway to cancer patients without unnecessary, non-medically justified delays in assessment, diagnosis, treatment and rehabilitation (342) |
| Oral Cancer Maryland US | Increase public and professional awareness/knowledge of oral cancer prevention/early detection; increase examinations; and develop activities to improve access to prevention, early detection and treatment (343) |
| RAC Republic of Ireland | 1) Accelerate the diagnostic process for patients with highly suspicious signs and/or symptoms of lung cancer and improve access to treatment; 2) Provide rapid access to a consultant opinion, and prostate biopsy if appropriate, to patients likely to have prostate cancer (344, 345) |
| Qatar's first national Cancer Plan Qatar | Improve cancer outcomes and prepare for population changes (no specific aim described) (275, 346-349) |
| Rapid Referral Pathway Madrid, Spain | Ensure that patients suspected of having colorectal cancer undergo colonoscopy within 15 days. Other targets: under 30 days waiting time to surgery/under 90 days overall waiting time to surgery (350) |
| SCPs Sweden | Part of a larger Cancer Strategy aiming to speed up cancer treatment. Three objectives: 1) to reduce waiting times from cancer suspicion to start of first treatment; 2) to increase patient satisfaction with cancer care; and 3) to reduce regional inequalities in cancer care. In the long term, it is expected that health services other than cancer will benefit from new and more streamlined ways of working (274, 351) |

## 4.3.4 Key components of included initiatives

### 4.3.4.1 Start dates

Oral Cancer Maryland is likely to be the earliest identified multilevel policy initiative. Although it is not fully clear when it was implemented, publications show that needs assessment activities commenced in the mid-1990s, while outcomes were assessed from 2000-2005 (343).

The 2WW initiative in England was the earliest initiative focusing on pathways for patients with symptoms indicating a high risk of cancer (1999-2000), and it was often mentioned by other initiatives. The NSS-CPP in Denmark (launched in 2012) was the first identified initiative developing different pathways for patients who did not present with high-risk symptoms (273). Finally, NAEDI in England (launched in 2008) (42) was the first national initiative to adopt multiple early diagnosis strategies.

#### 4.3.4.2 Key Stakeholders

As required by the review's inclusion criteria, all initiatives had key government involvement, often through their Department of Health, National Cancer Control Programme or equivalent. There was support from a range of other government departments, such as official data providers and purposively built, newly created bodies (these included intelligence networks, guideline development groups, implementation groups and transformation groups). Likewise, even when considering that not all countries had universal healthcare, all initiatives were either partially or fully funded by the government. Other funding often came from charity partners; only one initiative reported having received private donations (343).

Some initiatives were described as government-led in partnerships with charities or other not-for-profit organisations (such as professional bodies) (Table 4.6). All initiatives in the UK involved not-for-profit organisations. There was less involvement from for-profit stakeholders; these included marketing research companies working on awareness campaigns and providers of health care services in countries without universal healthcare. Only four initiatives mentioned involvement of patient representatives (Table 4.6). A comprehensive list of stakeholders is available (Appendix 10).

**Table 4.6.** Key stakeholders in addition to the national/state government

| Initiative | Charities, not-for-profit, advocacy | For profit | Academics, Scientists | Health care professionals | Patient reps |
|---|---|---|---|---|---|
| 2WW | ◆ | | ◆ | ◆ | ◆ |
| ACE | ◆ | | ◆ | ◆ | |
| BCOC | ◆ | ◆ | ◆ | ◆ | |
| CPPs | ◆ | | ◆ | ◆ | |
| DCE | ◆ | ◆ | | ◆ | |
| DAPs | ◆ | ◆ | | ◆ | |
| Fast-track Catalonia | | ◆ | | ◆ | |
| Fast-track Valencia | | | | ◆ | |
| Inside Knowledge | ◆ | | ◆ | ◆ | ◆ |

| Initiative | Charities, not-for-profit, advocacy | For profit | Academics, Scientists | Health care professionals | Patient reps |
|---|---|---|---|---|---|
| Listen out for lung cancer | ◆ | | | | |
| NAEDI | ◆ | | ◆ | ◆ | ◆ |
| NSS-CPPs | | | | ◆ | |
| CPPs in Norway | | | | ◆ | |
| Oral Cancer Maryland | ◆ | ◆ | ◆ | ◆ | |
| RAC | ◆ | | | ◆ | |
| Qatar's first national Cancer Plan | ◆ | ◆ | ◆ | ◆ | |
| Rapid Referral Pathway Madrid | | | | ◆ | |
| SCPs | | | | ◆ | ◆ |

***Abbreviations: reps: representatives***

#### 4.3.4.3 Policies

Initiatives in the UK mentioned cancer strategies published in England (134, 271, 337) and Scotland (136). Initiatives in Denmark mentioned the first two national cancer plans in this country, reported to be published in 2000 and 2005 (352, 353). Inside Knowledge referred to the Gynaecologic Cancer Education and Awareness Act of 2005, often described as Johanna's Law (354). Oral Cancer Maryland cited the Maryland Comprehensive Control Plan for 2004-2008 (355). The strategies carried out in Qatar are all part of the country's first national cancer strategy (347). The Swedish SCPs referred to the 2009 Swedish National Cancer strategy (351). National Cancer Control Programmes were also mentioned by the Rapid Access Clinics in Ireland (345) and Fast-Track Valencia (356).

#### 4.3.4.4 Initiatives and their key components

Initiatives adopting strategies to improve cancer awareness and/or knowledge among the public were characterised by initial work assessing population awareness, consultation with specialists (and sometimes with the public) to develop campaigns and information materials. A wide range of media (such as television, radio, social media and printed advertising) was used, and campaign materials were often shared online. Community, face-to-face events with the presence of trained staff and/or health care professionals were also adopted (Table 4.7).

Initiatives adopting professional education strategies comprised professional development, meetings, educational/training sessions to enable staff to recognise cancer symptoms and signs, to ask questions about strategies, to learn about early detection examinations and referral processes; to promote different ways to

incentivise early detection in community pharmacies; to learn how to use CDS tools in primary care; and to hone communication skills with patients (Table 4.7).

Initiatives that included referral pathways based on cancer symptoms focused on high-risk symptoms, serious, non-specific or vague symptoms. Pathways based on high-risk symptoms were often characterised by the development of guidelines (outlining such symptoms, recommending timelines for diagnosis and treatment, and often procedures and care). Guidelines were often evidence-based, developed with input from clinical specialists, and relevant organisational bodies. Patients or patient organisations were involved less often. Other common features were assigned pathway coordinators and defined waiting times targets or performance indicators (not only for referral and diagnostic investigations, but also for treatment/surgery). The development of pathways based on serious, non-specific and/or vague symptoms and the implementation of multidisciplinary diagnostic centres were more recent and less common strategies (i.e. NSS-CPP in Denmark and ACE in England); there were no references to national targets nor specific guidelines (Table 4.7).

*Tumour types*

Only two initiatives targeted a single tumour type; these were Listen Out for Lung Cancer in Australia (331) and Rapid Referral Pathway Madrid in Spain (which targeted colorectal cancer) (350). Choice of tumour type was often based on its importance in terms of cancer incidence/mortality, but at times it was also due to the recognition of associated challenges (e.g. treatment issues) or facilitators (such as the availability of clinical guidelines). Lung, colorectal and breast were the tumour types most commonly targeted, followed by prostate cancer (Table 4.7).

**Table 4.7.** Key components of included initiatives

| Initiative and start date | Key components |
|---|---|
| 2WW<br><br>Launched in 1999 (breast) and 2000 (all other cancers) | • **Wide range of tumour types**<br>• **Patient to be seen in secondary care within two weeks of the initial referral**. Other targets (Cancer Waiting Times) comprised 31 days (first definitive cancer treatment to begin within one month of being informed of diagnosis and agreeing a care plan) and 62 days (first definitive cancer treatment to begin within 62 days of being urgently referred by the GP/being referred from an NHS Cancer Screening Service). An operational standard of 93% was set and targets were monitored<br>• **Referral guidelines** approached high risk symptoms and recommended processes and care; **a 'risk threshold'** (3% positive predictive value or PPV) underpinned recommendations |
| ACE<br><br>Wave 1 launched in 2015<br>Wave 2 pilots live in 2017 | • **Wide range of tumour types**, often lung and colorectal for Wave 1<br>• Wave 1: **about 60 projects across England, split into eight clusters**: 1) new approaches for patients presenting with vague but concerning symptoms (e.g. new pathways and audits); 2) effective ways to remove barriers to screening for the vulnerable and minorities; 3) training for non-GP primary care professionals and pharmacies on how to promote early diagnosis; 4) pathways from lung cancer referral to diagnosis using proactive approaches for people at high risk of lung cancer (offers of CT scans and self-referral to CXR) and improving lung cancer pathways for people presenting with concerning symptoms; 5) use of CDS tools to identify high risk patients; 6) use of colorectal cancer pathways and referral thresholds; 7) effective strategies to improve bowel screening uptake among deprived groups; and 8) cost-effective approaches to find lung cancer early<br>• Wave 2: **'one-stop' diagnostic pathways for patients with non-specific but concerning symptoms, using Multidisciplinary Diagnostic Centres** (similar to the NSS-CPP in Denmark). There were five different projects; some looked at GP referrals, others considered self-referrals and referrals of patients who present at A&E departments |
| BCOC<br><br>Launched in 2011 | • **Tumour-specific** (bowel, lung, kidney, bladder, breast, ovarian, oesophageal, skin, and prostate cancers) and **symptomatic campaigns**: clear and concise information, highlighting the importance of key cancer symptoms and when to act.<br>• **Use of TV, radio and print advertising**. Web pages provided key information, more details on cancer symptoms and signs and campaign materials. Local pilots used community engagement strategies so the public could talk face-to-face to trained staff<br>• Other pilots held education sessions for primary and secondary care professionals. A community champion was assigned |
| CPPs<br><br>Launched in 2007 | • Included a **wide range of tumour types**; pathways were developed for 32 cancer sites<br>• Recommended **timelines for referral until first appointment with specialist/hospital, first hospital visit until diagnosis**, diagnosis until start of treatment, and overall referral until time of treatment. There was explicit identification of who was responsible for each phase. **Timelines varied according to tumour type**. For example, a patient with a "reasonable suspicion" of colorectal cancer should be seen by a specialist within nine days of referral. Targets were monitored<br>• **Referral guidelines** approached high-risk symptoms, recommended treatment, processes and care |

| Initiative and start date | Key components |
|---|---|
| DCE<br><br>Launched in 2012 | • Included a **wide range of tumour types** overall; campaigns and targets focused on breast, lung and colorectal cancers<br>• **Public Awareness and behaviour influencing:** awareness campaigns for the public (overarching and tumour specific)<br>• Primary care symptom management and referral: **awareness raising of cancer symptoms and signs among primary care** professionals; **update of referral guidelines** for patients with high-risk symptoms. There were **no specific targets described for referral nor diagnosis**, although there were other targets: 31-days from decision to treat until first treatment and 62-days from urgent referral with suspicion of cancer until first treatment. An operational standard of 95% was set<br>• Cancer screening and diagnostic capacity: **funds to expand capacity**, redesign services, develop pathways and action plans<br>• Performance management: development of a **HEAT target: improvement of cancers diagnosed at Stage I** (25% increase for lung, breast and bowel cancers), and financial rewards for reduction in bowel screening non-participation |
| DAP<br><br>Date not clear, likely 2004/2005 | • **Breast, lung, colorectal and prostate cancers**<br>• DAPs provided a **single point of access by concentrating/coordinating referral processes** from various points of entry from the time from initial abnormal results to the date of diagnosis. Clinical units provided multiple diagnostic services in one place (if appropriate, within one visit). Rapid access and priority booking were available |
| Fast-track Catalonia<br><br>Launched in 2005 | • **Breast, colorectal and lung cancers**<br>• A **fast-track programme synchronised clinical needs of patients with a high risk of cancer by implementing passive (e.g., slots in diagnostic tests) or active (e.g., case management) measures**. Included cases originated from GP referrals, screening and emergencies. Two organisational change components: 1) **from suspected cancer detection to confirmation of diagnosis**; and 2) from diagnosis to first treatment.<br>• **Guidelines were developed by specialists**, with recommendations for implementation (responsibilities and **maximum waiting times for diagnosis)** |
| Fast-track Valencia<br><br>Launched in 2009 | • **Breast, colorectal, cervical, lung and bladder cancers**<br>• Six hospital specialists, a Primary Care (PC) physician and the oncology coordinator **met regularly to discuss cases and develop guidelines** to be used by PC physicians to refer patients with suspected cancer. On the same day that the PC physician identified a patient with suspected cancer, an index card was sent to the oncology coordinator.<br>• **Referral guidelines** were developed by experts and informed by available evidence. **Health guidelines** were created for the public. No specific targets were described |
| Inside Knowledge<br><br>Launched in 2008 | • **Gynaecological cancers**: cervical, ovarian, uterine, vaginal and vulvar<br>• **Campaign messages about the importance of early detection; the need to pay attention to the body, unexplained signs and symptoms or warning signs; to attend cervical cancer and take the HPV vaccine**. Materials for the public included: cancer fact sheets, brochures, print and broadcast announcements, posters, outdoors, and a cancer symptoms diary. Use of media and social media (e.g. magazines, television, Facebook, Twitter, podcasts, CDC TV and YouTube channel) |

| Initiative and start date | Key components |
|---|---|
| | • **For health care providers, the campaign developed educational modules** to increase knowledge of each cancer; of genetic causes of gynaecologic cancers; and of HPV and the HPV vaccine. Resources were available at meetings and presented at professional gatherings. The campaign worked with key partners to ensure wide dissemination of materials. Free campaign materials were given to national and local governmental and nongovernmental partners. |
| Listen Out for Lung Cancer<br><br>Launched in 2013 | • **Lung cancer**<br>• **Social marketing campaign** developed and evaluated in five stages: formative research (understand the attitudes, knowledge & behaviours); concept testing (develop & test campaign concepts with consumers); media strategy (use information to design media strategy); implement campaign; evaluation. Only data on campaign development was available |
| NAEDI<br><br>Launched in 2008 | • **Wide range of tumour types**, with variation across different initiatives (e.g. CDS tools targeted colorectal, lung, oesophago-gastric (OG), pancreatic and ovarian cancers; for local initiatives tumour type was chosen based on assessments of local populations with most targeting lung, bowel or breast cancer, and others targeting prostate or cancer in general)<br>• **Cancer Networks Supporting Primary Care programme** (centrally coordinated, locally delivered improvement initiatives):<br>- **Clinical audit** (National Audit of Cancer Diagnosis): practices used a standard audit template to collect information on patient demographics and assessment processes in primary care, including the time taken from first presentation to referral.<br>- **Significant event analysis (SEA) template**: a quality improvement review by the practice team of what happened in relation to a cancer diagnosis, why it happened, what could be learned and what should be changed<br>- **Practice cancer plans**: often carried out after reviewing practice cancer profiles (performance measured against metrics for screening/diagnosis). Guidance and a template for plans were available to record data an outline tasks to improve outcomes.<br>- **CDS tools:** RAT or Risk Assessment tool or QCancer were used. Both tools were developed in electronic format and had distinct functions: a prompt, a symptom checker and a risk stratification list that presented the GP with a risk score for a patient. Practices were encouraged to use the tools. Training materials and training sessions for the GP were developed.<br>• Other activities: Development and validation of a **Cancer Awareness Measure (CAM) tool**; development and implementation of BCOC (before it became a standalone project); **development of the International Cancer Benchmarking Partnership (ICBP)** to understand international variation in cancer survival and explore associated factors (became a standalone project)<br>• **Local initiatives**: public-facing activity (e.g., advertising/community events to raise awareness and engage with the public); 2) changes to services (e.g., extending opening hours, liaising with hospitals to deal with demand, direct access to diagnostics; refinement of 2WW referral forms); and 3) liaising with local employers, councillors, and occupational health teams |
| NSS-CPPs Denmark Implemented in 2012 | • Included a **wide range of tumour types**<br>• CPPs became accompanied by two more referral routes: **the urgent referral for nonspecific, serious symptoms and the no-yes-clinics (NYC) for vague symptoms**. These routes allowed the GP to refer patients and carry out investigations when there was a suspicion of cancer, but the patient did not meet criteria for urgent referrals. GP suspicion was enough for a referral |

| Initiative and start date | Key components |
|---|---|
| | • The GP can order standard diagnostic investigations (i.e. blood and urine tests and diagnostic imaging) and results are received within four working days. The GP then decides on further steps within eight working days e.g. waiting or referral for further investigations. If relevant (e.g. there is no explanation for symptoms; a specific disease or type of cancer is suspected) the patient is referred to a diagnostic centre. The NYC for vague, 'low-risk-but-not- no- risk', symptoms take place in hospitals or specialist clinics. **The GP has direct access to fast investigations.** |
| Norwegian CPPs<br>Norway<br>Implemented in 2015 | • Included a **wide range of tumour types**<br>• **Introduction of 28 CPPs and 31 diagnostic guidelines** in primary and specialist healthcare. Described as "a logistics reform, and not new guidelines for diagnosis". No specific targets were described<br>• Pathway was developed to be predictable at all stages. The patient condition is discussed face-to-face and in iterative consultations. Information is made available in a written form for patients |
| Oral Cancer Maryland<br>Maryland, US<br>Launch date unclear | • **Oral cancers**<br>• Comprised: **examination training, educational and awareness programme for health care providers; educational and awareness campaign for the public; provision of tobacco settlement funds for initiatives**<br>• Key activities for the public comprised health education materials, oral cancer education (e.g. need for examinations and information about risks, signs and symptoms, and smoking cessation), oral cancer screening examinations and referral<br>• Professional education and training programs for dental/non-dental health care providers (to properly examine, diagnose, and refer patients). A public relations oral cancer prevention campaign was developed, with training programs for care providers.<br>• Targeted health educational activities and materials that addressed tobacco use were produced |
| Qatar's first national Cancer Plan<br>Qatar<br>Published in May 2011 | • Priority given to **cancers with the highest incidence** in Qatar (breast, urological, gastrointestinal, and haematological), but over time a wide range of tumour types was included<br>• **Three access targets were developed to ensure rapid referral, diagnosis & treatment**: appointment with a specialist within 48 hours of referral for patients with suspected cancer; 14 days from seeing a Specialist to a definitive diagnosis using a combination of imaging, pathology and physical examinations; 14 days from diagnosis to commencement of treatment. The latter two targets were managed by multi-disciplinary teams. A new Referral Management Office coordinated the process. Tumour boards developed, validated and published evidence-based care guidelines (for clinical management, screening and suspected cancer), coordinated service audits, and conducted other quality assurance activities. Multidisciplinary teams and a patient pathway coordinator were established, a rapid access clinic was opened.<br>• Awareness campaigns: **awareness and myth refutation campaign** with influential Qatari figures as Cancer Champions; use of media to fight cancer stigma and start a brave/optimistic conversation about battling cancer; tumour-specific campaigns. A **cancer awareness survey** was designed to assess the public understanding of cancer and their lifestyle habits. Education sessions in schools were planned, in addition to plans to create a comprehensive cancer information resource online |

| Initiative and start date | Key components |
|---|---|
| | • **Courses (communication skills such as timely and sensitive communication about a cancer diagnosis**); role in cancer treatment and referrals) for health care professionals<br>• **Development of an early detection indicator:** 30% increase in the proportion of cancers diagnosed at Stage I and 2 by 2016 |
| RAC<br>Republic of Ireland<br>First clinic opened in 2010 | • **Prostate and Lung cancers** initially, then breast and melanoma were added<br>• **Access to a specialist opinion within four weeks of initial appointment;** if cancer is confirmed patients should have immediate access to a multidisciplinary care team to arrange appropriate treatment.<br>• **Clinical guidelines** developed by specialists, multidisciplinary teams and the Irish College of General Practitioners, and with consultation of all relevant stakeholders. A National Rapid Access Clinical Referral Form was developed. Education meetings with GPs were held across the country so they could hear about how the clinics operated<br>• **Provision of funding** for recruiting consultant urologists, consultant respiratory physicians, radiologists, pathologists, radiographers, medical laboratory scientists, administrative staff; and for endoscopic ultrasound equipment<br>• Performance monitored for a wide range of indicators, including: **20 days from referral to appointment in RAC (prostate cancer, 90% standard); 10 days from referral to appointment in RAC (lung cancer, 95% standard)**;. Other targets referred to intervals between the date of decision to treat and date of first surgical intervention, targets for pathology reporting and surgery (345) |
| Rapid Referral Pathway Madrid<br>Spain<br>Introduced in 2004 | • **Colorectal cancer**<br>• **A rapid referral pathway between primary and specialised care**, for patients suspected of having colorectal cancer (meeting predefined high-risk criteria). The target was for patients to undergo colonoscopy within 15 days. Other targets were <30 days waiting time to surgery and <90 days overall waiting to surgery. The pathway allowed for direct referral without the need for a specialist consultation. A **referral pathway coordinator was appointed** in each primary health care centre (there was continuous communication with hospital specialists). Evidence was limited on guideline development |
| SCPs<br>Sweden<br>Implementation started in 2015 | • **Wide range of tumour types**; started with five (acute myeloid leukaemia, head and neck, oesophageal and stomach, prostate, and ureteral and bladder cancer); aimed to cover “almost all cancer diagnoses” over time<br>• The **model was based on a “well-founded suspicion of cancer” for diagnosis**; the pathway ended with the start of first cancer treatment. The total number of days from well-founded suspicion of cancer to start of first treatment is was defined by the total number of days for each step and constitutes the total target time for diagnosis. The patient must be informed about the process and timeframes to be expected.<br>• **Indicators were identified for each cancer diagnosis and a manual was developed** by diagnosis specific multi-professional expert teams. The manual outlined symptoms that should lead to a suspicion of cancer and require further investigations, what the referral must contain, the waiting times for a specialist appointment, each procedure prior to treatment and pathological/other analysis. A 12-day target (waiting time to start of treatment) is described in a chart (274) |

***Source: Included studies***

### 4.3.5 Target populations

Awareness campaigns targeted the general public, but also specific population groups for which most impact could be achieved in terms of improving cancer outcomes. These groups included all within the eligible age groups for cancer screening programmes, patients at higher risk of cancer (.e.g. smokers and ex-smokers; older patients since cancer is more common at older ages; and those from more deprived or remote areas as they were more likely to present late) (Table 4.8). Adaptations regarding access, language or other culturally sensitive changes were made in order to reach vulnerable populations (such as the hard of hearing or visually impaired in England (292)) and ethnic minority groups (such as Hispanic populations in the US (322), Black and Minority Ethnic Groups in the UK (292) and Aboriginal people in Australia (331)). In Qatar, initiatives aiming to increase awareness also targeted school students (348), while Oral Cancer Maryland also targeted “high risk populations” (343) (Appendix 11).

Professional education most often targeted GPs, dentists, dental hygienists, family nurses, medicine counter assistants, pharmacists and community pharmacists due to their current and potential role in promoting early diagnosis. Referral pathways targeted patients for which there was a high suspicion of cancer, or for which the possibility of cancer was sufficient to warrant further investigations (Table 4.8, Appendix 11).

Overall, patients suspected of having cancer based on high-risk symptom criteria were the most often targeted groups (n=12), followed by health care staff (n=8) and the general public (n=7) (Table 4.8).

**Table 4.8.** Target populations

| Initiative | Patients suspected of having cancer based on high-risk symptom criteria | Patients with vague or serious, non-specific symptoms | Patients at higher risk of developing cancer | General public | Ethnic minorities, vulnerable groups, people with disabilities | Health care staff[1] | Other[2] |
|---|---|---|---|---|---|---|---|
| 2WW | ◆ | | | | | | |
| ACE | ◆ | ◆ | ◆ | | ◆ | ◆ | ◆ |
| BCOC | | | ◆ | ◆ | ◆ | | ◆ |
| CPPs | ◆ | | | | | | |
| DCE | ◆ | | ◆ | ◆ | | ◆ | ◆ |
| DAPs | ◆ | | | | | | |
| FT Catalonia | ◆ | | | | | ◆ | |
| FT Valencia | ◆ | | | | | | |
| Inside Knowledge | | | | ◆ | ◆ | ◆ | |
| Listen out for lung cancer | | | ◆ | ◆ | ◆ | ◆ | |
| NAEDI | | | ◆ | ◆ | ◆ | ◆ | |
| NSS-CPPs | | ◆ | | | | | |
| CPPs in Norway | ◆ | | | | | | |
| Oral Cancer Maryland | | | ◆ | ◆ | ◆ | ◆ | ◆ |
| RAC | ◆ | | | | | | |
| Qatar's first national Cancer Plan | ◆ | | | ◆ | | ◆ | ◆ |
| Rapid Referral Pathway Madrid | ◆ | | | | | | |
| SCP | ◆ | | | | | | |

***[1]Referral guidelines, common tools from strategies based on symptoms, were prepared for health care professionals, even though the strategies themselves targeted patients. This is not shown in the table to avoid confusion when making sense of target populations and associated outcomes. [2]Other refers to key influencers such as friends and family, and celebrities (BCOC, DCE and Qatar's strategy), the media, policy makers and trainers (Oral Cancer Maryland), and students (Qatar's strategy). One of ACE initiatives also targeted patients who presented late to their GP with a new suspected cancer but a) were too ill to wait for an urgent referral; or b) there was uncertainty about the primary cancer site.***

## 4.3.6 Outcomes

The wide variation in adopted study designs and components of initiatives was accompanied by diversity in data collection methods and outcomes. It was not possible to report on all described outcome measures and outcomes within the scope of this review. A comprehensive description of study designs and outcome measures adopted by each initiative is available in Appendix 12.

High-level outcomes described in the updated NAEDI's hypothesis (130) are reported here. These refer to a) tumour stage at diagnosis (seven initiatives); b) cancer mortality (one initiative); and c) cancer survival (two initiatives; but limited national data). This is followed by key outcomes according to the type of strategy: professional education; strategies to improve public cancer awareness and/or knowledge; referral pathways based on cancer symptoms; and other activities.

### 4.3.6.1 High-level outcomes described in NAEDI's hypothesis

*Tumour stage at diagnosis*

All but two initiatives (out of seven) reporting on cancer staging data stated that cancers were often diagnosed at early stages. Cancer staging was mostly approached by referral pathway strategies. Statistical significance was seldom reported. Furthermore, strategies investigating the use of CDS tools in primary care (part of ACE and NAEDI) explicitly stated that staging data were not available for analysis (291, 334).

A review about 2WW stated that national data on staging was not available, although it identified two studies that reported no impact on identifying cancers at their earlier stages (269). An ACE component focusing on pathways for vague symptoms for lung cancer reported that when staging data were available, most cancers were in later stages (II-IV). Suitability for palliative care was used as an indication of later stages when data were not available (88).

Assessment of the Rapid Referral Pathway in Madrid reported that most patients diagnosed with colorectal cancer through the pathway were diagnosed at earlier stages. Authors also found that the referral route significantly influenced stage at diagnosis (with more cases being diagnosed in early stages in the rapid referral pathway compared to the standard referral pathway) (350). Reports about the Fast-Track Pathway in Valencia outlined that "most cancers were identified in curative

stages" (all cases for gynaecological cancers, about a quarter of thoracic cancer cases, 40% of head and neck cancers, and over 90% of bladder cancers) (321). Outcomes from DAPs included 90% of breast cancers being diagnosed in stages I-II and breast cancers being diagnosed (significantly) more often at later stages in the control group (318).

The DCE Programme in Scotland identified a relative 7.0% increase in the proportion of cancer diagnoses at Stage I for breast, colorectal and lung cancers combined (the official target was 25%) when comparing the baseline (years 2010 and 2011 combined) and Year 3 (years 2013 and 2014 combined). Reports also highlighted that an observed reduction in the proportion of cancers recorded with unknown stages may have contributed to the results (316).

Finally, an evaluation of the BCOC lung cancer campaign identified a positive stage shift for non-small-cell lung carcinoma (NSCLC) after campaign launch. Authors found that the proportion of lung cancers diagnosed at Stage I significantly increased during the campaign period, and this was accompanied by a significant decrease in the proportion diagnosed at Stage IV. Similar to DCE, authors acknowledged that significant decreases in stages coded as unknown during the same time period may have contributed to this shift (176).

*Cancer mortality*

Only one initiative (about 2WW) reported on cancer mortality at a national level. Møller et al found that cancer patients registered at primary care practices with the lowest use of the 2WW pathway had excess mortality (hazard ratio 1.07 (95%CI 1.05-1.08)) compared to patients registered in practices with intermediate or higher use of the 2WW (81). Cancer mortality was associated with referral ratio (a single general practice use of the 2WW compared to other practices) and detection rate; there were no significant associations with conversion rates (81). Mortality results were consistent across different tumour types (except for breast cancer) and did not change after adjusting for confounders (81).

*Cancer survival*

Cancer survival outcomes were described for the 2WW initiative, with limited, inconclusive results. Reviews of the use of the 2WW pathway reported on one study describing limited impact on survival for pancreatic cancer patients (268), and higher one-year survival rates for patients accessing care through the 2WW pathways

compared to other routes (except for screening), but differences were often small (269). A review of cancer waiting times standards (2WW) described how stakeholders such as clinicians and health managers believed that improvements in survival brought by the pathway were “impossible to quantify” (278).

BCOC calculated one-year survival when investigating the impact of awareness campaigns for lung cancer, but calculations were not available at a national level. For the pilot campaign, there were increases in age-standardised 1-year crude survival in both pilot and control areas (176).

#### 4.3.6.2 Strategies targeting professional education

Outcome data were available for five (out of eight) initiatives which adopted these strategies. Authors often referred to process measures such as how many professionals were trained or attended education sessions. Two initiatives reported positive changes in knowledge (one of them also described persisting knowledge gaps), with limited assessment of statistical significance.

Inside Knowledge described a range of process outcomes: publications in peer-reviewed journals, presentations in professional meetings and conferences, partnerships with a range of stakeholders, 57 in-person education sessions with 1,101 health care providers, an online module for nurses aiming to facilitate discussion and use of campaign materials, and a free Gynaecologic Cancer Curriculum for primary care professionals (as part of continuing education) (327).

Oral Cancer Maryland reported that 711 health care staff and 643 trainers were educated about oral cancer. Results from a follow-up study (2009; compared with a baseline survey in 1995) carried out with general practice dentists indicated persisting weaknesses in both knowledge and practices concerning oral cancer prevention and early detection, but also identified positive changes. There were no clear changes in reported knowledge of oral cancer risk factors and diagnostic procedures, although 88% of professionals recognised HPV is a risk factor for oral cancer (nonetheless, only 50% stated that they assessed their patient’s HPV history, and only about a fifth asked patients if they had had the HPV vaccine). There was higher compliance with recommended screening examinations and an increase in professionals stating that they routinely palpated lymph nodes. Furthermore, the percentage of dentists describing that they had taken an oral cancer continuing education course in the past 12 months increased from 14% to 29% (343).

In Qatar, it was reported that 31 doctors (including 8 consultants who were also trained to be instructors) and 123 members of the nursing team had completed the communication skills training about timely and sensitive communication of a cancer diagnosis (346). Only data on process measures were available.

Outcomes for the ACE programme training community pharmacy workers were also available, although they were reported separately for different areas/projects. Over three-quarters of (77%) of professionals completing a survey in one of the projects (Cumbria) stated that the training increased their understanding of bowel screening "a lot". Four professionals completed a survey for another initiative targeting lung cancer. When asked how much the training increased their understanding of the subject, all reported to understand lung cancer well or fully (prior to training 75% reported some knowledge of lung cancer and 25% reported very little knowledge). Limited information on costs was also provided (not shown here) (72, 272).

Some outcomes for professional training provided as part of the Cancer Networks supporting primary care programme (part of NAEDI) were also reported. Interviewed stakeholders reported that attendance was higher when it was "incorporated into formal protected learning sessions". Practitioners' attendance to education and training sessions was found to be associated with practice engagement (150).

No outcomes were identified in included publications for the remaining strategies that included a professional education component (RAC, BCOC, and DCE). Nonetheless, further outcomes for DCE are available as part of the evaluation (Chapter 7).

#### 4.3.6.3 Strategies to improve public cancer awareness and/or knowledge

Outcome data were available for three initiatives out of the seven that had a public cancer awareness/knowledge component (Figure 4.6): BCOC (national campaigns only), Inside Knowledge and Oral Cancer Maryland. In addition to outcomes, all three initiatives described a wide range of process measures (not described here) such as campaign reach, dissemination and other social marketing measures (such as estimates of how many times campaigns were viewed online, product service placements in television and radio, and outdoor advertising).

The most commonly reported outcome measures (all three initiatives) referred to changes in knowledge/awareness (prompted or unprompted) about cancer risk factors, cancer symptoms and signs, beliefs about cancer, and barriers to help-

seeking/presentation. Two initiatives described positive changes in knowledge and awareness, two described positive changes in behaviour, and two described persisting misconceptions about cancer and barriers to help-seeking.

Increase in awareness of cancer symptoms and signs as a result of campaigns was reported by BCOC (significant changes) (176, 177) and Inside Knowledge (327). Positive changes in help-seeking behaviour such as increase in consultations due to cancer symptoms and signs (BCOC; significant changes) (176, 177) or increase in screening participation (Oral Cancer Maryland) (343) were also described. Persisting misconceptions about cancer and/or barriers to help-seeking were reported by BCOC (significant changes) and Inside Knowledge (Table 4.9).

BCOC was the only initiative that consistently assessed whether changes associated with the campaigns were statistically significant. Furthermore, it also investigated and reported on campaign impact on system-level outcomes such as GP referrals, urgent GP referrals, diagnostic investigations and cancer diagnoses (reporting a statistically significant increase in all cases) (Table 4.9). BCOC also investigated tumour staging and survival, as previously reported in this Chapter.

No outcome data were reported for NAEDI as its national awareness initiative (BCOC) is shown separately; other relevant NAEDI strategies were only developed and implemented locally. There was no outcome data available for ACE, DCE, Listen Out for Lung Cancer (although data were available for campaign development) (331) and Qatar's Cancer Strategy at the time of review completion.

**Table 4.9.** Outcomes for strategies aiming to improve cancer awareness/knowledge among the public

| Initiative | Outcomes |
|---|---|
| BCOC | • **Significant increase in unprompted and prompted awareness of several lung and bowel cancer symptoms and warning signs**, including target symptoms, although there were no significant changes to the proportion saying 'blood in your poo for 3 weeks or longer' is a definite warning sign of bowel cancer (prompted). There were **no significant changes for being 'worried about wasting the doctor's time' or believing that the 'doctor would be difficult to talk to'**<br>*National bowel cancer campaigns*<br>• **Increase in attendances** amongst patients over 50 reporting key campaign-related symptoms (significance not clear)<br>• **Increase in the number of GP visits** during the campaign and three weeks after the campaign period<br>• **Statistically significant increase in 2WW referrals** for suspected lower GI cancer and in colonoscopies and flexible sigmoidoscopies<br>• **Non-significant increase in lower GI cancers diagnosed** following a 2WW referral; statistically significant decrease in conversion rates (although the same happened for the control groups) and **small increase in detection rates** (no mention to significance)<br>*National lung cancer campaigns*<br>• **Significant increase in presentations** of patients aged 50+ with a cough<br>• **Significant increase in urgent GP referrals** for suspected lung cancer, the number of CXRs following a GP referral (and from all referrals), and the number of GP-referred CTs<br>• **Significant increase in lung cancers diagnosed**; significant increase in the proportion of patients diagnosed with lung cancer via GP referral; significant decrease in the proportion diagnosed after an emergency admission or A&E attendance.<br>• Significant increase in lung cancer patients receiving surgical resection as a first definitive treatment<br>• **Non-significant reduction in conversion rates**<br>• *Both campaigns were reported to have reached the broad target audience, but also reached younger and more affluent audiences* |
| Inside Knowledge | • Ads were reported to be **effective in increasing awareness of cancer symptoms (no significance was reported), and in prompting women to seek additional information about gynaecological cancer**. Women in the intervention communities had greater knowledge of the gynaecological symptoms compared to women not in these communities (no significance reported).<br>• However, there was **no observable impact on intention to seek help**; and **misperceptions about the purpose of the Pap test (i.e. belief it tests for more than cervical cancer) and about the HPV vaccine persisted** |
| Oral Cancer Maryland | • **Increase in the % of those aged 40+ reporting that they have had an oral cancer exam** in the past year (no significance reported)<br>• **5,352 individuals screened for oral cancer** (81 with cancer findings or possible cancer, 4 cancers detected)<br>• Other outcomes: **Improvement in national rankings in terms of oral cancer incidence and mortality**; new Oral Cancer Legislation implemented; inclusion of oral cancer in the Maryland Cancer Control Plan; creation of an annual Oral Cancer Awareness week |

***Source: included studies***

#### 4.3.6.4 Referral pathways based on cancer symptoms

Initiatives in this category reported on an extensive range of outcomes. These included measures of healthcare utilisation and symptom presentation; estimated risk of cancer at referral; use of referral guidelines/criteria (i.e. whether this was met for referred patients or whether patients were accurately selected for pathway; GP compliance; whether guidelines identified correct referrals; whether GPs saw referrals as appropriate); number, type and results of investigations; impact of referral pathways on waiting times, intervals and outcomes; urgent and non-urgent referrals; cancer diagnoses and diagnoses other than cancer; cancer conversion and detection rates; and whether targets/indicators were met.

Data were available for 12 out of 14 initiatives that included referral pathways. There were no outcomes available for the SCPs in Sweden nor the CPPs in Norway, although a qualitative assessment of how information on the pathways was provided online was available (342).

The most commonly described outcomes were reductions in diagnostic intervals (other intervals such as diagnosis to treatment were also reported), performance against predefined targets, number and proportion of cancers diagnosed through the pathways, and detection and conversion rates. These are further described below.

*Diagnostic intervals and other intervals*

A reduction in diagnostic intervals (days, mean/median days) was found in six initiatives: 2WW and their guidelines (281), pathways for patients with vague symptoms (ACE) (88), CPPs in Denmark (179), DAPs (318), Fast Track-Catalonia (breast cancer only) (320) and Rapid Referral Pathway Madrid (350). Significance was reported in half of the cases. Variations by tumour type, symptom presentation, GP symptom interpretation (i.e. alarm or vague symptoms), GP cancer suspicion and adherence to guidelines were described. Reduction in other intervals was also reported, including time to ultrasound and CT scan (pathways for patients with vague symptoms – ACE) (88); chest x-ray to CT/outpatient appointment, referral to MDT; and quicker access to CT scans compared to the “normal CT referral route” (proactive approaches for patients with lung cancer – ACE) (286); abnormal mammography to case “resolution” (DAPs) (318); and overall waiting time (Rapid Referral Pathway Madrid) (350). Definitions for intervals varied across studies.

*Performance against predefined targets*

Four strategies focused on reporting whether referral targets/standard were met, with most describing positive results and an increase in referrals over time. In the case of 2WW, targets were consistently met (although the proportion of patients referred and seen by a specialist within two weeks reduced over time) (276, 277, 282, 283, 285). In the case of RAC, targets were not met overall (with poorer performance for prostate compared to lung RACs), although six out of eight designated centres met targets (345). In Qatar, there was an improvement over time for most targets, although there was a decrease in the proportion of patients receiving specialist treatment within two weeks in 2015 (346). DAP results indicated that patients going through the programme were more likely to have an abnormal mammography resolved in seven weeks compared to those going through other routes (318).

*Cancers diagnosed through the pathways, detection and conversion rates*

Detection rates can be defined as the proportion of all cancers referred through the pathway being investigated while conversion rates can be defined as the proportion of all referrals through the pathway being investigated that resulted in a cancer diagnosis (357). Exact terms used in included publications were used to ensure accuracy in reporting. There was wide variation in results, with some initiatives focusing on descriptive reporting of rates/proportions, and others comparing these with other routes/time periods.

FT Catalonia reported that at least half of new cancer diagnoses (colorectal, breast or lung) were diagnosed through the pathway, with variations by tumour type. There was a statistically significant decreasing trend in cancer detection rates (320). Similarly, in Ontario (Canada), 51% of breast cancer patients were found to have attended a DAP for a diagnostic assessment (318).

Over one in ten (12%) of all colorectal cancers were identified through the Rapid Referral Pathway in Madrid (18% if considering only the final study year – a potential indicator of an increase over time). Furthermore, about a fifth (20.6%) of the rapid referral patients were diagnosed with colorectal cancer (350).

2WW reported that the proportion of patients referred who were found to have cancer has decreased over time, and most referred patients were found not to have cancer (most cancers were diagnosed via other routes) (278). Comparisons between practices with higher, intermediate and lower 2WW referral rates found that those with

higher referral rates had significantly lower conversion rates and significantly higher detection rates. Practices with smaller list sizes had lower detection rates. Furthermore, cancer diagnoses from 2WW referrals corresponded to 43% of all first cancer treatments (81, 279).

One pathway providing CT scan after a normal chest x-ray but persisting symptoms (ACE) reported that 2.5% of direct access scans resulted in a lung cancer diagnosis. Conversion rates were found to be higher for patients who were more seriously ill and lower for patients who had non-specific, vague symptoms (88).

FT Valencia reported that 205 out of 705 (29%) patients who were referred (and went for consultation) had a cancer diagnosis (details were also provided for different tumour types) (321). The NSS-CPP reported that 16.2% patients referred through the pathway were diagnosed with cancer (341).

Finally, results for RAC in Ireland showed that over a third of newly referred patients were diagnosed with either prostate or lung cancer (345) (Table 4.10).

**Table 4.10.** Key outcomes for strategies adopting referral pathways based on cancer symptoms

| Strategy | Key outcomes |
|---|---|
| 2WW | • Annual government reports on waiting times targets reported that the **proportion of patients urgently referred for suspected cancer (any) by their GP who were seen by a specialist within two weeks of referral was above 95% across most years** for which evidence was available (2011-2012, 2012-2013, 2013-2014) , except for the latest two years available (proportion was 94.2% for 2014-2015 and 94.1% for 2015-2016). The operational standard of 93% was met for all types of suspected cancer over the years, with variations across tumour types. The number of patients included in the 2WW increased at a constant rate over time<br>• The latest systematic review (120) found several studies reporting that **delays further along the cancer pathway can offset the gains from fast-track referral**. It also found that **the proportion of 2WW patients with cancer had fallen** from 2006/7 to 2009/10, that only a minority of cancer patients were referred through 2WW, that while GP selection has improved over the years, **not all were aware of guidelines or used them**. The low PPV of guidelines and the fact that most referred patients would not have cancer was also approached. Evidence pointed to **wide variation in the use of 2WW** in different parts of the country<br>• Assessment of diagnostic intervals before and after implementation of the 2005 guidelines for urgent referral (281): First presentation of any cancer-related symptom to diagnosis: **significant reduction in mean diagnostic intervals** from 2001–2002 (before guideline implementation) to 2007–2008 (after guideline implementation) for first presentation of any cancer symptom, and for six cancers: kidney, head and neck, bladder, colorectal, oesophageal, and pancreatic. After guideline implementation the cancers with the shortest intervals were breast, testicular, oesophageal and the ones with the longest were myeloma, lung and lymphoma. For most cancer types (except for gastric, cervical and kidney cancers), before and after guideline implementation, **patients presenting with symptoms outlined in the guidelines had shorter diagnostic intervals compared to those who did not**<br>• **Practices with higher referral rates had significantly lower conversion rates and significantly higher detection rates**. Diagnoses from 2WW referrals accounted for 43% of all first cancer treatments. Practices with low referral ratios and smaller list sizes had lower detection rates. Median detection rate increased from 17% for practices in the lowest decile of conversion rate to 45–46% for practices in the highest four deciles of conversion rate (significant). **11% of referrals resulted in a cancer diagnosis**. **Practices with higher conversion rates generally had higher detection rates and vice versa (significant)** overall and for all practice and patient subgroups. **The median conversion rate increased from 4% to 14%**, for practices in the lowest to highest deciles of detection rate (statistically significant) (81, 279) |
| ACE | • Pathways for patients with vague symptoms (88): Outcomes reported for four projects (one in Manchester, one in Airedale and two in London). Time from referral to diagnosis varied, with most patients having a diagnosis within 2 (Manchester), 3 (Airedale), and 4 (London multidisciplinary clinic) weeks. In the other London clinic, where patients were too ill to wait for a 2WW, the **time from GP referral to diagnosis was reduced** (mean -7 days). One project (patients too ill for 2WW referral in London) reported a mean of 16.4 days from referral to treatment, while another (Manchester) reported **that time from ultrasound and CT scan to surgery decreased both pre-pathway and post-pathway (no significance reported)**. **Projects picked up a significant number of patients with other non-malignant diseases** (incidental findings or related to presenting symptoms). |

| Strategy | Key outcomes |
|---|---|
| | • Proactive approaches for patients at high risk of lung cancer (289): four different projects (straight-to-CT pathways) and an audit. **All reported improvements, but not always for the same intervals.** Two reported reduction in the CXR to CT interval (one reported increase in the proportion of 2WW referrals with CT prior to outpatient appointment (OPA) and improvement in 62 day performance (Crawley), reduction in the CXR to chest OPA interval (even with the addition of a diagnostic MDT discussion) (Horsham and Mid Sussex), reduction in the time interval from referral to MDT (South Staffordshire). One pathway providing CT after a normal x-ray but persisting symptoms reported "quicker access to CT than the normal CT referral route" in addition to reporting that 2.4% of over 150 direct access CT scans resulted in a lung cancer diagnosis (one other incidental cancer was also found) . An audit in Somerset reported that Trusts with poorer performance in relation to waiting times standards for lung cancer had longer intervals between CXR test to diagnosis and between CT request and diagnosis compared to top performers. Furthermore, they had a lower proportion of patients diagnosed via 2WW and a higher proportion of patients diagnosed via 'other outpatient' routes<br>• Conversion rates (88): **Pathways for patients who were more seriously ill had higher conversion rates. Pathways for patients with non-specific vague symptoms had lower conversion rates** |
| CPPs | • The GP used CPPs in 1,426 (37.3%) of all cases, also with variations across tumour types. GPs interpretation of a symptom as alarm, serious or vague varied according to tumour type. Overall, GPs interpreted symptoms as an alarm symptom (48.2%), serious symptom (19.5%) or vague symptom (32.3%)<br>• **Referral to a CPP was significantly less likely among patients who had symptoms interpreted to be serious or vague**<br>• Diagnostic interval varied significantly across tumour types (lowest for breast and highest for prostate), between GP symptom interpretation (lowest for alarm symptoms and highest for vague symptoms), and GP referral modes (lowest for CPPs and highest for "other"). **Adjusted diagnostic interval was longer when the GP did not suspect cancer and when the GP did not refer to a CPP. Vague symptoms had the strongest association with the diagnostic interval** compared to patients with alarm symptoms.<br>• The **median diagnostic interval was statistically significantly lower over time** for all cancers combined; it also reduced over time across all investigated tumour types. Overall results remained after adjusting for differences between populations<br>• The median diagnostic interval was 14 days shorter during the transition stage than before CPP implementation and 17 days shorter after CPP implementation. Compared to the period before CPPs, the **diagnostic intervals were shorter both during and after CPP implementation** for all tumour types (but not statistically significant at all percentiles)<br>• The unadjusted median diagnostic interval was (significantly) lower for both the after-CPP group and the after-no CPP group compared to before CPP implementation. The diagnostic interval was (significantly) longer for the after-no CPP group compared to the after-CPP group). **The adjusted median for the after-CPP group was 23 days shorter than before CPP implementation. The adjusted median for the after-no CPP group was 9 days shorter than before the CPP implementation**. The 90th percentile for the after-CPP group was 110 days shorter than before, while similar for the after-no CPP group than before. This trend was noted for all cancer types (not significant)<br>• Diagnostic interval by referral route compared to during CPP implementation: **The adjusted median diagnostic interval was 15 (95% CI 12-17) days shorter than during implementation for the after-CPP group, while it was 4 (95% CI 1-7) days longer than** |

| Strategy | Key outcomes |
|---|---|
| | **during implementation for the after-no CPP group**. Similarly, at the 90th percentile, the diagnostic interval 80 (95% CI: 34-126) days shorter than during the implementation for the after-CPP group compared to (non-significant) 48 (95% CI: −49-145) days longer than during the implementation for the after-no CPP group. This was the case for all tumour groups (although not significant for all percentiles). Sensitivity analysis did not alter the overall results |
| DAPs | • 51% of the breast cancer patients (organised or opportunistic screening) attended a DAP for diagnostic assessment. Median time to diagnosis was 29 days (IQR: 17–50), to diagnostic resolution was 9 days; reduced to 8.3 days (P< 0.001) after adjustments<br>• **Breast cancer patients diagnosed at a DAP were more likely to have an abnormal screening resolved within 7 weeks than those in usual care** (79.1% vs 70.2%, P= 0.001). **Those in the pathway were significantly more likely to meet the 7-week screening target** (90% of abnormal screens should be resolved within seven weeks if a tissue biopsy is required) |
| FT Catalonia | • 56,020 patients included in the pathway during 2006-2009.<br>• **At least half of all new patients with colorectal, breast or lung cancer were diagnosed through the pathway** (about 60% for colorectal and 40–50% for breast and lung cancer). When there was adherence to clinical criteria for inclusion in the pathway the proportions were higher (over 70% for all tumour types)<br>• There was a **statistically significant decreasing trend for the cancer detection rate (P<0.001).**<br>• Mean time from cancer detection in primary care to start of first treatment was 32 days for breast, 30 for colorectal and 37 for lung cancer (year 2009)<br>• **Breast cancer was the only tumour type showing a clear positive trend regarding reduction in waiting times (**proportions divided into 'under 30 days'; '30 to 45 days' and 'over 45 days'). For lung cancer, about 50% of cases were in the shortest wait category ('under 30 days') and about 50% in the two other categories ('30 to 45 days' and 'over 45 days' in the final year).<br>• Cancer detection rates were "around 30%"<br>• **The number of patients included in the programme increased over time** for all three tumour types (colorectal, breast and lung). |
| FT Valencia | • 897 suspected patients were referred to the pathway, 753 met criteria and 705 went for consultation<br>• The 144 who did not meet criteria were returned to the primary care professional (n=54; 2 cancers detected); referred to specialised departments (n=43; 10 cancers detected); cited in Oncology Department (n=46, 21 cancers detected)<br>• **205/705 patients had a confirmed cancer diagnosis (29%); 166 cases (82%) received a potentially curative treatment**<br>• Breast: 85/367 referred cases resulted in a breast cancer diagnosis; 56 of the diagnosed women were in an age range for which screening with mammography was not recommended. There were 29 interval cancers<br>• Colorectal: 43/168 referred cases resulted in a colorectal cancer diagnosis.<br>• Gynaecological cancer: 6/20 referred cases resulted in a gynaecological cancer diagnosis<br>• Thoracic cancer: 34/71 referred cases resulted in a cancer diagnosis (33 lung cancers and 1 mesothelioma)<br>• Head and neck cancer: 5/31 referred cases resulted in cancer diagnoses (1 non-Hodgkin's lymphoma, 1 chronic lymphocytic leukaemia, 2 lung cancers, 1 palatal cancer) |

| Strategy | Key outcomes |
|---|---|
| | • Urological cancer: 30/48 referred cases resulted in a cancer diagnosis (25 bladder carcinoma, 1 renal pelvic carcinoma, 2 localised germinal testicular tumours, 2 renal cancers)<br>• Waiting times (median days) from primary care to first specialist consultation: 15 for breast, 22 for CRC, 20 for gynaecological, 5 for lung, 11 for cervical lymph nodes and 10 for bladder<br>• Waiting times (median days) from specialist consultation to histopathological diagnosis: 9 for breast, 18 for gynaecological, 19 for lung, 19 for cervical, 57 for bladder, no data for CRC as colonoscopy and biopsy are performed on the same day<br>• Waiting times (median days) from histopathological diagnosis to start of treatment: 23.82 for breast, 34 for CRC, 1 for gynaecological, 20 for lung, 34 for cervical and 10 for bladder<br>• The median time from submission of a proposal to specialist assessment was 13 days, to histopathological diagnosis 23 days, to treatment 46 days<br>• Median time to confirm absence of cancer in 498 patients with an initial cancer suspicion: 22 days<br>• **Almost three-fold increase in the number of referrals between the first and last year** (164 cases were referred between 2009 and 2010, 305 between 2010 and 2011, and 428 between 2011 and 2012) |
| NSS-CPPs | • 82 different symptoms and 51 clinical findings were identified from the 1278 GP questionnaires. Non- specific symptoms (especially weight loss and fatigue) were the most common symptoms. Symptoms associated with the highest probability of cancer were jaundice (42.9%), dysphagia (36.7%), neurological dysfunction (35.3%) and lump/tumour (26.9%)<br>• Three most common clinical findings: affected general condition (35.8%), GPs' gut feeling (22.5%) and abdominal findings (13.0 %)<br>• The highest probability of cancer was found for enlarged lymph nodes (27.3%), neurological findings (26.7%), the GPs' gut feeling (24.0%) and abdominal findings (21.1%)<br>• Abnormal diagnostic test results were often related to blood samples and diagnostic imaging; no specific diagnostic test result was associated with a particularly high probability of cancer.<br>• **After six months, 16.2% of all patients were diagnosed with cancer.** The most common tumour types were lung (17.9%), CRC (12.6%), hematopoietic tissue cancer (10.1%) and pancreatic (9.2%).<br>• The median primary care interval for patients diagnosed with cancer was 15 days (75$^{th}$ percentile 72 days and the 90$^{th}$ percentiles 130 days). **Primary care intervals were shorter than average for breast, liver and biliary cancer patients, while they were longer for patients with metastases or cancer of the prostate, hematopoietic tissue, oesophagus, stomach or small intestine** (it was not possible to provide statistical estimates as the population was small)<br>• **Patients referred with five symptoms were (significantly) more likely to have cancer than patients referred with one symptom**. Having had one or more clinical/diagnostic test results was associated (significantly) with a higher probability of finding cancer<br>• A higher probability of cancer was found among patients who had not been referred to further examination compared to patients who had been referred (only significant for patients from one investigated hospital)<br>• Cancer probability was not associated with the number of chronic diseases and the length of the primary care interval, but it was strongly associated with the GP's assessments of estimated cancer risk at referral. The GPs' estimations were often higher than the |

| Strategy | Key outcomes |
|---|---|
| | cancer probability. **GP gut feeling was associated with the four most common clinical findings** (weight loss, fatigue, affected general condition and abnormal blood sample) for patients diagnosed with cancer (prevalence ratio: 1.50 (95 % CI: 0.82-2.75)) |
| RAC | • Prostate cancer: In 2013, 1591/2870 **(55%) attended or received an appointment to attend RAC within 20 working days of receipt of referral in the cancer centre. 36% of new patients were diagnosed with a primary prostate cancer**. Access "deteriorated" in in the first half of 2014 (Jan-May), with 479/1000 (44%) of patients being offered an appointment within 20 days and 39% of new patients diagnosed with a primary prostate cancer.<br>• Lung cancer: In 2013, **91% were assessed in a RAC by a respiratory physician within 2 weeks** of receipt of request from GP or Emergency Department for assessment. There were 1,920 attendances to Lung RAC clinics (733 primary lung cancer diagnoses or 38%) in 2011, 2,751 (909 diagnoses or 33%) in 2012 and 2,980 (868 diagnoses or 30%) in 2013 (provisional data). **40% of patients with lung cancer were referred to a Rapid Access Clinic. In 2014 (Jan – May), 1184/1320 (90%) were offered an appointment within 10 working days of receipt of referral**. 36% (n=473) of new patients were diagnosed with primary lung cancer<br>• Proportion of **patients attending who were diagnosed with primary lung cancer fell from 38% to 30%** between 2011 and 2013<br>• Six of the eight designated centres see over 95% of patients within two weeks of referral<br>• **Referrals to the RACs** (both lung and prostate cancers) have **increased over time** (new attendances and returns) |
| Qatar's first national Cancer Plan | • Cancer patient response times: 3**% seen within 48 hours in 2012, 24% in 2013 and 73% in 2014 and 2015**.<br>• 2015: **61% of patients were diagnosed within 14 days of being seen at a specialist clinic**<br>• Cancer patient treatment times: 94% received specialist treatment within 2 weeks (2012), 73% (2013), 88% (2014) and 69% (2015)<br>• **Increase in the number of patients referred over time** (45% when assessing the years 2014-2016) |
| Rapid Referral Pathway Madrid | • 272 patients were referred via the rapid referral pathway during the study period. 252 (92.6%) underwent colonoscopy. 200/252 (79.4%) fulfilled at least one high-risk criterion for rapid referral.<br>• **Fifty-two (20.6%) of the rapid referral patients were diagnosed with CRC.**<br>• The most common eligible symptom(s) for rapid referral was a change in bowel habits (49.8%), followed by rectal bleeding (23.9%), rectal bleeding plus a change in bowel habits (7.7%) and iron deficiency anaemia (10.1%).<br>• The waiting time to colonoscopy and overall waiting time were significantly shorter for patients in the rapid referral pathway compared to the standard pathway. There were no significant differences for waiting time to surgery.<br>• Overall compliance with the referral criteria was 80% (or 100% if only patients diagnosed with CRC are included). Patients who did not meet any criteria for rapid referral corresponded to 4% of all inappropriate referrals; patients who did not meet criteria but had symptoms and family history of CRC corresponded to 16% of inappropriate referrals.<br>• During the study period, **447 new cases of CRC were diagnosed: 12% via the rapid referral pathway, 69% via the standard pathway and 19% via emergency presentation**. If only considering the study final year (out of three years), the proportions were 18%, 59% and 22% respectively |

***Source: Included studies***

#### 4.3.6.5 Other activities (not part of three main strategies)

Outcomes were also available for additional activities carried out by NAEDI and ACE, although not all of them met criteria for inclusion in the review. The International Cancer Benchmark Partnership (39) (created under the auspices of NAEDI) did not meet inclusion criteria for the review, but a comprehensive list of its publications is available at the CRUK website (358). Publications describing the development of a Cancer Awareness Measure (CAM) Tool (relevant to both BCOC and NAEDI) can be found in the list of additional references for this review (Appendix 4).

Evaluation of the Cancer Networks Supporting Primary Care Programme (part of NAEDI) reported that general practices engaging in any of the four programme activities had a significantly greater increase in 2-week referral rates compared to practices that did not engage in any activities (although there were no significant differences in conversion, detection or emergency presentation rates) (150). General practices adopting the CDS tools had a significantly greater increase in referral rates for colorectal cancer, but no significance differences for conversions and detection rates (150).

Other outcomes for those using CDS tools (adopted by NAEDI and ACE) referred to how the tool influenced patient management, GP decision making and awareness of cancer; whether cancer risk scores provided by the tools were shared with the patient; whether the reason for the appointment was explained to the patient; the decision made by the GP (such as referral, reassurance, safety-netting, or no action); range of provided scores and variation by tumour type; perceived GP cancer risk compared with the calculated risk; whether GP decision would have been the same if tool had not been used; access to, and use of the tool (Table 4.11).

There was variation in patient management decisions, type of investigations/diagnostic tests carried out, choices of when to use the tool (i.e. during or after consultation) and in how tools influenced decision-making. Missing data or data unavailability were reported for both studies; this often precluded analysis of several cancer outcomes. Data on available quantitative outcomes is available (Table 4.11). Qualitative evaluation of the use of CDS tools provided richer information on tool usage and outcomes and is described in the next section.

**Table 4.11.** Key outcomes for the use of CDS tools

| Strategy | Key outcomes |
|---|---|
| ACE | Project 1 (London)<br>• GP decisions were fast-track (n=210), diagnostic tests (n=131), safety netting (n=69), reassurance (n=45), referral for further care (n=42) and active surveillance / review appointment (n=34).<br>• Most commonly ordered diagnostic tests were (in this order): blood test, referrals for chest x-ray; ultrasound scan; colonoscopy; endoscopy; and flexible sigmoidoscopy<br>• **The symptom checker influenced patient management more often during consultation compared to after consultation**. However, the tool was used more often after consultation. Missing data were an issue. 68% (40/59) of the cases in which the tool influenced management were when the tool was used during a consultation.<br>• **Risk scores had an impact on GPs' views on whether patient management was influenced by the tool**: risk <3 (15 yes, 117 no), risk 3-9.99 (35 yes, 122 no), risk 10-19.9 (6 yes, 50 no), risk 20+ (27 yes, 73 no); comments indicated that scores helped the GP to consider the next steps, reinforced the gut feeling and legitimised decisions.<br>• Risk scores were shared with the patient in about a fifth of cases<br>Project 2 (Tower Hamlets, London)<br>• Substantial amount of missing data resulted in analysis of cumulative scores: <3 (n=232) and ≥3 (n=335).<br>• Most commonly ordered diagnostic tests were (in this order): ultrasound, x-ray, endoscopy, MRI, and sigmoidoscopy<br>• Patient management decisions were fast track cancer referral pathway (34.0%), referral to further care (31.0%), active surveillance (21.5%), and patient reassurance (13.5%). **The proportion of patients reassured by GPs decreased as the risk score increased while the proportion of overall referrals increased in line with the risk score**.<br>• Cancer diagnoses: 16 patients received a cancer diagnosis. In all cases where the tool was used and a cancer diagnosis was made, the GP took positive action (instead of only reassuring the patient)<br>Project 3 (Gateshead)<br>• The data profiled patients mostly on the lung cancer smoker list, colorectal smoker list and oesophago-gastric smoker list. Most patients attended and received a CXR or were referred to lower GI for 2WW investigations. No one was diagnosed with the cancer being investigated (one unrelated cancer was diagnosed) |
| NAEDI | • Overall, **on more than half of recorded uses, GPs stated that their perceived risk was about the same as the risk calculated by the tool** (perceived risk was lower for 31% and higher for 15% of uses)<br>• Patient management decisions: referral (20%), further investigations (23%), no action taken (47%). **When a decision for referral was made, GPs reported that they would not have referred or investigated further for 19% of patients if they had not used the tool. The tool was more likely to have influenced the GP's decision to further investigate than to refer**, with variations across cancer types. If considering only patients that required further investigation, GPs reported they would not have done so without the tool on 28% of cases (10% for those who were referred).<br>• Impact **ranged from no impact at all, to increasing/shifting knowledge, to influencing patient management**<br>• **There was no evidence of impact of the tools on urgent GP referrals, conversion or detection rates**. It was not feasible to assess impact of access to, or use of the tools on cancer outcomes (such as cancer diagnoses) |

***Source: Included studies***

## 4.3.7 Participant views

Views from the public, patients and/or health care professionals were available for several initiatives. These were often obtained from interviews, focus groups or questionnaires. Most data were available from assessments and reviews of 2WW (278), evaluations of the Cancer Networks Supporting Primary Care Programme

(NAEDI) (150), CDS tools (NAEDI and ACE) (291, 334) and a process evaluation of ACE that included four different clusters (287). Additionally, data were also available from RAC (professional views) (345), BCOC (professional and public views) (177) and Fast-Track Catalonia (professional views) (320).

#### 4.3.7.1 Views on professional education strategies

There was limited evidence on professionals' views regarding education strategies (2 initiatives); when available views were often positive. Community pharmacy workers training as part of ACE often believed (75% respondents) that the training was very relevant to their role (72, 272). Stakeholders taking part in the evaluation of Cancer Networks Supporting Primary Care Programme (NAEDI) reported that the use of different approaches helped to keep training interesting. Both education and discussions generated from it were considered to be important (150).

Information on whether education strategies influenced knowledge/behaviour was also obtained from professionals (data were reported in the outcomes section).

#### 4.3.7.2 Views on strategies to improve public cancer awareness/knowledge

Views on strategies to improve public cancer awareness/knowledge were often positive (two initiatives). Inside Knowledge surveyed care providers (gynaecologists, primary care physicians, and nurse practitioners) on education materials for the public and reported that "most" professionals were positive towards them (328).

BCOC carried out qualitative research with the public and GPs, and in general both groups had positive or neutral views towards the campaigns. The public believed that the campaigns were targeted, sensible and easy to understand, drove action, helped with decision-making and with normalisation of help-seeking behaviour (177). About half of surveyed participants also believed that the campaigns showed them something new (51% for bowel campaign and 46% for the lung campaign), while more than half believed that the campaigns were relevant to them (67% bowel campaign and 55% lung campaign). GPs were also generally positive about the campaigns, and most agreed that it was important that such messages were shown to the public (177).

#### 4.3.7.3 Views on referral pathways based on cancer symptoms

Views on referral pathways were available for four initiatives. Views were mostly positive, although concerns were also raised by health care professionals.

A review of the 2WW initiative carried out with patient groups, cancer charities, clinicians and NHS managers reported that almost all unanimously agree that the strategy helped to improve services and resulted in benefits for patients (including reduction in patient anxiety). There was also support for the strategy to continue. There was recognition that the strategy was more straightforward (and targets more likely to be met) for some types of cancer (such as breast and skin) compared to other cancer types with more complex pathways. There were also discussions about how to improve referral processes (such as taking into account patients who wanted more time to think about treatment or considering different approaches for patients who are not meeting targets due to the need to be transferred between different areas) (278).

As part of Fast-Track Catalonia, semi-structured interviews with programme stakeholders indicated initial fears from hospital staff that the pathway would be overused by GPs, it would be used inappropriately, and guidelines would not be used accurately. However, this was not confirmed after implementation (320).

A GP survey carried out in the Republic of Ireland showed that 95.5% of GPs who had access to a RAC believed they had a ‘very good’ or ‘good’ experience (344).

Different ACE components carried out a range of surveys and interviews with patients and health care professionals. A patient experience survey carried out as part of the vague symptoms cluster found that patients were mostly positive about care, waiting times, information received and likelihood to recommend the service to others (88). Feedback on pharmacy training included a range of perceived benefits by professionals such as good communication between primary and secondary care and good local stakeholder engagement. However, concerns were raised by GPs about pharmacists making appropriate referrals; challenges identifying eligible patients, concerns about limited capacity and limited information (2015, 2017). One ACE pathway providing CT after a normal x-ray but persisting symptoms surveyed GPs and reported that GP satisfaction with the new pathway was rated 8.1 out of 10 (289).

Finally, stakeholder interviews covering four ACE clusters (287) identified a range of issues. Findings included: being part of ACE brought funds and credibility; some organisations were more able to change and develop services compared to others; diagnostic capacity was described as a potential or real pressure, with many concerned about whether they would be able to meet demand or would have enough time to deal with additional activity; belief that without a dedicated project manager

implementation would have been challenging; belief that efficient stakeholder communication about the project and specific roles, and identifying and engaging with the right people were fundamental to programme success; belief that the vague symptoms project prevented patients being subjected to unnecessary or inappropriate investigations and provided a faster route to diagnosis (although there were sustainability concerns due to pressures on endoscopy services). There was also anecdotal evidence that patients were positive towards ACE projects (287).

#### 4.3.7.4 Views on other activities

Stakeholder perspectives were also available regarding the Cancer Networks Supporting Primary Care Programme (NAEDI) and the CDS tools (ACE and NAEDI).

Stakeholders interviewed as part of the Cancer Networks Supporting Primary Care Programme reported challenges in maintaining engagement while there were structural changes happening to Cancer Networks in England. Concerns about information overload to GPs were also reported (150).

Both in the case of ACE and NAEDI, the use of CDS tools was reported to have helped to raise GP awareness of a possible cancer diagnosis during a consultation. Tools also helped with decisions regarding patient management. However, there was the acknowledgement that the tools were supporting the GP and were not a replacement for their own clinical judgement, and that not all GPs would wish to work with them (291, 334) (Table 4.12).

**Table 4.12.** Professional and patient views on the use of CDS tools

| Initiative | Professional and patient views |
|---|---|
| ACE | • **Criticisms/suggestions for improvements from professionals** included comments on how the tool did not take into account previous tests done or medical history, lack of symptoms for some types of cancer, failure to pick up on breast pain, cumbersome or confusing design, concerns about the tool's scientific validity (which could be due to limited awareness about the fact that tools had already been validated)<br>• **GPs reported that tools helped them to formulate their clinical decisions, to reinforce (or legitimise) decisions they had made and helped them explain clinical decisions to patients** (including providing reassurance in case of low cancer risk). They helped to raise awareness of cancer during a patient consultation and were (potentially) particularly useful in more complex cases (e.g. comorbidities), but less useful in the case of clear, red flag symptoms<br>• **Tools worked as support to the GPs' own clinical judgement**<br>• Patient experience questionnaire in one town (Gateshead in England) showed that 90% thought the reason for the appointment was clearly explained to them and 70% felt that being asked to come in made them feel nervous, anxious or on edge (although nine out of ten stated that the doctor made them feel less nervous, anxious or on edge). 80% thought telephoning them was the best way to contact them (nobody preferred a letter). Appointment times were considered to be suitable by 100% of patients |

| Initiative | Professional and patient views |
|---|---|
| NAEDI | • GP Interview data revealed **mixed preferences for use of the tool within the consultation, and with the patient. There were concerns about taking the focus away from patients and the potential for raising anxiety. Similar concerns about loss of focus were raised by patients**. However, when asked about the tools themselves, patient responses were generally positive. There were also **concerns from GPs about how referrals made based on the tools would be received by secondary care**, and about prompt overload (i.e. pop ups frequently flashing). **Time pressures in a GP consultation were reported to be barriers**. There were also uncertainties about how to interpret the information provided by the tools.<br>• Participants thought it unlikely that GPs would adapt their coding style in order to enhance the validity of tools and the scores presented.<br>• There was consensus that the **tools would not suit all GPs**, and that they were not necessarily the best support for early recognition of cancer symptoms |

***Source: Included studies***

## 4.4 Summary of Chapter 4

This Chapter describes the methods and results for a systematic review investigating the landscape of multilevel policy initiatives promoting the earlier diagnosis of cancer.

The review described 18 initiatives in 10 countries. The most often adopted early diagnosis strategies were referral pathways based on cancer symptoms, followed by strategies focused on improving cancer awareness/knowledge amongst the public and professional education. In addition to governments, health care professionals, charities and to a lesser extent for-profit organisations had an important role. Initiatives most often covered breast, lung and colorectal cancers.

As most initiatives were about referral pathways, the most commonly targeted groups were patients suspected of having cancer based on high-risk, alarm symptoms. More recent initiatives focused on patients at risk of cancer, or those with either vague, or serious, non-specific symptoms. However, other groups such as health care professionals, the general public, and minority ethnic groups were also targeted.

Few initiatives reported on high-level outcomes such as tumour staging, cancer mortality and survival, and significance was not always assessed. Outcome data on tumour staging was often positive (although improvements in recording were reported to contribute to this) (176, 316). Only one study (81) assessed mortality and found that practices with lowest use of the 2WW had excess mortality compared to practices with intermediate or high use. Limited available data on survival was inconclusive.

When assessing outcomes by type of strategy, results were mixed for professional education, with reports of both positive and no changes. Reports on awareness campaigns described positive changes in knowledge/awareness, but also persisting

misconceptions about cancer and barriers to help-seeking. BCOC was the only initiative reporting on statistical significance, including for health system outcomes such as GP referrals, diagnostic investigations and cancer diagnoses (176, 177).

In terms of referral pathways, there were several reports of reduction in diagnostic intervals (significance was reported in half of these cases), and mostly positive results on whether targets were met. There was mixed data on referral and conversion rates, and synthesis was complicated by heterogeneity (especially the use of different terminologies and comparisons). There were reports of more referrals to urgent pathways being made over time (277, 282, 283, 285, 320, 321, 345, 349), and for 2WW this resulted in a reduced yield of cancer diagnoses with many cancers being diagnosed through other routes (269, 278). Similar trends in increase in activity, but not in conversion nor detection rates were reported by those involved in NAEDI activities, including those using CDS tools in primary care (150, 334).

There were positive views on professional training (from professionals) and campaigns (from professionals and the public) in terms of their importance and relevance. For referral pathways, there were positive views from the public, patients and professionals, but also recognition that pathways worked better for some tumour types than others, and that referral processes could be improved (278). Across different initiatives, there were reported fears about the inappropriate use of pathways or referral guidelines and concerns about meeting demand due to limited capacity (72, 272, 287, 291, 320). Views on the CDS tools indicated that they helped to raise awareness of cancer but did not replace clinical judgement (291, 334).

This review described the landscape of multilevel policy initiatives promoting the earlier diagnosis of cancer. As such, it is not a review of each initiative, although more detailed information is available in appendices. This is a dynamic area, and since the review was carried out other publications have been made available for Inside Knowledge (359-361), ACE (362-368), CPPs in Denmark (369, 370), Sweden (86, 371, 372) and Norway (373). The review is currently being updated and these recent publications will be incorporated. Nonetheless, the current review provides crucial information to address the objectives 1, 3 and 4 of this PhD research project.

The next Chapters will focus on addressing Objective 2, i.e. to evaluate the Detect Cancer Early Programme, describing evaluation development (Chapter 5), methods (Chapter 6), and full evaluation results (Chapters 7 to 9).

# Chapter 5 Evaluation development and refinement (Study 2)

## 5.1 Overview

This Chapter describes the methods and results from evaluation development and refinement (Study 2). Furthermore, it outlines how Study 2 informed the methods adopted for the DCE evaluation (Study 3). When explaining how Study 2 outputs informed the evaluation, it was important to describe theories and frameworks that had not been described previously in this thesis. As a result, this is a complex Chapter, but it is hoped that it can show the processes and reflections required to develop the DCE evaluation.

## 5.2 Binding aims and components

Study 2's binding aims were to 1) elicit DCE programme theory; and 2) inform evaluation design and methods.

A robust evaluation needs a thorough, explicit description of the programme being investigated (154, 161). An explicit description of programme theory facilitates communication between researchers and stakeholders (154), and helps to inform evaluation design (154, 155). In Carol Weiss' words, "if the evaluator has no idea of what the program really is, he may fail to ask the right questions" (158).

A systematic description of DCE was not available; this is common in evaluation research (154, 161). Available evidence, stakeholder input and policy documents are often used to elicit programme theory (154, 158, 161, 165, 374). These sources were also used to elicit DCE programme theory. Therefore, Study 2 had two components: 1) analysis of policy documents; and 2) interviews with key DCE stakeholders.

### 5.2.1 Analysis of policy documents (Component 1)

#### 5.2.1.1 Aims and rationale

Documentary analysis is a systematic approach for reviewing documents often used alongside other methods (375). It aimed to 1) have a comprehensive description of the DCE programme; 2) inform the development of a logic model; and 3) facilitate the identification of stakeholders to be interviewed during evaluation development.

Documents are useful to inform the choice of questions to be asked in research (375) and the creation of data collection tools (376). They allow the researcher to capitalise

on existing evidence and can reduce research costs (377). Documents help to indicate chronology of events, to understand processes and official programme goals (204, 378), to identify stakeholders to be interviewed (378), and to show private interactions and decisions (204). Finally, documentary analysis has been adopted in evaluations assessing early diagnosis initiatives in the UK (150, 335).

#### 5.2.1.2 Methods: data collection and analysis

Although documentary analysis has benefits, it also has limitations. Documents are created with a purpose in mind, and are embedded in a specific context (379). They comprise assumptions and ideas that reflect those who produced the documents and intended audiences (380). Knowledge and power define what is to be included (380). Documents can be "selective" and report only on positive outcomes; details can be given for some components but not for others (158, 204). Moreover, documents can legitimise or justify actions (380).

Having a critical eye is required when doing documentary analysis (375, 379). Hence, prior to extracting data about DCE, it was important to interrogate the available documents. I developed a framework for analysis, informed by documentary analysis steps described by O'Leary (377); and other available guidance (375, 376, 379, 380) (Figure 5.1). Importantly, reviewing and interpreting documents should be always seen as a "tentative and provisional judgement" (381).

**Figure 5.1**. Developed framework for documentary analysis

| | |
|---|---|
| **Heuristics** | •Independent searches to understand what is available and relevant |
| **Planning** | •Consider what documents would be useful and how to access them<br>•Think of how to review and interrogate documents; plan what to extract<br>•Seek and obtain ethical approval if required |
| **Gathering** | •Request texts and organise them<br>•Save a copy of all unedited files in a separate folder |
| **Reviewing and interrogating** | •Interrogate background information: document source, publication year, document type, style, function and intended audience<br>•Investigate issues regarding relevance, authenticity, authorship, credibility, survivability and availability<br>•Consider how documents relate to each other<br>•Plan how to extract data |
| **Reflecting** | •Reflect upon the process, difficulties faced and own biases<br>•Discuss any issues in the thesis |
| **Analysing** | •Retrieve relevant data: summarise evidence from each document<br>•Describe the programme in a narrative (text) format and create diagrams |

***Source: adapted from (375-377, 379, 380)***

The first step comprised independent searches of DCE documents; this was followed by considering which documents would be relevant to explore, planning what to extract and seeking ethical approvals (second step). The third step comprised data gathering and organising; unique IDs were created for each document; they were then organised in folders based on document sources. Then, documents were reviewed and interrogated based on several criteria (Table 5.1). Definitions for the adopted criteria were retrieved from the relevant literature (377, 380, 381) and are available in Appendix 13. Importantly, even though I used predefined criteria and was transparent in adopted procedures, a certain level of interpretation and subjective decision-making was required when interrogating documents. The adopted criteria were not always sufficiently precise when making a decision. SPSS v.23 (245) was used to facilitate interrogation and data analysis. Charts were developed in Microsoft Excel 2016 for Windows (382).

**Table 5.1.** Document review and interrogation

| Criteria | Description |
|---|---|
| **Background information** | Source (who provided me with the document) |
| | Batch (when document was received) |
| | Publication year |
| | Document type (classified based on data; e.g. reports, minutes) |
| | Style (classified based on data; e.g. medical terms, lay terms) |
| | Function (persuade the reader, validate or justify something) |
| | Intended audience (classified based on data; e.g. DCE stakeholders) |
| | Readership (whether it is actual or implied) |
| **Relevance** | Whether document helped to address study aims (and if so, which aims) |
| | Whether documents had relevant data on process, outcomes or context |
| **Authenticity** | Version (draft or final) |
| | Soundness (whether document is sound, partially sound or unsound) |
| **Authorship** | Source (personal or official) |
| | Type of author (individual, group or anonymous) |
| **Credibility** | Sincerity (sincere or not sincere) |
| | Possible interests (personal interest, financial gain, political advantage) |
| | Type of source: first-hand (primary) or second-hand (secondary) |
| | Type of evidence (document represents facts, opinions or both) |
| **Survivability** | Whether document is published, filed, or just stored somewhere |
| **Availability** | Whether access to documents is closed, restricted or open access |

***Source: Adapted from (377, 380, 381)***

Therefore, when developing the evaluation, documentary analysis was not only about the content, but also about how documents looked like, what was their purpose and function, who the authors where and who was the intended readership (379). Issues such as authenticity and credibility were important, alongside other background information (377, 381).

A comprehensive qualitative thematic analysis (375) was considered for analysing policy documents, but not deemed necessary nor feasible to obtain the data to inform the evaluation within the study's timescales. Similarly, discourse analysis (380) was relevant, but not feasible. Instead, after reviewing and interrogating documents, all information that was useful to meet the study aims was extracted. A summary was developed for each document. Emerging questions/comments to aid evaluation design were added in italics to these summaries.

Summaries were used to create a narrative about DCE development and its four strategies (shown in Chapter 2 and the final report produced for the Scottish Government). Then, they informed the development of a service utilisation plan and a programme impact theory (Appendices 18 and 19). As described by Rossi (161), these diagrams helped to synthesise programme data in a way that was useful for logic model development.

#### 5.2.1.3 Results: Documentary analysis

Independent searches were carried out in late 2015; they resulted in six core DCE documents to be included in the documentary analysis: the DCE implementation plan, two social marketing newsletters and three documents with action notes and minutes from DCE Programme Board meetings. Searches also resulted in several references about cancer burden and cancer policies in the UK which informed Chapter 2.

I received 159 different policy documents by email, in four batches. The first batch (n=66) consisted of core documents sent by DCE managers in October 2015. Additional requests were made over time reduce the likelihood of only receiving documents focusing on a few components or with similar points of view. Requesting further documents was particularly important as I needed to obtain sufficient and adequate background information about the programme. Requests were made during informal meetings with DCE in late 2015 and early 2016. The second batch of documents was sent by DCE managers in February 2016 (n=62).

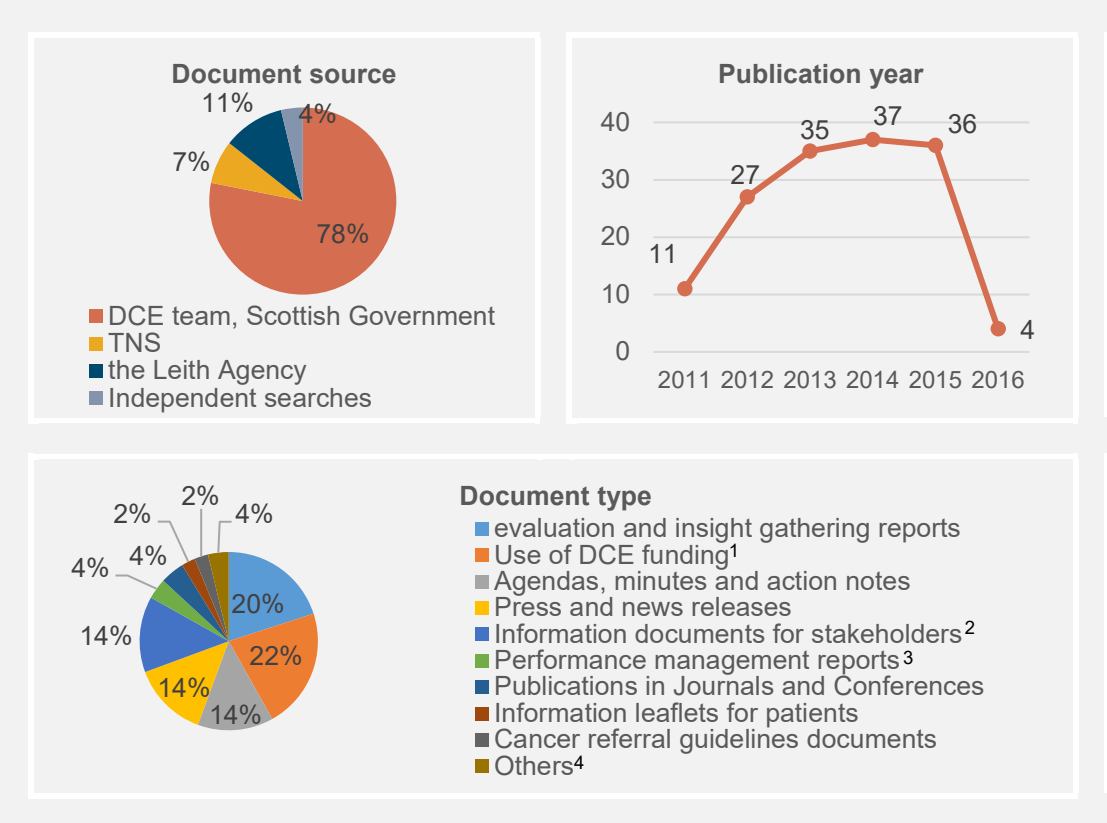
The market research company evaluating DCE campaigns (TNS) sent the third batch (n=14) in February 2016. Finally, the media agency coordinating the social marketing campaigns (the Leith Agency) sent the fourth and final batch (n=17) in April 2016.

Five documents were duplicates; the remaining 160 (six documents found by me plus 154 received documents after removing duplicates) were analysed.

*Reviewing and interrogating*

A list of documents reviewed and interrogated is available in Appendix 14. Most documents were provided by the Scottish Government. Evaluation reports (often prepared by TNS and the Leith Agency to report on campaigns) and reports about use of DCE funding comprised 42% of all documents (Figure 5.2).

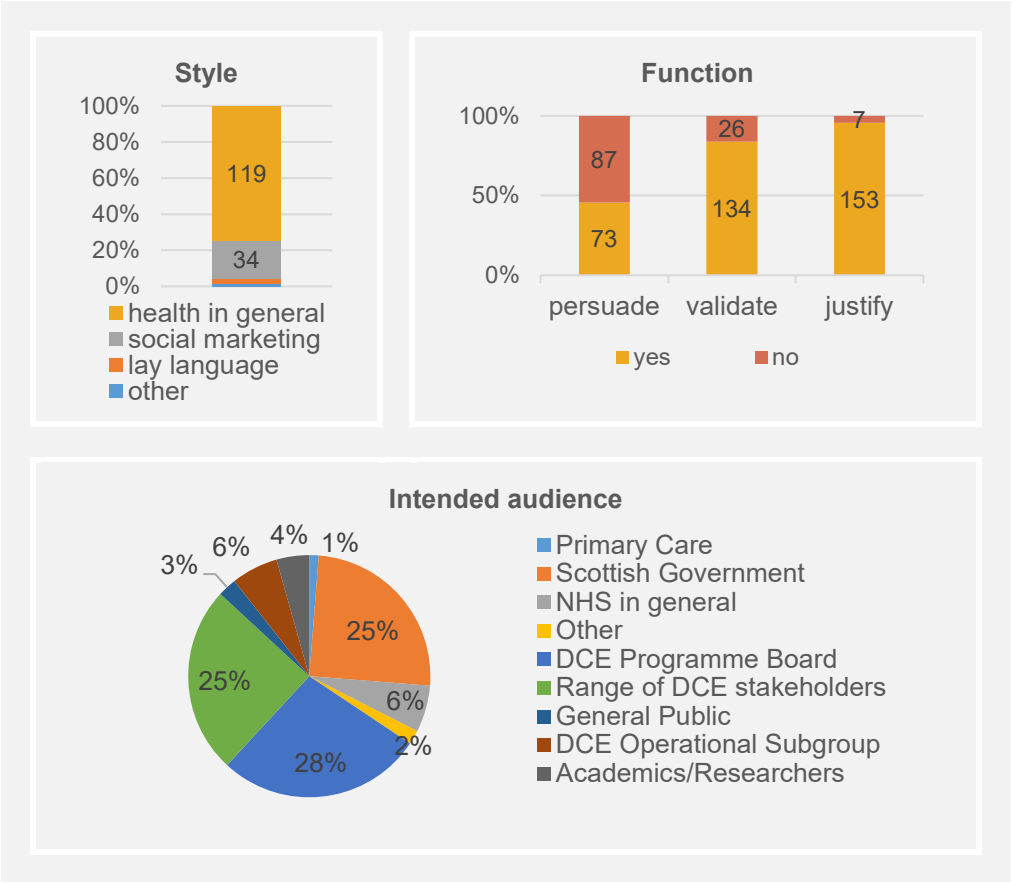
**Figure 5.2.** Background information: source, publication year and type




***[1]Annual reports sent by territorial Health Boards, DCE summaries of how funding was used, and allocation of DCE funding across different programme components. [2]Include the DCE Implementation plan, circulars, and social marketing campaign information packs. [3]Reports about HEAT targets, the bowel screening initiative and cancer waiting times.[4]Refer to a stakeholder report providing a clinical perspective about DCE and a report about Deep End Practices in Glasgow***

All documents were in a digital form, all were unsolicited (i.e. existed irrespective of requests). All were classified as copies. Most used general health terms (such as mortality and screening uptake), while 21% used social marketing jargon (such as "impressions" and "cost-per-click"). Less than half of documents explicitly attempted to persuade the intended audience, while over 80% of them used facts or opinions to try and validate or justify investment, decisions or further developments. The most common audiences were the DCE Programme Board (28%) and the Scottish Government (25%) (Figure 5.3).

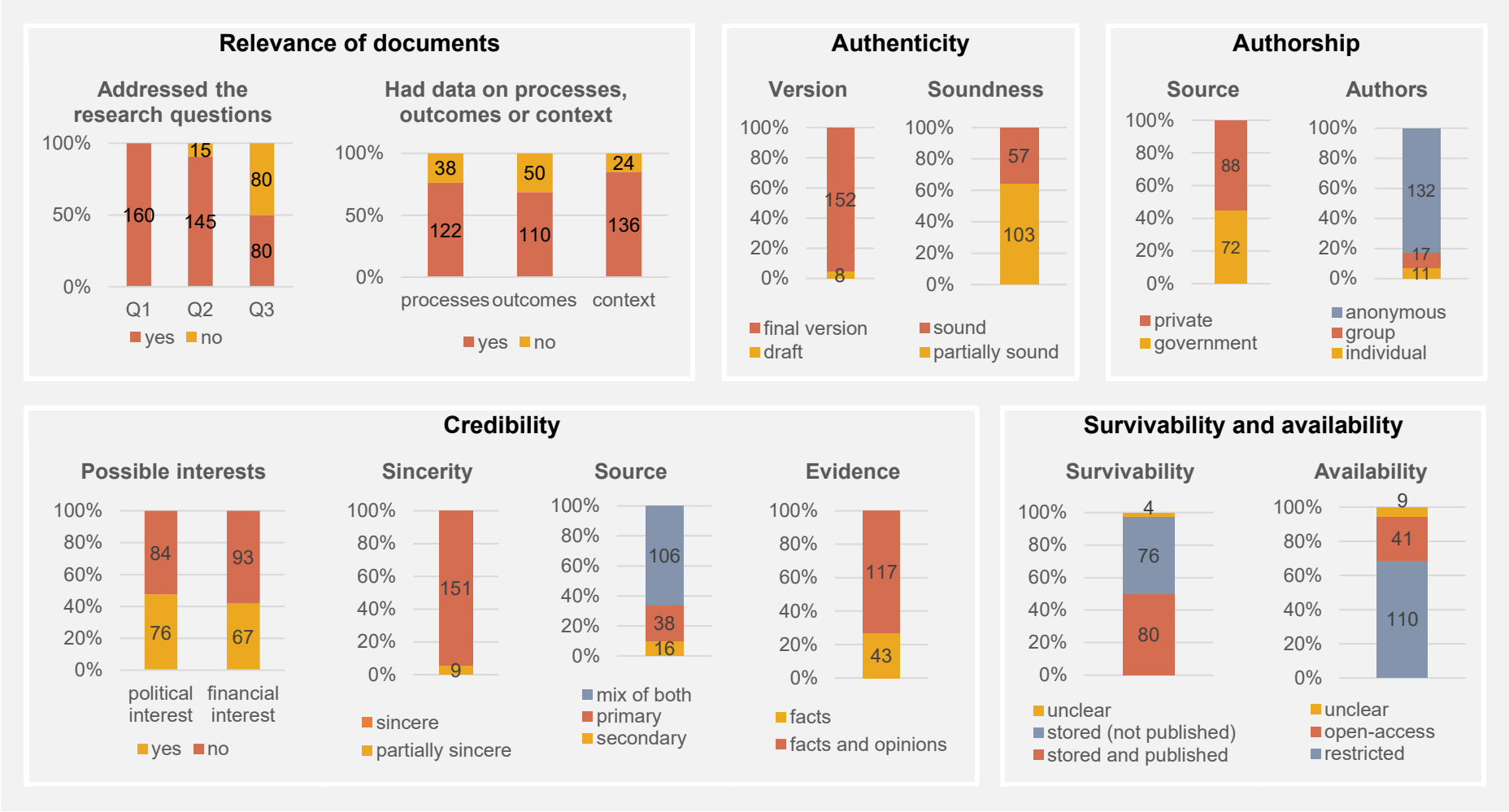
**Figure 5.3.** Style, function and intended audience




***Other style refers to documents that did not fit in any of the other three styles (n=2; a terms of reference document and a table with DCE funding allocation). Other audience refers to a document about campaigns prepared for a competition (further information not provided).***

All documents had information that helped to obtain a comprehensive description of the DCE programme; half of them were useful to identify stakeholders to be interviewed. More than half of them had information on processes, outcomes or context. Most documents were partially sound due to issues such as missing appendices and missing references. Most documents did not specify whether the author was a group or an individual. There was the possibility of political and financial interest/gain in over half of documents. Most documents appeared to be sincere. Most documents reported both primary and secondary data sources and described both facts and opinions. Half of documents were both stored and published, and most of them had restricted access (Figure 5.4).

**Figure 5.4.** Document interrogation



#### 5.2.1.4 Component 1 outputs

*Description of the DCE programme and development of a logic model*

The service utilisation plan, programme impact theory diagrams (Appendix 15) and draft logic model (Appendix 16) were developed in December and January 2015, using the first batch of 66 documents. All remaining documents were analysed between March 2016 and November 2017; they were used to refine the logic model and to inform the textual summary of DCE and its components (described in Chapter 2 and the final report for the Scottish Government).

In addition to evidence from documentary analysis, the logic model was informed by guidance in the literature (154, 161, 167). The DCE logic model described inputs, activities, outputs and outcomes (161), and included possible contextual factors that could have influenced the programme (154). Furthermore, a box on preliminary, potential assumptions regarding the programme based on policy documents was added to the model.

The draft logic model was shared with PhD supervisors and DCE managers in February 2016. It was amended after their feedback in order to focus on broader outcomes; minor corrections were also made to the described activities and outputs. The draft logic model is only available in Appendix 16 as the font was too small for the main thesis. It was printed in a larger size (A3 format) to ensure readability.

*Identification of stakeholders to be interviewed*

Potential stakeholders to be approached for interviews were identified in policy documents. Names mentioned by DCE management during initial meetings to discuss the evaluation were also added to the list, which had 11 names.

After I had a better understanding of the DCE programme and had prepared a list of stakeholders, the next step was to carry out the stakeholder interviews.

### 5.2.2 Interviews with key stakeholders (Component 2)

#### 5.2.2.1 Aims and rationale

The key stakeholder interviews aimed to: 1) refine DCE's programme theory (166), eliciting assumptions, mechanisms of impact, contextual influencers and unanticipated outcomes; 2) confirm the suitability of complexity theory and theory-based evaluation; 3) inform the choice of implementation and behaviour change theories for the evaluation; 4) help to prioritise aspects to be evaluated (162, 166); and 5) identify stakeholders to be interviewed in the process evaluation.

A small number of “carefully selected stakeholders” can help to identify key issues to be taken into account in an evaluation (161). By consulting stakeholders, evaluators may identify variations in how a programme is understood, in which components are more often emphasised, and regarding who is likely to benefit the most from programme. These different views help evaluators to anticipate challenges when carrying out a process evaluation (166). Furthermore, stakeholders can help to ensure that the right evaluation questions are identified (168). Finally, if stakeholders are involved, they are more likely to be supportive and to consider the recommendations from the evaluation. Poor stakeholder involvement, on the other hand, may lead to resistance, stark criticisms, or sabotage (168). For all these reasons, it was important to interview stakeholders during evaluation development.

#### 5.2.2.2 Methods

*Inclusion and exclusion criteria*

In order to be eligible to be interviewed, stakeholders needed to be directly involved in the development or in the running of the DCE programme (as a member of the DCE Programme Board or a frequent attender at the DCE Programme Board meetings). Stakeholders were excluded if they were unwilling to provide informed consent.

*Data collection*

Sampling and recruitment

I used the list prepared during documentary analysis to select stakeholders who could provide substantial information about the programme, while also ensuring there was variation in their geographic location, roles and experience. Characteristics such as gender and age were not deemed to be critical for selecting participants. Criterion sampling and maximum variation sampling (two different types of purposeful sampling) (Patton, 1990) were used to ensure that different groups of stakeholders (e.g. clinical, strategic or supportive backgrounds) from the South East, West and North of Scotland could provide their views about DCE. Eight potential participants were sampled from the list; all of them were invited for an interview by email.

Interview topic guide and setting

The interview topic guide (Appendix 17) was informed by the logic model and study aims. I also consulted guidance on designing interview guides (161, 166, 168); published evaluations (148, 150); and PhD theses reporting on evaluations (149, 160, 383-385).

Participants were asked questions about DCE development; its rationale, aims and objectives. Other questions focused on the participants' views on DCE implementation and expected outcomes, and perceived challenges when undertaking the DCE evaluation. All participants received the logic model prior to the interview and were asked for their views on how well the programme was described. Each interview was estimated to last 40-60 minutes.

Face-to-face interviews were preferred as interviewees were asked to review the logic model, which was a complex document (386). Furthermore, as these were initial interviews a face-to-face encounter would facilitate the development of rapport (386). Nonetheless, an option of a telephone interview was also given in case the interviewees found this a more practical alternative. Telephone interviews also have benefits such as being more cost-effective (386).

### Transcription

A well-established company, which regularly provides transcripts for the University of Edinburgh, transcribed all the interviews. I checked all transcripts for inaccuracies and made corrections as needed.

*Data analysis*

I read each transcript as soon as it was delivered in order to inform future interviews and to get acquainted with the data. Continuous analysis in qualitative research is "almost inevitable" as fieldwork makes the researcher think of what is being said (387). Furthermore, it helps to refine research questions, to pursue different avenues of enquiry, and to identify cases that may go against current hypotheses (387).

In line with the adoption of mixed methods and being underpinned by pragmatism, data analysis methods were chosen based on the study aims and what the findings were supposed to do (200). I had predefined aims and objectives; and the interview topic guide directed the participants towards describing the programme, its activities and outcomes. Due to my aims and methods, I did not wish to reach the grounded theory definition of "data saturation" (200) as I focused on very specific topics and a selective group of participants (described by Patton as "information rich cases") (204). Furthermore, I had a limited amount of time to analyse data. I considered using a simple thematic content analysis. However, I was concerned that simply reporting these themes would not do justice to the richness of data (200) and its policy context. Therefore, I chose to adopt the framework approach (388).

The framework approach is a systematic procedure developed by Ritchie and Spencer for the analysis of applied policy research (388). It is not aligned with a specific paradigm and can be used with different qualitative approaches aiming to generate themes (389). Framework analysis allows for the adoption of both inductive and deductive approaches. Themes can be generated from research questions, available literature or existing theories in addition to the participants' narratives (387, 389). The approach goes beyond a simple thematic content analysis as it also looks at relationships between codes (200). Framework analysis is commonly used when doing thematic analysis of interviews with data about similar topics/issues (389), and has been used to evaluate an early detection initiative in England (287).

Framework analysis approach comprised five stages: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation (Table 5.2). The structured steps allowed for the analysis to be made explicit and accessible (388).

**Table 5.2.** Stages and associated steps when doing framework analysis

| Stage | Steps |
|---|---|
| Familiarisation | • Check, correct, clean and anonymise transcripts<br>• Read field notes and transcripts, listen to recordings<br>• Write initial ideas and possible themes in the transcripts |
| Identifying a thematic framework | • Discuss a sample of transcripts (n=2) with another researcher and agree on emerging themes. Solve disagreements by consensus<br>• Develop a thematic framework informed by key recurrent themes and issues, notes, research aims and interview questions<br>• Apply the framework to a few transcripts (n=4) using NVIVO 11(390); write notes about amendments, additional themes and issues to consider when coding data. Make amendments to the original framework |
| Indexing | • Apply the amended framework to remaining transcripts. Continue writing notes, refining the framework and recoding transcripts<br>• Number all themes/sub-themes in a Word document, convert the text into a table and describe each theme |
| Charting | • Rearrange data (participant's views according to themes) in NVIVO |
| Mapping and interpretation | • Create a diagram representing the themes and subthemes<br>• Review transcripts and comments, field notes and the framework and look for patterns and linkages<br>• Refine definitions for each theme and describe associations between them; write a summary of findings<br>• Write about how findings addressed my research aims, and consider what to focus on when doing the evaluation |

***Source: adapted from Ritchie and Spencer 1994 (388)***

#### 5.2.2.3 Reflexivity

Recording reflexive notes and thoughts about data analysis is recommended from the earlier stages of data collection (389). I made brief notes during each interview (in order not to lose rapport), focusing on key aspects to be considered in future interviews. I also wrote field notes at the end of each interview and shared these with my principal supervisor. Key reflections are described in Chapter 10.

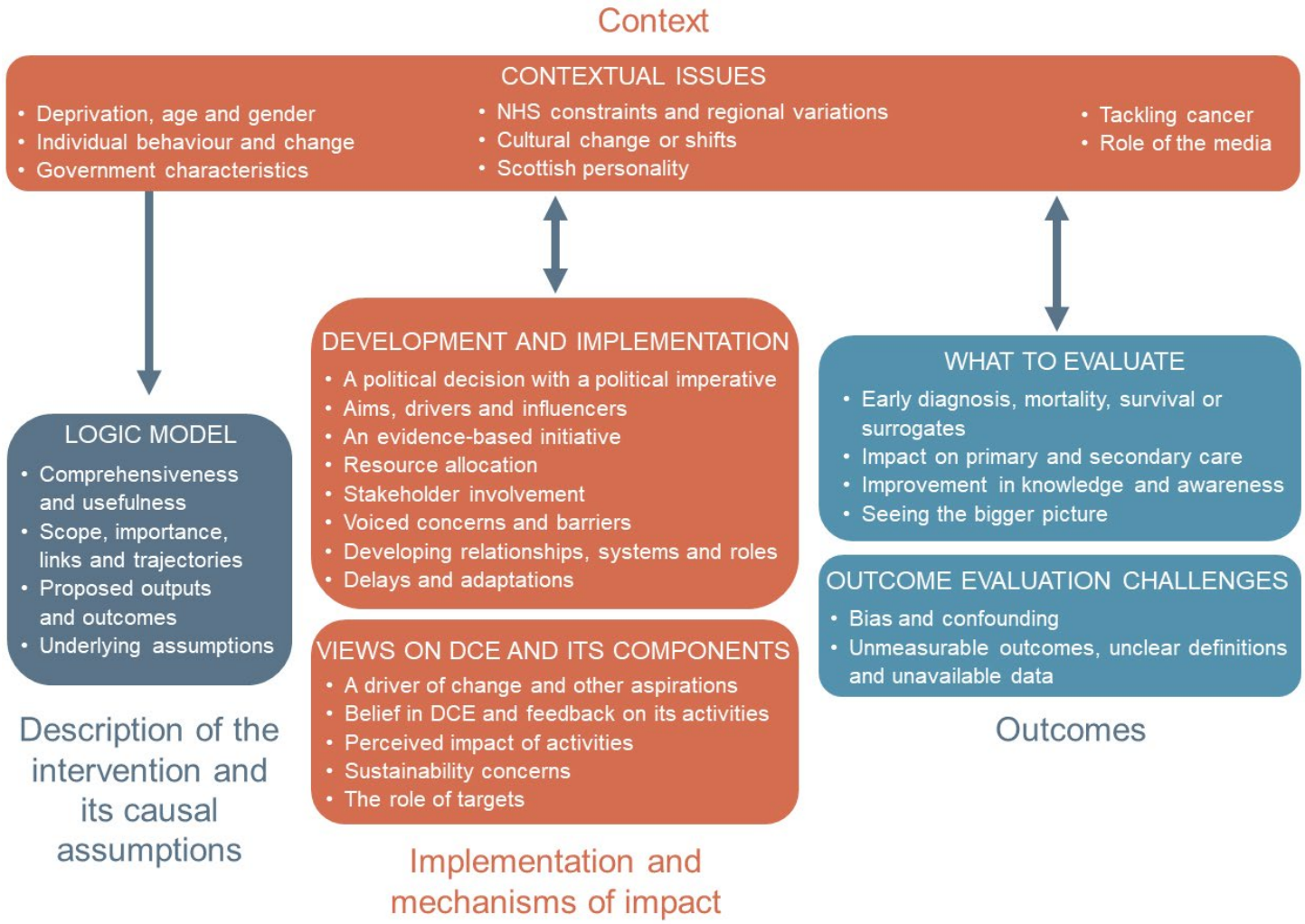
#### 5.2.2.4 Results

All eight sampled stakeholders were invited for an interview and accepted to take part. Interviews were carried out between April and June 2016. All stakeholders suggested I spoke to a ninth stakeholder whom I had aimed to interview during the full evaluation. This additional stakeholder was interviewed in August 2016 as part of evaluation development. All nine interviews were recorded, transcribed and checked. Eight were face-to-face and one was carried out over the telephone. Face-to-face interviews took place either at the interviewees' current or former workplaces (as some participants had retired or changed jobs since DCE had been implemented) or at another place suggested by them. The interviews ranged from 32 to 77 minutes (mean 53 minutes).

In order to avoid participant identification, information is limited on their characteristics. Five were men and four were women. Job roles included senior management in ISD Scotland; at DCE; in national screening programmes and in each of the Scottish Cancer Networks; GPs; and secondary care doctors. These roles are not mutually exclusive as some participants had more than one of them. Most stakeholders wore "many hats", giving their input and expertise to several initiatives in Scotland. Some had experience working in the private sector, others led or were core member of advisory groups at the Scottish Government. Participants represented five territorial Health Boards in Scotland: NHS Lothian, NHS Forth Valley, NHS Greater Glasgow & Clyde, NHS Tayside and NHS Grampian.

Feedback from stakeholders was organised according to the adopted MRC framework (166) and approached six areas: development and implementation; views on DCE and its components; logic model; contextual issues; what to evaluate; and outcome evaluation challenges (Figure 5.5). Theme definitions and relationships between themes are available (Appendix 18). The terms "participants" and "stakeholders" were used interchangeably.

**Figure 5.5.** Themes from key stakeholder interviews



*Theme 1: DCE development and implementation*

*A political decision with a political imperative*

DCE was described as a government programme with a political agenda and a strong political imperative, specific targets and investment. Government involvement was overall seen as positive as it allowed for the programme to be developed and implemented; and facilitated a national concerted effort to promote early detection. However, the political imperative meant that DCE "had to work" and resulted in pressure to achieve targets/complete tasks within a specific timescale.

Stakeholders highlighted that DCE was different from other government programmes, as it required primary and secondary care to work together with public health and gave a prominent role to social marketing campaigns. DCE's approach to health campaigns was also seen as different from everything that had been attempted before by the Scottish Government. DCE campaigns were different in terms of quality (considered to be more "professional"), vocabulary (with the use of humour) and "bold" messages (such as showing real breast cancers in national television). Another different characteristic was the choice given to Health Boards to invest DCE funding where they thought it would be most useful (see "Resource allocation").

Aims, drivers and influencers

Views on what DCE's key aims were varied across participants. While some emphasised the programme's aim to diagnose cancer at earlier stages in order to improve survival, others focused on the importance of improving population awareness, or of promoting system-level changes. Some acknowledged that wide changes would be difficult without generating a bit of "chaos" in the system.

> *"This programme, as I saw it, was to try and pull a number of strands of work together to try and make a concerted effort to raise awareness, to influence primary care, to improve diagnostic capacity and to promote screening or promote the benefits of screening, make people aware what the benefits and risks are." (ID 7)*

NAEDI in England was considered to have a strong influence in DCE. Contacts with key NAEDI implementers working for the charity Cancer Research UK (CRUK) and the UK Department of Health helped to inform the programme, with adaptations made for the Scottish context. Furthermore, the fact that bowel screening in Scotland had a leading role in early detection in the UK was described to positively influence how the clinical community embraced early detection initiatives.

### An evidence-based initiative

In addition to being strongly influenced by NAEDI, participants emphasised that the core tenets of the programme were based on evidence that cancer diagnosed in its earlier stages is more likely to be successfully treated. At the same time, emerging evidence from an independent review (50) on the benefits and harms of breast screening influenced DCE's strategy to initially target breast symptoms.

### Resource allocation

Stakeholders reported that Health Boards varied in their approach to use DCE funding, described uncertainties regarding how money was invested, and added that varying levels of engagement made it difficult to gather information.

> *"Primary care's quite defined, marketing's quite defined, then we come to secondary care and it's like what did you do? Well I suppose we invested in that and we gave boards money and then kinda left them to get on with it" (ID 2)*

### Stakeholder involvement

Participants described how expert advice was sought from a range of stakeholders, such as representatives from the Scottish Primary Care Cancer Group, from all regional cancer networks, and from cancer charities. Clinical leads at the bowel and breast screening programmes also gave input. In general, stakeholders believed that their opinions were listened to when DCE was developed. Nonetheless, not all agreed on whether clinical views were well represented.

DCE's attempts to engage with stakeholders were seen as helpful to provide them with a "sense of ownership" over a government-led programme.

> *"I think it was great and I think that everybody who was involved was enthusiastic, I think, you know, people came from different offices, everything, you had clinical input, you had patient input, you had the bureaucratic input and it was melding it in and it's good and it shows that you can move forward, you can achieve goals – we initially didn't agree on all the goals." (ID 6)*

### Voiced concerns and barriers

Participants described their concerns and shed light on other stakeholders' apprehensions regarding the programme. A recurrent theme referred to worries about DCE impact on primary and secondary care, especially regarding diagnostic capacity.

> *"There was a concern that we might just increase demand for services without actually detecting more people who had cancer […] that GP practices would become even busier with people being concerned about symptoms that were unlikely to be cancer, […] that imaging services such as x-ray, ultrasound, CT scanning would not be able to cope with the increased number of referrals*

*for imaging, and there were also concerns in other areas such as within endoscopy which they might not be able to manage increased numbers who come through for colonoscopy." (ID 3)*

### Developing new relationships, systems and roles

Participants involved in DCE implementation described the development of new processes and relationships in order to get the programme running. A Programme Board with wide stakeholder representation was created. New IT systems were developed in collaboration with ISD Scotland and a point of contact was established between them and the programme. Proxy outcomes for survival were discussed and agreed upon. Circulars were sent to territorial Health Boards. While in the initial stages of the programme stakeholders were mainly contacted through formal mechanisms, over time this became a more informal contact over the phone. Furthermore, levels of engagement were reported to vary according to Health Boards and Cancer Networks.

### Delays and adaptations

Implementation delays happened for some DCE components. This was the case for the provision of bowel screening non-responder data to general practices and creation of general practice profiles. These were perceived as missed opportunities to contact patients, and to compare performance.

Each territorial Health Board could have their own aims, in addition to the ones specified by the programme. Participants acknowledged that different Boards had different challenges to tackle and described how they also had different approaches to different programme strategies.

*Theme 2: Views on DCE and its components*

### A driver of change and other long-term aspirations

DCE was described as a driver of change in many ways. The programme was seen by some as a mechanism for improving confidence for primary and secondary care. Stakeholders believed that DCE could help to modify the way the population perceived cancer, without seeing it with fear or as a death sentence. They hoped that increased knowledge and awareness would instil a sense of confidence and empower patients to go see their GPs when they noticed symptoms. By improving knowledge among young people and other influencers (such as family and employers), stakeholders hoped that changes would be sustained "generation after generation".

Overall, stakeholders wished that DCE could lead to cultural changes in the long term, with early presentation and screening "becoming commonplace". Stakeholders were

aware that these changes were “complex” and challenging, but hoped that DCE would leave a legacy, with early detection becoming “business as usual”.

### Belief in the programme and feedback on its activities

Overall, participants “believed” in DCE, in its importance and in what it proposed to do, and often reported being proud of being part of it. Views were particularly positive about the quality of the social marketing campaigns. Nonetheless, challenges such as having difficult objectives were recognised. Furthermore, there were suggestions on issues that could have been done differently. These included targeting advanced disease (as survival is poorer; screening already targets early stages; and early diagnosis of lung cancer is challenging); updating the referral guidelines prior to starting the campaigns; and having more clinical input early on.

### Perceived impact of activities

Stakeholders were aware that there had been an increase in cancers diagnosed at Stage I over time, even though DCE’s key aim (i.e. 25% increase in cancers diagnosed at Stage I) had not been met. From their perspective, the increase was still positive. The observed impact that the symptomatic breast campaign had on capacity (increase in consultations but no more cancers were diagnosed) was noted. Conversely, the campaign was also perceived to be successful as the public remembered its messages.

Participants also provided views on other programme impact. They believed that DCE helped to drive attention towards cancer screening and prevention. Territorial Health Boards had to invest in audit teams, and this was perceived to have a long-term positive impact on better tracking patients. Education sessions were seen positively as they informed clinicians about the programme and became opportunities to discuss referrals.

### Sustainability concerns

Participants raised several concerns about DCE’s sustainability. Some highlighted the need to sustain public interest and acknowledged that campaigns with short bursts of activity might not have been the best approach (although limited funding did not allow for other alternatives).

> *“The problem is that public facing campaigns are very transient […], we always see an increase in uptake, but it comes back down to the baseline fairly shortly afterwards. […] You either need sustained activity in that area or you need something more concrete around the way that services are provided.” (ID 9)*

Stakeholders were aware of the importance of ensuring payment for GP practices so work promoting bowel screening uptake could continue. Other sustainability issues included having sufficient resources for diagnostics and treatment over time and ensuring continued stakeholder engagement.

### The role of targets

Participants had mixed views regarding performance targets. For some, they were a way to "focus the mind" and drive activity. Stakeholders believed that targets were useful for the politicians and the media, as they were quantifiable and easy to report.

Other stakeholders believed that targets were unhelpful as they diverted attention from professionals; led to using scarce diagnostic resources on patients with a very low cancer risk; and measured changes in a short period of time. Some questioned whether the targets were the best way to estimate the success of a programme aiming to drive system-level changes.

> *"If you put a target on it you drive activity, you drive the way they focus, the way they work, the way they do things around meeting that target. Now they might not meet it but what difference does it make whether they meet it or not, if they're doing everything to get there you've given them something to work towards, so… but that's maybe another thing, you know, were we right to have a target?" (ID 7)*

*Theme 3: Logic model*

### Comprehensiveness and usefulness

Participants stated that the logic model was comprehensive and mostly accurate; and was useful to summarise the programme. However, some believed that the logic model displayed too much information, making it difficult to find specific issues. Nonetheless, there were requests for adding more information (such as on other funded DCE projects, and activities related to diagnostic capacity).

### Scope, importance, links and trajectories

Participants thought that at times there was an artificial separation between primary and secondary care activities. For example, performance management activities and symptom management and referral involved both areas.

> *"I'd maybe put this QOF [bowel screening initiative] in there just because it was such a huge part of primary care engaging with secondary care I think, although it does come under performance management as well doesn't it" (ID 2)*

Stakeholders also stated that the logic model did not show the relative size/scope and importance of each DCE component. Some believed that "more important"

components should have been more prominent. Others argued that the model did not show the order in which activities happened, although it seemed to imply that the initiatives shown first also happened first. Finally, it was suggested that the DCE strategies were named exactly as described in the initial DCE implementation plan.

### Proposed outputs and outcomes

Increased number of bowel consultations due to signs and symptoms (shown as an outcome in the draft logic model) was described as inaccurate as DCE focused on bowel screening. Increase in participation and improvements in data capture were perceived as happening much sooner than what was described in the logic model. The practice profiles, on the other hand, were expected to be a longer-term outcome.

Some stakeholders suggested moving some of the middle-term outcomes into short-term instead. Others discussed whether the logic model should report what was expected to happen or what had happened. These stakeholders gave examples of initiatives which had not initially been planned but became an important DCE component. Finally, there were requests to add less quantifiable outcomes; such as cultural changes regarding cancer.

> *"These are quite specific long-term outcomes and I wondered about something about that cultural change about, recognising, you know, understanding that it's not something to be feared, that treatment's changing all the time and that survival's better and the earlier you're presenting the better the chance of a healthy… a long term outcome." (ID 7)*

### Underlying assumptions

The assumption that increase in demand would be managed with increase in capacity in screening, diagnosis and treatment was questioned. In certain cases, Health Boards were not aware of how much they could handle in terms of capacity. Stakeholders also discussed the (causal) relationships between described activities, outputs and outcomes, and questioned whether some of the proposed outcomes were positive. Increase in consultations, more diagnostic tests, and reduction in emergency presentation were not seen as successful outcomes, unless they also led to improvement in early detection and reduction in mortality. Emergency presentations were not always seen as a negative outcome as at times they are unavoidable.

> *"Increasing the number of patients consulting due to cancer related symptoms, yeah, I mean, I think... […] I don't think that's right, it's not a successful outcome unless you can demonstrate that it's associated with an increase in early diagnosis and*

*subsequently in mortality. So, I think one of my problems with that is this is not necessarily an index of success." (ID 9)*

*Theme 4: Contextual factors*

### Deprivation, age and gender

Participants described how social deprivation could influence cancer awareness, incidence, presentation, screening, diagnosis and mortality. Wide regional variations in Scotland according to social deprivation were acknowledged. Participants stated that reducing health disparities was paramount in order to improve outcomes for all but acknowledged that achieving this aim was beyond the remits of DCE.

*"Yeah, I think the main challenge in Scotland is around equity and there's no doubt, you know, Scotland's got a very sort of wide socioeconomic gap across its society" (ID 9)*

Population behaviour towards campaigns was described to vary according to social deprivation, with the most deprived taking longer to process information from the campaigns, or to act upon them. Population age and gender were described as interacting with deprivation and providing a more complex picture in terms or response to the awareness campaigns.

### Individual behaviour and change

Stakeholders discussed population's beliefs about cancer, the general population's concerns about wasting the doctors' time, cancer fear and fatalism, and how this influenced programme development and its expected outcomes. They acknowledged that behaviour change was challenging; increased knowledge did not necessarily translate into action; and that substantial behaviour changes would take a long time.

### Government characteristics

Stakeholders commented on how the nature of the campaigns could be in potential conflict with other messages coming from the government (i.e. DCE could be interpreted as an attempt to save money as opposed to a strategy to improve quality of life and promote early detection). Stakeholders also stated that since governments change over time, their priorities (and perceived DCE importance) may also change.

### NHS constraints and regional variations

Participants consistently reported challenges related to NHS capacity, especially regarding diagnostics, although surgery and primary care were also mentioned. Participants highlighted that the problems were pre-existing of DCE and influenced DCE's strategic decisions.

Reported primary care constraints referred to staff shortages and resource limitations. In fact, the need to have additional resources was described as a reason why some territorial Health Boards engaged with the programme.

> *"On the ground I get a sense, but I've got nothing, no evidence to support, I get a sense that some people were challenged for lots of different reasons way beyond DCE and they used DCE as a route to try and access monies […] I know of boards that appointed individuals to do maybe breast or colorectal work etc., but actually a lot of the challenges were pre-existing irrespective of DCE but they just used it as a mechanism and I suppose that's what happens." (ID 8)*

Participants described a perceived "disconnect" between primary and secondary care and a "silo mentality" which may have had an impact on the programme.

### Cultural change or shifts

Participants emphasised the need to have an increased focus on health promotion and cancer prevention. DCE was seen as part of a bigger picture, where work from cancer charities, development of screening programmes and new technologies would also make a large impact in cancer outcomes.

> *"Here was funds being channelled towards something that was happening in the community, but there's always been this kind of long term ambition in the wider health economy that we need to shift some of the resources away from acute medicine and surgery into preventative and early diagnosis and community work, where you're going to achieve the most for your money." (ID 7)*

Stakeholders described a perceived shift (albeit slow and ongoing) in the way the population talked about cancer, being more open to discuss the topic with others. Although they believed that DCE had helped to bring about this change, they thought that the changes were beyond DCE.

Changes towards a stratified risk approach for screening were mentioned. Furthermore, a drive towards realistic medicine was described. Finally, new developments such as the Scottish Primary Care Information Resource (SPIRE) in Scotland were highlighted.

### Scottish personality

The "Scottish personality", especially a fatalistic and stoical view towards cancer, was described as influencing help-seeking behaviour. Nonetheless, the Scottish population was also described as "passionate" and engaged when they believed in something.

### Tackling cancer

Participants discussed the role of early diagnosis in survival and approached other factors which may influence cancer outcomes, including deprivation, standards of care, multimorbidity, lifestyle factors, tumour biology, and more aggressive disease.

Finally, stakeholders stated that a more "targeted" and "efficient" way to diagnose patients with cancer was needed to reduce the number of unnecessary diagnostic investigations. Focusing on patients at risk was suggested. Some argued that GPs should be able to have direct access to diagnostics to expedite referrals.

### The role of the media

The media was described as a public influencer in several ways. Cancer deaths from celebrities could help to initiate conversation about the topic. On the other hand, the media was also seen as prone to "sensationalising things" and to focusing on negative stories. Their messages were perceived to affect the impact of the DCE campaigns. Furthermore, it was reported that the media, similar to the government, was more interested in short-term targets and more tangible outcomes, as opposed to wider, system-level, long-term changes.

*Theme 5: What to evaluate*

### Early diagnosis, survival, mortality or surrogates

Participants described the importance of analysing clinical data, especially tumour staging. Assessing screening uptake, mortality and waiting times was also recommended. Looking at one-year survival was suggested, preferably in combination with other variables. Additional clinical data included surgery, radical radiotherapy for lung cancer and readmissions to hospital. Investigating unanticipated outcomes was also suggested.

> *"I think the main thing is to look for adverse effects as well as the benefits […] particularly if you change your thresholds for referral and presentation referral, you're likely to... well almost certain to increase the numbers who don't have disease as well as those who do." (ID 1)*

### Impact on primary and secondary care

Stakeholders wished to understand the impact that the programme had on primary and secondary care, such as changes in capacity, systems and ways of working. Assessing impact on workload and variations in access to primary care were also suggested. They also wished to know whether (and if so, how) territorial Health Boards were using data from new IT systems, how funding was allocated and used. Views varied in terms of which components should be prioritised in an evaluation.

*"[W]hat's happening in secondary care, what changes have been put in place, how are they doing things differently, how are they working across the system better, how are they engaging with primary care better?" (ID 2)*

*"I know that there was an element of money for diagnostics and I know that boards put in bids and it would be, I don't know if we could ever do it, but it would be quite good to see the outcome of what happened to the money." (ID 8)*

### Improvements in knowledge and awareness

Participants suggested assessing whether there had been an increase in public knowledge/awareness of cancer symptoms and signs since the programme had been implemented; and whether there had been an increase in screening uptake.

### Seeing the bigger picture

Stakeholders suggested investigating whether people's attitudes had changed, assessing the extent of the improvement in data collection and any other wider impact in addition to hard data on survival.

*"Target aside, I think it's the improvement in data, it's an improvement in public awareness, it's improvement in professional awareness and it's, you know, this cultural shift that I've been talking about, it's all these things so it's not just the numbers". (ID 7)*

*Theme 6: Outcome evaluation challenges*

### Bias and confounding

Stakeholders described sources of bias and confounding which would make it challenging to evaluate DCE's impact. These included separating DCE from other early detection activities taking place at the same time and the fact that DCE was not a research project. Stakeholders described how survival analyses are affected by lead time bias, and mortality is affected by improvements in treatment.

*"[T]his is a government funded high profile, you know, 'let's cure cancer' push and I think it's got a lot of merit but it's not... you will never be able to tell at the end of the day what the cause and effect were because it wasn't set up like a research project. It's not like you could've randomised half of the population to have the DCE Programme and the other half not" (ID 9)*

### Unmeasurable outcomes, unclear definitions and unavailable data

Stakeholders acknowledged that it would be challenging to investigate improvements in awareness and changes in attitudes, wider cultural changes, or changes in primary and secondary care. They reported challenges obtaining data on additional funding provided by the programme, and in assessing the impact of DCE strategies such as the education sessions.

Some suggestions were followed by statements about data not being available in time, the need to have data for longer timeframes to observe impact (the case of survival data), and about data no longer being collected. Examples of unavailable data included data on lung resections, and on reasons for consultations in primary care (only collected by ISD Scotland until 2012).

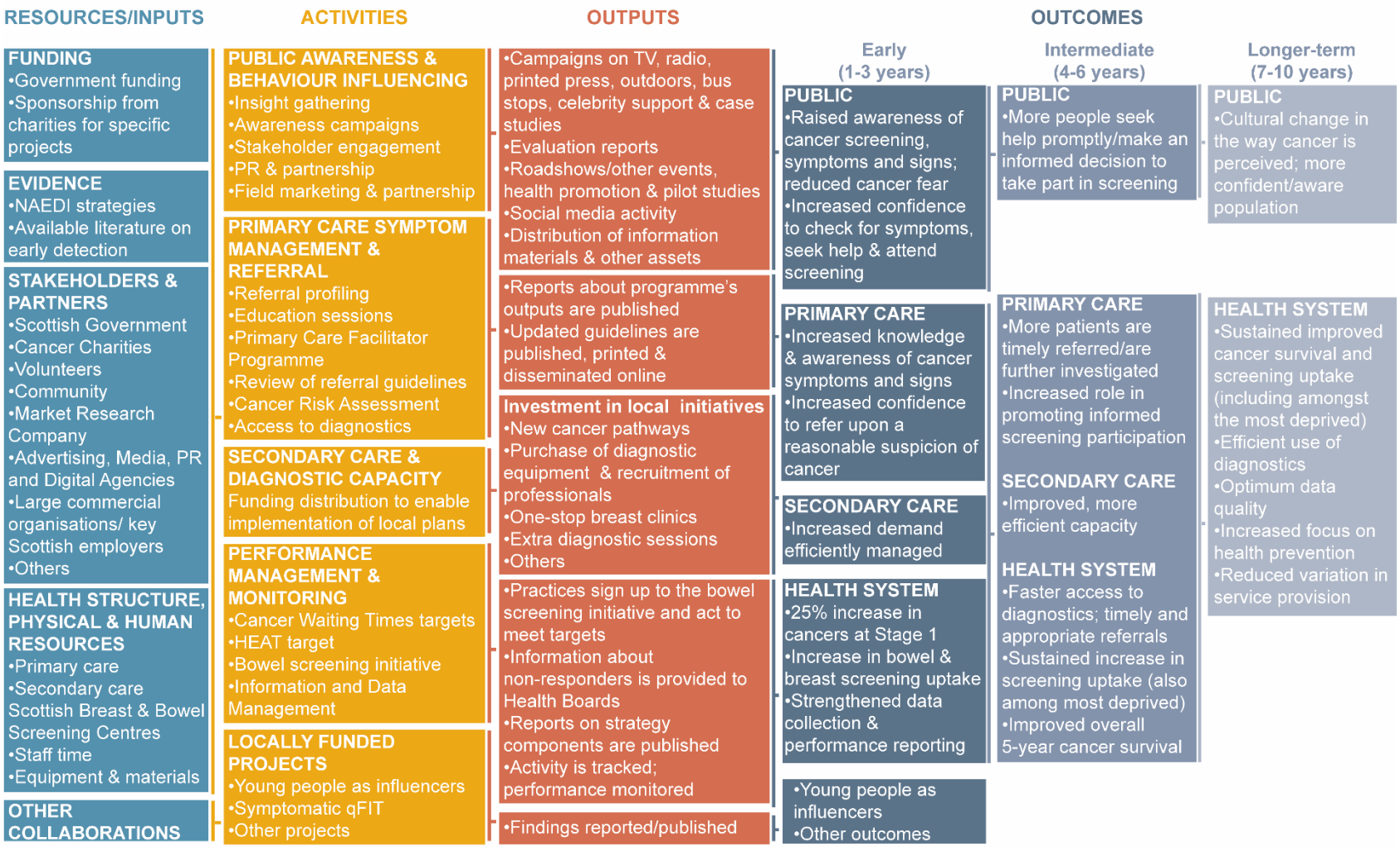
## 5.3 Using interview findings to inform the DCE evaluation

This section describes how interview findings were used to inform the DCE evaluation. Study 2 outputs are presented according to the key interview aims: refinement of programme theory and logic model representation (including elicited assumptions and mechanisms); adoption of complexity theory; adoption of a theory-based evaluation; choosing implementation and behaviour change theories to operationalise assumptions and mechanisms; prioritising what to evaluate (processes and outcomes); and identifying stakeholders to be interviewed.

### 5.3.1 Refinement of programme theory and logic model representation

DCE programme theory and logic model were amended after the interviews. Strategy names were replaced with the same ones from the DCE Implementation Plan, outcomes were refined and detailed information about activities and outputs was removed to facilitate reading (Figure 5.6). Assumptions and contextual issues were amended based on interviews, policy documents and relevant literature, removed from the logic model and kept aside as a separate output (also to ease reading).

**Figure 5.6.** Refined DCE logic model



## 5.3.2 Adopting complexity theory

### 5.3.2.1 DCE and complexity

Stakeholder descriptions of DCE were consistent with how the literature depicts complex programmes implemented into a complex system. Different Health Boards were reported to have diverse aims and needs, and different approaches to programme activities. DCE was described as part of a system with heterogeneous components that interacted at different levels in order to meet aims. These descriptions are in line with how complex systems are described in the literature (184). Furthermore, the context was a prominent theme emerging from interviews. Understanding the context is also expected when investigating complex systems (165, 391) and highlighted by the MRC Framework adopted in the evaluation (166).

DCE's description was also in line with simple, complex and complicated aspects of interventions (165). There were official objectives (simple), but stakeholders mentioned different objectives (complicated), and reported on additional objectives over time (complex). Some DCE activities were standardised (simple), and others such as targeting groups were adaptive (complex). DCE was one of the possible ways to achieve outcomes and not essential to achieve them; factors beyond the programme were needed for success (complicated). Some outcomes could be easily anticipated (e.g. increase in demand) and addressed (simple), but others were only likely in some situations, hard to predict and address, e.g. overdiagnosis (complicated). Thus, Study 2 (evaluation development) reinforced the need to incorporate complexity theory (within interventions and systems) into the evaluation.

### 5.3.2.2 Complexity and programme theory representation

In line with the literature stating that a logic model's somewhat rigid structure does not allow to show multiple interactions and causal relationships (165), participants highlighted the limitations of a linear logic model for describing DCE. In order to overcome this limitation, I prepared a textual description of DCE's programme theory (Figure 5.7), and followed available guidance to incorporate complex systems/systems thinking when describing the DCE programme (165).

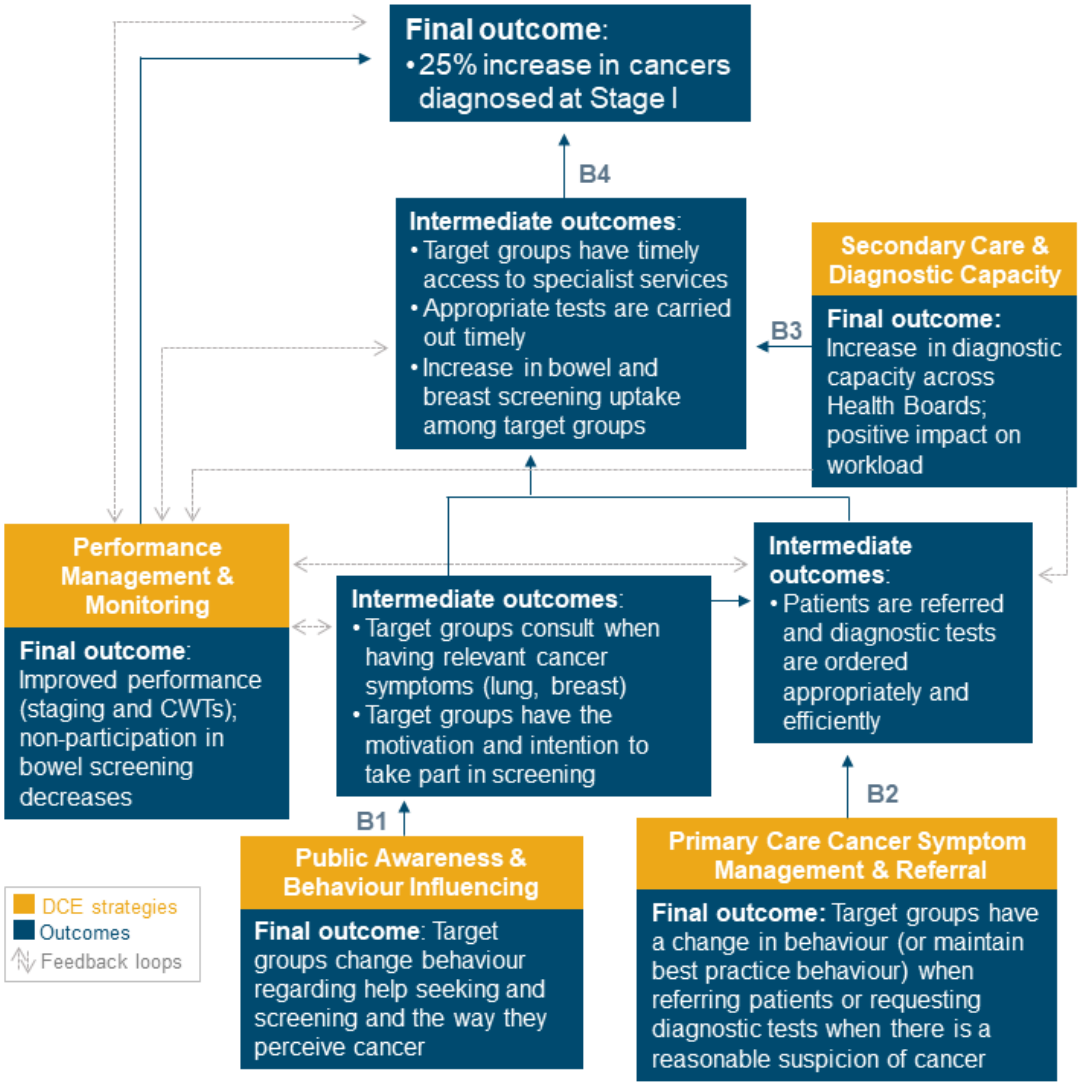
**Figure 5.7.** DCE textual programme theory: how DCE was expected to work

DCE awareness campaigns targeting the public allow for increased knowledge, confidence and motivation to seek help and get screened. Training for health care professionals leads to increased knowledge and confidence to assess symptoms, request tests, provide screening recommendations and refer to specialists. The provision and dissemination of updated referral guidelines also increases confidence and legitimises referrals. Performance targets drive activity and help to focus the health professionals' minds.

All these activities increase demand for diagnostic resources; this is managed with the provision of funding for Health Boards to invest in capacity while adopting a systems approach. Acceptance, appropriate communication and resource availability lead to better services alongside more knowledgeable and confident populations and workforce; this allows for more cancers to be diagnosed earlier. Over time, DCE may also trigger wider cultural changes in the way the population perceives cancer and the manner that it is tackled by health services.

Funnel and Rogers propose a different way to represent programme theory using outcomes chains, feedback loops and describing potential events that may break the chains and influence outcomes. Outcomes chains show assumed relationships between initial, intermediate and final outcomes in a programme (165). Feedback loops occur when an outcome further up the chain can lead to an earlier outcome (165). For example, someone who changed behaviour after watching a TV campaign may engage in a conversation and influence other people who may or may not have seen the campaign. Breaks in the chain refer to any event which may break the outcome chain, with the potential to influence the final outcome. Following Funnell and Rogers guidance, I developed outcomes chains and feedback loops for each DCE strategy (Appendix 19) and for the whole programme (Figure 5.8). I have also considered possible breaks in the chain of events that could influence the programme's intermediate and final outcomes (165). The authors' definitions for assumptions (factors directly related to the programme or outside its scope that can also influence the success of achieving aims or outcomes) and mechanisms ("ways in which an outcome will occur") (165) were adopted for consistency purposes.

**Figure 5.8.** New representation of programme theory: outcomes chains

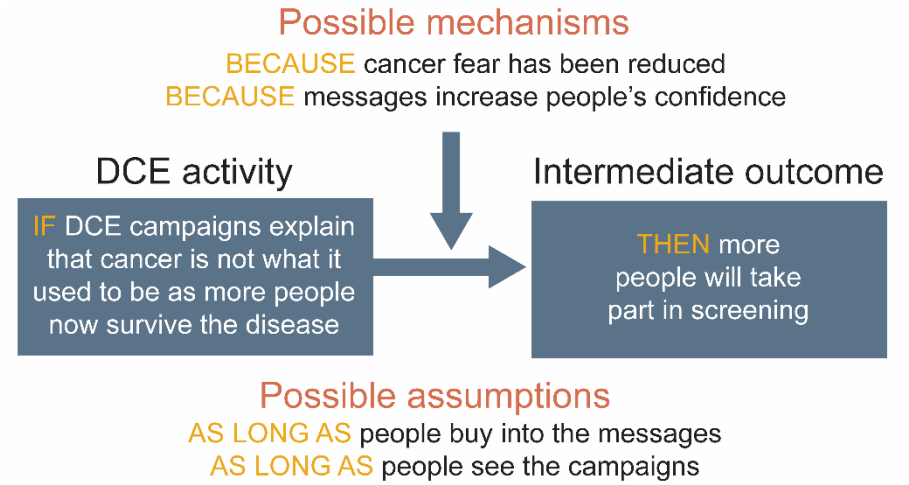



**Possible breaks in the chain**

**B1** Patient does not consult (too busy, cannot set an appointment, etc.)
**B2** Backlog for tests/referrals; or patient would have been referred anyway (no impact)
**B3** Additional capacity fills gaps but it is not enough to meet demand
**B4** Patient is diagnosed with another condition; no definite diagnosis; too many unknown stages; patient has aggressive tumour; patient presented late; other contextual reasons

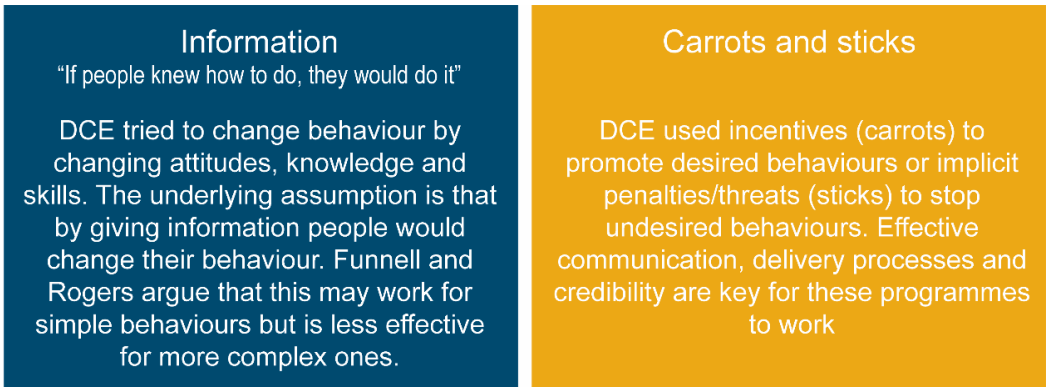
Funnell and Rogers describe an outcomes chain as an "if..then..story". Mechanisms are the "because" underlying the "if…then…story", while assumptions are the "as long as" addition to the "if… then… because…story". These relationships seem complicated but can be easily illustrated for the DCE programme (Figure 5.9).

**Figure 5.9**. Illustrated "if…then…story" for the DCE programme




In addition to findings from Study 2, evidence from the literature was used to inform these new depictions of DCE programme theory. Systems archetypes described by Funnell and Rogers were particularly helpful to inform the outcome chains (165). The authors define archetypes as interventions used to activate mechanisms that bring change. They outline five common programme archetypes and provide generic outcome chains for each of them (165). Two archetypes were found to be relevant for the DCE Programme: information; and carrots and sticks (Figure 5.10).

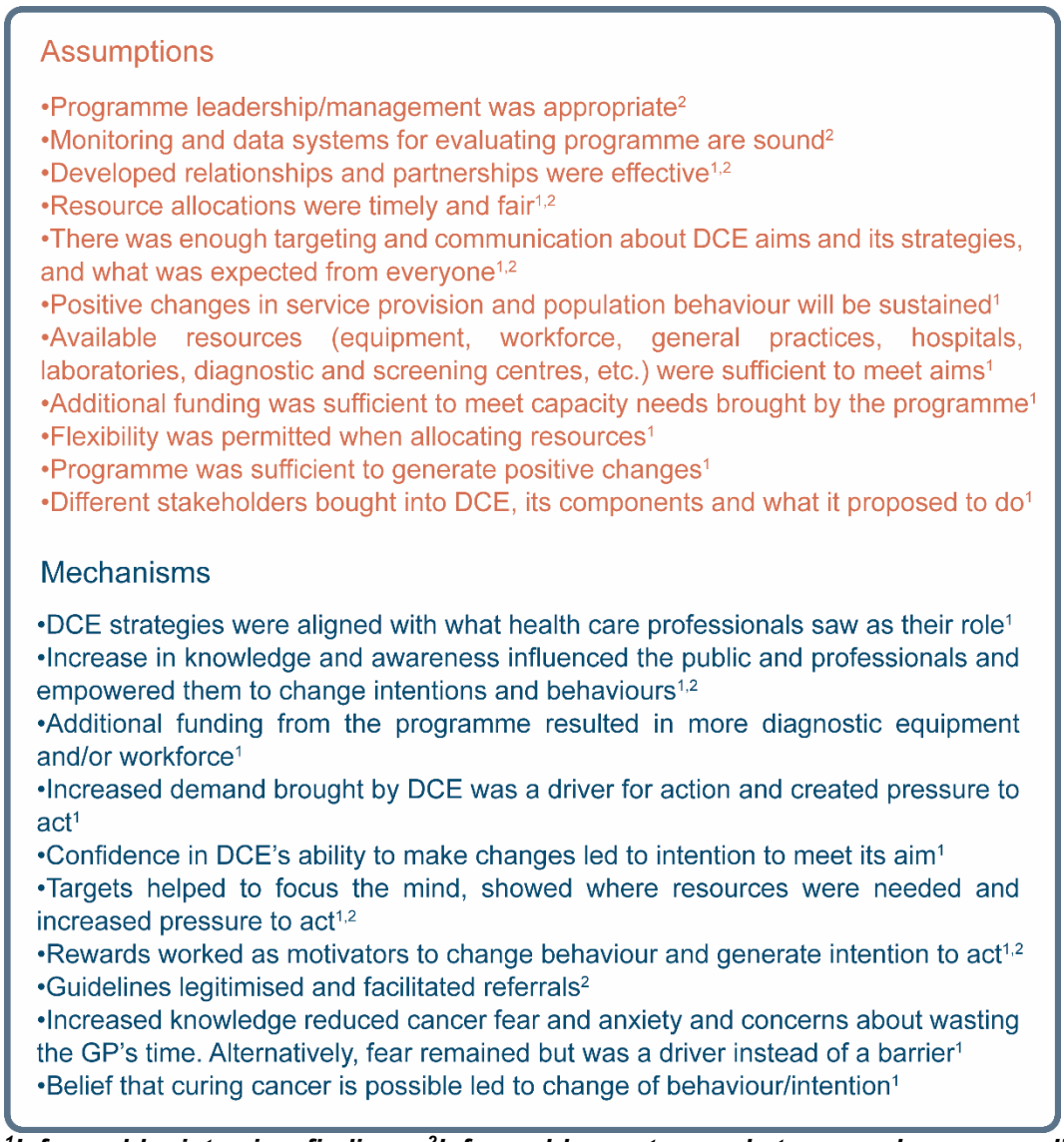
**Figure 5.10.** System archetypes found to be a good fit with the DCE programme




***Source: adapted from Funnell and Rogers 2011 (165)***

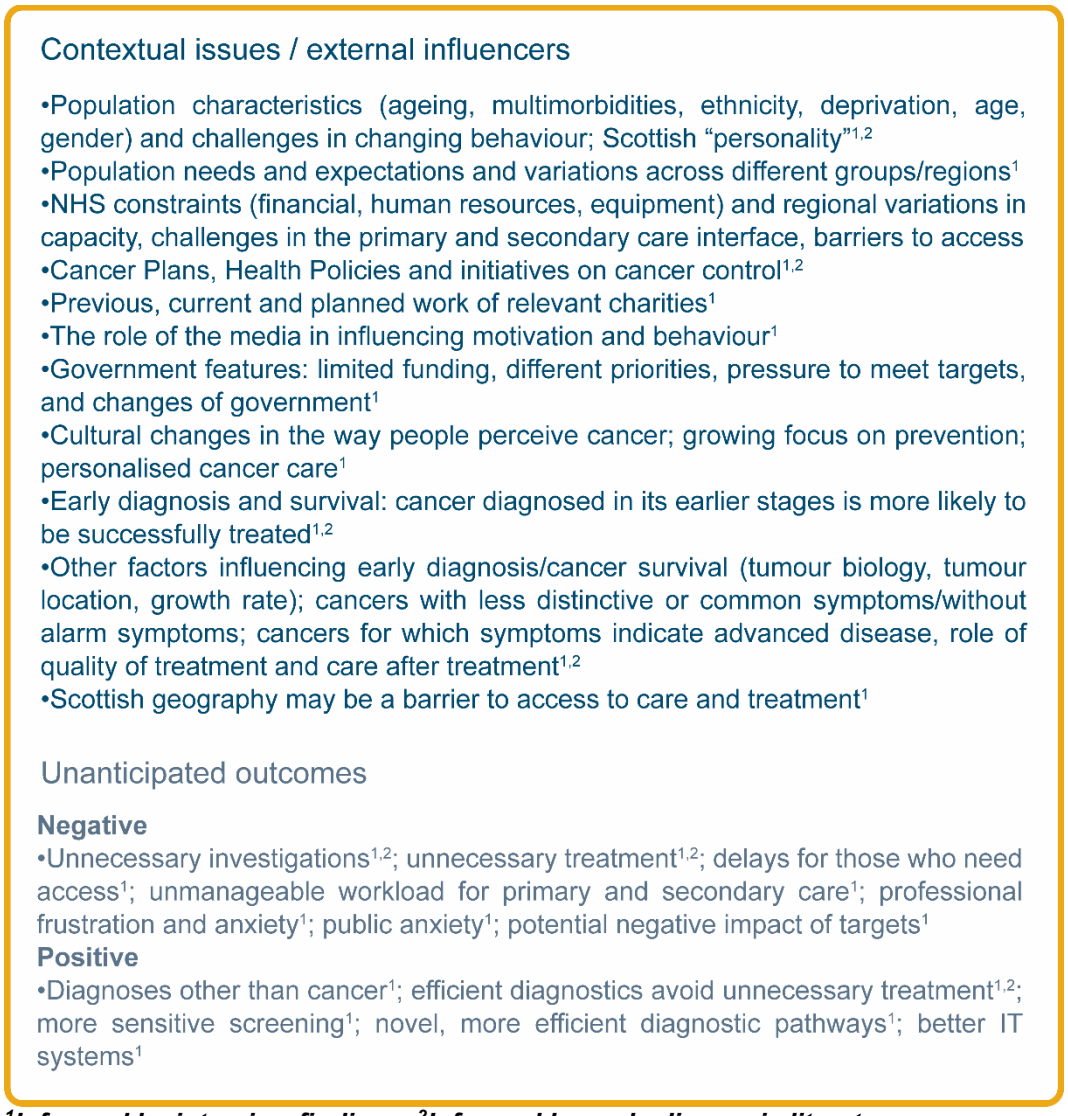
The final step in the new representation of programme theory was to list relevant contextual issues, and elicited assumptions and mechanisms of impact that were relevant to the programme overall (strategy-specific assumptions and mechanisms are available in Appendix 19 for information but were not investigated). Potential unanticipated outcomes were also added, as required to develop a sound programme theory (165) (Figures 5.11 and 5.12).

**Figure 5.11.** Assumptions and mechanisms relevant to the DCE programme




***[1]Informed by interview findings; [2]Informed by system archetypes and corresponding outcome chains described by Funnell and Rogers***

**Figure 5.12.** Contextual issues/external influencers and unanticipated outcomes




***[1]Informed by interview findings; [2]Informed by early diagnosis literature***

Importantly, these representations of programme theory developed to guide the evaluation should not be seen as the absolute truth. Programme theories can be refined indefinitely, and it is reported that a lot of time is wasted by doing so when a simpler program theory could suffice (165). Discrepancy between programme theory and reality is normal; the nature and magnitude of the discrepancy is explored during the evaluation (161). Therefore, evidence-based, elicited assumptions and mechanisms may not hold true after further investigations. Multiple programme theories may also be appropriate for a single programme (165).

### 5.3.3 Adopting a theory-based evaluation

Study 2 interviews resulted in better understanding the DCE programme, its underlying assumptions and mechanisms. Theory-based evaluation was confirmed as a good fit as it worked well with complexity and the adopted MRC framework.

When I wrote the evaluation proposal for the funder, I was inclined towards using realistic evaluation as their approach to investigate "what worked, for whom and in what circumstances" seemed relevant (152). After better understanding the DCE programme, I changed my mind as I could not see how to operationalise realistic evaluation when assessing such a complex and complicated programme, with so many interrelated components. Realistic evaluation seemed to be compartmentalising DCE initiatives into separate boxes without too many connections between them. Hence, it did not seem ideal for what I was proposing to do. I appreciate Pawson and Tilley's emphasis on the context, but the MRC framework (166, 172) and systems thinking (186) also postulate their importance, and both work well with broader definitions of theory-based evaluation.

As described in Chapter 3, I have chosen to follow Carol Weiss's definition of theory-based evaluation, aiming to achieve what she describes as "theories of change evaluation" by assessing both implementation and mechanisms of impact (159, 162, 187). Weiss also suggested limiting programme theory to a few central assumptions in a programme when it is not possible to investigate too many of them (162), which seemed very relevant for the DCE evaluation. Another reason for being informed by Weiss' approach was her focus on the political aspect of evaluation research, as DCE was a Scottish Government programme.

As Weiss provided little guidance on how to carry out a theory-based evaluation; I followed Funnell and Rogers' comprehensive guidance and definitions instead. These authors incorporated both systems thinking and theories of change in their approaches (165).

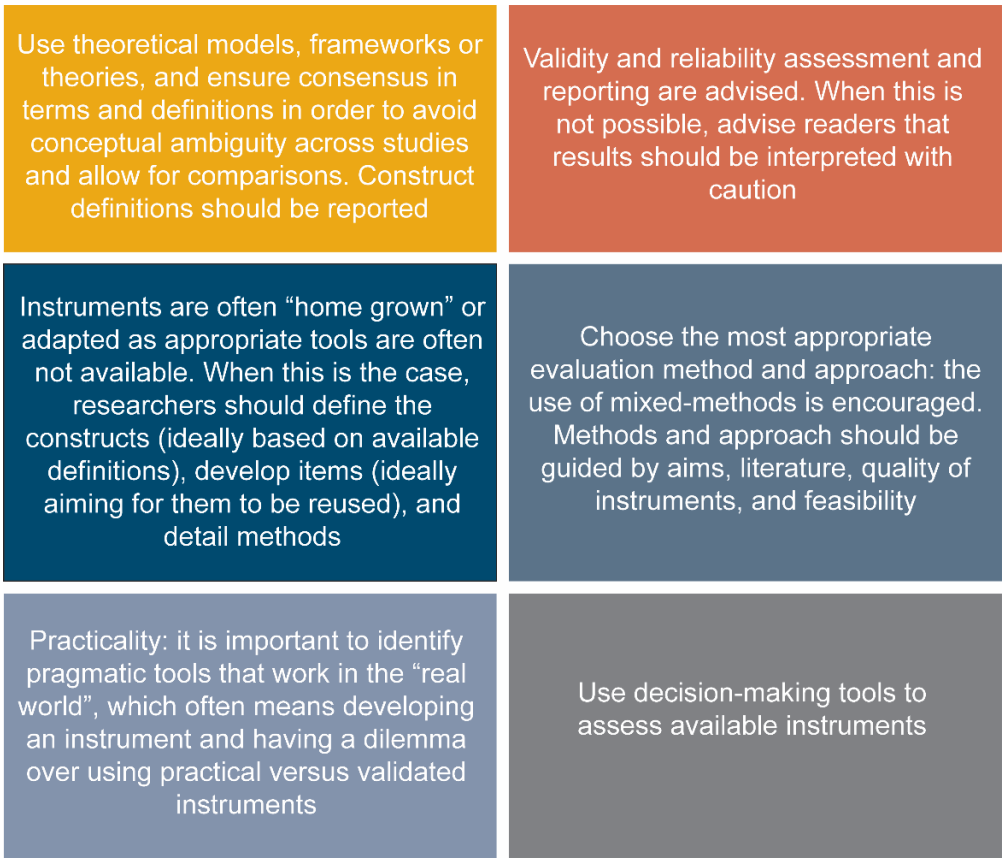
### 5.3.4 Choosing implementation and behaviour change theories to guide the evaluation

Implementation theories, models and frameworks can help to provide context, build knowledge, and outline issues to be examined when assessing implementation (392). They also help to investigate mechanisms bringing change (393, 394), and the role of contextual influencers (394, 395).

Therefore, it was important to investigate approaches described in the literature that would be suitable for the DCE evaluation. A table was prepared describing a range of theories, models and frameworks commonly adopted in evaluation research (Appendix 20). Some of the identified approaches focused on the individual and incorporated psychological theories, others focused on systems and incorporated sociological theory, and a few tried to incorporate both issues. These variations can be beneficial: as universal explanations of phenomena are unlikely in complex fields such as evaluation, it is expected that the need for different approaches investigating different issues will persist over time (392).

Irrespective of the choices made for the DCE evaluation, I was aware that there was a strong call for conceptual clarity, clear description of adopted concepts, and the need for better reporting in implementation and evaluation research (396). Instrumentation issues described by Martinez and colleagues (397) (Figure 5.13) also helped me to make an informed choice on the tools to be used in the evaluation.

**Figure 5.13.** Instrumentation issues to be considered in implementation research



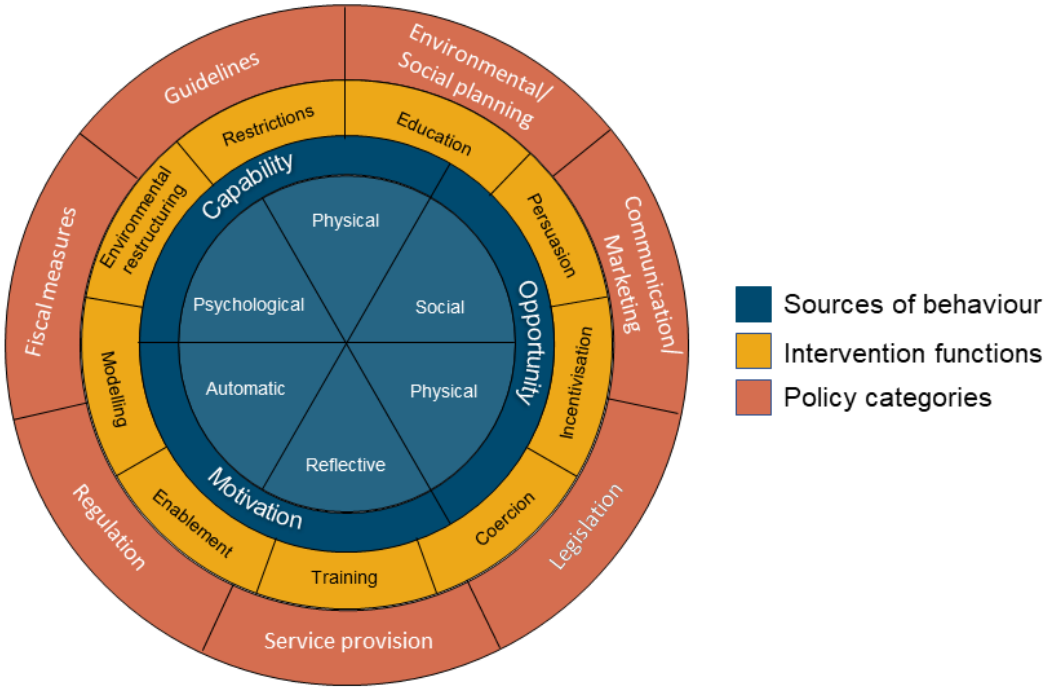

***Source: created based on guidance from Martinez et al 2014 (397)***

### 5.3.4.1 Operationalising mechanisms

The main challenge was to identify theories or frameworks that would fit well with such a broad and complex programme. After discussing available options (described in Appendix 20) with my supervisors, including their strengths and limitations regarding ease of use and applicability to the PhD project, we agreed that the Behaviour Change Wheel (BCW) was the best option to guide the DCE evaluation. The BCW was developed to aid intervention design, improve evaluations and develop theory (394, 398). It provides evidence-based guidance for identifying interventions and policies expected to work for a given behaviour, context and target individual or population (394).

The BCW is a result of a systematic review of frameworks of behaviour change interventions which identified 19 frameworks comprising nine intervention functions and seven policy categories (394) (Figure 5.14). Intervention functions refer to means by which interventions can change a target behaviour. Policy categories help to support and enable interventions (394).

**Figure 5.14.** The Behaviour Change Wheel

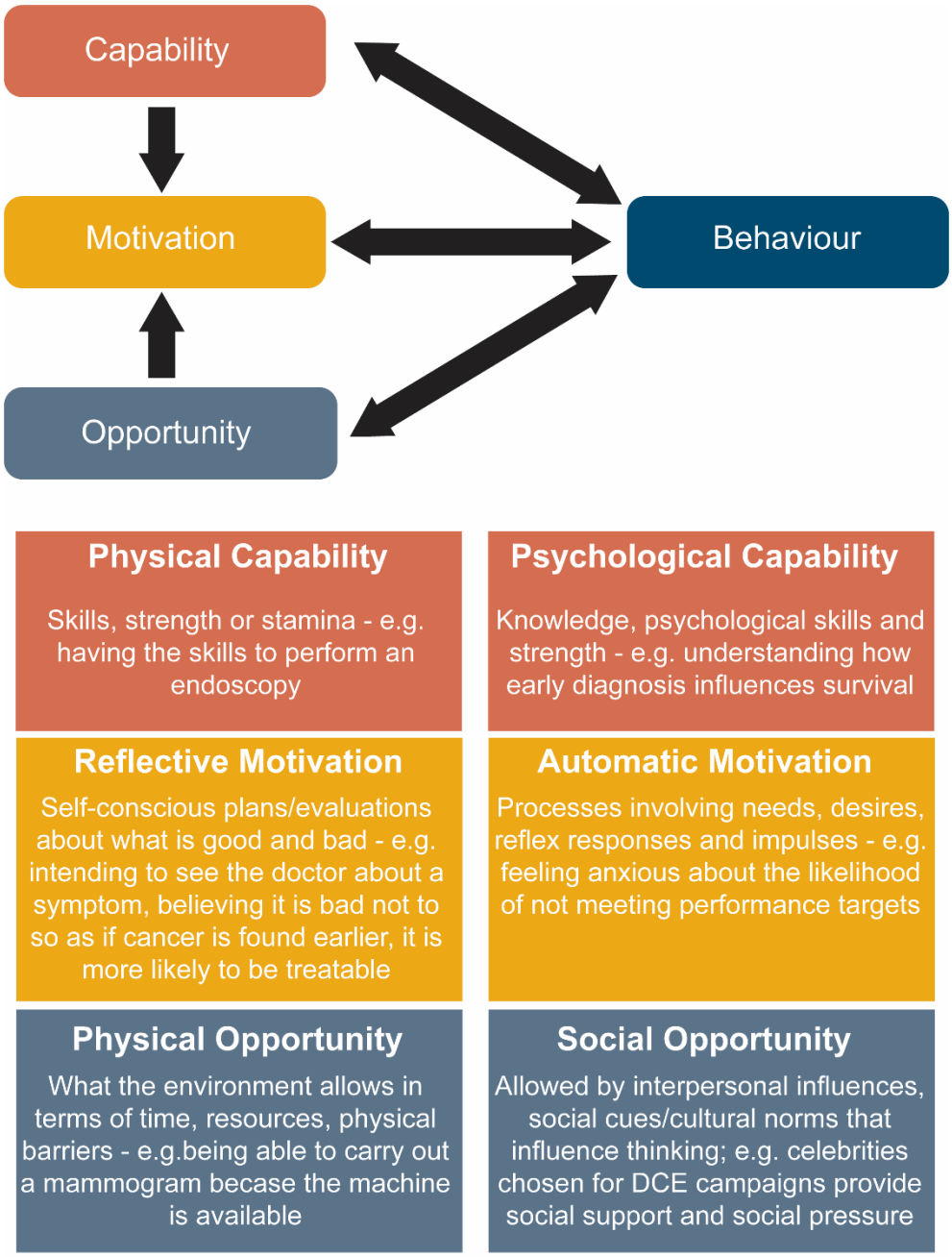



***Source: adapted from Michie et al 2014 (394)***

The starting point for understanding the BCW is the COM-B (Capability, Opportunity, Motivation – Behaviour) model. This model postulates that, in order for any behaviour to occur, there must be: 1) Capability to do it; 2) Opportunity for the behaviour to

occur; and 3) Motivation (motivation to do the behaviour must be stronger than motivation not to do the behaviour) (394). Furthermore, each COM-B component can be further divided into two types (Figure 5.15).

**Figure 5.15.** The COM-B model




***Source: adapted and informed by Michie et al 2014 (394)***

COM-B components can be further detailed into 14 domains, which are organised into the Theoretical Domains Framework (TDF). The TDF synthesises constructs from different behaviour change theories and was developed by psychologists and

implementation researchers (394). TDF domains, intervention functions and policies are comprehensively described in Appendix 21, alongside examples applied to DCE.

The BCW, and particularly the COM-B model, seemed relevant to inform mechanisms in the DCE evaluation. As an example, training health care professionals can increase their capability, providing diagnostic capacity resources can increase the opportunity to provide services, and financial rewards can increase motivation to meet targets. In order to assess the COM-B and the BCW suitability, I followed detailed guidance from those who developed the model and mapped DCE into the BCW components (394), checking for compatibility (as defined by experts who developed the model). The mapping exercise is available in Appendix 22. Furthermore, the BCW was described as having a range of features that applied to the DCE Programme: 1) it is well suited for "real world" settings; 2) it allows for the systematic characterisation of interventions and linkage of mechanisms of action to outcomes; 3) is helpful to assess why an intervention did not meet its goal; and 4) it is applicable to different levels (e.g. individuals, populations and organisations) (394, 398).

COM-B provided a better fit to the elicited mechanisms compared to well-known theories such as Diffusions of Innovations and the Normalisation Process Theory (399-401). These theories focused on innovations being adopted or new practices/systems becoming normalised; which are different from what DCE proposed to do (even though some of their constructs were relevant). DCE was a multilevel programme which incorporated existing initiatives alongside new ones (for example, screening programmes and cancer waiting times were pre-existing strategies, and referral guidelines were updated as opposed to being created by the programme).

After suitability was confirmed, guidance was followed to apply the COM-B model to elicited mechanisms (394, 398). Three COM-B constructs were applicable to elicited mechanisms: *reflective motivation*, *physical opportunity*, and *automatic motivation*.

#### 5.3.4.2 Operationalising implementation assumptions

Although the BCW is also an implementation framework, I have used specific implementation outcomes to investigate implementation as the BCW was chosen to suit a different purpose (i.e. conceptualise mechanisms). Furthermore, the approach allowed me to use outcomes widely investigated that the BCW did not cover.

As before, most theories/general guidance on implementation did not seem appropriate for the DCE programme. They focused on randomised controlled trials

(402), systematic review reporting (403), diffusing innovation (399) or normalising processes (400, 401). There were two promising alternatives: the Consolidated Framework For Implementation Research (CFIR) (404), and the Context and Implementation of Complex Interventions (CICI) framework (395) (Appendix 20). However, both of them were very broad frameworks with which I had no familiarity and it was unfeasible to use them considering the timescales. Therefore, I decided to follow guidance (as opposed to theory) on assessing implementation. I focused on key issues described as relevant by stakeholders in interviews, and then mapped these against operationalised implementation components described in the literature.

I prioritised relevant implementation outcomes from the adopted MRC Guidance (166) and their recommended readings (405), followed by others that had a good fit with the issues I wished to investigate (393). The MRC guidance recommended assessing reach, dose and fidelity (166); these components were also approached by Steckler and Linnan, alongside context and recruitment (405). Proctor and colleagues described a taxonomy of implementation outcomes which included items such as acceptability, adoption, feasibility and sustainability (393).

Not all these implementation outcomes seemed appropriate for a system-level evaluation of the DCE programme. There are also recognised limitations in assessing programme fidelity when evaluating complex interventions (166, 172). Furthermore, interviews indicated variation in contextual challenges, aims and implementation – indicating that fidelity was not appropriate. Assessing dose was also challenging as quantitative measures for this were not available for the DCE programme. The selected components for the evaluation were *feasibility, acceptability, sustainability, appropriateness, sufficiency, reach and communication*, and a*daptability* (Table 5.3). The aim was not to thoroughly investigate each of these implementation outcomes, but to explore them in order to clarify whether a selected number of assumptions about programme implementation held true.

**Table 5.3.** Chosen implementation components and definitions

| Components | Definitions |
|---|---|
| **Feasibility** | Refers to practicability/achievability. Related to "appropriateness", but different as something may be feasible, but not appropriate (and vice-versa) (393). It covers issues such as impact on workload |
| **Acceptability** | Whether DCE is acceptable/agreeable. It is different from "satisfaction" which refers to service experience (393) |
| **Sustainability** | DCE's ability to be sustained over time (393) |
| **Appropriateness** | Appropriateness refers to programme fit according to stakeholders. It is similar to ''acceptability'', but not equivalent as something may be appropriate but not acceptable (and vice-versa) (393) |
| **Sufficiency** | Whether resources were sufficient to meet demand brought by DCE, and strategies were enough to achieve intermediate outcomes. It was chosen instead of "dose delivered" and "dose received" (405) |
| **Reach and communication** | Refers to issues such as quality of information, access to it and quality of communication about strategies. Similar to "Penetration" (393) and "Reach" (405), but with a stronger focus on the role of communication |
| **Adaptability** | Adaptations to adjust to DCE/meet its aims, and how possible it was to make changes and be flexible. It was chosen instead of "fidelity" (393, 405) due to the challenges in defining fidelity for a non-experimental programme where adaptations were the rule rather than the exception |

The use of validated tools is recommended whenever possible when assessing implementation (166). However, it was also necessary to be practical and pragmatic (397). In the case of DCE, I concluded that it was more appropriate to identify implementation outcomes with a close match to my research questions and interview findings, so I could obtain results which were relevant to stakeholders and could inform policy recommendations. I trusted that by describing and defining the outcomes used, comparisons across different studies could still be made (397).

### 5.3.5 Prioritising what to evaluate in the process evaluation

Elicited assumptions and mechanisms were prioritised according to feasibility of data collection/analysis and likely impact on DCE outcomes (166). It was important to prioritise what to investigate as it was not possible to assess everything (162). Furthermore, robust measurement of fewer implementation outcomes is more likely to generate meaningful results than trying to measure all possible outcomes (405).

Four assumptions and four mechanisms were chosen to be investigated (Table 5.4). Assumptions focused on implementation issues from the perspective of health care professionals; no assumptions involving the public were investigated. Likewise, no elicited mechanisms involving the public were investigated (due to challenges in identifying those who were reached by the programme).

**Table 5.4.** Selected assumptions and mechanisms with corresponding implementation outcomes and COM-B constructs

| | Assumptions | Outcomes | Rationale for prioritisation |
|---|---|---|---|
| Assumptions | 1. Different stakeholders bought into DCE, its components and what it proposed to do | Feasibility<br>Acceptability<br>Sustainability<br>Appropriateness | Interviews showed that views about DCE and its different strategies varied across stakeholders. It was important to understand this variation and likely implications. Stakeholders reported that DCE generated a bit of "chaos" to drive changes, and this may have influenced stakeholder buy-in |
| | 2. There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone | Reach and communication | Interviews indicated that more clinical input would have been welcomed, that communication became more informal over time, and there was often a disconnect between primary and secondary care. Communication is also a key component in archetypes adopted in the DCE evaluation (165) |
| | 3. Available resources (equipment, workforce, general practices, hospitals, laboratories, diagnostic and screening centres, etc.) were sufficient to meet aims | Feasibility<br>Acceptability<br>Sufficiency | Stakeholders described how resource constraints existed prior to DCE. It was possible that, even with extra funding, resources were not sufficient to meet demand. As this has important implications for programme implementation and outcomes, the issue was further investigated |
| | 4. Flexibility was permitted when allocating resources | Feasibility<br>Adaptability | Flexibility is required in complex interventions (166). Interviews described variations in context and activities. Hence the need to understand what was delivered (approaching adaptations and changes) |
| | **Mechanisms** | **COM-B constructs** | **Rationale for prioritisation** |
| Mechanisms | 1. DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries | Reflective motivation | It was important to understand how DCE varied from usual work as some activities were inherited by the programme and others were added to the professionals' roles. The wording was changed after incorporating BCW guidance (394) |
| | 2. Additional DCE funding resulted in in more diagnostic equipment and/or workforce | Physical opportunity<br>Reflective motivation | Information was limited on how DCE funding was used. Since diagnostic resources were limited regardless of DCE, and there were concerns about the impact of DCE on capacity, it was important to explore this further |
| | 3. Increased demand brought by DCE was a driver for action and created pressure to act | Automatic motivation | Stakeholders reported concerns on DCE's negative impact on workload and wished to know more about what happened. Wording was informed by evidence on archetypes (165) and adapted after incorporating BCW guidance (394) |
| | 4. Targets helped to focus the mind, showed where resources were needed and increased pressure to act | Automatic motivation<br>Reflective motivation | There were conflicting views on targets. They were described as not only driving activity but also as being unhelpful and in contrast with DCE's wider aims. As DCE's main objective was measured with the new HEAT target, it was important to investigate this further |

Contextual issues and possible unanticipated outcomes were identified in Study 2, and a decision was made to investigate these further as part of the process evaluation. Due to time and resource limitations, unanticipated outcomes were only planned to be explored as part of the process evaluation. This was also in line with the adopted MRC Framework (166).

### 5.3.6 Prioritising what to evaluate in the outcome evaluation

Study 2 results showed how DCE had simple, complex and complicated aspects. Complicated aspects included activities taking place at different levels; and the fact that different strategies needed to work to achieve the final outcome (i.e. improvement in staging). In these cases, it is recommended that several programme components are investigated, as focusing on only one or some of them is "dysfunctional" (165). Importantly, complicated programmes are often not enough to generate changes, although they may still be necessary in order to achieve outcomes (165).

Furthermore, Study 2 results reiterated the challenges of trying to evaluate a government programme which was not set up as a controlled experiment. Therefore, it was likely that the outcome evaluation would lead to conclusions about DCE's potential contribution to the final outcome instead of reporting on causality.

The evaluation proposal funded by DCE planned to use customised datasets to explore the impact of DCE on survival, considering variables such as referral patterns, diagnoses, emergency presentations, cancer waiting times, and screening uptake. Nested case studies were planned to investigate awareness, cancer screening and early diagnosis in primary care. Advice from the PhD review panel members (Prof Amanda Amos and Prof John Frank) with experience in evaluating tobacco control programmes and a range of other public health initiatives, and from the DCE Programme Board indicated that the scope of the outcome evaluation was too ambitious. My supervisors and I agreed that it was important to reconsider the feasibility of the proposed evaluation. The evaluation steering group also recommended caution when committing to a broader evaluation, especially after hearing about the challenges in obtaining data (highlighted when I presented to them results from key stakeholder interviews). Furthermore, the literature indicated that some of the variables initially proposed to be investigated (i.e. variation in referral patterns and emergency presentations) were more complex than expected, and not necessarily an indication of late diagnosis (357, 406-408).

Interviewed stakeholders suggested a wide range of outcomes to be investigated, including quantifiable outcomes (such as screening uptake, stage at diagnosis, lung x-rays, CT scans, and radical radiotherapy) and less tangible outcomes such as cultural changes. It was difficult to decide and prioritise what to investigate, and it was clear that assessing all outcomes deemed important by stakeholders was impossible.

After discussing evaluation development results with my supervisors and considering feedback from the PhD review panel and the evaluation steering group, we made the decision to focus on assessing if, and to what extent, each of the eight DCE official objectives were met. By doing so, it was expected that the evaluation would cover the whole programme and would not be "dysfunctional". Importantly, several investigations proposed by stakeholders fitted well with the objectives, hence their perspectives were still heard. Moreover, the process evaluation would shed light on other issues described as important, such as impact on workload.

For feasibility reasons, outcome evaluation plans changed to reporting available outcome data from policy documents; and complementing this with a time-trends analysis of bowel screening outcomes (bowel screening data is systematically collected in Scotland). Other early diagnosis programmes in England (150, 176-178) adopted before-and-after analyses in their evaluations. Initially, I had proposed to my supervisors to do a time-series analysis as this is considered to be a more robust strategy when investigating government initiatives and changes over time (409, 410). However, limited data availability precluded this. Furthermore, two evaluation experts (the PhD review panel) and a statistician at the UoE were consulted and raised concerns about the approach. They described challenges of carrying out a complex analysis without having discrete timing of exposure (and no clear exposure for DCE strategies), the fact that there was no control group and that there were too many known and unknown confounding factors. Questions were raised over whether such analyses could achieve anything other than what would be achieved by analysing data from policy documents. It was suggested that a descriptive analysis of activities and outcomes would be less speculative and more informative. Trends shown over time (in time flow diagrams and graphs) would describe DCE's trajectory, highlighting specific time points and outcomes. These issues were discussed further in a supervision meeting after my second annual PhD review, and we agreed that the suggestions to carry out a time-trends analysis were appropriate. Further information on the approach is available in Chapter 6.

### 5.3.7 Identifying stakeholders to be interviewed in the evaluation

Study 2 indicated different views on DCE's aims; evaluation priorities, and on what constituted programme success. Hence, it was critical that different stakeholder groups were included in the evaluation (165).

Stakeholders provided several suggestions of whom to interview and at times also gave reasons for their suggestions (Table 5.5). Reasons often focused on the professionals' role in DCE, its potential impact on their work, or on whether participants could provide different or contrasting views (often implying that these views would be less positive). Stakeholders acknowledged that views would vary depending on who was contacted, and that not everyone would be available to take part.

**Table 5.5.** Suggested professionals and reasons for suggestions

| Job role/Institution | Why they are appropriate |
|---|---|
| **Charities:** CRUK; Roy Castle Lung Foundation; Bowel Cancer UK; British Lung Foundation; Scottish Cancer Coalition | • Due to their involvement in DCE – there were no mentions to smaller charities due to their "niche" remit |
| **Partners in social marketing campaigns:** Leith Agency; TNS | • They were personally invested, and were vital to campaigns |
| **Scottish Government (DCE or not):** Chief Operating Officer, Director for Performance; social marketing staff; Chief Medical Officer; ISD Scotland and NHS Health Scotland staff; DCE director and predecessors; Chairs of the Scottish Cancer Taskforce and the DCE Programme Board; former and current chairman of the Scottish Primary Care Cancer Group; Scottish Cancer Registry Director | • Different views, with a role managing performance across boards (COO)<br>• "They put the data together" and have "oversight of primary care"(ISD)<br>• They were "at the heart of it" (DCE director and predecessors)<br>• Have views on the programme since its development (Chair) |
| **Members of the public and tumour-specific patient representative groups** | • Were influenced by the programme |
| **Range of health care professionals:** colonoscopy provider/scoper; breast surgeon; radiologist (chest); someone involved in lung cancer imaging, chest x-ray; gastro surgeon; those involved in cancer networks; GPs; other primary care staff (practice nurses, health visitors); specialist doctors; pharmacists; specialist breast, lung and bowel nurses; "people involved in different cancer groups"; radiation oncologist; gynae specialist; "the margin of staff" in secondary care; Public Health practitioner; clinicians managing tumour types included in DCE; melanoma specialist | • "Key people"<br>• They are facing difficulties due to pressure in capacity; will have something to say<br>• GPs will provide views from primary care<br>• Can provide views on investigations in areas less accessible compared to bowel/breast (chest radiologist)<br>• May have different views, may not have been aware of DCE<br>• Were affected by DCE |
| **NHS management:** lead bowel and breast screening specialists; Cancer Network leads or Chief Executives; director of screening programmes; diagnostic service managers and | • "At the coalface, separate from decision making, may have different views" (clinical director of radiology) |

| Job role/Institution | Why they are appropriate |
|---|---|
| directors of diagnostics in NHS Boards; executive Leads in NHS Boards; clinical leads for tumour types included in DCE; clinical director of radiology; Cancer Leads; cancer managers in cancer centres; "managers, not clinicians" | • May have different views as they can see impact on diagnostics<br>• NHS Management see the impact/pressure on services, seek resources and have data on targets; their job includes managing "all this" |
| Other: Administrative teams; prevention specialist; those updating the referral guidelines | • To provide views on the impact of targets and atmosphere |

Based on stakeholder recommendations and policy documents, a comprehensive list of 47 potential stakeholders to be interviewed in the process evaluation was prepared.

## 5.4 Ethics

Study 2 documentation was submitted to the Centre for Population Health Sciences' Ethics Review Group on the 15th February 2016. Ethical approval was granted on the 4th April 2016 (Appendix 23). Before commencing each interview, I asked participants if they had any questions. Two copies of the consent form were signed (one for me and another for the participant). All participants consented to having their interviews recorded.

## 5.5 Summary of Chapter 5

This chapter described Study 2 methods and results, and how these helped to develop the DCE evaluation. Study 2 had two components: analysis of policy documents and interviews with key DCE stakeholders.

Policy documents were useful to understand the DCE programme, develop the logic model and identify stakeholders to be interviewed. However, they also reiterated limitations described in the literature (204, 380). Documents often referred to opinions in addition to facts. When documents were not created for the government, they were often prepared for the Government, and the possibility of political and/or financial gain was common. Bias in publication and reporting was likely, but it was impossible to ascertain the extent to which this happened. Nonetheless, data were invaluable to describe the programme and inform the DCE evaluation.

The stakeholder interviews provided rich information on DCE development, on the context, helped to refine the logic model, showed which outcomes were considered to be important by stakeholders, and provided evidence on assumptions and mechanisms to be investigated in the DCE evaluation. Interview findings confirmed the usefulness of adopting complexity theory and systems thinking, and these

theories informed the development of a textual programme theory and DCE outcomes chains. Finally, interview findings helped me to choose theories/frameworks to underpin the DCE evaluation.

A process of prioritisation was required for the evaluation, and four assumptions and mechanisms were chosen to be investigated further. Furthermore, as it was not possible to investigate all outcomes described by stakeholders, a decision was made to focus on DCE's key objectives.

As expected, Study 2 was paramount to inform the DCE evaluation (Study 3). The next Chapter describes the methods used to evaluate DCE processes and outcomes.

# Chapter 6 DCE evaluation methods (Study 3)

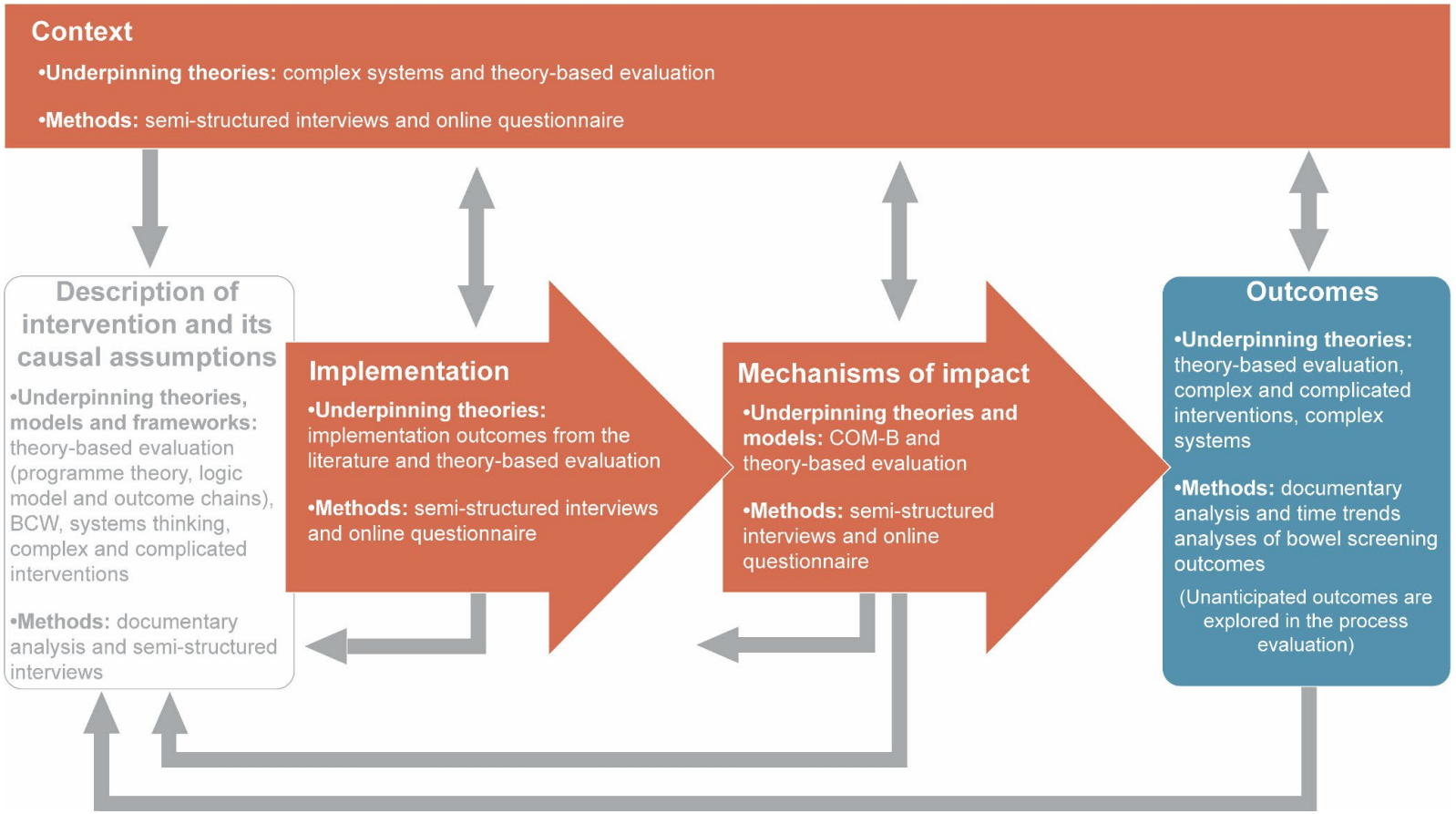
## 6.1 Overview

This Chapter outlines the methods adopted for the DCE evaluation (Study 3). First, it describes the evaluation binding aims and depicts the full evaluation in the adopted MRC framework for process evaluation of complex interventions. Then, it outlines the methods adopted for the outcome evaluation. Finally, it describes the two components of the process evaluation: a purpose-built online questionnaire and semi-structured interviews with DCE stakeholders.

## 6.2 Binding aim

The evaluation binding aim was to understand what happened, how and why it happened in the DCE programme. The DCE evaluation is described below, according to the MRC framework adopted in this PhD. (Figure 6.1). A comprehensive description of the DCE programme is illustrated in the first box shown in grey (data were obtained from Study 2). The process evaluation (shown in orange boxes in the diagram) investigates implementation, mechanisms of impact and context. Finally, the outcome evaluation is represented by the blue box in the diagram.

**Figure 6.1.** The DCE evaluation situated within the MRC Framework for process evaluation of complex interventions




***Source: adapted from the original MRC framework for process evaluation of complex interventions (166)***

## 6.3 Outcome Evaluation

### 6.3.1 Aim and rationale

The outcome evaluation aimed to investigate if, and to what extent, DCE official objectives were met. By including all eight official objectives, the outcome evaluation expected to have a system-level, broader view of DCE outcomes.

As described in Chapter 2, DCE developed a HEAT target (25% increase in cancers diagnosed at Stage I) which was used as a proxy for cancer survival. The HEAT target was assessed as part of DCE's first objective.

### 6.3.2 Data sources and analysis

#### 6.3.2.1 Data sources

The outcome evaluation comprised secondary analysis of published and unpublished reports, and a descriptive time-trends analysis of requests for bowel screening kits using a customised dataset provided by the Scottish Bowel Screening Centre.

Published reports comprised official health intelligence data from ISD Scotland on tumour staging (HEAT target reporting); on bowel and breast screening uptake; on consultations due to breast symptoms; purpose-built annual reports prepared by the Scottish Bowel Screening Centre reporting on DCE impact; and one published paper reporting on the use of symptomatic qFIT in primary care (411). Unpublished reports referred to before-and-after evaluation reports prepared by TNS (market research company responsible for carrying out social marketing campaign evaluations); DCE policy documents (such as reports, minutes, circulars and newsletters) reporting on data collected by TNS, Carat (Digital Media Agency), and Consolidated PR (Public Relations Agency); evaluation reports of education sessions prepared by Bowel Cancer UK and the Roy Castle Lung Cancer Foundation; and annual reports prepared by Health Boards describing how DCE funding was used. The level of detail in evaluation reports varied. Both ISD Scotland and TNS reports clearly explained their methodology and rationale for their decisions. TNS reports also described their efforts to ensure data were representative of their populations of interest (such as weighting samples), their internal validation and quality assurance procedures. Source questionnaires were also provided. Reports from other organisations were less clear regarding their adopted methods. Consequently, there was also less certainty regarding the quality and representativeness of their data.

The dataset (an Excel spreadsheet) provided by the Scottish Bowel Screening Centre had anonymised data on issued replacement test kits by territorial Health Board, from September 2010 to April 2017. The date the replacement kit was issued was considered as a proxy for the date in which the kit was requested (as the latter was not available). The dataset did not include requested kits which were not returned to the Bowel Screening Centre, nor test kits which were returned but not accurately completed (numbers are therefore an underestimation of all requests). No sociodemographic information was available for patients who had made the requests.

#### 6.3.2.2 Outcome measures

Outcomes referred to cancers diagnosed at Stage I; bowel and breast screening uptake; knowledge/motivation before and after campaigns; consultations due to breast symptoms; calls to the bowel screening helpline; reminder letters sent to bowel screening non-responders; request for bowel screening kits; investment in imaging, diagnosis and treatment (soft outcomes); perceived usefulness of education sessions (soft outcomes); perceived benefits of DCE funding (soft outcomes); cancers diagnosed with unknown staging; and impact on workload (soft outcomes).

When available, data were reported according to patient sociodemographic characteristics, Cancer Networks or territorial Health Boards. Data on Health Boards were only made available in Appendices for information; this was done to avoid unfair comparisons due to wide regional variations in population size, deprivation, performance at baseline, screening uptake, and cancer incidence.

Even though Cancer Waiting Times targets became part of DCE, these were not reported as part of DCE outcomes as data were not available on intervals to diagnosis. Similarly, no data on the Primary Care Facilitator Programme were reported (in this case, because the strategy was led by CRUK). Nonetheless, an evaluation report (prepared by a third-party) is available for information (412).

#### 6.3.2.3 Data analysis and reporting

Data analysis comprised the development of new summaries, tables and charts using aggregated level data from source documents. When data allowed, descriptive statistics N(%) were reported. Percentage changes over time were calculated whenever possible. Changes over time referred to relative changes; i.e. the final number/proportion at year/month of interest minus initial number/proportion at baseline, divided by the initial number/proportion at baseline and multiplied by 100. When original data sources did not pre-specify the baseline, I chose this based on the

data available (often the year prior to DCE launch); in these cases, I have used the term “proxy baseline” and this was specified when presenting results (Chapter 7). When the use of descriptive statistics was not possible nor appropriate (i.e. reports describing outcomes in a narrative form), textual summaries were prepared with key outcomes from source documents. In two cases (data on breast screening uptake and consultations due to breast symptoms), data were already available in a suitable format and diagrams were adapted and reproduced. In all other cases, additional data analyses, synthesis or graphical representations were required.

Time-trends analysis of requests for bowel screening kits was restricted to descriptive statistics due to lack of patient sociodemographic data; the only available independent variable was territorial Health Board. Data analysis steps are described in Box 6.1. The analysis aimed to summarise trends over time and show whether there was an increase in request for bowel screening test kits when the bowel screening campaign phases were launched and during the bowel screening initiative.

**Box 6.1.** Time trends analysis

- Data from the Scottish Bowel Screening Centre was converted to SPSS v.23 (245)
- Data were checked for completeness and inconsistencies. No problems were identified, but recoding was required
- Automatic recode was used to convert string variables into date variables. The variable describing the date (day, month and year) in which the kit was issued was used to automatically create 1) one variable for issue_month; 2) one variable for issue_year; and 3) a variable describing kits issued one year prior to DCE (Feb 2011- Jan 2012), Year 1 (Feb 2012 – Jan 2013); Year 2 (Feb 2013 – Jan 2014), Year 3 (Feb 2014-Jan 2015), Year 4 (Feb 2015 – Jan 2016) and Year 5 (Feb 2016 – Jan 2017). Data for Year 6 was only available up to October 2017.
- I ran frequencies and annual means and medians in order to identify seasonal effects (requests were found to be lower in November and December compared to all other months; this was the case in all years)
- A combination chart was created with columns reporting on number of requests by year and a line showing relative percentage increase over time.
- A time trends chart was created showing the number of requests by month, while also outlining when the bowel screening campaign phases and the bowel screening initiative took place. Simple smoothing was used to attenuate monthly peaks and troughs in order to facilitate visualising long-term trends (413). This was done by calculating a rolling average (mean average of the month of interest, the previous and the subsequent month). The time trends chart show both the actual number of requests and the rolling average
- Percentage change of requested kits over time was reported in tables

“Colorectal cancer” and “bowel cancer” were used interchangeably as both terms were mentioned by data sources. Objectives 2 and 3 were assessed together as outcomes often overlapped.

Even though the outcome evaluation focused on DCE's first three years (its initially planned duration), data were also shown for additional years when available. This was done for two reasons: 1) due to the recognition that longer timeframes are necessary to understand impact on cancer outcomes (especially for screening and tumour staging); and 2) to understand if changes were being sustained over time. The timeframes corresponding to DCE's first three years are outlined in each graph.

Table 6.1 describes the adopted approach for assessing whether DCE official objectives were met.

**Table 6.1.** DCE objectives, data sources and reporting

| DCE official objectives | Item | Description | | |
|---|---|---|---|---|
| 1. Increase the proportion of people with Stage I disease at diagnosis and to use performance against a HEAT target as a lever for whole systems improvement | Data sources | • Data collected, reported and published by ISD Scotland - aggregated data tables in Microsoft Excel spreadsheets | | |
| | Outcome measures | • Stage I over time (relative increase in proportion compared to baseline) | | |
| | Timeframes | • Baseline (2011-2012)<br>• Year 1 (2012-2013)<br>• Year 2 (2013-2014) | • Year 3 (2014-2015)<br>• Year 4 (2015-2016) | • Year 5 (2016-2017)<br>• Year 6 (2017-2018) |
| | Analysis | • Descriptive statistics: N (%), and % increase in Stage I over time | | |
| | Reporting | • New textual description, new combined column and line charts, new tables using ISD Scotland data – percentage changes were calculated for new tables and checked against official data | | |
| | Other variables | • Tumour type (lung, breast and bowel cancers combined and each tumour type separately)<br>• Region (nationally, by cancer network and by territorial Health Board)<br>• Level of social deprivation (SIMD quintiles – 1 most deprived to 5 least deprived) | | |
| 2. Improve informed consent and participation in national cancer screening programmes<br><br>3. Raise public awareness of cancer screening programmes and the early signs and symptoms of cancer | Data sources | • **Screening data (bowel and breast)** collected by Screening Centres, reported and published by ISD Scotland – aggregated data tables in Microsoft Excel spreadsheets showing trends in uptake over time (breast and bowel) and routine appointments, early recall and self/GP referrals (breast)<br>• Data on **consultations for breast symptoms** prepared by ISD Scotland, reporting on estimated increase in consultations for breast symptoms (using Practice Team Information) – customised report with tables and charts with N of women consulting, N of GP consultations, and 95% CIs<br>• Before-and-after tracking surveys (**bowel screening, breast screening, breast symptomatic and lung campaigns, and 3-year attitudinal tracking**) carried out and reported by TNS (market research company) – reporting on change in knowledge/motivation, with text, diagrams and tables<br>• DCE policy documents (circulars, newsletters and press releases) reporting on reach, business to business (B2B), public relations, and field and partnership for **all campaigns**, using data collected by Carat (Digital Media agency) and Consolidated PR (Public Relations agency)<br>• DCE policy document reporting on the impact of the **breast screening and lung cancer campaigns** – textual description of campaign impact for breast (calls to the breast screening centres, and outcomes for these) and lung (consultations and chest-x-rays)<br>• Annual reports prepared by the Scottish Bowel Screening Centre for DCE - textual description of N of calls to helpline and N of reminder letters sent to non-responders to screening over time | | |

| DCE official objectives | Item | Description |
|---|---|---|
| | | • Customised Microsoft Excel spreadsheet from the Scottish Bowel Screening Centre) reporting on **requested replacement bowel screening test kits** - prepared for the purposes of this evaluation |
| | Outcome measures | • Bowel screening uptake over time (relative increase in proportion compared to baseline)<br>• Breast screening uptake over time (relative increase in proportion compared to baseline)<br>• Knowledge/motivation before and after campaigns<br>• Consultations due to breast symptoms over time<br>• Calls to the bowel screening helpline over time and reminder letters to bowel screening non-responders (N(%), relative increase in numbers compared to baseline)<br>• Request for bowel screening kits over time (relative increase in numbers compared to baseline) |
| | Timeframes | • **Breast screening:** uptake from 2005-2008 to 2013-2016 (3-year periods); N screened, routine appointments, early recall and self/GP referrals from 2010-2011 to 2015-2016 (1-year periods)<br>• **Bowel screening:** uptake from 2009-2011 to 2015-2017 (2-year periods)<br>• **Consultations due to breast symptoms:** from June-August 2011 to September-November 2012 (monthly and 3-month periods)<br>• **Calls to the bowel screening helpline from** January 2013 to March 2015 (monthly and annually); **reminder letters to non-responders** from 2012-2013 until 2014-2015 (annually)<br>• **Requests for bowel screening kits**: from February 2011 to January 2016 (daily, recoded into monthly, also reported for one year prior to DCE, the first three DCE years and a fourth DCE year) – additional data prior to February 2011 and up to April 2017 was not used<br>• TNS reports published in 2012, 2013 and 2014; Scottish Bowel Screening reports published in 2014 and 2015, ISD Scotland on consultations due to breast symptoms published in 2013 |
| | Analysis | • Descriptive statistics: N (%), and % increase over time<br>• Data synthesis of evaluation reports and DCE policy documents reporting on campaigns<br>• Data synthesis of ISD Scotland and the Scottish Bowel Screening Centre reports |
| | Reporting | • **Social marketing campaigns:** new textual synthesis of findings from each evaluation report prepared by TNS and other DCE policy documents, for each campaign, grouped into three areas: 1) BA evaluation (changes in knowledge/motivation), 2)campaign reach, and 3) outcomes from business to business (B2B), public relations, and field and partnership. New textual synthesis of impact of the breast screening and the lung cancer campaigns using data from DCE policy documents. New textual synthesis of attitudinal tracking data from the TNS evaluation report, grouped into three areas: positive shifts in attitudes, mixed findings, and negative shifts in attitude<br>• **Breast screening uptake and consultation due to breast symptoms**: reproduced charts and tables from ISD Scotland, new % change over time |

| DCE official objectives | Item | Description |
|---|---|---|
| | | • **Bowel screening uptake:** new tables and charts using data from aggregated tables published by ISD Scotland, showing trends in screening uptake over time (%), and percentage change compared to baseline (2009/2011 used as a proxy baseline)<br>• New time trends chart plotting **calls to bowel screening helpline** alongside the bowel screening campaign and the bowel screening initiative using data from aggregated tables from the Scottish Bowel Screening Centre<br>• New tables reporting on **reminder letters and calls to the bowel screening helpline** by year, new calculated % increase using data from aggregated tables from the Scottish Bowel screening centre<br>• New tables and time trends chart plotting **requests for bowel screening test kits**, alongside bowel screening campaign phases and the bowel screening initiative, new calculated means and % changes over time - using customised dataset provided by the Scottish Bowel Screening Centre |
| | Other variables | • Bowel screening uptake by sex, by region (nationally, by cancer network and by territorial Health Board) and by level of social deprivation (SIMD quintiles – 1 most deprived to 5 least deprived)<br>• No information on region and level of social deprivation for breast screening |
| 4. Promote referral/investigation for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access | Data sources | • Evaluation report on education sessions for professionals – data collected, analysed and reported by Bowel Cancer UK and the Roy Castle Lung Cancer Foundation<br>• Paper published in a peer-reviewed journal |
| | Outcome measures | • Perceived usefulness of education sessions (soft outcomes)<br>• Demand for bowel screening information |
| | Timeframes | • Reports published in 2013; article published in 2016 reporting on data collected from October 2013 to March 2014 |
| | Analysis | • Data synthesis of evaluation reports, textual summary of key results from published paper |
| | Reporting | • New textual synthesis of outcomes from the education sessions, created from reports prepared by Bowel Cancer UK and the Roy Castle Lung Cancer Foundation |
| | Other variables | • Variation in attendance across Health Boards (not reported for confidentiality purposes)<br>• Sex and age for qFIT analysis (not reported here) |
| 5. Ensure sufficient capacity in the screening programmes to meet the expected increase in demand | Data sources | • Annual reports from the Scottish Bowel Screening Centre prepared for the DCE programme – textual description of programme impact on laboratory test time and laboratory activity and on time taken for patients to receive test results, in addition to strategies adopted to manage demand |
| | Outcome measures | • Impact on workload (soft outcomes) |
| | Timeframes | • Reports published in 2014 (referring to years 2013-2014) and 2015 (referring to years 2014-2015) |

| DCE official objectives | Item | Description | | |
|---|---|---|---|---|
| | Analysis | • Data synthesis of annual reports | | |
| | Reporting | • New textual synthesis of reported impact on workload and measures adopted to deal with impact, created from reports prepared by the Scottish Bowel Screening Centre | | |
| | Other variables | • N/A | | |
| 6. Ensure imaging, diagnostics and treatment are prepared for an increase in demand | Data sources | • DCE policy documents: annual reports submitted to DCE by territorial Health Boards, with a textual description of how funding was used, and perceived benefits brought by it | | |
| | Outcome measures | • Investment in imaging, diagnosis and treatment (soft outcomes)<br>• Benefits of DCE funding (soft outcomes) | | |
| | Timeframes | • Annual reports submitted for the years 2012-2013, 2013-2014, and 2014-2015 | | |
| | Analysis | • Descriptive synthesis of data described in individual reports | | |
| | Reporting | • New data table with a textual summary of how DCE funding was invested across Health Boards | | |
| | Other variables | • Territorial Health Boards (not all submitted reports every year) | | |
| 7. Strengthen data collection and performance reporting within NHSScotland | Data sources | • Data collected, reported and published by ISD Scotland – aggregated data tables in Microsoft Excel spreadsheets | | |
| | Outcome measures | • Unknown tumour stages over time (relative increase in proportion compared to baseline) | | |
| | Timeframes | • Baseline (2011-2012)<br>• Year 1 (2012-2013)<br>• Year 2 (2013-2014) | • Year 3 (2014-2015)<br>• Year 4 (2015-2016) | • Year 5 (2016-2017)<br>• Year 6 (2017-2018) |
| | Analysis | • Descriptive statistics: N (%), and % decrease in unknown stages over time | | |
| | Reporting | • New textual description, new combined column and line charts, new tables using ISD Scotland data – percentage changes were calculated for new tables and checked against official data | | |
| | Other variables | • Tumour staging (unknown) by tumour type (for lung, breast and bowel cancers combined and for each tumour type separately), by region (nationally, by cancer network and by territorial Health Board) and by level of social deprivation (SIMD quintiles – 1 most deprived to 5 least deprived) | | |
| 8. Facilitate further evaluation of the impact of public campaigns on the stage of cancer at presentation and to contribute to cancer survival research | N/A | • No secondary data were available for this objective; hence this objective is only approached in the Discussion Chapter | | |

### 6.3.3 Ethics

No ethical approvals were required for the outcome evaluation as it comprised secondary analysis of anonymised data that could not be traced back (directly or indirectly) to living nor deceased individuals. A completed Usher Research Ethics Group (UREG) Level 1 form is available in Appendix 24.

## 6.4 Process evaluation

### 6.4.1 Aims and rationale

The process evaluation aimed to investigate what happened and how it happened (i.e. the "how and what" in an evaluation) (170) by assessing implementation, mechanisms of impact and context (166). This was done by answering the following questions (Figure 6.2):

**Figure 6.2.** Process evaluation questions

| | |
|---|---|
| Implementation assumptions | 1. Are assumptions confirmed by stakeholders? |
| Mechanisms of impact | 2. Are mechanisms confimed by stakeholders? |
| Contextual barriers and facilitators | 3. What are the barriers and facilitators to processes and outcomes? |
| Unanticipated outcomes | 4. Were there any unanticipated outcomes? |

As described in Chapter 5, four assumptions and mechanisms were prioritised to be investigated, and mapped against implementation outcomes (assumptions) (Figure 6.3) and the COM-B (mechanisms) (Figure 6.4).

**Figure 6.3.** Investigated assumptions

| Assumptions | |
|---|---|
| 1. Different stakeholders bought into DCE, its components and what it proposed to do<br><br>**Feasibility; acceptability; sustainability; appropriateness** | 2. There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone<br><br>**Reach and communication** |
| 3. Available resources (equipment, workforce, time, general practices, hospitals, laboratories, diagnostic and screening centres, etc.) were sufficient to meet aims<br><br>**Feasibility; acceptability; sufficiency** | 4. Flexibility was permitted when allocating resources<br><br>**Feasibility; adaptability** |

**Figure 6.4.** Investigated mechanisms

| Mechanisms | |
|---|---|
| **1.** DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries<br><br>**Reflective motivation** | **2.** Additional DCE funding resulted in in more diagnostic equipment and/or workforce<br><br>**Physical opportunity; reflective motivation** |
| **3.** Increased demand brought by DCE was a driver for action and created pressure to act<br><br>**Automatic motivation** | **4.** Targets helped to focus the mind, showed where resources were needed and increased pressure to act<br><br>**Automatic motivation; reflective motivation** |

There was a clear relationship between assumptions and mechanisms. For example, acceptability (an implementation outcome) could have been influenced by whether professionals saw DCE in line with their professional role (a mechanism that may have influenced engagement). It was expected that the analysis of both implementation outcomes and mechanisms would provide a more complete description of what happened, as expected when adopting theories of change (159, 165).

The process evaluation had two components: 1) semi-structured interviews (qualitative) and 2) a purpose-built online questionnaire (quantitative) with stakeholders. While interviews sought to obtain in-depth accounts, the questionnaire aimed to analyse quantitative implementation outcomes from a representative sample of stakeholders. A self-completion questionnaire was the chosen tool for the quantitative component as it is useful to study large groups, participants can respond at their own time and costs are low (414).

Both the interview and questionnaire addressed the same process evaluation questions (Figure 6.2). It was expected that the questionnaire would allow for a deeper understanding in variations in views according to different stakeholders.

## 6.4.2 Inclusion and exclusion criteria

Inclusion and exclusion criteria for the interviews and questionnaire were the same to enable data integration; parallel samples were chosen (221). Stakeholders were eligible for inclusion if they were amongst those described in interviews or policy documents as being most affected by the programme (i.e. working in diagnostics and

primary/secondary care interface, managing health care services and the DCE programme), or having a key role in programme implementation (i.e. preparing health intelligence data, or developing partnerships with the Scottish Government). Eligible stakeholders were excluded if they were unwilling to provide informed consent or were not involved/influenced by DCE from the years 2011-2015 (one year prior to DCE launch and DCE's first three years). Four groups were included:

A. *Professionals working in primary and secondary care:* these included GPs, nurses, colonoscopy providers, breast screening radiologists, radiographers, surgeons, public health practitioners and staff working in administrative roles

B. *Stakeholders managing health care services and DCE strategies:* Scottish Government managers, DCE managers and programme directors, NHS managers; Cancer Leads; Clinical Leads

C. Providers of Health Intelligence Data: ISD Scotland staff

D. *Charities, creative agencies, and marketing research companies*: charities include CRUK, the Roy Castle Lung Cancer Foundation and Bowel Cancer UK; the Leith Agency (responsible for gathering evidence and developing the DCE awareness campaigns with the public); and TNS (the market research company responsible for evaluating the DCE campaigns).

## 6.4.3 Component 1: Interviews with stakeholders

### 6.4.3.1 Data collection and analysis

*Sampling and recruitment*

Similar to Study 2, purposive sampling was adopted for the process evaluation. Criterion sampling, maximum variation sampling and snowball sampling were used (204). I aimed to speak to participants from all four eligible groups, from different Health Boards in Scotland. The list of potential participants prepared in Study 2 was used to initially select 20 stakeholders to be invited for an interview; the remaining names were kept aside for additional invitations if there were refusals to take part. When stakeholders from one particular Health Board refused to take part, attempts were made to recruit another stakeholder from the same Health Board. One stakeholder interviewed as part of Study 2 (a DCE manager) was interviewed again due to his/her in-depth knowledge about the programme.

Sample size was decided based on several considerations. I had to reflect upon my study aims, while also being pragmatic due to time constraints. I had to consider ethical implications of not being able to analyse all data if I interviewed too many stakeholders (415). Finally, I also considered that I was collecting process data using two different methods. I expected that little new information on each process evaluation question would emerge after 20 stakeholders were interviewed (200).

Participants were contacted directly about the study by email. A face-to-face (at the participant's chosen venue) or telephone interview was then arranged. Interviews were expected to last 40-60 minutes.

*Interview topic guide and setting*

The interview topic guide (example in Appendix 25) was informed by elicited assumptions and mechanisms. I also consulted other evaluation studies (391, 416, 417), guidance on implementation (405), on the BCW (394), and on process evaluation (166) in order to identify questions used to investigate similar issues.

Four topic guides (one for each eligible group) were created, with common questions to allow for data analysis. Overarching topics included views on the programme; how DCE, its components and requirements were communicated; what happened when strategies were implemented and whether they were implemented as planned; and perceived barriers and facilitators. Topics were mapped to the chosen assumptions and mechanisms, unanticipated outcomes and barriers and facilitators. Variations across different topic guides are described below (Table 6.2).

**Table 6.2.** Eligible groups and topic guides

| Eligible groups | Specific areas covered in the topic guide |
|---|---|
| Professionals working in primary and secondary care | As they were "at the coalface" dealing with targets and the impact of the initiatives, they were also asked about how DCE influenced their daily work and about any potential impact on workload. |
| Stakeholders managing health care services and DCE strategies | The topic guide adopted a more systems-level, strategic approach about estimates of programme impact, available resources, views on programme implementation, and perceived acceptance across different groups. |
| Providers of Health Intelligence data | The topic guide had a stronger focus on the development of targets, data preparation, changes in data collection and other data-related topics (including feasibility and acceptability of adopted outcome measures and targets). |
| Charities, creative agencies, and marketing research companies | These interviews were seeking views of those whose work was influenced in a different way by DCE. The topic guide was overarching, but it was hoped that responses would provide a different perspective on DCE implementation. |

*Transcription*

All interviews were digitally recorded (with the participants' consent), anonymised and transcribed verbatim for analysis. The same company that provided transcription services for Study 2 also transcribed the Study 3 interviews. I checked all transcripts for inaccuracies and made corrections when needed.

*Data analysis*

As in Study 2, framework analysis was used to analyse data from interviews, NVivo 11 aided analysis (390). In Study 3, a preliminary thematic framework was developed after reading and analysing all interviews. It was then applied to eight transcripts and refined. Further refinements took place until all interviews had been coded. One of my supervisors also analysed eight transcripts, and changes to the thematic framework were made after discussions. Framework analysis was used as the process evaluation had pre-specified questions, and the topic guide was prepared according to mechanisms and assumptions being investigated. Findings were organised into themes derived from the research questions and themes emerging from interviews.

*Reflexivity*

I have continued to make field notes; key issues are presented in Chapter 10.

## 6.4.4 Component 2: Online questionnaire

### 6.4.4.1 Data collection and analysis

*Sampling*

I aimed to reach relevant stakeholders while also not approaching too many ineligible professionals (such as those whose work was not influenced by the programme, or health care professionals who did not have contact with cancer patients). In order to do so, my lead supervisor and I asked the Scottish Cancer Networks (NOSCAN, SCAN and WOSCAN – reaching health care professionals and other specialists working with cancer patients), the Scottish Cancer Coalition (i.e. a coalition of Cancer charities with representation in DCE Programme Board) and the Scottish Primary Care Cancer Group (comprising professionals from all territorial Health Boards, including primary and secondary care professionals) if they would be willing to send an invitation to all stakeholders in their mailing lists. The proposed recruitment strategy was raised during a Detect Cancer Early Programme Board meeting in early 2018; emails were also sent to each organisation. All agreed to send invitations. I was advised by NOSCAN and the Scottish Primary Care Cancer Group not to expect high

response rates, as these were uncommon when targeting busy health care professionals, even if the topic interested them.

Stakeholders were contacted via an email (prepared by me and sent to contacts at each of the organisations) describing the study and inviting them to take part in a questionnaire survey. The email provided them with a link to the questionnaire. Recognising the importance of sending reminders to increase response rates (418), two reminders (15 and 30 days after sending the initial invitation email) were planned. However, two Cancer Networks raised concerns about the procedure (i.e. they did not wish to commit to sending three waves of emails but were happy to send two). Therefore, only one reminder was sent 15 days after the initial email. Bearing in mind stakeholders' busyness and challenges with non-response, questionnaires were designed to take 15-20 minutes to be completed.

All potential participants received the same anonymised link to access the questionnaire. No names were asked, and data could not be traced back to the participants. An optional question asked for an email address if participants wished to receive a summary of the study results.

*Sample size*

Two options were considered for calculating sample size: power-based or precision-based (419). In power-based calculations, estimates are made of how many participants are needed to answer a specific research question in order to accept a null or an alternative hypothesis and avoid a type 1 (false positive) or type 2 (false negative) error (420). Two issues are particularly important: effect size and power analysis. The effect size refers to the magnitude of differences between two groups. A power analysis assesses how many participants are required so this effect is significant, i.e. generalisable to the population of interest (419, 421). Power-based calculations are often informed by similar studies in the literature, or a pilot study (422). It was not possible to identify studies similar to the DCE questionnaire to help estimate sample size. Furthermore, it was not feasible to pilot the questionnaire in advance, and there was uncertainty regarding how many stakeholders would agree to participate in the questionnaire survey. Hence, with advice from a statistician at the UoE, I opted for a precision-based sample size calculation instead (423). A precision-based calculation stipulates the ideal width of the study confidence interval (i.e. the ideal precision/acceptable margin of error) and then explores how this width varies according to study size (419). In other words, a precision-based calculation estimates

what precision can be achieved with the responses obtained in a study. Better precision requires larger sample sizes (424).

Question 6.2.a in the questionnaire was chosen to estimate sample size *("The benefits brought by DCE outweighed the time and effort required to work towards its aims"*). This question was chosen as I expected that all eligible groups would be able to answer it, and it investigated overall DCE acceptance. A Likert scale of 1-7 (strongly disagree to strongly agree) was used for this question; it was recoded into binary (1-3 and 5-7) to calculate the proportion of responses of those *who either strongly disagreed or disagreed* (1-3) versus those *who either agreed or strongly agreed with the statement* (5-7). A neutral response (4) was excluded from calculations.

Then, I used a table provided by the National Audit Office (423) to investigate what sample size would be needed to achieve 5% precision in confidence intervals (at a 95% confidence level) according to different population proportions agreeing/strongly agreeing with the above statement (Table 6.3). The next paragraph explains how to interpret Table 6.3.

More heterogeneous populations require larger sample sizes in order to obtain a higher level of precision (425). Therefore, a 50/50 split (highest possible variability when answering question 6.2.a) would require 384 stakeholders in order to achieve the planned 5% precision (i.e. for me to be confident that, if I had asked the entire relevant population, 45 to 55% of them would also have chosen this answer) (Table 6.3). This narrow confidence interval indicates better confidence that results are representative of the population of interest. On the other hand, if only 66 participants took part in the study (also with the 50/50 split in response patterns), then precision would be 12%, confidence intervals would be wider (38 to 62%), and I would be less confident about representativeness. In other words, better precision not only requires larger sample sizes, but samples also need to be larger when there is heterogeneity in responses (424, 425).

Reassessment was made after data collection to ascertain what precision was achieved based on the number of obtained responses. An online sample calculator (426) was used to calculate the obtained level of precision after data collection as Table 6.3 was not sufficiently comprehensive to do so.

**Table 6.3.** Estimated sample size

| Proportions for question 6.2.a | Required sample size according to different levels of precision | | | |
|---|---|---|---|---|
| | +-12% | +-10% | +-8% | +-5% (planned) |
| 50% | 66 | 96 | 150 | 384 |
| 45% or 55% | 66 | 95 | 148 | 380 |
| 40% or 60% | 64 | 92 | 144 | 369 |
| 35% or 65% | 60 | 87 | 136 | 349 |
| 30% or 70% | 56 | 81 | 126 | 323 |
| 25% or 75% | 50 | 72 | 112 | 288 |
| 20% or 80% | 42 | 61 | 96 | 246 |
| 15% or 85% | 34 | 48 | 76 | 195 |
| 10% or 90% | 24 | 35 | 54 | 138 |
| 5% or 95% | 12 | 18 | 28 | 72 |

***Source: adapted from the National Audit Office 2001 (423). Precision was estimated at a 95% confidence level.***

*Questionnaire design*

As there was no suitable existing instrument that could answer the evaluation questions, a purpose-built questionnaire was developed. Relevant guidance on questionnaire design was followed; this is summarised in Box 6.2.

**Box 6.2.** Guidance on questionnaire design informing the study

**General guidance**

- Add estimates on how long it should take to complete the survey (414)
- Provide guidance and directions throughout the questionnaire (414, 427), use transitional phrases (414)
- Have questions in a logical sequence and use filter questions (414)
- Start with general questions that most people can answer, and then add more specific/sensitive questions (414, 427). Demographic data is sensitive information (428)
- Consider factors shown to improve response rates such as reminders (418, 427), clear layout, clear study aims, keeping the participant interested (427), short questionnaires, offering results, simple headers (418), relevance, institutional logos (414)

**Specific guidance when developing questions**

- Free-text boxes help participants can explain their answers (427)
- Avoid ambiguous, double-barrelled questions (414, 427), technical words or jargon, leading/presuming questions, vague questions, double negatives, loaded words and hypothetical questions (414); be as specific as possible; add all possible response alternatives (including “don’t know”) (414)
- Present both negative and positive statements on attitudinal scales to deal with “yeah sayers”/acquiescence bias (427, 429)
- “Questions should be short and to the point”, except for sensitive/personal questions as then they may be seen as abrupt or threatening (427)
- Use Likert scales to assess attitudes and values but avoid terms such as “always” or “better”. Include a middle response category to avoid forced choices (414, 429)
- Start response categories with “the least desirable option”, use numbers if there are too many answer options (414)
- Response categories should be “mutually exclusive and “collectively exhaustive” (414)

Questions were derived from publications using different BCW components (COM-B and TDF) that either evaluated programmes or validated questionnaires (394, 430-436). Questions about implementation outcomes were also aided by examples provided in the literature (394, 405). An audit trail showing the source for the adopted questions is available (Appendix 26). Mix of positive and negative statements was used to avoid participant fatigue; this was accounted for in data analysis.

The questionnaire had 50 questions and two parts. Part 1 had five sections (one for DCE overall and one for each of the four DCE strategies), with multiple-choice (mandatory) and open-ended (all optional) questions. Part 2 comprised socio-demographic questions and three optional open-ended questions (so participants could give their views on what worked and did not work in the programme, outline any barriers/facilitators and provide their views on anything else that the questionnaire did not approach). The questionnaire is available in Appendix 27; questions were mapped to investigated assumptions/mechanisms for information.

*Online provider*

An online questionnaire was chosen instead of a postal of face-to-face questionnaire as it was more cost-effective considering the number of professionals I was trying to reach (427). Furthermore, obtaining addresses for all potentially eligible participants would have been unfeasible. A postal or face-to-face approach would have required access to personal data. No need to do data entry reduced the workload (427) and the potential for human error when inputting data manually.

The Bristol Online Survey (BOS) Tool was chosen to host the questionnaire survey. BOS is fully compliant with UK Data Protection Laws and is used by approximately 130 Universities in the UK (437). The system allowed for skip functions, multiple choice questions, ranking questions and comments boxes. It indicated on each page the proportion of the survey that had been completed. Furthermore, it provided each participant with a unique receipt completion number that allowed them to request the research team for their data to be withdrawn (if this was their wish). BOS has a user-friendly layout and I was responsible for adding the questionnaire to the system. I tested it with four Usher Institute colleagues to identify any progression errors or inconsistencies. None were found.

*Questionnaire pre-testing*

In order to ensure that the questionnaire was fit for purpose among the target population, it was also pre-tested in November and December 2017. Pre-testing aimed to: 1) assess whether the instructions were easy to understand (199); 2) explore the meaning of specific questions and whether they were difficult, confusing, and/or misunderstood (438, 439); 3) assess whether there were appropriate response options available for all questions and all reasonable alternatives were included (199); 4) assess the flow and order of sections, including the skip patterns (439); 5) investigate the time taken to answer each section and the whole questionnaire (438, 439); 6) investigate respondent interest and attention overall (438, 439); and 7) explore participants' overall views about the questionnaire (199).

The pre-testing was carried out by professionals who would also have been eligible to take part in the process evaluation. They had experience working in primary or secondary care (for the latter, they had to work in any area related to oncology) or in relevant cancer charities in Scotland. Professionals were invited for pre-testing via an email to the PhD students' mailing list and another to DCE contacts. My principal supervisor also sent emails to a GP and an oncologist working in secondary care.

The literature recommends that data are reported on general characteristics of those involved in the pre-testing, on how pre-testing was carried out (setting, duration, number of actual recruited participants), and on changes made to the instrument as a result of the pre-testing (438). Four professionals were invited, and all agreed to pre-test the questionnaire: two GPs, one oncologist working in secondary care, and a senior manager in a cancer charity who also had prior experience as a health care professional. Pre-testing was carried out at the University of Edinburgh (n=2), at a general practice (n=1), and at a cancer charity (n=1). Meeting duration ranged from 20 to 40 minutes. Time taken to read the questionnaire is available below, alongside a summary of issues raised and resulting changes to the questionnaire (Table 6.4).

**Table 6.4.** Recommendations from pre-testing and resulting changes to the questionnaire

| Sections | Recommendations | Changes |
|---|---|---|
| **Instructions** | • The introductory section should briefly state what DCE is about as professionals may not know about its activities (or that activities they know about were part of DCE)<br>• The term "involved" should be replaced with a statement about whether DCE influenced the participants' work or whether they helped with implementation. This is to avoid non-response from eligible stakeholders who may misinterpret the term | These issues were amended as suggested |
| **Specific questions** | • Recommendations to clarify statements, change one statement to a yes/no question, check consistency of verb tenses and the logic flow between questions referring to different implementation periods, and between expectations and facts<br>• Some questions/statements should be removed from the broad DCE section and placed in a section about a specific DCE activity | Statements were clarified (one of them was changed to a question); verb tenses were made consistent; questions about expectations were moved before the ones about facts; a logic flow was respected; questions were removed |
| **Response options** | • More comment boxes should be added after questions that may bring back memories as these can clarify important issues not covered by the questionnaire<br>• Views may vary for different cancer types, and this is not currently captured | Boxes and a "please specify" probe were added to different questions; a question was added to capture variation across cancer types |
| **Sections** | As the sections are not really connected to each other, there may be issues regarding relevance. Sections not relevant to a target group may be relevant to other groups, and professionals may get frustrated if questions are not relevant to them | More skip options were added to try to avoid this |
| **Time taken reading each section and overall** | • Introduction: 00:01:20 to 00:03:00<br>• Part 1: DCE overall 00:02:00 to 00:06:00; awareness campaigns: 00:00:25 to 00:02:00; education sessions 00:00:40 to 00:04:00; funding 00:01:00 to 00:03:00; targets 00:01:00 to 00:02:00<br>• Part 2 (demographic information): 00:00:25 to 00:04:00<br>• All sections: median 00:13:08; range 00:07:25 to 00:21:36 | Questionnaire should take less time to complete than expected |
| **Interest and attention** | Questionnaire may not be as relevant to oncologists working further down the cancer journey - because of the very clear referral patterns for several types of cancer, perceptions of the impact of DCE on the oncologists' work may be watered down – those working with diagnostics may find the questionnaire more relevant. | DCE activities are now described, the term "involved" was clarified and filter questions were added to help potential participants to assess relevance. |
| **Overall** | Questionnaire was described as useful, but there are issues regarding clarity and relevance to specific groups | Amendments were made (as above) to deal with these issues |

*Data analysis and reporting*

All questionnaire responses were downloaded from the online system and converted into a *.sav format to be analysed in SPSS v.23 (245). An unedited, raw data file was kept aside. Standardised codes for missing data were added. Frequencies were run to assess completeness of information, and to identify any inaccuracies. I then checked for out of range/unexpected values. Recoding was necessary for all Likert-type questions and other questions that had more than two answer options as BOS created a single variable for each possible answer. I also recoded questions that had reverse scores, open-ended questions clarifying closed-ended questions and questions which allowed for "other" issues to be mentioned. Month and day of birth were defined as the 1st June in order to estimate age based on year of birth provided by participants. Changes to the original dataset were recorded in a diary. After checks were made, descriptive, one-way tables for all numeric variables in the dataset were created.

Summary tables, descriptive statistics and inferential statistics were used for quantitative data. Syntaxes were saved whenever applicable (recoding and bivariate analyses). A table describing sample characteristics was created; summary tables and graphs were used for 1) questions about assumptions; and 2) questions about mechanisms. N(%) was reported alongside means, standard deviations, medians and interquartile ranges (IQR) for ordinal data (in the main thesis and in Appendices). Bar and pie charts were created in Microsoft Excel 2016 (382). Inferential statistics were used to investigate variations in views across different groups of professionals, based on their job role, involvement in DCE, and the tumour type they worked with. Non-parametric tests were used for ordinal scales in order to investigate differences in rating distributions between two groups (Mann Whitney U test) and more than two groups (Kruskal-Wallis H test, followed by pairwise comparisons with Bonferroni correction for multiple testing). Chi-squared tests (or Fisher's Exact test when counts were less than five) were used for nominal (categorical data) to check for differences in proportions.

Content analysis was used for open-ended questions; this is a structured approach for coding qualitative data (199). Content analysis helps to avoid cherry-picking quotes that seem relevant to multiple choice questions (427). Comments were coded by themes/categories (assumptions, mechanisms, barriers and facilitators, unanticipated outcomes and additional themes), and counts of the frequencies with

which themes occurred were produced (199). All open-ended comments and a preliminary list of themes/categories were shared with my lead supervisor; we then agreed on the final list of themes.

### 6.4.5 Ethics

In August 2017, both an NHS Ethics Scientific Officer and the Head of Research Governance at the Academic and Clinical Central Office for Research and Development were consulted about the need for ethical approvals for the process evaluation. They confirmed that the study was a service evaluation and that no ethical approval was needed from an NHS Research Ethics Committee nor Research & Development.

Documentation for the process evaluation interviews was submitted to Usher Research Ethics Group (UREG) on the 13th October 2017. Unconditional approval was granted on the 11th January 2018 (Appendix 29). As in Study 2; study participants signed a consent form before taking part. Both the study participants and the researcher kept a copy of the signed consent form.

I was informed by UREG that ethical approval was not required for pre-testing the questionnaire as 1) I was not going to record participants' answers to the questionnaire (i.e. I would not be collecting research data); 2) the questionnaire was not likely to cause harm; and 3) I was only going to report on overall changes made to the questionnaire. The full questionnaire survey required UREG approval; documentation was submitted on the 5th March 2018 and approval was granted on the 9th April 2018 (Appendix 30).

Potential questionnaire participants were provided with the research team's contact details so they could ask questions before agreeing to take part in the study. Participants consented to take part online after reading an information page (which also had a link to a comprehensive downloadable information sheet). Invited stakeholders only had access to the questionnaire if they ticked the appropriate consent box.

## 6.5 Feedback from the evaluation steering group

Results from Study 2 were presented to the evaluation steering group in December 2016. The evaluation protocol and topic guide for the Study 3 interviews were shared with the steering group in September 2017 and amended based on their feedback.

Comments referred to emphasising barriers and facilitators further and asking whether stakeholder views about the programme changed over time.

The questionnaire was sent to the steering group in October 2017 for comments and was also amended after their feedback. Comments were overall positive, and minor issues were raised regarding clarity and avoiding the use of ambiguous terms (i.e. “such as”, efficiency” and “sustainability”). It was also suggested I replaced the socio-demographic question about urbanisation level (which had been adapted from an European Social Survey questionnaire (440)) with the official Urban/Rural Classification from the Scottish Government (441) to allow for comparisons between studies in Scotland. All suggested changes were made.

## 6.6 Summary of Chapter 6

This Chapter described the methods adopted for Study 3 (the DCE evaluation). The outcome evaluation comprised secondary analysis of data from policy documents, and a time-trends analysis of bowel screening outcomes. The process evaluation had two components: qualitative interviews with DCE stakeholders and a purpose-built, online questionnaire for stakeholders. The next three Chapters describe the results for these three Study 3 components.

# Chapter 7 Results: Outcome evaluation

## 7.1 Overview

This Chapter describes the results from the outcome evaluation of the DCE programme, which aimed to assess if, and to which extent, each of the eight official DCE objectives were met. This was done by secondary analyses of published and unpublished reports, and a descriptive time-trends analysis of requests for bowel screening kits. As described in Chapter 6, quality and representativeness of the data varied across data sources. Descriptive statistics (N, %) were reported and relative percentage changes over time were calculated whenever possible. Textual summaries/syntheses were also adopted. The outcome evaluation was carried out between May and December 2018.

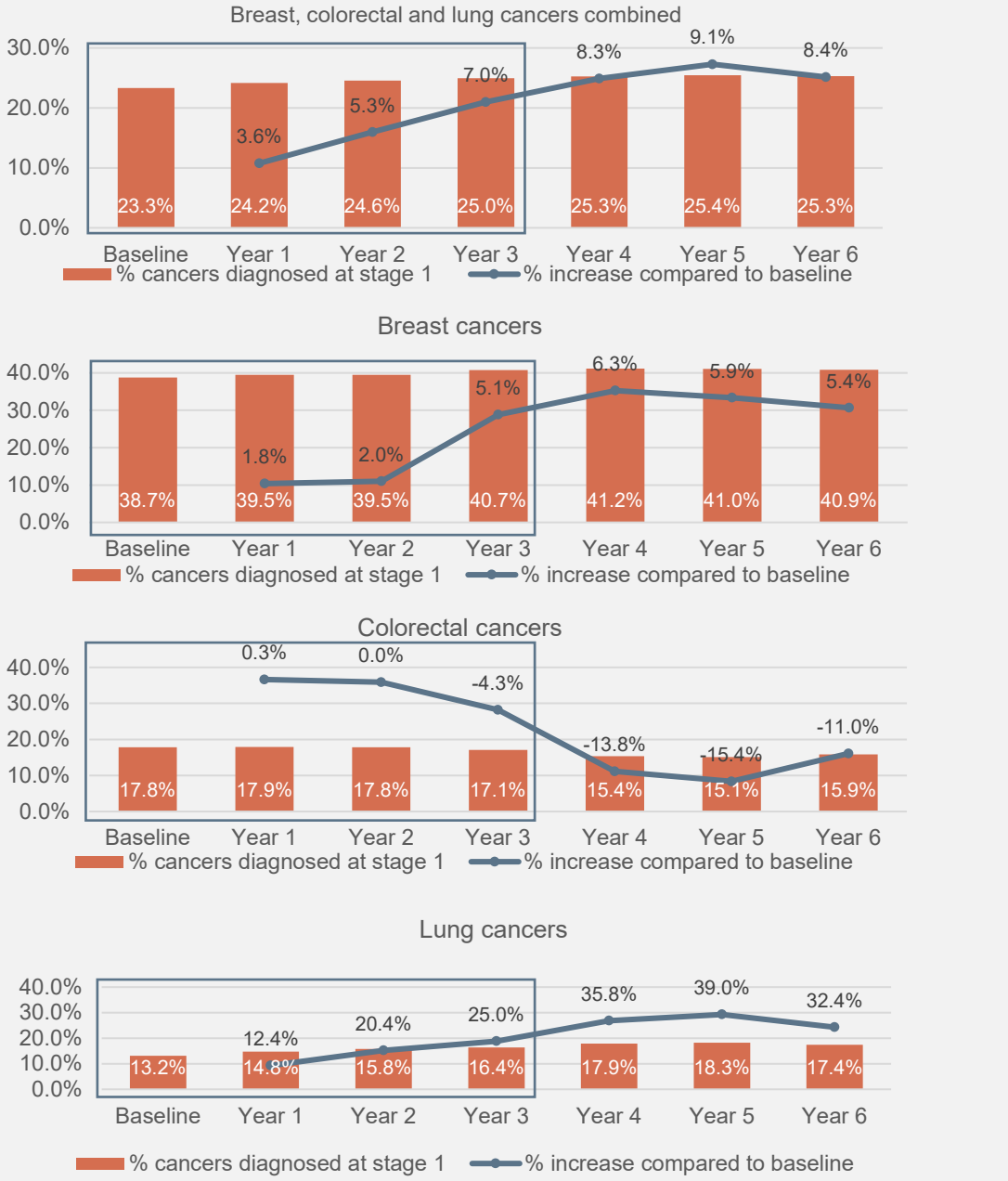
## 7.2 Objective 1

To increase the proportion of breast, colorectal and lung cancers diagnosed at Stage I by 25% and use performance as a lever for whole systems improvement

The first part of this objective was equivalent to the HEAT target, the official proxy for improvement in cancer survival (DCE's key aim). Data produced and published by ISD Scotland was analysed to report on this objective.

There was a 7.0% relative increase in the proportion of breast, colorectal and lung cancers (combined) diagnosed at Stage I at Year 3 (2014-2015) compared to baseline (years 2011-2012) (442). When analysing each tumour type separately (i.e., not as a HEAT target), there were relative increases in the proportion of breast (5.1%) and lung cancers (25.0%), and a decrease in the proportion of bowel cancers (4.3%) diagnosed at Stage I (442) (Figure 7.1).

**Figure 7.1.** Stage I and % change (combined) and for each tumour type



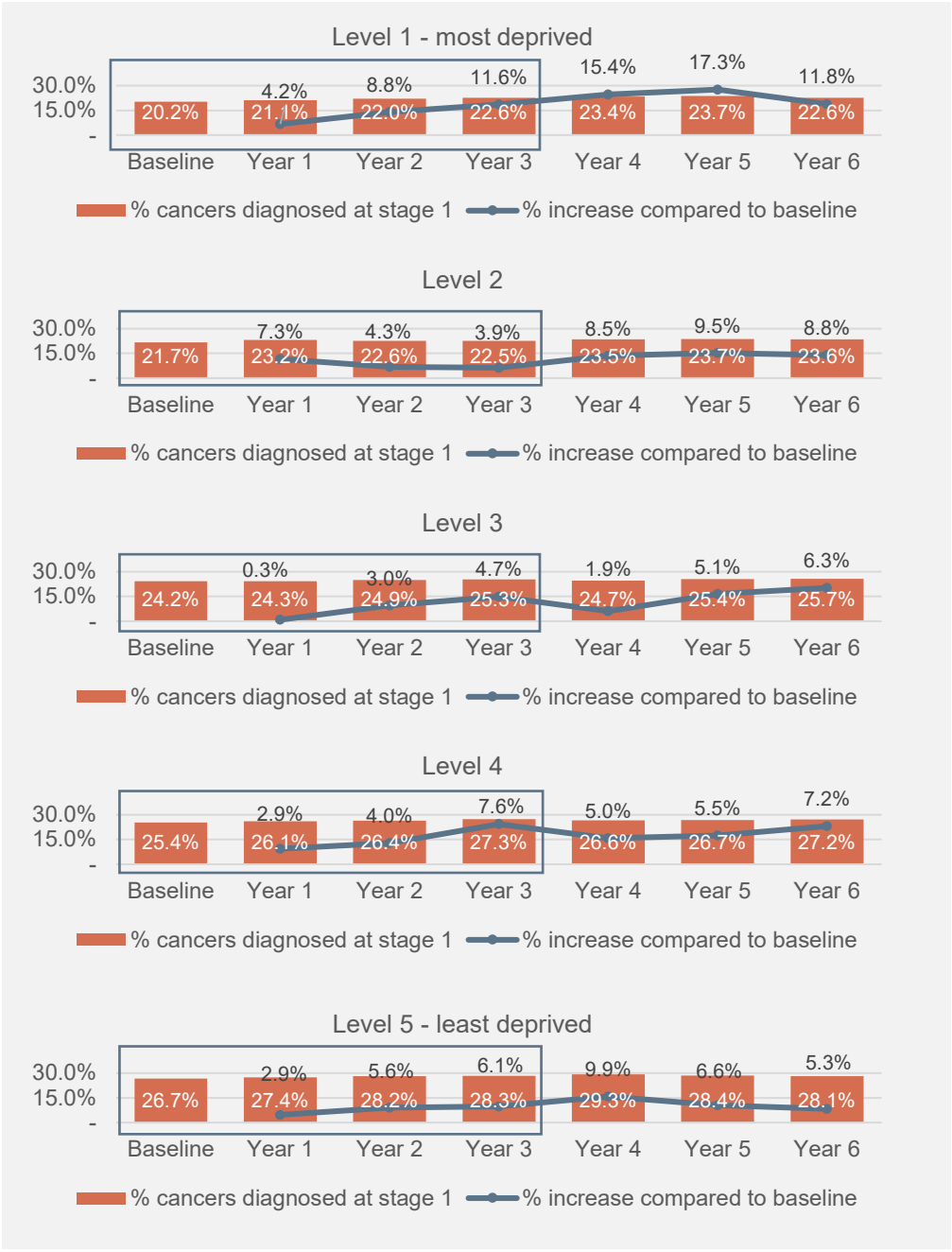

N(%) cancers diagnosed at Stage I

| Tumour type | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| 3 cancers combined | 5581 (23.3) | 5946 (24.2) | 6074 (24.6) | 6198 (25.0) | 6272 (25.3) | 6207 (25.4) | 6129 (25.3) |
| Breast | 3184 (38.7) | 3341 (39.5) | 3378 (39.5) | 3477 (40.7) | 3538 (41.2) | 3530 (41.0) | 3502 (40.9) |
| Colorectal | 1261 (17.8) | 1257 (17.9) | 1213 (17.8) | 1136 (17.1) | 1021 (15.4) | 996 (15.1) | 1040 (15.9) |
| Lung | 1136 (13.2) | 1348 (14.8) | 1483 (15.8) | 1585 (16.4) | 1713 (17.9) | 1681 (18.3) | 1587 (17.4) |

***Source: created using ISD Scotland data and aggregated tables (442).***

Increases were noted across all levels of social deprivation (1 most deprived to 5 least deprived) for the three tumour types combined, for breast and lung. Considering the three tumour types combined, the highest increase was among the most deprived (11.6%) (Figure 7.2; Table 7.1) (442).

**Figure 7.2.** Stage I cancers and % change across deprivation levels




***Source: created using ISD Scotland data and aggregated tables (442)***

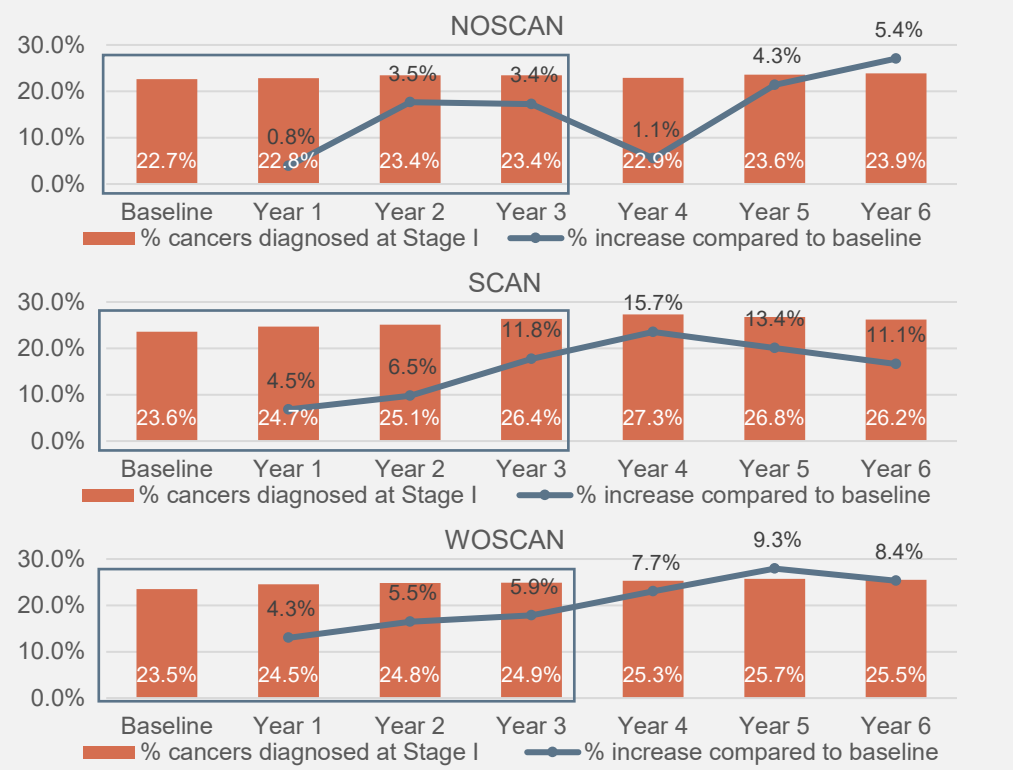
**Table 7.1.** N(%) of cancers diagnosed at Stage I by deprivation levels

| Deprivation level | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| Level 1 = most deprived | 1128 (20.2) | 1205 (21.1) | 1269 (22.0) | 1304 (22.6) | 1344 (23.4) | 1307 (23.7) | 1203 (22.6) |
| Level 2 | 1144 (21.7) | 1261 (23.2) | 1214 (22.6) | 1209 (22.5) | 1236 (23.4) | 1243 (23.7) | 1244 (23.6) |
| Level 3 | 1132 (24.2) | 1162 (24.3) | 1198 (24.9) | 1231 (25.3) | 1217 (24.7) | 1237 (25.4) | 1229 (25.7) |
| Level 4 | 1114 (25.4) | 1199 (26.1) | 1208 (26.4) | 1262 (27.3) | 1223 (26.6) | 1202 (26.7) | 1232 (27.2) |
| Level 5 = least deprived | 1049 (26.7) | 1111 (27.4) | 1172 (28.2) | 1180 (28.3) | 1247 (29.3) | 1212 (28.4) | 1206 (28.1) |

***Source: created using ISD Scotland aggregated tables (442)***

There were also increases for all three tumour types (combined) in the three Cancer Networks in Scotland. SCAN had the highest % change in Year 3 compared to baseline (11.8% increase), while NOSCAN had the lowest (3.4%) (442) (Figure 7.3; Table 7.2). There were wide variations across territorial Health Boards, with the highest percentage change for NHS Lothian (15.8% increase in all three tumour types combined at Year 3) and the lowest for NHS Highland (a 6.7% decrease) (442) (Appendix 31).

**Figure 7.3**. Stage I cancers and % change across Cancer Networks




***Source: created using ISD Scotland data and aggregated tables from: (442)***

**Table 7.2.** N(%) of cancers diagnosed at Stage I by Cancer Networks

| Cancer networks | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| NOSCAN | 1328 (22.7) | 1344 (22.8) | 1399 (23.4) | 1393 (23.4) | 1389 (22.9) | 1478 (23.6) | 1461 (23.9) |
| SCAN | 1557 (23.6) | 1670 (24.7) | 1675 (25.1) | 1775 (26.4) | 1831 (27.3) | 1727 (26.8) | 1711 (26.2) |
| WOSCAN | 2696 (23.5) | 2932 (24.5) | 3000 (24.8) | 3030 (24.9) | 3052 (25.3) | 3002 (25.7) | 2957 (25.5) |

***Source: created using ISD Scotland aggregated tables (442)***

While the first part of Objective 1 was measurable, it was not possible to ascertain whether performance was used as a lever for system-level improvement.

## 7.3 Objectives 2 and 3

Objective 2: To improve informed consent and participation in national cancer screening programmes to help detect cancer earlier and improve survival rates

Objective 3: To raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier.

Outcomes for both objectives are shown together as they overlapped. Outcome data are shown by tumour type. The tumour-specific sections are followed by synthesis of a TNS evaluation that covered awareness campaigns across all tumour types (443).

There was limited information on whether informed consent improved, although one of the campaign evaluations shed light on whether this was the case for breast screening (see below and summary of Chapter).

### 7.3.1 Breast cancer

#### 7.3.1.1 Measuring changes in knowledge/awareness and motivation

TNS carried out before-and-after evaluations of the breast symptomatic (444, 445) and the breast screening campaigns (446). Carat and Consolidated PR collected data on campaign reach and other process measures; these data were then disseminated through DCE documents. Data from these sources are synthesised here.

Data from the symptomatic breast campaign evaluation show that the campaign had high level of awareness and recognition among women, especially among the target groups (lower socioeconomic status) (Figure 7.4). There was a significant increase in awareness of cancer symptoms and signs other than lumps highlighted by the campaign. Furthermore, there was an increase in the proportion of women checking

their breasts and an increase in the proportion of women stating they would see the GP straightaway if noticing symptoms (444, 445).

**Figure 7.4.** Synthesis of key findings: symptomatic breast cancer campaign

**Before-and-after evaluation: symptomatic breast cancer**

Spontaneous awareness of breast cancer symptoms and signs highlighted by the campaign significantly increased over time. Those recognising the campaign were significantly more likely to mention any sign of breast cancer spontaneously.

There was improvement in knowledge among DEs, although it was less pronounced than for C1C2s. Awareness of specific symptoms remained lower across DEs, but there were significant improvements across most symptoms highlighted by the campaign.

- Significantly stronger disagreement with the statement **' I worry about feeling silly if I go to my doctor with small changes to my body, thinking they could be cancer'**
- Significant stronger disagreement with the statement about being **confused about what symptoms to look for, other than lumps**

82% of all campaign recognisers were motivated by it. Half of those who recognised the campaign reported having done something as a result of seeing it (mainly checking their breasts, 39%).

There was an increase in the proportion of women who would see the GP straighaway if noticing symptoms (from 63% to 68%). Furthermore, the proportion who claimed to have checked their breast in the last two months increased significantly (from 73% to 82%).

**Campaign reach: TV, radio, newspapers and leaflets**

- 81% of surveyed women recognised the TV ad (82% among DEs); prompted recognition of the TV ad was high among all groups (the lowest was 76% among those aged 65-75)
- There was lower recognition for radio, with 24% having heard it (25% of DEs)
- 34% had seen magazine inserts/leaflets (41% of DEs)
- 33% had seen posters/newspapers (40% of DEs)
- 86% had seen or heard of any campaign element (88% of DEs)

**Business to Business, Public Relations and Field and Partnership**

- Over 55 days of field activity, with 23,365 engagements (9,015 in-depth), and 6,615 leaflets distributed
- 100,000 pieces of campaign material distributed via NHS Boards and other public sector organisations
- 3,700 private sector partners supporting the campaign; 36,910 leaflets distributed by local businesses across Scotland
- Over 10,000 visits to the NHS Inform website
- Over 130,000 YouTube views in the month after launch, 195,000 views at July 2013

***Sources: data synthesised from TNS and DCE documents (444, 445). Note: TNS does not report on social deprivation. Instead, they refer to six social grades which are based on the current or former occupation of the main income earner in a household (ABC1 refers to "professional, managerial and non-manual occupations", while C2DE refers to "manual and unskilled occupations and the long-term unemployed") (source ID 43).***

As for the breast screening campaign, the evaluation reported that those who recognised it had higher levels of awareness and understanding of breast screening that those who did not recognise it. TNS also found that those who had never been

invited or had never attended screening recognised adverts less often than those who had experience attending screening (446, 447) (Figure 7.5). Conversely, those who recognised the campaign more often strongly agreed that breast screening did not carry any risks compared to those who did not recognise it.

**Figure 7.5.** Synthesis of key findings: breast screening campaign

**Before-and-after evaluation: understanding breast screening**

Women who recognised the campaign (i.e. recognisers) had higher levels of awareness and understanding of breast screening compared to women who did not recognise it (i.e. non-recognisers). The percentage of recognition was lower for older age groups, higher for the target group, higher for the West of Scotland, and the lowest for those who had never attended and were never invited to screening.

- **"I don't think breast screening carries any risks"**: 34% of recognisers strongly agreed compared to 21% of non-recognisers
- **"Breast screening can find cancers that you couldn't see or feel yourself"**: 54% of recognisers agreed compared to 38% of non-recognisers
- **"Breast screening can find cancers that your GP couldn't see or feel"**: 49% of recognisers agreed compared to 33% of non-recognisers
- **"If you've missed a breast screening in the past two years, you need to wait until you are next invited"**: 68% of recognosers disagreed compared to 51% of non-recognisers
- **"You don't need to check your breasts yourself in between screenings"** - 82% of recognisers disagreed compared to 69% of non-recognisers

Across all groups, there was high agreement that **breast screening is the best way to detect cancer early** (lower for those who never attended screening and non-recognisers), and that breast screening saves lives.

**Campaign reach: radio and newspaper**

- 22% of those who never attended breast screening heard the radio advert (the lowest among all types of screening history). However, the highest % was still low (41%)
- The lowest % of recognition of newspaper adverts was among those never invited for screening (34%), followed by those who never attended (44%)
- Newspaper recognition was higher than for radio

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- Over 500 breast screening resources were downloaded from the DCE website
- Over 37 pieces of breast screening media coverage
- Elaine C Smith's video attending mammography was seen over 2,200 times
- Over 25 field events
- 50,000 breast cancer keychains distributed
- DCE website had over 5,000 hits during the campaign period

***Source: data synthesised from TNS and DCE documents (446, 447)***

#### 7.3.1.2 Breast screening uptake (routine and self/GP referrals)

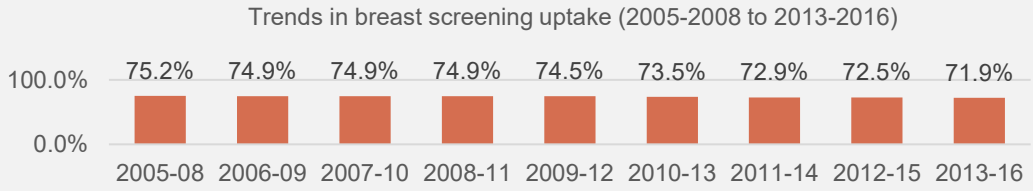
ISD Scotland reports on both routine (screening invitations every three years to all eligible asymptomatic women) and non-routine (recall, self-referral and GP referral) appointments (9).

Routine breast screening uptake has been slowly declining for over a decade (9, 448). As results were available for a three-year rolling period, it was not possible to assess

whether there was an increase in breast screening uptake during the DCE campaign (which took place in 2014).

During 2012-2015 (DCE's first three years), breast screening uptake (72.5%) was lower than in any of the available previous periods. Uptake continued to decrease in the 2013-2016 period (71.9%) (Figure 7.6).There was an increase in the number of women screened in 2013-2014 (in this case, information was only available on a two-year rolling period) compared to the previous periods, but it was not possible to attribute this change to DCE (449). When considering non-routine breast screening appointments (also a two-year rolling period), there were increases in self/GP referrals in 2011-2012, 2013-2014 and 2014-2015 compared to baseline (9). The symptomatic breast campaign took place in 2012; due to limited data granularity it was not possible to estimate the extent to which it may have contributed to these increases (Figure 7.6).

**Figure 7.6.** Trends in breast screening uptake, N screened and % change




| | 2010-11 (proxy baseline) | 2011-2012 | 2012-2013 | 2013-2014 | 2014-2015 | 2015-2016 |
|---|---|---|---|---|---|---|
| Routine appointments | | | | | | |
| Number screened | 170,664 | 167,486 | 164,472 | 172,929 | 158,405 | 154,641 |
| % change from baseline | - | -1.9% | -3.6% | +1.3% | -7.2% | -9.4% |
| Early Recall | | | | | | |
| Number screened | 27 | 26 | 22 | 17 | 5 | 12 |
| % change from baseline | - | -3.7% | -18.5% | -37.0% | -81.5% | -55.6% |
| Self / GP Referral | | | | | | |
| Number screened | 11,195 | 12,151 | 10,439 | 11,972 | 13,311 | 11,251 |
| % change from baseline | - | +8.5% | -6.8% | +6.9% | +18.9 | +0.5% |

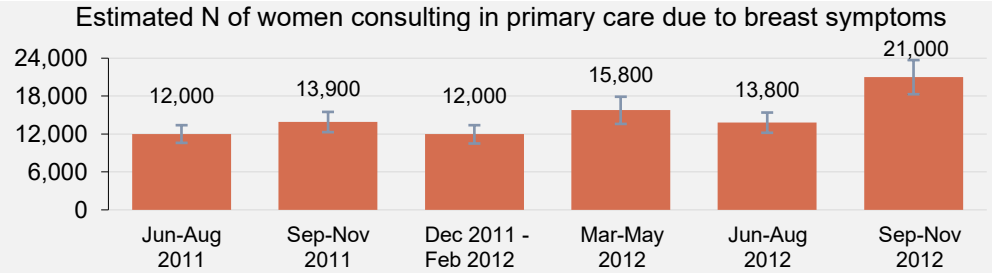
***Source: Adapted from ISD Scotland 2018 (9)***

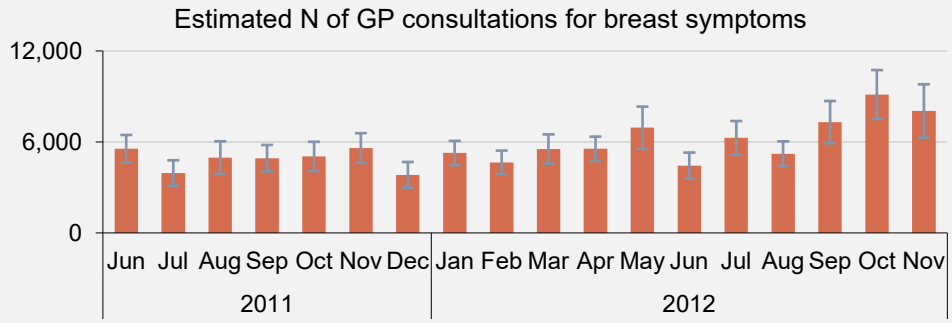
#### 7.3.1.3 Consultations due to breast symptoms

ISD Scotland prepared a customised report for DCE estimating the number of consultations due to breast symptoms in order to help assess the impact of the symptomatic breast campaign (450). Data were derived from a sample of general practices, and included symptoms (lumps, pain and infection) which may not

necessarily indicate breast cancer (450). There was a 51% increase in the number of women seeking a GP consultation due to breast symptoms during September-November 2012 (the campaign was carried out in September and October in that year) compared to the same period in the previous year (Figure 7.7).

**Figure 7.7.** Estimated consultations in primary care due to breast symptoms




| Consultations for breast symptoms (females) | | | |
|---|---|---|---|
| 2011 | Estimate | 2012 | Estimate |
| Jan | - | Jan | 5,270 |
| Feb | - | Feb | 4,650 |
| Mar | - | Mar | 5,540 |
| Apr | - | Apr | 5,550 |
| May | - | May | 6,940 |
| Jun | 5,550 | Jun | 4,440 |
| Jul | 3,950 | Jul | 6,270 |
| Aug | 4,960 | Aug | 5,220 |
| Sep | 4,930 | Sep | 7,310 |
| Oct | 5,050 | Oct | 9,130 |
| Nov | 5,600 | Nov | 8,040 |
| Dec | 3,830 | Dec | - |

***Source: adapted from ISD Scotland 2013 (450)***

When checking the estimated number of GP consultations for breast symptoms, there was a 48% increase in September 2012 (compared to September 2011), and an 81% increase in October 2012 (compared to October 2011).

#### 7.3.1.4 Other outcomes: responses to call to action from breast screening campaign

The breast screening campaign prompted women to text SCREEN and their postcode to a purposively assigned number in order to book a screening appointment. The telephone number of their regional screening centre was then provided. The Breast Screening Centres collected data on how many women texted them as a result of the campaign (which had two phases), and how many of those resulted in a booked appointment (451).

In the first phase of the campaign, 372 women left text messages and were sent the telephone number of their regional Breast Screening Centre. However, these text messages did not translate into many booked/rescheduled appointments at the Breast Screening Centres (no actual numbers were provided) (451). In the second phase of the campaign, 500 women left text messages and were called back by the Screening Centres so an appointment could be booked. However, several women did not answer the calls and there were some IT issues when trying to record data in the South East of Scotland. Furthermore, women who left text messages were often not the target population (i.e. deprived women eligible for screening) (451).

When women called the Breast Screening Programme, about 10% of them (94 out of 932) stated that they were prompted by DCE campaigns. More than a third of them (n=35) called to change or cancel an appointment, 41 were not eligible for screening, 11 had general enquiries and 7 declined an appointment (451).

### 7.3.2 Colorectal cancer

#### 7.3.2.1 Measuring changes in knowledge/awareness and motivation

TNS evaluations assessing awareness and understanding of bowel screening after six phases of the bowel campaign showed persisting high spontaneous awareness of campaigns (although with a decrease over time). There was persisting agreement with several key campaign messages, but also weakening of agreement with others. Furthermore, there was a decline in those claiming that they had returned their test kit, a decline in motivation, and in wanting to see the campaign again (452) (Figure 7.8).

**Figure 7.8.** Synthesis of key findings: bowel screening campaign

**Before-and-after evaluation: bowel screening**

Spontaneous awareness of campaigns remained high (68%) after six campaign phases, but there was a significant decline over time (especially among men, those aged 45-64 and C2s). Increase in prompted campaign recognition was recorded amongst all groups, with significant increases for females and 65-74s. Campaign recognisers continued to exhibit more positive views about screening compared to non-recognisers.

- There was increase in spontaneous awareness of the main message **"do the test"**, but there were no changes for **messages about survival/cure**, which resonated more with those aged 45-54. Females were significantly more likely to mention **"do the test"** than males
- There was slight weakening of agreement with the statements **"the best way to detect bowel cancer early is to do the home screening kit"**; **"when detected early, most people survive bowel cancer"**; and **"as I get older, my risk of getting bowel cancer increases"**.
- There was continued strong agreement with the statements: **"you could have bowel cancer and not even know it, as the early stages often have no symptoms"**; and **"if bowel cancer is detected early it can often be cured"**
- There was a slight decline in those claiming that they had returned the test kit (especially among men, C1s and those aged 55-64) although there was an increase in those claiming that they had received the kit at home. There was also a slight decrease in the likelihood of doing the test next time. Similar to previous evaluations, the most common reason for doing the test was that **"it is the best way to find bower cancer early"**

Decline in motivation already noticed in previous evaluations continued in most groups, with the exception of 65-74s and C1C2s. There was also continued decrease in the proportion wanting to see or hear the advert again. These issues highlighted potential campaign wear out.

**Campaign reach: television and radio**

- Very high level of TV recognition (minimum of 75%) for all groups
- There was lower recognition of new radio advert, especially among males and DEs. Campaign recognition declined significantly with age

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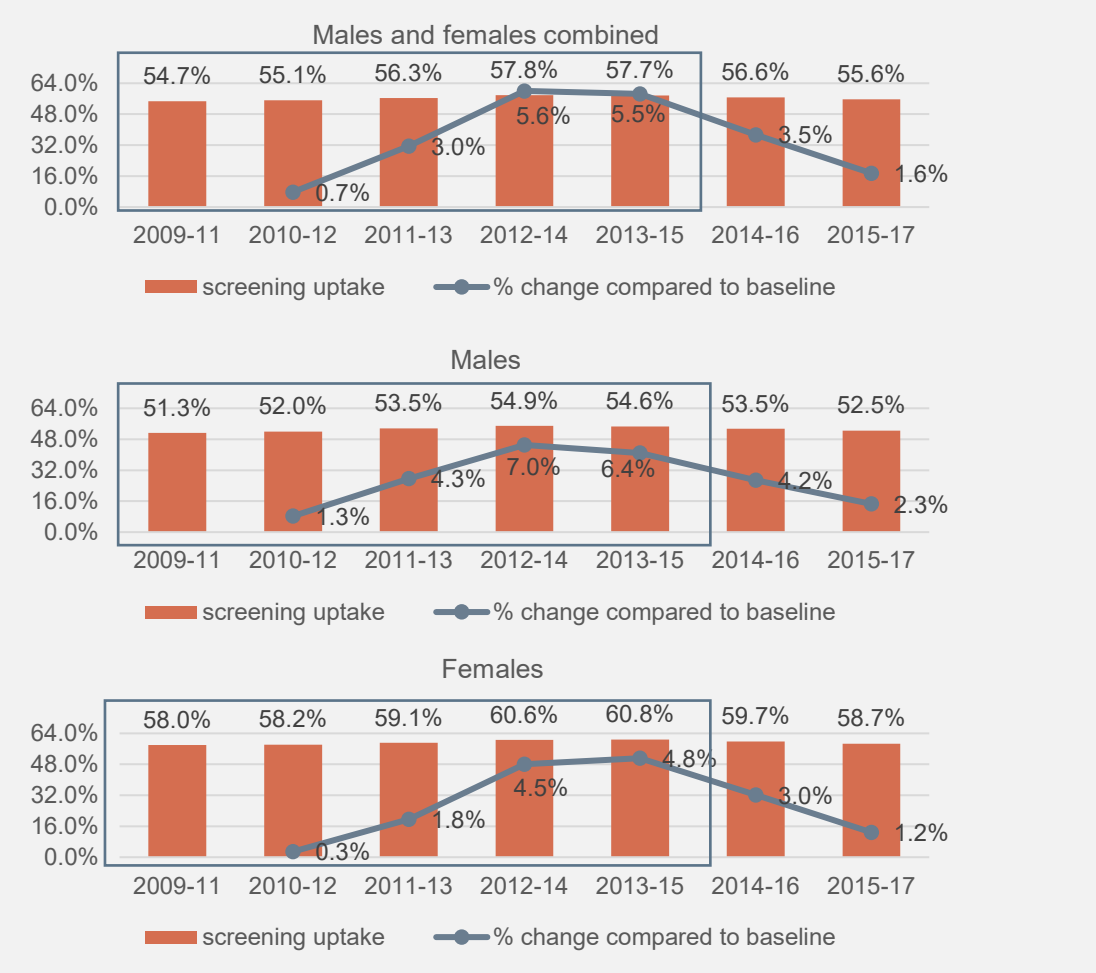
- During the first three phases, the DCE page had 5,379 visits, while the bowel screening page had 8,385 visits. Increase in traffic was observed around campaign times.
- As of February 2015, the "poo song" had almost 96,151 YouTube views; a "how to do the bowel cancer test" film had 3,629 views
- At least 274 pieces of media coverage
- About 20,500 in-depth engagements

***Sources: data synthesised from TNS and DCE documents (452, 453)***

#### 7.3.2.2 Colorectal cancer screening uptake

Official ISD Scotland data show that bowel screening uptake had been slowly, but steadily increasing over time. This trend continued during DCE's first three years. Screening uptake increased for both males and females, with a higher % increase among males (Figure 7.9; 2009-2011 as proxy baseline), and across all deprivation levels (124). Despite improvements over time, uptake remained lower in more deprived areas (Figure 7.10) (124). It was challenging to ascertain the extent to which the bowel screening campaigns, and the bowel screening initiative contributed to these improvements.

**Figure 7.9.** Trends in bowel screening uptake overall and by sex, and % change




***Source: created using ISD Scotland data and aggregated tables (124)***

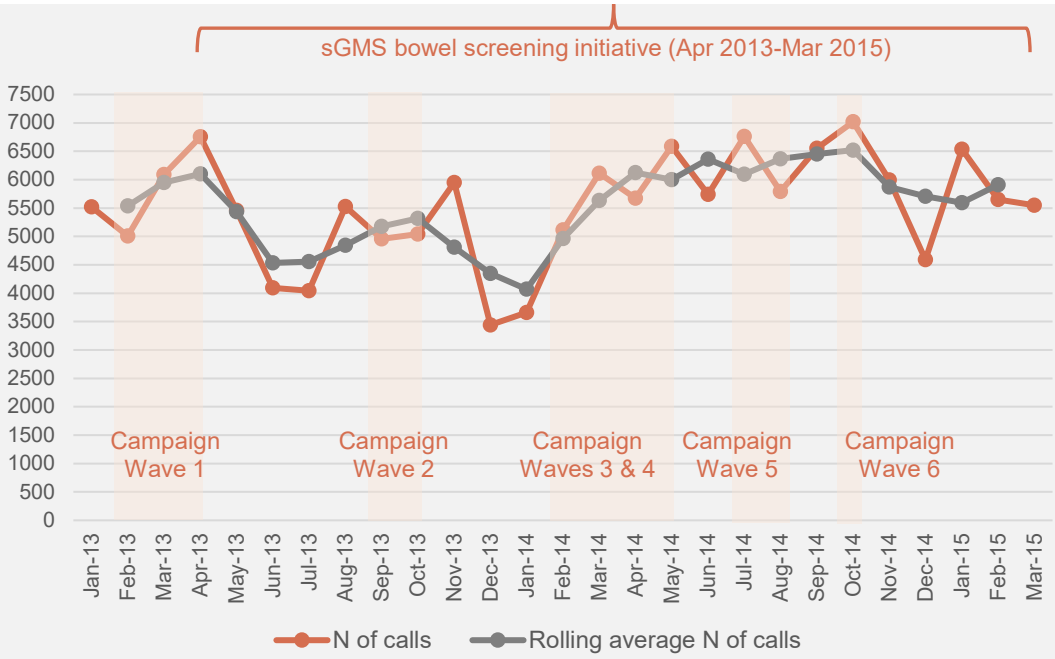
**Figure 7.10.** Bowel screening uptake by deprivation levels and % change


***Source: created using ISD Scotland data and aggregated tables (124)***

### 7.3.2.3 Calls to the bowel screening helpline

Annual reports from the Scottish Bowel Screening Centre indicate an increase in calls when campaign phases were launched. The highest number of monthly calls was in October 2014 (during the sixth phase of the campaign) (454) (Figure 7.11).

**Figure 7.11.** Calls to the bowel screening helpline



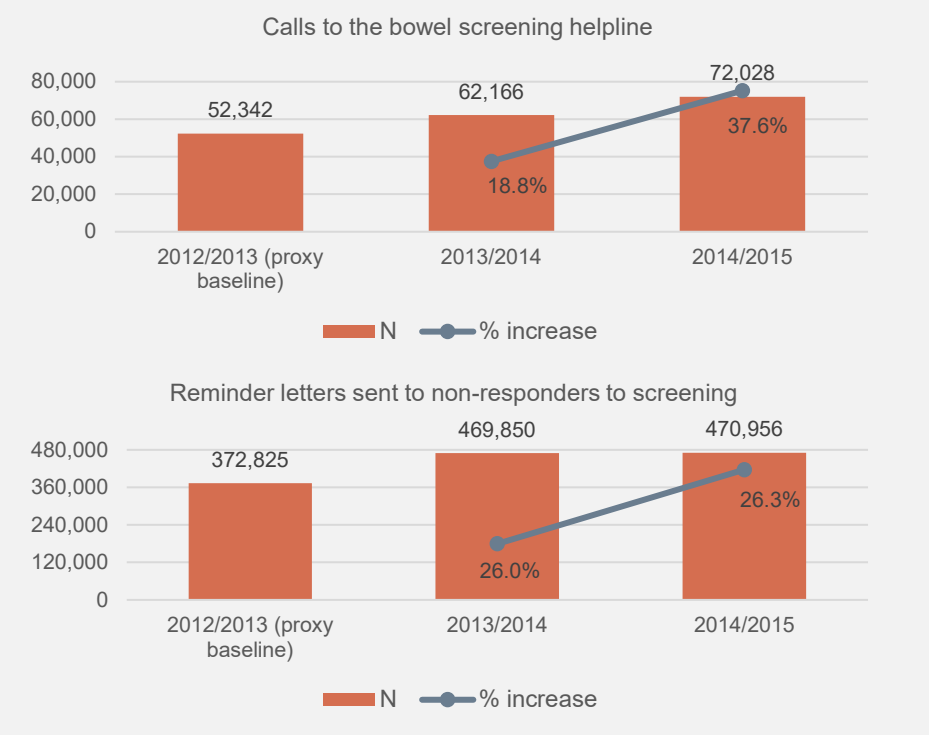

| 2013 (Campaign phases 1 & 2; bowel screening initiative launched) | | 2014 (Campaign phases 3-6; bowel screening initiative ongoing) | | 2015 (Final three months of the bowel screening initiative) | |
|---|---|---|---|---|---|
| Months | N | Months | N | Months | N |
| Jan-13 | 5521 | Jan-14 | 3659 | Jan-15 | 6534 |
| Feb-13 | 5007 | Feb-14 | 5112 | Feb-15 | 5649 |
| Mar-13 | 6092 | Mar-14 | 6112 | Mar-15 | 5550 |
| Apr-13 | 6754 | Apr-14 | 5673 | | |
| May-13 | 5456 | May-14 | 6587 | | |
| Jun-13 | 4096 | Jun-14 | 5739 | | |
| Jul-13 | 4045 | Jul-14 | 6762 | | |
| Aug-13 | 5528 | Aug-14 | 5789 | | |
| Sep-13 | 4958 | Sep-14 | 6552 | | |
| Oct-13 | 5043 | Oct-14 | 7018 | | |
| Nov-13 | 5947 | Nov-14 | 5994 | | |
| Dec-13 | 3442 | Dec-14 | 4591 | | |

***Source: created using data from the Scottish Bowel Screening annual reports (454, 455)***

When comparing 2012-2013 (proxy baseline) with 2014-2015, there was a 37.6% increase in the number of calls (from 52,342 to 72,028 calls) (Figure 7.12). Furthermore, there was an increase in reminder letters sent to non-responders to

screening (a 26.3% increase from 2012-2013 to 2014-2015) (454, 455). Reminder letters were sent as part of the Bowel Screening Initiative.

**Figure 7.12.** Reminder letters and calls to helpline by year (N and % change)




***Source: created using data from the Scottish Bowel Screening Centre (454, 455)***

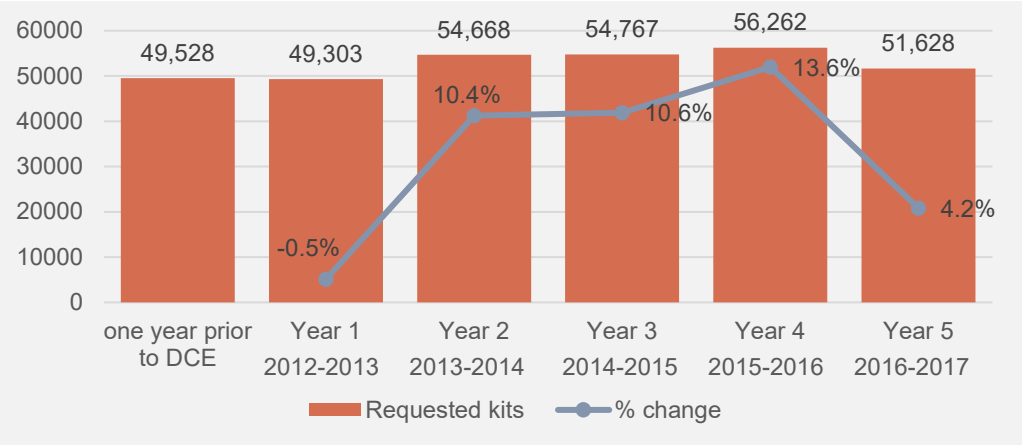
#### 7.3.2.4 Requests for bowel screening kits

Anonymised data from the Scottish Bowel Screening Centre on requested and returned replacement kits were used for this analysis (456).

During DCE's first year (Feb 2012-Jan 2013) the number of requested replacement kits was fairly similar to the previous year (Feb 2011-Jan 2012 – used as proxy baseline). This changed in DCE's second year (Feb 2013 – Jan 2014) when social marketing campaigns targeting bowel screening commenced and the bowel screening initiative was launched. There was a 10.4%, 10.6% and 13.6% increase in the number of requested kits in Year 2, Year 3 and Year 4 respectively. The number of requests then decreased in Year 5 (4% compared to baseline) (Figure 7.13).

The increase in requested kits occurred across all territorial Health Boards (with variations), except for NHS Tayside and NHS Orkney in DCE's third year (bearing in mind small numbers for the latter) (Appendix 32).

**Figure 7.13.** Requests for bowel screening kits and % change




***Source: created using data from a customised dataset provided by the Scottish Bowel Screening Programme***

When checking monthly data, the highest percentage increases in Year 2 and Year 3 compared to proxy baseline occurred during campaign periods (April and October 2013, a 21.4% and 15.9% increase respectively; and February and October 2014, with a 19.2% and a 27.0% increase respectively) (Figure 7.14, Table 7.3). Importantly, there were also substantial increases in requests in months when there were no campaigns. There were no data available to ascertain whether the bowel screening initiative contributed to these increases.

**Figure 7.14.** Requested screening kits over time

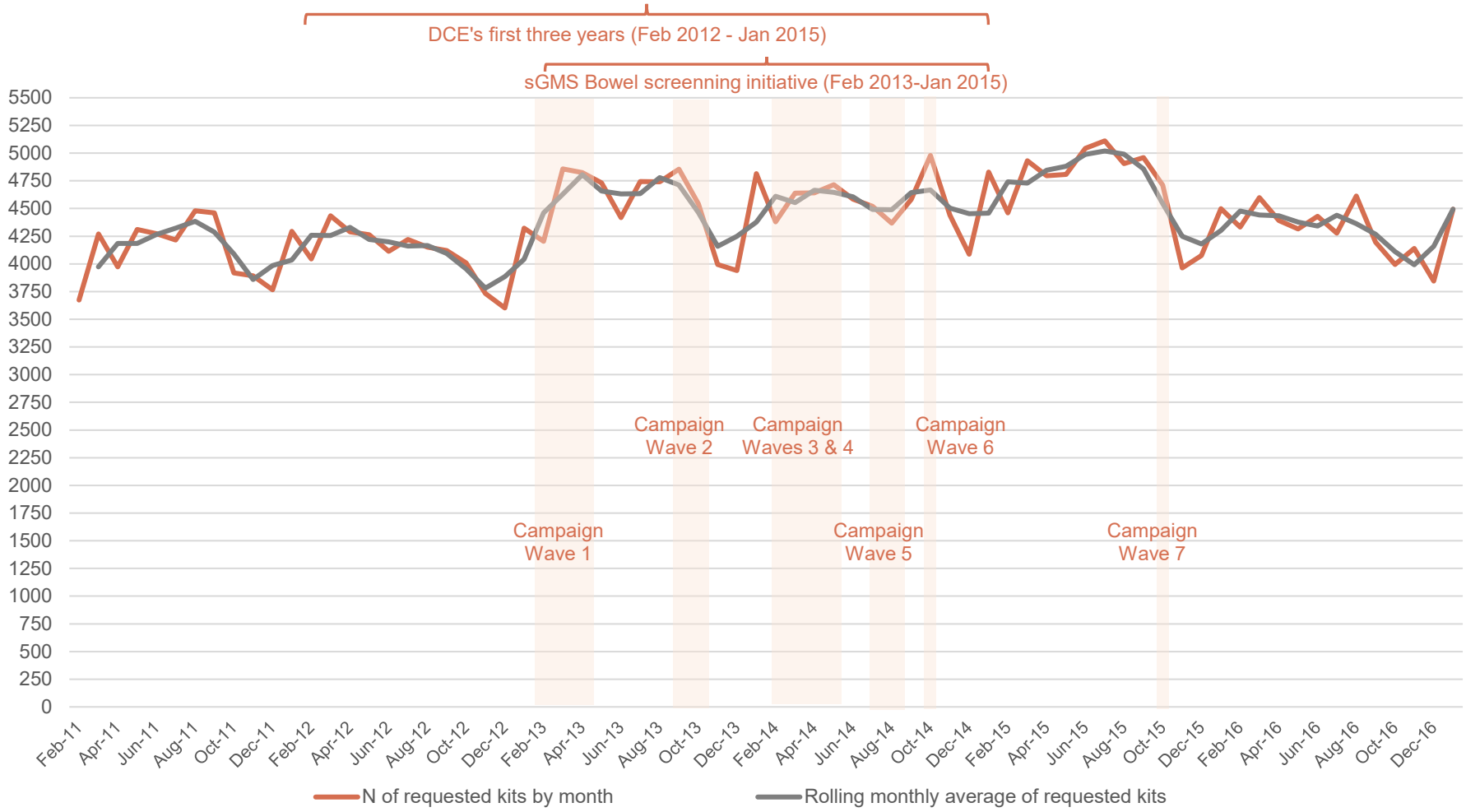


**Table 7.3.** Requested kits over time and % change compared to proxy baseline

| | Year prior to DCE (proxy baseline) | Year 1 (prior to bowel specific strategies) | | Year 2 (Campaign phases 1 & 2, bowel screening initiative) | | Year 3 (Campaign phases 3-6; bowel screening initiative) | | Year 4 (Campaign phase 7; end of bowel screening initiative) | | Year 5 | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Months | N | N | % change | N | % change | N | % change | N | % change | N | % change |
| Feb | 3674 | 4045 | 10.1% | 4205 | 14.5% | 4381 | 19.2% | 4460 | 21.4% | 4332 | 15.2% |
| Mar | 4270 | 4435 | 3.9% | 4857 | 13.7% | 4640 | 8.7% | 4932 | 15.5% | 4599 | 7.2% |
| Apr | 3973 | 4289 | 8.0% | 4825 | 21.4% | 4641 | 16.8% | 4795 | 20.7% | 4391 | 9.5% |
| May | 4311 | 4263 | -1.1% | 4732 | 9.8% | 4715 | 9.4% | 4809 | 11.6% | 4315 | 0.1% |
| Jun | 4273 | 4113 | -3.7% | 4418 | 3.4% | 4585 | 7.3% | 5043 | 18.0% | 4429 | 3.5% |
| Jul | 4215 | 4221 | 0.1% | 4744 | 12.6% | 4519 | 7.2% | 5111 | 21.3% | 4278 | 1.5% |
| Aug | 4479 | 4152 | -7.3% | 4741 | 5.8% | 4368 | -2.5% | 4905 | 9.5% | 4614 | 2.9% |
| Sep | 4460 | 4121 | -7.6% | 4856 | 8.9% | 4581 | 2.7% | 4959 | 11.2% | 4197 | -6.3% |
| Oct | 3919 | 4008 | 2.3% | 4542 | 15.9% | 4979 | 27.0% | 4710 | 20.2% | 3995 | 1.9% |
| Nov | 3893 | 3732 | -4.1% | 3994 | 2.6% | 4440 | 14.1% | 3964 | 1.8% | 4139 | 5.9% |
| Dec | 3766 | 3602 | -4.4% | 3940 | 4.6% | 4088 | 8.6% | 4076 | 8.2% | 3845 | 2.1% |
| Jan | 4295 | 4322 | 0.6% | 4814 | 12.1% | 4830 | 12.5% | 4498 | 4.7% | 4494 | 4.4% |
| Total | 49528 | 49303 | -0.5% | 54668 | 10.4% | 54767 | 10.6% | 56262 | 13.6% | 51628 | 4.2% |
| Mean (monthly) | 4127 | 4109 | - | 4556 | - | 4564 | - | 4689 | - | 4302 | - |

***Percentage change always refers to proxy baseline. For annual calculations, the year prior to DCE (Feb 2011-Jan 2012) was used as the proxy baseline. For monthly calculations, the corresponding month in that year was used as the proxy baseline***

## 7.3.3 Lung cancer

### 7.3.3.1 Measuring changes in knowledge/awareness and motivation

As there is no organised lung screening programme in Scotland, the lung cancer campaign (with three phases) only focused on signs and symptoms, and on changing the perception that nothing could be done after a lung cancer diagnosis. Campaign evaluations reported a significant increase in spontaneous awareness of lung cancer activities, persisting high campaign recognition and increase in motivation over time. There was also a significant increase in spontaneous awareness about the "three-week cough" message. Although many felt more comfortable to see the doctor in three weeks if they noticed small changes, there was also an increase in those saying they would not see the GP at all (Figure 7.15).

**Figure 7.15.** Synthesis of key findings: lung cancer campaign

**Before-and-after evaluation: Lung cancer symptoms and signs**

After the campaign phase in November 2014, there was significant increase in spontaneous awareness of activity about lung cancer, with a similar pattern found across most groups (with the exception of those aged 75+ for whom spontaneous awareness decreased). Campaign recognition remained high over different campaign phases. Motivation increased over time, especially for men, DEs and 75+.

- The **"get checked"** message remained strong after three phases of the campaign
- There were high levels of agreement that **much can be done to treat symptoms**, and an increase in agreement over time (over 70% agreed)
- There was a significant increase in spontaneous awareness of the **"three-week cough"** (over 70% awareness) as a symptom and smaller increase in prompted awareness (over 90% awareness)
- Prompted symptom awareness increased over time, more as a result of rise in awareness of lesser known symptoms, as awareness of the **"three-week cough"** remained similar

There was a significant increase in the proportion taking action as a result of campaign. Those who were not motivated by it were significantly less likely to take action than those who were motivated.

In terms and attitudes and behaviours, the target audience stated that they felt more comfortable going to the doctor with small changes. While there was a significant increase in those who would go to the GP after three weeks, more also said they would not go at all.

**Campaign reach: television and radio**

- Television was the most dominant media. Recognition was significantly higher among C2s when compared to C1DEs
- Written media (press) showed declined recognition (significantly among DEs)

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- During campaign times, the campaign website received over 16,200 visits
- Sir Alex Ferguson's TV advert received around 4,500 views on You Tube; his video saying that "lung cancer isn't what it used to be" was shared on Get Checked Early's Facebook page and reached 294,656 people
- The events team engaged with over 29,000 members of the public in over 28 events
- Over 95 pieces of coverage in the media

***Sources: data synthesised from TNS and DCE documents (457-461)***

#### 7.3.3.2 Consultations due to lung symptoms and associated examinations

There was limited data on impact on consultations and associated examinations. A DCE Newsletter sent to GPs reported that more patients were referred for a chest x-ray by a GP during the first month of the campaign (compared to the previous month). There was also a 3% increase in chest x-rays during the campaign (compared to the same time in the year prior to the campaign) (460).

### 7.3.4 Attitudinal tracking before and after DCE campaigns

TNS compared people's attitudes before all the social marketing campaigns (2011) and after DCE's first three years (early 2015) regarding 11 statements (443). Several positive, significant changes in attitudes were reported over time (Figure 7.16) but there were also mixed and negative shifts (Figure 7.17).

**Figure 7.16.** Synthesis of key findings: 3-year attitudinal tracking (positive shifts)

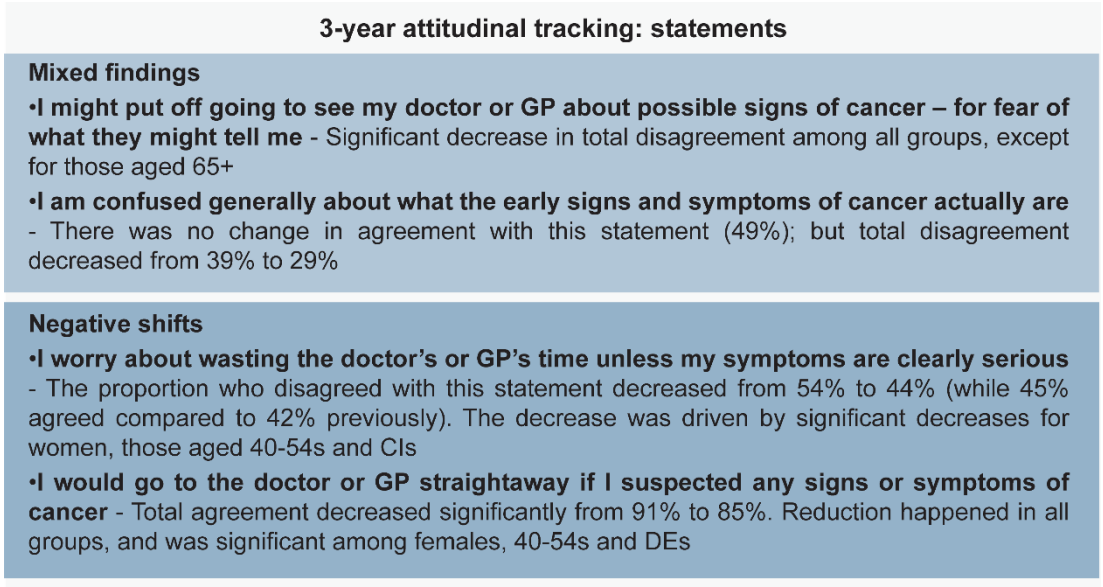
**3-year attitudinal tracking: statements**

**Positive shifts**

- **There's not much doctors can really do for cancer** - The proportion who disagreed increased significantly from 76% to 83%, with strong disagreement increasing from 27% to 38%. Significant increases happened for both total disagreement and strong disagreement for men, those aged 65+ and DEs
- **You can't survive cancer so what's the point in worrying about the early signs and symptoms of it** - Total disagreement increased significantly from 85% to 91%, with strong disagreement increasing from 39% to 55%; there were significant increases in total disagreement among men, those aged 65+ and DEs
- **Just the thought of cancer puts me off thinking about checking for the signs and symptoms of it** - Total disagreement fell significantly from 76% to 65%, without a change in strong disagreement. Agreement with the statement showed no substantial changes
- **Spotting signs of cancer early improves your chances of survival** - Total agreement increased significantly from 94% to 97%, with strong agreement increasing significantly from 50% to 66%
- **People who take part in screening (when invited) are improving their chances of surviving cancer** - No change in total agreement, but strong agreement increased significantly from 41% to 51%, including among men, those aged 65+ and DEs
- **If you get lung cancer there's little or no chance of you surviving** - Total disagreement increased from 48% to 58%, with significant increases among men, those aged 65+ and DEs. There was a significant increase in strong disagreement (11% to 15%) overall and for C2s
- **Taking part in cancer screening (e.g. bowel / breast) reduces the need to look out for signs and symptoms yourself** - Total agreement decreased significantly from 42% to 32%, while total disagreement increased significantly from 50% to 58%. There were significant increases in disagreement among women, those aged 65+, C2s and DEs.

***Source: data synthesised from TNS (443)***

**Figure 7.17.** Synthesis of key findings: 3-year attitudinal tracking (mixed and negative shifts)




***Source: data synthesised from TNS (443)***

## 7.4 Objective 4

To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access

The Primary Care Symptom Management and Referral Strategy addressed this objective through the updated referral guidelines and the education sessions for professionals. The development of practice profiles is also relevant, but this activity was not implemented (personal communication, DCE Programme Board meetings).

Local activities carried out by different Health Boards also addressed this objective in different ways (such as developing different referral pathways or implementing one-stop breast clinics), but outcome data were not available for these activities. A pilot study in NHS Tayside using qFIT with symptomatic patients is also relevant (see below), although outcome information is limited. It was not possible to assess whether resources were used efficiently or whether there was an adverse impact on access.

### 7.4.1 Referral guidelines

With funding from DCE, the existing Scottish referral guidelines for suspected cancer were updated and published in 2014 (462). Quick guides were printed and disseminated across Scotland. A third-party evaluation about the use of the guidelines

was being carried out while this study was ongoing (personal communication, Dr Douglas Rigg), but results were not available when this Chapter was written.

#### 7.4.1.1 Education sessions

Education sessions were led and evaluated by Bowel Cancer UK and the Roy Castle Lung Cancer Foundation (463, 464). Seven engagement sessions and one Webcast were delivered to 424 health care professionals between September and October 2013. GP Sessions covered both colorectal and lung cancers. Key outcomes synthesised from evaluation reports prepared by the charities are available (463) (Figure 7.18).

**Figure 7.18.** Synthesis of key findings from the education sessions

- Priorities for attending the education sessions were finding out about the bowel screening initiative, the Bowel Screening Programme and the bowel cancer referral guidelines
- Attendees agreed that the day met their expectations, that the education session was relevant and that they were taking away knowledge that they could use
- Professionals attending the sessions stated that the lung and bowel sessions were useful; the symptoms and social marketing sessions were the most highly rated
- Bowel Cancer UK reported an increase in demand for their endoscopy booklet and the Bowel Health and Screening resource for people with learning disabilities and their care providers. There were also requests for awareness talks to surgeries on bowel cancer symptoms, screening, risk factors and prevention messages
- Attendance was reported to be poor from three territorial Health Boards and further engagement sessions were planned
- A third of professionals attending the sessions answered a question about how they would share information from the sessions within the practice; 68% of them planned to do so at a practice meeting

***Sources: Synthesised from Roy Castle Lung Cancer Foundation and Bowel Cancer UK documents (463, 464)***

### 7.4.2 Symptomatic qFIT

Initial results from using qFIT with symptomatic patients in NHS Tayside have been published (411). Authors concluded that it was a good “rule-out test”, with negative predictive values of 100% for colorectal cancer, 97.8% for higher-risk adenoma and 98.4% for inflammatory bowel disease. There was no available data on roll out in other Health Boards (411).

## 7.5 Objective 5

To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part

Data were limited on investment or plans to ensure that screening capacity was sufficient. Data describing increase in consultations due to breast symptoms and

increase in self-referrals (shown when reporting outcomes for Objectives 2 and 3) indicated increase in workload for the breast screening programme (as its resources were required for examinations of patients with symptoms).

Two annual reports from the Scottish Bowel Screening Centre described increase in activity during DCE awareness campaigns and the bowel screening initiative (as described for Objectives 2 and 3)(454, 455). The increase in activity was also reported to have influenced laboratory test time and the Centre's ability to meet the NHS Quality Improvement Scotland desirable standard (95% of participants receiving their results within 7 days of receipt by the Screening Centre). Nonetheless, all screening participants received their results within 12 days (2013-2014) and 14 days (2014-2015). Reports also stated that there was a seasonal peak in laboratory activity during February and March 2014 (phase 3 of the bowel screening campaign); this was then reduced in April and returned to pre-campaign levels (454, 455).

Several strategies were adopted to manage impact; these included an automated telephone option so those calling could order a replacement kit by leaving a recorded message (added in February 2014). About one third of callers used this option, with 90% accuracy (i.e. without the need to call back) (454).

## 7.6 Objective 6

To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early disease requiring treatment

Revenue funding was allocated to Health Boards via NRAC share, taking into account population projections, age/sex distribution, needs due to morbidity, deprivation and remoteness (465). Health Boards submitted brief annual reports to DCE describing how funding was used and perceived benefits. Use of funding varied widely across Health Boards (Table 7.4), although many used it to support improvements in diagnostics, data capture and reporting; and local awareness initiatives/support for national campaigns. There was limited information about resources for treatment and no consistent data on whether capacity was sufficient.

**Table 7.4.** How DCE funding was used and reported outcomes

| Territorial Health Board | How additional funding was used | Reported outcomes |
|---|---|---|
| NHS Ayrshire & Arran | • Investment in diagnostics (Radiography, Pathology, Endoscopy, Laboratory, local EBUS services) and purchase of videoconferencing equipment for MDT meetings<br>• Baseline assessment and ongoing measurement (cancer tracking and audit staff)<br>• Awareness raising activities, engagement with men and other hard-to-reach bowel screening non-responders<br>• Recruitment of locum staff to deal with demand; increase in breast surgery capacity<br>• Support for GPs to increase bowel screening uptake | • Better communication with GPs, improved GP engagement to increase bowel screening uptake<br>• Better communication and engagement with patients, volunteers and the public<br>• Increase in breast screening/mammography capacity (with reduction in waiting times); increase in diagnostic capacity (bowel screening, imaging and pathology)<br>• Improved audit of cancers diagnosed (A&E admission and routine referral); more accurate/complete staging data<br>• Improved efficiency of MDTs; additional CT capacity |
| NHS Borders | • Assignment of managers to coordinate work on awareness and communication with deprived populations<br>• Funding for a clinical nurse specialist in lung cancer; additional colonoscopy/CT scan capacity; additional breast clinics and a consultant radiologist<br>• Development of local material to support staff; staff survey on awareness of bowel screening<br>• Training and support for practices in order to meet bowel screening targets<br>• Use of local radio for early detection messages | • New network of contacts to reach deprived and vulnerable populations; work with local initiatives and companies<br>• Dedicated staff to work on DCE helped to increase bowel screening uptake<br>• A multidisciplinary team was established<br>• Plans developed to support gaps in service provision with new resources brought by funding<br>• Events held with GP practices to provide support<br>• Messages on risk factor and early detection were embedded in staff conversations with patients |
| NHS Dumfries & Galloway | • Development of new cross-cancer site MDT data recording system; employment and training of new audit staff<br>• Display of advertising/marketing from national campaigns in local NHS and regional publication; increase in communication activity<br>• Increase in capacity in Head and Neck Clinical Nurse Specialist role; building capacity in endoscopy (including equipment) and Pathology | • Better planning for future services and audit of practice (developments were incorporated in services provided)<br>• Increased engagement with Community Health Teams and Educational Institutes<br>• Improved reporting in cancer staging data |
| NHS Fife | • Investment in diagnostics (Endoscopy, Radiology and Pathology); recruitment of a respiratory physician; appointment of a lead Cancer GP | • Reduction in the capacity deficit |

| Territorial Health Board | How additional funding was used | Reported outcomes |
|---|---|---|
| | • Funding for additional clinical sessions to tackle delays | |
| NHS Forth Valley | • Funding for additional diagnostics (Radiology and Pathology consultants, technical staff for breast services and fast-track x-ray for lung) and training<br>• Support and redesign the Outpatient Department breast service; funding for a breast surgeon, nursing and administrative staff; pilot using breast physician to support one-stop clinics<br>• Purchase of an additional ultrasound machine; additional endoscopy capacity for surveillance<br>• Funding for Health Promotion and to train volunteers to work with hard to reach groups<br>• Cancer prevention activities and awareness raising events, local case studies, work in the community, distribution of campaign packs; use of websites, social media and community newsletters | • Additional endoscopy capacity eased the pressure on the endoscopy unit<br>• Reduced pathway delays, improved patient centred breast service<br>• Bowel screening awareness training indicated lack of awareness of the screening test, of knowledge about the importance of symptoms and signs, body and practical issues of doing the test. A short weekly briefing session implemented for breast has continued and has been rolled out to other pathways |
| NHS Grampian | • Support for endoscopy, radiology, cancer audit team and Managed Clinical Network<br>• Funding for cancer nurse specialists, cancer pathways team and MDT support<br>• Complementary early detection initiatives carried out in partnership with voluntary and partners | • Increased diagnostic capacity<br>• Network approach to funding allocation taken by consulting widely and identifying priorities (this also resulted in better engagement of different professionals)<br>• Ability to undertake systematic review of pathways; establishment of a Cancer Care Network<br>• Development of a work plan |
| NHS Greater Glasgow & Clyde | • Additional breast and radiology sessions (including evenings and weekends); additional imaging capacity, scanning and reporting capacity for CT scanning; infrastructure for developing a Sentinel Lymph Node Biopsy in Breast Cancer service<br>• Targeted marketing for the breast campaign; increase in lung capacity ahead of campaigns; additional endoscopy capacity<br>• Increase in medical and diagnostic sessions (respiratory medicine) | • Improved “real time” audit in terms of staging data<br>• Improved understanding of residual consequences of campaigns<br>• Audit system put in place to enable continuous improvement and understanding of trends in presentation |
| NHS Highland | • Procurement of a mammography unit, of an ultrasound machine (lung) and a prostate biopsy probe for urology | • Reduced waiting times for the diagnosis and treatment of breast patients; reduced waiting time for TRUS biopsies with greater flexibility for treatment. |

| Territorial Health Board | How additional funding was used | Reported outcomes |
|---|---|---|
| NHS Lanarkshire | • Production of teaser letters for breast screening and bowel diaries; joint work with partners to raise awareness of bowel and breast cancers; health improvement (training, screening toolkits, work in prisons and leisure centres)<br>• Investment in digital mammography, recruitment of a breast surgeon and support for the appointment of a breast clinical assistant<br>• Purchase of EBUS services and an introduction of a wide screen monitor; purchase of rigid thoracoscopy equipment<br>• Investment in specialist Radiology and CT Colonography; piloting a one-stop breast clinic; training for nurse endoscopists<br>• Support for clinical audit and data gathering; radiology, care pathways, and local campaigns | • Cemented relationships with local authority partners<br>• Improved clinical audit data and key performance indicators; reduced backlog in data collection; quality assurance timescales were met and a rolling programme of quality assurance for all tumours was facilitated<br>• Development of local reporting and better collection of staging data<br>• Improved access and local treatment (lung); more efficient approaches that reduce the risk and need of anaesthetics<br>• Continuous review of pathways to ensure a robust and streamlined approach, and to improve services<br>• Improvement in data capture and integration of CT colonography into Colorectal Services as standard |
| NHS Lothian | • Increase in diagnostic, screening capacity and treatment costs to maintain cancer waiting times targets<br>• Baseline assessment and ongoing measurement (audit staffing, programme management, analytical capacity, e-health developer time and others)<br>• To assess, profile and influence primary care referral behaviour<br>• Investment in breast symptomatic and screening services, radiology for breast, lung and bowel, respiratory medicine (staff, nursing and administrative support), breast imaging, biopsy and Magnetic Resonance Imaging, support to EBUS/imaging<br>• Investment in a pilot study to improve screening uptake<br>• Funded additional sessions to increase GP Cancer Lead time | • Increased understanding of the system while using cancer intelligence - changing service provision and delivering pathways that support early detection; improved cancer analytical capacity and audit<br>• Development of a governance and leadership structure through the DCE Board<br>• 10 pilots on primary care engagement and innovation, with improved engagement with general practice and screening<br>• Increase in breast service (including one additional one-stop clinic) and radiology capacity<br>• Improved referral guidance<br>• Early diagnosis became central to the Board's Strategy |
| NHS Orkney | • Funding for new scopes; endoscopy redesign to support screening campaigns; establishment of a CT service; new multifunction room<br>• Support for Health Promotion<br>• Development of the "Bin your Bra" campaign<br>• Support for DCE campaigns locally - giving away keyrings, doing radio interviews with local women, having articles in local magazines, distributing resources to local businesses and public | • Increase in the number of scopes<br>• Awareness raised for breast cancer and enhanced engagement with staff)<br>• Increased scrutiny on performance at practice level<br>• Rolling programme of replacement scopes to maintain scope numbers; adoption of protocols to order scans and help to deal with having no radiologist |

| Territorial Health Board | How additional funding was used | Reported outcomes |
|---|---|---|
| | venues, and sharing information and links on local pages and websites (including social media). | • Promotion of educational programmes; knowledge and skills to be maintained and mainstreamed<br>• Revised networked approach through the Isles Network of Care to the delivery of care |
| NHS Shetland | • Investment in DCE leads, data capture, and diagnostic equipment<br>• Purchase of video conferencing equipment and use of funding to assist with modernising scopes; additional colonoscopy capacity<br>• Pump priming for initiatives to support DCE<br>• Support of Health Promotion activities (alongside work with pharmacists funded by Macmillan); funding allocation alongside Urological Cancer Charity (UCAN) and Prostate UK | • DCE embedded in core business; became a recurring item in Cancer Lead Team meetings<br>• Increased opportunities for patients to be referred via the pharmacist; links with services improved<br>• Increased awareness of trigger symptoms and pathways across primary care services and improved links between specialists and health services – resulting in increased capacity and reduction of waiting times for patients requiring ongoing surveillance after cancer treatment |
| NHS Tayside | • Investment in breast capacity though additional staff, and lung and colorectal capacity through staff and equipment<br>• Investment in capacity for Pathology, Radiology, IT, Primary Care, and Medical Records through staff and equipment<br>• Pilot development of a cancer decision support tool in primary care<br>• Support for national marketing activities | • Sustained and embedded social marketing.<br>• Increased understanding of the importance of systematic data collection and analysis, of having an effective and influential clinical engagement with DCE, having effective senior leadership, good management and administration<br>• More capacity (breast, lung, colorectal and supporting services) |
| NHS Western Isles | • Funding used towards cancer awareness (breast, bowel, lung, prostate, testicular and general cancer awareness) - contacting existing cancer support groups, setting up stalls at community events, disseminating information in community halls, GP practices and workplaces; using survival stories in different media channels to engage with the public; targeting men using local media channels and women through ladies' film night<br>• Use of out of hours helpline and set up of a dedicated website | • Breast screening uptake increased<br>• Learning built into Health Promotion approaches to enhance awareness and screening uptake<br>• Increased vigilance for early detection; continued input and support for local cancer groups |

***Sources: Data synthesised from annual reports sent to DCE by territorial Health Boards (466-499). Abbreviations: EBUS: Endobronchial Ultrasound; MDT: multidisciplinary team; CT: computed tomography; GPs: general practitioners; A&E: accident and emergency; IT: information technology; NHS: National Health Service***

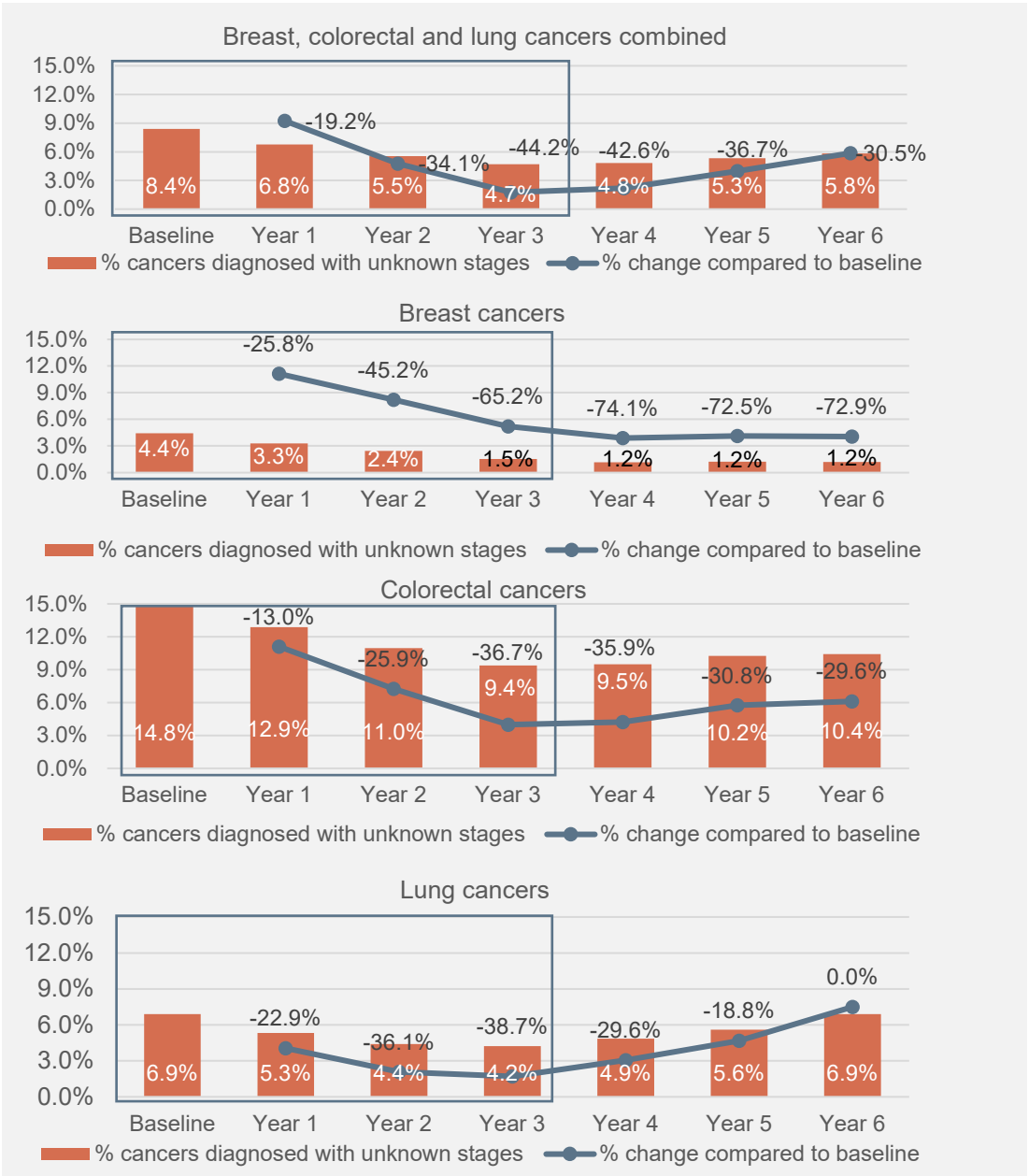
## 7.7 Objective 7

To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral, and survival

As part of HEAT target reporting, ISD Scotland reported not only on cancer staging for breast, bowel and lung cancers, but also on changes in the proportion of cancers diagnosed with unknown stages over time. This was the only available measure to assess whether Objective 7 was met.

There was a 44.2% reduction in cancers diagnosed with unknown stages when checking breast, bowel and lung cancer combined, comparing Year 3 (2014-2015) to baseline (2011-2012). The highest reduction happened for breast cancer (65.2% in Year 3), while the reduction for colorectal and lung cancers in Year 3 was similar (36.7% and 38.7% respectively). (Figure 7.19) (442). Reductions occurred across all deprivation levels, with the most deprived having the highest reduction in Year 3 (52.7%) (442) (Figure 7.20, Table 7.5).

**Figure 7.19.** Cancers diagnosed with unknown stage and % changes

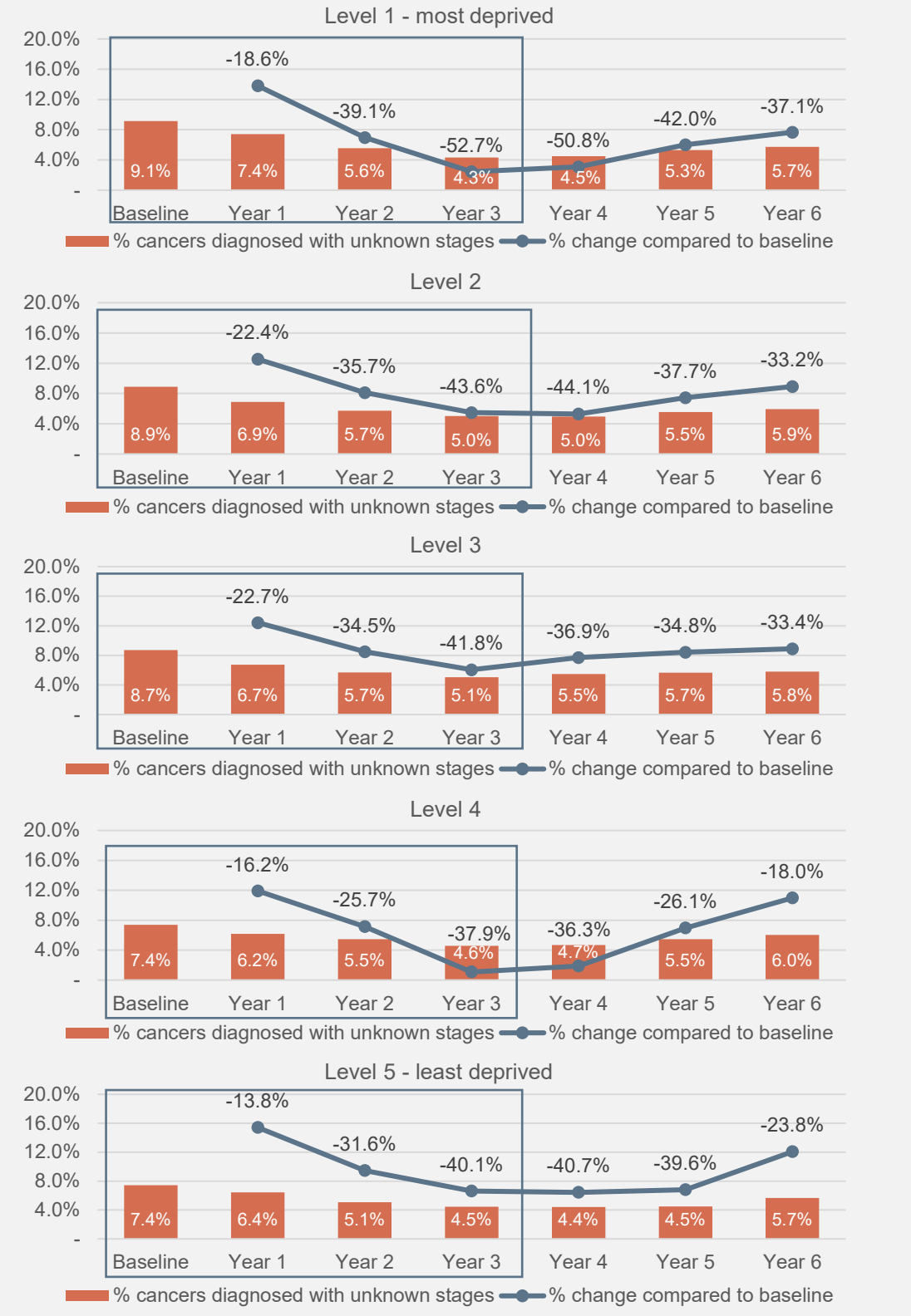



N(%) cancers diagnosed with unknown stages

| Tumour type | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| 3 cancers combined | 2008 (8.4) | 1669 (6.8) | 1368 (5.5) | 1164 (4.7) | 1195 (4.8) | 1296 (5.3) | 1415 (5.8) |
| Breast | 365 (4.4) | 279 (3.3) | 208 (2.4) | 132 (1.5) | 99 (1.2) | 105 (1.2) | 103 (1.2) |
| Colorectal | 1047 (14.8) | 905 (12.9) | 747 (11.0) | 624 (9.4) | 630 (9.5) | 676 (10.2) | 683 (10.4) |
| Lung | 596 (6.9) | 485 (5.3) | 413 (4.4) | 408 (4.2) | 466 (4.9) | 515 (5.6) | 629 (6.9) |

***Source: created using ISD Scotland data and aggregated tables (442)***

**Figure 7.20.** Unknown stages and % change across deprivation levels




***Source: created using ISD Scotland data and aggregated tables (442)***

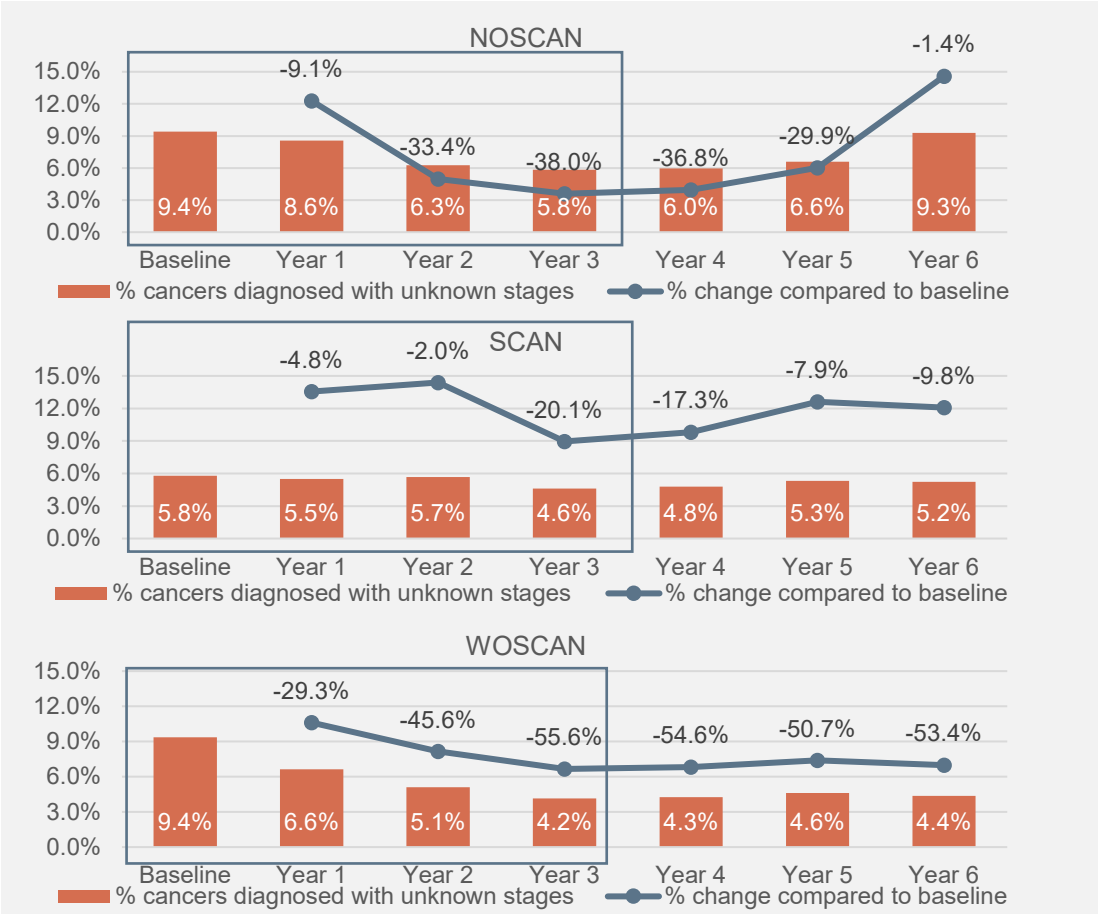
**Table 7.5.** N(%) of cancers diagnosed with unknown stages by deprivation levels

| Deprivation level | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| Level 1 = most deprived | 508 (9.1) | 424 (7.4) | 320 (5.6) | 249 (4.3) | 258 (4.5) | 291 (5.3) | 305 (5.7) |
| Level 2 | 469 (8.9) | 374 (6.9) | 307 (5.7) | 269 (5.0) | 261 (5.0) | 290 (5.5) | 313 (5.9) |
| Level 3 | 407 (8.7) | 322 (6.7) | 274 (5.7) | 246 (5.1) | 271 (5.5) | 276 (5.7) | 277 (5.8) |
| Level 4 | 324 (7.4) | 284 (6.2) | 251 (5.5) | 212 (4.6) | 216 (4.7) | 245 (5.5) | 274 (6.0) |
| Level 5 = least deprived | 293 (7.4) | 260 (6.4) | 212 (5.1) | 186 (4.5) | 188 (4.4) | 192 (4.5) | 244 (5.7) |

***Source: created using ISD Scotland data and aggregated tables (442)***

There were reductions in the proportion of cancers diagnosed with unknown stages across all Cancer Networks (the highest reduction happened for WOSCAN) (Figure 7.21; Table 7.6) (442). Reductions did not occur across all territorial Health Boards (Appendix 34) (442).

**Figure 7.21.** Proportion of unknown stages and % changes by Cancer Networks




***Source: created using ISD Scotland data and aggregated tables (442)***

**Table 7.6.** N(%) of cancers diagnosed with unknown stages by Cancer Networks

| Cancer networks | Baseline N (%) | Year 1 N (%) | Year 2 N (%) | Year 3 N (%) | Year 4 N (%) | Year 5 N (%) | Year 6 N (%) |
|---|---|---|---|---|---|---|---|
| NOSCAN | 552 (9.4) | 504 (8.6) | 374 (6.3) | 347 (5.8) | 361 (6.0) | 413 (6.6) | 568 (9.3) |
| SCAN | 382 (5.8) | 373 (5.5) | 378 (5.7) | 311 (4.6) | 321 (4.8) | 344 (5.3) | 341 (5.2) |
| WOSCAN | 1074 (9.4) | 792 (6.6) | 616 (5.1) | 506 (4.2) | 513 (4.3) | 539 (4.6) | 506 (4.4) |

***Source: created using ISD Scotland aggregated tables (442)***

## 7.8 Objective 8

To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit

There were no available outcome measures to assess this objective. Challenges in assessing DCE objectives are discussed below and in Chapter 10.

## 7.9 Summary of Chapter 7

This Chapter outlines the results from the outcome evaluation, which investigated DCE official objectives using secondary data sources. Several objectives were aspirational, referred to soft outcomes or did not have specific key performance indicators/outcome measures, and there was limited outcome data available. Therefore, it was not always possible to assess whether objectives had been met.

Objective 1 was not met, although a positive increase in the proportion of cancers diagnosed at Stage I was noted overall, for breast and lung cancers, and across all deprivation levels. Conversely, there was a decrease for bowel cancer. Reasons for this are hard to interpret in the absence of relevant data (i.e. staging for cancers diagnosed through screening and through symptomatic presentation; and profile of screening participants). Possible explanations include removal of precancerous polyps through screening, long-term non-responders becoming responders but presenting with late-stage disease, or more patients presenting with symptoms (which often indicate more advanced bowel cancer) (500, 501). These possibilities would need to be checked in further studies. Analyses of other shifts in staging (such as shifts from Stages III and IV to stage II) may be helpful, but these were beyond the scope of this evaluation. Importantly, results show that having a composite performance target can mask variations that may be important when trying to promote early detection for different tumour groups.

Several data sources were used to assess Objectives 2 and 3. It was not possible to note any positive impact on breast screening uptake. In terms of symptomatic breast presentation, results from campaigns showed positive impact on knowledge, awareness of symptoms and intention to act, and likely increase in help-seeking behaviour. ISD Scotland data (450) showed increase in consultations for breast symptoms during the campaign periods. A recent systematic review found that awareness interventions in the UK had a positive impact in both breast screening and self-examinations; this was only partially confirmed for DCE (502). Two important issues would deserve further investigation (beyond the scope of this evaluation). The first is the finding that women more aware of campaigns more often agreed that breast screening carried no risks; the second is the risk of overdiagnosing and overtreating the increasing number of worried well consulting with symptoms.

For colorectal cancer, it is possible that the bowel screening campaigns and the bowel screening initiative have contributed towards the (existing) trends in increase in uptake. There were positive increases for males (who take part in bowel screening less often) and amongst the most deprived (who also have lower participation and present more often with late stage disease) (124). Both groups were specifically targeted by DCE activities. Data showed an increase in requested and returned test kits when different phases of the campaign were launched. The impact of the bowel screening initiative could not be ascertained.

For lung, there were high levels of awareness of the campaign message about the 3-week cough, but also an increase in the proportion of people not wanting to see the GP at all if they noticed small changes. There were very limited outcome data as data on consultations/examinations were not routinely collected for the purposes of the programme. Finally, the 3-year attitudinal tracking showed positive changes in population knowledge/awareness and intention to act, but also persisting challenges regarding prompt help-seeking.

It was not possible to assess the extent to which Objective 4 was met due to limited data on referrals/investigations and the use of NHS resources. Professionals taking part in the education sessions found them useful and planned to share information with work colleagues, but engagement varied across Health Boards. Symptomatic qFIT was found to be a good rule out test for bowel diseases.

Similarly, it was not possible to ascertain to which extent Objective 5 was met. There were (limited) data on increase in workload for the Breast and Bowel Screening

Centres, but there was no information on whether capacity was sufficient (nor on how this could have been measured).

Funding was provided to Health Boards in order to ensure that Objective 6 was met. Data from Health Boards described a wide variety of (positive) soft outcomes, including better communication and more efficient diagnostic processes. However, data were lacking on whether capacity was sufficient to meet demand.

There were clear improvements in data collection, for different tumour types and among the most deprived. These results indicated that Objective 7 was partially met. ISD Scotland acknowledged that increases in the proportion of cancers diagnosed at Stage I were partly due to improvements in data recording (316).

Finally, due to the aspirational, long-term nature of Objective 8, no outcome data were available to assess whether it had been met.

In summary, outcome evaluation results showed that DCE's key aim was not met, and in most cases DCE objectives were partially met. Results should be interpreted with caution due to limited data availability, lack of outcome measures, the descriptive nature of the analysis, and the use of aspirational objectives.

The next two Chapters describe the results from the process evaluation of the DCE programme, in order to shed light how and why objectives were met, not met, or were only partially met.

# Chapter 8 Results: Process evaluation (Questionnaire survey)

## 8.1 Overview

This Chapter describes the results from the questionnaire survey, carried out as part of the process evaluation of the DCE Programme. Interview results are described in Chapter 9. The process evaluation aimed to investigate implementation, mechanisms of impact, barriers and facilitators and unanticipated outcomes. Questionnaire results are organised according to the process evaluation questions, followed by additional issues/themes highlighted by stakeholders.

### 8.1.1 Recruitment

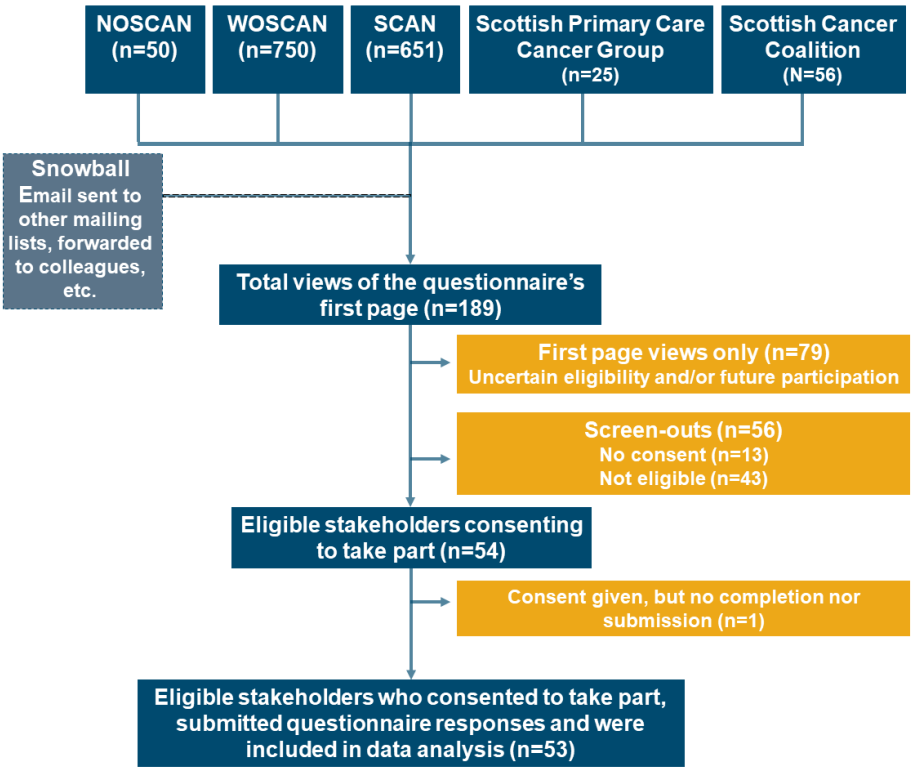
The process evaluation questionnaire is available (Appendix 27). Initial invitations to complete it were sent on the 8th May 2018, except for invitations sent by SCAN (sent on the 11th May 2018 due to operational issues). A reminder email was sent on the 22nd May 2018. The questionnaire was available for completion until the 6th July 2018 (inclusive).

The first page of the online questionnaire was viewed 189 times; 79 of these were first-page views only, before eligibility could be checked and before reaching the informed consent page.

Fifty-six potential participants were screened out of the study; i.e. they either did not consent to take part (n=13) or they ticked the box stating that DCE did not influence their daily work during 2011-2015 and they did not help develop/implement one or more of its activities (n=43).

Fifty-four eligible participants consented to complete the questionnaire, and 53 of them submitted it after completion. All 53 submissions were used for data analysis (Figure 8.1).

**Figure 8.1.** Questionnaire recruitment flowchart




***Abbreviations: NOSCAN, North of Scotland Cancer Network; SCAN, South East Scotland Cancer Network; WOSCAN, West of Scotland Cancer Network***

## 8.1.2 Questionnaire survey results

### 8.1.2.1 Response rates

Response rates were only estimated as it was not possible to accurately determine the denominators; i.e. how many stakeholders were invited, and among these, how many were eligible to take part. The organisations sending the invitation emails provided me with an estimated number of emails sent by them (shown in Figure 8.1). All of them highlighted that some email addresses referred to different organisations or tumour-specific groups, and it was not possible to estimate how many times the invitations were forwarded to others. Based on these estimates, the emails were sent to about 1,532 potentially eligible stakeholders; an estimated 12% (n=189) viewed the questionnaire first page, and 53 completed it (28% of those who viewed the first page and 4% of those who received the email). Therefore, estimates indicate a low response rate. Low response rates can result in non-response bias when there are systematic differences between those who take part and those who choose not to take part in a survey (503). Implications of the low response rate are approached in Chapter 10 (Discussion).

Furthermore, I had aimed for 5% precision (95% confidence level). Across all participants, 40.5% either agreed or strongly agreed that "benefits brought by DCE outweighed the time and effort required to work towards its aims" (after removing those who neither agreed nor disagreed with the statement). Therefore, I would have needed 369 participants (Table 6.3) to reach 5% precision. With 53 participants, the achieved precision was 13.2% instead. Hence, I could be confident that, if I had asked the entire relevant population, 27.3% to 53.7% of them would have chosen this answer. The small sample size and wide confidence intervals indicate larger margins of error/less precision of results obtained from the survey compared to the relevant population. As the planned level of precision was not reached, there is more uncertainty regarding external validity and generalisability. Precision was even lower when considering answers to different questionnaire sections, as participants could skip commenting on a DCE strategy if it was not relevant to them.

#### 8.1.2.2 Questionnaire completion over time

Almost half (45.3%, n=24) of the 53 responses were returned on the invitation and reminder dates (8th May, 11th May and 22nd May). Most questionnaires (90.6%; n=48) were returned in May 2018.

#### 8.1.2.3 Characteristics of questionnaire participants

Most participants were women (59.2%). Mean age was 50.8 (normal distribution; Shapiro-Wilk Test, p=0.481). Most common job roles were secondary (62.7%) and primary care doctors (13.7%). Over three-quarters (75.8%) were involved in/had their work influenced by DCE for at least three years. Most worked in urban areas (73.6%) and hospitals (73.1%) (Table 8.1).

**Table 8.1.** Characteristics of questionnaire participants

| Characteristics | N (%) |
|---|---|
| **Sex** | |
| Men | 20 (40.8) |
| Women | 29 (59.2) |
| *Total* | *49 (100.0)* |
| **Age** | |
| Mean (SD) | 50.8 (5.7) |
| **Age bands** | |
| 35-39 | 1 (2.9) |
| 40-44 | 4 (11.8) |
| 45-49 | 8 (23.5) |
| 50-54 | 11 (32.4) |
| 55-59 | 8 (23.5) |
| 60-64 | 2 (5.9) |
| *Total* | *34 (100.0)* |

| Characteristics | N (%) |
|---|---|
| **Profession** | |
| Medical – secondary care | 32 (62.7) |
| Medical – primary care | 7 (13.7) |
| Nursing | 6 (11.8) |
| Other | 6 (11.8) |
| *Total* | *51 (100.0)* |
| **Cancer type** | |
| Tumour specific | 39 (75.0) |
| Breast | 18 (46.2) |
| Bowel, anal and/or upper GI | 8 (20.5) |
| Lung | 4 (10.3) |
| One tumour type, but not specified | 9 (23.1) |
| More than one tumour type | 13 (25.0) |
| *Total* | *52 (100.0)* |
| **Period programme influenced work** | |
| from pre-implementation to at least the first three years | 14 (42.4) |
| from programme launch to at least the first three years | 11 (33.3) |
| at least 2 years | 4 (12.1) |
| at least one year | 4 (12.1) |
| *Total* | *33 (100.0)* |
| **Territorial Health Board** | |
| NHS Ayrshire and Arran | 9 (17.6) |
| NHS Dumfries and Galloway | 2 (3.9) |
| NHS Fife | 4 (7.8) |
| NHS Forth Valley | 2 (3.9) |
| NHS Greater Glasgow and Clyde | 11 (21.6) |
| NHS Lanarkshire | 3 (5.9) |
| NHS Lothian | 17 (33.3) |
| NHS Tayside | 2 (3.9) |
| Whole of Scotland | 1 (2.0) |
| *Total* | *51 (100.0)* |
| **Urbanisation level** | |
| Large urban areas | 28 (52.8) |
| Other urban areas | 11 (20.8) |
| Accessible small towns | 4 (7.5) |
| Remote rural areas | 2 (3.8) |
| Mix of rural and urban areas | 7 (13.2) |
| Other | 1 (1.9) |
| *Total* | *53 (100.0)* |
| **Workplace** | |
| Hospital | 38 (73.1) |
| Primary Care Practice | 8 (15.4) |
| Diagnostic Centre (not in hospital) | 4 (7.7) |
| Cancer charity | 1 (1.9) |
| Other | 1 (1.9) |
| *Total* | *52 (100.0)* |

***Sums may not add up to 100% due to rounding. Missing data: sex (n=4); age (n=19); profession (n=2); tumour type (n=1); period programme influenced work (n=20); Health Board (n=2); workplace (n=1); other workplace (n=1). Other medical professions included one consultant and one endoscopy lead; 14 participants chose medical as a profession but did not specify any further. Other professions correspond to two audit staff and four respondents who ticked "other" but did not specify. Other urbanisation level (n=1) was not specified; other workplace (n=1) refers to "Board wide"***

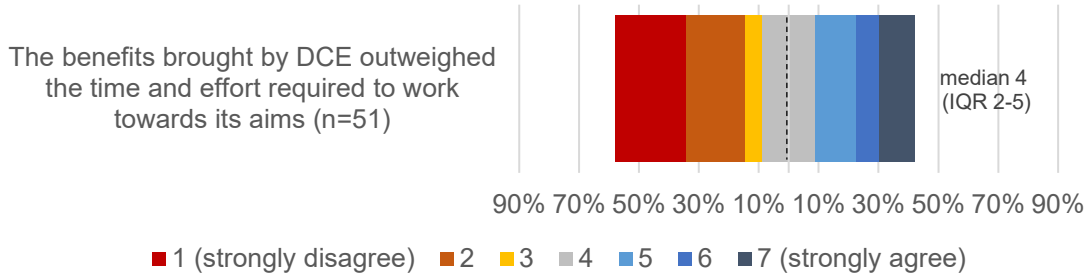
All questionnaire responses are available in Appendix 35 (including for recoded variables used in the analysis); all bivariate analyses are available in Appendix 36. Results are described below according to the process evaluation research questions.

## 8.1.3 Assumptions about programme implementation

### 8.1.3.1 Assumption 1. Different stakeholders bought into DCE, its components and what it proposed to do

Stakeholder views were mixed over whether DCE's benefits outweighed the time and effort required to work towards its aim. Almost a fifth (17.6%, n=9) neither agreed nor disagreed with the statement. About half (49.0%) disagreed to a certain extent (somewhat disagree, disagree or strongly disagree), while 33.3% agreed to a certain extent with the statement (somewhat agree, agree or strongly agree) (Figure 8.2).

**Figure 8.2.** DCE overall acceptability – benefits and costs



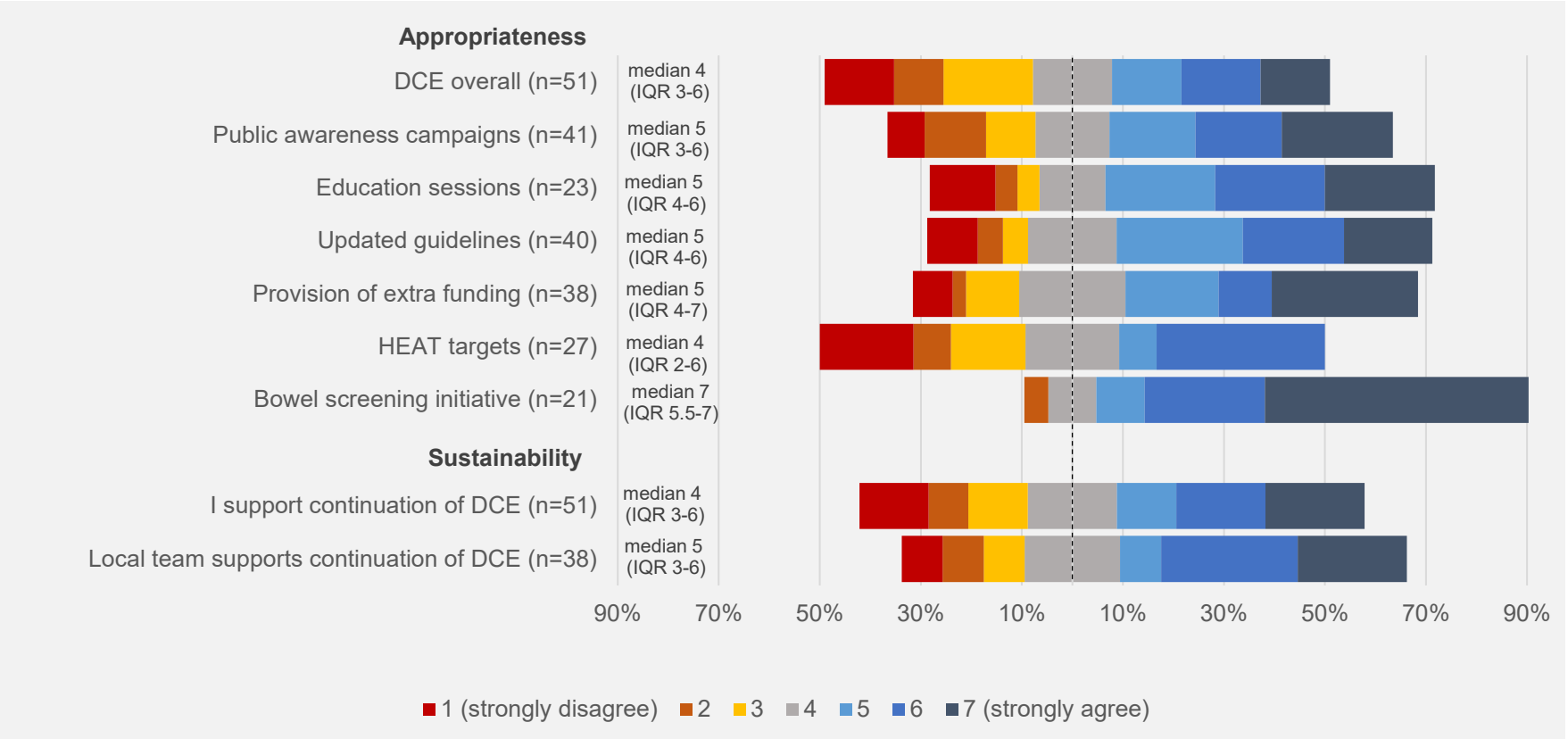

***The higher the median scores, the higher the agreement with the statement (range 1 strongly disagree to 7 strongly agree). Missing data: 2 (don't know)***

Median scores were significantly differently depending on tumour type (H(4)=14.445, p=0.006). Post-hoc tests showed that significant differences were between professionals working with breast cancer compared to those who worked with bowel, anal and/or upper GI cancers (adjusted p=0.017). Those working with breast cancer had lower median scores (indicating lower agreement with the statement).

While 22 participants (43.1%) agreed to a certain extent that DCE was appropriate to promote early detection, 21 (41.1%) disagreed to a certain extent. Perceived appropriateness varied according to DCE strategies (85.7% agreement for the bowel screening initiative, and 40.7% for the HEAT targets) (Figure 8.3).

About half of participants (49.0%) agreed to a certain extent that they supported DCE continuation; the proportion was slightly higher for whether they believed that their team supported DCE continuation (55.3%), although there was considerable missing data for the latter (n=14) (Figure 8.3).

**Figure 8.3.** DCE appropriateness and sustainability




***The higher the median scores, the higher the agreement with the statement. Missing data for appropriateness: DCE overall (n=2; don't know), public awareness campaigns (n=12; 2 don't know, 10 section not applicable); education sessions (n=30; 10 don't know, 14 section not applicable, 6 question not applicable); guidelines (n=13; 5 don't know; 7 section not applicable, 1 question not applicable); provision of extra funding (n=15; 2 don't know, 12 section not applicable, 1 question not applicable); HEAT targets (n=26; 7 don't know, 18 section not applicable,1 question not applicable); bowel screening initiative (n=32; 31 section not applicable; 1 question not applicable). Missing data for sustainability: individual support (n=2, don't know); team support (n=15; 14 don't know, 1 not applicable).***

There were significant variations in responses according to DCE involvement and job role (Box 8.1).

**Box 8.1. Bivariate analysis results: appropriateness**

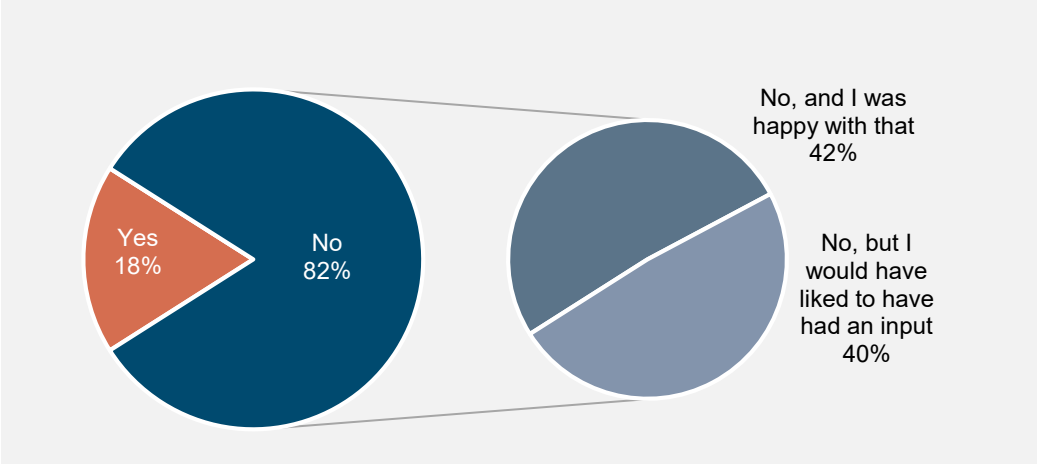
Median scores for appropriateness of DCE and HEAT targets were significantly differently depending on DCE involvement (H(2)=8.191, p=0.017 and H(2)=6.028, p=0.049 respectively). Post-hoc tests showed significant differences between those who were not involved in developing or implementing DCE strategies, but would have liked to have had an input compared to 1) those who were involved (adjusted p=0.047) (DCE appropriateness) and 2) those who were not involved, but were happy with that (adjusted p=0.042) (appropriateness of HEAT targets). In both cases, those who were not involved but wished they had had an input had lower median scores (indicating lower agreement with statements).

Median scores for appropriateness of DCE (H(3)=12.386, p=0.006), of public awareness campaigns (H(3)=8.915, p=0.030), of updated guidelines (H(3)=8.827, p=0.032), and individual support for DCE continuation (H(3)=10.544, p=0.014) also varied significantly according to job role. Post-hoc tests did not provide evidence to elucidate between which pairs of professionals there were significant differences.

#### 8.1.3.2 Assumption 2. There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone

About a fifth of participants (18.0%) were involved in developing and/or refining DCE or its strategies. Among those who were not involved, a similar proportion was either happy not to be involved or would have liked to have had an input (Figure 8.4).

**Figure 8.4.** DCE involvement and wish to have further input (n=50)

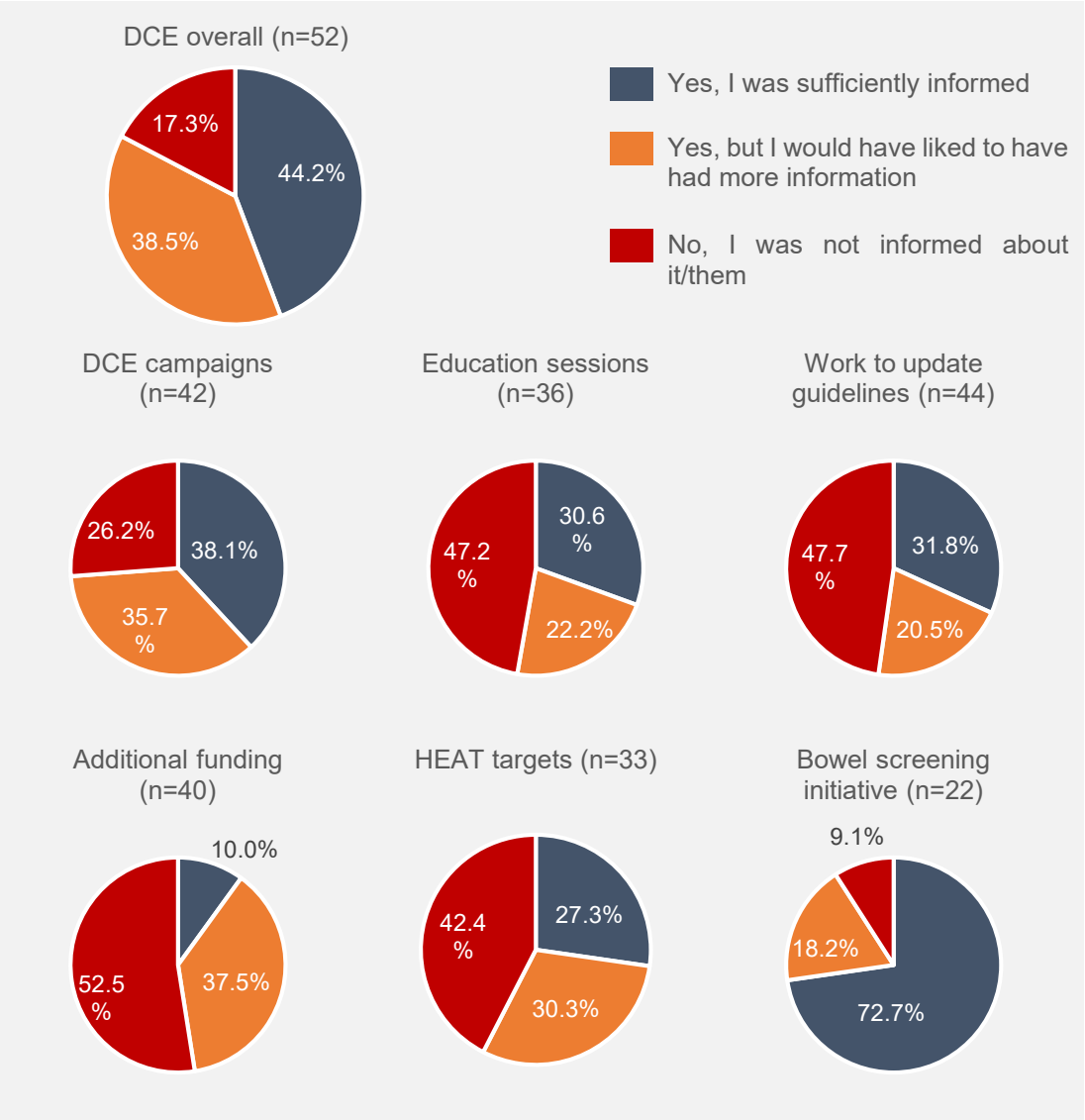



***Missing data: three participants chose "other": one did not specify further, one stated: "not applicable as was still in training"; another wrote "my colleague was involved in implementation, so I heard by word of mouth and from tv adverts".***

In terms of receiving information prior to DCE launch/implementation, most participants (72.7%) reported being sufficiently informed about the bowel screening initiative. A minority reported having been sufficiently informed about extra funding

(10.0%). A substantial proportion of participants would have liked to have received more information about DCE and its components (38.5%), especially about additional funding (37.5%), the public awareness campaigns (35.7%) and the HEAT targets (30.3%) (Figure 8.5).

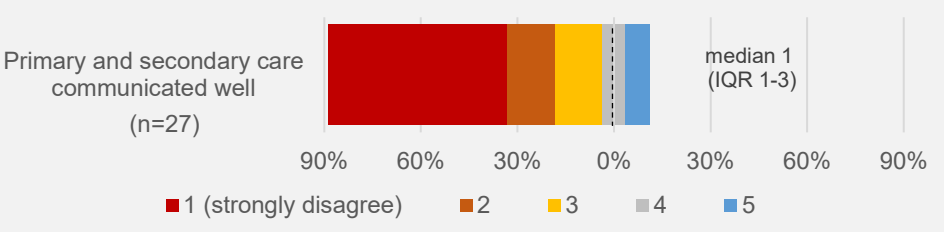
**Figure 8.5.** Information about DCE and its strategies before implementation




***Missing data: DCE overall (n=1; other); public awareness campaigns (n=11, 1 other, 10 section not applicable); education sessions (n=17; 3 other, 14 section not applicable); work to update guidelines (n=9, 2 other, 7 section not applicable); provision of extra funding (n=13, 1 other, 12 section not applicable); HEAT targets (n=20, 2 other, 18 section not applicable); bowel screening initiative (n=31, section not applicable)***

When asked about communication between primary and secondary care regarding how to use DCE funding, over half (55.6%) strongly disagreed that communication went well (85.2% disagreed to a certain extent) (Figure 8.6).

**Figure 8.6.** Communication between primary and secondary care




***The higher the median score, the higher the agreement with the statement. Missing data: n=26 (10 don't know; 4 question not applicable, 12 section not applicable)***

There were significant variations in responses according to tumour type and job role (Box 8.2).

**Box 8.2. Bivariate analysis results: communication**

Professionals working with more than one tumour type were significantly more likely to report being sufficiently informed about DCE campaigns (p=0.004, FET) and the bowel screening initiative (p=0.016, FET) compared to professionals working with a single tumour type.

Secondary care doctors were significantly less likely to report being sufficiently informed about education sessions (p=0.036, FET), referral guidelines (p=0.001, FET), and additional funding (p=0.002, FET) compared to GPs, nurses and other professionals.

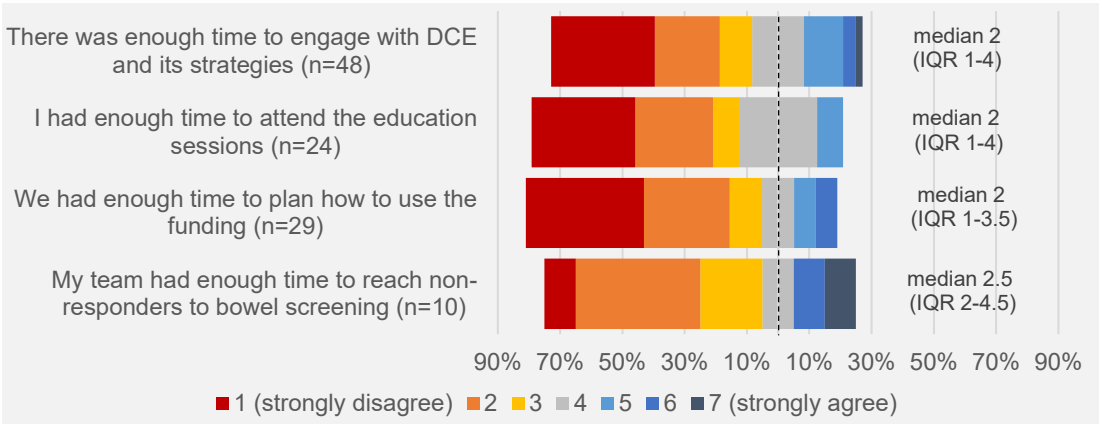
Professionals involved in developing DCE (overall) were significantly more likely to report being sufficiently informed about the referral guidelines (p=0.009, FET) compared to those not involved in developing the programme.

Median scores for question about whether communication between primary care and secondary care went well varied according to professional roles (H(3)=9.686, p=0.021). Post-hoc tests comparisons showed significant differences between secondary care doctors and nurses (adjusted p=0.028). Secondary care doctors had lower median scores, indicating lower agreement with the statement.

#### 8.1.3.3 Assumption 3. Available resources were sufficient to meet aims (focusing on time)

Most participants (64.5%) disagreed to a certain extent that there was enough time to engage with DCE and its strategies (Figure 8.7).

**Figure 8.7.** Sufficiency (time)




***The higher the median scores, the higher the agreement. Missing data: DCE and its strategies (n=5, 2 don't know, 3 question not applicable); education sessions (n=29; 3 don't know, 12 question not applicable and 14 section not applicable); funding (n=24; 6 don't know, 6 question not applicable and 12 section not applicable); reach non-responders (n=43; 4 don't know, 8 section not applicable and 31 section not applicable)***

Median scores for questions regarding time varied significantly by tumour type and involvement in DCE (Box 8.3).

**Box 8.3. Bivariate analysis results: sufficiency**

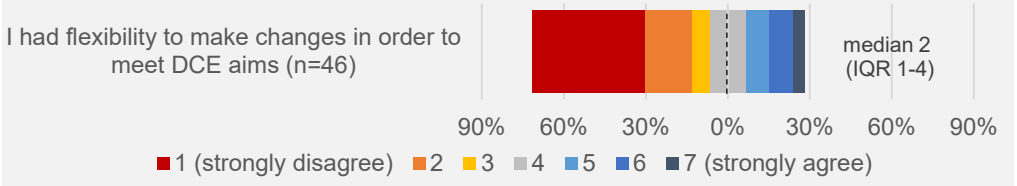
Median scores for the question on whether there was enough time to engage with DCE and its activities varied according to tumour type (H(4)=13.051, p=0.011), job role (H(3)=8.484, p=0.037) and involvement in DCE development (H(2)=6.925, p=0.031). Post-hoc tests to test pairwise comparisons showed:

- significant differences between those working with breast cancer and those working with more than one tumour type (adjusted p=0.031), with lower median scores for the former
- no significant differences between any pairs of job roles
- significant differences between those who were not involved in developing DCE but wished they had had an input and those who were involved in DCE development (adjusted p=0.040), with lower median scores for the former

#### 8.1.3.4 Assumption 4. Flexibility was permitted when allocating resources

Regarding DCE overall, most participants (65.2%) disagreed to a certain extent that they had flexibility to make changes in order to meet DCE aims (Figure 8.8).

**Figure 8.8.** Flexibility to make changes in order to meet aims




***The higher the median score, the higher the agreement with the statement. Missing: n=7; 3 don't know, 4 question not applicable***

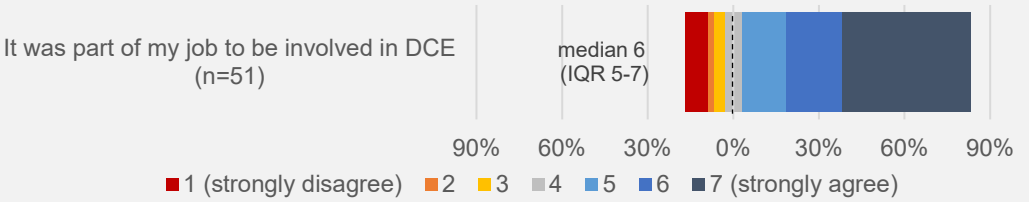
Median scores varied significantly according to job role (H(3)=9.795, p=0.020). Post-hoc tests showed that there were significant differences between secondary care doctors and nurses (adjusted p=0.026), with lower median scores for the former (indicating lower agreement with the statement).

## 8.1.4 Mechanisms of impact

### 8.1.4.1 Mechanism 1. DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries

Most participants (77.4%) agreed to a certain extent that it was part of their job to be involved in the DCE Programme (Figure 8.9). There were no statistically significant variations across groups.

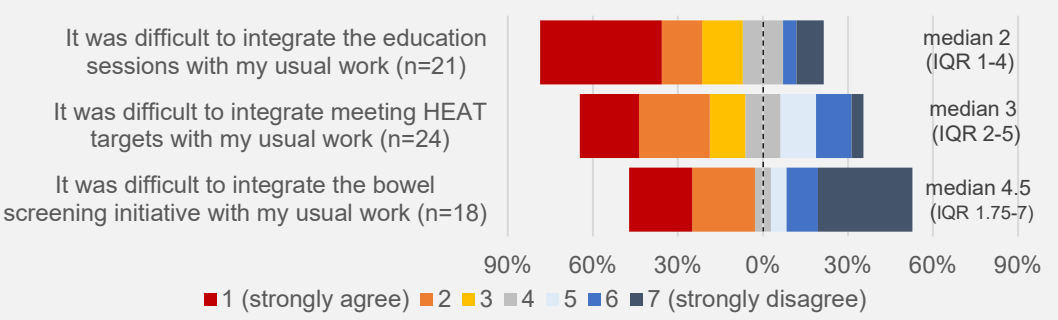
**Figure 8.9.** DCE and the professionals' role




***The higher the median scores, the higher the agreement with the statement. Missing data: n=2 (1 don't know, 1 not applicable)***

When asked about integrating DCE components into their usual work, most participants (86.8%) stated that it was difficult to do so to a certain extent. Challenges were particularly evident for the education sessions (71.4%), and less so for the bowel screening initiative (44.0%) (Figure 8.10). There were no statistically significant relationships.

**Figure 8.10.** Challenges integrating DCE components into usual work

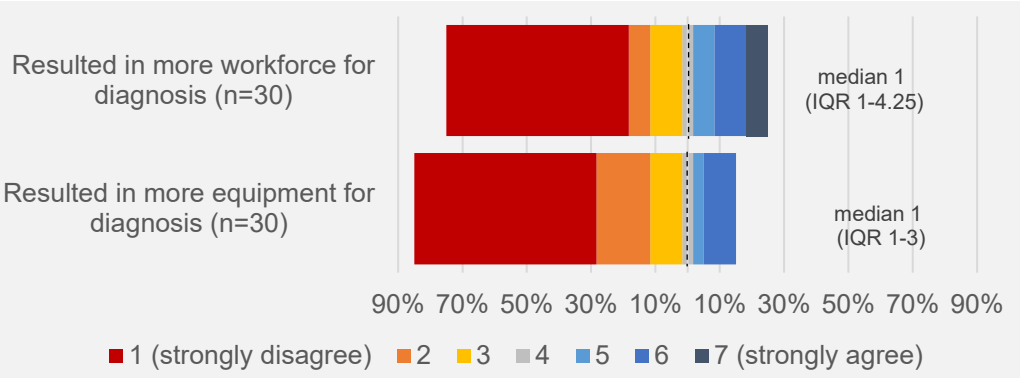



***Low median scores indicate stronger agreement that it was difficult to integrate DCE components into usual work. Missing data: education sessions (n=32; 5 don't know, 13 question not applicable, 14 section not applicable); HEAT targets (n=29; 8 don't know, 3 question not applicable, 18 section not applicable); bowel screening initiative (n=35; 4 question not applicable, 31 section not applicable)***

#### 8.1.4.2 Mechanism 2. Additional DCE funding resulted in more diagnostic equipment and/or workforce

Most participants disagreed to a certain extent that additional funding resulted in more diagnostic equipment (83.4%) and workforce (73.4%) (Figure 8.11).

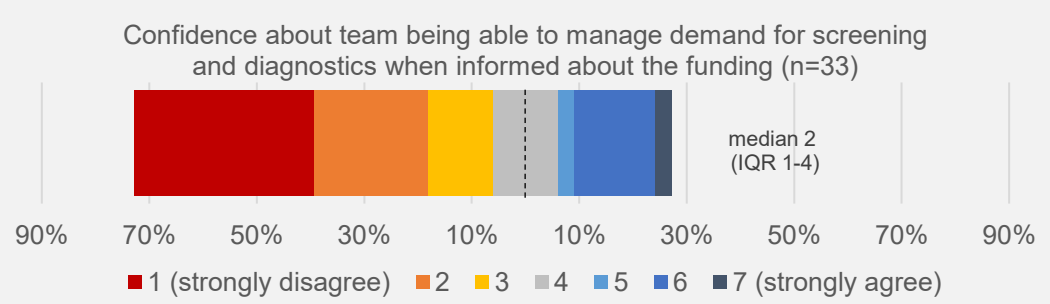
**Figure 8.11.** Additional funding




***The higher the median scores, the higher the agreement with the statement. Missing data: n=23 for each; 9 don't know, 2 question not applicable, 12 section not applicable***

Most (66.6%) also disagreed to a certain extent that they were confident about their ability to manage demand when informed about additional funding (Figure 8.12).

**Figure 8.12.** Confidence about being able to manage demand




***The higher the median scores, the higher the agreement with the statement. Missing data: (n=20; 4 don't know, 4 question not applicable, 12 section not applicable).***

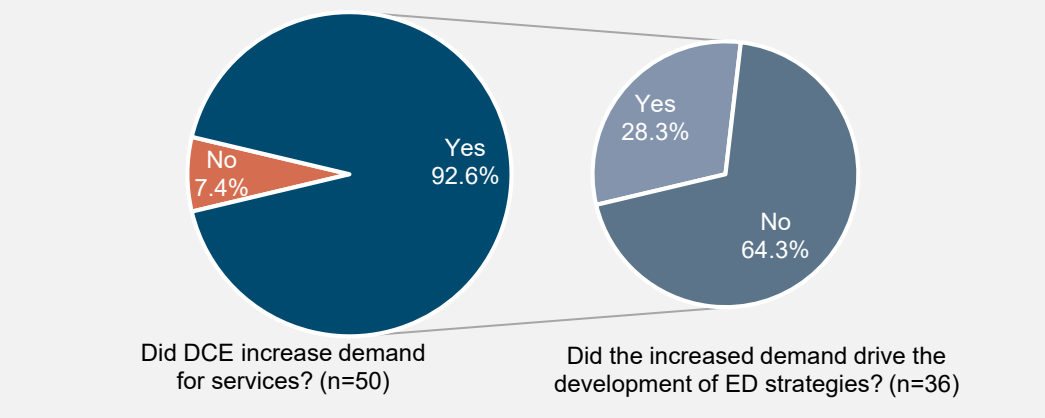
There were significant variations depending on job role and tumour type (Box 8.4)

| Box 8.4. Bivariate analysis results: funding |
|---|
| Median scores for the question about additional funding resulting in more equipment for diagnosis varied across job role (H(3)=9.942, p=0.019) and tumour type (H(4)=10.096, p=0.039). Post-hoc tests showed:<br>- significant differences between secondary care doctor and nurse (adjusted p=0.024), with lower median scores for the former<br>- no significant differences between any pairs of tumour types<br>Median scores for the question on whether stakeholder was confident about the team being able to manage demand varied according to job role (H(3)=8.875, p=0.031) – post-hoc tests did not find significant differences between any pairs of job roles |

#### 8.1.4.3 Mechanism 3. Increased demand brought by DCE was a driver for action and created pressure to act

When asked about the programme overall, most participants (92.6%) stated that DCE increased demand for services. The majority of them also reported that the increased demand did not drive the development of early detection strategies (Figure 8.13)

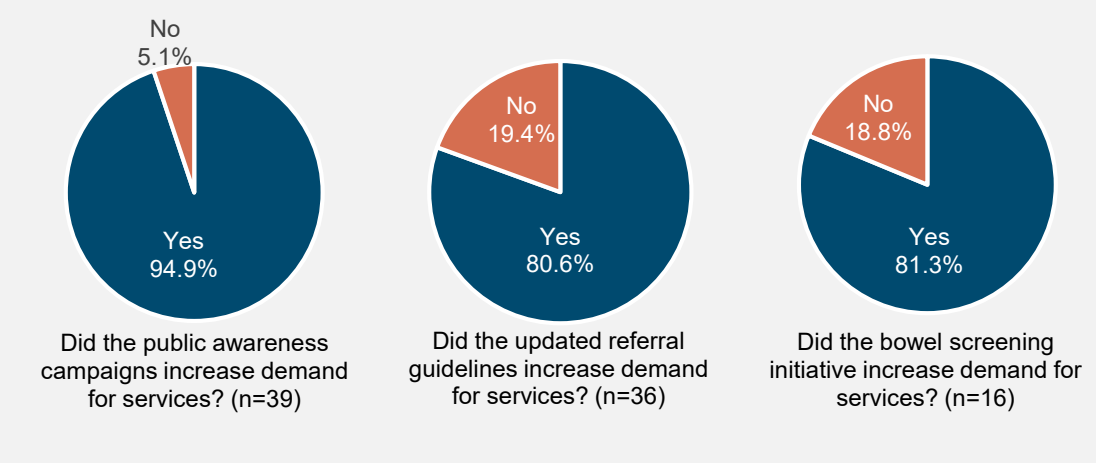
**Figure 8.13.** Whether DCE increased demand for services




***ED: early detection. Missing data: whether DCE increased demand (n=3, 1 don't known, 2 question not applicable), whether increased demand led to development of strategies (n=17; 1 other, 1 don't know, 6 question not applicable, 1 no response).***

Similarly, most participants stated that the awareness campaigns (94.9%), the updated referral guidelines (80.6%) and the bowel screening initiative (81.3%) increased demand for services (Figure 8.14). There were no statistically significant relationships.

**Figure 8.14.** Whether DCE activities increased demand for services

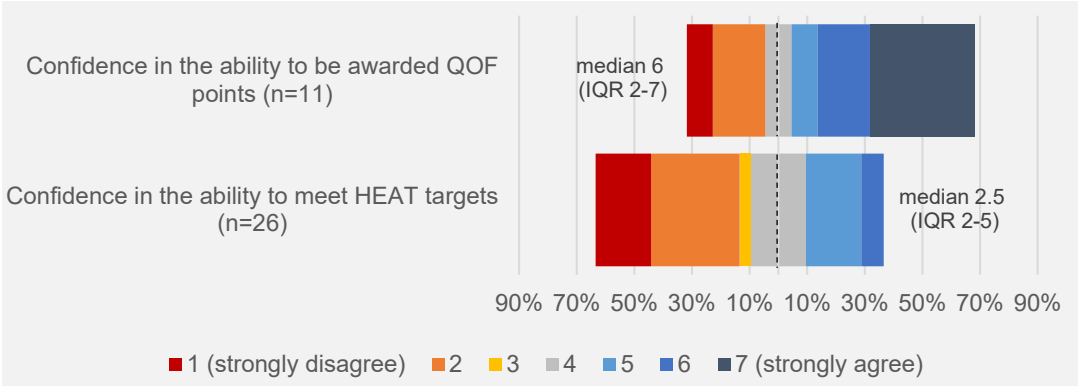



***Missing data: awareness campaigns (n=14; 1 don't know, 3 question not applicable, 10 section not applicable); updated referral guidelines (n=17; 8 don't know, 2 question not applicable, 7 section not applicable); and bowel screening initiative (n=37; 3 don't know, 3 not applicable, 31 section not applicable.***

#### 8.1.4.4 Mechanism 4. Targets helped to focus the mind, showed where resources were needed and increased pressure to act

Most participants (63.7%) agreed to a certain extent that they were confident in their ability to meet QOF targets. The situation was different for the HEAT targets (53.8% disagreed to a certain extent) (Figure 8.15).

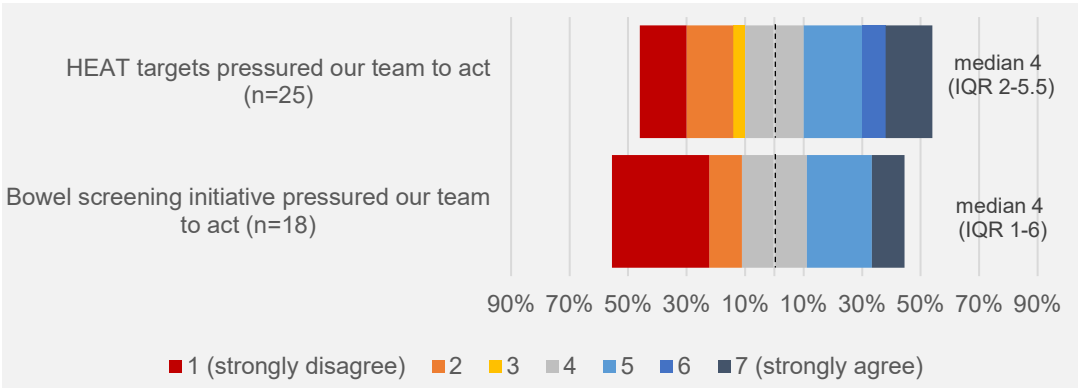
**Figure 8.15**. Confidence in the ability to meet targets




***The higher the median scores, the higher the agreement with the statement. Missing data: confidence in the ability to be awarded QOF points (n=42; 4 don't know, 7 question not applicable, 31 section not applicable); confidence in the ability to meet HEAT targets (n=27; 7 don't know, 2 question not applicable, 18 section not applicable)***

Views were less contrasting for whether targets pressured the team to act, with the same median scores for the HEAT targets and the bowel screening initiative (Figure 8.16)

**Figure 8.16.** Pressure to act

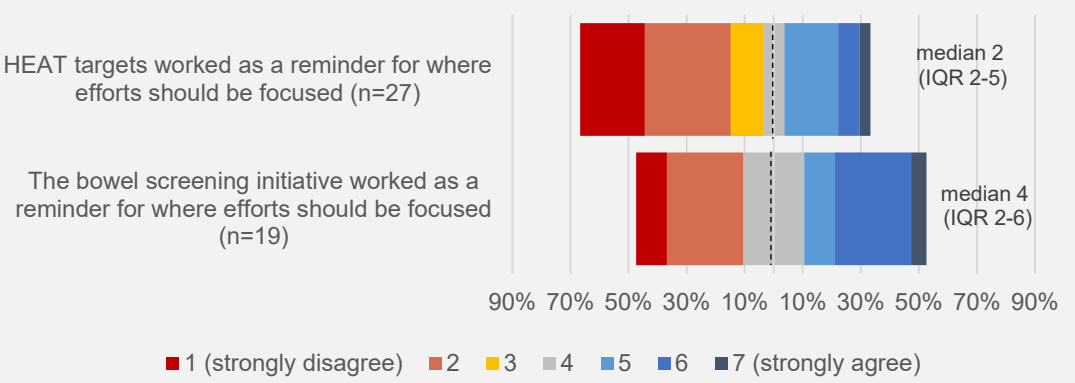



***The higher the median scores, the higher the agreement with the statement. Missing data: HEAT targets pressured team to act (n=28; 8 don't know, 2 question not applicable, 18 section not applicable); bowel screening initiative pressured team to act (n=35; 1 don't know, 3 question not applicable, 31 section not applicable)***

Finally, most participants (62.9%) disagreed to a certain extent with the statement that HEAT targets worked as a reminder for where efforts should be focused. The

proportion was much lower (36.8%) for the bowel screening initiative, with 41.3% of participants agreeing with the statement to a certain extent (Figure 8.17).

**Figure 8.17.** Reminder on where to focus efforts




***The higher the median scores, the higher the agreement with the statement. Missing data: HEAT targets worked as a reminder (n=26; 6 don't know, 2 question not applicable, 18 section not applicable), bowel screening initiative worked as a reminder (n=34; 1 don't know, 2 question not applicable, 31 section not applicable)***

## 8.1.5 Content analysis

Over two-thirds of questionnaire participants (n=37) completed one or more open-ended questions (median 4 comments per participant; range 1-16 comments per participant). There were 175 comments, and all were included in the content analysis (Table 8.2).

**Table 8.2.** Themes derived from content analysis

| | Themes | N |
|---|---|---|
| Question 1 | A1: Stakeholder buy-in | |
| | Confirmed by stakeholders | 15 |
| | Not confirmed by stakeholders | 48 |
| | A2. Enough targeting and communication | |
| | Confirmed by stakeholders | 9 |
| | Not confirmed by stakeholders | 35 |
| | A3. Available resources were sufficient to meet aims | |
| | Not confirmed by stakeholders | 17 |
| | A4. Flexibility when using resources | |
| | Confirmed by stakeholders | 1 |
| | Not confirmed by stakeholders | 10 |
| Question 2 | M1. DCE in line with the professionals' role and organisational commitment | |
| | Not confirmed by stakeholders | 2 |
| | M2. Additional DCE funding resulted in more diagnostic equipment/workforce | |
| | Confirmed by stakeholders | 5 |
| | Not confirmed by stakeholders | 23 |
| | M3. Increased demand was a driver for action and created pressure to act | |
| | Confirmed by stakeholders | 7 |
| | M4. Targets helped to focus the mind and increased pressure to act | |
| | Not confirmed by stakeholders | 5 |

| | Themes | N |
|---|---|---|
| Question 3 | Barriers | |
| | NHS challenges (recruitment challenges, stretched resources) | 11 |
| | Early detection challenges (overdiagnosis, overtreatment, fear, poor awareness) | 8 |
| | Competing responsibilities not being recognised | 3 |
| | Facilitators | |
| | Consistency in data recording, good quality data, digital data for bowel screening | 3 |
| | Good leadership, management and teamwork | 2 |
| | Ability to plan for changes and demand | 2 |
| | Having an open, transparent process and 'attempt' to share learning | 1 |
| | Having an effective screening method (bowel) | 1 |
| Question 4 | Unanticipated outcomes | |
| | Negative impact for other patients in need of care and for other performance targets | 14 |
| | Inappropriate referrals | 9 |
| | Negative impact for professionals (stress, burn-out and anxiety) | 3 |
| | Fears of over diagnosing the worried well | 3 |
| | Cancers being diagnosed at later stages instead of earlier | 3 |
| Additional themes | References to DCE official outcomes | |
| | Comments on official DCE objectives perceived to be met | 13 |
| | Comments on positive service changes brought by DCE | 2 |
| | Comments on how DCE did not lead to positive service changes | 15 |
| | Comments on how DCE did not result in more cancers being diagnosed | 14 |
| | Views on other DCE processes not covered by assumptions and mechanisms | |
| | Impact on service provision and workload | 46 |
| | Increasing numbers of worried well seeking reassurance | 17 |
| | Limited planning (e.g. not estimating impact nor considering other intervals in the pathway) | 14 |
| | Recommendations | |
| | Better planning, more time to plan and better communication | 11 |
| | Target different tumour types or population groups | 8 |
| | Focus on breast screening as it is effective; symptoms indicate late disease | 5 |
| | Consider the whole cancer pathway, have diagnostic clinics and direct GP access to diagnostics | 5 |
| | Review the HEAT targets (e.g. use a QI approach instead) | 3 |
| | Have ongoing campaigns instead of short bursts of activity | 2 |
| | Other (HPV vaccination for anal cancer; more professional education) | 2 |
| | Other | |
| | References to previous questions, statements about questions not being applicable, feedback to the researcher | 12 |

***As one comment may refer to more than one theme, sums add up to more than 175.***

Open-ended comments provided further evidence on investigated assumptions and mechanisms. Furthermore, they provided evidence on barriers and facilitators, unanticipated outcomes and other process issues.

#### 8.1.5.1 Content analysis: implementation assumptions

Elicited implementation assumptions were more often not confirmed by stakeholders. Comments shed light on the reasons why views on DCE appropriateness and sustainability were mixed. Stakeholders stated that although they agreed with DCE's premise of promoting early detection, raising public awareness and educating professionals, there were several DCE approaches perceived not to be appropriate

(such as the focus on breast symptoms or the targeted tumour types). Other criticisms referred to campaigns with timings coinciding with other awareness events and reaching populations with a very low cancer risk. In terms of sustainability, one participant stated that DCE remained in their cancer strategy, another argued that non-recurring funding was “fairly pointless” as a long-term strategy, and others believed that changes needed to be made so the programme was accepted in the long-term.

Closed-ended questions highlighted that a substantial proportion of stakeholders would have liked to have had more input about the programme, and levels of information varied according to different DCE strategies. Comments also referred to the ability to give input. Participants appreciated when experts were heard and complained about not being asked for their views, and about giving their input and not having it considered. Others complained about not being fully informed about DCE, the scale of the campaigns and their likely impact, or about delays in receiving information. Some were not aware of the education sessions for GPs, the HEAT targets, nor the additional funding provided. Three participants did not know that DCE had continued after 2015. Concerns about now knowing about DCE outcomes were also common. Those who started working when DCE was already ongoing complained about challenges regarding handover.

There was only one closed-ended question about assumption 3 (DCE resources being sufficient to meet aims), and it focused on the professional’s time (with most disagreeing that time was sufficient). Comments, on the other hand, focused on workforce and physical resources. Stakeholders emphasised that existing resources were limited and stated that DCE stretched resources to maximum or unsustainable levels (with the service “near to collapse”). Some areas ran evening and weekend clinics to “get things back under control”, with perceived impact on services and staff’s wellbeing, often without extra resources to deal with demand.

Finally, closed-ended questions showed that most stakeholders disagreed that they had flexibility to make changes in order to meet DCE aims. Comments highlighted several complaints from areas reported to having received no funding in different Health Boards (including endoscopy, pathology, staff at the “shop floor”, symptomatic breast screening, primary care and other clinical teams). One stakeholder reported to be pleased that funding could be used in line with their local work. Illustrative quotes for implementation assumptions are shown in Figure 8.18.

**Figure 8.18.** Illustrative quotes: implementation assumptions

| Assumption 1 | Assumption 2 |
|---|---|
| "DCE is an excellent concept - raising public awareness of early cancer signs is good; primary health care worker education is important" Secondary Care Doctor, NHS Fife<br>"Breast and colorectal cancer have screening programmes already. Lung cancer is largely related to smoking and that should be the target for campaigns" Secondary Care Doctor (Pathologist), Health Board not specified | "Public campaign raising lung cancer awareness: DCE team listened to expert advice on how to approach this group of patients" Secondary Care Nurse, NHS Greater Glasgow & Clyde<br>"I was given the option to feed in, but it didn't seem to affect the outcome" GP, NHS Tayside<br>"It was forced upon us with no discussion" Job role and Health Board not specified |
| **Assumption 3** | **Assumption 4** |
| "We were expected to absorb a significant increase in demand into already stretched capacity" Secondary Care Doctor (Pathologist), Health Board not specified<br>"There was no thought re. what the current service was able to deliver" Secondary Care Doctor, NHS Forth Valley | "From where I was positioned (as a GP) it increased demand and pressure with no extra resources. Waiting times went up, and it is not clear anything was gained" GP, NHS Tayside<br>"Now that we can take the funding and target it in line with our programme it can be put to good use" Allied Health Professional (Breast Diagnostic Centre not in Hospital), NHS Lothian |

#### 8.1.5.2 Content analysis: mechanisms

Elicited mechanisms were often not confirmed by stakeholders in open-ended comments.

Results from closed-ended questions showed how professionals often agreed to a certain extent that it was part of their job to be involved in the DCE Programme, but there were issues when integrating DCE components into usual work. Comments highlighted the role of competing responsibilities, and the fact that the HEAT target was not a clinical measure.

In closed-ended questions stakeholders reported disagreement with the statement that funding resulted in more equipment and workforce and were often not confident about their ability to manage demand. Most comments referred to not being aware of funding, or to funding not being sufficient (especially in a scenario where qualified professionals were not available). However, two stakeholders reported cases in which funding provided benefits; one of them stated that the "funding rightly ensured that diagnostics were sufficient".

Similar to closed-ended questions, stakeholder comments highlighted that DCE increased demand for services. Comments also highlighted how DCE drove action. Increase in demand led to recruitment of specialist staff and training of non-medical

staff to perform colonoscopies; and stimulated focus on diagnostic capacity. However, demand also led to increased waiting times and stress, although at times the experience was used to make changes to improve services.

Finally, comments reiterated disagreement with the role of targets. Stakeholders argued that external targets were not needed as they already knew where "efforts should be focussed". HEAT targets were described as "unhelpful", "unrealistic", and requiring review, and different approaches were suggested. Illustrative quotes for mechanisms of impact are available (Figure 8.19).

**Figure 8.19.** Illustrative quotes: mechanisms of impact

| Mechanism 1 | Mechanism 2 |
|---|---|
| "These are strategic public health measures not clinical" Secondary Care Doctor (Endoscopy Lead), NHS Fife | "How can you get more workforce when there are hundreds of consultant (and other staff vacancies). Completely different planet the DCE group live in". Secondary Care Doctor, NHS Forth Valley |
| **Mechanism 3** | **Mechanism 4** |
| "As a Board we had to focus our attention on ensuring capacity to meet potential increase in demand" Secondary Care Nurse, NHS Tayside | "We know where our efforts should be focussed, without external targets" Medical Radiologist, NHS Lanarkshire |

#### 8.1.5.3 Barriers and facilitators

Barriers and facilitators were only approached in open-ended questions. Stakeholders acknowledged that stretched diagnostic capacity and limited workforce pre-dated DCE. Persisting early detection challenges such as cancer fear, lack of knowledge and/or awareness among more deprived communities, over investigations and overdiagnosis were also mentioned. Some recognised that "there is NOT a one size fits all for cancer".

Having good quality data, being consistent when recording cancer staging data and having electronic results for bowel screening were some of the facilitators described by participants. Having a designated lead and receiving advice about the programme early on, good teamwork, and being able to plan and share learning were also highlighted. One participant referred to the fact that bowel screening was an evidence-based early detection method (Figure 8.20).

**Figure 8.20.** Illustrative quotes: barriers and facilitators

| Barriers | Facilitators |
| --- | --- |
| "Reminder! We have other targets that DCE have never considered and are as important" Secondary Care Doctor, NHS Forth Valley<br>"Workforce issues in diagnostics are the single largest stumbling block; this cannot happen overnight or even in a few months" Secondary Care Doctor, NHS Fife<br>"Overdiagnosis is another major issue with many cancers" Secondary Care Doctor (Colorectal Surgeon), NHS Lothian | "Electronic results were extremely helpful, it meant that they were filed straight into the patient's notes without the need for extra admin processes" GP, NHS Lanarkshire<br>"Having a designated lead, taking the time to find out our priority areas and having an open and transparent process for identifying funding priorities. Attempting to share the learning. Being consistent about the recording of staging" Secondary Care Nurse, NHS Tayside |

#### 8.1.5.4 Unanticipated outcomes

Participants referred to increasing numbers of "inappropriate referrals" attributed to reasons driven by DCE: both following/not following referral guidelines; the worried well seeking reassurance from professionals; and GPs' attempts to get patients seen quickly. Consequences described included delays for patients requiring surveillance or patients with cancer, and impact on other performance targets. There were also reports on negative impact on staff well-being (including stress and burn-out). Some participants raised concerns about overdiagnosing the worried well. Finally, some stated that the symptomatic approach for breast cancer led to patients presenting at later instead of earlier stages (Figure 8.21).

**Figure 8.21.** Illustrative quotes: unanticipated outcomes

| Unanticipated outcomes |
| --- |
| "DCE resulted in very large numbers of women who had nothing wrong with them asking to be referred [...] This in fact hindered access to breast services for patients with breast cancer" Secondary Care Doctor (Surgeon), NHS Greater Glasgow and Clyde<br>"The increase in demand caused major impact on the resource that was available at the time, this led to increased stress levels for those on the front line leading to burn out for staff and consequently poorer service for those requiring care" Secondary Care Nurse, NHS Forth Valley |

#### 8.1.5.5 Other issues raised by questionnaire participants

Open-ended comments also referred to issues not covered by the investigated assumptions and mechanisms. Stakeholders highlighted not being aware of changes brought by DCE and wished to know more about its outcomes. Many stated that DCE did not result in more cancers being diagnosed earlier; some reported that they did

not see any changes in practice. Some stated that planning on how to deal with DCE impact was limited or underestimated and complained about DCE's impact on workload (Figure 8.22).

**Figure 8.22.** Illustrative quotes: views on DCE outcomes and other process issues

| Views on DCE outcomes | Other process issues |
|---|---|
| "I would like to see results of the impact, and additional work associated with, the DCE programme" Secondary Care Doctor (Radiologist), NHS Lanarkshire<br>"Did not diagnose any more cancers during this time. Extra work, no extra cancers" Secondary Care Doctor, NHS Fife | "Our symptomatic breast service has never really recovered" Secondary care Doctor (Breast Surgeon), NHS Greater Glasgow & Clyde<br>"At the outset the planners failed to anticipate the need to know the mode of referral i.e. screening versus symptomatic, and this had to be added to the required data fields at a later date". Audit staff in Hospital, NHS Lothian |

Finally, stakeholders provided a range of recommendations. These included more planning (with better communication and multidisciplinary discussions), early advice about DCE initiatives and more time to prepare bids for funding. Some recommended focusing on breast screening, others suggested DCE focused on tumour types for which there were no screening programmes or for which there was a "greater chance of influencing behaviour" (no examples were given). Some suggested targeting patients at risk of lung cancer (e.g. "annual low dose CT of the chest for smokers" or having "direct access for GP to CTs"). Others recommended targeting more deprived populations through education and information. Two participants recommended that a QI approach replaced the HEAT targets. One participant recommended the establishment of a clinic for patients with vague symptoms, while others commented on the importance of looking at the whole cancer pathway (Figure 8.23).

**Figure 8.23.** Illustrative quotes: recommendations

| Recommendations |
|---|
| "Money could have been better spent in education of poorer socioeconomic areas where screening uptake is low and patients present late with symptom." Secondary Care Doctor (Radiologist), NHS Greater Glasgow & Clyde<br>"This is essential - the launch of DCE should be filtered to all teams in advance and additional clinics planned for." Secondary care Doctor (Breast Cancer), NHS Fife |

## 8.2 Summary of Chapter 8

This chapter described the results from the questionnaire survey, one of the components of the DCE profess evaluation. Key findings are summarised below.

### 8.2.1 Implementation assumptions

Stakeholder buy-in varied according to DCE strategies, with the bowel screening initiative seen more positively compared to other DCE strategies. Support for DCE continuation was limited. Involvement in programme development was associated with stakeholder buy-in. Nonetheless, a substantial proportion of stakeholders was happy not to be involved.

Perceived sufficiency of information varied according to DCE strategies. There was often disagreement with the statement that communication went well between primary and secondary care when using funding, with secondary care doctors showing higher levels of disagreement. Those working in secondary care also more often reported not being sufficiently informed about DCE strategies.

Stakeholders often disagreed that time was sufficient to engage with the programme. Those who wished they had had further input in DCE had higher levels of disagreement about time being sufficient. Comments highlighted that there were also issues regarding limited resources and workforce.

Most stakeholders disagreed about having flexibility on how to use funding, with secondary care doctors having higher levels of disagreement compared to nurses.

### 8.2.2 Mechanisms of impact

Stakeholders often agreed that it was part of their role to be involved in the programme. However, they also often disagreed that it was easy to integrate DCE components into their usual work and reported on competing responsibilities.

There was often disagreement that additional funding resulted in more diagnostic capacity. Comments indicated that funding did not reach all relevant areas or departments. Secondary care doctors had higher levels of disagreement with the statement that funding was sufficient (compared to nurses). A substantial proportion of stakeholders disagreed they were confident about being able to manage demand.

There was agreement that DCE increased demand for services, but this did not necessarily drive the development of early detection strategies. Impact on workload was often described as a negative experience.

Stakeholders were more confident about their ability to meet targets for the bowel screening initiative compared to HEAT targets. Views were mixed over whether targets pressured the team to act. There was often disagreement that HEAT targets reminded professionals of where efforts should be focused.

### 8.2.3 Barriers and facilitators, and unanticipated outcomes

Shortage of professionals, competing responsibilities and persisting early detection challenges were some of the barriers mentioned. Facilitators included good quality data, good IT resources, good management and early planning.

Unanticipated outcomes included delays for other patients, impact on performance targets, risk of overdiagnosis, patients presenting late instead of early, and stress and anxiety for professionals.

### 8.2.4 Other issues raised by stakeholders

Stakeholders reported wanting to know more about DCE outcomes. They also described additional process issues (such as planning not being appropriate). Finally, stakeholders provided a series of recommendations for the programme. These included targeting other tumour types and population groups, focusing on the whole cancer pathway and better planning.

In sum, questionnaire results indicated that stakeholders agreed with being involved in promoting early detection but buy-in varied according to involvement in the programme and different DCE strategies. There were issues regarding communication, and time to engage with strategies was limited. Funding did not reach all required areas and was often not sufficient to result in more diagnostic resources. Demand had a negative impact on workload, and at times on professional well-being. The increase in worried well seeking help was a reason for concern. Targets did not necessarily drive action nor showed where efforts should be focused.

The next Chapter describes the results from the second component of the process evaluation, i.e. stakeholder interviews.

# Chapter 9 Results: Process evaluation (Interviews)

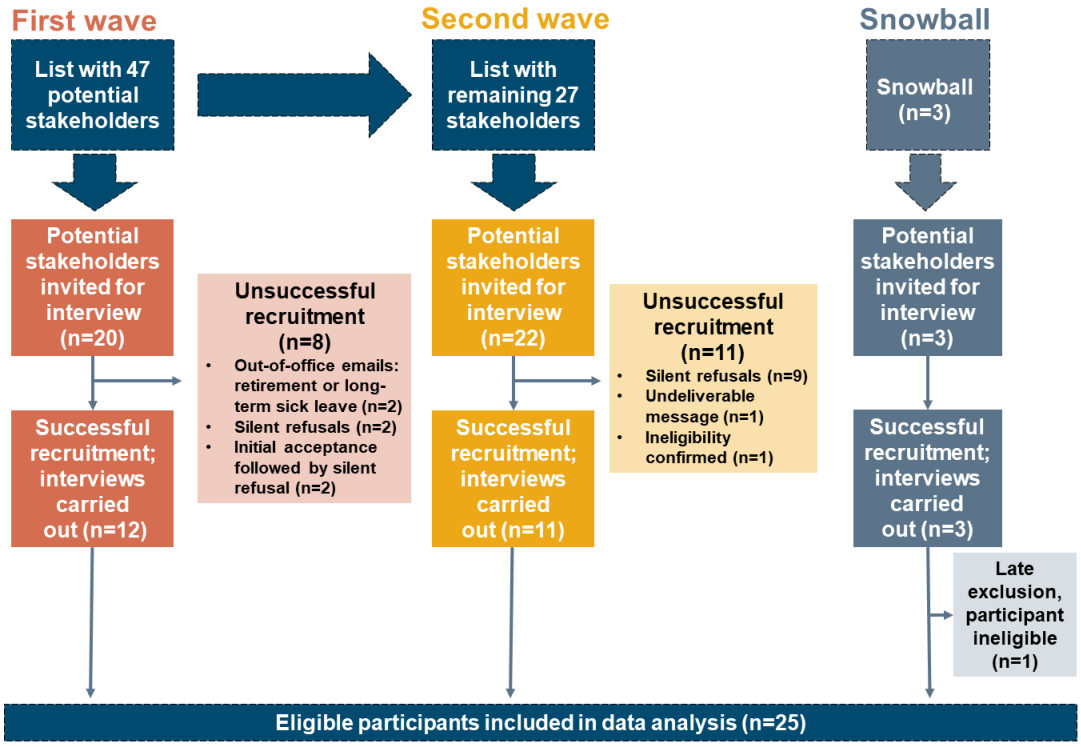
## 9.1 Overview

This Chapter describes the results from stakeholder interviews carried out as part of the process evaluation of the DCE programme. The process evaluation aimed to investigate assumptions regarding implementation, mechanisms of impact, barriers and facilitators, and unanticipated outcomes.

## 9.2 Recruitment

Interview recruitment was carried out in two waves; in the first wave 20 potential participants were invited and 12 interviews were carried out. In the second wave, 27 potential participants were invited and 11 took part. Interview participants also recommended three additional stakeholders, and all were interviewed (Figure 9.1).

**Figure 9.1.** Interview recruitment flowchart



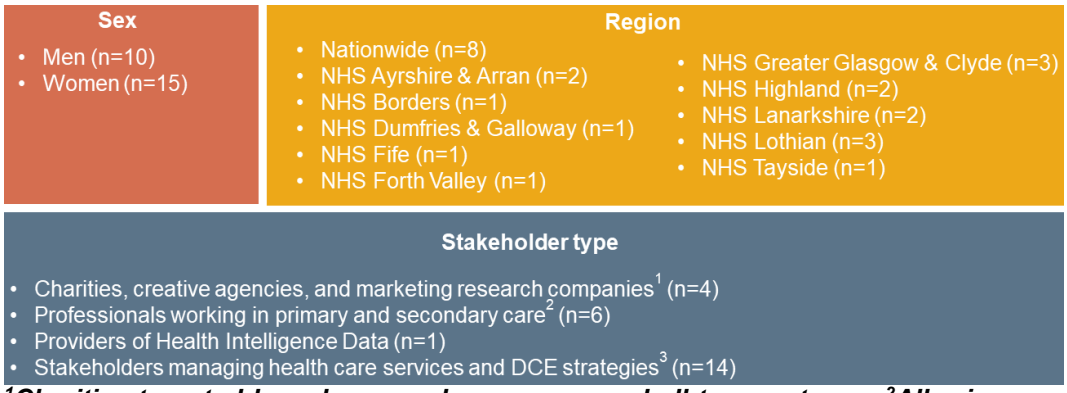

In total, 26 interviews were carried out between January and July 2018. One of them was excluded from analysis as during the interview it became clear that the participant did not meet eligibility criteria (i.e. s/he had been involved in DCE only after 2015). Nonetheless, the interview provided relevant background information that was useful in subsequent interviews; it also helped to inform discussions in Chapter 10.

Sixteen stakeholders were interviewed face-to-face and nine over the telephone. Two stakeholders were interviewed in a single telephone call; the other stakeholders were interviewed individually. Face-to-face interviews were carried out at the stakeholders' workplaces (offices, meeting rooms, cafeterias or empty hospital rooms), coffee shops, and a meeting room at the University of Edinburgh. Interview duration ranged from 17 to 79 minutes (mean 48 minutes).

## 9.3 Characteristics of interview participants

No individual-level stakeholder characteristics are described in order to avoid direct or indirect identification. Most stakeholders managed health care services or DCE strategies; 10 territorial Health Boards were represented (Figure 9.2).

**Figure 9.2.** Interview participants

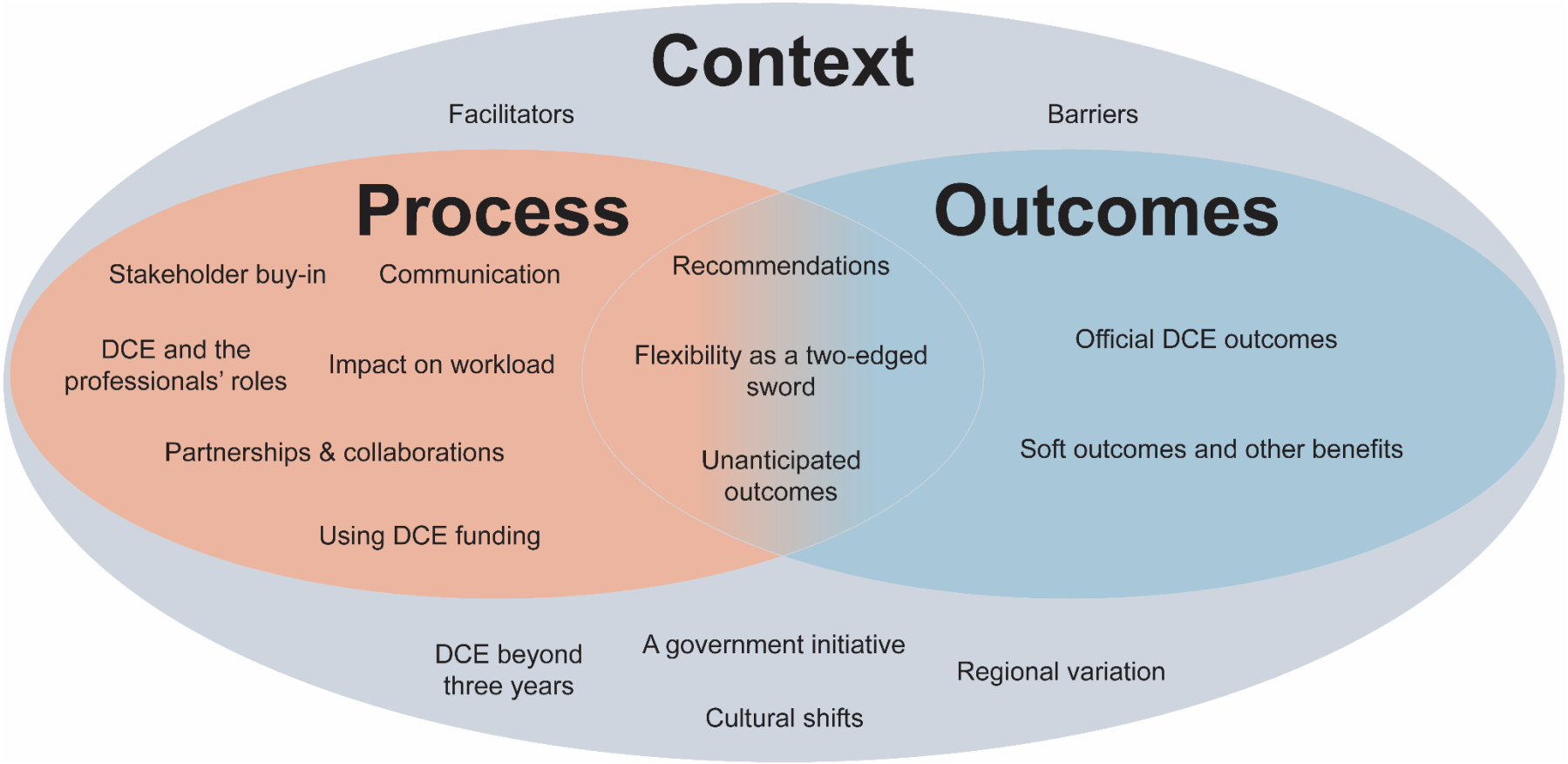



***[1]Charities targeted bowel cancer, lung cancer and all tumour types. [2]All primary care professionals were GPs, some were also GP leads or Clinical leads. Secondary care professionals worked in respiratory care and urology. [3]Included DCE managers and those managing NHS services (i.e. Access; Imaging, Public Health, Policy, Screening, and Strategy).***

## 9.4 Interview results

Data analysis was done iteratively, revisiting and refining emerging themes, in discussion with my lead supervisor (Dr Christine Campbell). Interview findings were categorised according to 1) process (stakeholder buy-in, communication, DCE and the professionals' roles, using DCE funding, impact on workload, and partnerships and collaborations); 2) outcomes (official DCE outcomes and soft outcomes and other benefits); 3) overlapped processes and outcomes (flexibility as a two-edged sword, unanticipated outcomes, and recommendations); and 4) contextual issues (barriers, facilitators, a government initiative, cultural shifts, regional variation, and DCE beyond three years) (Figure 9.3). Definitions for themes are available in Appendix 37.

**Figure 9.3.** Interview themes



### 9.4.1 Theme: Stakeholder buy-in

#### 9.4.1.1 Support for core aim

Overall, stakeholders supported DCE's premise to promote early detection and believed it was a worthwhile initiative. They recognised that early detection was important, and that Scotland's cancer outcomes could be improved. Some openly acknowledged that reasons for disagreement were about how to promote early diagnosis, but not about the programme's overall aim.

> *"I think the focus as well, everyone agrees that we want to try and diagnose people at an earlier stage, you know, where differences of opinion lay was perhaps how best to go about doing that […] but I think the actual underlying ethos people supported. So, I think that was having a focus on trying to up our game around early detection I think was helpful, I think most people bought into that" (ID 34)*

Nonetheless, there were reports that the "enthusiasm" about the programme and its activities varied according to specialist interest in cancer diagnosis or level of engagement of lead primary care clinician/lead cancer GP in each Health Board.

Buy-in was also described as being influenced by the perception over whether DCE would result in improvements in service provision.

> *"In the broader picture, you know, early intervention means people live longer and better and have more effective treatment, you know, so in principle obviously there's sign up to that but I'm not sure if there was that sense 'well this will help us do our jobs better, this will improve the system'".(ID 31)*

#### 9.4.1.2 Early detection approaches and chosen tumour types

Stakeholder views were mixed over whether the programme should have focused on screening or early diagnosis of symptomatic patients, and similarly on which tumour types should have been targeted.

Focusing on screening was viewed favourably as evidence shows it is effective to identify cancer at earlier stages. If there was a screening programme in Scotland (i.e. for bowel or breast cancer), concerns were raised when campaigns focused on symptoms, either because of fears that the health system would not be able to cope, or because symptoms in these cases often indicated late stage disease. Similarly, there were concerns about highlighting lung cancer symptoms (there is no screening programme for lung cancer in Scotland) as lung cancer is often asymptomatic in its early stages.

Conversely, other stakeholders believed that the programme should have focused on tumour types for which there were no screening programmes in order to improve outcomes for them. Informing the population about cancer signs and symptoms was also considered to be important to increase awareness and potentially reduce inequalities.

> *"The clinicians and managers were unhappy with the focus on signs and symptoms, but I think that we're doing our population a disservice if we don't make sure that the population understands the signs and symptoms. Those people who are well educated it's a no brainer to them, but there's a lot of people […] So I think that part is really important, and it tackles inequalities (ID 30)*

Prostate cancer was often mentioned as a tumour type that should have been included in the programme (stakeholders did not specify how they believed this should have been done). However, professionals working in urology disagreed with including prostate cancer for many reasons, including the fact that urology services were already struggling to cope with demand, and issues with overdiagnosing and overtreating patients.

While some stakeholders believed that the DCE's tumour choices (breast, bowel and lung) were "sensible and pragmatic" as they were the most prevalent in Scotland, others were frustrated that their tumours of choice were not included (despite perceived promises that this would happen over time).

#### 9.4.1.3 Feedback on different strategies

The process of updating the Scottish referral guidelines for suspected cancer was widely accepted by stakeholders, as there was an Independent Chair, consensus from experts (described as very "labour intensive") and use of evidence. The process was also described as a less complex procedure than the one carried out by the equivalent NICE guidelines in England. However, some were concerned about the guidelines' low yield, the fact that they did not identify early stages for some tumour types, and that too many patients met referral criteria. There was recognition that not all professionals used the guidelines (or used them in the same way), and that buy-in was lower among secondary care professionals.

> *"Cancer guidelines are quite helpful but the yield from cancer guidelines is not incredibly... it's not as good as you get from screening programmes, and the other problem is that the stage at which you might identify them through symptoms is obviously going to be later." (ID 30)*

Views on the bowel screening initiative were always positive. It was considered to be a good use of primary care and DCE money. Reasons for buy-in were also described. The incentive for improvement was clear, general practices developed their own plans on how to improve bowel screening uptake (influencing their sense of ownership about the initiative) and often could see the result of their activities (such as change in uptake or local cases of bowel cancers being diagnosed).

> *"I think it just seemed to catch their imagination, their enthusiasm actually, the fact that a lot of enhanced services that they do, I think they often think 'I'm actually not really very sure why we're doing this and how this is going to help' but for a lot of practices they're looking at it and thinking 'actually, d'you know, you can see why we're doing this' and practices would be feeding back to us about 'actually we had somebody who wasn't going to do their bowel screening and they did and they did have cancer'" (ID 17)*

However, there was also disappointment when the initiative ended after two years, especially since the first year was dedicated to planning and implementation, and there were delays for practices in terms of receiving data on non-responders. In most cases, activities related to the strategy also ended after two years.

> *"QOF was very much to be encouraged, I was very disappointed to see after it being there for basically the two years, the year for planning and the year for delivery, for then the money just disappeared again. […] There's a timing involved in that for a member of staff and practices have to make a business decision at that point, you know, if we are going to encourage two or three people or four people or five people to screen but it's taken us 52 weeks to do it" (ID 13)*

Stakeholders often shared their views on the social marketing campaigns. They were generally liked, described as "clever", "well made", and (more often than not) necessary in order to increase population knowledge and awareness. However, there were reports of disagreements between health care professionals and the social marketing team. Some wished that the marketing team had spent more time getting clinical buy-in as this could have had a positive impact on stakeholder engagement and sense of ownership and could potentially have resulted in more effective strategies. Others believed that DCE money could have been invested in other areas instead of campaigns (such as other early detection initiatives in primary care).

> *"I think where things were perhaps not so successful was the kind of... I'm using management guru nonsense terminology but a whole systems approach, so the kind of responsibility and ownership for the campaign sat with DCE and I think there was an element where, if you like, both the primary care but also the*

*diagnostic services didn't really engage with it as an opportunity to look at 'right how can we get more of the most likely people through our doors and into early diagnosis and what do we need to do to the service to make that easier?' so I think there was more focus on trying to get the right people through the same front door, rather than going 'is this the best shape, size, location for the front door'. (ID 31)*

The bowel cancer campaign was described as having "the right level of humour" and was praised for targeting more deprived populations. The symptomatic breast campaign had lower clinical support due to concerns over its impact on workload. The breast screening campaigns had limited acceptance from clinicians who did not perceive breast screening to be an appropriate early detection method.

The lung cancer campaign was described as "powerful", with a respected, non-judgemental public figure. However, there were concerns about using the term "3-week cough" (as it is common for patients with chronic obstructive pulmonary disease) and having campaigns during wintertime (when the flu and colds are more prevalent resulting in persistent cough for many patients).

*"There was certainly sometimes where we launched lung cancer campaign or had lung cancer pushes, kind of in the winter months when you'd expect an increase in people presenting with coughs and colds, and coughs was the kind of symptoms that the campaign was highlighting. So, I think people understood the nature of the campaign and the rationale for it, but the timing perhaps was a bit of an issue coinciding with winter months and upper respiratory tract infections" (ID 34)*

#### 9.4.1.4 Performance targets

In principle, stakeholders were not averse to having targets, as they served the purpose of focusing minds, indicated what to measure, set a level/standard and helped to show what stakeholders should aim for. However, several limitations of using targets were described: the need for sustained funding so they could continue working (as professionals have other jobs to do); the need to carefully choose the target to ensure that the right things are being measured; the fact that targets become repetitive and over time require a lot of work for very small returns; and the risk of missing important outcomes by focusing on a very specific target.

Stakeholders referred to both DCE performance targets: QOF and HEAT. QOF was described as a clear incentive for improvement that provided GPs with a sense of ownership and facilitated engagement. As for the HEAT targets, stakeholders widely acknowledged that they were unlikely to be achieved. Some believed that the

“unrealistic” targets resulted in limited engagement and sense of ownership, caused frustration and perplexity. Others were unsure if the targets were the right measure, and whether they were clinically relevant. Finally, some wished the targets had been designed using data that were already available (as new data had to be collected in order to assess performance).

> *“Right away it seemed like a figure that would not be achievable. So, for some people it was then well 'we'll just keep on doing what we're doing anyway because we're not going to be able to have that big an influence'” (ID 15)*

> *“Well the 25%, I think a number of boards have been challenged around that figure, hugely challenged around that figure, and that maybe [it] wasn’t the right measure? So where's the learning around all of that as well and how do people think that the next time there's possibly an initiative that is hugely well intentioned and based on lots of really good and sound principles, but how do we make sure that we do that in a better way that gets the right support and is seen as a clinically important and meaningful thing as opposed to something that we're never going to achieve and therefore we didn't hit 25% so what does that mean?” (ID 20)*

Other stakeholders believed that the ambitious target was needed to generate change. For them, the target was inspiring, aspirational, in order to push boundaries. Stakeholders from charities reported being comfortable with such targets as they were used to having them. Those managing DCE strategies emphasised that there was much more to DCE than the aspirational targets.

> *“That was always an over ambitious aim in my mind but sometimes you need to be over ambitious to actually pull the curve to the left” (ID 13)*

Some stakeholders highlighted that, on a daily basis, healthcare professionals most likely did not worry about the HEAT targets, as they were likely “quite focused on the specific job at hand”.

## 9.4.2 Theme: Communication

### 9.4.2.1 Source of information

Several stakeholders reported that they had had formal contact with DCE and were involved in developing some of its strategies, especially the referral guidelines, initial training sessions and the bowel screening initiative. Communication took a number of forms including emails, discussions in Cancer Boards and hospitals, letters, government circulars and meetings, in addition to government documentation. The DCE team visited Health Boards to meet stakeholders, and representatives from

different Boards were nominated to take part in specific DCE groups (often the Communications Group or the DCE Programme Board). There were bowel screening groups with representatives from primary and secondary care. Meetings/workshops about the referral guidelines were carried out in several locations across Scotland. Decisions from the DCE Programme Board were filtered to Health Boards, which then took different approaches on how to disseminate information (although Cancer Leads and Executive Leads were often involved).

A stakeholder acknowledged that it was hard for GPs to find time to read everything in their Inbox, and unless they had a specific reason to search for DCE documents, it was likely that any communication "got lost among hundreds of circulars".

Stakeholders recognised that involvement in specific meetings and groups, or involvement in policymaking made a difference over whether they were aware of DCE strategies and the rationale for them. However, there was reported uncertainty regarding some DCE components even when stakeholders were more involved.

#### 9.4.2.2 Ongoing communication and timeliness

Stakeholders reported that over time it became more difficult to follow information about the programme and act upon it, especially regarding the social marketing campaigns.

> *"[W]e always got information as a Board but it got a little bit more difficult to follow I guess as the social marketing programme matured and started to try different things […] I guess at the end of whatever it would've been going into year three we kind of ended up shrugging our shoulders saying, you know, I was pressing forward saying more radio adverts are going, more... but because they were stretched out over time it was something that we simply acknowledged rather than specifically planned for in all occasions" (ID 11)*

While groups more involved with DCE often believed that they had received "plenty of notice" about DCE and its strategies, others acknowledged that the same may not have been true for front line staff and primary and secondary care professionals. Several stakeholders complained about limited notice before campaigns and short campaign timelines. A "strict embargo" was reported for campaign materials, and this resulted in delays sending them. As a result, it was difficult to support the activities and engage with the community. Gaps in information that resulted in "periods of guesswork" were also reported.

*"Then I'd be saying 'right okay, so I've been to the communications group meeting, they've said they're going to do something about breast signs and symptoms so I'll be getting all the stuff out to you', and then it was just so badly organised that the campaign had suddenly hit the TV and somebody phoned me up and said 'I just seen it on TV' and I was like 'I don't have any resources for that'. And then I looked stupid, then people thought that I was the one that hadn't done anything and you'd be getting posters a week later coming from the Scottish Government, the marketing team, and then some various things to put on websites and different things, all the images and stuff and, you know, email signature things you could do, but it was always after the fact" (ID 15)*

#### 9.4.2.3 Rationale for strategies

Stakeholders reported uncertainty over DCE's rationale for a range of strategies. This was particularly salient for information on the groundwork informing the social marketing campaigns, and further explanations about the HEAT targets (such as how they were decided upon, and what they meant).

*"That 25% figure, we sort of banged ourselves over the head with it for years and I probably shouldn't say this, but it did feel like it had slightly been plucked from nowhere at the start." (ID 24)*

#### 9.4.2.4 Input from the healthcare community and charities

Stakeholders gave examples of good communication between DCE and primary care professionals. Nonetheless, stakeholders often commented on the fact that decisions had often already been made when they were consulted (even in the case of early involvement). As a result, some stakeholders reported frustration and limited engagement from specialists, charities and health care professionals.

*"I think the other thing might have been better engagement with the clinical... and I'm sure people think they did do that and there's a level of how much you can but, you know, engagement with clinical teams about what did they think actually is important to do here, what actually if you had something and wanted to try and improve your detection rates around cancer, how do you do that in a way that's meaningful and is the way that we did it, was that the right way that we did it?" (ID 20)*

Those managing the DCE programme acknowledged the importance of having effective communication with stakeholders and keeping an open dialogue as this facilitated buy-in and engagement. However, they also discussed the challenges of balancing communication with getting the work done in a timely manner.

*"So we were always wanting that dialogue between the Boards and ourselves at a national perspective to be seamless […] you know,*

*getting them on board from very early, not too early mind you because it's a difficult balance I suppose cause you want stakeholder buy in, but at the same time it's realising that we're the experts in this area. Otherwise nothing will get done" (ID 25)*

#### 9.4.2.5 Dissemination of DCE activities and outcomes

There were suggestions from both DCE managers and other stakeholders that dissemination of activities could have been better managed, especially regarding sharing information from local activities, successful stories and best practice; and disseminating referral guidelines more widely to secondary care professionals.

*"I don't think that's necessarily always been as well communicated in terms of sharing good practice, so you know, if an area has done pilot projects for service redesign to make the front door bigger or wider or easier to access, the potential is that has benefit for services in other areas but I'm not sure how widely that has been shared". (ID 31)*

DCE organised a Conference in 2016 to disseminate local and national activities, but stakeholders acknowledged that a single conference was not sufficient to disseminate all DCE activities to different audiences.

### 9.4.3 Theme: DCE and the professionals' roles

#### 9.4.3.1 Business as usual

The DCE programme was often described as "business as usual" by stakeholders for several reasons. GPs could see their role in engaging with patients regarding bowel screening participation; lead Cancer GPs saw DCE activities as part of their core work; and screening coordinators were involved due to the nature of their jobs. Some participants described DCE as "just more work". In a particular Board, DCE was seen as something to be embedded into core activities (in order to acknowledge the work of those already carrying out similar work and ensure sustainability). For those working at ISD Scotland, DCE activities related to health intelligence data were incorporated into their jobs.

*"In my lead cancer GP role, it was core work, it wasn't extra work, it was what I was there to do, it was core work and it was positive and well-focused work. I thought the project from a primary care perspective it was a useful project that helped my role as a lead cancer GP, gave some real focus that could have an impact". (ID 23)*

#### 9.4.3.2 Competing responsibilities and new tasks

For other stakeholders, many other issues were also important, and time and resources were needed so they could be involved in DCE activities.

*"So for example we run a local road show in our area and they wanted to provide some staff and we're happy to do that and staff are happy to support these things but if we don't get enough notice it's extremely difficult, we don't have people who are ready and waiting to down tools and go and run off and do a roadshow, we need to kind of free them up, so that presented difficulties" (ID 34)*

Furthermore, DCE also resulted in the need to have professionals assigned to new tasks/responsibilities; i.e. there was nobody "in the NHS whose job is to go to the bingo and engage with women".

## 9.4.4 Theme: Using DCE funding

### 9.4.4.1 Allocation and variation

In general, DCE funding was reported to being mostly allocated to secondary care, in order to deal with an expected increase in demand brought by the programme. Funding was invested in diagnostics (including colonoscopy, thoracoscopy, radiology, other machine and equipment, one-stop breast clinics); hiring professionals; treating patients; health intelligence and informatics; increasing GP sessions; surveying health care professionals and the public; and developing local community initiatives to increase population awareness of cancer signs and symptoms. Stakeholders acknowledged that without funding, many DCE-related activities would not have happened. Additional resources were needed and welcomed and helped to ease concerns about the programme impact on diagnostic capacity.

Although funding was used for new activities and to deal with resource implications from the programme, there were also reports of money being used to fill already existing gaps, and to fund services that were under-resourced.

*"Other difficulties, problems... getting people to see the DCE actually as money that needed to be focused on changing the way things were dealt with in detecting early cancers rather than just being used as an extra pot of money to shore up a grossly under resourced service in total, and I think there were times when I was at meetings, both national level and board level, where secondary care were saying 'oh excellent here's £100,000 that's just what we need just to keep the ordinary service running" (ID 23)*

Some primary care professionals accepted that it was difficult to be allocated funding and recognised that it made sense to invest mostly in diagnostics. Others could not understand how allocation was decided in their Health Boards and wished there had been more transparency.

*"Actually when it came to it there was this big round table discussion with all the clinicians and of course our bids, mine and the nurses' bids, were the bids that were put last on the list cause they were felt to be least relevant to be preferred to the money by the people who wouldn't really know anyway because their job isn't to do that bit of it!" (ID 27)*

While some stakeholders openly stated that funding was sufficient for what they wished to do, others stated that funding was less than what they expected and not enough to make all required changes.

*"Clinicians would still say that it wasn't quite enough money to do the sort of changes that they would've wanted to have done and some of it still felt like sticking plaster". (ID 19)*

A stakeholder commented on the fact that funding was diluted across different areas, and some areas (such as laboratories) ended up getting very little. Some stakeholders were frustrated as they believed that some Health Boards managed to benefit more from funding than others, which allowed them to develop novel initiatives (such as testing the qFIT with symptomatic patients).

#### 9.4.4.2 Funding is not necessarily the solution

Stakeholders often highlighted that although funding was important, it did not necessarily solve diagnostic problems faced by Health Boards, such as shortage of radiologists or pathologists. For similar reasons, it was not always possible to use funding as initially intended. If there were no professionals available to be recruited, funding was used to pay for overtime work instead.

*"I suppose many of our problems then and especially now are as a result of vacancies, long term vacancies where we haven't been able to recruit to established posts. So, we've probably had to use the money available in a less efficient way by having to pay members of staff overtime rates to cover posts that we might have filled in a different way and more efficient way" (ID 34)*

Hiring professionals while also knowing that funding would not be available in the long-term was described as a challenge. There were reports of professionals only being able to stay for a couple of years, and more permanent staff having to absorb their roles when funding ended.

## 9.4.5 Theme: Impact on workload

### 9.4.5.1 Impact of different strategies

Stakeholders reported on the impact that DCE activities had on workload; these were particularly associated with social marketing campaigns (especially the symptomatic breast campaign).

> *"To cut a long story short the outstanding additional activity pressure that we actually felt was in the breast pathway after the first Elaine C Smith campaign [breast symptomatic]" (ID 11)*

The impact of the symptomatic breast campaign was reported to have happened quickly, requiring drawing on resources from both symptomatic services and breast screening in order to get the required radiological support. Demand in breast clinics was reported to increase considerably. Stakeholders often stated that the campaign resulted in the system being flooded with the worried well, and this caused frustration among health care professionals. A stakeholder highlighted that the frustration was more due to the limited impact on cancer outcomes than due to the impact on workload.

> *"I think the reward was not there for the work and that was for me the major difference. So, there was an enormous amount of activity, a lot of pressure on the service and the cancers didn't turn up. I think if the cancers turned up then there wouldn't have been unhappiness […] We don't mind working hard and having a lot of activity if you see why" (ID 22)*

The bowel campaign was reported to result in an increase in demand for endoscopies (and a knock-on impact on pathology), with spikes during each campaign wave. Work was carried out with the Bowel Screening Centre to make sure they would be able to cope with increase in calls and returned bowel screening kits to their laboratory. Weekend working and overtime were also required. The bowel screening initiative also required extra work in order to provide information on non-responders to screening to each primary care practice.

There were reports of increased anxiety among professionals when young people started to show up with post-viral cough after the lung cancer campaigns, and concerns over whether the right groups were being targeted.

### 9.4.5.2 Unexpected impact

While some stakeholders believed that the impact on workload was "entirely predictable" and short-lived, there was reported surprise from others when demand

increased during the campaigns. Some wished they had been better warned about the potential impact on workload. Those who had planned for the increase in demand often reported that the impact was higher than expected.

Some Health Boards were able to put in additional resources for appointments, using resources they already had in place or obtained with additional funding provided by DCE. Others faced challenges as there was no funding left to deal with the demand.

## 9.4.6 Theme: Partnerships and collaborations

### 9.4.6.1 The role of charities

Cancer charities were described not only as important collaborators/stakeholders, but also as leads in early detection strategies that were supported by DCE. For example, CRUK approached DCE regarding implementing the primary care facilitator programme in Scotland (it had already been implemented by the charity in England). CRUK worked directly with practices, and DCE supported the programme expansion into five other Health Boards.

Relationships were reported to be driven by common aims (such as promoting early cancer detection, or even targeting cancer prevention) and the opportunity to share knowledge and expertise. Charities were able to gather outcome information on their own and prepare evaluation reports, although at times they had to rely on official health intelligence data.

Charities could have a different relationship with health care professionals compared to the government (as they were able to have a more customised approach). Furthermore, charities had a different relationship with the public as they were a non-governmental agency.

> *"Is it more powerful if it seems as though it's coming from Cancer Research UK or a charity, there's a charity affiliation compared to the government speaking to you" (ID 25)*

As a result, charities were reported to facilitate the development and implementation of initiatives, and at times also ensured sustainability when DCE funding ended. Stakeholders (especially the ones at the government) were cognisant of the importance of having charity support and aimed to ensure that their input was obtained regarding DCE initiatives (thorough ongoing consultation, participation at Programme Board meetings and the Scottish Cancer Coalition). Those working in charities agreed that consultation took place at times, but some wished they had had

the opportunity to give more input (including expert advice on how to engage with communities in more deprived areas).

> *"The social marketing stuff and the coming with a done deal to people and saying 'this is what we're going to do' rather than letting the experts in the room have some sort of opinion and contribution to that as well. So that was the one thing I really did want to get across and something that has been a continual problem" (ID 15)*

#### 9.4.6.2 The role of creative and market research agencies

Different agencies contributed with expert knowledge that the Scottish Government often lacked. This included insight gathering among the public, developing, testing and refining creative campaigns, evaluating and interpreting them. Different agencies had different roles, although they worked in coordination, with the Leith Agency working as the lead.

Although agencies collected their own data and triangulated different data sources, they were also dependent on the government to provide them with data to help them understand the impact of social marketing activities. Data were not always available.

While the Scottish Government and agencies worked in partnership, views on what constituted programme success varied. This was particularly evident regarding the symptomatic breast campaign, as from a social marketing perspective the outcomes were very positive (persistent results for increase in awareness and change in help-seeking behaviour with more women presenting in primary care).

> *"If it was the case that actually they just got a lot of worried well and they didn't find any more cases then that's fine, you know, that's a valid learning and reason not to do it, but it sounds terribly unacademic to say but intuitively it always felt like it didn't quite add up, and also had anecdotal stories of people from GPs and people we all know who'd been diagnosed as a result, and we used PR case studies of people who'd been diagnosed as a result, and yet all the feedback coming back was 'it's not working, it's not working, we'll never do it again'" (ID 24)*

Furthermore, there was reported frustration when calculations made by agencies showed that it would be virtually impossible to meet performance targets.

#### 9.4.6.3 The role of the media

There were reports of both positive and negative interactions with the media. Although it helped to disseminate early detection messages, issues arose when the media and DCE had different interests. There were reports of the media criticising a DCE

campaign showing a GP at a “coughing” bus stop (to highlight lung cancer symptoms). Instead of encouraging readers with a cough to go see their GP, the emphasis was on the fact that “highly paid GPs” do not take the bus.

Negative messages (e.g. reporting bad cancer experiences) were commonly reported by the media, and mixed messages were described to cause confusion among the public: while DCE campaigns focused on encouraging the public to seek help and attend screening, the media constantly reported that the NHS was struggling to cope.

## 9.4.7 Theme: Official DCE outcomes

### 9.4.7.1 Joining the dots

Stakeholders widely acknowledged that it was complex and challenging to understand DCE impact on cancer outcomes. They reported uncertainty over attributing positive cancer outcomes to the programme, as other relevant activities were happening at the same time, and often it was not possible to determine exposure to DCE strategies.

*“Okay you've got numbers yes, but we don't know whether these people who turned up and be staged even had any idea of the DCE programme” (ID 29)*

Understanding which DCE components contributed to changes was also described as a challenge, and so was the ability to evaluate all different activities. The challenges were not only due to their large number, but also due to their characteristics. For example, it was reportedly difficult to measure change in practice as a result of the new referral guidelines or change in behaviour after digital social marketing activities. Other reported limitations included challenges when trying to link intermediate and final outcomes (such as how increase in knowledge resulted in an early stage diagnosis).

*“It's very difficult to distil out what was the contract [bowel screening initiative], what was the adverts, what was the stuff that you were doing, what was the stuff that local NHS boards were doing, but I think it's we always talked about DCE being this whole systems approach so it's always going to be difficult to evaluate individual pieces of work” (ID 33)*

*“The holy grail is where you've got a continuation of information, so we know that somebody saw the campaign, we know that somebody went to the GP, we know that that person was then referred on, we know they were diagnosed at an earlier stage and I think that... it's very, very hard to do that” (ID 24)*

#### 9.4.7.2 Anecdotal evidence

Stakeholders often referred to local, anecdotal evidence when discussing positive or negative programme outcomes. This was due to having limited knowledge of national outcome data (whether because it was not collected, had ceased to be collected, or because they were not aware of national data). Anecdotal data were commonly mentioned when discussing changes in cancers being diagnosed over time or specialist referrals.

> *"I don't know if it's backed up, but I certainly feel like I do a whole load more chest x-rays now than I would've done previously" (ID 10)*

Stakeholders also believed that even small, local activities could have a long-term impact but acknowledged that maybe this would never be measured.

#### 9.4.7.3 Views on official outcomes

Stakeholders talked about the positive impact of campaigns on knowledge and awareness, on presentation due to symptoms, and referrals for diagnostics. Stakeholders also discussed the large numbers of worried well patients seeking reassurance, the (often limited) impact on cancers being diagnosed, or cancers being diagnosed in earlier stages. Some believed that the limited perceived impact on staging was because symptoms are not necessarily associated with early stage detection. Others acknowledged that shifts would take a long time to be noticed.

> *"[C]hanging something like stage at diagnosis at population level, it's like turning an ocean liner, you know, it's very small increments if possible, but hopefully the liner won't suddenly just drift back to the original course and will have some lasting benefit in terms of people being less fearful of cancer, understanding how screening programmes work and taking up the opportunity". (ID 16)*

There were reported improvements in staging for lung and breast cancers. Stakeholders were surprised when national data did not show improvements for bowel cancer, and possible explanations for this were discussed (e.g. screening found pre-invasive disease or removed polyps).

The temporary effect of campaigns and the challenges of campaign wear out were also mentioned. The breast screening campaign was described as having had limited impact on shifts in staging, and this caused frustration.

> *"Obviously when you look at the outcomes lung shows the biggest one, breast there's been good movement, sort of stage one/two, and there is some inequalities ones within those and the screening*

*outputs are frustrating cause you just look at the figures and it doesn't look like a huge amount has shifted" (ID 24)*

There were reported positive outcomes associated with the bowel screening initiative, such as high participation rates from primary care practices, and increase in requested kits. However, data were often anecdotal, increases were often described as temporary and did not necessarily translate into increase in uptake. Figures were also reported to have dropped after funding ended. There were criticisms towards a perceived limited evaluation of this initiative.

*"I don't think we capitalised enough on the learning from the contract initiative and we did feed that back, we didn't then bring it together and say 'X number of practices participated, X met the target and here's what they said in their action plans' cause we got detailed action plans from the practices, we never really captured that learning and built that into something and looked at it for other screening programmes or any of that kinda thing" (ID 12)*

## 9.4.8 Theme: Soft outcomes and other benefits

### 9.4.8.1 A cumulative effect

Stakeholders believed and expected that DCE would have a long-term impact on health-seeking behaviour and would contribute to long-term changes in cancer outcomes. Some gave examples of activities introduced as part of DCE that had continued after funding had ended.

### 9.4.8.2 Changes in service provision

Stakeholders reported on a range of changes in service provision. These included having more telephone consultations, discussing patient cases in meetings and reflecting upon diagnoses and referrals, developing new referral pathways and referral processes, and implementing one-stop clinics. They acknowledged that these changes were not solely due to DCE.

Other perceived benefits included the development of a good practice guide for bowel screening (in collaboration with Cancer Research UK), the opportunity to access better data, put research into practice, and focus on inequalities; and new IT developments (such as referral guidelines added to computer systems, development of tools to access information on bowel screening non-responders, and being able to use electronic referrals).

*"In terms of positive things, I think the opportunity to get better data, the opportunity to put into place some of the things that people had been researching I think was really positive. The*

*attention to this area was positive. The focus that we had on inequalities was positive. The ability to eventually get data for bowel screening, eventually get data on non-attendance and being able to do something about it. The understanding that where we had issues with uptake of screening and different things we could do, the opportunity to work with groups of people to understand what the barriers were and to try and start to address them, all of those things were good." (ID 19)*

Furthermore, some believed that DCE helped to re-establish communications between primary and secondary care; helped to make the linkage between cancer prevention, early diagnosis and the health care system; improved conversations between secondary care and the government; and united different stakeholders with an interest in early cancer detection.

*"I think overall the campaign has added something, it's making that linkage both between prevention, early diagnosis and the healthcare system that responds to those people presenting, it's the longer term and bigger challenge for all of us" (ID 31)*

#### 9.4.8.3 Opportunity to develop local activities

Stakeholders described how DCE facilitated the development of a range of small activities, standalone projects and ideas that would not have been tested otherwise. These included engagement with local businesses/employers, work in deprived areas, activities with minority ethnic groups, engagement with pharmacists, surveys with health care professionals and the public, and a CPD session with health improvement professionals.

#### 9.4.8.4 Enhanced partnerships

DCE was also reported to result in long-term projects with charity partners. It allowed for the CRUK facilitator programme to be implemented in Scotland, for prevention activities to be developed in partnership with the Teenage Cancer Trust, and for new partnerships with the media to be developed.

#### 9.4.8.5 Normalised discussions about cancer

Stakeholders believed that DCE "got people talking" about early detection; and brought the topic to the centre of attention of the public and health care professionals. DCE was reported to help normalise discussions about cancer.

*"Yeah. I think probably the biggest one and I think one that was really, really welcome and one of the great successes of the programme is the fact that it got people talking about cancer, and I think the information that was circulated at the time and subsequently in relation to about early diagnosis […] I think that*

*change and shift in public perception is probably really, really important" (ID 32)*

#### 9.4.8.6 Measuring soft outcomes

Stakeholders recognised the challenges of measuring soft outcomes.

*"Would we do a piece of activity, you know, that is a difficult thing with the roadshow, how do you measure that impact, you know, we get reports through and it's you know 'we handed out X number of leaflets and we engage with X many people and here's some lovely quotes that people have said'" (ID 25)*

### 9.4.9 Theme: Flexibility as a two-edged sword

#### 9.4.9.1 A "chameleon" programme

Stakeholders managing DCE activities described the programme as a "chameleon" due to its flexibility regarding funded local and national activities, and its ability to adapt according to contextual changes. The programme targeted not only patients eligible for screening, but also the general public and those presenting with cancer symptoms and signs. Furthermore, DCE was involved in prevention activities, and over time increased its focus on addressing health inequalities. The programme tried to be as flexible as possible when providing funding to Health Boards, as it believed that different areas knew better about how to invest in capacity.

*"So I suppose it can be seen as a positive and a negative in terms of the programme in its flexibility and its... you know, we can put out messages tomorrow if we wanted to, depending on what happens today, we're like chameleons aren't we really, we're very adaptable, and in this current climate we have to be just that I suppose" (ID 25)*

Importantly, there were also reports of limited programme flexibility. This was the case for requesting to use and adapt campaign materials in local areas, due to copyright and embargo issues, and delays in distributing materials.

#### 9.4.9.2 Challenges brought by flexibility

DCE flexibility was reported to make it difficult for a Health Board to decide on how to incorporate the programme into their work, as it did not fit within a specific structure.

*"I think it's some time it was where that line was about the DCE, is it within public health, cause if it's sat with the screening coordinators in the first place then it probably would've been a clearer route, but because it included different sites and it included just not screening population but the whole population, then it seemed to have arms and legs" (ID 29)*

The flexibility when providing funding to Health Boards was also reported to result in limited ability to assess the local impact of the programme and ensure accountability from different Health Boards.

> *"[W]hat we said was 'these are the five areas of work and it's up to you to prioritise your funding and where it goes' and we left boards to it. And then we went back on an annual basis to try and get an evaluation of what they spent the money on and that was hugely difficult to do. It was just like, it was almost like so difficult to get the accountability for the funding and where they spent it […]So if we were to do it again I think you probably would be more prescriptive to say 'this is where the funding should be sent to and actually give us your proposals of where you're putting that money" (ID 33)*

Stakeholders also commented on how the ability to be flexible could result in the programme becoming "piecemeal". Comments focused particularly on the inclusion of prevention strategies into the programme. Stakeholders emphasised that DCE was an early detection strategy, even though it recognised the increasing importance of cancer prevention. They also acknowledged that prevention was a challenging area that would most likely need a programme of its own.

### 9.4.10 Theme: Unanticipated outcomes

Some stakeholders were concerned about conditions other than cancer being downgraded due to the need to urgently see patients with a suspected cancer, about patients who had high-risk cancer symptoms to be moved to the bottom of waiting lists due to increasing demand for diagnostics or about potentially slowing down cancer treatment for patients.

Initial concerns about mobilising the worried well or patients with trivial symptoms to seek help were confirmed when demand for diagnostics increased, but no more cancers were diagnosed. Furthermore, the increase in demand resulted in the need to hire more specialist staff, and competition across Health Boards due to professional shortage in Scotland. The increase in demand was also reported to increase professional anxiety (due to fears that they would not be able to cope) and public anxiety (indicated by the large number of patients with a low risk of cancer seeking reassurance).

A range of positive unanticipated outcomes were also reported; these included lessons learned from DCE informing other government campaigns; DCE's strong focus on hard to reach groups being reflected on a new Cancer Strategy; the

development of a staff survey in a Health Board which showed that reluctance to see the doctor and limited knowledge of screening were not only an issue among the public; and the purchasing of a thoracoscopy machine that was useful to diagnose and treat patients with metastatic cancer and mesothelioma. Stakeholders also believed it was likely that the programme resulted in diagnosing conditions other than cancer (such as a patient with a persistent cough being diagnosed with COPD) and hoped that campaigns encouraging help-seeking resulted in the public seeking help for tumour types not included in the programme.

### 9.4.11 Theme: Stakeholder recommendations

#### 9.4.11.1 Consider other early-diagnosis approaches

Suggestions included implementing one-stop multi-diagnostic centres, piloting different strategies with direct access to diagnostics, focusing on tumour types for which early detection gives the best results (no examples were given), targeting patients at high-risk of lung cancer, involving other professionals (such as dentists) in early cancer detection, and focusing more on health improvement strategies.

Some also believed that changes in the way GPs and the public interpreted early cancer symptoms were needed (highlighting the need for follow-up and to continue with help-seeking if symptoms persisted).

#### 9.4.11.2 Broader views: national umbrella and the whole cancer pathway

Stakeholders believed it was important to keep DCE's national umbrella (without stopping with local initiatives). They also highlighted that it was important to focus on the whole cancer pathway instead of only up to cancer diagnosis.

#### 9.4.11.3 Tackle health inequalities and inequities in access

Stakeholders acknowledged the need to tackle health inequalities and recognised that the issue was beyond DCE. Recommendations included improvements in access, better supporting patients in more remote areas, investing on health literacy, and considering not only diagnostics but also treatment burden and risk of social isolation. Some described social deprivation as the biggest challenge to be tackled in other to make a substantial impact on public health.

#### 9.4.11.4 Have good local and national data

Stakeholders acknowledged that better data were needed so the programme could be properly evaluated. Having staging data for more tumour types was also suggested.

#### 9.4.11.5 Better planning, evaluation and dissemination

Stakeholders believed it was important to assess more programme components (including how funding was used and any potential unanticipated outcomes) and disseminate results to stakeholders. Gathering information on lessons learned from the programme was also considered to be important.

#### 9.4.11.6 Reconsider some adopted strategies

While some stakeholders suggested DCE continued to focus on screening, others believed it was more important to focus on signs and symptoms and on understanding help-seeking behaviour.

Some believed that awareness campaigns should continue as cancer fear and limited awareness of cancer symptoms and signs were persisting barriers. Others suggested focusing on patients at high risk of cancer using tailored messages (to avoid attracting the worried well and overwhelming services).

While some suggested larger investment in primary care, others believed DCE should be investing more in capacity (especially radiologists, scanners, and direct access to CT).

Finally, some believed that DCE should consider more clinically relevant outcomes (and reassessed the HEAT target). Others suggested DCE explored further the role of influencers, maximised the use of qFIT with symptomatic patients and had IT systems in place before starting strategies.

#### 9.4.11.7 Engage further in prevention

Some stakeholders also suggested a stronger focus on prevention due to its importance for improving cancer outcomes, even though others recognised that this was not DCE's aim.

#### 9.4.11.8 Improve communication and stakeholder engagement

Recommendations included better engagement with screening programmes, clinical teams, charities and other stakeholders, ensuring they were part of the process rather

than just being informed about it. Better dissemination of programme outcomes was also recommended.

## 9.4.12 Theme: Barriers

### 9.4.12.1 Health system barriers

Several health system barriers were reported by stakeholders. There was recognition that diagnostic services were struggling irrespective of DCE, that funding was already not sufficient, and that there was overspending across cancer services. Increase in demand for services was reported for both primary and secondary care, alongside shortage of professionals (GPs and nurses for the former and radiologists, endoscopists and pathologists for the latter). Primary care was also reported to struggle with more and more responsibilities added to their work, while secondary care had to deal with increasing pressures such as waiting times targets.

> *"I think everybody's just got so busy and we haven't actually... instead of being honest about it and saying, 'here's the capacity we've got', particularly in primary care, everything just keeps getting added and added and added and there's no way of saying stop. We need some space to think things through" (ID 13)*

There were reported difficulties in booking appointments with a GP, long waiting times for diagnostics, and delays for GPs in receiving diagnostic information. Challenges were described as being compounded by the GP gatekeeping system in the UK and their limited ability to access diagnostic services.

The way the health system was organised was also criticised, especially regarding booking systems that did not recognise barriers to access for the most vulnerable populations (such as people having to take two or three buses very early in the morning for a consultation).

### 9.4.12.2 Factors influencing early detection

*Individual variation and help-seeking behaviour*

Stakeholders acknowledged a range of factors that influenced early detection. These included individual lifestyle behaviours, barriers to help-seeking (especially cancer fear, fatalism, Scottish stoicism, and concerns about wasting the doctor's time), and co-morbidity. Stakeholders recognised that health behaviours were "ingrained" and changing them was a long-term endeavour.

*Social deprivation*

Social deprivation was a salient theme when describing barriers to early detection. Stakeholders were widely aware of its association with low screening uptake, late presentation and poor cancer survival. Reasons for these differences in outcomes were also widely mentioned: different priorities, chaotic lifestyles, lower literacy levels, poorer health in general, accumulation of risk behaviours, financial barriers (such as fear of losing a job or not having enough money for transportation), lower locus of control and tragic cancer experiences.

> *"Their lived experience of cancer is sort of the worst possible, it's lots of people dying fast in horrible ways with seemingly no hope of treatment working. So, we sort of come into that going 'oh don't get scared get checked' you know" (ID 24)*

#### 9.4.12.3 Funding system in Scotland

Some stakeholders criticised the way funding was provided to health services in Scotland. They reported that having different funding streams with different conditions attached to them was detrimental to improving the whole patient experience.

#### 9.4.12.4 Data challenges

Stakeholders commented on the challenges on getting practice level data, especially regarding referrals, and on the implications for service improvement. There were also comments about data on consultation due to breast symptoms that ceased to be collected over time and limited availability of data on lung cancer examinations in secondary care. Some recognised that progress was still to be made before Scotland had better data on cancer-related services.

> *"[T]o get your practice level data is really, really difficult. Same with breast, it's so difficult to get that and not even the primary care facilitators can get that easily for you, it's always behind time, behind time, behind time. It's really frustrating that something that you think should be such a high priority that you can't get the data that you're looking for at the touch of a button" (ID 10)*

### 9.4.13 Theme: Facilitators

#### 9.4.13.1 Country size

Some stakeholders believed that the relatively small size of the country facilitated DCE being seen as a priority, adaptations over time and allowed for scaling up activities when needed.

#### 9.4.13.2 Cancer prevalence

The fact that cancer affects everyone's lives was also described as a motivator and facilitator to engagement in DCE and its activities.

#### 9.4.13.3 Good quality data

Being able to access and use data to make plans/develop strategies was also described as a facilitator. Data were described as important to make good decisions, to make national comparisons, for practices to benchmark themselves, to start meaningful conversations about what could be changed, and to be able to assess programme impact.

> *"One of the things that Be Clear [on Cancer] in terms of results and impact addressed that DCE has been slightly less direct about is that having done this intervention here are the number of people who have had earlier diagnosis, here's the stage shift and I think Be Clear on Cancer have been able to have more of that data and put more of that data into the public domain […] what it also does is it's part of that convincing healthcare professionals that this is an issue that's worth engaging with, and I don't think DCE have been able to present the data in the same way and been able to kinda demonstrate the impact quite as directly" (ID 31)*

#### 9.4.13.4 Funding as a hook

DCE funding was reported to facilitate engagement.

> *"It brought people to the table, so my imaging colleagues if I can use them as an example, always up to their eyes in waiting times pressures, the demands on imaging are horrific as we lean on imaging more and more in the diagnostic and treatment pathway. They came to the table because they knew that there was new investment" (ID 11)*

Funding provided as part of the bowel screening initiative was described as particularly useful as it allowed primary care to focus on it alongside a range of other responsibilities.

> *"To be honest it wasn't much funding that was needed, and it's not like the practices were making a big profit out of it or anything like that, it was more I think I used the term it's financial enablement. The money allowed them to do that work because they could pay for extra admin time and such like, and a lot of it was admin really to be honest rather than it having to be a clinician doing it" (ID 17)*

Funding was also reported to facilitate the introduction of the CRUK facilitator programme to general practices, and their subsequent engagement with the programme.

When funding ended, activities also often ended, although there were exceptions across Health Boards.

> *"If it's incentivised for a short period of time what happens is if nothing else is incentivised they would continue with that, but because then something else comes in they have to take the admin and the resource off that first project and put it to the next one" (ID 12)*

#### 9.4.13.5 Benefiting from existing activities and relationships

Stakeholders from territorial Health Boards that could build upon earlier work in cancer detection reportedly found it easier to implement the programme and decide where to invest additional funding.

#### 9.4.13.6 Tailoring messages

Stakeholders often believed that it was important to make initiatives meaningful to different groups, tailoring messages to them and linking activities to their current needs and demands.

### 9.4.14 Theme: A government initiative

#### 9.4.14.1 Prioritisation of early detection

Stakeholders described how the policy focus of DCE brought early cancer detection to the centre of attention, helping to "bring coherence and forward direction". As DCE was a flagship, high priority government programme, time, effort and resources were spent to develop and implement it. The HEAT target was also reported to help drive efforts, as it was based on an established framework and included in local delivery plans. Hence, early cancer detection was prioritised and DCE gained visibility.

> *"What would've happened if there was no policy focus on it, I think the programme would've remained in the back corridors of public health […] the policy focus on it really pulled it to the top of the pyramid in terms of the boards, and I mean the Health Board members, executive and non-executive directors, understanding of what we were tasked to do" (ID 11)*

#### 9.4.14.2 A dual purpose: politics and health

There were also perceived downsides of being a government programme. For stakeholders, political involvement also meant not receiving full information about where decisions about the programme came from.

A salient issue was the need to deal with increased time pressures. This was particularly true for timing between campaigns (which was reported to affect engagement and evaluations), and short intervals between them.

> *"[T]hen there was breast and then there was bowel and then there was lung, so in some ways it was good that we had those four defined phases […] But then there was also something about... you felt that you were being concertinaed, that you were working on the bowel and then 'stop that now I've got to do the lung' […] you spend a lot of time and effort getting teed up ready to go with the bowel cancer and then you were still analysing that when the lung cancer one came along and when you didn't have definite resources that meant you had to put things to one side" (ID 28)*

Furthermore, time pressures were perceived to be in conflict with being able to change cancer outcomes (as they require large timescales).

> *"Realising that there was political need to get an impact within a matter of a couple of years or a few years, that cancer doesn't do that and making big changes in the way things happen, it's very difficult to get measurable outcomes in that sort of timescale" (ID 23)*

There were also divergences between government aims and what health care professionals believed to be important. These included the use of ambitious targets (perceived to be important for politicians, but less so for health care professionals), and the need to emphasise benefits and harms of screening (instead of only promoting screening participation in government-funded campaigns).

> *"[T]here was a lot of discussion about whether or not it [HEAT target] was achievable and whether it was an evidence based clinically manageable target, or whether it was driven by political ambition! So, I know there was that discussion, you know, 'yeah, this is just politicians spouting forth and telling us how it ought to be but actually they haven't thought through whether this is possible and how this can be achieved in reality'" (ID 31)*

> *"At the end of the day it is a Scottish Government campaign, but initially there was quite a lot of, if you like, educating from the part of the NHS, of the marketing team, about the fact that screening is a choice and you can't just promote screening because it's going to be good for you because there is the potential to do harm to otherwise healthy people" (ID 14)*

Furthermore, stakeholders discussed DCE's dual purpose of promoting early cancer detection while also showing the public that the Scottish Government was fulfilling its political role and commitment.

> *"I don't mind the government telling people things about cancer, I think as I said it's good that the government is consistent in its messages, but there is another reason for DCE which isn't actually about detecting cancer early, it's about showing the public that the government cares about them and that it's doing something about cancer, and that isn't pure about actually getting the message across, that's pure about showing that they're doing something" (ID 27)*

Finally, as a government initiative using public money, DCE was described as being under constant scrutiny. There was the need to justify its activities and impact, and the HEAT target had a key role in showing this. Consequently, when reports showed that targets had not been met, the programme came under a lot of criticism.

#### 9.4.14.3 A new type of initiative

Stakeholders described how DCE was a new policy, not only approaching an unexplored area but also trying to implement a whole systems approach. DCE also adopted new, bold approaches to social marketing. There was a deliberate attempt to engage with people in deprived areas to encourage conversations about cancer in their own environment. Stakeholders also commented on how the DCE management team was paramount for enabling such innovations. The team was described as having sought opportunities for new projects, as being willing to push new boundaries, and trying to avoid unnecessary bureaucracy.

### 9.4.15 Theme: Cultural shifts

*Realistic/personalised medicine: patient perspective*

Stakeholders often commented on the need to respect patients' autonomy and informed choice, including on decisions to attend screening and choice of treatment (including choosing not to have treatment), and on giving time for patients to make decisions (irrespective of waiting times targets). Respecting individual differences and reaching out to patients (instead of waiting for them or expecting them to reach out) were also urged. A more holistic approach towards patients was described, approaching not only early detection, but also incorporating cancer prevention advice.

*Image of cancer has changed*

Stakeholders commented on how the image of cancer had changed in the past decade, with reduced fear and normalised discussions (irrespective of DCE role).

*"it feels like it's something people can talk about, it is talked about, it's not taboo, it's not that slightly witchcrafty thing that if I say the word I'm going to get it" (ID 24)*

### 9.4.16 Theme: Regional variation

Stakeholders discussed regional variation when talking about a range of issues. There was reported diversity in terms of population and geography, including deprivation (and how this was distributed), literacy issues, health status, prevalence of cancer risk factors, remoteness and rurality (and corresponding barriers to health promotion, disseminating strategies, and access to services). In terms of health system characteristics, there were reported differences in how services were organised, in available routes to cancer diagnoses, examinations, specialists, and in whether GPs had direct access to diagnostic tests. These variations were reported to influence DCE implementation, evaluation, sustainability and cancer outcomes.

*"There was quite a lot of work across Scotland, each Board doing it their own little way" (ID 23)*

Health Boards had different levels of engagement with DCE activities, assigned different staff for specific roles and responsibilities, had diverse partnerships with local business and charities, engagement with other health care professionals and other government programmes (such as Keep Well or Transforming Care After Treatment programmes). Some areas were reported to benefit more from nationally organised roadshows than others (due to bigger population sizes or ease of access), and this caused frustration at times.

*Where the Lidls and Aldis are situated, certainly in Highland, they're situated in more of our […] deprived areas, you know, so if you had the campaign there or a stall you might have more chance of actually reaching some of the sort of people that we'd like to reach, but it's a smaller store and maybe it's more difficult perhaps to make the connections and get things set up. That's an example perhaps where convenience perhaps sometimes dictated where they went rather than necessarily need. (ID 34)*

Boards received different amounts of funding and invested it in different ways. Some already had strategies in place and data that facilitated DCE implementation, or capacity to carry out additional early detection activities and evaluate them (using a range of tools), others could not do so. While some Boards had the ability to supplement national campaigns with local activities and continue with them after funding ended, others struggled to do this.

Furthermore, Health Boards had different exposure to TV ads (with those close to England not always seeing Scottish ads, but being potentially influenced by Be Clear on Cancer, and NICE referral guidelines).

In terms of outcomes, performance also varied widely across Health Boards, and stakeholders were aware that interpreting this variation was difficult. From the perspective of DCE managers, variations influenced their ability to coordinate the programme nationally, and to communicate with different Boards.

Wide variation in HEAT target outcomes over time (often due to small numbers) was reported to cause anxiety across different Health Boards. Having a national target that had to be extrapolated back to local populations was also seen as counterintuitive.

> *"What we've noticed is that the variation from quarter to quarter and then from year to year is difficult in the percentage change and that sometimes makes people anxious about why there's so much variation, so we can look like we're doing okay one quarter and the next time we've gone really down and the non-execs and the execs as well in the organisation they get quite upset with this, and it's really just because the numbers are small" (ID 30)*

Concerns were also raised by stakeholders from Health Boards that had high bowel screening uptake at baseline, as it was more difficult for them to meet targets compared with those with poorer performance.

### 9.4.17 Theme: DCE beyond three years

Stakeholders often commented on a range of other activities taking place alongside the DCE programme, which either influenced DCE or were influenced by it. Most of these happened after DCE's first three years.

Scotland adopted FIT for bowel screening in November 2017 (replacing the FOBt). This was reported not only to increase uptake across Health Boards and increase the demand for diagnostics, but it also influenced the decision not to target bowel screening in social marketing campaigns any longer (as increase in uptake was already expected).

Funding for DCE dramatically decreased after three years, and this required a change in strategy. Social marketing campaigns on TV ceased to be tumour-specific (although tumour-specific campaigns were still targeted using other media) and it was no longer possible to allocate funding to Health Boards (although there was still some funding available for local, innovative pilots).

Although funding was reduced for DCE activities, a new Cancer Fund was developed to provide funding to specifically target inequalities in screening. This was welcomed by stakeholders.

Demand for diagnostic services was reported to have increased over the years. This was accompanied by added challenges to diagnostic capacity in Scotland, especially in terms of limited workforce. A stakeholder believed that it would have been impossible for DCE to be launched in these new circumstances. Another described a perceived conflict between the current austerity agenda and the perception that a range of investigations can happen.

> *"The workforce we just don't have enough now, so I think five/six years ago when we introduced the programme we'd a very different workforce mix in that we'd a lot of people working, a lot of clinicians approaching the age of 50 or so who have now since hit 55 and retired cause it's not worth them staying longer so we've got a bit of a workforce crisis, and particularly in terms of diagnostics we don't have enough radiologists to read reports, we're outsourcing a lot of reports, we don't have enough radiographers to actually go through a lot of the diagnostic investigations" (ID 33)*

The HEAT target continued to be measured after three years (it became a Local Delivery Plan standard), as those managing DCE activities believed it was still important to measure staging (although there was reported disagreement on whether targets should have been kept).

> *"The other thing is I suppose, you know, when they said it [HEAT target] was going to finish in 2015 it should finish in 2015. There's so many things that just end up still on as a priority" (ID 30)*

The referral guidelines were updated again in 2018 in order to include new evidence, and DCE changed not only the updating process (using a rapid review process) but the dissemination strategy, aiming to more closely involve secondary care, and better disseminate the use of apps instead of printed materials. There was the recognition that some professionals still referred to NICE in England instead of the Scottish guidelines, that communication between primary and secondary care did not always happen, and that variation regarding direct access to diagnostics was still an issue.

DCE also implemented different melanoma pilots across Scotland, and qFIT for symptomatic patients continued to be piloted across different Health Boards. A new ministerial group was developed looking at performance and delivery of CWTs.

Professionals involved in DCE were also reported to have changed over the years. A stakeholder believed that staff changes, added to the programme's length, resulted in a certain level of accommodation in terms of efforts to ensure stakeholder engagement.

> *"So that was a very personal approach I suppose, you know, yet individuals have changed in certain teams and I think that approach probably has maybe been slightly lost, and I don't know, maybe it is because the programme's been running for that length of time, there's maybe been a bit of a loss of... there's not laziness in terms of who's engaged but maybe it is more about 'I'll fire an email and that's me, I've done that' as opposed to actively engaging and having a communication, as opposed to this is what we're doing, here it is and it's based on research"(ID 25)*

## 9.5 Summary of Chapter 9

This chapter reported on results from the interview component of the process evaluation of the DCE programme. Interview findings showed that there was wide support for a national programme promoting early cancer detection, even though there were disagreements with some of the approaches adopted by DCE. Importantly, sense of ownership and perceived ability to positively change service provision and cancer outcomes influenced engagement and buy-in.

DCE adopted a range of communication channels to keep stakeholders informed and consult with them. Over time, communication became patchier, with "gaps" and limited notice regarding social marketing campaigns and associated activities (with implications for stakeholder engagement). Stakeholders often reported uncertainty regarding the rationale for a range of DCE strategies and wished that their input/expertise had been sought before decisions about the programme had been made. Additional knowledge of, and involvement in, decision-making regarding DCE strategies was reported to influence engagement and sense of ownership. Stakeholders wished that there had been more dissemination of local activities and sharing of best practices, so they could learn from different experiences.

There was wide variation in resource availability across different Health Boards, but in general it was clear that both primary and secondary care were under-resourced and understaffed irrespective of DCE. Hence, there were concerns regarding DCE's impact on workload, as many professionals did not think they would be able to cope with increase in demand brought by the programme.

Stakeholders also reported wide variability in how funding was used. Flexibility was not only allowed by DCE but also encouraged. Nonetheless, there was evidence that the process of allocating funds was not always transparent (which caused frustration), and that some areas benefited more from funding than others. Too much flexibility made it difficult to evaluate how DCE funding was used, and any associated outcomes. At a national level, flexibility allowed for investing in a range of activities, but also resulted in the programme having “arms and legs” and running the risk of becoming piecemeal.

Stakeholders often saw DCE as part of their role, but many also highlighted that DCE activities required additional work, resources, and sufficient notice so tasks could be properly allocated.

(Limited) evidence on how funding was used indicated that it was most often used in secondary care, although it was also used to keep the normal service running. Funding on its own was often not sufficient to increase capacity.

DCE strategies resulted in increase in demand for diagnostics and corresponding increase in workload. This increase drove professionals to act, but caused frustration when patients were not the ones they expected to see and there were no corresponding improvements in cancer outcomes.

Targets were reported to focus minds and to help bring DCE and early detection to the centre of attention, but different targets generated different reactions. While the QOF targets were seen positively, HEAT targets caused frustration and affected buy-in. Some believed that the HEAT targets were a politically driven measure with limited clinical relevance. Others liked the idea of having an ambitious target, as it was aspirational and helped to drive improvements.

A range of barriers were reported by stakeholders; including the ones referring to an overstretched health system, other factors influencing early detection, and limited availability of data. Likewise, several facilitators were reported; these included having good quality data and having funding as an enabler.

Both positive and negative unanticipated outcomes were reported. Negative outcomes included delays diagnosing patients with a higher risk of cancer, delays treating cancer patients or increasing professional and patient anxiety. Positive

outcomes included lessons learned from DCE being used to inform other government initiatives, and new equipment to provide better treatment to cancer patients.

This was the final Chapter reporting on results from the DCE evaluation. The next (and final chapter) in this thesis integrates and discusses evaluation results and addresses the two remaining PhD objectives.

# Chapter 10 Discussion

## 10.1 Overview

This PhD project aimed to investigate the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer. It had four objectives: 1) to understand the international landscape of such initiatives; 2) to evaluate the DCE programme; 3) to compare DCE with other initiatives; and 4) to provide recommendations for policy.

The systematic review (Study 1, Chapter 4) reported on 18 multilevel policy initiatives which often targeted 1) public cancer awareness and/or knowledge; 2) professional education; 3) referral pathways based on cancer symptoms; or combinations of these strategies. Evidence was limited on high-level outcomes such as survival, mortality and tumour staging. There were data for intermediate outcomes such as positive changes in knowledge/awareness (and limited data on change in behaviour) and reduced diagnostic intervals. Stakeholder views on initiatives were often positive.

Evaluation development and refinement (Study 2, Chapter 5) resulted in a comprehensive description of DCE, development of a logic model, a textual programme theory, outcomes chains, and assumptions and mechanisms of impact which were then investigated in the DCE evaluation.

Finally, the DCE evaluation (Study 3, Chapters 6 to 9) outlined that DCE's key aim was not met, although there were improvements in tumour staging. There was increase in awareness of cancer symptoms and signs and in help-seeking behaviour, but barriers to help-seeking persisted. Process evaluation results showed that there was wide support for an early detection initiative but buy-in varied according to different programme strategies. Communication challenges influenced buy-in and sense of ownership. Increase in demand drove action but had negative implications. Views on targets were mixed, especially when they were unachievable or perceived to have limited clinical relevance. Stakeholders valued "soft outcomes" which were not often assessed and wished that local activities had been better disseminated.

This final chapter integrates findings from these three studies. Recommendations for policy and research are provided. Study strengths and limitations are outlined, followed by personal reflections about the PhD journey and overall conclusions. References to relevant literature are made throughout the chapter.

## 10.2 Integrating evaluation findings

### 10.2.1 Evaluation development and the DCE evaluation

Prior to the evaluation, it was necessary to have a clear description of the DCE programme, its components, underlying assumptions and mechanisms, and contextual issues (154, 158, 161, 165, 374). This was achieved with Study 2, which also reinforced the importance of incorporating complexity-theory/systems thinking into the evaluation and helped to identify suitable implementation and behaviour change theories/frameworks. It would not have been possible to carry out the DCE evaluation without the evidence obtained in Study 2.

Several stakeholder responses from evaluation development were similar to responses which came out of the DCE evaluation (Box 10.1). These similarities were inevitable as the studies were connected, and issues raised in the initial interviews were further investigated in the DCE evaluation. Furthermore, in both cases several interview participants had a similar profile (i.e. were involved in the development or in the running of the DCE programme).

**Box 10.1.** Similar issues identified in Study 2 and Study 3

- **Stakeholder buy-in**: overall belief in the programme, despite criticisms. Concerns about how demand brought by DCE would be managed
- **Reach and communication**: Some reports of limited clinical input and limited clinical relevance of measures/strategies, challenges in the primary and secondary care interface, comments on how information provision helped with sense of ownership
- **Sustainability:** funding needed over time, challenges with communication over time
- **Contextual issues:** regional variation (challenges, aims, and use of funding); NHS constraints; political imperative and pressure to work; political conflict of interest; deprivation; behaviour change challenges (fear, fatalism, Scottish stoicism); cultural shifts and changes in the way cancer is perceived (irrespective of DCE, but helped by it)
- **The role of targets:** can focus the mind and drive activity at times, but also uncertainty regarding their usefulness, and its short-term aspect
- **DCE outcomes:** challenges in showing causality, aspiration for long-term changes, intermediate outcomes do not equal success, different views on what success means
- Challenges when **interacting with the media**
- **Recommendations** to target patients at risk and provide direct access to diagnostics

### 10.2.2 Integrating process evaluation findings

The process evaluation investigated whether implementation outcomes and mechanisms of impact identified during evaluation development were confirmed by stakeholders, looked for barriers and facilitators, and unanticipated outcomes. Data were collected through semi-structured interviews and a purpose-built online questionnaire.

The same inclusion/exclusion criteria were applied for interviews and the questionnaire in order to obtain parallel samples and carry out a merged data analysis (221). There was a different composition of DCE stakeholders between the studies. While most interview participants managed health care services or DCE strategies, most questionnaire participants were secondary care doctors. There was also variation in terms of views, with those answering the questionnaire often having more negative views about the programme. This could be due to variations in the respondents' profile, but it could also be due to guaranteed anonymity for those answering the questionnaire. There is evidence that anonymised questionnaires can increase willingness to report sensitive information and can also result in more accurate reporting (504). Interviews, on the other hand, are more prone to social desirability bias, although ensuring anonymity and confidentiality (as done in this study) can help to avoid this (504).

Furthermore, the observed low level of precision (and wide confidence intervals) obtained with the questionnaire indicates less confidence that the population of interest would have answered the questions in a similar way. No power-based calculations were carried out, but the very small sample size (n=53) also indicates uncertainty over whether the observed effect (i.e. variations in responses across groups) would be true to the population of interest. Therefore, even though the use of mixed methods aimed to obtain both in-depth accounts and representative responses from the population of interest (i.e. DCE stakeholders), the latter may not have been achieved in this study.

Bearing in mind these limitations, Table 10.1 comprises a joint display (195, 226) synthesising results from the interviews and questionnaire, while also showing process evaluation questions. Results are then integrated using a narrative approach. Furthermore, illustrative quotes from interviews and open-ended questions in the questionnaire were mapped onto implementation outcomes and COM-B components; these are available in Appendix 38.

**Table 10.1.** Joint display of findings: interviews and questionnaire

| Interviews (I) | Questionnaire (Q) |
|---|---|
| **Stakeholders' profile** | |
| • N=25; women (n=15)<br>• Most managed health care services or DCE strategies (n=14)<br>• Interview duration 17-79 minutes (mean 48 minutes) | • N=53; women (59.2%); mean age 50.78 (SD 5.66)<br>• Secondary care doctors (62.7%); GPs (13.7%)<br>• Worked with a specific tumour type (75.0%; most often breast) |
| **Assumption 1:** Different stakeholders bought into DCE, its components and what it proposed to do | |
| • Wide support for promoting early detection, but disagreements regarding DCE approaches (i.e. appropriateness of focusing on symptoms that did not indicate early stages, choice of tumour types and timing of campaigns)<br>• Sense of ownership and perceived ability to improve services and cancer outcomes influenced engagement and buy-in<br>• Wide support for the bowel screening initiative (and frustration when it stopped), but less support for the HEAT targets ("unachievable")<br>• DCE not as feasible in the current environment; reduced funding<br>• Persisting barriers to help-seeking, campaigns with temporary impact<br>• Many activities ended when funding ended (Health Board variations)<br>• Stakeholders have different perspectives of what constitutes success<br>• Views on other approaches to adopt, such as focusing on the most deprived<br>• **Themes***:* stakeholder buy-in, impact on workload, official outcomes, recommendations, a government initiative, DCE beyond three years | • 49.0% disagreed to a certain extent that DCE's benefits outweighed the time and effort required to work towards its aim<br>• Mixed views on *appropriateness*, high agreement for the *bowel screening initiative* (85.7%) and low for *HEAT targets* (49.0%)<br>• Mixed support for *DCE continuation* (49.0% agreement)<br>• Those who wished they had had an input in programme development/implementation had lower median scores for the *appropriateness* of DCE (p=0.047) and HEAT targets (p=0.042)<br>• Content analysis: assumption often not confirmed (48 counts). Comments referred to issues such as the focus on breast symptoms (attracting the worried well and not resulting in more cancer diagnoses), and timings of campaigns<br>• **Questions:** Q6.1a, Q6.2a,Q11.1.a, Q11.1.b, Q15.1.a, Q20.1.a, Q24.1.a, Q29.1.a, Q33.1.a, Q37.1.a., general feedback |
| **Assumption 2:** There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone | |
| • Reports of limited information for some components but recognition that information may have been provided, but got lost among other information<br>• Over time, communication became patchier, with "gaps" and limited notice regarding campaigns (with implications for stakeholder engagement)<br>• Stakeholder uncertainty regarding the rationale for DCE strategies, and frustration when expert views were not heard – knowledge and involvement in decision-making influenced engagement and sense of ownership<br>• Referral guidelines could have been better disseminated to secondary care<br>• Calls for further dissemination of local activities (including soft outcomes), national outcome data, and sharing of best practices | • About half of those not involved in developing/implementing DCE would have liked to have had an input<br>• Mixed views on whether information was sufficient; highest for the bowel screening initiative (72.7%) and lowest for funding (10.0%)<br>• 85.2% disagreed that communication between primary and secondary care went well on how to use funding, secondary care doctors had lower median scores (p=0.028)<br>• They were also less informed about guidelines (10.7%, p=0.001), education sessions (13.0%; p=0.036) and funding (0%, p=0.002) |

| Interviews (I) | Questionnaire (Q) |
|---|---|
| • Calls for better stakeholder engagement (including with screening programmes), ensuring stakeholders were involved in decision-making<br>• **Themes:** communication, DCE beyond three years, recommendations, soft outcomes and other benefits | • Content analysis: assumption often not confirmed (39 counts), comments about not having the opportunity to give input, not being aware of DCE strategies, and delays in receiving information<br>• **Questions:** Q3, Q4, Q14, Q19, Q23, Q28, Q29.4.a, Q32, Q36, general feedback |
| **Assumption 3:** Available resources were sufficient to meet aims | |
| • Wide recognition that primary care and diagnostic services were understaffed, under-resourced and overstretched irrespective of DCE, and concerns about not being able to cope with increase in demand brought by the programme<br>• Variation in resource availability across Health Boards both facilitated or hindered implementation, evaluation and sustainability of early detection strategies<br>• **Themes:** impact on workload, barriers, facilitators, regional variation | • Most disagreed that there was enough time to engage in DCE (64.5%). Those working with breast cancer had lower scores (p=0.031) compared to more than one tumour type<br>• Those who were not involved in developing/refining DCE but wished they had had an input on DCE had lower median scores compared to those who were involved (p=0.040)<br>• Content analysis: assumption often not confirmed (17 counts). Comments on limited resources/planning and impact on workload<br>• **Questions:** Q7.3.a, Q20.3.a, Q29.3.a, Q37.4.a, general feedback |
| **Assumption 4:** Flexibility was permitted when allocating resources | |
| • Wide variability in how funding was used; flexibility was encouraged. However, there was frustration when funding allocation was not clear<br>• Too much flexibility resulted in challenges when trying to assess how funding was used, and evaluate programme impact<br>• Flexibility allowed for investing in local strategies, in more innovative approaches and in prevention activities<br>• DCE had the ability to adapt and change according to need, but flexibility resulted in the programme having “arms and legs”<br>• Recommendation to be more prescriptive about how to use funding<br>• **Themes:** flexibility as a two-edged sword, using DCE funding, recommendations, regional variation | • Most disagreed that flexibility was permitted (65.2%) with secondary care doctors having significantly lower median scores than nurses (p=0.026)<br>• Content analysis: assumption often not confirmed (10 counts). Comments often referred to complaints about areas that did not receive funding<br>• **Questions:** Q7.2.a, general feedback |
| **Mechanism 1:** DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries | |

| Interviews (I) | Questionnaire (Q) |
|---|---|
| • DCE strategies were in line with the job carried out by many professionals - for others, time and resources were needed so they could be involved in DCE activities in addition to their daily jobs (most were happy to participate)<br>• Novel aspects of the programme (e.g. engaging with women at the Bingo) were not described as being part of the professionals' roles<br>• **Theme:** DCE and the professionals' roles | • Most agreed that it was part of their job to be involved in DCE (77.4%). However, most also agreed that it was difficult to integrate DCE components into their usual work (86.8%)<br>• Content analysis: mechanisms often not confirmed (2 counts). Targets not seen as clinical measures, competing responsibilities<br>• **Questions:** Q7.1.a, Q20.2.a, Q33.3.a, Q37.3.a |
| **Mechanism 2:** Additional DCE funding resulted in in more diagnostic equipment and/or workforce | |
| • Funding often invested in secondary care to increase capacity (with wide variations in activities), but also used to keep the service running<br>• Funding on its own not enough to increase capacity if there were not enough specialists to recruit – at times it paid for overtime or to cover empty posts<br>• Funding did not reach all areas that had projects in mind for DCE, and some believed it was not enough for what they had proposed to do<br>• Calls for transparency on how funding was used<br>• **Themes:** using DCE funding, barriers, regional variation, facilitators, stakeholder buy-in, recommendations | • Most disagreed that additional funding resulted in more equipment (83.4%) or workforce (73.4%), secondary care doctors had significant lower median scores than nurses (p=0.019)<br>• Most disagreed that they were confident about their ability to manage demand (66.6%)<br>• Content analysis: mechanism often not confirmed (23 counts). Comments about funding not being sufficient, being used to deal with backlogs, and not being the solution for recruiting specialists<br>• **Questions:** Q29.2.a, Q29.5.a, Q29.6.a, general feedback |
| **Mechanism 3:** Increased demand brought by DCE was a driver for action and created pressure to act | |
| • DCE strategies resulted in an increase in demand for primary care consultations, diagnostics and corresponding increase in workload<br>• Impact of the symptomatic breast campaign in primary care ("flooded with the worried well") and in breast screening services; increase in demand at the bowel screening centre, for endoscopy and pathology services<br>• Primary care practices developed diverse strategies to identify and engage with non-responders to bowel screening<br>• Mixed views on impact (expected, unexpected, underestimated)<br>• Frustration when there were no improvements in cancer outcomes<br>• **Themes**: impact on workload, stakeholder buy-in | • Most stated that DCE increased demand (92.6%), but often this did not drive the development of ED strategies<br>• Most stated that campaigns (94.9%), referral guidelines (80.6%) and bowel screening initiative (81.3%) increased demand for services<br>• Content analysis: mechanism confirmed (7 counts). Comments referred to how demand drove the recruitment of professionals, stimulated focus on capacity, and increased pressure (this was not always seen as a positive outcome)<br>• **Questions:** Q8, Q9, Q16, Q25, Q38, general feedback |
| **Mechanism 4:** Targets helped to focus the mind, showed where resources were needed and increased pressure to act | |
| • In general, targets were reported to focus minds and to bring early detection to the centre of attention. However, while QOF facilitated engagement and helped to develop a sense of ownership, HEAT targets affected engagement<br>• Recognition that changes in cancer outcomes required longer time frames – in contrast with short-term targets | • Variation in confidence to meet targets; 63.7% agreed (QOF); 53.8% disagreed (HEAT) – but same median scores (4) for QOF and HEAT on whether targets pressured the team to act<br>• Disagreement that HEAT target was a reminder for where efforts should be focused (62.9%); lower disagreement for QOF (36.8%) |

| Interviews (I) | Questionnaire (Q) |
|---|---|
| • For some, HEAT targets were a politically driven measure with limited clinical relevance. Others liked the aspirational target to help drive improvements, but believed DCE was not about targets<br>• Variation in performance (HEAT) caused anxiety across Health Boards<br>• **Themes**: stakeholder buy-in, a government initiative, official DCE outcomes, soft outcomes and other benefits | • Content analysis: mechanism not confirmed (5 counts). Comments referred to HEAT targets being unhelpful and unrealistic, and being public health measures (instead of clinical)<br>• **Questions:** Q33.2.a, Q33.4.a, Q33.5.a, Q37.2.a, Q37.5.a, Q37.6.a, general feedback |
| **Barriers** | |
| • Overstretched professionals, limited resources, long-term vacancies, challenges in accessing care and meeting waiting times targets<br>• Lifestyle behaviours, barriers to help-seeking (fear, fatalism, stoicism and concerns about wasting the doctor's time) and social deprivation<br>• Limited data availability, especially practice-level data on referrals<br>• **Themes:** barriers, using DCE funding, DCE beyond three years, regional variation | • Content analysis: 22 counts referring to NHS challenges (stretched capacity and recruitment issues), early detection challenges (barriers to help-seeking) and competing responsibilities<br>• **Questions:** Q49, general feedback |
| **Facilitators** | |
| • Country size; cancer being an experience most people can relate to; having good quality data; funding as a hook to facilitate engagement; benefiting from existing activities and relationships (wide variations); and tailoring messages to different stakeholders<br>• **Themes**: facilitators, using DCE funding, regional variation | • Content analysis: 9 counts referring to good quality data, IT resources, good leadership, management and teamwork, ability to plan and share learning and having an effective screening method<br>• **Questions:** Q49, general feedback |
| **Unanticipated outcomes** | |
| • Negative unanticipated outcomes: delays diagnosing high risk patients/treating cancer patients; competing for professionals across different Health Boards; increasing professional and patient anxiety<br>• Positive unanticipated outcomes: lessons learned from DCE informing other government initiatives; new equipment to provide better treatment to cancer patients; identifying knowledge gaps among health care professionals; potential diagnoses of conditions other than cancer (such as COPD); increase in help-seeking behaviour for other tumour types<br>• **Theme**: unanticipated outcomes | • Content analysis:29 counts referring to negative impact of the worried well seeking reassurance (such as delays for other patients who needed care), stress and burn-out for professionals, concerns about overdiagnosis and breast campaigns leading to patients presenting with symptoms of late stage disease<br>• **Questions:** general feedback (Q5, Q10, Q12, Q14.a, Q17, Q19.a, Q21, Q23.a, Q26, Q28.a, Q30, Q32.a, Q34, Q36.a, Q39, Q48, Q50) |

#### 10.2.2.1 Data integration: implementation assumptions

Views on DCE *appropriateness* were more positive across interview participants, although there was overall agreement that it was important to promote early detection. Reasons for disagreement were similar across both groups; these referred to the choice between focusing on screening or symptoms and signs, and timing of awareness campaigns. The bowel screening initiative was more widely *accepted* compared to HEAT target (which was perceived to be *unachievable*) both among interview and questionnaire participants. Furthermore, both qualitative and quantitative findings showed that buy-in was associated with involvement in the programme, and with being able to see positive outcomes. About half of questionnaire participants agreed to a certain extent that they supported DCE *continuation*; interview participants wished that the bowel screening initiative had been *sustained* for a longer period and were aware that many activities ended when funding ended. Hence, **assumption 1 (different stakeholders bought into DCE, its components and what it proposed to do) was partially confirmed by stakeholders, with variations across different DCE strategies and stakeholder groups**.

Both interview and questionnaire findings indicated that those providing direct services to patients (i.e. those at the frontline) knew less about DCE and its activities. This was particularly evident among secondary care professionals, especially regarding referral guidelines and awareness campaigns. Furthermore, there was reported frustration across stakeholders when expert views were not heard, when there was not enough notice before campaigns were launched, and when information on programme outcomes was not made available. Results indicated that **assumption 2 (there was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone) was often not confirmed as neither *reach* nor *communication* were perceived to be sufficient by a range of stakeholders**. Nonetheless, it is important to highlight contextual issues mentioned by stakeholders that may have affected these results, such as information overload or overstretched professionals.

Both interview and questionnaire participants recognised that the NHS had limited resources and was struggling irrespective of DCE, and this resulted in raised concerns about resources not being *sufficient* to cope with demand brought by the programme. Furthermore, these concerns were reported to have become a reality for many stakeholders and influenced *acceptability* across questionnaire participants.

**Assumption 3 (available resources were sufficient to meet aims) was therefore not confirmed.**

Interview participants who managed DCE commented on the programme's ability to *adapt*; other interviewed stakeholders also highlighted DCE's flexibility (especially regarding the use of funding). Questionnaire participants, however, most often disagreed that flexibility was permitted when using funding. Results indicated that those at the frontline (at least in the case of those answering the questionnaire) may have had less influence on how funding was used. **Assumption 4 (flexibility was permitted when allocating resources) was partially confirmed by stakeholders.**

#### 10.2.2.2 Data integration: mechanisms of impact

Both questionnaire and interview data indicated **agreement with mechanism 1 (DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries), with very few exceptions**. Stakeholders consciously believed that DCE was part of their professional role and identify (*reflective motivation*). Nonetheless, challenges were reported in terms of competing responsibilities and engaging in novel activities.

Compared to interview participants, views were more negative across questionnaire participants over whether funding resulted in more diagnostic capacity (equipment or workforce), although in both cases there were examples of new equipment/staff bought with DCE funding (*physical opportunity*). Concerns were also raised by both groups. There were reports of funding not being sufficient, criticism regarding funding being used to deal with pre-existing challenges (i.e., evaluations/beliefs about what is good and bad - *reflective motivation*), and shortage of qualified professionals impeding the recruitment of required diagnostics staff. Therefore, **mechanism 2 (additional DCE funding resulted in in more diagnostic equipment and/or workforce) was only partially confirmed** and was mostly influenced by contextual barriers (especially limited resources and workforce challenges).

Both interview and questionnaire participants reported that DCE increased demand for services in primary and secondary care, and this had a direct impact on workload, requiring adjustments and changes from health care professionals. In both cases, there were reports of services being "flooded" with the worried well (especially due to the symptomatic breast campaign), and both short- and long-term impact on services. This resulted in "angst" and stress among professionals (*automatic motivation*).

Therefore, **mechanism 3 (increased demand brought by DCE was a driver for action and created pressure to act) was confirmed by stakeholders**. Importantly, increase in demand caused frustration when it did not result in more cancers being diagnosed or early detection (as described both in questionnaires and interviews).

Views on targets were more negative across questionnaire participants, although concerns about HEAT targets were raised both in interviews and questionnaires. Some interview participants were happy for the HEAT targets to be a driver of change even though they were not met (*reflective motivation*); similar views were not shared by those answering the questionnaire. In both cases, there were references to targets not being clinically relevant (*reflective motivation*), and mixed views over whether the targets pressured the team to act. Wide variations in meeting HEAT targets was reported to make stakeholders anxious in different Health Boards (*automatic motivation*). Both for questionnaire and interview participants, QOF targets were seen more positively than the HEAT targets. In the case of interviews, this was reportedly due to the ability to see impact with the bowel screening initiative (*reflective motivation*). Therefore, **mechanism 4 (targets helped to focus the mind, showed where resources were needed and increased pressure to act) was partially confirmed**. Evidence indicated that views differed based on previous experience with aspirational targets, and their relevance to the professionals' work.

#### 10.2.2.3 Data integration: barriers and facilitators

Several barriers were reported by stakeholders, with marked similarities between interview and questionnaire participants. In both cases, health system barriers (namely overstretched capacity, limited resources and scarce workforce) and barriers to help-seeking were described.

Likewise, facilitators were similar. Having good quality data and good IT resources, and benefiting from existing relationships, good management and teamwork were mentioned both in interviews and questionnaires.

#### 10.2.2.4 Data integration: unanticipated outcomes

In both cases, unanticipated outcomes due to increase in demand and workload (often resulting from an increase in the worried well seeking reassurance) were mentioned. Unanticipated outcomes included increase in professional anxiety and negative impact on patients who needed urgent care. Positive unanticipated outcomes were only mentioned by interview participants. Importantly, while some unanticipated

outcomes were based on actual experience, others referred to concerns and expectations (that may or not have become reality). It was not always possible to differentiate between these two possibilities due to limited data on patient outcomes.

#### 10.2.2.5 Summary: integrating process evaluation findings

In sum, when integrating findings, assumptions and mechanisms were most often only partially confirmed (Figure 10.1). Key implementation issues referred to challenges regarding reach and communication and having sufficient resources (assumptions not confirmed). It was clear that DCE was line with the professionals' roles and that demand was a driver for action (confirmed mechanisms), although the latter had a negative impact on professionals.

**Figure 10.1.** Were assumptions and mechanisms confirmed by stakeholders?

| Assumptions | | Mechanisms | |
|---|---|---|---|
| A1.Different stakeholders bought into DCE, its components and what it proposed to do | Partially confirmed | M1.DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries | Confirmed |
| A2.There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone | Not confirmed | M2. Additional DCE funding resulted in in more diagnostic equipment and/or workforce | Partially confirmed |
| A3. Available resources were sufficient to meet aims | Not confirmed | M3. increased demand brought by DCE was a driver for action and created pressure to act | Confirmed |
| A4. Flexibility was permitted when allocating resources | Partially confirmed | M4. Targets helped to focus the mind, showed where resources were needed and increased pressure to act | Partially confirmed |

## 10.2.3 Integrating findings from the full evaluation

#### 10.2.3.1 Integrating process, context and outcomes

The purpose of having a process and an outcome evaluation was to understand not only what happened, but also how and why it happened. In order to do so, it was necessary to integrate process and outcome evaluation findings (166). This was done in a joint display table (195, 226) (Table 10.2) and in a textual narrative. Perceived benefits of carrying out a process evaluation are also highlighted.

**Table 10.2**. Process and outcomes

| Outcome evaluation | Process evaluation |
|---|---|
| **Objective 1:** To increase the proportion of breast, colorectal and lung cancers diagnosed at Stage I by 25% and use performance as a lever for whole systems improvement | |
| • Objective was not met, but improvements in staging were noted<br>• 7.0% increase in the proportion of cancers diagnosed at Stage I (lung, breast and bowel combined) at Year 3<br>• 25.0% increase for lung, 5.1% increase for breast, and 4.3% decrease for bowel at Year 3<br>• Increase across all five levels of social deprivation (lung, breast and bowel combined), with the highest increase for the most deprived (11.3%)<br>• Increases across all three cancer networks (lung, breast and bowel combined) at Year 3<br>• Variations across territorial Health Boards | • HEAT target was ambitious, and some agreed that was useful to drive change – most stakeholder did not expect it would be met<br>• For some, an unachievable target resulted in frustration, reduced engagement and sense of ownership – questions were also raised over what it meant if target was not met (i.e. how the programme's impact would be ascertained)<br>• Some were unsure of the rationale for the target and its limited clinical significance<br>• Stakeholders believed that soft outcomes were important but not measured<br>• Recognition that change in staging would take a long time (although measured with a short-term target), and that the target made more sense for politicians<br>• **Process evaluation measures:** Assumption 1, Assumption 2, Mechanism 1, Mechanism 4, Barriers and Facilitators |
| **Objective 2:** To improve informed consent and participation in national cancer screening programmes. **Objective 3:** To raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier. | |
| • Objectives were met to a certain extent<br>*Breast screening*<br>• No perceived impact; calls to screening centre to book appointments did not result in increased screening uptake<br>• Campaign recognition, awareness of screening risks, benefits and limitations higher for those already invited and screened<br>*Breast (symptomatic)*<br>• 51.1% increase in consultation for breast symptoms during the campaign periods; potential increase in GP/self-referrals<br>• Campaigns showed positive impact on intention to act, knowledge and awareness of symptoms<br>*Bowel screening*<br>• Increase in uptake overall, for males and the most deprived (targeted by campaigns) – but in line with existing trends | • Increase in workload was not perceived to translate in more cancer diagnoses – this resulted in frustration (there were also anecdotal reports of women presenting with late stage cancer)<br>• Variations in the perception of whether the symptomatic breast campaign was successful<br>• Acknowledgement that buy-in for breast screening may not have been high across some professionals<br>• Concerns over whether the right people had been targeted, as there were lots of worried well – some recommended a stronger focus on patients at risk and the most deprived, or more investment in primary care instead<br>• Mixed views on whether the focus should have been on screening or symptomatic presentation<br>• Reports that outcomes from local awareness initiatives were not disseminated – acknowledgement that perhaps results would never be known |

| Outcome evaluation | Process evaluation |
|---|---|
| • Campaigns well recognised, but decline in motivation, in returned kits and in intention to get screened over time<br>• Increase in requested and returned kits when different phases of the campaign were launched - no outcomes for bowel screening initiative other than increase in reminder letters<br>*Lung cancer*<br>• Higher levels of awareness of the campaign message about the 3-week cough, and higher levels of agreement with the statement that much could be done to improve symptoms<br>• Limited evidence on increase in x-rays during campaigns<br>• Increase in the proportion of people not wanting to see the GP at all if noticing small changes<br>*Changes in attitudes (3-year attitudinal tracking)*<br>• Positive changes in population knowledge/awareness and intention to act, but persisting challenges in prompt help-seeking, and concerns about wasting the doctor's time | • Frustration about the bowel screening initiative having been cancelled as they believed it worked well - also frustration when outcomes were not measured<br>• Considerations over whether the screening programmes should have been more involved due to their important role in the programme<br>• Frustration with lung campaigns at wintertime<br>• Recognition that it was hard to have good data, especially data on referrals, and that this was important<br>• Recognition that different territorial Health Boards had different abilities to carry out, evaluate and sustain local activities<br>• Recognition that it was hard to measure programme impact and change in behaviour, and that there were challenges in changing behaviour in the long-term<br>• Hopes that DCE would be a long-term endeavour facilitating incremental changes<br>• **Process evaluation measures:** Assumption 1, Assumption 2, Barriers and Facilitators |
| **Objective 4:** To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access | |
| • Limited data for assessment; objective met to a certain extent<br>• No data on referrals/investigations nor use of NHS resources<br>• qFIT with symptomatic patients a good rule out test<br>• Referral guidelines were updated; professionals who attended associated training found it useful and planned to share information, but engagement varied across Health Boards | • Recognition that referral guidelines could have been better disseminated and that secondary care was less involved<br>• Recognition that use of guidelines varied across Scotland<br>• Frustration about not being able to use qFIT in their local area<br>• Frustration over the challenges of getting referral data<br>• **Process evaluation measures:** Assumption 2, Mechanisms 2, Barriers and Facilitators |
| **Objective 5:** To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part | |
| • Not possible to assess whether objective was met – some data on increase in workload, no information on funding or on whether capacity was enough<br>• Limited data on increase in workload for the Breast and Bowel Screening Centres - seasonal peaks in laboratory activity in the bowel screening centre | • Stakeholders reported an increase in workload brought by DCE, and explained that the breast screening centres were affected by increase in symptomatic presentation<br>• Evidence showed that screening programmes did not receive additional funding<br>• **Process evaluation measures:** Assumption 2, Mechanism 3 |

| Outcome evaluation | Process evaluation |
|---|---|
| **Objective 6:** To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early disease requiring treatment | |
| • Objective met to a certain extent - no information on treatment nor on whether capacity was enough<br>• Textual data on a range of investments across Health Boards to increase diagnostic capacity and improve service provision<br>• Textual data on several soft outcomes, including better communication and more efficient diagnostic processes | • While stakeholders highlighted the importance of soft outcomes, they also acknowledged the challenges of measuring them<br>• They also wished that there was more transparency in funding allocation, and that DCE had been more prescriptive regarding how to use funding<br>• Stakeholders highlighted that capacity was often not sufficient before the programme started, and that increase in demand was often more than what they could cope with, especially for breast cancer - this caused anxiety<br>• Some wished they had had more time to plan for increase in demand, others were frustrated when planning underestimated capacity needs<br>• Funding was not sufficient to increase capacity (no professionals available)<br>• **Process evaluation measures:** Assumption 1, Assumption 2, Assumption 3, Assumption 4, Mechanism 2, Mechanism 3, Unanticipated outcomes, Barriers |
| **Objective 7:** To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral, and survival | |
| • Objective partially met, with decrease in the proportion of breast, lung and bowel cancers recorded with unknown stages<br>• No data available on the bowel screening initiative – it was also not possible to measure the second part of the objective<br>• 44.2% reduction in the proportion of cancers diagnosed with unknown stages (lung, breast and bowel combined) at Year 3<br>• 38.7% reduction for lung, 65.2% reduction for breast, and 36.7% reduction for bowel at Year 3<br>• Reduction across deprivation levels (lung, breast and bowel combined), highest reduction among the most deprived (52.7%)<br>• Reductions across all three cancer networks (lung, breast and bowel combined) at Year 3<br>• Variations across territorial Health Boards | • Recognition that having better data was one of the benefits brought by DCE, but also that improvements were still needed<br>• **Process evaluation measures:** Barriers and facilitators |
| **Objective 8:** To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit | |
| • Not possible to assess whether this objective was met as no relevant outcomes were available | • Acknowledgement that some outcomes would take a long time to appear<br>• **Process evaluation measures:** Barriers |

Available outcome data showed that, from the eight official programme objectives, one was not met (Objective 1 – the one associated with the key programme aim), five were met to a certain extent; and for two of them evidence was not sufficient for assessment. Without the process evaluation, conclusions would have been that 1) most of the programme objectives were difficult to measure; 2) when measurement was possible, positive impact of the programme was limited when considering its objectives; and 3) the key programme aim was not achieved. Hence, the DCE programme failed to meet its key aim and only partially met several of its objectives. Although these are reasonable conclusions, they do not tell the whole story about the programme. By incorporating a process evaluation, it was possible to have a much better understanding of what happened, and possible reasons why (in addition to the measurement issues mentioned above) the programme objectives were not/may not have been met. Furthermore, the process evaluation shed light on additional programme impact that would not have been noticed otherwise.

Process evaluation results showed that the inability to see programme impact (because data were not available, targets were unachievable, or increase in workload did not result in tangible improvements) caused frustration and influenced buy-in. Stakeholder reports on impact associated with official objectives were often based on anecdotal information, except for data on the HEAT targets and screening outcomes (which require long timeframes so changes can be observed). These issues are likely to have influenced stakeholder engagement in programme activities and consequently overall programme impact.

Furthermore, stakeholders commented on a range of relevant local initiatives and potential positive impact (also often referring to anecdotal data), but in these cases evaluations were not carried out, data were not collected, or evaluations were not disseminated. It is possible that DCE's actual impact was underestimated; and it is likely that additional unanticipated outcomes (either positive or negative) would have been identified if more data on activities was made available. Without the process evaluation, these possibilities beyond the programme's official, national strategies and the eight official outcomes would not have been known.

For many stakeholders, the DCE programme was *much more than its key aim and associated HEAT target*. "Soft outcomes", improvements in services and cumulative changes in the way people perceived symptoms and sought help were some of the areas that stakeholders also considered to be important when assessing impact

(although they recognised the challenges of measuring such outcomes). Perceived cultural shifts in the way the population perceived cancer were highlighted during evaluation development and the process evaluation. Hence, many saw DCE as a contributor towards long-term changes rather than a time-limited programme. These views are in line with the aspirational nature of some of DCE objectives but are not in line with a programme that was initially planned to last three years (with targets to measure changes during this short period). As described by the process evaluation, this may be related to the conflict between being a government programme (with the need to show results in the short-term) and a programme that makes a difference to cancer outcomes in the long-term. Therefore, even though the government can bring early detection to the centre of attention and help to drive action, there are also possible negative impacts (including the inability to show results). Furthermore, by attaching a very specific target (that was also unrealistic), the programme risked being assessed only based on this target and having its value underestimated.

Process evaluation results highlighted limited communication of the rationale for the programme and its strategies, gaps in communication and limited notice about activities. These were reported to influence buy-in, the ability to engage in different programme activities, and to plan for impact on workload. This was also likely to have influenced implementation and DCE's ability to meet its objectives.

Results also highlighted that local activities were adapted to local needs and circumstances and incentivised by DCE's flexible approach to funding. This flexibility also resulted in additional challenges to estimate programme impact. This evidence clearly shows that implementation influenced the ability to measure outcomes.

Finally, process evaluation resulted in a comprehensive understanding of structural barriers which influenced the ability to meet objectives, in addition to a range of facilitators. Findings also indicated wide regional variation needs, activities and implementation, and these are likely to have influenced outcomes (172).

#### 10.2.3.2 Revisiting programme theory

After the evaluation, DCE programme theory was revisited (Figures 10.2 and 10.3). Many changes were made, as assumptions and mechanisms were often only partially or not confirmed and DCE's key aim was not met. The new representation illustrates how achieving intermediate outcomes does not necessarily result in expected final outcomes, as outlined by interviews and the literature (165). For example, increase in breast consultations did not result in more breast cancer diagnoses, and positive

changes in bowel screening outcomes did not result in positive shifts in tumour staging. These findings show the importance of having good data that helps to link intermediate and final outcomes, with sufficient granularity to show variations across populations with different characteristics. For example, it would have been useful to know who was consulting with breast symptoms, or the proportion of late tumour stages for bowel cancer according to routes to diagnosis (i.e. screening or symptomatic presentation).

**Figure 10.2.** Revisited textual programme theory: how DCE worked

DCE awareness campaigns targeting the public increased knowledge and motivation to seek help and get screened, although some barriers to help-seeking persisted. Campaigns resulted in increase in consultations due to breast symptoms (with no associated increase in screening uptake nor breast cancer diagnoses) and increase in requests for bowel screening test kits (with possible increase in screening uptake, including among men and the most deprived, but no evidence on increase in bowel cancer diagnoses nor improvements in tumour staging).

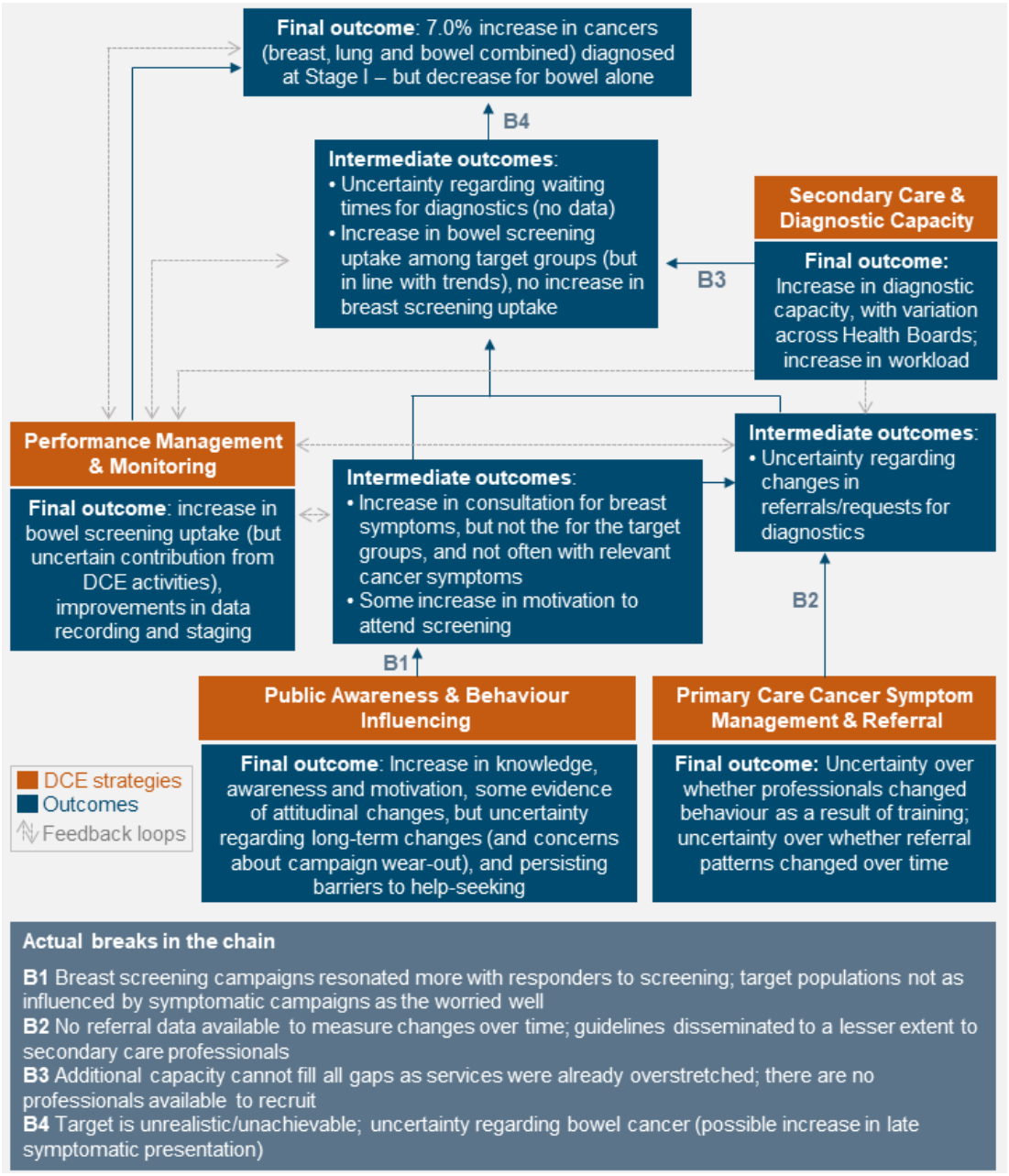
Training for health care professionals was considered useful, but engagement varied across Health Boards. There was reported increase in knowledge and motivation to share information. It was unclear whether provision and dissemination of updated referral guidelines increased confidence and legitimised referrals, while there was recognition that not all professionals used the guidelines or used them the same way. There were mixed views on whether performance targets drove activity and helped to focus the professional's minds. While QOF targets were seen positively as stakeholders saw they could make a difference, HEAT targets were criticised for being unrealistic, short-term and of limited clinical significance.

DCE activities increased demand for diagnostic resources; this was partially managed by the provision of funding for Health Boards to invest in capacity, but there was shortage of professionals available to recruit, and funding was not always sufficient nor shared across primary and secondary care (nor across different specialities). Flexibility was allowed for using resources, but this resulted in concerns about transparency and challenges in measuring programme impact.

While stakeholders widely recognised the importance of having an early detection initiative, programme acceptability varied across different DCE strategies. Communication challenges influenced buy-in and engagement. The impact on service improvements was hard to measure due to wide regional variation in implementation, and "soft outcomes" for which measurement was challenging. There were improvements in cancers diagnosed at Stage I, although this was partly influenced by improvements in recording and DCE's official target was not met.

It is likely that DCE has contributed towards wider cultural changes in the way the population perceives cancer (although this is hard to measure) and the way that it is managed by health services (although resource constraints and other barriers to help-seeking also influence this).

**Figure 10.3.** Revisited outcomes chain




### 10.2.3.3 Summary: integrating findings from the full evaluation

Data integration for the full evaluation shed light on how/why DCE objectives were not met. It highlighted issues regarding implementation (such as communication challenges and flexibility/adaptability) which are likely to have influenced outcomes and the ability to measure them. Furthermore, it showed that for many stakeholders DCE was much more that the programme's targets. The revisited programme theory showed that expectations of how the programme was supposed to work (elicited in Study 2) did not often become reality.

## 10.3 Comparing systematic review and DCE findings

One of the thesis objectives was to compare DCE with other multilevel policy initiatives. The systematic review reported on 18 of such initiatives (including the DCE programme). Both in the case of DCE and other initiatives in the review, evidence was often available in government reports and other stakeholder reports/grey publications. There was a wealth of information available in lengthy reports, and careful reading was required to identify specific information. Comparisons are made below in a narrative format; key similarities and differences are then summarised in a table.

### 10.3.1 Characteristics of initiatives

Multilevel policy initiatives were arranged in three specific groups, or a combination of them. DCE, NAEDI, ACE and the Cancer Strategy in Qatar crossed all identified groups. Most initiatives included at least one type of diagnostic pathway, often for patients presenting with alarm symptoms. Awareness campaigns were also a common component of initiatives, while professional education was less common. Due to wide heterogeneity in populations, measures and outcomes (even beyond what was initially expected), comparisons across initiatives were not straightforward.

Perhaps unsurprisingly, most strategies (including DCE) focused specifically on factors directly linked to cancer diagnosis. A minority of initiatives targeted access to primary care as part of their initiatives. Considering the important role of general practitioners as gatekeepers of services in many of the investigated countries (104, 505, 506), this limited focus on access may need to be reconsidered. It is worth noticing, however, that several initiatives recognised the importance of other steps in the cancer care continuum (although the focus was often on interval to treatment).

Governments either led or co-led initiatives, but charities and not-for-profit organisations had an active role in many of them, especially in the UK, US and Australia. They were involved in implementation, prepared evaluation reports and helped to disseminate information about the initiatives. Furthermore, for-profit organisations provided expert knowledge in social marketing, or health care services in countries where care was not free at the point of delivery. Academic institutions were often involved in the analysis and reporting of outcome data. Therefore, multilevel policy initiatives are also multi-actor policy initiatives (although most funding still comes from the government). As highlighted by the DCE evaluation, these

relationships can be beneficial, but also have implications in terms of expectations and communication needs.

### 10.3.2 Outcomes and data availability

As expected, there were challenges in showing how initiatives contributed to improved cancer outcomes. This was recognised by initiatives included in the review and by stakeholders in the DCE evaluation. Although these challenges are inherent to uncontrolled experiments (172, 175), they were managed by adopting a range of statistical methods and triangulating different sources of information. Initiatives that were able to access relevant data on outcomes, patient sociodemographic characteristics and other covariates (such as BCOC (176, 177), some NAEDI activities (150, 336), 2WW (81, 279) and both initiatives in Denmark (179, 273, 308, 309, 341)) were often able to show positive (with statistically significant results) impact regarding changes in knowledge/awareness, help-seeking behaviour, diagnostic intervals, and (less often) mortality and tumour staging. Different studies recognised the challenges in having access to data (particularly DCE, NAEDI and ACE).

There were only systematic reviews available for a single initiative (2WW in England). Hence, in order to report on higher level outcomes, it was necessary to first try and synthesise evidence for each initiative. The need to do so in the review and to use policy documents to understand DCE impact identified that national (or equivalent) policy initiatives do not necessarily translate into national level outcomes. Local activities were common and approaches to evaluation varied. It is important that local activities, small scale studies are carried out prior to wider implementation (172), but it was not always possible to estimate wider impact as a consequence, since local results were not always comparable. In the case of DCE, data on local activities was often not available, and there were concerns about limited dissemination of best practices. Perhaps a better balance is needed in terms of understanding local activities and outcomes (as contextual issues are important, and populations and needs may be different), and being able to assess overall programme impact.

Across initiatives, high level outcomes such as cancer survival, mortality and tumour staging were seldomly reported. This is not surprising considering recognised challenges in accessing data, the recognition that it takes a long time to be able to assess impact on survival (173), and that survival analyses on their own (without data on mortality and prevalence) can be misleading (507). A recent analysis of cancer

policies between 1996 and 2013 showed that these had limited impact on cancer survival in England, and that the deprivation gap persisted (508). Hence, other outcomes are likely to provide a more appropriate short-term measure of impact, although linkages to higher level outcomes would still be expected in the long-term.

Results from the review and the DCE evaluation indicated limitations in showing overall impact and long-term impact; the next subsections discuss impact across different strategies. Although these limitations are inherent to the types of initiatives being evaluated, evidence showed that more sophisticated analyses are possible provided that relevant data are available.

### 10.3.3 The role of awareness campaigns

Initiatives reported on several process measures of reach and dissemination, and on changes in knowledge/awareness in the short term. It was more challenging to link programme activities to long-term changes, changes in health seeking behaviour or improved cancer outcomes, although some evidence on positive changes in behaviour was available for BCOC (176), Oral Cancer Maryland (343) and DCE.

Cancer fear and concerns about wasting the doctor's time persisted both in England and Scotland. There could be many reasons for this, including issues raised in the DCE evaluation such as being aware of NHS constraints and stoicism. The importance of these issues was also confirmed by an ICBP study, which showed that they were also present in other countries (509).

The DCE process evaluation highlighted concerns about the impact of campaigns in demand for services and about them attracting the worried well. Even though evidence on this was limited in the review, the literature indicates that these concerns are shared at least by health care professionals in England, alongside fears that such initiatives may increase health inequalities (510, 511).

Evidence from Health Psychology indicates that knowledge is necessary, but not sufficient to result in target behaviours (48). Different theories highlight the role of motivation, relevance and other issues, in addition to barriers such as poor literacy (48). Moreover, studies underpinned by Medical Anthropology indicate that the decision not to seek help or to delay help seeking is not necessarily due to lack of knowledge or limited awareness. In fact, it can be a rational and pragmatic decision due to individual and social circumstances (111).

A review assessing impact of campaigns promoting cancer awareness and early presentation found that campaigns increased awareness in the short-term, but evidence was limited on the impact in early presentation and high level outcomes such as tumour staging (512). The ABC-Deep Consortium is currently updating this review, and it will be important to see if changes were noted since then as a result of current initiatives (513). The US National Cancer Institute's guidance on mass health communication campaigns highlights that communication can increase and reinforce knowledge and awareness, influence views, refute myths, show benefits of changes in behaviour and increase demand for services (514). However, it cannot result in sustained change for complex health behaviours without being part of a larger programme addressing contextual issues, and it cannot overcome barriers such as limited access to care. Furthermore, the guidance recognises that it is often impossible to isolate the impact of such communications, because changes often do not only occur due to them, and audiences are influenced by a range of activities/messages at the same time (514). Similar issues were recognised by DCE stakeholders; those evaluating BCOC campaigns also acknowledged that determining exposure to campaigns was not straightforward (298).

### 10.3.4 The role of diagnostic pathways

Diagnostic pathways were the most commonly adopted strategies. The mostly commonly reported outcomes were diagnostic intervals, but this information was not available for DCE as waiting times were only available for decision to treat/referral and treatment (515). Therefore, it was challenging to compare DCE with other referral strategies. Data on routes to diagnosis are now being collected in Scotland (73), and it is hoped that comparisons can be made in the near future.

DCE process evaluation highlighted challenges in accessing referral data, and the detrimental impact this had for benchmarking and service improvements. The systematic review described increase in referrals (patients with high-risk symptoms) over time across different initiatives; this increase did not necessarily translate into more cancers being diagnosed. Increase in demand is likely to continue considering the increased cancer burden worldwide, and this will have implications in terms of resources, and risks of overdiagnosis and overtreatment of cancers that would not have progressed. These implications will need to be balanced against the risk of missing cancers.

There is increasing recognition that urgent referral pathways are less likely to be beneficial for patients without alarm symptoms and that additional pathways are needed to ensure earlier diagnosis for a range of tumour types with different symptomatic presentation (85, 87, 134). More recently, DCE has shown interest in focusing more in such pathways (personal communication, DCE Programme Board). Importantly, these different pathways are coexisting, demonstrating their importance for different population and tumour groups.

### 10.3.5 The role of professional education

There was little information from either DCE or other initiatives which adopted this strategy (eight initiatives had this as a component). There were mixed findings regarding change of knowledge/behaviour over time. The DCE evaluation reported that professionals found the sessions useful and planned to share information, but attendance/engagement varied across territorial Health Boards. Process evaluation results indicated that health care professionals can have limited knowledge/awareness about cancer, and this may not be particularly obvious. Results do not allow for firm conclusions on the usefulness of education sessions for professionals, but they do highlight that needs assessments may be beneficial in order to identify any potential gaps in knowledge regarding early cancer diagnosis. A systematic review has found such gaps (and wide variations) among nurses (516); it is possible that this is also the case among other health care professionals.

### 10.3.6 Stakeholder views on initiatives

Most evidence on stakeholder views referred to DCE (obtained through the process evaluation), although some initiatives included in the review also had data. Educational training was often considered to be important for professionals. Overall, most professionals also had positive (or neutral) views on awareness campaigns, and GPs often agreed that it was important to show such messages to the public. BCOC also sought patient views and these were often positive (with campaigns being described as sensible, relevant and showed something new) (177).

Views on referral pathways were mostly positive from professionals and the public as they believed pathways were beneficial to patients, but there was also recognition that these pathways had limitations. Professionals raised concerns about primary care professionals overusing the pathway, pharmacists making inappropriate referrals, or guidelines not being used appropriately (the latter was also raised by DCE

stakeholders). A qualitative study assessing challenges in implementing 2WW in England (included as an additional file in the review as it only approached colorectal cancer) (517) described a range of challenges with the 2WW pathway (such as difficulties applying referral criteria and their low predictive value), but also proposed a range of strategies to deal with challenges.

Other findings from ACE and NAEDI also resonated with DCE process evaluation findings, although at a much broader scale (i.e. they referred to the programme overall instead of only to referral pathways). Indeed, there was substantial overlap between ACE (287) and DCE process evaluation findings. Similarities included contextual barriers such as limited diagnostic capacity and concerns about not being able to meet demand, references to the importance of having good management, good communication and engagement. Challenges in maintaining engagement over time were also reported (287). Both England and Scotland are struggling with NHS workforce and resource challenges (518, 519), so these commonalities across the initiatives are not surprising.

There were no reports about the use of CDS tools as part of DCE, although there were plans to implement this over time (personal communication, DCE Programme Board). For ACE and NAEDI (291, 334), there were reports of technical difficulties and challenges in accessing outcome data. If DCE is planning to use similar tools, it is important that these challenges are considered.

### 10.3.7 Summary: review and DCE evaluation

Evidence from initiatives included in the review and data from the DCE evaluation showed that initiatives often approach referral pathways, awareness campaigns and to a lesser extent professional education. Different initiatives faced similar challenges when assessing programme impact, although some managed to carry out more robust analyses. DCE adopted strategies which had been implemented by different initiatives included in the review, in line with review findings showing that initiatives influence each other. DCE did not have the same ability to show impact compared to initiatives in Denmark and England (Table 10.3) . This was often due to limited data availability, but also due to other issues such as limited dissemination and the chosen targets/objectives. Based on lessons learned from the DCE experience and review findings, the next section discusses recommendations for policy.

**Table 10.3.** DCE and other initiatives: similarities and differences

| Characteristics | Similarities | Differences |
|---|---|---|
| Document sources | • Sources were often grey literature | • Grey literature not as accessible (most DCE documents were only available through the evaluation) |
| Designs | • Observational studies (often cross-sectional, BA and cohort), qualitative studies (interviews and focus groups) | • None, but see "Outcomes (public awareness)" |
| Strategies | • Adopted strategies: aiming to improve public knowledge and awareness, to educate professionals and to develop referral pathways based on cancer symptoms | • Locally implemented activities not centrally coordinated.<br>• Referral pathways varied widely as they were implemented locally according to need<br>• Clinical audits were also happening locally<br>• Use of an adapted version of CAM (not validated) |
| Stakeholders | • Involvement of charities, academics, health care professionals, and for-profit organisations | • Several (local) partnerships with local businesses to raise awareness |
| Target populations | • Patients with a suspicion of cancer (high-risk symptom criteria, vague symptoms, high risk of cancer); health care professionals, deprived populations, key influencers, celebrities | • Children as key influencers (bowel screening campaign) |
| High-level outcomes | • Data on tumour staging, limited evidence on mortality and survival | • None found |
| Outcomes (professional education) | • Some evidence of change in knowledge<br>• Description of process measures | • No evidence on persisting knowledge gaps as part of professional education, but gaps were found in a Health Board (survey with professionals) |
| Outcomes (public awareness) | • Description of process measures<br>• Positive changes in knowledge/awareness<br>• Persisting misconceptions/ barriers to help-seeking<br>• Some evidence of change in behaviour | • Not possible to carry out statistical analysis to understand impact of campaigns in help-seeking behaviour and high-level cancer outcomes (limited data availability) |
| Outcomes (referral pathways) | • Heterogeneity in outcome measures and definitions | • Not possible to assess diagnostic intervals (as identified in several initiatives) – although this may have been assessed locally<br>• No targets for urgent referrals, no data on referral/detection rates, no data on cancers detected through different pathways – although this may have been assessed locally |
| Outcomes (bowel screening initiative) | • None, DCE strategy only | • Financial reimbursement for reduction in bowel screening non-participation, but no data available on outcomes |
| CDS tools | • None found | • No evidence of the use of CDS tools (although they may have been used locally and there were plans to implement this on a wider scale) |
| Professional views | • Views on initiatives were often positive (interviewed stakeholders only in the case of DCE) | • Mixed views depending on strategies, secondary care professionals more often had negative views |

## 10.4 Recommendations for policy

A key objective of this PhD was to provide recommendations to inform DCE and other initiatives. Draft recommendations were presented at a Workshop with DCE stakeholders (a deliverable to the study funder) on the 18th September 2018 (Appendix 37). The workshop aimed to ensure that recommendations were fit for purpose and realistic. Acknowledging that DCE adopted a whole-systems approach, and that contextual barriers and facilitators were important, recommendations were given at a provider level, organisational level, local level, and national level. These recommendations are available in the final report prepared for the Scottish Government (Appendix 37 – formatting was changed to meet thesis requirements).

In order to inform both DCE and other initiatives, recommendations were further refined after integrating review results (Figure 10.4).

**Figure 10.4.** Recommendations for policy


Recommendations outline what is needed, why it is needed, and provide a list of possible issues to consider (these issues were found to have an impact on implementation, outcomes, and the ability to compare data from DCE and other initiatives). The levels of contextual influence (242) are also reported.

The first recommendation refers to careful consideration of data to be collected as part of a multilevel initiative, especially regarding quality, relevance and availability. This recommendation is meant to facilitate measuring the impact of initiatives, build knowledge, facilitate stakeholder buy-in and enhance discussions on how to improve early cancer detection (Figure 10.5). As part of this recommendation, it is suggested that data on costs are collected so cost-effectiveness analyses can be carried out. It

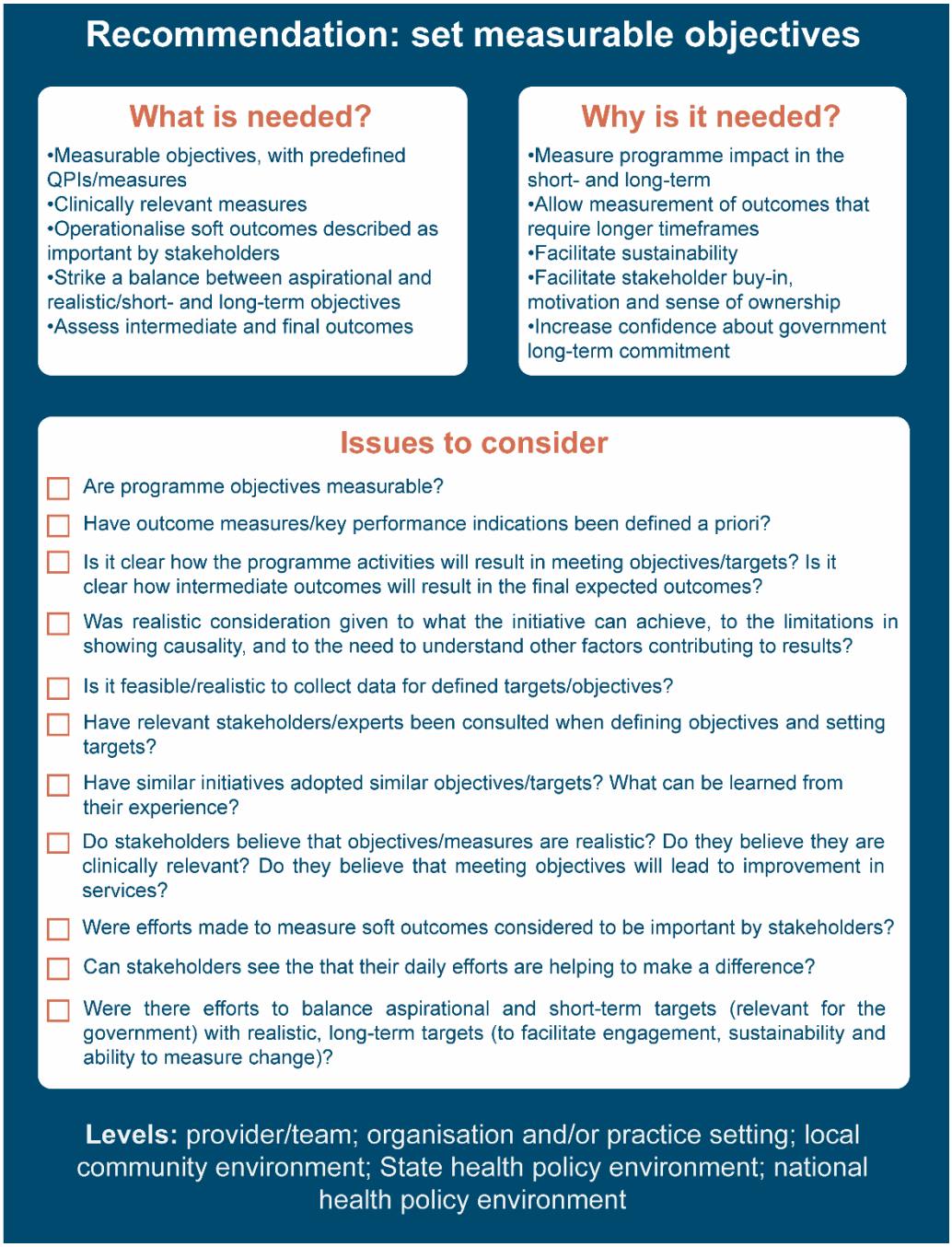
was beyond the scope of this PhD research project to carry a cost-effectiveness analysis (hence, the issue was not approached in the review either). Nevertheless, these are important and beneficial to decision-makers (172), and there are available examples in the field or earlier cancer diagnosis (59, 363, 520).

**Figure 10.5**. Consider data quality, relevance and availability


The second recommendation refers to setting measurable objectives (Figure 10.6). This was a particular issue with the DCE programme, but it may also apply to other

government initiatives. This recommendation also approaches other areas highlighted by the WHO's guidance on cancer control programmes, such as defining SMART (specific, measurable, achievable, realistic and timely) objectives (46). As described earlier in this Chapter, when investigating intermediate outcomes, it is also important to consider how these will result in the final expected outcomes.

**Figure 10.6.** Set measurable objectives

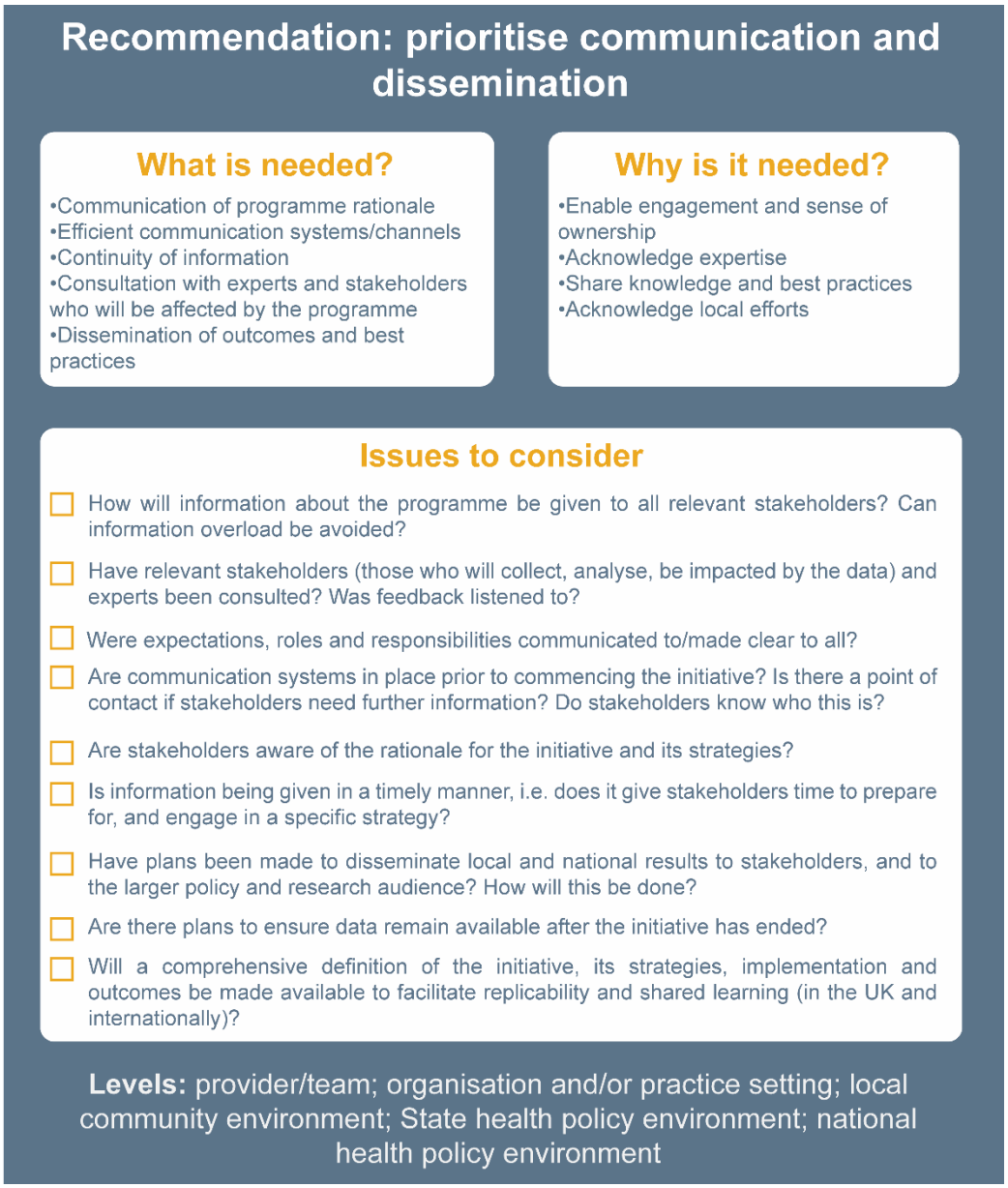


The third recommendation refers to targeting populations at risk (Figure 10.7). This recommendation aims to target groups for whom cancer outcomes are often the poorest, to avoid targeting the worried well and to make the most of available resources. It is based on the recognition of social determinants of health, and the role of social deprivation in cancer outcomes. Importantly, as described in Chapter 2, tackling social determinants of health requires coordination from a range of actors in a system (115). This recommendation also recognises the role of primary prevention, especially among groups with a high prevalence of high-risk lifestyle behaviours (7).

**Figure 10.7.** Target populations at risk

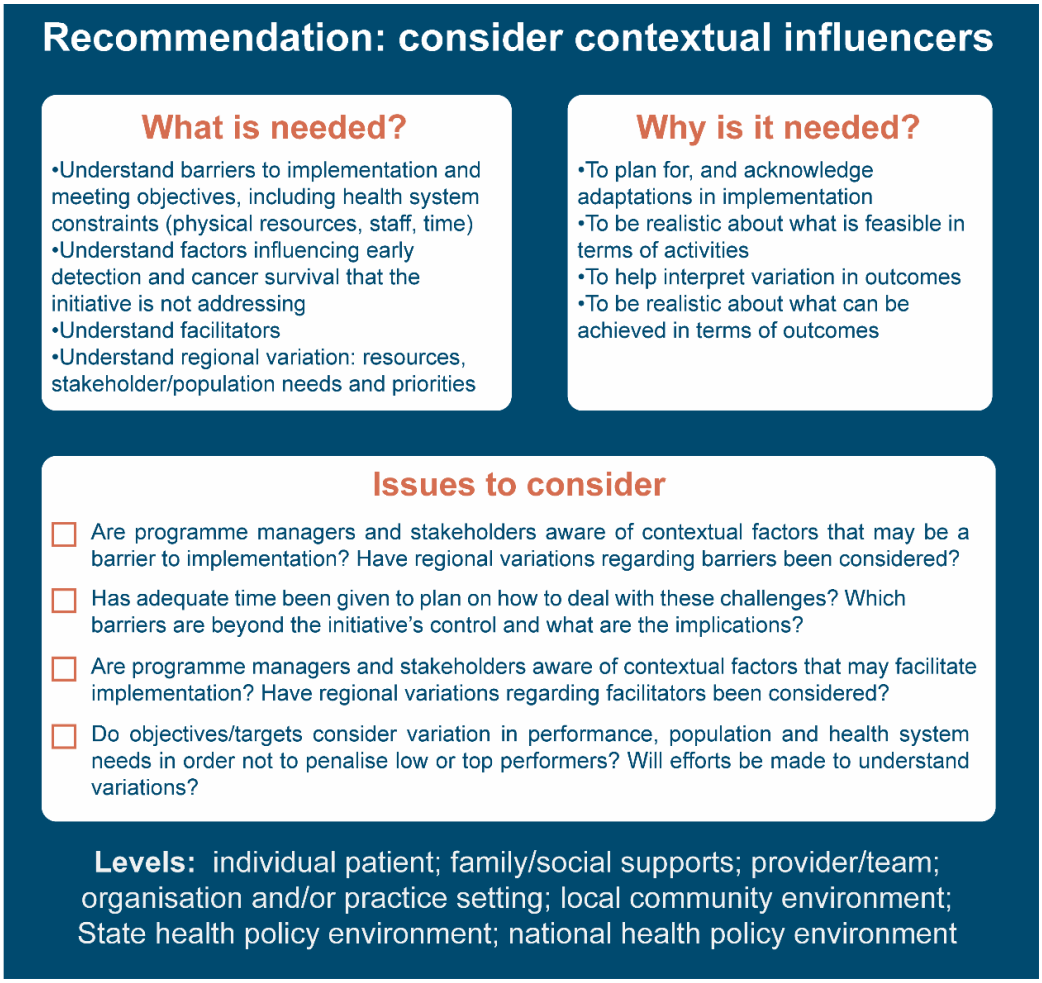
The fourth recommendation refers to prioritising communication and dissemination (Figure 10.8). Communication challenges are a recognised problem in programme evaluation (165), and in initiatives promoting the earlier diagnosis of cancer (287, 372). Furthermore, communication challenges were reported to influence stakeholder buy-in (DCE evaluation). The importance of having stakeholder input, and especially clinical input has been recognised (287, 521, 522). Furthermore, disseminating evidence is paramount in order to learn from previous initiatives. In addition to reports, policy briefs, press-releases and peer-reviewed publications, online dissemination platforms (such as social media and blogs) should also be considered (523, 524).

**Figure 10.8.** Prioritise communication and dissemination



The final recommendation refers to the need to acknowledge the context, due to its recognised role in complex interventions (166, 172), and the way it can influence both processes and outcomes (Figure 10.9). The DCE evaluation and the literature described in Chapter 2 indicate that issues to consider include social deprivation, population needs, resource availability, access to care, and factors influencing cancer survival.

**Figure 10.9.** Consider contextual influencers




In addition to these recommendations, it is worth highlighting important prerequisites already mentioned in this thesis: full programme evaluations need to be planned as part of programme development, and ideally should be preceded by pilot and feasibility studies (172). It is recognised that policy initiatives (especially the ones deriving from political manifestos) are often implemented before such studies are carried out and evaluations can be properly planned, as there is pressure to show results quickly (525). As indicated by the DCE evaluation, all these issues influence

the ability to demonstrate programme impact. At a minimum, it is important that evaluation guidance is followed (168, 172, 180, 526), especially those focusing on cancer control (18, 19, 46, 527), and that lessons are learned from previous experiences.

## 10.5 Recommendations for research

Further recommendations specifically targeting researchers were developed (Figure 10.10). The first three discuss issues to consider when carrying out evaluations; the fourth refers to areas that could benefit from further research.

**Figure 10.10.** Recommendations for research


### 10.5.1 Acknowledging the benefits and limitations of developing a theory-based evaluation

This thesis used theory-based evaluation in order to better understand the DCE programme. Its premises fit well with the adopted theories and frameworks, and it helped to prioritise elements in the evaluation. As described in the literature, it was also expected that theory-based evaluation would show mechanisms that worked (or did not work) (155) and potentially inform other early detection initiatives. Although there were many benefits in adopting a theory-based evaluation, there were also challenges. Table 10.4 outlines some of these benefits and challenges. By being transparent about my experience, I hope to help other researchers to make an informed decision about their evaluation approach.

**Table 10.4.** Benefits and limitations of using a theory-based evaluation

| Benefits | Limitations/challenges faced |
|---|---|
| Theory-based evaluation | |
| • Allowed me to have a comprehensive understanding of the DCE programme, identifying its "reality rather than its illusion" (158) – this resulted in a much deeper understanding of what happened (outcomes), how and why it happened (process) and how and why implementers expected the programme to work (the programme theory)<br>• Contributed to building knowledge on mechanisms of impact in early diagnosis - an area for which evidence is scarce<br>• Allowed for theory to be applied in practice | • It took a long time to elicit programme theory as there was no clear, comprehensive description of the programme a priori. This is a recognised problem with theory-based evaluation (154, 218, 528)<br>• DCE evolved over time, and adapted according to need – complicating programme description<br>• Despite available guidance, differentiating assumptions and mechanisms was not always easy (definitions overlapped depending on the source), and results also overlapped |
| Using a logic model and outcomes chains | |
| • After refinements, the logic model provided a clear description of programme inputs, activities, outputs and outcomes – this informed the evaluation and was welcomed by the funder<br>• Outcomes chains were found to be quite useful to represent the DCE programme as they incorporated complexity (and a range of relationships) well | • Initial model was overcrowded (529)<br>• Logic model was not ideal for complex studies (530), flexible and adaptable programmes<br>• Logic model was done retrospectively<br>• The distinction between logic model outputs and outcomes was clear in text, but it was not clear for stakeholders. Many of the reported outcomes/impact (both reported by authors from initiatives included in the review and by stakeholders in the DCE evaluation) can be classified as outputs or process measures |

Based on my experience, the benefits of using theory-based evaluation and the underpinning theories and frameworks outweighed the costs, as they provided me with an opportunity to build knowledge in different areas and apply theory to a national early detection programme. Nonetheless, I believe that important issues and preconditions need to be considered before deciding to carry out a theory-based evaluation.

The key consideration is what the theory-based approach is expected to add to the evaluation. If there is uncertainty about how programme activities will result in expected outcomes, the evaluation aims to build theory and contribute to knowledge, then in principle the approach is justifiable. However, if there is no uncertainty regarding mechanisms (i.e. evidence is clear on how such interventions are supposed to work), and the aim is to assess whether objectives were met (and if not, whether

this was due to poor implementation), then a simpler evaluation covering processes (addressing implementation) and outcomes would suffice.

Preconditions refer to: 1) available time, resources and expertise (as a theory-based evaluation will require more of each); and 2) access to comprehensive information on the programme components, implementation and context – and to stakeholders who developed the programme (needed for all evaluations, but I found it to be critical for a theory-based evaluation). If preconditions are met, a theory-based evaluation is an intensive, but rewarding experience. If not, other approaches may be more appropriate.

### 10.5.2 The need for collaborations and dissemination

Evidence showed that initiatives were not fully independent entities. Indeed, they often influenced each other. Hence, being able to share information about different initiatives, in a way that allows for comparisons is paramount. It has already been recognised that sharing best practices and using available knowledge can be widely beneficial to early diagnosis research (130). In order to do so, more consistency in definitions is needed, but also in evaluation methods and reporting. National and International collaborations and coordinated approaches such as the Aarhus statement (99), ICBP (39) and CanTest (531) are welcomed. Further collaborations of researchers with government initiatives and policymakers are also paramount. NAEDI was a good example of such collaborations, and resulted in a wealth of publications, including two special supplements in the British Journal of Cancer (532, 533) and the evidence-based hypothesis of factors influencing cancer survival and premature mortality adopted in this PhD project (130).

There are recognised challenges in engaging with policy (534), but these collaborations have a stronger potential to improve cancer outcomes for patients. A “middle ground” approach has been proposed as a good compromise so research can better inform practice and policy, and more robust initiatives can be developed and evaluated (535, 536). Suggested approaches include collaborations between researchers and health care providers in programme evaluations; and co-creation of complex interventions / models of care (535). This “middle ground” may also be useful for multilevel initiatives promoting earlier cancer diagnosis. It incorporates the notion of realistic medicine (emphasised by DCE stakeholders), which has gained prominence in Scotland since a report was published in 2016 (537). Realistic medicine

emphasises shared-decision-making and a personalised approach to care while aiming to reduce harm, waste, and unnecessary variation in practices and outcomes (537).

Importantly, research and policy collaborations often result in peer-reviewed publications, helping to reduce bias and enhancing transparency. Peer-reviewed publications have a unique identifier and are easier to retrieve compared to reports (although open access issues need to be considered). During this PhD project, links to relevant reports changed, and not all of them could be identified again (I was fortunate as I had saved all files when I found them).

The MRC guidance on process evaluation of complex interventions recommends that evaluators publish a report describing all evaluation components, or a protocol paper that also refers to all articles reporting on the evaluations (166). This advice may also be useful for early detection initiatives, in order to share knowledge and facilitate replicability.

### 10.5.3 The need to try new approaches to tackle recognised challenges

While reflecting upon the PhD findings alongside the available literature, it was clear there was more corroborating than contrasting evidence available. This was particularly evident when comparing results from the process evaluation of ACE (287) and DCE. The existence of corroborating data is perhaps not surprising considering the exploratory, and descriptive (rather than hypothesis testing) nature of this PhD. However, the fact that the same issues feature consistently in multiple programmes may also indicate the need to better learn from our experiences. Box 10.2 highlights some issues which were consistently shown in publications. They are not easy to tackle, but it is important that further attempts are made if we wish to continue improving cancer outcomes.

**Box 10.2.** Issues consistently shown in publications and in the DCE evaluation

- **Communication challenges**, limited clinical input and dissemination are widely recognised issues. It is important to consider optimum ways to tackle these. A recent publication has highlighted lessons learned in 20 years assisting with implementation of communication efforts as part of US cancer control strategies (538). Evidence from other fields (such as management and organisational science) may also be helpful
- **The mixed role of performance targets and/or financial incentives:** over 20 years ago, Smith had highlighted a range of unintended consequences of performance data, including issues which were found in the DCE evaluation: tunnel vision (i.e. target does not cover everything that is seen as important), myopia (using short-term targets at the expense of long-term objectives), measure fixation (emphasis on the measures instead of the underlying objective), and ossification (targets leading to stakeholders ignoring other opportunities and threats) (539). Reviews focusing on QOF in England (540, 541) and Scotland (542) found that positive results in performance associated with QOF did not persist over time. This indicates that stakeholder engagement with the bowel screening initiative as part of DCE was likely to be short-lived if the strategy had continued for longer (and QOF had not been abolished in Scotland in 2016 (535)). Furthermore, these reviews showed that the use of targets carry the risk of a crowding out effect (i.e. a negative impact on patients that need access to care), concerns which were also raised by DCE, and by those using waiting times targets (371). Aspirational targets, on the other hand, have the ability to "demoralise and distort" (543). Further discussions about the role of performance targets and financial incentives in earlier cancer diagnosis are needed, while also recognising that they can be useful and that they are not all the same (as outlined in the DCE evaluation).
- **The use of mass awareness campaigns:** there is persisting evidence of limited impact of mass awareness campaign in changes in behaviour. The impact of campaigns in the worried well is a reason for concern. Although it is hard to argue against the need to increase knowledge/awareness of cancer symptoms and signs, there is scope for reassessing what awareness campaigns can and cannot do. It is paramount to widely acknowledge their benefits and limitations in order to optimise awareness raising strategies and promote positive changes in behaviour. The risks of overdiagnosing and overtreating the worried well also need to be considered.
- **In terms of measuring outcomes,** the importance of triangulating data to better show impact is recognised by researchers, but challenges in accessing data persist, influencing the ability to measure outcomes. Furthermore, despite wide recognition that changes in cancer outcomes require long timeframes, there is still the expectation that evaluations in the short-term can show impact. Perhaps better clarity is needed on what can be expected from evaluations of earlier diagnosis initiatives. The role of contextual barriers (such as limited data or short follow-up periods) over which researchers may have no control also needs to be better acknowledged.
- **Barriers:** a range of **health system barriers** were reported for the UK (there was wider variation across other countries, although there will be resource implications for all as the burden of cancer increases). **Social inequalities** are likely to persist as a key barrier to improving cancer outcomes. Sharing best practices and disseminating successful stories is helpful, but (as previously discussed) a wider, coordinated approach outwith earlier cancer diagnosis is also needed to overcome these challenges.

### 10.5.4 Looking forward: early diagnosis research

While carrying out this PhD research project, different opportunities for further research were identified:

- Carry out more systematic reviews for a single multilevel policy initiative, focusing on understanding both variation across different population groups and overall impact. Such reviews would have facilitated analysis and reporting for Study 1, and would make evidence more accessible to other researchers
- Carry out systematic reviews about 1) barriers and facilitators to implementation and to meeting outcomes; and 2) unanticipated outcomes for multilevel policy initiatives promoting the earlier diagnosis of cancer
- Carry out qualitative reviews seeking to identify causal mechanisms, theories and assumptions underlying multilevel policy initiatives promoting the earlier diagnosis of cancer
- Carry out and publish more process evaluations of multilevel policy initiatives, as evidence is available but still limited
- Carry out further early diagnosis research to identify effective ways to reach out to populations in deprived areas and vulnerable groups

Future studies should also try to have a stronger public involvement from evaluation development, in order to measure system-level changes from the perspectives of both professionals and the public. This was not possible for the DCE evaluation (see strengths and limitations), but I recognise the importance of doing so, especially considering the current drive towards shared patient/professional decision-making.

Finally, there is increasing recognition (particularly in the UK) that diagnostic resources are finite, and that increasing demand for examinations such as colonoscopies is unsustainable (83). These issues have also been raised by DCE stakeholders and other initiatives. Therefore, it is important that more research continues to look for simpler, preferably non-invasive, cost-effective tests in primary care that can be used as rule-out tests (531) including for tumour types for which survival is poorest. For colorectal cancer, there is increasing evidence of the benefit of using qFIT in primary care (411, 544, 545). Further research into inflammatory markers (546, 547) and safety netting for patients presenting with vague symptoms (93, 548) is also needed.

## 10.6 Methodological considerations

### 10.6.1 Managing potential conflicts of interest

The DCE evaluation was funded by the Scottish Government and DCE had an interest in the evaluation results. Although feedback from stakeholders at the Scottish

Government was sought, it was only considered if it did not compromise the independent nature of the DCE evaluation. In order to ensure independence and transparency, key measures were taken:

1. The funded evaluation proposal was prepared by me and refined with my supervisors' feedback. The Scottish Government knew that the evaluation would be carried out independently, as part of a PhD. They were also informed that results would be presented in Conferences and published in peer-reviewed journals. Dissemination was a key study component in order to ensure transparency and knowledge sharing. The final evaluation output to the funder (available in Appendix 39) will be made available after thesis submission.
2. An independent steering group provided feedback on the DCE evaluation.
3. Purposive sampling and a snowball technique were used in order to reach stakeholders with diverse views on the programme. Confidentiality and anonymity were ensured so stakeholders could be open about their views.
4. All study information sheets, presentations, and reports to the Scottish Government stated how the study was funded, while also highlighting that the evaluation was being carried out independently.
5. There was a continuous process of reflexivity regarding the evaluation, changes in relationships during the study and potential impact on the evaluation (166).

### 10.6.2 Strengths and limitations

This thesis comprised three different studies. It followed respected guidance on systematic reviewing and evaluating complex interventions. The complexity lens highlighted the dynamic aspect of the health system, the importance of the context and the limitations in showing causality in cancer control initiatives. The use of a process and outcome evaluation provided a much more informative view of the DCE programme, while the use of a theory-based evaluation helped to build knowledge in implementation assumptions and mechanisms. The systematic review synthesised and discussed a wealth of evidence in order to learn from national and international experiences of carrying out multilevel early diagnosis initiatives. Results have informed evidence-based recommendations which are expected to be useful not only

for the DCE programme in Scotland, but also for early diagnosis initiatives being developed, implemented and evaluated worldwide.

Nonetheless, this thesis also had limitations. Some of these have already been addressed throughout the thesis; additional limitations are described below.

#### 10.6.2.1 Systematic review (Study 1)

Challenges when carrying out the review referred mainly to three areas: quality assessment, inclusion and exclusion criteria, and data extraction and reporting.

*Quality assessment*

Most included studies could not be assessed for quality. When quality assessment was possible, key issues across quantitative studies referred to limited data on sampling, validity, reliability, contamination and co-intervention. As for qualitative studies, very few of them described methods, sampling, and data analysis. Interrater reliability was low, indicating inconsistent use and interpretation of the adopted quality assessment tools (likely to having been influenced by the wide range of designs/publication types included in the study). Even though disagreements were solved by consensus, low reliability raises questions about the soundness/validity of the assessments. Furthermore, while assessing quality of publications is important, it is important to consider whether it was appropriate to include quality assessment in a review including papers for which there were no properly suitable tools. Perhaps a scoping review (as opposed to a systematic review) would have been more appropriate. While still adopting procedures consistent with a systematic review (such as robust search strategies), the approach does not seek to investigate the quality of evidence, includes a wide range of study designs, and is deemed more appropriate for reviews aiming to map the available literature in a specific area (549).

*Inclusion and exclusion criteria*

Initiatives were required to have a leading role from the government, as this PhD was interested in multilevel policy initiatives which were comparable to the DCE programme. Consequently, many initiatives led by research groups and charities (even if there was government funding) were excluded from the review. These included several charity-led initiatives in the US, and a randomised controlled trial in Australia that had initially been included (550, 551). A review with broader inclusion criteria is likely to generate additional relevant findings to initiatives promoting the earlier diagnosis of cancer.

*Data extraction and reporting*

Wide heterogeneity in terms of chosen outcome measures and their definitions complicated data synthesis. The level of detail in which outcomes were reported varied, and data were not available for every investigated outcome. A choice was made to report on outcomes which were more often described while making additional information available in appendices. Heterogeneity not only precluded meta-analysis (this was expected), but also made it challenging to use narrative synthesis. As a result, evidence was often shown in large tables, with lots of text.

It was only possible to report on some contextual factors (such as drivers, policies, and source of funding). There was a wealth of additional contextual information, including implementation challenges. A review focusing on contextual issues would provide useful information for those developing multilevel policy initiatives (as described in recommendations for research).

Since the review focused on higher level outcomes, there were important variations in outcomes across different population groups, regions and tumour types that it did not cover. Nonetheless, amendments had to be made as some national initiatives were comprised of local activities distributed across a country. In these cases, data were synthesised whenever possible, or reported separately in tables. It is important to emphasise that additional publications (Appendix 4) have important evidence about outcomes at a local level, or for specific tumour types.

#### 10.6.2.2 Developing and refining the evaluation (Study 2)

Even though I carried out independent searches of DCE documents, made requests for specific documents over time and gathered documents from different sources, I was still mostly dependent on DCE's decision on which documents would be shared. Therefore, in addition to specific limitations of documentary analysis highlighted in Chapter 4, it is impossible to ascertain how many more documents had relevant information, were available, but were not shared (and the impact that adding these would have had to the evaluation). Nonetheless, those managing DCE activities openly shared several documents I did not expect to have access to, including drafts for internal circulation only, and minutes with tracked changes. Hence, I expect that I received most documents they had available.

DCE programme theory and its graphical representations (i.e. the logic model and the outcomes chains) were all developed retrospectively. For the logic model, this meant

that some of the outputs and short-term outcomes were informed by actual experience and events rather than expectations. On the other hand, the resulting logic model was more realistic regarding programme activities, outputs and outcomes.

Although the Behaviour Change Wheel was found to be a good fit for DCE, mapping was done retrospectively. Similarly, implementation outcomes were mapped retrospectively. There were no predefined/validated measurement tools to measure implementation assumptions nor mechanisms of impact. This resulted in new tools being developed. Although this is common in evaluation studies (397), it results in uncertainties regarding validity and reliability. In order to minimise this, the questionnaire was informed by studies adopting the same implementation outcomes/behaviour change theories. Definitions were provided for all outcomes and constructs and the questionnaire was pre-tested, but further validations are needed.

While the questionnaire allowed for developing very specific questions approaching implementation assumptions and mechanisms of impact, the same approach was not deemed feasible for interviews, where broader questions and prompts were used instead in order to avoid leading stakeholders into confirming/rejecting specific assumptions and mechanisms. Themes were derived both from the data and the investigated assumptions and mechanisms. Mixed methods research has been criticised by being prone to subordinating qualitative to quantitative components (230), and this was avoided by allowing each method to contribute as much as possible to the evaluation results. While it may seem easier to operationalise constructs and outcomes in a questionnaire, it was clear from the study results that 1) open-ended comments in the questionnaire were crucial to understand quantitative results, in addition to generating data not approached by closed-ended questions); 2) the richness of qualitative interviews was paramount to answer all research questions, and to shed light on why DCE objectives were (or not met). Therefore, the evaluation confirmed what is recommended in the literature, i.e. the use of mixed methods is beneficial in evaluations, especially theory-based evaluations (161, 166, 195).

#### 10.6.2.3 The DCE evaluation (Study 3)

*Outcome evaluation component*

DCE was a large, complex government programme, with little predefined evaluation parameters prior to the study being funded. This had implications in terms of the ability to measure programme impact.

During a meeting with the evaluation steering group in 2017, after presenting findings from Study 2, there was a discussion about how this study had several similarities to an evaluability assessment. An evaluability assessment comprises systematic, early engagement with stakeholders; development and testing of programme theory/theory of change; identification and assessment of available data sources; and development of recommendations for and against a full evaluation (552). If the evaluation is deemed not feasible nor useful to improve a programme, then it is not recommended (552, 553). As a government programme using publicly funded money, it was agreed that it was important to carry out the evaluation regardless of identified limitations in terms of data availability. Furthermore, one of the key interests was to learn lessons from the programme (to inform DCE and other initiatives). Considering all the evaluation challenges, I believe I made the most of the available data and resources in order to meet the thesis aims, funder requirements and to develop evidence-based recommendations.

Although I did not expect to demonstrate causality due to the nature of the programme (165, 186), being able to triangulate different sources as done by other initiatives (150, 176, 298, 310, 341) would have helped to ascertain DCE's potential contribution to observed outcomes (165). The alternative was to carry out a descriptive analysis of secondary data sources. Data on proxy measures (i.e. tumour staging) and screening were only available in aggregated tables. Data on request for bowel screening kits did not have any patient sociodemographic information. Variation in outcomes across Health Boards and Cancer Networks was difficult to interpret. It was not possible to assess exposure to different DCE components, or to other activities that may have influenced outcomes. Furthermore, although data on tumour staging and screening uptake were routinely reported by ISD Scotland, timelines varied even for the same outcomes.

The Scottish Government was aware of data limitations and welcomed receiving a final report which synthesised very significant amounts of evidence into a single document (as this had not been done for the programme). The descriptive outcome evaluation was necessary to integrate data on processes and outcomes, and indeed was a key component of the theory-based evaluation. Furthermore, the analysis was needed to generate evidence-based recommendations. Therefore, although the outcome evaluation did not happen as planned, it was still a demanding, labour

intensive process of data collection, synthesis and analysis that made the most of the available published and unpublished evidence.

### Knowledge of programme outcomes

When the evaluation was carried out, most stakeholders were aware that the HEAT targets had not been met. I had also already read policy documents reporting on a range of outcomes, although I only synthesised outcome data while carrying out the outcome evaluation. It is likely that this prior knowledge influenced design and analysis of the process evaluation (166). Interviews were an opportunity to discuss what worked and did not work, and the awareness that targets had not been met may have driven participants to suggest the assessment of other outcomes or discuss potential programme benefits that they would not have discussed otherwise. This additional knowledge may have also influenced expectations of what long-term impact DCE could be expected to have in the future.

*Process evaluation*

#### 10.6.2.4 Assurance of confidentiality and anonymity

Evidence indicated that the professionals' roles can have an impact on their views on the programme. However, in order to avoid indirect identification, I did not refer to roles when reporting interview findings. This is a limitation as this information would have helped the reader to make sense of the results, but it was necessary as Scotland is a small country and some job roles are not very common. Several interview participants raised concerns about indirect identification, and ensuring anonymity took priority.

### Views represented in the process evaluation

Stakeholders from NHS Orkney, NHS Shetland and NHS Western Isles did not take part in the study (despite repeated attempts during interview recruitment, and invitation emails to the questionnaire being sent). It may be that their views about the programme would be different. There were also no stakeholders from NHS Grampian represented in the process evaluation, although one interview was managed during evaluation development.

The evaluation did not seek views from the public as it focused on process issues from the perspective of professionals who influenced or were influenced by the programme. The evaluation steering group and the workshop to discuss evaluation results both included a lay representative to ensure that their views were included in evaluation design and recommendations for policy. While recognising the importance

of public views for a programme that aimed to improve population cancer outcomes, the evaluation focused on understanding service provision according to professionals. These views were shared during a DCE Programme Board meeting when I was asked about public involvement. It was agreed that it was best not to include the public if there was no clear purpose to do so based on the evaluation aims and objectives (for both ethical and practical reasons).

### Survey questionnaire

Key limitations of the questionnaire referred to non-response bias, and issues regarding representativeness and generalisability.

It was not possible to ascertain how many professionals in Scotland were eligible to take part in the questionnaire survey as eligibility was dependent on personal experience, and professionals' perception of how DCE influenced their work. It was only possible to estimate the denominator in order to calculate response rates.

Estimated response rates were low (4%). Low response rates are common when recruiting health care professionals in the UK (554-557), although there are also examples of high response rates in studies recruiting a specific group of professionals (558, 559). No data were collected on non-responders, but official estimates on NHSScotland and GP workforce in Scotland (560, 561) were used to help shed light on non-response bias regarding sex, age and profession. Most of the workforce in Scotland is female (560, 561); this was also the case in the questionnaire but there was a likely overrepresentation of female secondary care doctors.

Questionnaire participants were often older compared to official statistics. Furthermore, as medical professions represent 9% of the NHSScotland workforce and nurses (and midwifery) represent 45%, the former was over- and the latter under-represented in the survey (560). Statistics for GPs are shown separately and representativeness is difficult to ascertain, although GPs are likely to have been slightly overrepresented if adding GP numbers to the overall workforce (561). As secondary care professionals often showed statistically higher levels of disagreement to a range of statements in the questionnaire; it is possible that this overrepresentation biased overall results towards more negative experiences. However, this possibility would need to be checked further.

A 2008 systematic review on surveys for physicians and other medical professionals reported that studies often found minimal non-response bias. When there was bias,

non-specialist physicians, young physicians and women were more likely to take part (562). Only the latter seemed to have been the case in the DCE evaluation.

Guidance on how to improve response rates was followed. Only one reminder was sent instead of the planned two, as requested by Cancer Networks. Most questionnaire responses happened on the day of the first invitation and the reminder; it is likely that a second reminder would have resulted in more responses. Resonance/relevance (414, 504) is another issue that could have influenced response rates. Even though DCE was still ongoing, questions were being asked about events that happened up to 2015 (while the survey was carried out in 2018). Recall bias is also a key issue in questionnaire surveys (504), although in the case of DCE the impact is likely to have been small due to the broad nature of questions.

Despite limitations, the survey questionnaire managed to reach professionals whose views were important (as they were at the frontline or services) and not yet known (as they were less often approached in stakeholder interviews). Based on the large number of open-ended comments, these professionals also had a lot to say about the programme. Therefore, although the survey had limitations in terms of representativeness, it provided much needed data for an important group of relevant professionals.

#### 10.6.2.5 DCE changes

The evaluation funded by the Scottish Government referred to the first three years of the programme (its original planned duration). However, the programme did not end as planned in 2015. In fact, it remained a key component in the most recent Scottish Cancer Strategy (563), with a stronger focus on tackling health inequalities. New campaigns were also developed, but not described here. These changes had implications for the evaluation, as balance was needed between having defined evaluation timeframes while also ensuring that evaluation results were still relevant and useful. Outcomes available after 2015 were shown to ensure relevance. Furthermore, as described in Study 2 and Study 3, DCE constantly adapted to contextual changes and needs. A decision had to be made to focus on DCE's four main strategies.

Despite variation in outcome data, results often showed fewer positive results in terms of performance, especially regarding tumour staging (although still better compared to baseline) and bowel screening uptake over the years. Process evaluation results

showed that DCE funding was drastically reduced after three years. It is possible that these constraints limited DCE ability to make a longstanding impact on cancer outcomes.

Finally, it is worth noting that when DCE was implemented, cancer waiting times targets were being met in Scotland (138). This is no longer the case, and a clinical review was carried out (564) to assess whether targets were still fit for purpose. An interview participant highlighted that in such a scenario it would have been impossible to implement DCE. It is possible that DCE activities (and the corresponding impact on workload) had an impact on these pre-existing targets (it could be an unanticipated outcome, for example), but assessing this was beyond the scope of this PhD project.

## 10.7 Reflexivity

#### 10.7.1.1 Research background and scope of this evaluation

Perhaps due to my previous experience as a researcher, when I started this PhD project I planned to consider it as a standard research study; i.e. a research project with several milestones to be met, and outputs to be prepared for the research funder. After commencing my PhD project, I quickly realised that it was much more than a research study and understood why friends and colleagues often called it a PhD journey. I also have a background in business administration and I am often quite task oriented. Hence, not being able to track progress when working towards “invisible milestones” (such as investing time to read and assess theories and frameworks), was challenging.

Connecting all three individual studies of this PhD through a single aim, while ensuring that the underpinning methods, theories and frameworks were compatible was a challenging experience. Preparing both academic and policy-driven outputs, attending DCE meetings and presenting at Conferences was also demanding. Synthesising vast amounts of evidence in this thesis, while also aiming to write a coherent story outlining my PhD trajectory was also challenging. I believe that evaluation development was the most demanding PhD component, although it was one of the most rewarding experiences as it allowed me to look for/identify connections between theory and evidence.

In hindsight, this was an ambitious project to be carried out in three years, even with constant supervision, support from other researchers in quality assessment and data extraction (systematic review), and from an independent evaluation steering group.

Nonetheless, all three studies were needed to reach the conclusions outlined in this discussion.

I was not shy from trying different approaches in this PhD, but I was also careful to justify all my decisions. If I were to undertake this evaluation again, I would have developed a narrower evaluation plan, perhaps focusing on two assumptions and two mechanisms (instead of four each). Even though I believe that theory-based evaluation was helpful, I also believe I was trying to test too much theory. Furthermore, even though it is important to be faithful to the programme when choosing frameworks, an already established implementation framework (with validated questionnaires) could have facilitated data analysis, data interpretation and comparisons with other studies.

#### 10.7.1.2 Stakeholder interviews

I am also a Psychologist with prior experience interviewing research participants. Although I was aware of the importance of establishing rapport in interviews and helping to make participants feel comfortable, I found *myself* feeling very uncomfortable prior to commencing my initial interviews with key stakeholders (Study 2). I was speaking to busy professionals who were quite knowledgeable about the programme (and at times, personally invested in it), while I was an outsider who was planning to evaluate it. Furthermore, I was still learning about DCE and became worried about professionals questioning my ability to carry out the evaluation. Although this never happened during the interviews, I was questioned about the usefulness of the evaluation during a government meeting in 2017, and it took me a while to regain confidence. The experience taught me some hard lessons on the challenges of evaluating a high-profile government initiative which involved stakeholders with different interests and expectations.

I took care to listen to recordings and read interview transcripts not only to inform data analysis, but also to identify scope for improvements. This was a difficult experience as it required identifying my own shortcomings at a time when I was still gaining confidence about the PhD journey. English is not my native language, and it was uncomfortable to notice grammatical errors in my speech. I identified some key areas for improvement: do more prompting when stakeholders did not elaborate on something that seemed relevant to the evaluation or something that was not fully clear, be more careful in order not to break the flow of conversation, use the topic

guide but not let it constrain me when unexpected (and useful) comments about other topics arose.

I relaxed over time as I was feeling more comfortable with my role as an interviewer and evaluator, and with my knowledge about the programme. The interviews then became richer conversations, with the participants also feeling more comfortable to share their views on what worked well and what did not work so well with the programme. When participants could see that I was aware of a certain programme component, then they focused on describing their experiences rather than what the component was about. Importantly, I believe that the focus on programme processes in order to learn lessons about what worked and did not work in the programme (instead of being a “pass or fail assessment”) (166) also helped stakeholders to relax.

Data analysis of interviews also evolved over time. When analysing data from Study 2, everything seemed novel and important. When analysing data from Study 3, there were many more common/overlapping themes, and I am aware that my knowledge of the programme facilitated the identification of these.

Another factor that may have facilitated data collection over time was my attendance to DCE programme board meetings and presentations at different meetings and Conferences. Some stakeholders knew about the evaluation when I approached them for an interview or when they received an invitation to complete the questionnaire. Over time, the DCE evaluation became a recurring item in the DCE Programme Board Agenda. Meetings became opportunities for stakeholders to ask questions about the evaluation, and for me to provide updates. I believe that this increased involvement may have influenced my views on the programme. Even though I never stopped being an outsider as I was not part of DCE, closer involvement allowed me to better understand different roles and interests from different stakeholders. It was also easier to see and understand “different truths”, realities and priorities. Having an evaluation steering group, carrying out the workshop with professionals to discuss evidence-based recommendations and receiving constant supervision were helpful for me to maintain a balanced view of what happened.

#### 10.7.1.3 Process evaluation questionnaire

Developing the questionnaire was a challenging experience not only in terms of methods, but also in terms of how to approach the programme. It became clear over time that some professionals still wished to give their views about DCE even if they

did not think that it had directly influenced their work. Conversely, even when it was clear that DCE strategies had influenced the professionals' work, some stakeholders were not aware of this as they did not see the strategy as part of DCE. I found out about these issues when pre-testing the questionnaire (when a GP highlighted that s/he did not know that the referral guidelines had been updated as part of DCE) and when I received an email about the questionnaire (a secondary care professional who had been screened out after the eligibility question, but still wanted to give their views about the programme). The experience highlighted two issues: 1) I became so immersed in the programme that I forgot that the professionals' lives did not revolve around DCE (as mine did because of my PhD), with many carrying out their work as usual and incorporating whichever DCE component was introduced in the health system; and 2) having a single questionnaire about the whole programme, asking about involvement before stakeholders could see the questions (even though DCE components were described in the introductory page), may have resulted in missing professionals who wished to share their views about the programme (even though in principle they were not eligible to do so). If I were to carry out the evaluation again, I would probably reconsider the eligibility question in order to be more inclusive, even though a broader approach would have likely meant more missing data in the questionnaire.

## 10.8 Concluding remarks

This PhD aimed to understand the role of multilevel policy initiatives in promoting the earlier diagnosis of cancer. In order to do so, three studies were carried out. These studies identified that such initiatives have an important role in promoting the earlier diagnosis of cancer. However, they are influenced by the context, and dependent on collaborations with several other stakeholders. Importantly, although these initiatives are necessary to bring earlier diagnosis to the centre of attention, in isolation they are not sufficient to generate long-term changes in cancer outcomes. Furthermore, it is challenging to ascertain their contribution due to their nature (uncontrolled experiments), limited data availability, and heterogeneity across different initiatives. Perhaps we need to be more realistic about what government initiatives can do, while also specifying parameters of what is acceptable in terms of incremental changes and ensuring that measures are in place so expected long-term changes can be assessed in due time. Collaborations between research and policy are necessary to ensure initiatives are well designed, implemented, evaluated and disseminated.

### 10.8.1 How this PhD contributes to knowledge

A key feature of this PhD was the adoption of a range of theories and frameworks in the evaluation of a government-led initiative. To my knowledge, this is the first time that a multilevel policy initiative promoting the earlier diagnosis of cancer is assessed using theory of change and adopting outcomes chains in addition to a logic model. Evaluations of NAEDI and ACE adopted realist evaluation, a type of theory-based evaluation which was found not to be an ideal fit for the DCE programme. The DCE evaluation builds much needed knowledge on mechanisms of impact in early diagnosis initiatives, while also incorporating behaviour change theory. There are not many available examples of the BCW and COM-B being used in early diagnosis research (565, 566), and this thesis helps to build knowledge in the field.

Another important thesis contribution was the comprehensive description of how to design a theory-based evaluation. By being transparent about evaluation development, I believe this thesis is a useful (and rare) example for other researchers aiming to carry out similar evaluations.

In terms of implementation research, this thesis reinforces calls for better understanding of variation in implementation. Challenges in assessing implementation fidelity are already recognised (166, 172), and in this study adaptability was used instead. Adaptability and flexibility were key characteristics of the DCE programme, although these were not always described as positive characteristics. Adaptability has been reported as a core characteristic of other cancer control programmes (521). It is important that adaptability is further investigated in future evaluations of similar initiatives.

The MRC framework for process evaluation of complex interventions is fairly recent, and the number of studies adopting it has been increasing in the past few years (417, 567-569). To the best of my knowledge, this PhD is the first to adopt it to evaluate a multilevel policy initiative promoting the earlier diagnosis of cancer. Hence, the DCE evaluation enhances understanding on how to use the framework in this context. Furthermore, the separate data collection and analysis of processes and outcomes followed by integration of results generated two important lessons for those planning to adopt the MRC framework while using mixed-methods research. First, merging results led to a more complex set of relationships between evaluation components, creating a “whole” that was more than the sum of its parts (224). Second, not all data

could be integrated. Each component on its own provided rich data that would have been missed without independent data analyses. I would recommend that data integration approaches in mixed-methods evaluation research are carefully considered in order not to miss important evidence. The guidance adopted in this PhD project (195, 226) was invaluable.

This thesis also provided a range of evidence-based recommendations for policy and research, including about issues that consistently appear in programme evaluation and may require further coordinated, collaborative thinking to identify creative solutions.

Finally, it is hoped that the data described in this thesis and the evidence-based report prepared for the Scottish Government are helpful to generate ideas and fruitful discussions on how to promote earlier cancer diagnosis in Scotland and worldwide. A recent ICBP publication has shown that cancer survival has improved over time (period 1995-2014) across seven high-income countries (all represented in the review except for New Zealand), but that the UK (including Scotland) still has poorer 1- and 5- year survival (570). Considering the persisting burden of cancer and the challenges in ensuring better cancer outcomes for all, helping to generate these discussions on how to move forward would be the most important contribution of this PhD project.

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# PhD STUDY OUTPUTS

## Published manuscript

- Calanzani N, Weller D, Campbell C. The characteristics of national health initiatives promoting earlier cancer diagnosis among adult populations: a systematic review protocol. BMJ Open. 2017;7:e015922(7).

## Manuscript under review

- Calanzani N, Weller D, Campbell C. Development of a theory-based evaluation of a national early cancer detection initiative in Scotland (submitted to Evaluation and Program Planning on the 26th May 2019)

## Manuscripts in preparation

- Calanzani N, Weller D, Campbell C. The characteristics of national health initiatives promoting earlier cancer diagnosis among adult populations: a systematic review.
- Calanzani N, Weller D, Campbell C. A mixed-methods evaluation of a national early cancer detection initiative in Scotland - how can it inform other policy initiatives?

## Evidence-based report

- Calanzani N, Weller D, Campbell C (2018). Evaluation of the Detect Cancer Early Programme in Scotland. Reporting on processes and outcomes. University of Edinburgh.

## Presentations of PhD work

| Conference/Event | Location | Date | Presentation type |
|---|---|---|---|
| 12th Cancer and Primary Care Network (Ca-PRI) Conference | Toronto, Canada | May/19 | Oral presentation |
| CRUK Early Diagnosis Conference | Birmingham, England | Feb/19 | Oral presentations (n=2); bursary awarded |
| ADEGS Conference | Carnoustie, Scotland | Jan/19 | Oral presentation |
| National Cancer Research Institute (NCRI) Conference | Glasgow, Scotland | Nov/18 | Poster presentation |
| Faculty of Public Health Conference | Peebles, Scotland | Nov/18 | Poster and short presentation |
| World Cancer Congress | Kuala Lumpur, Malaysia | Oct/18 | Poster and short presentation (presented by Dr. Christine Campbell on my behalf) |
| 11th Cancer and Primary Care Network (Ca-PRI) Conference | Groningen, Netherlands | Apr/18 | E-poster presentations (n=2) |
| 10th Cancer and Primary Care Network (Ca-PRI) Conference | Edinburgh, Scotland | Apr/17 | E-poster presentations (n=2) |

| Conference/Event | Location | Date | Presentation type |
|---|---|---|---|
| CRUK Early Diagnosis Conference | London, England | Feb/17 | Poster presentation |
| NADEGS Conference | Stirling, Scotland | Jan/17 | Oral presentation |
| Detect Cancer Early Conference | Glasgow, Scotland | Sep/16 | Invited speaker; oral presentation |
| Lunchtime seminar | Aarhus, Denmark | Aug/16 | Oral presentation |
| Usher Institute Annual Research Day | Edinburgh, Scotland | May/16 | Poster presentation |

## Professional development: training on policy and evaluation

| Event | Organiser/Location | Date |
|---|---|---|
| 2-day course: Science Policy: Improving the Uptake of Research into UK Policy | Wellcome Genome Campus (Hinxton, Cambridgeshire) | Aug 2018 |
| Conference: Priorities for cancer care policy - early diagnosis, treatment and research | Royal College of Physicians, Edinburgh (Scotland Policy Conferences Keynote) | May 2018 |
| 3-day Course: Evaluating Complex Public Health Interventions | Cardiff University (DECIPHER) | Jun 2016 |
| 1-day workshop: Politics and Partnership in Health | Scottish Parliament | Apr 2016 |
| Module: Developing and Evaluating Complex Public Health Interventions | UoE (Masters of Public Health) | Jan-Mar 2016 |
| Lunchtime seminar: Connecting with policymaking: Scottish Parliament | Knowledge Exchange Office | Nov 2015 |
| Lunchtime seminar: Engaging with the Scottish Government | Knowledge Exchange Office | Oct 2015 |

# APPENDICES

# Appendix 1. MRC framework checklist

| 1. Working with policy and practice stakeholders | |
|---|---|
| 1.1 Are there any potential conflicts of interest arising from the relationship between evaluators and policy/practice stakeholders? | Yes, these issues are addressed and discussed in Chapter 10 |
| 1.2 Have the authors described how they will address these and ensure that the evaluation remains independent? | Yes, the evaluation steering group I described in Chapter 3, issues are discussed in Chapter 10 |
| 1.3 Does the proposal set out a clear plan for communicating findings to policy and practice stakeholders during the evaluation? | Yes, this is discussed in the thesis: stakeholders were involved from early stages (Chapter 3) and evaluation was disseminated as widely as possible (Chapter 10) |
| **2. Relationships between evaluation components** | |
| 2.1 Is the relationship between the process evaluation and other evaluation components clearly defined and justified? | Yes, this is presented in Chapter 3, reiterated in Chapters 5-9 and discussed in Chapter 10 |
| 2.2 Will process and outcomes evaluation be conducted by the same team or by separate teams? | Conducted by one researcher, with advice from supervisors, a steering group and evaluation courses |
| 2.3 If the former, how will researchers ensure that knowledge of outcomes or process does not bias analysis of the other? | This was addressed by constant reflexivity; the issue is discussed in Chapter 10 |
| 2.4 If the latter, is there clear oversight of the two components? | Yes, process and outcome evaluations were carried out independently and then integrated |
| 2.5 Is it clear that the principal investigator values all aspects of the evaluation, and will provide effective oversight of all aspects of the evaluation? | There was constant supervision, and support from an evaluation steering group. I also attended several evaluation courses, including a course designed by the authors who developed the MRC framework adopted in this evaluation |
| **3. Intervention description and theory** | |
| 3.1 Is the intended intervention fully described? Are standardised terminology and definitions of intervention components adopted where possible? | Yes, descriptions are available throughout the thesis (especially Chapter 5 and Chapters 5-9), in addition to Appendices |
| 3.2 Are the structures and processes involved in intervention delivery fully described? If appropriate, will a full intervention manual be made publicly available? | There was no full description available; evaluation development and refinement was paramount for this. Publications are planned with full programme descriptions |
| 3.3 Is s a clear, plausible, set of causal assumptions specified and justified (for example, in a logic model)? | Yes; the logic model was developed after analysing policy documents and refined after feedback from stakeholders; the outcomes chains were revisited after the full evaluation |
| 3.4 Does this draw upon appropriate theories? | Yes; robust and well-recognised theories and frameworks were adopted; published guidance on how to implement them was followed |
| 3.5 If not, are there plans to develop a theory as part of the research? | N/A |
| 3.6 Have the authors planned to review these assumptions with policy and practice stakeholders to explore agreement and divergence on what the intervention is, and how it will work? | Yes, these were investigated during the evaluation and revisited afterwards. |

| 4. Process evaluation aims and research questions | |
|---|---|
| 4.1 Are the research questions clear, important and well justified with reference to the theory of the intervention and the status of the evidence base? What decisions will they inform? | Yes, the research questions were informed by evidence, data collection and adopted theories. The aim was not only to generate knowledge but to inform policy |
| 4.2 Have the authors considered whether previous process evaluations have been conducted of interventions involving similar components or theories of change? | Literature was consulted for similar evaluations. Terms and descriptions from the adopted frameworks/theories (BCW and theories of change, especially archetypes) were adopted in the evaluation |
| 4.3 Have they adopted comparable aims and methods, or justified not doing so? | When it was not possible to use validated tools, definitions of adopted constructs were provided |
| 4.4 Has the theory of the intervention (or logic model) been used to identify key areas of uncertainty for investigation by process evaluation? | The programme theory was informed by evidence and critical issues/uncertainties identified during evaluation development (documentary analysis and interviews) |
| 4.5 Have the authors considered which components may prove most challenging to implement (e.g. which represent more fundamental change, or for which there is least agreement on what they are and the purposes they serve)? | Areas of disagreement/uncertainty were identified during evaluation development and investigated further |
| 4.6 Have the authors considered for which causal assumptions evidence is most equivocal? | Several areas of uncertainty were investigated as it was not clear which one was most equivocal during evaluation development |
| 4.7 How will unanticipated consequences be captured? | Due to limited data availability, these were investigated in the process evaluation only |
| 4.8 Is there linkage between research aims? | Binding aims are described throughout the thesis, especially in Chapter 3 and figure 3.3 |
| 4.9 Do they fit together to address the overall study aim? | Yes, described in Chapter 3 and figure 3.3 |
| 4.10 If conducted alongside an outcomes evaluation, is the added value of the process evaluation explained? Is it clear how the research will enhance the interpretation of outcomes? | The rationale for a process evaluation is described in Chapter 3, its benefits are reiterated in Chapter 10 when integrating findings |
| 4.11 Will process evaluation provide sufficient assurances regarding the internal validity of the outcomes evaluation? | There were several limitations when carrying out the outcome evaluation, but the process evaluation still helped to show why objectives were met/not met |
| 4.12 Will it enable policymakers/practitioners to understand how the intervention might be applied in different contexts? | Contextual influencers were often approached, regional variation is outlined in Chapter 9, impact of variation is also approached in Chapter 10 |
| 4.13 Have the authors stated how and when they will combine process and outcomes data? | This is described in Chapters 3 and 10 |
| **5. Selection of methods to address research questions** | |
| 5.1 Are the quantitative and qualitative methods selected appropriate to the research questions? | These issues are comprehensively described and justified in Chapters 3-6 |
| 5.2 Will implementation be captured in sufficient detail to establish consistency with the theory of the intervention? | I tried to obtain and report on as much detail as possible |

| | |
|---|---|
| 5.3 Are existing validated measures used where possible? Are plans to validate new measures included? | These were used whenever possible (e.g. COM-B). When this was not possible (e.g. questionnaire), justification was provided and adopted concept/constructs were defined to enable comparisons. Currently, there are no plans to validate the evaluation questionnaire |
| 5.4 How will emerging changes, adaptations or additions to the intervention be captured? | These issues are described in Chapter 9 and discussed in Chapter 10, acknowledging limitations to evaluate a dynamic programme |
| 5.5 Are the quantitative methods appropriate? (e.g. 'tick box' self-report by implementers of intervention delivery should be avoided if possible). | It was impossible to avoid self-reporting, but the questionnaire reached stakeholders who were not involved in implementation. There were issues regarding representativeness. Limitations are discussed in Chapter 10 |
| 5.6 Are the qualitative methods appropriate? | Purposive sampling and framework approach were chosen, justification and rationale are provided in Chapters 5 and 6 |
| 5.7 Have the authors considered how change in practice as a result of being observed or measured will be minimised? | N/A; the evaluation was carried out retrospectively |
| 5.8 Have the authors considered the timing of data collection, and its impact on the data collected? | Yes, challenges and limitations are available in Chapter 10 |
| 5.9 Have the authors investigated whether any routine programme monitoring data can be used? If so, are there plans to check their validity and reliability? | Yes, policy documents were used as much as possible, for both evaluation development and the outcome evaluation. A framework for reviewing and interrogating data was developed based on available guidance |
| 5.10 Have the authors stated how quantitative and qualitative methods will be combined? | Yes, this is approached in Chapters 3 (see Figure 3.3) and 10 |
| 5.11 Have the authors considered how they will respond if challenges emerge during the evaluation - for example, if serious implementation failures are identified which need deeper investigation? | This was not planned but was not needed |
| **6. Resource considerations in collecting/analysing process data** | |
| 6.1 Who will lead or conduct the process evaluation? Do they have, or have direct access to, appropriate expertise and experience? | I was the lead (a PhD student). I am an experienced researcher and attended several courses on evaluation. I also had two supervisors and support from an evaluation steering group |
| 6.2 Does the research team have sufficient expertise in quantitative and qualitative methods, and relevant social science theory? | I have a diverse background (business and psychology), and experience in qualitative and quantitative methods. I immersed myself in theory for several months in order to develop the DCE evaluation |
| 6.3 Is sufficient time, funding and staff resource included for data collection, analysis (including sufficient time to conduct good quality analysis of qualitative data, with quality checks by a second coder where appropriate) and reporting? | Yes; the evaluation was carried out as part of a full-time PhD, with full-time dedication. Sampling for interviews considered the time resources available to analyse data. One of my supervisors also read transcripts and helped to refine the thematic framework |

***Source: Moore et al 2014. Process evaluation of complex interventions. Available from: https://mrc.ukri.org/documents/pdf/mrc-phsrn-process-evaluation-guidance-final/***

# Appendix 2. Published systematic review protocol

Open Access Protocol

BMJ Open

# The characteristics of national health initiatives promoting earlier cancer diagnosis among adult populations: a systematic review protocol

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## ABSTRACT

**Introduction** The increasing burden of cancer morbidity and mortality has led to the development of national health initiatives to promote earlier cancer diagnosis and improve cancer survival. This protocol describes a systematic review aiming to identify the evidence about such initiatives among the adult population. We will describe their components, stakeholders and target populations, and summarise their outcomes.

**Methods and analysis** We will search databases and websites for peer-reviewed publications and grey literature on national health initiatives in high-income countries as defined by the World Bank. Quantitative, qualitative and mixed-methods studies will be included and assessed for their methodological quality. Study selection, quality assessment and data extraction will be carried out independently by two reviewers. Narrative synthesis will be used to analyse the findings.

**Ethics and dissemination** This systematic review analyses secondary data and ethical approval is not required. Review findings will be helpful to researchers, policy makers, governments and other key stakeholders developing similar initiatives and assessing cancer outcomes. The results will be submitted to a peer-reviewed journal in order to reach a diverse group of healthcare professionals, researchers and policy makers. This systematic review protocol is registered at PROSPERO (CRD42016047233).

## Strengths and limitations of this study

- ► To our knowledge, there are no other studies systematically reviewing national cancer strategies promoting the earlier diagnosis of cancer and describing their characteristics, populations and overall outcomes.
- ► Limitations include challenges related to wide heterogeneity in the composition and intensity of initiatives, populations and contexts, and carrying out comprehensive literature searches in such a broad area.

## INTRODUCTION

Cancer imposes a significant public health burden worldwide; in 2012, there were over 14 million diagnoses and 8.2 million cancer deaths.[1] Cancer incidence has increased over time,[2] partly due to population ageing and lifestyle factors such as diet, tobacco use, alcohol consumption, obesity and physical inactivity.[3] In the UK, it is estimated that one in two people born after 1960 will be diagnosed with cancer at some time in their lives.[4]

Furthermore, the number of people surviving cancer is increasing, mainly as a result of improvements in early detection and treatment.[5 6] In 2012, there were 32.6 million 5-year cancer survivors worldwide.[7] There is, however, a wide survival gap between different countries.[8] In Europe, England and Denmark have been identified as having poor survival rates compared with other Western European countries.[5 9] Late cancer stage at diagnosis and quality of treatment have been described as important explanatory factors for international variation in cancer survival.[10–12]

The increased burden of cancer and the opportunity to improve survival have driven the development of organised health system level initiatives related to early cancer detection. In 2002, the WHO recommended the development of national cancer control programmes adopting 'strategies for prevention, early detection, diagnosis, treatment, and palliation' of cancer. Suggested early detection strategies included promoting the awareness of cancer signs and symptoms and training health professionals.[13] Acknowledging resource variation across countries, the WHO recommended the adoption and implementation of nationwide strategies in countries with high level of resources and community approaches in countries where resources are limited.[13] In 2005, the WHO approved a resolution on Cancer Prevention and Control[14]; one of its recommendations

was to reduce late presentation for cancers that are amenable to early detection and treatment.[15]

In the UK, the National Awareness and Early Diagnosis Initiative (NAEDI) was launched in 2008, led by the Department of Health and Cancer Research UK (a leading cancer charity) with the aim of improving cancer outcomes.[16] A similar initiative (the Detect Cancer Early Programme) was launched by the Scottish government in 2012, aiming to improve overall 5-year survival for patients with lung, breast and colorectal cancers.[17] In Denmark, a novel strategy focusing on different pathways for patients presenting with a range of symptoms was established with the aim to expedite early diagnosis and treatment.[18]

These health initiatives are complex, with several interacting components[19] and often require behaviour change from their target population. Furthermore, they may focus on different groups or organisational levels and can change depending on the context.[19] Synthesising results of such initiatives in a systematic way is methodologically challenging, from defining the research questions to discussing the applicability of findings.[20] Nonetheless, efforts should be made to review the evidence in order to inform and enhance future initiatives aiming to promote early cancer diagnosis and influence cancer survival. Reporting on their activities and outputs is also important to enhance transparency and accountability, especially when these initiatives are directly or indirectly funded by the public.[21]

Previous reviews have attempted to summarise the evidence on national health initiatives in promoting the early diagnosis of cancer. González-Robledo *et al* carried out a database and documentary analysis of Latin American governmental actions for early detection of breast cancer and described how these often operated through regulation, design and implementation of early diagnosis programmes, care provided by public and private services and the development of guidelines for early detection.[22] Palmer's overview of different UK cancer policies cited a few government interventions aiming to promote the earlier diagnosis of cancer and described factors associated with poor cancer survival, including socioeconomic deprivation.[23] Brown and colleagues investigated how different healthcare system characteristics (several regions in six countries were investigated) could contribute towards a number of cancer outcomes, including early diagnosis. The authors acknowledged that identifying causal relationships between healthcare system characteristics and cancer outcomes was challenging in complex, context-specific systems.[24]

To our knowledge, there are no existing systematic reviews summarising national cancer initiatives at a health system-level worldwide, describing their characteristics, populations and overall outcomes. This review will add to existing knowledge into the area, systematically reviewing the international literature on national cancer initiatives promoting the earlier diagnosis of cancer.

## METHODS AND ANALYSIS

This protocol describes a systematic review that is investigating health system level initiatives promoting the earlier diagnosis of cancer. We are guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) P-checklist,[25] the PRISMA guidelines for reporting systematic reviews,[26] the Cochrane Handbook for Systematic Reviews of Interventions[27] and the Centre for Reviews and Dissemination's guidance for undertaking systematic reviews[28] when developing this protocol. Guidance on reviewing complex interventions has also been consulted.[19 29]

### Study objectives

The review seeks to identify, describe and categorise the available evidence on national initiatives aiming to promote early diagnosis of cancer among the adult population. Our review methodology was developed in order to answer the following broad research questions:

1. What are the key components of these initiatives?
2. Who are the target populations and what are their sociodemographic characteristics?
3. What are the reported overall outcomes of these initiatives?
4. Where reported, what are the perspectives of participants (patients, professionals and policy makers) on these multilevel cancer initiatives?

If available in the included studies, we will also explore relevant contextual issues or any barriers/facilitators that may help to shed light on *how/why* the initiatives' specified objectives were (or not) achieved.

### Study selection criteria

Study selection criteria are described in text and summarised in table 1.

### Study designs and publication types

We will include experimental and non-experimental (observational) study designs. Quantitative, qualitative and mixed-methods studies are eligible for inclusion.

Study protocols, reviews/overviews, editorials, commentaries, short reports, viewpoints and letters to the editor are eligible for inclusion as these publications can provide important information on the components of national initiatives and their target populations (in addition to contextual information). Theses, government reports and other official documents are also eligible for inclusion.

Conference abstracts are eligible for inclusion provided that full-text about the initiative is also identified. Reviews/overviews are eligible for inclusion if they report on data from a single multilevel initiative (eg, describing its different components/programmes). Those reporting on more than one initiative will be excluded, but their references will be checked in order to identify additional eligible studies. Published guidelines from professional bodies that are not part of a government initiative will be excluded.

Table 1 Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| *Design and publication types* | |
| ► Experimental and non-experimental studies<br>► Studies using quantitative, qualitative or mixed methods<br>► Protocols, editorials, commentaries, short reports, viewpoints and letters to the editor<br>► Reviews/overviews and systematic reviews reporting on a number of components from a single national strategy/initiative<br>► Conference abstracts when full-text about initiatives is also available | ► Reviews and systematic reviews reporting on more than one national initiative<br>► Conference abstracts when full-text about initiatives is not available<br>► Published guidelines/recommendations from professional bodies that are not part of a government initiative<br>► Publications without full-text in English |
| *Population and setting* | |
| ► Adults (aged 18 years or older)<br>► Patients/member of the public with or without medical conditions<br>► Healthcare professionals<br>► Health institutions/settings<br>► High-income countries (World Bank) | ► Children (aged 17 years or younger)<br>► Professionals working in an administrative capacity (even if within a health system)<br>► Low-income and middle-income countries (World Bank) |
| *Interventions* | |
| ► Initiatives aiming to promote early diagnosis<br>► Initiatives addressing the patient/member of the public and at least two more levels of contextual influence (see Taplin *et al*)<br>► National level initiatives or equivalent (ie, state or provincial level depending on health system structure and autonomy) | ► Initiatives aiming to support the entire cancer trajectory or to reduce cancer disparities (in which early diagnosis is only a component)<br>► Initiatives focusing on primary prevention, surveillance programmes, genetic counselling, cancer recurrence or screening programmes<br>► Cost-effectiveness studies<br>► Initiatives addressing the patient/public only<br>► Small, localised research studies and purely academic research studies/projects |
| *Comparators and outcomes* | |
| ► Any comparators (studies without comparators are also eligible for inclusion)<br>► High-level outcomes (national or equivalent) related to the initiatives' main aims (eg, improve awareness and diagnose cancer earlier)<br>► Overall views/experiences about initiatives | ► Local, setting-specific outcomes<br>► Outcomes for a single cancer type (when strategies targeted more than one type) |

## Study population and setting

Initiatives aiming to promote earlier cancer diagnosis for the adult population (aged 18 years and over) will be included due to their relevance regarding the increased burden of cancer incidence and mortality. Initiatives aiming to promote earlier cancer diagnosis for any cancer types are eligible for inclusion. Health status will not be a reason for exclusion; we are interested in early diagnosis initiatives aiming at healthy participants or patients with any underlying medical conditions (provided that the focus is not on these other conditions).

Initiatives may also involve interventions with healthcare professionals. Hence, interventions targetted at general practitioners, other medical doctors, nurses and any allied professionals (such as pharmacists and radiographers) are eligible for inclusion. Initiatives carried out solely with professionals working on an administrative capacity (such as practice managers and hospital administrators) will be excluded. Finally, initiatives may also have healthcare providers, institutions and governments in receipt of an intervention. These groups are therefore also eligible for inclusion.

Initiatives carried out in high-income countries as classified by the World Bank[30] are eligible for inclusion. Low-income and middle-income countries are being excluded due to the diversity of health systems, populations and challenges (which would impair the ability to compare review results with activities from the Detect Cancer Early Programme in Scotland—as part of a large study of which this review is a component).

## Interventions

We will include national initiatives/strategies with the explicit aim to promote earlier cancer diagnosis at a

health system level. Healthcare delivery occurs in a multilevel system, where multiple levels of contextual influence may affect behaviour.[31] Taplin *et al* describe seven different levels: (1) the individual patient, (2) family and social supports, (3) provider/team, (4) organisation and/or practice setting, (5) local community environment, (6) state health policy environment and/or (7) national health policy environment. The authors stipulate that multilevel interventions should address the patient (individual level) in addition to at least two more levels.[31] All included studies will be required to meet this requirement, although adaptations are possible (eg, a member of the general public may also represent the individual level, and not all countries may have a state level). Interventions will be required to have involvement from governments (at state or national level), although non-governmental organisations may also be involved. Small, localised research studies within a single hospital/other institution and purely academic research studies are not considered a national initiative and will therefore be excluded. Importantly, we are adopting Taplin *et al*'s definition of interventions, that is, any 'specified strategy or set of strategies designed to change the knowledge, perceptions, skills, and/or behaviour of individuals, groups, or organisations, with the aim of improving patients' health outcomes'.[31] Hence, interventions may refer to trials or observational studies (including natural experiments).

Possible interventions aiming to promote earlier cancer diagnosis include but are not limited to campaigns to increase knowledge/awareness of cancer, training for healthcare professionals and development of care pathways to cancer diagnosis and treatment. We are particularly interested in initiatives that (1) raise awareness of symptoms and encourage prompt presentation by patients; and (2) facilitate timely investigation and referral in primary care. Initiatives focusing solely on primary cancer prevention such as those targeting lifestyle changes, reduction of exposure to environmental factors that may cause cancer or vaccinations (ie, against human papillomavirus), surveillance programmes for patients with *Helicobacter pylori* (a risk factor for stomach cancer) or Barrett's oesophagus (a risk factor for oesophageal cancer) will be excluded. Studies focusing on patients with genetic susceptibility of cancer, aiming to avoid cancer recurrence or cost effectiveness studies will also be excluded. Likewise, publications solely describing cancer screening programmes will be excluded (as these refer to a different, vast body of literature).

### Comparators

Due to our broad aim, the diverse nature of the initiatives and the inclusion of quantitative and qualitative studies, it is likely many included studies will not have comparator populations. When these are present, they are likely to include: (1) indicators before (baseline) and after (one or more time points) at an individual and group level; or at the provider, organisation, local community, state and national levels; or (2) those in receipt versus those either not in receipt of any initiative or in receipt of a different initiative.

### Outcomes

This review aims to provide an overview of different initiatives as opposed to systematically assess all available outcomes for each identified initiative, as this would require a number of different reviews. We will only report overall, high-level outcomes (as the review's aim is to identify, describe and categorise national health initiatives without focusing on the outcomes). The review will summarise key features, target populations and reported measures used to monitor and evaluate different strategies. Local, setting-specific outcomes described in small studies about different initiatives will therefore not be reported. We will identify core publications for each initiative (from which data will be extracted) and list all other relevant, additional publications identified in the searches (categorising them according to the strategies they are referring to). We expect that the search strategy will identify a number of such additional publications.

High-level quantitative outcomes may include but are not limited to measures of knowledge/awareness of cancer, cancer symptoms or cancer screening; proxy measures of survival such as cancer stage at diagnosis may also be available.

Qualitative outcomes of interest include any views or experiences from professionals regarding the initiatives that may shed light on issues regarding implementation, feasibility and acceptability of initiatives. Patients and the public may provide perspectives on the impact of the initiatives and the importance of outcomes.[19] Findings from qualitative studies may also help to shed light on the context (geographical, cultural, social, organisational or political) in which initiatives were implemented.[19]

Some studies may be reporting ongoing interventions and data on health outcomes may not yet be available. It is also possible that some eligible publications will be descriptive in nature, presenting an overview of programmes.

### Search strategy

A search strategy has been developed by the authors by making a list of keywords considered to be relevant based on the authors' knowledge of available literature on cancer and early diagnosis and looking at search strategies from specific publications in the area.[32 33] The search strategy was then refined after discussions with a senior academic liaison librarian experienced with developing systematic review protocols in the field of health sciences. The search strategy was tested to ensure it was identifying relevant publications. It is broad as it was challenging to define specific keywords based on the research questions, and there was the possibility of missing too many relevant studies. It is also likely that national health initiatives are not described as such even when this is the case. We are therefore prioritising sensitivity over precision[27] in order

Table 2 MEDLINE search strategy*

| | |
|---|---|
| 1 | government or policy$ or policies or national or regional or multi-level$ or system-level or whole-system$ or NAEDI or 'Detect Cancer Early' or 'National Awareness and Early Diagnosis Initiative' or 'Find Cancer Early' or 'Be Cancer Aware' or 'Be Clear on Cancer' or initiative$ or program$ or campaign$ or strateg$ or engagement or awareness.mp |
| 2 | health$ adj2 (care or service$ or system$ or seek$ or provi$).mp |
| 3 | surviv$.mp |
| 4 | delay$ adj4 (diagnos$ or present$ or treat$ or consult$ or patient$ or doctor$ or system$ or refer$ or therap$ or care or detect$).mp |
| 5 | time adj4 (diagnos$ or present$ or treat$ or refer$ or care or detect$).mp |
| 6 | late adj4 (diagnos$ or treat$ or refer$ or present$ or detect$).mp |
| 7 | earl$ adj4 (diagnos$ or present$ or treat$ or refer$ or therap$ or detect$).mp |
| 8 | 3 or 4 or 5 or 6 or 7 |
| 9 | Cancer$ or neoplas$ or tumour or tumor or malign$ or oncolog$.mp |
| 10 | Randomi$ or RCT or intervention or trial or cross-sectional or survey$ or questionnaire$ or train$ or 'natural experiment' or interview$ or 'focus group$' or 'case study' or observation$ or time-series or 'time series' or CBA or 'controlled before and after' or 'controlled before-after' or prospective or retrospective or cohort or case-control or cross-over or 'case series' or case-reports or 'case reports' or feasibility or pilot or narrative or qualitative or quantitative or mixed-methods or 'mixed methods' or evaluat$ or assess$ or attitude$ or view$ or perception$ or perspective$ or 'discourse analysis' or 'content analysis' or 'thematic analysis' or 'narrative analysis' or phenomenolog$ or 'purposive sampl$' or ethnograph$ or 'theoretical sampl$' or 'grounded theory'.mp |
| 11 | 1 and 2 and 8 and 9 and 10 |
| 12 | 11 not (child$ or pediatric$ or paediatric$ or adolesc$ or teenag$).ti |
| 13 | 12 not (palliative or terminal or 'end of life' or end-of-life or 'advance directive$' or hospice$).ti |
| 14 | 13 not (biomarker$ or molecul$).ti. |
| 15 | limit 14 to (english language and humans and yr='2005 -Current') |

*'.mp' searches automatically for subject heading (MeSH) fields.

not to miss important eligible studies. This is especially important when including qualitative studies.[32] Syntaxes/Boolean operators will be changed to meet the requirements of different research platforms. The MEDLINE search strategy is shown in table 2.

A number of databases (such as EMBASE, PsycInfo, MEDLINE and ASSIA; table 3) will be searched electronically, including those focusing on grey literature. Government and charity websites will be searched in addition to different data repositories for randomised controlled trials and studies funded by the European Commission.

We will check the reference lists of all included studies. If relevant references are not available online, we will contact the authors to request these. Finally, the list of included studies will be checked by all authors to verify whether any relevant studies known to them are missing.

We will include all studies published from 2005 onwards. This cut-off point was chosen as this was the year that the WHO approved its resolution on Cancer Prevention and Control.[15] Broader inclusion criteria will allow for the identification of less well-known initiatives worldwide, with diverse health contexts (such as universal health coverage) and approaching different populations (such as deprived groups, those living in rural areas and ethnic minorities). Due to resource limitations, only publications in English will be included. Initially, we envisioned to include publications in Spanish and Portuguese (as we have the resources to translate these), but we were concerned that the results would then be biased towards initiatives in countries where these languages are spoken. We do acknowledge, however, that publications will be biased towards studies published in English (implications will be discussed). Full-text publications in any language other than English will be excluded even if the abstracts are available in this language. We will prepare a descriptive supplementary table listing these potentially eligible abstracts that only had full-text in a different language.

### Data management, selection and extraction

Citations and abstracts from searches will be exported into EndNote X7 for Windows. After removing duplicates, the studies will be screened using a multistep procedure. First, one author will screen all the titles and abstracts against the inclusion criteria. Another author will screen a random selection (30%) of the excluded studies at this step. Second, two review authors will independently screen the full-text of reports in order to select papers for inclusion. Finally, the two authors will carefully reassess the full-text of all included articles (independently) in order to ensure they have relevant information which could be extracted. Articles that do not have this will be excluded from the analysis. The study selection process will be recorded in SPSS version 22 for Windows. A

Table 3 Electronic data sources

| Search platform/provider | Databases |
|---|---|
| Cochrane Library (single search) | ▶ Cochrane Database of Systematic Reviews (CDSR)<br>▶ Cochrane Central Register of Controlled Trials (CENTRAL)<br>▶ Database of Abstracts of Reviews of Effects (DARE)<br>▶ Health Technology Assessment Database (HTA)<br>▶ NHS Economic Evaluation Database (EED) |
| Ovid (searching each database independently) | ▶ Embase Classic + Embase<br>▶ MEDLINE(R) and MEDLINE(R) In-Process & Other Non-Indexed Citations<br>▶ PsycInfo<br>▶ PsycARTICLES full-text |
| Web of Science Core Collection (single search) | ▶ Scielo<br>▶ Science and Social Sciences<br>▶ Conference Proceedings in Science and Social Science & Humanities |
| ProQuest (single search) | ▶ ProQuest Dissertations & Theses Global<br>▶ Applied Social Sciences Index and Abstracts (ASSIA)<br>▶ International Bibliography of the Social Sciences (IBSS)<br>▶ PAIS International |
| EBSCOhost (single search) | ▶ Cinahl Plus<br>▶ SocINDEX with full-text |
| Other sources of data | ▶ *United Kingdom:* UK Department of Health Publications and Statistics; The Knowledge Network (NHS e-library); UK Clinical Research Network; Healthcare Management Information Consortium (HMIC) database<br>▶ *United States:* Centers for Disease Control and Prevention<br>▶ International Agency for Research on Cancer<br>▶ European Commission's Community Research and Development Information Service (CORDIS)<br>▶ OECD iLibrary<br>▶ *Charities worldwide:* Cancer Research UK, Marie Curie, Macmillan Cancer Support, The King's Fund, The Nuffield Trust, National Cancer Research Institute, World Cancer Research Fund International, American Lung Association, American Cancer Society, Cancer Research Institute, National Cancer Institute, Cancer Council Australia, Canadian Cancer Society, Danish Cancer Society, Cancer Society of New Zealand, German Cancer Aid, Irish Cancer Society, Dutch Cancer Society, Norwegian Cancer Society, Portuguese Cancer League, Asociación Española Contra el Cáncer, Swedish Cancer Society, Nordic Cancer Union, German Cancer Society<br>▶ *Theses*: EThOS - Electronic Theses Online Service; Dart-Europe<br>▶ *Clinical Trials*: U.S. National Institutes of Health's Clinical Trials Database; WHO International Clinical Trials Registry Platform Search Portal; UK Clinical Trials Gateway<br>▶ *Grey literature*: Open Sigle |

PRISMA flow diagram[26] will be developed. Study authors will be contacted if additional information is required to decide eligibility. One reminder will be sent if there are no replies. All disagreements at each step will be solved by consensus; a third review author will be consulted if consensus cannot be obtained.

A data extraction template has been created in Microsoft Word for Windows (see online supplementary file S1). It includes contextual information on the initiatives and a description of its key components, in addition to information on study design, setting, location, other characteristics of the intervention, of study participants and outcomes. Two reviewers will independently extract data from three randomly selected included studies and compare their forms in order to reduce bias and ensure the forms are being used in a similar manner. Afterwards, one reviewer will extract data from 50% of the included studies and another will extract data from the remaining 50%. The two researchers will compare form content and discuss any disagreements. A third reviewer will be consulted if disagreements cannot be solved by consensus. Extracted data will be described in text, tables and diagrams.

## Quality assessment

We anticipate that the included studies will be varied in terms of study design and that most will be observational studies.[34] This leads to challenges in choosing a

quality assessment tool that can be used appropriately for different designs. We will therefore use more than one assessment tool.

Quantitative studies will be analysed using the McMaster Critical Review Form for Quantitative Studies,[35] available in online supplementary file S2. This tool is suitable for different types of quantitative studies (cross-sectional, cohort, case–control, among many others). It contains multiple choice questions regarding the study purpose, literature, design, sample, outcomes, intervention, results, conclusions and implications. The tool also approaches issue of bias, validity and reliability. Percentage agreement between two researchers has been assessed (from 75% to 86%) and guidance on how to assess studies is also provided.[35]

Qualitative studies will be assessed using the quality assessment tool from Hawker and colleagues,[36] which was developed to evaluate the quality of heterogeneous studies in systematic reviews. The original tool has nine items and allows for four possible answer options ('good', 'fair', 'poor' and 'very poor'). Item six will be divided into two different items in order to separately assess issues related to ethics and bias as these are shown together in the original instrument (adapted tool is available in online supplementary file S3). This adaptation has been successfully done in a previous systematic review assessing qualitative studies.[37] Study protocols, editorials, commentaries, short reports and viewpoints will also be assessed using this tool (limitations will be acknowledged).

Letters to the editor, conference abstracts and grey literature such as government reports/cancer strategies will not be assessed for quality; potential methodological issues and risks of bias will be discussed. Reviews and systematic reviews will be assessed using the validated Oxman and Guyatt's 10-item checklist (Overview Quality Assessment Questionnaire), as this tool is suitable for both systematic and non-systematic reviews[38 39] (see online supplementary file S4).

Mixed-methods studies will be assessed using both the tools for qualitative and quantitative studies; results for both assessments will be reported. For all studies we will report each quality component separately in a supplementary table due to recognised problems with calculating single summed quality scores.[40 41]

Each study will be independently assessed by two reviewers, with disagreements solved by consensus. A third reviewer will be consulted if no consensus can be reached. We will report the % agreement and kappa scores using the Landis and Koch guidelines.[42]

### Data synthesis

We expect wide heterogeneity in the composition and intensity of initiatives, populations and contexts[29 43] and predict that meta-analysis will not be possible nor appropriate considering the review aims. We will carry out narrative synthesis; this is a widely used method when there is heterogeneity.[28 43] Narrative synthesis is an approach that relies on using words and text to 'tell a story' of findings.[44] It is useful in reviews investigating questions that are not solely focused on the effectiveness of interventions[43] and well suited for complex interventions.[19] Narrative synthesis has also been described as particularly effective to synthesise qualitative and quantitative evidence[45] and to make explicit different study designs and contexts.[46] We will follow published guidelines for using this method[44] and take into account reported limitations of this approach.[47]

Data will be reported irrespective of the results from the quality assessment; implications will be discussed. Findings will be described in text and in tables and categorised in line with Taplin *et al*'s refined model of multilevel influences on the cancer care continuum.[31] We will provide details of key features of initiatives such as contextual issues (eg, described policies and source of funding), key components (such as relevant guidelines for referring patients to specialist services), target populations and timelines. When reporting outcomes we will take into account the updated NAEDI's hypothesis of factors influencing cancer survival and premature mortality.[11] If feasible, a diagram will be created to summarise these results.

## ETHICS AND DISSEMINATION

This systematic review protocol did not require ethical approval as there is no direct contact with research participants. There are also no issues of confidentiality or potential harms. Only secondary data from published studies and grey literature will be analysed.

The review results will be submitted to a peer-reviewed journal in early 2018 in order to reach a diverse group of healthcare professionals, researchers and policy makers.

## DISCUSSION

To our knowledge, this is the first systematic review aiming to describe the full breadth of national health initiatives in promoting earlier diagnosis of cancer in high-income countries, exploring their main characteristics (such as key components and target populations) and describing available high-level outcomes. This is an important research area considering the burden of cancer worldwide and the predicted increased number of cancer cases, especially in the context of an ageing population. Furthermore, as health systems, governments and other stakeholders invest in, and develop programmes to tackle the issue, it is paramount that evidence on similar initiatives is made available. This review will provide a more nuanced understanding of the components of such initiatives.

There are challenges to be faced due to the likely complexity of the included interventions, populations and health systems. Furthermore, carrying out comprehensive literature searches in such a broad knowledge area will be time-consuming. We are following several available guidelines and developing strategies to deal with these challenges.

In conclusion, this review addresses a relevant, timely health issue that affects a large proportion of the worldwide population. The findings will be helpful to researchers, policy makers, government departments and key cancer charities developing similar initiatives and assessing cancer outcomes.

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**Contributors** NC, CC and DW developed and refined the systematic review protocol. NC drafted the manuscript, which was then critically assessed by both CC and DW. All authors approved the final version of this manuscript. NC is the guarantor.

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**Competing interests** None declared.

**Patient consent** This systematic review protocol did not require ethical approval as there is no direct contact with research participants, no issues of confidentiality or potential harms. Only secondary data from published studies and grey literature will be analysed.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Any data related to this protocol and not published are available upon request to the authors (by email or post). These may include final search strategies for all databases, completed data extraction forms, among others. Please contact the corresponding author (natalia.calanzani@ed.ac.uk) if you would like to obtain these data.



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# Appendix 3. List of additional publications included in the review

| N | Reference | Source | Initiative | Type of reference |
|---|---|---|---|---|
| 1 | Allgar VL, Neal RD, Ali N, et al. Urgent GP referrals for suspected lung, colorectal, prostate and ovarian cancer. Br J Gen Pract. 2006;56(526):355-62. | website or other | 2WW | full paper |
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| 4 | Bethell GS, Leftwick P. Views of general practitioners and head and neck surgeons on the referral system for suspected cancer: a survey. J Laryngol Otol. 2015;129(9):893-7. | database search | 2WW | full paper |
| 5 | Blick C, Bailey D, Haldar N, et al. The impact of the two-week wait rule on the diagnosis and management of bladder cancer in a single UK institution. Ann R Coll Surg Engl 2010;92(1):46-50. | reference lists | 2WW | full paper |
| 6 | Chohan DPK, Goodwin K, Wilkinson S, et al. How has the 'two-week wait' rule affected the presentation of colorectal cancer? Colorectal Disease. 2005;7(5):450-3. | reference lists | 2WW | full paper |
| 7 | Currie AC, Evans J, Smith NJ, et al. The impact of the two-week wait referral pathway on rectal cancer survival. Colorectal Disease. 2012;14(7):848-53. | database search | 2WW | full paper |
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| 9 | Department of Health. Implementation of the right to access services within maximum waiting times. Guidance for strategic health authorities, primary care trusts and providers. 2010. | website or other | 2WW | Report |
| 10 | Department of Health. Improving Outcomes: A Strategy for Cancer. Department of Health, 2011. | website or other | 2WW | Official Cancer Plan or Strategy |
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| 17 | Hobson JC, Malla JV, Sinha J, et al. Outcomes for patients referred urgently with suspected head and neck cancer. J Laryngol Otol. 2008;122(11):1241-4. | database search | 2WW | full paper |
| 18 | Hodder RJ, Ballal M, Selvachandran SN, et al Variations in the evaluation of colorectal cancer risk. Colorectal Dis. 2005;7(3):254-62. | reference lists | 2WW | full paper |
| 19 | Humphries A, Clarke J, Bhatnagar G, et al. A new lower gastrointestinal 2-week wait -direct to test' pathway results in earlier diagnosis of cancer. Gut. 2013;62:A262. | database search | 2WW | Abstract |
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| 33 | Patel RK, Sayers AE, Seedat S, et al. The 2-week wait service: a UK tertiary colorectal centre's experience in the early identification of colorectal cancer. Eur J Gastroen Hepat. 2014;26(12):1408-14. | reference lists | 2WW | full paper |
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# Appendix 4. Review search strategies

## Web of Science Core Collection

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|---|---|
| 17 | (#16) *AND* **LANGUAGE:** (English)<br>*DocType=All document types; Language=All languages;* |
| #16 | #11 NOT #15 |
| #15 | #14 OR #13 OR #12 |
| #14 | TI=(biomarker* or molecul*) |
| #13 | TI=(palliative or terminal or "end of life" or end-of-life or "advance directive*" or hospice*) |
| #12 | TI=(child* or pediatric* or paediatric* or adolesc* or teenag*) |
| #11 | #10 AND #9 AND #8 AND #2 AND #1 |
| #10 | TS=(Randomi* or RCT or intervention or trial or cross-sectional or survey* or questionnaire* or train* or "natural experiment" or interview* or "focus group*" or "case study" or observation* or time-series or "time series" or CBA or "controlled before and after" or "controlled before-after" or prospective or retrospective or cohort or case-control or cross-over or "case series" or case-reports or "case reports" or feasibility or pilot or narrative or qualitative or quantitative or mixed-methods or "mixed methods" or evaluat* or assess* or attitude* or view* or perception* or perspective* or "discourse analysis" or "content analysis" or "thematic analysis" or "narrative analysis" or phenomenolog* or "purposive sampl*" or ethnograph* or "theoretical sampl*" or "grounded theory") |
| #9 | TS=(Cancer* or neoplas* or tumour or tumor or malign* or oncolog*) |
| #8 | #7 OR #6 OR #5 OR #4 OR #3 |
| #7 | TS=(late near/4 diagnos*) OR TS=(late near/4 treat*) OR TS=(late near/4 refer*) OR TS=(late near/4 present*) OR TS=(late near/4 detect*) |
| #6 | TS=(earl* near/4 diagnos*) OR TS=(earl* near/4 present*) OR TS=(earl* near/4 treat*) OR TS=(earl* near/4 refer*) OR TS=(earl* near/4 therap*) OR TS=(earl* near/4 detect*) |
| #5 | TS=(time near/4 diagnos*) OR TS=(time near/4 present*) OR TS=(time near/4 treat*) OR TS=(time near/4 refer*) OR TS=(time near/4 care) OR TS=(time near/4 detect*) |
| #4 | TS=(delay* near/4 diagnos*) OR TS=(delay* near/4 present*) OR TS=(delay* near/4 treat*) OR TS=(delay* near/4 consult*) OR TS=(delay* near/4 patient*) OR TS=(delay* near/4 doctor*) OR TS=(delay* near/4 system*) OR TS=(delay* near/4 refer*) OR TS=(delay* near/4 therap*) OR TS=(delay* near/4 care) OR TS=(delay* near/4 detect*) |
| #3 | TS=(surviv*) |
| #2 | TS=(health* near/2 care) OR TS=(health* near/2 service*) OR TS=(health* near/2 system*) OR TS=(health* near/2 seek*) OR TS=(health* near/2 provi*) |
| #1 | TS=(government or policy* or policies or national or regional or multi-level* or system-level or whole-system* or NAEDI or "Detect Cancer Early" or "National Awareness and Early Diagnosis Initiative" or "Find Cancer Early" or "Be Cancer Aware" or "Be Clear on Cancer" or initiative* or program* or campaign* or strateg* or engagement or awareness) |

## Cochrane library

Search Name: Cochrane_130916_corrected
Last Saved: 13/09/2016 14:12:44
ID Search
#1 government or policy* or policies or national or regional or multi-level* or system-level or whole-system* or NAEDI or "Detect Cancer Early" or "National Awareness and Early Diagnosis Initiative" or "Find Cancer Early" or "Be Cancer Aware" or "Be Clear on Cancer" or initiative* or program* or campaign* or strateg* or engagement or awareness with Publication Year from 2005 to 2016

#2 health* near/2 (care or service* or system* or seek* or provi*) with Publication Year from 2005 to 2016
#3 surviv* with Publication Year from 2005 to 2016
#4 delay* near/4 (diagnos* or present* or treat* or consult* or patient* or doctor* or system* or refer* or therap* or care or detect*) with Publication Year from 2005 to 2016
#5 time near/4 (diagnos* or present* or treat* or refer* or care or detect*) with Publication Year from 2005 to 2016
#6 late near/4 (diagnos* or treat* or refer* or present* or detect*) with Publication Year from 2005 to 2016
#7 earl* near/4 (diagnos* or present* or treat* or refer* or therap* or detect*) with Publication Year from 2005 to 2016
#8 #3 or #4 or #5 or #6 or #7
#9 Cancer* or neoplas* or tumour or tumor or malign* or oncolog* with Publication Year from 2005 to 2016
#10 Randomi* or RCT or intervention or trial or cross-sectional or survey* or questionnaire* or train* or "natural experiment" or interview* or "focus group*" or "case study" or observation* or time-series or "time series" or CBA or "controlled before and after" or "controlled before-after" or prospective or retrospective or cohort or case-control or cross-over or "case series" or case-reports or "case reports" or feasibility or pilot or narrative or qualitative or quantitative or mixed-methods or "mixed methods" or evaluat* or assess* or attitude* or view* or perception* or perspective* or "discourse analysis" or "content analysis" or "thematic analysis" or "narrative analysis" or phenomenolog* or "purposive sampl*" or ethnograph* or "theoretical sampl*" or "grounded theory" with Publication Year from 2005 to 2016
#11 #1 and #2 and #8 and #9 and #10
#12 child* or pediatric* or paediatric* or adolesc* or teenag*.ti
#13 palliative or terminal or "end of life" or end-of-life or "advance directive*" or hospice*:ti
#14 biomarker* or molecul*:ti
#15 #12 or #13 or #14
#16 #11 not #15
#17 #16 with Publication Year from 2005 to 2016

## PROQUEST (Dissertations and Theses Global)

noft(government OR policy* OR policies OR national OR regional OR healthcare OR multi-level* OR system-level OR whole-system* OR NAEDI OR "Detect Cancer Early" OR "National Awareness and Early Diagnosis Initiative" OR "Find Cancer Early" OR "Be Cancer Aware" OR "Be Clear on Cancer" OR initiative* OR program* OR campaign* OR strateg* OR engagement OR awareness) AND noft(health* NEAR/2 (care OR service* OR system* OR seek* OR provi*)) AND (noft(surviv*) OR noft(delay* NEAR/4 (diagnos* OR present* OR treat* OR consult* OR patient* OR doctor* OR system* OR refer* OR therap* OR care OR detect*)) OR noft(time NEAR/4 (diagnos* OR present* OR treat* OR refer* OR care OR detect*)) OR noft(late NEAR/4 (diagnos* OR treat* OR refer* OR present* OR detect*)) AND noft(earl* NEAR/4 (diagnos* OR present* OR treat* OR refer* OR therap* OR detect*))) AND noft(Cancer* OR neoplas* OR tumour OR tumor OR malign* OR oncolog*) AND noft(Randomi* OR RCT OR intervention OR trial OR cross-sectional OR survey* OR questionnaire* OR train* OR "natural experiment" OR interview* OR "focus group*" OR "case study" OR observation* OR time-series OR "time series" OR CBA OR "controlled before and after" OR "controlled before-after" OR prospective OR retrospective OR cohort OR case-control OR cross-over OR "case series" OR case-reports OR "case reports" OR feasibility OR pilot OR narrative OR qualitative OR quantitative OR mixed-methods OR "mixed methods" OR evaluat* OR assess* OR attitude* OR view* OR perception* OR perspective* OR "discourse analysis" OR "content analysis" OR "thematic analysis" OR "narrative analysis" OR phenomenolog* OR "purposive sampl*" OR ethnograph* OR "theoretical sampl*" OR "grounded theory") NOT ti(child* or pediatric* or paediatric* or adolesc* or teenag*) NOT ti(palliative or terminal or "end of life" or end-of-life or "advance directive*" or hospice*) NOT ti(biomarker* or molecul*)

## PROQUEST (ASSIA, IBSS, PAIS)

(government OR policy* OR policies OR national OR regional OR healthcare OR multi-level* OR system-level OR whole-system* OR NAEDI OR "Detect Cancer Early" OR "National Awareness and Early Diagnosis Initiative" OR "Find Cancer Early" OR "Be Cancer Aware" OR "Be Clear on Cancer"

OR initiative* OR program* OR campaign* OR strateg* OR engagement OR awareness) AND (health* NEAR/2 (care OR service* OR system* OR seek* OR provi*)) AND ((surviv*) OR (delay* NEAR/4 (diagnos* OR present* OR treat* OR consult* OR patient* OR doctor* OR system* OR refer* OR therap* OR care OR detect*)) OR (time NEAR/4 (diagnos* OR present* OR treat* OR refer* OR care OR detect*)) OR (late NEAR/4 (diagnos* OR treat* OR refer* OR present* OR detect*)) AND (earl* NEAR/4 (diagnos* OR present* OR treat* OR refer* OR therap* OR detect*))) AND (Cancer* OR neoplas* OR tumour OR tumor OR malign* OR oncolog*) AND (Randomi* OR RCT OR intervention OR trial OR cross-sectional OR survey* OR questionnaire* OR train* OR "natural experiment" OR interview* OR "focus group*" OR "case study" OR observation* OR time-series OR "time series" OR CBA OR "controlled before and after" OR "controlled before-after" OR prospective OR retrospective OR cohort OR case-control OR cross-over OR "case series" OR case-reports OR "case reports" OR feasibility OR pilot OR narrative OR qualitative OR quantitative OR mixed-methods OR "mixed methods" OR evaluat* OR assess* OR attitude* OR view* OR perception* OR perspective* OR "discourse analysis" OR "content analysis" OR "thematic analysis" OR "narrative analysis" OR phenomenolog* OR "purposive sampl*" OR ethnograph* OR "theoretical sampl*" OR "grounded theory") NOT ti(child* OR pediatric* OR paediatric* OR adolesc* OR teenag*) NOT ti(palliative OR terminal OR "end of life" OR end-of-life OR "advance directive*" OR hospice*) NOT ti(biomarker* OR molecul*)

# EBSCO

TX ( government or policy* or policies or national or regional or multi-level* or system-level or whole-system* or NAEDI or "Detect Cancer Early" or "National Awareness and Early Diagnosis Initiative" or "Find Cancer Early" or "Be Cancer Aware" or "Be Clear on Cancer" or initiative* or program* or campaign* or strateg* or engagement or awareness ) AND TX ( Health* N2 (care or service* or system* or seek* or provi*) AND (TX ( (delay* N4 (diagnos* or present* or treat* or consult* or patient* or doctor* or system* or refer* or therap* or care or detect*)) OR (time N4 (diagnos* or present* or treat* or refer* or care or detect*)) OR (late N4 (diagnos* or treat* or refer* or present* or detect*)) OR (earl* N4 (diagnos* or present* or treat* or refer* or therap* or detect*)) OR (surviv*) )) AND TX ( Cancer* or neoplas* or tumour or tumor or malign* or oncolog* ) AND TX ( Randomi* or RCT or intervention or trial or cross-sectional or survey* or questionnaire* or train* or "natural experiment" or interview* or "focus group*" or "case study" or observation* or time-series or "time series" or CBA or "controlled before and after" or "controlled before-after" or prospective or retrospective or cohort or case-control or cross-over or "case series" or case-reports or "case reports" or feasibility or pilot or narrative or qualitative or quantitative or mixed-methods or "mixed methods" or triangulat* or evaluat* or assess* or attitude* or view* or perception* or perspective* or "discourse analysis" or "content analysis" or "thematic analysis" or "narrative analysis" or phenomenolog* or "purposive sampl*" or ethnograph* or "theoretical sampl*" or "grounded theory ) AND TX ( NOT (child* or pediatric* or paediatric* or adolesc* or teenag*) ) AND TX ( not (palliative or terminal or "end of life" or end-of-life or "advance directive*" or hospice*) ) AND TX ( not (biomarker* or molecul*) )

# Appendix 5. Data extraction template

| | |
|---|---|
| Reviewer's initials: | |
| Date of data extraction (*completion*): | |

| **General Information** | | |
|---|---|---|
| Study ID (*from EndNote*): | | |
| Publication Title: | | |
| Publication year and Journal/Publisher | | |
| N and Study ID of publications about the same study (*or other supporting information sources*): | | |
| Country and region within country where study took place: | | |
| Language | ☐ English | ☐ other (specify): |

| **Inclusion criteria (final check)** | | | |
|---|---|---|---|
| Is the initiative aiming to promote earlier cancer diagnosis or improve cancer survival? | ☐ Yes | ☐ No | ☐ Unclear (discuss with peers) |
| Is it aiming to promote earlier cancer diagnosis/ improve survival for adults (*18 and older*)? | ☐ Yes | ☐ No | ☐ Unclear (discuss with peers) |
| Is it a health system level initiative? | ☐ Yes | ☐ No | ☐ Unclear (discuss with peers) |
| It is a multi-level initiative (as per *Taplin et al's model*)? | ☐ Yes | ☐ No | ☐ Unclear (discuss with peers) |
| Does the publication type meet inclusion criteria (*reviews, overviews, editorials, commentaries and published guidelines are to be* ***excluded***)? | ☐ Yes | ☐ No | ☐ Unclear (discuss with peers) |

**ONLY PROCEED IF THE STUDY MEETS INCLUSION CRITERIA**

| **Study design** | | | |
|---|---|---|---|
| Study type | ☐ qualitative | ☐ quantitative | ☐ mixed methods |
| If a qualitative study or with a qualitative component, please specify design (*multiple options possible*): | ☐ interviews | ☐ focus groups | ☐ observation |
| | ☐ other (*specify*): | | |
| If a quantitative study or with a quantitative component, please specify design (*multiple options possible*): | ☐ RCT | ☐ observational study (*specify*): | |
| | ☐ CCT | ☐ case-control | |
| | | ☐ ITS | |
| | | ☐ before-after (controlled or not)/pre-post | |
| | | ☐ cross-sectional | |
| | | ☐ natural experiment | |
| | | ☐ other (*specify*): | |

RCT: randomised controlled trial; CCT: controlled clinical trial; ITS: interrupted time series

| Study characteristics (all study designs) | | |
|---|---|---|
| Study aim(s): | | |
| Is an evidence base given for the initiative? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Is a theoretical rationale given for the initiative? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Are any relevant health policies mentioned? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Target population: | | |
| Who is carrying out the initiative (*key stakeholders*)? | | |
| Contextual information – (*e.g. universal health care provision, cultural, geographical, political issues, etc.)* | | |
| How many levels does the initiative cover and what are they (*as per Taplin et al's model*)? | | |
| Has the study finished? | ☐ Yes (and results are reported):<br>☐ Yes (but results are not reported)<br>☐ No, but preliminary results are reported | ☐ No, and no results are reported<br>☐ Unclear |

| Quantitative studies only OR quantitative components of a mixed-methods study | | |
|---|---|---|
| Study design (*if RCT report if blinding occurred*) | | |
| Sampling strategy | | |
| Setting | | |
| Population characteristics (*if there is more than one group report these separately*) | | |
| Intervention components (*if there is more than one group report these separately and explain what the control group received*) | | |
| Time duration of the intervention | | |
| Outcome measures (*including definition of outcomes such as survival, etc.*) | | |
| According to the NAEDI's model (*Hiom 2015*), which factors influencing survival are being taken into account? | | |
| Measurement tools (*including time points investigated*) | | |
| Statistical analysis (*report if the study controlled for confounders and if so how this was done)* | | |
| Main results | | |
| Any unanticipated outcomes? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Significance | | |
| Authors' interpretation of results | | |

| |
|---|
| Any reported barriers/facilitators? (*even if only in the discussion section*) |
| Any reported implementation issues? (*even if only in the discussion section*) |

| **Qualitative studies only OR qualitative components of a mixed-methods study** | | |
|---|---|---|
| Study design | | |
| Sampling strategy | | |
| Setting | | |
| Population characteristics (*if there is more than one group report these separately*) | | |
| Main components of the initiative (*if there is more than one group report these separately*) | | |
| Time duration of the study | | |
| Phenomena of interest | | |
| According to the NAEDI's model (*Hiom 2015*), are any factors influencing survival being discussed? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Data collection tools | | |
| Data analysis methods (*including theoretical underpinnings*) | | |
| Main results | | |
| Any reported unanticipated outcomes? | ☐ Yes (*specify*): | ☐ No<br>☐ Unclear |
| Authors' interpretation of results | | |
| Any reported barriers/facilitators? | | |
| Any reported implementation issues (*including issues of feasibility and acceptability)*? | | |

# Appendix 6. Results from quality assessment

## Quantitative studies and mixed-method studies with a quantitative component (n=19)

| Strategy | References | Q1 | Q2 | Q3 | Q4A | Q4b | Q5A | Q5B | Q6A | Q6B | Q6C | Q7A | Q7B | Q7C | Q7D | Q8 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 2WW | Meechan et al 2012 | yes | yes | cross-sectional | yes | N/A | not add | not add | yes | N/A | no | yes | yes | yes | no | yes |
| | Møller et al 2015 | yes | yes | cohort | no | N/A | not add | not add | yes | N/A | not add | yes | yes | yes | no | yes |
| | Neal et al 2014 | yes | yes | case control | no | N/A | not add | not add | yes | N/A | no | yes | yes | yes | no | yes |
| BCOC | Ironmonger et al 2015 | yes | yes | BA | no | no | yes | yes | yes | not add | not add | yes | yes | yes | no | yes |
| | Moffat et al 2015 | yes | yes | BA and CS | no | no | yes | yes | yes | N/A | not add | yes | yes | no | no | yes |
| | Power et al 2015 | yes | yes | BA | yes | no | not add | yes | yes | not add | yes | yes | yes | yes | N/A | yes |
| CPPs Denmark | Jensen et al 2014 | yes | yes | cross-sectional | yes | N/A | not add | not add | yes | N/A | not add | yes | yes | yes | no | yes |
| | Jensen et al 2015 | yes | yes | natural experiment | yes | N/A | not add | yes | yes | N/A | not add | yes | yes | yes | no | yes |
| | Jensen et al 2016 | yes | yes | Cohort | yes | N/A | not add | not add | yes | not add | not add | yes | yes | yes | N/A | yes |
| | Olesen et al 2009 | yes | yes | Not stated (descriptive, observational) | no | N/A | not add | not add | no | not add | not add | no | not add | N/A | N/A | yes |
| | Probst et al 2012 | yes | yes | not stated (observational) | no | N/A | not add | not add | yes | not add | no | no | not add | not add | N/A | yes |
| Fast-track Catalonia | Prades et al 2011 | yes | yes | not stated (observational) | no | N/A | not add | not add | no | not add | not add | yes | not add | yes | N/A | yes |
| Fast-track Valencia | Martinez et al 2015 | yes | no | Cohort | no | N/A | not add | not add | no | not add | not add | no | not add | yes | yes | yes |
| Inside knowledge | Cooper et al 2015 | no | yes | BA | no | N/A | not add | not add | yes | N/A | no | yes | yes | not add | no | yes |
| | Cooper et al 2016 | yes | no | cross-sectional | no | N/A | not add | not add | yes | N/A | N/A | N/A | yes | no | no | yes |

| Strategy | References | Q1 | Q2 | Q3 | Q4A | Q4b | Q5A | Q5B | Q6A | Q6B | Q6C | Q7A | Q7B | Q7C | Q7D | Q8 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NAEDI | Rubin et al 2015 | yes | yes | BA | yes | N/A | yes | yes | no | no | not add | yes | yes | yes | N/A | yes |
| NSS-CPP Denmark | Ingeman et al 2015 | yes | yes | cross-sectional | yes | N/A | yes | yes | yes | N/A | not add | yes | yes | yes | no | yes |
| Oral Cancer Maryland | Maybury et al 2012 | yes | no | not stated (observational) | yes | no | not add | not add | yes | not add | not add | no | not add | yes | N/A | yes |
| Rapid Referral Madrid | Valentin-Lopez et al 2012 | yes | yes | case control | yes | N/A | not add | not add | yes | N/A | not add | yes | not add | yes | yes | yes |

***N/A: not applicable: not add: not addressed; BA: before and after; Q: question. Source: included studies***

## Qualitative studies and mixed-method studies with a qualitative component (n=13)

| Strategy | References | Pub Type | Q1 | Q2 | Q3 | Q4A | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ACE | Fuller 2016 | editorial | N/A | poor | very poor | very poor | very poor | very poor | very poor | poor | poor | fair |
| CPPs Denmark | Olesen et al 2009 | qualitative component (MM) | good | good | fair | very poor | very poor | very poor | very poor | poor | poor | good |
| CPPs Norway | Gilstad 2016 | qualitative study | fair | good | good | fair | good | very poor | very poor | fair | fair | fair |
| Fast-track Catalonia | Prades et al 2011 | qualitative component (MM) | fair | good | fair | good | good | Fair | very poor | fair | fair | poor |
| Inside Knowledge | Rim et al 2011 | descriptive paper | fair | poor | very poor | very poor | very poor | very poor | very poor | very poor | poor | very poor |
| NAEDI | Hiom et al 2015 | Introduction to NAEDI supplement | very poor | good | very poor | very poor | very poor | very poor | very poor | fair | poor | poor |
| | Richards 2009 | Introduction to NAEDI supplement | poor | fair | poor | very poor | very poor | very poor | very poor | poor | poor | poor |
| | Richards 2009 | Discussion paper | good | poor | poor | very poor | very poor | very poor | very poor | poor | poor | fair |
| | Rubin et al 2015 | qualitative component (MM) | good | fair | fair | fair | fair | very poor | very poor | fair | fair | fair |

| Strategy | References | Pub Type | Q1 | Q2 | Q3 | Q4A | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NSS-CPP Denmark | Vedsted et al 2015 | descriptive paper | good | good | N/A | N/A | N/A | very poor | very poor | N/A | N/A | good |
| Oral Cancer Maryland | Maybury et al 2012 | qualitative component (MM) | fair | fair | fair | poor | poor | very poor | very poor | fair | poor | fair |
| Rapid Referrals Qatar | Howitt et al 2014 | descriptive paper | fair | poor | very poor | very poor | very poor | very poor | very poor | very poor | poor | fair |
| Waiting times in Sweden | Wilkens et al 2016 | descriptive paper | fair | poor | very poor | very poor | very poor | very poor | very poor | very poor | poor | poor |

***Q: question; N/A: not applicable; MM: mixed methods. Source: included studies***

## Reviews (n=3)

| References | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 |
|---|---|---|---|---|---|---|---|---|---|---|
| Hanna et al 2005 | yes | can't tell | no | can't tell | no | can't tell | no | yes | partially | mid-range extensive to major flaws |
| Harrison & Foot 2012 | partially | can't tell | partially | can't tell | no | can't tell | no | yes | yes | mid-range extensive to major flaws |
| Lewis et al 2005 Lewis et al 2005 | yes | yes | yes | yes | yes | yes | yes | yes | yes | minimal flaws |

***Quality assessment was merged for both of Lewis publications as they refer to the same review. If one of the publications had the required information but the other one did not, then the best rating was considered. Source: included studies.***

## Interrater reliability: % agreement, kappa and strength of agreement

| | Questions | % agreement | Cohen's k (95% CI) | Strength of agreement | p-value |
|---|---|---|---|---|---|
| Quantitative tool | Q1 | 94.7% | Not calculated | N/A | N/A |
| | Q2 | 68.4% | 0.109 (-0.095 - 0.508) | slight | 0.554 |
| | Q3 | 57.9% | 0.729 (0.611 - 0.960) | substantial | <0.001 |
| | Q4A | 63.2% | 0.232 (0.058 - 0.573) | fair | 0.216 |
| | Q4B | 57.9% | 0.244 (0.071 - 0.583) | fair | 0.142 |
| | Q5A | 57.9% | 0.24 (0.107 - 0.500) | fair | 0.107 |
| | Q5B | 57.9% | 0.283 (0.149 - 0.545) | fair | 0.077 |
| | Q6A | 68.4% | 0.288 (0.143 - 0.572) | fair | 0.029 |
| | Q6B | 57.9% | 0.228 (0.05 - 0.576) | fair | 0.216 |
| | Q6C | 42.1% | 0.114 (-0.02 - 0.376) | slight | 0.283 |
| | Q7A | 89.5% | 0.719 (0.554 - 1.04) | substantial | <0.001 |
| | Q7B | 84.2% | 0.565 (0.343 - 1.000) | Moderate | 0.013 |
| | Q7C | 73.7% | 0.431 (0.262 - 0.762) | Moderate | 0.006 |
| | Q7D | 73.7% | 0.585 (0.444 - 0.861) | Moderate | <0.001 |
| | Q8 | 100% | Not calculated | N/A | N/A |
| Qualitative tool | Q1 | 61.5% | 0.524 (0.155-0.893) | Moderate | 0.007 |
| | Q2 | 69.2% | 0.639 (0.335-0.943) | substantial | 0.002 |
| | Q3 | 53.8% | 0.636 (0.321-0.950) | substantial | 0.002 |
| | Q4 | 69.2% | 0.823 (0.675-0.971) | Almost perfect | 0.001 |
| | Q5 | 61.5% | 0.776 (0.541-1.010) | Substantial | 0.003 |
| | Q6 | 92.3% | Not calculated | N/A | N/A |
| | Q7 | 100% | Not calculated | N/A | N/A |
| | Q8 | 46.2% | 0.366 (0.152-0.580) | fair | 0.008 |
| | Q9 | 69.2% | 0.656 (0.328-0.985) | substantial | 0.007 |
| | Q10 | 30.8% | 0.093 (-0.135-0.321) | poor | 0.416 |
| Review tool | Q1 | 75% | 0.364 (-0.211-0.939) | fair | 0.212 |
| | Q2 | 100% | 1.000 (1.000-1.000) | Almost perfect | 0.008 |
| | Q3 | 75% | 0.851 (0.594-1.108) | Almost perfect | 0.013 |
| | Q4 | 50% | Not calculated | N/A | N/A |
| | Q5 | 100% | 1.000 (1.000-1.000) | Almost perfect | 0.008 |
| | Q6 | 75% | 0.632 (0.393-0.870) | Substantial | 0.008 |
| | Q7 | 100% | 1.000 (1.000-1.000) | Almost perfect | 0.008 |
| | Q8 | 100% | Not calculated | N/A | N/A |
| | Q9 | 75% | Not calculated | N/A | N/A |
| | Q10 | 75% | 0.881 (0.764-0.999) | Almost perfect | 0.009 |

***K: kappa; CI: Confidence intervals. Significant p-values indicate that agreement is significantly different from what would be achieved by chance. Kappa was not calculated when all ratings were the same for at least one rater; in these cases SPSS considers that the variable is a constant as there is no variation, and measures of association are not calculated.***

# Appendix 7. Outcomes from review searches

## Database searches – all searched on 13/09/2016

| Search platform | Database | Hits | Duplicates | Total without duplicates |
|---|---|---|---|---|
| OVID (.mp) | MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present | 4741 | 327 | 4414 |
| | Embase Classic+Embase 1947 to 2016 September 13 | 9698 | 216 | 9482 |
| | PsycARTICLES Full Text | 1011 | 6 | 1005 |
| | PsycINFO 1806 to July Week 4 2016 | 569 | 1 | 568 |
| Web of Science (topic) | Core Collection Timespan: 2005-2016. Indexes:SCI-EXPANDED, SSCI, CPCI-S, CPCI-SSH | 2634 | 1 | 2633 |
| | SciELO Citation Index Collection Timespan: 2005-2016 | 20 | 0 | 20 |
| Cochrane Library (search all text) | Database of Abstracts of Reviews of Effect : Issue 2 of 4, April 2015 | 35 | 24 | 11 |
| | Health Technology Assessment Database : Issue 3 of 4, July 2016 | 22 | | 22 |
| | NHS Economic Evaluation Database : Issue 2 of 4, April 2015 | 287 | | 287 |
| | Cochrane Central Register of Controlled Trials : Issue 8 of 12, August 2016 | 461 | | 461 |
| | Cochrane Database of Systematic Reviews : Issue 9 of 12, September 2016 | 302 | | 302 |
| EBSCO (all fields) | CINAHL Plus | 1778 | 35 | 1743 |
| | SocINDEX with Full Text | | | |
| PROQUEST (anywhere) | Applied Social Sciences Index and Abstracts (ASSIA) (1987 - current) | 301 | 29 | 272 |
| | International Bibliography of the Social Sciences (IBSS) (1951 - current) | | | |
| | PAIS Index (1914 - current) | | | |
| PROQUEST (anywhere but full-text) | ProQuest Dissertations & Theses Global | 256 | 2 | 254 |
| Total | | 22115 | 641 | **21474** |
| Total after merging files and removing papers published before 2005 | | | | 21331 |
| **Total after merging file and removing dups** | | | **6485** | **14846** |

## Searches – Other Digital sources

| Region | Website | Results | Search date |
|---|---|---|---|
| UK | UK Department of Health Publications and Statistics https://www.gov.uk/government/publications?departments%5B%5D=department-of-health | • 2923 publications; 139 with the word cancer<br>• Several publications on Be Clear on Cancer, ACE<br>• Several publications on the 2011 National Cancer Strategy, GP databases, Cancer Waiting Times and Guidance and Cancer Referrals, Cancer Plans in England | 26/04/2017 |
| UK | The Knowledge Network (NHS e-library) http://www.knowledge.scot.nhs.uk/home.aspx | • Looked for Cancer AND (programme or initiative or strategy or campaign – title only) AND (early detection or early diagnosis) - 211 hits<br>• Changed programme or initiative or strategy or campaign to any field instead of title only, then got 1277 results; - several references included as part of already identified initiatives (BCOC, NAEDI, 2WW) | 11/06/2017 |
| UK | UK Clinical Research Network http://www.ukcrc.org/research-infrastructure/clinical-research-networks/uk-clinical-research-network-ukcrn/ | • 13 results when searching for the word cancer | 26/04/2017 |
| UK | Healthcare Management Information Consortium (HMIC) database (EBSCO) | • 97 hits (88 after duplicates), five kept for further examination – two eligible but already included, two reviews kept for checking references | 11/06/2017 |
| US | Centers for Disease Control and Prevention https://www.cdc.gov/ https://nccd.cdc.gov/DCPC_SCS/index.aspx#/ | • Checked the cancer specific page only (https://www.cdc.gov/cancer/). Most screening only, or already included (i.e. Inside Knowledge)<br>• Searched for “cancer” at the NCCD website (2005-2017), found 704 publications. Restricted it to “detection OR diagnosis OR pathway OR referral” and found 47 hits – all about screening. Searched for “awareness” and found two publications for Inside Knowledge<br>• References to initiatives across the US carried out as part of Comprehensive Cancer Control Programmes, but none met inclusion criteria. There were 66 Cancer Plans available for US States and territories and all were checked – no initiatives met inclusion criteria | 02/05/2017 – 11/05/2017 |
| Worldwide | International Agency for Research on Cancer https://www.iarc.fr/ | • IARC staff publications http://www.iarc.fr/en/publications/scientific-papers/index.php. Using keywords: referral awareness diagnosis detection programme program initiative campaign strategy survival delay engage (title searches, 2005-2017) – 265 hits – none eligible | 27/04/2017 |

| Region | Website | Results | Search date |
|---|---|---|---|
| | | • IARC Databases, publications, page for the IARC Screening Group, Cancer Topics page, guidebooks for early detection, and publications list for the Early Detection and Prevention Groups – no new initiatives<br>• IARC Book and Report Series – checked all sections on early detection/prevention for all biannual reports (2015/2015, 2012/2013, 2010/2011,and 2008/2009) –none eligible. | |
| Worldwide | CORDIS http://cordis.europa.eu/home_en.html | • Cancer AND early retrieved 2309 hits – research studies and collaborative research, but none eligible | 27/04/2017 |
| Worldwide | OECD iLibrary http://www.oecd-ilibrary.org/ | • 198 results for All Fields containing 'cancer' AND All Fields containing 'early' OR All Fields containing 'referral' - none eligible<br>• Cancer Care and improving survival (online access only): http://www.oecd-ilibrary.org/social-issues-migration-health/cancer-care_9789264181052-en – refers to waiting times for several countries, but no new eligible initiatives were identified<br>• Specific report focusing on waiting times - no new eligible initiatives | 27/04/2017 |
| UK | Cancer Research UK https://www.cancerresearchuk.org/ | • "early diagnosis" retrieved 378 pages of hits - 3,772 results, "detection" retrieved 325 hits in 33 pages<br>• Range of ED initiatives; references to studies relevant for background information, to Be Clear on Cancer, NICE guidance for urgent referrals, ACE, DCE, NAEDI – additional references of included initiatives. Small research studies that did not meet criteria, links to all UK Cancer plans | 02/05/2017 |
| UK | Marie Curie https://www.mariecurie.org.uk/ | • Cancer AND early retrieved 575 results; diagnosis retrieved 102 results – focus on end of life care, no eligible initiatives | 01/05/2017 |
| UK | Macmillan Cancer Support https://www.macmillan.org.uk/ | • "early diagnosis" OR "early detection" – 25 hits; "routes to diagnosis" – 35 hits; "diagnostic pathways" – 7 hits<br>• Eligible ACE documents, other local initiatives did not meet criteria | 01/05/2017 |
| UK | The King's Fund https://www.kingsfund.org.uk/ King's Fund Library | • "Cancer" retrieved 642 results, no new eligible initiatives.<br>• Library Database: searched for 'ti,wrdl: cancer and kw,wrdl: early or kw,wrdl: referral' with limit(s): 'yr,st-numeric=2005-2017' - 837 results, additional references for included initiatives (2WW, NAEDI, BCOC | 27/04/2017 and 01/05/2017 |
| UK | The Nuffield Trust https://www.nuffieldtrust.org.uk/ | • Keyword cancer from 2005-2017 retrieved 111 results – none eligible | 27/04/2017 |

| Region | Website | Results | Search date |
|---|---|---|---|
| UK | National Cancer Research Institute http://www.ncri.org.uk/ | • One reference to NAEDI, no new eligible initiatives<br>• Searched for word “early” – no total hits shown, but there were seven pages of results available. Reference to an International Cancer Research Partnership (ICRP) – did not meet inclusion criteria | 27/04/2017 |
| Worldwide | World Cancer Research Fund International http://www.wcrf.org/ | • Specific section on policy – no eligible initiatives<br>• Looked for “early diagnosis” (2 hits, none relevant), “early detection” (no hits), referral (no hits), and pathway (3 hits, none relevant) | 02/05/2017 |
| US | American Lung Association http://www.lung.org/ | • Several initiatives, none led by the government, focus on prevention | 27/06/2017 |
| US | American Cancer Society - Cancer.org https://www.cancer.org/research.html | • “early diagnosis” OR “early detection” retrieved 6271 hits. No new eligible initiatives | 01/05/2017 |
| US | Cancer Research Institute https://www.cancerresearch.org/ | • Search for detection on diagnosis retrieved several hits (total number not shown) – no new initiatives | 01/05/2017 |
| US | National Cancer Institute (part of National Institutes of Health - NIH) https://www.cancer.gov/ | • Section on diagnosis and staging – no eligible initiatives<br>• Publications pages – no new initiatives<br>• "Division of Cancer Control and Population Sciences (DCCPS) website - no eligible initiatives, often focus on screening<br>• Press releases were checked from 2012 to 2017<br>• Another publications web page: https://publications.nci.nih.gov/ , searched for detection, early AND detection, early AND diagnosis, awareness, campaign, initiative AND diagnosis, initiative AND detection. All were imported to EndNote (1889 in total) – some duplicates for included initiatives, no new initiatives | 08/05/2017 – 10/05/2017 |
| Australia | Cancer Council Australia http://www.cancer.org.au/ | • Early Detection Policy focuses on screening – not eligible for inclusion<br>• Reference to “Listen out for lung cancer” which met inclusion criteria<br>• Improving rural cancer outcomea trial and Find Cancer Early campaign - excluded as research study<br>• Frequent awareness initiatives for skin cancer – not eligible | 24/04/2017 |
| Canada | Canadian Cancer Society http://www.cancer.ca/en/region-selector-page/?region=on&url=%2fen%2f%3fregion%3don | • Different pages for different provinces/territories; partnerships with the government, private organisations and charities. Website sections on screening and early diagnosis, but no references to initiatives | 24/04/2017 |

| Region | Website | Results | Search date |
|---|---|---|---|
| Denmark | Danish Cancer Society<br>https://www.cancer.dk/om-os/the-danish-cancer-society/ | • Annual reports refer to Danish initiatives already included, fundraising campaigns and charity-led initiatives did not meet criteria for inclusion | 24/04/2017 |
| New Zealand | Cancer Society of New Zealand<br>https://cancernz.org.nz/ | • Materials on prevention (and reference to SunSmart) and information on early diagnosis (but not part of any initiative) | 24/04/2017 |
| Germany | German Cancer Aid<br>https://www.krebshilfe.de/ | • Information not available in English | 24/04/2017 |
| Republic of Ireland | Irish Cancer Society<br>https://www.cancer.ie/ | • Initiatives focusing on prevention did not meet inclusion criteria, other initiatives were led by charities | 24/04/2017 |
| The Netherlands | Dutch Cancer Society<br>https://www.kwf.nl/english/Pages/The-organisation.aspx | • Report on early diagnosis, but not about initiatives<br>• Reports on surveillance, primary prevention, screening and treatment did not meet inclusion criteria | 24/04/2017 |
| Norway | Norwegian Cancer Society<br>https://kreftforeningen.no/ | • Search within site (early diagnosis, campaigns, etc.) – no results<br>• Cancer prevention focuses on lifestyle and screening programmes<br>• Pathways were introduced in 2015 – met inclusion criteria | 24/04/2017 |
| Portugal | Portuguese Cancer League<br>https://www.ligacontracancro.pt/ | • Website not available in English | 24/04/2017 |
| Spain | Asociación Española Contra el Cáncer<br>https://www.aecc.es/Paginas/PaginaPrincipal.aspx | • Website not available in English | 24/04/2017 |
| Sweden | Swedish Cancer Society<br>http://www.uicc.org/membership/swedish-cancer-society-cancerfonden | • Very limited information in English. Reference to Cancer Plans which were checked further for initiatives | 24/04/2017 |
| Nordic countries | Nordic Cancer Union (NCU)<br>http://www.ncu.nu/Default.aspx?ID=27 | • Reference to Norwegian Diagnostic Pathways and waiting times. Annual reports referred to CPPs in Denmark – no new eligible initiatives | 24/04/2017 |
| Germany | German Cancer Society<br>https://www.krebsgesellschaft.de/german-cancer-society.html | • Search within website for both English and German 'early diagnosis / detection / delay / initiative – no results<br>• Associate partner at the EU-project CanCon and part of EPAAC (European Partnership for Action Against Cancer) – screening only<br>• Reference to earlier diagnosis strategies but they were research studies | 24/04/2017 |
| Worldwide | EThOS - Electronic Theses Online Service | • "early diagnosis" OR "early detection" AND cancer – 97 records; "cancer diagnosis" OR "cancer detection" – 163 records; "Cancer pathway" – 9 records; "routes to diagnosis" OR "diagnostic pathway" – | 24/04/2017 |

| Region | Website | Results | Search date |
|---|---|---|---|
| | | 14 records; awareness AND cancer – 88 records; referral AND cancer – 54 records – no new initiatives | |
| Europe | Dart-Europe -http://www.dart-europe.eu/basic-search.php | • early diagnosis" AND cancer - 61 hits in English; "early detection" AND cancer - 126 hits English; "diagnostic pathway" AND cancer - 0 hits; awareness AND cancer - 58 hits in English; "routes to diagnosis" and cancer – 0 hits; Referral AND cancer – 25 hits – no new initiatives | 24/04/2017 |
| USA | U.S. National Institutes of Health's Clinical Trials Database https://clinicaltrials.gov/ | • cancer AND (diagnosis OR detection OR referral OR pathway OR awareness) – 12580 hits (11,926 when restricting time period, 11,718 when restricting to adults only) – exported to EndNote as Tab Delimited and individually checked – none eligible | 25/04/2017-26/04/2017 |
| Worldwide | WHO International Clinical Trials Registry Platform Search Portal http://apps.who.int/trialsearch/ | • Cancer AND detection OR diagnosis OR pathway OR referral OR awareness. 518 records for 271 trials – none eligible | 25/04/2017 |
| UK | UK Clinical Trials Gateway https://www.ukctg.nihr.ac.uk/#popoverSearchDivId | • "early diagnosis" OR "early detection" – 31 trials; cancer AND referral – 17 trials; cancer AND awareness – 5 trials; cancer AND pathway – 69 trials; detection AND cancer – 60 trials; diagnosis AND cancer – 468 trials - none eligible | 24/04/2017 |
| Worldwide | Open Sigle http://www.opengrey.eu/ All searches restricted to English | • Cancer AND referral – 20 hits, including about already included initiatives (2WW); cancer AND pathway, restricted to English – 318 hits, none eligible; cancer AND awareness, restricted to English - 15 hits, none eligible; cancer AND diagnosis, restricted to English – 238 hits, none eligible; cancer AND detection, restricted to English – 204 hits, none eligible; cancer AND strategy, restricted to English – 150 hits, none eligible; cancer AND initiative, restricted to English - 1 hit, none eligible; cancer AND program, restricted to English – 27 hits, none eligible; cancer AND programme, restricted to English – 86 hits – none eligible; cancer AND plan, restricted to English – 25 hits – retrieved old publications for NHS Cancer Plans for background information; cancer AND campaign, restricted to English – 23 hits, none eligible; cancer AND policy, restricted to English – 30 hits, none eligible; cancer AND government, restricted to English – 14 hits – relevant, but not recent enough | 24/04/2017 |

# Appendix 8. Drivers and rationale for included initiatives

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| 2WW | • National burden of cancer (mortality and survival)<br>• Government's commitment to focus on cancer outcomes and prioritise assessment of patients with suspected cancer<br>• Health policy for achieving early cancer diagnosis<br>• Belief that patients in England accessed specialist care too late in the progression of their disease.<br>• Poorer cancer outcomes compared to European countries and others | • Tumours can progress during the time taken to reach a diagnosis and start treatment<br>• There is an association between time to diagnosis and mortality<br>• There is (limited) evidence that early diagnosis and shorter overall time to diagnosis can improve cancer outcomes and avoid cancer deaths<br>• Diagnostic delay may explain the poor UK performance |
| ACE | • Cancer outcomes in England poorer than in other countries in Europe (even when health systems are comparable) and late stage diagnosis play a key role<br>• Informed in part by developments in cancer diagnostic services in other countries, especially the NSS-CPP in Denmark | • Enhancing GP's ability to identify those in need of a rapid referral can help to achieve earlier diagnosis. Cancer decision support tools can have a positive impact on their performance<br>• Community pharmacies can help with early diagnosis (raising awareness or even directly referring patients) due to their accessibility (even to more deprived populations), opening hours and familiarity with the local population<br>• The best way to improve lung cancer survival is to identify lung cancers early when treatments are most effective. Approaches focusing on finding and 'checking' people at high risk before symptoms have developed may be useful<br>• Some cancers can be more difficult to diagnose, especially for patients who present with vague symptoms. Some symptoms or combinations of symptoms can have a number of causes and can also be symptoms of several types of cancer. This can result in an extended diagnostic interval when comparing with easier to suspect cancers. The result may be poorer clinical outcomes and a poor patient experience<br>• A bit more than a quarter of cancers are diagnosed through urgent referral routes, but only about half of cancer patients present with symptoms that indicate a particular type of cancer .This can result in delays for patients with vague symptoms, or patients who present |

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| | | at earlier stages with less clear symptoms. Referral guidelines lowering the referral threshold can help, but the urgent referral pathway still requires the GP to identify a specific site pathway. Access to diagnostic tests for symptoms that do not meet referral criteria can help<br>• Survival for lung cancer patients is closely related to stage at diagnosis. Later stages are associated with poorer survival. Despite improvements in cancer outcomes, there is still scope to save more patients through a specific route |
| BCOC | • Cancer burden (incidence and mortality)<br>• Poor cancer survival rates compared to other countries, particularly 1-year survival (for which late diagnosis is a major contributor)<br>• High levels of cancers diagnosed through emergency routes<br>• Reducing the 'patient interval' by encouraging prompt presentation after the onset of symptoms was a key NAEDI issue<br>• Poor cancer awareness, especially among men and individuals from lower socioeconomic groups<br>• Possibility to reduce avoidable cancer deaths due to late diagnosis | • Broad agreement that late diagnosis is due to low symptom awareness, delays in presentation to the GP, practitioner or system delay, insufficient use of 2WW and insufficient access to diagnostic tests<br>• People's reluctance to visit the GP with what may seem like minor symptoms, or concerns about wasting the doctor's time |
| CPPs in Denmark | • Denmark has a higher incidence of cancer and poorer cancer survival rates than many other European countries<br>• Publication of several case stories of cancer patients experiencing delayed diagnosis or delayed treatment with fatal consequences<br>• Politically agreed timeframes | • In 2007 scientific evidence on the negative impact of waiting time for patients with head and neck cancer was presented to Danish decision makers - it showed the importance of system delay<br>• Double gatekeeping in Denmark (for GP referral to specialist and for specialist to refer to investigations) resulting in delays |
| DCE | • Burden of cancer in Scotland (mortality), especially for lung, colorectal and breast cancers, with a deprivation gradient | • Evidence that excess in mortality is due to advanced disease at presentation, bearing in mind other factors such as co-morbidity, tumour biology, stage of disease at treatment, pre-treatment |

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| | • Poor cancer survival in the UK compared to the European counterparts and its association with late stage diagnosis<br>• Population ageing and its consequences<br>• Influenced by NAEDI in England<br>• In line with the Scottish Government's purpose and five strategic objectives, in addition to fitting with the Healthcare Quality Strategy | physical and psychological well-being, and quality of care immediately and after treatment |
| DAPs | • Motivation for improving efficiency of diagnostic care derived from the work carried out in breast cancer and provincial wait times initiative<br>• There was also a policy gap as cancer programmes had little guidance and support for improving diagnostic intervals | • The interval from suspicion to diagnosis is complex and important in cancer care; there is the need for several tests and consultations – this often results in considerable anxiety among patients<br>• Diagnostic delays may result in a greater likelihood of disease progression and this may lead to worse patient outcomes<br>• In the usual care route (UC), positive screening mammogram results (organised or opportunistic) are sent to the primary care doctor who must then order diagnostic tests and refer for specialist consultation – this results in a disconnection between screening and assessment that can increase the diagnostic interval |
| Fast-track Catalonia | • The incidence of breast, colorectal and lung cancer | • The reduction in waiting time was assumed to reduce psychosocial impact (patient anxiety and a sensation of vulnerability intervening between suspicion of cancer, definitive diagnosis and the start of treatment) |
| Fast-Track Valencia | • National burden of cancer<br>• Insufficient cooperation between the different healthcare professionals involved in cancer diagnosis, treatment, and follow-up | • Early detection increases the chances of an effective treatment and better outcomes<br>• Warning symptoms and prompt action can lead to early diagnosis - symptom detection by professionals may result in a referral to specialist and earlier diagnosis<br>• Optimum timing for diagnosis and treatment requires integration of care resources |
| Inside Knowledge | • Burden of gynaecologic cancers (incidence and mortality), even though it is easy to prevent cervical cancers with regular screening and follow-up, there have been advances in treatment | • Education and awareness has the potential to benefit patients with gynaecological symptoms; and to improve surveillance and diagnostic workup. Campaigns informed by gynaecologic cancer experts and further refined based on focus group research and |

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| | | formative research with healthcare providers, national health surveys on women's and healthcare providers' knowledge, attitudes, and practices related to gynaecologic cancer.<br>• Educational materials developed in consultation with scientists and external gynaecologic cancer experts |
| Listen out for lung cancer | • National burden of cancer (incidence, mortality and poor survival) | N/A |
| NAEDI | • NAEDI was one of the key commitments of the English Cancer Reform Strategy due to the recognition that more needed to be done to promote early diagnosis in the majority of patients who present with symptoms<br>• Informed by the EUROCARE studies<br>• Poor 1-year survival rates (often a proxy for advanced stage of cancer at diagnosis)<br>• Delays following referral to specialist services<br>• Unacceptable within country variation in diagnosis: some groups are more likely to be diagnosed with later stages than others<br>• Low public awareness of cancer signs and symptoms among men, most deprived and ethnic minority groups<br>• Burden of cancer (mortality) and the possibility to reduce avoidable deaths | • Primary care professionals have key roles in early detection as most cancer patients present first to a GP. More than referral guidance and checklists should be available to support them<br>• Pharmacists and social workers can also plan an important role<br>• Low awareness of cancer and the benefits of early detection lead to low screening uptake and late presentation with symptoms. Robust data on levels of awareness is needed to highlight groups for whom awareness raising initiatives are likely to be of greatest benefit<br>• NAEDI's key underpinning hypothesis: delays result in patients being diagnosed with more advanced disease, resulting in poor 1-year and 5-year survival and potentially avoidable deaths<br>• Many factors affect staging at diagnosis, so it is important to raise awareness; tackle negative attitudes to cancer and barriers to help-seeking; support primary care, and ensure optimum and prompt access to diagnostics and referral pathways<br>• When cancer is diagnosed early, treatment options and chances of a full recovery are greater<br>• Missed cancer diagnoses are important - it is important to understand more about the nature and extent of diagnostic delays |
| NSS-CPPs | • Burden of cancer in Denmark (mortality) and poorer cancer survival compared to other Western European countries<br>• Motivated by poor cancer control, public discontent with long waiting times and search for efficiency in standardised diagnostic pathways | • Danish cancer patients' confidence in their GPs decreases with increasing time to diagnosis<br>• The way the health system is organised can have adverse effects which are associated with longer diagnostic intervals<br>• Gatekeeping can result in reluctance to refer early to diagnostic investigations |

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| | • Relatively long waiting times due to delays in presentation, diagnosis and treatment (associated with higher mortality and stage progression)<br>• Danish CPPs not appropriate to ensure timely diagnosis of all cancer patients - only about 40% of cancer patients seem to have benefitted, and only half of cancer patients initially present symptoms classified as alarm symptoms | • Despite screening, most cancers are diagnosed through symptomatic presentation. It is still the GP's duty to identify the cancer over the whole symptom continuum. Some cancer patients do present in general practice, but not with symptoms indicative of cancer. If the GP regards the symptom as vague, 50% of cancer patients will wait at least one month more and 25% at least 2.5 months longer until diagnosis, compared with those with alarm symptoms<br>• General practice use increases significantly several months before a patient is diagnosed |
| Norwegian CPPs | • Although eHealth is widely available, there is a cultural and social gap between those who use the eHealth services and those who do not – this can negatively influence health outcomes and needs to be considered in the communication and information distributed to patients<br>• "Politically decided" introduction of CPPs and guidelines<br>• Influenced by CPPs in Denmark | • N/A |
| Oral Cancer Maryland | • Passage of legislation and related funding for a statewide Oral Cancer Prevention Initiative<br>• Oral cancer identified as one of the seven cancers to be targeted, with the receipt of tobacco settlement funds<br>• Oral cancer mortality rate was higher than the US average<br>• Substantial disparities in oral cancer mortality rates between blacks and whites<br>• Less than a third (28%) of oral cancers are detected at the earliest stage | • Evidence that most oral cancers were diagnosed by physicians, not dentists<br>• Most dentists and dental hygienists provide oral cancer examinations, but do not perform palpation and many do not know what to look for<br>• Despite awareness that tobacco and alcohol are risk factors for oral cancer, the issue was not addressed with patients<br>• Adult public not knowledgeable about oral cancer prevention and early detection |
| RAC Ireland | • Burden of lung cancer (diagnosis and mortality); survival compares poorly with best international outcomes<br>• Late diagnosis helps to explain poor cancer survival in Ireland, including in cross-national comparisons<br>• High smoking prevalence | • Earlier diagnosis, efficient and correct diagnosis and staging, and modern multidisciplinary management lead to improved short and long term survival with good quality of life<br>• Early diagnosis of lung cancer increases the chance for a cure |

| Strategy | Drivers and influencers | Evidence/rationale |
|---|---|---|
| | • Improvements in the delivery of care are necessary<br>• The NCCP prioritised the establishment of the rapid access clinics, focusing on lung and prostate cancers | |
| Qatar's first national cancer strategy | • Qatari population is growing and ageing and this requires a more comprehensive cancer strategy<br>• Changing lifestyles and a unique demographic profile have already led to a high burden of non-communicable diseases<br>• Some elements of the population had misconceptions about cancer, e.g. it is always fatal or most cancers are hereditary or contagious<br>• A National Cancer Program team was established within the Ministry of Public Health (MoPH)<br>• Reference to the Danish Cancer Plans and experiences in the UK and New Zealand | • N/A |
| Rapid Referral Pathway Madrid | • Burden of cancer (incidence and mortality) | • Stage at diagnosis is the most important factor associated with survival<br>• Direct referrals for colonoscopy is practical and effective to reduce N of specialist consultations and diagnostic delay (although evidence is more limited on the impact on survival) |
| SCP | • Influenced by CPPs in Denmark and their outcomes<br>• Perceived unacceptable delays in care pathways | • N/A |

***Source: included studies***

# Appendix 9. Key stakeholders in included initiatives

| Initiative | Key Stakeholders |
|---|---|
| 2-week wait | • The Department of Health (policy, monitoring, reporting and funding)<br>• NICE<br>• The National Collaborating Centre for Cancer<br>• The Guideline Development Group (guideline development and updates). It comprised healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, which reviewed the evidence and drafted recommendations which were finalised after public consultation<br>• GPs, primary and secondary care professionals were responsible for the urgent referral pathway<br>• NHS Trusts monitored performance and gave feedback to GPs. Trusts and Strategic Health Authorities (SHA) were expected to submit and collate national waiting times data and encouraged to carry out clinical audits |
| Accelerate, Coordinate, Evaluate (ACE) | • NHS England initiative supported by Cancer Research UK and Macmillan Cancer Support, with a team made up of staff from the three organisations<br>• Support on evaluation provided by the Department of Health's Policy Research Units (PRUs)<br>• Other stakeholders include:: national lung cancer experts, Lung Cancer Clinical Expert Group (LCCEG), CRUK primary care facilitators, primary care professionals, secondary care professionals, Clinical Commissioning Groups across England, NHS Foundation Trusts across England, University Hospitals, One-step cancer clinics, cancer experts |
| Be Clear on Cancer (BCOC) | • Department of Health working with the National Cancer Action Team, COI (pilots), NHS England, NHS Improving Quality and Public Health England working in partnership. The Office for National Statistics was also involved<br>• The charity Cancer Research UK (CRUK) was appointed in 2011 to help develop the evaluation framework and coordinate the data flows for evaluations. CRUK led evaluations of BCOC activities until March 2013, after this date evaluation was led by PHE through the National Cancer Intelligence Network. An expert advisory group (academics, clinicians, statisticians and epidemiologists) has helped to guide the evaluation<br>• For each BCOC campaign a market research agency (TNS BMRB) was commissioned to conduct campaign tracking surveys with the target audience and GPs<br>• The University of York and University of Sheffield estimated the cost effectiveness of the lung/bowel campaigns |
| Cancer Patient Pathways (CPPs) | • The National Board of Health (NBH) was given the task to facilitate the process of developing the national CPPs.<br>• Five health regions were responsible for both primary and secondary health services and for CPP implementation<br>• CPP development: Administrators contributed with organisational knowledge; Health professionals with health specific knowledge; Politicians with the patient's voice and political power. All stakeholders were able to influence the process which could be characterised as a 'bottom-up and top-down' |

| Initiative | Key Stakeholders |
|---|---|
| | • The Danish Prime Minister announced that cancer should be treated as an acute condition; this led to a political agreement between the government and health regions to implement the CPPs<br>• Danish Multidisciplinary Cancer Groups (DMCGs); National Cancer Task Force |
| Detect Cancer Early (DCE) | • A partnership involving the Scottish Government (including public health, health promotion, health improvement services and the Cabinet Secretary), Regional Cancer Networks, Scottish Primary Care Cancer Group, Third Sector, NHS Health Boards, primary and secondary care professionals, cancer charities<br>• Clinical leadership was required to drive the initiative. Media was also expected to be involved |
| Diagnostic Assessment Pathways (DAPs) | • Cancer Care Ontario, regional cancer programmes, nurses, primary and secondary health care providers, radiologists, private donors and corporations |
| Fast-track Catalonia | • Department of Health and Catalonia Health Service (mix of private- and publicly-owned health facilities)<br>• Professionals in primary and secondary care |
| Fast-track Valencia | • Clinico-Malvarrosa Health Department in Valencia<br>• Primary and secondary care professionals, including a hospital specialist, primary care physicians and a pathway coordinator |
| Inside Knowledge | • Developed and implemented by the Centres for Disease Control and Prevention (CDC), in collaboration with the U.S. Department of Health and Human Services' (HHS) Office on Women's Health<br>• Professionals include gynaecologic oncologists, gynaecologists, paediatricians, nurses, other medical practitioners, health and behavioural scientists, and representatives of non-profit and advocacy organisations committed to raising awareness of gynaecologic cancers<br>• Other stakeholders include Sheryl Silver (instrumental in the creation of Johanna's Law), the Society of Gynaecologic Oncologists, the Foundation for Women's Cancer, the Allied Support Group of the FWC; the Ovarian Cancer National Alliance; the National Cervical Cancer Coalition; Fran Drescher's Cancer Schmance |
| Listen out for lung cancer | • New South Wales (NSW) government and Cancer Institute NSW |
| National Awareness and Early Diagnosis Initiative (NAEDI) | • Public sector/third sector partnership, led by NHS England, Public Health England, Cancer Research UK and the Department of Health, co-chaired by the National Cancer Director and Cancer Research UK's Chief Executive<br>• Other stakeholders include other public and voluntary sector organisations (such as Macmillan Cancer Support), the National Cancer Action Team (NCAT), the Royal College of General Practitioners (RCGP), the National Patient Safety Agenda (NPSA), the National Cancer Research Institute (NCRI), local Authorities, primary care trusts, the research community (including included behavioural scientists, experts in social marketing, public health physicians, primary care academics and epidemiologists), health care professionals, patient groups and patients. A National Cancer Intelligence Network (NCIN) was also established by the initiative |
| Non-Specific Symptoms CCPs (NSS-CPPs) | • the National Board of Health and Danish Regions<br>• Primary and secondary care including primary care practices, hospitals, diagnostic centres and "yes-no-clinics" |

| Initiative | Key Stakeholders |
|---|---|
| Norwegian CPPs | • Norwegian Government and the Directorate for Health<br>• Primary and secondary care |
| Oral Cancer Maryland | • A "small group of stakeholders" developed, implemented and evaluated the programmes. It expanded over time to include members/partners from the "Maryland Department of Health and Mental Hygiene (DHMH), Office of Oral Health; the National Institute of Dental and Craniofacial Research (NIDCR); the University of Maryland's schools of dentistry and nursing; health care provider associations such as dentists, dental hygienists, and family practice physicians; local health departments; and the American Cancer Society" |
| Rapid Access Clinic (RAC) | • Department of Health, the National Cancer Registry of Ireland (NCRI), the National Cancer Control Programme, All Ireland Cancer Foundation Ltd, the Irish College of General Practitioners, the Irish Thoracic Society<br>• Primary and secondary care professionals, designated centres/clinics, national multidisciplinary prostate cancer team |
| Qatar's first national cancer strategy | • "Collaborative effort" led by the Ministry of Public Health, the Supreme Council of Health (SCH) and health care providers (Hamad Medical Corporation and Primary Health Care Corporation), in addition to several other stakeholders (such as small care providers, care staff, multidisciplinary teams and private surgeons)<br>• A National Cancer Committee was established to guide strategy development<br>• Other stakeholders included the Supreme Education Council and the Qatar National Cancer Society (awareness campaigns), government officials; international health policy experts from the Institute of Global Health Innovation, Imperial College London, in the United Kingdom<br>• Two key Implementation groups, the Cancer Implementation Group (CIG) and The Cancer Transformation Team (CTT) drove the clinical application of the strategy |
| Rapid Referral Pathway Madrid | • "Developed and coordinated by a committee consisting of hospital and primary care managers and specialists involved in the health care process".<br>• GPs, hospital specialists and a coordinator were involved in each health centre |
| Standardized Care Pathways | • The Swedish Central Government (through the Ministry of Health and Social Affairs) initiated it, funds its monitoring and evaluation. SALAR (six regional cancer centres), Swedish regions and patient representatives are responsible for designing and implementing the programme. There is continuing dialogue between both groups<br>• Diagnosis-specific multi-professional teams provide medical knowledge and represent health care professionals - they make the reform bottom-up instead of top-down (which they describe as similar to the Danish reform)<br>• The Swedish National Board of Health and Welfare monitors and evaluates the SCPs through an expert group with different expertise (improvement sciences, quality assessment, clinicians and patient representatives).<br>• There is a central agreement with SALAR and the independent Swedish counties that incentivises implementation, but the grant is described as "of a more symbolic nature") |

***Source: included studies***

# Appendix 10. Population groups targeted by initiatives

| Initiative | Target populations |
|---|---|
| 2-week wait | • Patients with a suspicion of cancer (presenting with alarm symptoms)<br>• Different studies investigated several subgroups (patients referred through the pathway, often aged 40 or older, patients going through other routes (for comparison purposes), patients diagnosed and not diagnosed with cancer, treated and followed up after a cancer diagnosis) and targeted health professionals in order to assess their views on the strategy<br>• Referral guidelines targeted patients with high-risk symptoms suggesting cancer (covering children, young people and adults – although guideline assessment did not include children and young people aged 17 and younger), healthcare professionals and people involved in clinical governance in both primary and secondary care |
| Accelerate, Coordinate, Evaluate (ACE) | • Primary care professionals (General practitioners, pharmacists and other community pharmacy staff)<br>• Patients at high risk of lung cancer<br>• Patients that present with non-specific but concerning symptoms that do not indicate a likely primary tumour site, or meet the criteria for a site specific urgent referral pathway for cancer<br>• Patients that present late to their GP with new suspected cancer, but the GP regards the patient as already too ill to wait for a two week wait (2WW) referral or is unsure of the primary cancer site<br>• clinicians, managers, commissioners and other key informants in different AE projects (as part of ACE evaluation) |
| Be Clear on Cancer (BCOC) | • Varied according to campaigns<br>• Most campaigns targeted men and women from lower socioeconomic groups (C2DE) aged 50+ (55 years for the early bowel activity) where most improvements could be made, with adaptations according to the type of media used<br>• Key influencers, such as friends and family<br>• Television campaigns adapted for the hard of hearing; easy versions of leaflets were developed, in addition to versions in Braille, audio, and large print on-line for the visually impaired – this aimed to reduce inequalities<br>• To counter cultural, religious and language barriers preventing Minority Ethnic Groups from presenting early to their GPs, work was carried out with a specialist multicultural marketing consultancy |
| Cancer Patient Pathways (CPPs) | • Patient for whom a cancer diagnosis was suspected (based on alarm symptoms).<br>• Different studies often assessed subgroups, e.g. focused on specific cancer types, or on patients who attended general practice prior to being diagnosed with cancer |
| Detect Cancer Early (DCE) | • Anyone at risk of cancer, focusing on patients at high risk, deprived populations and non-responders to screening (e.g. men for bowel cancer initiatives as they were more likely to have poorer outcomes.<br>• Primary and secondary care professionals |
| Diagnostic Assessment Pathways (DAPs) | • Patients suspected of having breast, lung, colorectal or prostate cancers |

| Initiative | Target populations |
|---|---|
| Fast-track Catalonia | • Patients suspected of having a breast, lung or colorectal cancer<br>• Study also targeted health professionals who participated in fast-track management as stakeholders or data manager |
| Fast-track Valencia | • Patients suspected of having breast, colorectal, cervical, lung, or bladder cancers<br>• Primary and secondary health care professionals |
| Inside Knowledge | • Women of all ages, races, and ethnic groups, especially those aged 35 years and older; YouTube female users, female users actively searching for gynaecologic cancer content online<br>• Health care providers |
| Listen out for lung cancer | • General public (campaign development)<br>• All adult population, especially the ones at risk of lung cancer: 50 years or older, smokers & ex-smokers, low SES, Regional & Remote NSW; aboriginal people (awareness campaigns) |
| National Awareness and Early Diagnosis Initiative (NAEDI) | • Several different groups depending on the strategy. General public, targeted activities for specific subgroups such as older ages (e.g. 50 +), more deprived populations, specific ethnic groups<br>• Primary care practices and health care professionals |
| Non-Specific Symptoms CCPs (NSS-CPPs) | • Patients for which there was a suspicion of a cancer diagnosis, with alarm symptoms, nonspecific, serious symptoms or vague symptoms<br>• Different studies focused on specific population subgroups (e.g. focusing on a specific referral pathway) |
| Norwegian CPPs | • Patient suspected of having cancer<br>• Primary and secondary health care professionals |
| Oral Cancer Maryland | • General public (several settings), focus on underserved, high-risk populations<br>• Health care providers (dentists; dental hygienists; family nurses/physicians), trainers, the media and policy makers |
| Rapid Access Clinic (RAC) | • Patients with highly suspicious signs and/or symptoms of lung or prostate cancers |
| Qatar's first national cancer strategy | • Target group varied according to the strategy<br>• General public, students (schools)<br>• Patients suspected of having cancer based on high-risk symptoms<br>• Health Care providers |
| Rapid Referral Pathway Madrid | • Patients suspected of having colorectal cancer based on high-risk symptom criteria – targeting patients who consulted with a GP between Aug/2004 and Oct/2007 and met high risk criteria for CRC cancer |
| Standardized Care Pathways | • Patients with a "well-founded suspicion" of cancer (see components) |

***Source: included studies***

# Appendix 11. Study designs and outcome measures for included initiatives

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| 2WW | |
| • Quantitative: cohort study (investigating the association between the propensity of general practices to use the urgent referral pathway and the precision of its use, and overall mortality among their patients diagnosed with cancer) (1) and cross sectional analysis (of data from the Cancer Waiting Times database for urgent referrals and patients receiving a first definite treatment) (2)<br>• Reviews (systematic and non-systematic) (3-6)<br>• Audit (annual government reports) (7-11): time-series analysis, time-trends analyses and descriptive statistics.<br>• Review of cancer waiting times standards (12): literature review, qualitative and quantitative findings from meetings of advisory groups, written communication and an engagement event with health professionals, patient groups, charities and NHS managers<br>• Guideline development (13): evidence from primary care was used as the basis for the guidelines. Recommendations were developed using a 'risk threshold', whereby if the risk of symptoms being caused by cancer is above a certain level then action (investigation or referral) is warranted.<br>• Assessment of guidelines (14): cohort study, assessing cancer diagnostic intervals before and after guideline implementation. | • Referral metrics (1): practice referral ratio (indirectly standardised number of urgent referrals for suspected cancer by general practitioners, standardised according to list size and to the age and sex distributions of patients); practice conversion rate (proportion of urgent referrals for suspected cancer by general practitioners that result in a diagnosis of cancer; this is the PPV for cancer among the patients selected for urgent referral; practice detection rate (% of CWT recorded cancers resulting from an urgent referral; this is the sensitivity of the selection of patients for urgent referral).<br>• Referral metrics (2): age standardised referral ratio (indirectly standardised number of urgent referrals relative to list size), conversion rate (% or urgent referrals that result in a cancer diagnosis or PPV) and detection rate (% of cancers treated which were urgent referrals – sensitivity).<br>• Reviews (3-6): outcome measures included: waiting time to first appointment; GP conformity to guidelines, cancer detection, appropriateness of type of referral according to the clinician, the ability of guidelines to identify correct referrals, process of referral (referrals received by the hospital within 24 hours and the mode of referral – fax or post/letter or proforma), compliance with the 2WW target); impact on timeliness (whether cancer patients are now being seen more quickly than before); accuracy of patient selection (successfully minimising both 'underuse' and 'over-use' of the pathway); impact on clinical outcomes (whether survival rates or tumour staging improves); impact on patients accessing care by other routes (whether routine referrals or patients diagnosed through other routes have longer waits or poorer outcomes).<br>• Audit (annual government reports) (7-11): proportion of patients urgently referred for suspected cancer by their GP who were seen by a specialist within two weeks of referral and changes over time (N and % increase over time); proportion of patients urgently referred with an exhibited breast symptom (where cancer was not initially suspected) who were seen by a specialist within two weeks of referral (N and % increase over time)<br>• Review of cancer waiting times standards (12): Whether 2WW was consistently achieved and whether there was regional variation; % of patients reported being seen by a hospital doctor within 2 and 4 weeks of referral, whether CWTs helped to drive service improvement |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| | and resulted in benefits for patients, whether targets led to improvements in cancer survival, helped to reduce patient anxiety; whether there was support for continuation of standards; whether targets continued to be justified and should be retained; whether standards should apply to all types of cancer. Qualitative outcomes not predefined.<br>• Assessment of guidelines (14): Diagnostic interval (duration from the first occurrence of a symptom code in the database to the date of cancer diagnosis); date of diagnosis (first entry of the code pertaining to a cancer diagnosis in the primary care record); % of patients who had any identifiable symptom code during the year prior to diagnosis |
| ACE | |
| • All references were evaluation reports<br>• Qualitative evaluation of four clusters: detailed case studies at purposefully selected nine of the 60 ACE sites (distributed between four of the eight ACE clusters: Colorectal cancer pathways, Proactive approach to patients with a high risk of lung cancer, cancer screening uptake for vulnerable groups and vague symptoms pathway). Data was collected through sequential one-to-one interviews, review of meeting notes and observation of cluster action learning sets. Interviews were recorded, transcribed and analysed using a Framework approach. Realistic evaluation (investigating context, mechanisms and outcomes) and Normalisation Process Theory were adopted (15) | • Vague but concerning symptoms (16): Time to diagnosis (N and means); stage at diagnosis (I to IV); other diagnoses (non-cancer); conversion rates; referral rates, patient experience (survey): how patients rated their care; the length of time they had to wait for tests and appointments; the information they received and whether they were likely to recommend the service to friends and family<br>• Pharmacy training (17, 18): project costs, feedback on training, knowledge of cancer<br>• Pathways from lung cancer referral to diagnosis (19): Attendances to the self-referral CXR services; N of invitations to CT scans; N of booked appointments; N of health checks undertaken; N of referrals to CT scan; N of CT scans; N of identified lung nodules and non-cancer significant findings; N of referral to local lung cancer services, imaging follow up and surgery; N of patients eligible to attend (RR); N of allocated health assessment slots; N of lung health checks completed<br>• CDS tools (20) : Project 1: Range of risk scores (more or less than 3%); decision made as a result of consultation (e.g. fast-track, diagnostic tests, safety-netting); N and type of diagnostic test (e.g. bloods, ultrasound); what prompted use of tool (own clinical judgement, CDS tool); whether symptom checker was using during and/or after consultation; whether tool influenced management of patient; whether risk score was shared with the patient. Project 2: previous cancer diagnosis, co-morbidities, referral to diagnostic imaging procedures (e.g. ultrasound, endoscopy, x-ray, patient management decisions (fast-track pathway, referral for further care, active surveillance, reassurance, proportion of patients where the GP reassured the patient that their risk of cancer was low; proportion of overall referrals (fast track and referral for further care); proportion of patients being reassured by a GP; % patients who were fast-tracked; proportion of active surveillance, N receiving a cancer diagnosis, tumour type, range of cumulative QCancer risk score. Qualitative methods: GP |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| | survey carried out independently from quantitative data, but aimed at GPs from the same area investigating access to, and use of the tool, training on how to use the tool, whether tool raised the professional's awareness of cancer, whether tools helped with decision making. Project 3: (acceptability and utility of using a CDS Tool to detect patients at high risk of five types of cancer); Patient suitability to attend clinic; Which tumour types had the highest scores; Referrals to diagnostic investigation; N of cancers diagnosed after investigations; Whether reason for appointment was clearly explained to patients; Emotional/psychological impact of being asked to come to the clinic; Patients' views on the best way to be contacted |
| BCOC | |
| Before-and-after studies:<br>• (21): Evaluation of national and regional lung cancer campaigns. Data relating to the period during and/or immediately after the campaign were compared with data from a pre-campaign time period (often the same time in the previous year) for several metrics. Before and after campaign surveys were carried out by a third-party to evaluate campaign impact.<br>• (22): Evaluation of the BCOC bowel and lung campaigns' impact across the entire pathway comparing estimates of outcome measures of interest before and during or after the intervention for the sample as a whole and stratified by population subgroups. Public awareness was assessed by a third-party<br>• (23): Analysis of data from awareness surveys using the validated CAM measure to test the prediction that there would be greater awareness of the symptoms highlighted in these national campaigns than non-targeted symptoms, and the hypothesis that barriers associated with the 'approachability' of the GP would be reduced<br>• Evaluation reports: Over 40 complex data sets were reviewed. Evaluations waited until as much | Before-and-after study (21):<br>• Public awareness of symptoms of lung cancer<br>• GPs' views on numbers of patients presenting with symptoms of lung cancer, numbers of suspected lung cancer referrals made, as well as GPs' views on the campaign's communications.<br>• N of patients presenting to GP practices with symptoms directly linked to the campaign (a cough) and selected control symptoms<br>• N of visits over the 8 weeks around the campaign compared with the same weeks in the previous year<br>• N of attendances ('working days')<br>• Urgent GP referrals for suspected lung cancer (N)<br>• N of referrals made during the months of the campaign and month directly following compared to a control period<br>• Proportion of urgent referrals for suspected lung cancer that resulted in a diagnosis of lung cancer (the conversion rate)<br>• N of chest X-ray and chest with or without abdomen CT scan (CT) from all referral pathways, and those following a GP referral during campaign compared with a control period<br>• Clinical impact of the campaign: (a) Number of cases diagnosed; (b) Stage at diagnosis (TNM) and changes in proportions of lung cancers diagnosed at each; (c) First definitive treatment; (d) Performance status; e) source of referral; (f) One-year survival (only for regional campaign) compared with control in previous year (age-standardised 1-year crude survival calculated using International Cancer Survival Standard weights).<br>Before-and-after study (22) |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| information as possible has been gathered. They focused on shifts in campaign recognition and knowledge pre- and post-activity, adding a control group whenever possible. | • Unprompted and prompted awareness of bowel/lung cancer symptoms<br>• Public views on whether the advertising had told them something new and whether they considered it relevant to them.<br>• N of patients presenting with Read codes associated with symptoms directly linked to the campaign and a set of control symptoms over a specified time period, compared with numbers in the same time in the previous year ('working days').<br>• Urgent referrals for suspected cancer; diagnostic and treatment activity; stage of disease at diagnosis; survival and mortality data<br>Analysis of data from awareness surveys (23)<br>• Awareness of warning signs and symptoms (prompted and unprompted)<br>• Change in recall and recognition of the three symptoms that were closest to those targeted in the campaign: 'cough' or 'hoarseness', 'change in bowel or bladder habits'; remaining six symptoms served as control symptoms<br>• Perceived barriers to help-seeking (prompted)<br>• Change in the frequency of the two barriers closest to those targeted in the campaign (worry about wasting the doctor's time, the doctor being difficult to talk to). Other cited barriers were treated as control items<br>• Cancer experience (participants, friends or family)<br>• Evaluation reports: Diagnostic imaging data |
| CPPs | |
| • Descriptive paper explaining programme inception (24, 25) and PhD thesis (26)<br>• Population-based GP survey and registry study (27)<br>• Ecological study comparing data from three cohorts (28)<br>• Comparative cohort study (29) | • Median waiting times (measured in days)<br>• Incident cancer (having a cancer diagnosis as the primary diagnosis, except for non-melanoma skin cancer; and no prior history of cancer recorded in the Danish Cancer Registry - previous non-melanoma skin cancer was allowed).<br>• Diagnostic interval (the time interval from the date of the patient' s first presentation of symptoms in primary care until the date of diagnosis in accordance with the Aarhus Statement (measured in days))<br>• % of people with alarm symptoms; % of people referred to CPP; Clinical tumour stage TNM |
| DCE | |
| • Official Health Intelligence Reports to assess whether HEAT targets were met (30-33) | • Heat targets assessed by describing N, percentages, and percentage increase; percentage of people with unknown cancer stage (breast, lung, colorectal and combined) |
| DAPs | |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| • Review of DAPs worldwide(34)<br>• Retrospective cohort study (35), comparing the diagnostic interval between group. | • Diagnostic interval (the time from the initial screen to the date of diagnosis). Initial screen defined as the earliest abnormal OBSP screening test within 12 months before diagnosis or the earliest opportunistic screening mammogram within 6 months before diagnosis<br>• Tumour histology (Nottingham/Bloom-Richardson) and staging (TNM)<br>• Usual health-care utilisation characteristics between 36 months and 12 months prior to the date of diagnosis, including frequency of doctor visits, primary care provider (yes/no), continuity of care based on Usual Provider Continuity index (high/low/non-user), preventive services index (the proportion of preventive services used out of the total number of preventive services for which an individual was eligible) |
| Fast-track Catalonia | |
| • Mixed-methods: Cohort study and semi-structured interviews (36) | • N of patients included in the CFP; N of cancer patients diagnosed through the CFP route<br>• Patients referred from general practitioners (GPs); compliance with referral guidelines; cancer detection rate; mean time between detection of suspected cancer and start of treatment |
| Fast-track Valencia | |
| • Cross-sectional study: all patients that went through the pathway (37) | • % of patients diagnosed with a specific cancer<br>• % of patients with suspected cancer diagnosis meeting the guideline criteria<br>• Time (in days) from submission to initiation of treatment |
| Inside Knowledge | |
| • Audit data, before-and-after comparisons, overview documentation, focus groups . Monitoring website hits, publication orders, public inquiries, social media and search engines, and PSAs. Evaluation of campaign advertising mandated by Congress.(38-44)<br>• Before and after comparisons (without control groups); comparisons were analysed using t tests (45)<br>• Cross-sectional (descriptive metrics on video views provided by YouTube) (46) | • Use of search engine advertisements (45): Impressions (N of times adverts were displayed); Clicks (N of times users activated web page links in adverts); Click-through rate (clicks divided by impressions); Cost-per-click (cost of placing adverts divided by clicks); N of visits to web pages linked to search engine adverts; duration of visits to web pages linked to search engine adverts<br>• Providing gynaecological cancer information on YouTube (46): Impressions: N of times that pre-roll videos played automatically, or N of times that keyword-targeted listings appeared; Views: N of times pre-roll videos were viewed for longer than the mandatory 5 s, or N of times that users initiated playing videos in keyword-targeted listings.; View-through rate: number of views divided by number of impressions; Cost-per-view: sponsorship cost divided by number of views; Portion of video viewed: percentage of the video shown before users halted play electronic impressions; Amount of USD spent in total; Total cost per click in USD; N of partners reached; N of publications |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| Listen out for lung cancer | |
| • Campaign development (47): Before-and-after telephone interviews with at risk general population.<br>• Qualitative study: focus groups with GPs (n=125); general community groups, Aboriginal groups, culturally and linguistically diverse community groups; and interviews with GPs and lung cancer survivors | • Knowledge of cancer symptoms<br>• Intention to see a GP |
| NAEDI | |
| • Local initiatives: mixed methods; self-reported online surveys (interventions). Campaign and cancer awareness projects were encouraged to use a "pre-post" survey using the validated Cancer Awareness measure (48)<br>• CDS tools: use of quantitative (case-control study, online experience tab in CDS tool) and qualitative (interviews, online experience tab in CDS tool and focus groups) data analysis. Controls referred to practices not recruited to the project, or those which were recruited but did not have the CDS software installed before November 2013, which were in the same (former) Cancer Network (CN) areas that the participating practices belonged to. The framework method was used to analyse qualitative data. Evaluation of use of CDS tools in practice, impact on practice and the management of patients, and considerations and implications for further work (49)<br>• Cancer Networks Supporting Primary Care programme: mixed-methods; qualitative, realistic evaluation of overall implementation and impact using interviews (50) and quantitative, before and after analysis of cancer outcomes (51)<br>• Report on outcomes of the national audit (52) | • Local initiatives: Centrally collected metrics: two-week-wait referral activity and screening uptake (bowel and breast cancers). Locally collected metrics: area(s) and general practices where the intervention ran in; detailed description of the interventions; campaign outcomes (prompted and unprompted awareness of cancer signs and symptoms, confidence in noticing symptoms, attitudes to cancer, early detection and treatment, barriers to presentation); behaviour change (e.g. intention to see the GP about signs and symptoms, and how quickly, actual or reported visits to the GP); GP requests for diagnostic tests; percentage of cancer cases diagnosed following emergency presentation; number of cancers diagnosed; stage of disease at diagnosis; radical treatment rate; duration of time prior to presentation to primary care; number of presentations to primary care. Also information on % of local activities dedicated to Public-facing activity (e.g., advertising/community events); GP engagement; other health professional engagement; making changes to services (e.g. direct access to chest x-ray)<br>• CDS tools: Quantitative evaluation: Differences in referrals, conversion or detection rates for each of the referral routes between participating and control practices, between practices allocated to the RAT algorithm compared with those allocated to the QCancer algorithm; impact on referral activity by age, gender and deprivation, urgent GP referrals, percent changes in number of referrals between the time periods (e.g. quarters) in 2012 compared with the same time period in 2013. Other (quantitative) measures were presented in the tool's experience tab and referred to: perceived risk compare with the calculated risk; (lower, about the same as, higher); additional patient management (admitted, referred, investigation required, other, none); whether investigation or referral would have happened if tool had not been used (yes, no), tests ordered (list provided). Qualitative evaluation assessed how the tools were used in practice, how they impacted in clinical practice and patient management, the associated impact on urgent referrals or diagnostic investigations, impact on the primary |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| | and secondary care interface, suggestions on how to improve tools, barriers to use; comparison with other tools, potential for dissemination of tools, among other issues. Qualitative evaluation also investigated overall patient views on tools and on knowing their potential cancer risk, and about decision-making about one's own healthcare<br>• Clinical audit: stage at diagnosis; number of times patient attended surgery; investigations ordered; symptoms at presentation; cancer site; patient interval (date of onset of symptoms to the first consultation); primary care interval (date of first presentation to the date of referral); referral interval (date of referral to the date the patient first attended for specialist assessment in secondary care)<br>• Cancer Networks supporting primary care (quantitative evaluation): referral activity before the start of the programme compared with during the programme; comparison of practices that chose to engage at any point in one or more of the four activities against those that did not engage in any of them; N of urgent GP referrals for all suspected cancers; N of cancers receiving a first treatment during the same period, based on 'treatment start date'; referral rate; conversion rate (percentage of urgent GP referrals resulting in a cancer diagnosis); detection rate (percentage of CWT recorded cancers resulting from an urgent GP referral); new cancer cases and mode of presentation; % of Hospital Episode Statistics identified cancers first presenting as an emergency (i.e. emergency in-patient admission from an A&E department or an outpatient clinic or a GP or Bed Bureau referral, or referral to outpatients following A&E attendance or emergency admission) |
| NSS-CPPs | |
| • Cross-sectional study describing the characteristics of patients referred to the NSSC-CPP and estimating cancer probability and distribution in this population, using questionnaires completed by GPs and Danish databases (53)<br>• Descriptive/commentary paper (54) and PhD thesis (55) | • Patient's symptoms; known chronic diseases; estimated risk of cancer at referral; clinical findings (GP's abnormal findings during the clinical examination of the patient); abnormal diagnostic test results; level of the GP's 'gut feeling' regarding possible serious disease; date of the first symptom presentation to the GP/practice; presence or absence of 21 specified symptoms at the time of referral (other symptoms could be added); primary care interval (time from the patient's first symptom presentation at the GP/practice until referral to the NSSC-CPP); referral date (registered inclusion date); cancer diagnoses; date of diagnosis (first date of the hospital admission at which the cancer diagnosis was confirmed in the Danish Cancer Registry); cancer probability (% of included patients who were diagnosed with a new cancer within six months after the referral date). |
| Norwegian CPPs | |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| • No quantitative studies/data yet available<br>• Qualitative study | • Theoretical and analytical analysis of online information about the CPP drawing upon critical discourse analysis |
| Oral Cancer Maryland | |
| Qualitative (focus groups) and quantitative components (cross-sectional surveys, descriptive statistics). Comprised three phases (56):<br>• Needs assessment: available funds; review of epidemiological data; surveys and focus groups<br>• Development and pilot testing of educational materials and interventions<br>• Programme evaluation (data collected from health care professionals and trainers at courses and seminars, and from the general public at community events, health fairs, and cancer screenings) | • Needs assessment: knowledge, opinions, and practices related to oral cancer early detection and prevention (professionals); knowledge of risk factors/signs and symptoms of oral cancer, experience of oral cancer examinations (adults – public)<br>• Evaluation: N of individuals educated about oral cancer; N of individuals screened for oral cancer; N of people reached through the media and resource materials<br>• Follow-up: knowledge of oral cancer risk factors (HPV as a risk factor for oral cancer); use of (adjunctive) diagnostic procedures; oral cancer screening practices and compliance with recommended screening exams (i.e. palpating lymph nodes)<br>• Attendance to an oral cancer CE course |
| RAC | |
| • Audit data(57)<br>• Quantitative survey on GP experience on the National Cancer Control Programme and their views in relation to service priorities (58) | • Referrals to RACs (N and % change) - all attendances, number of primary cancers diagnosed; % of attendances who had a primary cancer diagnosed<br>• Patients referred to RAC offered an appointment to attend within 20 working days of receipt of referral<br>• N of patients that attended a Prostate RAC within a month<br>• N of patients that attended or received an appointment to attend RAC within 20 working days of receipt of referral in the cancer centre<br>• % new patients diagnosed with primary prostate/lung cancers<br>• N of primary prostate/lung cancers diagnosed<br>• Patients referred to RAC offered an appointment to attend within 10 working days of receipt of referral<br>• The number of new patients that attended a lung RAC within reporting calendar month; of those: the number of new patients that attended or received an appointment to attend RAC within 10 working days of receipt of referral in the cancer centre; the number of attendances (excluding new DNAs) at lung rapid access clinics during the month<br>• GP survey: experience with RACs when referring patients |
| Qatar's first national Cancer Plan | |

| Study designs (including comparators and definitions if applicable) | Outcome measures |
|---|---|
| • Descriptive/overview paper (59), Cancer Strategy (60) and government publications reporting on progress (61-64) | • N (%) of patients referred to a specialist within 48 hours; N (%) patients diagnosed within 14 days of being seen with a specialist; N (%) patients treated within 4 days of being diagnosed; N of professionals completing communication skills training; Measures of population awareness (not described); % of cancers diagnosed at stages I and II; National screening coverage (%) |
| Rapid Referral Pathway Madrid | |
| • Case control study (65)<br>• Cases: patients referred through the rapid referral pathway (prospective data collection)<br>• Comparator: patients also diagnosed via colonoscopy but referred through the standard referral pathway (retrospective data collection) | • Signs and symptoms of cancer of referred patients; whether referral criteria were met for referred patients; cColonoscopy results for referred patients<br>• Waiting times for referred patient (days): between the request for colonoscopy made by the GP and its performance by a specialist (waiting time to colonoscopy), between firm diagnosis and surgery (waiting time to surgery) and the overall delay to surgery (waiting time between the request for colonoscopy by GP until surgery including any time required for anatomopathological diagnosis).<br>• Whether waiting time targets were met<br>• N of cancers diagnosed; N of endoscopic polypectomies performed; surgery for CRC; cancer staging at surgery |
| SCPs | |
| • Descriptive paper (66) and government report (67) | No outcome measures described |

***References (please see thesis for full references): 1.Møller et al 2015. 2.Meechan et al 2012. 3.Hanna et al 2005. 4.Harrison & Foot 2012. 5.Lewis et al 2005 (DARE). 6.Lewis et al 2005. 7.Abdullah et al 2011. 8.Aveyard et al 2013. 9.Pearson et al 2014. 10.Pearson et al 2015. 11.Samuels et al 2016. 12.Department of Health (Review of CWT) 2011. 13.National Institute for Health and Care Excellence 2015. 14.Neal et al 2014. 15.Ablett-Spence et al 2017. 16.Lewis et al 2017. 17.Accelerate, Coordinate, Evaluate 2015. 18.Pharmacy training for early diagnosis of cancer Accelerate, Coordinate, Evaluate (ACE) Programme, 2017. 19.Gill 2017. 20.Robinson et al 2017. 21.Ironmonger et al 2015. 22.Moffat et al 2015. 23.Power & Wardle 2015. 24.Olesen et al 2009. 25.Probst et al 2012. 26.Jensen 2015 (thesis). 27.Jensen et al 2014. 28.Jensen et al 2015. 29.Jensen et al 2016. 30.ISD Scotland. Detect Cancer Early Baseline 2013. 31.ISD Scotland. Detect Cancer Early Year 3 2015. 32.ISD Scotland. Detect Cancer Early Year 2 2014. 33.ISD Scotland. Detect Cancer Year 1 2014. 34.Cancer Care Ontario 2009. 35.Jiang 2013. 36.Prades et al 2011. 37. Martinez et al 2015. 38.Inside Knowledge 2012. 39.Inside Knowledge 2013. 40.Inside Knowledge 2014. 41.Inside Knowledge 2015. 42.Inside Knowledge 2016 (Campaign Background). 43.Inside Knowledge 2016 (2015 Year End Report). 44.Rim et al 2011. 45.Cooper et al 2015. 46.Cooper et al 2016. 47. Lyons 2014. 48.Department of Health 2012 (First report 2010/11 local projects. 2012). 49.Moffat et al 2014. 50.Ablett-Spence et al 2012. 51.Rubin et al 2015. 52.Rubin et al 2011. 53.Ingeman et al 2015. 54.Vedsted & Olesen 2015. 55.Ingeman 2015 (thesis). 56.Maybury et al 2012. 57.National Cancer Control Programme 2014. 58.O'Shea & Collins 2016. 59.Howitt et al 2014. 60.Supreme Council of Health 2011. 61.Supreme Council of Health 2013. 62.Supreme Council of Health 2014. 63.Supreme Council of Health 2015. 64.National Cancer Program 2016. 65.Valentin-Lopez et al 2012. 66.Wilkens et al 2016. 67.Swedish Government 2009.***

# Appendix 12. Document analysis: definitions for adopted criteria

| Area | Term | Definition | How to classify |
|---|---|---|---|
| Authenticity: refers to whether documents are originals or copies, drafts or final versions, sound or unsound (1) | version | Whether document is a draft or a final version | • Draft: document has tracked changes, highlighted terms or references to pending issues; or is explicitly defined as a draft<br>• Final version: document is clean, without tracked changes or pending issues, or is explicitly described as a final version |
| | soundness | Whether document is corrupted in any way (1); e.g. with contradictions or missing information | • Sound: document without (apparent) contradictions, grammatical issues that affect meaning; with references to data; with included attachments/data referred to in the text<br>• Partially sound: document has some (but not all) issues above<br>• Unsound: document has none of the issues mentioned above |
| Authorship: refers to whether authorship is private or from the State, from an individual or group (1) | source | Whether document was prepared by the Scottish Government or by a private institution (1) | • Government: Prepared by the Scottish Government, territorial Health Boards, Cancer Networks, Health Boards or others<br>• Private: prepared by stakeholders other than the government |
| | authors | Whether document authors are anonymous, a single individual or a group (irrespective of sources) (1) | • Anonymous: no reference to who the author is<br>• Individual: when a single individual is described as the author<br>• Group: when more than one individual is described as authors |
| Credibility: appraisal of how distorted document contents are likely to be, includes issues of interest. Sincerity, source and evidence (1) | interest | Whether there is the possibility of political or financial interest/gain (1) | • Political interest: when document can result in political gains<br>• Financial interest: when document can result in financial gains |
| | sincerity | Extent to which one is sincere in the choice of a standpoint and in the attempt to have an accurate account from that chosen standpoint. Something that is not accurate can still be sincere (1) | • Sincere: When to the researchers' knowledge, accounts seem honest, without any alterations to change meaning or facts<br>• Partially sincere: when the researcher can see that changes were made to the document, altering accounts (e.g. moderating criticism in minutes from programme meetings)<br>• Insincere: when it is obvious that the document present lies, or is deliberately misleading the intended audience |
| | source | Whether document reports on primary or secondary sources | • Primary: when document reports on first-hand data<br>• Secondary: when document reports on second-hand data |
| | evidence | Whether document describes facts, opinions or both (2) | • Facts: When document describes facts without discussing what it means or any implications<br>• Opinions: When document describes views, or suggestions<br>• Both: When document describes both facts and opinions |

| Area | Term | Definition | How to classify |
|---|---|---|---|
| Representativeness: whether documents are representative of all relevant documents (1) | overall | Dependent upon being aware of what has been produced and is available (1) | • Discussed in text as a narrative |
| | survivability | Whether document is deposited in a form that allows it to survive (e.g. stored in a data repository or published) (1) | • Stored but not published: not published but was stored in a folder/data repository (by those who developed the document)<br>• Stored and published: document was shared (e.g. reports for the Scottish Government, newsletters for stakeholders) and reached different groups (irrespective of whether this was open access)<br>• Stored, but unclear if published: when it is not clear whether document was published or widely shared |
| | availability | Refers to the ability to access a document (1). Closed access is mentioned in the literature (1), but not approached here. If a document was received, it was never considered to be closed access | • Restricted: not freely available; access would not have been possible without actively requesting documents<br>• Open access: reported to be available (may need rigorous searches)<br>• Unclear: even though documents are reported to be open access, searches for them to confirm this were not successful |
| Background information: data on publication date, intended audience, purpose, style, function and document type (2) | date | Year of publication | • Descriptive information in chart |
| | audience | Who was the intended audience, i.e. who the document was planning to reach (2) | • Categories created based on received documents |
| | purpose | Purpose of publication; i.e. what it aimed to describe (2) | • Described in supplementary tables (based on document content) and briefly summarised in the main thesis |
| | style | Refers to the language used, e.g. lay terms, health in general, among others (2) | • Categories created based on received documents |
| | function | Document function refers to whether it aim to persuade, validate or justify activities, decisions, outcomes, among others (2) | • Persuade: provide reasons (facts or opinions) for the intended audience to believe in/do something; try to convince the audience<br>• Validate: show the value of doing something/its accuracy<br>• Justify: to show that actions/results are reasonable |
| | document type | Type of document, such as reports or others | • Categories created based on received documents |

***References: 1.Scott J. A Matter of Record: Documentary Sources in Social Research. Scott J, editor. Cambridge: Polity Press; 1990. 2.O'Leary Z. Indirect data collection: working with observations and existing text. 2009. In: Essential guide to doing your research project . Sage. 3. Prior L. Using documents in social research. Prior L, editor. London: SAGE; 2011***

# Appendix 13. List of policy documents reviewed and interrogated

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 1 | Publications in Journals and Conferences | no | DCE team | 2015 | Show whether weekly monitoring can contribute towards meeting CWT targets |
| 2 | Publications in Journals and Conferences | no | DCE team | 2014 | Show results from bowel screening campaigns in requested bowel screening kits and bowel screening uptake, in addition to changes in knowledge and awareness of bowel cancer symptoms and signs |
| 3 | Publications in Journals and Conferences | no | DCE team | 2015 | Show results from the symptomatic breast cancer campaigns in increase in knowledge/awareness, consultations, cancer diagnoses and staging |
| 4 | Publications in Journals and Conferences | no | DCE team | 2014 | Show whether campaigns had an impact on the reduction of inequalities in bowel screening uptake and staging (bowel, lung and breast) |
| 5 | Publications in Journals and Conferences | no | DCE team | 2015 | Assess whether a psychoeducational increased adolescents' cancer awareness and addressed help-seeking barriers |
| 6 | Publications in Journals and Conferences | no | DCE team | 2014 | Describe Scottish adolescents' sun-related behaviours and tanning attitudes and assess associations with skin cancer awareness |
| 7 | Publications in Journals and Conferences | no | DCE team | 2015 | Study the diagnostic accuracies of faecal haemoglobin (FHb) and faecal calprotectin (FC) in a cohort of symptomatic patients. |
| 8 | Information documents shared with stakeholders | no | DCE team | unknown | Describe DCE's terms of reference: remit, governance, core and non-core members |
| 9 | Agendas, minutes and action notes | no | DCE team | 2011 | Outline minutes and action notes from a DCE Programme Board meeting |
| 10 | Agendas, minutes and action notes | no | DCE team | 2011 | Outline minutes and action notes from a DCE Programme Board meeting |
| 11 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Programme Board meeting |
| 12 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Programme Board meeting |
| 13 | Agendas, minutes and action notes | no | DCE team | 2013 | Outline minutes and action notes from a DCE Programme Board meeting |
| 14 | Agendas, minutes and action notes | no | DCE team | 2013 | Outline minutes and action notes from a DCE Programme Board meeting |
| 15 | Performance management reports | no | DCE team | 2015 | Describe Cancer Waiting Times in Scotland from January to March 2015 |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 16 | Performance management reports | no | DCE team | 2015 | Describe bowel screening key performance indicators from Nov 2012 until Oct 2014 |
| 17 | Information documents shared with stakeholders | no | DCE team | 2013 | Detail the rationale for choosing, and calculating the baseline for HEAT, and how data will be validated and coded separately by ISD Scotland. |
| 18 | Performance management reports | no | DCE team | 2013 | Present the numbers and percentages of patients diagnosed during 2010 and 2011 by type of cancer, stage of disease at diagnosis for NHS Board, Cancer Network of residence and Scotland. These figures were chosen as the baseline for the DCE HEAT target |
| 19 | Performance management reports | no | DCE team | 2014 | Present the numbers and percentages of patients diagnosed during 2011 and 2012 by stage at diagnosis for NHS Board of residence, Cancer Network and Scotland for breast, colorectal and lung cancers combined and individually (Year 1 - DCE Target) |
| 20 | Performance management reports | no | DCE team | 2014 | Present the numbers and percentages of patients diagnosed during 2011 and 2012 by stage at diagnosis for NHS Board of residence, Cancer Network and Scotland for breast, colorectal and lung cancers combined and individually (Year 1 - DCE Target) |
| 21 | Performance management reports | no | DCE team | 2015 | Present the numbers and percentages of patients diagnosed during 2011 and 2012 by stage at diagnosis for NHS Board of residence, Cancer Network and Scotland for breast, colorectal and lung cancers combined and individually (Year 3 - DCE HEAT target) |
| 22 | evaluation and insight gathering reports | no | DCE team | 2013 | Describe the outcomes from engagement sessions to inform primary care on DCE's work, lung and bowel cancer symptoms and signs, and bowel screening |
| 23 | Cancer referral guidelines documents | no | DCE team | 2014 | Outline evidence (UK and international guidelines) for patients with suspected cancer (tables created to inform the update of referral guidelines) |
| 24 | Cancer referral guidelines documents | no | DCE team | 2014 | Present the updated Scottish Cancer Referral Guidelines. The guidelines' aim was to facilitate appropriate referral between primary and secondary care for patients whom a GP suspects may have cancer. |
| 25 | Cancer referral guidelines documents | no | DCE team | 2015 | Present the updated Scottish Cancer Referral Guidelines in a user friendly, quick format for consultation. |
| 26 | Information documents shared with stakeholders | no | DCE team | 2013 | Describe the background for the bowel screening initiative, the rationale for it, its aims and provide general guidance to relevant stakeholders |
| 27 | Cancer referral guidelines documents | no | DCE team | 2014 | Described who gave feedback to (suggested) updated guidelines, what the feedback was and how comments/concerns were addressed |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 28 | Use of DCE funding | no | DCE team | unknown | Describe all DCE related activity carried out by the Roy Castle Lung Cancer foundation in 2013 (processes, outputs and outcomes) |
| 29 | Information documents shared with stakeholders | no | DCE team | 2011 | Seek stakeholder feedback on a draft implementation plan for the DCE Programme |
| 30 | Press and news releases | no | DCE team | 2012 | Describe DCE launch and the programme's initial developments |
| 31 | Press and news releases | no | DCE team | 2012 | Describe the symptomatic breast cancer campaign and other developments |
| 32 | Press and news releases | no | DCE team | 2012 | Describe the launch and initial results of the symptomatic breast cancer campaign and other developments |
| 33 | Press and news releases | no | DCE team | 2012 | Describe results of the symptomatic breast cancer campaign and other developments |
| 34 | Press and news releases | no | DCE team | 2014 | Describe published data on staging, programme activities across different territorial Health Boards and the primary care education programme |
| 35 | Press and news releases | no | DCE team | unknown | Describe the updated Scottish referral guidelines and activities taking place across all Cancer Networks in Scotland |
| 36 | Press and news releases | no | DCE team | 2015 | Commemorate the first three years of the DCE programme and provide update on activities in some territorial Health Boards |
| 37 | Information documents shared with stakeholders | no | DCE team | 2015 | Describe the campaign rationale, resources and outcomes. |
| 38 | Information leaflets for patients | no | DCE team | 2013 | Describe to the general public how and why bowel screening can find cancer early and improve survival |
| 39 | Information documents shared with stakeholders | no | DCE team | 2013 | Introduce the bowel screening stakeholder pack |
| 40 | Information documents shared with stakeholders | no | DCE team | 2013 | Describe the bowel cancer campaign (and all different types of media used), its rationale and information resources available to stakeholders |
| 41 | evaluation and insight gathering reports | no | DCE team | 2014 | Describe attitudinal tracking results for six bursts of the bowel screening campaign |
| 42 | Press and news releases | no | DCE team | 2013 | Describe the bowel screening campaign, some of its outcomes and outline endorsements from survivors, celebrities and relevant DCE stakeholders |
| 43 | evaluation and insight gathering reports | no | DCE team | 2014 | Describe the methodology for the evaluation of the breast screening campaign and outline results (data tabulations) |
| 44 | Information documents shared with stakeholders | no | DCE team | unknown | Describe the breast screening campaign (background, rationale, components and results) |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 45 | Information leaflets for patients | no | DCE team | 2014 | Describe to the general public how and why breast screening can find cancer early and improve survival |
| 46 | Information documents shared with stakeholders | no | DCE team | 2014 | Describe the breast screening campaign, all types of media used, its rationale and the information resources available to stakeholders |
| 47 | Information documents shared with stakeholders | no | DCE team | 2012 | Describe the breast symptomatic campaign, all types of media used, its rationale and the information resources available to stakeholders |
| 48 | Information documents shared with stakeholders | no | DCE team | unknown | Describe the breast symptomatic campaign (background, rationale, components and results) |
| 49 | Press and news releases | no | DCE team | 2012 | Describe the symptomatic breast campaign and outline endorsements from survivors, celebrities and relevant DCE stakeholders |
| 50 | Information leaflets for patients | no | DCE team | 2012 | Describe to the general public early detection of breast cancer can improve survival and highlight and describe breast cancer signs and symptoms other than lumps |
| 51 | Information documents shared with stakeholders | no | DCE team | 2012 | Introduce the symptomatic breast campaign to GPs, outlining signs and symptoms from referral guidelines and eligibility criteria for breast screening |
| 52 | Information documents shared with stakeholders | no | DCE team | 2013 | Describe the lung campaign, all types of media used, its rationale and the information resources available to stakeholders |
| 53 | evaluation and insight gathering reports | no | DCE team | 2015 | Describe attitudinal tracking results for four bursts of the lung campaign |
| 54 | Information documents shared with stakeholders | no | DCE team | 2015 | Describe the lung campaign (background, rationale, components and results) |
| 55 | Press and news releases | no | DCE team | 2013 | Describe the lung campaign and outline endorsements from survivors, celebrities and relevant DCE stakeholders |
| 56 | Information documents shared with stakeholders | no | DCE team | 2014 | Introduce the lung campaign focusing on the 3-week cough, describing the rationale for it, the target population, symptoms requiring referral, and addressing potential concerns regarding increase in demand |
| 57 | Information leaflets for patients | no | DCE team | 2014 | Describe to the general public how early detection of lung cancer can improve survival and highlight that if one is experiencing a three-week cough (or other symptoms) it is important to go see the GP |
| 58 | Press and news releases | no | DCE team | 2014 | Describe outcomes for the breast screening campaign, the bowel screening campaign and the lung cancer campaign |
| 59 | Press and news releases | no | DCE team | 2014 | Describe outcomes for the bowel and lung campaigns, and outline plans for 2015, including the two new initiatives “wee c” and #getchecked |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 60 | Press and news releases | no | DCE team | 2015 | Announce a new bowel screening test, DCE's third anniversary, highlight key outcomes and endorsements from key stakeholders |
| 61 | Press and news releases | no | DCE team | 2015 | Describe the main findings from the 3-year attitudinal tracking carried out by TNS |
| 62 | Press and news releases | no | DCE team | 2015 | Describe DCE achievements in its first three years |
| 63 | Press and news releases | no | DCE team | 2015 | Describe DCE achievements in its first three years |
| 64 | Press and news releases | no | DCE team | 2015 | Describe #getchecked and the “wee c” campaign, with supporting statements from key stakeholders |
| 65 | Press and news releases | no | DCE team | 2015 | Describe #getchecked and the “wee c” campaign, with supporting statements from key stakeholders |
| 66 | Information documents shared with stakeholders | no | DCE team | 2015 | Describe “wee c” and #getchecked to stakeholders, focusing on their rationale, key messages and available resources |
| 67 | evaluation and insight gathering reports | no | DCE team | 2015 | Explain the rationale for the bowel campaign and describe results from attitudinal tracking |
| 68 | Information documents shared with stakeholders | no | DCE team | 2015 | Describe key areas of DCE activity in the last quarter of 2014 and first quarter of 2015 (NHS Dumfries and Galloway) |
| 69 | Information documents shared with stakeholders | no | DCE team | unknown | Describe DCE-related activities in NHS Lothian |
| 70 | Information documents shared with stakeholders | no | DCE team | 2015 | Describe DCE-related activities in NHS Shetland |
| 71 | Information documents shared with stakeholders | no | DCE team | 2015 | This presentation aimed to discuss Comms plans for 2015/16, talk about wee c and #getchecked, answer questions and provide local spotlights (NHS Greater Glasgow & Clyde, NHS Grampian and NHS Forth Valley) |
| 72 | Press and news releases | no | DCE team | 2015 | Provide an update on the DCE social marketing campaigns |
| 73 | Agendas, minutes and action notes | no | DCE team | 2015 | Provide the DCE Programme Board with an update on recent social marketing activity |
| 74 | Press and news releases | yes | DCE team | 2014 | Describe latest news on the bowel cancer campaign, inform about the new wave of the lung cancer campaign, describe changes to the programme's website and plans for the future |
| 75 | Press and news releases | no | DCE team | 2016 | Describe DCE-related activities in NHS Lanarkshire while commemorating the World Cancer Day |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 76 | Agendas, minutes and action notes | no | DCE team | 2015 | Provide an update for the Programme Board, reflecting on DCE's achievements in its first three years, announce the new bowel screening test, and show key programme outputs |
| 77 | evaluation and insight gathering reports | no | TNS | 2014 | Describe the methodology for the evaluation of the symptomatic breast campaign and results (data tabulations) |
| 78 | evaluation and insight gathering reports | no | TNS | 2014 | Describe the methodology for the evaluation of the breast screening campaign and outline results (data tabulations) |
| 79 | evaluation and insight gathering reports | yes | TNS | 2015 | Describe Scottish adolescents' sun-related behaviours and tanning attitudes and assess associations with skin cancer awareness |
| 80 | evaluation and insight gathering reports | yes | TNS | 2015 | Describe the main findings from the 3-year attitudinal tracking carried out by TNS |
| 81 | evaluation and insight gathering reports | no | TNS | 2015 | Describe the methodology for the 3-year attitudinal tracking and outline results (data tabulations) |
| 82 | evaluation and insight gathering reports | no | TNS | 2015 | Describe the methodology and results for the evaluation of first wave of attitudinal tracking after DCE's first three years (data tabulations) |
| 83 | evaluation and insight gathering reports | no | TNS | 2012 | Describe the background, aims, and methodology for the attitudinal tracking, describe sample characteristics, risk behaviours, barriers and facilitators to early detection overall, for breast, bowel and lung cancers, plus provide a summary of results and present conclusions |
| 84 | evaluation and insight gathering reports | no | TNS | 2015 | Describe evaluation results from the seventh wave of the bowel screening campaign |
| 85 | evaluation and insight gathering reports | no | TNS | 2014 | Describe public spontaneous and prompted awareness of cancer symptoms and signs prior to the symptomatic breast campaign wave (Aug 2012), post-wave (Oct 2012) and in Feb 2014 |
| 86 | evaluation and insight gathering reports | no | TNS | 2012 | Describe awareness of cancer symptoms and signs before and after the priming campaign, in addition to providing information about risky behaviour (all part of the HITS survey) |
| 87 | evaluation and insight gathering reports | no | TNS | 2012 | Describe outcomes for the symptomatic breast campaign regarding reach, communication and motivation to check signs and symptoms of cancer |
| 88 | evaluation and insight gathering reports | no | TNS | 2013 | Describe the methodology for the evaluation of the breast screening campaign (Sep/ Oct 2013) using data tabulations |
| 89 | evaluation and insight gathering reports | no | TNS | 2014 | Describe population views regarding the Big C prior to the development of the wee c campaign (to inform it) |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 90 | evaluation and insight gathering reports | no | TNS | 2012 | Describe outcomes for the priming campaign regarding reach, communication and motivation |
| 91 | Use of DCE funding | no | DCE team | 2015 | Describe DCE funding allocation from 2011/2012 to 2015/2016 |
| 92 | Others | no | DCE team | 2012 | Present the outcomes of a workshop with GPs at the Deep End in Scotland, in which particular problems of early detection in deprived areas and how these could (or not) be addressed by the DCE programme |
| 93 | Others | no | DCE team | 2012 | Present the concerns raised by clinicians from across NOSCAN in respect of DCE |
| 94 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Programme Board meeting |
| 95 | Information documents shared with stakeholders | yes | DCE team | 2011 | Seek stakeholder feedback on a draft implementation plan for the DCE Programme |
| 96 | evaluation and insight gathering reports | no | DCE team | 2014 | Describe the outcomes and learning points from the primary care pilot in NHS Lothian (aiming to improve bowel and breast screening uptake) |
| 97 | Others | no | DCE team | unknown | Summarise outcomes of visits to territorial Health Boards to introduce the DCE programme |
| 98 | Information documents shared with stakeholders | no | DCE team | 2013 | Detail the rationale for choosing, and calculating the baseline for HEAT, and how data will be validated and coded separately by ISD Scotland. |
| 99 | Agendas, minutes and action notes | no | DCE team | 2011 | Outline Agenda items for a DCE Operational Subgroup meeting |
| 100 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline Agenda items for a DCE Operational Subgroup meeting |
| 101 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Operational subgroup meeting |
| 102 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Operational subgroup meeting |
| 103 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline Agenda items for a DCE Operational Subgroup meeting |
| 104 | Agendas, minutes and action notes | yes | DCE team | 2012 | Outline minutes and action notes from a DCE Operational subgroup meeting |
| 105 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Operational subgroup meeting |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 106 | Agendas, minutes and action notes | no | DCE team | 2012 | Outline minutes and action notes from a DCE Operational subgroup meeting |
| 107 | Agendas, minutes and action notes | no | DCE team | 2013 | Outline Agenda items for a DCE Operational Subgroup meeting |
| 108 | Agendas, minutes and action notes | no | DCE team | 2013 | Outline Agenda items for a DCE Operational Subgroup meeting |
| 109 | Agendas, minutes and action notes | no | DCE team | 2013 | Outline minutes and action notes from a DCE Operational subgroup meeting |
| 110 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Orkney in 2012/2013 |
| 111 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Borders in 2012/2013 |
| 112 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for all territorial Health Boards in 2012/2013 |
| 113 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Fife in 2012/2013 |
| 114 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Ayrshire and Arran in 2012/2013 |
| 115 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Forth Valley in 2012/2013 |
| 116 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Grampian in 2012/2013 |
| 117 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Greater Glasgow & Clyde in 2012/2013 |
| 118 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Highland in 2012/2013 |
| 119 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Dumfries and Galloway in 2012/2013 |
| 120 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Lanarkshire in 2012/2013 |
| 121 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Lothian in 2012/2013 |

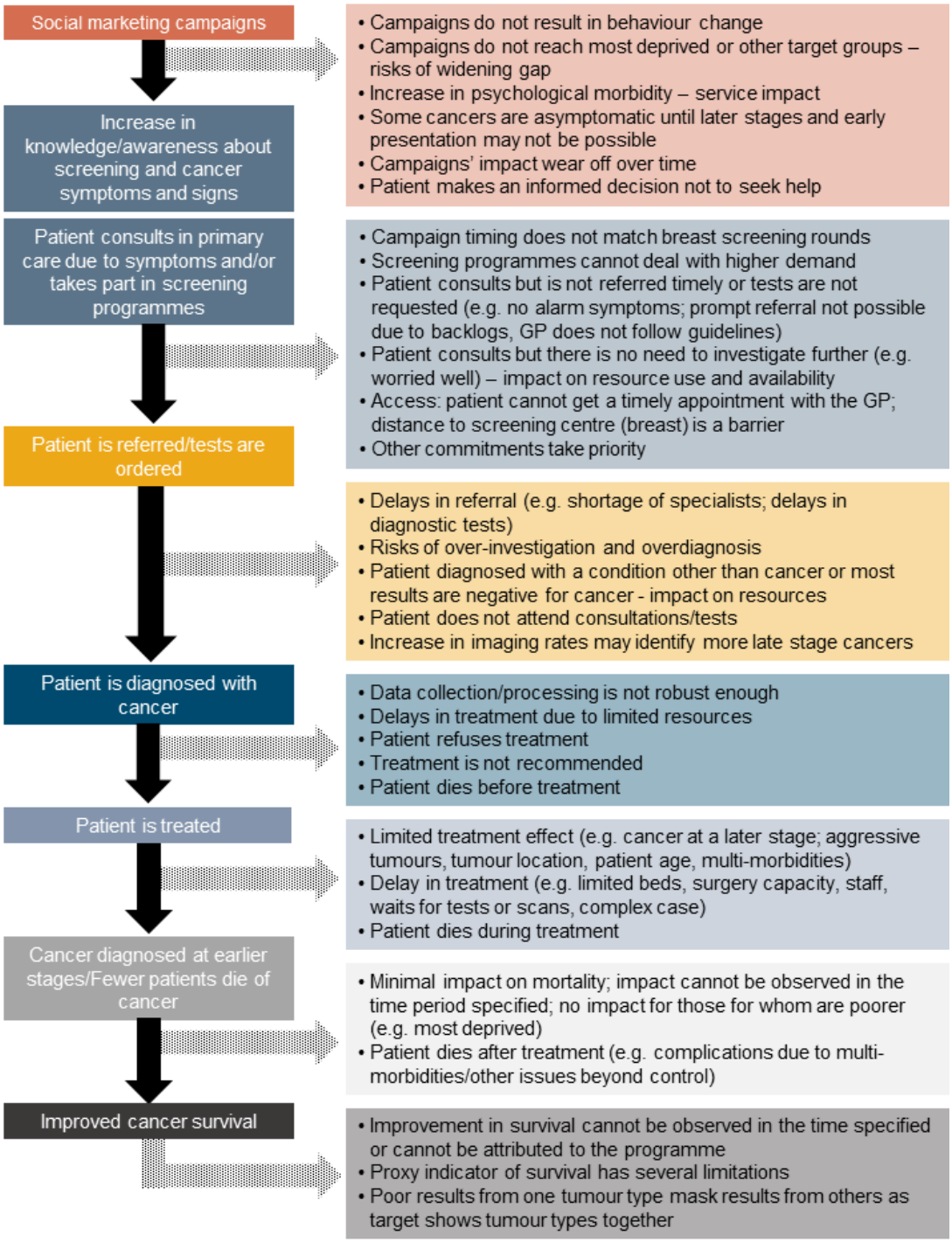
| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 122 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Shetland in 2012/2013 |
| 123 | Use of DCE funding | no | DCE team | 2013 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Tayside in 2012/2013 |
| 124 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Ayrshire and Arran in 2013/2014 |
| 125 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Borders 2013/2014 |
| 126 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Shetland in 2013/2014 |
| 127 | Use of DCE funding | no | DCE team | 2011 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for all territorial Health Boards in 2013/2014 |
| 128 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Forth Valley in 2013/2015 |
| 129 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Dumfries and Galloway in 2013/2014 |
| 130 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Grampian in 2013/2014 |
| 131 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Greater Glasgow and Clyde in 2013/2014 |
| 132 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Lanarkshire in 2013/2014 |
| 133 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Lothian in 2013/2014 |
| 134 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Tayside in 2013/2014 |
| 135 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Western Isles in 2013/2014 |
| 136 | Use of DCE funding | no | DCE team | 2014 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Orkney in 2013/2014 |
| 137 | Use of DCE funding | no | DCE team | 2016 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Ayrshire and Arran in 2015/2016 |

| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 138 | Use of DCE funding | no | DCE team | 2016 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Lanarkshire in 2015/2016 |
| 139 | Use of DCE funding | no | DCE team | 2015 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Grampian in 2014/2015 |
| 140 | Use of DCE funding | no | DCE team | 2015 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Orkney in 2014/2015 |
| 141 | Use of DCE funding | no | DCE team | 2015 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Forth Valley in 2014/2015 |
| 142 | Use of DCE funding | no | DCE team | 2016 | Describe activities, challenges, benefits, achievements and issues regarding sustainability for NHS Tayside in 2015/2016 |
| 143 | evaluation and insight gathering reports | no | the Leith Agency | 2012 | Present the qualitative research findings from the creative carried out to inform the bowel cancer campaign |
| 144 | evaluation and insight gathering reports | no | the Leith Agency | 2013 | Present the qualitative research findings from the creative carried out to inform the lung cancer campaign |
| 145 | evaluation and insight gathering reports | no | the Leith Agency | 2012 | Describe awareness of cancer symptoms and signs before and after the priming campaign, in addition to providing information about risky behaviour (all part of the HITS survey) |
| 146 | evaluation and insight gathering reports | no | the Leith Agency | 2011 | Present the qualitative research findings from the creative carried out to inform the priming campaign |
| 147 | evaluation and insight gathering reports | no | the Leith Agency | 2012 | Present the qualitative research findings from the creative carried out to inform the symptomatic breast campaign |
| 148 | evaluation and insight gathering reports | no | the Leith Agency | 2012 | Present the qualitative research findings from the creative carried out to inform the symptomatic breast campaign (public consultation) |
| 149 | evaluation and insight gathering reports | no | the Leith Agency | 2015 | Present the qualitative findings from insight and creative development research for the bowel screening campaign |
| 150 | evaluation and insight gathering reports | no | the Leith Agency | 2011 | Describe awareness of cancer symptoms and signs, of bowel and breast screening, and of risk behaviour (all part of the HITS survey) |
| 151 | evaluation and insight gathering reports | no | the Leith Agency | 2013 | Present the qualitative research findings from the consultation with lung cancer experts (to inform the lung cancer campaign) |
| 152 | evaluation and insight gathering reports | no | the Leith Agency | 2015 | Describe results from the lung cancer campaign that focused on the three-week cough |
| 153 | evaluation and insight gathering reports | no | the Leith Agency | 2011 | Describe desk research carried out to inform social marketing campaign development |

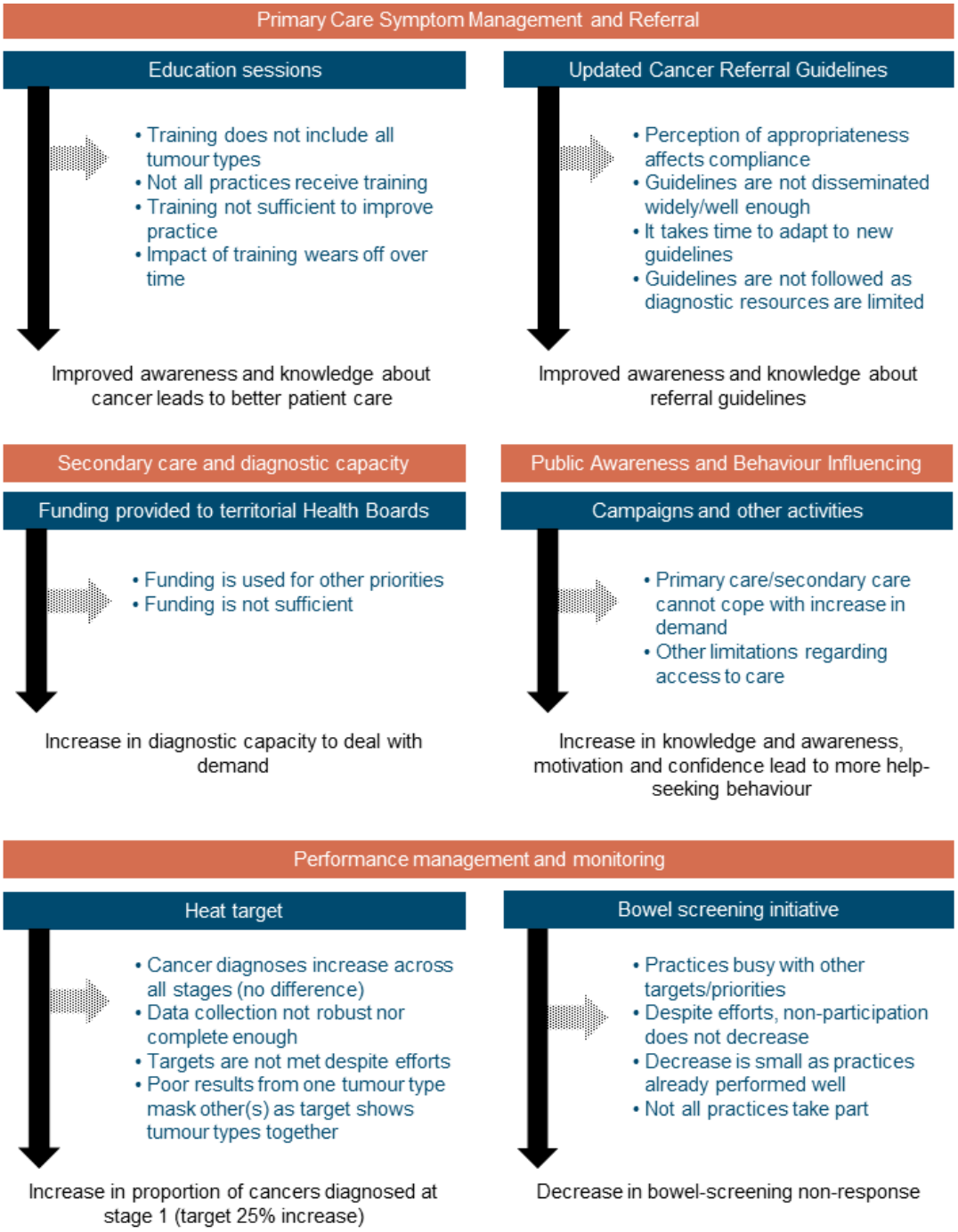
| ID | Document type | Duplicate | Source | Pub year | Purpose |
|---|---|---|---|---|---|
| 154 | Others | no | the Leith Agency | unknown | Describe the lung cancer campaign as a case study, its rationale, creative testing, implementation and outcomes |
| 155 | evaluation and insight gathering reports | no | the Leith Agency | 2011 | Present findings from insight gathering carried out with health care professionals, breast, lung and bowel cancer patients and survivors in order to inform the campaigns |
| 156 | evaluation and insight gathering reports | no | the Leith Agency | 2013 | Describe results from the priming, breast cancer and bowel cancer campaigns |
| 157 | evaluation and insight gathering reports | no | the Leith Agency | 2011 | Present findings from the professional Audience Creative Consultation testing routes for DCE campaigns |
| 158 | Others | no | the Leith Agency | unknown | Describe the symptomatic breast campaign as a case study, its rationale, creative testing, implementation and outcomes |
| 159 | Others | no | the Leith Agency | unknown | Describe the bowel screening campaign as a case study, its rationale, creative testing, implementation and outcomes |
| 160 | Information documents shared with stakeholders | no | Independent searches | 2011 | Present the final DCE implementation plan (after amendments according to the stakeholder consultation) |
| 161 | Agendas, minutes and action notes | no | Independent searches | 2013 | Outline minutes and action notes from a DCE Programme Board meeting |
| 162 | Agendas, minutes and action notes | no | Independent searches | 2014 | Outline minutes and action notes from a DCE Programme Board meeting |
| 163 | Agendas, minutes and action notes | no | Independent searches | 2014 | Outline minutes and action notes from a DCE Programme Board meeting |
| 164 | Press and news releases | no | Independent searches | 2014 | Describe updates in different territorial health boards and the partnership with Teenage Cancer Trust |
| 165 | Press and news releases | no | Independent searches | 2015 | Describe updates in different Health Boards, about campaigns and describe the partnership with CRUK for the Facilitator Programme |

# Appendix 14. DCE service utilisation plan and programme impact theory

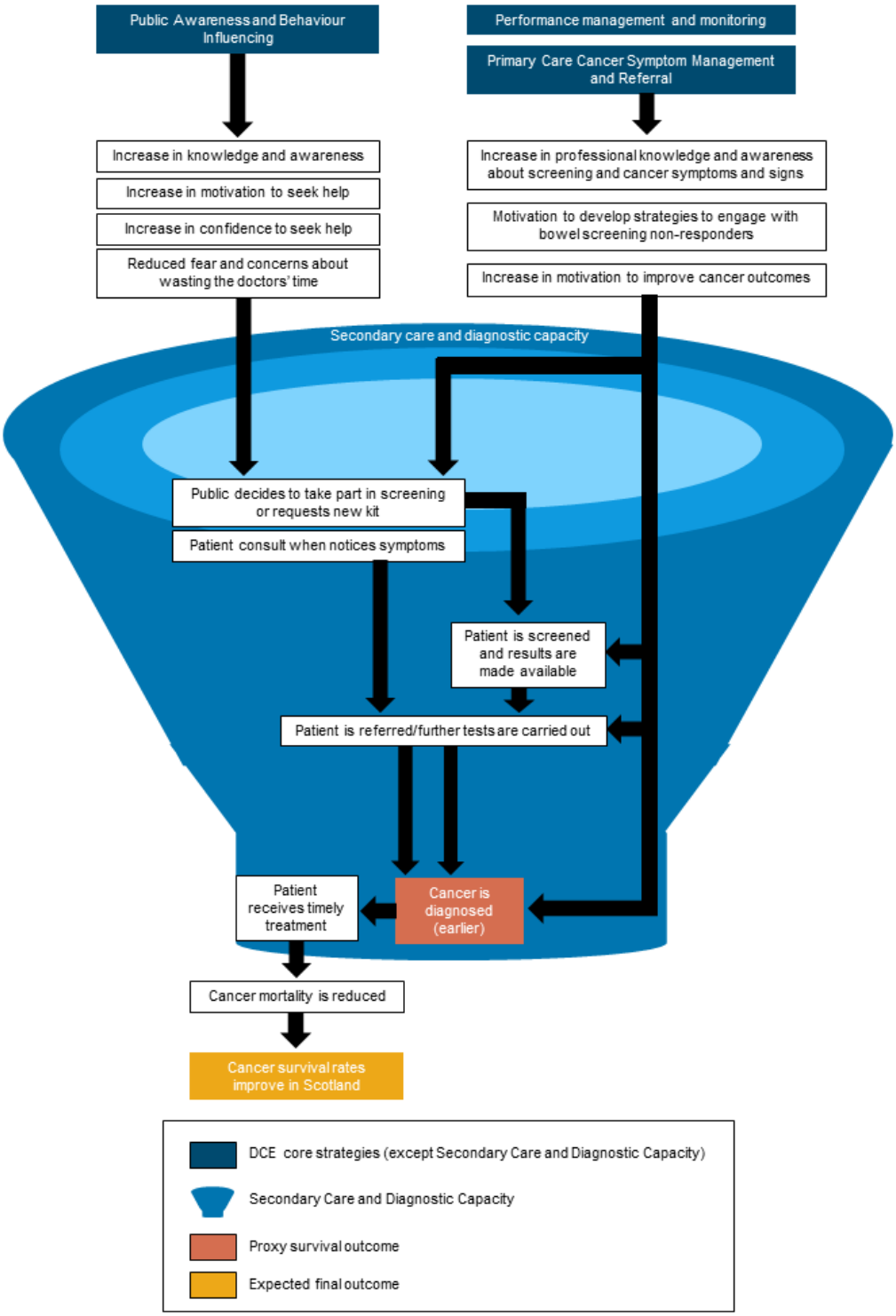
## Service utilisation plan – patient journey after campaigns



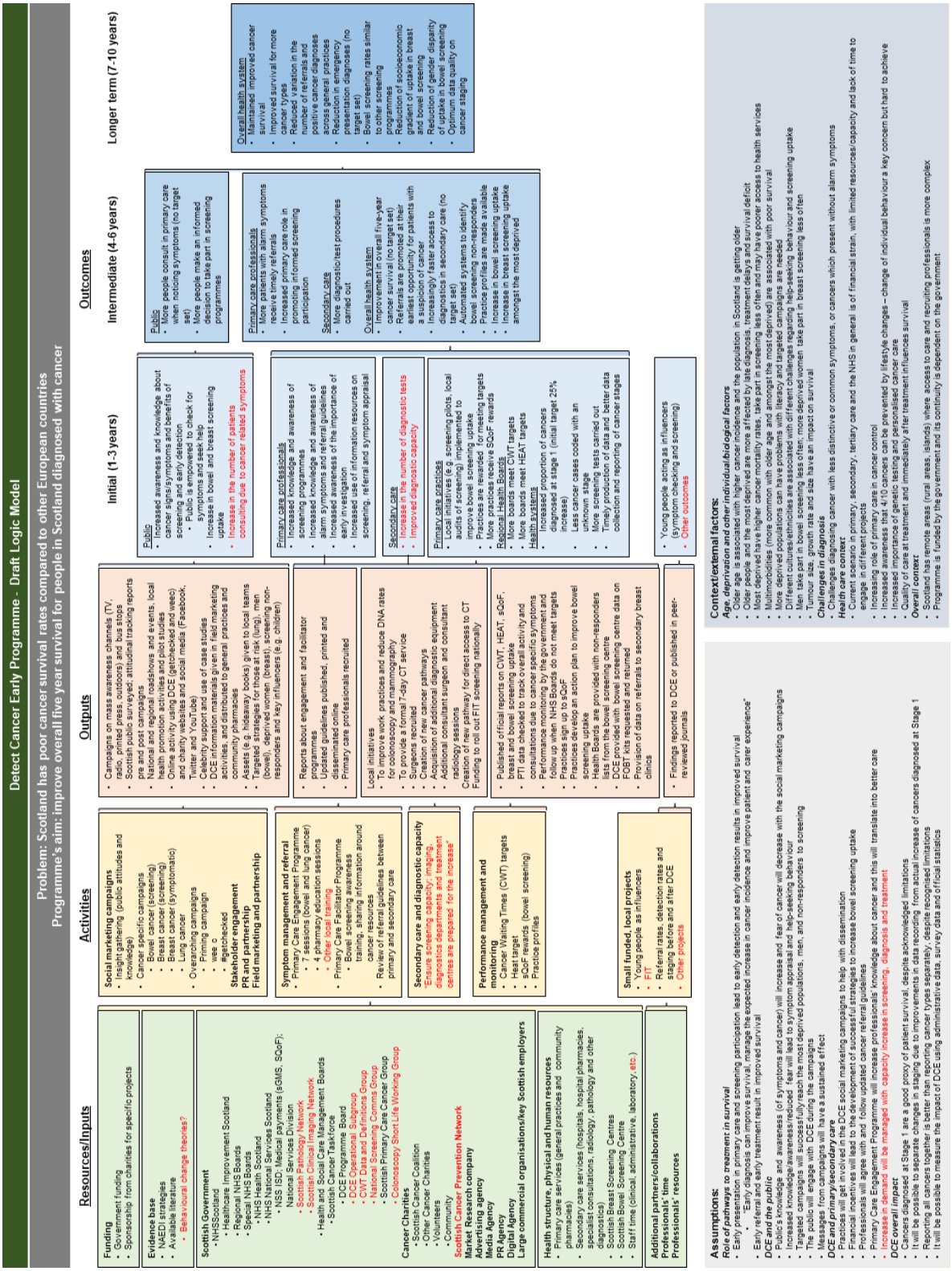
## Service utilisation plan – care provision



## Programme impact theory diagram



# Appendix 15. Draft logic model



# Appendix 16. Interview topic guide (Study 2)

*The role of government policy initiatives in promoting earlier diagnosis of cancer – what can we learn from the Detect Cancer Early (DCE) programme in Scotland?*

**Interview topic guide**
**Key stakeholders**

**The role of government initiatives in promoting earlier diagnosis of cancer**
*Development and refinement of the DCE process evaluation*

**The guide will be used in a flexible and responsive manner, allowing participants to introduce new areas for discussion. Ensure signed consent form has been received.**

**Introduction:** Thank you for agreeing to be interviewed. The aim of this interview is to learn more about the DCE programme from the perspective of a key stakeholder, to hear your views on its rationale, objectives, activities, outputs and expected outcomes. Questions will be open ended and quite broad. Firstly I will ask you some background questions (such as your role in DCE), then I will ask you about the programme itself. The logic model describing DCE which I sent you via email (I also have a larger copy here) will help to guide the discussion but I will also ask for your views on how it can be improved. All information you provide is confidential. The interview will be recorded and the transcripts will be anonymised. Please feel free to ask me any questions at any time.

## Interview questions/topics

1. Firstly could you please tell me a bit about yourself? (*ask for job title/role if needed*)
2. How did you become involved in DCE? Could you tell me about your role in it?
3. In your own words, why is a programme like DCE needed in Scotland?
4. *(Only if involved in the development of DCE)*
   a. Could you talk about that time period and your role in DCE's development? *(ask about the process of designing the programme)*
   b. At the time, were there any concerns about the way DCE was developed?
5. DCE logic model *(go through each section: input, activities, outputs, outcomes, assumptions and context; ask about missing issues or inaccuracies)*
   a. Does the diagram represent well how DCE was supposed to work? What could be changed?
   b. Did some DCE activities work better than others? Why might this be the case?
   c. Which changes could DCE bring? Which of the DCE components would bring most change? (ask about i*ndividual and system level changes)*
   d. What are the main challenges DCE faces regarding its ability to be successful? (*ask about the contextual challenges and causal assumptions if needed)*
6. If you were to evaluate DCE, what would you focus on, and why?
7. This is the initial stage of DCE's process evaluation, and I will be interviewing more stakeholders in the future. Would you be willing to be interviewed again?
8. Do you have any key person to suggest, either because of their role in DCE or their views about it?
9. Would you like to comment further on anything I asked you or comment on anything else?

**Thank the interviewee for his/her participation.**



v1.0, 15.02.2016

# Appendix 17. Theme definitions and relationships between themes

| Theme | Description |
|---|---|
| 1. DCE development and implementation | |
| 1.1 A political decision with a political imperative | Comments on how DCE was a government funded programme, with a political agenda and a strong political imperative, with specific targets and investment. Also includes views on how/why DCE was different from other government programmes. This theme is linked with "Resource allocation". |
| 1.2 Aims, drivers and influencers | Views on the purpose of DCE, its aims, drivers, and influencers (with variations across participants). This theme is linked with overall contextual themes such as "Deprivation, age and gender". |
| 1.3 An evidence-based initiative | Comments on how the programme was informed both by evidence and preliminary research carried out by DCE, especially regarding the social marketing campaigns. It also includes views on whether evidence was sufficient. |
| 1.4 Resource allocation | Descriptions of how funding was allocated and perceived challenges in assessing how it was utilised across boards. This theme is linked with "Outcome evaluation challenges". |
| 1.5 Stakeholder involvement | Descriptions of the range of stakeholders involved, their roles, input and leadership, and variation in terms of influence. This theme is linked with “Voiced Concerns and barriers” and “Belief in DCE and feedback on its activities". |
| 1.6 Voiced concerns and barriers | These refer to concerns raised by interviewees or reported by them, and the programme’s response to these concerns. This theme is linked with “Perceived impact of activities” and “NHS constraints and regional variations”. |
| 1.7 Developing relationships, systems and roles | References to newly developed IT systems and staff roles (such as the Cancer leads in each Health Board). |
| 1.8. Delays and adaptations | Reports of any unexpected delays in implementing programme components and required adaptations according to different contextual challenges. This theme is linked with “Overall contextual challenges” themes. |
| 2. Views on DCE and its components | |
| 2.1 A driver of change and other aspirations | Views on how DCE can help to promote change in behaviour and attitudes towards cancer, and potentially change service provision (becoming “a legacy”). Theme also includes acknowledgements that changes will take a long time and that DCE on its own is not capable of changing everything. This theme is linked with "Sustainability concerns" and "Cultural change or shifts". |
| 2.2 Belief in DCE and feedback on its activities | This refers to positive and negative views about the DCE programme, its aims and each of its components (such as their relevance and robustness), with a special focus on the social marketing campaigns. |

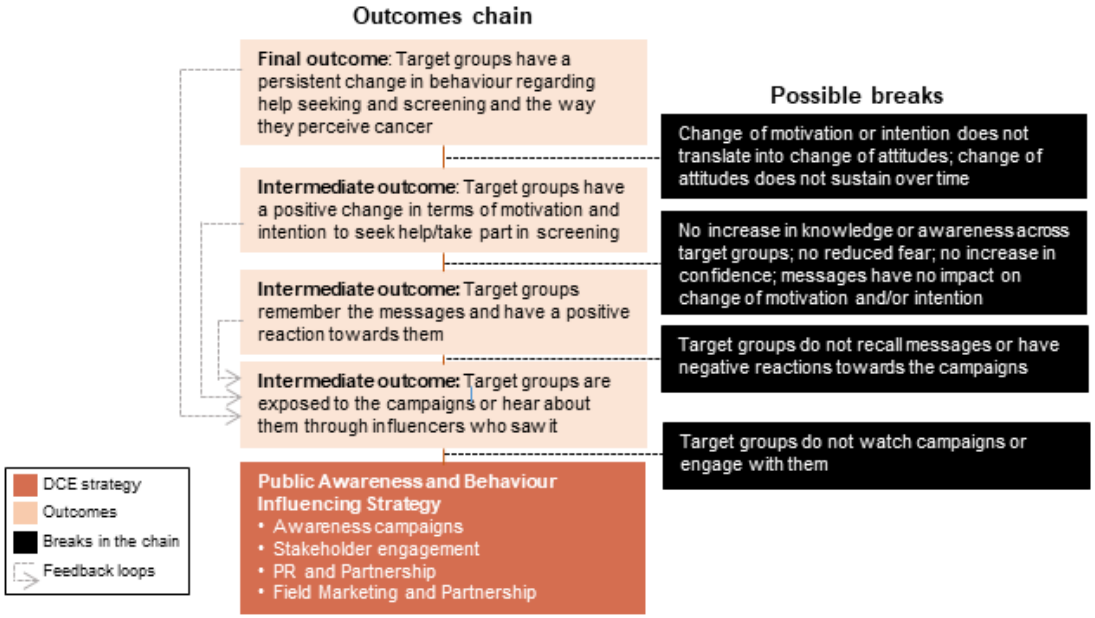
| Theme | Description |
|---|---|
| 2.3 Perceived impact of activities | Comments about perceived impact of the DCE programme and its individual activities. It also includes references to negative impact and/or unanticipated consequences. This theme is linked with “The role of targets” and “NHS constraints and regional variations". |
| 2.4 Sustainability concerns | Perspectives on the challenges to sustain DCE activities and any perceived changes brought by the programme. This is related to “Government characteristics” and “NHS constraints and regional variations”. |
| 2.5 The role of targets | Views on whether/why targets are needed, and the impact these may have on workload and staff. This is related to “A political decision with a political imperative” and “NHS constraints and regional variations". |
| 3. Logic model | |
| 3.1 Comprehensiveness and usefulness | Any views on the usefulness and comprehensiveness of the logic model. |
| 3.2 Scope, importance, links and trajectories | Remarks on how the logic model does not highlight importance of components, omits processes behind any activities, and does not show a temporal flow in terms of activities. Challenges in separating activities in boxes are also highlighted. |
| 3.3 Proposed outputs and outcomes | Any views on the applicability or likelihood of proposed outcomes. This theme also includes queries about whether proposed outcomes should be short, middle or late and any perspectives on how outcomes may vary according to different populations. This theme is linked with “Deprivation and other regional variations”. |
| 3.4 Underlying assumptions | This concept includes any remarks about the assumptions shown in the model, but also any comments on whether proposed outputs or outcomes could result from activities or whether activities would lead to DCE’s main aim to improve survival. |
| 4. Overarching contextual issues | |
| 4.1 Deprivation, age and gender | Comments on how deprivation may affect cancer outcomes and population behaviour. Also includes any comments about variation in behaviour and cancer outcomes according to population age and gender. The theme is linked with "Individual behaviour and change". |
| 4.2 Individual behaviour and change | Any views on challenges to change behaviour (“not a quick fix”) and how to transform knowledge into action. |
| 4.3 Government characteristics | Descriptions on how DCE may be influenced by the fact that it is a government-driven program (such as challenges with financing and governance requirements). This theme is linked with “A political decision with a political imperative”, “Sustainability concerns”, and “The role of targets”. |
| 4.4 NHS constraints and regional variations | Any references to NHS constraints such as working under pressure and having limited resources (especially regarding diagnostic capacity), busyness, and a “silo mentality” in primary and secondary care. The theme also includes references to regional challenges due to remoteness or the way Cancer Networks are structured. |

| Theme | Description |
|---|---|
| 4.5 Cultural change or shifts | Any references to system changes in terms of focusing more on preventative behaviour and health promotion, starting health education at schools and focusing on realistic medicine. |
| 4.6 Scottish personality | Any comments on how Scottish initiatives (including DCE) have not yet been carried out elsewhere. Also includes references to the country size (and how it can be beneficial to drive change) and the Scottish culture (such as being fatalistic about a cancer diagnosis). |
| 4.7 Tackling cancer | |
| 4.7.1 Early detection and survival | Any views on the role of early diagnosis in improving survival (and other factors which may also influence this). |
| 4.7.2 Screening and survival | Any references to screening programmes in Scotland, and the role of primary care in promoting this. |
| 4.7.3 Variation by cancer type | Any comments on how DCE approaches and/or cancer outcomes may vary by cancer type. |
| 4.7.4. Efficiency and different approaches to diagnosis | Any comments on the need to be efficient when using finite resources; also includes comments on approaches such as direct GP access to diagnostics. |
| 4.8 Role of media | Any comments on how the media can influence behaviour, and the challenges in liaising with it. |
| 5. What to evaluate | |
| 5.1 Early diagnosis, mortality, survival or surrogates | Comments on how the focus should be on “hard data”, such as survival or other surrogates (such as stage at diagnosis), or screening uptake. This concept also approaches unanticipated (hard) outcomes. |
| 5.2 Impact on primary and secondary care | Descriptions of how the focus should be on the impact the programme had on secondary care (such as how funding was used) or on the primary-secondary care interface. |
| 5.3 Improvement in knowledge and awareness | Views that the focus should be in improving knowledge/awareness for the overall population. |
| 5.4 Seeing the bigger picture | Views that a cultural change and/or change in attitudes are as important, or more important than the hard outcomes. |
| 6. Outcome evaluation challenges | |
| 6.1 Bias and confounding | Any comments on potential biases and confounding (such as having no control group or the influence of other initiatives taking place) which may influence the evaluator’s ability to demonstrate cause and effect. This theme is linked with “A political decision with a political imperative”. |
| 6.2 Unmeasurable outcomes, unclear definitions and unavailable data | Any descriptions of possible outcomes that, even when relevant, could not possibly be assessed as measurement is not possible, data are “woolly” or there are too many different definitions, or data were not collected. This is related to the theme “Seeing the bigger picture” and “Improved in knowledge and awareness”. This theme also includes any comments on how results (such as shift in attitudes or change in survival outcomes) take a long time and this may affect the ability to measure programme effectiveness. |

# Appendix 18. Outcomes chains and feedback loops for each DCE strategy

## Programme theory component 1 – Public Awareness and Behaviour Influencing Strategy

Information programme archetype (Funnell and Rogers 2011): "If people knew what to do, they would do it"




**Target population**
- General public within the age range eligible for bowel and breast screening
- Bowel and breast screening non-responders (focusing on deprived men for the former and deprived women for the latter)
- Those at risk of lung cancer
- Key influencers (e.g. children and teenagers)

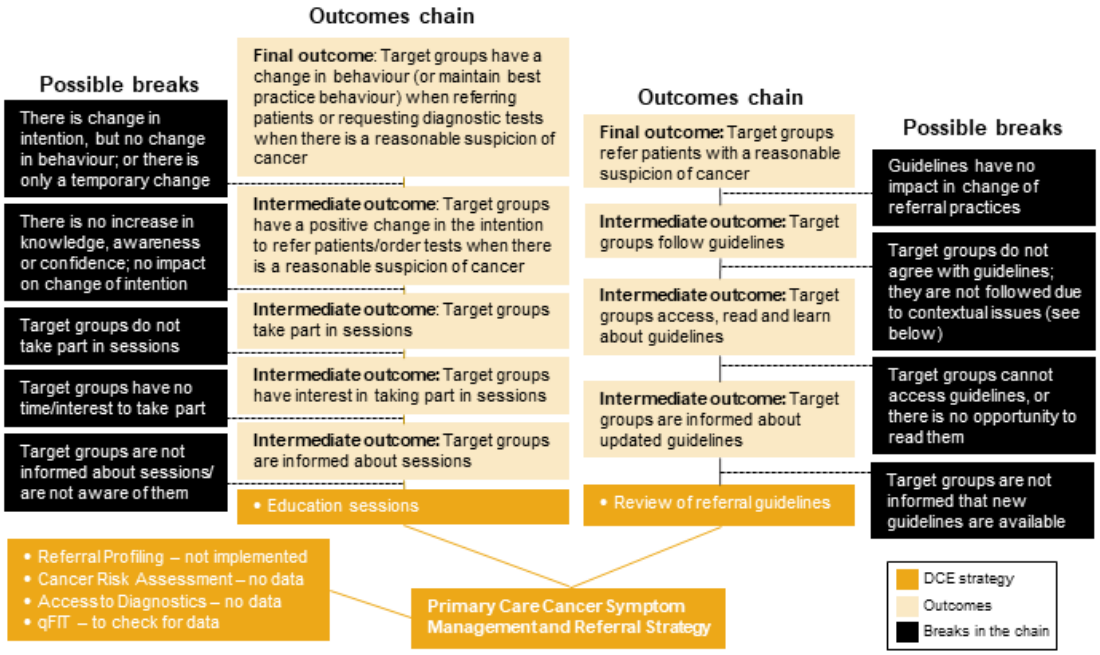
**Possible assumptions**
- Campaigns have efficient targeting and different groups engage with campaigns
- Campaigns are sufficient to generate intention to change behaviour
- Target groups agree with the rationale, content and usefulness of campaigns and these are deemed understandable and accurate

**Possible mechanisms**
- The topic interests the target population and they think it is important
- Increased knowledge, confidence or awareness or empowerment leads to change of intention and behaviour
- Influencers provide social support and social pressure that lead to change of intention and behaviour; target group trusts the influencers
- Increased knowledge reduces cancer fear and anxiety and reduced concerns about wasting the GP's time. Alternatively, fear remains but is a driver instead of a barrier
- Belief that cure is possible/early diagnosis is possible leads to change of public behaviour/intention

**Context/external influences**
- Other factors influencing behaviour (e.g. deprivation, experience, family history)
- Cultural changes irrespective of campaigns
- Influence of campaigns from charities, the media and other agents/institutions
- NHS constraints in primary/secondary care (e.g. that may limit the ability to access services)
- Limited government funding for continuing campaigns

## Programme theory component 2 – Primary Care Cancer Symptom Management and Referral Strategy

Information programme archetype (Funnell and Rogers 2011): "If people knew what to do, they would do it"



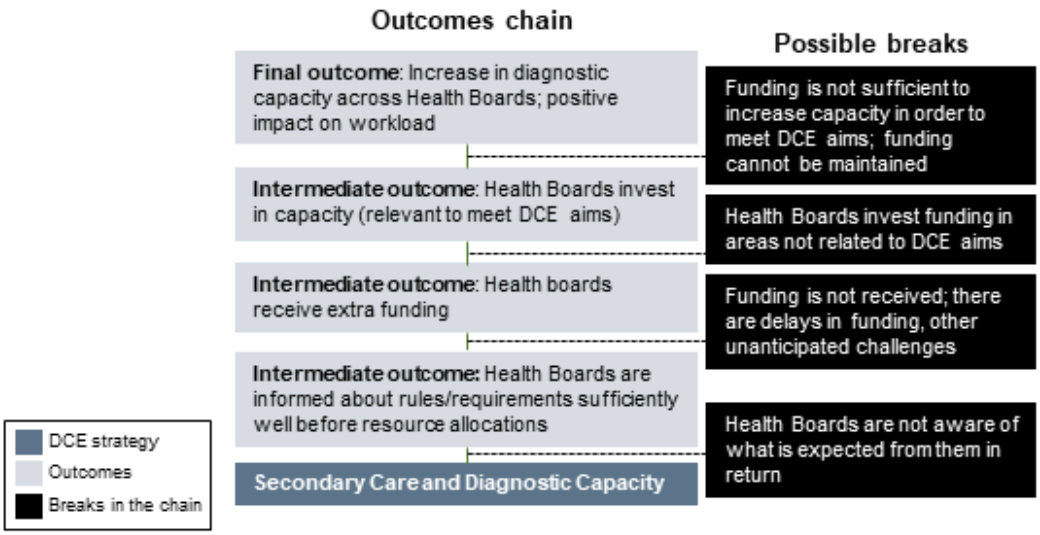

**Target population**
- GPs and other primary care staff
- Secondary care staff

**Possible assumptions**
- Training/guidelines are sufficient to generate intention to change behaviour
- Different target groups will engage with training
- Target groups agree with the rationale, content and usefulness of new guidelines/training and these are deemed understandable, efficient and accurate
- Efficient targeting and communication about training and new guidelines; efficient training
- Guidelines needed updating and professionals needed training

**Possible mechanisms**
- Target groups are confident that new guidelines will lead to positive changes
- Increase in knowledge, confidence and awareness about referral guidelines/cancer symptoms and signs results in change of intention and behaviour
- Guidelines legitimise and facilitate referrals

**Context/external influences**
- Other factors influencing professionals' behaviour (such as cultural changes)
- NHS constraints to refer patients or do tests
- Regional variations in capacity (including staff) and population needs
- Primary and secondary care interface
- Diagnosing patients is already part of professional's usual work
- Other factors influencing diagnosis through symptomatic presentation (e.g. for some cancers symptoms actually indicate advanced disease)

## Programme theory component 3 – Secondary Care and Diagnostic Capacity




**Target population**
- Secondary care
- Primary and secondary care interface

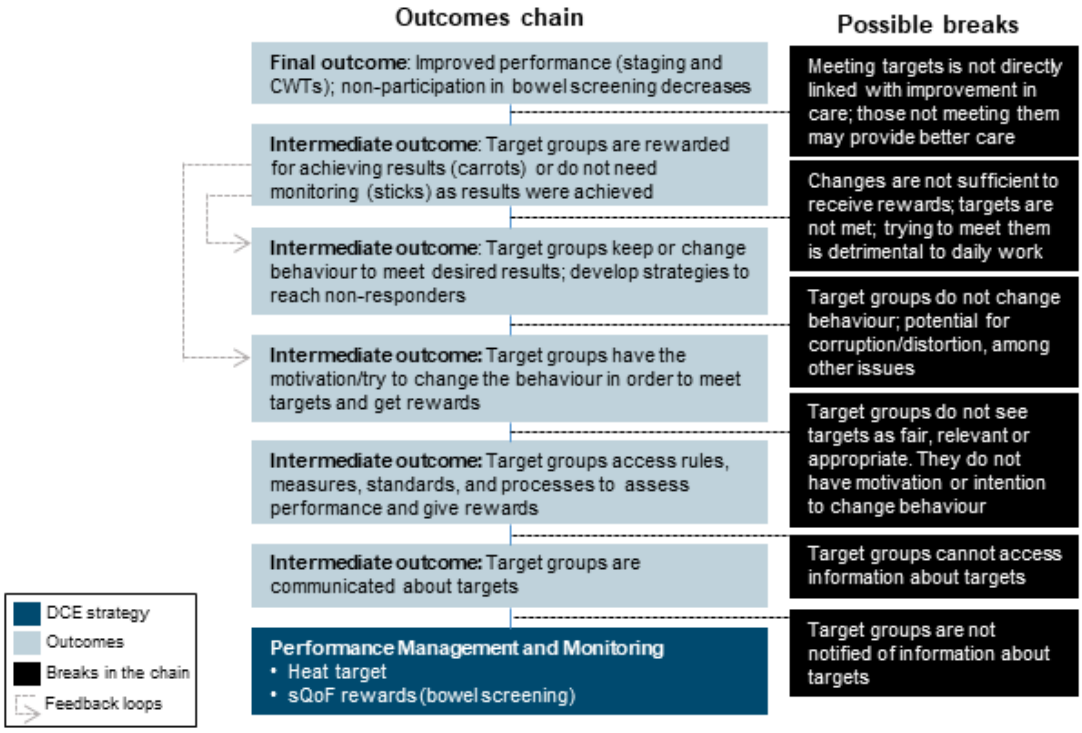
**Possible assumptions**
- Efficient targeting, efficient communication about funding, programme aims and objectives
- Health Boards have time to plan where to invest additional funding
- Funding will help to meet DCE aims and existing needs
- Funding is sufficient to increase capacity
- Additional capacity will be well-established and maintained over time
- Health boards agree that investment in capacity is a good idea
- Timely funding/resource allocation, fair distribution according to need areas of highest need

**Possible mechanisms**
- Additional funding results in more diagnostic resources (i.e. more diagnostic equipment, workforce, etc.), which results in increased diagnostic capacity
- Increased demand brought by DCE works as a driver and creates pressure to act

**Context/external influences**
- Regional variation in capacity
- Constraints in capacity
- Prior knowledge of current capacity and where to invest in order to meet DCE aims
- Variation in population needs and characteristics
- Primary and secondary care interface

## Programme theory component 4 – Performance Management and Monitoring

Carrot and sticks programme archetype (Funnell and Rogers 2011)




**Target population**
- Primary care
- Secondary care

**Possible assumptions**
- Target groups agree with the proposed rules, measures, standards, processes and rewards, which are deemed understandable, efficient, fair and reliable
- Target groups can make positive changes
- Efficient targeting, communication and monitoring
- Rewards are sufficient to generate change in behaviour
- Different Health Boards will engage in order to meet targets

**Possible mechanisms**
- Targets help to focus the mind
- Targets show where resources are needed
- Targets increase pressure to act
- Meeting targets is in line with what the professionals perceive as their role
- Rewards work as motivators to change behaviour and generate intention to act
- Rewards will have a positive impact; and this will be higher than the negative impact of having targets (stress, anxiety, demotivation, etc.)

**Context/external influences**
- NHS constraints
- Regional variations in constraints, capacity and population needs
- Primary and secondary care interface
- Systems being in place to identify non-responders
- Resources being in place to contact non-responders.

# Appendix 19. Key theories, models and frameworks in the literature

| Name | Rationale for development | Key constructs | Recommended uses |
|---|---|---|---|
| **Behaviour Change Wheel (BCW)** (1, 2) | Developed to aid intervention design, improve the evaluation process and develop theory | Synthesis of 19 frameworks of behaviour change from the literature:<br>• It incorporates a model of behaviour called COM-B (capability, opportunity, motivation and behaviour). In order to change behaviour one or more of these components need to change.<br>• Linked to the COM-B is the Theoretical Domains Framework (TDF), which synthesises constructs from behaviour change theories into 14 domains (knowledge, skills, memory, attention and decision processes, behavioural regulation, beliefs about capabilities, social/professional role and identity, optimism, beliefs about consequences, intentions, goals, reinforcement, emotion, environmental context and resources, and social influences)<br>• The BCW describes nine interventions to change behaviour (education, persuasion, incentivisation, coercion, training, restriction, environmental restructuring, modelling and enablement) and seven policies that can deliver them (regulation, guidelines, fiscal measures, environmental/social planning, communication/marketing, legislation, and service provision) | • Suitable for "real world" settings<br>• Allows for the systematic characterisation of interventions and linkage of mechanisms of action to outcomes<br>• Helpful to assess why an intervention did not meet its goal<br>• Applicable at different levels; i.e. individual, groups and different populations, organisational levels<br>• Useful so the evaluator does not think about a single level |
| **Consolidated Framework for Implementation Research (CFIR)** (3). | Arose as an attempt to consolidate many overlapping implementation theories, complete each other, while also having consistent definitions for constructs. | There are five domains:<br>• intervention characteristics (intervention source, evidence strength and quality, relative advantage, adaptability, trialability, complexity, design quality and packaging, and cost)<br>• outer setting (patient needs and resources, cosmopolitanism, peer pressure, external policy and incentives)<br>• inner setting (structural characteristics, culture, networks and communications, implementation climate and readiness)<br>• characteristics of individuals (knowledge and beliefs about the intervention, self-efficacy, individual stage of change, individual identification with the organisation, other personal attributes)<br>• process (planning, engaging, executing, reflecting and evaluating) | • The CFIR can be used during and after implementation<br>• Evaluators should choose the relevant constructs, adapt and operationalise them, consider levels to be evaluated, time points, how to measure them and assess them, and also document these processes. |

| Name | Rationale for development | Key constructs | Recommended uses |
|---|---|---|---|
| **Context and Implementation of Complex Interventions (CICI) framework** (4) | To fill a gap and be able to assess and conceptualise both context and implementation of complex interventions | Three dimensions interact with one another:<br>• context (with geographical, epidemiological, socio-cultural, socio-economic, ethical, legal and political domains)<br>• implementation (with implementation theory, process, strategies, agents and outcomes)<br>• setting (physical location where the intervention takes place) | The authors propose the use of the framework in conjunction with logic models to help undertake both reviews and health technological assessments, and understand complexity |
| **Diffusions of innovations theory** (5, 6) | Original study investigated diffusion of agricultural innovations in Iowa, USA in the 1950s (5) | Key attributes of innovations explain variation in rates of adoption (bearing in mind they are necessary, but not sufficient for adoption):<br>• Relative advantage: more effective/cost-effective innovations are more easily adopted and implemented.<br>• Compatibility: if innovations are compatible with values, norms and needs, they are more easily adopted and assimilated<br>• Complexity: simpler innovations are more easily adopted. Innovations can be more easily adopted if they can be broken down in different components and adopted incrementally<br>• Trialability: if users can experiment on an innovation it is more likely to be adopted and assimilated<br>• Observability: If intended users can see benefits, innovations are adopted and assimilated more easily<br>• Reinvention: modifiable innovations are more easily adopted<br>There are also additional attributes to adoption and assimilation such as fuzzy boundaries; risk, task issues, knowledge and support. | Wide range of fields, areas and applications. Since its development, the theory has expanded broadly, especially in the field of Public Health (5) |
| **Normalisation process theory/model** (7, 8) | To facilitate understanding of how new practices are implemented, embedded and sustained in a new social context | Implementation is a result of four generative mechanisms:<br>• coherence (practices are held together by a set of meanings and a range of competencies)<br>• cognitive participation (symbolic and real engagement of actors)<br>• collective action (actions that organise/enact a practice)<br>reflexive monitoring (constant evaluation of collective action and the results of these actions) | • To guide process evaluations, approaching implementation and sustainability of complex interventions in health care<br>• It was not designed to deal with diffusion and adoption, nor intention and volition<br>• A tool (NoMad) was developed (9) |

| Name | Rationale for development | Key constructs | Recommended uses |
|---|---|---|---|
| **Process evaluation framework** (10) | Several; including the need to understand which components in an intervention led to its success | There are seven key process evaluation components:<br>• Context: environmental issues that may affect implementation<br>• Reach: proportion of the target group taking part<br>• Dose delivered: Amount of the interventio/components delivered<br>• Dose received: Extent to which groups engaged with, interacted with/and were receptive towards the intervention<br>• Fidelity: extent to which the intervention was delivered as intended<br>• Implementation: composite score of reach, dose and fidelity<br>• Recruitment: processes to approach/attract relevant groups | • Not stated; process evaluation (overall) is useful to understand how and why interventions work |
| **RE-AIM framework** (11) | To conceptualize the public health significance of an intervention | Five factors influence the impact of an intervention:<br>• Reach (individual level of participation – to assess representativeness and whether groups in need were reached);<br>• Efficacy (both positive and negative outcomes – including behavioural and psychological);<br>• Adoption (proportion that adopts a programme),<br>• Implementation (whether the programme was delivered as intended – both at individual and programme-level);<br>• Maintenance (long-term)<br>• A "public health impact score" is calculated by combining factors | • Developed to be used with a range or designs<br>• It is compatible with systems-based thinking and public health interventions<br>• Investigation of only a few factors is not recommended |
| **Working taxonomy of implementation outcomes** (12) | Solve the pending issue in the field of implementation on how to conceptualise and measure implementation success | Based on a review of implementation outcomes from the literature, eight implementation outcomes indicate implementation success, implementation processes and intermediate outcomes:<br>• Acceptability: whether a practice is agreeable<br>• Adoption: intention or action to employ a practice<br>• Appropriateness: whether the practice is a good fit<br>• Feasibility: extent that a certain practice be used<br>• Fidelity: degree to which a practice was implemented as planned<br>• Implementation cost: cost impact of the implementation<br>• Penetration: integration of a practice<br>• Sustainability: extent to which a practice is maintained | • Outcomes should be measured and tested to shed light on mechanisms and causal relationships in implementation research |

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# Appendix 20. Additional definitions for BCW components

Evidence described in this Appendix was obtained from: Michie S, Atkins L, West R. The Behaviour Change Wheel. A guide to designing interventions: Silverback Publishing; 2014.

## The Theoretical Domains Framework (TDF)

COM-B components can be further detailed into 14 domains, which are organised into the Theoretical Domains Framework (TDF). The TDF synthesises constructs from different behaviour change theories and was developed by psychologists and implementation researchers. Its 14 domains are described below, alongside interview questions proposed by Michie et al, adapted in line with the DCE programme.

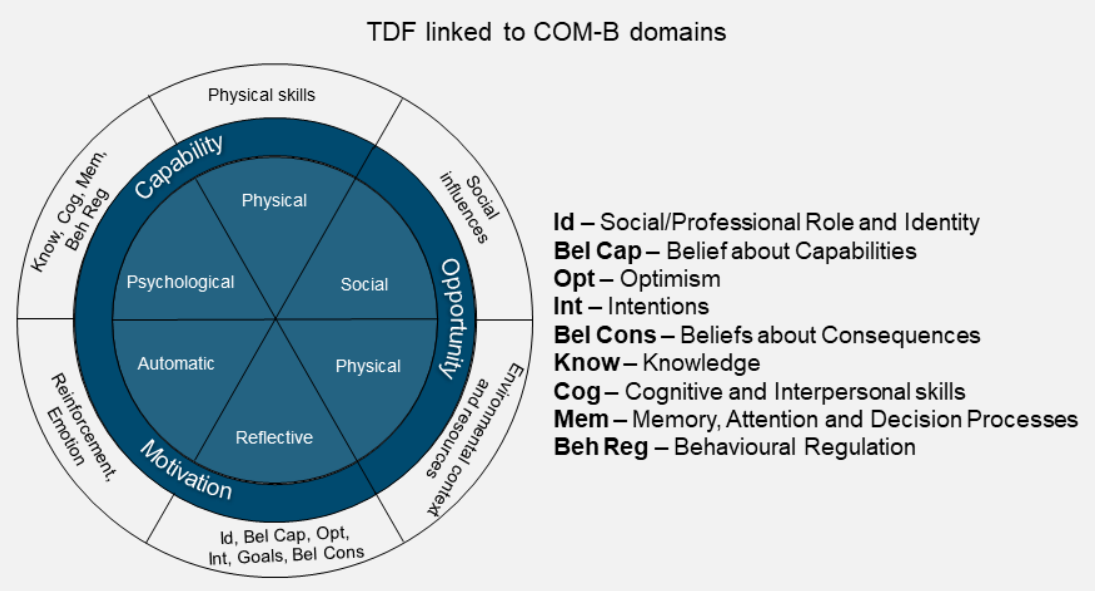
| Domain | Definition | Example of questions |
|---|---|---|
| Knowledge | Being aware of the existence of something | Do you know about the HEAT targets? |
| Skills | Ability acquired through practice | Do you know how to use the referral guidelines? |
| Memory, attention and decision processes | Ability to retain information, focus selectively on it and choose between alternatives | As a GP, is speaking to patients about non-response to bowel screening something you usually do? |
| Behavioural regulation | Managing or changing actions | Do you have systems in place to monitor whether or not QOF targets or the HEAT targets are being met? |
| Social/professional role and identity | Coherent group of behaviours and personal qualities in a social or work setting | Is being involved with DCE compatible or in conflict with your professional standards/identity? |
| Beliefs about capabilities | Acceptance of the reality of an ability/talent | How difficult or easy is it for your Health Boards to meet the HEAT targets? |
| Optimism | Confidence that things will work out or that goals will be achieved | How confident are you that you will be able to meet targets? |
| Beliefs about consequences | Acceptance of the reality of outcomes of a behaviour | What do you think will happen if the targets are not met? |
| Intentions | Conscious decision to carry out a behaviour or act in a specific way | Has the general practice made the decision to be involved in the bowel screening initiative? |
| Goals | Mental representations of outcomes that one wants to achieve | How much do you wish to meet the HEAT targets? |
| Reinforcement | Increasing the likelihood of a response by establishing a contingency between stimuli and responses | Are there incentives to meet DCE targets? |
| Emotion | Complex reactions based on experiential, behavioural and physiological components, by which someone tries to deal with a personally significant event | Do the DCE strategies evoke an emotional response? |

| Domain | Definition | Example of questions |
|---|---|---|
| Environmental context and resources | Any circumstances that encourage or discourage the development of skills, abilities, independence, social competence and other behaviours | To what extent do physical or resource factors facilitate or hinder your ability to detect cancer early? |
| Social influences | Interpersonal issues that result in change of thoughts, feelings or behaviours | To what extent do social influences facilitate or hinder engagement with the DCE programme? |

***Source: adapted from Michie et al 2014***

TDF can be used at the individual level, organisational level, community level and to identify contextual issues influencing behaviour. If it is not feasible to assess all 14 domains, COM-B can give an indication of which domains to select. The TDF can be linked to all COM-B domains (Figure A).

Figure A. TDF linked to COM-B domains




***Source: adapted from Michie et al 2014***

## Intervention functions

These refer to means by which interventions can change behaviour. Authors highlight that one particular intervention or behaviour change technique can have more than one function. The BCW describes nine intervention functions; these are shown below.

| Intervention function | Definition | Example applied to DCE |
|---|---|---|
| Education | Increase knowledge/understanding | Giving information on how to check for breast cancer symptoms |
| Persuasion | Use of communication to induce positive/negative feelings or stimulate action | Using campaign images to motivate help-seeking behaviour |
| Incentivisation | Create an expectation of a reward | Providing financial rewards for reducing bowel screening non-response |

| | | |
|---|---|---|
| Coercion | Create an expectation of punishment or cost | Explaining that Health Boards not meeting targets will be monitored |
| Training | Teach skills | Education sessions about referral guidelines |
| Restriction | Use rules to reduce the opportunity to engage in target behaviour (or increase behaviour by decreasing the opportunity to engage in competing behaviours | Not applicable to DCE |
| Environmental restructuring | Change of the physical or social context | Introducing meetings to discuss referral pathways |
| Modelling | Give an example for people to aspire or copy | Showing the celebrity Elaine C Smith having a mammogram on television |
| Enablement | Increase means or reduce barriers to increase capability (above education and training) or opportunity (beyond environmental restructuring | Distribution of desk versions of referral guidelines |

***Source: adapted from Michie et al 2014***

## Policies

When synthesising the 19 frameworks, authors identified seven policy categories that help to support and enable interventions (shown below).

| Policy category | Definition | Example applied to DCE |
|---|---|---|
| Communication/marketing | Use of media | Carrying out social marketing campaigns |
| Guidelines | Creation of documents that mandate practice | Updating referral guidelines for suspected cancer |
| Fiscal measures | Use of tax to increase or decrease financial costs | Not applicable to DCE |
| Regulation | Establishing rules or principles of behaviour | Giving feedback on performance according to targets |
| Legislation | Make/change laws | Not applicable to DCE |
| Environmental/social planning | Design/control the physical or social environment | Plans on how to invest DCE funds |
| Service provision | Service delivery | Establish early detection services |

***Source: adapted from Michie et al 2014***

## Behaviour change techniques

BCW also identified behaviour change techniques that can deliver each intervention function under the relevant policy categories. A BCT can be defined as “an active component of an intervention designed to change behaviour”. This component should be “observable, replicable an irreducible component, and an active ingredient in an intervention”. The BCT taxonomy has 93 items organised into 16 groupings by experts: goals and planning; feedback and monitoring; social support; shaping knowledge; natural consequences; comparison of behaviour; associations; repetition and substitution; comparison of outcomes; reward and threat; regulation; antecedents; identity; scheduled consequences; self-belief; and covert learning. These are not described further here as they were not adopted in the DCE evaluation, except when mapping DCE components to ensure suitability of the BCW for the programme.

# Appendix 21. DCE mapped into BCW components

| | | | | | COM-B and TDF components | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | CAPABILITY | | | | OPPORTUNITY | | MOTIVATION | | | | | | | | |
| | | | | | Phys | Psych | | | Soc | Phys | Reflective | | | | | | | Auto | |
| **DCE strategy** | **Textual description** | **Behaviour Change Techniques** | **Functions** | **Policy category** | Skills | Knowledge | Memory, attention and decision processes | Behavioural regulation | Social influences | Environmental context and resources | Beliefs about capabilities | Beliefs about consequences | Intention | Social professional role & identity | Optimism | Goals | Reinforcement | Emotions |
| **Public Awareness and Behaviour Influencing** | • Public is informed about cancer symptoms and signs; that cancer found earlier is more likely to be treated; that cancer is not what it used to be; that much can be done after lung cancer has been diagnosed; and that the GP wants to see them<br>• Public is persuaded to get checked and to attend screening<br>• Young people as influencers, family as influencers<br>• Trustworthy people give advice<br>• Public share their experience<br>• Experts give advice<br>• Campaigns aim to reduce fear and anxiety, and increase confidence | 5.1 Information about health consequences | Education | Communication/ marketing | | ■ | | | | | | | | | | | | |
| | | 5.2 Salience of consequences | Education and persuasion | | | | | | | | | ■ | | | | | | |
| | | 5.6 Information about emotional consequences | Persuasion and modelling | | | | | | | | | ■ | | | | | | |
| | | | Incentivisation, coercion and enablement | | | | | | | | | | | | | | | ■ |
| | | 6.1 Demonstration of the behaviour | Modelling and enablement | | | | | | ■ | | | | | | | | | |
| | | 7.1 Prompts/cues | Environmental restructuring | Environment/ social planning | | | | | | ■ | | | | | | | | |
| | | 8.3 Habit formation | Training | Regulation | ■ | | | | | | | | | | | | | |
| | | 8.6 Generalisation of a target behaviour | Training | Regulation | ■ | | | | | | | | | | | | | |
| | | 9.1 Credible source | Persuasion and modelling | Communication/ marketing | | | | | | | | ■ | | | | | | |
| | | 15.1 Verbal persuasion about capability | Persuasion, modelling and enablement | | | | | | | | ■ | | | | ■ | | | |
| | | 16.3 Vicarious consequences | Persuasion and modelling | | | | | | | | | ■ | | | | | | |
| | | | Modelling and enablement | | | | | | ■ | | | | | | | | | |
| **Primary Care Cancer Symptom Management and Referral** | Professionals receive training about cancer symptoms and signs | 4.1 Instruction on how to perform a behaviour | Education | Guidelines, regulation | | ■ | | | | | | | | | | | | |
| | Urgent referral guidelines for suspected cancer are revised and disseminated | 7.1 Prompts/cues | Environmental restructuring and enablement | Guidelines, service provision | | | | | | ■ | | | | | | | | |
| **Secondary Care and Diagnostic Capacity** | Health Boards receive funding to invest in diagnostic capacity and related services | 12.1 Restructuring the physical environment | Environmental restructuring and enablement | Environment/ social planning & service provision | | | | | | ■ | | | | | | | | |
| **Performance Management and Monitoring** | • Heat target: increase the proportion of cancers diagnosed at Stage 1 by 25%<br>• Bowel screening initiative: financial rewards for reduction in bowel screening non-participation | 2.2 Feedback on behaviour | Education | Regulation | | ■ | | | | | | | | | | | | |
| | | 5.3 Information about social and environmental consequences | Education, persuasion and modelling | Regulation | | | | | | | | ■ | | | | | | |
| | | 6.2 Social comparison | Restriction and environmental restructuring | Regulation | | | | | ■ | | | | | | | | | |
| | | 7.1 Prompts/cues | Environmental restructuring and enablement | Regulation & service provision | | | | | | ■ | | | | | | | | |
| | | 10.1 Material incentive (behaviour) | Incentivisation, coercion | Regulation & service provision | | | | | | | | | | | | | ■ | |
| | | 10.8 Incentive (outcome) | Incentivisation, coercion | Regulation & service provision | | | | | | | | | | | | | ■ | |
| | | 10.10 Reward (outcome) | Incentivisation, coercion | Regulation & service provision | | | | | | | | | | | | | ■ | |

Abbreviations: DCE: Detect Cancer Early; Phys: physical; Psych: psychological; Soc: social; Phys: physical; Auto: automatic. Source: table adapted from Michie S, Atkins L, West R. The Behaviour Change Wheel. A guide to designing interventions: Silverback Publishing; 2014

# Appendix 22. Ethical approval (Study 2)

THE UNIVERSITY *of* EDINBURGH

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04 April 2016

Mrs Natalia Calanzani

Dear Natalia

**Re: The role of government policy initiatives in promoting earlier diagnosis of cancer – what can we learn from the Detect Cancer Early programme in Scotland**

Thank you for resubmitting your documentation with the revisions that were requested/suggested by the CPHS ethics committee/ reviewer. The revisions have been judged satisfactory. I am therefore pleased to be able to inform you that the above study has been granted ethical approval.

Please be aware that the ethical approval hereby granted is in respect of the protocol and methods as described in the documents that have been submitted to the committee (with revised and resubmitted documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check whether this means your level 2 application form needs to be revised, and submit to the committee (via me), any documents that have been revised (study materials/protocol/level 2 form), using tracked changes. You should make clear in your covering email whether:

(i) you are requesting ethical review of a study amendment; or

(ii) you are not sure whether such is needed and, in the first instance, would like the committee's opinion on whether a formal approval is needed of the amended design/methods.

We agree the item 8 is a good addition to the consent form. However, while the current wording of item 8 is not unacceptable, in our view it would be clearer if reworded to "*I understand that, in order to preserve my anonymity, my name and any other identifiable features (such as post, role or organisation) will not be part of any data repository, quotes or extracts.*" If you decide to make this change, solely, it has approval 'in advance'. However, please be sure return the consent form thus revised, to us, prior to commencing data collection, referring to this letter and stating that the revised consent form it is to be substituted for the current version in our records.

Yours sincerely

Diane White

**Diane White**
**Ethics Review Group Administrator**

Usher Institute
Population Health Sciences & Informatics

# Appendix 23. Level 1 Ethics Form (outcome evaluation)

**University of Edinburgh,**
**Usher Institute of Population Health Sciences and Informatics**
**RESEARCH ETHICS SUBGROUP**

**Self-Audit Checklist for Level 1 Ethical Review for PGR projects**

See **Intra** website for further information: http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php

**NOTE to student:** *Completion of this form should be under the **oversight** of your supervisor. A good strategy would be to complete a draft as best you can, then discuss with your supervisor before completing a final copy for your supervisor to sign.*

***Proposed Project** (State research question and topic area, and briefly describe method/ data. Specify also countries in which data will be collected.):*
This study comprises an outcome evaluation of a Scottish Government programme aiming to improve cancer survival (the Detect Cancer Early Programme or DCE), which will comprise secondary analyses of:
1) policy documents (published and grey literature): evaluation reports, internal activity reports, agendas, minutes, press and news releases, information documents, performance management reports, publications in journals, information leaflets for patients, cancer referral guidelines
2) official health intelligence data available in the public domain: these refer to performance management reports, reports on bowel and breast screening uptake, customised reports assessing impact of the DCE programme
3) anonymised data on requests for bowel screening kits (from Feb 2011 to Jan 2016) to be provided by the Scottish Bowel Screening Centre: with the date 1) replacement kits were issued; 2) kits were returned to the screening centre, and 3) screening results were available.

No personal data (i.e. information that relates to an identified or identifiable individual, directly or indirectly) will be analysed; all documents will contain only truly anonymous data and therefore the Data Protection Act will not apply. Findings from documents will be summarised in text and tables. When data allows, charts and tables will be developed to show trends over time. Likewise, descriptive statistics (N(%) and percentage changes over time) will be calculated and reported whenever possible. Textual narratives will also be used.

**1. Bringing the University into disrepute**

*Is there any aspect of the proposed research which might bring the University into disrepute?* YES/(NO)

**2. Data protection and consent**

*Are there any issues of DATA PROTECTION or CONSENT which are NOT adequately dealt with via established procedures?* YES/(NO)

These include well-established sets of undertakings. For example, a 'No' answer is justified *only if*:

(a) There is compliance with the University of Edinburgh's Data Protection procedures (see www.recordsmanagement.ed.ac.uk);

(b) Respondents give consent regarding the collection, storage and, if appropriate, archiving and destruction of data;

(c) Identifying information (eg consent forms) is held separately from data;

(d) There is Caldicott Guardian approval for (or approval will be obtained prior to) obtaining/ analysing NHS patient-data.

(e) There are no other special issues arising about confidentiality/consent.

**3. Study participants**

*a) Will a study researcher be in direct contact with participants to collect data, whether face-to-face, or by telephone, electronic means or post, or by observation? (eg interviews, focus groups, questionnaires, assessments)* YES/(NO)

*b)* **Answer this only if qu. 3 above = 'YES':**
*In ethical terms, could any participants in the research be considered to be '**vulnerable**'?*
*e.g. children & young people under age of 16, people who are in custody or care (incl. school), a marginalised/stigmatised group*
Please tick one: 'vulnerable' ☐ not 'vulnerable' ☒

**4. Moral issues and Researcher/Institutional Conflicts of Interest**

*Are there any SPECIAL MORAL ISSUES/CONFLICTS OF INTEREST?* YES/(NO)

(a) An example of conflict of interest for a researcher would be a financial or non-financial benefit for him/herself or for a relative of friend.

(b) Particular moral issues or concerns could arise, for example where the purposes of research are concealed, where respondents are unable to provide informed consent, or where research findings could impinge negatively/ differentially upon the interests of participants.

(c) Where there is a dual relationship between researcher and participant (eg where research is undertaken by practitioners so that the participant might be unclear as to the distinction between 'care' and research)

**5. Protection of research subject confidentiality**

*Are there any issues of CONFIDENTIALITY which are NOT adequately handled by normal tenets of confidentiality for academic research?* YES/(NO)

These include well-established sets of undertakings that should be agreed with collaborating and participating individuals/organisations. For example, a 'No' answer is justified *only if*:

(a) There will be no attribution of individual responses;

(b) Individuals (and, where appropriate, organisations) are anonymised in stored data, publications and presentation;

(c) There has been specific agreement with respondents regarding feedback to collaborators and publication.

**6. Potential physical or psychological harm, discomfort or stress**

(a) Is there a FORSEEABLE POTENTIAL for PSYCHOLOGICAL HARM or STRESS for participants? YES/(NO)

(b) Is there a FORSEEABLE POTENTIAL for PHYSICAL HARM or DISCOMFORT for participants? YES/(NO)

(c) Is there a FORSEEABLE RISK to the researcher? YES/(NO)

*Examples of issues/ topics that have the potential to cause psychological harm, discomfort or distress and should lead you to answer 'yes' to this question include, but are not limited to:*

*relationship breakdown; bullying; bereavement; mental health difficulties; trauma / PTSD; violence or sexual violence; physical, sexual or emotional abuse in either children or adults.*

**7. Duty to disseminate research findings**

*Are there issues which will prevent all relevant stakeholders* having access to a clear, understandable and accurate summary of the research findings if they wish?* YES/(NO)

** If, and only if, you answered 'yes' to 3 above, 'stakeholders' includes the participants in the research*

---

**Overall assessment**

- If every answer above is a definite NO, the self-audit has been conducted and confirms the ***ABSENCE OF REASONABLY FORESEEABLE ETHICAL RISKS*** – *please tick box* ✓

  *This means that regarding this study, as currently self-audited, no further ethical review actions are required within Usher. However, if in the coming weeks/months there is any change to the research plan envisaged now (and outlined above), the study should be **re-audited** against a Level 1 form, because it may be that the change made negates the absence of ethical risks signed off here.*

  Two copies of this form should be taken for inclusion in the final dissertation/thesis and **the original should be returned to Usher Ethics admin –** usher.ethics@ed.ac.uk

  **Receipt of this form will be acknowledged, but no formal letter of approval can be/will be sent.** *If some formal letter is required for a funder or collaborator, please be sure to ask in your covering email, and we will send a form of words explaining the self-audit process.*

- If one or more answers are YES, then risks have been identified and prior to commencing any data collection **formal ethical review** is required - either:
  - ~ by NHS REC (NB a copy of ethics application and decision letter, and this level 1 form, must be sent to Usher Ethics usher.ethics@ed.ac.uk); or
  - ~ if not to be formally reviewed by NHS REC, then Usher level 2/3 ethical review required. *[If either 4 is 'yes' or 3b is 'vulnerable' then it is possible level 3 review is required.]*

| Natalia Monteiro Calanzani | Christine Campbell |
|---|---|
| Student Name | Supervisor Name |
| Natalia Monteiro Calanzani | Christine Campbell |
| Student Signature | Supervisor Signature * |

*** NOTE to supervisor:** *The Usher Ethics Subgroup will not check this form (the light touch Level 1 form means we have insufficient detail to do so). By counter-signing this check-list as truly warranting all 'No' answers, **you** are taking responsibility, on behalf of Usher and UoE, that the research proposed truly poses no potential ethical risks. Therefore, if there is any doubt on any issue, it would be a wise precaution to mark it as 'uncertain' and contact the Ethics Subgroup as to whether a level 2 form might be required as well. (See Intra Ethics website – URL at top of form)* *28 Jan 2017*

# Appendix 24. Interview topic guide (Study 3)

*The role of health system level initiatives in promoting the earlier diagnosis of cancer– what can we learn from the Detect Cancer Early (DCE) programme in Scotland?*

## Interview topic guide
## Professionals working in primary and secondary care

## Process evaluation of the DCE Programme

**The guide will be used in a flexible and responsive manner, allowing participants to introduce new areas for discussion. Ensure signed consent form has been received.**

**Introduction:** Thank you for agreeing to be interviewed. This interview is part of a process evaluation of DCE. We are particularly interested in processes and changes from 2011 until 2015. Firstly, I will ask you to tell me a bit about yourself and your involvement with DCE, then I will ask you specific questions about the programme and about how it may have influenced your work. All information you provide is confidential. The interview will be recorded and the transcripts will be anonymised. Please feel free to ask me any questions at any time.

### Interview questions/topics

10. Ask the participant to tell you a bit about himself/herself and their level of involvement with DCE (*ask for job role and experience*)
11. Ask about the first time they heard about DCE, their initial views about it and whether these changed over time *(prompts: information on communicating requirements/strategies*) (A1, A2, M1)
12. Ask for their views on DCE aims and outcomes (**mention them**) *(prompts: how confident they were about meeting aims, and why they think some aims were met/not met; unanticipated outcomes)* (A1)
13. Ask for their views on whether the programme made a difference *(e.g. what would have happened if there was no DCE?)* and on any noticeable barriers/facilitators (*such as rural/urban differences*) (A1)
14. Ask (**health care professionals only***)* whether they noticed an increase in patients worried about possible cancer *(*prompt for whether *patients mentioned the social marketing campaigns)*
15. Ask about what changed in their daily work because of DCE, and whether any adaptations were needed *(prompt: whether they though their role in the programme was appropriate)* (A4)
16. Ask whether DCE estimates on impact on workload were accurate *(think of each of the strategies; prompt: was DCE a driver for action? Ask for their views on who carried the greatest workload)* (A1, M3)
17. Ask whether there were any challenges to meet targets, follow guidelines, attend sessions or meet demand after campaigns *(prompt: ask for their views on the role of performance targets)* (M4)
18. Ask about the level of resources available for what they were required to do *(think about human and financial resources, equipment, time, and knowledge – prompt: were resources sufficient?)* (A3, M2)
19. Ask about any other external factors influencing implementation and DCE's success

**Thank the interviewee for his/her participation and ask if they would like to comment on anything you had asked – or anything else.**
**Finally, ask whether they would like to receive a summary of the study results. If so, make a note for future reference.**



v1.0, 13.10.2017

# Appendix 25. Questionnaire audit trail

| Survey questions | Source, constructs, theory |
|---|---|
| Q1. Please choose ONE option | New – informed by interviews and pre-testing |
| Q2. Informed consent. Please choose one option | N/A |
| Q3. Were you informed about the DCE programme before it was implemented in 2012? | Adapted from (1). Implementation outcome: Reach and communication |
| Q4. Were you involved in developing or refining DCE or any of its strategies? | New – informed by interviews. Implementation outcome: Reach and communication |
| Q6.1a. DCE was appropriate to promote early detection | New – informed by interviews Implementation outcome: appropriateness |
| Q6.2.a The benefits brought by DCE outweighed the time and effort required to work towards its aims | Adapted from (1). Implementation outcome: acceptability |
| Q7.1.a It was part of my job to be involved in DCE | Adapted from. (2, 3). COM-B Component: Reflective Motivation. TDF domain: Social/Professional Role & Identity |
| Q7.2.a I had flexibility to make changes in order to meet DCE aims | New – informed by interviews. Implementation outcomes: feasibility and adaptability |
| Q7.3.a There was enough time to engage with DCE and its strategies | Adapted from (1). Implementation outcome: appropriateness |
| Q8 Did the DCE programme increase demand for the services you provided to patients? | New – informed by interviews. COM-B construct: automatic motivation (filter for next question) |
| Q9 If you said yes to the question above, did the increased demand drive the development of local initiatives to detect cancer early? | New – informed by interviews. COM-B construct: automatic motivation |
| Q11.1.a I support continuation of DCE | Adapted from (1). Implementation outcome: sustainability |
| Q11.1.b My local team supports continuation of DCE | Adapted from (1). Implementation outcome: sustainability |
| Q13, Q18, Q22, Q27, Q31, Q35 | New – filter questions informed by guidance on questionnaire development |
| Q14 Were you informed about the DCE campaigns before they were launched? | Adapted from (1). Implementation outcome: Reach and communication |
| Q15.1.a Public awareness campaigns were an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q16 Did this strategy increase demand for the services you provided to patients? | New – informed by interviews. COM-B construct: automatic motivation (filter for open-ended comments) |

| Survey questions | Source, constructs, theory |
|---|---|
| Q19 Were you informed about the education sessions before they commenced? | Adapted from (1). Implementation outcome: Reach and communication |
| Q20.1.a The education sessions were an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q20.2.a It was difficult to integrate the education sessions with my usual work | New – informed by interviews. COM-B construct: reflective motivation |
| Q20.3.a I had enough time to attend the education sessions | Adapted from (1). Implementation outcome: appropriateness |
| Q23 Were you informed about the work being carried out to update the guidelines before they were published? | Adapted from (1). Implementation outcome: Reach and communication |
| Q24.1.a The updated guidelines were an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q25 Did the updated referral guidelines increase demand for the services you provided to patients? | New – informed by interviews. COM-B construct: automatic motivation (filter for open-ended comments) |
| Q28 Were you informed about the additional funding before it became available? | Adapted from (1). Implementation outcome: Reach and communication |
| Q29.1.a Providing extra funding was an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q29.2.a I was confident that my team would be able to manage demand for screening and diagnostics when I was informed about the funding | Adapted from (2-4). COM-B construct: Reflective motivation. TDF domain: Belief about capabilities |
| Q29.3.a We had enough time to plan how to use the funding | Adapted from (1). Implementation outcome: appropriateness |
| Q29.4.a Primary and secondary care communicated well with each other when planning how to use the funding | New – informed by interviews. Implementation outcome: Reach and communication |
| Q29.5.a Additional funding resulted in more equipment for diagnosis | New: informed by interviews. COM-B construct: Physical opportunity. TDF domain: Environmental context and resources |
| Q29.6.a Additional funding resulted in more workforce for diagnosis | New: informed by interviews. COM-B construct: Physical opportunity. TDF domain: Environmental context and resources |
| Q32 Were you informed about the HEAT targets before they were launched? | Adapted from (1). Implementation outcome: Reach and communication |
| Q33.1.a HEAT targets were an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q33.2.a I was confident in my ability to meet HEAT targets | Adapted from (2-4). COM-B construct: Reflective motivation. TDF domain: Belief about capabilities |

| Survey questions | Source, constructs, theory |
|---|---|
| Q33.3.a It was difficult to integrate meeting HEAT targets with my usual work | New – informed by interviews. COM-B construct: reflective motivation |
| Q33.4.a HEAT targets pressured our team to act | New – informed by interviews. COM-B constructs: reflective motivation and automatic motivation |
| Q33.5.a HEAT targets worked as a reminder for where our efforts should be focused | New – informed by interviews. COM-B constructs: reflective motivation and automatic motivation |
| Q36 Were you informed about the bowel screening initiative before it was launched? | Adapted from (1). Implementation outcome: Reach and communication |
| Q37.1.a The bowel screening initiative was an appropriate strategy to promote early detection | New – informed by interviews. Implementation outcome: appropriateness |
| Q37.2.a I was confident in my ability to be awarded the QOF points | Adapted from (2-4). COM-B construct: Reflective motivation. TDF domain: Belief about capabilities |
| Q37.3.a It was difficult to integrate the bowel screening initiative with my usual work | New – informed by interviews. COM-B construct: reflective motivation |
| Q37.4.a My team had enough time to reach non- responders to bowel screening | Adapted from (1). Implementation outcome: appropriateness |
| Q37.5.a The bowel screening initiative pressured our team to act | New – informed by interviews. COM-B constructs: reflective motivation and automatic motivation |
| Q37.6.a The bowel screening initiative worked as a reminder for where our efforts should be focused | New – informed by interviews. COM-B constructs: reflective motivation and automatic motivation |
| Q38 Did the bowel screening initiative increase demand for the services you provided to patients? | New – informed by interviews. COM-B construct: automatic motivation (filter for open-ended comments) |
| Q40 Would you describe yourself as: | Informed by the European Social Survey questionnaire (5)<br>Question needed to understand the participants' profile and estimate whether sample is representative |
| Q41 In what year were you born? | Informed by the European Social Survey questionnaire (5); recoded into age groups as per official ISD Scotland publications<br>Question needed to understand the participants' profile and estimate whether sample is representative |
| Q42 What was your profession from 2011 until 2015? You can tick more than one answer or choose "Other" if appropriate. | Questions on profession informed by interviews and categories from the National NHS Staff Survey (6); other questions informed by interviews |
| Q43 Does your work focus on a specific cancer type (e.g. breast, lung, bowel cancer)? | |

| Survey questions | Source, constructs, theory |
|---|---|
| Q44 Still thinking of the 2011-2015 period, please write down the years DCE was relevant to your work. For example, from 2012 to 2014. | Question needed to allow for group comparisons and understand whether views on the programme differ across stakeholders with different characteristics |
| Q45 In which territorial Health Board do you work? You can tick more than one answer or choose "Other" if appropriate. | Question created by listing all Health Boards in Scotland and adding "Whole of Scotland" for those working at a national level<br>Question needed to understand the participants' profile |
| Q46 Which best describes the area where you work? | Categories the same as used by Official Urban/Rural Classification from the Scottish Government (7)<br>Question needed to understand the participants' profile |
| Q47 Which best describes your workplace? You can tick more than one answer or choose "Other" if appropriate. | Created with information obtained from interviews<br>Question needed to understand the participants' profile and estimate whether sample is representative |
| Q48. If you wish, please use this space to write your views about what worked well and what did not work so well in the programme. | General feedback question – informed by interviews |
| Q49 If you wish, please let us know your views on barriers/facilitators to DCE success. | Question on barriers and facilitators (one of the process evaluation questions) – created with information obtained from interviews |
| Q5, Q6.2.a, Q10, Q12, Q14.a, Q17, Q19.a, Q21, Q23.a, Q26, Q28.a, Q30, Q32.a, Q34, Q36.a, Q39, Q50 | General feedback questions – informed by guidance on designing questionnaires (described on Chapter 6) |

***References: 1.Steckler A, Linnan L. Process Evaluation for Public Health Interventions and Research. San Francisco, California: Wiley; 2002. 2.Huijg JM, Gebhardt WA, Crone MR, et al. Discriminant content validity of a theoretical domains framework questionnaire for use in implementation research. Implement Sci. 2014;9(1):11. 3.Huijg JM, Gebhardt WA, Dusseldorp E, et al. Measuring determinants of implementation behavior: psychometric properties of a questionnaire based on the theoretical domains framework. Implement Sci. 2014;9(1):33. 4.Skoien W, Page K, Parsonage W, et al. Use of the Theoretical Domains Framework to evaluate factors driving successful implementation of the Accelerated Chest pain Risk Evaluation (ACRE) project. Implement Sci. 2016;11(1):136. 5. ESS. Source questionnaire. Round 8. 2016/2017 2016. Available from: https://www.europeansocialsurvey.org/docs/round8/fieldwork/source/ESS8_source_questionnaires.pdf [Accessed 9 August 2019]. 6. NHS. National NHS Staff Survey Co-ordination Centre 2019. Available from: https://www.nhsstaffsurveys.com/Page/1056/Home/NHS-Staff-Survey-2019/ [Accessed 9 August 2019]. 7.The Scottish Government. Scottish Government Urban/Rural Classification 2013-2014: Scottish Government; 2014. Available from: http://www.gov.scot/Resource/0046/00464780.pdf [Accessed 9 August 2019]***

# Appendix 26. The process evaluation questionnaire

## Process evaluation of the Detect Cancer Early Programme

### Questionnaire survey

Thank you for considering taking part in this survey. We would like to hear your views about the role of the Detect Cancer Early (DCE) programme in your daily work, and to learn lessons from what worked and did not work during programme implementation.

DCE was launched in 2012 and aimed to improve cancer survival in Scotland, focusing on early detection. We are interested in what happened between the years 2011 (pre- implementation) and 2015 (implementation period).

DCE strategies may have influenced your work in different ways; you may also have been involved in developing them. DCE targeted primary care, secondary care and the general public through:

- **Public Awareness and Behaviour Influencing Strategy:** Awareness campaigns for the public about cancer symptoms/signs, and screening – TV, radio, press, roadshows, etc.
- **Primary Care Cancer Symptom Management and Referral Strategy:** Educational sessions for health care professionals and review of urgent referral guidelines for suspected cancer
- **Strategy for Managing Demand for Cancer Screening and Diagnostics:** Additional funding for territorial Health Boards to manage increasing demand for diagnostics
- **Performance Management Strategy:** HEAT target (25% increase in cancers diagnosed at Stage 1) and an sGMS Contract Bowel Screening Initiative (awarded the equivalent of 6 Quality and Outcomes Framework (QOF) points for reduction in bowel screening non-participation)

**Q1. Please choose ONE option:** ** Required*

Eligibility question

- ○ Detect Cancer Early influenced my daily work during 2011-2015 AND/OR I did help develop/implement one or more of its activities
- ○ Detect Cancer Early did NOT influence my daily work during 2011-2015 AND I did NOT help develop/implement one or more of its activities

### Information and consent page

You are being invited to take part in a research study. It is up to you to decide whether or not to take part.

**Note:** This is an abbreviated version of the information sheet; you can access the full version here.

This questionnaire was developed by researchers (Prof David Weller, Dr Christine Campbell and Natalia Calanzani) at the University of Edinburgh (UoE) as part of a process evaluation of Detect Cancer Early (DCE). The study has been reviewed and approved by the Usher Research Ethics Group at the UoE. The evaluation is funded by the Scottish Government and carried out independently by the UoE.

This process evaluation aims to understand what happened when DCE and its different components were implemented. You have received an anonymous link to access this survey; the organisation that sent you the link will not know whether you decided to take part or not.

If you decide to take part, you can still withdraw before submitting your answers or up to four weeks after submission, provided that you contact us quoting the completion receipt number you will be given at the end of the survey. The receipt number is required as the survey is anonymised.

Data will be analysed by researchers at the UoE; comments will be anonymised. Results will be published in a report, peer-reviewed journals and a PhD thesis. Data may be stored in a secure data repository if required by journals, and reused by other researchers at the UoE.

Contact the research team (Natalia.Calanzani@ed.ac.uk; Tel 0131 650 3818, or Christine.Campbell@ed.ac.uk , Tel 0131 650 9252) if you would like more information. If you have any concerns or complaints about this research, please contact Prof Sarah Cunningham Burley, Dean of Molecular, Genetic and Population Health Sciences [sarah.c.burley@ed.ac.uk; Tel 0131 650 3217].

The survey is expected to take 15-20 minutes to complete. Please skip sections which are not relevant to you.

If you agree to take part, please tick the box below to confirm that you wish to do so.

**Q2. Informed Consent - please choose ONE option:** **Required*

Informed consent

- ○ I have read the information above AND I agree to take part in this survey
- ○ I do not agree to take part in this survey

### Part 1. DCE and your work

We will ask about your experience with DCE and your views about how it may have influenced your work. The first questions will be about DCE in general, then we will ask specific questions about each of DCE strategies.

Unless otherwise specified, please consider the events happening between 2011 and 2015 when answering the questions.

There are no right or wrong answers, and not having an opinion about a question is acceptable. There is also space if you wish to write any comments.

## The DCE Programme

**Q3. Were you informed about the DCE programme before it was implemented in 2012?** **Required*
Assumption 2

- ○ Yes, I was sufficiently informed about DCE
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q4. Were you involved in developing or refining DCE or any of its strategies?** This could have happened by taking part in DCE meetings, giving feedback on the implementation plan, on the urgent referral guidelines for suspected cancer, etc. ** Required.*
Assumption 2

- ○ Yes
- ○ No, but I would have liked to have had an input
- ○ No, and I was happy with that
- ○ Other

**Q5.** If you wish, you can use the box below to comment on your answers to the questions above. *Optional*
General feedback

**Q6.** Please indicate your level of agreement or disagreement with the statements below. There are seven possible options (from strongly disagree to strongly agree). You can also choose DK (I don't know) or N/A (not applicable) if appropriate.

** Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q6.1.a** DCE was appropriate to promote early detection<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q6.2.a** The benefits brought by DCE outweighed the time and effort required to work towards its aims<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## The next questions are about the role of DCE in your daily work.

**Q7.** Please indicate your level of agreement or disagreement with the statements below.

** Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q7.1.a** It was part of my job to be involved in DCE<br>Mechanism 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q7.2.a** I had flexibility to make changes in order to meet DCE aims<br>Assumption 4 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q7.3.a** There was enough time to engage with DCE and its strategies<br>Assumption 3 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q8. Did the DCE programme increase demand for the services you provided to patients?** **Required*

**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q9. If you said yes to the question above, did the increased demand drive the development of local initiatives to detect cancer early?** *Optional*

**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q10. You can use this space to write comments about any of the questions above.** *Optional*

**General feedback**

**The next questions refer to your views about DCE from the year 2015 onwards.**

**Q11.** Please indicate your level of agreement or disagreement with the statements below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q11.1.a** I support continuation of DCE<br>**Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q11.1.b** My local team supports continuation of DCE<br>**Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q12. You can use this space to write any comments about this section.** *Optional*

**General Feedback**

## Strategy 1: Public Awareness and Behaviour Influencing

The Public Awareness and Behaviour Influencing Strategy consisted of awareness campaigns for the public, engagement with the public, partnerships with public relations and private organisations, among other activities to increase public awareness. For example, there were campaigns for bowel, breast and lung cancer, in addition to the "wee c" and "#getchecked" campaigns.

**Q13.** If this strategy is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:** ** Required*

**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Public awareness and behaviour influencing

**Q14. Were you informed about the DCE campaigns before they were launched?** *Required*
**Assumption 2**

- Yes, I was sufficiently informed about the campaigns
- Yes, but I would have liked to have had more information
- No, I was not informed aboutthem
- Other

**Q14.a.** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q15.** Please indicate your level of agreement or disagreement with the statement below.

* *Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q15.1.a** Public awareness campaigns were an appropriate strategy to promote early detection<br>**Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q16. Did this strategy increase demand for the services you provided to patients?** ***Required***
**Mechanism 3**

- Yes
- No
- Other
- I don't know
- Not applicable

**Q17. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Strategy 2: Symptom Management and Referral

The Primary Care Cancer Symptom Management and Referral Strategy consisted of education sessions for health care professionals, in addition to updating the urgent referral guidelines for suspected cancer.

**First, we will ask a few questions about the education sessions for health care professionals.**

**Q18.** If the education sessions are not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:*** *Required*
**Filter question (skip function)**

- This strategy influenced my daily work AND/OR I helped to develop/implement it
- This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Symptom Management and Referral: Education Sessions

**Q19. Were you informed about the education sessions before they commenced?** ***Required***
**Assumption 2**

- Yes, I was sufficiently informed about the sessions
- Yes, but I would have liked to have had more information
- No, I was not informed about them
- Other

**Q19.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q20.** Please indicate your level of agreement or disagreement with the statements below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q20.1.a** The education sessions were an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q20.2.a** It was difficult to integrate the education sessions with my usual work **Mechanism 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Q20.3.a I had enough time to attend the education sessions **Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q21. You can use this space to write comments about any of the questions above.** ***Optional***
**General feedback**

## Symptom Management and Referral: Urgent Referral Guidelines for Suspected Cancer

**Now we will ask some questions about the updated urgent referral guidelines for suspected cancer.**

**Q22.** If the referral guidelines are not relevant to your work, you will be able to go to a different section.
**Please choose ONE option:** * *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Symptom Management and Referral: Urgent Referral Guidelines for Suspected Cancer

**Q23. Were you informed about the work being carried out to update the guidelines before they were published?** * *Required*
**Assumption 2**

- ○ Yes, I was sufficiently informed about the work
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q23.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q24.** Please indicate your level of agreement or disagreement with the statement below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q24.1.a** The updated guidelines were an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q25. Did the updated referral guidelines increase demand for the services you provided** to patients? ****Required***
**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q26. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Strategy 3: Managing demand for cancer screening and diagnosis

The Strategy for Managing Demand for Cancer Screening and Diagnostics consisted of providing additional funding to territorial Health Boards so this could be invested to improve capacity.

**Q27.** If this strategy is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:*** *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Managing demand for cancer screening and diagnostics

**Q28. Were you informed about the additional funding before it became available?** ***Required***
**Assumption 2**

- ○ Yes, I was sufficiently informed about the funding
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q28.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q29.** Please indicate your level of agreement or disagreement with the statements below.

| | * *Required* | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q29.1.a** Providing extra funding was an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.2.a** I was confident that my team would be able to manage demand for screening and diagnostics when I was informed about the funding **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.3.a** We had enough time to plan how to use the funding **Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.4.a** Primary and secondary care communicated well with each other when planning how to use the funding **Assumption 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.5.a** Additional funding resulted in more equipment for diagnosis **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.6.a** Additional funding resulted in more workforce for diagnosis **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q30. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Strategy 4: Performance Management

The Performance Management Strategy consisted of specific performance targets. There were HEAT targets for cancers diagnosed at Stage 1, and a bowel screening initiative awarding the equivalent of 6 QOF points for reduction in bowel screening non-response.

**First, we will ask a few questions about the HEAT targets.**

**Q31.** If the HEAT targets are not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:*** *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Performance Management: the HEAT targets

**Q32. Were you informed about the HEAT targets before they were launched? *Required**
**Assumption 2**

- ○ Yes, I was sufficiently informed about these HEAT targets
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about them
- ○ Other

**Q32.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q33.** Please indicate your level of agreement or disagreement with the statements below.

*Required

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q33.1.a** HEAT targets were an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.2.a** I was confident in my ability to meet HEAT targets **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.3.a** It was difficult to integrate meeting HEAT targets with my usual work **Mechanism 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.4.a** HEAT targets pressured our team to act **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.5.a** HEAT targets worked as a reminder for where our efforts should be focused **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q34. You can use this space to write comments about any of the questions above.**
*Optional*
**General feedback**

## Performance Management: the Bowel Screening Initiative

**Now, we will ask you some questions about the bowel screening initiative that awarded QOF points for reduction in bowel screening non-participation.**

**Q35.** If the Bowel Screening Initiative is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:** * *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Performance Management: the Bowel Screening Initiative

**Q36. Were you informed about the bowel screening initiative before it was launched?** **Required*
**Assumption 2**

- ○ Yes, I was sufficiently informed about the bowel screening initiative
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q36.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q37.** Please indicate your level of agreement or disagreement with the statements below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q37.1.a** The bowel screening initiative was an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.2.a** I was confident in my ability to be awarded the QOF points **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.3.a** It was difficult to integrate the bowel screening initiative with my usual work **Mechanism 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.4.a** My team had enough time to reach non- responders to bowel screening **Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.5.a** The bowel screening initiative pressured our team to act **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.6.a** The bowel screening initiative worked as a reminder for where our efforts should be focused **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Q38. Did the bowel screening initiative increase demand for the services you provided to patients? ***Required***
**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q39. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Part 2. Please tell us a bit about yourself

**We have reached the last part of the questionnaire. Here we will ask a few questions about yourself.**

**Q40. Would you describe yourself as:** * *Required*
**Socio-demographic information**

- ○ Male
- ○ Female
- ○ Other (please specify)
- ○ I prefer not to say

**Q40.a** Please use this box if you wish to specify any answers: *Optional*
**Socio-demographic information**

**Q41.** In what year were you born? *Optional*
Socio-demographic information

**Q42. What was your profession from 2011 until 2015?** *You can tick more than one answer or choose "Other" if appropriate. *Required*
Socio-demographic information

- ☐ Allied Health Professionals, Healthcare Scientists and Scientific & Technical staff (please specify)
- ☐ Medical staff (please specify)
- ☐ Registered nurse (please specify)
- ☐ Other nurses or Healthcare Assistants (please specify)
- ☐ Public Health / Health Improvement (please specify)
- ☐ Commissioning managers / support staff (please specify)
- ☐ Wider Healthcare Team (please specify)
- ☐ General managers (please specify)
- ☐ Charity Worker (please specify)
- ☐ Other (s) (please specify)
- ☐ I prefer not to say

**Q42.a** Please use this box if you wish to specify any answers: *Optional*
Socio-demographic information

**Q43. Does your work focus on a specific cancer type (e.g. breast, lung, bowel cancer)? * *Required***
Socio-demographic information

- ○ Yes (please specify)
- ○ No, my work includes more than one cancer type
- ○ Not applicable

**Q43.a** Please use this box if you wish to specify any answers: *Optional*
Socio-demographic information

**Q44.** Still thinking of the 2011-2015 period, please write down the years DCE was relevant to your work. *For example, from 2012 to 2014. Optional*
Socio-demographic information

**Q45. In which territorial Health Board do you work?** *You can tick more than one answer or choose "Other" if appropriate. * Required*
Socio-demographic information

- ☐ Ayrshire & Arran
- ☐ Borders
- ☐ Dumfries & Galloway
- ☐ Fife
- ☐ Forth Valley
- ☐ Grampian
- ☐ Greater Glasgow & Clyde
- ☐ Highlands
- ☐ Lanarkshire
- ☐ Lothian
- ☐ Orkney
- ☐ Shetland
- ☐ Tayside
- ☐ Western Isles
- ☐ Whole of Scotland
- ☐ Other (please specify)
- ☐ I prefer not to say

**Q45.a** Please use this box if you wish to specify any answers: *Optional*
**Socio-demographic information**

**Q46.** Which best describes the area where you work? **Required*
**Socio-demographic information**

**Drop-down menu)**
Large urban areas (Settlements of over 125,000 people) Other urban areas (Settlements of 10,000 to 125,000 people)
Accessible small towns (Settlements of between 3,000 and 10,000 people, and within a 30-minute drive time of a Settlement of 10,000 or more)
Remote small towns (Settlements of between 3,000 and 10,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more)
Accessible rural areas (Areas with a population of less than 3,000 people, and within a 30-minute drive time of a Settlement of 10,000 or more)
Remote rural areas (Areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more)
Other (please specify)
I prefer not to say

**Q46.a** Please use this box if you wish to specify any answers *Optional*
**Socio-demographic information**

**Q47. Which best describes your workplace?** *You can tick more than one answer or choose "Other" if appropriate. * Required*
**Socio-demographic information**

- ☐ Primary Care practice
- ☐ Hospital (please specify area/Department)
- ☐ Diagnostic Centre, but not in a hospital
- ☐ Laboratory, but not in a hospital
- ☐ Cancer Charity (if you wish, please specify which one)
- ☐ Scottish Government
- ☐ Other (please specify)
- ☐ I prefer not to say

**Q47.a** Please use this box if you wish to specify any answers: *Optional*
**Socio-demographic information**

## Just a couple more things before we finish....

**Q48.** If you wish, please use this space to write your views about what worked well and what did not work so well in the programme. *Optional*
**General feedback**

**Q49.** If you wish, please let us know your views on barriers/facilitators to DCE success. These could be specific populations, financial issues, regional characteristics, or anything else you find relevant. *Optional*
**Barriers and facilitators**

**Q50. Finally, if we missed any issues you wished to talk about, please let us know below.** *Optional*
**General feedback**

If you would like to receive a summary of the study results, please add a contact email address below (we will not be able to contact you without this). Alternatively, please contact Natalia (Natalia.Calanzani@ed.ac.uk) at any time to request this. *Optional*

**Ethics and dissemination**

Thank you very much for your contribution.

If you have any questions about the survey, please contact Natalia Calanzani, the PhD researcher at: Natalia.Calanzani@ed.ac.uk (Tel 0131 650 3818). You can also reach her at: University of Edinburgh. Room 123, Doorway 1. Medical Quad, Teviot Place. Edinburgh EH8 9AG

Redirection page
(when potential participants were not eligible or did not consent to take part)

# Process evaluation of the Detect Cancer Early Programme

Thank you for considering taking part in the study.

You have been redirected to this page as you have either stated that 1) DCE did not influence your work; or 2) you have decided not to take part in the study. If this is in error and you wish to take part, please open the link sent to your email again.

If you have any questions or comments about the study, please contact natalia.calanzani@ed.ac.uk (phone 0131 650 3818), the PhD student carrying out this research at the University of Edinburgh.

# Appendix 27. Ethical approval (Study 3 - interviews)

THE UNIVERSITY of EDINBURGH

**USHER RESEARCH ETHICS GROUP**
**The Usher Institute of Population Health Sciences and Informatics**
The University of Edinburgh
Medical School
Teviot Place
Edinburgh
EH8 9AG
**Tel:** +44 (0)131 650 3214
**Fax** +44 (0)131 650 6909
http://www.cphs.mvm.ed.ac.uk/intra/
email: usher.ethics@ed.ac.uk

11 January 2018

Ms N Calanzani

Dear Natalia

**Process evaluation of the Detect Cancer Early (DCE) programme – interviews with stakeholders**

Thank you for resubmitting your documentation with the revisions that were needed to meet the conditions imposed by the Usher Research Ethics Group (UREG). It is very helpful to receive, in reply to our previous letter, a clear explanation of process. All the revisions have been judged satisfactory. I am therefore pleased to be able to inform you that the above study has been granted ethics approval.

This reply has taken a bit longer than it might have done because of UREG member annual leave. However we trust you will not have lost too much time and your research will now proceed with all due success.

Please be aware that this ethics approval is in respect of the protocol and methods as described in the documents submitted to the committee (with revised documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check with UREG whether this means your level 2 ethics approval needs to be **amended**.[1]

Best wishes for your research.

Yours sincerely

Diane White

**Diane White**
**Usher Research Ethics Group Administrator**

1 Guidance for **amendments** can be found in the Usher shared area, in doc 'Amendment Guidance' at path U:\Datastore\CMVM\smgphs\shared\Usher\ResAdmin\ETHICSdocsForms\CPHS Ethics Group docs

# Appendix 28. Ethical approval (Study 3 - questionnaire)

THE UNIVERSITY *of* EDINBURGH

**USHER RESEARCH ETHICS GROUP**
**The Usher Institute of Population Health Sciences and Informatics**
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Teviot Place
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**Tel:** +44 (0)131 650 3214
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http://www.cphs.mvm.ed.ac.uk/intra/
email: usher.ethics@ed.ac.uk

09 April 2018

Ms N Calanzani

Dear Natalia

**Re: Process evaluation of the DCE Programme: questionnaire survey**

Thank you for resubmitting your documentation with the revisions needed to meet the conditions that were imposed by the Usher Research Ethics Group (UREG). The revisions have been judged satisfactory i.e. conditions met. I am therefore pleased to be able to inform you that the above study has been granted amendment ethics approval.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the documents submitted to the committee (with amended/revised documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check with UREG whether this means your level 2 ethics approval needs to be **amended** further. [1]

Best wishes for your research.

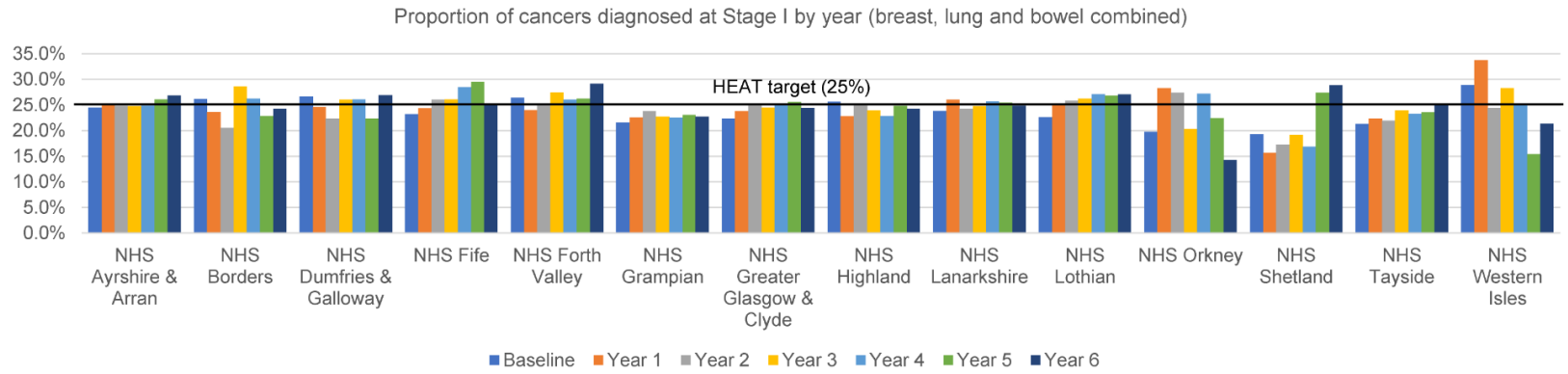
Yours sincerely

Diane White

**Diane White**
**Usher Research Ethics Group Administrator**

1 Guidance for **amendments** can be found in the Usher shared area, in doc 'Amendment Guidance' at path U:\Datastore\CMVM\smgphs\shared\Usher\ResAdmin\ETHICSdocsForms\CPHS Ethics Group docs

# Appendix 29. Tumour staging by Health Boards

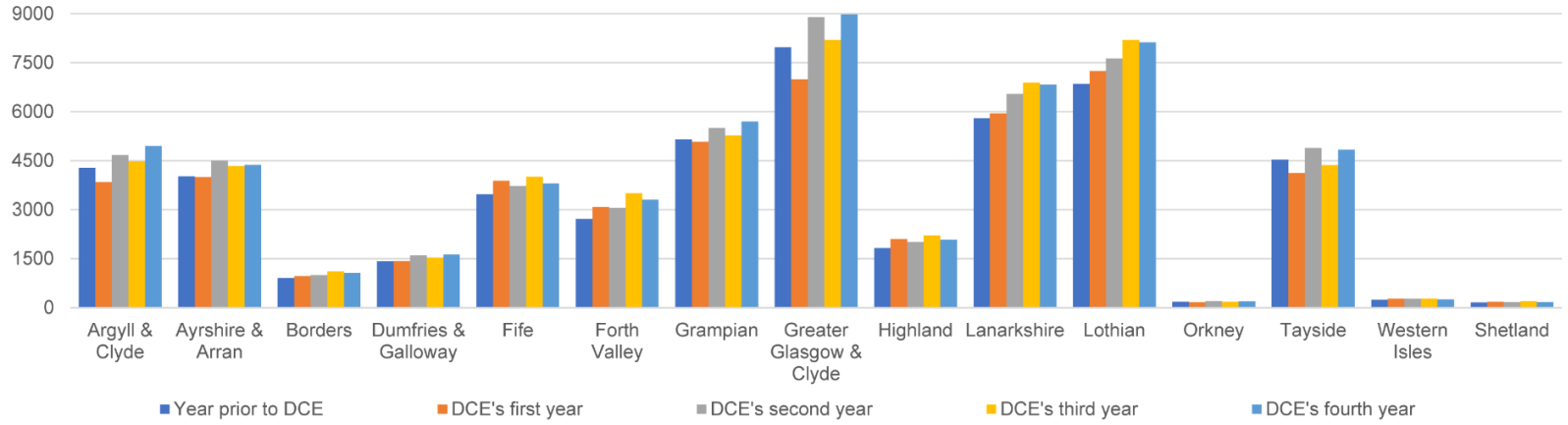



N (%) cancers diagnosed at Stage I by Health Boards

| Territorial Health Boards | Baseline N (%) | Year 1 N (%) | % change | Year 2 N (%) | % change | Year 3 N (%) | % change | Year 4 N (%) | % change | Year 5 N (%) | % change | Year 6 N (%) | % change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NHS Ayrshire & Arran | 448 (24.5) | 470 (25.3) | 3.3% | 480 (24.8) | 1.2% | 490 (24.7) | 0.9% | 484 (24.9) | 1.5% | 496 (26.1) | 6.6% | 521 (26.9) | 9.8% |
| NHS Borders | 157 (26.2) | 130 (23.7) | -9.5% | 103 (20.5) | -21.6% | 164 (28.6) | 9.2% | 139 (26.2) | 0.0% | 115 (22.9) | -12.6% | 147 (24.3) | -7.3% |
| NHS Dumfries & Galloway | 209 (26.7) | 191 (24.6) | -7.8% | 160 (22.4) | -15.9% | 184 (26.1) | -2.2% | 192 (26.1) | -2.1% | 154 (22.4) | -15.9% | 185 (26.9) | 1.0% |
| NHS Fife | 386 (23.2) | 420 (244) | 4.9% | 451 (26.0) | 12.1% | 456 (26.1) | 12.5% | 498 (28.5) | 22.7% | 514 (29.5) | 27.0% | 437 (25.0) | 7.6% |
| NHS Forth Valley | 336 (26.4) | 305 (23.9) | -9.4% | 336 (25.3) | -4.3% | 374 (27.4) | 3.8% | 332 (26.0) | -1.5% | 319 (26.2) | -0.8% | 379 (29.2) | 10.4% |
| NHS Grampian | 468 (21.6) | 494 (22.6) | 4.5% | 513 (23.8) | 10.0% | 503 (22.7) | 5.0% | 514 (22.5) | 4.1% | 533 (23.1) | 6.6% | 538 (22.7) | 4.9% |
| NHS Greater Glasgow & Clyde | 1298 (22.4) | 1462 (23.8) | 6.2% | 1538 (24.9) | 11.3% | 1460 (24.5) | 9.3% | 1465 (25.1) | 12.1% | 1429 (25.6) | 14.2% | 1311 (24.4) | 9.1% |
| NHS Highland | 375 (25.6) | 346 (22.8) | -10.9% | 406 (24.9) | -2.7% | 349 (23.9) | -6.7% | 344 (22.9) | -10.7% | 404 (24.8) | -3.2% | 354 (24.3) | -5.3% |
| NHS Lanarkshire | 614 (23.9) | 695 (26.0) | 8.8% | 646 (24.3) | 1.6% | 706 (24.7) | 3.6% | 771 (25.7) | 7.7% | 758 (25.5) | 6.7% | 746 (24.9) | 4.2% |
| NHS Lothian | 805 (22.7) | 929 (25.0) | 10.2% | 961 (25.9) | 14.1% | 971 (26.2) | 15.8% | 1002 (27.1) | 19.8% | 944 (26.8) | 18.3% | 942 (27.0) | 19.3% |
| NHS Orkney | 13 (19.7) | 26 (28.3) | 43.5% | 23 (27.4) | 39.0% | 12 (20.3) | 3.3% | 25 (27.2) | 38.0% | 22 (22.4) | 14.0% | 9 (14.3) | -27.5% |
| NHS Shetland | 22(19.3) | 17 (15.6) | -19.2% | 21 (17.2) | -10.8% | 23 (19.2) | -0.7% | 15 (16.9) | -12.7% | 32 (27.4) | 41.7% | 32 (28.8) | 49.4% |
| NHS Tayside | 404 (21.3) | 410 (22.3) | 4.9% | 404 (21.9) | 2.9% | 465 (23.9) | 12.3% | 456 (23.3) | 9.4% | 469 (23.6) | 10.9% | 499 (25.2) | 18.4% |
| NHS Western Isles | 46(28.9) | 51 (33.8) | 16.7% | 480 (24.8) | -15.6% | 41 (28.3) | -2.3% | 35 (25.0) | -13.6% | 18 (15.4) | -46.8% | 29 (21.3) | -26.3% |

***Source: created with aggregated tables from ISD Scotland: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Time Period: 01 January 2010 - 31 December 2017. In: DCE_Staging_Trends. Microsoft Excel. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206***

# Appendix 30. Requests for bowel screening kits by Health Boards

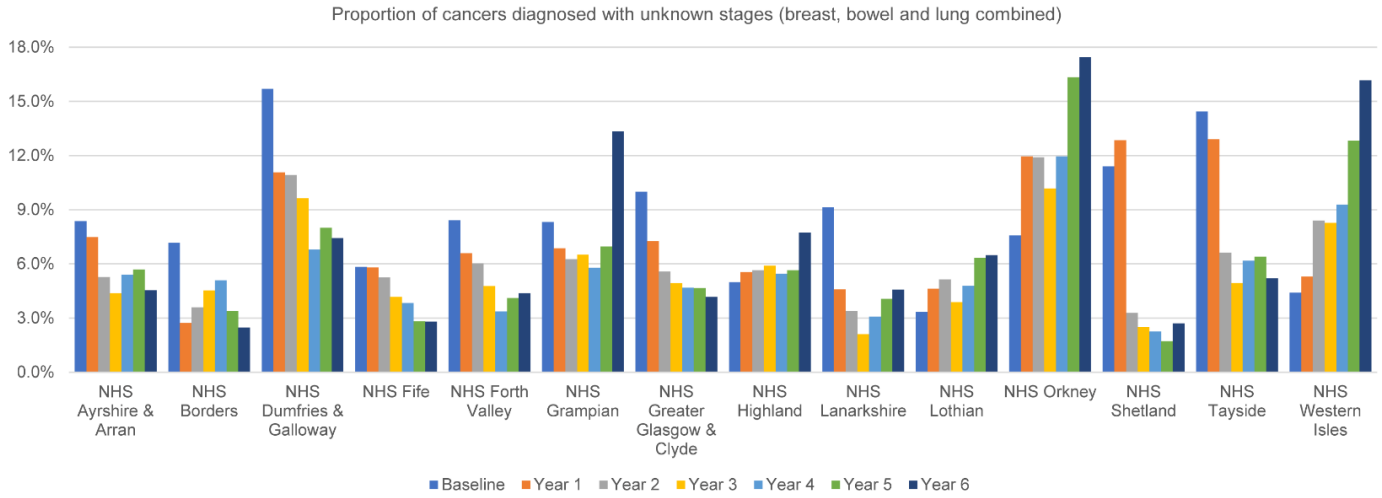



Number of annual requests for bowel screening kits by Health Board and % change compared to proxy baseline

| Territorial Health Boards | Year prior to DCE (proxy baseline) | DCE's first year | % change | DCE's second year | % change | DCE's third year | % change | DCE's fourth year | % change |
|---|---|---|---|---|---|---|---|---|---|
| NHS Argyll & Clyde | 4285 | 3844 | -10.3% | 4679 | 9.2% | 4485 | 4.7% | 4947 | 15.4% |
| NHS Ayrshire & Arran | 4019 | 4001 | -0.4% | 4500 | 12.0% | 4335 | 7.9% | 4369 | 8.7% |
| NHS Borders | 902 | 966 | 7.1% | 994 | 10.2% | 1110 | 23.1% | 1057 | 17.2% |
| NHS Dumfries & Galloway | 1415 | 1423 | 0.6% | 1601 | 13.1% | 1529 | 8.1% | 1632 | 15.3% |
| NHS Fife | 3476 | 3882 | 11.7% | 3726 | 7.2% | 4011 | 15.4% | 3806 | 9.5% |
| NHS Forth Valley | 2714 | 3075 | 13.3% | 3063 | 12.9% | 3506 | 29.2% | 3301 | 21.6% |
| NHS Grampian | 5154 | 5076 | -1.5% | 5499 | 6.7% | 5274 | 2.3% | 5702 | 10.6% |
| NHS Greater Glasgow & Clyde | 7971 | 6991 | -12.3% | 8891 | 11.5% | 8201 | 2.9% | 8972 | 12.6% |
| NHS Highland | 1828 | 2100 | 14.9% | 2009 | 9.9% | 2209 | 20.8% | 2072 | 13.3% |
| NHS Lanarkshire | 5799 | 5948 | 2.6% | 6548 | 12.9% | 6887 | 18.8% | 6827 | 17.7% |
| NHS Lothian | 6848 | 7244 | 5.8% | 7626 | 11.4% | 8200 | 19.7% | 8120 | 18.6% |
| NHS Orkney | 182 | 170 | -6.6% | 205 | 12.6% | 181 | -0.5% | 190 | 4.4% |
| NHS Tayside | 4527 | 4123 | -8.9% | 4881 | 7.8% | 4367 | -3.5% | 4835 | 6.8% |
| NHS Western Isles | 246 | 276 | 12.2% | 272 | 10.6% | 274 | 11.4% | 252 | 2.4% |
| Shetland NHS Board | 157 | 183 | 16.6% | 171 | 8.9% | 195 | 24.2% | 176 | 12.1% |

***Source: created with customised data provided by the Scottish Bowel Screening Centre***

# Appendix 31. Tumour staging coded as unknown by Health Boards




N (%) cancers diagnosed with unknown stages by Health Board

| Territorial Health Boards | Baseline N (%) | Year 1 N (%) | % change | Year 2 N (%) | % change | Year 3 N (%) | % change | Year 4 N (%) | % change | Year 5 N (%) | % change | Year 6 N (%) | % change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NHS Ayrshire & Arran | 153 (8.4) | 139 (75) | -10.5% | 102 (5.3) | -37.0% | 87 (4.4) | -47.5% | 105 (5.4) | -35.5% | 108 (5.7) | -32.0% | 88 (4.5) | -45.7% |
| NHS Borders | 43 (7.2) | 15 (2.7) | -61.9% | 18 (3.6) | -50.0% | 26 (4.5) | -36.8% | 27 (5.1) | -29.1% | 17 (3.4) | -52.8% | 15 (2.5) | -65.5% |
| NHS Dumfries & Galloway | 123 (15.7) | 86 (11.1) | -29.5% | 78 (10.9) | -30.4% | 68 (9.6) | -38.6% | 50 (6.8) | -56.7% | 55 (8.0) | -49.0% | 51 (7.4) | -52.7% |
| NHS Fife | 97 (5.8) | 100 (5.8) | -0.6% | 91 (5.3) | -10.0% | 73 (4.2) | -28.4% | 67 (3.8) | -34.3% | 49 (2.8) | -51.8% | 49 (2.8) | -52.0% |
| NHS Forth Valley | 107 (8.4) | 84 (6.6) | -21.7% | 80 (6.0) | -28.4% | 65 (4.8) | -43.4% | 43 (3.4) | -59.9% | 50 (4.1) | -51.2% | 57 (4.4) | -47.9% |
| NHS Grampian | 180 (8.3) | 150 (6.9) | -17.5% | 135 (6.3) | -24.8% | 144 (6.5) | -21.9% | 132 (5.8) | -30.5% | 161 (7.0) | -16.3% | 316 (13.3) | 60.2% |
| NHS Greater Glasgow & Clyde | 579 (10.0) | 446 (7.3) | -27.4% | 344 (5.6) | -44.2% | 294 (4.9) | -50.7% | 273 (4.7) | -53.2% | 260 (4.7) | -53.4% | 224 (4.2) | -58.2% |
| NHS Highland | 73 (5.0) | 84 (5.5) | 11.1% | 92 (5.7) | 13.3% | 86 (5.9) | 18.1% | 82 (5.5) | 9.3% | 92 (5.6) | 13.2% | 113 (7.7) | 55.2% |
| NHS Lanarkshire | 235 (9.1) | 123 (4.6) | -49.7% | 90 (3.4) | -63.0% | 60 (2.1) | -77.0% | 92 (3.1) | -66.4% | 121 (4.1) | -55.5% | 137 (4.6) | -50.0% |
| NHS Lothian | 119 (3.3) | 172 (4.6) | 38.1% | 191 (5.1) | 53.5% | 144 (3.9) | 16.1% | 177 (4.8) | 43.1% | 223 (6.3) | 89.0% | 226 (6.5) | 93.6% |
| NHS Orkney | 5 (7.6) | 11 (12.0) | 57.8% | 10 (11.9) | 57.1% | 6 (10.2) | 34.2% | 11 (12.0) | 57.8% | 16 (16.3) | 115.5% | 11 (17.5) | 130.5% |
| NHS Shetland | 13 (11.4) | 14 (12.8) | 12.6% | 4 (3.3) | -71.2% | 3 (2.5) | -78.1% | 2 (2.2) | -80.3% | 2 (1.7) | -85.0% | 3 (2.7) | -76.3% |
| NHS Tayside | 274 (14.4) | 237 (12.9) | -10.6% | 122 (6.6) | -54.2% | 96 (4.9) | -65.8% | 121 (6.2) | -57.2% | 127 (6.4) | -55.7% | 103 (5.2) | -64.0% |
| NHS Western Isles | 7 (4.4) | 8 (5.3) | 20.3% | 11 (8.4) | 90.7% | 12 (8.3) | 88.0% | 13 (9.3) | 110.9% | 15 (12.8) | 191.2% | 22 (16.2) | 267.4% |

***Source: created with aggregated tables from ISD Scotland: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Time Period: 01 January 2010 - 31 December 2017. In: DCE_Staging_Trends. Microsoft Excel. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206***

# Appendix 32. All questionnaire responses

**Q1 and Q2. Eligibility and informed consent**

| | % | Valid % | Cumulative % |
|---|---|---|---|
| Detect Cancer Early influenced my daily work during 2011-2015 AND/OR I did help develop/implement one or more of its activities | 100.0 | 100.0 | 100.0 |
| I have read the information above AND I agree to take part in this survey | 100.0 | 100.0 | 100.0 |

**Q3. Were you informed about the DCE programme before it was implemented in 2012?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about DCE | 23 | 43.4 | 44.2 | 44.2 |
| Yes, but I would have liked to have had more information | 20 | 37.7 | 38.5 | 82.7 |
| No, I was not informed about it | 9 | 17.0 | 17.3 | 100.0 |
| Total | 52 | 98.1 | 100.0 | |
| Missing (Other) | 1 | 1.9 | | |
| Total | 53 | 100.0 | | |

**Q4. Were you involved in developing or refining DCE or any of its strategies? This could have happened by taking part in DCE meetings, giving feedback on the implementation plan, on the urgent referral guidelines for suspected cancer, etc.**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 9 | 17.0 | 18.0 | 18.0 |
| No, but I would have liked to have had an input | 20 | 37.7 | 40.0 | 58.0 |
| No, and I was happy with that | 21 | 39.6 | 42.0 | 100.0 |
| Total | 50 | 94.3 | 100.0 | |
| Missing (Other) | 3 | 5.7 | | |
| Total | 53 | 100.0 | | |

**Q5. If you wish, you can use the box below to comment on your answers to the questions above.**

| |
|---|
| As someone whose practice was impacted by the DCE campaign I would have been very interested in commenting on the messages which were used, when they were in draft form, as I think several were poorly though through. |
| Did survey of Breast Cancer units across Scotland regarding the impact of the first DCE campaign for Breast Cancer and it's effect on referral numbers and cancer numbers. |
| I provided information / advice for the lung cancer strategy's approach for the public campaign to raise awareness of the disease and when patients should see their GP |
| I was given the option to feed in, but it didn't seem to affect the outcome. |
| I was involved in early meetings regarding the data which would be required |
| Mostly involved in the communications and marketing materials developments. |
| my colleague was involved in implementation, so I heard by word of mouth and from tv adverts |
| No thought was given to available resources. This program has resulted in an enormous extra spend and will help bring the NHS to its knees. No program should be launched without consideration of workforce available |
| not applicable as was still in training |
| started post in 2015 now spending most of my time re educating and undoing the harm created by poor referral criteria. |

| |
|---|
| The initial DCE campaign was targeted at the general population and did not increase the cancer detection in target group. |
| tv advert for breast cancer was ill thought out |

**Q6.1.a. DCE was appropriate to promote early detection**

*Median 4.0 (IQR 3.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 7 | 13.2 | 13.7 | 13.7 |
| Disagree | 5 | 9.4 | 9.8 | 23.5 |
| Somewhat disagree | 9 | 17.0 | 17.6 | 41.2 |
| Neither agree nor disagree | 8 | 15.1 | 15.7 | 56.9 |
| Somewhat agree | 7 | 13.2 | 13.7 | 70.6 |
| Agree | 8 | 15.1 | 15.7 | 86.3 |
| Strongly agree | 7 | 13.2 | 13.7 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing (Don't know) | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q6.2.a. The benefits brought by DCE outweighed the time and effort required to work towards its aims**

*Median 4.0 (IQR 2.0-5.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 12 | 22.6 | 23.5 | 23.5 |
| Disagree | 10 | 18.9 | 19.6 | 43.1 |
| Somewhat disagree | 3 | 5.7 | 5.9 | 49.0 |
| Neither agree nor disagree | 9 | 17.0 | 17.6 | 66.7 |
| Somewhat agree | 7 | 13.2 | 13.7 | 80.4 |
| Agree | 4 | 7.5 | 7.8 | 88.2 |
| Strongly agree | 6 | 11.3 | 11.8 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing (Don't know) | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q7.1.a. It was part of my job to be involved in DCE**

*Median 6.0 (IQR 5.0-7.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 4 | 7.5 | 7.8 | 7.8 |
| Disagree | 1 | 1.9 | 2.0 | 9.8 |
| Somewhat disagree | 2 | 3.8 | 3.9 | 13.7 |
| Neither agree nor disagree | 3 | 5.7 | 5.9 | 19.6 |
| Somewhat agree | 8 | 15.1 | 15.7 | 35.3 |
| Agree | 10 | 18.9 | 19.6 | 54.9 |
| Strongly agree | 23 | 43.4 | 45.1 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing (Don't know) | 1 | 1.9 | | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Total missing | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q7.2.a. I had flexibility to make changes in order to meet DCE aims**

*Median 2.0 (IQR 1.0-4.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 19 | 35.8 | 41.3 | 41.3 |
| Disagree | 8 | 15.1 | 17.4 | 58.7 |
| Somewhat disagree | 3 | 5.7 | 6.5 | 65.2 |
| Neither agree nor disagree | 6 | 11.3 | 13.0 | 78.3 |
| Somewhat agree | 4 | 7.5 | 8.7 | 87.0 |
| Agree | 4 | 7.5 | 8.7 | 95.7 |
| Strongly agree | 2 | 3.8 | 4.3 | 100.0 |
| Total | 46 | 86.8 | 100.0 | |
| Missing (Don't know) | 3 | 5.7 | | |
| Missing (Question not applicable) | 4 | 7.5 | | |
| Total missing | 7 | 13.2 | | |
| Total | 53 | 100.0 | | |

**Q7.3.a. There was enough time to engage with DCE and its strategies**

*Median 2.0 (IQR 1.0-4.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 16 | 30.2 | 33.3 | 33.3 |
| Disagree | 10 | 18.9 | 20.8 | 54.2 |
| Somewhat disagree | 5 | 9.4 | 10.4 | 64.6 |
| Neither agree nor disagree | 8 | 15.1 | 16.7 | 81.3 |
| Somewhat agree | 6 | 11.3 | 12.5 | 93.8 |
| Agree | 2 | 3.8 | 4.2 | 97.9 |
| Strongly agree | 1 | 1.9 | 2.1 | 100.0 |
| Total | 48 | 90.6 | 100.0 | |
| Missing (Don't know) | 2 | 3.8 | | |
| Missing (Question not applicable) | 3 | 5.7 | | |
| Total missing | 5 | 9.4 | | |
| Total | 53 | 100.0 | | |

**Q8. Did the DCE programme increase demand for the services you provided to patients?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 46 | 86.8 | 92.0 | 92.0 |
| No | 4 | 7.5 | 8.0 | 100.0 |
| Total | 50 | 94.3 | 100.0 | |
| Missing (Don't know) | 1 | 1.9 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Total missing | 3 | 5.7 | | |
| Total | 53 | 100.0 | | |

**Q9. If you said yes to the question above, did the increased demand drive the development of local initiatives to detect cancer early?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 11 | 20.8 | 29.7 | 29.7 |
| No | 25 | 47.2 | 67.6 | 97.3 |
| Other | 1 | 1.9 | 2.7 | 100.0 |
| Total | 37 | 69.8 | 100.0 | |
| Missing (Don't know) | 9 | 17.0 | | |
| Missing (Question not applicable) | 6 | 11.3 | | |

| | | | | |
|---|---|---|---|---|
| Missing (no answer given) | 1 | 1.9 | | |
| Total missing | 16 | 30.2 | | |
| Total | 53 | 100.0 | | |

**Q10. You can use this space to write comments about any of the questions above.**

| |
|---|
| As a board we had to focus our attention on ensuring capacity to meet potential increase in demand |
| Big increase in worried well. No change in cancer diagnosis but increased delays for all. Revision to focus on screening more sensible but less visible. |
| Due to anticipated and actual extra demand, help to provide impetus for new consultant post (mine) in my department |
| Endoscopy and diagnostic services are overwhelmed with the worried well. GPs are referring all patients as urgent and urgent cancer in order to have any chance of being seen. The waiting list has escalated beyond control. People who should be having colonoscopic surveillance who are at high risk are suffering the opportunity cost of sending everyone up to hospital. There have been notable cases where patients due for recall have not had surveillance and have presented with established cancer. This is because of the increasing demand since 2012 and before then. DCE is not the only factor responsible but anything that does increase demand depletes ability to prioritise to those in most need. Over-diagnosis is another major issue with many cancers, breast and prostate being the most visible |
| From where I was positioned (as a GP) it increased demand and pressure with no extra resources. Waiting times went up, and it is not clear anything was gained. |
| Higher number of Urgent suspicion of cancer GP referrals than previous years. Fewer new referrals via emergency A&E admission |
| I personally don't provide a service to patients. |
| Increased colonoscopy lists, increased recruitment & training of non-medical endoscopists |
| It drove local initiatives to deal with the flood of "worried well". |
| NO increase in staff or resources to deal with large influx of patients. These patients were detected with pre-cancerous changes mainly. This attitude of 'early breast cancer' need to change |
| not enough planning for impact of DCE and totally inappropriate referrals to Outpatients subsequently caused - thereby delaying some true cancer referrals |
| patients for instance, got the message about early chest x-rays, and organising the first x-ray was easy enough but dealing with the unclear results, particularly those with "normal" x-rays in those who had risk factors for lung cancer, was and remains difficult. I often have email conversations with respiratory consultants regards such patients, many of whom go on to have CT chest, sometimes CT CAP, and yet I would struggle to remember any who had lung cancer. I come to the conclusion that an annual low dose CT of the chest for smokers over 60 would be a far better use of resources. (or direct access for GP to CTs) |
| Referral to breast services across Scotland, with, I believe, the exception of Dumfries and Galloway, rose by approximately 30-40% - data previously presented by Phillipa Whitford. There was no increase in cancers detected. Our symptomatic breast service has never really recovered. All of the clinical signs used in the campaign - orange peel skin etc are LATE signs of breast cancer. |
| The breast screening service was not consulted early enough with the strategy and when they were consulted the campaigns were not targeted in line with the programme. |
| the drive to detect cancer early has led to inappropriate referrals and investigation of the worried well - almost no guidelines or evidence is used by referring clinicians. |
| The first DCE Breast Cancer campaign coincided with October which is already Breast Cancer Awareness month. It was very intense and resulted in 30% - 50% increases in Clinic referrals across Scottish units (except Dumfries as the TV adverts were not shown on Border TV) but, while there were individual women who came forward as a direct result of the information, there was no significant increase in the cancers detected nor change to earlier disease stage. Anecdotally, in our unit, it was more advanced cancers with the other symptoms highlighted by the campaign (skin dimpling or colour change or change in breast |

| |
|---|
| shape) who came forward. I fed back the survey results and we proposed less intense campaigns but more prolonged throughout the year to increase the chance of a woman seeing an advert when she might have symptoms rather than stimulating concerns generally. |
| The increase in demand caused major impact on the resource that was available at the time, this led to increased stress levels for those on the front line leading to burn out for staff and consequently poorer service for those requiring care. However, the experience was used positively to look at working practice and how staff could be better supported and change to meet needs of service. |
| There was a massive surge in referrals with no commensurate rise in staffing or resource |
| There was no thought re what the current service was able to deliver. No realisation that most team(s) who diagnose cancer also provide emergency care and care to planned care |
| These responses refer primarily to colonoscopy for bowel cancer |
| We did the same amount of work. There were no resources put in to do extra operations or see extra patients in clinics. So, it just did not matter whether you detected cancer early or not. Everybody just stayed in the queue. What would have made a difference was if you had predicted a certain number of cancer cases being picked up early and estimated how much extra operating spaces or clinic spaces would be required to deal with new cases you would be picking up. |
| we were swamped with the worried well. we found some incidental cancers but generally our service was near to collapse. |
| Within the breast service, DCE resulted in very large numbers of women who had nothing wrong with them asking to be referred from their GP to specialist breast clinics for reassurance. This in fact hindered access to breast services for patients with breast cancer as no additional resources were put in place to deal with the increased number of referrals. |

**Q11.1.a. I support continuation of DCE**

*Median 4.0 (IQR 3.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 7 | 13.2 | 13.7 | 13.7 |
| Disagree | 4 | 7.5 | 7.8 | 21.6 |
| Somewhat disagree | 6 | 11.3 | 11.8 | 33.3 |
| Neither agree nor disagree | 9 | 17.0 | 17.6 | 51.0 |
| Somewhat agree | 6 | 11.3 | 11.8 | 62.7 |
| Agree | 9 | 17.0 | 17.6 | 80.4 |
| Strongly agree | 10 | 18.9 | 19.6 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing (Don't know) | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q11.2.a. My local team supports continuation of DCE**

*Median 5.0 (IQR 3.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 3 | 5.7 | 7.9 | 7.9 |
| Disagree | 4 | 7.5 | 10.5 | 18.4 |
| Somewhat disagree | 3 | 5.7 | 7.9 | 26.3 |
| Neither agree nor disagree | 7 | 13.2 | 18.4 | 44.7 |
| Somewhat agree | 3 | 5.7 | 7.9 | 52.6 |
| Agree | 10 | 18.9 | 26.3 | 78.9 |
| Strongly agree | 8 | 15.1 | 21.1 | 100.0 |
| Total | 38 | 71.7 | 100.0 | |
| Missing (Don't know) | 14 | 26.4 | | |

| | | | | |
|---|---|---|---|---|
| Missing (Question not applicable) | 1 | 1.9 | | |
| Total missing | 15 | 28.3 | | |
| Total | 53 | 100.0 | | |

**Q12. You can use this space to write any comments about this section.**

| |
|---|
| Breast and colorectal cancer have screening programmes already. Lung cancer is largely related to smoking and that should be the target for campaigns not DCE. |
| breast screening is the best way to detect breast cancer early- this was implemented in the 1980s |
| DCE promotes the worried well not the patients we need to see |
| DCE works for some cancers but most definitely has limitations e.g. detection of DCIS, CSL/RS, tubular cancers (of little clinical significance) |
| Detect Cancer Early remains a standing item as part of cancer strategy group remit |
| Everybody supports Detecting Cancer early. The problem is there is NOT a one size fits all for cancer. Colorectal cancer is best detected early using the population screening programme. This is not appropriate for other cancers |
| I didn't know it was still going? What is different now to if we stopped it? |
| I didn't know that DCE had continued beyond 2015. |
| I don't see much benefit unless it is focusses on other cancers rather than 2 which are already covered by screening programmes. |
| I think that a dedicated clinic with sufficient resources, to whom unclear cases are referred, would be most useful. I have, too often seen people referred UCS to the one specialty, given the all clear and then turn out to have cancer of a different system. Also, those who cannot be referred UCS seem to be waiting a lot longer to be seen urgently than they used to |
| important but need to be more targeted |
| More patients referred for assessment which has not subsequently reduced. small number of additional cancers detected compared to our yearly average |
| Not in its current format. The target, 25% increase in Stage 1, requires review. Many Boards had introduced initiatives prior to the baseline year and therefore struggle to achieve this target. A QI approach to early detection would be more beneficial. |
| Not sure how this could be addressed. The harms of investigating the worried well - rendering the population worried about cancer is another dysbenefit. Cancer phobia is rife and yet there is no grade A evidence that early diagnosis of symptomatic people provides any benefit. Screening does for colon cancer, but no other cancers have RCT evidence. The balance of risks and benefits is the issue here. As well as opportunity cost that is often glossed over. Just because someone is identified with a high-risk condition doesn't mean to say they are well looked after when on a waiting list that is swamped with people without cancer but requiring investigation precipitated by a desire not to "wait and see". Ironically, the more people come up to hospital for "cancer investigations" the better the figures look because of the vagaries of reporting cancer survival figures. The incidence date is the last date that any given patient attended secondary care. So, if GPs send everyone up all the time for irrelevant reasons, the time from incidence to death will be artificially shortened. Hence cancer survival statistics look worse in Britain for spurious reasons |
| Now that we can take the funding and target it in line with our programme it can be put to good use. |
| See above! We are overwhelmed with worried well women and we need no further encouragement of women to attend with breast symptoms. If we want to pick up more early breast cancers spend the campaign money in encouraging the uptake of breast screening |
| See above. |
| The current target of 25% increase in stage 1 is unrealistic - a trajectory outlining expected year on year increases towards this would be more achievable. |
| The overall principle of raising awareness to encourage early presentation is important and widely supported but must avoid simply engendering fear. |
| we would have to have serious input into the project otherwise the referral criteria set by fife will be evidenced based and we will ignore the Scottish or DCE guidelines - for endoscopic investigation. our current level of investigation is at 0.3% RR (NICE is 3%) |

| |
|---|
| While the funding from DCE would be welcome, the major resource needed - more radiologists to deal with additional workload - is difficult to come by, hence existing resources are heavily overloaded and taxed. DCE should happen in conjunction with additional resources put in place to deal with surge. |
| Whilst supporting clinical early detection of breast cancer and the importance of women being aware of signs and symptoms the only way to detect early impalpable disease is through mammographic screening and DCE should have emphasised that. The increase in patients presenting to already busy One Stop Clinics as a result of DCE did not result in any increase in cancer detection. This was a very stressful time for patients and staff struggling to cope with referrals. We need to encourage Screening uptake which fails the Screening standard in West of Scotland. Money could have been better spent in education of poorer socioeconomic areas where screening uptake is low, and patients present late with symptoms. I support continuation of DCE in symptomatic and screening settings and not the original format. Benefits must justify the cost. |

**Q13. If this strategy is not relevant to you or your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 43 | 81.1 | 81.1 | 81.1 |
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 10 | 18.9 | 18.9 | 100.0 |
| Total | 53 | 100.0 | | |

**Q14. Were you informed about the DCE campaigns before they were launched?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about the campaigns | 16 | 30.2 | 38.1 | 38.1 |
| Yes, but I would have liked to have had more information | 15 | 28.3 | 35.7 | 73.8 |
| No, I was not informed about them | 11 | 20.8 | 26.2 | 100.0 |
| Total | 42 | 79.2 | 100.0 | |
| Missing (Other) | 1 | 1.9 | | |
| Missing (Section not applicable) | 10 | 18.9 | | |
| Total missing | 11 | 20.8 | | |
| Total | 53 | 100.0 | | |

**Q14.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| It was forced upon us with no discussion and NO additional resources |
| More time between agreement of final content and 'go live' dates would have been helpful in affording time to coordinate local reinforcement of key messages during campaigns. |
| NA |
| See prev |
| The exact scale of the campaign was not clear nor the likely impact on referral numbers. Our unit was completely swamped (as were many others). |
| This is essential - the launch of DCE should be filtered to all teams in advance and additional clinics planned for. |

**Q15.1.a. Public awareness campaigns were an appropriate strategy to promote early detection**

*Median 5.0 (IQR 3.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 3 | 5.7 | 7.3 | 7.3 |
| Disagree | 5 | 9.4 | 12.2 | 19.5 |
| Somewhat disagree | 4 | 7.5 | 9.8 | 29.3 |
| Neither agree nor disagree | 6 | 11.3 | 14.6 | 43.9 |
| Somewhat agree | 7 | 13.2 | 17.1 | 61.0 |
| Agree | 7 | 13.2 | 17.1 | 78.0 |
| Strongly agree | 9 | 17.0 | 22.0 | 100.0 |
| Total | 41 | 77.4 | 100.0 | |
| Missing (Don't know) | 2 | 3.8 | | |
| Missing (Section not applicable) | 10 | 18.9 | | |
| Total missing | 12 | 22.6 | | |
| Total | 53 | 100.0 | | |

**Q16. Did this strategy increase demand for the services you provided to patients?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 37 | 69.8 | 94.9 | 94.9 |
| No | 2 | 3.8 | 5.1 | 100.0 |
| Total | 39 | 73.6 | 100.0 | |
| Total | 42 | 79.2 | 100.0 | |
| Missing (Don't know) | 1 | 1.9 | | |
| Missing (Question not applicable) | 3 | 5.7 | | |
| Missing (Section not applicable) | 10 | 18.9 | | |
| Total missing | 14 | 26.4 | | |
| Total | 53 | 100.0 | | |

**Q17. You can use this space to write any comments about this section.**

| |
|---|
| Always challenging to meet public expectations and speed of access to diagnostics and tests. Difficult to determine the "Harm" associated with the worried well. Small yield in relation to number of new cancers identified against the significant increase in numbers of people having to undergo tests is often difficult to argue |
| As above. Early diagnosis is not a means in itself. The cost of doing this is substantial |
| Breast screening got an increase in funding, but the symptomatic service did not! |
| It does not matter if demand increases. We have done the same amount of work (since 2010). There have been no extra resources put in for extra operating slots or clinic spaces. What should really be done is extra operating slots over the weekend, which should be in addition to the operating slots we already have during weekdays. What is the point in detecting cancer early, when we do not even provide timely treatment to those whose cancers are detected (often late) via conventional routes, like going to the GP when symptoms develop? |
| Little dedicated health improvement resource for cancer related activity. |
| My average working day is now 14 hours! |
| Referrals increased, but I haven't seen any evidence that early cancer detection increased. Perhaps more should have been done to encourage uptake of screening (re breast cancer). |
| see prev |
| see previous section |
| The campaigns often resulted in patients presenting with longstanding problems e.g. nipple inversion for >10 years. The symptoms that the campaign highlighted were not those of early cancer e.g. skin changes are often a sign of cancer presenting late. |
| The first DCE Breast Cancer campaign coincided with October which is already Breast Cancer Awareness month. It was very intense and resulted in 30% - 50% increases in Clinic referrals across Scottish units (except Dumfries as the TV adverts were not shown on Border TV) but, while there were individual women who came forward as a direct result of |

| |
|---|
| the information, there was no significant increase in the cancers detected nor change to earlier disease stage. Anecdotally, in our unit, it was more advanced cancers with the other symptoms highlighted by the campaign (skin dimpling or colour change or change in breast shape) who came forward. I fed back the survey results and we proposed less intense campaigns but more prolonged throughout the year to increase the chance of a woman seeing an advert when she might have symptoms rather than stimulating general concern. |
| while cancer detection rates did not significantly increase referrals for assessment increased dramatically and have stayed high |

**Q18. If the education sessions are not relevant to you or your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 39 | 73.6 | 73.6 | 73.6 |
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 14 | 26.4 | 26.4 | 100.0 |
| Total | 53 | 100.0 | 100.0 | |

**Q19. Were you informed about the education sessions before they commenced?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about the sessions | 11 | 20.8 | 30.6 | 30.6 |
| Yes, but I would have liked to have had more information | 8 | 15.1 | 22.2 | 52.8 |
| No, I was not informed about them | 17 | 32.1 | 47.2 | 100.0 |
| Total | 36 | 67.9 | 100.0 | |
| Missing (Other) | 3 | 5.7 | | |
| Missing (Section not applicable) | 14 | 26.4 | | |
| Total missing | 17 | 32.1 | | |
| Total | 53 | 100.0 | | |

**Q19.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| for colorectal cancer it has had an adverse effect on referral criteria we are now trying to rescue that by using qFIT |
| I don't think there were any for GPs? If there were, change my answer above to "No" |
| I think there should have been more sessions |

**Q21.1.a. The education sessions were an appropriate strategy to promote early detection**

*Median 5.0 (IQR 4.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 3 | 5.7 | 13.0 | 13.0 |
| Disagree | 1 | 1.9 | 4.3 | 17.4 |
| Somewhat disagree | 1 | 1.9 | 4.3 | 21.7 |
| Neither agree nor disagree | 3 | 5.7 | 13.0 | 34.8 |
| Somewhat agree | 5 | 9.4 | 21.7 | 56.5 |
| Agree | 5 | 9.4 | 21.7 | 78.3 |
| Strongly agree | 5 | 9.4 | 21.7 | 100.0 |
| Total | 23 | 43.4 | 100.0 | |
| Missing (Don't know) | 10 | 18.9 | | |
| Missing (Question not applicable) | 6 | 11.3 | | |

| | | | | |
|---|---|---|---|---|
| Missing (Section not applicable) | 14 | 26.4 | | |
| Total | 30 | 56.6 | | |
| Total | 53 | 100.0 | | |

**Q20.2.a. It was difficult to integrate the education sessions with my usual work**

*Median 2.0 (IQR 1.0-4.0) – reverse scoring*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 2 | 3.8 | 9.5 | 9.5 |
| Disagree | 1 | 1.9 | 4.8 | 14.3 |
| Neither agree nor disagree | 3 | 5.7 | 14.3 | 28.6 |
| Somewhat agree | 3 | 5.7 | 14.3 | 42.9 |
| Agree | 3 | 5.7 | 14.3 | 57.1 |
| Strongly agree | 9 | 17.0 | 42.9 | 100.0 |
| Total | 21 | 39.6 | 100.0 | |
| Missing (Don't know) | 5 | 9.4 | | |
| Missing (Question not applicable) | 13 | 24.5 | | |
| Missing (Section not applicable) | 14 | 26.4 | | |
| Total | 32 | 60.4 | | |
| Total | 53 | 100.0 | | |

**Q20.3.a. I had enough time to attend the education sessions**

*Median 2.0 (IQR 1.0-4.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 8 | 15.1 | 33.3 | 33.3 |
| Disagree | 6 | 11.3 | 25.0 | 58.3 |
| Somewhat disagree | 2 | 3.8 | 8.3 | 66.7 |
| Neither agree nor disagree | 6 | 11.3 | 25.0 | 91.7 |
| Somewhat agree | 2 | 3.8 | 8.3 | 100.0 |
| Total | 24 | 45.3 | 100.0 | |
| Missing (Don't know) | 3 | 5.7 | | |
| Missing (Question not applicable) | 12 | 22.6 | | |
| Missing (Section not applicable) | 14 | 26.4 | | |
| Total | 29 | 54.7 | | |
| Total | 53 | 100.0 | | |

**Q21. You can use this space to write comments about any of the questions above.**

| |
|---|
| If, and I bet this is the case, they offered teaching sessions to GPs without backfill then they are plonking buffoons who don't understand how independent contractors work. |
| Not aware of sessions or content |
| not very apparent that any education has gone on 40% referral are inappropriate and 10% of routine referral have to be escalated because GP's have misinterpreted or failed to refer as USC |
| Unaware of any education sessions |

**Q22. If the referral guidelines are not relevant to your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 46 | 86.8 | 86.8 | 86.8 |

| | | | | |
|---|---|---|---|---|
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 7 | 13.2 | 13.2 | 100.0 |
| Total | 53 | 100.0 | 100.0 | |

**Q23. Were you informed about the work being carried out to update the guidelines before they were published?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about the work | 14 | 26.4 | 31.8 | 31.8 |
| Yes, but I would have liked to have had more information | 9 | 17.0 | 20.5 | 52.3 |
| No, I was not informed about it | 21 | 39.6 | 47.7 | 100.0 |
| Total | 44 | 83.0 | 100.0 | |
| Missing (Other) | 2 | 3.8 | | |
| Missing (Section not applicable) | 7 | 13.2 | | |
| Total missing | 9 | 17.0 | | |
| Total | 53 | 100.0 | | |

**Q23.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| Breast and lung seemed stupid and lacking in evidence at the time. I have no idea if I was wrong about that. |
| I was involved in the updated guideline development |
| Impact assessment and workforce to meet demand never considered |
| NA |
| see last answer 40% inappropriate and 10% routines need escalating to USC. they might as well toss a coin. |

**Q24.1.a. The updated guidelines were an appropriate strategy to promote early detection**

*Median 5.0 (IQR 4.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 4 | 7.5 | 10.0 | 10.0 |
| Disagree | 2 | 3.8 | 5.0 | 15.0 |
| Somewhat disagree | 2 | 3.8 | 5.0 | 20.0 |
| Neither agree nor disagree | 7 | 13.2 | 17.5 | 37.5 |
| Somewhat agree | 10 | 18.9 | 25.0 | 62.5 |
| Agree | 8 | 15.1 | 20.0 | 82.5 |
| Strongly agree | 7 | 13.2 | 17.5 | 100.0 |
| Total | 40 | 75.5 | 100.0 | |
| Missing (Don't know) | 5 | 9.4 | | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Missing (Section not applicable) | 7 | 13.2 | | |
| Total missing | 13 | 24.5 | | |
| Total | 53 | 100.0 | | |

**Q25. Did the updated referral guidelines increase demand for the services you provided to patients?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 29 | 54.7 | 80.6 | 80.6 |
| No | 7 | 13.2 | 19.4 | 100.0 |

| | | | | |
|---|---|---|---|---|
| Total | 36 | 67.9 | 100.0 | |
| Missing (Don't know) | 8 | 15.1 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Total missing | 7 | 13.2 | | |
| Total | 17 | 32.1 | | |

**Q26. You can use this space to write any comments about this section.**

| |
|---|
| Again, they appeared risk averse and to increase work without adequate resources, leading to delay in other services. I am not aware of any evidence it helped (except in bowel), but happy to be proved wrong |
| Don't think I'm aware how these changed things, or indeed that they had been rewritten, unless this refers to the vast review of all studies on presenting symptoms of cancer, but even this made no detectable difference to practice. |
| Due to waiting times from primary to secondary care many GPs mark referrals as urgent suspicion even where this is not appropriate e.g. young breast pain. This becomes non-discriminatory and triage of referrals is required which is time consuming for medical staff. |
| Have managed to break service. Well done. |
| inappropriately so |
| More patients referred from primary care for assessment |
| Not sure whether it was guidelines themselves |
| Revised guidelines should have reduced demand for services but no obvious change. |
| see previous section |
| We can only do a certain amount of work. Increasing referrals does not mean our workload increases. The patients just have to wait in a queue. Because we do not have the flexibility to work more, we certainly are not allowed to work more. (lack of resources). |

**Q27. If this strategy is not relevant to you or your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 41 | 77.4 | 77.4 | 77.4 |
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 12 | 22.6 | 22.6 | 100.0 |
| Total | 53 | 100.0 | 100.0 | |

**Q28. Were you informed about the additional funding before it became available?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about the funding | 4 | 7.5 | 10.0 | 10.0 |
| Yes, but I would have liked to have had more information | 15 | 28.3 | 37.5 | 47.5 |
| No, I was not informed about it | 21 | 39.6 | 52.5 | 100.0 |
| Total | 40 | 75.5 | 100.0 | |
| Missing (Other) | 1 | 1.9 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total missing | 13 | 24.5 | | |
| Total | 53 | 100.0 | | |

**Q28.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| funding still a mystery - no one knows and run the service!! bowel cancer screening gone up by 120% with no extra funding. |

| |
|---|
| I am totally unaware of ANY addition funding available to staff on the 'shop floor'. I saw NO evidence WHATSOEVER of this |
| it was not recurring funding, therefore fairly pointless as a long-term strategy |
| More time to prepare bids. |
| NA |
| No funds were made available to help manage demand in my area of practice (Pathology). |
| There was insufficient time to have employed additional staff so our clinic like many others was overwhelmed and patients were waiting up to 12 weeks to be seen. We had to run evening and weekend clinics for a considerable time to get things back under control. As we did not detect significantly more breast cancers, patients with cancer actually waited longer. All of these issues applied most strongly to the first DCE Breast Cancer Campaign. |
| Was there additional funding? It certainly did not reach as far as the clinicians. |
| Was used to fund some respiratory consultant posts, but not clear whether they were asked to document any increase in workload |
| Well, we didn't get any of it in primary care. |

**Q29.1.a. Providing extra funding was an appropriate strategy to promote early detection**

*Median 5.0 (IQR 4.0-7.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 3 | 5.7 | 7.9 | 7.9 |
| Disagree | 1 | 1.9 | 2.6 | 10.5 |
| Somewhat disagree | 4 | 7.5 | 10.5 | 21.1 |
| Neither agree nor disagree | 8 | 15.1 | 21.1 | 42.1 |
| Somewhat agree | 7 | 13.2 | 18.4 | 60.5 |
| Agree | 4 | 7.5 | 10.5 | 71.1 |
| Strongly agree | 11 | 20.8 | 28.9 | 100.0 |
| Total | 38 | 71.7 | 100.0 | |
| Missing (Don’t know) | 2 | 3.8 | | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 15 | 28.3 | | |
| Total | 53 | 100.0 | | |

**Q29.2.a. I was confident that my team would be able to manage demand for screening and diagnostics when I was informed about the funding**

*Median 2.0 (IQR 1.0-4.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 11 | 20.8 | 33.3 | 33.3 |
| Disagree | 7 | 13.2 | 21.2 | 54.5 |
| Somewhat disagree | 4 | 7.5 | 12.1 | 66.7 |
| Neither agree nor disagree | 4 | 7.5 | 12.1 | 78.8 |
| Somewhat agree | 1 | 1.9 | 3.0 | 81.8 |
| Agree | 5 | 9.4 | 15.2 | 97.0 |
| Strongly agree | 1 | 1.9 | 3.0 | 100.0 |
| Total | 33 | 62.3 | 100.0 | |
| Missing (Don’t know) | 4 | 7.5 | | |
| Missing (Question not applicable) | 4 | 7.5 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 20 | 37.7 | | |
| Total | 53 | 100.0 | | |

**Q29.3.a. We had enough time to plan how to use the funding**

*Median 2.0 (IQR 1.0-3.5)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 11 | 20.8 | 37.9 | 37.9 |
| Disagree | 8 | 15.1 | 27.6 | 65.5 |
| Somewhat disagree | 3 | 5.7 | 10.3 | 75.9 |
| Neither agree nor disagree | 3 | 5.7 | 10.3 | 86.2 |
| Somewhat agree | 2 | 3.8 | 6.9 | 93.1 |
| Agree | 2 | 3.8 | 6.9 | 100.0 |
| Total | 29 | 54.7 | 100.0 | |
| Missing (Don't know) | 6 | 11.3 | | |
| Missing (Question not applicable) | 6 | 11.3 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 24 | 45.3 | | |
| Total | 53 | 100.0 | | |

**Q29.4.a. Primary and secondary care communicated well with each other when planning how to use the funding**

*Median 1.0 (IQR 1.0-3.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 15 | 28.3 | 55.6 | 55.6 |
| Disagree | 4 | 7.5 | 14.8 | 70.4 |
| Somewhat disagree | 4 | 7.5 | 14.8 | 85.2 |
| Neither agree nor disagree | 2 | 3.8 | 7.4 | 92.6 |
| Somewhat agree | 2 | 3.8 | 7.4 | 100.0 |
| Total | 27 | 50.9 | 100.00 | |
| Missing (Don't know) | 10 | 18.9 | | |
| Missing (Question not applicable) | 4 | 7.5 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 26 | 49.1 | | |
| Total | 53 | 100.0 | | |

**Q29.5.a. Additional funding resulted in more equipment for diagnosis**

*Median 1.0 (IQR 1.0-3.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 17 | 32.1 | 56.7 | 56.7 |
| Disagree | 5 | 9.4 | 16.7 | 73.3 |
| Somewhat disagree | 3 | 5.7 | 10.0 | 83.3 |
| Neither agree nor disagree | 1 | 1.9 | 3.3 | 86.7 |
| Somewhat agree | 1 | 1.9 | 3.3 | 90.0 |
| Agree | 3 | 5.7 | 10.0 | 100.0 |
| Total | 30 | 56.6 | 100.0 | |
| Missing (Don't know) | 9 | 17.0 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 23 | 43.4 | | |
| Total | 53 | 100.0 | | |

**Q29.6.a. Additional funding resulted in more workforce for diagnosis**

*Median 1.00 (IQR 1.00-4.25)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 17 | 32.1 | 56.7 | 56.7 |
| Disagree | 2 | 3.8 | 6.7 | 63.3 |
| Somewhat disagree | 3 | 5.7 | 10.0 | 73.3 |
| Neither agree nor disagree | 1 | 1.9 | 3.3 | 76.7 |
| Somewhat agree | 2 | 3.8 | 6.7 | 83.3 |
| Agree | 3 | 5.7 | 10.0 | 93.3 |
| Strongly agree | 2 | 3.8 | 6.7 | 100.0 |
| Total | 30 | 56.6 | 100.0 | |
| Missing (Don't know) | 9 | 17.0 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 12 | 22.6 | | |
| Total | 23 | 43.4 | | |
| Total | 53 | 100.0 | | |

**Q30. You can use this space to write any comments about this section.**

| |
|---|
| Additional consultant post (breast surgery) |
| Again, we got squat all, and secondary waiting times went up. So, I'm not impressed that resources matched demand. |
| How can you get more workforce when there a hundreds of consultant (and other staff vacancies)? Completely different planet the DCE group live in |
| In the initial round the extra funding was used to provide overtime to catch up with the backlog. Future tranches were perhaps better spent. |
| No funding came to Pathology. |
| Not aware of any funding. That could be due to my lack of being aware. or that it was never communicated |
| temporary funding caused a lot of problems down the line when there was no more money |
| There was as far as I know no increase in funding locally. We were expected to absorb a significant increase in demand into already stretched capacity. |
| This is news to me that additional funding was available. |
| unaware of any funding coming to endoscopy or bowel cancer screening in NHS fife |
| while funding was directed at diagnosis there seemed to be no additional planning to potential increased in treatment requirements following diagnosis or increased demand for support to patients |
| Workforce issues in diagnostics are the single largest stumbling block; this cannot happen overnight or even in a few months. But existing teams can plan appropriately and use funds wisely (e.g. equipment, locums) if advised well in advance of project start. |

**Q31. If the HEAT targets are not relevant to you or your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 35 | 66.0 | 66.0 | 66.0 |
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 18 | 34.0 | 34.0 | 100.0 |
| Total | 53 | 100.0 | 100.0 | |

**Q32. Were you informed about the HEAT targets before they were launched?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about these HEAT targets | 9 | 17.0 | 27.3 | 27.3 |

| | | | | |
|---|---|---|---|---|
| Yes, but I would have liked to have had more information | 10 | 18.9 | 30.3 | 57.6 |
| No, I was not informed about them | 14 | 26.4 | 42.4 | 100.0 |
| Total | 33 | 62.3 | 100.0 | |
| Missing (Other) | 2 | 3.8 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 20 | 37.7 | | |
| Total | 53 | 100.0 | | |

**Q32.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| it's all smoke and mirrors with no reality of the difference between strategy and operational delivery |
| The targets & how they were to be evaluated were late in being disseminated. |
| what are heat targets |
| Would have liked an opportunity to influence the targets. |

**Q33.1.a. HEAT targets were an appropriate strategy to promote early detection**

*Median 4.0 (IQR 2.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 5 | 9.4 | 18.5 | 18.5 |
| Disagree | 2 | 3.8 | 7.4 | 25.9 |
| Somewhat disagree | 4 | 7.5 | 14.8 | 40.7 |
| Neither agree nor disagree | 5 | 9.4 | 18.5 | 59.3 |
| Somewhat agree | 2 | 3.8 | 7.4 | 66.7 |
| Agree | 9 | 17.0 | 33.3 | 100.0 |
| Total | 27 | 50.9 | 100.0 | |
| Missing (Don't know) | 7 | 13.2 | | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 26 | 49.1 | | |
| Total | 53 | 100.0 | | |

**Q33.2.a. I was confident in my ability to meet HEAT targets**

*Median 2.5 (IQR 2.0-5.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 5 | 9.4 | 19.2 | 19.2 |
| Disagree | 8 | 15.1 | 30.8 | 50.0 |
| Somewhat disagree | 1 | 1.9 | 3.8 | 53.8 |
| Neither agree nor disagree | 5 | 9.4 | 19.2 | 73.1 |
| Somewhat agree | 5 | 9.4 | 19.2 | 92.3 |
| Agree | 2 | 3.8 | 7.7 | 100.0 |
| Total | 26 | 49.1 | 100.0 | |
| Missing (Don't know) | 7 | 13.2 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 27 | 50.9 | | |
| Total | 53 | 100.0 | | |

**Q33.3.a. It was difficult to integrate meeting HEAT targets with my usual work**

*Median 3.0 (IQR 2.0-5.0) – reverse scoring*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 1 | 1.9 | 4.2 | 4.2 |
| Disagree | 3 | 5.7 | 12.5 | 16.7 |
| Somewhat disagree | 3 | 5.7 | 12.5 | 29.2 |
| Neither agree nor disagree | 3 | 5.7 | 12.5 | 41.7 |
| Somewhat agree | 3 | 5.7 | 12.5 | 54.2 |
| Agree | 6 | 11.3 | 25.0 | 79.2 |
| Strongly agree | 5 | 9.4 | 20.8 | 100.0 |
| Total | 24 | 45.3 | 100.0 | |
| Missing (Don't know) | 8 | 15.1 | | |
| Missing (Question not applicable) | 3 | 5.7 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 29 | 54.7 | | |
| Total | 53 | 100.0 | | |

**Q33.4.a. HEAT targets pressured our team to act**

*Median 4.0 (IQR 2.0-5.5)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 4 | 7.5 | 16.0 | 16.0 |
| Disagree | 4 | 7.5 | 16.0 | 32.0 |
| Somewhat disagree | 1 | 1.9 | 4.0 | 36.0 |
| Neither agree nor disagree | 5 | 9.4 | 20.0 | 56.0 |
| Somewhat agree | 5 | 9.4 | 20.0 | 76.0 |
| Agree | 2 | 3.8 | 8.0 | 84.0 |
| Strongly agree | 4 | 7.5 | 16.0 | 100.0 |
| Total | 25 | 47.2 | 100.0 | |
| Missing (Don't know) | 8 | 15.1 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 28 | 52.8 | | |
| Total | 53 | 100.0 | | |

**Q33.5.a. HEAT targets worked as a reminder for where our efforts should be focused**

*Median 2.0 (IQR 2.0-5.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 6 | 11.3 | 22.2 | 22.2 |
| Disagree | 8 | 15.1 | 29.6 | 51.9 |
| Somewhat disagree | 3 | 5.7 | 11.1 | 63.0 |
| Neither agree nor disagree | 2 | 3.8 | 7.4 | 70.4 |
| Somewhat agree | 5 | 9.4 | 18.5 | 88.9 |
| Agree | 2 | 3.8 | 7.4 | 96.3 |
| Strongly agree | 1 | 1.9 | 3.7 | 100.0 |
| Total | 27 | 50.9 | 100.0 | |
| Missing (Don't know) | 6 | 11.3 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 18 | 34.0 | | |
| Total missing | 26 | 49.1 | | |
| Total | 53 | 100.0 | | |

**Q34. You can use this space to write comments about any of the questions above.**

| |
|---|
| I presume you mean QOF points, not HEAT in primary care? I am guessing that whoever wrote this survey is secondary care based.... |
| Reminder! We have other targets that DCE have never considered and are as important. |
| these are strategic public health measures not clinical |
| Very unhelpful HEAT target. Suggest a QI approach |
| We know where our efforts should be focussed, without external targets. |

**Q35. If the Bowel Screening Initiative is not relevant to you or your work, you will be able to go to a different section. Please choose ONE option:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| This strategy influenced my daily work AND/OR I helped to develop/implement it | 22 | 41.5 | 41.5 | 41.5 |
| This strategy did NOT influence my daily work and I did NOT help to develop/implement it | 31 | 58.5 | 58.5 | 100.0 |
| Total | 53 | 100.0 | 100.0 | |

**Q36. Were you informed about the bowel screening initiative before it was launched?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes, I was sufficiently informed about the bowel screening initiative | 16 | 30.2 | 72.7 | 72.7 |
| Yes, but I would have liked to have had more information | 4 | 7.5 | 18.2 | 90.9 |
| No, I was not informed about it | 2 | 3.8 | 9.1 | 100.0 |
| Total | 22 | 41.5 | 100.0 | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total | 53 | 100.0 | | |

**Q36.a. If you wish, you can use the box below to comment on your answer.**

| |
|---|
| This seemed sensible! |

**Q37.1.a. The bowel screening initiative was an appropriate strategy to promote early detection**

*Median 7.0 (IQR 5.5-7.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Disagree | 1 | 1.9 | 4.8 | 4.8 |
| Neither agree nor disagree | 2 | 3.8 | 9.5 | 14.3 |
| Somewhat agree | 2 | 3.8 | 9.5 | 23.8 |
| Agree | 5 | 9.4 | 23.8 | 47.6 |
| Strongly agree | 11 | 20.8 | 52.4 | 100.0 |
| Total | 21 | 39.6 | 100.0 | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 32 | 60.4 | | |
| Total | 53 | 100.0 | | |

**Q37.2.a. I was confident in my ability to be awarded the QOF points**

*Median 6.0 (IQR 2.0-7.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|

| | | | | |
|---|---|---|---|---|
| Strongly disagree | 1 | 1.9 | 9.1 | 9.1 |
| Disagree | 2 | 3.8 | 18.2 | 27.3 |
| Neither agree nor disagree | 1 | 1.9 | 9.1 | 36.4 |
| Somewhat agree | 1 | 1.9 | 9.1 | 45.5 |
| Agree | 2 | 3.8 | 18.2 | 63.6 |
| Strongly agree | 4 | 7.5 | 36.4 | 100.0 |
| Total | 11 | 20.8 | 100.0 | |
| Missing (Don't know) | 4 | 7.5 | | |
| Missing (Question not applicable) | 7 | 13.2 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 42 | 79.2 | | |
| Total | 53 | 100.0 | | |

**Q37.3.a. It was difficult to integrate the bowel screening initiative with my usual work**

*Median 4.5 (IQR 1.75-7.0) – reverse scoring*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 6 | 11.3 | 33.3 | 33.3 |
| Disagree | 2 | 3.8 | 11.1 | 44.4 |
| Somewhat disagree | 1 | 1.9 | 5.6 | 50.0 |
| Neither agree nor disagree | 1 | 1.9 | 5.6 | 55.6 |
| Agree | 4 | 7.5 | 22.2 | 77.8 |
| Strongly agree | 4 | 7.5 | 22.2 | 100.0 |
| Total | 18 | 34.0 | 100.0 | |
| Missing (Question not applicable) | 4 | 7.5 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 35 | 66.0 | | |
| Total | 53 | 100.0 | | |

**Q37.4.a. My team had enough time to reach non-responders to bowel screening**

*Median 2.5 (IQR 2.0-4.5)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 1 | 1.9 | 10.0 | 10.0 |
| Disagree | 4 | 7.5 | 40.0 | 50.0 |
| Somewhat disagree | 2 | 3.8 | 20.0 | 70.0 |
| Neither agree nor disagree | 1 | 1.9 | 10.0 | 80.0 |
| Agree | 1 | 1.9 | 10.0 | 90.0 |
| Strongly agree | 1 | 1.9 | 10.0 | 100.0 |
| Total | 10 | 18.9 | 100.0 | |
| Missing (Don't know) | 4 | 7.5 | | |
| Missing (Question not applicable) | 8 | 15.1 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 43 | 81.1 | | |
| Total | 53 | 100.0 | | |

**Q37.5.a. The bowel screening initiative pressured our team to act**

*Median 4.0 (IQR 1.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 6 | 11.3 | 33.3 | 33.3 |
| Disagree | 2 | 3.8 | 11.1 | 44.4 |
| Neither agree nor disagree | 4 | 7.5 | 22.2 | 66.7 |

| | | | | |
|---|---|---|---|---|
| Agree | 4 | 7.5 | 22.2 | 88.9 |
| Strongly agree | 2 | 3.8 | 11.1 | 100.0 |
| Total | 18 | 34.0 | 100.0 | |
| Missing (Don't know) | 1 | 1.9 | | |
| Missing (Question not applicable) | 3 | 5.7 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 35 | 66.0 | | |
| Total | 53 | 100.0 | | |

**Q37.6.a. The bowel screening initiative worked as a reminder for where our efforts should be focused**

*Median 4.0 (IQR 2.0-6.0)*

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Strongly disagree | 2 | 3.8 | 10.5 | 10.5 |
| Disagree | 5 | 9.4 | 26.3 | 36.8 |
| Neither agree nor disagree | 4 | 7.5 | 21.1 | 57.9 |
| Somewhat agree | 2 | 3.8 | 10.5 | 68.4 |
| Agree | 5 | 9.4 | 26.3 | 94.7 |
| Strongly agree | 1 | 1.9 | 5.3 | 100.0 |
| Total | 19 | 35.8 | 100.0 | |
| Missing (Don't know) | 1 | 1.9 | | |
| Missing (Question not applicable) | 2 | 3.8 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 34 | 64.2 | | |
| Total | 53 | 100.0 | | |

**Q38. Did the bowel screening initiative increase demand for the services you provided to patients?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes | 13 | 24.5 | 81.3 | 81.3 |
| No | 3 | 5.7 | 18.8 | 100.0 |
| Total | 16 | 30.2 | 100.0 | |
| Missing (Don't know) | 3 | 5.7 | | |
| Missing (Question not applicable) | 3 | 5.7 | | |
| Missing (Section not applicable) | 31 | 58.5 | | |
| Total missing | 37 | 69.8 | | |
| Total | 53 | 100.0 | | |

**Q39. You can use this space to write any comments about this section.**

| |
|---|
| bowel cancer screening now causing serious disruption to clinical routine and surveillance work. miscalculation ad communication where responsible. Clinical teams advised of a 10-15% increase (compliance) they failed to inform us that the positivity rate would increase from 2% to 3.4 % (public health aware but did not understand the impact and did not pass information on) |
| Huge increase in demand for scopes, with subsequent increase in operative activity with no increase in funding or other support. |
| people would come to discuss the positive result, and sometimes would want referred privately for the colonoscopy so that it was done even sooner |
| Screening in CRC is effective. Demand is highly sensitive to sensitivity of the test and concordance. Demand has increased substantially since qFIT was introduced for both these reasons |

| |
|---|
| The idea made sense. The approach in primary care was an incoherent mess. No idea if it helped, we mostly ignored it. |
| well done qFIT |

**Q40. Would you describe yourself as:**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Male | 20 | 37.7 | 40.8 | 40.8 |
| Female | 29 | 54.7 | 59.2 | 100.0 |
| Total | 49 | 92.5 | 100.0 | |
| Missing (I prefer not to say) | 4 | 7.5 | | |
| Total | 53 | 100.0 | | |

**Q40.a. Please use this box if you wish to specify any answers:**

| |
|---|
| How is this relevant? |

**Q41. In what year were you born?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| 1957 | 1 | 1.9 | 2.9 | 2.9 |
| 1958 | 1 | 1.9 | 2.9 | 5.9 |
| 1960 | 1 | 1.9 | 2.9 | 8.8 |
| 1961 | 2 | 3.8 | 5.9 | 14.7 |
| 1962 | 4 | 7.5 | 11.8 | 26.5 |
| 1963 | 1 | 1.9 | 2.9 | 29.4 |
| 1964 | 2 | 3.8 | 5.9 | 35.3 |
| 1965 | 2 | 3.8 | 5.9 | 41.2 |
| 1967 | 4 | 7.5 | 11.8 | 52.9 |
| 1968 | 3 | 5.7 | 8.8 | 61.8 |
| 1969 | 3 | 5.7 | 8.8 | 70.6 |
| 1970 | 3 | 5.7 | 8.8 | 79.4 |
| 1972 | 2 | 3.8 | 5.9 | 85.3 |
| 1974 | 1 | 1.9 | 2.9 | 88.2 |
| 1975 | 1 | 1.9 | 2.9 | 91.2 |
| 1978 | 2 | 3.8 | 5.9 | 97.1 |
| 1980 | 1 | 1.9 | 2.9 | 100.0 |
| Total | 34 | 64.2 | 100.0 | |
| Missing | 19 | 35.8 | | |
| Total | 53 | 53 | 100.0 | |

Year of birth recoded to have complete date, 01/06 chosen for day and month

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| 38 | 1 | 1.9 | 2.9 | 2.9 |
| 40 | 2 | 3.8 | 5.9 | 8.8 |
| 43 | 1 | 1.9 | 2.9 | 11.8 |
| 44 | 1 | 1.9 | 2.9 | 14.7 |
| 46 | 2 | 3.8 | 5.9 | 20.6 |
| 48 | 3 | 5.7 | 8.8 | 29.4 |
| 49 | 3 | 5.7 | 8.8 | 38.2 |
| 50 | 3 | 5.7 | 8.8 | 47.1 |
| 51 | 4 | 7.5 | 11.8 | 58.8 |
| 53 | 2 | 3.8 | 5.9 | 64.7 |

| | | | | |
|---|---|---|---|---|
| 54 | 2 | 3.8 | 5.9 | 70.6 |
| 55 | 1 | 1.9 | 2.9 | 73.5 |
| 56 | 4 | 7.5 | 11.8 | 85.3 |
| 57 | 2 | 3.8 | 5.9 | 91.2 |
| 58 | 1 | 1.9 | 2.9 | 94.1 |
| 60 | 1 | 1.9 | 2.9 | 97.1 |
| 61 | 1 | 1.9 | 2.9 | 100.0 |
| Total | 34 | 64.2 | 100.0 | |
| Missing | 19 | 35.8 | | |
| Total | 53 | 100.0 | | |

Age variable recoded into age bands used by ISD Scotland to describe NHS workforce

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| 35-39 | 1 | 1.9 | 2.9 | 2.9 |
| 40-44 | 4 | 7.5 | 11.8 | 14.7 |
| 45-49 | 8 | 15.1 | 23.5 | 38.2 |
| 50-54 | 11 | 20.8 | 32.4 | 70.6 |
| 55-59 | 8 | 15.1 | 23.5 | 94.1 |
| 60-64 | 2 | 3.8 | 5.9 | 100.0 |
| Total | 34 | 64.2 | 100.0 | |
| Missing | 19 | 35.8 | | |
| Total | 53 | 100.0 | | |

**Q42. What was your profession from 2011 until 2015? You can tick more than one answer or choose "Other" if appropriate.**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Allied Health Professionals, Healthcare Scientists and Scientific & Technical staff | 1 | 1.9 | 2.0 | 2.0 |
| Medical Staff | 39 | 73.6 | 76.5 | 78.4 |
| Registered nurse | 6 | 11.3 | 11.8 | 90.2 |
| Public Health or Health Improvement | 1 | 1.9 | 2.0 | 92.2 |
| General managers | 1 | 1.9 | 2.0 | 94.1 |
| Charity worker | 1 | 1.9 | 2.0 | 96.1 |
| Other | 2 | 3.8 | 3.9 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing (I prefer not to say) | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q42.a. Please use this box if you wish to specify any answers**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Audit staff/coordination | 2 | 3.8 | 6.7 | 6.7 |
| Consultant | 1 | 1.9 | 3.3 | 10.0 |
| Consultant Nurse and Co-Chair of our Board Strategy Group | 1 | 1.9 | 3.3 | 13.3 |
| Endoscopy Lead | 1 | 1.9 | 3.3 | 16.7 |
| GP | 5 | 9.4 | 16.7 | 33.3 |
| GP+ specialty doctor+ hospice on call | 1 | 1.9 | 3.3 | 36.7 |
| Histopathologist | 1 | 1.9 | 3.3 | 40.0 |
| Lung Cancer CNS | 1 | 1.9 | 3.3 | 43.3 |
| nurse endoscopist | 1 | 1.9 | 3.3 | 46.7 |
| Pathologist | 2 | 3.8 | 6.7 | 53.3 |
| Radiologist | 3 | 5.7 | 10.0 | 63.3 |

| | | | | |
|---|---|---|---|---|
| Surgeon | 11 | 20.8 | 36.7 | 100.0 |
| Total | 30 | 56.6 | 100.0 | |
| Missing data | 23 | 43.4 | | |
| Total | 53 | 100.0 | | |

Question on profession shortened to have fewer categories, based on answers to Q42 and Q42.a

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Medical | 39 | 73.6 | 76.5 | 76.5 |
| Nursing | 6 | 11.3 | 11.8 | 88.2 |
| Audit | 2 | 3.8 | 3.9 | 92.2 |
| Other | 4 | 7.5 | 7.8 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing data | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q43. Does your work focus on a specific cancer type (e.g. breast, lung, bowel cancer)?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Yes (please specify) | 39 | 73.6 | 75.0 | 75.0 |
| No, my work includes more than one cancer type | 13 | 24.5 | 25.0 | 100.0 |
| Total | 52 | 98.1 | 100.0 | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Total | 53 | 100.0 | | |

**Q43.a. Please use this box if you wish to specify any answers**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Bowel and upper GI | 1 | 1.9 | 3.3 | 3.3 |
| Bowel, colorectal or anal | 7 | 13.2 | 23.3 | 26.7 |
| Breast | 18 | 34.0 | 60.0 | 86.7 |
| Lung | 4 | 7.5 | 13.3 | 100.0 |
| Total | 30 | 56.6 | 100.0 | |
| Missing (Question not applicable) | 14 | 26.4 | | |
| Missing data | 9 | 17.0 | | |
| Total missing | 23 | 43.4 | | |
| Total | 53 | 100.0 | | |

Q43 recoded to indicate more than one tumour type/specific tumour type in the same variable

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| More than one tumour type | 13 | 24.5 | 25.0 | 25.0 |
| Focus on breast | 18 | 34.0 | 34.6 | 59.6 |
| focus on bowel, anal or upper GI | 8 | 15.1 | 15.4 | 75.0 |
| focus on lung | 4 | 7.5 | 7.7 | 82.7 |
| focus on one cancer type, missing info on which one | 9 | 17.0 | 17.3 | 100.0 |
| Total | 52 | 98.1 | 100.0 | |
| Missing (Question not applicable) | 1 | 1.9 | | |
| Total | 53 | 100.0 | | |

**Q44. Still thinking of the 2011-2015 period, please write down the years DCE was relevant to your work. For example, from 2012 to 2014**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| 12-15 | 1 | 1.9 | 2.9 | 2.9 |
| 2011 to present | 1 | 1.9 | 2.9 | 5.9 |
| 2011-2015 | 11 | 20.8 | 32.4 | 38.2 |
| 2011-present | 1 | 1.9 | 2.9 | 41.2 |
| 2012 - 2016 | 1 | 1.9 | 2.9 | 44.1 |
| 2012 on | 1 | 1.9 | 2.9 | 47.1 |
| 2012 to present day | 1 | 1.9 | 2.9 | 50.0 |
| 2012 until the present | 1 | 1.9 | 2.9 | 52.9 |
| 2012-2014 | 3 | 5.7 | 8.8 | 61.8 |
| 2012-2015 | 1 | 1.9 | 2.9 | 64.7 |
| 2012-2015 and in fact still influencing our referral numbers | 1 | 1.9 | 2.9 | 67.6 |
| 2013-2015 | 1 | 1.9 | 2.9 | 70.6 |
| 2014 | 2 | 3.8 | 5.9 | 76.5 |
| 2014-2015 | 1 | 1.9 | 2.9 | 79.4 |
| 2015 | 1 | 1.9 | 2.9 | 82.4 |
| All | 2 | 3.8 | 5.9 | 88.2 |
| All | 1 | 1.9 | 2.9 | 91.2 |
| All years. | 1 | 1.9 | 2.9 | 94.1 |
| can' remember | 1 | 1.9 | 2.9 | 97.1 |
| No idea of end-date | 1 | 1.9 | 2.9 | 100.0 |
| Total | 34 | 64.2 | 100.0 | |
| Missing data | 19 | 35.8 | | |
| Total | 53 | 100.0 | | |

Q44 recoded into categorical variables

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| from pre-implementation to at least the first three years | 14 | 26.4 | 42.4 | 42.4 |
| from programme launch to at least the first three years | 11 | 20.8 | 33.3 | 75.8 |
| at least 2 years in the programme | 4 | 7.5 | 12.1 | 87.9 |
| at least one year in the programme | 4 | 7.5 | 12.1 | 100.0 |
| Total | 33 | 62.3 | 100.0 | |
| Missing data | 20 | 37.7 | | |
| Total | 53 | 100.0 | | |

Q44 recoded - at least three years involvement versus 1 or 2 years of involvement – not used for analysis

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| at least three years of involvement | 25 | 47.2 | 75.8 | 75.8 |
| one to two years of involvement | 8 | 15.1 | 24.2 | 100.0 |
| Total | 33 | 62.3 | 100.0 | |
| Missing data | 20 | 37.7 | | |
| Total | 53 | 100.0 | | |

**Q45. In which territorial Health Board do you work? You can tick more than one answer or choose "Other" if appropriate.**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Ayrshire and Arran | 9 | 17.0 | 17.6 | 17.6 |
| Dumfries and Galloway | 2 | 3.8 | 3.9 | 21.6 |
| Fife | 4 | 7.5 | 7.8 | 29.4 |
| Forth Valley | 2 | 3.8 | 3.9 | 33.3 |
| Greater Glasgow and Clyde | 11 | 20.8 | 21.6 | 54.9 |
| Lanarkshire | 3 | 5.7 | 5.9 | 60.8 |
| Lothian | 17 | 32.1 | 33.3 | 94.1 |
| Tayside | 2 | 3.8 | 3.9 | 98.0 |
| Whole of Scotland | 1 | 1.9 | 2.0 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing data (I prefer not to say) | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q46. Which best describes the area where you work?**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Large urban areas (Settlements of over 125,000 people) | 29 | 54.7 | 54.7 | 54.7 |
| Other urban areas (Settlements of 10,000 to 125,000 people) | 13 | 24.5 | 24.5 | 79.2 |
| Accessible small towns (Settlements of between 3,000 and 10,000 people, and within a 30-minute drive time of a Settlement of 10,000 or more) | 4 | 7.5 | 7.5 | 86.8 |
| Remote rural areas (Areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more) | 2 | 3.8 | 3.8 | 90.6 |
| Other (please specify) | 5 | 9.4 | 9.4 | 100.0 |
| Total | 53 | 100.0 | | |

**Q46.a. Please use this box if you wish to specify any answers**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Across the whole of Scotland | 1 | 1.9 | 14.3 | 14.3 |
| additionally: 1. accessible small towns 2. accessible rural areas 3. remote rural areas | 1 | 1.9 | 14.3 | 28.6 |
| All of the above | 1 | 1.9 | 14.3 | 42.9 |
| Mix of rural and urban | 1 | 1.9 | 14.3 | 57.1 |
| Mixed urban and rural. Large town (with mixed severe deprivation to middle class) plus surrounding villages and farms | 1 | 1.9 | 14.3 | 71.4 |
| Screening covers both urban and rural population | 1 | 1.9 | 14.3 | 85.7 |
| work at breast screening and also in that time period I worked in Clyde symptomatic breast service | 1 | 1.9 | 14.3 | 100.0 |
| Total | 7 | 13.2 | | |
| Missing (Question not applicable) | 46 | 86.8 | | |
| Total | 53 | 100.0 | | |

Q46 recoded to include both information for Q46 and Q46.a

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Large urban areas (Settlements of over 125,000 people) | 28 | 52.8 | 52.8 | 52.8 |
| Other urban areas (Settlements of 10,000 to 125,000 people) | 11 | 20.8 | 20.8 | 73.6 |
| Accessible small towns (Settlements of between 3,000 and 10,000 people, and within a 30-minute drive time of a Settlement of 10,000 or more) | 4 | 7.5 | 7.5 | 81.1 |
| Remote rural areas (Areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more) | 2 | 3.8 | 3.8 | 84.9 |
| Other (please specify) | 1 | 1.9 | 1.9 | 86.8 |
| Mix of rural and urban | 7 | 13.2 | 13.2 | 100.0 |
| Total | 53 | 100.0 | | |

**Q47. Which best describes your workplace? You can tick more than one answer or choose "Other" if appropriate.**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Primary Care practice | 8 | 15.1 | 15.4 | 15.4 |
| Hospital | 38 | 71.7 | 73.1 | 88.5 |
| Diagnostic centre, but not in a hospital | 4 | 7.5 | 7.7 | 96.2 |
| Cancer charity | 1 | 1.9 | 1.9 | 98.1 |
| Other | 1 | 1.9 | 1.9 | 100.0 |
| Total | 52 | 98.1 | 100.0 | |
| Missing (I prefer not to say) | 1 | 1.9 | | |
| Total | 53 | 100.0 | | |

**Q47.a. Please use this box if you wish to specify any answers**

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Acute Services | 1 | 1.9 | 4.8 | 4.8 |
| Board wide | 1 | 1.9 | 4.8 | 9.5 |
| Breast surgery | 1 | 1.9 | 4.8 | 14.3 |
| Breast Surgery | 1 | 1.9 | 4.8 | 19.0 |
| Breast unit | 1 | 1.9 | 4.8 | 23.8 |
| Cancer Research UK | 1 | 1.9 | 4.8 | 28.6 |
| Cardiothoracic Surgery | 1 | 1.9 | 4.8 | 33.3 |
| colorectal surgery and endoscopy | 1 | 1.9 | 4.8 | 38.1 |
| General? Colorectal surgery | 1 | 1.9 | 4.8 | 42.9 |
| Head and Neck Service | 1 | 1.9 | 4.8 | 47.6 |
| oncology | 1 | 1.9 | 4.8 | 52.4 |
| Pathology. | 1 | 1.9 | 4.8 | 57.1 |
| QEUH | 1 | 1.9 | 4.8 | 61.9 |
| Quality Department | 1 | 1.9 | 4.8 | 66.7 |
| Queen Margaret Hospital, Dunfermline | 1 | 1.9 | 4.8 | 71.4 |
| radiology | 1 | 1.9 | 4.8 | 76.2 |
| Radiology | 1 | 1.9 | 4.8 | 81.0 |
| Radiology and Screening | 1 | 1.9 | 4.8 | 85.7 |
| Respiratory | 1 | 1.9 | 4.8 | 90.5 |
| Respiratory dept | 1 | 1.9 | 4.8 | 95.2 |

| | | | | |
|---|---|---|---|---|
| Surgery | 1 | 1.9 | 4.8 | 100.0 |
| Total | 21 | 39.6 | 100.0 | |
| Missing data | 32 | 60.4 | | |
| Total | 53 | 100.0 | | |

Variable on profession and workplace created with data from Q42, Q42.a, Q47 and Q47.a.

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Medical - Surgeon | 11 | 20.8 | 21.6 | 21.6 |
| Medical - GP | 7 | 13.2 | 13.7 | 35.3 |
| Medical - Radiologist | 3 | 5.7 | 5.9 | 41.2 |
| Medical - Pathologist | 3 | 5.7 | 5.9 | 47.1 |
| Medical - Other/not specified | 15 | 28.3 | 29.4 | 76.5 |
| Nurse | 6 | 11.3 | 11.8 | 88.2 |
| other | 6 | 11.3 | 11.8 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing data | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

Final recoded variable to be used for profession

| | N | % | Valid % | Cumulative % |
|---|---|---|---|---|
| Medical - Secondary care | 32 | 60.4 | 62.7 | 62.7 |
| Medical - GP | 7 | 13.2 | 13.7 | 76.5 |
| Nurse | 6 | 11.3 | 11.8 | 88.2 |
| other | 6 | 11.3 | 11.8 | 100.0 |
| Total | 51 | 96.2 | 100.0 | |
| Missing data | 2 | 3.8 | | |
| Total | 53 | 100.0 | | |

**Q48. If you wish, please use this space to write your views about what worked well and what did not work so well in the programme.**

| |
|---|
| 3 years later, impossible to detect any impact on practice |
| Any programme that improves the knowledge of the general public to be aware of their own health and seek medical attention is vital, however within my area of work the sudden increase in work at the time caused a great deal of stress on the workforce. We were fortunate to have good management that kept us informed of what was happening and helped us to reshape the service provision following on from diagnosis. I would comment that while the funding rightly ensured the diagnostics were sufficient, further work to look at the complete pathway including treatment and follow up should have been included. The service was swamped very quickly and due to the good will and hard work of the team the service managed the workload, but this was not an easy process. |
| At the outset the planners failed to anticipate the need to know the mode of referral i.e. screening versus symptomatic, and this had to be added to the required data fields at a later date. It had been suggested at the early meetings but was not taken up by the analysts at ISD. |
| Breast cancer has a well-publicised screening programme. DCE filled our clinics with the "worried well" and resulted in delays to the diagnosis and management of patients with cancer. |
| DCE is an excellent concept - raising public awareness of early cancer signs is good; primary health care worker education is important. However, the downstream effects on |

| |
|---|
| diagnostics and treatment centres needs more thought and input - often the extra workload stretches already stretched resources. |
| DCE was completely unsuited to breast cancer diagnosis where there is already a screening programme in place. |
| did not diagnose any more cancers during this time. Extra work, no extra cancers |
| Electronic results were extremely helpful, it meant that they were filed straight into the patient's notes without the need for extra admin processes. They were readily available to the GPs and a member of the admin team who sent reminders to patients who did not attend for screening. |
| Great for patients. TERRIBLE for staff leading to low morale (overworked, underpaid, health deterioration of staff, emotional blackmail) |
| I don't have the data to usefully answer this. How much did it cost? How many QALYs did we get? Based on my limited exposure and internal bias I'm guessing that bowel made a bit of a difference, but I don't know at what cost; and lung and breast were a complete waste of time and money with the resulting opportunity cost of impacts on non-DCE targets? |
| I thought the bowel screening programme worked very well and the adverts were very good at raising public awareness. |
| Inadequate staff there huge premiums paid to meet demand - sadly no more staff and 5% year on year saving means that something has to give/ Should we stop all care except DCE? |
| Needed more clarity and preliminary discussion with clinicians to determine which approach would work best for which tumour type. Need much more intelligence on what are causes of delays to diagnosis. how many presentations to GP before referral, what are reasons patients do not present? Even how do most cancers present |
| None of it worked well from our services point of view |
| patient more anxious about minor changes. |
| Poorly: The introduction of the programme. I attended a national meeting at which someone from my Health Board said that staff were fully informed and had developed plans to implement DCE - this was completely untrue - we knew nothing until the campaign was upon us, and no plans were made to cope with additional referrals. Please note - in radiology, the issue is not necessarily funding, but finding trained staff. I have never seen any assessment of the value of the programme. The only thing which worked well was that we were eventually given some additional funding. |
| Public campaign raising lung cancer awareness DCE team listened to expert advice on how to approach this group of patients. |
| Significant increase in the worried well attending with non-high-risk symptoms. No increase in the detection rate of symptomatic breast cancer. Resources stretched with increase in appt times for urgent referrals including those with cancer. |
| The basic principle of DCE is good and using Elaine C Smith was excellent as she lightened the adverts while also seeming like a familiar face. It is not good to just run a short intense campaign that creates a flood of the ‘worried well’ which overwhelms a service a causes cancer patients to wait longer for diagnosis and treatment. An ongoing campaign is more likely to be seen by someone at the time they have a symptom or are due to take part in Screening. |
| To be honest none of it, cannot see any improvement prior to me starting in 2015, improvements have been local and not driven by this project. In fact, the reason to improve might have been as a result of unsustainable service pressures caused by the project. |
| we didn't pick up any extra cancers as a result of the programme..... |
| What did not work well was the marketing campaigns that were not scheduled in line with the breast screening programme. |
| Worked well - Having a designated lead, taking the time to find out our priority areas and having an open and transparent process for identifying funding priorities. Attempting to share the learning. Being consistent about the recording of staging in proformas and databases |
| worked well in appropriate age group but generally swamped with young people at low risk who were anxious and well .. very time consuming and labour intensive |

**Q49 If you wish, please let us know your views on barriers/facilitators to DCE success. These could be specific populations, financial issues, regional characteristics, or anything else you find relevant.**

| |
|---|
| Again, did it work? Assuming it didn't in at least two of the three groups, my guess would be that specialists did what specialists ought to do - pushed for resources for their own service. I'm also guessing that there was minimal competent health economist involvement. SG went along with it because who would argue with stopping people dying from cancer? And, as pretty much always, nobody cared what primary care thought. :- ) |
| Deprived populations continue to have poorer understanding and uptake. Better education in schools and communities is required to remove fear and stigma from the word cancer. Certain societies continue to have limited understanding and ignorance in cancer due to fear. |
| didn't meet anyone! clearly no follow up - I suspect team may have made contact with fife earlier on but not sustained involved and not made aware of any ongoing work when I took over service. |
| In the initial stages the screening service had meetings with SG DCE colleagues however the marketing strategies were not influenced by frontline staff and they went ahead as planned. |
| Lack of engagement with front line clinical staff |
| Lack of finance, especially initially. Lack of trained personnel. Lack of planning at Health Board level. |
| Managers who know little or nothing of a service but make judgements based on paper statistics. Speak to staff who know!! |
| Our clinics were completely swamped with the "worried well" requesting reassurance. The uptake should have been predicted in advance and a strategy set in place for dealing with the increased number of referrals. |
| Screening with qFIT may work well. HPV immunisation should be considered for specific population groups to reduce risk of anal cancer (and head and neck) |
| Short projects - worked when post holders were in place. Difficult to maintain or mainstream when the projects come to an end. |
| STAFFING - they do not exist to recruit. 2020 vision medical staff went to university c2005 and choose their specialty in 2013. How does this fit with DCE? |
| Was also important to advise patients on benefits of breast screening programme which is the best current method of diagnosing cancer at an early stage, this message was somewhat overshadowed by DCE info |
| waste of time and money but SG would not listen |
| Without the availability of good quality data, it would never have got off the ground. It might have been more effective if other cancer sites had been chosen where there was a greater chance of influencing behaviour. |

**Q50. Finally, if we missed any issues you wished to talk about, please let us know below.**

| |
|---|
| I found the earlier "rounds" of questions in this questionnaire odd - do those who didn't utilise certain aspects in their work not have a contribution to make? e.g. I attended a training course on DCE at its inception, but it had no impact on my work, so I answered "no" - and therefore didn't have the opportunity to comment on the training course, as the questionnaire flipped to the next section. I would like to see results of the impact, and additional work associated with, the DCE programme. |
| If this project is to continue, then you need to review engagement because people leave and do not necessarily handover that projects such as this exist. Clearly if the endoscopy and bowel cancer lead doesn't know you exist you have a problem. |
| Would be interesting to known what the plans are/were to assess the impact of DCE on patient outcomes (i.e. survival, symptom control). |

# Appendix 33. All bivariate analyses

**Table 1.** Assumption 1

| Participant characteristics | Q6.1.a Median (IQR) | Q6.2.a Median (IQR) | Q11.1.a Median (IQR) | Q11.1.b Median (IQR) | Q15.1.a Median (IQR) | Q20.1.a Median (IQR) | Q24.1.a Median (IQR) | Q29.1.a Median (IQR) | Q33.1.a Median (IQR) | Q37.1.a Median (IQR) |
|---|---|---|---|---|---|---|---|---|---|---|
| *Profession* | H(3)=12.386; **p=0.006**; N=49[1] | H(3)=5.919; p=0.116; N=49 | H(3)=10.544; **p=0.014**; N=50[4] | H(3)=5.520; p=0.137; N=38 | H(3)=8.915; **p=0.030**; N=40[5] | H(3)=7.064; p=0.070; N=22 | H(3)=8.827 **p=0.032**; N=39[6] | H(3)=1.853; p=0.604; N=37 | H(3)=6.280; p=0.099; N=26 | H(3)=0.230; p=0.093; N=20 |
| Medical – secondary care | 3 (2-5) | 2 (1-4) | 3 (2-5) | 4 (2-6) | 4 (2-5.5) | 4 (1-6) | 4 (3-5) | 4 (3.5-7) | 3 (1-4) | 7 (4-7) |
| Medical – GP | 5 (4-6) | 5 (4-5) | 6 (5-7) | 6 (5.5-7) | 5.5 (3.75-7) | 6 (5.5-7) | 6 (5-7) | 6 (3-6.5) | 5.5 (3.75-6) | 7 (6-7) |
| Nurse | 6 (4.25-7) | 5 (3.25-6) | 6 (5.5-7) | 6 (4.5-6.5) | 7 (4-7) | 6.5 (4.5-7) | 6 (5-7) | 6.5 (4.5-7) | 6 (3.75-6) | 6.5 (6-) |
| Other | 6 (4-6.25) | 5 (2-5.5) | 4.5 (3.5-6.25) | 5.5 (3.5-6.25) | 6.5 (5.25-7) | 4 (3-) | 6 (6-6) | 5 (5-) | 5 (1-) | 6 (6-) |
| *Cancer type* | H(4)=5.312; p=0.257; N=50 | H(4)=14.445; **P=0.006**[3]; N=50 | H(4)=8.818; p=0.066; N=50 | H(4)=3.825; p=0.430; N=37 | H(4)=3.926; p=0.416; N=40 | H(4)=5.416; p=0.247; N=22 | H(4)=2.341; p=0.673; N=39 | H(4)=3.607; p=0.462; N=37 | H(4)=1.958; p=0.743; N=26 | H(4)=4.207; p=0.122; N=20 |
| More than one tumour type | 5 (3.5-6) | 4 (2.25-5) | 6 (4-6.5) | 6 (4-7) | 5.5 (3.75-7) | 6 (5-6.75) | 6 (3.5-7) | 5 (3-6.5) | 4.5 (2.25-6) | 6 (5-7) |
| Breast | 3.5 (2-5.25) | 2 (1-2.25) | 3 (2-5) | 4 (2-6.5) | 4.5 (2-6) | 5 (2-7) | 5 (4-6) | 6 (4-7) | 3 (2-6) | (-) |
| Bowel, anal and/or upper GI | 4 (2-6) | 6 (2.5-7) | 5.5 (3.25-6.75) | 6 (3.5-6.5) | 4.5 (2.25-6) | 5 (4-) | 4.5 (1.75-5.25) | 5 (2.5-6.5) | 4 (4-5.5) | 7 (6.25-7) |
| Lung | 5.5 (3.25-7) | 5 (3.25-6.75) | 6.5 (4.5-7) | 6 (3-) | 6 (4.25-7) | 7 (7-7) | 4.5 (3.25-6.5) | 6 (5-) | 3 (2-) | (-) |
| One tumour type, unclear which one | 2.5 (1-5.5) | 4 (1-5.75) | 3.5 (1.25-5) | 4.5 (3.25-5.25) | 4.5 (1.75-6.25) | 3.5 (1.5-4.75) | 5.5 (3.75-6.0) | 4 (3.25-4.75) | 1 (1-) | 7 (7-7) |
| *DCE involvement* | H(2)=8.191; **p=0.017**; N=48[2] | H(2)=2.484; P=0.289; N=48 | H(2)=3.035; p=0.219; N=48 | H(2)=1.458; p=0.482; N=36 | H(2)=1.935; p=0.380; N=38 | H(2)=2.902; p=0.234; N=22 | H(2)=1.953; p=0.377; N=38 | H(2)=0.685; p=0.710; N=35 | H(2)=6.028; **p=0.049**; N=26)[7] | H(2)=6.556; **p=0.038**; N=20[8] |
| Yes | 5 (3.5-6.5) | 4 (2.25-4.75) | 6 (4-7) | 5 (4-7) | 6 (3.5-6.5) | 5.5 (5-6.25) | 5 (4-6) | 5 (4-7) | 4 (2.5-5.5) | 6 (5.25-6.75) |

| Participant characteristics | Q6.1.a Median (IQR) | Q6.2.a Median (IQR) | Q11.1.a Median (IQR) | Q11.1.b Median (IQR) | Q15.1.a Median (IQR) | Q20.1.a Median (IQR) | Q24.1.a Median (IQR) | Q29.1.a Median (IQR) | Q33.1.a Median (IQR) | Q37.1.a Median (IQR) |
|---|---|---|---|---|---|---|---|---|---|---|
| No, and I was happy with that | 5 (3-6) | 4 (2-5.75) | 4.5 (2.25-6) | 6 (2.5-6) | 5 (2.75-6.25) | 6 (3.5-7) | 5 (4-6) | 5 (4-6.75) | 6 (4-6) | 7 (7-7) |
| No, but I would have liked to have had an input | 2.5 (1-4.75) | 2 (1-5) | 4 (2-6) | 4 (3-6) | 4 (2-6) | 4 (1-6) | 4 (3-6) | 4.5 (2.75-7) | 2.5 (1-4.5) | 6 (4.5-6) |

[1,4,5,6,8]No significant differences found between any pairs in post-hoc tests. [2]Post-hoc tests showed that distributions were different between those who said "yes" and those who said "no, but I would have liked to have had an input (p=0.047).[3]Post-hoc tests showed that distributions were different between groups focusing on breast cancer and those focusing on bowel, anal or upper GI cancers. [7]Post-hoc tests showed that distributions were different between those who said "no, but I would have liked to have had an input" and those who said "no, and I was happy with that" (p=0.042).

**Table 2.** Assumption 2 (except communication between primary and secondary care) – Fishers' Exact Test used in all cases

| Participant characteristics | Q3 | | Q14 | | Q19 | | Q23 | | Q28 | | Q32 | | Q36 | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf |
| *Profession* | p=0.272; N=50 | | p=0.098; n=40 | | **p=0.036**; n=35 | | **p=0.001**; N=43 | | **p=0.002**; n=38 | | p=0.157; n=33 | | p=0.265; n=21 | |
| Medical – secondary care | 32.3% | 48.4% | 24.0% | 44.0% | 13.0% | 21.7% | 10.7% | 28.6% | 0.0% | 36.0% | 15.0% | 30.0% | 44.4% | 33.3% |
| Medical – GP | 42.9% | 28.6% | 83.3% | 0.0% | 60.0% | 20.0% | 71.4% | 0.0% | 0.0% | 40.0% | 42.9% | 42.9% | 100% | 0.0% |
| Nurse | 66.7% | 33.3% | 60.0% | 40.0% | 60.0% | 20.0% | 66.7% | 0.0% | 75.0% | 25.0% | 50.0% | 0.0% | 100% | 0.0% |
| Other | 83.3% | 16.7% | 50.0% | 25.0% | 50.0% | 50.0% | 100% | 0.0% | 0.0% | 75.0% | 50.0% | 50.0% | 66.7% | 33.3% |
| *Cancer type* | p=0.756; N=51 | | **p=0.004**; N=41 | | p=0.462; n=35 | | p=0.422; n=43 | | p=0.942; n=39 | | p=0.112; n=32 | | **p=0.016**; n=21 | |
| More than one tumour type | 53.8% | 23.1% | 70.0% | 10.0% | 55.6% | 11.1% | 54.5% | 18.2% | 20.0% | 30.0% | 45.5% | 36.4% | 91.7% | 0.0% |
| Breast | 33.3% | 50.0% | 6.3% | 56.3% | 9.1% | 27.3% | 14.3% | 28.6% | 8.3% | 41.7% | 14.3% | 42.9% | 0.0% | 0.0% |
| Bowel, anal and/or upper GI | 28.6% | 57.1% | 25.0% | 50.0% | 16.7% | 33.3% | 14.3% | 28.6% | 0.0% | 60.0% | 0.0% | 28.6% | 50.0% | 50.0% |
| Lung | 50.0% | 50.0% | 50.0% | 50.0% | 33.3% | 0.0% | 25.0% | 25.0% | 0.0% | 33.3% | 50.0% | 50.0% | - | - |
| One tumour type, unclear which one | 55.6% | 22.2% | 71.4% | 0.0% | 50.0% | 16.7% | 42.9% | 0.0% | 11.1% | 22.2% | 20.0% | 0.0% | 100% | 0.0% |
| *DCE involvement* | p=0.229; n=49 | | p=0.766; n=40 | | p=0.159; n=35 | | **p=0.009**; n=42 | | p=0.420; n=38 | | p=0.458; n=31 | | p=0.916; n=21 | |
| Yes | 77.8% | 22.2% | 55.6% | 33.3% | 66.7% | 16.7% | 85.7% | 14.3% | 16.7% | 66.7% | 66.7% | 33.3% | 75.0% | 25.0% |

| Participant characteristics | Q3 | | Q14 | | Q19 | | Q23 | | Q28 | | Q32 | | Q36 | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf | Suff. Inf | More inf |
| No, and I was happy with that | 33.3% | 52.4% | 42.9% | 35.7% | 33.3% | 13.3% | 33.3% | 16.7% | 12.5% | 31.3% | 26.7% | 26.7% | 61.5% | 23.1% |
| No, but I would have liked to have had an input | 42.1% | 36.8% | 29.4% | 41.2% | 14.3% | 35.7% | 11.8% | 29.4% | 6.3% | 37.5% | 15.4% | 38.5% | 100% | 0.0% |

Abbreviations: Suff Inf: sufficiently informed; More Inf: would have liked more information.

**Table 3.** Assumption 2 (communication between primary and secondary care)

| Participant characteristics | Q29.4.a Median (IQR) |
|---|---|
| *Profession* | H(3)=9.686; **p=0.021**; N=25[1] |
| Medical – secondary care | 1 (1-1.25) |
| Medical – GP | 3 (1-3.5) |
| Nurse | 4 (2-) |
| Other | 2 (1-) |
| *Cancer type* | H(4)=3.823; p=0.430; N=26 |
| More than one tumour type | 3 (1-4.5) |
| Breast | 1 (1-2.75) |
| Bowel, anal and/or upper GI | 1 (1-1) |
| Lung | 1 (1-1) |
| One tumour type, unclear which one | 1.5 (1-2) |
| *DCE involvement* | H(2)=1.272; p=0.529; N=25 |
| Yes | 2 (1-4) |
| No, and I was happy with that | 2 (1-3) |
| No, but I would have liked to have had an input | 1 (1-2.5) |

[1]Post-hoc tests showed that distributions were different between secondary care doctors and nurses (p=0.028)

**Table 4.** Assumption 3

| Participant characteristics | Q7.3.a Median (IQR) | Q20.3.a Median (IQR) | Q29.3.a Median (IQR) | Q37.4.a Median (IQR) |
|---|---|---|---|---|
| *Profession* | H(3)=8.404; **p=0.037**; N=46[1] | H(3)=2.491; p=0.477; n=23 | H(3)=5.514; p=0.138; n=28 | H(3)=2.121; p=0.548; n=10 |

| Participant characteristics | Q7.3.a Median (IQR) | Q20.3.a Median (IQR) | Q29.3.a Median (IQR) | Q37.4.a Median (IQR) |
|---|---|---|---|---|
| Medical – secondary care | 2 (1-3) | 2 (1-3) | 1 (1-2) | 3 (3-3) |
| Medical – GP | 3 (2-4) | 2 (1.5-3.5) | 2 (1-) | 2 (2-4) |
| Nurse | 5 (3.25-5.25) | 4 (1-4) | 4 (2-) | 2 (2-2) |
| Other | 2.5 (1-5) | 3.5 (2-) | 3 (2-) | 6 (6-6) |
| *Cancer type* | H(4)=13.051; **p=0.011**; n=47[2] | H(4)=2.294; p-0.682; n=23 | H(4)=2.165; p=0.705; n=28 | H(4)=1.932; p=0.381; n=10 |
| More than one tumour type | 3 (2-4.5) | 2.5 (1.25-4) | 2 (1-6) | 2.5 (2-3.75) |
| Breast | 1 (1-2) | 2 (1-4) | 1.5 (1-3.25) | (-) |
| Bowel, anal and/or upper GI | 4 (2-4) | 1.5 (1-3.5) | 1 (1-) | 2 (2-2) |
| Lung | 3 (1.25-4.75) | 1 (1-1) | 1.5 (1-) | (-) |
| One tumour type, unclear which one | 4 (1.25-5) | 2.5 (1.25-3.75) | 2 (1.75-2.50) | 6 (6-6) |
| *DCE involvement* | H(2)=6.925; **p=0.031**; n=46[3] | H(2)=1.621; p=0.445; n=24 | H(2)=0.335; p=0.846; n=26 | H(2)=0.837; p=0.658; n=10 |
| Yes | 4 (2.5-5) | 3.5 (1-5) | 2 (1-4.5) | 2 (2-2) |
| No, and I was happy with that | 3 (2-4) | 2 (1-3.25) | 2 (1-4) | 3 (2-4) |
| No, but I would have liked to have had an input | 1 (1-2.5) | 2 (1.25-4) | 2 (1-3) | 4.5 (2-) |

[1]No significant differences found between any pairs in post-hoc tests. [2]Post-hoc tests showed that distributions were different between groups focusing on breast and those focusing on more than one tumour type (p=0.031). [3]Post-hoc tests showed that distributions were different between those who said “yes” and those who said “no, but I would have liked to have had an input” (p=0.040).

**Table 5.** Assumption 4

| Participant characteristics | Q7.2.a Median (IQR) |
|---|---|
| *Profession* | H=9.795; **p=0.020**; N=44[1] |
| Medical – secondary care | 1 (1-3) |
| Medical – GP | 3.5 (1.75-5.25) |
| Nurse | 4.5 (3.5-6) |
| Other | 1 (1-6) |
| *Cancer type* | H=5.684; p=0.224; n=45 |
| More than one tumour type | 3 (1-6) |
| Breast | 1 (1-3.25) |
| Bowel, anal and/or upper GI | 1 (1-) |
| Lung | 3 (1.25-4) |

| Participant characteristics | Q7.2.a<br>Median (IQR) |
|---|---|
| One tumour type, unclear which one | 3 (1-5.5) |
| *DCE involvement*<br>Yes<br>No, and I was happy with that<br>No, but I would have liked to have had an input | H=4.674; p=0.097; n=43<br>3 (3-6)<br>2 (1-5)<br>1 (1-3) |

1Post-hoc tests showed that distributions were different between secondary care doctors and nurses (p=0.026).

**Table 6.** Mechanism 1

| Participant characteristics | Q7.1.a<br>Median (IQR) | Q20.2.a<br>Median (IQR) | Q33.3.a<br>Median (IQR) | Q37.3.a<br>Median (IQR) |
|---|---|---|---|---|
| *Profession* | H=1.660,<br>p=0.646, n=49 | H=5.076;<br>p=0.166; N=20 | H=6.573;<br>p=0.087; n=23 | H=5.501;<br>p=0.139; n=17 |
| Medical – secondary care | 7 (IQR 5-7) | 2.5 (1.25-6.25) | 4 (2-5.5) | 7 (6-7) |
| Medical – GP | 6 (IQR 5-7) | 1 (1-1.5) | 2 (1-2.25) | 2 (1-4) |
| Nurse | 6.5 (IQR 5.5-7) | 1 (1-4) | 3 (3-) | 2 (2-2) |
| Other | 5 (3.25-7) | 3 (3-3) | 1 (1-1) | 4 (2-) |
| *Cancer type* | H=0.985;<br>p=0.912; n=50 | H=2.839;<br>p=0.585; n=20 | H=2.564;<br>p=0.633; n=24 | H=3.860;<br>p=0.145; n=17 |
| More than one tumour type | 6 (IQR 4.5-7) | 1.5 (1-3.5) | 2 (1-6) | 2 (1-5.5) |
| Breast | 6.5 (IQR 4.75-7) | 1 (1-5.5) | 2 (1.25-4.25) | (-) |
| Bowel, anal and/or upper GI | 6 (IQR 4-7) | 2 (1-) | 4.5 (2.5-5.75) | 7 (4-7) |
| Lung | 7 (2.5-7) | 4 (4-4) | 4 (4-4) | (-) |
| One tumour type, unclear which one | 6(5-7) | 3.5 (1.5-6.25) | 3 (1-) | 4.5 (2-) |
| *DCE involvement* | H=1.118;<br>p=0.572; n=48 | H=4.977;<br>p=0.083; n=21 | H=1.525;<br>p=0.467; n=23 | H=0.018;<br>p=0.991; n=17 |
| Yes | 7 (IQR 5.5-7) | 3.5 (2.5-6.25) | 5 (2-) | 5 (2-) |
| No, and I was happy with that | 6 (IQR 5-7) | 1 (1-2) | 2 (1-4) | 2 (1-7) |
| No, but I would have liked to have had an input | 7 (IQR 4-7) | 2.5 (1-4.75) | 3 (1.5-4.5) | 4 (1-) |

**Table 7.** Mechanism 2

| Participant characteristics | Q29.2.a Median (IQR) | Q29.5.a Median (IQR) | Q29.6.a Median (IQR) |
|---|---|---|---|
| *Profession* | H=8.875; **p=0.031**; n=32[1] | H=9.942; **p=0.019**, n=28[2] | H=6.627; p=0.085; n=28 |
| Medical – secondary care | 2 (1-2.5) | 1 (1-2) | 1 (1-3) |
| Medical – GP | 3 (1.5-6) | 2.5 (2-) | 4 (2-) |
| Nurse | 4 (4-) | 5 (3-) | 5 (4-) |
| Other | 4 (3-) | 1.5 (1-) | 1.5 (1-) |
| *Cancer type* | H=3.598; p=0.463; n=32 | H=10.096; **p=0.039**; n=30[3] | H=2.952; p=0.566; n=30 |
| More than one tumour type | 3 (1.5-6) | 2.5 (2-6) | 2.5 (1-6) |
| Breast | 1.5 (1-4.5) | 1 (1-2.75) | 1 (1-4.5) |
| Bowel, anal and/or upper GI | 1.5 (1-3.5) | 1 (1-1) | 1 (1-) |
| Lung | 1.5 (1-) | 1 (1-1) | 1 (1-1) |
| One tumour type, unclear which one | 3 (2-4) | 1 (1-3) | 2 (1-5) |
| *DCE involvement* | H=1.229; p=0.541; n=31 | H=3.279; p=0.194; n=27 | H=1.180; p=0.554; n=27 |
| Yes | 2 (1.5-4.5) | 6 (1-) | 3 (1-) |
| No, and I was happy with that | 3.5 (1-4.5) | 1.5 (1-3.25) | 1 (1-3.25) |
| No, but I would have liked to have had an input | 2 (1-4.5) | 1 (1-2.25) | 1 (1-3.5) |

[1,3]No significant differences found between any pairs in post-hoc tests. [2]Post-hoc tests showed that distributions were different between secondary care doctors and nurses (p=0.024)

**Table 8.** Mechanism 3 – Fishers' Exact Test used in all cases

| Participant characteristics | Q8 (% answering yes) | Q9 (% answering yes) | Q16 (% answering yes) | Q25 (% answering yes) | Q38 (% answering yes) |
|---|---|---|---|---|---|
| *Profession* | p=0.071; N=48 | p=0.105; N=36 | p=1.000; N=37 | p=0.218; N=36 | p=0.079; N=16 |
| Medical – secondary care | 93.5% | 13.0% | 92.0% | 78.3% | 100% |
| Medical – GP | 100% | 50.0% | 100% | 85.7% | 66.7% |
| Nurse | 100% | 60.0% | 100% | 100% | 100% |
| Other | 50.0% | 50.0% | 100% | 0% | 0.0% |
| *Cancer type* | p=0.104; N=49 | p=0.101; N=36 | p=0.142; N=39 | p=0.125; N=36 | p=0.314; N=16 |
| More than one tumour type | 91.7% | 66.7% | 100% | 88.9% | 75.0% |
| Breast | 100% | 12.5% | 100% | 81.8% | - |
| Bowel, anal and/or upper GI | 100% | 25.9% | 100% | 100% | 100% |

| Participant characteristics | Q8 (% answering yes) | Q9 (% answering yes) | Q16 (% answering yes) | Q25 (% answering yes) | Q38 (% answering yes) |
|---|---|---|---|---|---|
| Lung | 75.0% | 0.0% | 75% | 75.0% | - |
| One tumour type, unclear which one | 77.8% | 25.0% | 85.7% | 40.0% | 50.0% |
| *DCE involvement* | p=0.359; N=47 | p=0.749; N=35 | p=0.644; N=36 | p=0.72; N=34 | p=0.516; N=15 |
| Yes | 100% | 33.3% | 100.0% | 80.0% | 100% |
| No, and I was happy with that | 95.2% | 33.3% | 100.0% | 93.3% | 83.3% |
| No, but I would have liked to have had an input | 84.2% | 21.4% | 87.5% | 61.5% | 50.0% |

**Table 9.** Mechanism 4

| Participant characteristics | Q33.2.a Median (IQR) | Q33.4.a Median (IQR) | Q33.5.a Median (IQR) | Q37.2.a Median (IQR) | Q37.5.a Median (IQR) | Q37.6.a Median (IQR) |
|---|---|---|---|---|---|---|
| *Profession* | H=7.391; p=0.060; n=25 | H=5.867; p=0.118; n=24 | H=2.528; p=0.470; n=26 | H=1.599; p=0.660; n=11 | H=2.929; p=0.403; n=18 | H=7.398; p=0.060; n=19 |
| Medical – secondary care | 2 (1-4) | 4 (1-4.5) | 2.5 (1-4) | 4 (1-) | 1.5 (1-4) | 3 (1.25-4) |
| Medical – GP | 5 (2-5.25) | 4 (2-6.25) | 2 (2-5.5) | 5.5 (2-7) | 4 (1-6) | 5 (2-6) |
| Nurse | 5 (4-) | 5 (5-) | 5.5 (2-6) | 6 (6-6) | 6 (6-6) | 6 (6-6) |
| Other | 2.5 (1-) | 6 (5-) | 3 (1-) | 7 (7-7) | 5 (4-) | 5.5 (5-) |
| *Cancer type* | H=1.834; p=0.766; n=35 | H=0.224; p=0.994; n=24 | H=6.335; p=0.175; n=26 | H=1.722; p=0.423; n=11 | H=3.430; p=0.189; n=17 | H=0.871; p=0.647; n=18 |
| More than one tumour type | 2 (2-5) | 2 (2-6) | 2 (2-5) | 5 (2-7) | 2 (1-6) | 3.5 (2-6) |
| Breast | 3 (1.5-5) | 4 (2.5-6) | 2 (1-2.5) | (-) | (-) | (-) |
| Bowel, anal and/or upper GI | 2 (2-3.5) | 4 (3-) | 4 (2.5-5.5) | 6 (4-) | 3 (1-4.5) | 4 (1.75-4.5) |
| Lung | 4 (4-4) | 4 (4-4) | 4.5 (4-) | (-) | (-) | (-) |
| One tumour type, unclear which one | 1 (1-) | 5 (1-) | 1 (1-) | 7 (7-7) | 6.5 (6-) | 5 (4-) |
| *DCE involvement* | H=1.839; p=0.399; n=25 | H=0.847; p=0.655; n=24 | H=2.392; p=0.302; n=26 | H=1.337; p=0.512; n=11 | H=1.169; p=0.557; n=17 | H=0.186; p=0.911; n=18 |
| Yes | 2 (2-3.5) | 3.5 (2-5) | 3.5 (2-5) | 2 (2-2) | 3 (2-) | 3.5 (2-) |
| No, and I was happy with that | 4 (2-5) | 4 (2-5.25) | 2.5 (2-5) | 6 (2-7) | 4 (1.25-6) | 4 (2.5-6) |
| No, but I would have liked to have had an input | 3.5 (1-4.25) | 4.5 (3.25-7) | 1.5 (1-4.25) | 6 (4-) | 1 (1-) | 4 (2-6) |

# Appendix 34. Theme definitions and relationships between themes

| Theme | Description |
|---|---|
| 1. Stakeholder buy-in | |
| 1.1 Support for core aim | Comments on support for the DCE programme, what influenced this and variations across stakeholders |
| 1.2 Early detection approaches and chosen tumour types | Comments on the appropriateness of focusing on screening or on cancer symptoms and signs, and on the tumour types chosen to be targeted by the programme |
| 1.3 Feedback on different strategies | Views on the referral guidelines, the bowel screening initiative and the social marketing campaigns, with information on mixed-buy-in, appropriateness, and engagement |
| 1.4 Performance targets | Comments on performance targets, their benefits and limitations, approaching both SQOF and the HEAT targets and issues regarding feasibility, clinical relevance and sense of ownership |
| 2. Communication | |
| 2.1 Source of information | Descriptions of different ways in which DCE shared information about the programme |
| 2.2 Ongoing communication and timeliness | References to how communication between DCE and stakeholders changed over time and limited notice about strategies (especially campaigns). This theme is linked with “Stakeholder buy-in” |
| 2.3 Rationale for strategies | Comments on whether the rationale for DCE and its strategies was known across different stakeholders. This theme is linked with “Stakeholder buy-in” |
| 2.4 Input from the health care community and charities | Views over whether stakeholders were able to give input on the programme before activities were implemented. This theme is linked with “Stakeholder buy-in” |
| 2.5 Dissemination of activities and outcomes | Views on DCE’s approaches to disseminating activities and outcomes |
| 3. DCE and the professionals’ roles | |
| 3.1 Business as usual | Comments on how professionals saw DCE as part of their core role |
| 3.2 Competing responsibilities and new tasks | Comments on how DCE was additional work, and at times indicated a new role altogether |
| 4. Using DCE funding | |
| 4.1 Allocation and variation | Description of how DCE funding was allocated across Health Boards, whether it was used for additional capacity or to fill existing gaps, which areas received funds and whether funding was perceived to be adequate. This theme is linked to “Regional variation” |
| 4.2 Funding is not necessarily the solution | Comments on how funding was not enough to solve capacity issues if professionals were not available to be recruited, and limitations brought by short-term funding. This theme is linked to “Barriers”. |
| 5. Impact on workload | |
| 5.1 Impact of different strategies | Reports of DCE impact on workload, especially regarding the impact of the symptomatic breast campaign |

| Theme | Description |
|---|---|
| 5.2 Unexpected impact | Views on whether DCE impact on workload was expected, happened as planned or plans underestimated impact |
| 6. Partnerships and collaborations | |
| 6.1 The role of charities | Comments on how charities were collaborators, partners, and leads in DCE activities, and how they added value/expertise to the programme. This theme is linked with “Communication” |
| 6.2 The role of creative and market research agencies | Comments on how different agencies helped to develop and evaluate DCE activities, and variations in the perception of programme success. This theme is linked with “Stakeholder buy-in” |
| 6.3 The role of the media | Comments on how interaction with the media had both positive and negative implications |
| 7. Official DCE outcomes | |
| 7.1 Joining the dots | Reports on the challenges of showing programme impact on cancer outcomes (attribution, which components contributed to changes), and linking intermediate and final outcomes |
| 7.2 Anecdotal evidence | References to anecdotal data when describing DCE impact , due to limited knowledge of national data, or limited measurement of impact |
| 7.3 Views on official outcomes | Any comments on programme impact associated with DCE’s main strategies and official programme objectives. This theme is linked to “Barriers” |
| 8. Soft outcomes and other benefits | |
| 8.1 A cumulative effect | Comments on an expected cumulative, long-term effect on help-seeking behaviour and cancer outcomes |
| 8.2 Changes in service provision | Comments on perceived changes brought by DCE in the way care was provided to patients, services were organised, and communication between primary and secondary care, prevention and early diagnosis, health care professionals and the Scottish Government |
| 8.3 Opportunity to develop local activities | Comments on how DCE enabled the implementation of local activities and projects which would not have happened otherwise |
| 8.4 Enhanced partnerships | Comments on how DCE helped to enhance government-charity partnerships |
| 8.5 Normalised discussions about cancer | Comments on how DCE helped to normalise discussions about cancer |
| 8.6 Measuring soft outcomes | Reports on recognised challenges in measuring soft outcomes |
| 9. Flexibility as a two-edged sword | |
| 9.1. A “chameleon” programme | Comments on DCE’s ability to be flexible in terms of funding different activities, focusing on different areas (such as cancer prevention) and allowing Health Boards to use funding as they saw appropriate. |
| 9.2. Challenges brought by flexibility | References to challenges brought by DCE flexibility in terms of implementing strategies, measuring outcomes and ensuring accountability. This theme is linked to “Barriers” |
| 10. Unanticipated outcomes | Any comments on unanticipated outcomes (positive or negative) brought by the programme (no sub-themes) |

| Theme | Description |
|---|---|
| 11. Stakeholder recommendations | Any recommendations on how DCE should proceed/change, and what should continue. Recommendations were listed in a table |
| 12. Barriers | |
| 12.1 Health system barriers | Any references to current challenges faced by the NHS in Scotland |
| 12.2 Factors influencing early detection | Any reference to individual factors and socio-demographic factors influencing early detection |
| 12.3 Funding system in Scotland | Description of how the way the funding system in Scotland is organised can be detrimental to a holistic approach to patient care |
| 12.4 Data challenges | Comments on challenges in accessing data, especially on referrals |
| 13. Facilitators | |
| 13.1 Country size | Comments on how Scotland's small size was a facilitator |
| 13.2 Cancer prevalence | Reflections upon the fact that cancer affects everyone's lives in different ways and this can be a motivator |
| 13.3 Good quality data | Any comments on the benefits of having good quality data |
| 13.4 Funding as a hook | Any comments on how funding enabled involvement. This theme is linked with "Stakeholder buy-in" |
| 13.5 Benefiting from existing activities and relationships | Reports on existing activities and developed relationships that facilitated DCE implementation |
| 13.6 Tailoring messages | Comments on how addressing specific needs worked as a facilitator |
| 14. A government initiative | |
| 13.1 Prioritisation of early detection | Any comments on how DCE, as it was a government programme, heled to bring early cancer detection to the centre of attention |
| 13.2 A dual purpose: politics and health | Any comments on the challenges brought by being a government programme, including the inevitable conflict between short- and long-term changes (and the use of performance targets), and the need to show that the government was fulfilling its commitment to improve population health |
| 13.3 A new type of initiative | Any comments on how DCE was a new, novel approach for government initiatives |
| 15. Cultural shifts | |
| 15.1 Realistic/personalised medicine | Any comments on a drive towards respecting patient's autonomy and informed choice, individual preferences, and towards a more holistic approach to care |
| 15.2 Image of cancer has changed | Reflections on how discussions about cancer are less often considered to be "taboo" |
| 16. Regional variation | Any comments on regional variation and its impact on programme implementation, engagement, evaluation, sustainability and outcomes |
| 17. DCE beyond three years | Any comments on contextual changes that happened after DCE's first three years, and how these influenced and were influenced by the programme |

# Appendix 35. Illustrative quotes mapped into implementation outcomes and COM-B components

## Implementation assumptions

| Examples from interviews and open-ended comments from questionnaire according to implementation outcomes |
|---|
| Assumption 1: Different stakeholders bought into DCE, its components and what it proposed to do |
| **Feasibility**<br>“I found it very frustrating and had serious practical implications for us which meant that you felt as though you were waiting and waiting and waiting and then you had to rush at everything and try and finish” (Interview participant, ID 28) |
| **Acceptability**<br>“I think it's just become accepted that this is probably the right thing to do. You'll still get your group who will never think it's the right thing to do and we should’ve invested our money in prevention or different areas” (Interview participant, ID 33) |
| **Sustainability**<br>“[I]t's always the case with any of these type of campaigns, unless you [inaudible] sustainable and the pressure and the momentum, you lose those gains that you saw in the early days” (Interview participant, ID 28)<br>“If this project is to continue then you need to review engagement because people leave and do not necessarily handover that projects such as this exist” (Questionnaire participant, Secondary Care Doctor, NHS Fife) |
| **Appropriateness**<br>“But there are times […] that there might be disagreement between the people that are working in the service and the marketing team and the advertising contractor that they use about what they think is appropriate” (Interview participant, ID 14) |
| Assumption 2: There was enough targeting and communication about DCE aims and its strategies, and what was expected from everyone |
| **Reach and communication**<br>“[A] lot of the time I would be watching social media and stuff to see what was coming up because that would be where you would hear about it first” (Interview participant, ID 15)<br>“Needed more clarity and preliminary discussion with clinicians to determine which approach would work best for which tumour type” (Questionnaire participant, Colorectal Surgeon, NHS Lothian) |
| Assumption 3: Available resources were sufficient to meet aims |
| **Feasibility**<br>“So the one stop breast clinics are very good in that people will get the process done right there and right then and get as close to the diagnosis as possible on the one visit.” (Interview participant, ID 13)<br>“No thought was given to available resources. This program has resulted in an enormous extra spend and will help bring the NHS to its knees. No program should be launched without consideration of workforce available” (Questionnaire participant, Secondary Care Doctor, NHS Forth Valley) |
| **Acceptability**<br>“[F]or us it wasn’t actually a financial incentive, it was that we had money to pay them to do things that we had both agreed there was some evidence of likely benefit, both at a population level and at an individual patient level (Interview participant, ID 19) |
| **Sufficiency**<br>“The service managers say that there wasn’t enough money [laugh] so money's never enough” (Interview participant, ID 22) |
| 4. Flexibility was permitted when allocating resources |

| Examples from interviews and open-ended comments from questionnaire according to implementation outcomes |
|---|
| **Feasibility**<br>“When you've got all these different things that you're asking these people to do you almost have to prioritise those and go well actually smoking would disproportionately, you know, beneficial to tackle, actually you're betting putting your money behind that than trying to get people to do the eat this and do the 10,000 steps and do this, this and this. It's always a trade off with how much stuff you can do” (Interview participant, ID 24) |
| **Adaptability**<br>“We did weigh the funding, so if you had a practice population that had, yeah, so it was weighted on practice population over 50 and also deprivation, so a more deprived practice, a deep end practice for example, they would in theory get more money when they increased participation”. (Interview participant, ID 33)<br>“Now that we can take the funding and target it in line with our programme it can be put to good use” (Questionnaire participant, Allied Health Professional, NHS Lothian) |

## Mechanisms of impact

| COM-B construct | Examples from interviews and open-ended comments from questionnaire |
|---|---|
| Mechanism 1: DCE strategies were in line with what professionals perceived as their role, identity, organisational commitment and professional boundaries | |
| Reflective motivation | **Confirming mechanism**<br>“So I just took it as part of my job” (Interview participant, ID 11)<br>“In my lead cancer GP role it was core work, it wasn’t extra work, it was what I was there to do, it was core work and it was positive and well-focused work” (Interview participant, ID 23) |
| Mechanism 2: Additional DCE funding resulted in more diagnostic equipment and/or workforce | |
| Physical opportunity | **Confirming mechanism**<br>“I think it was very effective, it certain brought to me, you know, it was a great mechanism financially to put some resources into services, into messages, into buy in from staff to sell the message” (Interview participant, ID 29)<br>“Increased colonoscopy lists, increased recruitment & training of non-medical endoscopists” (Questionnaire participant, bowel surgeon, NHS Greater Glasgow & Clyde) |
| | **Not confirming mechanism**<br>“The only other point I would make around that is that in some areas actually the money wasn’t the problem, so being allocated the money was great, don't get me wrong, but if you can't recruit pathologists or radiologists then you're stuck” (Interview participant, ID 20) |
| Reflective motivation | **Confirming mechanism**<br>“It basically went on clinical care and it went on clinical care on the argument, two arguments, one was well if you're going to do a lot of social marketing nationally or locally we'll have to shore up the local services so that they're ready for this vast quantity of people coming through the door, and partly because the service has always got difficulty” (Interview participant, ID 27) |
| | **Not confirming mechanism**<br>How can you get more workforce when there a hundreds of consultant (and other staff vacancies). Completely different planet the DCE group live in (Questionnaire participant, breast surgeon, NHS Ayrshire & Arran) |
| Mechanism 3: Increased demand brought by DCE was a driver for action and created pressure to act | |

| COM-B construct | Examples from interviews and open-ended comments from questionnaire |
|---|---|
| Automatic motivation | **Confirming mechanism**<br>"It caused a lot of angst at the time cause we deal with the same breast surgeons obviously as those in symptomatic" (Interview participant, ID 14) |
| Mechanism 4: Targets helped to focus the mind, showed where resources were needed and increased pressure to act | |
| Automatic motivation | **Unclear whether confirming or not confirming mechanism**<br>"[T]he variation from quarter to quarter and then from year to year is difficult in the percentage change and that sometimes makes people anxious about why there's so much variation, so we can look like we're doing okay one quarter and the next time we've gone really down and the non-execs and the execs as well in the organisation they get quite upset with this, and it's really just because the numbers are small" (Interview participant, ID 30) |
| Reflective motivation | **Confirming mechanisms**<br>"In general, as I said, targets, especially with financial incentives, do focus minds and I think they do work in general" (Interview participant, ID 10)<br>"So having those targets, those stage one increase targets, saw that reflected in our local delivery plan because it's based largely on the HEAT framework, so that pulled it straight to the centre of attention at the board" (Interview participant, ID 11) |
| | **Not confirming mechanism**<br>"For some of the tumour groups, you know, I think there was recognition lung again that you weren't going to be able to do that cause you weren't changing anything" (Interview participant, ID 20) |
| | **Confirming mechanisms for one target, but not for the other**<br>"And I guess where with both screening and the SQOF points there was an incentive, there was a clear incentive for the improvement, I'm not sure if from a clinical perspective there was a clear incentive for encouraging stage one diagnosis" (Interview participant, ID 31) |

# Appendix 36. The DCE workshop

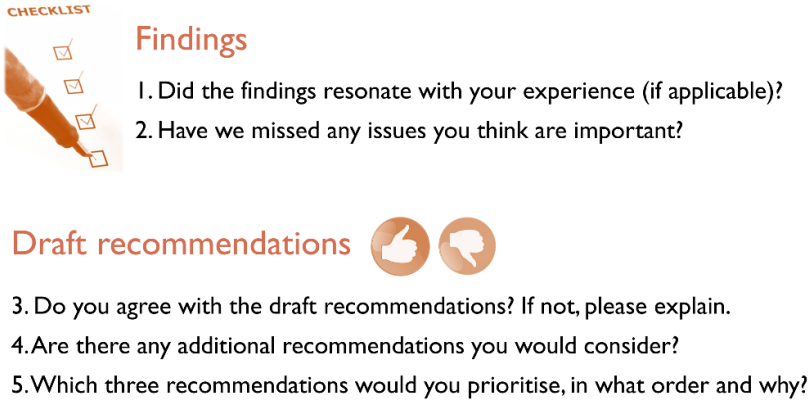
One of the deliverables to the Scottish Government was a workshop with DCE stakeholders. Although it was not a study component, the workshop was useful to engage with stakeholders, generate reflections on how to move forward, and ensure recommendations were relevant. The workshop had two aims: 1) to present a) results from the academic evaluation of the DCE Programme; and b) recommendations for policy; and 2) to discuss and refine recommendations to ensure that they were fit for purpose and realistic.

In early August 2018, 56 stakeholders were invited by email to attend the workshop (the aim was to have up to 25 participants). Stakeholders' names were obtained from the list prepared during evaluation development and included stakeholders who had been invited for an interview. An extended invitation was made to members of the Scottish Cancer Coalition. The invitation email encouraged stakeholders to forward the invitation to their colleagues. Twenty-three stakeholders contacted me to say that they wished to take part. And introductory brief describing the evaluation and an Agenda (Figure A) were sent in advance to all participants.

Figure A. Workshop Agenda

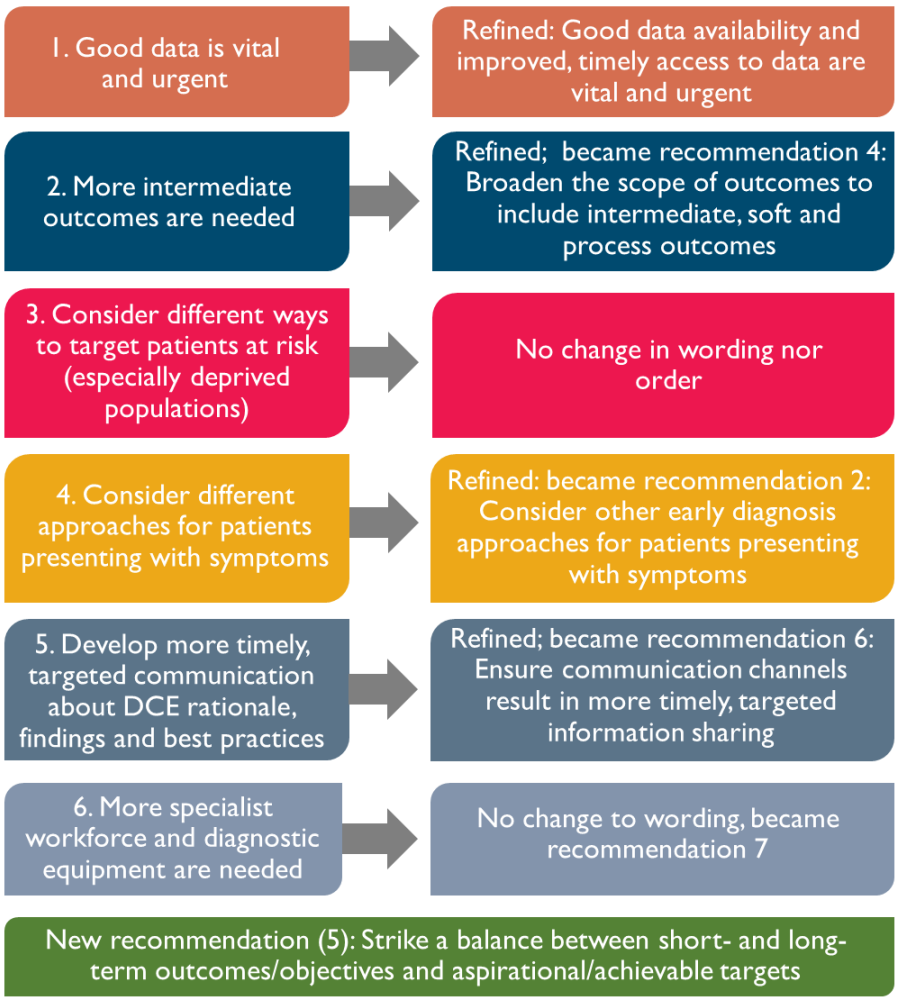

The workshop took place at a central Edinburgh location (a University of Edinburgh venue) on the 18th September 2018. Twenty stakeholders took part. After I presented evaluation findings and six draft recommendations, stakeholders were divided into four groups to discuss five questions (Figure B). My supervisors worked as facilitators.

Figure B. Workshop questions



Overall, findings resonated with the stakeholders' experience, although some mentioned issues not approached in the evaluation. Stakeholders agreed with the recommendations but asked for clarifications and discussions of findings resulted in a 7th recommendation. It was reportedly challenging to prioritise three recommendations as all seemed important, but changes to the order of recommendations were suggested. A more detailed description of stakeholders' feedback on recommendations is available in the final evaluation report prepared for the Scottish Government (Appendix 37), but a summary of changes made to recommendations is available below (Figure C).

Figure C. Draft and refined recommendations after the DCE workshop



# Appendix 37. Final evaluation report for the Scottish Government

# Evaluation of the Detect Cancer Early Programme in Scotland

## Reporting on processes and outcomes

Natalia Calanzani, David Weller and Christine Campbell

University of Edinburgh, Usher Institute

# Final Report

December 2018

THE UNIVERSITY of EDINBURGH

Usher Institute
Population Health Sciences & Informatics

Funded by:

The Scottish Government
Riaghaltas na h-Alba

## Disclaimers

The Detect Cancer Early (DCE) Evaluation was funded by the Scottish Government, designed and carried out independently by the Report authors. The Evaluation is also a component of a PhD study funded by scholarships from the University of Edinburgh (UoE). Leith Agency was responsible for insight gathering, development and creative testing of the DCE social marketing campaigns, while TNS, Carat and Consolidated PR evaluated the impact of awareness initiatives. Information Services Division (ISD) Scotland has published reports about several DCE outcomes. References are provided when this Evaluation describes secondary data sources.


## Acknowledgements

This work was only possible with the support and collaboration of many individuals and organisations. We thank the Scottish Government and the UoE for providing funding. Special thanks to David Linden, Nicola Barnstaple and Diane Primrose at the Scottish Government; and all who attended the DCE Programme Board meetings. We also thank Thea McGovern (Leith Agency); Alastair Graham (TNS); Audrey Irvine and Bob Steele (Scottish Bowel Screening Centre); and David Brewster, Greig Stanners, Amy McKeown and Roger Black (ISD Scotland). We are grateful to the Evaluation steering group (Ruth Jepson, Peter Murchie, Andrew Thompson and Tom Haswell) and to all stakeholders who pre-tested the questionnaire. We thank the Scottish Primary Care Cancer Group, the Scottish Cancer Coalition, NOSCAN, WOSCAN and SCAN (especially Hugh Brown, Claire Donaghy, Sami Shimi, Lisa Quarmby, Fran Coleman, James Mander and Kate MacDonald) for distributing the link to the questionnaire to their mailing lists. We thank everyone who attended the Workshop to discuss the Evaluation results and gave feedback on draft recommendations. Finally, we are very grateful to all stakeholders who donated their time to take part in the interviews and the questionnaire and made this Evaluation possible.


## Patient and public involvement

Data were not collected directly from patients nor the public, although this Evaluation reports on secondary data for both groups. The Process Evaluation focused on the health system and programme implementation from the perspective of professionals. Both the Evaluation steering group and the Evaluation workshop had public involvement (Mr Tom Haswell and Mrs Elspeth Banks respectively).

## Ethics

No NHS Research and Development (R&D) nor Research Ethics Committee (REC) approvals were required. Institutional ethical approval at the UoE was mandatory. Approval for interviews carried out during evaluation development was granted in April 2016 by the Centre for Population Health Sciences' Ethics Review Group. Approvals for the interviews and questionnaire (full evaluation components) were granted in January and April 2018 (respectively) by the Usher Research Ethics Group. Participants signed a consent form before interviews and agreed for these to be recorded, transcribed and anonymised. Participants gave online consent before completing the anonymised questionnaire.

## Use, dissemination and sharing



**Suggested citation:** Calanzani N, Weller D, Campbell C (2018). **Evaluation of the Detect Cancer Early Programme in Scotland. Reporting on processes and outcomes**. University of Edinburgh.



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# Contents

# Executive summary

## Overview

This Report describes key findings from an Evaluation of the Detect Cancer Early (DCE) Programme's processes and outcomes until 2015 (i.e. the initial phase). The Report firstly provides background evidence on why early detection initiatives are needed, with recognition of the limitations of early detection strategies in improving cancer survival. Cancer policies leading to DCE development, DCE components and objectives are then outlined. Evaluation methods are described. We then report on programme outcomes, followed by findings from the process evaluation. Finally, recommendations underpinned by findings and refined in a Workshop with stakeholders to ensure relevance and appropriateness are presented. It is hoped that the results and recommendations can be useful as a tool to guide future directions for DCE and other early cancer detection programmes.

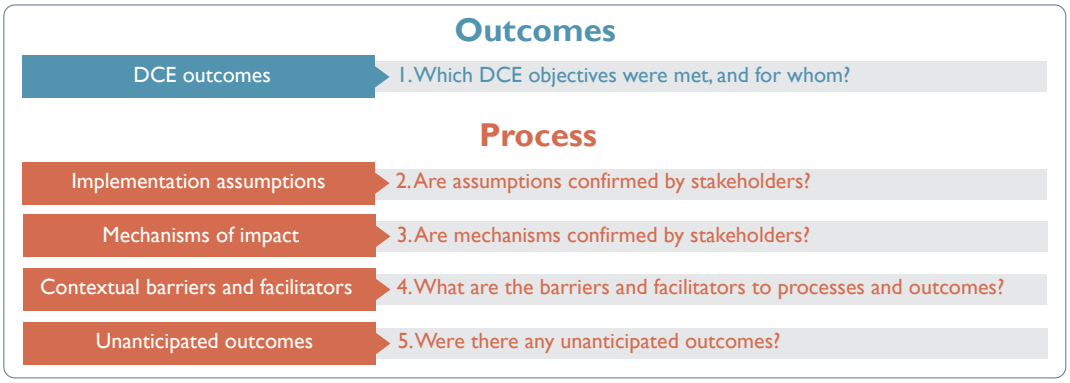
## The DCE Programme

- DCE is a multi-level early detection initiative launched in 2012 with the aim to improve cancer survival, initially focusing on breast, colorectal and lung cancers (the three main causes of cancer death in Scotland at the time)
- DCE's initiatives involve collaboration with multiple stakeholders, including primary care practices, charities and official providers of health intelligence data
- Originally planned to last three years, DCE remains a key component of the Scottish Cancer Strategy. In its initial phase (2012-2015), DCE had four main strategies: public awareness and behaviour influencing; primary care symptom management and referral; secondary care and diagnostic capacity; and performance management and monitoring.

## Evaluation methods

- Evaluation design was informed by interviews with nine DCE stakeholders, analysis of 159 policy documents, and review of health system evaluation methods
- Theory-based evaluation and the Medical Research Council's Framework for Process Evaluation of Complex Interventions were selected as the most appropriate methodology to evaluate DCE outcomes and processes
- Outcome evaluation assessed DCE official objectives, while the process evaluation assessed contextual barriers and facilitators; mechanisms of impact and assumptions about implementation; and explored unanticipated outcomes
- Outcome evaluation comprised secondary analysis of published and unpublished data, and a time-trends analysis of requests for bowel screening kits

- Process evaluation consisted of in-depth interviews and an anonymised online questionnaire survey with DCE stakeholders (including primary and secondary care professionals, public health specialists, and those managing DCE activities) from across Scotland
- Evidence-based draft recommendations were developed and discussed with DCE stakeholders at a Workshop in September 2018. Recommendations were refined according to their feedback.




Evaluation questions

## Key findings: Outcome Evaluation

- **DCE had eight main objectives - not all of them could be assessed through this Evaluation**. Some objectives were broad and aspirational; in other cases insufficient data meant rigorous assessment was not possible
- **Although the main programme's targets (HEAT) were not met in full, critical improvements in cancers diagnosed in earlier stages were observed**. By Year 3, there was a 7.0% increase in cancers (breast, colorectal and lung combined) diagnosed at Stage 1. There was a 25.0% increase for lung and a 5.1% increase for breast cancer; and increases were seen across all levels of social deprivation. On the other hand, there was a decrease in the proportion of colorectal cancers diagnosed at Stage 1 (4.3% reduction in Year 3)
- **Improvements in recording of staging data have been observed** (44.2% reduction in Year 3 for all three cancers combined), with fewer breast (65.2% reduction), colorectal (36.7% reduction) and lung cancers (38.7% reduction) being recorded with unknown tumour stages. Reductions occurred across all levels of social deprivation; with the most deprived having the highest reduction in Year 3 (54.5%). Early improvements in staging (especially in Year 1) were partially due to improvements in recording.
- Independent evaluation of awareness campaigns indicate an **increase in awareness of screening, cancer signs and symptoms among the public, but also highlight**

**the need to continue with campaigns in the long-term** (with refinements to avoid message fatigue). **Attitudinal changes over time were reported,** although barriers such as cancer fear and concerns about wasting the doctor's time persisted

- Increases in requests for bowel screening kits and in breast consultations are further indications that the campaigns reached the public, although there is no evidence that the increases resulted in more breast cancer diagnoses. Furthermore, the increases did not result in a higher proportion of bowel cancers being diagnosed at Stage 1. Reasons for these results need to be further discussed and investigated.

## Key findings: Process Evaluation

- Interviews (n = 25) and online questionnaire responses (n =53) provided valuable insights on both strengths and weaknesses of DCE processes from the perspectives of stakeholders, including front-line clinical and Health Promotion staff
- Although hard to quantify, stakeholders identified **enhanced professional working across cancer diagnostic pathways, heightened awareness of early diagnosis, and 'normalisation' of conversations about cancer with patients and the public as valuable intangible benefits of DCE** that transcend the more formal programme objectives
- Short-term, **ambitious DCE targets were perceived by some to have impacted negatively on stakeholder engagement as the objectives were felt to be unachievable**; questions were also raised over whether targets were a good measure of success
- Short-term plans were seen to be **in tension with the ability to improve cancer outcomes as these often require long-term strategies**; and with establishing and sustaining successful early detection strategies
- Campaigns that focused on symptoms had an **impact on workload in both primary and secondary care, but limited impact on cancer outcomes**
- Communication issues consistently emerged from interviews and free-text comments within the questionnaire survey: **some stakeholders indicated that more information about the programme, the rationale for its activities, and its outcomes, was required**. Limited information was associated with a reported reduced sense of ownership and engagement
- Stakeholders emphasised that DCE supported many local, successful campaigns and **recommended the national dissemination of results and best practice in order to share learning**
- Contextual barriers such as l**ack of radiologists, stretched capacity and limited GP availability were highlighted** as challenges to DCE implementation.

# Recommendations

Based on Evaluation results and Workshop discussions, we make the following recommendations:

| | |
|---|---|
| Recommendation 1 | Good data availability and improved, timely access to data are vital and urgent |
| Recommendation 2 | Consider other early diagnosis approaches for patients presenting with symptoms |
| Recommendation 3 | Consider different ways to target patients at risk, especially deprived populations |
| Recommendation 4 | Broaden the scope of outcomes to include intermediate, "soft" and process outcomes |
| Recommendation 5 | Strike a balance between short- and long-term outcomes/objectives and aspirational/achievable targets |
| Recommendation 6 | Ensure communication channels result in more timely, targeted information sharing |
| Recommendation 7 | More specialist workforce and diagnostic equipment are needed |

## Evidence-based recommendations

"There's lots of wee projects that have been funded over the years that have not been properly shared nationally, so if you sit at the Programme Board you hear about things [...] I think there's a lot more than even I'm aware of [...] That kind of sharing and showing all the stuff that's been done with the money could be done a bit better and a bit more robustly so that people did see all the great things that came out of it and, you know, yeah, really get to reflect on all of it"

Interview participant, ID 15

# 1. Introduction

## 1.1 Background to the study

Researchers at the University of Edinburgh contacted the Detect Cancer Early (DCE) team in late 2014 to propose an academic evaluation of the programme. The study started in late 2015.

Four Progress Reports have been prepared; this Final Report describes the Evaluation of DCE's first three years (2012-2015 - its originally planned duration), while also summarising key changes that happened since then.

## 1.2 Intended use and users

This Report seeks to inform cancer policy and policy-making. We expect that it will be useful to health care professionals, providers of health intelligence data, and those designing or evaluating early cancer detection initiatives.

A Workshop was carried out with DCE stakeholders in September 2018 to discuss the Evaluation results, to obtain feedback on the relevance of the findings and to assess if the draft recommendations were applicable and realistic in the current context. The recommendations presented here have been refined based on the stakeholders' feedback. Furthermore, the lead author has attended DCE Programme Board meetings since 2015 to ensure the Evaluation and recommendations were up-to-date and appropriate.

## 1.3 Cancer burden, early detection and survival

Before describing DCE and the Evaluation, it is important to understand why such an initiative may be needed. To do so, it is necessary to recognise the burden of cancer, and the role (and limitations) of early detection in cancer survival.

### *1.3.1 The burden of cancer*

Due to ageing populations and increase in lifestyle behaviours such as consuming tobacco, alcohol drinking, obesity, and lack of exercise, cancer will remain an important public health problem for the upcoming decades[1,2]. This is also the case for Scotland (Box 1). Nonetheless, more people are surviving cancer due to improvements in early detection and treatment[3].

Improvements in survival vary across countries. The EUROCARE research programme reports that England and Denmark have poorer survival rates compared to other Western European countries[4-6]. Furthermore, Scotland has the worse age-standardised relative survival and age and case mix-standardised relative survival in the United Kingdom (UK) for all cancers combined at five years after diagnosis[7].

Delays in diagnosis, limited investment in healthcare and poor care can help to explain the cross-national variation[8,9]. EUROCARE results describing poor 1-year survival outcomes[10], and studies showing higher number of deaths close to diagnosis[11] also indicate that cancers diagnosed at later stages are important explanatory factors.

**Box 1.** Cancer burden and survival in Scotland

In Scotland, it is estimated that more than two out of five people will have cancer in their lifetime[12]. In 2016, 31,331 people were diagnosed with cancer[13] and 15,814 died from the disease[14] (excluding non-melanoma skin cancers). Lung cancer was the most common cause of cancer death, followed by colorectal and breast cancers[14]. Lung cancer rates in Scotland (both incidence and prevalence) are among the highest in the world and are higher in Scotland compared to other UK countries[15]. Furthermore, cancer mortality rates in Scotland are 15% higher than the UK average[16, 17].

Importantly, cancer mortality rates have decreased over time, even though the absolute number of cancer deaths have increased (mainly due to population ageing)[14]. Mortality rates decreased partly due to improvements in treatment, screening, and decrease in the prevalence of diseases that increase the risk of cancer[14, 18].

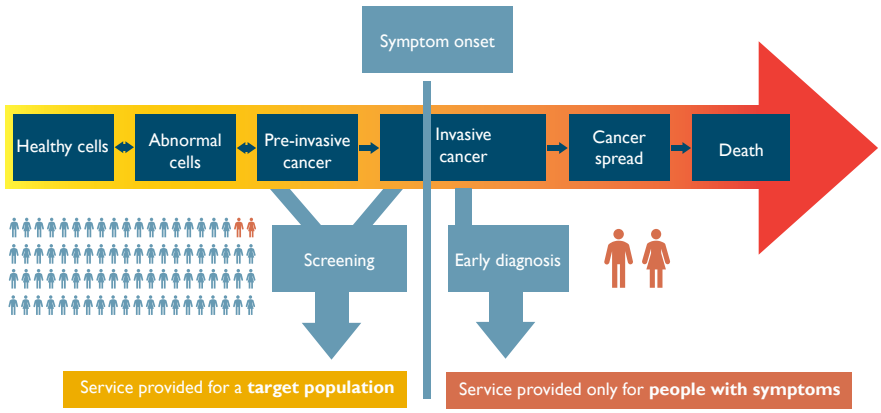
Cancer survival has improved in Scotland and is better for cancers detected early through screening and cancers for which treatment has improved substantially over time. Survival is lower for patients with cancers often presented at later stages (such as pancreas, lung and stomach)[19]. Among the three biggest cancer killers in Scotland, lung cancer has the poorest estimated five-year age standardised relative survival (9.5% for men and 12.0% for women), while breast cancer has the best (82.8% for women). Colorectal cancer survival is similar for men (59.9%) and women (59.8%)[19].

### *1.3.2 Early detection and survival*

Detecting cancer early is therefore an important way to improve cancer survival. Early cancer detection is a key strategy recommended by the World Health Organization (WHO) when implementing national cancer control programmes (alongside prevention, diagnosis, treatment and palliation)[20]. The WHO defines early detection as diagnosing cancer at an earlier stage (e.g. in a specific organ and not yet invading any surrounding tissue)[21,22] through two strategies: 1) organised screening of individuals without symptoms (i.e. asymptomatic) that can find lesions before they become cancer or cancer in its earlier stages; and 2) early diagnosis of patients with symptoms (i.e. symptomatic)[23] (Figure 1). The WHO defines three steps to early diagnosis: awareness of cancer symptoms and accessing care; clinical evaluation, diagnosis and staging; and access to treatment, including pain relief[21].

Several policies and initiatives aiming to improve cancer outcomes[24] focus on

Fig 1. The WHO's distinction between screening and early diagnosis




Adapted from: World Health Organization. Guide to cancer early diagnosis. Geneva: World Health Organization, 2017.

early detection. Early detection is also well described in evidence-based models investigating factors associated with delays in diagnosis[25, 26] and with cancer survival[27].

There is a recognised relationship between tumour staging and prognosis[28]. Cancers detected at earlier stages are more likely to benefit from treatment and to be cured[23]. Early detection can result in less aggressive treatments and reduced treatment costs[23]. Nonetheless, both screening and early diagnosis have limitations (Box 2) and several other factors can influence early detection and cancer survival (Box 3). Approaches that explore human behaviour and the role of social influencers are useful to understand the challenges when trying to promote early detection (Box 4).

### The role of health system characteristics

Resource availability (such as finance, equipment and specialist staff) and access to care also influence what can be done in terms of early detection[21, 23]. Health system characteristics can influence early diagnosis, although there is mixed evidence on which factors are most important[29].

**Box 2.** Screening and early diagnosis: the key facts

Screening is important to early detection as cancers can be found before they are advanced. Benefits of screening in reducing cancer mortality have been shown in several high-quality studies[23, 30-34]. Importantly, screening has both benefits and harms (such as physical and psychological risks, and overdiagnosis)[30, 32], and several requirements need to be met before implementing a screening programme[30, 35]. Moreover, a successful screening programme needs increased participation to be effective[36]. Screening will miss some cancers, and cancers can also develop between screening rounds[37, 38].

In countries such as the UK and Denmark where primary care is the first point of contact for patients, most cancers are diagnosed after a patient has had one or more consultations with a primary care professional followed by one or more diagnostic investigations[39, 40]. It is important that patients with cancer symptoms are investigated quickly, but symptoms vary according to tumour type and location[39]. Not all cancers have serious, specific, and alarming symptoms; and they may only appear when the disease is advanced[28]. Cancer may also have non-specific, vague symptoms that are common for several conditions (serious or not)[41, 42]. Most people presenting with vague, non-specific symptoms will not have cancer. This is also true for patients presenting with alarm symptoms[39, 43]. Primary care professionals only see a few cancer cases in a year among thousands of consultations[39, 44], and need to constantly balance the risks of missing a cancer against referring for unnecessary (and sometimes uncomfortable, invasive and harmful) tests, overdiagnosing or overtreating patients. Additionally, there is the risk of wasting limited diagnostic resources that other patients need urgently (and delay care to them as a consequence).

Evidence-based cancer referral guidelines highlighting alarm symptoms are used to help professionals refer for certain cancers, but other resources are also needed. Cancer risk prediction tools such as the Risk Assessment Tool (RAT)[45], QCancer[46, 47] and combinations such as Macmillan Cancer Decision Support (CDS)[48] are also helpful. Safety netting can help to diagnose patients with vague symptoms[49], although there are current discussions on what safety netting actually is and how to use it well[50]. Finally, the professionals' "gut feeling" (something is not right but it is difficult to figure out what it is) can also help[51-53].

**Box 3.** Other factors influencing cancer survival

- **Tumour biology:** aggressive tumours are associated with poorer prognosis. Even if a patient is diagnosed early, survival will be poor if the tumour is very aggressive and grows too quickly[54]. This has been described as the "waiting time paradox"[55].
- **Tumour location:** for example, patients with right-sided metastatic colorectal tumours have been found to have worse prognosis[56]
- **Patient characteristics** such as co-morbidities (associated with poorer prognosis), general health, lifestyle behaviours (e.g. drinking alcohol and sedentarism), and age (as older people often have poorer survival)[57]
- **Lead time and length time bias**[58-60]: analyses of survival from diagnosis of cancers detected through screening are affected by length and lead time bias[58], and it is important that other measures (such as mortality rates) are used to measure the benefits of screening[59]. Overdiagnosis is an extreme case of length time bias[58, 60]. Screening will be more successful if it finds cancers that can kill if they are not treated, cancers for which there are good treatments, and cancers for which treatment is more likely to work if administered earlier[61].

**Box 4.** Behaviour and social theories

Theories from Psychology, Social Sciences and Medical Anthropology describe how people perceive symptoms and act upon them[62]; and shed light on barriers and facilitators to help-seeking and fast presentation when noticing symptoms[30, 63]. These theories discuss concepts such as fear[64], fatalism[65, 66] and perception of risk[67]. They also discuss a range of social issues such as power relations, how competing responsibilities and concerns about wasting the doctor's time influence health care decisions, the challenges people may face to configurate bodily sensations into symptoms, and to be sensitive to these when dealing with multimorbidities and a range of challenging social circumstances they face on a daily basis[63, 68, 69].

There is mixed evidence on the role of gatekeeping referrals to specialists in delays to diagnosis[29, 70-72], and some evidence of health system factors that may influence both the patient and the professional's behaviour (such as centralisation of services, free movement of patients between different providers and access to secondary care)[29].

### The importance of providing information

As described by the WHO, the population needs to be able to access services, and to be aware of screening programmes and cancer symptoms and signs. Provision of information is needed so people can make an informed choice about what they wish to do, considering both the benefits and potential harms of early detection.

### The role of social deprivation

A key factor influencing both cancer detection and cancer survival is socioeconomic deprivation. Evidence from several countries and early detection models show the role of socioeconomic status on cancer outcomes[57, 73]. In England and Wales, cancer survival is worse for more deprived groups[74]. In Scotland, those living in the most deprived areas are more likely to have poorer access to primary care and poorer health outcomes (while also having higher levels of multi-morbidity)[15]. Both cancer incidence and overall cancer death rates are higher amongst the most deprived (although there are variations by cancer type)[15]. Uptake for breast and bowel screening is lower amongst the most deprived[15], and the three main cancer types (breast, colorectal and lung) are most often diagnosed at advanced stages among the most deprived compared to the least deprived populations[75].

### *1.3.3 Strategies to promote early detection*

Acknowledging variations in survival and the need to improve cancer outcomes, the UK and Denmark were pioneers in developing strategies to promote early detection. In addition to organised screening programmes for asymptomatic individuals, urgent referral pathways for suspected cancer based on alarm symptoms have been implemented[25, 76-79].

Launched in 2009, the National Awareness and Early Diagnosis Initiative (NAEDI)[24,27,80,81] managed and supported a range of activities promoting the earlier diagnosis of cancer in England. In line with recommendations from the WHO and the Cancer Reform Strategy in England[82], NAEDI also supported strategies focusing on cancer awareness such as the development and validation of a Cancer Awareness Measure (CAM)[83, 84]. Awareness campaigns were further developed at regional and national levels by Be Clear on Cancer (BCOC) in England and Wales[85-87].

More recently, Denmark has developed referral pathways for serious, non-specific symptoms and "No-Yes-Clinics" for common symptoms that may result in a cancer being missed[42, 88]. The approach is now being adopted in England through the Accelerate, Coordinate, Evaluate (ACE) Programme[89, 90].

In Scotland, where there are screening programmes for bowel, breast and cervical cancers, and urgent referral pathways for patients with alarm symptoms, a national, multi-levelled early detection initiative (the DCE programme) was introduced in 2012. DCE is the focus of this Evaluation and will be introduced next.

# 2. The DCE Programme

## 2.1 Cancer policies prior to DCE

The Scottish Government has considered cancer to be a clinical priority for many years[91]. In 1998, a Scottish Cancer Group (SCG) was established to provide "leadership, direction, advice and guidance for cancer services in Scotland"[91]. In 2001, the Scottish Government published: "Cancer in Scotland: Action for Change". The strategy focused on prevention, diagnosis (including screening and urgent referrals) and treatment of cancer. It also proposed the establishment of regional cancer networks to oversee the patient journey[91].

In 2008, "Better Cancer Care: An action Plan" was published. It also focused on prevention, early diagnosis, testing for cancer, referral and treatment. A Scottish Cancer Taskforce was established to oversee the implementation of this plan. The strategy supported the roll-out of the bowel screening programme and looked at ways to encourage participation, promote public awareness of cancer symptoms and encourage patients to seek help early in primary care. A primary care cancer lead would be nominated within each territorial Health Board in Scotland[92]. This strategy paved the way for the development of the DCE Programme.

## 2.2 DCE: an overview

In March 2011, the Cabinet Secretary for Health and Wellbeing in Scotland announced that the Scottish Government would commit £30 million to a 3-year "Detect Cancer Early Initiative", raising cancer awareness and increasing diagnostic capacity in order to increase the number of patients diagnosed with cancer in its earlier stages. The Scottish National Party (SNP) Manifesto published in April 2011 reiterated the commitment[93].

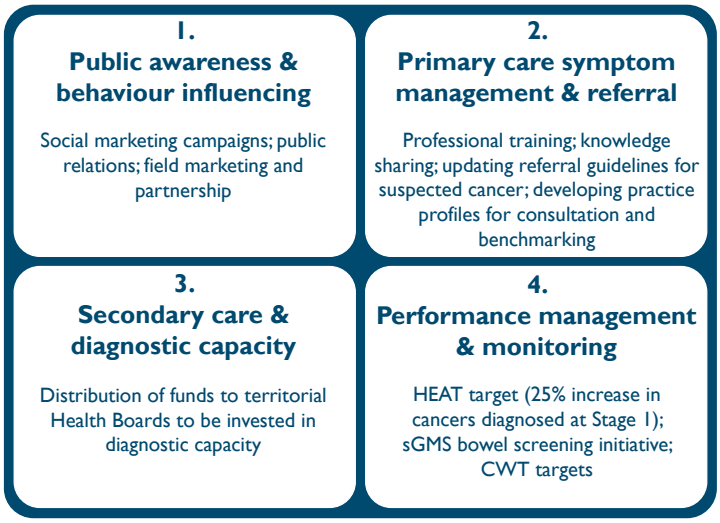
A draft Implementation Plan was circulated to several stakeholders, to all territorial Health Boards, different Scottish Government departments and cancer charities[94]. Different groups were created to coordinate and ensure the management of the programme. The already established National Cancer Waiting Times Delivery Group became the Detect Cancer Early Programme Board[94].

DCE wished to be "a fundamental shift in how Scottish Government engages with the NHS in delivery of a cancer target", adopting a whole systems-level approach instead of only focusing on secondary care[94].

DCE was officially launched in February 2012 by the Cabinet Secretary for Health and Wellbeing[95]. It had four main strategies (Figure 2; Appendix 1)[94], in addition to several projects in collaboration with cancer charities, Health Boards and Scottish universities (with or without funding from DCE).

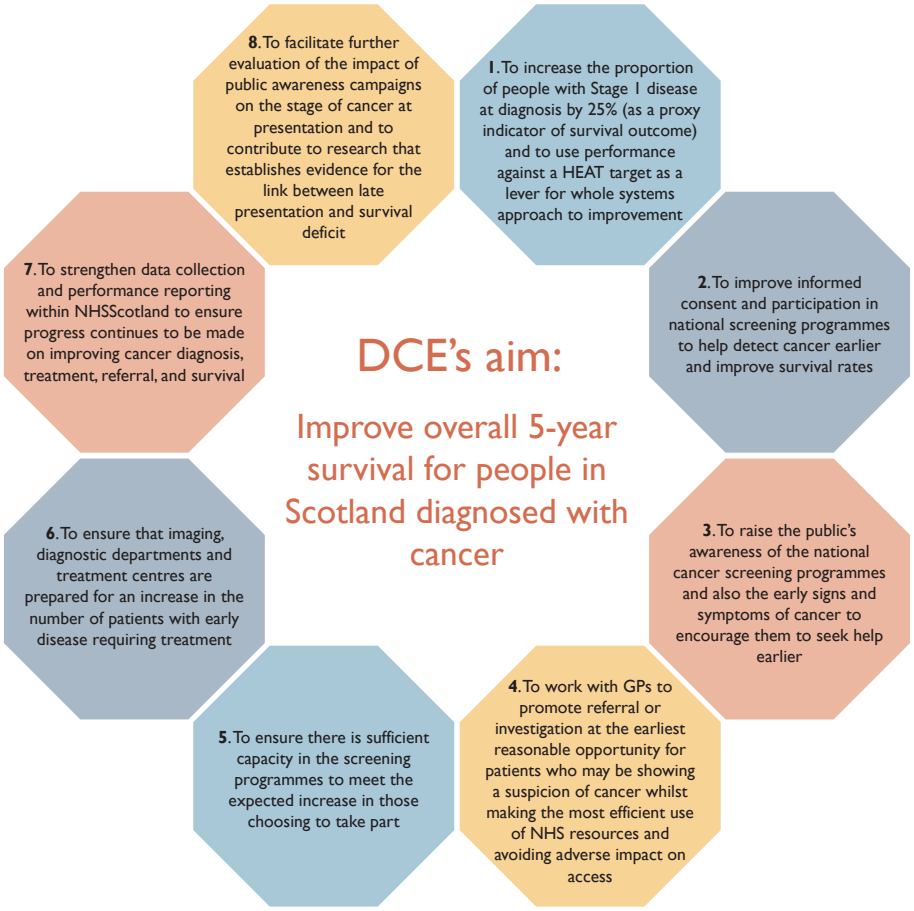
DCE's main aim was to improve overall 5-year survival for people in Scotland diagnosed with cancer, but there were also several programme objectives (Figure 3). The Programme initially focused on the three main causes of cancer death in Scotland (lung, breast and colorectal cancers)[94]. Although it was supposed to last three years, DCE has continued after 2015 and remains a key component in the most recent Scottish Cancer Strategy "Beating Cancer: Ambition and Action"[96].

## Fig 2. DCE's four main strategies according to the Implementation plan*




*A fifth strategy focusing on screening (Informed Decision Making Around Screening Programme Participation) was added over time; and the other four changed names slightly: Public Awareness (1); Primary Care Recognition and Referral Behaviour (2); Increasing Diagnostic Capacity (3); and Data, Evaluation and Outcomes (4). This Report has kept the original strategy names; screening outcomes are discussed as part of Strategies 1 and 4. Abbreviations: HEAT - Health Improvement (H), Efficiency (E), Access to treatment (A), and Treatment (T); sGMS - Scottish General Medical Services contract; CWT - Cancer Waiting Times.

## Fig 3. DCE aim and objectives according to the Implementation Plan



# 3. Methods

## 3.1 Overall aim and theories

This Evaluation aimed to report on DCE processes and outcomes in order to learn from the programme's experience and provide recommendations for DCE and other early detection initiatives (Box 5).

The Evaluation was guided by the Medical Research Council's (MRC) Framework for Process Evaluation of Complex Interventions[97]. This Framework describes how a process evaluation should investigate programme implementation (how intervention was delivered, and what was done), mechanisms of impact (how the intervention generated change) and contextual issues (exploring how they influenced both implementation and outcomes)[97]. The Framework also describes the relationship between these three functions and the programme outcomes (Figure 4).

**Box 5.** Why is this Evaluation needed?

Government-led programmes such as DCE should be evaluated to check if they benefit the population, and to ensure transparency and accountability[102]. Although DCE and collaborators have created documents with analyses of different outcomes, not all are easily available, and no system-level evaluation of the programme had been carried out.

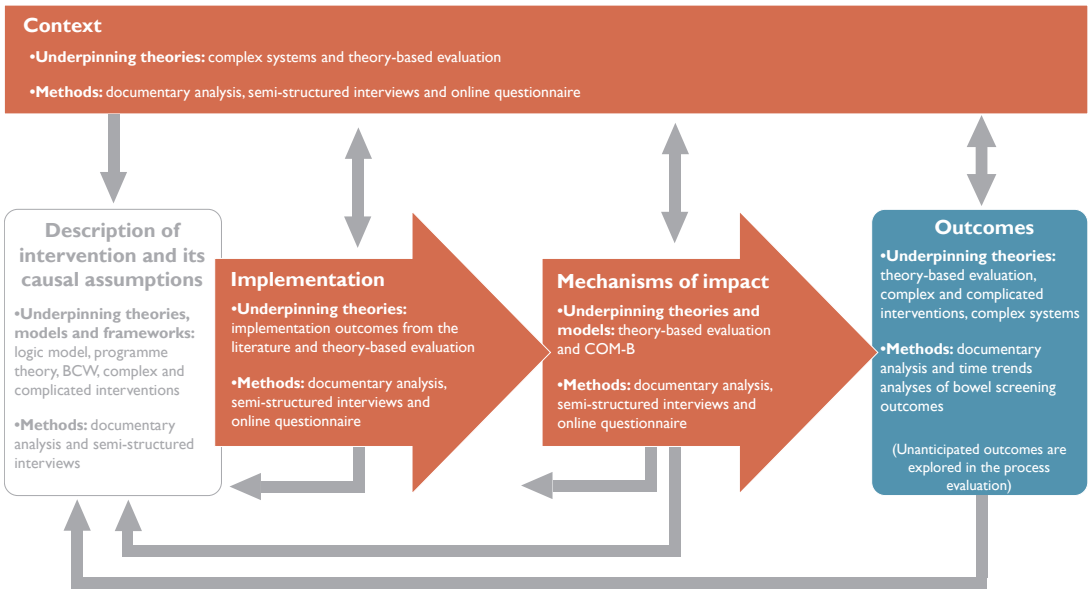
Importantly, an evaluation that only describes outcomes gives limited information. Analysis of cancer survival needs a long timeframe[103]; DCE was a national programme as opposed to a scientific experiment and there are several limitations in demonstrating causality. Conversely, an evaluation checking if the programme was implemented well, was acceptable and appropriate to stakeholders, and had positive outcomes[97] for professionals, patients and the public is much more informative - it shows how a programme worked and sheds light on why it worked. This type of evaluation can also describe unanticipated benefits (or harms) that would otherwise have been missed. Therefore, we have designed an evaluation of both DCE processes and outcomes.

The DCE Evaluation was also a theory-based evaluation; which is based on the premise that all programmes have implicit or explicit assumptions on how they are supposed to work[98]. Theory-based evaluation is informed by programme theory, which is a description of what should be done to achieve programme aims, what other outcomes can be anticipated, and how these aims and outcomes will be generated[99]. The DCE Evaluation assessed both mechanisms of impact and implementation.

This was a mixed-methods[100] Evaluation; mixed-methods are often required in a theory-based evaluation as it includes many different elements[101]. The approach is also recommended by the MRC Framework[97].

Before the Evaluation was carried out, it was necessary to ensure that DCE and its programme theory were well described. Therefore, the Evaluation had two steps: development and full evaluation.

Fig 4. The DCE evaluation according to the MRC Framework[97]




Abbreviations: BCW: Behaviour Change Wheel; COM-B: Capability, Opportunity, Motivation and Behaviour

## 3.2 Evaluation development

Evaluation development consisted of analysis of policy documents; key informant interviews with DCE stakeholders; and literature reviews on the burden of cancer, evaluation and implementation theories.

The analysis of policy documents aimed to: 1) better understand DCE; 2) inform the development of a logic model (i.e. a graphical representation of DCE's programme theory); and 3) identify several assumptions regarding implementation; and mechanisms of impact. Furthermore, documents facilitated the identification of stakeholders for interviews.

Documents were read and summarised, with emerging issues to aid evaluation design added to the summaries. A list of DCE stakeholders was prepared. Guidance was followed to draft DCE's logic model[101, 104, 105], assumptions and mechanisms[106-108]. One hundred and fifty-nine policy documents were analysed from October 2015 to November 2017. These comprised minutes and agendas from the DCE Programme Board and Operational Subgroup meetings, official reports on DCE outcomes from ISD Scotland, newsletters, posters, leaflets, press releases, social marketing reports and evaluations of social marketing campaigns.

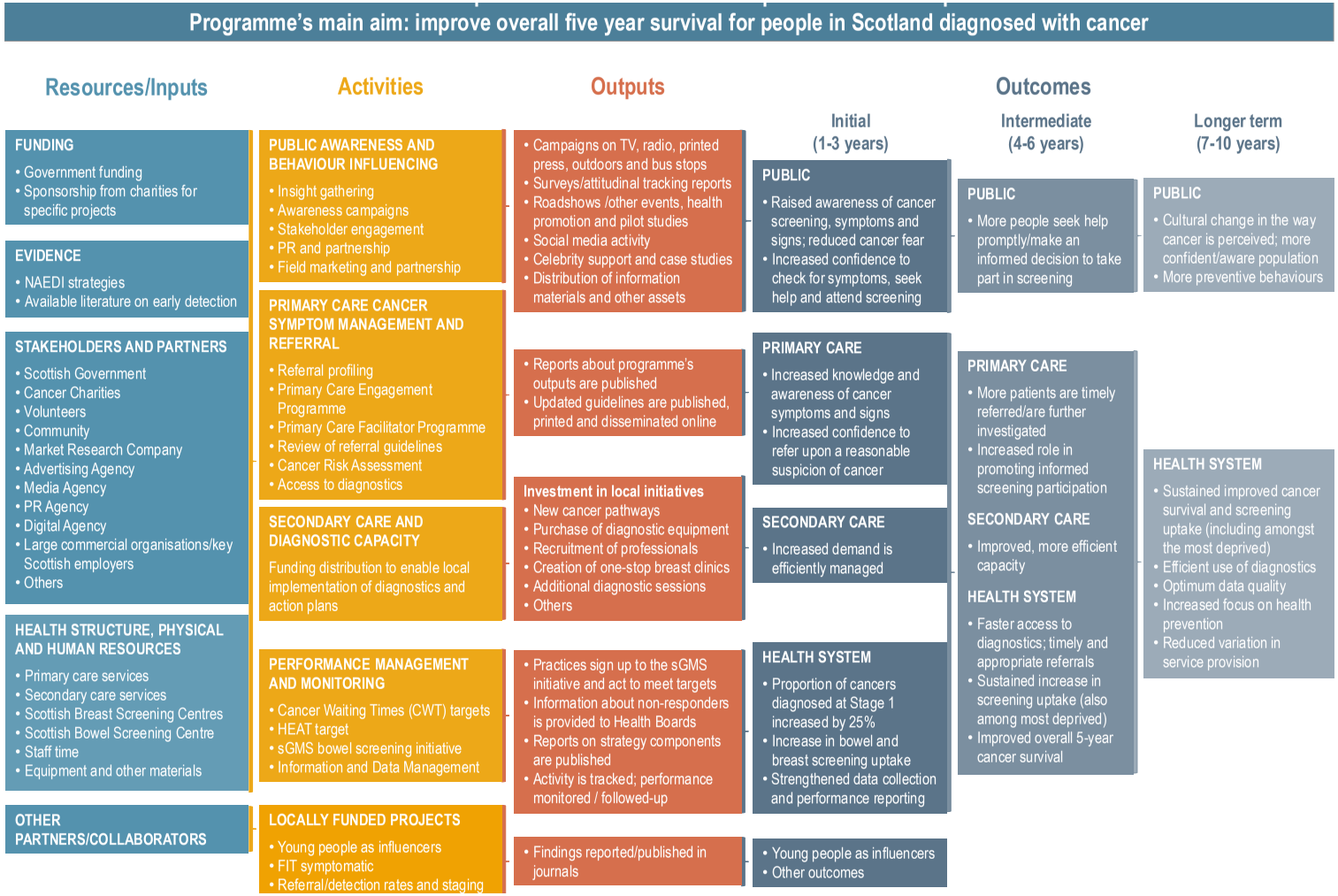
The interviews aimed to: 1) improve understanding of DCE; 2) ensure stakeholder views were included in the Evaluation; 3) refine the logic model, assumptions and mechanisms; and 4) inform on additional theories to guide the Evaluation[97, 106]. Stakeholders who had been directly involved in the development

or in the running of the DCE programme were interviewed. Purposive sampling was used to include professionals with clinical, strategic or supportive backgrounds from different regions in Scotland. Nine potential participants from the list of stakeholders were invited by email to an interview (face-to-face or over the telephone); all agreed to take part. Interviews took place between April and August 2016. Participants were asked about DCE development; its rationale and aims; and evaluation challenges. They received the logic model before the interview and were asked for their views on how well DCE was described.

The framework approach[109] was adopted for data analysis; the software NVivo 10[110] was used to facilitate this. Key themes from the interviews are available (Appendix 2).

Evaluation development resulted in a refined logic model describing DCE components (Figure 5), a new diagram representing DCE's programme theory and describing assumptions about the programme and potential mechanisms of impact (Appendix 3) and evidence that informed the choice of theories and helped to prioritise issues to be investigated. With this information, the full DCE Evaluation was designed.

## Fig 5. Refined logic model



## 3.3 The DCE Evaluation

### *3.3.1 Evaluation aims*

The DCE Evaluation aimed to understand what worked and what did not work in the DCE programme in terms of processes and outcomes (and why this was the case) in order to provide recommendations. The Evaluation research questions are described below (Figure 6).

The outcome evaluation focused on official DCE objectives. The process evaluation assessed whether assumptions and mechanisms were confirmed by stakeholders, examined barriers and facilitators and unanticipated outcomes.

Implementation outcomes from the literature were used to operationalise assumptions about implementation, while concepts from the COM-B (Capability, Opportunity, Motivation and Behaviour) model and the Theoretical Domains Framework (TDF)[111, 112] were used for mechanisms (further information is available in Appendix 4). Four assumptions and four mechanisms were investigated. (Figure 7).

Fig 6. Evaluation questions

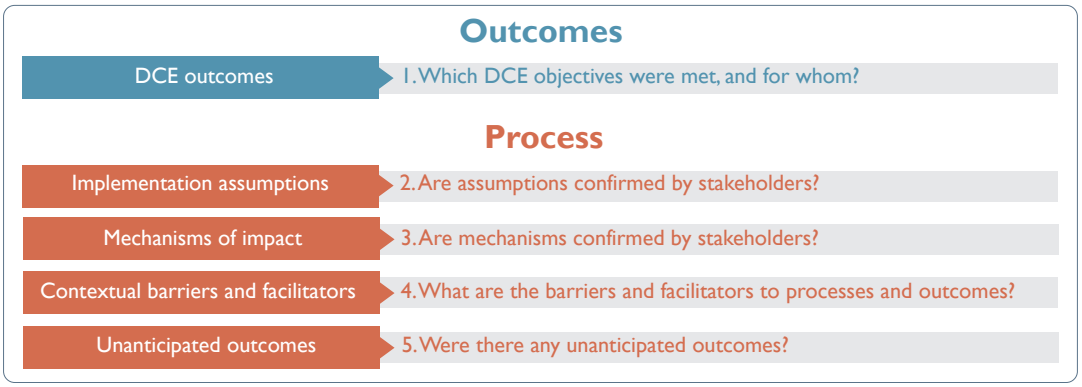
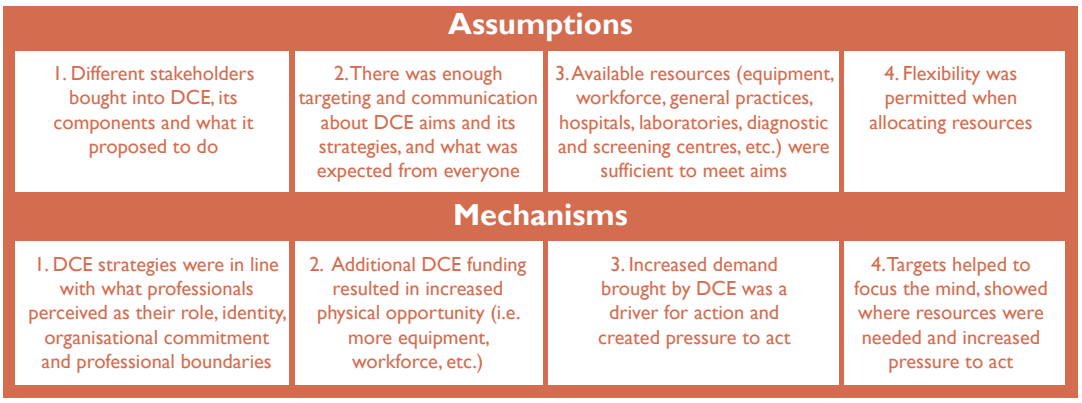



Fig 7. Investigated assumptions and mechanisms



### *3.3.2 Outcome evaluation*

DCE aimed to improve overall 5-year survival, but there was no specific survival measurement. Instead, the HEAT target was developed (25% increase in cancers diagnosed at Stage 1) and adopted as a proxy measure.

The Evaluation focused on the eight objectives from the DCE implementation plan (described in Figure 2). Outcome data (such as staging, screening participation and potential impact on workload) were synthesised from policy documents and other reports published by Information Services Division (ISD) Scotland, and the Screening Programmes (Bowel and Breast). Data on requested replacement bowel screening test kits were provided by the Scottish Bowel Screening Centre in Dundee. "Colorectal cancer" and "bowel cancer" are used interchangeably in the Report as both terms were used by data sources.

TNS (a Market Research Company) has carried out before-and-after evaluations of all DCE campaigns and investigated changes in attitudes regarding cancer after DCE's first three years. Key results from these evaluations are summarised in this Report. Carat, Consolidated PR and Leith Agency also evaluated the impact of campaigns using a range of metrics (such as number of engagement events and presence in the media). These results are also summarised.

When data allowed, charts and tables were developed to show trends over time. Likewise, descriptive statistics (N(%) and percentage changes over time) were calculated and reported whenever possible. Percentage change refers to the difference between two numbers being compared (i.e. number at year of interest and number at baseline), divided by the number at baseline and multiplied by 100. Negative numbers refer to percentage decrease.

Only a few charts show data at territorial Health Board level; this is to avoid unfair comparisons due to wide variations in population size and characteristics, performance at baseline, screening uptake, cancer incidence and other issues. Tables showing numbers, percentages and percentage change by territorial Health Board are available as appendices for information, but comparisons should be made with caution.

Even though this Evaluation is investigating outcomes up to 2015 (Year 3 of DCE); data is shown for Years 4-6 to generate discussions regarding DCE's next steps and sustainability.

There were no quantitative outcomes (or limited information available) for many DCE objectives. Hence, the outcome evaluation used descriptive tables and boxes in order to report on all types of relevant outcome data. Furthermore, the process evaluation also sheds light on whether objectives were met (and why).

Appendix 5 describes how each official DCE objective was assessed in the outcome evaluation.

### *3.3.3 Process evaluation*

The process evaluation had two components: qualitative interviews and a purpose-built, mixed-methods online questionnaire. Participant eligibility criteria were the same for both components: stakeholders who were involved in and/or were influenced by DCE from the years 2011-2015 (corresponding to one year prior to programme launch and the first three years of programme implementation). These included any professionals working in primary and secondary care; professionals managing health care services and DCE strategies; providers of Health Intelligence (national statistics) data; and staff from charities, creative agencies and market research companies who were DCE partners.

#### Interviews

A topic guide was developed for different stakeholder groups, with common questions to allow for data analysis (example in Appendix 6). Purposive and snowball sampling were used to prepare a list of eligible stakeholders[113]. During evaluation development, stakeholders suggested names for the full evaluation. The list was complemented by names mentioned in policy documents.

Stakeholders were contacted about the study by email; interviews were either face-to-face or over the telephone. The framework approach was used to analyse data[114, 115].

#### Questionnaire

Questionnaire development was informed by publications adopting the same frameworks [111, 116-122], and implementation outcomes[111, 123]. It was designed to take 15-20 minutes to be completed. Pre-testing was carried out by four professionals (two GPs, one oncologist working in secondary care, and a senior manager in a cancer charity). Online Surveys (former Bristol Online Survey (BOS) Tool ©) (https://www.onlinesurveys.ac.uk/) hosted the questionnaire. The questionnaire is available in Appendix 7.

No similar studies were identified to aid sample size and power calculations for the questionnaire. Possible impact of non-response and under-/over-representation of stakeholders is approached in the Discussion.

Invitation emails with an anonymised link to the survey were sent by the Scottish Cancer Networks (SCAN, NOSCAN and WOSCAN), the Scottish Cancer Coalition and the Scottish Primary Care Cancer Group to everyone in their mailing lists. One reminder was sent 15 days after the initial invitation and the online survey was active for two months.

Responses to the questionnaire were downloaded from Online Surveys and analysed in SPSS v.22. Variables were recoded as needed (e.g. reverse scores, questions that allowed for multiple answers, and questions which allowed for "other" issues to be mentioned).

Descriptive statistics (N, %, means, standard deviations, medians and interquartile ranges) were used to report on stakeholders' characteristics and views about the programme. Inferential statistics were used to investigate variations in views across different groups. Most of the questionnaire items were rating scales. Non-parametric tests were used to investigate differences in distributions on ratings between two groups (Mann Whitney U test) and more than two groups (Kruskal-Wallis H test with adjusted p-value after pairwise comparisons and Bonferroni correction). Chi-squared tests (or Fisher's Exact test when counts were less than five) were used to check for differences in proportions when questions generated categorical data. Content analysis was used for open-ended questions.

## 3.4 How results are organised

Instead of focusing on academic research questions and theories guiding the Evaluation, this Report focuses on policy-relevant findings.

First, we present available evidence for DCE official objectives. Objectives 2 and 3 are addressed together as it was not possible to separate outcomes for them. This is followed by reporting on the key themes and findings from the process evaluation. The terms "stakeholders" and "participants" are used interchangeably when reporting findings. Job role and territorial Health Board are only mentioned for questionnaire participants; this is to avoid indirect identification of interview participants and to comply with their dissemination choices (specified in their consent forms).

# 4. Results

## 4.1 DCE outcomes

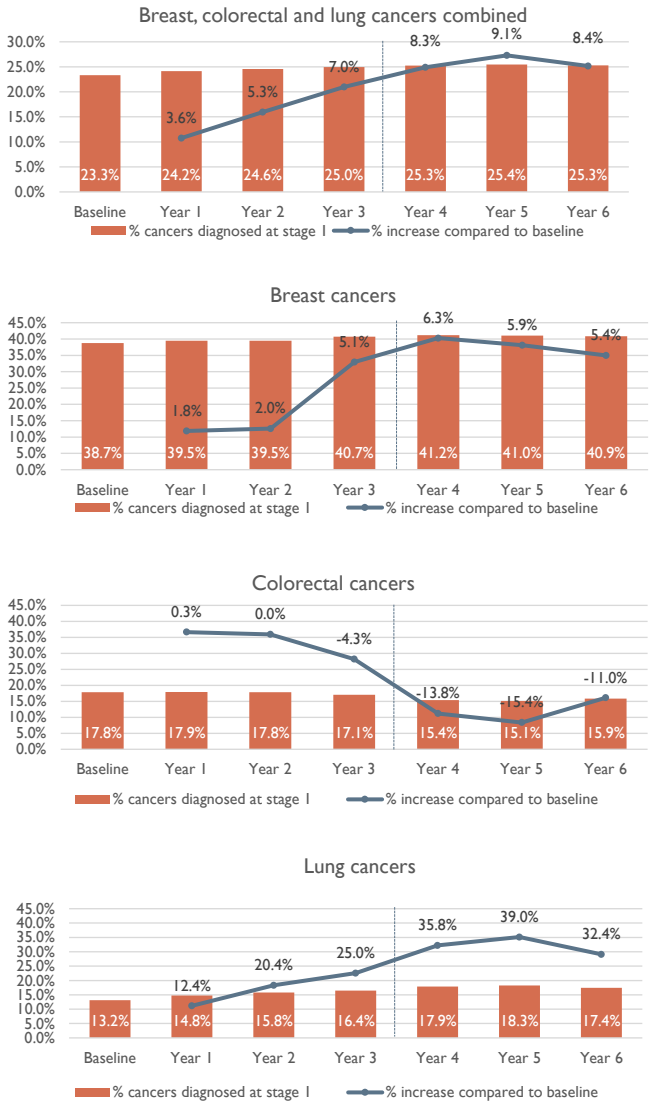
*Objective 1: Increase the proportion of breast, colorectal and lung cancers diagnosed at Stage I by 25% and to use performance as a lever for whole systems improvement*

According to the most up-to-date trends published by ISD Scotland[124], there was a 7.0% increase in cancers diagnosed at Stage I (breast, colorectal and lung cancers combined) by the end of DCE's third year (Year 3). There were wide variations across tumour types (Figure 8), deprivation levels (Figure 9) and territorial Health Boards (Appendix 8)[124]. By Year 3, there was a 5.1% increase in breast cancers diagnosed at Stage 1, while there was a 25.0% increase for lung cancers, and a 4.3% decrease for colorectal cancers (Figure 8).

There were increases in the proportion of Stage 1 cancers across all different levels of deprivation (1 most deprived – 5 least deprived); for all three tumour types combined, for breast cancer and lung cancer. On the other hand, there was a decrease in the proportion of colorectal cases diagnosed at Stage 1 across all five deprivation levels. The most deprived groups showed the highest percentage increase in Year 3 (11.6%) for breast, colorectal and lung cancers combined[124] (Figure 9).

Increases in the proportion of breast, bowel and lung cancers combined happened for all three regional Cancer Networks. SCAN showed the highest % increase in Year 3 compared to baseline (11.8%), while NOSCAN showed the lowest (3.4%). (Figure 10)[124].

## Fig 8. Stage I cancers (Baseline - Year 6) and % increase over time




| Cancer type | N(%) at Stage I and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| 3 cancers combined | N (%) at Stage I | 5581 (23.3) | 5946 (24.2) | 6074 (24.6) | 6198 (25.0) | 6272 (25.3) | 6207 (25.4) | 6129 (25.3) |
| | % change | | 3.6% | 5.3% | 7.0% | 8.3% | 9.1% | 8.4% |
| Breast | N (%) at Stage I | 3184 (38.7) | 3341 (39.5) | 3378 (39.5) | 3477 (40.7) | 3538 (41.2) | 3530 (41.0) | 3502 (40.9) |
| | % change | | 1.8% | 2.0% | 5.1% | 6.3% | 5.9% | 5.4% |
| Colorectal | N (%) at Stage I | 1261 (17.8) | 1257 (17.9) | 1213 (17.8) | 1136 (17.1) | 1021 (15.4) | 996 (15.1) | 1040 (15.9) |
| | % change | | 0.3% | 0.0% | -4.3% | -13.8% | -15.4% | -11.0% |
| Lung | N (%) at Stage I | 1136 (13.2) | 1348 (14.8) | 1483 (15.8) | 1585 (16.4) | 1713 (17.9) | 1681 (18.3) | 1587 (17.4) |
| | % change | | 12.4% | 20.4% | 25.0% | 35.8% | 39.0% | 32.4% |

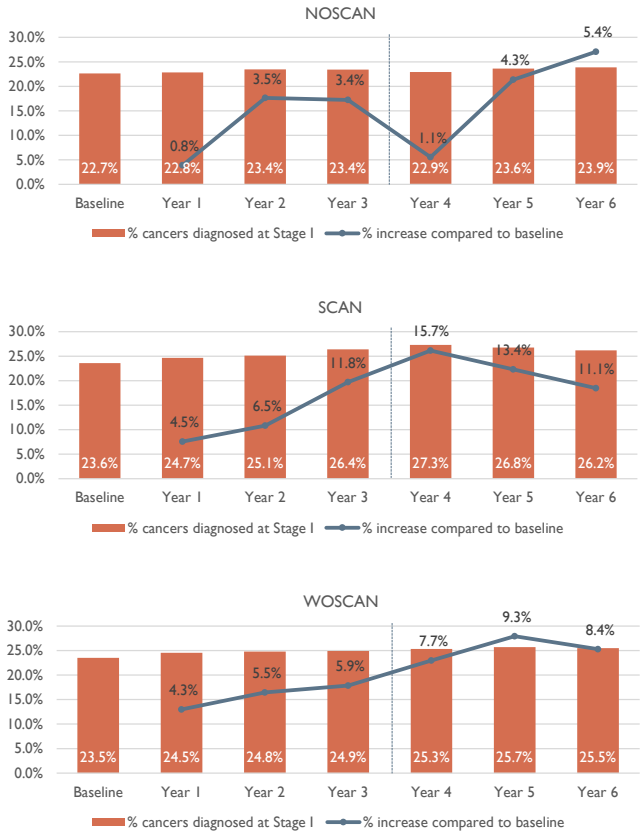
Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

## Fig 9. Percentage increase in Stage 1 cancers (Baseline - Year 6) across deprivation levels (breast, colorectal and lung combined)


| Deprivation level | N(%) at Stage 1 and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| Level 1 = most deprived | N (%) at Stage 1 | 1128 (20.2) | 1205 (21.1) | 1269 (22.0) | 1304 (22.6) | 1344 (23.4) | 1307 (23.7) | 1203 (22.6) |
| | % change | | 4.2% | 8.8% | 11.6% | 15.4% | 17.3% | 11.8% |
| Level 2 | N (%) at Stage 1 | 1144 (21.7) | 1261 (23.2) | 1214 (22.6) | 1209 (22.5) | 1236 (23.5) | 1243 (23.7) | 1244 (23.6) |
| | % change | | 7.3% | 4.3% | 3.9% | 8.5% | 9.5% | 8.8% |
| Level 3 | N (%) at Stage 1 | 1132 (24.2) | 1162 (24.3) | 1198 (24.9) | 1231 (25.3) | 1217 (24.7) | 1237 (25.4) | 1229 (25.7) |
| | % change | | 0.3% | 3.0% | 4.7% | 1.9% | 5.1% | 6.3% |
| Level 4 | N (%) at Stage 1 | 1114 (25.4) | 1199 (26.1) | 1208 (26.4) | 1262 (27.3) | 1223 (26.6) | 1202 (26.7) | 1232 (27.2) |
| | % change | | 2.9% | 4.0% | 7.6% | 5.0% | 5.5% | 7.2% |
| Level 5 = least deprived | N (%) at Stage 1 | 1049 (26.7) | 1111 (27.4) | 1172 (28.2) | 1180 (28.3) | 1247 (29.3) | 1212 (28.4) | 1206 (28.1) |
| | % change | | 2.9% | 5.6% | 6.1% | 9.9% | 6.6% | 5.3% |

Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

## Fig 10. Percentage increase in Stage 1 cancers (Baseline - Year 6) across Cancer Networks (breast, colorectal and lung combined)




| Cancer networks | N(%) at Stage 1 and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| NOSCAN | N (%) at Stage 1 | 1328 (22.7) | 1344 (22.8) | 1399 (23.4) | 1393 (23.4) | 1389 (22.9) | 1478 (23.6) | 1461 (23.9) |
| | % change | | 0.8% | 3.5% | 3.4% | 1.1% | 4.3% | 5.4% |
| SCAN | N (%) at Stage 1 | 1557 (23.6) | 1670 (24.7) | 1675 (25.1) | 1775 (26.4) | 1831 (27.3) | 1727 (26.8) | 1711 (26.2) |
| | % change | | 4.5% | 6.5% | 11.8% | 15.7% | 13.4% | 11.1% |
| WOSCAN | N (%) at Stage 1 | 2696 (23.5) | 2932 (24.5) | 3000 (24.8) | 3030 (24.9) | 3052 (25.3) | 3002 (25.7) | 2957 (25.5) |
| | % change | | 4.3% | 5.5% | 5.9% | 7.7% | 9.3% | 8.4% |

Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

*Objective 2: To improve informed consent and participation in national cancer screening programmes to help detect cancer earlier and improve survival rates*

*Objective 3: To raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier*

There was no available evidence on whether informed consent has improved, although the programme expected that this would be helped by the Public Awareness and Behaviour Influencing Strategy.

DCE had campaigns aiming to reduce cancer fear and encourage the public to seek help when noticing symptoms (e.g. priming campaign). Campaigns also targeted bowel and breast screening participation, and breast and lung cancer symptoms and signs. Further information about the campaigns, their key messages and timelines is available in Appendix 1.

### Priming campaign

The TNS evaluation investigated reach; communication of the key campaign messages; and motivation with regards to the early detection of cancer before and after the priming campaign. Other priming activities were evaluated by using metrics such as engagement with the public, and distribution of campaign materials. Key findings are described in Box 6.

## **Box 6.** Key results from the priming campaign

**TNS evaluation**

- There was no change in the level of spontaneous awareness about getting checked early after the campaign, although there were high levels of prompted recognition, especially among women, those who had carried out a self-examination in the past three months and those aged 55-74
- One third of the participants who had seen the TV advert described its aspects. Prompted recognition of the TV advert was at least 70% across all groups, except for those aged 75+. 85% of participants recognised at least one type of advertising
- While the message about getting checked was communicated well (81% saw this as the main message), the message "don't get scared" was seen as the main message only by 15% of participants. Seeing more than one type of media was associated with being more likely to pick up on the "don't get scared" message. Women were significantly more likely than men to mention "get checked" (84% vs 77%)
- Very high levels of being both motivated and involved were recorded among C1C2DE* adults aged 40+ (72%) and all participants who recognised the campaign (77%)
- 64% motivation was recorded among participants who saw/heard at least one advert, and 87% for those who saw/heard more than one advert. There were higher levels of motivation among women, those aged 40-54 and those who regularly self-examine
- 72% of participants agreed that the adverts increased their interest in getting checked early
- Those aware of the campaign were more likely to agree that more people are surviving cancer and early detection increases chances or survival, but also more likely to worry about seeing a doctor (i.e. feeling silly about it or worrying about wasting the doctor's time)
- Those aware of the campaign were more likely to have increased confidence in approaching their GP (51% versus 35% for those who were not aware)
- Over half of the participants (55%) who saw the advert stated that it would make them get checked earlier if they had signs and symptoms; the lowest proportion was for those aged 75+ (43%)

**Field and Partnership, Business to Business (B2B) and Public Relations (PR) Activities**

- Early Cancer Detection Roadshow: In 70 days, there were 24,917 topline engagements (contact lasting up to a minute) and 2,918 in-depth engagements (lasting 1-5 minutes)
- B2B activity & results: In 35 days, 1176 local businesses were visited. Partners were large employers, local newsagents, local leisure and entertainment providers, relevant charities and places of worship (examples include Belhaven Brewery, Gala Bingo, M&CO., Caledonian MacBraybe, STV, and the Edinburgh Woollen Mill).
- Media Relations: campaign launch, case studies and creative, support media for roadshows resulted in over 50 pieces of coverage. Securing the backing of over 10 different celebrities resulted in 34 pieces of coverage

* According to TNS, C1C2DE consists of six social grades based on the current or previous occupation of the chief income earner in a household. ABC1 includes professional, managerial and non-manual occupations, while C2DE includes manual and unskilled occupations and the long-term unemployed. Sources: Policy documents received during evaluation development. These included communications from the DCE team sent to stakeholders and an evaluation presentation prepared by TNS ("Detect Cancer Early Campaign Evaluation Presentation of Results 29th May 2012")

## Breast cancer

Data from social marketing campaigns, about consultations for breast symptoms and about breast screening are relevant to address Objectives 2 and 3. These are discussed separately.

*Social marketing campaigns*

Social marketing campaigns focused initially on breast cancer symptoms and signs, and then on breast screening. Key results from both campaigns are described in Boxes 7 and 8.

### **Box 7.** Key results from the symptomatic breast campaign

**TNS evaluation**

- Before-and-after campaign evaluation showed that 88% of DE women recognised some aspect of the campaign, and 49% of them could spontaneously mention the key message "check yourself/be aware of changes"
- Spontaneous awareness of symptoms described in the campaign doubled after the campaign; women who had seen the advert were about three times more likely to spontaneously refer to a symptom compared to women who had not seen it
- 82% of those who recognised the campaign were motivated by it
- There was significant stronger disagreement with the statement "I worry about feeling silly if I go to my doctor with small changes to my body, thinking they could be cancer"
- There was significantly less confusion about spotting signs and awareness of what to recognise
- Half of women who recognised the campaign reported to having taken action as a result of it (such as checking their breasts)

**Field and Partnership, B2B an PR activities**

- There was broad and persistent media coverage in newspapers such as the Dundee Evening Telegraph, the Aberdeen Evening Express, Glasgow Evening Times, Edinburgh Evening News, the Daily Record, the Scottish Sun, and Sunday Mail
- 55 days of roadshows (in high footfall areas such as shopping centres and supermarkets) resulted in 25,365 topline and 9,015 in-depth engagements with the public. There were 1,411 interactions on an iPad presentation that allowed people to explore signs and symptoms privately; 1,563 interactions with symptom cards; and 97 pictures taken for Facebook
- 16,615 leaflets were given out during roadshows, 181 Posters and 181 Vinyl stickers were placed at the roadshow locations
- During 63 days of activity, 1,884 local businesses were visited, with 1,653 A3 posters, 1,423 vinyl stickers, and 44,840 leaflets sited
- 1,700 partners signed up to campaign and received campaign materials; partners included local authorities, large employers, retailers, local newsagents, housing associations and entertainment providers (examples: Tunnock's, Vion Food Group, Robert Wiseman Dairies, TKMaxx, Sodexo, Semichem, Mecca Bingo, M&Co. and ASDA)

Sources: Policy documents received during evaluation development. These included a case study document with campaign outcomes prepared by the DCE team and sent to stakeholders, and an evaluation report prepared by Made in Leith, Carat and Consolidated PR ("Detect Cancer Early campaign wash-up. Priming, Breast Cancer, Bowel Cancer, June 2013")

**Box 8.** Key results from the breast screening campaign

**TNS evaluation**

- Women who recognised the campaign (i.e. recognisers) showed higher levels of awareness and understanding of breast screening compared to women who did not recognise the campaign (i.e. non-recognisers). The percentage of recognition was lower for older age groups, higher for the target group, higher for the West of Scotland, and the lowest for the never attended and never invited to screening
- 34% of recognisers strongly agreed with the statement "I don't think breast screening carries any risks", compared to 21% of non-recognisers
- There was high agreement across all groups that breast screening is the best way to detect cancer early (a bit lower for those who never attended screening and non-recognisers), and that breast screening saves lives
- Over half (54%) of recognisers agreed that "breast screening can find cancers that you couldn't see or feel yourself" (compared to 38% of non-recognisers)
- Almost half (49%) of recognisers agreed that "breast screening can find cancers that your GP couldn't see or feel" (compared to 33% of non-recognisers)
- Over two thirds of recognisers (68%) disagreed with the statement that "if you've missed a breast screening in the past two years, you need to wait until you are next invited" (compared to 51% of non-recognisers)
- 82% of those recognising the campaign disagreed that "you don't need to check your breasts yourself in between screenings" (compared to 69% of non-recognisers)
- 22% of the never attended group heard the breast screening radio advert; this was the lowest among the different types of screening history. Nonetheless, the highest percentage was 41%
- Regarding the newspaper adverts, the lowest percentage of recognition was amongst the never invited (34%), followed by the never attended (44%). Newspaper recognition was higher than for radio. Recognition was similar for all age groups, although it decreased with age

**Field and Partnership, B2B an PR activities**

- Over 500 breast screening resources were downloaded from the DCE website
- There were over 37 pieces of breast screening media coverage, the Elaine C Smith's Video was seen over 2,200 times
- There were over 25 field events and 50,000 keychains (thingymaboob) distributed
- DCE website had over 5,000 hits during the campaign period

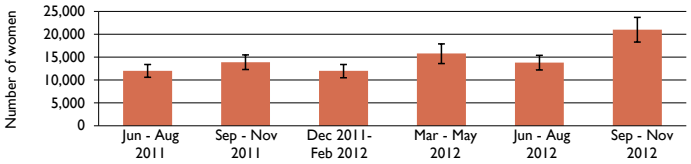
Sources: Policy documents received during evaluation development. These included a case study document with campaign outcomes prepared by the DCE team and sent to stakeholders, and an evaluation report prepared by TNS ("Breast Cancer Screening October '14(All women 50+) Data Tabulations. Date: 11th November 2014")

*Consultations for breast symptoms*

ISD Scotland and policy documents show that during the symptomatic breast campaign there was an increase of 50% in women seeing the GP with breast symptoms (Figure 11)[125].

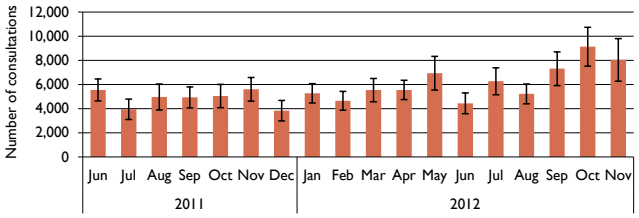
# Fig 11. Consultations for breast symptoms

Estimated number of women consulting a GP with breast symptoms including lumps, pain and infection




| Quarter | Estimate | 95% confidence interval | |
|---|---|---|---|
| | | Lower | Upper |
| Jun - Aug 2011 | 12,000 | 10,600 | 13,400 |
| Sep - Nov 2011 | 13,900 | 12,300 | 15,500 |
| Dec 2011 - Feb 2012 | 12,000 | 10,500 | 13,400 |
| Mar - May 2012 | 15,800 | 13,600 | 17,900 |
| Jun - Aug 2012 | 13,800 | 12,200 | 15,400 |
| Sep - Nov 2012 | 21,000 | 18,300 | 23,700 |

Estimated number of GP consultations for breast symptoms including lumps, pain and infection




| | | Consultations for breast symptoms (females) | | | All consultations (males and females) | | | % of all consultations |
|---|---|---|---|---|---|---|---|---|
| | | Estimate | 95% confidence interval | | Estimate (millions) | 95% confidence interval (millions) | | |
| | | | Lower | Upper | | Lower | Upper | |
| 2011 | Jun | 5,550 | 4,640 | 6,460 | 1.35 | 1.28 | 1.42 | 0.41 |
| | Jul | 3,950 | 3,100 | 4,790 | 1.22 | 1.15 | 1.28 | 0.32 |
| | Aug | 4,960 | 3,890 | 6,040 | 1.39 | 1.32 | 1.46 | 0.36 |
| | Sep | 4,930 | 4,060 | 5,800 | 1.37 | 1.30 | 1.43 | 0.36 |
| | Oct | 5,050 | 4,080 | 6,010 | 1.45 | 1.37 | 1.54 | 0.35 |
| | Nov | 5,600 | 4,620 | 6,580 | 1.47 | 1.38 | 1.56 | 0.38 |
| | Dec | 3,830 | 2,980 | 4,680 | 1.28 | 1.22 | 1.35 | 0.30 |
| 2012 | Jan | 5,270 | 4,470 | 6,070 | 1.44 | 1.37 | 1.51 | 0.37 |
| | Feb | 4,650 | 3,870 | 5,430 | 1.42 | 1.35 | 1.50 | 0.33 |
| | Mar | 5,540 | 4,570 | 6,500 | 1.53 | 1.45 | 1.61 | 0.36 |
| | Apr | 5,550 | 4,750 | 6,350 | 1.39 | 1.31 | 1.46 | 0.40 |
| | May | 6,940 | 5,540 | 8,330 | 1.54 | 1.45 | 1.64 | 0.45 |
| | Jun | 4,440 | 3,580 | 5,300 | 1.34 | 1.25 | 1.43 | 0.33 |
| | Jul | 6,270 | 5,150 | 7,380 | 1.42 | 1.33 | 1.51 | 0.44 |
| | Aug | 5,220 | 4,400 | 6,040 | 1.48 | 1.39 | 1.57 | 0.35 |
| | Sep | 7,310 | 5,910 | 8,700 | 1.32 | 1.24 | 1.40 | 0.55 |
| | Oct | 9,130 | 7,520 | 10,740 | 1.63 | 1.51 | 1.74 | 0.56 |
| | Nov | 8,040 | 6,270 | 9,800 | 1.50 | 1.41 | 1.60 | 0.53 |

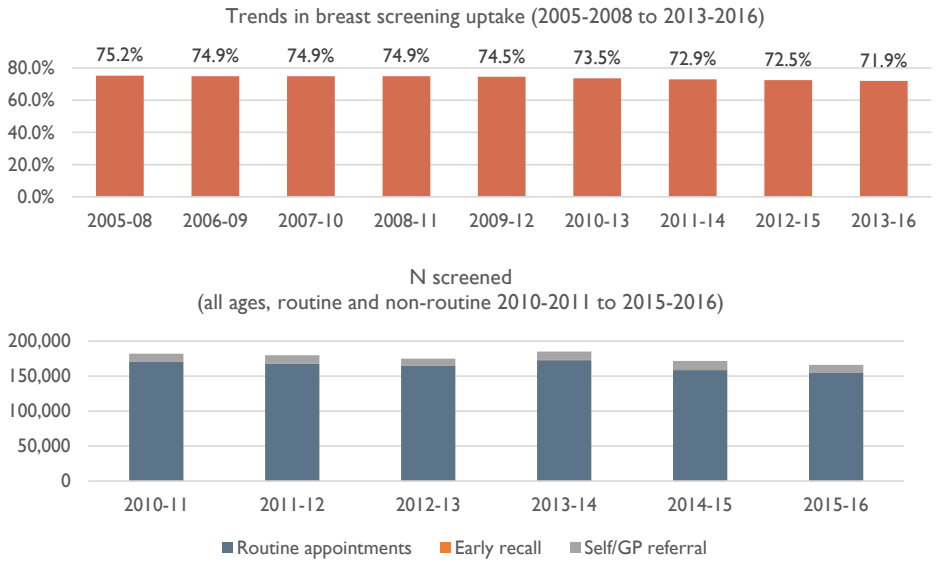
Reproduced from: ISD Scotland. GP consultations for breast symptoms September to November 2012 Publication date – 26 March 2013 https://isdscotland.scot.nhs.uk/Health-Topics/General-Practice/Publications/2013-03-26/2013-03-26-GP-Breast-Symptoms-Summary.pdf?44254702330

*Breast screening appointments and referrals*

The Breast Screening Centre reports on both routine (screening invitations every three years to all eligible asymptomatic women) and non-routine (recall, self-referral and GP referral) appointments. Routine breast screening uptake has been slowly declining for over a decade[126] (Figure 12), and there was no noticeable increase in breast screening uptake during the DCE campaigns.

When considering both routine and non-routine breast screening appointments (data provided for every two years), and defining 2010-2011 as a baseline period, trends in screening do not follow a linear pattern (there are both % increases and % decreases up to 2015-2016 for all types of appointments). There were increases in self/GP referrals in 2011-2012, 2013-2014 and 2014-2015 compared to baseline[127] (Figure 12). The symptomatic breast campaign took place in 2012; it is not possible to estimate the extent to which it has contributed to these increases.

## Fig 12. Breast screening uptake and appointments (routine, early recall and self/GP referrals)




| | 2010-11 (proxy baseline) | 2011-12 | 2012-13 | 2013-14 | 2014-15 | 2015-16 |
|---|---|---|---|---|---|---|
| Routine appointments | | | | | | |
| Number screened | 170,664 | 167,486 | 164,472 | 172,929 | 158,405 | 154,641 |
| % change from baseline | - | -1.9% | -3.6% | +1.3% | -7.2% | -9.4% |
| Early Recall | | | | | | |
| Number screened | 27 | 26 | 22 | 17 | 5 | 12 |
| % change from baseline | - | -3.7% | -18.5% | -37.0% | -81.5% | -55.6% |
| Self / GP Referral | | | | | | |
| Number screened | 11,195 | 12,151 | 10,439 | 11,972 | 13,311 | 11,251 |
| % change from baseline | - | +8.5% | -6.8% | +6.9% | +18.9 | +0.5% |

Created with data from: 1) ISD Scotland. Scottish Breast Screening Programme Statistics 2015-16. Uptake by NHS Board of Residence: Scotland, 1st April 2006 to 31st March 2016. 2) ISD Scotland. Scottish Breast Screening Programme Statistics 2015-16. Attendance by appointment type: Scotland, 1st April 2006 to 31st March 2016. Both files are available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206

Data was also collected on how many women texted the Breast Screening Programme as a result of the breast screening campaign[128].

In the first phase of the campaign, 372 women left text messages and were sent the telephone number of their regional Breast Screening Centre. However, these text messages did not translate into many booked/rescheduled appointments at the Breast Screening Centres[128].

In the second phase of the campaign, 500 women left text messages and were called back by the Screening Centres so an appointment could be booked. However, several women did not answer the call and there were some IT issues when trying to record data in the South East. Furthermore, women who left text messages were often not the target population (deprived women eligible for screening)[128].

In terms of calls to the Breast Screening Programme, one in ten women who called stated that they were prompted by DCE (94 out of 932). More than a third of them (n=35) called to change or cancel an appointment, 41 were not eligible for screening, 11 had general enquiries and 7 declined an appointment[128].

## Colorectal cancer

Colorectal cancer was targeted both through social marketing campaigns and the bowel screening initiative. We report on evaluations of the social marketing campaigns, trends in bowel screening uptake and in requested replacement bowel screening kits.

*Note about the bowel screening initiative*

There is limited quantitative information on the outcomes for the bowel screening initiative. A total of 857 practices took part (84%), with most of them being rewarded to a certain extent for decreasing bowel screening non-participation (personal communication, DCE Programme Board). No policy documents with further information were available.

*Social marketing campaigns*

Social marketing campaigns focused on bowel screening. Key results from six phases of the bowel campaign are available in Box 9. Campaigns continued after DCE's first three years (data not shown).

*Bowel screening*

Differently from breast cancer, bowel cancer screening uptake has been slowly, but steadily increasing over time. This trend has continued during DCE's first three years (Figure 13). Screening uptake increased for both males and females, with a higher % increase among males[129]. Uptake remains lower in more deprived areas, although there have been improvements over time (Figure 13).

**Box 9.** Key results from the bowel screening campaign

**TNS evaluation**

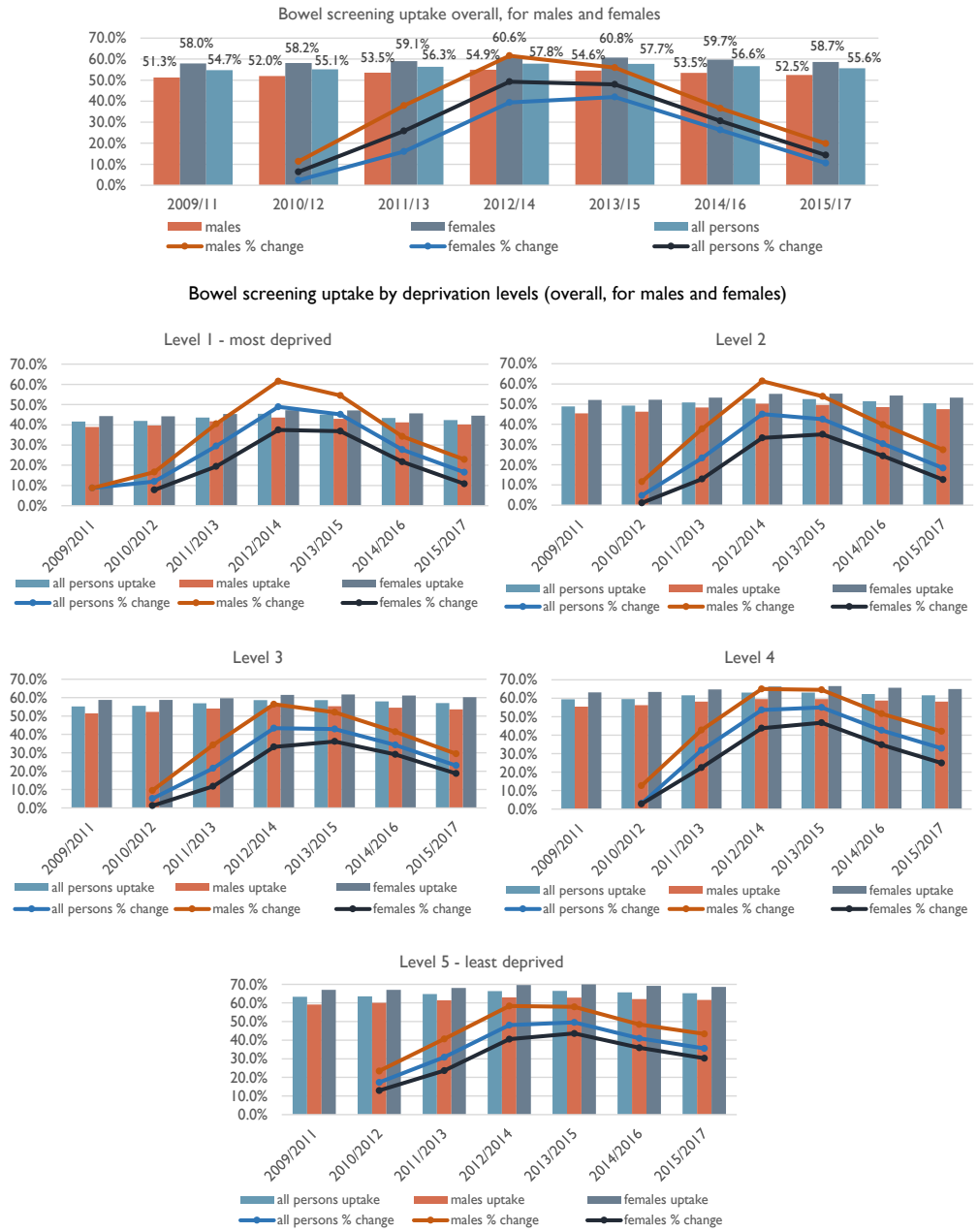
- Spontaneous awareness of campaigns remained high (68%) after six phases, but there was a significant decline over time (especially among men, those aged 45-64 and C2s)
- Increase in prompted campaign recognition was recorded amongst all groups, with significant increases for females and 65-74s. There was a very high level of TV recognition (minimum of 75%) for all groups. However, there was lower recognition of new radio advert, especially among males and DEs. Campaign recognition declined significantly with age
- There was increase in spontaneous awareness of the main message "do the test", but there were no changes for messages about survival/cure, which resonated more with those aged 45-54. Females were significantly more likely to mention "do the test" than males
- Decline in motivation noticed in evaluations of previous campaign phases continued in most groups, with the exception of 65-74s and C1C2s. There was also continued fall in the proportion wanting to see or hear the advert again. These issues highlighted potential campaign wear out
- There was slight weakening of agreement with the statements "the best way to detect bowel cancer early is to do the home screening kit"; "when detected early, most people survive bowel cancer"; and "as I get older, my risk of getting bowel cancer increases". On the other hand, there was continued strong agreement with the statements: "you could have bowel cancer and not even know it, as the early stages often have no symptoms"; and "if bowel cancer is detected early it can often be cured"
- Campaign recognisers continue to exhibit more positive views about screening compared to non-recognisers
- There was a slight decline in those claiming that they had returned the test kit (especially among men , C1s and those aged 55-64) although there was an increase in those claiming that they had received the kit at home. There was also a slight decrease in the likelihood of doing the test next time. Similar to previous evaluations, the most common reason for doing the test was that "it is the best way to find bower cancer early"

**Field and Partnership, B2B an PR activities**

- During the first three phases, the DCE page received 5,379 visits, while the bowel screening page received 8,385 visits. Increase in traffic was observed around campaign times.
- As of February 2015, the "poo song" had almost 96,151 views on YouTube; a "how to do the bowel cancer test" film had 3,629 views
- PR activity resulted on at least 274 pieces of media coverage
- Scottish football clubs and celebrities supported the campaigns; and about 20,500 in-depth engagements took place

Sources: Policy documents received during evaluation development. These included a case study document with campaign outcomes prepared by the DCE team and sent to stakeholders, and an evaluation report prepared by TNS ("Bowel Cancer Campaign Evaluation / Tracking December 2014"). The "poo song" is still available at: https://www.youtube.com/watch?v=UrwA_p8H6WY

## Fig 13. Bowel screening uptake from 2009-2011 until 2015-2017




Source: ISD Scotland. Scottish Bowel Screening Programme. Key Performance Indicators Report: May 2018 data submission. Invitations between 1st November 2015 and 31st October 2017. Available from: https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-08-07/2018-08-07-Bowel-Screening-Publication-Report.pdf: ISD Scotland; 2018.

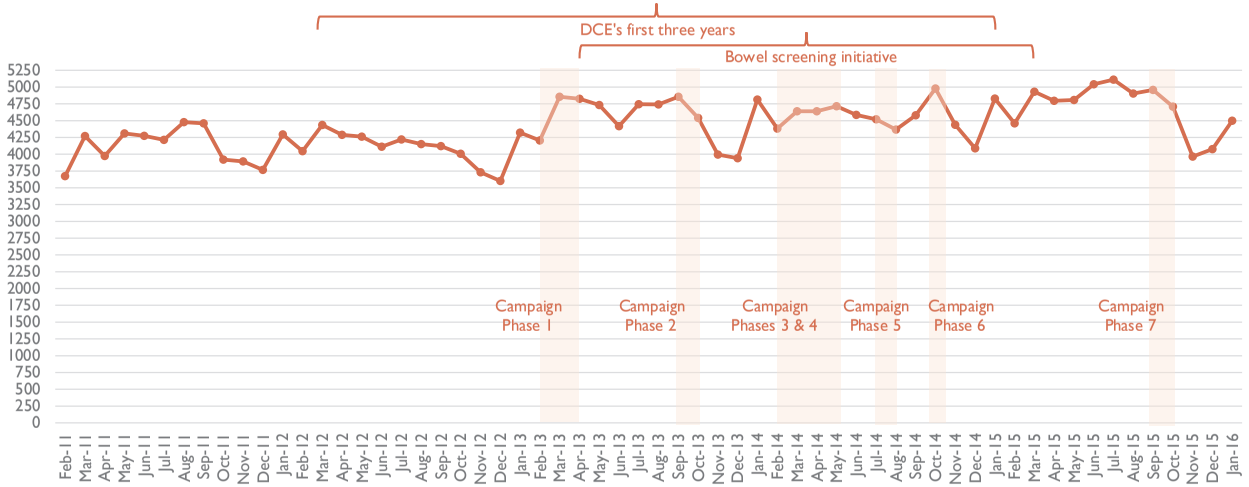
*Requested replacement bowel screening kits*

Annual reports from the Scottish Bowel Screening Centre indicated an increase in requests for replacement kits (and consequent increase in calls to the screening centre in Dundee, and in laboratory activity)[130,131]. The section in this Evaluation Report describing outcomes for Objective 5 has further information regarding impact on workload.

During the first 12 months of DCE, there was often a decrease in monthly requests for bowel replacement test kits compared to the same month in the previous year (2011 used as proxy baseline). This changed in DCE's second year when social marketing campaigns targeting bowel screening commenced (Figure 14), and numbers remained higher every month compared to baseline for the three subsequent years, except for August 2014 (2.5% decrease compared to August 2011). There was a 10.4% (DCE's second year), 10.6% (DCE's third year) and 13.6% (DCE's fourth year) annual increase in the number of requested and returned kits; corresponding to 5140, 5239 and 6734 additional test kits per year respectively compared to baseline (source: customised data provided by the Bowel Screening Centre in Dundee).

The increase in requested kits occurred across all territorial Health Boards (with variations), except for NHS Tayside and NHS Orkney in DCE's third year (bearing in mind small numbers for the latter) (Appendix 9). As both the size of the eligible screening population and bowel screening uptake vary across Health Boards, absolute numbers in this figure should not be used to compare performance.

## Fig 14. Requested and returned replacement test kits (Feb 2011 - Jan 2016), and percentage changes




| Year prior to DCE (proxy baseline) | | DCE's first year (prior to bowel specific strategies) | | | DCE's second year (Campaign phases 1 & 2, bowel screening initiative) | | | DCE's third year (Campaign phases 3-6; bowel screening initiative) | | | DCE's fourth year (Campaign phase 7; bowel screening initiative) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Months | N | Months | N | % change | Months | N | % change | Months | N | % change | Months | N | % change |
| Feb-11 | 3674 | Feb-12 | 4045 | 10.1% | Feb-13 | 4205 | 14.5% | Feb-14 | 4381 | 19.2% | Feb-15 | 4460 | 21.4% |
| Mar-11 | 4270 | Mar-12 | 4435 | 3.9% | Mar-13 | 4857 | 13.7% | Mar-14 | 4640 | 8.7% | Mar-15 | 4932 | 15.5% |
| Apr-11 | 3973 | Apr-12 | 4289 | 8.0% | Apr-13 | 4825 | 21.4% | Apr-14 | 4641 | 16.8% | Apr-15 | 4795 | 20.7% |
| May-11 | 4311 | May-12 | 4263 | -1.1% | May-13 | 4732 | 9.8% | May-14 | 4715 | 9.4% | May-15 | 4809 | 11.6% |
| Jun-11 | 4273 | Jun-12 | 4113 | -3.7% | Jun-13 | 4418 | 3.4% | Jun-14 | 4585 | 7.3% | Jun-15 | 5043 | 18.0% |
| Jul-11 | 4215 | Jul-12 | 4221 | 0.1% | Jul-13 | 4744 | 12.6% | Jul-14 | 4519 | 7.2% | Jul-15 | 5111 | 21.3% |
| Aug-11 | 4479 | Aug-12 | 4152 | -7.3% | Aug-13 | 4741 | 5.8% | Aug-14 | 4368 | -2.5% | Aug-15 | 4905 | 9.5% |
| Sep-11 | 4460 | Sep-12 | 4121 | -7.6% | Sep-13 | 4856 | 8.9% | Sep-14 | 4581 | 2.7% | Sep-15 | 4959 | 11.2% |
| Oct-11 | 3919 | Oct-12 | 4008 | 2.3% | Oct-13 | 4542 | 15.9% | Oct-14 | 4979 | 27.0% | Oct-15 | 4710 | 20.2% |
| Nov-11 | 3893 | Nov-12 | 3732 | -4.1% | Nov-13 | 3994 | 2.6% | Nov-14 | 4440 | 14.1% | Nov-15 | 3964 | 1.8% |
| Dec-11 | 3766 | Dec-12 | 3602 | -4.4% | Dec-13 | 3940 | 4.6% | Dec-14 | 4088 | 8.6% | Dec-15 | 4076 | 8.2% |
| Jan-12 | 4295 | Jan-13 | 4322 | 0.6% | Jan-14 | 4814 | 12.1% | Jan-15 | 4830 | 12.5% | Jan-16 | 4498 | 4.7% |
| Total requests | 49528 | - | 49303 | -0.5% | - | 54668 | 10.4% | - | 54767 | 10.6% | - | 56262 | 13.6% |
| Mean (monthly) | 4127 | - | 4109 | - | - | 4556 | - | - | 4564 | - | - | 4689 | - |

Source: Customised data provided by the Scottish Bowel Screening Centre in Dundee. Data refers only to requested kits that were completed, returned to the Bowel Screening Centre and had a valid result. Hence, data underestimates the number of requested kits as not everyone who requests one completes it

## Lung cancer

As there is no organised lung screening programme in Scotland, the lung cancer campaign (with three phases) only focused on signs and symptoms. Key outcome data from the campaign is shown in Box 10.

A DCE Newsletter sent to GPs reported that more patients were referred for a chest x-ray by a GP during the first month of the campaign (compared to the previous month). There was also a 3% increase in chest x-rays during the campaign (compared to the same time in the year prior to the campaign)[132]. No further information on outcomes was available.

### **Box 10.** Key results from the lung campaign

**TNS evaluation**

- After the campaign phase in November 2014, there was significant increase in spontaneous awareness of activity about lung cancer, with a similar pattern found across most groups (with the exception of those aged 75+ for whom spontaneous awareness decreased)
- Campaign recognition remained high over different campaign phases, with television being the most dominant media. Recognition was significantly higher among C2s when compared to C1DEs. Written media (press) showed declined recognition (significantly among DEs)
- The "get checked" message remained strong after campaigns; the "three week cough" message was also being more recognised
- Motivation has increased over time, especially for men, DEs and 75+
- There were high levels of agreement that much can be done to treat symptoms, and an increase in agreement over time (over 70% agreed)
- There was a significant increase in the proportion taking action as a result of campaign. Those not motivated by it were significantly less likely to take action than those who were motivated
- In terms and attitudes and behaviours, target audience stated that they felt more comfortable going to the doctor with small changes. While there was a significant increase in those who would go to the GP after three weeks, more also said they would not go at all
- There was a significant increase in spontaneous awareness of the three-week cough (over 70% awareness) as a symptom and smaller increase in prompted awareness (over 90% awareness)
- Prompted symptom awareness increased over time, more as a result of rise in awareness of lesser known symptoms, as awareness of the three-week cough remained similar

**Field and Partnership, B2B an PR activities**

- During campaign times, the campaign website received over 16,200 visits; Sir Alex Ferguson's TV advert received around 4,500 views on You Tube
- Sir Alex Ferguson's video saying that "lung cancer isn't what it used to be" was shared on Get Checked Early's Facebook page and reached 294,656 people
- The events team engaged with over 29,000 members of the public in over 28 events
- PR activity resulted in over 95 pieces of coverage in the media

Sources: 1) Consolidated PR Detect Cancer Early campaign briefing pack. Lung Cancer. 2013. 2) TNS. Lung Cancer Campaign Evaluation – 2014/15. Presentation of Results to Scottish Government 26 May 2015. 3) DCE News release; 4) Case study document with campaign outcomes prepared by the DCE team; 5) Detect Cancer Early Lung Cancer, GP update; 6) DCE Lung Cancer leaflet

### TNS Attitudinal Tracking

TNS compared people's attitudes before all the social marketing campaigns (2011) and after DCE's first three years (early 2015) regarding 11 statements (Box 11). Several significant changes in attitudes were reported.

**Box 11.** Key results from the 3-year attitudinal tracking

- **Statement: There's not much doctors can really do for cancer -** The proportion who disagreed increased significantly from 76% to 83%, with strong disagreement increasing from 27% to 38%. Significant increases happened for both total disagreement and strong disagreement for men, those aged 65+ and DEs
- **Statement: You can't survive cancer so what's the point in worrying about the early signs and symptoms of it -** Total disagreement increased significantly from 85% to 91%, with strong disagreement increasing from 39% to 55%; there were significant increases in total disagreement among men, those aged 65+ and DEs
- **Statement: Just the thought of cancer puts me off thinking about checking for the signs and symptoms of it -** Total disagreement fell significantly from 76% to 65%, without a change in strong disagreement. Agreement with the statement showed no substantial changes
- **Statement: I might put off going to see my doctor or GP about possible signs of cancer – for fear of what they might tell me -** Significant decrease in total disagreement among all groups, except for those aged 65+
- **Statement: I would go to the doctor or GP straightaway if I suspected any signs or symptoms of cancer -** Total agreement decreased significantly from 91% to 85%. Reduction happened in all groups, and was significant among females, 40-54s and DEs
- **Statement: Spotting signs of cancer early improves your chances of survival -** Total agreement increased significantly from 94% to 97%, with strong agreement increasing significantly from 50% to 66%
- **Statement: People who take part in screening (when invited) are improving their chances of surviving cancer -** No change in total agreement, but strong agreement increased significantly from 41% to 51%, including among men, those aged 65+ and DEs
- **Statement: If you get lung cancer there's little or no chance of you surviving -** Total disagreement increased from 48% to 58%, with significant increases among men, those aged 65+ and DEs. There was a significant increase in strong disagreement (11% to 15%) overall and for C2s
- **Statement: I am confused generally about what the early signs and symptoms of cancer actually are** - There was no change in agreement with this statement (49%); but total disagreement decreased from 39% to 29%
- **Statement: I worry about wasting the doctor's or GP's time unless my symptoms are clearly serious** - The proportion who disagreed with this statement decreased from 54% to 44% (while 45% agreed compared to 42% previously). The decrease was driven by significant decreases for women, those aged 40-54s and CIs
- **Statement: Taking part in cancer screening (e.g. bowel / breast) reduces the need to look out for signs and symptoms yourself -** Total agreement decreased significantly from 42% to 32%, while total disagreement increased significantly from 50% to 58%. There were significant increases in disagreement among women, those aged 65+, C2s and DEs.

Source: TNS. DCE Attitude Tracking – 3 Year Anniversary Comparison. 2015

*Objective 4: To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access*

In order to meet this objective there were three key components: the updated referral guidelines for suspected cancer, the educational sessions for professionals and the use of qFIT with symptomatic patients. Local activities using additional funding from DCE (Objective 6) have also resulted in relevant activities for this objective (although there is limited information on outcomes for these).

The development of practice profiles was also aimed to help meet objective 4. However, it was not feasible to launch them until 2015 (work is currently ongoing - personal communication, DCE Programme Board). Hence, no outcomes are shown for this programme component.

*Education sessions*

Bowel Cancer UK and the Roy Castle Lung Cancer Foundation delivered seven engagement sessions and one Webcast to over 424 professionals between September and October 2013. GP Leads helped to develop an Agenda for the sessions, which covered both colorectal and lung cancers. Developed resources included one Marketing flyer, handouts covering cancer prevention and treatment, one action plan document (for bowel screening), one resource document (detailing where to find supporting literature) and one evaluation form[133,134]. Key results from the evaluation (carried out by the charities) are described in Box 12.

**Box 12.** Key results from the evaluation of the education sessions

- Finding out about the bowel screening initiative, the Bowel Screening Programme and the bowel cancer referral guidelines were the priorities for attending the sessions
- Attendees thought that the lung and bowel sessions were useful; symptoms and social marketing were the most highly rated sessions
- Overall the attendees agreed that the day met their expectations, the event was relevant and they were taking away knowledge that they could use
- A third of attendees answered the question about how they would share information within the practice and 68% of these planned to do so at a practice meeting
- Bowel Cancer UK saw an increase in demand for their endoscopy booklet and the Bowel Health and Screening resource for people with learning disabilities and their care providers. There were also requests for awareness talks to surgeries on bowel cancer symptoms, screening, risk factors and prevention messages
- Attendance was reported to be poor from three territorial Health Boards and further engagement sessions were planned.

Sources: 1) Roy Castle Lung Cancer Foundation. Report to Scottish Government – Detect Cancer Early Workstream 2013; 2) Roy Castle Lung Cancer Foundation and Bowel Cancer UK. Detect Cancer Early Primary Care Engagement Project. 2013.

*Referral guidelines*

The key output to reach this objective was the publication of the updated referral guidelines for suspected cancer[135]. After reviewing international guidelines and assessing them for quality (Appendix 1), there was wide consultation with different professionals and experts in order to develop the Scottish guidelines. Quick guides were printed and disseminated across Scotland.

The use of the guidelines is being evaluated (personal communication, Dr Douglas Rigg), and results are expected to be published at a later date. Furthermore, the current guidelines are being updated again (see Discussion).

*Symptomatic qFIT*

DCE has also funded research assessing the use of the Faecal Immunochemical Test (FIT) with symptomatic patients (personal communication - DCE Programme Board), in order to assess if this approach would be effective for early diagnosis of bowel cancer. More recent developments (beyond this Evaluation time frames) included testing the approach in one Health Board in Scotland (followed by dissemination to other Health Boards). Results are also expected to be published at a later date.

*Objective 5: To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part*

Breast and Bowel Screening Centres were not allocated additional funding (Strategy 3) alongside Health Boards, although DCE funded specific screening initiatives.

*Breast screening capacity*

There is limited information on breast screening capacity. Data describing increase in consultations due to breast symptoms and increase in self-referrals indicate increase in workload for screening programmes (as resources were used for screening and self/GP referrals). The process evaluation also sheds light on whether capacity was sufficient.

*Bowel screening capacity*

Two annual reports from the Scottish Bowel Screening Centre describe increase in activity during DCE awareness campaigns and the bowel screening initiative. These included increases in the number of reminder letters, helpline calls and emails (accompanied by an increase in requested and returned replacement kits - as described in the previous section)[130,131].

The increase in activity was also reported to have influenced laboratory test time and the Centre's ability to meet the NHS Quality Improvement Scotland (QIS) desirable standard (95% of participants receiving their results within 7 days of receipt by the Screening Centre). Nonetheless, all screening participants received their results within 12 days (2013-2014) and 14 days (2014-2015). Reports also stated that there was a seasonal peak in laboratory activity during February and March 2014; this was then reduced in April and returned to pre-campaign levels[130,131].

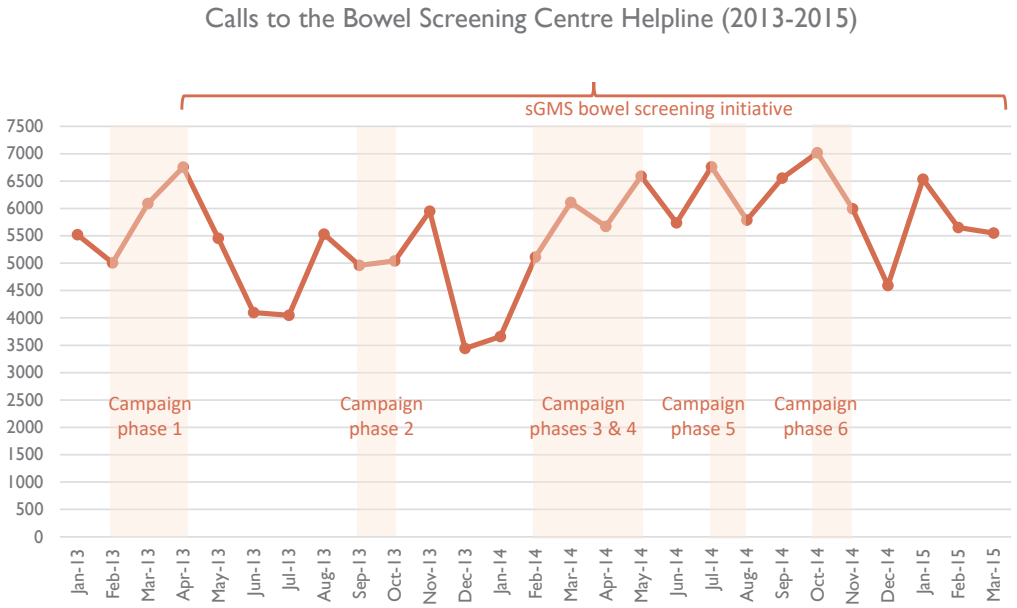
Several strategies were adopted to manage impact; these included an automated telephone option so those calling could order a replacement kit by leaving a recorded message (added in February 2014). About one third of callers used this option, with 90% accuracy (i.e. without the need to call back)[130,131].

Replacement kits were also requested by email. At the time of the first report (2014), there were about 60 email requests per month. The second report (2015) stated that the number of monthly requests was 350[130,131]. Calls from GPs and GP practices were also reported to have increased (Figure 15).

Initially, additional Medical Laboratory Assistants (MLAs) fixed term contracts were introduced to increase laboratory staff resource. This was followed by a review of MLA working hours which resulted in adjustments in shifts and better management of workload[130,131].

Revenue funding was allocated to Health Boards via NRAC share (Appendix 1). DCE adopted a flexible approach to funding; territorial Health Boards could use it according to their population and health system needs and characteristics

## Fig 15. Calls to the Bowel Screening Centre helpline and reminder letters (2013-2015)




| 2013 (Campaign phases 1 & 2; bowel screening initiative launched) | | 2014 (Campaign phases 3-6; bowel screening initiative ongoing) | | 2015 (Final three months of the bowel screening initiative) | |
|---|---|---|---|---|---|
| Months | N | Months | N | Months | N |
| Jan-13 | 5521 | Jan-14 | 3659 | Jan-15 | 6534 |
| Feb-13 | 5007 | Feb-14 | 5112 | Feb-15 | 5649 |
| Mar-13 | 6092 | Mar-14 | 6112 | Mar-15 | 5550 |
| Apr-13 | 6754 | Apr-14 | 5673 | | |
| May-13 | 5456 | May-14 | 6587 | | |
| Jun-13 | 4096 | Jun-14 | 5739 | | |
| Jul-13 | 4045 | Jul-14 | 6762 | | |
| Aug-13 | 5528 | Aug-14 | 5789 | | |
| Sep-13 | 4958 | Sep-14 | 6552 | | |
| Oct-13 | 5043 | Oct-14 | 7018 | | |
| Nov-13 | 5947 | Nov-14 | 5994 | | |
| Dec-13 | 3442 | Dec-14 | 4591 | | |

Reminder letters and calls to helpline by year

| Contacts | 2012/2013 (proxy baseline) | 2013/2014 | | 2014/2015 | |
|---|---|---|---|---|---|
| | N | N | % increase | N | % increase |
| Reminder letters | 372,825 | 469,850 | 26.0% | 470,956 | 26.3% |
| Helpline calls | 52,342 | 62,166 | 18.8% | 72,028 | 37.6% |

Sources: Created from 1) Scottish Bowel Screening Centre. Scottish Bowel Screening Centre Annual Report 2014-2015. April 2014 to March 2015 as reported in May 2015. Scottish Bowel Screening Centre; 2015. 2) Scottish Bowel Screening Centre. Scottish Bowel Screening Centre Annual Report 2013-2014. April 2013 to March 2014 as reported in May 2014. Scottish Bowel Screening Centre; 2014.

(provided that funding was used to meet DCE aims). Consequently, investments varied across Scotland. Nonetheless, many Health Boards used some of their funding to support improvements in diagnostics (such as purchasing new equipment or hiring more staff), data capture and reporting; local awareness initiatives and support for national campaigns. Many reported challenges in recruiting professionals such as radiologists and difficulties when funding was reduced. There was little information about resources for treatment (personal communication, DCE Programme Board).

DCE received brief annual reports from Health Boards about how funding was used, challenges faced, perceived benefits, actions to ensure sustainability and lessons learned. Examples of how funding was used and perceived benefits are described below (Table 1). Evidence on challenges faced and how these were tackled is available in Appendix 10.

## Table 1. How additional funding was used across Scotland

| Health Board | Examples of how additional funding was used | Reported benefits (including soft outcomes) |
|---|---|---|
| NHS Ayrshire & Arran | • Investment in diagnostics (Radiography, Pathology, Endoscopy, Laboratory, local Endobronchial Ultrasound (EBUS) services) and purchase of videoconferencing equipment for multidisciplinary team (MDT) meetings<br>• Baseline assessment and ongoing measurement (cancer tracking and audit staff)<br>• Awareness raising activities, engagement with men and other hard-to-reach bowel screening non-responders<br>• Recruitment of locum staff to deal with demand; increase in breast surgery capacity<br>• Support for GPs to increase bowel screening uptake | • Better communication with GPs, improved GP engagement to increase bowel screening uptake<br>• Better communication and engagement with patients, volunteers and the public<br>• Increase in breast screening and mammography capacity (with subsequent reduction in waiting times); increase in diagnostic capacity (bowel screening, imaging and pathology)<br>• Improved audit of cancers diagnosed following A&E admission and routine referral; more accurate and complete staging data<br>• Improved efficiency of MDTs; additional CT capacity<br>• Plans to have continuous evaluation, funding and awareness raising, work on health improvement and reduce inequalities, develop and strengthen partnerships, and review cancer pathways |
| NHS Borders | • Assignment of managers to coordinate work on awareness and communication with deprived populations<br>• Funding for an additional clinical nurse specialist in lung cancer; additional colonoscopy/computed tomography (CT) scan capacity; additional breast clinics and a consultant radiologist<br>• Development of local material to support staff; staff survey on awareness of bowel screening<br>• Training and support for practices in order to meet bowel screening targets<br>• Use of local radio for early detection messages | • New network of contacts to reach deprived and vulnerable populations; work with local initiatives and companies<br>• Dedicated staff to work on DCE helped to increase bowel screening uptake<br>• Establishment of a multidisciplinary team<br>• Plans developed to support gaps in service provision with new resources were brought by funding<br>• Events were held with GP practices to provide follow-up support<br>• Messages on risk factor and early detection were embedded in conversations staff have with patients |

| Health Board | Examples of how additional funding was used | Reported benefits (including soft outcomes) |
|---|---|---|
| NHS Dumfries and Galloway | • Development of new cross-cancer site MDT data recording system; employment and training of new audit staff<br>• Display of advertising/marketing from national campaigns in local NHS and regional publication; increase in communications activity<br>• Increase in capacity in Head and Neck Clinical Nurse Specialist (CNS) role; building capacity in endoscopy (including equipment) and Pathology | • Better planning for future service developments and audit of practice (developments were incorporated in services provided); plans for updated IT systems to prevent long term need for Cancer Audit staff and to improve MDT data; plans to develop universal and specialist workforce capacity and continue engagement with hard to reach groups<br>• Increased engagement with Community Health Teams and Educational Institutes<br>• Improved reporting in cancer staging data |
| NHS Fife | • Investment in diagnostics (endoscopy, radiology and pathology); recruitment of a respiratory physician; and appointment of a lead Cancer GP<br>• Funding for additional clinical sessions to tackle system delays | • Reduction in the capacity deficit |
| NHS Forth Valley | • Funding for additional diagnostics (Radiology and Pathology consultants, technical staff for breast services and fast-track x-ray for lung) and training<br>• Support and redesign the Outpatient Department breast service; funding for a breast surgeon, nursing and administrative staff; pilot using breast physician to support one-stop clinics<br>• Purchase of an additional ultrasound machine; additional endoscopy capacity for surveillance<br>• Funding for Health Promotion and to train volunteers to work with hard-to-reach groups<br>• Cancer prevention activities through events; awareness raising in prisons, locally through case studies, work in the local community, distribution of campaign packs; use of websites, social media and community newsletters | • Networking with other Boards to share scarce resources in providing services<br>• Additional endoscopy capacity eased the pressure on the endoscopy unit<br>• Reduced pathway delays, improved patient centred breast service<br>• Analysis undertaken at the start of DCE to identify where additional capacity would be needed<br>• Bowel screening awareness training indicated lack of awareness of the screening test, of knowledge about the importance of symptoms and signs, body and practical issues of doing the test. A short weekly briefing session implemented for breast has continued and has been rolled out to other cancer pathways |
| NHS Grampian | • Support for endoscopy, radiology, cancer audit team and Managed Clinical Network (MCN)<br>• Funding for cancer nurse specialists, cancer pathways team and MDT support | • Increased diagnostic capacity<br>• Complementary early detection initiatives carried out in partnership with voluntary and partners<br>• Network approach to funding allocation taken by consulting widely and identifying priorities (this also resulted in better engagement of different professionals)<br>• Ability to undertake systematic review of pathways; establishment of a Cancer Care Network and development of a work plan |
| NHS Greater Glasgow & Clyde | • Additional breast and radiology sessions (including in the evening and over the weekend); additional imaging capacity, scanning and reporting capacity for CT scanning; additional infrastructure associated with developing a Sentinel Lymph Node Biopsy in Breast Cancer service<br>• Targeted marketing for the breast campaign<br>• Increase in lung capacity ahead of campaigns; additional endoscopy capacity<br>• Increase in medical and diagnostic sessions within respiratory medicine and diagnosis | • Improved "real time" audit in terms of staging data<br>• Improved understanding of residual consequences of campaigns<br>• Audit system put in place to enable continuous improvement and understanding of trends in presentation |
| NHS Highland | • Procurement of a mammography unit, of an ultrasound machine (lung) and a prostate biopsy probe for urology | • Reduced waiting times for diagnosis and treatment of breast patients; reduced waiting time for TRUS biopsies with greater flexibility for treatment. |

| Health Board | Examples of how additional funding was used | Reported benefits (including soft outcomes) |
|---|---|---|
| NHS Lanarkshire | • Production of teaser letters for breast screening and bowel diaries; joint work with partners to raise awareness of bowel and breast cancers; health improvement (training, screening toolkits, work in prisons and leisure centres)<br>• Investment in digital mammography, recruitment of a breast surgeon and support for the appointment of a breast clinical assistant<br>• Purchase of EBUS services and an introduction of a wide screen monitor; purchase of rigid thoracoscopy equipment<br>• Investment in specialist Radiology (x2) and CT Colonography; piloting of a one-stop breast clinic<br>• Training for nurse endoscopists<br>• Support for clinical audit and data gathering; radiology, care pathways, and local campaigns | • Cemented relationships with local authority partners<br>• Improvement of clinical audit data and KPIs; backlog in data collection was reduced; quality assurance timescales were met and a rolling programme of quality assurance for all tumours was facilitated<br>• DCE funding allowed for the development of local reporting (and for better data collection on staging)<br>• EBUS can improve diagnosis, staging information for lung cancer and can reduce invasive procedures<br>• Improved access and local treatment (lung); more streamlined approaches that reduce the risk and the need of anaesthetics<br>• Continuous review of pathways to ensure a robust and streamlined approach, and to improve services<br>• Improvement in data capture and integration of CT colonography into Colorectal Services as standard |
| NHS Lothian | • Increase in diagnostic, screening capacity and treatment costs to maintain CWT targets<br>• Baseline assessment and ongoing measurement (audit staffing, programme management, analytical capacity, e-health developer time and others)<br>• Assessing, profiling and influencing primary care referral behaviour<br>• Investment in breast symptomatic and screening services, radiology for breast, lung and bowel, respiratory medicine (staff, nursing and administrative support), investment in breast imaging, biopsy and Magnetic Resonance Imaging (MRI) family history, support to EBUS/imaging<br>• Investment in a pilot study to improve screening uptake and additional session funding to increase GP Cancer Lead time availability | • Increased understanding of the system while using cancer intelligence - changing service provision and delivering pathways that support early detection; improved cancer analytical capacity and audit<br>• Development of a governance and leadership structure through the DCE Board; improved learning about supporting management and clinical leads<br>• Awareness activities carried out without DCE budget<br>• 10 pilots on primary care engagement and innovation, with improved engagement with general practice and screening programmes<br>• Increase in breast service (including one additional one-stop clinic) and radiology capacity<br>• Improved referral guidance and plans for updating of the Lothian Refhelp system for cancer pathways<br>• Early diagnosis now central to NHS Lothian's Cancer Strategy |
| NHS Orkney | • Funding for new scopes; endoscopy redesign to support screening campaigns; establishment of a CT service; new multifunction room<br>• Support for Health Promotion<br>• Development of the "Bin your Bra" campaign<br>• Support for DCE campaigns locally - giving away thingymaboob keyrings, doing radio interviews with local women, having articles in local magazines, distributing resources to local businesses and public venues, and sharing information and links on local pages and websites (including social media) | • Increase in the number of scopes carried out, awareness raised through "Bin your Bra" (there was also enhanced engagement with staff)<br>• Increased scrutiny on performance at practice level<br>• Rolling programme of replacement scopes to maintain scope numbers<br>• Promotion of educational programmes; knowledge and skills to be maintained and mainstreamed<br>• New room allows for reshaping and sustaining work<br>• Adoption of protocols to order scans and help to deal with having no radiologist<br>• Discussing performance with lead clinicians helped to support a revised networked approach through the Isles Network of Care to the delivery of care |

| Health Board | Examples of how additional funding was used | Reported benefits (including soft outcomes) |
|---|---|---|
| NHS Shetland | • Investment in capacity of DCE leads, data capture, and new diagnostic equipment<br>• Purchase of video conferencing equipment and use of funding to assist with modernising scopes; additional colonoscopy capacity<br>• Pump priming for initiatives to support DCE; support of Health Promotion activities (alongside work with pharmacists funded by Macmillan); funding allocation alongside Urological Cancer Charity (UCAN) and Prostate UK | • DCE embedded in core business; ideas are being generated for engagement; DCE became a recurring item in Cancer Lead Team meetings<br>• Collaborations with charities led to increased opportunities for patients to be referred via the pharmacist; links with services improved; there were increased awareness of trigger symptoms and pathways across primary care services and improved links before specialists and health services. These resulted in increased capacity and reduction of waiting times for patients requiring ongoing surveillance after cancer treatment |
| NHS Tayside | • Investment in breast capacity though additional staff, and lung and colorectal capacity through staff and equipment<br>• Investment in capacity for Pathology, Radiology, Information Technology, Primary Care, and Medical Records through staff and equipment<br>• Pilot development of a cancer decision support tool in primary care<br>• National marketing support | • Investment in service improvement methodology (to happen irrespective of DCE) and sustained and embedded social marketing<br>• DCE Programme perceived as a whole rather than individual silos<br>• Increased understanding of the importance of systematic data collection and analysis, of having an effective and influential clinical engagement with the DCE Programme, having effective senior leadership, good management and administration<br>• More capacity in breast, lung, colorectal and supporting services |
| NHS Western Isles | • Funding used towards cancer awareness (breast, bowel, lung, prostate, testicular and general cancer awareness) - contacting existing cancer support groups, setting up stalls at community events, disseminating information in community halls, GP practices and workplaces; using survival stories in different media channels to engage with the public; targeting men using local media channels and women through ladies' film night<br>• Use of out of hours helpline and set up of a dedicated NHS Western Isles Cancer website | • Breast screening uptake increased<br>• Learning built into Health Promotion approaches to enhance awareness and screening uptake<br>• Increased vigilance for early detection; continued input and support for local cancer groups |

Sources: Annual reports submitted to DCE by territorial Health Boards (2012/2013; 2013/2014 and 2014/2015), and summaries of reports prepared by the DCE team

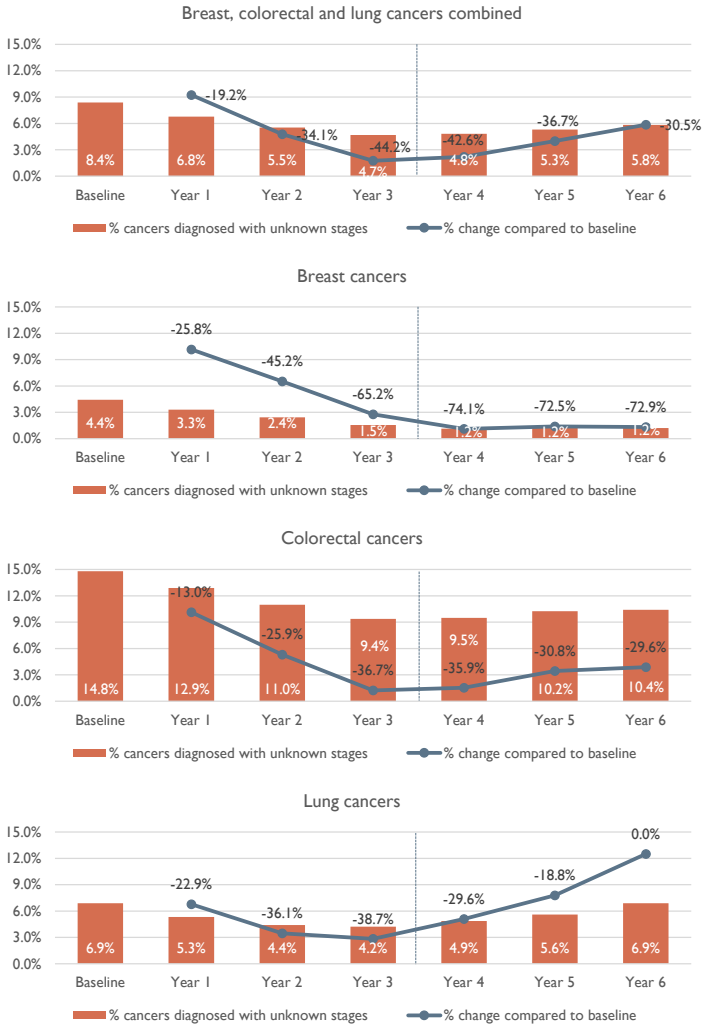
## *Objective 7: To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral, and survival*

This was a broad objective, and one way to measure it was to assess whether the proportion of cancers diagnosed with unknown stages decreased over time.

When looking at all three cancer types combined, there was a 44.2% reduction in cancers diagnosed with unknown stages (Year 3 compared to baseline). The highest reduction happened for breast cancer (65.2% in Year 3). The reduction for colorectal and lung cancers in Year 3 was similar (36.7% and 38.7% respectively) (Figure 16)[124]. Reductions occurred across all deprivation levels, with the most deprived having the highest reduction in Year 3 (52.7%) (Figure 17)[124].

There were reductions in the proportion of cancers diagnosed with unknown stages across all Cancer Networks (the highest reduction happened for WOSCAN) (Figure 18). Reductions did not occur across all territorial Health Boards (Appendix 11).

## Fig 16. Proportion of cancers diagnosed with unknown stages and % changes




| Cancer type | N(%) at Stage I and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| 3 cancers combined | N (%) at Stage I | 2008 (8.4) | 1669 (6.8) | 1368 (5.5) | 1164 (4.7) | 1195 (4.8) | 1296 (5.3) | 1415 (5.8) |
| | % change | | -19.2% | -34.1% | -44.2% | -42.6% | -36.7% | -30.5% |
| Breast | N (%) at Stage I | 365 (4.4) | 279 (3.3) | 208 (2.4) | 132 (1.5) | 99 (1.2) | 105 (1.2) | 103 (1.2) |
| | % change | | -25.8% | -45.2% | -65.2% | -74.1% | -72.5% | -72.9% |
| Colorectal | N (%) at Stage I | 1047 (14.8) | 905 (12.9) | 747 (11.0) | 624 (9.4) | 630 (9.5) | 676 (10.2) | 683 (10.4) |
| | % change | | -13.0% | -25.9% | -36.7% | -35.9% | -30.8% | -29.6% |
| Lung | N (%) at Stage I | 596 (6.9) | 485 (5.3) | 413 (4.4) | 408 (4.2) | 466 (4.9) | 515 (5.6) | 629 (6.9) |
| | % change | | -22.9% | -36.1% | -38.7% | -29.6% | -18.8% | 0.0% |

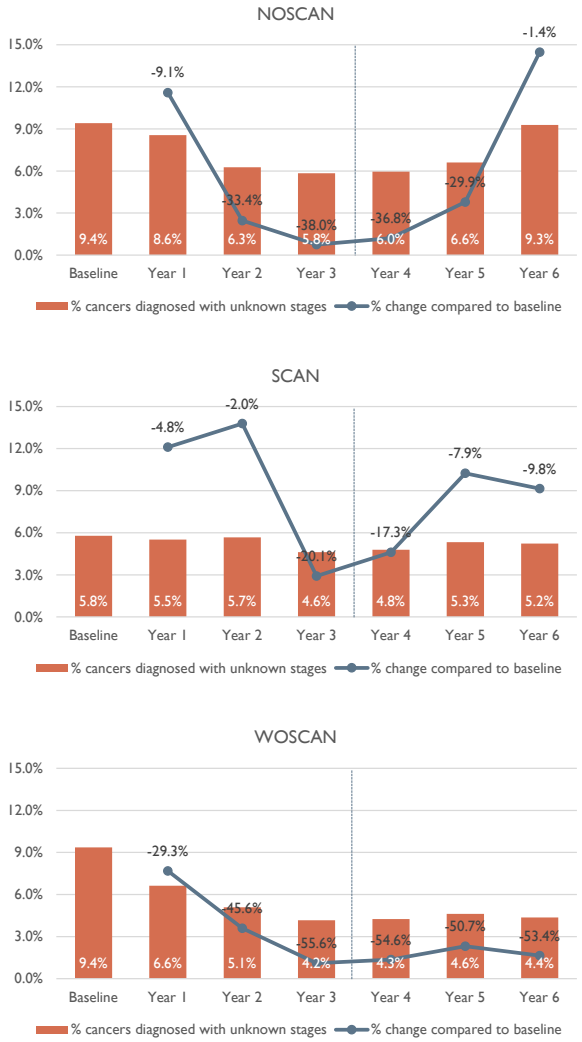
Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Time Period: 01 January 2010 - 31 December 2017. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

## Fig 17. Proportion of breast, colorectal and lung cancers (combined) diagnosed with unknown stages and % changes by deprivation levels


| Cancer type | N(%) unknown stage and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| Level 1 = most deprived | N (%) unknown | 508 (9.1) | 424 (7.4) | 320 (5.6) | 249 (4.3) | 258 (4.5) | 291 (5.3) | 305 (5.7) |
| | % change | | -18.6% | -39.1% | -52.7% | -50.8% | -42.0% | -37.1% |
| Level 2 | N (%) unknown | 469 (8.9) | 374 (6.9) | 307 (5.7) | 269 (5.0) | 261 (5.0) | 290 (5.5) | 313 (5.9) |
| | % change | | -22.4% | -35.7% | -43.6% | -44.1% | -37.7% | -33.2% |
| Level 3 | N (%) unknown | 407 (8.7) | 322 (6.7) | 274 (5.7) | 246 (5.1) | 271 (5.5) | 276 (5.7) | 277 (5.8) |
| | % change | | -22.7% | -34.5% | -41.8% | -36.9% | -34.8% | -33.4% |
| Level 4 | N (%) unknown | 324 (7.4) | 284 (6.2) | 251 (5.5) | 212 (4.6) | 216 (4.7) | 245 (5.5) | 274 (6.0) |
| | % change | | -16.2% | -25.7% | -37.9% | -36.3% | -26.1% | -18.0% |
| Level 5 = least deprived | N (%) unknown | 293 (7.4) | 260 (6.4) | 212 (5.1) | 186 (4.5) | 188 (4.4) | 192 (4.5) | 244 (5.7) |
| | % change | | -13.8% | -31.6% | -40.1% | -40.7% | -39.6% | -23.8% |

Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Time Period: 01 January 2010 - 31 December 2017. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

## Fig. 18. Proportion of breast, colorectal and lung cancers (combined) with unknown stages and % changes over time by Cancer Networks




| Cancer type | N(%) unknown stage and % change | Baseline | Year 1 | Year 2 | Year 3 | Year 4 | Year 5 | Year 6 |
|---|---|---|---|---|---|---|---|---|
| NOSCAN | N (%) unknown | 552 (9.4) | 504 (8.6) | 374 (6.3) | 347 (5.8) | 361 (6.0) | 413 (6.6) | 568 (9.3) |
| | % change | | -9.1% | -33.4% | -38.0% | -36.8% | -29.9% | -1.4% |
| SCAN | N (%) unknown | 382 (5.8) | 373 (5.5) | 378 (5.7) | 311 (4.6) | 321 (4.8) | 344 (5.3) | 341 (5.2) |
| | % change | | -4.8% | -2.0% | -20.1% | -17.3% | -7.9% | -9.8% |
| WOSCAN | N (%) unknown | 1074 (9.4) | 792 (6.6) | 616 (5.1) | 506 (4.2) | 513 (4.3) | 539 (4.6) | 506 (4.4) |
| | % change | | -29.3% | -45.6% | -55.6% | -54.6% | -50.7% | -53.4% |

Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Time Period: 01 January 2010 - 31 December 2017. http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

*Objective 8: To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit*

This was an aspirational, long-term objective for which there are no known outcomes. It is possible that evaluations of the social marketing campaigns, reports of outcomes from ISD Scotland and this Evaluation will help to shed light on whether (or to which extent) this objective was met.

## 4.2 Process evaluation

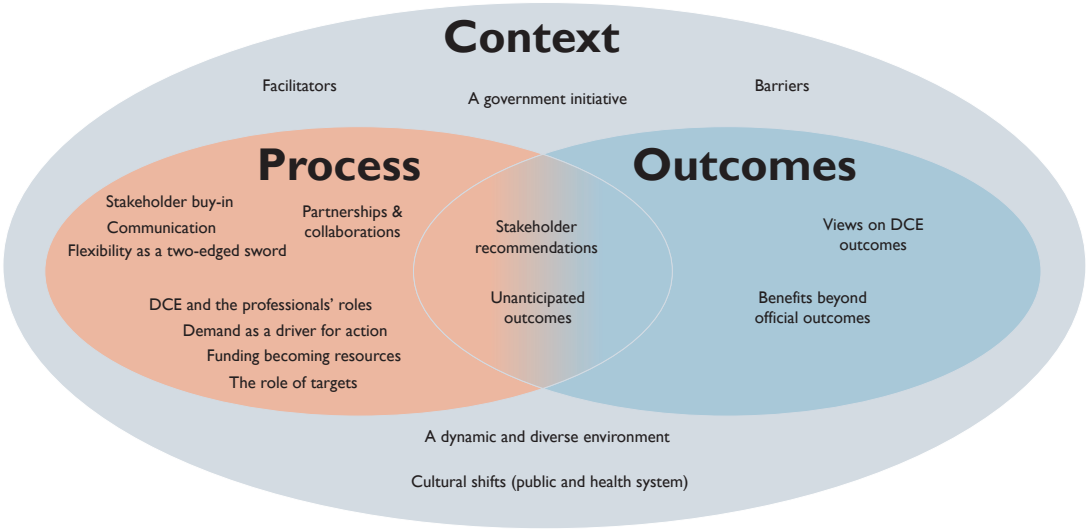
Data collection for the process evaluation (interviews and questionnaire) took place between January and July 2018. Twenty-five stakeholders were interviewed (mean interview duration: 48 minutes) and 53 submitted a completed online questionnaire.

While questionnaire participants were often secondary care doctors (67.7%), interview participants often managed health services or DCE components (56.0%). Ten territorial Health Boards were represented. Appendix 12 has further information on the stakeholders who took part in the interviews and questionnaire.

Over two-thirds of questionnaire participants (n=37) completed one or more open-ended questions (range 1-16 comments per participant). There were 175 comments; all were included in the content analysis. Resulting themes from the content analysis are available in Appendix 13.

Key themes and findings from the interviews and questionnaire were arranged in three areas: context, processes and outcomes (Figure 19).

### Fig 19. Key findings from the process evaluation




### *4.2.1 Context*

There were four main themes in this area: facilitators, barriers, a government initiative, and cultural shifts (public and health system).

#### Theme: Facilitators

*Questionnaire*

Having good quality data, being consistent

when recording staging data and having electronic results for bowel screening were some of the facilitators described. Having a designated lead for the Programme and receiving advice early on, good teamwork, and being able to plan and share learning were also highlighted.

> "Electronic results were extremely helpful [...] they were filed straight into the patient's notes without the need for extra admin processes"
>
> Manager, NHS Lanarkshire

*Interviews*

Interview participants also emphasised the importance of having good quality outcome data. Referral data was described as particularly useful to primary care as GPs have control over it (differently from centralised screening data). Good data was also described as an enabler for conversations about what can be improved. In some territorial Health Boards, stakeholders reported that the ability to access data helped to evaluate local initiatives and plan for future activities.

Several other facilitators were mentioned (Box 13).

> "Data is the start of a meaningful conversation and it's not about getting into the detail of what the data says, it's what you can do as a result of that data"
>
> Interview participant, ID 3

**Box 13.** Facilitators described by interview participants

- **International drive towards early cancer detection** (EUROCARE, International Cancer Benchmarking Partnership (ICBP), ACE, BCOC and different Danish Pathways were highlighted)
- **Cancer being "close to home"** i.e. a personal experience many can identify with
- **The existence of a proactive Primary Care Cancer Group** with good representation (Health Boards, lead GPs, lead nurses, third sector, and academics) that allows for useful discussions about the primary care aspects of cancer
- **Benefiting from established infrastructure and knowledge:** these included having similar interests to DCE, having relevant activities taking place when DCE was implemented, being able to assess bottlenecks in the cancer pathway before deciding where to invest
- **Ensuring that the team was motivated and engaged:** this involved making initiatives meaningful to stakeholders, listening to different groups to allocate resources, tailoring messages and addressing different professional needs
- **Assigning roles and responsibilities** to carry out DCE related activities
- **Reaching out:** this involved understanding the needs of deprived communities
- **Funding as an enabler:** funding was reported to bring coherence and forward direction, and to facilitate stakeholder engagement. In Primary Care, funding was described as a requirement to implement initiatives (otherwise other issues would need to be prioritised)
- **Accessing and using good evidence:** this was reported to facilitate DCE acceptance, clarify its rationale, and increase professional awareness regarding barriers to help-seeking
- **Being able to use digital resources** (including digital proformas, electronic referrals, desktop guides with referral guidelines, and applications that update at real time).

### Theme: Barriers

*Questionnaire*

Questionnaire participants reported that stretched capacity and workforce issues pre-dated DCE. Limited workforce was highlighted, as some specialties (such as radiologists) "do not exist to recruit". Other participants referred to competing responsibilities (such as the need to meet other targets, or to care for patients in different settings) that they perceived as not being recognised.

> "Workforce issues in diagnostics are the single largest stumbling block; this cannot happen overnight or even in a few months"
>
> Secondary care doctor (breast cancer), NHS Fife

*Interviews*

The overstretched health system, limited resources, the shortage of radiologists and radiographers, and competing responsibilities (such as caring for patients with conditions other than cancer) were also highlighted by interview participants. Endoscopy services and lung pathways were described as being "under enormous pressure". There were concerns about GPs having to deal with information overload and an increasing number of responsibilities and reported struggles with waiting times. Because of these barriers, fears of DCE impact on workload were common. System and staff changes over time (including GP retirement and no available replacements) were also mentioned. Staff changes were reported to have had an impact on relationships and sustainability of programme activities.

Several other contextual barriers were mentioned (Box 14).

**Box 14.** Barriers described by interview participants

- **Challenges associated with early cancer detection:** acknowledgement that early detection does not always mean improved clinical outcomes, and that it is challenging to assess vague, non-specific symptoms in a context of limited resources. Screening controversies (such as benefits vs. harms, unpleasant tests and examinations, and timing of screening invitations) were also described as barriers
- **Persisting barriers to help seeking:** these included stoicism, cancer fear and concerns about wasting the doctor's time. Other barriers included limited access to consultations, treatment, specialists and hospitals (due to costs, affordability and distance). Stakeholders acknowledged that there are many challenges in changing behaviour and social norms (and that these challenges vary across different groups). They were also aware of the need to have constant messages in order to influence behaviour. Some noted that behaviour change challenges also applied to health care professionals regarding the way they assess cancer symptoms and refer patients
- **Regional variation:** Scotland is a relatively small country, but it has 14 territorial Health Boards and three Cancer Networks with variations in size, distribution of deprived populations, direct access to radiology and investigations and different pathways, levels of remoteness and rurality. These variations were reported to have implications for programme coordination, communication, implementation and engagement
- **Prevalence of lifestyle behaviours in Scotland that increase cancer risk:** these referred to smoking, drinking, obesity and the prevalence of co-morbidities (which were also reported to have a role in symptom appraisal and cancer survival)

**Box 14.** Barriers described by interview participants (continued)

- **Social deprivation:** stakeholders were aware of the multiple challenges brought by social deprivation, such as its association with poorer health outcomes, poor literacy (with implications for information materials), suspicions regarding the government, low perceived locus of control, competing prioritisations, different needs, among many other issues
- **Lack of practice level data and limited IT systems** connecting different data: these were reported to hinder plans for quality improvement, limit discussions about referral behaviour, cancer symptoms and signs, and about whether referrals were appropriate. Lack of data also affected the ability to compare outcomes in Scotland and England
- **Issues with copyright** that did not allow campaign materials to be used over time **and embargoes** which influenced timely communication of campaign information were also mentioned.

"I suppose one of the biggest challenges we have, and we're not unique in this regard, is the pressure on primary care [...] there are significant number of practices here that have either far fewer or far poorer access to a GP and some practices have had to be taken over by the Health Board because there aren't GPs [...]. It's not just with general practitioners but all of primary care. So the advice given 'if you're worried talk to your GP' that's all very well if there's a GP"

Interview participant, ID 22

### Theme: A government initiative

*Interviews*

Stakeholders reported that as DCE involves publicly funded money, it was frequently scrutinised, and all activities needed to be justified. Being a government-led initiative was perceived as having both benefits and limitations. As DCE is part of a national cancer strategy, the programme was prioritised and had visibility, and a whole systems approach could be adopted.

Having "an unusual amount of funding" (for a government programme) for social marketing campaigns, alongside a team that wished to have an innovative strategy resulted in award-winning campaigns and "risky" approaches that had never been used before (such as showing real breasts on television when describing cancer symptoms and signs).

"What would have happened if there was no policy focus on it, I think the programme would've remained in the back corridors of public health [...] the policy focus on it really pulled it to the top of the pyramid"

Interview participant, ID 2

Nonetheless, stakeholders commented on a governmental "dual purpose". DCE was not only about early detection, but also an indication that the government cared about population health and was doing something to tackle cancer. As a government initiative, DCE may have been seen with cynicism by groups who are often targeted by Health Promotion initiatives. There was the need to show impact, which involved defining very specific, short-term targets. These resulted in time pressures that did not

allow for piloting many initiatives before implementing them nationally. There was also a perceived tension between having short-term targets and trying to improve outcomes that require long timescales.

> "Realising that there was political need to get an impact within a matter of a couple of years or a few years, that cancer doesn't do that and making big changes in the way things happen, it's very difficult to measure outcomes in that sort of timescale"
>
> Interview participant, ID 13

As DCE was a new strategy, intensive, fast learning from experiences in England such as NAEDI and BCOC in England was required. Learning from experience, being aware of new early diagnosis evidence and health system changes were issues often mentioned by stakeholders.

Furthermore, there was the need to develop and maintain relationships, build trust from a very diverse group of stakeholders, manage their different aims and concerns, roles and expertise, and match diverse interests in order to facilitate implementation. It was important to engage with stakeholders "soon, but not too soon" to ensure that decisions could be made within tight time frames. Stakeholders managing DCE and/or its activities were aware that buy-in and engagement would differ across different groups, and that it would be impossible for everyone involved to agree with all DCE decisions and strategies.

### Theme: Cultural shifts

*Interviews*

Stakeholders talked about cultural shifts towards cancer prevention and patient empowerment. There were references to issues pertinent to both personalised and realistic medicine, such as having a patient perspective, respecting autonomy and informed consent, and individual preferences and needs.

Some stakeholders reported an inevitable tension between having an expedited diagnosis pathway and adopting the best clinical approach (as at times the best approach may be to watch and wait) or addressing patient needs (these could be reassurance, but also requests for more time before making a decision about care and treatment options).

Other stakeholders were concerned about whether the screening campaigns and the bowel screening initiative were balanced enough regarding benefits and harms. Others reflected upon the challenges when trying to introduce informed choice in a 40 seconds advert with a very specific call to action.

> "If you don't want to take part in the bowel screening programme or the breast screening programme, cervical screening programme and you understand what you're not wanting to take part in, that is completely your choice, nobody is going to force you to do that, but if you don't understand what you're refusing that's not good"
>
> Interview participant, ID 8

### 4.2.2 Process

#### Theme: Stakeholder buy-in

*Questionnaire*

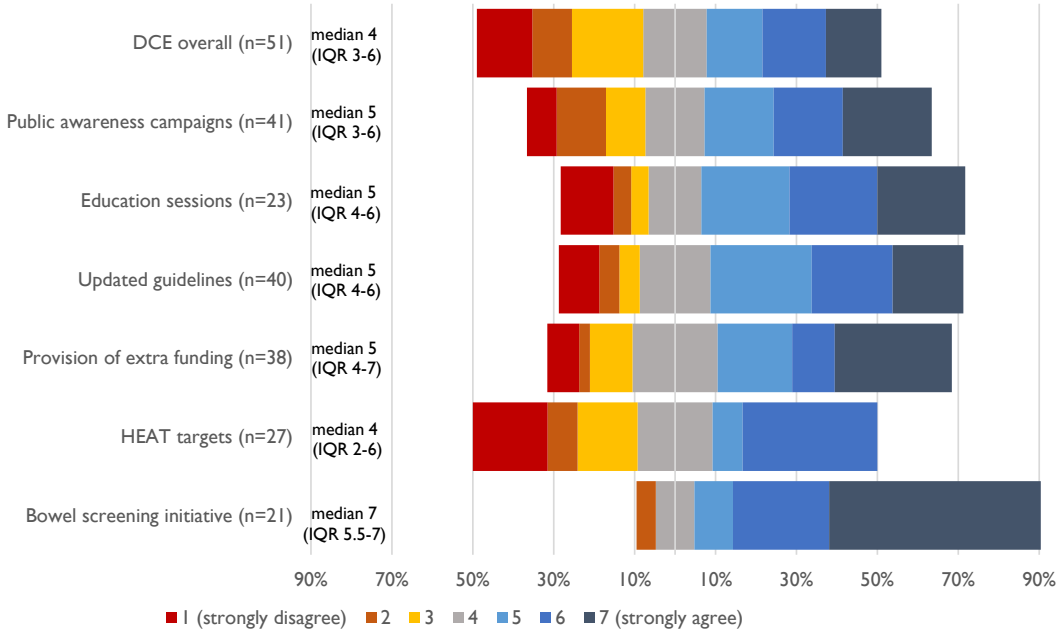
Questionnaire participants were asked whether they agreed with the statement that DCE and its strategies were appropriate to promote early detection. While 22 of them (43.1%) agreed to a certain extent (somewhat agree, agree or strongly agree) that the programme was appropriate, 21 (41.1%) disagreed with it to a certain extent (somewhat disagree, disagree or strongly disagree) (Figure 20).

Perceived appropriateness varied according to DCE strategies. While 85.7% of participants agreed to a certain extent that the bowel screening initiative was appropriate, the proportion was 40.7% for the HEAT targets (Figure 20).

Questionnaire participants who were not involved in developing or implementing DCE strategies, but would have liked to have had an input presented statistically significant lower median scores when asked about the appropriateness of DCE overall (compared to those who were involved in DCE; adjusted p=0.047), and the appropriateness of the HEAT targets (compared who those who were not involved, but were happy with that; adjusted p=0.042).

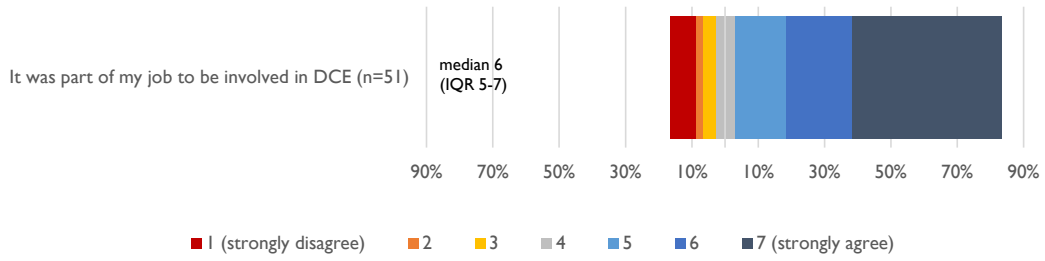
Most questionnaire participants (77.4%) agreed to a certain extent that it was part of their job to be involved in the DCE Programme, with no statistically significant variations across groups (Figure 21).

Fig 20. Level of agreement with statements about DCE and its strategies being appropriate to promote early detection




The higher the median scores, the higher the agreement. Missing data: DCE overall (n=2; don't know), public awareness campaigns (n=12; don't know and not applicable); education sessions (n=30; don't know, section/question not applicable); guidelines (n=13; don't know; section/question not applicable); provision of extra funding (n=15; don't know, section/question not applicable); HEAT targets (n=26; don't know, section/question not applicable; bowel screening initiative (n=32; section/question not applicable).

## Fig 21. Level of agreement with the statement that it was part of their job to be involved in DCE




The higher the median scores, the higher the agreement. Missing data: n=2 (don't known and not applicable)

Comments in the questionnaire showed that stakeholders agreed with the premise of raising public awareness and educating professionals and shed light on why many disagreed on the appropriateness of certain DCE strategies. Many were critical of the choice to target breast, colorectal and lung cancers, of campaigns that coincided with other awareness events, and of the breast cancer campaign focusing on symptoms. The use of short/intense campaigns and reaching populations with a very low cancer risk also generated concerns.

There were also criticisms regarding DCE's impact on workload and service provision. Some referred to increased stress levels and burnout across professionals. Participants believed that there should have been more planning on how to deal with the impact caused by the programme, including assessing whether available resources were sufficient. For others, additional funding should have been provided sooner, and temporary funding was perceived not to allow for a long-term strategy.

> "DCE is an excellent concept - raising public awareness of early cancer signs is good; primary health care worker education is important. However, the downstream effects on diagnostics and treatment centres needs more thought and input"
>
> Medical doctor (secondary care), NHS Fife

*Interviews*

Across interview participants, there was also recognition that early detection was part of their jobs, and overwhelming support for DCE's overall aim. The rationale for an early detection programme was well understood and accepted. Stakeholders also commented on DCE's impact on service provision and workload and how this affected relationships, especially after the symptomatic breast campaign. While some stakeholders believed that increase in consultations and demand for diagnostics were expected and could be predicted, others complained that predictions widely underestimated demand for diagnostics. Stakeholders had diverse views on focusing

on screening or symptoms, or on which tumour types to target. While some believed it was ideal to focus on cancers for which there are screening programmes, for others the programme should have focused on cancers without screening programmes as they often have poorer outcomes. Others believed this strategy was counterproductive as symptoms often indicate late stage disease.

Several comments referred to the appropriateness of DCE strategies. Strategies perceived to be appropriate included having funding that allowed for looking at service improvements, the bowel screening initiative (as it had support from the clinical community, was perceived to work well and helped to transfer ownership of screening to primary care), and the approach of the social marketing campaigns and other awareness initiatives. Accepted approaches included the use of humour in the campaigns, attaching non-judgemental, high public profile individuals who can communicate with the target population (Sir Alex Ferguson and Elaine C Smith), and the thingymaboob strategy (distributing a keychain with beads demonstrating the size of breast tumours).

"We had really high involvement in sQOF [bowel screening initiative], about 87% of practices were involved and they really liked it and I think what was nice about that was it sort of put over to them the onus on trying to come up with ways of engaging with their population"

Interview participant, ID 20

DCE strategies perceived not to be appropriate included funding that oscillated between years and only allowed to have dedicated staff for a short time period, delays to accessing digital data on bowel screening non-responders, and stopping the bowel screening initiative when it was structured and functioning well. There were also criticisms towards carrying out lung cancer campaigns during flu season (as this resulted in a large number of patients with respiratory tract infections seeking help) and focusing on breast symptoms (as this resulted in large numbers of worried well seeking reassurance). Some participants believed that the breast and bowel screening programmes should have been considered as a special Health Board (with specially allocated funding).

"I think the sQOF was very much to be encouraged, I was very disappointed to see after it being there for basically the two years, the year for planning and the year for delivery, for the money just disappeared again"

Interview participant, ID 4

Finally, there were mixed views on the HEAT targets. For some, the "ambitious" targets brought early detection to the centre of attention and resulted in galvanised action from professionals in different areas. Aspirational targets were reported to be common in different organisations (such as charities and the government), but acceptance across other stakeholders varied. Some argued that the target was "borderline impossible" and had "slightly been plucked from nowhere". There was reported uncertainty over whether Stage I was a good measure of DCE's success.

"If you have a target then you'll find people working towards that target, you just need to make sure that the target is actually what you want to achieve"

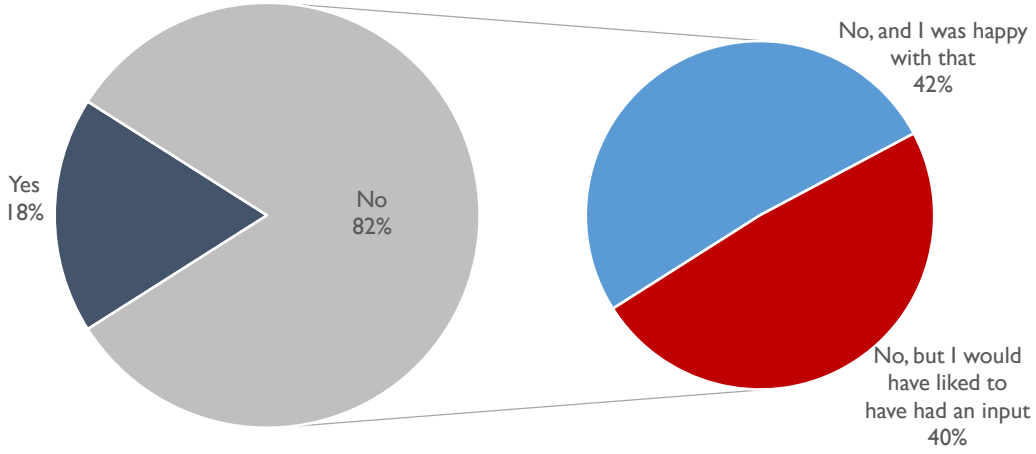
Interview participant, ID 16

## Theme: Communication

*Questionnaire*

Questionnaire participants were asked about whether they were involved in developing or refining DCE strategies. About a fifth of them reported being involved. Among those who were not involved, a similar proportion was either happy not to be involved or would have liked to have had an input (Figure 22).

### Fig 22. Whether stakeholders were involved in developing or refining DCE strategies




Missing data: three participants chose "other" when asked about involvement: one did not specify any further, other responses were: "not applicable as was still in training"; "my colleague was involved in implementation so I heard by word of mouth and from TV adverts".

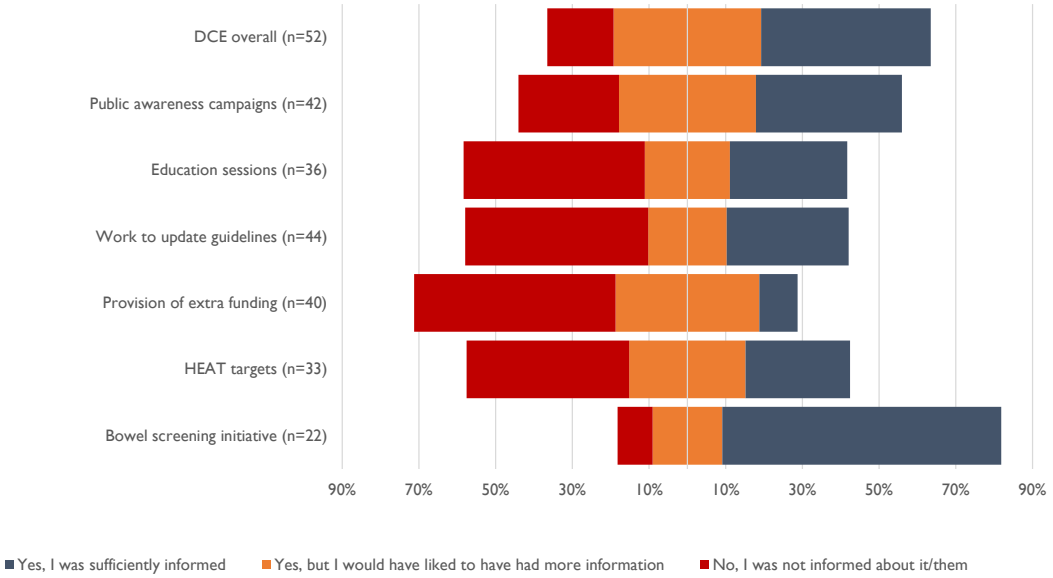
In terms of receiving information about the programme and its components prior to their launch/implementation, views also varied according to different DCE strategies. While most participants (72.7%) reported being sufficiently informed about the bowel screening initiative, a minority reported having been sufficiently informed about extra funding (10.0%). A substantial proportion of participants would have liked to have received more information about DCE and its components (38.5%), especially regarding the additional funding (37.5%), the public awareness campaigns (35.7%) and the HEAT targets (30.3%) (Figure 23).

The proportion of professionals working with more than one tumour type stating that they were sufficiently informed about the campaigns ($p=0.004$) and the bowel screening initiative ($p=0.016$) was significantly higher than the proportion of professionals working with only breast, bowel, anal and/or upper gastrointestinal and lung cancers.

The proportion of professionals working in hospitals stating that they were sufficiently informed about the campaigns (p=0.037) and the updated referral guidelines (p=0.023) was significantly lower than the proportion of professionals working in other settings (primary care practice, diagnostic centre but not in hospital, charity, other). Furthermore, the proportion of participants who were involved in developing DCE or its strategies and stated that they were sufficiently informed about the work on the referral guidelines was significantly higher than the proportion of participants who were not involved in the programme stating that they were sufficiently informed (p=0.009).

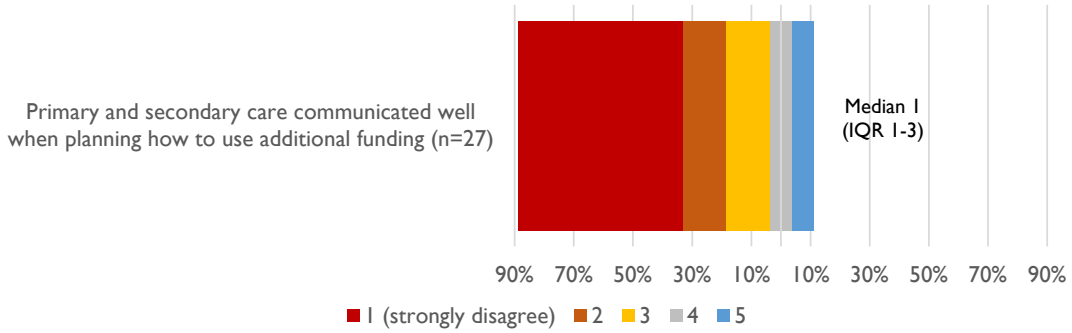
When asked about communication between primary and secondary care regarding how to use additional funding, over half of participants (55.6%) strongly disagreed that communication went well (85.2% disagreed to a certain extent) (Figure 24). Secondary care doctors had significantly lower median scores when compared to nurses (adjusted p=0.028). Their scores were also lower than the GPs' median scores, but the difference was not statistically significant.

## Fig 23. Level of agreement with the statement that information about DCE was sufficient




Missing data: DCE overall (n=1; other); public awareness campaigns (n=11, other and section not applicable); education sessions (n=17; other and section not applicable); work to update guidelines (n=9, other and section not applicable); provision of extra funding (n=13, other and section not applicable); HEAT targets (n=20, other and section not applicable); bowel screening initiative (n=31, section not applicable).

## Fig 24. Level of agreement with the statement that communication about the use of funding went well




The higher the median score, the higher the agreement with the statement. Missing data: n=26 (don't knows, question/section not applicable

Stakeholders' comments also highlighted issues regarding involvement and information. Stakeholders appreciated when experts were heard.

> "Public campaign raising lung cancer awareness - DCE team listened to expert advice on how to approach this group of patients"
> Respiratory Nurse,
> NHS Greater Glasgow & Clyde

Nevertheless, others wished they had received more information about DCE, the scale of the campaigns and their likely impact. Some were not aware of the education sessions for GPs, the HEAT targets, the additional funding provided, nor of DCE outcomes. Three participants did not know that DCE had continued after 2015. Some wished they had had the opportunity to give input, while others complained about giving it and not having it considered (clinicians, frontline staff, breast screening services), or about delays in receiving information. Those who started working when DCE was already ongoing raised concerns about sustained involvement and challenges regarding handover.

> "I attended a national meeting at which someone from my Health Board said that staff were fully informed and had developed plans to implement DCE - this was completely untrue - we knew nothing until the campaign was upon us, and no plans were made to cope with additional referrals"
> Medical Radiologist, NHS Lanarkshire

*Interviews*

DCE's communication team was described as friendly, welcoming, accessible and enthusiastic. Stakeholders received information about the programme through word of mouth, colleagues involved in DCE, documents, Chief Executive letters, meetings with policy makers, visits from the DCE team, and team meetings.

However, some stated that dissemination of DCE components and outputs did not reach all relevant stakeholders. For example, referral guidelines were reported to be disseminated well in primary, but not in secondary care. Stakeholders often reported not understanding the rationale for some DCE strategies and were not

aware of any preparatory work (such as research, insight gathering and reasons for strategic decisions). Some believed that more information sharing would have improved sense of ownership and responsibility for campaigns, and could have enhanced engagement from primary care and diagnostic services.

"Certainly we got all the stuff about bowel screening but I was thinking in general in terms of the programme itself at the outset or at yearly updates or that type of thing, I don't know that we actually received anything. [...] I went to some of the DCE conferences and all that type of thing so I kept pretty up to date [...] Unless you have a specific reason to look out the DCE documents I don't know that they've been that obvious [...] If you go into any GP's mailbox you'll find a hundred plus a week emails coming through with various information, bits and pieces from all sorts of different teams and people asking this, that and the next thing"

Interview participant, ID 1

Concerns were raised about limited ongoing contact and explanations for change in direction, with some stating that they had to chase information themselves. There were also comments about limited warning in advance of the start date of campaigns, the time allowed to make bids for extra funding, and the required speed of response for preparing roadshows (as Health Boards needed more time to get involved and distribute materials, especially in more remote and rural areas). Some believed that at times their concerns were not listened to, and that often there was a one-way communication process (i.e. stakeholders were informed that something was about to happen instead of being asked about something that was planned to happen).

"They've said they're going to do something about breast signs and symptoms so 'I'll be getting all the stuff out to you' [...] the campaign had suddenly hit the TV and somebody phoned me up and said 'I [have] just seen it on TV' and I was like 'I don't have any resources for that'. And then I looked stupid, then people thought that I was the one that hadn't done anything and you'd be getting posters a week later [...] It did get better with each campaign..."

Interview participant, ID 6

Finally, there was reported frustration and disappointment when there were no perceived attempts to share findings in order to learn from local strategies/pilots and from the bowel screening initiative.

### Partnerships and collaborations

*Interviews*

Stakeholders commented on a range of partnerships and collaborations developed as part of the programme. Charities were described not only as collaborators, but also as leads in initiatives supported by DCE (with or without DCE funding). The relationships were developed due to common interests, and the ability to share expertise and knowledge.

Charities had an established relationship with the public and had the ability (and benefits) of being a non-governmental agency. Charities relied on health intelligence from the government, but were also able to triangulate data from different sources and carry out evaluations on their own. Stakeholders reported that charities facilitated the implementation of initiatives and helped to ensure that relevant activities continued when DCE funding ended. Stakeholders were aware that support from charities was paramount and sought their input regarding relevant initiatives (although charities wished that they had received more information and could have given input sooner).

> "From our perspective there have been good engagement with the voluntary sector as a partner [...] there's a recognition that cancer organisations have a role to play in terms of public perception and engagement"
>
> Interview participant, ID 21

Creative and market research agencies contributed with expertise that the Scottish Government lacked. However, their views on what constituted programme success varied at times. For example, the evaluation of the symptomatic breast campaign showed positive results in terms of awareness and atittudes, but the campaign was not run again due to its impact on workload and limited effect on more cancers being diagnosed earlier.

Relationships and collaborations with the media were reported to be both positive and negative. A good relationship facilitated dissemination of important early detection messages and helped the government to save money on disseminating campaign messages. However, the media and DCE interests did not always match. Stakeholders reported that the media helped to disseminate mixed messages to the public: while the government and health system were emphasising health promotion, prevention and intervention, media reports were emphasising the fact that the NHS was "at breaking point". Negative messages (such as high-profile deaths, experiences of suffering and reports of bad care, in addition to criticism towards campaign strategies) were also common. Stakeholders believed that these messages helped to confuse the public and influenced help-seeking behaviour.

> "You've just got to be very careful with interaction with the media and how that's controlled"
>
> Interview participant, ID 4

### Flexibility as a two-edged sword

*Interviews*

Interview participants often described DCE as being flexible and open to innovations. This flexibility was reported to enable funding for local strategies, allow for the programme to evolve and adapt over time according to new evidence.

However, the scope of the programme and its many approaches reportedly also resulted in mixed messages about which activities were part of DCE and which ones were not. It was also challenging to demonstrate the programme's impact when reporting on spin-off initiatives that were not part of DCE's core components.

Furthermore, flexibility when providing funding resulted in limited evidence on how it was used to improve diagnostic capacity. Some stakeholders also raised issues regarding transparency, and about whether funding was used appropriately. While some Health Boards tried to ensure that the money was used to meet DCE aims, others reported that they used it to deal with backlogs. Some stakeholders acknowledged that funding had to be used in a "less efficient way" to pay for overtime or cover posts for which there was no staff available to recruit. In some areas, stakeholders reported that clinicians took most of the funding, and nurses and Public Health took very little. As funding was diluted into different areas, some departments (such as laboratories) received very little money (or no money at all).

> "It's a bit of a balancing act because it was this whole systems approach we felt at the time we couldn't be very prescriptive with the boards on what they should spend the money on, what we said was 'these are the five areas of work and it's up to you to prioritise your funding and where it goes' and we left Boards to it. And then we went back on an annual basis to try and get an evaluation of what they spent the money on and that was hugely difficult to do [...] we found that those who did come back there was varying of where they spent it, some was in Public Health, some Boards didn't spend any on Public Health, it all went into secondary care, some went into staffing and funding, a lot went into audit and data collection"
>
> Interview participant, ID 23

Importantly, some stakeholders gave examples of instances when the programme was not flexible. There were issues regarding one-way communication (as described previously). Furthermore, there were reports that it was not often possible to adapt social marketing materials to local populations due to copyright issues.

### 4.2.3 Outcomes

#### Views on DCE outcomes

*Questionnaire*

Stakeholders often highlighted not being aware of changes brought by DCE and demonstrated interest in finding out more about programme outcomes. Some added that they could not identify the impact of DCE initiatives (including impact on practice) and reported frustration when activities did not result in more cancers being diagnosed at earlier stages.

> "Big increase in worried well. No change in cancer diagnosis but increased delays for all"
>
> Breast Surgeon, NHS Lothian

*Interviews*

Interview participants also wished to know more about DCE impact and were disappointed when DCE activities did not result in better cancer outcomes. However, they acknowledged that there were many challenges to show impact. It was difficult to measure softer outcomes such as change in practice, or longer-term outcomes such as change in behaviour over time due to increased knowledge and awareness.

> "Having a national campaign you will not be able to attach causality ever [...] unless we have a kind of experiment"
>
> Interview participant, ID 12

"Joining the dots" between different chains of activities (such as trying to assess whether increase in knowledge led to help-seeking) was often not possible. Several DCE initiatives happened at the same time; making it difficult to demonstrate the role of each of them in outcomes (some recognised this as an inherent challenge of adopting a whole systems approach).

> "We've got a much more educated bunch of women now that are aware of their symptoms other than lumps and I think that is like pinning down a bit of jelly at times in terms of from a measuring perspective trying to figure out the impact that we've had outwith driving early stage diagnoses"
>
> Interview participant, ID 15

As briefly mentioned in Barriers, limited data was also reported to hinder the ability to show impact. For example, it was not possible to evaluate the awareness campaigns using the same approaches used in England for BCOC because data on consultations and referrals were not available. Data on reasons for consultation ceased to be collected in late 2012.

> "I sometimes got the impression that the English campaign, the way they reported it in the media and the success seemed to have a greater connection of data points than we did"
>
> Interview participant, ID 14

Challenges when trying to access staging data differentiating bowel cancers diagnosed through screening from those diagnosed through symptomatic presentation were also mentioned.

Stakeholders often referred to local initiatives, local evaluations and other analyses (as opposed to national level evaluations), and referred to anecdotal evidence when describing outcomes. While some reported not being able to evaluate local activities (due to time or resource limitations), others carried out evaluations frequently but were only able to disseminate findings locally.

### Benefits beyond official outcomes

*Interviews*

As before, some participants raised concerns about whether performance targets were a good measure of the programme's success. Others highlighted that soft outcomes should be better acknowledged.

> "You can look at the short term benefit and outcomes and you can look at the medium and the long term, the main benefit is regardless of whether your board has met the targets or not I think that's very short-sighted to think that is a good evaluation of the programme because what you'll have is it's raising awareness of the messages and that's to me the main benefit of the DCE programme and encouraging people to understand that if they've got signs and symptoms they've to go to the GP"
>
> Interview participant, ID 19

Stakeholders stated that DCE helped to undermine cultural reticence about cancer; and to change the public perception about wasting the doctor's time. It challenged the perception that lung cancer was not worth talking about nor acting upon, and increased overall public awareness about screening, and cancer symptoms and signs. The programme also encouraged conversations and reflections about cancer diagnoses between primary and secondary care and enhanced both local and national partnerships. Acknowledging challenges in changing behaviour, many saw DCE as a programme with a cumulative effect that contributes to long-term changes by normalising discussions about cancer.

> "My impression is that it has [...] united and galvanised everybody who has a stake in cancer policy/ clinicians [...] everybody's come together and genuinely contributed into that, whether that's diagnostic services, GPs [...] it feels like a fully rounded piece of policy making and so whether or not that's worked as much as people hoped at the start, I feel that has to be a good thing for the cancer community [...] everybody is more joined up than they were"
>
> Interview participant, ID 14

DCE was also described as an opportunity to get better data, to develop events and share learning (although stakeholders wished that dissemination and shared learning had happened more often).

The programme provided an opportunity to develop community events to engage with hard to reach communities, to fund different approaches to promote early detection (such as using the qFIT with symptomatic patients) and to enhance collaborations with charities (such as piloting Cancer Research UK's Primary Care Facilitator Programme in Scotland, and developing a "good practice guide" informed by the bowel screening initiative).

In some territorial Health Boards, stakeholders developed different diagnostic pathways. In others, regular team meetings to discuss patient cases were implemented (in order to be able to do so, there was an increase in telephone consultations). In some areas, stakeholders continued with DCE strategies even after funding ceased to be provided.

### *4.2.4 Overlapping themes*

#### Unanticipated outcomes

*Questionnaire*

Questionnaire participants commented on an increasing number of "inappropriate" referrals that they perceived to be driven by DCE: clinicians either following or not following the new referral guidelines, the increasing number of worried well in need of reassurance, and GPs' attempts to get their patients seen quickly in a context of increasing waiting times. Some of the described consequences were delays for patients requiring surveillance or patients with a cancer diagnosis, and impact on other performance targets. Some stated that the symptomatic approach for breast cancer led to patients presenting at later instead of earlier stages (in discordance with the programme's targets). Others were concerned about overdiagnosing the worried well.

*Interviews*

Interviewed stakeholders commented on the need to draw on resources from the breast screening programme in order to deal with demand brought by the symptomatic breast campaign, and on the knock-on impact that some initiatives had on services (such as an increased demand in Endoscopy generating an increase in Pathology).

For some, DCE resulted in raised anxiety for both the public and health care professionals. Professionals were anxious about not being able to meet patient expectations to be seen promptly, and about delays happening for other patients. Furthermore, stakeholders reported that some patients were getting anxious due to delays after diagnosis. Stakeholders also described the need to compete with other Health Boards for specialised staff due to shortages in skills and expertise.

> "You can't just knit a pathologist. So if every Board's looking for a pathologist and there is a shortage of them... [...] Then you might become, you know, all competing in a very small pool for a very limited amount of staff and I think that at times that was actually the reality of what some Boards found themselves in"
>
> Interview participant, ID 11

Positive unanticipated outcomes included enhanced collaborations with cancer charities and better GP engagement with patients. There were reports of GPs taking the opportunity to help patients with long-standing problems while having conversations about cancer. In one Health Board, DCE influenced the development of pathways for gastrointestinal conditions other than cancer. Finally, the novel aspect of DCE campaigns became an influencer for other Scottish Government initiatives.

## Stakeholder recommendations

*Questionnaire*

Questionnaire participants recommended more planning, improved communication and discussions between different teams, speaking to "staff who know", and planning handovers. Being advised "well in advance" of DCE initiatives (such as when campaigns would go live or giving more time for Health Boards to prepare bids) was also urged. Some recommended focusing on tumour types for which there is a "greater chance of influencing behaviour" (no examples were given). Others suggested targeting only patients at risk of lung cancer (with an "annual low dose CT of the chest for smokers over 60"), allowing GPs to have direct access to CTs, setting up diagnostic clinics, and targeting smoking prevention. Others stated that DCE should focus on deprived populations through education and provision of information.

> "I think that a dedicated clinic with sufficient resources, to whom unclear cases are referred, would be most useful. I have too often seen people referred UCS [urgent suspected cancer] to the one specialty, given the all clear and then turn out to have cancer of a different system"
>
> GP and Specialist Doctor
> NHS Ayrshire & Arran

*Interviews*

Interview participants provided a wide range of recommendations; these are shown in Box 15.

**Box 15.** Stakeholder recommendations

- **Target patients at risk** using tailored messages to help ensure that the right population benefits, and that the system is not overwhelmed with the worried well
- **See the big and the small picture**: seeing the importance of both the whole cancer pathway and of local initiatives was recommended in order to understand bottlenecks, wide barriers to access, and acknowledge local needs and characteristics. Participants believed it was important to keep the national early detection umbrella, while also investing in more local initiatives
- **The role of prevention and educating younger generations:** Some stakeholders recommended more initiatives with younger people so they are aware of early detection and can develop a more holistic approach to their health. Some acknowledged that prevention was not DCE's main aim, but believed that DCE could still contribute to it
- **Tackle health inequalities/inequities in access**: recommendations included improving access; giving support to those in remote areas, who struggle with costs or competing responsibilities; investing on health literacy and welfare rights; working with minority ethnic groups; thinking not only about diagnostics but also the burden of treatment and challenges due to social isolation
- **Focus on signs and symptoms and in understanding help-seeking behaviour**: as signs and symptoms represent the "here and now", they may resonate better with populations who do not engage with screening. Stakeholders acknowledged that a change in paradigm was required for this to happen (i.e. the patient should be aware that a negative result does not mean one should stop seeking help if symptoms persist, and professionals may need to reconsider the way they assess symptoms). Learning from the ACE experience in England for vague, non-specific symptoms was described as helpful. There was the acknowledgement that adopting a similar strategy would incur costs, but also reflections on the fact that other countries are managing to do it nonetheless

**Box 15.** Stakeholder recommendations (continued)

- **Have better local and national data**: stakeholders acknowledged that better data was needed in order to evaluate the programme, and that data for the whole cancer trajectory was required. Being able to see staging for more tumour types was also suggested

- **Make the most of opportunities to talk to patients**: e.g. if tests show no cancer but there are cancer risks, take the opportunity to inform the patient about these risks

- **Continue with professional training and awareness raising**: stakeholders highlighted that there was lack of knowledge and awareness about cancer among NHS staff; and that barriers such as fear of wasting the doctor's time also applied to them. Adding more information on early detection to young doctors' curriculum was also recommended

- **Do not rely on staff who have other jobs to do**: have well-assigned roles to ensure that required work is done. Often, this recommendation also implied providing additional funding

- **Challenge the** *status quo*: focus on innovative strategies that change the way services are provided, while also bearing in mind low-cost approaches that have shown to be effective (such as GPs sending reminder letters to patients)

- **Develop more plans outlining possible impacts of initiatives on workload**, and design evaluations for all DCE components, while also investigating unanticipated outcomes

- **Identify different ways to target breast screening** in line with the Breast Screening Centres' recruitment timescales

- **Be more prescriptive about how additional funding should be used** and ask for more information on how it was used

- **Continue with campaigns to increase population awareness and knowledge**: interview participants recognised that the campaigns did not fully tackle the issue of cancer fear or limited awareness of signs and symptoms, and that more information was needed as barriers to help-seeking persisted

- **Enhance engagement and ongoing communication** with screening programmes, clinical teams, charities and others, aiming to ensure that all feel part of the process

- **Be more explicit about the rationale for DCE strategies**, and about their importance

- **Disseminate DCE outcomes widely** and look for further **opportunities to share learning**

- **Incorporate the new referral guidelines into GP systems** (this has been done in some Health Boards), bearing in mind that "you don't want the IT to get between you and the patient" (for example, having to code during a consultation)

"People from the more deprived communities for a variety of reasons don't engage with screening processes. They don't engage because they don't know about them or they don't engage because they don't think it's for them. There's something about being more mindful of the best way of getting information to people [...] If people are living in outer areas with poor housing and no jobs and low income, and you know, basically living in poverty, the relative importance they're going to place on taking up a screening test [...] it's going to be low and so we need to also tackle that by raising people out of poverty"

Interview participant, ID 18

# 5. Discussion

## 5.1 Strengths and limitations

This Evaluation was informed by behaviour, implementation and complexity theories. It was designed to be methodologically robust in order to provide evidence-based recommendations. By adopting a range of methods and having a multi-step procedure, the Evaluation was able to describe a complex programme, and synthesise vast quantities of data about DCE processes and outcomes in a single document.

As a dynamic programme, DCE has evolved over the years. Even though we aimed to evaluate DCE up to 2015, the process evaluation allowed for more recent issues to emerge. The outcome evaluation also described data beyond 2015 to help clarify programme evolution and potential issues regarding sustainability. Although this Evaluation did not aim to comprehensively describe and discuss changes beyond 2015, a brief outline of contextual and strategic changes is described in Box 16 to facilitate further discussions about DCE and our recommendations.

It was not possible to carry out a cost-effectiveness analysis of DCE components due to limited data and the large scope of the Evaluation. It is important that future initiatives (including pilot studies) incorporate a cost-effectiveness analysis when feasible.

The outcome evaluation consisted mainly of secondary analysis of published data. This happened for several reasons. First, there was already a wealth of information available. It was important to acknowledge the work carried out by several DCE stakeholders and collaborators. Second, initially planned analyses of customised datasets were not feasible due to limited data availability, delays in accessing data, and challenges to demonstrate causality.

No response rates were calculated for the questionnaire as it was not possible to know how many eligible stakeholders were invited to take part. It is likely that due to their profile (i.e. busy professionals) the response rates were low. Based on the participants' characteristics, there was an overrepresentation of secondary care doctors, while other relevant groups were underrepresented. Therefore, the views described here do not necessarily represent the experiences and opinions of all DCE stakeholders. Nonetheless, secondary care doctors are difficult to recruit and their views are important.

Perhaps due to the assurance of anonymity, questionnaire participants were much more critical of DCE than interview participants (although this may also have been due to having different job roles and different levels of DCE involvement). Hence, it is likely that the questionnaire overrepresented those who had more negative views about the programme and were more motivated to take part in the Evaluation.

Four Health Boards were not represented in the process evaluation despite attempts: NHS Orkney, NHS Western Isles, NHS Shetland and NHS Grampian (the latter was represented in evaluation development). It is possible that their views on DCE would differ.

The MRC[136] recommends that evaluations are planned as soon as possible, preferably during programme design. This helps to ensure that baseline data are available, and that proposed evaluations are feasible. We strongly recommend that any future policy initiatives develop evaluation plans of both processes and outcomes before implementing new programmes.

## **Box 16.** Relevant developments after 2015

Since 2015, DCE has continued to develop awareness campaigns and initiatives, including the "wee c" (aiming to reduce the fear surrounding cancer) and "#getchecked". A DCE Conference in September 2016 disseminated programme results to stakeholders. A new Cancer Plan has been published[96]; and DCE remains a key component. Documents outlining DCE progress according to the new Cancer Plan have been made available[137]. Cancer Research UK has published a report indicating the next steps for cancer services in Scotland (and discussing DCE objectives)[138], while the Scottish Parliament has discussed the role of DCE in Cancer Prevention[139].

There has been a review of CWT Standards[140] and attempts to reach clinical consensus on optimal links between pathways and waiting times. Screening programmes have been allocated funding, and DCE has a stronger focus on targeting health inequalities and identifying improvement strategies[96]. Furthermore, DCE's reduced budget required changes in awareness campaigns (such as not focusing on a single tumour type) and Strategy 3 (additional funding for Health Boards) is no longer possible. However, there is still scope for funding innovative pilots such as multi-diagnostic centres and studies investigating direct access to diagnostics (personal communication, DCE Programme Board).

An app with referral guidelines was launched in 2016; there is a stronger emphasis in using digital resources to optimise the referral process, reduce costs, facilitate usage and sustainability, and ensure that the most up-to-date guidelines are being used (personal communication, DCE Programme Board). Referral guidelines are being updated again through a rapid review process. There is current work on Cancer Decision Support Tools; qFIT for symptomatic patients is being piloted in different Health Boards; and pilots to improve the early detection of melanoma have been implemented (personal communication – DCE Programme Board). The Faecal Occult Blood Test adopted for bowel screening was replaced with the FIT in November 2017[96]. The CRUK Facilitator Programme is being implemented in different areas in Scotland, and an evaluation of the initiative in NHS Greater Glasgow & Clyde has been published[141]. There is ongoing work with Teenage Cancer Trust, targeting both cancer prevention and young influencers to help promote early detection (personal communication, DCE Programme Board).

Quality and Outcomes Framework (QOF) ended in April 2017 and was replaced with a new quality framework for GP clusters[142, 143]. HEAT targets are now part of Local Delivery Plan (LDP) Standards alongside other Standards such as Treatment Time Guarantee[144].

In terms of data, the practice profiles (part of Strategy 2) will be implemented with fewer data variables in order to be feasible (personal communication, DCE Programme Board). The Scottish Primary Care Information Resource (SPIRE) is being introduced in Scotland[145]. Furthermore, the first National Cancer Diagnosis Audit in Scotland has been published[146]. There have been promising findings in breast cancer treatment[147] and an European position statement on lung cancer screening has been published[148]. Innovative work adopting the Danish model for vague, non-specific symptoms[42, 88] is happening in England[149], and more reviews of cancer pathways and direct access to diagnostics have been published[150.151]. Relevant discussions on how to make the most of limited diagnostics resources are also available[43].

## 5.2 Reflecting upon results

This Evaluation aimed to investigate DCE processes and outcomes and provide recommendations for DCE and future initiatives. Evaluation results described a complex programme that has a widely accepted overall premise, but is accompanied by different stakeholder views on how it should be implemented and how early detection should be promoted. Built into a context where health care and workforce resources are limited, population need for diagnostics are increasing (with inequalities across different groups) and tight time frames are required to show success, DCE was (and remains) a challenging undertaking.

### *5.2.1 Outcome evaluation*

Analysis of DCE objectives indicated that these were not always associated with measurable outcomes. Not all objectives were systematically assessed by the programme nor by this Evaluation. This was due to lack of data (not yet collected, expected but not made available, collected only for a short period), or barriers to accessing available data, challenges in gathering and sharing local data, and pressures in order to meet the programme's deadlines and key targets.

There were also situations in which analyses were carried out, but not all stakeholders had access to the results. As a consequence, stakeholders taking part in the process evaluation often referred to anecdotal evidence, and wished to know more about the programme's impact.

The HEAT targets were not met, but there was an increase in cancers diagnosed at Stage 1 overall, and for breast and lung cancers (the latter reached 25% in Year 3). Improvements in recording of staging data have also been noted (such as 44.2% reduction in Year 3 for all three cancers combined). These improvements, especially in Year 1, explain some of the improvements in the proportion of cancers diagnosed at Stage 1.

Evaluations of DCE social marketing campaigns showed increase in knowledge and awareness, and indicated attitudinal changes over time. However, they also highlighted the need to continue with messages. Data showing increase in breast consultations and in requests for replacement bowel screening kits also indicated that campaigns have reached the public (although not necessarily the target population). Increase in consultations for breast symptoms did not result in more breast diagnoses (as most who consulted were the worried well). Increase in requested kits did not result in a higher proportion of colorectal cancers diagnosed at Stage 1. In fact, there was a decrease. There are many possible explanations for these results. Screening identifies precancerous polyps; perhaps there were no improvements in staging for symptomatic patients; or populations that did not attend screening in the past started to take part and their cancer was advanced (personal communication, DCE Programme Board). Reasons need to be further investigated. In order to do so, data on routes to diagnoses would be useful.

Furthermore, it was challenging to assess objectives when they were associated with soft outcomes. From the perspective of stakeholders, these objectives were equally or even more important than those associated with hard outcomes. Table 1 provided a range of examples of activities carried out as a result of DCE funding, but benefits are hard to quantify.

Finally, stakeholders often recognised that despite having short-term targets, the

required behavioural changes and shifts in cancer outcomes were a long-term endeavour (and that DCE benefits may not be seen for many years, or it may not be possible to measure all of them).

### *5.2.2 Process evaluation*

Findings showed that there was overwhelming support for early cancer detection, even when stakeholders disagreed with DCE strategies or reported that the programme had a negative impact on workload. Furthermore, findings highlighted how communication and buy-in were associated with engagement and sense of ownership. Results also shed light on collaborations that resulted in developing and continuing early detection initiatives, sharing specialised knowledge, and disseminating early detection messages.

Results indicated that there was a direct relationship between involvement in DCE (and being able to give input) and considering the programme and its strategies to be appropriate. Furthermore, understanding the rationale for programme initiatives and being able to see their impact positively influenced buy-in and engagement. Nonetheless, concerns about not receiving sufficient (nor timely) information were common among both interview and questionnaire participants. Conversely, questionnaire findings showed that a substantial proportion of stakeholders was happy not to be involved. This indicates that some professionals may prefer more detailed information, while others would be satisfied with general, less frequent communication. It is important to identify ways to differentiate these groups.

Stakeholders had positive views about the bowel screening initiative, and some argued that this was because it was easier to see its impact compared to other DCE strategies, and stakeholders believed that they could make a difference. It is crucial to identify and maintain initiatives which are successful and widely accepted if DCE wishes to be sustainable over time.

Some stakeholders disapproved of the HEAT targets as they were perceived not to be achievable (and this was detrimental to stakeholder engagement and sense of ownership) and caused frustration. When the targets were not met, some were uncertain of whether the programme was worthwhile. Conversely, the ones who saw the target as aspirational (often stakeholders who were more involved in the programme or were used to aspirational targets) celebrated the results as they indicated improvements (even if confounded by better data recording – as this was also an improvement). Furthermore, others wondered whether meeting the target was an indication of success.

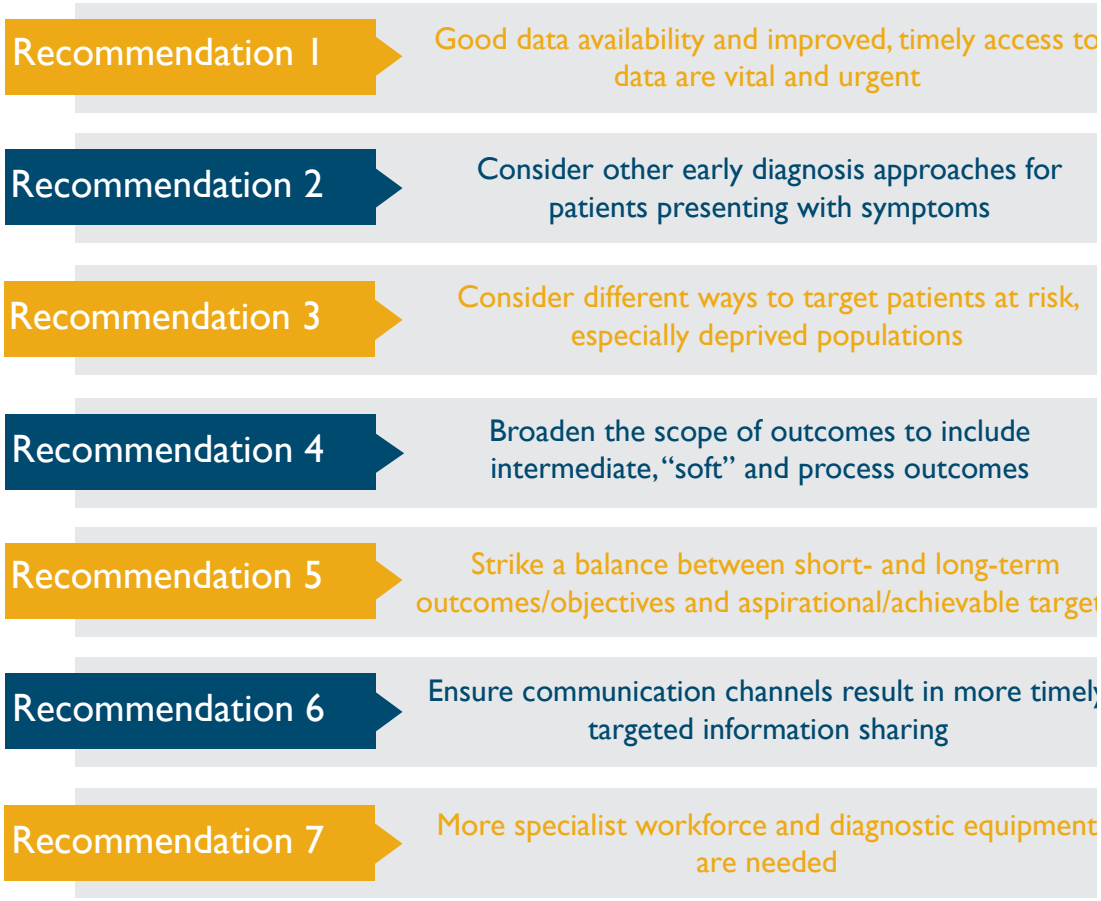
Finally, findings showed that initiatives (local or national) that are shown to work and then are not disseminated can result in frustration, disengagement and potentially missed opportunities for sharing knowledge. Furthermore, it is likely that this limited dissemination helped to drive attention only to aspirational targets, minimising programme impact and not making the most of generated evidence that can potentially improve practice.

# 6. Recommendations

Evaluation findings informed the development of draft recommendations; these were then presented at a Workshop with DCE stakeholders and a lay representative (Edinburgh – 18th September 2018). They helped to refine and prioritise the recommendations shown below. Prioritisation was perceived to be dependent on personal interests, and a challenging task as recommendations were often connected and interdependent.

Acknowledging that DCE adopts a whole-systems approach, and that contextual barriers and facilitators are important, recommendations are given at a provider level, organisational level, local level, and national level (for DCE and beyond DCE)[152] (Figure 25).

Fig 25. Evidence-based recommendations



## Recommendation 1: Good data availability and improved, timely access to data are vital and urgent

Evaluation findings showed that data availability influenced the ability to measure outcomes, compare results with initiatives in other countries, and influenced stakeholder engagement. Good data is paramount to assess programme outcomes and identify ways to improve service provision.

•National level (beyond DCE): we urgently need better IT systems and datasets. ISD Scotland should be consulted about feasibility and sustainability of data collection, storage and retrieval.
•Local level: experienced academics and charities should be consulted further to give advice on relevant early detection data to be included in datasets
•Organisational level: general practices have information on feasibility of data collection, barriers and facilitators

Workshop participants added that having good data also means fixing recognised IT problems in computer systems, including at Breast Screening Centres. Furthermore, they highlighted that it is not only about having good data, but also having the right kind of data (the National Cancer Diagnosis Audit in England was given as an example). Having consistent, established, real-time data was urged.

## Recommendation 2: Consider other early diagnosis approaches for patients presenting with symptoms

This recommendation is based on process evaluation findings and evidence from the literature showing that most cancers are still diagnosed after symptomatic presentation. Hence, in order to improve early detection, it is important to improve early diagnosis for patients with symptoms.

•National level (beyond DCE): consider funding one-stop clinics and multi-diagnostic centres, providing more direct access to diagnostics and adopting successful strategies currently taking place elsewhere
•National level (DCE): continue funding pilots with innovative ideas on how to diagnose symptomatic patients (such as qFIT) – incorporate a cost-effectiveness analysis when doing so

Some workshop participants recommended prioritising this recommendation above others, and suggested adopting the Danish approach for vague, non-specific symptoms. Others referred to local, successful experiences implementing pathways for patients with vague symptoms (such as providing direct access to CT scan). One of the described initiatives had to end (despite being successful) due to limited resources in Radiology.

## Recommendation 3: Consider different ways to target patients at risk (especially deprived populations)

Despite attempts to target deprived populations and other groups at a higher risk of cancer, DCE campaigns also attracted a high number of worried well seeking reassurance. The deprivation gradients for cancer screening, mortality and survival persist despite improvements. Hence, it is important to consider different ways to target those most in need, not only to improve cancer outcomes and reduce inequalities in health, but also to use valuable, scarce resources efficiently.

•National level (beyond DCE): ongoing work to reduce inequalities and increase prevention strategies should continue
•National level (DCE): charities have experience working with deprived communities and can provide further input
•Local level: charities and the community have expert knowledge; past DCE collaborations with local businesses have also been positive
•Provider level: primary care has a key role in engaging with deprived communities – but additional funding is required to enable this

Workshop participants mentioned current work trying to tackle inequalities such as the Screening Inequalities Fund; and DCE's current focus on reducing inequalities.

## Recommendation 4: Broaden the scope of outcomes to include intermediate, soft and process outcomes

Evaluation findings indicated that these outcomes facilitated stakeholder engagement and enhanced assessment of programme impact (for stakeholders, patients and the public). In order to define intermediate outcomes, it is crucial to understand barriers and facilitators in different areas, and for different professionals, and assess the feasibility and acceptability of data collection. It is also important to understand stakeholders' expectations.

•National level (beyond DCE): IT systems and data collection should be in place before an initiative begins.
•National level (DCE): 1) consult with clinicians and allied health professionals to decide on relevant intermediate outcomes (these may be already available) – while ensuring that these are feasible and measurable over time; 2) assess and acknowledge improvements in these outcomes; 3) continue focusing on new evidence/new developments in early detection

Workshop participants mentioned a range of intermediate outcomes that were already available to be assessed. Some believed that measures other than cancer survival should be equally promoted. Recommendations included having outcomes that are measured every year or every 18 months, and reporting on numbers instead of percentage change (as percentages were reported to give unfair advantage to those with poorer performance, and penalising those with good performance at baseline). Some suggested the assessment of 1-year lung cancer survival for deprived populations.

## Recommendation 5: Strike a balance between short- and long-term outcomes/objectives and aspirational/achievable targets

This recommendation was developed after presentations and discussions at the Workshop. While there may be tension between political and health service aims, there is the need to strike a balance between short- and long-term outcomes and the choice of targets. This is important to ensure engagement, ownership, measurement of programme benefits (including those that require long-term assessments), and sustainability of effective strategies.

•National level (beyond DCE): It is important to ensure at least mid-term sustainability and ongoing support for initiatives (including financial enablers)
•National level (DCE): If stakeholders can see how an objective is relevant to them and result in positive benefits, while also having the assurance that successful initiatives will continue, engagement (and sense of ownership) will be facilitated – good two-way communication is also crucial for this to happen

Workshop participants discussed these issues at length. They believed that successful DCE strategies (e.g. bowel screening initiative) should have continued. One-off resources and funding announced year to year were described as not being conducive to long-term planning. Longer-term financial planning would allow for bigger (and more sustainable) changes in service provision. Workshop participants also discussed the benefits and limitations of having short-term (avoiding challenges due to high staff turnover and system changes but hindering engagement) and long-term objectives (which facilitate sustainability, but people change over time). Some argued that the key was to ensure that stakeholders had confidence about long-term commitment

## Recommendation 6: Ensure communication channels result in more timely, targeted information sharing

Communication challenges and requests for more information were often mentioned by stakeholders. It is important to ensure that appropriate information systems and communication channels are in place, while also avoiding information overload.

•National level (beyond DCE): good IT systems and good data are needed to enable communication and dissemination
•National level (DCE): 1) Ensure DCE rationale, findings and best practices are well disseminated; 2) Identify further avenues for disseminating results, best practice and peer learning; 3) acknowledge local work/efforts to promote early detection; 4) identify local "communication champions" to help with information sharing

Workshop participants discussed the challenges of communicating with different groups and facilitating engagement. There was the recognition that regional representatives had a key role ensuring that information was disseminated, as it was not possible to engage with everyone, nor address everyone's needs and concerns. Others emphasised the importance of shared learning not only within Scotland, but also across the UK.

### Recommendation 7: More specialist workforce and diagnostic equipment are needed

Evaluation findings described several challenges regarding limited workforce and diagnostic capacity. Hence, this final recommendation refers to this broad, complex issue.

•National level (beyond DCE): 1) more training and incentives for several areas of expertise are needed, in addition to having the ability to recruit outside the UK when necessary; 2) Consider carrying out a national consultation and audit of key issues and bottlenecks across the whole cancer pathway – otherwise delays may just happen after diagnosis.

Some workshop participants believed that this recommendation should be a long-term guiding principle, and that smarter use of workforce was also required.

# 7. Conclusion

This was a large scale, system-level Programme Evaluation carried out over three years. It generated and synthesised a wealth of information on DCE processes and outcomes, in addition to highlighting key contextual barriers and facilitators, and providing stakeholder and Evaluation recommendations.

It is hoped that the results will be useful as a tool alongside other early detection evidence to guide not only future directions for DCE, but also to inform other early cancer detection programmes.

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# 9. Appendices

## Appendix 1. Description of the four DCE strategies

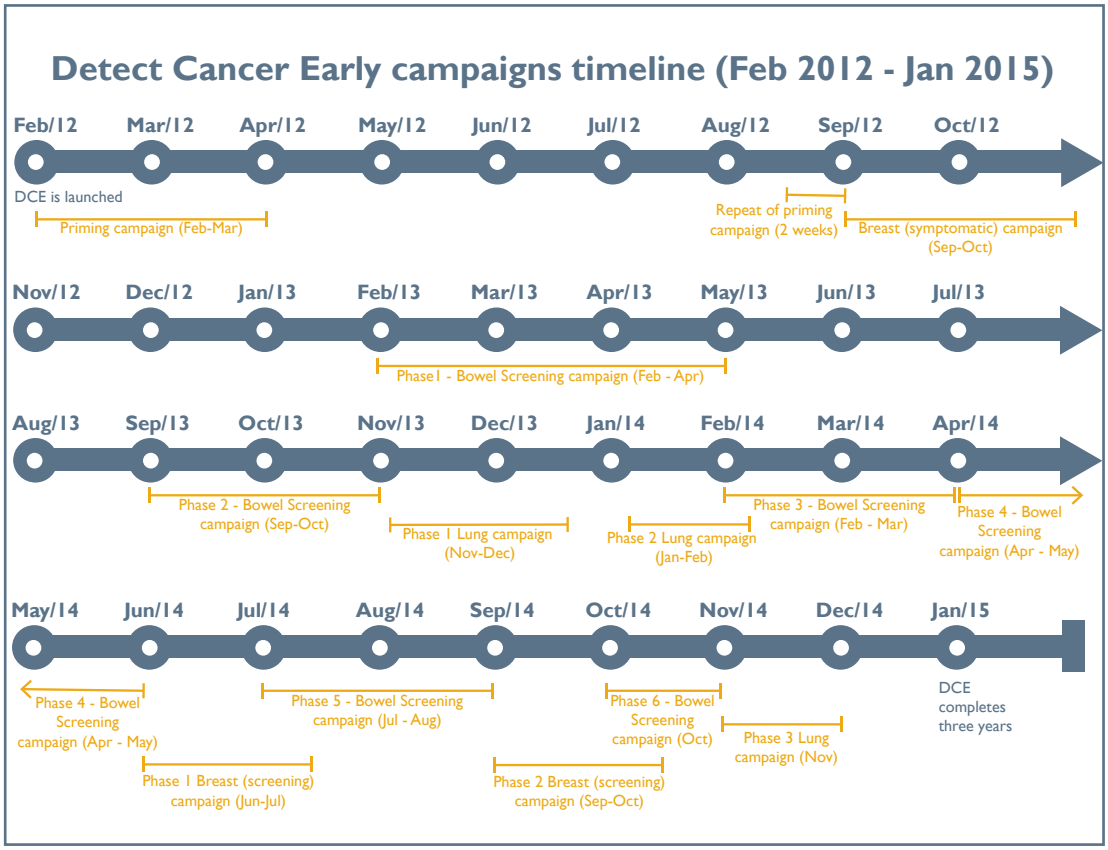
### 1. Public Awareness and Behaviour Influencing Strategy

The DCE Programme developed several social marketing campaigns in order to increase public awareness about cancer and generate behaviour change. The overall aim of social marketing was to raise awareness of the benefits of early detection, build belief that one can survive cancer (as it is not what it used to be) and to drive people to attend screening or seek help if they have any concerns. Campaign timelines are described below.

Social marketing activity started at the DCE launching event in February 2012. Insight gathering was carried out before campaigns started in order to inform them.

The campaigns involved collaborations with a number of agencies. An Advertising Agency (Leith Agency) was responsible for insight gathering, campaign development, dealing with field and partnership, engaging with commercial organisations and working with Health Boards on campaigns. It also coordinated work with a Media Agency (Carat - which prepared television adverts and other press outputs), a Market Research Company (TNS - which organised focus groups with members of the public to inform the social marketing campaigns and carried out campaign evaluations), and a Public Relations (PR) Agency (Consolidated PR – which prepared case studies for the campaigns, secured free editorials, opinion pieces and magazine features). DCE also liaised with a Digital Agency (initially Storey and then the Union) which was responsible for website development.

The overall media strategy for campaigns



included shared media (television to maximise coverage – with defined strategies on what programmes to target to ensure the right groups would see them), one-to-one media (radio delivering more personal messages in daytime, with coverage in community radio, more rural and hard-to-reach areas). There were also activities in rural and deprived areas (surgeries, pharmacies, libraries). Outdoor was used tactically. Furthermore, campaigns were supported by the use of social media and pay-per-click (PPC).

DCE also aimed to do additional PR and social media activity around the breast (October), bowel (April) and lung (November) cancer awareness months. All campaigns had a key message and specific call to action for the public.

There were several campaigns over the years, this appendix describes the key strategies in DCE's first three years: the priming campaign, the breast (symptomatic) campaign, the breast (screening) campaign, the bowel cancer campaign, and the lung cancer campaign.

## Priming campaign

The priming campaign targeted adults aged 40+, C1C2DE in Scotland. The first phase of the campaign ran between Feb-Mar 2012, with the use of TV and radio adverts, posters and leaflets. The priming campaign aimed to reduce fear associated with cancer and encourage earlier detection; both issues were salient during insight gathering. It was carried out in February and March 2012. Core messages included: "Cancer. Don't' get scared, get checked"; "the earlier we find cancer, the easier it is to treat"; "twice as many people survive cancer now compared to 30 years ago". It targeted C2DE Adults 45+ in Scotland through television adverts (shown for 6 weeks - a GP encouraged people to seek help when noticing symptoms), radio (shown for four weeks - interviews with real doctors), washroom posters, leaflets, 6-sheet, and PPC. In both rural and deprived areas, media vinyls were placed in washrooms in doctor/dentist surgeries, pharmacies, community centres and libraries to deliver a personal message. PR activity and digital media were also used.

## Breast (symptomatic) campaign

The first tumour-specific campaign focused on symptomatic breast cancer. It aimed to target women aged 45+ (as breast cancer incidence is higher for this group) living in the most deprived areas of Scotland (as they are less likely to attend screening and tumours are more likely to be detected at later stages).

The campaign was informed by insight gathering showing that women in Scotland had little knowledge about breast cancer symptoms and signs beyond lumps. Often, they also believed that a negative screening result meant an "all clear" and that there was no need to check for symptoms between screening rounds. The decision to focus initially on symptoms instead of screening was also influenced by an independent review of breast screening (Marmot et al 2012. The benefits and harms of breast cancer screening: an independent review. *Lancet*; 380(9855);1778-86). It was not considered appropriate to focus on screening before the review results were available.

The campaign 'Let's talk about breasts' featured Scottish actress Elaine C Smith holding boards over her breasts, showing real images of breast cancers. Creative testing was carried out before launching the campaign; focus group participants were overwhelmingly in favour of this new, bold approach.

TV adverts were shown for four weeks in September 2012 (other activities continued until Breast Cancer Awareness month in October). Adverts could only be shown after watershed, i.e. time when adult content can be broadcast, to avoid children from watching graphic images.

Magazine inserts were placed in titles often read by the target audience (such as Bella, Take a Break, and Chat). Radio and press adverts were also used; and leaflets and posters were distributed to general practices, community pharmacies and businesses. Radio and press adverts further supported the reach and frequency to build awareness across Scotland, as well as allowing more secondary messages such as the importance of participating in screening to be incorporated. PR was adopted with the use of real-life case studies, while Field and Partnership marketing supported a range of local messages across Scotland.

## Breast (screening) campaign

This campaign aimed to increase breast screening uptake, especially among non-attenders from deprived areas, by clarifying myths about the breast screening process and highlighting the benefits of screening (following principles of informed choice).

Differently from other campaigns, it adopted a regional roll-out (as opposed to national) in order to reach areas with the poorest uptake and match areas where breast screening was taking place (breast screening invitations are based upon primary care practices and patients are invited every three years).

The campaign was divided in two phases; the first one took place in June-July 2014 and the second phase took place in September-October 2014. Close work with the Scottish Breast Screening Programme was required in order to target the correct locations. The West and the South East of Scotland were chosen to be targeted first, and each Breast Screening centre provided data on practices due to send invitations for screening (including the location of mobile screening units when applicable).

As Elaine C Smith was well accepted for the symptomatic campaign, she was also a key part of the screening campaign. Her presence also helped to ensure that the same target audience made a connection between the different campaigns. "Real women" from across Scotland also took part and shared why they chose to attend screening. Different women were shown in local press in order to connect with the target audience and give the campaign a sense of locality. If this was not possible the overarching Elaine C Smith execution was used.

The campaign used local radio, press advertising, PR activity and digital media. Leaflets were distributed to Health Boards, primary care practices and community pharmacies.

Elaine C Smith voiced a radio advert describing the importance of screening in finding cancers that cannot be seen or felt, and that are easier to treat. A trained team visited locations with high footfall (such a shopping centres and local supermarkets) in areas due to be invited for screening. There were face-to-face interactions, time to answer questions, distribution of campaign materials and a breast challenge (putting their hands in two holes where there were two prosthetic breasts and counting the lumps they could feel). A a keyring (nicknamed "thingymaboob") which illustrated how screening could detect very small cancers was also distributed.

Households in deprived areas that had just been invited for screening received a mail drop (acting as a reminder or a primer). PR activity took place to address screening myths, share positive screening stories and try to normalise screening through education about its benefits and harms. "Screen Stars" was one of these activities: a walk of fame was created recognising women who are stars of breast screening.
The call to action was the same across different channels: *"If you've missed a screening in the last two years, or have recently received an invite through your letterbox for a time that doesn't suit you, text SCREEN and your postcode to 61611 to rearrange"*. The telephone number of their regional screening centre was then provided. As text responses did not result in many screening appointments, a second six-week phase was developed with a different message: *"Thanks for contacting us. Your local centre will soon call you from a 0800 number to discuss your next screening appointment. No SMS? Reply SCREEN STOP"*. The relevant regional screening centre then called to book an appointment.

## Bowel (screening) campaign

The bowel screening campaign had six phases up to January 2015 (further phases have happened since then). The first phase of the bowel campaign was launched in February 2013 and lasted six weeks. Other five campaign phases ran from September 2013 (four weeks), March 2014 (four weeks), April 2014 (three weeks), July 2014 (three weeks) and October 2014 (four weeks).

The campaign's overall aim was to increase bowel screening participation. Behaviour shifts were planned by 1) providing information about how early detection of bowel cancer (through screening) was the best way to survive bowel cancer; and 2) empowering the population to take part in bowel screening. The population of interest was both men and women aged 45-74 from the C1C2DE demographic (although men were more targeted as they take part in screening less often than women).

The social marketing team wished to normalise bowel screening and tackle the social stigma attached to it, while also appealing to the male population. A touch of humour was therefore added to the campaigns.

The campaign's key messages were "bowel cancer is the third most common cancer in Scotland", and "bowel screening is the best way to detect bowel cancer early".

A key initial campaign component was a TV advert voiced by a Scottish actor (Ford Kiernan). Ford was a hidden voice talking to a regular guy on the toilet about facts he didn't know about bowel cancer, such as "the early signs are often hidden". Humour was also used in a developed 'poo song' (launched in April 2013 – Bowel Screening Awareness Month) that aimed to increase conversations about the subject and encourage children of those eligible for screening to work as influencers.

Printed materials had three key messages: "the early signs of bowel cancer are often hidden"; "9 out of 10 people survive bowel cancer when it is detected early"; and "the best way to find bowel cancer early is to do your home screening test". The call to action was "Bowel Cancer. Don't Take a Chance. Take the Test" accompanied by the Scottish Bowel Screening Centre Helpline number and the campaign website (bowelscreeningtest.org).

Television was used to generate widespread awareness and create maximum impact. Press advertising supported television in reaching the targeted DE male audience, while also reaching women. There were radio executions (two generic and a third carrying a stronger call to action - using Ford Kieran's voice to ensure the link between television and radio campaigns). Small outdoor formats were placed in areas of high deprivation and low screening uptake; these included over 800 lenticular posters in washrooms, bars, clubs, and Rangers and Celtic football club stadiums; 500 panels in toilet cubicles; over 2000 bus headliners in buses covering areas in Glasgow, Edinburgh, Forth Valley and Lanarkshire. Leaflets and posters were distributed to primary care practices and community pharmacies. Partnerships were developed with football clubs across Scotland in order to reach more men.

Different campaign phases used television, radio, outdoor, press and digital resources. PPC activity underpinned all phases.

Campaigns were also supported by Field and Partnership and PR activity. There were engagement events with the public in over 60 locations across Scotland, Event staff visited high attendance football matches to engage with large numbers of men. Furthermore, the PR team worked with Bowel Cancer UK to ensure that there was media coverage during and beyond the campaigns.

The sixth phase slighted shifted its focus to have a stronger message in terms of cancer survival. The message "9 out of 10 people survive bowel cancer if found early" evolved to become "when bowel cancer is found early, it can often be cured". A range of resources (such as hideaway books to store the bowel screening test and football cards) were developed.

## Lung (symptomatic) campaign

The lung campaign was carried out after the breast and bowel campaigns, and had three phases. The first phase was launched in November 2013 (Lung Cancer Awareness Month) and lasted four weeks. A second phase was launched in January 2014 and was live for a month. The third phase was launched in November 2014 and lasted four weeks.

The first two phases aimed to build belief that something can be done for lung cancer when it is found earlier and highlight that people can have better quality of life if cancer is diagnosed earlier. The call to action was 'Don't Get Scared, Get Checked", accompanied by "If you're worried about a change to your cough, see your GP as soon as possible". The campaign targeted men and women aged 55+ from the most deprived areas in Scotland.

Compared to the breast and bowel campaigns, the lung campaign was less positive around survival and more focused on controlling symptoms. There was the acknowledgement that early detection of lung cancer is challenging as symptoms are not often present until later disease stages; diagnosis and treatment are also difficult.

Lung cancer was also the only tumour type (included in DCE's first three years) for which there was no organised screening programme available. In order not to discourage smokers as they were a crucial group to reach, the campaign did not approach smoking cessation.

The use of emotion was perceived to be crucial to help with behaviour change. The campaign was fronted by Sir Alex Ferguson, someone well-trusted and known for his honesty, and whose parents died of lung cancer.

The first phase used television for two weeks to generate widespread awareness and create impact. There was also press advertising in national, evening and local press titles for eight weeks. Radio was not used as it was not considered to be effective for the target audience. Signs were placed in bus panels. In January, television, press and six-sheets were used, and campaign messages were placed in pharmacy bags across Scotland.

Field and Partnership and PR activities also took place in both phases, with one-to-one engagement across Scotland (especially in more deprived areas as deprived populations are known to be at a higher risk of lung cancer due to higher smoking prevalence). There were PR collaborations with The Roy Castle Lung Cancer Foundation and The British Lung Foundation to ensure that there was media coverage about the campaigns.

### Change in direction

Attitudinal tracking showed that almost half of Scots did not know that a persistent cough was a sign of lung cancer. Furthermore, BCOC in England had emphasised coughs in their campaign, with perceived benefits. Hence, there was engagement with the Roy Castle Lung Cancer Foundation, British Lung Foundation and lead clinicians in both primary and secondary care to decide on whether the approach should be taken in Scotland. A decision was made to use a more direct call to action for phase 3: 'If you've had a cough for three weeks, your GP wants to see you.'

The campaign objectives shifted to raising awareness that a three-week cough can be a sign of lung cancer, and reassuring people that their GP wanted to see them. Sir Alex Ferguson's was also involved in the three-week cough message.

Radio was used to illustrate how a persistent cough can be disruptive (advertising space was bought before, during and at the end of advert breaks) and targeted influencers (those who notice someone close to them coughing too often). Pharmacy bags carrying the three-week cough message were circulated throughout pharmacies in more deprived areas in Scotland.

Bus panels were added to bus routes in deprived areas; and a "coughing bus stop" was added to two locations with a special message after the coughing: "don't hang around waiting for that cough to clear up, see your GP".

Field and partnership, television, press, and PR activity also took place. A doctor from a deprived area in Glasgow and representatives from Roy Castle Lung Cancer Foundation and British Lung Foundation were photographed showing lit-up letters spelling "cough"; and GPs across Scotland were used to reinforce the message that they wished to see patients with a three-week cough.

**Data sources for Strategy 1**: Policy documents received during evaluation development and personal communication at the DCE Programme Board meetings. Documents comprised: Consolidated PR Detect Cancer Early campaign briefing packs for breast screening, symptomatic breast and lung cancers; breast screening, breast symptomatic, lung and bowel screening case study documents prepared by DCE, evaluation report prepared by TNS ("Bowel Cancer Campaign Evaluation / Tracking December 2014), evaluation report prepared by Made in Leith, Carat and Consolidated PR ("Detect Cancer Early campaign wash-up. Priming, Breast Cancer, Bowel Cancer, June 2013")

## 2.Primary Care Symptom Management and Referral Strategy

This strategy consisted of education sessions for health care professionals and review of urgent referral guidelines for suspected cancer.

Before DCE implementation, there were also plans to develop practice profiles, describing primary care referral behaviour in order to facilitate planning, reduce variation in referral behaviour and potentially decrease rates of emergency presentations. However, the practice profiles were not made available before DCE completed three years.

### Education sessions

Seven primary care engagement sessions were delivered by experts from Roy Castle Lung Cancer Foundation and Bowel Cancer UK between September-October 2013. The sessions informed primary care professionals of DCE's strategies (such as bowel and lung campaigns, and the bowel screening initiative), and the role of primary care in them. Sessions also discussed cancer signs and symptoms, and presented the new referral guidelines for lung and bowel cancer.

There were also four pharmacy education sessions in Dundee, Edinburgh, Glasgow and Dumfries.

### Referral guidelines for suspected cancer

In order to update referral guidelines, evidence tables with recommendations from UK and international guidelines (published in English) were prepared. Other guidelines were identified from websites for several guideline-producing organisations in June 2012 (and updated in January 2013), and Medline and Embase searches. Recommendations were then assessed for methodological quality using the validated Appraisal of Guidelines for Research and Evaluation II (AGREEII) instrument. A note was added on whether they should be further recommended (yes/no).

Stakeholders then systematically analysed differences in the available recommendations, while also considering their clinical and practical experience, knowledge of the literature, and the Scottish context. Stakeholders included academics, members of the Royal College of General Practitioners, from the Scottish General Practitioner Committee (SGPC), the Scottish Medical School Committee (SMSC), the British Medical Association Scotland, clinical leads from Cancer Networks, staff from charities, clinical directors, directors of imaging, among many others.

**Data sources for Strategy 2**: Policy documents received during evaluation development and personal communications at the DCE Programme Board meetings. Documents comprised: Roy Castle Lung Cancer Foundation. Report to Scottish Government – Detect Cancer Early Workstream 2013; Roy Castle Lung Cancer Foundation and Bowel Cancer UK. Detect Cancer Early Primary Care Engagement Project. 2013 and the Scottish Referral Guidelines for Sspected Cancer May 2014 (available from: http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/scottish_referral_guidelines.aspx).

## 3. Secondary Care & Diagnostic Capacity Strategy

Territorial Health Boards were asked to make bids for funding, which was allocated via NRAC share (http://www.tagra.scot.nhs.uk/research/). The NRAC formula was developed by the NHSScotland Resource Allocation Committee (NRAC). It takes into account population projections, while adjusting for age/sex composition, needs due to morbidity or other factors such as deprivation, and costs due to remoteness. Territorial Health Boards were required to send brief annual reports to DCE describing:

1. Main activities supported by the funding allocation in order to help achieve DCE objectives from the implementation plan
2. Main challenges to achieving planned objectives and action taken to tackle these
3. Main benefits realised as a result of funding
4. Description of how improvements would be sustained beyond DCE
5. Key achievements and lessons learned

**Data sources for Strategy 3**: Policy documents received during evaluation development. These comprised summaries prepared by DCE describing how funding was used and the source documents used by DCE to prepare these summaries (i.e. annual reports submitted by territorial Health Boards (2012/2013, 2013/2014 and 2014/2015)

# 4. Performance Management & Monitoring Strategy

This strategy comprised a newly developed HEAT target (25% increase in cancers diagnosed at Stage 1) and an sGMS Contract Bowel Screening Initiative that awarded up to the equivalent of 6 Quality and Outcomes Framework (QOF) points for reduction in bowel screening non-participation.

Cancer Waiting Times (CWT) targets were also managed by DCE, but this initiative was not implemented by the programme and is not mentioned here. The other targets are described below.

## The HEAT target

### Developing the target and gathering data

The HEAT target was "to increase the proportion of people diagnosed and treated in the first stage of breast, colorectal and lung cancer by 25% by 2015". Breast, colorectal and lung cancers were chosen as they were the most common in Scotland (45% of all cancers in 2011).

Cancer Registry Data was initially used for the DCE baseline (by adopting an average annual performance for 2005 to 2009); this was later reviewed due to the large number of unknown stages and delay between data collection and data publication. Cancer Audit data was chosen to be used instead after consultation with stakeholders.

A two-year average for baseline was used instead of a single year in order to account for variation between years. This was especially important in smaller Health Boards which show large percentage changes from small numbers. Since the DCE priming campaign was launched in February 2012, the latest data prior to this (2010-2011) was considered to be the best choice for the baseline. Rolling two-year averages were used to compare performance with baseline data over the years.

Audit data were recorded onto Boards' prospective cancer audit systems and submitted quarterly to ISD Scotland before being validated to ensure code consistency and loaded onto the DCE database. In order to define staging, a combination of clinical and pathological information was used.

### Unknown cancer stages

Staging data cannot be determined at times, or it is not appropriate to try to determine it. Hence, it was unlikely that staging data would ever reach 100% completion. Unknown values were included when reporting the baseline and the impact of their inclusion was considered. It was expected that including these unknowns would encourage Boards to improve their performance. The level of variation in the proportion of unknowns was considered when setting targets.

Since the distribution of stages amongst the unknown is uncertain it is often not possible to separate increases in Stage 1 due to better recording or from a potential shift from more advanced stages of disease. Both the number and percentage of unknown stages should be considered when comparing stage distribution figures for individual cancers across geographical areas.

### Different tumour types

The percentage of patients diagnosed at Stage 1 can vary due to factors such as the presence and uptake of national screening programmes.

When making comparisons for breast cancer data it is worth noting that in the Island NHS Boards the breast screening mobile unit only visits once every three years. Furthermore, more rural Health Boards such as NHS Borders and NHS Dumfries & Galloway may also not be visited by mobile units every year.

For several Health Boards, the start of the bowel screening occurred during baseline. The first round of bowel screening can result in a higher number of patients diagnosed at Stage 1 than in later years (depending on uptake). Hence, some boards could see higher than usual proportions of diagnosis at stage 1.

### Revisions and corrections

The national cancer audit datasets for individual cancers have changed since 2010. Efforts were

made to ensure that the data items referring to DCE remained stable. NHS Dumfries and Galloway resubmitted colorectal data in 2010 after correcting errors in staging.

There was a revision in 2014 as some small differences were identified in the assignment of Board of Residence. An error was also found in the implementation of the algorithm used to derive breast cancer staging. Finally, on 1 April 2014 NHS Board Boundaries were changed to align with those of local authorities. Reports with both the previous and the new Board Boundaries were made available.

## The Bowel Screening Initiative

As part of DCE, a new sGMS initiative focusing on bowel screening was funded. General practices received up to 6 QOF points for reducing the proportion of non-responders to bowel screening. The initiative lasted two years (01/04/13 until 31/03/15). The first year involved identifying ways to improve screening uptake and developing an action plan. The most recent uptake data at the time (2011-2012) was proposed as baseline data. In the second year, practices implemented the action plan.

Rewards were given to practices that showed decrease in non-participation rates of at least 2% (compared to their previous uptake). Two points were given for a relative 2% increase, 4 for a decrease between 2.1-4% and 6 points for a relative decrease over 4.1%. The percentage reduction in non-participation was a relative reduction (e.g. a relative 4% reduction in a practice with 60% non-participation would correspond to 57.6% non-participation).

All practices registering for the initiative were asked to commit for the two-year programme. Full payment was possible when targets were not met provided that practices could show that the action plan was followed and patients were offered evidence-based information to enable them to make an informed decision. Full payment would also be available if practices could provide good written evidence of their reasons for not achieving the targets, and developed a revised action plan.

Payment weighting was applied based on the size of the eligible practice population and the most updated information on uptake (higher weighting for practices with poorer uptake). Weighting was applied to 50% of the payment (3 QOF points). Practices obtained data directly from the Bowel Screening Centre in order to calculate baseline data; data on non-responders was also obtained from the Bowel Screening data (there were recognised delays in receiving this). A list of recommended medical READ codes was provided so primary care practices could keep a record of their activities.

**Data sources for Strategy 4**: The Scottish Government Circular, Detect Cancer Early - Bowel Screening Initiative - July 2013; The Scottish Government, Technical note on the calculation of the baseline for the Detect Cancer Early HEAT target, 2013.; and annual reports about Detect Cancer Early Staging data (Baseline-Year 6, available here: http://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp)

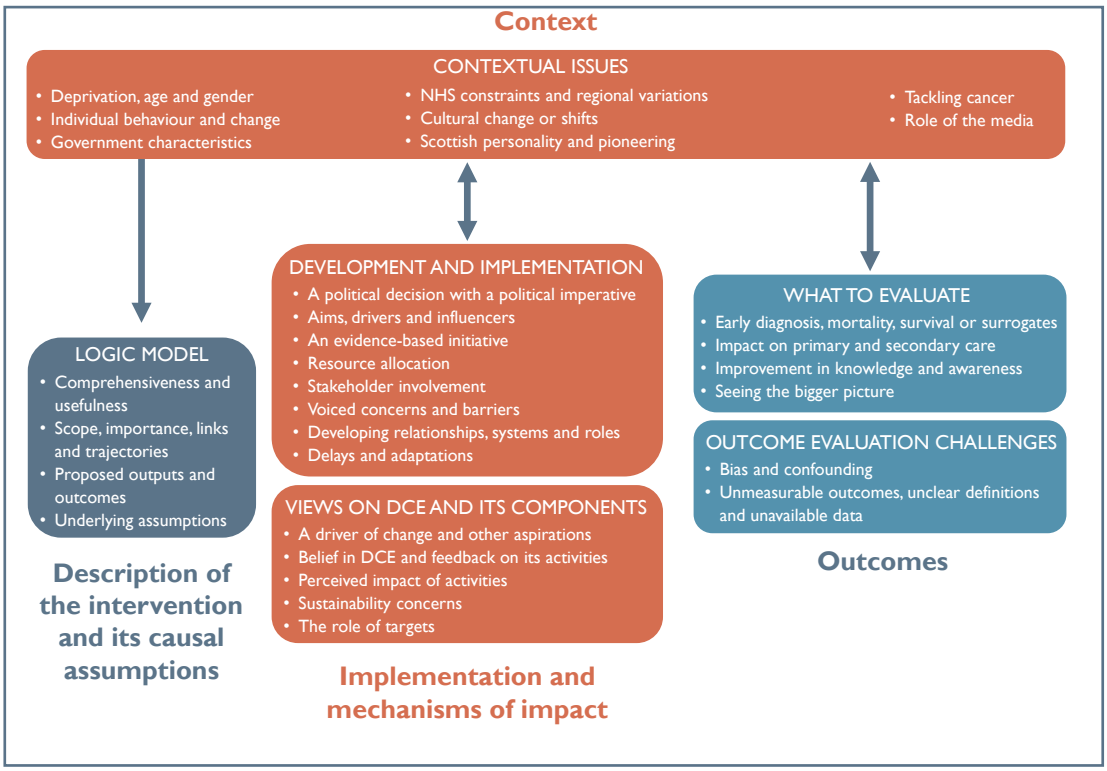
# Appendix 2. Key findings from evaluation development interviews

## 1. Characteristics of interview participants

Nine stakeholders were interviewed during evaluation development. Job roles included senior management in ISD Scotland; at DCE; in national screening programmes and in each of the three Scottish Cancer Networks; general practitioners; and secondary care doctors. Some stakeholders had more than one role. They worked in five territorial Health Boards: NHS Forth Valley, NHS Grampian, NHS Greater Glasgow & Clyde, NHS Lothian and NHS Tayside.

Feedback from stakeholders focused on six themes: **DCE development and implementation; views on DCE and its components**; **logic model**; **overall contextual issues**; **what to evaluate**; and **outcome evaluation challenges**. Participants also gave suggestions of whom to contact when evaluating DCE (staff at cancer charities, range of Scottish Government staff, range of health care professionals, NHS managers and those working in the NHS in an administrative capacity).

### Themes from stakeholder interviews organised in the MRC Framework



## 2. Key themes

### Theme 1: development and implementation

DCE was described as a programme with a political agenda, specific targets and investment. It was driven by the need to improve cancer survival, informed by evidence on early detection and influenced by existing initiatives in England. It aimed to improve cancer survival, and aspired to provide changes in the way the population perceived cancer and acted towards it, in addition to generating more efficient and prompt service provision.

Stakeholders described how, since the initial stages of the programme, advice was sought from a wide range of stakeholders. In general, they thought that their opinions were listened to, but acknowledged that views would differ based on the level of involvement with the programme. Concerns were raised before and during DCE implementation about the programme's impact on diagnostic capacity, about increasing the number of "worried well" or causing delays for patients who had cancer.

Stakeholders' views differed in which element of DCE they regarded as the programme's key aim (e.g. earlier cancer diagnosis, improved public awareness, or system-level changes). Each territorial Health Board was described as having specific additional aims, depending on local priorities, and different approaches regarding programme components (such as how to engage with patients and the public or how to use additional DCE funding).

### Theme 2: views on DCE and its components

DCE was considered to be a driver for change and a mechanism for reducing inequities in screening across deprived communities. In the long-term, it could help to modify the way the population perceived cancer (reducing fear) and could empower patients to go see their doctor when they noticed symptoms. DCE was also seen as an opportunity to develop more efficient ways to investigate patients with symptoms, to assess how the health system worked, and make changes as appropriate.

In general, stakeholders believed in the programme's importance and in what it proposed to do, and often reported being proud of being a part of it. Nonetheless, they recognised that some of the programme objectives were difficult to achieve.

Awareness campaigns were complimented for their "bold" and "professional" approach, but concerns were raised about whether information was retained by the population and resulted in change in attitudes. There was also recognition that campaigns on their own would not be sufficient to completely change population behaviour towards cancer.

Participants raised several concerns about the programme's sustainability. They highlighted that people may get tired of campaign messages and emphasised the need to sustain public interest. They also emphasised the importance of ongoing investment for primary care, for diagnostics and treatment.

Stakeholders had mixed views regarding performance targets. For some, they drove activity, were useful for politicians and the media, and a measurable outcome. However, targets were also perceived to be unhelpful and some questioned whether they were a good measure of the programme's success.

### Theme 3: Contextual issues

Stakeholders described how contextual issues such as social deprivation, regional differences, political interest, and NHS constraints influenced and were influenced by the programme. They acknowledged the need to reduce health disparities to improve cancer outcomes but acknowledged that achieving this aim was beyond the remits of DCE.

Population behaviour towards campaigns was described to vary according to different levels of social deprivation, with the most deprived taking longer to process information, or to act upon it. Population age and gender were also described as interacting with deprivation and providing a more complex picture in terms of response to awareness campaigns.

Stakeholders reported challenges related to NHS capacity, especially diagnostics (equipment

and staff availability), and acknowledged that these problems pre-dated DCE. Resource needs were also described as a potential reason why Health Boards engaged with the programme, i.e. in order to obtain additional funds which could help with pre-existing challenges. Finally, participants described a perceived disconnect between primary and secondary care and a "silo mentality" that was likely to have affected DCE development and implementation.

Stakeholders described a perceived shift (albeit slow and ongoing) in the way the population talked about cancer, being more open to discuss the topic with others. Although they believed that DCE had helped to effect this change, they considered many changes were beyond DCE's influence, and that they were part of a current drive towards healthier behaviours and cancer prevention.

Stakeholders discussed the role of early diagnosis in survival, describing several factors which influence cancer outcomes. The "Scottish personality" was described as an important contextual factor, especially a perceived fatalistic and stoical view towards cancer. Nonetheless, the Scottish population was also described as "passionate" and engaged when they believed in something.

### Theme 4: what to evaluate

Interview participants were specifically asked what elements of DCE they considered should be included in the evaluation. In response, while they emphasised the importance of assessing clearly quantifiable outcomes such as stage at diagnosis and screening uptake, they also wished to understand the impact that the programme had on primary and secondary care. There was the recognition that additional investment in secondary care would not be sufficient if primary and secondary care were not working together as a system. Understanding the impact that the programme had on capacity, systems and ways of working due to additional investment was also considered important, as was examining whether DCE generated increase in knowledge, awareness and attitudinal changes towards cancer, assessing (if possible) any broader cultural health system changes, and examining any adverse (as opposed to only investigating positive) effects.

### Theme 5: outcome evaluation challenges

Bias and confounding were cited as important challenges when assessing outcomes. Participants indicated that separating the programme from other early detection activities taking place at the same time was difficult. They also emphasised that DCE was a national programme and that it would not be possible to show causality.

Other described evaluation challenges included lack of data and measuring soft outcomes. Stakeholders recommended the investigation of improvement in awareness and change in attitudes, and of wider cultural changes, but acknowledged that it would be difficult to measure these.

### Theme 6: logic model

The logic model was considered useful to describe the programme, and mostly accurate in terms of DCE components. However, stakeholders believed that it displayed large amounts of information, which at times made it difficult to find or make sense of data in it.

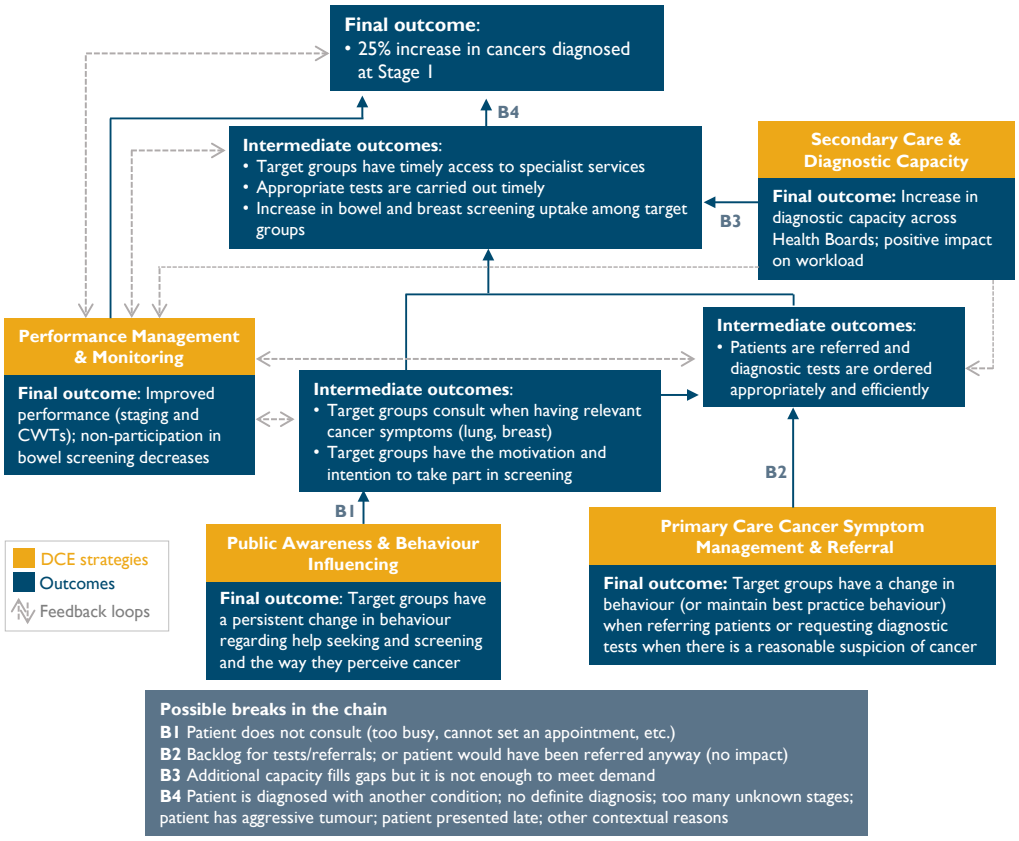
# Appendix 3. Diagram representing DCE programme theory, and elicited assumptions and mechanisms

## DCE textual programme theory

DCE awareness campaigns targeting the public allow for increased knowledge, confidence and motivation to seek help and get screened. Training for health care professionals leads to increased knowledge and confidence to assess symptoms, request tests, provide screening recommendations and refer to specialists. The provision and dissemination of updated referral guidelines also increases confidence, and legitimises referrals. Performance targets drive activity and help to focus the health professionals' minds.

All these activities increase demand for diagnostic resources; this is managed with the provision of funding for Health Boards to invest in capacity while adopting a systems approach. Acceptance, appropriate communication and resource availability lead to better services alongside more knowledgeable and confident populations and workforce; this allows for more cancers to be diagnosed earlier. Over time, DCE may also trigger wider cultural changes in the way the population perceives cancer and the way that it is managed by health services.

## DCE outcomes chain




## Target population

- General public within the age range eligible for bowel and breast screening
- Bowel/breast screening non-responders (focusing on deprived men for the former and deprived women for the latter)
- Those at risk of lung cancer
- Key influencers (e.g. children and teenagers)
- GPs and other primary care staff
- Secondary care staff
- Primary and secondary care interface

## ASSUMPTIONS

- Programme leadership/management is appropriate (*feasibility; acceptability; sustainability and appropriateness*)
- Monitoring and data systems for evaluating programme are sound (*feasibility; acceptability; sustainability and appropriateness*)
- Developed relationships and partnerships are effective (*feasibility; acceptability and sustainability*)
- Resource allocations are timely and fair (*feasibility; acceptability ; sustainability and appropriateness*)
- There is sufficient targeting and communication about the programme, its aims and strategies, and what is expected from everyone (*reach and communication*)
- Positive changes in service provision and population behaviour will be sustained (*acceptability; sustainability*)
- Available resources are sufficient in terms of equipment, specialist health professionals, primary care practices, laboratories, diagnostic centres, hospitals, screening, etc. in order to meet aims (*sufficiency; feasibility*)
- Additional funding is sufficient to meet capacity needs brought by the programme (*sufficiency and sustainability*)
- Flexibility is permitted when allocating resources (*feasibility and adaptability*)
- Programme is sufficient to generate positive changes (*sufficiency*)
- Different stakeholders buy into the programme, its components and what they propose to do (*feasibility ; acceptability; sustainability and appropriateness*)

## MECHANISMS

- DCE strategies are in line with what the professionals perceive as their role, identity, organisational commitment and professional boundaries (*reflective motivation*)
- Increase in knowledge, confidence and awareness influence the public and professionals and empower them to change intentions and behaviours (*psychological capability; and reflective motivation for guidelines*)
- Additional funding from the programme results in increased *physical opportunity* (e.g. more diagnostic equipment or workforce)
- Increased demand brought by DCE works as a driver and creates pressure to act (*automatic motivation*)
- Confidence in DCE's ability to make changes leads to intention/goal setting to meet its aims (*reflective motivation*)
- Targets help to focus the mind, show where resources are needed and increase pressure to act (*automatic motivation and reflective motivation*)
- Rewards work as motivators to change behaviour and generate intention to act (*reflective motivation*)
- Guidelines legitimise and facilitate referrals (*reflective motivation*)
- Influencers are trusted by target groups and provide social support and social pressure that lead to change of intention and behaviour (*social opportunity*)
- Increased knowledge reduces cancer fear/anxiety and concerns about wasting the GP's time (*automatic motivation*); OR fear remains but is a driver instead of a barrier (*automatic motivation*)
- Belief that cure is possible/early diagnosis is possible leads to change of behaviour/intention (*reflective motivation*)

## CONTEXT / EXTERNAL INFLUENCERS

- Population characteristics (ageing, multimorbidities, ethnicity, deprivation, age, gender) and challenges in changing behaviour in the short- and long-term; Scottish stoicism
- Population experiences, needs, demands and expectations and variations across different groups/regions
- NHS constraints (financial, human resources, equipment) and regional variations in capacity, challenges in the primary and secondary care interface, challenges accessing services
- Current and previous Cancer Plans, Health Policies and initiatives on cancer control
- Previous, current and planned work of relevant charities
- The role of the media in influencing motivation and behaviour
- Government features: limited funding, different priorities, pressure to meet targets, and changes of government
- Cultural changes in the way people perceive cancer; growing focus on prevention; increasing role of primary care in cancer control; increased focus on genetic testing; stratified risk screening/other types of personalised cancer care
- Early diagnosis and survival: cancer diagnosed in its earlier stages is more likely to be successfully treated
- Other factors influencing early diagnosis/cancer survival (tumour biology, tumour location, growth rate); cancers with less distinctive or common symptoms/without alarm symptoms; cancers for which symptoms indicate advanced disease, role of quality of treatment and care after treatment
- Scottish geography may be a barrier to access to care and treatment

## UNANTICIPATED OUTCOMES

- Unnecessary investigations; unnecessary treatment; delays for those who need access
- Unmanageable workload for primary and secondary care; professional frustration and anxiety
- Increase in the worried well among patients; increased public anxiety
- Negative impact of targets (e.g. tunnel vision, measure-fixation, gaming and ossification)

\+ Relevant diagnoses other than cancer

\+ Adopters become influencers

\+ Avoidance of unnecessary treatment

\+ Better IT systems

# Appendix 4. Theories adopted for operationalising implementation assumptions and mechanisms of impact

## 1. Implementation components and definitions

| Components | Definitions |
|---|---|
| **Feasibility** | Refers to the practicability/achievability of an initiative. Related to "appropriateness", but different as something may be feasible, but not appropriate (and vice-versa)[1]. It covers issues such as impact on workload |
| **Acceptability** | Whether DCE is acceptable/agreeable. It refers to views on a specific strategy and is different from "satisfaction" which refers to service experience[1] |
| **Sustainability** | DCE's ability to be sustained over time[1] |
| **Appropriateness** | Appropriateness refers to programme fit according to stakeholders. It is similar to "acceptability", but not equivalent as something may be appropriate but not acceptable (and vice-versa)[1] |
| **Sufficiency** | Whether resources (physical, staff, or skills) were sufficient to meet demand brought by the programme, and strategies (training, campaigns) were enough to achieve intermediate outcomes. It was chosen instead of "dose delivered" and "dose received"[2] as quantitative measures of dosage did not seem appropriate for the DCE programme |
| **Reach and communication** | Refers to issues such as quality of information, access to it and quality of communication about strategies. Similar to "Penetration" [1] and "Reach"[2], but with a stronger focus on the role of communication |
| **Adaptability** | Adaptations to adjust to the programme/meet its aims, and how possible it was to make changes. It was chosen instead of "fidelity" [1,2] due to the challenges in defining fidelity for a non-experimental programme where adaptations were the rule rather than the exception |

References:
1. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Administration and policy in mental health 2011; 38:65-76.
2. Steckler A, Linnan L. Process Evaluation for Public Health Interventions and Research. San Francisco, California: Wiley, 2002.

## 2. The COM-B model

| The COM-B model adopted in the evaluation |
|---|
| The COM-B (Capability, Opportunity and Motivation) postulates that in order to change behaviour one or more of these three components need to be changed[1,2]. For example, training health care professionals can increase their capability, providing diagnostic capacity resources can increase the opportunity to provide services, and financial rewards can increase motivation to meet targets. DCE proposed mechanisms were mapped into the COM-B constructs:<br>• **Reflective motivation:** Reflective processes involving plans (i.e. self-conscious intentions) and evaluations (related to beliefs about what is good and bad)[1]; e.g. intending to attend screening<br>• **Physical opportunity:** Opportunity provided by the environment; this could be time, resources, locations, cues, and "physical affordance" [1]; e.g. being able to run tests for patients because a chest x-ray machine is available<br>• **Automatic motivation:** Automatic processes relating to emotional reactions, desires, impulses, inhibitions, drive states and reflex responses[1]; e.g. feeling anticipated fear and worries about the prospects of not meeting targets |

References:
1. Michie S, Atkins L, West R. The Behaviour Change Wheel. A guide to designing interventions. Silverback Publishing, 2014.
2. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implementation Science 2011; 6:1-12.

# Appendix 5. Methods and data sources to assess DCE objectives

| DCE Objective | Outcome evaluation |
|---|---|
| 1. Increase the proportion of people with stage I disease at diagnosis and to use performance against a HEAT target as a lever for whole systems improvement | • Data from ISD Scotland used to create charts showing % of Stage I over time (baseline, Years 1-6); for all tumour types combined and breast, colorectal and lung separately; for Scotland and for each Cancer Network; and for each deprivation quintile (1-most deprived to 5-least deprived)<br>• Tables in the Appendix describe trends on Stages II-IV over time and Stage I over time across territorial Health Boards |
| 2. Improve informed consent and participation in national cancer screening programmes<br><br>3. Raise public awareness of cancer screening programmes and the early signs and symptoms of cancer | • Data from ISD Scotland used to create charts describing screening uptake:<br>o Breast: national uptake from 2005-2008 to 2013-2016; N screened from 2010-2011 to 2015-2016; and table outlining N and percentage change for routine appointments, early recall and self-GP referral from 2010-2011 to 2015-2016 (2010-11 used as a proxy baseline). Data was reproduced from ISD Scotland reports (graphs and tables)<br>o Colorectal: National uptake data from 2009-2011 to 2015-2017 reproduced from ISD Scotland reports. Uptake by deprivation and % change is also reported for the same time period (graphs only)<br>• Data from ISD Scotland, the Scottish Bowel Screening Centre, TNS, Carat and Consolidated PR used to report on evidence of raised public awareness:<br>o Practice Team Information (PTI) data on consultation for breast cancer signs and symptoms (Jun-Aug 2011 – Sep-Nov 2012) reproduced in the report, with estimates and confidence intervals. PTI data ceased to be collected after this period<br>o Customised data from the Bowel Screening Centre was used to develop time trends graphs showing requested and returned replacement test kits (and % changes) from Feb 2011 to Jan 2016 alongside the timing of different DCE initiatives targeting bowel screening. Time periods were grouped as one year prior to DCE, the first three DCE years and a fourth DCE year). N of request by Health Boards (and percentage changes) are shown in graphs and tables<br>o Results from social marketing campaigns (TNS before and after reports on awareness and attitudes; Carat and Consolidated PR data on N of events, media impact, among other metrics) are shown in boxes (text only) for the priming campaign, breast, colorectal and lung cancer campaigns |
| 4. Promote referral/investigation for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access | • Evidence from personal communications (DCE Programme Board meetings) used to briefly report on the use of qFIT for symptomatic patients and on the updated referral guidelines for suspected cancer (in text)<br>• Evidence from evaluation reports of education sessions authored by the Roy Castle Lung Cancer Foundation and Bowel Cancer UK |
| 5. Ensure sufficient capacity in the screening programmes to meet the expected increase in demand | • Annual reports from the Bowel Screening Centre used to create 1) time trends graph showing monthly calls to request replacement kits from January 2013 to March 2015 alongside the timing of different DCE initiatives targeting bowel screening; 3) tables with N of calls to helpline (by month and year) and issued reminder letters (by year); 3) text describing increase in laboratory activity, email requests, among other issues<br>• There was no available information for breast screening, although data shown for Objectives 2-3 may be relevant |
| 6. Ensure imaging, diagnostics and treatment are prepared for an increase in demand | • Policy documents (annual reports submitted to DCE by territorial Health Boards) used to create descriptive summary tables about how additional funding was used, and perceived benefits of funding |
| 7. Strengthen data collection and performance reporting within NHSScotland | • Data from ISD Scotland used to create charts showing the % of tumour staging recorded as "unknown" over time (baseline, Year 1-6) for all tumour types combined and breast, colorectal and lung separately; for Scotland and for each Cancer Network; and for each deprivation quintile (1-most deprived to 5-least deprived)<br>• Table in the Appendix shows unknown stages (N(%) over time by territorial Health Board |
| 8. Facilitate further evaluation of the impact of public campaigns on the stage of cancer at presentation and to contribute to cancer survival research | • Outcomes not available for this objective |

# Appendix 6. Interview topic guide

## Stakeholders managing health care services and DCE strategies
## Process evaluation of the DCE Programme

**The guide will be used in a flexible and responsive manner, allowing participants to introduce new areas for discussion. Ensure signed consent form has been received.**

**Interview questions/topics**

1. Ask the participant to tell you a bit about himself/herself (*ask for job role and experience*)
2. Ask about their involvement in DCE development and overall views about the programme (A1, M1) (*prompt: information on communicating requirements/strategies; whether targeted groups were the right ones; whether staff were ready for the programme)* (A1, A2)
3. Ask for their views on DCE aims and outcomes (**mention them**) *(prompts: whether they thought DCE aims would be met, why they think some aims were met/not met; unanticipated outcomes)* (A1)
4. Ask for their views on whether the programme made a difference *(e.g. what would have happened if there was no DCE; prompt for whether they thought DCE was a success*) and on any noticeable barriers/facilitators (*think of urban/rural differences*) *(A1)*
5. Ask whether DCE estimates on impact on workload were accurate *(think of each of the strategies; prompt: was DCE a driver for action?)* (A1, M3)
6. Ask about intermediate outcomes related to implementation (*think of improved efficiency; increase in capacity; developed strategies to meet targets; patients presenting more often in primary care)* (A1-A4)
7. Ask them to what extent they think DCE was implemented as planned (*prompt: staff involvement, reaching the target groups as planned, organisational and personnel functions handled well, consistent implementation across areas; components difficult to implement)* (A1-A4, M2)
8. Ask about the level of resources available for what they were required to do *(think about human and financial resources, equipment, time, and knowledge – prompt: were resources sufficient?)* (A3, M2)
9. Ask about any other external factors influencing implementation and the programme's success

**Thank the interviewee for his/her participation and ask if they would like to comment on anything you had asked – or anything else.**

**Finally, ask whether they would like to receive a summary of the study results. If so, make a note for future reference.**

A1-A4: Assumptions 1-4
M1-M4: Mechanisms 1-4

# Appendix 7. Questionnaire survey

## Process evaluation of the Detect Cancer Early Programme

### Questionnaire survey

Thank you for considering taking part in this survey. We would like to hear your views about the role of the Detect Cancer Early (DCE) programme in your daily work, and to learn lessons from what worked and did not work during programme implementation.

DCE was launched in 2012 and aimed to improve cancer survival in Scotland, focusing on early detection. We are interested in what happened between the years 2011 (pre- implementation) and 2015 (implementation period).

DCE strategies may have influenced your work in different ways; you may also have been involved in developing them. DCE targeted primary care, secondary care and the general public through:

- **Public Awareness and Behaviour Influencing Strategy:** Awareness campaigns for the public about cancer symptoms/signs, and screening – TV, radio, press, roadshows, etc.
- **Primary Care Cancer Symptom Management and Referral Strategy:** Educational sessions for health care professionals and review of urgent referral guidelines for suspected cancer
- **Strategy for Managing Demand for Cancer Screening and Diagnostics:** Additional funding for territorial Health Boards to manage increasing demand for diagnostics
- **Performance Management Strategy:** HEAT target (25% increase in cancers diagnosed at Stage 1) and an sGMS Contract Bowel Screening Initiative (awarded the equivalent of 6 Quality and Outcomes Framework (QOF) points for reduction in bowel screening non-participation)

**Q1. Please choose ONE option:** ** Required*
Eligibility question

- ○ Detect Cancer Early influenced my daily work during 2011-2015 AND/OR I did help develop/implement one or more of its activities
- ○ Detect Cancer Early did NOT influence my daily work during 2011-2015 AND I did NOT help develop/implement one or more of its activities

### Information and consent page

You are being invited to take part in a research study. It is up to you to decide whether or not to take part.

**Note:** This is an abbreviated version of the information sheet; you can access the full version here.

This questionnaire was developed by researchers (Prof David Weller, Dr Christine Campbell and Natalia Calanzani) at the University of Edinburgh (UoE) as part of a process evaluation of Detect Cancer Early (DCE). The study has been reviewed and approved by the Usher Research Ethics Group at the UoE. The evaluation is funded by the Scottish Government and carried out independently by theUoE.

This process evaluation aims to understand what happened when DCE and its different components were implemented. You have received an anonymous link to access this survey; the organisation that sent you the link will not know whether you decided to take part or not.

If you decide to take part, you can still withdraw before submitting your answers or up to four weeks after submission, provided that you contact us quoting the completion receipt number you will be given at the end of the survey. The receipt number is required as the survey is anonymised.

Data will be analysed by researchers at the UoE; comments will be anonymised. Results will be published in a report, peer-reviewed journals and a PhD thesis. Data may be stored in a secure data repository if required by journals, and reused by other researchers at the UoE.

Contact the research team (Natalia.Calanzani@ed.ac.uk; Tel 0131 650 3818, or Christine.Campbell@ed.ac.uk , Tel 0131 650 9252) if you would like more information. If you have any concerns or complaints about this research, please contact Prof Sarah Cunningham Burley, Dean of Molecular, Genetic and Population Health Sciences [sarah.c.burley@ed.ac.uk; Tel 0131 650 3217].

The survey is expected to take 15-20 minutes to complete. Please skip sections which are not relevant to you.

If you agree to take part, please tick the box below to confirm that you wish to do so.

**Q2. Informed Consent - please choose ONE option:** **Required*
Informed consent

- ○ I have read the information above AND I agree to take part in this survey
- ○ I do not agree to take part in this survey

### Part 1. DCE and your work

We will ask about your experience with DCE and your views about how it may have influenced your work. The first questions will be about DCE in general, then we will ask specific questions about each of DCE strategies.

Unless otherwise specified, please consider the events happening between 2011 and 2015 when answering the questions.

There are no right or wrong answers, and not having an opinion about a question is acceptable. There is also space if you wish to write any comments.

## The DCE Programme

**Q3. Were you informed about the DCE programme before it was implemented in 2012?** ***Required***
Assumption 2

- ○ Yes, Iwas sufficiently informed about DCE
- ○ Yes, but I would have liked to have had more information
- ○ No, Iwas not informed about it
- ○ Other

**Q4. Were you involved in developing or refining DCE or any of its strategies?** This could have happened by taking part in DCE meetings, giving feedback on the implementation plan, on the urgent referral guidelines for suspected cancer, etc. ** Required.*
Assumption 2

- ○ Yes
- ○ No, but I would have liked to have had an input
- ○ No, and I was happy with that
- ○ Other

**Q5.** If you wish, you can use the box below to comment on your answers to the questions above. *Optional*
General feedback

**Q6.** Please indicate your level of agreement or disagreement with the statements below. There are seven possible options (from strongly disagree to strongly agree). You can also choose DK (I don't know) or N/A (not applicable) if appropriate.

| | ** Required* | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q6.1.a** DCE was appropriate to promote early detection<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q6.2.a** The benefits brought by DCE outweighed the time and effort required to work towards its aims<br>General feedback | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

## The next questions are about the role of DCE in your daily work.

**Q7.** Please indicate your level of agreement or disagreement with the statements below.

| | ** Required* | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q7.1.a** It was part of my job to be involved in DCE<br>Mechanism 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q7.2.a** I had flexibility to make changes in order to meet DCE aims<br>Assumption 4 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q7.3.a** There was enough time to engage with DCE and its strategies<br>Assumption 3 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q8. Did the DCE programme increase demand for the services you provided to patients?** *Required
Mechanism 3

- Yes
- No
- Other
- I don't know
- Not applicable

**Q9. If you said yes to the question above, did the increased demand drive the development of local initiatives to detect cancer early?** *Optional*
Mechanism 3

- Yes
- No
- Other
- I don't know
- Not applicable

**Q10. You can use this space to write comments about any of the questions above.** *Optional*
General feedback

**The next questions refer to your views about DCE from the year 2015 onwards.**

**Q11.** Please indicate your level of agreement or disagreement with the statements below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| **Q11.1.a** I support continuation of DCE<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q11.1.b** My local team supports continuation of DCE<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q12. You can use this space to write any comments about this section.** *Optional*
General Feedback

## Strategy 1: Public Awareness and Behaviour Influencing

The Public Awareness and Behaviour Influencing Strategy consisted of awareness campaigns for the public, engagement with the public, partnerships with public relations and private organisations, among other activities to increase public awareness. For example, there were campaigns for bowel, breast and lung cancer, in addition to the "wee c" and "#getchecked" campaigns.

**Q13.** If this strategy is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:** * *Required*
Filter question (skip function)

- This strategy influenced my daily work AND/OR I helped to develop/implement it
- This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Public awareness and behaviour influencing

**Q14. Were you informed about the DCE campaigns before they were launched?** *Required*
Assumption 2

- Yes, I was sufficiently informed about the campaigns
- Yes, but I would have liked to have had more information
- No, I was not informed aboutthem
- Other

Q14.a. If you wish, you can use the box below to comment on your answer. *Optional*
General feedback

Q15. Please indicate your level of agreement or disagreement with the statement below.

| | * Required | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
| Q15.1.a Public awareness campaigns were an appropriate strategy to promote early detection<br>Assumption 1 | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q16. Did this strategy increase demand for the services you provided to patients?** ***Required***
Mechanism 3

- Yes
- No
- Other
- I don't know
- Not applicable

**Q17. You can use this space to write any comments about this section.** *Optional*
General feedback

## Strategy 2: Symptom Management and Referral

The Primary Care Cancer Symptom Management and Referral Strategy consisted of education sessions for health care professionals, in addition to updating the urgent referral guidelines for suspected cancer.

**First, we will ask a few questions about the education sessions for health care professionals.**

Q18. Ifthe education sessions are not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:*** *Required*
Filter question (skip function)

- This strategy influenced my daily work AND/OR I helped to develop/implement it
- This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Symptom Management and Referral: Education Sessions

**Q19. Were you informed about the education sessions before they commenced?** *Required*
Assumption 2

- Yes, I was sufficiently informed about the sessions
- Yes, but I would have liked to have had more information
- No, I was not informed about them
- Other

Q19.a If you wish, you can use the box below to comment on your answer. *Optional*
General feedback

**Q20.** Please indicate your level of agreement or disagreement with the statements below.

** Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q20.1.a** The education sessions were an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q20.2.a** It was difficult to integrate the education sessions with my usual work **Assumption 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| Q20.3.a I had enough time to attend the education sessions **Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q21. You can use this space to write comments about any of the questions above.** *Optional*
**General feedback**

## Symptom Management and Referral: Urgent Referral Guidelines for Suspected Cancer

**Now we will ask some questions about the updated urgent referral guidelines for suspected cancer.**

**Q22.** If the referral guidelines are not relevant to your work, you will be able to go to a different section.
**Please choose ONE option:** ** Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Symptom Management and Referral: Urgent Referral Guidelines for Suspected Cancer

**Q23. Were you informed about the work being carried out to update the guidelines before they were published?** ** Required*
**Assumption 2**

- ○ Yes, I was sufficiently informed about the work
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q23.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q24.** Please indicate your level of agreement or disagreement with the statement below.

** Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q24.1.a** The updated guidelines were an appropriate strategy to promote early detection<br>**Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q25. Did the updated referral guidelines increase demand for the services you provided** to patients? ***Required***
**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q26. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Strategy 3: Managing demand for cancer screening and diagnosis

The Strategy for Managing Demand for Cancer Screening and Diagnostics consisted of providing additional funding to territorial Health Boards so this could be invested to improve capacity.

**Q27.** If this strategy is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:** ** Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Managing demand for cancer screening and diagnostics

**Q28. Were you informed about the additional funding before it became available?** *Required*
**Assumption 2**

- ○ Yes, I was sufficiently informed about the funding
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q28.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

Q29. Please indicate your level of agreement or disagreement with the statements below:

*Required

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q29.1.a** Providing extra funding was an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.2.a** I was confident that my team would be able to manage demand for screening and diagnostics when I was informed about the funding **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.3.a** We had enough time to plan how to use the funding **Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.4.a** Primary and secondary care communicated well with each other when planning how to use the funding **Assumption 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.5.a** Additional funding resulted in more equipment for diagnosis **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q29.6.a** Additional funding resulted in more workforce for diagnosis **Mechanism 2** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q30. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Strategy 4: Performance Management

The Performance Management Strategy consisted of specific performance targets. There were HEAT targets for cancers diagnosed at Stage 1, and a bowel screening initiative awarding the equivalent of 6 QOF points for reduction in bowel screening non-response.

**First, we will ask a few questions about the HEAT targets.**

**Q31.** If the HEAT targets are not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option:*** *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Performance Management: the HEAT targets

**Q32. Were you informed about the HEAT targets before they were launched? *Required**
**Assumption 2**

- ○ Yes, I was sufficiently informed about these HEAT targets
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about them
- ○ Other

**Q32.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q33.** Please indicate your level of agreement or disagreement with the statements below.

*Required

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q33.1.a** HEAT targets were an appropriate strategy to promote early detection **Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.2.a** I was confident in my ability to meet HEAT targets **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.3.a** It was difficult to integrate meeting HEAT targets with my usual work **Assumption 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.4.a** HEAT targets pressured our team to act **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q33.5.a** HEAT targets worked as a reminder for where our efforts should be focused **Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**Q34. You can use this space to write comments about any of the questions above.**
*Optional*
**General feedback**

## Performance Management: the Bowel Screening Initiative

**Now, we will ask you some questions about the bowel screening initiative that awarded QOF points for reduction in bowel screening non-participation.**

**Q35.** If the Bowel Screening Initiative is not relevant to you or your work, you will be able to go to a different section. **Please choose ONE option: *** *Required*
**Filter question (skip function)**

- ○ This strategy influenced my daily work AND/OR I helped to develop/implement it
- ○ This strategy did NOT influence my daily work and I did NOT help to develop/implement it

## Performance Management: the Bowel Screening Initiative

**Q36. Were you informed about the bowel screening initiative before it was launched?** *Required*
**Assumption 2**

- ○ Yes, I was sufficiently informed about the bowel screening initiative
- ○ Yes, but I would have liked to have had more information
- ○ No, I was not informed about it
- ○ Other

**Q36.a** If you wish, you can use the box below to comment on your answer. *Optional*
**General feedback**

**Q37.** Please indicate your level of agreement or disagreement with the statements below.

** Required*

| | 1 - Strongly disagree | 2 | 3 | 4 | 5 | 6 | 7 - Strongly agree | DK | N/A |
|---|---|---|---|---|---|---|---|---|---|
| **Q37.1.a** The bowel screening initiative was an appropriate strategy to promote early detection<br>**Assumption 1** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.2.a** I was confident in my ability to be awarded the QOF points<br>**Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.3.a** It was difficult to integrate the bowel screening initiative with my usual work<br>**Assumption 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.4.a** My team had enough time to reach non- responders to bowel screening<br>**Assumption 3** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.5.a** The bowel screening initiative pressured our team to act<br>**Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Q37.6.a** The bowel screening initiative worked as a reminder for where our efforts should be focused<br>**Mechanism 4** | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Q38. Did the bowel screening initiative increase demand for the services you provided to patients?
***Required***
**Mechanism 3**

- ○ Yes
- ○ No
- ○ Other
- ○ I don't know
- ○ Not applicable

**Q39. You can use this space to write any comments about this section.** *Optional*
**General feedback**

## Part 2. Please tell us a bit about yourself

**We have reached the last part of the questionnaire. Here we will ask a few questions about yourself.**

**Q40. Would you describe yourself as: *** *Required*
**Socio-demographic information**

- ○ Male
- ○ Female
- ○ Other (please specify)
- ○ I prefer not to say

**Q40.a** Please use this box if you wish to specify any answers: *Optional*
**Socio-demographic information**

Socio-demographic information

Q42. **What was your profession from 2011 until 2015?** *You can tick more than one answer or choose "Other" if appropriate.* *Required

Socio-demographic information

- ☐ Allied Health Professionals, Healthcare Scientists and Scientific & Technical staff (please specify)
- ☐ Medical staff (please specify)
- ☐ Registered nurse (please specify)
- ☐ Other nurses or Healthcare Assistants (please specify)
- ☐ Public Health / Health Improvement (please specify)
- ☐ Commissioning managers / support staff (please specify)
- ☐ Wider Healthcare Team (please specify)
- ☐ General managers (please specify)
- ☐ Charity Worker (please specify)
- ☐ Other (s) (please specify)
- ☐ I prefer not to say

Q42.a Please use this box if you wish to specify any answers: *Optional*

Socio-demographic information

Q43. **Does your work focus on a specific cancer type (e.g. breast, lung, bowel cancer)?** * ***Required***

Socio-demographic information

- ○ Yes (please specify)
- ○ No, my work includes more than one cancer type
- ○ Not applicable

Socio-demographic information

Q44. Still thinking of the 2011-2015 period, please write down the years DCE was relevant to your work. *For example, from 2012 to 2014.* *Optional*

Socio-demographic information

Q45. **In which territorial Health Board do you work?** *You can tick more than one answer or choose "Other" if appropriate.* * *Required*

Socio-demographic information

- ☐ Ayrshire & Arran
- ☐ Borders
- ☐ Dumfries & Galloway
- ☐ Fife
- ☐ Forth Valley
- ☐ Grampian
- ☐ Greater Glasgow & Clyde
- ☐ Highlands
- ☐ Lanarkshire
- ☐ Lothian
- ☐ Orkney
- ☐ Shetland
- ☐ Tayside
- ☐ Western Isles
- ☐ Whole of Scotland
- ☐ Other (please specify)
- ☐ I prefer not to say

Socio-demographic information

Q46. Which best describes the area where you work? *Required*
Socio-demographic information

**Drop-down menu)**
Large urban areas (Settlements of over 125,000 people) Other urban areas (Settlements of 10,000 to 125,000 people)
Accessible small towns (Settlements of between 3,000 and 10,000 people, and within a 30-minute drive time of a Settlement of 10,000 ormore)
Remote small towns (Settlements of between 3,000 and 10,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more)
Accessible rural areas (Areas with a population of less than 3,000 people, and within a 30-minute drive time of a Settlement of 10,000 or more)
Remote rural areas (Areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a Settlement of 10,000 or more)
Other (please specify)
I prefer not tosay

Q46.a Please use this box if you wish to specify any answers *Optional*
Socio-demographic information

Q47. **Which best describes your workplace?** *You can tick more than one answer or choose "Other" if appropriate.* * *Required*
Socio-demographic information

- ☐ Primary Care practice
- ☐ Hospital (please specify area/Department)
- ☐ Diagnostic Centre, but not in a hospital
- ☐ Laboratory, but not in a hospital
- ☐ Cancer Charity (if you wish, please specify which one)
- ☐ Scottish Government
- ☐ Other (please specify)
- ☐ I prefer not tosay

Socio-demographic information

## Just a couple more things before we finish....

Q48. If you wish, please use this space to write your views about what worked well and what did not work so well in the programme. *Optional*
General feedback

Q49. If you wish, please let us know your views on barriers/facilitators to DCE success. These could be specific populations, financial issues, regional characteristics, or anything else you find relevant. *Optional*
Barriers and facilitators

Q50. **Finally, if we missed any issues you wished to talk about, please let us know below.** *Optional*
General feedback

If you would like to receive a summary of the study results, please add a contact email address below (we will not be able to contact you without this). Alternatively, please contact Natalia (Natalia.Calanzani@ed.ac.uk) at any time to request this. *Optional*

**Ethics and dissemination**

Thank you very much for your contribution.

If you have any questions about the survey, please contact Natalia Calanzani, the PhD researcher at: Natalia.Calanzani@ed.ac.uk (Tel 0131 650 3818). You can also reach her at: University of Edinburgh. Room 123, Doorway 1. Medical Quad, Teviot Place. Edinburgh EH8 9AG

Redirection page
(when potential participants were not eligible or did not consent to take part)

# Process evaluation of the Detect Cancer Early Programme

Thank you for considering taking part in the study.

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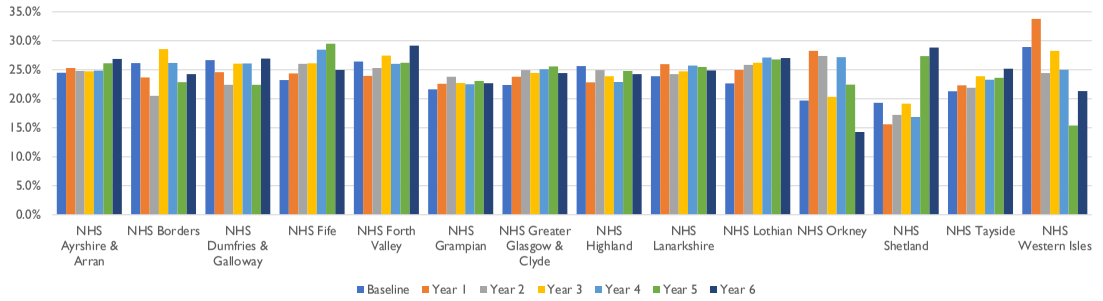
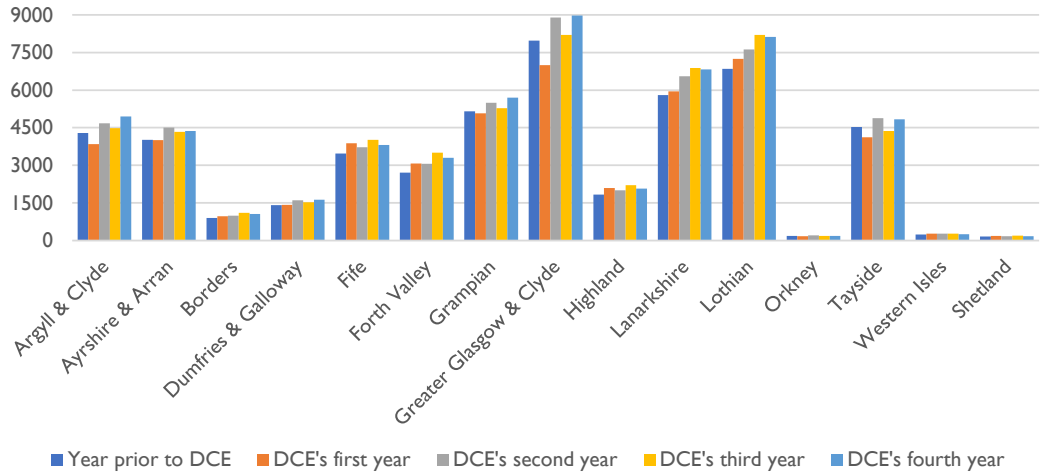
If you have any questions or comments about the study, please contact natalia.calanzani@ed.ac.uk (phone 0131 650 3818), the PhD student carrying out this research at the University of Edinburgh.

# Appendix 8. Proportion of cancers diagnosed at Stage 1 across territorial Health Boards and % change (breast, colorectal and lung combined) over time




| Territorial Health Boards | Baseline N (%) | Year 1 N (%) | % change | Year 2 N (%) | % change | Year 3 N (%) | % change | Year 4 N (%) | % change | Year 5 N (%) | % change | Year 6 N (%) | % change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NHS Ayrshire & Arran | 448 (24.5) | 470 (25.3) | 3.3% | 480 (24.8) | 1.2% | 490 (24.7) | 0.9% | 484 (24.9) | 1.5% | 496 (26.1) | 6.6% | 521 (26.9) | 9.8% |
| NHS Borders | 157 (26.2) | 130 (23.7) | -9.5% | 103 (20.5) | -21.6% | 164 (28.6) | 9.2% | 139 (26.2) | 0.0% | 115 (22.9) | -12.6% | 147 (24.3) | -7.3% |
| NHS Dumfries & Galloway | 209 (26.7) | 191 (24.6) | -7.8% | 160 (22.4) | -15.9% | 184 (26.1) | -2.2% | 192 (26.1) | -2.1% | 154 (22.4) | -15.9% | 185 (26.9) | 1.0% |
| NHS Fife | 386 (23.2) | 420 (244) | 4.9% | 451 (26.0) | 12.1% | 456 (26.1) | 12.5% | 498 (28.5) | 22.7% | 514 (29.5) | 27.0% | 437 (25.0) | 7.6% |
| NHS Forth Valley | 336 (26.4) | 305 (23.9) | -9.4% | 336 (25.3) | -4.3% | 374 (27.4) | 3.8% | 332 (26.0) | -1.5% | 319 (26.2) | -0.8% | 379 (29.2) | 10.4% |
| NHS Grampian | 468 (21.6) | 494 (22.6) | 4.5% | 513 (23.8) | 10.0% | 503 (22.7) | 5.0% | 514 (22.5) | 4.1% | 533 (23.1) | 6.6% | 538 (22.7) | 4.9% |
| NHS Greater Glasgow & Clyde | 1298 (22.4) | 1462 (23.8) | 6.2% | 1538 (24.9) | 11.3% | 1460 (24.5) | 9.3% | 1465 (25.1) | 12.1% | 1429 (25.6) | 14.2% | 1311 (24.4) | 9.1% |
| NHS Highland | 375 (25.6) | 346 (22.8) | -10.9% | 406 (24.9) | -2.7% | 349 (23.9) | -6.7% | 344 (22.9) | -10.7% | 404 (24.8) | -3.2% | 354 (24.3) | -5.3% |
| NHS Lanarkshire | 614 (23.9) | 695 (26.0) | 8.8% | 646 (24.3) | 1.6% | 706 (24.7) | 3.6% | 771 (25.7) | 7.7% | 758 (25.5) | 6.7% | 746 (24.9) | 4.2% |
| NHS Lothian | 805 (22.7) | 929 (25.0) | 10.2% | 961 (25.9) | 14.1% | 971 (26.2) | 15.8% | 1002 (27.1) | 19.8% | 944 (26.8) | 18.3% | 942 (27.0) | 19.3% |
| NHS Orkney | 13 (19.7) | 26 (28.3) | 43.5% | 23 (27.4) | 39.0% | 12 (20.3) | 3.3% | 25 (27.2) | 38.0% | 22 (22.4) | 14.0% | 9 (14.3) | -27.5% |
| NHS Shetland | 22(19.3) | 17 (15.6) | -19.2% | 21 (17.2) | -10.8% | 23 (19.2) | -0.7% | 15 (16.9) | -12.7% | 32 (27.4) | 41.7% | 32 (28.8) | 49.4% |
| NHS Tayside | 404 (21.3) | 410 (22.3) | 4.9% | 404 (21.9) | 2.9% | 465 (23.9) | 12.3% | 456 (23.3) | 9.4% | 469 (23.6) | 10.9% | 499 (25.2) | 18.4% |
| NHS Western Isles | 46(28.9) | 51 (33.8) | 16.7% | 480 (24.8) | -15.6% | 41 (28.3) | -2.3% | 35 (25.0) | -13.6% | 18 (15.4) | -46.8% | 29 (21.3) | -26.3% |

# Appendix 9. Requests for replacement bowel screening kits across territorial Health Boards and % change over time




| Territorial Health Boards | Year prior to DCE | DCE's first year | % change | DCE's second year | % change | DCE's third year | % change | DCE's fourth year | % change |
|---|---|---|---|---|---|---|---|---|---|
| NHS Argyll & Clyde | 4285 | 3844 | -10.3% | 4679 | 9.2% | 4485 | 4.7% | 4947 | 15.4% |
| NHS Ayrshire & Arran | 4019 | 4001 | -0.4% | 4500 | 12.0% | 4335 | 7.9% | 4369 | 8.7% |
| NHS Borders | 902 | 966 | 7.1% | 994 | 10.2% | 1110 | 23.1% | 1057 | 17.2% |
| NHS Dumfries & Galloway | 1415 | 1423 | 0.6% | 1601 | 13.1% | 1529 | 8.1% | 1632 | 15.3% |
| NHS Fife | 3476 | 3882 | 11.7% | 3726 | 7.2% | 4011 | 15.4% | 3806 | 9.5% |
| NHS Forth Valley | 2714 | 3075 | 13.3% | 3063 | 12.9% | 3506 | 29.2% | 3301 | 21.6% |
| NHS Grampian | 5154 | 5076 | -1.5% | 5499 | 6.7% | 5274 | 2.3% | 5702 | 10.6% |
| NHS Greater Glasgow & Clyde | 7971 | 6991 | -12.3% | 8891 | 11.5% | 8201 | 2.9% | 8972 | 12.6% |
| NHS Highland | 1828 | 2100 | 14.9% | 2009 | 9.9% | 2209 | 20.8% | 2072 | 13.3% |
| NHS Lanarkshire | 5799 | 5948 | 2.6% | 6548 | 12.9% | 6887 | 18.8% | 6827 | 17.7% |
| NHS Lothian | 6848 | 7244 | 5.8% | 7626 | 11.4% | 8200 | 19.7% | 8120 | 18.6% |
| NHS Orkney | 182 | 170 | -6.6% | 205 | 12.6% | 181 | -0.5% | 190 | 4.4% |
| NHS Tayside | 4527 | 4123 | -8.9% | 4881 | 7.8% | 4367 | -3.5% | 4835 | 6.8% |
| NHS Western Isles | 246 | 276 | 12.2% | 272 | 10.6% | 274 | 11.4% | 252 | 2.4% |
| Shetland NHS Board | 157 | 183 | 16.6% | 171 | 8.9% | 195 | 24.2% | 176 | 12.1% |

Source: Customised data provided by the Scottish Bowel Screening Centre in Dundee. Data refers only to requested kits that were completed, returned to the Bowel Screening Centre and had a valid result. Hence, data underestimates the number of requested kits as not everyone who requests one completes it. NHS Argyll & Clyde was dissolved in 2006 and incorporated by NHS Highland and NHS Greater Glasgow & Clyde. To avoid misplacing requested kits, numbers are shown as in the original data source. Cumbria and Northumbria Boards were included in the original data source but are not shown here due to small numbers (<5 per year in each Board). Numbers for both areas were included in Figure 14 reporting on overall requested and returned kits.

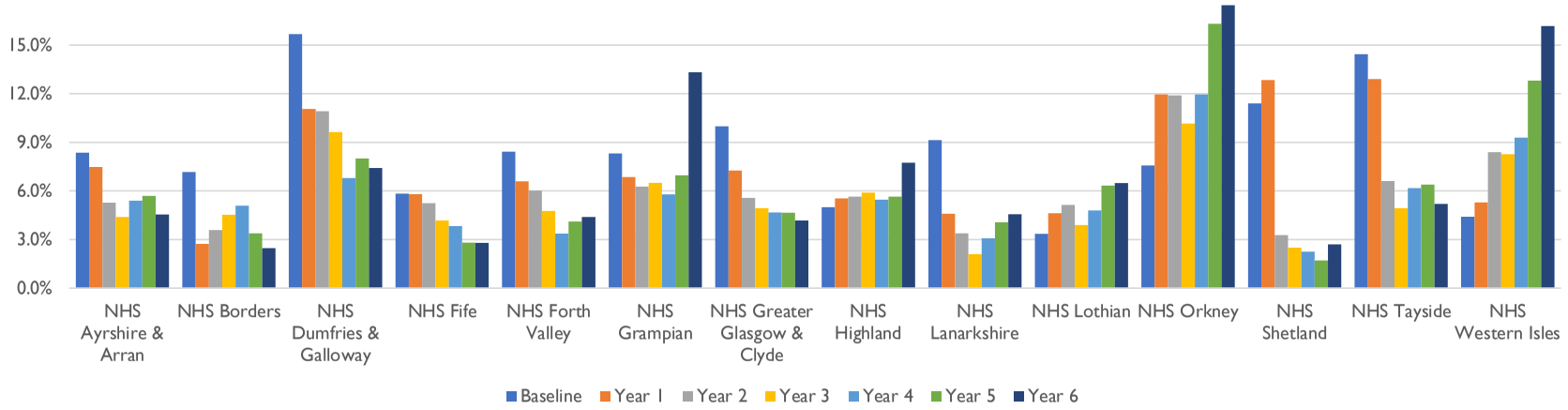
# Appendix 10. Challenges faced and strategies developed by territorial Health Boards

| Health Board | Described challenges and strategies to overcome them |
|---|---|
| NHS Ayrshire & Arran | • **Challenges:** being able to accurately plan for the likely impact of campaigns, engage with hard to reach groups, and ensure enough diagnostic capacity (including being able to recruit diagnostic staff such as Radiologists). Over time, another challenge referred to shortfall in funding and managing increasing demand for urgent referrals.<br>• **Strategies:** assumptions regarding impact were compared with other Health Boards and advice was taken from the Government; short-term initiatives were carefully planned to avoid issues with timing of campaigns and funding allocation; urgent referrals were prioritised, additional sessions were implemented, clinics and endoscopy lists were added, and the booking system for breast patients was changed. Non-recurring funding was also identified. |
| NHS Borders | • **Challenges:** establish baseline data to quantify the impact of campaigns; develop new governance structure to oversee DCE areas; agree on a sustainable approach to increase bowel screening uptake amongst the most deprived and support GP practices to promote this; embed knowledge and awareness of early detection and risk factors into routine processes and team assessments; and learn about DCE impact elsewhere.<br>• **Strategies:** a data specification report was produced to be populated by monthly data submissions, a project group and a multidisciplinary group were established to do better reporting and better reach the most deprived groups; short-term funding was used to hire an advisor to work with hard to reach groups; local radio channels were used for early detection messages; collaborations with local initiatives and businesses were developed; and a bowel screening survey was carried out with staff. Events were held in GP practices in order to provide support, especially in more deprived areas. |
| NHS Dumfries and Galloway | • **Challenges:** creating a business case for construction of a new hospital while trying to ensure coordinated spending and plans for service design; not having the national television campaign aired in the region and not being included in the roll out of national communications activity for breast cancer; lack of clarity regarding recurring funding; challenges to recruit staff; and dealing with QPIs.<br>• **Strategies:** some of the funding was held; local advertising campaigns were launched and there was close communication with DCE in order not to commit funding in areas where it could not be sustained; capacity was increased in Head and Neck; plans were developed to build capacity for Endoscopy Nursing; and ongoing support was provided to the Cancer Audit Team. |
| NHS Fife | • **Challenges:** recruitment, uncertainty about demand for secondary care and increased demand in primary care.<br>• **Strategies:** more widespread recruitment and funding allocation to meet demand |
| NHS Forth Valley | • **Challenges:** large increase in referrals to breast services after the campaign that exceeded expectations; being unable to appoint a Consultant Breast Surgeon; challenges to provide additional ultrasound, endoscopy, radiology, and laboratory capacity; and costs that were higher than the allocated funding.<br>• **Strategies:** additional OPD clinics were set up in the short-to-medium term, a locum Consultant Breast Surgeon was hired; a Consultant Breast Surgeon and Consultant Radiologists were shared with another Health Board (a Breast Surgeon was appointed later) and there was additional endoscopy capacity. The breast services were redesigned (with more one-stop clinics for urgent referrals and attempts to expedite routine referrals) |
| NHS Grampian | • **Challenges:** increase in referrals from breast and bowel campaigns, implementation of QPIs, challenges in recruiting staff and general workforce capacity issues.<br>• **Strategies:** adopting a MCN approach, reviewing resources and processes before deciding on funding, and carrying forward funding so allocations could be made according to priorities |
| NHS Greater Glasgow & Clyde | • **Challenges:** financial risks of not knowing revenue allocation for the following year; decrease in funds over time; lack of early clarification on baseline data (HEAT); fluctuations on early stage presentations after the breast campaign; unpredictable increase in demand due to campaigns; and recurring issues with breast capacity<br>• **Strategies:** no recurring allocations were deployed; internal estimations were made to define a baseline, non-recurring sessional staff was established to accommodate demand peaks in breast and colorectal services; the Board's financial profile was revised; assessments of staging data were made; and surgical and diagnostic plans for breast cancer were designed to deal with increase in demand. A LEAN redesign was also rescheduled. |
| NHS Highland | • **Challenges:** having to defer decisions due to uncertainty regarding recurring money and impact upon diagnostic services.<br>• **Strategies:** funding was carried forward to allow a more strategic approach in terms of funding allocation based on both local and national priorities |

| Health Board | Described challenges and strategies to overcome them (continued) |
|---|---|
| NHS Lanarkshire | • **Challenges:** "patchy" early communication that affected ability to plan; not being able to recruit radiologists due to national shortages; challenges to implement a CT colonography pathway; and having to deal with increasing demand for this and the EBUS service<br>• **Strategies:** effective communication was established with DCE to be informed about upcoming campaigns and plan for their work; job applicants were actively targeted; the Clinical Director and the Senior Management Team developed a plan to increase the number of sessions worked by the existing consultant radiologists; discussions took place within Radiology & Colorectal teams to agree on an operational pathway; it was agreed to test CT colonography before roll out; and demand was reviewed in order to provide additional endoscopic capacity and alternatives to diagnostic tests. |
| NHS Lothian | • **Challenges:** establish "an effective programme focus and steering structure"; to respond to the significant increase in demand due to the breast campaign (also to link it with their ongoing work); to predict impact of campaigns; delays in receiving information from non-responders to bowel screening; maintaining the 62-day lung cancer performance<br>• **Strategies:** the Board reviewed the cancer inequalities evidence base, used Information services and obtained input from clinical leads; was involved in the DCE Programme Board and Executive; agreed on an approach to be adopted in order to meet the programme aims; allocated funding for capacity and redesigned the breast service; established a service redesign group; did pathways analyses and estimated impact. There was also close work with national colleagues, the bowel screening centre and the bowel screening coordinator to support pilot practices. |
| NHS Orkney | • **Challenges:** having only one theatre which was also the scoping room; not having all GPs engaged with DCE; targeting individual practices where screening uptake was low; engaging with staff to redesign services; staff changes in small teams impacting on the ability to prioritise DCE<br>• **Strategies:** plans were developed for a separate scoping room, there were conversations with practices that were not engaging and additional work was undertaken on profile uptake by practice; a new population health governance group was set up to discuss uptake and engage with lead clinicians in primary care; there were significant discussions with staff to gain buy-in and work with long standing members of staff to support new and relieved staff. |
| NHS Shetland | • **Challenges:** capturing data for patients seen in NHS Grampian; engaging with clinicians in Grampian; completing capital programme to modernise diagnostics; increasing public awareness (as local data showed that people presented late); creating consistency across primary care services for urgent referrals; and linking health promotion activities to DCE statistics and outcomes<br>• **Strategies:** further engagement with NHS Grampian; purchase of video conferencing equipment; funding was used to assist with modernising scopes; the Board worked across agencies to ensure that patients had access to resources and advice; and developed a long-term goal to increase awareness and seek help early. GPs also received training about urgent referral pathways. |
| NHS Tayside | • **Challenges:** obtain data for baseline performance and be able to attribute outcomes to the DCE programme; delays in appointing staff due to recruitment and workforce issues; achieving consensus on resource allocation and redesigning the financial plan when funding allocation was reduced.<br>• **Strategies:** working with the NHS Tayside Cancer Information Team and DCE to clarify definite resource allocation; progressing through the Executive Management team and administrative steps as promptly as possible; and developing shared understanding through consultation and discussion. |
| NHS Western Isles | • **Challenges:** engaging with rural communities, tackling low bowel screening uptake among males; and challenges in demonstrating changes for breast screening due to the three-year rolling geographic programme<br>• **Strategies:** issues were tackled by contacting existing cancer support groups, setting up stalls at community events, disseminating information in community halls, GP practices and workplaces; using survival stories to engage with the public and targeting men through local networks. |

Sources: Annual reports submitted to DCE by territorial Health Boards (2012/2013; 2013/2014 and 2014/2015), and summaries of reports prepared by the DCE team

# Appendix 11. Proportion of cancers recorded with unknown stages across territorial Health Boards and % change (breast, colorectal and lung combined) over time




| Territorial Health Boards | Baseline N (%) | Year 1 N (%) | % change | Year 2 N (%) | % change | Year 3 N (%) | % change | Year 4 N (%) | % change | Year 5 N (%) | % change | Year 6 N (%) | % change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| NHS Ayrshire & Arran | 153 (8.4) | 139 (75) | -10.5% | 102 (5.3) | -37.0% | 87 (4.4) | -47.5% | 105 (5.4) | -35.5% | 108 (5.7) | -32.0% | 88 (4.5) | -45.7% |
| NHS Borders | 43 (7.2) | 15 (2.7) | -61.9% | 18 (3.6) | -50.0% | 26 (4.5) | -36.8% | 27 (5.1) | -29.1% | 17 (3.4) | -52.8% | 15 (2.5) | -65.5% |
| NHS Dumfries & Galloway | 123 (15.7) | 86 (11.1) | -29.5% | 78 (10.9) | -30.4% | 68 (9.6) | -38.6% | 50 (6.8) | -56.7% | 55 (8.0) | -49.0% | 51 (7.4) | -52.7% |
| NHS Fife | 97 (5.8) | 100 (5.8) | -0.6% | 91 (5.3) | -10.0% | 73 (4.2) | -28.4% | 67 (3.8) | -34.3% | 49 (2.8) | -51.8% | 49 (2.8) | -52.0% |
| NHS Forth Valley | 107 (8.4) | 84 (6.6) | -21.7% | 80 (6.0) | -28.4% | 65 (4.8) | -43.4% | 43 (3.4) | -59.9% | 50 (4.1) | -51.2% | 57 (4.4) | -47.9% |
| NHS Grampian | 180 (8.3) | 150 (6.9) | -17.5% | 135 (6.3) | -24.8% | 144 (6.5) | -21.9% | 132 (5.8) | -30.5% | 161 (7.0) | -16.3% | 316 (13.3) | 60.2% |
| NHS Greater Glasgow & Clyde | 579 (10.0) | 446 (7.3) | -27.4% | 344 (5.6) | -44.2% | 294 (4.9) | -50.7% | 273 (4.7) | -53.2% | 260 (4.7) | -53.4% | 224 (4.2) | -58.2% |
| NHS Highland | 73 (5.0) | 84 (5.5) | 11.1% | 92 (5.7) | 13.3% | 86 (5.9) | 18.1% | 82 (5.5) | 9.3% | 92 (5.6) | 13.2% | 113 (7.7) | 55.2% |
| NHS Lanarkshire | 235 (9.1) | 123 (4.6) | -49.7% | 90 (3.4) | -63.0% | 60 (2.1) | -77.0% | 92 (3.1) | -66.4% | 121 (4.1) | -55.5% | 137 (4.6) | -50.0% |
| NHS Lothian | 119 (3.3) | 172 (4.6) | 38.1% | 191 (5.1) | 53.5% | 144 (3.9) | 16.1% | 177 (4.8) | 43.1% | 223 (6.3) | 89.0% | 226 (6.5) | 93.6% |
| NHS Orkney | 5 (7.6) | 11 (12.0) | 57.8% | 10 (11.9) | 57.1% | 6 (10.2) | 34.2% | 11 (12.0) | 57.8% | 16 (16.3) | 115.5% | 11 (17.5) | 130.5% |
| NHS Shetland | 13 (11.4) | 14 (12.8) | 12.6% | 4 (3.3) | -71.2% | 3 (2.5) | -78.1% | 2 (2.2) | -80.3% | 2 (1.7) | -85.0% | 3 (2.7) | -76.3% |
| NHS Tayside | 274 (14.4) | 237 (12.9) | -10.6% | 122 (6.6) | -54.2% | 96 (4.9) | -65.8% | 121 (6.2) | -57.2% | 127 (6.4) | -55.7% | 103 (5.2) | -64.0% |
| NHS Western Isles | 7 (4.4) | 8 (5.3) | 20.3% | 11 (8.4) | 90.7% | 12 (8.3) | 88.0% | 13 (9.3) | 110.9% | 15 (12.8) | 191.2% | 22 (16.2) | 267.4% |

Created with data from: ISD Scotland. Detect Cancer Early - Year 6 Staging Data. Available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/data-tables2017.asp?id=2206#2206: ISD Scotland; 2018.

# Appendix 12. Characteristics of stakeholders taking part in the process evaluation

## Interview participants

In order to avoid indirect identification of interview participants, only aggregated data is provided. Twenty-five stakeholders were interviewed between January and June 2018. Fiffteen participants were female and 10 were male. Interviews were carried out face-to-face at the participant's chosen venue (n=16) or over the telephone (n=9).

| Stakeholder groups | Job roles | Territorial Health Boards |
|---|---|---|
| Charities, creative agencies, and marketing research companies | Managers in cancer charities and agencies/marketing research | Nationwide |
| Professionals working in primary and secondary care | GPs and secondary care doctors (Respiratory and Urology) | NHS Ayrshire & Arran<br>NHS Dumfries & Galloway<br>NHS Fife<br>NHS Forth Valley<br>NHS Greater Glasgow & Clyde<br>NHS Lothian |
| Providers of Health Intelligence data | Data manager | Nationwide |
| Stakeholders managing health care services and DCE strategies | Stakeholders managing access, Public Health, imaging, strategy, breast and bowel screening | NHS Ayrshire & Arran<br>NHS Borders<br>NHS Greater Glasgow & Clyde<br>NHS Highland<br>NHS Lanarkshire<br>NHS Lothian<br>NHS Tayside<br>Nationwide |

## Questionnaire participants

Initial invitations to complete the questionnaire were sent on the 8th May 2018, except for invitations sent by SCAN, which were sent on the 11th May 2018 due to operational issues. A reminder was sent on the 22nd May 2018. The questionnaire was available for completion until the 6th July 2018 (inclusive). Fifty-three stakeholders submitted a completed questionnaire.

| Characteristics of questionnaire participants | N (%) |
|---|---|
| **Sex** | |
| Men | 20 (40.8) |
| Women | 29 (59.2) |
| **Total** | **49 (100.0)** |
| **Age** | |
| Mean (SD) | 50.78 (5.66) |
| Age bands | |
| 35-39 | 1 (2.9) |
| 40-44 | 4 (11.8) |
| 45-49 | 8 (23.5) |
| 50-54 | 11 (32.4) |
| 55-59 | 8 (23.5) |
| 60-64 | 2 (5.9) |
| **Total** | **34 (100.0)** |
| **Profession** | |
| Medical – secondary care | 32 (62.7) |
| Medical – primary care | 7 (13.7) |
| Nurse | 6 (11.8) |
| Other | 6 (11.8) |
| **Total** | **51 (100.0)** |
| **Cancer type** | |
| Tumour specific | 39 (75.0) |
| Breast | 18 (46.2) |
| Bowel, anal and/or upper GI | 8 (20.5) |
| Lung | 4 (10.3) |
| Specific tumour type, but not specified | 9 (23.1) |
| More than one tumour type | 13 (25.0) |
| **Total** | **52 (100.0)** |
| **Period programme influenced work** | |
| from pre-implementation to at least the first three years | 14 (42.4) |
| from programme launch to at least the first three years | 11 (33.3) |
| at least 2 years | 4 (12.1) |
| at least one year | 4 (12.1) |
| **Total** | **33 (100.0)** |
| **Territorial Health Board** | |
| NHS Ayrshire & Arran | 9 (17.6) |
| NHS Dumfries & Galloway | 2 (3.9) |
| NHS Fife | 4 (7.8) |
| NHS Forth Valley | 2 (3.9) |
| NHS Greater Glasgow & Clyde | 11 (21.6) |
| NHS Lanarkshire | 3 (5.9) |
| NHS Lothian | 17 (33.3) |
| NHS Tayside | 2 (3.9) |
| Whole of Scotland | 1 (2.0) |
| **Total** | **51 (100.0)** |
| **Urbanisation level** | |
| Large urban areas | 28 (52.8) |
| Other urban areas | 11 (20.8) |
| Accessible small towns | 4 (7.5) |
| Remote rural areas | 2 (3.8) |
| Mix of rural and urban areas | 7 (13.2) |
| Other | 1 (1.9) |
| **Total** | **53 (100.0)** |
| **Workplace** | |
| Hospital | 38 (73.1) |
| Primary Care Practice | 8 (15.4) |
| Diagnostic Centre (not in hospital) | 4 (7.7) |
| Cancer charity | 1 (1.9) |
| Other | 1 (1.9) |
| **Total** | **52 (100.0)** |

Sums may not add up to 100 due to rounding. Missing data: sex (n=4); age (n-=19); profession (n=2); tumour type (n=1); period programme influenced work (n=20); territorial Health Board (n=2); workplace (n=1); other workplace (n=1). Other medical professions included one consultant and one endoscopy lead; fourteen participants chose medical as a profession but did not specify any further. Other professions correspond to two audit staff and four respondents who ticked "other" but did not specify any further. Other urbanisation level (n=1) was not specified by the respondent; other Workplace (n=1) corresponds to "Board wide".

# Appendix 13. Content analysis of open-ended questions in the process evaluation questionnaire

| Themes | N |
|---|---|
| **A1.** Different stakeholders bought into DCE and what it proposed to do | 53 |
| **A2.** There was sufficient targeting/communication about DCE | 41 |
| **A3.** Available resources were sufficient to meet aims | 17 |
| **A4.** Flexibility was permitted when allocating resources (no quotes available) | 0 |
| **M1.** DCE strategies were in line with what the professionals perceived as their role | 2 |
| **M2.** Additional DCE funding resulted in increased physical opportunity | 28 |
| **M3.** Increased demand was a driver for action and created pressure to act | 7 |
| **M4.** Targets helped to focus the mind and increased pressure to act | 5 |
| **Barriers** | |
| NHS challenges (recruitment challenges, stretched resources) | 10 |
| Early detection challenges (overdiagnosis, overtreatment, cancer fear, poor awareness) | 8 |
| Competing responsibilities | 3 |
| **Facilitators** | |
| Consistency in data recording, good quality data and electronic data for bowel screening | 3 |
| Good leadership, management and teamwork | 2 |
| Ability to plan for changes and demand | 2 |
| Having an open, transparent process and 'attempt' to share learning | 1 |
| Having an effective screening method (bowel) | 1 |
| **Unanticipated outcomes** | |
| Negative impact for other patients in need of care and for other performance targets | 14 |
| Inappropriate referrals | 9 |
| Fears of over diagnosing the worried well | 3 |
| Cancers being diagnosed at later stages instead of earlier (due to focus on symptoms) | 2 |
| **References to DCE official outcomes** | |
| Increase in demand and investigations not resulting in more cancers being diagnosed | 14 |
| Not being aware of outcomes, and wishing to know more about them | 10 |
| No perceived positive impact on service provision | 5 |
| **What worked well** | |
| DCE components (positives) | 8 |
| To receive funding and be able to use it according to local plans | 4 |
| **What did not work well** | |
| Impact on service provision and workload (including stress among professionals) | 46 |
| Increasing numbers of worried well seeking reassurance | 17 |
| Limited planning (e.g. not estimating impact nor considering delays in the cancer pathway) | 14 |
| DCE components (negatives) | 12 |
| Having temporary funding | 3 |
| **Recommendations** | |
| Better planning, more time to plan and better communication | 11 |
| Target: tumour types for which campaigns can be more effective and there is no screening; groups at risk (including smokers) and more deprived populations | 8 |
| Focus on breast screening as it is effective; symptoms indicate late disease | 5 |
| Consider different steps in the cancer pathway (e.g. surgery and follow up) as they influence survival, have diagnostic clinics and direct GP access to diagnostics | 4 |
| Review the HEAT targets (e.g. use a QI approach instead) | 3 |
| Have ongoing campaigns instead of short bursts of activity | 2 |
| Other (HP vaccination for anal cancer; more professional education) | 2 |

As a single comment may refer to more than one theme, sums add up to more than 175.
A: assumption; M=mechanism