

**Understanding the influences on cancer symptom
presentation behaviour in the context of socioeconomic
deprivation: development of a targeted cancer awareness
intervention**

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Summary

Inequalities in cancer survival outcomes can partly be explained by prolonged cancer symptom presentation among socioeconomically deprived groups. This PhD aimed to (1) understand the barriers to cancer symptom presentation among low socioeconomic groups and (2) develop a targeted cancer awareness intervention to promote timely symptom presentation.

The COM-B (Capability, Opportunity, Motivation-Behaviour) model was selected to guide understanding of the influences on cancer symptom presentation behaviour. Systematic review and qualitative methods (30 in-depth interviews and six focus groups) were employed to identify the factors influencing symptom presentation. Findings from these studies and a scoping review of cancer awareness interventions were used to inform intervention development, guided by the Behaviour Change Wheel. The intervention was tested for acceptability with two groups of potential users.

The combination of poor cancer symptom knowledge, fearful and fatalistic beliefs about cancer, and barriers such as problems associated with obtaining and accessing a primary care appointment prolonged cancer symptom presentation among low socioeconomic groups. In addition, the wider social and environmental opportunities available to people from low socioeconomic groups including economic hardship and negative experiences of cancer were identified as key influences on behaviour.

An intensive community group based educational session was developed targeted at current or former smokers and family members of smokers, aged 40 years or over from socioeconomically deprived communities. Content was developed to increase cancer symptom knowledge, modify beliefs and enable timely symptom presentation by utilising strong social networks in the community. Findings from user testing confirmed that group education was an acceptable mode of intervention delivery.

Understanding the complex interaction between individual psychological characteristics and the wider environment in which people from low socioeconomic groups live in is essential for modifying cancer symptom presentation behaviour. Community education could be used as a strategy to engage low socioeconomic groups in early cancer detection and warrants further feasibility and pilot testing.

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List of abbreviations

ABACus- Awareness and Beliefs About Cancer study
AMSTAR A Measurement Tool to Assess Systematic Reviews
APEASE- Affordability, Practicability, Effectiveness and Cost-effectiveness, Acceptability, Side-effects/safety, Equity
BCT- Behaviour Change Techniques
BME- Black and ethnic minority groups
CBMSM- Community Based Multi-faceted Social Marketing
CAM- Cancer Awareness Measure
CASP- Critical Appraisal Skills Programme tool
COPD- Chronic Obstructive Pulmonary Disease
CRUK- Cancer Research UK
CSM- Common Sense Model of Illness Self-Regulation
EPPM- Extended Parallel Processing Model
ESA- Employment and Support Allowance
GP- General Practitioner
HBM- The Health Belief Model
I-Interviewer
ICBP- International Cancer Benchmarking Partnership
LDCT- Low Dose Computed Tomography
LSOA- Lower Layer Super Output Areas
MOD- Moderator
MRC- Medical Research Council
MPT- Model of Pathways to Treatment
NAEDI- National Awareness and Early Diagnosis Initiative
NHS- National Health Service
NRES- National Research Ethics Committee
OECD- Organisation for Economic Co-operation and Development
P- Participant
PCT- primary care trust
PICO- Population, Intervention, Comparison, Outcomes
RCT- Randomised Control Trial
SPIDER- Sample, Phenomenon of Interest, Design, Evaluation, Research type
TDF- Theoretical Domains Framework

TPB- The Theory of Planned Behaviour

UK- United Kingdom

US- United States

WIMD- Welsh Index of Multiple Deprivation

2WW- Two Week Wait

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Chapter 1

Introduction

This PhD aims to achieve an in-depth understanding of the barriers to cancer symptom presentation among low socioeconomic groups using qualitative research methods and review methodology. The results will be used to develop a pilot cancer awareness intervention targeted at socioeconomically deprived communities to encourage timely presentation with potential cancer symptoms. The current chapter aims to provide an overview of the context and problem of cancer survival among low socioeconomic groups, and how the need to reduce socioeconomic inequalities in cancer outcomes is reflected in policy and initiatives. Encouraging earlier cancer symptom presentation through interventions will be discussed as a strategy for improving cancer outcomes. The rationale for a shift in focus for the current intervention content from generic cancer to lung cancer will be discussed in relation to changes in public policy. Finally, the aims and objectives of the PhD will be presented.

1.1 Cancer survival in the UK

Overall survival rates for cancer are improving. In the UK, 10 year survival has doubled over the past 40 years and around half of those living in the UK diagnosed with cancer can expect to survive for 10 years or more (Cancer Research UK, 2015a). However, there is large variation across tumour sites, where 10 year survival ranges from 3% in pancreatic cancer to 98% in testicular cancer (Cancer Research UK, 2015a). In addition, when compared with similar countries within Europe, survival rates for cancer have been consistently lower in the UK (Sant *et al*, 2001; Berrino, 2009; Sant *et al*, 2009; Verdecchia *et al*, 2009; Coleman *et al*, 2011; Foot and Harrison, 2011) and may be linked to socioeconomic inequalities in cancer outcomes (Machenbach *et al*, 2003; Sant *et al*, 2003; Rachet *et al*, 2010; Ellis *et al*, 2012; McPhail *et al*, 2015). It has been estimated that around 5000 deaths from cancer annually would be avoided if survival in England was comparable to the European average (Abdel-Rahman *et al*, 2009; Richards, 2009a).

Through earlier diagnosis of cancer, survival outcomes can be improved (McPhail *et al*, 2015). Early detection of cancer can be achieved through screening programmes and prompt symptomatic presentation. Socioeconomic inequalities in cancer screening uptake and the timeliness of presenting with symptoms to a primary care doctor partly explain poorer

cancer survival outcomes among low socioeconomic groups in the UK, with people from socioeconomically deprived groups less likely to engage in screening and/or more likely to prolong symptom presentation (Macleod *et al*, 2009; McPhail *et al*, 2015).

1.2 Socioeconomic inequalities in cancer incidence, survival and mortality

People from low socioeconomic groups are more likely to receive a diagnosis of cancer, are less likely to survive cancer and are more likely to die from cancer compared to those from high socioeconomic groups (National Cancer Intelligence Network, 2014; Welsh Cancer Intelligence and Surveillance Unit, 2014; McPhail *et al*, 2015; Cancer Research UK Statistics, 2015b). Whilst overall survival rates for cancer have improved, the rate of improvement is much faster amongst high socioeconomic groups, and as a consequence cancer survival inequalities are widened (Coleman *et al*, 2004; Lyratzopoulos *et al*, 2010). One, three and five year cancer survival is lowest and mortality is highest in the UK among low socioeconomic groups (Coleman *et al*, 2001; Rachet *et al*, 2010; Moller *et al*, 2012; Cancer Research UK Statistics, 2015b).

The relationship between cancer outcomes and socioeconomic group is likely to reflect more advanced stage disease at diagnosis, where access to curative treatment is limited (Macleod *et al*, 2000; Shack *et al*, 2008a; Lyratzopoulos *et al*, 2013; McPhail *et al*, 2015). This can partly be explained by prolonged cancer symptom presentation (Macleod *et al*, 2009) and a high incidence of smoking-related cancers such as lung or head and neck cancers among low socioeconomic groups (Shack *et al*, 2008b; McDonald *et al*, 2014; Cancer Research UK Statistics, 2015c) which are harder to diagnose in the early stages (Birt *et al*, 2014; Neal *et al*, 2014; Cancer Research UK Statistics, 2015c). These types of cancer have poor survival outcomes, with minimal improvement in survival rates in comparison to other cancer sites such as breast or prostate (Cancer Research UK Statistics, 2015a). Poor outcomes could reflect difficulties in detecting these types of cancer promptly due to vague and non-specific symptoms in the early stages, where individuals may perceive symptoms as not serious and therefore prolong symptom presentation (Birt *et al*, 2014; Neal *et al*, 2014).

If inequalities in cancer outcomes were reduced, overall cancer survival could be improved. By eradicating socioeconomic inequalities at stage of diagnosis, it has been estimated that 5600 patients in the UK annually could be diagnosed with earlier stage disease (Lyratzopoulos *et al*, 2013). Studies suggest that 11% of deaths from common cancer in the

UK could be avoided if 3 year survival in low socioeconomic groups matched that in high socioeconomic groups, accounting for approximately 7122 lives annually (Ellis *et al*, 2012).

1.3 Characteristics of a low socioeconomic group

1.3.1 Low socioeconomic group: a definition

A low socioeconomic group can be defined as referring to individuals within a group or a collective group of individuals, who are socially and economically disadvantaged in relation to others (Kawachi *et al*, 2002). It is common for researchers to use the terms socioeconomic gradient, socioeconomic status or socioeconomic position. Such terms could be perceived as value-laden, therefore throughout this thesis, the terms socioeconomic group or socioeconomically deprived community will be used.

Socioeconomic group can be measured using individual level indicators such as income, educational attainment and occupation, where lower annual income, lower educational attainment and manual or unskilled occupations are defined as representing low socioeconomic groups. Group level indicators such as postcode data can be used to indicate area level deprivation and are frequently used to measure socioeconomic group. There are strengths and limitations associated with the use of group and individual level indicators. Individual level indicators attempt to capture the assets of the individual and are relatively simple to measure (Galobardes *et al*, 2006a). However, some individual level indicators such as occupation or educational attainment are age relevant, where educational attainment level varies with different birth cohorts and an older study population is more likely to be retired, making socioeconomic group classification difficult. In addition, individual level indicators, particularly when measured in isolation, may not accurately represent an individual's current social circumstances (Galobardes *et al*, 2006a). Therefore, it is important to measure multiple individual level indicators to overcome these limitations.

Socioeconomic group level indicators are calculated using aggregated measures such as employment and crime rates in a pre-defined area for a collective group of individuals. These are usually calculated based on the most recent census or similar data available (Galobardes *et al*, 2006b). This can be problematic as the deprivation score assigned to an individual within the area may not fully represent the individual's social circumstances: they

might live in a deprived area as defined by the area level indicator but are not experiencing social or economic hardship, or vice versa. In addition, when the pre-defined area is large, there is potential for misclassification of the particular area (Galobardes *et al*, 2006b). A combination of both individual and group level indicators is likely to overcome some of these issues and ensure a more complete indication of socioeconomic group.

In Wales, postcode data can be used to generate a Welsh Index of Multiple Deprivation (WIMD) score, which is an area level socioeconomic group indicator. Wales has been organised into 1896 Lower Layer Super Output Areas (LSOAs) with approximately 1500 people in each area. Each LSOA was ranked from 1 (the most deprived) to 1896 (the least deprived) (WIMD, 2011). Their WIMD score reflects this, for example a WIMD score of 1 represents the most deprived LSOA in Wales. Scores are calculated based on employment, income, educational attainment, health, crime rates, geographical access to services, housing standards and quality of physical environment within the LSOA (WIMD, 2011).

In an attempt to tackle poverty in Wales, the Welsh Government initiative 'Communities First' was set up. There are 52 Communities First clusters in Wales supporting the most deprived areas in Wales based on WIMD score. This PhD aims to target individuals within a low socioeconomic group defined as an individual living in the most deprived quartile (those with a WIMD score between 1 and 474) and/or those living in a 'Communities First' area. Due to the graded effect of deprivation and its association with cancer survival outcomes, those within a low rather than lower socioeconomic groups were targeted for this PhD in order to ensure that those in the most deprived areas were targeted. A low socioeconomic group is defined as the most deprived quartile, whereas a lower socioeconomic group could be defined as the lowest two quartiles.

1.3.2 The social gradient in health

Health inequalities can be defined as 'uneven distributions of health benefits and disease burdens that are unjust, unfair and avoidable' (Mabhala, 2014). The social gradient in health and health outcomes refers to disparities in health in relation to socioeconomic group, where health decreases with increasing deprivation (Marmot, 2015). Life expectancy is lower, and there is a higher prevalence of obesity and chronic illnesses such as heart disease and diabetes among low socioeconomic groups (Department of Health, 2009; Buck and

Maguire, 2015; Office for National Statistics, 2015). In addition, there is a gradient for perceptions of health, where those from low socioeconomic groups are more likely to self-report poor health (Welsh Health Survey, 2015). Socioeconomic inequalities in cancer outcomes are one example of the social gradient in health.

1.3.3 The social determinants of health

The relationship between socioeconomic group and health is complex, and is likely to reflect a complex interaction between the environment and the individual. There are various factors which can directly and indirectly affect health, which have been termed the social determinants of health.

Lifestyle factors such as smoking, alcohol consumption, poor diet and non-active lifestyles can directly affect health and are more prevalent in low socioeconomic groups (Fone *et al*, 2012; Hiscock *et al*, 2012; Farrell *et al*, 2013; Welsh Health Survey, 2015). People from a low socioeconomic group are more than twice as likely to smoke, are less likely to eat the recommended five pieces of fruit and vegetables per day, and report the highest number of zero active days compared to high socioeconomic groups (Farrell *et al*, 2013; Welsh Health Survey, 2015). One explanation for the high prevalence of smoking and alcohol consumption in low socioeconomic groups is to buffer individuals against the psychosocial stresses of their circumstances created by the environment (Wilkinson, 1997). Feelings of disempowerment as a consequence of a perceived lack of control over daily life are likely to impact health and present as reluctance to engage in healthy behaviours, or increase the likelihood of participating in unhealthy behaviours (Pampel *et al*, 2010). Therefore, it could be argued that health inequalities and the social gradient in health are a consequence of the environment and social conditions in which people live (Marmot, 2010). Whilst lifestyle factors can directly affect health, these are generally a product of the environment and any opportunities afforded to the individual are not always choices made by the individual; instead, in some cases they reflect a lack of availability of resources and opportunities.

According to The Health Map (Barton and Grant 2006; Figure 1.1), a major determinant of health is the wider physical, social and economic environment in which an individual lives. The Health Map takes into account the influence of the immediate environment such as lifestyle and the broader cultural, political and economic factors as determinants of health.

Unemployment, poor housing conditions, lower levels of educational attainment and higher levels of crime are all associated with socioeconomically deprived communities and are likely to influence risk of illness and health outcomes (Acheson, 1997). For example, unemployment or low income restricts the financial resources available to the individual, which can act as a barrier to maintaining a healthy lifestyle due to cost and lack of availability of 'healthier' foods (James *et al*, 1997; Mabhala, 2014). Whilst these factors are important in determining health and cancer outcomes, it is not within the scope of this PhD to explore these, or attempt to change the social determinants of health at these levels. The focus of this PhD will be to understand the influences on cancer symptom presentation behaviour among low socioeconomic groups and to design an intervention to encourage timely cancer symptom presentation at the individual level, whilst being mindful of the broader social determinants.

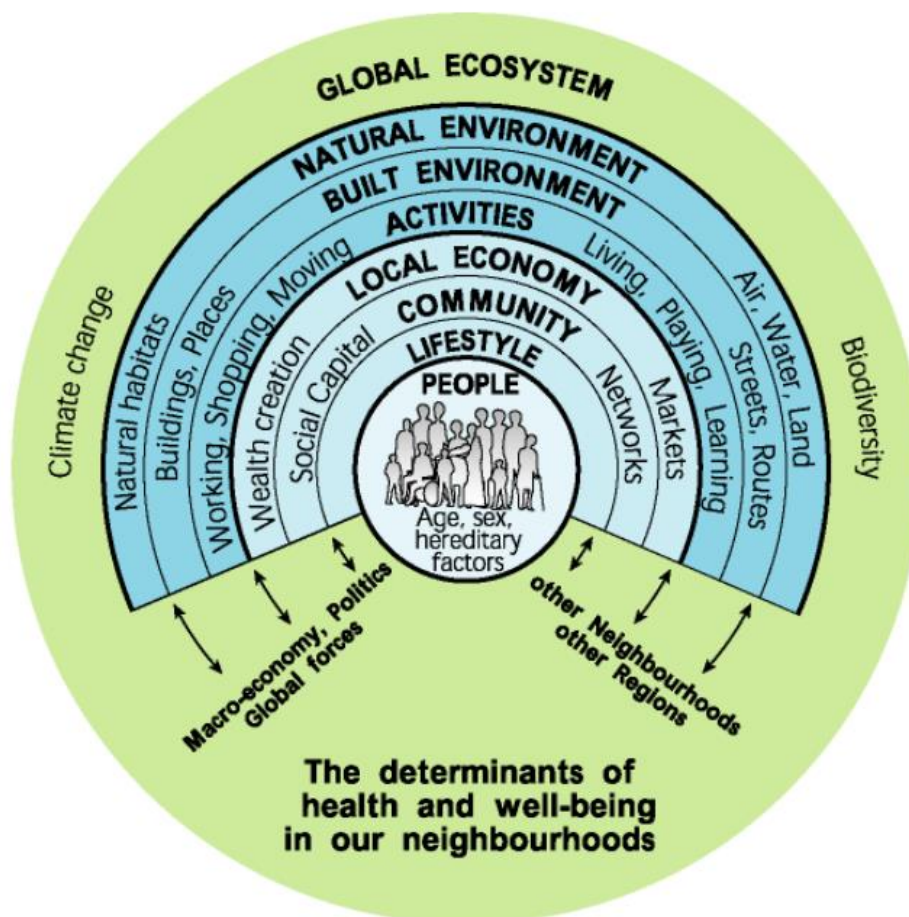


Figure 1.1 The Health Map (Barton and Grant, 2006)

1.4 The National Awareness and Early Diagnosis Initiative (NAEDI) and the Model of Pathways to Treatment (MPT)

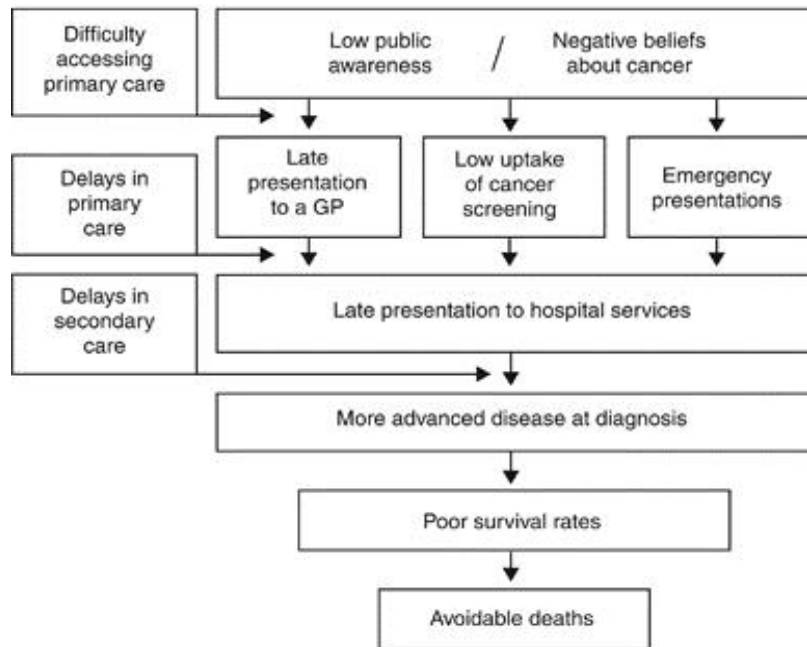
1.4.1 The National Awareness and Early Diagnosis Initiative (NAEDI)

NAEDI was launched in 2008 as part of the Cancer Reform Strategy (Department of Health, 2007), led by Cancer Research UK, the Department of Health, NHS England and Public Health England. NAEDI aims to improve cancer survival outcomes through research and activities which promote earlier diagnosis of cancer. It outlined seven work streams, including regular assessment of public cancer symptom awareness and the development of interventions to promote early symptom presentation.

1.4.2 The NAEDI pathway

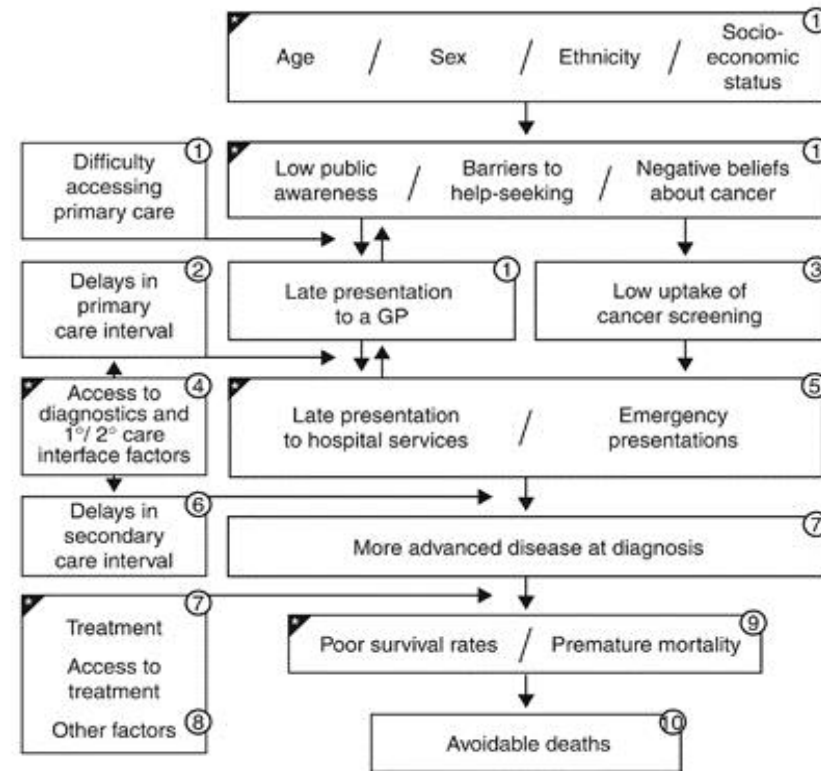
The NAEDI pathway was developed in 2009 (Richards, 2009b) and updated in 2015 as a framework for testing hypotheses related to potentially avoidable deaths from cancer (Hiom, 2015) (Figure 1.2). According to the NAEDI hypothesis, advanced stage disease reflects late presentation to secondary care as a consequence of low uptake of cancer screening or late presentation to a primary care doctor. Low public awareness of cancer, negative beliefs about cancer, barriers to help seeking and difficulty accessing primary care are considered likely to contribute to late presentation to a general practitioner (GP) and/or low uptake of cancer screening. The terms awareness of cancer and cancer knowledge are often conceptualised as a broad understanding of cancer including knowledge of the aetiology, prevention and symptoms of cancer; however, throughout this PhD thesis, the term 'cancer knowledge' refers specifically to cancer symptom awareness. In the updated version of the NAEDI hypothesis, demographic background factors including socioeconomic group were included as influences on prolonged presentation (Hiom, 2015).

Original NAEDI hypothesis



Updated NAEDI hypothesis

Factors influencing cancer survival and premature mortality



▣ New or changed since original hypothesis

Figure 1.2 The original and updated NAEDI pathway (Richards, 2009; Hiom, 2015)

1.4.3 Empirical evidence underlying the NAEDI pathway

Empirical evidence supports the earlier stages of the NAEDI pathway where cancer awareness, beliefs about cancer and barriers to help-seeking appear to influence the decision to present to a primary care doctor with symptoms, or affect cancer screening uptake. Low cancer symptom knowledge has been associated with reduced likelihood to engage in cancer screening (Wardle *et al*, 2000). Poor cancer symptom knowledge contributes to misattribution of symptoms and attenuates the decision to present to the doctor with symptoms, because individuals are more likely to perceive symptoms as not serious and therefore not requiring medical help (Mitchell *et al*, 2008; Macleod *et al*, 2009; Simon *et al*, 2010; Noonan, 2014; Walter *et al*, 2012; Whitaker *et al*, 2014). Poorer knowledge of the symptoms for cancer and lower suspicion that a current symptom could indicate cancer has been associated with low socioeconomic groups (Robb *et al*, 2009; Brain *et al*, 2014; Whitaker *et al*, 2015a) and could contribute to prolonged cancer symptom presentation among these groups.

Negative fearful and fatalistic beliefs about cancer have been associated with non-uptake of cancer screening due to fear of undergoing the screening test and fear of test results (Wardle *et al*, 2000; Austin *et al*, 2002; Waller *et al*, 2009; Miles *et al*, 2011). Fearful beliefs about cancer such as fear of receiving a diagnosis of cancer or fear of the treatments for cancer have also been associated with prolonged cancer symptom presentation (Sheikh and Ogden, 1998; Bish *et al*, 2005; Smith *et al*, 2005; Mitchell *et al*, 2008; Macleod *et al*, 2009). Fatalistic beliefs about cancer such as 'cancer is a death sentence' or 'there is no cure for cancer' have been associated with more advanced stage disease at diagnosis (Lyrtzopoulos *et al*, 2015a), which could reflect the influence of such beliefs on the decision to seek medical help, where symptom presentation is prolonged.

Fearful and fatalistic beliefs about cancer are more common among low socioeconomic groups (Niederdeppe and Levy, 2007; Beeken *et al*, 2011; Miles *et al*, 2011; Lyrtzopoulos *et al*, 2015a; Quaife *et al*, 2015a). Those from a low socioeconomic group have reported lower perceived value of early detection and higher fear associated with disclosing cancer symptoms to a primary care doctor (Beeken *et al*, 2011). Emotions such as fear of cancer are likely to influence interpretation of symptoms (Whitaker *et al*, 2015b) and the decision to seek medical help, where negative fearful and fatalistic beliefs are likely to prolong symptom presentation (Balasooriya-Smeekens *et al*, 2015; Sheikh and Ogden, 1998; Bish *et al*, 2005;

Smith *et al*, 2005; Mitchell *et al*, 2008; Macleod *et al*, 2009) particularly among low socioeconomic groups.

Barriers such as difficulty making or getting to an appointment for cancer screening have been associated with a lower likelihood of cancer screening attendance (Maheswaran *et al*, 2006; Waller *et al*, 2009). More reported barriers to cancer symptom presentation have been associated with the longest anticipated times to cancer symptom presentation (Robb *et al*, 2009; Simon *et al*, 2010). The types of barriers reported have been found to vary with socioeconomic group: emotional barriers such as embarrassment and worry what the doctor might find were more prevalent among low socioeconomic groups, whereas high socioeconomic groups were more likely to endorse practical barriers such as 'being too busy' (Robb *et al*, 2009).

Whilst the influences on cancer screening attendance and prompt cancer symptom presentation to primary care appear to be similar, the prompts preceding screening and symptom presentation behaviours are different. Those who attend screening are often asymptomatic, and in most cases receive a letter or screening kit through the post inviting them to take part in screening. This bypasses the stages of noticing and appraising a symptom, and deciding whether or not to seek medical help (Walter *et al*, 2012). Symptomatic individuals do not receive a prompt or reminder letter to encourage them to seek help for a symptom and are therefore required to consciously assess their symptom and decide whether to seek medical help. It is beyond the scope of this PhD to explore both screening and symptom presentation behaviour, therefore the barriers to cancer symptom presentation will be the focus of this thesis.

Studies of cancer symptom presentation support the NAEDI hypothesis that poor knowledge, negative beliefs and barriers to help-seeking contribute to prolonged cancer symptom presentation. In addition, studies provide an indication of which of these factors are more prominent in low socioeconomic groups. However, a more detailed understanding is required regarding the ways in which socioeconomic group influences the relationship between each of the factors highlighted in the NAEDI hypothesis and symptom presentation is required. Therefore, the primary focus of this PhD is to explore the barriers to cancer symptom presentation among low socioeconomic groups.

1.4.4 The Model of Pathways to Treatment (MPT)

The MPT (Walter *et al*, 2012; Figure 1.3) was developed from the Anderson Model of Total Patient Delay (Andersen and Cacioppo, 1995), to conceptualise time between detection of a bodily symptom and the start of cancer treatment. The MPT outlines four time intervals, the processes involved during each interval, and suggests patient factors that are likely to influence each of the time intervals. The first two intervals, representing appraisal and help seeking, can be conceptualised as the 'patient interval', where symptoms are appraised and the individual decides whether to seek medical help for the detected bodily change (Walter *et al*, 2012). This time period is often referred to as patient delay; however this term carries connotations of blame (Dobson *et al*, 2014; Weller *et al*, 2012), therefore the term 'prolonged' cancer symptom presentation will be used throughout this PhD thesis.

The factors involved in the NAEDI pathway can facilitate understanding of the processes involved at each stage which influence the decision to seek medical help for symptoms. The 'appraisal interval' refers to the process of appraising a bodily change once detected (Walter *et al*, 2012). This requires conscious cognitive processing and an awareness of cancer symptoms to facilitate appraisal (Scott *et al*, 2012; Walter *et al*, 2012). Knowledge of the symptoms of cancer is considered to be most influential at this stage and emotions such as fear are likely to influence interpretation of symptoms (Walter *et al*, 2012). Once the symptom is appraised, the individual must decide whether to consult a health care professional (HCP) and arrange an appointment during the 'help-seeking interval'. The remaining factors from the NAEDI pathway- beliefs about cancer, barriers to symptom presentation- are likely to lengthen or shorten the help-seeking interval. Throughout this PhD thesis, the term 'cancer symptom' will be used to refer to bodily changes that are perceived by the symptomatic individual as unusual, troubling or of potential oncological significance.

The patient interval has been found to account for the greatest proportion of time in the pathway from symptom discovery to the start of cancer treatment (Allgar and Neal, 2005; Ristvedt and Trinkaus, 2005; Lyratzopoulos *et al*, 2015b), and has been found to lengthen with increasing socioeconomic deprivation (Macleod *et al*, 2009). Both the MPT and NAEDI pathway suggest that patient factors influence the decision to seek medical help; however, due to their descriptive nature, neither model provides an explanation for how

socioeconomic factors mediate symptom presentation. A more detailed understanding of how knowledge, beliefs, barriers and other factors relating to low socioeconomic groups might influence symptom presentation is required. Through identification of the factors influencing the appraisal of symptoms and the decision to seek medical help for a cancer symptom, interventions may be developed to encourage prompt symptom presentation in low socioeconomic groups in order to reduce inequalities in cancer outcomes.

1.5 Diagnosing cancer in primary care

Primary care doctors face pressure from patients and policy makers to diagnose cancer earlier and refer to secondary care more promptly, but also pressure from secondary care to reduce the number of referrals. Each year, a GP will see on average 8 new cases of cancer per year (Roope, 2015) which is relatively small considering a GP will engage in five to ten thousand interactions with patients each year. The symptoms that patients present with are often vague and can be symptoms of many other benign conditions, thus GPs are challenged with the difficult task of knowing when a referral to secondary care is appropriate (Baughan *et al*, 2011; Andersen and Vedsted, 2015; Neal *et al*, 2015). Patients are often required to visit the GP multiple times before a referral to secondary care is made which can be problematic if the patient also prolongs a return visit. For example it takes an average three consultations with the GP before a chest x-ray is ordered (Lyratzolplous *et al*, 2012; Neal *et al*, 2015). Although it is beyond the scope of this PhD thesis to explore doctor/patient interactions within the primary care consultation or the referral behaviour of GPs, the difficulties of diagnosing cancer in primary care are acknowledged.

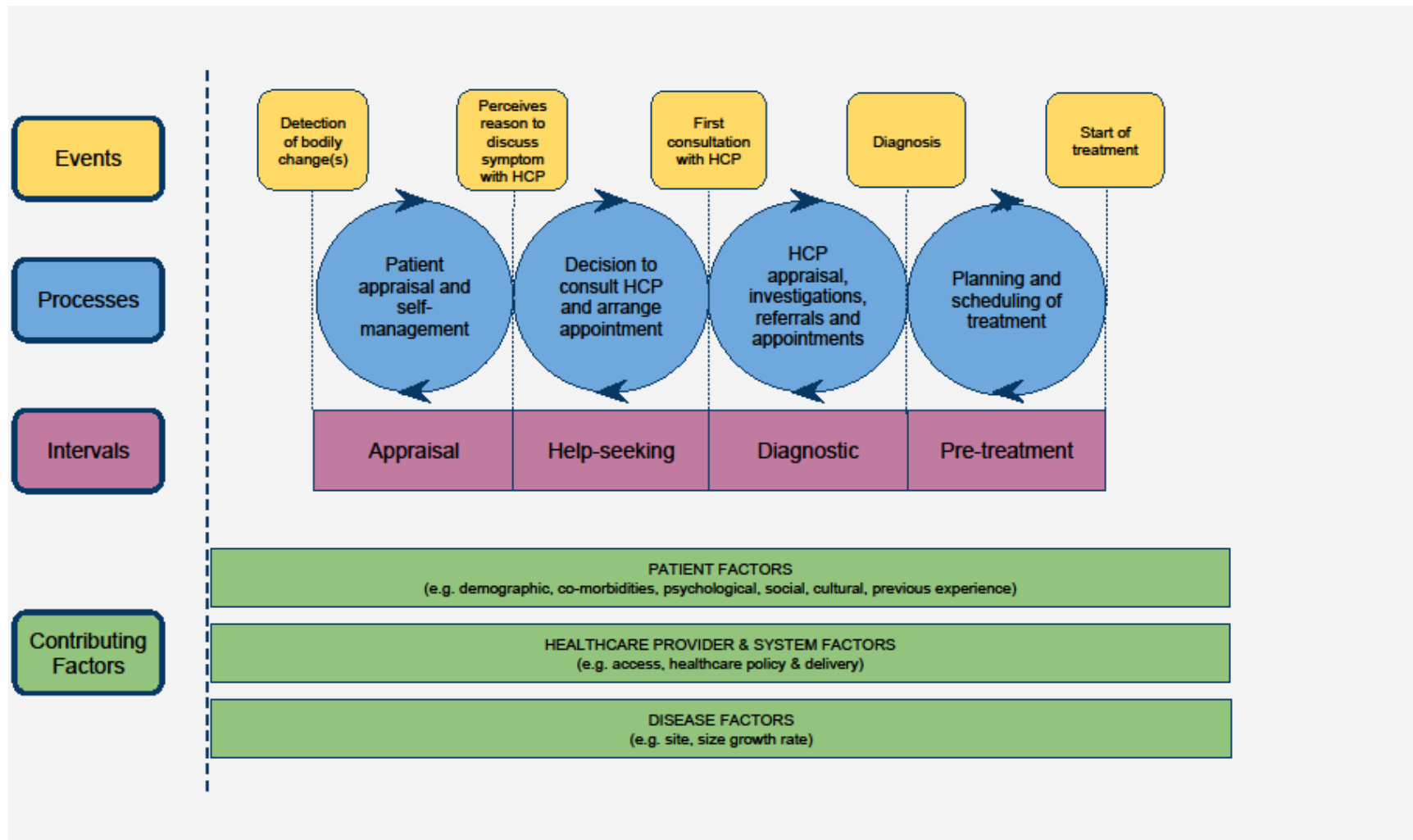


Figure 1.3 The Model of Pathways to Treatment (MPT) (Walter et al, 2012)

1.6 UK Policy

The need to reduce inequalities in cancer outcomes is consistently reflected in UK policy. In 2000, the National Health Service (NHS) Cancer Plan prioritised the need to improve cancer outcomes in the NHS (Department of Health, 2000). Its aims were to improve cancer survival rates in the UK so that they were comparable with the best in Europe by 2010, improve cancer services and tackle socioeconomic inequalities in cancer survival. A strategy was outlined to facilitate delivery of these aims.

To build on the progress in relation to cancer survival since the NHS Cancer Plan (Department of Health, 2000), the Cancer Reform Strategy (Department of Health, 2007) was developed. It outlined the direction for cancer services in the UK for the next five years, acknowledging that there were further advances to be made. Its main aims were to save more lives and reduce inequalities in cancer outcomes. The document outlined various areas of action to improve cancer outcomes including earlier cancer diagnosis through screening programmes, improving public awareness of the signs and symptoms of cancer, and reducing cancer inequalities in incidence, access to services and outcomes according to various demographic risk factors for poorer cancer survival, including deprivation.

In Wales, the Cancer Delivery Plan (2012) outlined a five year strategic plan to reduce cancer incidence, improve survival rates and decrease cancer mortality. In the annual updates, there was an overall increase in cancer survival; however, each report acknowledged areas for improvement (Welsh Government, 2013). In the 2014 update, it was reported that survival rates for stomach, lung and kidney cancer were still lower than the European average, and that socioeconomic inequalities in incidence, mortality and survival remained (Welsh Government, 2014). In the 2015 update, there was a particular focus on the need to improve lung cancer outcomes in Wales in response to the National Lung Cancer Audit, where 5 year lung cancer survival was 6.5%. It was reported that lung cancer accounted for the highest proportion of cancer related deaths in Wales and almost half of all lung cancer cases were diagnosed in the advanced stages (Welsh Government, 2015; National Lung Cancer Audit, 2015; Welsh Cancer Intelligence and Surveillance Unit, 2015). Consequently, lung cancer and the need to improve lung cancer outcomes were considered a national priority in Wales in 2015/16 and 2016/17 as part of the Welsh Lung Cancer Initiative (Welsh Government, 2015).

In response to these policy developments, the decision to focus the intervention on lung cancer was made during the course of the PhD. Whilst the primary aim of the thesis is to understand the barriers to cancer symptom presentation in low socioeconomic groups, the secondary aim is to develop a lung cancer intervention targeted at low socioeconomic groups. This change in focus will be reflected in the narrative of subsequent chapters.

1.7 Lung cancer as a priority

1.7.1 Lung cancer statistics

Lung cancer survival is particularly poor. In the UK, 32% of people survive for one year or more after a diagnosis of lung cancer, 10% survive for 5 years or more and 5% of people diagnosed with lung cancer survive for 10 years or more (Cancer Research UK Statistics, 2015d). Whilst survival rates for many other cancers have improved, lung cancer survival has remained stable over the past 40 years (Cancer Research UK Statistics, 2015d). It is the third most commonly diagnosed cancer in the UK, with around 40,000 new cases each year (National Lung Cancer Audit, 2015) and is the leading cause of cancer related death in the UK (Kmietowicz, 2015). In 2012, lung cancer became the second biggest cause of death in men and the fifth biggest cause of death in women in the UK, where over 35,000 people died from lung cancer (National Lung Cancer Audit, 2015; Kmietowicz, 2015). In Wales, there are more deaths from lung cancer each year than deaths from breast and bowel cancer combined, and it has been estimated that if lung cancer survival in Wales matched that of the best in Europe in 2012, 113 more women and 77 more men each year might survive at least five years (Welsh Cancer Intelligence and Surveillance Unit, 2015).

1.7.2 Lung cancer and socioeconomic group

Lung cancer is reported to represent the strongest association with deprivation of all the common cancers across the UK context (Welsh Cancer and Surveillance Unit, 2015). Lung cancer incidence and mortality is higher amongst low socioeconomic groups compared to high socioeconomic groups (Welsh Cancer Intelligence and Surveillance Unit, 2015). Age-standardised incidence rates for Scotland are 61.3/100,000 for high socioeconomic groups versus 183.7/100,000 for low socioeconomic groups (Information Service Division Scotland,

2015b). Similar disparities are observed in Wales where lung cancer is two and a half times more common among low socioeconomic groups compared with high socioeconomic groups (Welsh Cancer Intelligence and Surveillance Unit, 2015). This represents an absolute difference of 79 more new cases of lung cancer per 100,000 of the population per year between low and high socioeconomic groups, and this incidence-deprivation gap has widened over the past ten years by 27% (Welsh Cancer Intelligence and Surveillance Unit, 2015). The high incidence of lung cancer among low socioeconomic groups reflects the high prevalence of smoking, which accounts for 80% of new lung cancer cases each year (Welsh Cancer Intelligence and Surveillance Unit, 2015; Parkin, 2011) and industrial employment such as mining among low socioeconomic groups which contributes to increased risk for lung cancer (Welsh Cancer Intelligence and Surveillance Unit, 2015).

The inequalities in lung cancer mortality follow a similar pattern to the inequalities observed for cancer incidence. In Scotland, age-standardised mortality rates are 48.3/100,000 for high socioeconomic groups compared to 148.2/100,000 for low socioeconomic groups (Information Service Division Scotland, 2015). In Wales, the difference between high and low socioeconomic groups represents an absolute difference of 61 deaths per 100,000 population (Welsh Cancer Intelligence and Surveillance Unit, 2015). Survival differences by socioeconomic group in the UK are 1.4% between high and low socioeconomic groups, which has been estimated to account for around 1300 deaths from lung cancer as a result of socioeconomic inequalities in cancer outcomes (Coleman, 2004; Cancer Research UK Statistics, 2015d).

1.7.3 Lung cancer early detection strategies

Low dose computed tomography (LDCT) can be used to screen for lung cancer and is currently being evaluated in trials across Europe and the US involving high risk individuals (Aberle *et al*, 2011; Aggestrup *et al*, 2012; Rasmussen *et al*, 2015; van den Bergh *et al*, 2011; Brain *et al*, 2016). Although the results of lung cancer screening trials are promising in terms of lung cancer mortality (Aberle *et al*, 2011), the number of false positive results has been reported to range from 20%-50% (Aberle *et al*, 2011; O'Connor and Hatabu, 2012) and could contribute to distress and anxiety among those who take part in screening. LDCT is currently not available routinely through the NHS to screen for lung cancer. Therefore, lung cancer is diagnosed on the basis of individuals presenting with symptoms in primary care, or in

secondary care as an emergency case. It has been reported that around half of lung cancer cases present through emergency services (Ellis-Brookes *et al*, 2012).

Due to the vague nature of symptoms of lung cancer (NICE <https://www.nice.org.uk/Guidance/CG121> [accessed 30.09.2016]), particularly in the early stages, and rapid progression of lung cancer from the early to late stages, patients are faced with the difficulty of knowing when to present to the doctor with symptoms (Lyratzolplous *et al*, 2012; Mitchell *et al*, 2013). Early symptoms such as a persistent cough or breathlessness can be symptoms of minor ailments such as a cold or other co-morbid conditions such as COPD, or attributed to smoking habit. These types of symptoms are often ignored or dismissed as normal, prolonging cancer symptom presentation (Birt *et al*, 2014; Corner *et al*, 2006; Chatwin and Sanders, 2013). Furthermore, 80% of lung cancer cases are smoking related (Welsh Cancer Intelligence and Surveillance Unit, 2015) and those who smoke or are ex-smokers are at the highest risk for developing lung cancer. Smokers are less likely than non-smokers to go to the doctor with symptoms suggestive of lung cancer (Friedemann-Smith *et al*, 2016). This could reflect worry about being told by their primary care doctor to stop smoking, or feelings of shame if they associate their smoking habit to be the cause of their symptoms adding to the perception of lung cancer as a self-inflicted disease (Corner *et al*, 2006). Lung cancer is highly stigmatised in comparison to other cancers such as breast cancer (Marlow *et al*, 2015), due to the association of lung cancer with smoking (Chatwin and Sanders, 2013; Chapple *et al*, 2004a) and low public awareness of other risk factors other than smoking (Simon *et al*, 2012). Consequently, individuals with symptoms of lung cancer are likely to experience feelings of blame and guilt, and not feel worthy of seeking help or treatment for symptoms (Quaife *et al*, 2016a). In addition, it has been reported that smokers are more likely than non-smokers to hold fearful and fatalistic beliefs about cancer (Quaife *et al*, 2015b; Quaife *et al*, 2016a) and more pessimistic beliefs about early detection (Silvestri *et al*, 2007; Quaife *et al*, 2016b). Such beliefs have been associated with advanced stage disease at diagnosis (Lyratzopoulos *et al*, 2015a). These and other factors which potentially prolong symptom presentation will be discussed throughout the thesis, followed by an outline for an intervention designed to overcome these issues.

1.8 The Medical Research Council (MRC) Framework

The MRC framework is a guide for the development and evaluation of complex interventions (Craig *et al*, 2008), and will be used to guide intervention development for this PhD. The MRC framework outlines four phases of development and evaluation (Figure 1.4). During the first development phase, researchers should identify the evidence base, relevant theory and model processes and outcomes for intervention development. Studies relating to intervention development using primary and secondary data will be reported in Chapters 3 to 5. The second MRC feasibility and piloting phase involves preliminary testing of intervention acceptability and feasibility of recruitment procedures before a full-scale evaluation is carried out. Intervention acceptability testing will be described in Chapter 8. The evaluation phase can be used to assess effectiveness and cost-effectiveness of intervention and to understand change process (Craig *et al*, 2008). The final MRC phase refers to implementation if the intervention is feasible and shows evidence of effectiveness, and requires intervention surveillance and monitoring through long term follow-up.

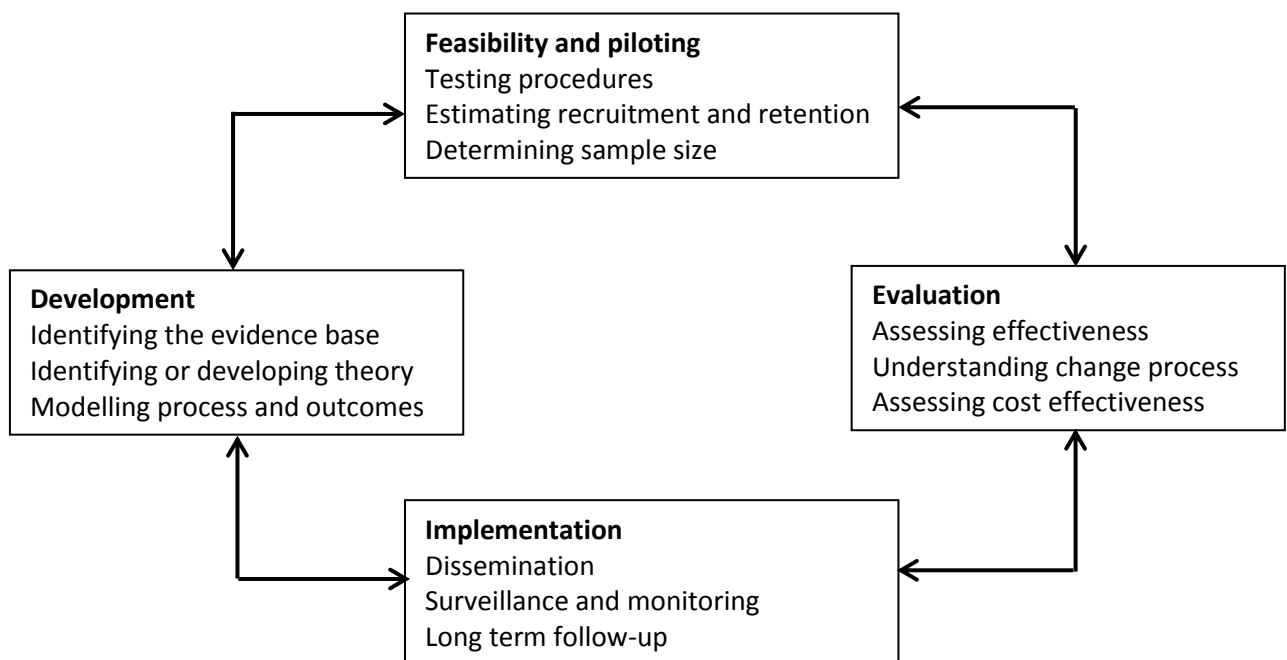


Figure 1.4 The key elements of the MRC intervention development and evaluation process (Craig *et al*, 2008)

1.9 The Behaviour Change Wheel

Intervention development will be guided by the Behaviour Change Wheel (Michie *et al*, 2011). The Behaviour Change Wheel was developed in response to the need for a comprehensive, theory based framework for intervention development that can be applied to a wide range of behaviour change contexts. The MRC framework highlights the importance of theory in intervention development; however, there is a lack of guidance regarding how to select or use theory when developing behaviour change interventions (Michie *et al*, 2005). In an attempt to reduce researcher bias in the selection of theory and provide a systematic framework for the development of behaviour change interventions, the Behaviour Change Wheel was developed by Michie and colleagues for use in conjunction with the MRC framework (Michie *et al*, 2011; Michie *et al*, 2014). The Behaviour Change Wheel is underpinned by the Theoretical Domains Framework (TDF) and the COM-B model (Capability, Opportunity, Motivation-Behaviour) (Michie *et al*, 2011). The TDF and COM-B model provide a potentially useful framework for understanding cancer symptom presentation behaviour and will be discussed in more detail in the forthcoming chapters.

The COM-B model and TDF are used in the first stage of the Behaviour Change Wheel process to perform a 'behavioural analysis' of the target behaviour. The behavioural analysis is performed to understand the barriers and facilitators to the target behaviour, which in this context is cancer symptom presentation behaviour among low socioeconomic groups. Based on the sources of behaviour identified by mapping barriers and facilitators to the COM-B model constructs, findings at this stage determine which intervention functions (the type of intervention) and behaviour change techniques (intervention content) could be used to bring about change (Michie *et al*, 2011). Finally, suggested policy categories and mode of intervention delivery are considered to guide the researcher on how the intervention could be implemented to bring about behaviour change (Michie *et al*, 2011). For this PhD, the Behaviour Change Wheel was used to guide intervention development due to its systematic nature and theoretical underpinning. All steps involved in the intervention development process using the Behaviour Change Wheel are described in Chapter 7.

1.10 Aims and objectives of this PhD thesis

The primary aim of this PhD thesis is to understand the barriers to cancer symptom presentation among low socioeconomic groups. The contributions of cancer symptom knowledge, beliefs about cancer and barriers to symptom presentation will be explored using primary qualitative data (interviews and focus groups) and secondary systematic review data. This will involve exploration of the wider socio-environmental influences on cancer symptom presentation behaviour, in order to gain an understanding of how socioeconomic factors influence knowledge, beliefs and symptom presentation.

Secondary aims are to develop a theory-driven cancer awareness intervention targeted at low socioeconomic groups, and to pilot test the draft intervention for acceptability with a group of potential users. This will be guided by the MRC framework for intervention development and relevant theory to ensure that the mechanisms underlying the behaviour (cancer symptom presentation) can be understood in terms of a theoretical framework, and are addressed in the content of the intervention. This is important because theory can be used to guide intervention content and facilitate the selection of suitable evaluation measures. The decision to shift the intervention focus away from generic cancer and focus exclusively on lung cancer awareness was made in response to recent cancer intelligence data that highlighted particular socioeconomic disparities in lung cancer incidence and survival, and the subsequent policy drive to reduce inequalities and improve lung cancer outcomes.

Objective for this PhD are: (1) to identify relevant theory for cancer awareness, beliefs about cancer and symptom presentation behaviour; (2) to identify studies of cancer symptom knowledge, beliefs about cancer, barriers to cancer symptom presentation and actual or anticipated cancer symptom presentation behaviour using systematic review methods; (3) to identify the factors influencing cancer symptom presentation among low socioeconomic group using qualitative methods; (4) to identify and review interventions designed to encourage earlier cancer symptom presentation among low socioeconomic groups; (5) to develop an intervention to encourage earlier lung cancer symptom presentation among low socioeconomic groups and examine its acceptability with a sample of potential users.

1.11 Thesis structure

Chapter 2

Chapter two presents the theoretical underpinning of this thesis. Health behaviour theories relevant to cancer symptom presentation behaviour will be described and critically evaluated. The TDF and COM-B model will be discussed as most relevant in this context.

Chapter 3

This chapter describes a systematic review of the literature up to July 2015 relating to cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation and time to symptom presentation. It reports the variation of cancer symptom knowledge, beliefs about cancer and barriers/facilitators to symptom presentation according to socioeconomic group to consider how these might influence cancer symptom presentation behaviour.

Chapter 4

The findings from a qualitative interview study with men and women over the age of 50 from a low socioeconomic group are reported in Chapter 4. Individual factors such as cancer knowledge and the wider socio-environmental factors are explored and discussed in terms of their influences on cancer symptom presentation behaviour.

Chapter 5

Chapter 5 reports the results of a focus group study with members of public living in deprived communities and local stakeholders (healthcare professionals and community partners) who work in deprived communities. It reports findings from a cancer symptom attribution task and discusses the influence of the wider social environment on interpretation of symptoms and timely cancer symptom presentation behaviour.

Chapter 6

This chapter describes a scoping review using database and online searches to identify cancer awareness interventions targeted at low socioeconomic groups. It describes the type, content and effectiveness (if data available) of cancer awareness interventions and implications for intervention development in this PhD.

Chapter 7

Chapter 7 presents the development of an intensive lung cancer awareness group based educational intervention targeted at individuals living in deprived communities. The Behaviour Change Wheel was used in combination with findings from studies described in Chapters 3-6 to facilitate intervention development. The intervention is designed to increase lung cancer symptom knowledge, break down negative beliefs about cancer and mobilise social networks to encourage more timely lung cancer symptom presentation for individuals living in a deprived community.

Chapter 8

This chapter presents findings from an intervention acceptability testing study with a group of potential users: people over the age of 40 from socioeconomically deprived communities who were current smokers, former smokers or family members of smokers.

Chapter 9

The concluding chapter summarises the key findings of the thesis and locates the findings within the wider context of cancer inequalities. Methodological limitations and implications of findings are discussed. Suggestions for further evaluation and potential for implementation are provided.

1.12 The Awareness and Beliefs about Cancer (ABACus) study

The focus group study reported in Chapter 6 was conducted as part of an aligned project “Development of the Tenovus health check: a targeted cancer awareness intervention for people from deprived communities” funded Cancer Research UK (the ABACus study, Smits *et al*, 2016). Focus groups were conducted to understand the influences on cancer symptom presentation in deprived communities and to offer feedback on the Tenovus health check, followed by intervention development using the Behaviour Change Wheel. All focus group data reported in this PhD thesis were analysed by the PhD researcher independently of the ABACus study. In addition, intervention development for this PhD thesis using the Behaviour Change Wheel was conducted independently of the ABACus study. The role of the PhD researcher in the development and conduct of focus groups will be described in more detail in Chapter 6.

Chapter 2

Critical evaluation of behavioural and sociological theories relevant to cancer symptom awareness, beliefs and presentation in low socioeconomic groups

2.1 Chapter overview

The theoretical underpinning of the PhD will be presented in this chapter. Theories and models of symptom attribution, attitude and belief formation, and the wider social and environmental influences on behaviour will be described and critically evaluated. A range of behavioural and sociological theories and models will be used to discuss the influences on cancer symptom presentation behaviour in the context of socioeconomic deprivation. The Theoretical Domains Framework (TDF) and COM-B model (Capability, Opportunity, Motivation-Behaviour) will be discussed as most relevant in the context of cancer symptom presentation behaviour (Michie *et al*, 2011). Finally, the role of theory in this PhD thesis and the development of a cancer awareness intervention using the Behaviour Change Wheel, which is underpinned by the TDF and COM-B model, will be discussed.

2.2 Introduction

As discussed in Chapter 1, the present PhD is concerned with understanding the barriers to cancer symptom presentation among people in low socioeconomic groups, to ultimately develop an intervention targeted at low socioeconomic groups to encourage timely cancer symptom presentation. The updated National Awareness and Early Diagnosis Initiative (NAEDI) pathway (Hiom, 2015) outlined in Chapter 1 suggests that low public awareness of cancer, negative beliefs about cancer, barriers to symptom presentation and socioeconomic factors are likely to prolong cancer symptom presentation. Whilst the NAEDI pathway provides a framework for testing hypotheses, it does not attempt to provide detailed explanations for the influences of awareness, beliefs and barriers on symptom presentation behaviour. Examining theories that are relevant to the “patient interval” component of the NAEDI pathway, is likely to facilitate a deeper understanding of which factors are most likely to affect cancer symptom presentation behaviour, and why these might influence behaviour. Relevant theories can then be used to guide intervention design and evaluation.

As outlined in Chapter 1, the Medical Research Council (MRC) framework for developing and evaluating complex behaviour change interventions highlights the importance of identifying relevant theory in order to guide the researcher to certain aspects of behaviour, and to gain an understanding of the barriers and facilitators to behaviour (Campbell *et al*, 2007; Craig *et al*, 2008). This is to allow insight into the likely processes underlying the behaviour before pilot testing, so that intervention content is designed to specifically address these processes, and suitable evaluation measures can be selected to test for intervention efficacy (Campbell *et al*, 2007; Craig *et al*, 2008).

Theories and models from health psychology textbooks, studies of cancer symptom presentation behaviour and all theories and models underpinning the Behaviour Change Wheel were reviewed. A selection of behavioural and sociological theories and models that were considered to be most relevant to cancer symptom presentation behaviour among low socioeconomic groups were selected and will be presented in this chapter. The most relevant theory or model to cancer symptom presentation behaviour will be selected for this PhD.

It is helpful to understand the distinction between the terms theories and models, since these terms are often used interchangeably. Theories are explanatory and predictive, helping to guide selection of appropriate methods for conducting research, and predicting behaviour to guide intervention development (Gabrenya, 2003). Models are generally descriptive, showing simplified cause and effect of the key aspects of behaviour, often as simplified versions of theories (Gabrenya, 2003).

2.3 Relevant theories and models of the influences on cancer symptom presentation behaviour

2.3.1 The Common Sense Model of Illness Self-Regulation of Health and Illness

The Common Sense Model of Illness Self-Regulation (CSM) (Leventhal *et al*, 1984) is a model of illness cognitions, attempting to explain how illness is inferred, understood and acted upon. The CSM provides a useful framework for understanding how a symptom may or may not be attributed to cancer and an explanation of which factors influence the decision to seek medical help. There are three key constructs of the CSM: (1) representation of illness;

(2) the coping response to the health threat; (3) appraisal of coping efforts after coping response (Figure 2.1). The model assumes that the individual is an active problem solver, responding to a health threat through two parallel processes: cognitive processing (understanding, identifying and responding to the health threat) and emotional processing (the individual's feelings towards the health threat, and what steps can be taken cope with their emotions) (Leventhal *et al*, 1997).

According to the CSM, when forming representations of illness, an individual makes common sense interpretations about their bodily signs or symptoms to infer illness. Interpretations are based on mental representations of illness, formed from previous illness experiences. The model describes five domains on the cognitive processing pathway which affect interpretation of symptoms and the decision to act on symptoms: identity (the label given to the illness or health threat), causes (whether the illness is perceived to be caused by internal or external factors), timeline (perceptions of how long the illness will last), consequences (possible physical and emotional consequences of illness), and curability/controllability (perceptions of whether the illness could be treated or cured), (Leventhal *et al*, 2003; Figure 2.1).

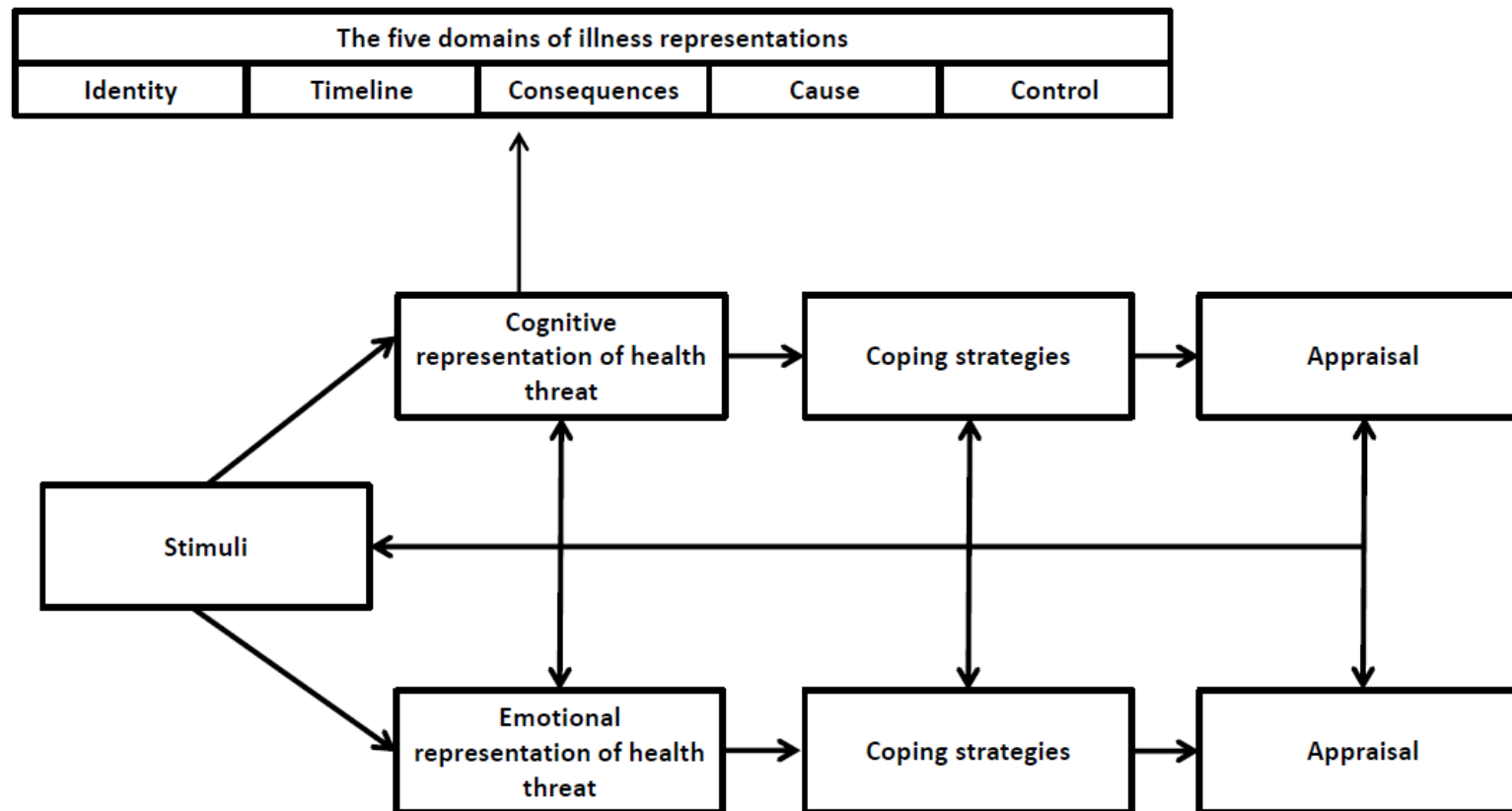


Figure 2.1. Common Sense Model of Illness Self-Regulation (adapted from a figure from Leventhal et al, 2003, p50)

According to the CSM, when a bodily change is detected, an automatic initial (unconscious) assessment is made. Bodily changes which do not exceed the unconscious threshold for inferring illness will be dismissed as normal and attributed to part of the body's normal function. Bodily changes which exceed the threshold for inferring illness are perceived as a symptom, which the individual may interpret as abnormal, depending on the outcome of a conscious assessment of the symptom. During the conscious assessment of the symptom, previous illness episodes and schema are used as reference points to explain the current illness episode. For example, the individual might notice blood in their stools. According to the CSM, the individual will consciously assess the symptom against previous symptom episodes, such as bleeding from haemorrhoids and reference points such as 'blood in poo' cancer awareness campaigns. In addition, the timeline of the symptom (how long they have had the symptom or expect the symptom to last) may be used to decide if the symptom is part of their normal functioning i.e. a symptom of their haemorrhoids, or something abnormal i.e. bowel cancer.

If bodily changes or symptoms are dismissed as 'normal' during the conscious or unconscious assessments of symptoms, this provides a potential opportunity for prolonged symptom presentation. If an individual attributes their symptom to normal bodily functioning such as haemorrhoids, they may decide no medical help is required. If the individual interprets the symptom as abnormal and thus requiring medical intervention, the final three domains of consequences, internal and external causes and control are used to guide action planning and coping responses. The individual uses past experiences and schema to guide response to the symptom, such as beliefs about cancer treatments causing unpleasant side effects, beliefs about curative treatment for cancer, or beliefs about the benefits of early diagnosis of cancer. For example, if the individual with blood in stools decides the symptom is abnormal, their knowledge of the screening tests for bowel cancer, any family history of bowel cancer and beliefs about the treatments for bowel cancer would influence their coping response of whether to seek medical help or not.

In addition to cognitive representations of illness, the CSM posits that an individual makes emotional representations of their illness. The cognitive and emotional processes are thought to occur simultaneously. Emotional reactions such as fear or worry guide illness representations and action, and coping strategies are used to deal with emotions. Finally, all coping strategies on the cognitive and emotional dimension are appraised. The individual

evaluates the impact of their coping strategy on illness outcome and their emotional reaction (Figure 2.1).

Many of the symptoms of cancer are vague, particularly in the early stages, and often go unnoticed during the unconscious assessment stage, or are misattributed to benign causes during the conscious processing stage and dismissed as normal (Carter-Harris, 2015; Emery *et al*, 2013; Scott *et al*, 2007). There is evidence of people who received a diagnosis of cancer where symptoms of cancer were retrospectively recalled, but often misattributed to symptoms of other health problems such as haemorrhoids or other factors such as ageing (Andersen *et al*, 2010; Brandner *et al*, 2014; Whitaker *et al*, 2014), which supports the CSM. In addition, there is evidence of the role of emotions in the decision to seek medical help once a symptom is perceived as abnormal (Balasooriya-Smeekens *et al*, 2015), where beliefs such as cancer fatalism can prolong cancer symptom presentation on the emotional processing pathway (Bergamo *et al*, 2013; Chonjnacka-Szwalowska, 2013; Shahid *et al*, 2009; Lyratzopoulos *et al*, 2015a).

The CSM is a useful model for understanding how individuals might notice, interpret and decide to seek medical help for symptoms of cancer, and is clearly applicable in the current context. A strength of the model is the inclusion of emotional factors such as fear, worry and anxiety which are missing from many other behavioural models and theories. However, certain emotional factors such as embarrassment are currently not represented in the CSM but have been found to influence cancer symptom presentation (Marlow *et al*, 2014). In addition, the CSM does not include the influence of family and friends on illness representation and the coping response. Finally, testing the predictive validity of the CSM is challenging due to its complexity (Llwelln *et al*, 2007) and studies have reported low predictive power in the context of cancer symptom presentation (Grunfield *et al*, 2003; Hunter *et al*, 2003).

2.3.2 The Health Belief Model

The Health Belief Model (HBM; Rosenstock *et al*, 1988) was initially developed to explain risk-related health behaviour. More recently, the HBM has been used to predict other health related behaviours, in particular screening behaviour for cancer (Austin *et al*, 2002; Wardle *et al*, 2000; Murray & McMillan, 1993) and studies of ovarian cancer symptom

awareness (Brain *et al*, 2014; Smits, PhD thesis). According to the HBM, behaviour is determined by perceptions of the disease and the strategies available to guide health behaviour (Rosenstock *et al*, 1988). The model assumes that when faced with a health threat, an individual will take into account their perceptions of: susceptibility to illness, the severity of illness, perceived barriers and benefits of behavioural performance (Stretcher and Rosenstock, 1997). The HBM suggests that these four constructs are influenced by demographic variables such as age, gender and socioeconomic group, as well as structural variables such as knowledge of the disease and self-efficacy. In addition, cues to action are included in the HBM as influences on behaviour. Cues to action include social cues such as advice from a family member prompting an individual to seek medical help, or system-related cues such as cancer awareness campaigns in the media (see Figure 2.2).

Perceived susceptibility refers to an individuals' perception of their risk associated with acquiring the disease. Greater perceived susceptibility is assumed to motivate the individual to engage in behaviour to minimise the risk. In the context of cancer symptom presentation, perceptions of risk might influence symptom attributions. For example, if an individual has a family history of bowel cancer, they might assume they are more susceptible to receiving a diagnosis of bowel cancer in future. Someone who perceives themselves to be at high risk for bowel cancer might be more likely to attribute a symptom such as change in bowel habit to cancer, rather than something benign such as irritable bowel syndrome.

Perceptions of severity of illness are often based on an individual's medical knowledge and the beliefs an individual has formed about the disease. Beliefs about the disease severity include perceptions of what impact a diagnosis of disease could have on their daily life, and are usually formed from other members of the community or media sources. For example, an individual may know someone with breast cancer whose treatment was limited to surgery, where their recovery was good with little disruption to daily life. Conversely, they may know someone with breast cancer who underwent multiple treatments such as surgery, chemotherapy and radiotherapy, with a long recovery time and extensive disruption to daily life during and after treatment. Based on these experiences, an individual would perceive breast cancer as a more serious disease in the latter example when compared to the first example. The perceived impact that a diagnosis of cancer would have on daily life is taken into account when deciding how serious a symptom of cancer is. For example, if an individual perceives a diagnosis of cancer as disruptive, requiring extensive time off work for

treatment and recovery, any potential financial difficulties which might arise from unemployment during this time would guide the individual to perceive cancer as more serious.

According to the HBM, when the perceived benefits of behavioural performance outweigh the perceived barriers, the likelihood of action is greater. In the context of cancer symptom presentation, an individual may understand the benefits of early cancer detection of cancer, prompting them to seek medical help quickly for a symptom of cancer. However, they might perceive barriers to symptom presentation such as lack of time to get to a GP appointment. The HBM suggests that an individual would present with symptoms if the perceived benefits (their beliefs about the need to diagnose cancer early) outweighed any perceived barriers (their perceptions of lack of time to get to an appointment). In support of the model, an ovarian symptom presentation study reported that emotional and practical barriers were predictors of anticipated delay (Brain *et al*, 2014).

While aspects of the HBM are potentially useful for understanding how symptoms might be perceived as a health threat and certain factors which are taken into account when deciding to seek medical help, there are limitations. Unlike the CSM, the HBM does not include emotions such as fear and worry which are particularly salient in this context and have been reported to influence cancer symptom presentation behaviour (Balasooriya-Smeekens *et al*, 2015). In addition, although demographic variables such as age and gender are taken into account, environmental or contextual factors are not included in the HBM and are likely to be important in the context of socioeconomic deprivation. Furthermore, there is evidence to suggest that the HBM is most useful when applied to higher risk individuals, rather than the general population (Smits, PhD thesis chapter 4).

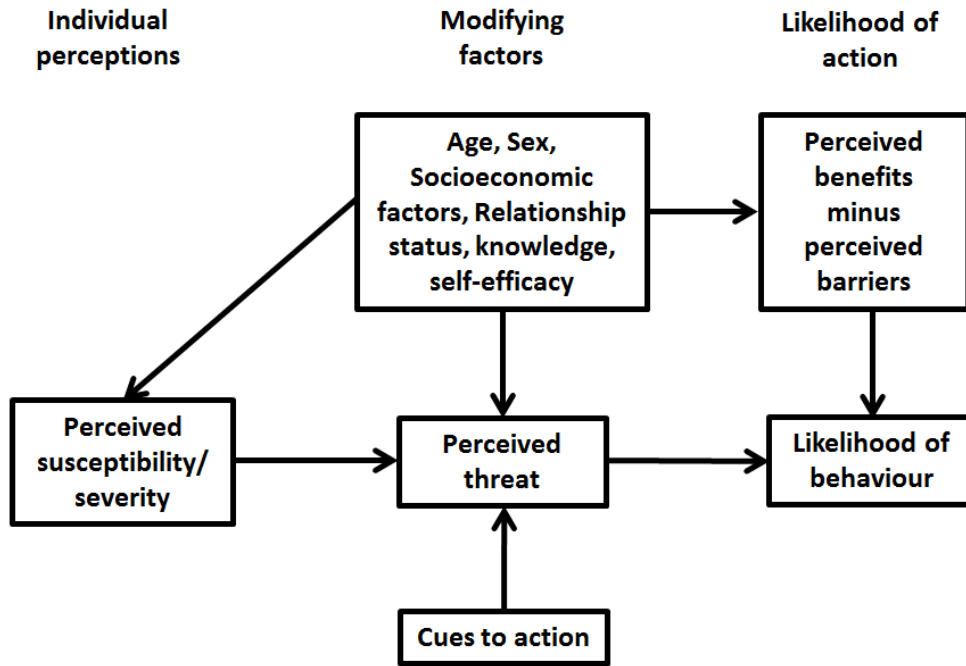


Figure 2.2 *The Health Belief Model adapted from Strecher & Rosenstock (1997) in Glanz et al (2008), p.34.*

2.3.3 The Extended Parallel Processing Model

The Extended Parallel Processing Model (EPPM; Witte, 1992) was developed from Protection Motivation Theory (Rogers, 1975). The EPPM has previously been applied to assess the impact of health risk information on behaviour. The EPPM is relevant to understanding behavioural responses to health threats such as a potential cancer symptom, or fear inducing messages used in cancer awareness campaigns. Similarly to the HBM, the EPPM posits that a threat is appraised by the individual based on perceived susceptibility (how likely they are to be affected by the threat) and severity of the threat (how serious they perceive the threat to be), Figure 2.3. If the threat is perceived to be moderate or high, fear may be elicited and the individual may re-appraise the threat based on perceptions of self-efficacy (their ability to respond to the threat) and response efficacy (the likelihood that their response will be effective). The EPPM assumes that if perceived threat and perceived efficacy are high, the fear-inducing message is likely to be accepted and the individual is motivated to change behaviour to avoid the threat, termed 'adaptive changes'. However, if perceived threat is high and perceived efficacy is low, the individual may devise fear-reducing strategies such as denial, as a way of coping with fear, termed 'maladaptive changes' (Witte, 1992).

In the context of cancer symptom presentation, a fearful response to a cancer symptom is likely to result in an adaptive response (seeking medical help) if the individual perceives themselves to have the ability to effectively seek medical help (high self-efficacy). In addition, beliefs about the benefits of early diagnosis and effectiveness of treatments for cancer (response efficacy) are likely to promote an adaptive response. For an individual who responds to a symptom of cancer with fear, but does not perceive themselves able to cope with the threat (low self-efficacy), or believes the treatments for cancer are ineffective (response efficacy), symptom presentation may be prolonged or completely inhibited. For individuals from a low socioeconomic group where fearful and fatalistic beliefs about cancer are more common (Quaife *et al*, 2015a), perceptions of self- and response efficacy are likely to be important when deciding whether to seek medical help for a cancer symptom, and could potentially explain prolonged symptom presentation.

There is evidence to support the EPPM from a meta-analysis of interventions using fear-inducing messages in public health campaigns for various target groups, including smoking cessation messaging and skin cancer messaging (Witte & Allen, 2000). The review found that public health campaigns were most effective when high fear-inducing messages were combined with high self-efficacy messages (Witte & Allen, 2000). However, the authors recommend using fear-inducing messaging with caution, and suggest that certain demographic characteristics such as age or gender influence how fear appeals are perceived (Witte & Allen, 2000). Considering fear of cancer is prevalent among low socioeconomic groups, the use of fear-inducing messages in a cancer awareness intervention should be avoided. Whilst the inclusion of individual differences is a strength of the EPPM, the model assumes that fear is the only response to a health threat and that fear is required to initiate a behavioural response. Other emotional responses such as embarrassment may be relevant in this context and influence the decision to present with symptoms (Marlow *et al*, 2014), but are currently not represented in the model. In addition, there is no representation in the EPPM for symptom attributions to decide whether the symptom is a health threat or not.

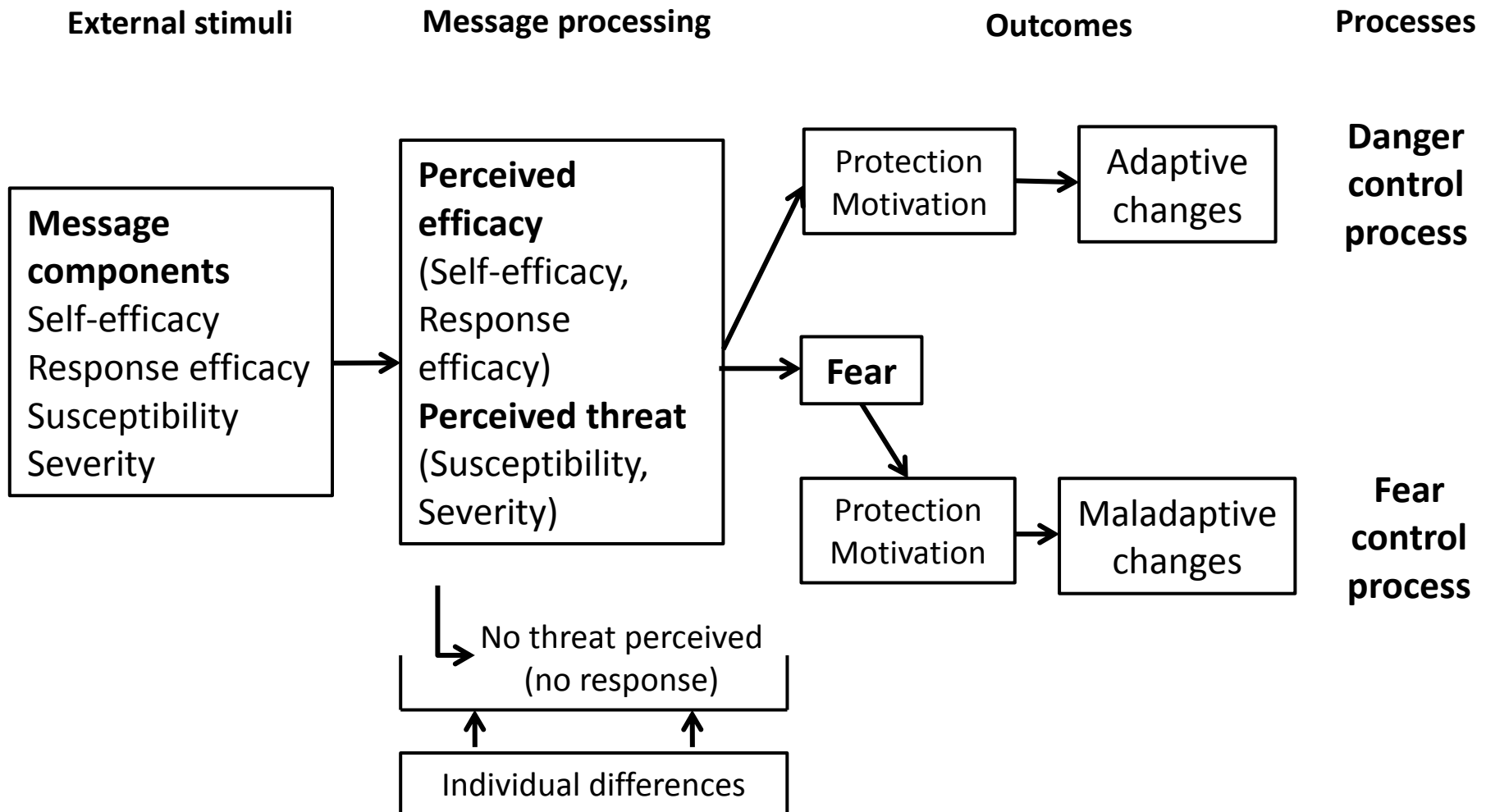


Figure 2.3 The Extended Parallel Processing Model (adapted from Witte, 1992)

2.3.4 The Theory of Planned Behaviour

The Theory of Planned Behaviour (TPB; Ajzen, 1991) was developed as an extension of the Theory of Reasoned Action (Fishbein and Ajzen, 1975). A key assumption of the TPB is that behavioural, normative and control beliefs influence intentions to perform a given health behaviour, which in turn influence performance or non-performance of behaviour (Ajzen, 1991; figure 2.4). Behavioural beliefs are defined as beliefs about the likely outcomes of behaviour, which produce a favourable or unfavourable attitude towards the behaviour. Normative beliefs result in perceived social pressure and subjective norms, which are formed as a result of normative expectations of others and the individual's motivation to comply with these. Finally, control beliefs result in perceived behavioural control, which refers to the perceived ease or difficulty of performing a given behaviour. According to the TPB, performance of a health behaviour is governed by the strength of intention to perform behaviour. Strong intentions are formed from favourable beliefs about the behaviour and high perceived behavioural control, which are more likely to translate into behavioural performance.

According to the TPB, if an individual discovers a symptom of cancer, the strength of intention to seek medical help is influenced by behavioural beliefs about the consequences of seeking medical help and undergoing diagnostic testing, normative beliefs such as social pressure from friends and family to seek medical help, and control beliefs such as perceptions about how easy or difficult seeking medical help would be. For example, if an individual believes the diagnostic tests for cancer to be non-invasive (behavioural beliefs), the individual is faced with social pressure from family members to present to the doctor with symptoms (normative beliefs), and they predict ease of performing the behaviour (control beliefs), their intention to visit the doctor would be high, and more likely to result in symptom presentation.

The TPB has been applied to testicular self-examination (Brubaker and Wickersham, 1990), cancer screening attendance (Rutter, 2000) and a range of non-health and health behaviours including self-examination (Armitage and Conner, 2001). The TPB constructs subjective norms and perceived behavioural control were found to be most influential for self-examination behaviour (Brubaker and Wickersham, 1990). Subjective norms were more influential for screening behaviour (Rutter, 2000), and only weakly related to intentions in

the review of health and non-health behaviour (Armitage & Conner, 2001). However, there is evidence for an intention-behaviour gap, in that the TPB has been observed to predict intentions to perform a behaviour (Hunter *et al*, 2003), but not actual behaviour (Sheeran, 2002). In addition, the role of emotions is not represented in the TPB (Perugini and Bagozzi, 2001), but as previously discussed are important in the context of cancer symptom presentation behaviour (Balasooriya-Smeekens *et al*, 2015). Furthermore, the TPB does not attempt to explain how an individual decides or interprets whether a symptom requires medical help or not.

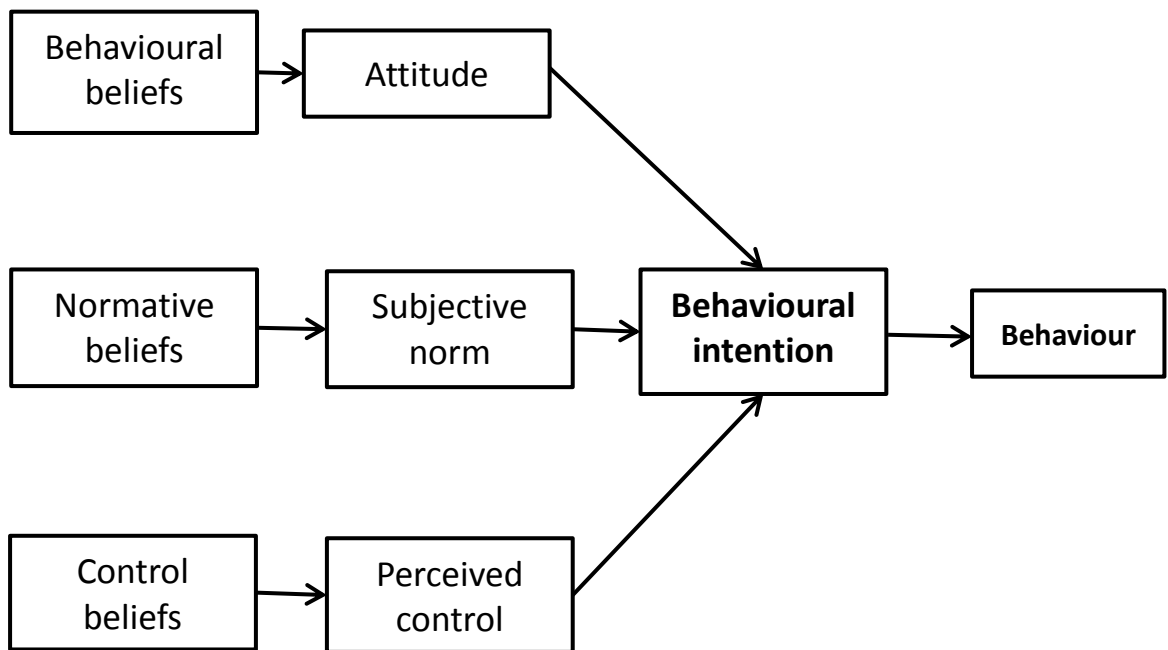


Figure 2.4 *Theory of Planned Behaviour (Armitage and Conner, 2001)*

2.3.5 Ecological Model of Health Behaviour

Ecological models take into account the environmental causes of behaviour, assuming that there are multiple, interacting levels of influence on behaviour (Sallis *et al*, 2003).

Descriptions and definitions of the levels of influence vary between ecological models, but generally start with levels of influence closest to the individual such as family members and friends, and ending with wider societal influences on behaviour, such as policies or cultural values.

The Ecological Model of Health Behaviour (McLeory *et al*, 1988) was developed as a variation of Bronfenbrenner’s ecological model of child development (Bronfenbrenner,

1977), with a specific focus on health behaviour. The model proposes that there are five levels of influence on health behaviour (Figure 2.5). The first level, 'intrapersonal factors', is defined as characteristics of the individual such as knowledge, attitudes and self-efficacy. The second level, 'interpersonal factors', is defined as formal and informal relationships within social networks such as family members friends and work groups. The model suggests that social relationships at this level are essential aspects of social identity, where social relationships can provide social support and influence behaviour through social norms. The third level, 'institutional factors', refers to social and organisational institutions that can influence behaviour such as the work place, neighbourhood organisations and the church. Organisations at this level provide economic and social resources for the individual, and can have both positive and negative effects on behaviour. For example, workplaces might support healthy behaviours by providing health promotion activities or incentives for smoking cessation. The fourth level of influence, 'community factors', is defined as relationships among organisations and informal networks and relationships within defined demographic and geographic boundaries. The fifth, and final level of influence described by the model is 'public policy', defined as laws and public policy that influence and restrict behaviour, for example a ban on smoking in public places.

Although the Ecological Model of Health Behaviour has not been applied specifically to cancer symptom presentation, it is likely that each level of influence can affect symptom presentation behaviour. For example, at the interpersonal level, friends and family may have previously discussed negative experiences in a healthcare setting. These experiences might influence behaviour at the individual level, where the individual recalls these instances and decides not to seek medical help based on these negative experiences. In addition, revisions of policy at the public policy, level such as the need to focus on lung cancer in Wales as a national priority, are likely to bring about change at the community and institutional levels through local initiatives and changes in lung cancer services. Initiatives or campaigns at community and institutional levels have the potential to influence the intrapersonal and interpersonal levels, for example, awareness campaigns might improve lung cancer knowledge for people in the community.

The Ecological Model of Health Behaviour has been applied to various health behaviours, and has been used to create multi-level interventions to successfully reduce socioeconomic inequalities for various aspects of health (Trickett and Beehler, 2013). In addition, ecological

models have been used to understand sources of smoking behaviour to aid development of successful interventions reducing smoking behaviour using a multi-level approach (Fisher, 2004). Using multi-level interventions based around ecological models is considered most important for low socioeconomic groups, taking into account wider environmental influences on behaviour and modifying factors at these levels (Trickett and Beehler, 2013; Hill *et al* 2005). Most interventions focus on an intervention at a single level, usually at the individual level, and it has been suggested that interventions designed to target behaviour at a single level are likely to increase health inequalities between affluent and deprived groups (Hill *et al*, 2005) and have short-term effects on behaviour change (Schensul, 2005). Ecological models are useful to facilitate detailed analysis of the target behaviour across the various levels of influence and in a specific context, in order to understand the wider contextual influences on behaviour. However, they do not attempt to offer insight into how cancer knowledge, beliefs or barriers could influence the decision to seek medical help for a potential cancer symptom.

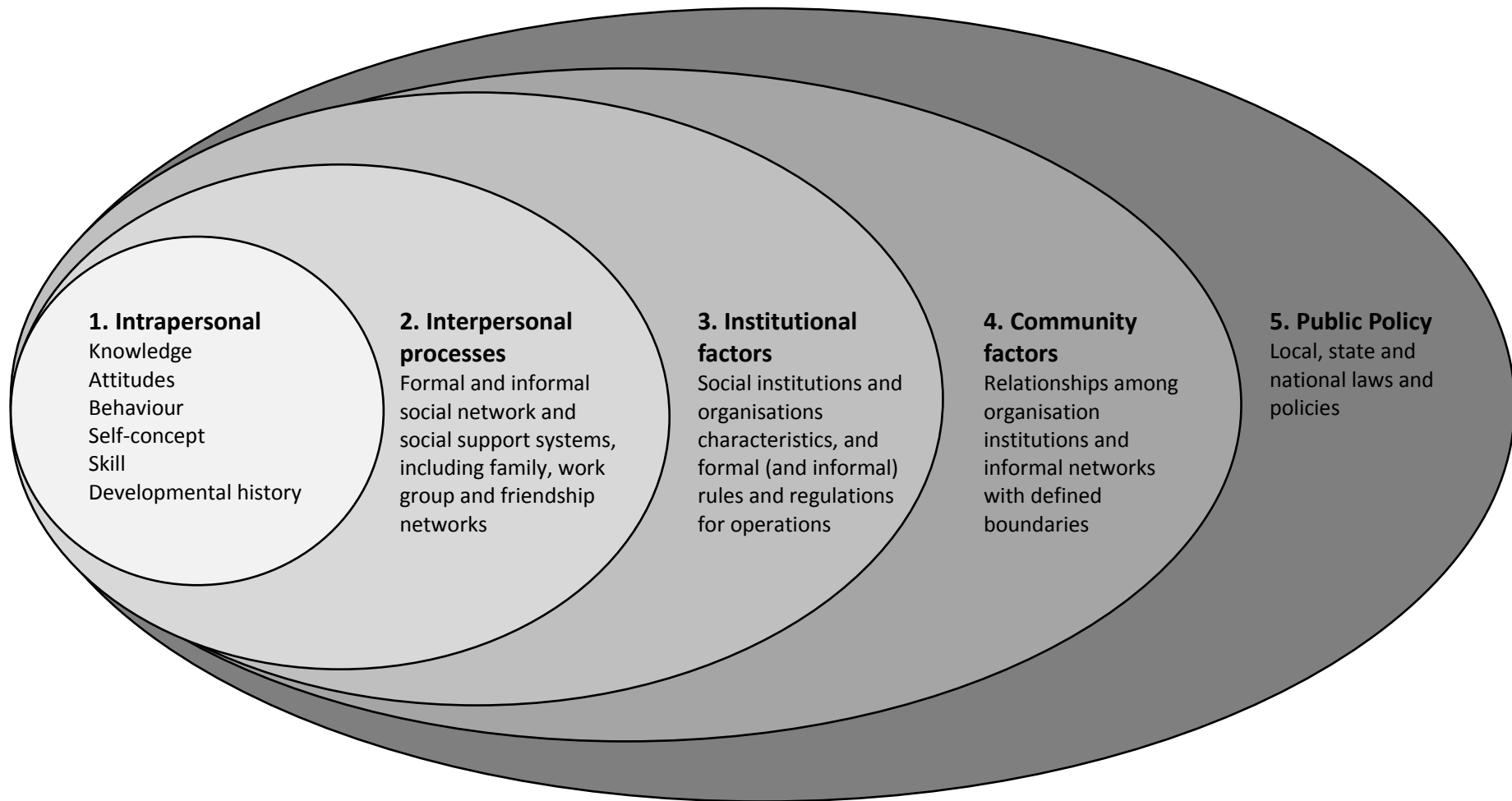


Figure 2.5 *Ecological Model of Health Behaviour (McLeory et al, 1988)*

2.3.6 Diffusion of Innovations Theory

Diffusion of Innovations Theory (Rogers, 1983) attempts to explain how an 'innovation' (a new or novel behaviour to the community) is diffused throughout the community, and adopted or rejected by an individual or social group (Figure 2.6). The theory assumes that social networks can disseminate information and adoption of the innovation through a process called diffusion. Diffusion refers to the different ways in which information about the innovation is communicated over time. According to Diffusion of Innovations theory, there are two types of communication channels: mass media communication channels (transmission of a message to a large audience) and interpersonal communication channels (face-to-face communication). The theory suggests that communication through interpersonal channels is more effective in adoption of the innovation, especially when the message is communicated by a peer. The speed with which the innovation is adopted is termed the rate of adoption. According to the theory, the rate of adoption can be influenced by the social system, where adoption or dismissal of an innovation may be dependent on the adoption or rejection of the innovation by an opinion leader (an individual who is socially accessible, conforms to social norms and has technical ability).

Although Diffusion of Innovations Theory has not been applied to cancer symptom presentation behaviour, it is likely to be useful for understanding how intervention messages can be diffused through the community to encourage cancer symptom presentation. Diffusion of Innovations Theory has been used in peer-led educational sexual health and school based smoking interventions (Campbell *et al*, 2008; Hart & Elford, 2003). In these interventions, well regarded and popular members of a particular social network were selected and trained as peer educators, to disseminate information about the risks of unprotected sex or smoking within their social network. Both interventions found a positive effect on condom use among gay men and smoking behaviour in schools, respectively, and were effective methods of using social networks to disseminate messages about health protective behaviour. The school based smoking intervention (ASSIST) was most effective in clearly defined and close-knit communities, such as the Welsh Valleys (Campbell *et al*, 2008). This was assumed to reflect the well-defined and stable relationships between peer supporters who have regular interpersonal contact (Campbell *et al*, 2008). This has implications in the current context as the Welsh Valleys are areas of deprivation, and such a strategy could be used to guide intervention message communication.

Although sexual health and smoking interventions provide evidence of the predictive value of the Diffusion of Innovations Theory, there are limitations. The theory assumes that adoption of an innovation is a linear process, from the individual who decided to diffuse the information, to early innovation adopters and finally late innovation adopters. However, in reality it is unlikely that adoption of an innovation is completely linear. In addition, although media channels are included in the theory as a type of innovation communication, the Diffusion of Innovations Theory has been criticised for downplaying the role of media (Afolayan *et al*, 2012). Media is considered to create innovation awareness and stimulate discussion, and is thought to play a bigger role in adoption than that stated by the model (Afolayan *et al*, 2012). Finally, Diffusion of Innovations Theory does not attempt to explain how beliefs or barriers might influence adoption of an innovation and the decision to seek medical help for a symptom.

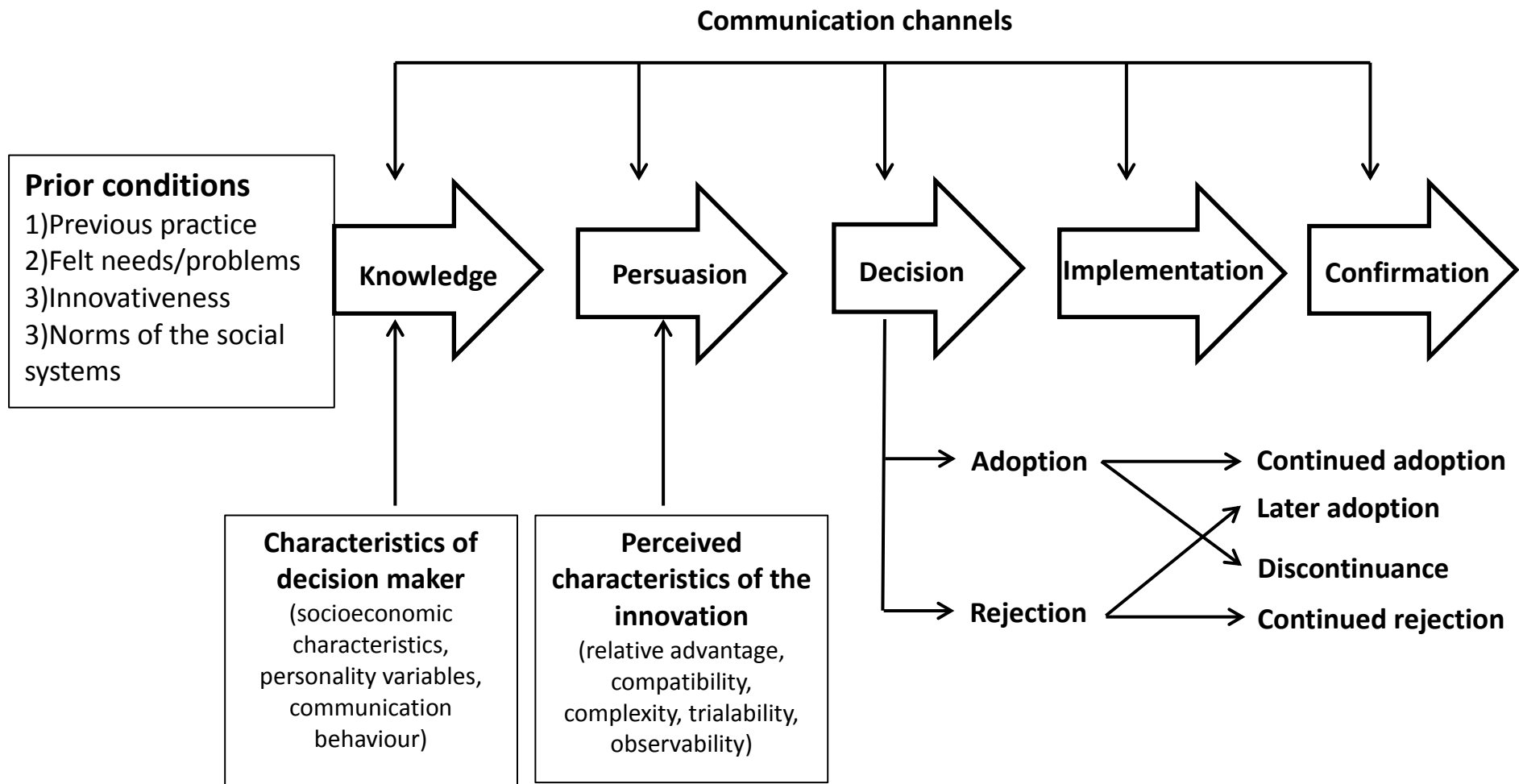


Figure 2.6 The five stages in the Innovation-Decision Process (adapted from Rogers, 1983)

2.3.7 The COM-B model and Theoretical Domains Framework

The Theoretical Domains Framework (TDF) was developed by a consensus group of experts in response to the overlapping nature of behaviour change theories, to create one unifying theory of behaviour change (Cane *et al*, 2012). In addition, the TDF was intended to overcome some of the problems associated with selecting theory for intervention development, providing a framework which could be applied to any behaviour change context. Eighty three behaviour change theories comprising a total of 122 constructs were identified, and refined into 14 theoretical domains (Cane *et al*, 2012), as shown in Table 2.1.

Table 2.1 TDF domain definitions and corresponding COM-B model construct (adapted from Cane *et al* 2012 and Michie *et al*, 2014 p88-91).

TDF domain	Definition of TDF domain	Corresponding COM-B model construct
Knowledge	An awareness of the existence of an entity or concept e.g. knowledge of a health condition	Capability
Skills	An ability or proficiency acquired through practice e.g. interpersonal skills	
Memory attention and decision processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives e.g. decision making	
Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions e.g. self-monitoring	
Social/professional role and identity	A set of behaviours and displayed personal qualities of an individual in a social or work setting e.g. social or professional identity	Motivation
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent or faculty that a person can put to constructive use e.g. self-efficacy	
Optimism	The confidence that things will happen for the best or that desired goals will be attained e.g. unrealistic optimism	
Beliefs about consequences	Acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation e.g. outcome expectancies	
Intentions	A conscious decision to perform a behaviour or resolve to act in a certain way e.g. stability of interventions	
Goals	Mental representations of outcomes or end states that an individual wants to achieve e.g. action planning	
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus e.g. incentives	
Emotions	A complex reaction pattern, involving experiential, behaviour and psychological elements, by which the individuals attempts to deal with a personally significant matter or event e.g. fear	
Environmental context and resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour e.g. resources/material resources	Opportunity
Social influences	Interpersonal processes that can cause individuals to change their thoughts, feelings and behaviours e.g. social norms	

The COM-B (Capability, Opportunity, Motivation-Behaviour) model was developed from the TDF, where each of the TDF constructs fit under each of the COM-B constructs (see Table 2.1). According to the COM-B model, behaviour is influenced through the constructs 'Capability', 'Opportunity' and 'Motivation' (Michie *et al*, 2011) (Figure 2.7). The COM-B model suggests that in order for behaviour to occur, an individual must have the 'Capability' (physical or psychological capacity of a person to perform behaviour) as well as the 'Opportunity' (physical opportunities created by the physical environment or social opportunities created by the cultural environment) (Michie *et al*, 2011). In addition, 'Motivation' to engage in the target behaviour must outweigh motivation to engage in competing behaviours. 'Motivation' may be automatic (automatic process e.g. habitual or emotional responses) or reflective (slower, deliberative processes e.g. conscious decision making) (Michie *et al*, 2011). The TDF can be used in combination with the COM-B model to provide a more granular level of understanding for each of the COM-B model constructs.

The arrows within the COM-B model represent how each construct could influence another within the system (Figure 2.7). The model assumes that both 'Capability' and 'Opportunity' can influence 'Motivation'. The bidirectional nature of the arrows with relation to each of the constructs and behaviour suggest that 'Capability', 'Opportunity' and 'Motivation' all influence behaviour, but also that behaviour influences them. The interaction between 'Opportunity' and 'Capability' is currently not represented in the model, and will be explored in this PhD. Each COM-B model construct will be described in further detail.

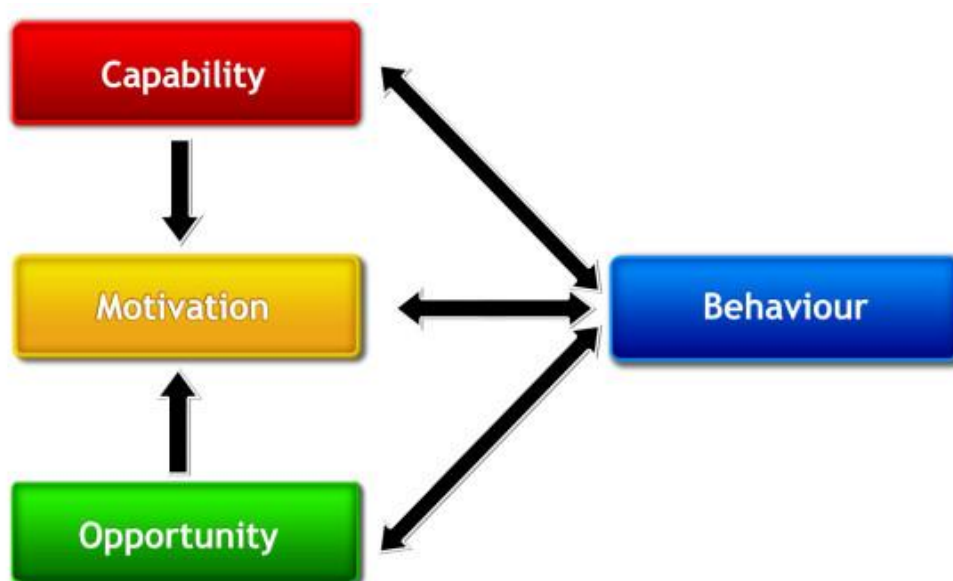


Figure 2.7 The COM-B Model (Michie *et al*, 2011)

Capability

The COM-B model construct 'Capability' is defined as the individual possessing the relevant skills or knowledge and capacity to engage in the necessary thought processes to perform the behaviour (Michie *et al*, 2011). As shown in, the TDF constructs 'knowledge', 'cognitive and interpersonal skills', 'memory, attention and decision processes', 'behavioural regulation', and 'physical skills' are represented under the Capability construct in the COM-B model. In the context of cancer symptom presentation, knowledge of cancer symptoms and perceptions of interpersonal skills in relation to presenting to the doctor with symptoms are required. Once a symptom is appraised using their knowledge of the symptoms of cancer, the individual decides whether to seek medical help or not (Walter *et al*, 2012). At this point, perceptions of whether they hold the interpersonal skills to present to the doctor with symptoms are likely to influence their decision to present to the GP. If an individual perceives themselves to not hold the necessary interpersonal skills to discuss symptom concerns with the doctor, they might prolong cancer symptom presentation.

Motivation

The construct 'Motivation' refers to psychological processes that energise and direct behaviour, conceptualised as automatic and reflective processes. Automatic motivation is defined as fast, unconscious processes such as emotions, involving automatic impulses as a result of associative learning. Reflective motivation involves slower, more deliberative processes, using conscious reflective decision making and goal directed behaviour involving evaluations and plans. The TDF constructs 'reinforcement', 'emotions', 'social/professional role and identity', 'beliefs about capabilities', 'beliefs about consequences', 'goals' and 'intentions' are represented under the Motivation construct in the COM-B model (see Table 2.1).

Beliefs about cancer can be used to understand the processes underlying automatic and reflective motivation. As previously discussed, beliefs about cancer are important in the context of cancer symptom presentation behaviour among people from a low socioeconomic group. Studies of beliefs about cancer report that participants often hold contradictory beliefs about cancer, in which fear of cancer co-exists with positive beliefs about treatments and cures for cancer (Robb *et al*, 2014; Quaife *et al*, 2015a). A study by Robb *et al*, (2014) of public perceptions of cancer found that most negative responses

towards cancer were fast and emotional, representing automatic motivation. However, for those who expressed positive beliefs about cancer, such as improved survival rates for cancer, such responses tended to be slower and much less emotional, representing reflective motivation (Robb *et al*, 2014). There is evidence to suggest that people from a low socioeconomic group hold more pessimistic beliefs about cancer and are less likely endorse statements reflecting positive beliefs about cancer (Quaife *et al*, 2015). It is likely that negative beliefs about cancer are represented on both the automatic and reflective motivation systems to prolong cancer symptom presentation.

Opportunity

Opportunity is defined as 'all the factors that lie outside of the individual that make the behaviour possible' (Michie *et al*, 2011). The COM-B model distinguishes between two types of opportunity: those created by the physical environment, such as financial resources or cues, and those created by the social environment, such as social networks and the cultural environment. The TDF constructs 'social influences', 'environmental context and resources' are represented under the Opportunity construct in the COM-B model. Whilst many psychological theories neglect to consider the wider physical and socio- environmental influences on behaviour (Glanz and Bishop 2010), the construct of Opportunity takes these influences into account. In socioeconomically deprived communities, where many people are living with economic hardship, poor housing and limited access to services, opportunity afforded by the environment is likely to impact on health and medical help seeking behaviour (Stephoe and Feldman, 2001; Ellen *et al*, 2001). Exploring the wider influences on symptom presentation behaviour is important in the context of this PhD, due to the focus on symptom awareness, beliefs and presentation in deprived communities of South Wales.

Although the TDF and COM-B model have not been applied in the current context, they offer a potentially useful insight into how both individual and socio-environmental factors might lengthen time to cancer symptom presentation in low socioeconomic groups. As previously discussed, both individual and environmental factors appear important in the context of cancer symptom presentation among low socioeconomic groups. Since the COM-B model and TDF take both individual and environmental factors into account, but other models and theories focus solely on either individual influences on behaviour or the environmental

influences on behaviour, the COM-B model and TDF were considered most comprehensive and relevant in this context.

Furthermore, four of the six theories and models described in this chapter underpin the TDF and COM-B model, with the exception of the CSM and the Ecological Model of Health Behaviour. Although the Ecological Model of Health Behaviour (McLeary *et al*, 1988) does not formally underpin the TDF and COM-B model, other ecological models applied to a specific health context such as diabetes (Burnet *et al*, 2002) were included in the development of the TDF and COM-B model. Therefore the theoretical constructs from ecological models are represented under the Opportunity construct of the COM-B model and associated TDF constructs of 'social influences' and 'environmental context and resources'. A general ecological model of health (the Ecological Model of Health Behaviour) was selected and described in this chapter because this was considered most useful in this context, rather than describing an ecological model adapted to a specific health context. The CSM attempts to explain how illness is inferred; however, the COM-B model and TDF are not formally underpinned by this model or a similar model. Therefore, symptom interpretations are not explicitly represented by the TDF or COM-B model. However, the domains of 'knowledge' and 'memory, attention and decision processes' are implicitly similar to the CSM construct of symptom identity and timeline. In addition, the CSM construct of consequences could be linked to the TDF domain beliefs about consequences. Therefore, although the CSM does not formally underpin the COM-B model or TDF, there is overlap between the models.

Since the COM-B model and TDF appear most relevant and comprehensive in the context of cancer symptom presentation among low socioeconomic groups, they will be used throughout this PhD thesis. The role of theory will be discussed in further detail later in this chapter.

2.4 Discussion

This chapter presented the theoretical underpinning of this PhD, which is concerned with understanding the influences on cancer symptom presentation behaviour in the context of socioeconomic deprivation. Eight theories and models of symptom attribution, attitude and belief formation, and the wider social and environmental influences on behaviour were

described and critically evaluated. A range of psychological and sociological theories including the Health Belief Model, Theory of Planned Behaviour, the Extended Parallel Processing Model, Diffusion of Innovations Theory, the Common Sense Model of Illness Self-Regulation, the Ecological Model of Health Behaviour, the Theoretical Domains Framework, and the COM-B model were identified as relevant in the current context. The TDF and COM-B model were considered most useful in the context of cancer symptom presentation behaviour among low socioeconomic groups, combining both individual and environmental factors to understand behaviour.

Although the six theories and models presented before the TDF and COM-B model could be applied to the context of cancer symptom presentation, they were considered to be potentially limiting if used in isolation. The main limitations were a lack of inclusion of emotional factors and the wider social and environmental influences on behaviour. For example, the HBM was useful for understanding how perceptions of severity, susceptibility, barriers and facilitators, and cues to action could guide behaviour. However, the HBM does not include emotions or environmental factors, which were discussed as important in this context (Balasooriya-Smeekens *et al*, 2015). In addition, the Ecological Model of Health Behaviour focused entirely on the environmental factors with no detail to guide understanding of how cancer knowledge and beliefs, or barriers to cancer symptom presentation could influence behaviour.

The TDF and COM-B model were identified as the most comprehensive of all the theories or models described in this chapter, and was selected as most relevant to the context and aims of this PhD. The breadth of the COM-B model and TDF including individual and environmental factors was considered key a strength. Therefore, the COM-B model and TDF could offer a potential solution to the limitations of each individual theory or model discussed, by including individual factors such as cancer symptom knowledge, motivational factors such as beliefs about cancer, and wider social and environmental factors such as contextual factors in the community.

However, there are potential limitations associated with reducing 83 behaviour change theories to a single framework. The main criticism of the TDF and COM-B model is that they are overly broad and reductionist. There are limitations associated with the wide range of theories which underpin the COM-B model and TDF, where certain theories are unrelated to

the context of cancer symptom presentation behaviour. For example, some of the 83 included theories are theories of non-health behaviour, including offending behaviour (e.g. General Theory of Deviant Behaviour; Kaplan, 1972), and are therefore redundant in the context of cancer symptom presentation behaviour. Finally, as previously discussed symptom interpretations are currently not explicitly represented under the COM-B model or TDF which could potentially limit in depth exploration of how symptoms might be interpreted. However, using the Common Sense Model of Illness Self-Regulation for this PhD thesis would be potentially limiting due to lack of inclusion of certain emotional factors and environmental influences on behaviour. Although there are limitations of the COM-B model and TDF, they implicitly or explicitly include all of the factors discussed, and are likely to be useful for understanding the factors influencing cancer symptom presentation behaviour among low socioeconomic groups.

2.5 The role of theory in this PhD

The primary aim of this PhD is to explore the barriers to cancer symptom presentation among low socioeconomic groups, using qualitative interviews and focus group studies. The qualitative studies will be supported by semi-structured topic guides, and will be developed in accordance with relevant theory identified in this chapter. Qualitative data analysis will involve framework analysis based around each of the COM-B constructs, to facilitate understanding of the influences on cancer symptom presentation behaviour among low socioeconomic groups. Themes generated from the data will be grouped under each of the COM-B model constructs, with the TDF used to facilitate grouping of themes.

The Behaviour Change Wheel will be used to facilitate intervention development for the secondary aim of this PhD. The Behaviour Change Wheel is theoretically underpinned by the TDF and the COM-B model, which are used to guide intervention development in the first stage of the intervention mapping process. This first stage involves mapping the barriers and facilitators of behaviour to the TDF and COM-B model, in order to understand the potential influences on cancer symptom presentation behaviour among low socioeconomic groups. It is important to fully understand the theoretical frameworks of the COM-B model and TDF, since these form the basis of the Behaviour Change Wheel. Basing qualitative data analysis around the TDF and COM-B model will be an advantage when using the Behaviour Change Wheel for intervention development, facilitating accurate mapping through an in depth

understanding of these barriers and facilitators to behaviour. All steps involved in the intervention development process using the Behaviour Change Wheel are described in Chapter 7.

Chapter 3

Systematic review of cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation and time to symptom presentation

3.1 Chapter overview

This chapter presents a systematic review of literature relating to cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation and time to symptom presentation (McCutchan *et al*, 2015; Appendix 1). The influences of knowledge, beliefs, and barriers/facilitators to symptom presentation on actual or anticipated cancer symptom presentation behaviour are explored. Further analysis of studies which include measures of socioeconomic group and lung specific studies were undertaken to allow insight into barriers to symptom presentation specific to certain socioeconomic groups or lung cancer, respectively. Finally, the evidence was critically appraised to explore the strength of evidence in relation to the research question for this systematic review.

3.2 Introduction

As outlined in Chapter 1, the Model of Pathways to Treatment (Walter *et al*, 2012) conceptualises the period of time between noticing a symptom and the start of cancer treatment into various intervals. The National Awareness and Early Diagnosis Initiative (NAEDI) framework provides a potentially useful insight into the factors influencing cancer symptom presentation behaviour, and suggests poor knowledge, negative beliefs and barriers can prolong the decision to seek medical help.

Knowledge of cancer symptoms is likely to be important during the appraisal stage, with potential misattribution of symptoms attenuating the decision to present (Low *et al*, 2015; Whitaker *et al*, 2015b). Beliefs about cancer are considered to be important in both the appraisal and help-seeking stages, where emotions such as fear might influence interpretation of symptoms (Whitaker *et al*, 2015b) and the decision to seek medical help (Bish *et al*, 2005; Macleod *et al*, 2009; Mitchell *et al*, 2008; Sheikh & Ogden, 1998; Smith *et al*, 2005). Barriers such as competing life events and ease of getting a medical appointment are thought to prolong symptom presentation during the help-seeking interval (Walter, 2012). However, a more detailed understanding of the psychosocial influences on cancer

symptom presentation is needed, in particular its relation to socioeconomic deprivation. Such insight is essential for developing behavioural interventions designed to promote timely symptom presentation and reduce socioeconomic inequalities in cancer outcomes. Previous reviews have focused on tumour site-specific delay factors (Bish *et al*, 2005; Mitchell *et al*, 2008; Ramirez *et al*, 1999) or common cancers only (Macleod *et al*, 2009), or have been restricted to qualitative studies (Smith *et al*, 2005) and patients with cancer (Macleod *et al*, 2009; Mitchell *et al*, 2008; Smith *et al*, 2005). The current review is the first to systematically examine the relationship between cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation and actual or anticipated cancer symptom presentation across all tumour sites, with a particular focus on socioeconomic deprivation.

3.2.1 Aims of present review

The present systematic review was conducted to:

- Identify literature relating to the domains of interest (cancer symptom knowledge, beliefs about cancer, barriers/facilitators to cancer symptom presentation, and time to symptom presentation).
- Provide insight into the relationship between cancer symptom presentation behaviour and cancer symptom knowledge, beliefs about cancer, and barriers/facilitators to symptom presentation.
- Gain insight into relationship between the domains of interest and socioeconomic group.
- Identify gaps in the literature and assess the quality of studies.
- Identify lung specific studies to explore how the domains of interest outlined above might influence lung cancer symptom presentation.

3.2.2 Systematic review methods

A systematic review involves using a clearly defined, prospectively developed research question, and explicit methods at each stage of the search, study selection, critical appraisal of studies and data analysis (Khan *et al*, 2003). All stages of the systematic review method are double checked by an independent coder to reduce any potential bias during study selection, critical appraisal and data analysis (Khan *et al*, 2003). Consequently, systematic

reviews are regarded as the highest level of evidence, due to measures taken to reduce bias and explicit, transparent methods utilised (Khan *et al*, 2003).

A systematic review differs from other types of review methods such as scoping review mainly due to the types of literature searches performed and the stages involved for the methodology (Davis *et al*, 2009). For example, a scoping review does not formally require the researcher to perform quality assessments of studies, or involve an independent coder to double check each stage of the methodology. In addition, the research question can be adapted throughout a scoping review, whereas for a systematic review, the research question remains fixed and should be formally registered prospectively on a systematic review protocol register. Finally, systematic reviews typically involve searches of multiple academic databases, where grey literature searches are optional. Whereas for a scoping review, a mixture of sources such as academic databases and grey literature (e.g. Google and key organisation websites) are searched for potential studies for inclusion in the review (Cacchione, 2016). Grey literature searches are performed to identify studies which have not formally undergone peer-review, and to allow the inclusion of smaller scale local studies. A systematic review method was considered most appropriate for the present review due to the high number of studies on the topic of cancer symptom presentation behaviour published in academic journals. Using systematic review method was considered to limit any potential bias at all stages of the review, and provide high strength of evidence.

3.3 Method

This systematic review followed the PRISMA guidelines for conduct of systematic reviews (Moher *et al*, 2009). The protocol was registered on PROSPERO which is an international prospective register for systematic review protocols (CRD42014013220; McCutchan *et al*, 2014) and is available on the NIHR HTA programme website (www.hta.ac.uk). At all stages of the search, data extraction and quality appraisal, 10% of studies were double checked for consistency by another PhD student. All discrepancies were resolved through discussion.

3.3.1 Search Strategy

The literature was searched up to July 2015 on the electronic databases of MEDLINE, PsycINFO, EMBASE and CINAHL. The de-duplicate function was used on Ovid and CINAHL

before reviewing abstracts. Manual searches of reference lists of included studies were performed. No grey literature was searched due to the high number of peer reviewed articles available for the topic of barriers to cancer symptom presentation. Smaller scale studies, potentially of lower quality, were therefore considered irrelevant for this review. A SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) search strategy tool was used for retrieval of studies (Appendix 2; Cooke *et al*, 2012). Other search tools such as PICO (Population, Intervention, Comparison, Outcomes) were considered; however, the 'Intervention' element in other search tools such as PICO was redundant because the present review was not concerned with outcomes of an intervention. Therefore, SPIDER was selected as most relevant in this context. Databases were searched using terms relating to *symptom presentation, cancer symptom knowledge, beliefs about cancer, perceived barriers and facilitators to symptom presentation* (Appendix 2).

3.3.2 Inclusion criteria

Included publications reported data from two or more of the following domains: symptom presentation, knowledge, beliefs and perceived barriers/facilitators. Definitions for each domain were:

- 'Symptom presentation': studies which measured actual symptom presentation (retrospectively recalled) or anticipated symptom presentation (hypothetically estimated) measured as continuous (time to presentation) or binary (did/did not present) variables. Studies of actual symptom presentation examined time to symptom presentation using a timeline for participants awaiting a diagnosis for suspected cancer symptoms or those who had previously received a diagnosis of cancer. Studies which examined anticipated time to symptom presentation asked participants to predict the length of time it might take for them to present to their doctor with a symptom. Studies which did not report duration of time to symptom presentation reported whether symptomatic participants did/did not present or asked asymptomatic participants to anticipate if they would/would not present with symptoms.
- 'Knowledge': studies which assessed knowledge for the symptoms of cancer through recall e.g. 'What symptoms of cancer can you list?' or recognition methods e.g. 'Which of these are symptoms of cancer?', or through retrospective recall of symptom interpretation and attributions at the time of symptom discovery.

- ‘Beliefs’: studies which explored any positive (e.g. beliefs about the benefits of early diagnosis and curability) or negative (e.g. fear and fatalism) beliefs surrounding cancer.
- ‘Perceived barriers/facilitators’: studies which assessed any actual or anticipated barriers or facilitators to symptom presentation.

There were no restrictions on date of publication or study methodology. Only English language studies from high income countries as classified by Organisation for Economic Co-operation and Development (OECD) membership (OECD, 2014) were included.

3.3.3 Socioeconomic group

Further analysis was undertaken for studies which measured socioeconomic group. Measures for socioeconomic group included individual or group level indicators such as education, income, postcode data, occupation, employment, or area level indicators such as postcode. Where measured and reported, the association between the domains of interest and socioeconomic indicator was described and the relevant statistics were extracted.

3.3.4 Lung cancer

Additional analysis was undertaken for studies examining lung cancer due to the change in focus of the proposed intervention (described in Chapter 1). Studies relating to lung cancer were further analysed to explore the influences of the domains of interest on lung cancer symptom presentation.

3.3.5 Exclusion criteria

Studies not relating to cancer and those that did not measure two or more of the domains of interest were excluded. Studies of self-examination behaviour, efficacy of interventions, genetic risk, healthcare professionals’ perspective, cancer prevention, treatments for cancer or living with cancer, and studies involving children were excluded. Studies not written in English, review papers or conference abstracts were excluded. Studies of screening behaviour and studies using participants with screen detected cancer were excluded as the barriers to presenting to the doctor with self-detected symptoms are likely to be different to

the barriers experienced in a potentially asymptomatic sample, prompted with a letter reminding them to engage in screening. Studies from low/middle income countries were excluded as the barriers to presentation are likely to be different in low income countries where healthcare provision is poor (Figure 3.1).

3.3.6 Data extraction and synthesis

Data were extracted onto a template using the following headings: method, sample characteristics, tumour site, symptom presentation, knowledge, beliefs, perceived barriers/facilitators, socioeconomic group measure, statistical association between variables of interest and socioeconomic measure. Headings were selected based around the NAEDI framework outlined in Chapter 1. Typically, systematic reviews involve a meta-analysis; however, due to the heterogeneity of included studies a meta-analysis was precluded, and a narrative synthesis was performed using guidance outlined by Popay *et al* (2006).

Data from the narrative of qualitative and quantitative articles were extracted and entered onto an Excel spreadsheet under each heading outlined above. Where reported, statistical associations between the variables of interest were entered onto the spreadsheet. The spreadsheet was subsequently used to explore relationships within and between studies to identify similar and disparate themes (Popay *et al*, 2006).

3.3.7 Critical Appraisal

The methodological quality of all included studies was examined using a Critical Appraisal Skills Programme tool (CASP, 2014) appropriate for the study design. Quality was assessed according to each domain on the CASP checklists: rationale of study, methodology, design, recruitment, data collection, data analysis, ethical issues, reporting of findings and contribution to research. The CASP tool was adapted to assess contribution of research to the specific research question to include quality assessments on timeliness of study post diagnosis, use of theory, socioeconomic variation within sample etc. (see Appendix 3 for adapted CASP tool). For example, if lung cancer patients were interviewed 12 months post diagnosis, the sample would be biased due to poor lung cancer survival rates. Overall quality was categorised as good, medium or poor.

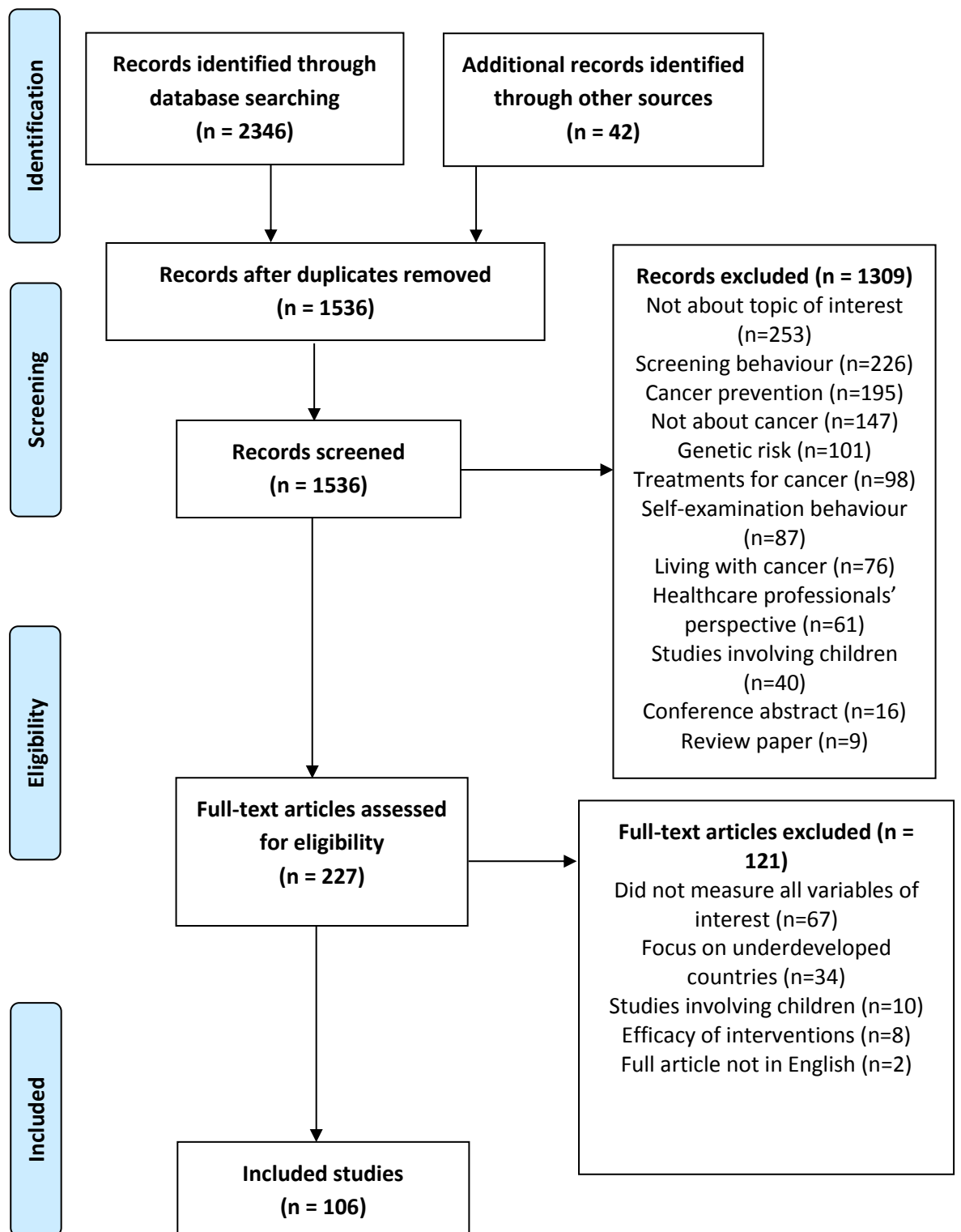


Figure 3.1 PRISMA flow chart

3.4 Results

The search returned a total of 1536 studies after 810 duplicates had been removed. A total of 1309 studies were excluded based on title and abstract, leaving 227 studies to be read in full. A total of 106 studies met the inclusion criteria (Figure 3.1). Twenty-two of these studies were found through hand searching reference lists.

Included studies employed qualitative methods (n=36), quantitative methods (n=61) and mixed methods (n=9). Quality of studies was good (n=21), medium (n=72) and poor (n=13). Limitations of lower quality studies included measuring but not reporting socioeconomic group differences for all outcome measures, leaving a long period of time between cancer diagnosis and participation in the study, and recruitment of samples biased towards higher socioeconomic groups. The overall combined percentage agreement between raters (GM and RR) for inclusion/exclusion of studies, critical appraisal and data extraction was 87%. A total of 70 studies examined time to symptom presentation, 14 studies reported presentation behaviour (if participants did/did not present or anticipate presenting to their doctor with reported symptoms), 66 studies retrospectively measured actual time to symptom presentation, 17 studied anticipated time to symptom presentation, 82 studies assessed knowledge for cancer symptoms, 54 studies explored beliefs about cancer and 83 studies examined perceived barriers/facilitators to symptom presentation. Studies by tumour site included: breast (n=30), any cancer/multiple tumour sites (n=29), colorectal (n=12), skin (n=10), oral and pharyngeal (n=7), lung (n=5), ovarian (n=4), prostate (n=3) gynaecological (n=2), testicular (n=2), lymphoma (n=1) and endometrial (n=1) (Table 3.1). Results are presented according to domain headings.

3.4.1 Symptom presentation

Studies examining anticipated symptom presentation reported shorter time to symptom presentation compared with studies that examined actual time to symptom presentation. In the former, most participants anticipated seeking medical help within one week (Brain *et al*, 2014; Forbes *et al*, 2011; Hunter, 2003) or within one month (Cooper *et al*, 2013; Low *et al*, 2013; Quaipe *et al*, 2014; Robb *et al*, 2009), in contrast to real-world studies where it was more common for patients to have waited over two months before seeking medical help

(Blum *et al*, 1999; Cassileth *et al*, 1988; Chonjnacka-Szwalowska, 2013; Corner *et al*, 2005; Crosland & Jones, 1995; Emery *et al*, 2013; Freidman, 2006; Gascoigne *et al*, 1999; Gould, 2010; Henderson, 1965; Kakagia *et al*, 2013; Lund-Nielsen *et al*, 2011; Oliveria, 1999; Ristvedt, 2014; Roncoroni *et al*, 1999; Schmid-Wendtner *et al*, 2002; Scott *et al*, 2009; Scott *et al*, 2008; Siminoff *et al*, 2014; Trivers *et al*, 2011; Walter *et al*, 2014). The most prompt actual and anticipated symptom presentation was reported for lumps (Burgess *et al*, 2001; Burgess *et al*, 2006; Burgess *et al*, 1998; Caplan, 1995; Chapple *et al*, 2004b; Coates *et al*, 1992; de Nooijer *et al*, 2001; Emery *et al*, 2013; Freidman, 2006; Grunfeld *et al*, 2003; Lauver *et al*, 1995; Meechan, 2003; O'Mahony & Hegarty, 2009; Quaiife *et al*, 2014; Sheikh & Ogden, 1998) or bleeding (Birt *et al*, 2014; Cooper *et al*, 2013; Corner *et al*, 2005; de Nooijer *et al*, 2001; Hale *et al*, 2007; McCaffery *et al*, 2003; Quaiife *et al*, 2014; Robb *et al*, 2009; Sheikh & Ogden, 1998; Simon *et al*, 2010; Smith & Anderson 1985; Trivers *et al*, 2011; van Osch *et al*, 2007; Waller *et al*, 2009). Studies examining participants who reported experiencing a potential symptom of cancer in the past three months found that between 41% and 75% of participants had consulted a doctor about their symptom (Cameron & Hinton, 1968; Cockburn, 2003; Courtney *et al*, 2012; Simon *et al*, 2010; Whitaker *et al*, 2014).

Disparity between actual and anticipated symptom presentation relating to socioeconomic group was observed. In five studies, shorter anticipated time to symptom presentation was observed in lower compared to higher socioeconomic groups (Brain *et al*, 2014; Low *et al*, 2013; Quaiife *et al*, 2014; Robb *et al*, 2009; van Osch *et al*, 2007). Conversely, in two studies, longer anticipated time to symptom presentation was reported in those from lower socioeconomic groups compared with higher socioeconomic groups (Facione *et al*, 2002; Fitzpatrick *et al*, 1998).

Studies which measured actual time to symptom presentation reported the longest times to symptom presentation among individuals with lower educational attainment (Cameron & Hinton, 1968; Coates *et al*, 1992; Cockburn, 2003; Facione, 2006; Goldsen *et al*, 1957; Kakagia *et al*, 2013; Ristvedt, 2014; Tomlinson *et al*, 2012), lower annual income (Goldsen *et al*, 1957; Samet *et al*, 1988), lower occupation and employment (Burgess *et al*, 2001; Goldsen *et al*, 1957; Lam, 2003) and those from deprived areas (Forbes *et al*, 2014; Scott *et al*, 2008). This effect was also observed in studies of actual symptom presentation where multiple socioeconomic indices were reported (Caplan, 1995; Coates *et al*, 1992; Goldsen *et al*, 1957; Kakagia *et al*, 2013; Li *et al*, 2012; Rauscher *et al*, 2010). In addition, later stage

cancer was associated with lower annual income (Lannin *et al*, 1998) and higher tumour thickness was associated with lower educational attainment (Baumert *et al*, 2007). Twenty-three studies found no group differences for socioeconomic group indicators and time to symptom presentation (Brouha *et al*, 2005; Burgess *et al*, 1998; Burgess *et al*, 2000; Carter-Harris, 2015; Chonjnacka-Szwalowska, 2013; Esteva *et al*, 2013; Greer, 1974; Hunter, 2003; Loehrer *et al*, 1991; Magery *et al*, 1977; McCaffery *et al*, 2003; Meechan, 2003; Mor, 1990; Oliveria, 1999; Richard *et al*, 2000; Ristvedt, 2014; Rozniatowski *et al*, 2005; Siminoff *et al*, 2014; Simon *et al*, 2010; Temoshok, 1983; Tomlinson *et al*, 2012; Trivers *et al*, 2011).

3.4.2 Knowledge

Knowledge of symptoms based on recall methods was generally lower than in studies that used recognition methods. Lump symptoms were the most recalled and well-recognised potential cancer symptom (de Nooijer *et al*, 2001; Facione *et al*, 2002; Forbes *et al*, 2014; Grunfeld *et al*, 2002; Hvidberg *et al*, 2014; Marlow *et al*, 2014; McCaffery *et al*, 2003; Niksic *et al*, 2015; Phillips & Taylor, 1961; Quaife *et al*, 2014; Robb *et al*, 2009; Sheikh & Ogden, 1998; van Osch *et al*, 2007; Waller *et al*, 2009). This was supported by retrospective studies where patients presenting with a lump were most likely to have attributed their lump symptom to cancer (Burgess *et al*, 2001; Burgess *et al*, 1998; Gould, 2010; Mor, 1990; O'Mahony *et al*, 2011).

Knowledge was generally poor for non-specific symptoms of cancer. Symptoms such as fatigue or unexplained weight loss were poorly recalled or recognised as potential symptoms of cancer (Brain *et al*, 2014; de Nooijer *et al*, 2001; Forbes *et al*, 2011; Hvidberg *et al*, 2014; Low *et al*, 2013; Marlow *et al*, 2014; Tod & Joanne, 2010; Waller *et al*, 2009). In retrospective studies, patients experiencing non-specific symptoms recalled attributing them to other benign causes or life stresses (Andersen *et al*, 2010; Brandner *et al*, 2014; Brouha *et al*, 2005; Carter-Harris, 2015; Cochran *et al*, 1986; Gascoigne *et al*, 1999; Li *et al*, 2012; Siminoff *et al*, 2014; Smith & Anderson 1985; Tod *et al*, 2008; Tod & Joanne, 2010; Whitaker *et al*, 2015c; Whitaker *et al*, 2014) or not recognising the seriousness of their symptoms (Andersen *et al*, 2010; Brouha *et al*, 2005; Burgess *et al*, 2001; Burgess *et al*, 2006; Burgess *et al*, 1998; Cameron & Hinton, 1968; Coates *et al*, 1992; Cockburn, 2003; Facione & Giancarlo, 1998; Fitzpatrick *et al*, 1998; Grant *et al*, 2010; Greer, 1974; Henderson, 1965; Howell *et al*, 2008; Larkey *et al*, 2001; Li *et al*, 2012; O'Mahony & Hegarty, 2009; Oliveria, 1999; Richard *et al*,

2000; Ristvedt, 2014; Ristvedt & Trinkaus, 2005; Roncoroni *et al*, 1999; Schmid-Wendtner *et al*, 2002; Siminoff *et al*, 2014; Smith & Anderson 1985; Tomlinson *et al*, 2012; Whitaker *et al*, 2015c; Whitaker *et al*, 2014) resulting in patients prolonging symptom presentation (Brandner *et al*, 2014; Brouha *et al*, 2005; Gould, 2010; Henderson, 1965; Howell *et al*, 2008; Roncoroni *et al*, 1999; Siminoff *et al*, 2014; Smith & Anderson 1985) or experiencing later stage at diagnosis (Carter-Harris, 2015).

There was a tendency to normalise symptoms, attributing symptoms to ageing (Brandner *et al*, 2014; Burgess *et al*, 2006; Corner *et al*, 2005; Emery *et al*, 2013; Howell *et al*, 2008) or other benign causes such as haemorrhoids (Brandner *et al*, 2014; Chapple *et al*, 2004b; Cooper *et al*, 2013; Courtney *et al*, 2012; Emery *et al*, 2013; Ramos *et al*, 2009; Roncoroni *et al*, 1999) before interpreting symptoms as potentially serious (Cassileth *et al*, 1988; Cooper *et al*, 2013; Courtney *et al*, 2012; Scott *et al*, 2009; Scott *et al*, 2008). Two studies found that symptom interpretations were influenced by perceptions of cancer risk. Individuals who perceived themselves as low risk for cancer, were less likely to attribute symptoms as potentially indicative of cancer and consequently prolonged symptom presentation (Andersen *et al*, 2010; Emery *et al*, 2013).

Four studies examined the relationship between knowledge and symptom presentation. Good cancer symptom knowledge was associated with appropriately timed intentions to seek medical help (de Nooijer *et al*, 2003; Grunfeld *et al*, 2003; Ruiter *et al*, 2008; Sheikh & Ogden, 1998).

Poorer cancer symptom knowledge was associated with low socioeconomic group when measured by educational attainment (Brain *et al*, 2014; Cockburn, 2003; Facione *et al*, 2002; McCaffery *et al*, 2003; Quaife *et al*, 2014; Schmid-Wendtner *et al*, 2002), occupation (Grunfeld *et al*, 2002; Waller *et al*, 2009) and multiple indicators (Brain *et al*, 2014; Hvidberg *et al*, 2014; Lannin *et al*, 1998; Niksic *et al*, 2015; Rauscher *et al*, 2010; Robb *et al*, 2009; Scanlon *et al*, 2006). These findings were consistent across site-specific and non site-specific studies, suggesting poor general cancer symptom knowledge in low socioeconomic groups regardless of cancer type. One study found that people from low socioeconomic groups attributed poor cancer knowledge to reluctance to talk about cancer in the community (Scanlon *et al*, 2006).

3.4.3 Beliefs about cancer

In most studies, beliefs were formed from participants' past experiences of cancer, usually witnessing friends or family with the disease (Burgess *et al*, 2001; Chonjnacka-Szwalowska, 2013; Facione, 2006; Henderson, 1965; Marlow *et al*, 2014; O'Mahony & Hegarty, 2009; O'Mahony *et al*, 2011; Shahid *et al*, 2009). Positive beliefs were identified in nine studies (Blum *et al*, 1999; Burgess *et al*, 2001; Cameron & Hinton, 1968; Chonjnacka-Szwalowska, 2013; Cockburn, 2003; Hunter, 2003; Marlow *et al*, 2014; O'Mahony *et al*, 2011; van Osch *et al*, 2007) and tended to focus on the effectiveness of modern cancer treatments, where participants expressed trust in doctors and the medical system and endorsed the benefits of early diagnosis (Blum *et al*, 1999; Cameron & Hinton, 1968; Facione, 2006; Grunfeld *et al*, 2003; Hunter, 2003; Marlow *et al*, 2014; Scanlon *et al*, 2006) or acknowledged that cancer can be cured (Marlow *et al*, 2014; Scanlon *et al*, 2006). Such beliefs tended to encourage timely symptom presentation to a primary care physician (Cameron & Hinton, 1968; Facione, 2006; Grunfeld *et al*, 2003; Hunter, 2003; Lauver *et al*, 1995; Marlow *et al*, 2014; O'Mahony *et al*, 2011; Scott *et al*, 2009). Two studies found that those with low educational attainment were less likely to endorse positive beliefs about the benefits of early detection (Cockburn, 2003; Quaife *et al*, 2015a).

Negative beliefs tended to manifest in fear or fatalism regarding cancer. Fear was frequently reported across all studies examining beliefs. This included fear of diagnosis (Cameron & Hinton, 1968; Chapple *et al*, 2004b; Facione, 1995; Gould, 2010; Hale *et al*, 2007; Henderson, 1965; Kakagia *et al*, 2013; Lam, 2003; Larkey *et al*, 2001; Lauver *et al*, 1995; Lyubomirsky *et al*, 2006; Mor, 1990; Tod *et al*, 2008; Tod & Joanne, 2010; Whitaker *et al*, 2015c), fear of treatment (Burgess *et al*, 2001; Cameron & Hinton, 1968; Chapple *et al*, 2004b; Facione, 1995; Facione, 2006; Fitzpatrick *et al*, 1998; Greer, 1974; Grunfeld *et al*, 2003; Hunter, 2003; Lyubomirsky *et al*, 2006; Marlow *et al*, 2014), and fear of dying (Facione, 1995; Facione, 2006; Marlow *et al*, 2014; Sheikh & Ogden, 1998). Fatalistic beliefs were a common theme throughout studies, but were expressed only by a minority of participants per study (Chapple *et al*, 2004b; Chonjnacka-Szwalowska, 2013; Coates *et al*, 1992; Facione *et al*, 2002; Facione, 1997; Facione, 2006; Goldsen *et al*, 1957; Kakagia *et al*, 2013; Marlow *et al*, 2014; O'Mahony *et al*, 2011; Price, 1993; Sheikh & Ogden, 1998). Fearful and fatalistic beliefs about cancer were more likely to be expressed by individuals from low socioeconomic groups based on educational attainment (Chonjnacka-Szwalowska, 2013; McCaffery *et al*,

2003; Quaife *et al*, 2015a), or multiple indices (Coates *et al*, 1992; Loehrer *et al*, 1991; Scanlon *et al*, 2006). People from low socioeconomic groups were more likely to hold negative beliefs around cancer survival (Grunfeld *et al*, 2002) or wrongly estimate five-year cancer survival (Hvidberg *et al*, 2014) based on occupation and multiple indices respectively.

When considering time to symptom presentation, fearful beliefs about cancer appeared to operate at the two extremes of immediate or prolonged symptom presentation (de Nooijer *et al*, 2001). For participants whose fearful beliefs encouraged immediate (actual or hypothetical) presentation to doctors (Burgess *et al*, 2001; Burgess *et al*, 1998; Cameron & Hinton, 1968; de Nooijer *et al*, 2001; Facione, 1997; Facione, 2006; Goldsen *et al*, 1957; Marlow *et al*, 2014; Mor, 1990; O'Mahony *et al*, 2011; Ramos *et al*, 2009), a visit to the doctors was used to alleviate anxiety associated with the symptom (Burgess *et al*, 2001; Cameron & Hinton, 1968; de Nooijer *et al*, 2001; Facione, 2006; Goldsen *et al*, 1957; Lund-Nielsen *et al*, 2011; Marlow *et al*, 2014; O'Mahony & Hegarty, 2009; Richard *et al*, 2000; Rogers *et al*, 2011; Scott *et al*, 2009). This was usually coupled with the participant expressing trust in the medical profession and positive beliefs surrounding early diagnosis (Burgess *et al*, 2001; Facione, 2006; Scott *et al*, 2009).

For individuals whose fearful beliefs led to prolonged symptom presentation (sometimes years) (Burgess *et al*, 2001; Burgess *et al*, 2006; de Nooijer *et al*, 2001; Freidman, 2006; Goldsen *et al*, 1957; Gould, 2010; Greer, 1974; Grunfeld *et al*, 2003; Hale *et al*, 2007; Hunter, 2003; Kakagia *et al*, 2013; Lannin *et al*, 1998; Lauver *et al*, 1995; Marlow *et al*, 2014; Mor, 1990; O'Mahony & Hegarty, 2009; O'Mahony *et al*, 2011; Ramos *et al*, 2009; Scanlon *et al*, 2006; Smith & Anderson 1985; Tod & Joanne, 2010), denial of or ignoring symptoms initially alleviated anxiety associated with the symptom (Brouha *et al*, 2005; Chapple *et al*, 2004b; de Nooijer *et al*, 2001; Facione, 2006; Freidman, 2006; Gould, 2010; Greer, 1974; Hale *et al*, 2007; Henderson, 1965; Lauver *et al*, 1995; Magarey *et al*, 1977; Marlow *et al*, 2014; O'Mahony & Hegarty, 2009; O'Mahony *et al*, 2011; Shahid *et al*, 2009; Sheikh & Ogden, 1998). Such beliefs were usually combined with fatalistic beliefs such as 'cancer cannot be cured' (Facione, 2006; Goldsen *et al*, 1957; Lannin *et al*, 1998; O'Mahony *et al*, 2011; Scanlon *et al*, 2006; Tod & Joanne, 2010), and were associated with the longest times to symptom presentation or were expressed by those with advanced stage disease (Bergamo *et al*, 2013; Chonjnacka-Szwalowska, 2013; Facione *et al*, 2002; Facione, 1997; Facione, 2006; Shahid *et*

al, 2009). This is likely to reflect a lack of perceived benefit in presenting to doctors due to the belief that ‘nothing can be done’ (Facione, 2006; Marlow *et al*, 2014).

3.4.4 Barriers to symptom presentation

Some participants reported service barriers relating to concerns about wasting doctors’ time (Burgess *et al*, 2001; Forbes *et al*, 2011; Hale *et al*, 2007; Kakagia *et al*, 2013; Low *et al*, 2013; Robb *et al*, 2009; Scott *et al*, 2009; Tod *et al*, 2008; Tod & Joanne, 2010; Walter *et al*, 2014; Whitaker *et al*, 2015c; Whitaker *et al*, 2014), lack of continuity with their primary care doctor (Coates *et al*, 1992; Emery *et al*, 2013; Whitaker *et al*, 2015c) or difficulties with accessing and making an appointment (Burgess *et al*, 2006; Facione *et al*, 2002; Forbes *et al*, 2011; Freidman, 2006; Hale *et al*, 2007; Kakagia *et al*, 2013; Li *et al*, 2012; Marlow *et al*, 2014; Quaife *et al*, 2014; Scanlon *et al*, 2006; Tod & Joanne, 2010; Waller *et al*, 2009; Whitaker *et al*, 2015c; Whitaker *et al*, 2014). Low general health service utilisation for acute or long term conditions lengthened time to cancer symptom presentation (Burgess *et al*, 2001; Cameron & Hinton, 1968; Coates *et al*, 1992; Cooper *et al*, 2013; Corner *et al*, 2005; Facione, 1997; Fitzpatrick *et al*, 1998; Goldsen *et al*, 1957; Greer, 1974; Kakagia *et al*, 2013; Lannin *et al*, 1998; Larkey *et al*, 2001; Marlow *et al*, 2014; Rauscher *et al*, 2010; Richard *et al*, 2000; Ristvedt & Trinkaus, 2005; Rozniatowski *et al*, 2005; Tod *et al*, 2008). In addition, a poor relationship with the doctor (Bergamo *et al*, 2013; Henderson, 1965; Larkey *et al*, 2001) or the belief that the doctor could not do anything to treat their symptoms prolonged symptom presentation (de Nooijer *et al*, 2001; Shahid *et al*, 2009).

Practical barriers such as being ‘too busy to make an appointment’ prolonged symptom presentation (Burgess *et al*, 2001; Gould, 2010; Low *et al*, 2013; Marlow *et al*, 2014; Mor, 1990; Richard *et al*, 2000; Schmid-Wendtner *et al*, 2002; Simon *et al*, 2010) and such barriers were more frequently reported in high socioeconomic groups (Robb *et al*, 2009). Other practical barriers reported included work and family commitments (Andersen *et al*, 2010; Chapple *et al*, 2004b; de Nooijer *et al*, 2001; Emery *et al*, 2013; Lauver *et al*, 1995; Scott *et al*, 2009) or ill health of another family member (Brandner *et al*, 2014; Lund-Nielsen *et al*, 2011), prolonging symptom presentation due to time constraints. Those from a low socioeconomic group based on multiple indices were more likely to report problems with transportation to get to an appointment (Niksic *et al*, 2015; Scott *et al*, 2009).

Emotional barriers included embarrassment or fear associated with undergoing intimate diagnostic tests (Emery *et al*, 2013; Fitzpatrick *et al*, 1998; Forbes *et al*, 2011; Hale *et al*, 2007; Henderson, 1965; Kakagia *et al*, 2013; Larkey *et al*, 2001; Low *et al*, 2013; Marlow *et al*, 2014; Price, 1993; Robb *et al*, 2009; Shahid *et al*, 2009; Siminoff *et al*, 2014; Simon *et al*, 2010; Tod & Joanne, 2010; Whitaker *et al*, 2015c) or embarrassment associated with disclosing symptoms to the doctor (Cameron & Hinton, 1968; Chapple *et al*, 2004b; de Nooijer *et al*, 2001; Gascoigne *et al*, 1999; Hale *et al*, 2007; Henderson, 1965; Shahid *et al*, 2009; Sheikh & Ogden, 1998). Worry about being perceived as a hypochondriac (Chapple *et al*, 2004b) and worry about what the symptoms might be were also reported as barriers to symptom presentation (Crosland & Jones, 1995; Tod & Joanne, 2010). Stoicism in men prolonged symptom presentation, where seeking medical help was perceived as a sign of weakness (Chapple *et al*, 2004b; Emery *et al*, 2013; Hale *et al*, 2007; Scanlon *et al*, 2006). People from low socioeconomic groups based on multiple indices were more likely to report embarrassment, being too scared, or worry what the doctor might find as barriers to symptom presentation (Niksic *et al*, 2015). One study found that those with low education attainment were more likely to report not wanting to know if they had cancer (Quaife *et al*, 2015a).

One study reported that confidence in the ability to communicate symptoms was a barrier to symptom presentation in low socioeconomic groups based on multiple indices (Niksic *et al*, 2015). In countries where patients pay for their healthcare, those with lower annual income were more likely to report the cost of consultation as a barrier to symptom presentation (Cooper *et al*, 2013; Freidman, 2006; Lam, 2003; Lannin *et al*, 1998).

3.4.5 Facilitators of symptom presentation

The most common facilitator of symptom presentation was disclosure of symptoms to a family member or friend (Andersen *et al*, 2010; Brandner *et al*, 2014; Brouha *et al*, 2005; Burgess *et al*, 2001; Burgess *et al*, 2006; Burgess *et al*, 1998; Crosland & Jones, 1995; de Nooijer *et al*, 2001; Emery *et al*, 2013; Esteva *et al*, 2013; Facione & Giancarlo, 1998; Facione, 1997; Goldsen *et al*, 1957; Gould, 2010; Hale *et al*, 2007; Howell *et al*, 2008; Kakagia *et al*, 2013; Li *et al*, 2012; Marlow *et al*, 2014; O'Mahony & Hegarty, 2009; O'Mahony *et al*, 2011; Pedersen *et al*, 2011; Ramos *et al*, 2009; Richard *et al*, 2000; Rogers *et al*, 2011; Rozniatowski *et al*, 2005; Scott *et al*, 2009; Tod & Joanne, 2010; Trivers *et al*, 2011; Walter *et*

al, 2014; Whitaker *et al*, 2015c; Whitaker *et al*, 2014). For some participants, symptom disclosure acted as a facilitator when symptoms were re-evaluated as potentially serious (Andersen *et al*, 2010), or acted as a cue to action (de Nooijer *et al*, 2001) when participants were encouraged to seek help by family members and friends (Andersen *et al*, 2010; Burgess *et al*, 2006; Gascoigne *et al*, 1999; Trivers *et al*, 2011). In some cases, disclosure of symptoms reduced time to symptom presentation by half (Chonjnacka-Szwalowska, 2013) or by six times (Burgess *et al*, 1998). However, one study found that symptom presentation was sometimes prolonged following disclosure of symptoms, as friends and family confirmed beliefs about the benign nature of symptoms or reinforced fears of diagnostic tests (Emery *et al*, 2013). One study found that individuals from a low socioeconomic group who disclosed their symptom to a family member or friend took longer to seek medical help compared to those from a high socioeconomic group (Li *et al*, 2012).

The appearance of a new symptom (Brouha *et al*, 2005; Burgess *et al*, 2001; Carter-Harris, 2015; Cooper *et al*, 2013; de Nooijer *et al*, 2001; Facione, 1995) or persistence of the current symptom(s) (Brouha *et al*, 2005; Burgess *et al*, 1998; Carter-Harris, 2015; Cooper *et al*, 2013; Courtney *et al*, 2012; Facione, 1997; Gascoigne *et al*, 1999; Ramos *et al*, 2009; Scott *et al*, 2009; Whitaker *et al*, 2015c) facilitated decisions to seek medical help. When symptoms interfered with daily life (Brandner *et al*, 2014; Emery *et al*, 2013), were painful (Cameron & Hinton, 1968; Scott *et al*, 2009) or opposed the ideal body image held by patients, this often triggered symptom presentation (Brandner *et al*, 2014). In eight studies, participants waited until they developed another health complaint or tagged their cancer symptom on to the end of a consultation which provided an opportunity to disclose the cancer symptom during the consultation (Burgess *et al*, 1998; Cameron & Hinton, 1968; Coates *et al*, 1992; Courtney *et al*, 2012; Grant *et al*, 2010; Greer, 1974; Howell *et al*, 2008; Whitaker *et al*, 2015c).

3.4.6 Lung cancer specific studies

Nine studies reported data relating to lung cancer symptom presentation. One study found that those with lung cancer were more likely to be diagnosed with advanced stage cancer when compared to participants with breast or colorectal cancers (Mor, 1990). Six studies retrospectively examined lung cancer symptom attributions. Many participants reported experiencing vague and non-specific symptoms such as a cough or fatigue prior to diagnosis (Andersen *et al*, 2010; Carter-Harris, 2015; Emery *et al*, 2013; Mor, 1990; Tod *et al*, 2008;

Tod & Joanne, 2010). Participants often prolonged presenting with such symptoms, dismissing them as not serious (Andersen *et al*, 2010; Emery *et al*, 2013; Mor, 1990), or attributing them to acute conditions such as a cold, symptoms of other chronic conditions such as COPD (Andersen *et al*, 2010; Carter-Harris, 2015; Emery *et al*, 2013; Tod *et al*, 2008; Tod & Joanne, 2010) or smoking habit (Carter-Harris, 2015). Participants reported a reluctance to seek help for vague and non-specific symptoms due to worries about wasting the doctor's time (Tod *et al*, 2008; Tod & Joanne, 2010). Such barriers were reinforced by cultural messages encouraging patients to reduce consultation behaviour (Tod *et al*, 2008). Three studies found that participants who perceived themselves as low risk for developing lung cancer were more likely to provide benign explanations for symptoms, further prolonging symptom presentation (Andersen *et al*, 2010; Emery *et al*, 2013; Tod *et al*, 2008). This was particularly salient in never and ex-smokers who perceived their risk for developing lung cancer as nil or low (Tod *et al*, 2008).

Four studies reported that fearful and fatalistic beliefs about lung cancer were related to prolonged medical help seeking (Mor, 1990; Tod *et al*, 2008; Tod & Joanne, 2010) or later stage lung cancer (Bergamo *et al*, 2013). Two studies found that negative beliefs were formed by media campaigns associating lung cancer with death (Tod *et al*, 2008; Tod & Joanne, 2010). The stigma surrounding lung cancer and its association with smoking attenuated the decision to present with symptoms (Corner *et al*, 2005; Tod *et al*, 2008; Tod & Joanne, 2010), even in those who had never smoked (Tod *et al*, 2008).

Haemoptysis prompted the fastest symptom presentation (Corner *et al*, 2005; Tod & Joanne, 2010). When symptoms persisted, worsened or new symptoms developed, medical help was sought (Carter-Harris, 2015). Family members facilitated symptom presentation, legitimising the need to seek medical attention for symptoms (Tod *et al*, 2008; Tod & Joanne, 2010). In addition, family members helped with making an appointment with the doctor and accompanying participants to an appointment (Tod *et al*, 2008; Tod & Joanne, 2010), overcoming previously reported barriers.

Table 3.1 Table of included studies

Study	Method	Sample	Country	Tumour site	Socio-economic measure	Measures: Knowledge (K), Beliefs (B), Perceived barriers (PB), Perceived facilitators (PF), Symptomatic Presentation (SP)	Measure of association between and socioeconomic indicator	Quality Appraisal
Andersen <i>et al</i> (2010)	Retrospective, Qualitative	30 men (n=16) and women (n=14)	Netherlands	Lung, Malignant Melanoma, Colon		K: Symptom interpretation PB: Competing life priorities, holiday booked PF: Symptom disclosure, worsening of symptoms, symptoms interfering with daily life	N/A	Medium
Arnold-Reed <i>et al</i> (2008)	Hypothetical, Quantitative	503 men. Mean age: 62 years	Australia	Prostate	Education	K: Recognition (best for difficulty urinating, impotence, chronic groin pain) B: 'Prostate cancer will cause rapid death' (58%)	K: NR B: NR	Poor
Baumert <i>et al</i> (2007)	Retrospective, Quantitative	217 men (n=101) and women (n=116). Mean age: 54.7 years	Germany	Melanoma	Education	K: Knowledge pre-diagnosis (no, n=17.5%; yes, n=82.5%) SP: Sought medical help within 1 month (16.1%); tumour thickness	K: NR SP: Lower education associated with thicker tumours (MR 1.53, 95% CI: 1.11-2.11, p<0.05)	Poor
Bergamo <i>et al</i> (2013)	Retrospective, Quantitative	357 men (n=252) and women (n=105) from minority groups (n=142, mean age: 64.5 years) or non-minority groups (n=215, mean age: 66 years)	US	Lung	Education, employment, health insurance, annual income	K: Recognition B: Fatalism PB: Medical mistrust	K: NR B: NR PB: NR	Medium
Blum <i>et al</i> (1999)	Retrospective, Quantitative	429 men (n=184) and women (n=245). Median age: 52 years	Germany	Melanoma		B: 82% understood the benefits of early diagnosis PB: Misdiagnosis from physician on first visit PF: Symptoms noticed by another person SP: Mean time to symptom presentation (61 days)	N/A	Medium
Brain <i>et al</i> (2014)	Hypothetical, Quantitative	1043 women. Aged 50 years and over	Wales	Ovarian	Postcode, education	K: Recognition (mean, 6.85) B: Cancer worry PB: Emotional and practical barriers SP: Sought medical help in under 3 weeks (n=898)	K: Lower education associated with lower knowledge ($F_{(2, 1005)}=8.23$, $p<0.001$); higher deprivation (postcode) associated with lower knowledge ($F_{(3, 886)}=2.82$, $p<0.05$) B: NR PB: NR SP: Higher education associated with longer time to SP, (OR=2.64, $p<0.001$); NS difference between deprivation by postcode and anticipated delay ($X^2_{(3)}=6.73$, $p>0.05$) NS	Good

Brandner <i>et al</i> (2014)	Retrospective, Qualitative	42 women. Mean age: 57 years	Germany	Ovarian		K: Symptom interpretations (symptoms normalised) PB: Competing life priorities, symptom disclosure PF: Symptom interfering with daily life, symptom opposed specific body image, social responsibilities	N/A	Medium
Brouha <i>et al</i> (2005)	Retrospective, Quantitative	189 men and women. Mean age: 59 years	Holland	Oral and Pharyngeal	Education, income	K: Symptom interpretation ('cancer', n=2) PB: Symptom did interfere with daily life PF: Persistence of symptom, development of new symptom SP: Mean time to symptom presentation (pharyngeal, 45 days; oral, 28 days)	K: NR PB: NR PF: NR SP: Education and income not associated with time to SP (statistics NR)	Medium
Burgess <i>et al</i> (1998)	Retrospective, Qualitative	185 women. Mean age: 54 years	UK	Breast	Occupation	K: Symptom interpretation (46% thought their symptom indicated cancer) B: Fear PF: Symptom disclosure, appearance of new symptoms, appointment booked with GP for another reason SP: Waited over 3 months to seek medical help (19%)	N/A	Medium
Burgess <i>et al</i> (2000)	Retrospective, Qualitative	158 women. Mean age: 53 years	UK	Breast	Occupation	PB: Life events SP: Waited over 3 months to seek medical help (18%)	N/A	Medium
Burgess <i>et al</i> (2001)	Retrospective, Qualitative	46 women	UK	Breast	Occupation	K: Symptom interpretation ('lump' most attributed to cancer) B: Consequences of treatment PB: Not wanting to bother the doctor, poor health service utilisation, competing life priorities PF: Symptom disclosure, change in symptom SP: Waited over 3 months to seek medical help (n=31)	N/A	Medium
Burgess <i>et al</i> (2006)	Retrospective, Mixed	69 women. Aged 65 years and over	UK	Breast		K: symptom interpretation ('cancer', n=27) B: Fear PB: Competing life priorities, reservations about seeing GP PF: symptom disclosure SP: Waited over 3 months to seek medical help (n=29)	N/A	Medium
Cameron and Hinton (1968)	Retrospective, Quantitative	83 women	UK	Breast	Education, occupation	K: Symptom interpretation B: Fear, worry SP: sought medical help within 1 month (61%)	K: NR B: NR SP: Higher education associated with shortest time to SP for lump symptoms ($\chi^2=6.6$, $p<0.05$); Higher social group (husband's occupation) associated with shortest time to SP ($\chi^2=3.02$, $p<0.01$)	Poor

Caplan (1995)	Retrospective, Quantitative	162 women	US	Breast	Income, education, employment	PB: Fluctuating symptoms, relationship with GP SP: Waited over 2 months to seek medical help (n=27)	PB: NR SP: Lower socioeconomic group (various indices) associated with longer time to SP, but NS: High vs low income (OR 2.56, 95% CI: 0.68-8.64*); High vs low education (OR 1.07, 95% CI: 0.41-2.77*); Working vs non-working (OR 0.72, 95% CI: 0.27-1.99*)	Poor
Carter-Harris <i>et al</i> (2015)	Retrospective Qualitative	11 men (n=4) and women (n=7). Age range: 40-76 years	US	Lung	Education, employment	K: Symptom interpretations (one participant was alarmed at symptoms) PB: Vague and intermittent nature of symptoms PF: Worsening of symptoms, good relationship with GP SP: Immediate (n=1)	N/A	Medium
Cassileth <i>et al</i> (1988)	Retrospective, Mixed	275 men (n=148) and women (n=127). Median age: 45 years	US	Melanoma	Occupation, health insurance	K: Symptom interpretation (interpreted as 'cancer', 13%) SP: Mean time to symptom presentation (8.6 months)	K: NR SP: NR	Poor
Chapple <i>et al</i> (2004b)	Retrospective, Qualitative	45 men. Age range 21 to 55 years	UK	Testicular	Employment	K: Symptom interpretation B: Fear, fatalism PB: Machoism, embarrassment, competing life priorities PF: Symptom disclosure SP: Waited over 3 months to seek medical help (n=11)	N/A	Good
Chonjnacka - Szawłowska <i>et al</i> , (2013)	Retrospective, Quantitative	301 men (n=186) and women (n=115). Mean age: 42.3 years	Poland	All	Education	K: Recall, mean: 1.51 B: Fatalism and cancer curability SP: Mean time: 6 months and 10 days	K: NR B: NR SP: NS correlation between education and stage of cancer (statistics NR)	Medium
Coates <i>et al</i> (1992)	Retrospective, Quantitative	735 women (410 black and 325 white). Aged range: 20 to 79	US	Breast	Education, occupation, income	K: Symptom interpretation B: Fatalism PB: Symptom disclosure, other comorbid conditions, appointment with doctor booked for another reason SP: Median time to symptom presentation (black women, 16 days; white women, 14 days)	K: NR B: NR PB: NR SP: Higher education associated with shorter time to SP (Mantel-cox 1.43, 95% CI: 1.11-1.86, p<0.05); Low deprivation (poverty index) associated with shorter time to SP (Mantel-Cox 1.24, 95% CI: 1-1.54, p<0.05)	Good
Cochran <i>et al</i> (1986)	Retrospective, Qualitative	37 women. Median age: 64 years	US	Endometrial	Employment, education	K: Symptom interpretation (interpreted as 'cancer', n=3) PB: Perceived lack of emotional support, low social support SP: Median time to symptom presentation (28 days)	N/A	Poor

Cockburn <i>et al</i> (2003)	Retrospective, Quantitative	1332 men (40%) and women (60%). Aged 40 years and over	Australia	Colorectal (Bowel)	Education	K: Recall (25% could not recall any symptom), symptom interpretation B: Benefits of early diagnosis SP: 306 had experienced a symptom, 31.9% did not seek medical help	K: Higher education associated with higher K of symptoms (PR 0.93, 95% CI: 0.89-0.96*) B: Higher education more likely to hold positive beliefs about the benefits of early diagnosis (statistics NR) SP: NR	Medium
Cooper <i>et al</i> (2013)	Hypothetical, Qualitative	15 focus groups with 132 women. Age range: 40 to 60 years	US	Gynaecological	Education, employment, income, health insurance	K: Which symptoms would cause most concern (bleeding= most concern) PB: Lesion not visible, tendency to ignore health, cost SP: Range in time to symptom presentation (immediate to years). Changes in the skin on vulva= most timely and consistent response.	N/A	Medium
Courtney <i>et al</i> (2012)	Retrospective, Quantitative	1085 men (n=508) and women (n=577). Age range: 56 to 88 years	Australia	Colorectal	Education	K: Symptom interpretation PB: Watchful waiting PF: Persistence of symptom, appointment booked for another reason SP: 41% had experienced a symptom, 18% of those with rectal bleeding and 37% of those with a change in bowel habit (37%) waited over 1 month to seek medical help	K: NR PB: NR PF: NR SP: NR	Medium
Corner <i>et al</i> (2005)	Retrospective, Qualitative	22 men (n=12) and women (n=10). Median age: 68 years	England	Lung	Occupation	K: Symptom interpretations PB: Self-medication, stigma PF: symptoms interfering with daily life SP: Median time to symptom presentation (12months)	N/A	Good
Crosland and Jones (1995)	Retrospective, Mixed methods	Postal survey: 1200 men and women. Of these, 150 men and 137 women experienced 'blood in stools'. Of these, 24 men and 36 women were interviewed	UK	Colorectal		K: Symptom interpretation ('cancer', n=42) PF: Symptom disclosure, pain, embarrassment, appointment booked for another reason, worry symptom might be something serious PB: Worry symptom might be serious SP: 41% had sought medical advice for symptom, median time to symptom presentation (2 months)	N/A	Good
de Nooijer <i>et al</i> (2001)	Retrospective, Qualitative	23 men (n=10) and women (n=13). Age range: 32-75 years	Netherlands	Breast, colon, Melanoma, Testicular		K: Recall (1 or more symptoms, n=17) and symptom interpretation B: Fear PB: Embarrassment, perception doctor could not do anything PF: Symptom disclosure, worsening of symptoms, appearance of new symptoms SP: Immediate to several years.	N/A	Medium

de Nooijer <i>et al</i> (2003)	Hypothetical Quantitative	588 men (n=135) and women (n=453). Mean age: 47 years	Netherlands	All	Education	K: Recognition (good, mean 8.4) PB: Anticipated regret, social norms, self-efficacy	K: NR PB: NR	Medium
Emery <i>et al</i> (2013)	Retrospective, Mixed methods	66 men (n=28) and women (n=38). Mean age: 60.5 years	Australia	Breast, Colorectal, prostate, lung		B: Fear PB: Intermittent and mild symptoms, machoism in men, holiday booked, symptom disclosure, distance to get to surgery, competing life priorities PF: symptom disclosure SP: Mean time to symptom presentation: breast (33 days), colorectal (135 days), lung (37 days), prostate (320 days)	K: NR PB: NR PF: NR SP: NR	Medium
Esteva <i>et al</i> (2013)	Retrospective, Quantitative	795 men and women	Spain	Colorectal	Social class, education	K: Symptom interpretation (interpreted as 'not serious', 65.6%) PF: Symptom disclosure, good relationship with GP (trust) SP: Median time to symptom presentation (19 days)	K: NR SP: NS association between social class and time to SP (statistics NR), NS association between education and time to SP (statistics NR)	Medium
Facione and Facione (2006)	Retrospective, Qualitative	28 women. Mean age: 42.34 years	US	Breast	Income, education, health insurance	K: Symptom interpretation B: Fear, fatalism, benefits of early diagnosis PB: Worry about losing relationship with partner if diagnosed with cancer PF: Symptom disclosure SP: Waited over 3 months to seek medical help (n=15)	N/A	Medium
Facione and Giancarlo (1998)	Retrospective, Qualitative	80 women into 16 focus groups. Aged 20 years and over	US	Breast	Income, employment, education	K: Symptom interpretation (best for lump symptoms) B: 'Cancer is a bad word', fatalism PB: Stoicism, not wanting to bother the doctor, use of alternative therapies, embarrassment, influence of male partner, cost PF: Symptom disclosure, good relationship with doctor	N/A	Medium
Facione <i>et al</i> (2002)	Hypothetical, Quantitative	669 women. Mean age: 46.95 years	US	Breast	Income, education, health care insurance	K: Recognition (10% recognised all or all but one symptoms) B: Fatalism PB: Difficulties with access, prejudice in health care, concerns about deportation, use of alternative therapies SP: Likely to delay (23.7%).	K: Higher education associated with higher symptom recognition ($F_{3,690}=32.32, p<0.001$) B: NR PB: NR SP: Lack of insurance associated with longer time to SP (Cramer's V = 0.187, $p<0.001$); Lower education associated with longer time to SP (Cramer's V = 0.288, $p<0.001$); Lower income associated with longer time to SP (Cramer's V = 0.291, $p<0.001$)	Good

Facione <i>et al</i> (1997)	Hypothetical, Quantitative	352 African American or Black women. Mean age: 38.6 years	US	Breast	Income, Education, Employment	B: Fear, fatalism PB: Poor health service utilization SP: 11.6%= strong disposition to SP.	B: NR PB: NR SP: Stronger disposition to SP associated with lower education (r=0.19, p<0.01) and lower income (r=0.32, p<0.001)	Medium
Facione and Dodd (1995)	Retrospective, Qualitative	39 women. Mean age: 49.6 years	US	Breast	Income, education	K: Symptom interpretation B: Fear PB: Competing life priorities PF: Appearance of new symptom, worsening of symptoms, symptom disclosure SP: 59% sought medical help within 1 week	N/A	Medium
Fitzpatrick <i>et al</i> (1998)	Hypothetical, Quantitative	280 men. Mean age: 53.7 years	Ireland	Prostate	Health insurance, occupation	B: Fear PB: Poor health service utilisation, dislike of doctors, embarrassment SP: 81% would seek medical help if developed urinary symptoms	B: NR PB: NR SP: Non-manual social class associated with higher willingness to attend GP with symptoms (OR 1.8, p<0.05**)	Good
Forbes <i>et al</i> (2011)	Hypothetical, Quantitative	1515 women from various ethnic groups (White, South Asian, Black). Aged 30 years and over	UK	Breast	Postcode	K: Recognition (18% recognised 5 or more non-lump symptoms) PB: self-efficacy, worry what the doctor might find, embarrassment, worry about wasting doctors time, difficulty getting an appointment SP: would seek help within 1 week (73%)	K: Differences between ethnic groups for cancer awareness not due to IMD score or lower level of education (statistics NR) PB: Differences between ethnic groups for PB not due to IMD score (statistics NR) SP: NR	Good
Forbes <i>et al</i> (2014)	Retrospective, Quantitative	1999 men (n=1077) and women (n=922). Aged 50 or over	UK	All	Postcode	K: Symptom interpretation PB: 48% of patients reported at least one barrier SP: Delay over 3 months (n=21%)	B: NR PB: NR SP: Lowest socioeconomic group associated with longest time to SP (1.51, 95% CI: 1.18-1.88*)	Good
Freidman <i>et al</i> (2006)	Retrospective, Quantitative	124 women. Mean age: 44.3 years	US	Breast	Employment, education	B: Fear PB: Worry what the symptom might be, difficulty getting an appointment, cost, denial SP: Mean time to symptom presentation (9 months)	B: NR PB: NR SP: Lower education associated with longest time to SP (Fishers Exact test, p<0.01**)	Medium
Gascoigne and Whitear (1999)	Retrospective, Qualitative	16 men	Wales	Testicular		K: Symptom interpretation ('cancer', n=1) B: Fear PB: Previous misdiagnosis, symptoms manageable, embarrassment PF: symptom disclosure (wife), worsening of symptoms SP: Range in time to symptom presentation (6-52 weeks)	N/A	Medium

Goldsen <i>et al</i> (1957)	Retrospective, Quantitative	727 men and women	US	All	Income, education and occupation	K: Symptom interpretation (20% thought symptoms indicated cancer) B: Cancer worry, fatalism PB: Poor health service utilization, poor noticeability of symptom PF: Symptom disclosure SP: 51.3% sought medical help under 30 days	K: NR B: NR PB: NR PF: NR SP: Lower income, education and occupation associated with longest time to SP (statistics NR)	Medium
Gould <i>et al</i> (2010)	Retrospective, Qualitative	14 women. Aged range: 30 to 69 years	Canada	Breast	Education, employment, income	K: Symptom interpretation (poor for non-lump symptoms) B: Fear PB: Previous benign disease, watchful waiting, competing life priorities PF: Symptom disclosure, already have another appointment booked. SP: All women waited 8+ weeks	N/A	Medium
Grant <i>et al</i> (2010)	Retrospective, Qualitative	15 men (n=7) and women (n=8). Aged 45 years and under	Scotland	Oral	Postcode	K: Symptom interpretation PB: Self medication PF: Already had an appointment booked SP: Sought medical help within 8 weeks (n=8)	N/A	Medium
Greer (1974)	Retrospective, Quantitative	160 women with stage I or stage II cancer. Aged 70 years and under	UK	Breast	Social Class	K: Symptom interpretation B: Fear, fatalism PB: Embarrassment SP: 64% sought medical help within 1 month	K: NR B: NR PB: NR SP: NS difference between time to SP and social class (statistics NR)	Poor
Grunfield <i>et al</i> (2002)	Hypothetical, Quantitative	996 women. Mean age: 47 years	UK	Breast	Occupation	K: Recognition (mean, 5.3 symptoms) B: Beliefs about treatment, cancer survival outcomes	K: 'Unskilled workers' or 'never worked' associated with poorer recognition (F(4,109)=10.43, p<0.001) B: 'Professional' and 'intermediate' skilled workers more likely to hold positive beliefs about cancer survival ($\chi^2=25.30$, d.f.=4, p<0.01)	Medium
Grunfield <i>et al</i> (2003)	Hypothetical, Quantitative	546 women. Mean age: 47 years	UK	Breast	Occupation	PF: Easy to speak to doctor SP: Most likely to seek prompt medical help for lump symptoms	PB: NR SP: NR	Medium
Hale <i>et al</i> (2007)	Retrospective, Qualitative	20 men. Age range: 51 to 75 years	UK	Prostate	Social class, education	K: Symptom interpretations (poor) B: Fear PB: Embarrassment, machoism, medical mistrust PF: Symptom disclosure (wife), symptoms interfering with daily life	N/A	Medium

Henderson (1966)	Retrospective, Quantitative	50 men (n=2) and women (n=48). Age range: 26-67 years	Scotland	Breast, Cervix, Bowel.		<p>K: Symptom interpretation (39.4% thought Symptom not serious)</p> <p>B: Fear</p> <p>PB: Embarrassment, financial constraints</p> <p>SP: Wait over 3 months to seek medical help, n=38</p>	N/A	Medium
Hvidberg <i>et al</i> (2014)	Hypothetical, Quantitative	3000 men (n=1341) and women (n=1659) over the age of 30.	Netherlands	Bowel, breast, ovarian, lung	Education, occupation, income	<p>K: Recognition (median 9/11). Most recognised were change in mole (97.2%) and lump (94.3%). Least recognised were night sweats (15.6%) and sore that does not heal (67.8%)</p> <p>B: Beliefs about cancer survival. Correctly estimated 5-year survival (% participants): Bowel (42%), breast (49%), ovarian (9%), lung (19%). Survival overestimated for ovarian (86% participants) and lung (78% participants).</p>	<p>K: Fewer symptoms recognised for those with lower education (PR 1.57, 95% CI: 1.39-1.78, p<0.01), those outside the labour force (PR 1.27, 95% CI: 1.11-1.46, p<0.01) and lower income (PR 1.33, 95% CI: 1.15-1.54, p<0.01)</p> <p>B: Participants outside the labour force were more likely to wrongly estimate survival for breast cancer (PR 1.15, 95% CI: 1.01-0.31), p<0.01); Lower income was associated with wrongly estimated survival for bowel cancer (PR 1.18, 95% CI: 1.05-1.33, p<0.01)</p>	Medium
Howel <i>et al</i> (2008)	Retrospective, Qualitative	32 men (n=12) and women (n=20). Aged 65 years and over	England	Lymphoma		<p>K: Symptom interpretation (non-lump symptoms poorly attributed to cancer)</p> <p>PB: Intermittent nature of symptoms, competing life priorities, poor general health service utilisation</p> <p>PF: Worsening of symptoms, symptom disclosure</p>	N/A	Medium
Hunter <i>et al</i> (2003)	Hypothetical, Quantitative	546 women. Mean age: 47 years	UK	Breast	Occupation	<p>K: Recognition (good, mean 6.65)</p> <p>B: Beliefs about treatment</p> <p>SP: 58.6% would seek immediate medical help.</p>	<p>K: NR</p> <p>NR: NR</p> <p>SP: Socioeconomic group not associated with time to SP ($F_{(1,518)} = 0.29, p>0.05$)</p>	Medium
Kakagia <i>et al</i> (2013)	Retrospective, Quantitative	513 men (n=56.5%) and women (n=43.5%). Mean age: 67.5 years	Greece	Skin	Education, ethnicity, area of residence	<p>K: Symptom interpretation</p> <p>B: Fear, fatalism</p> <p>PB: Other serious comorbidities, poor health service utilisation, dislike of doctors and hospitals, transport issues, worry about wasting docs time, embarrassment, competing life demands</p> <p>PF: Symptom disclosure, active encouragement to seek medical help</p> <p>SP: Mean time to symptom presentation (3.9 months)</p>	<p>K: NR</p> <p>B: NR</p> <p>PB: NR</p> <p>PF: NR</p> <p>SP: Longer time to SP associated with lower socioeconomic group (OR 1.89, 95% CI: 0.9-3.8. p<0.001*****) and lower education (OR 3.01, 95% CI: 1.6-5.6, p<0.001)</p>	Poor

Lam <i>et al</i> (2009)	Retrospective, Qualitative	37 women. Age range 20-81 years	Hong Kong	Breast	Employment, education	K: Symptom interpretation B: fear, fatalism PB: Watchful waiting, poor general health service utilisation, cost, competing life priorities, embarrassment PF: Persistence of symptoms, appearance of new symptom, symptom disclosure, symptom interfering with daily life, appointment booked for another reason SP: Waited over 3 months to seek medical help (n=14)	N/A	Medium
Lannin <i>et al</i> (1998)	Retrospective, Quantitative	540 women from ethnic minority groups (30%) or majority groups (70%)	US	Breast	Education, income, health insurance	B: Fear, fatalism, folk beliefs, beliefs about treatment PB: Cost, poor general health service utilisation SP: Advanced stage cancer (17.4%)	K: Higher knowledge associated with higher income and higher education (statistics NR) PB: NR SP: NS association with higher education and earlier stage cancer (OR1.6, 95% CI: 0.9-2.7, NS). Higher income associated with earlier stage disease (OR 3.7, 95% CI:2.1-6.5)**- p value NR	Medium
Larkey <i>et al</i> (2001)	Hypothetical (focus group) and retrospective (questionnaire) Mixed	11 Focus groups: 90 men (n=56) and women (n=34). Mean age: 39 Questionnaire: 132 men and women. Mean age:44.7years	US	All	Occupation, income	K: Symptom interpretation PB: Practical barriers, cost, emotional barriers, previous negative experiences with health services PF: Trust in medical system, symptom disclosure	K: NR PB: NR PF: NR	Medium
Lauver <i>et al</i> (1995)	Retrospective, Qualitative	138 women. Mean age: 37.5 years	US	Breast	Education, occupation, annual family income, health insurance	B: Fear PB: Competing life priorities, cost, transport PF: 50% reported no barriers SP: Waited over 3 months to seek medical help (23%), 38% sought medical help within 1 week	N/A	Medium
Li <i>et al</i> (2012)	Retrospective, Quantitative	425 women. Mean age: 51.97 years	Hong Kong	Breast	Employment, education	B: Fear PB: cost, gender of doctor, unsure where to seek medical help, competing life priorities, no history of breast problems PF: Symptom disclosure SP: Median time to symptom presentation (14 days)	B: NR PB: Symptom disclosure for women with lower education less likely to translate into immediate SP ($\chi^2=6.4$, d.f.=2, p<0.05) PF: NR SP: Longer time to SP associated with higher education (OR 3.35, 95% CI:1.19-9.42, p<0.05) and full time employment (OR 2.52, 95% CI: 1.18-5.36, p<0.05)	Good

Loehrer <i>et al</i> (1991)	Retrospective, Qualitative	128 men (n=33) and women (n=95). Mean age: 63 years	US	All	Employment, income, education	B: Curability of cancer, cancer is contagious, surgery causes cancer to spread SP: Poor for non-specific symptoms	N/A	Medium
Low <i>et al</i> (2013)	Hypothetical, Quantitative	1000 women. Mean age: 47 years	UK	Ovarian	Education, car ownership, home ownership	K: Recall (poor, mean 0.6) and recognition (good, mean 6.3) PB: Mean number of barriers endorsed (2.2), emotional, practical and service barriers SP: Varied by symptom, most would seek help under 2 weeks	K: NR PB: NR SP: Higher socioeconomic group associated with longer time to SP (beta=0.12, SE 0.05, p<0.001**)	Good
Lund-Nielson <i>et al</i> (2011)	Retrospective, Qualitative	17 women. Median age: 69 years	Denmark	Breast	Education	B: Fear, beliefs about treatment PB: Competing life priorities, lack of resources SP: Median time to symptom presentation (24 months)	N/A	Medium
Lyubomirsky <i>et al</i> (2006)	Hypothetical and Retrospective, Quantitative	Study 1 (hypothetical): 147 women. Age range: 18 to 61 years Study 2 (retrospective): 139 women. Age range 32-86 years	US	Breast	Occupation, education	Study 1 K: Recognition of lump symptoms B: Fear PB: Cost, personality type (ruminators vs non ruminators) Study 2 PB: Personality type (ruminators vs non ruminators) SP: Median time to symptom presentation (Ruminators, 52.5 days; non-ruminators, 13.9 days)	K: NR B: NR PB: NR SP: NR	Poor
Magarey <i>et al</i> (1977)	Retrospective, Qualitative	64 women	Australia	Breast	Education	PB: Denial, anxiety SP: Sought medical help within 2 weeks (n=35)	PB: NR SP: Education not associated with time to SP (statistics NR)	Poor
Marlow <i>et al</i> (2014)	Hypothetical, Qualitative	54 women from ethnic minority groups living with a comparison of white women. Age range: 25-64 years	UK	Breast and Ovarian	Employment, education, living arrangement	K: Recall (good for lump/ bleeding, poor for other symptoms) B: Fear, fatalism, benefits of early diagnosis PB: Poor relationship with GP, emotional barriers, practical barriers, competing life priorities	N/A	Medium
McCaffery <i>et al</i> (2003)	Hypothetical, Quantitative	1637 men (n=763) and women (n=874). Age range: 16-74 years	UK	Colorectal	Education	K: Recall (poor) B: Fear SP: 92.8% would anticipate seeking medical help if noticed blood in stool for more than 2 weeks.	K: Higher education associated with higher symptom recall ($\chi^2[4]=73.98$, p<0.001) B: Lower education associated with most negative beliefs ($\chi^2[4]=74.96$, p<0.001) SP: NS association with education and SP intentions (statistics NR)	Good
Meehan <i>et al</i> (2003)	Retrospective, Mixed	85 women. Mean age: 38.9 years	New Zealand	Breast		PB: Having a family member with cancer, low emotional response to symptom PF: High emotional response to symptom SP: Median time to symptom presentation (14 days)	PB: NR PF: NR SP: NS association between education and time to SP (t(83)= -1.26, p>0.05)	Medium

Mor (1990)	Retrospective, Qualitative	700 patients. Age range: 45 to 90 years	US	Lung, Breast and Colorectal	Education, housing, income, education	<p>K: Symptom interpretation (best knowledge breast cancer patients)</p> <p>B: Fear (16.8% of delayers)</p> <p>PB: "thought it would go away" (60.5% of delayers), too busy (8.4% of delayers)</p> <p>SP: Waited over 3 months to seek medical help: lung (54.9%), breast (56.2%), colorectal (87.6%)</p>	<p>K: NR</p> <p>B: NR</p> <p>PB: NR</p> <p>SP: NS relationship between socioeconomic group and time to SP (statistics NR)</p>	Medium
Niksic <i>et al</i> (2015)	Hypothetical, Quantitative	49270 men (55%) and women (45%). Aged 54 and under (62%) and 55 and over (33%), missing (5%)	UK	All	Education, employment, postcode (area income deprivation)	<p>K: Recognition (mean: 7.2/9). Most recognised was lump (94%); least recognised was cough/hoarseness (68%) and sore that does not heal (68%)</p> <p>B: Mean barriers endorsed= 1.8. Most highly endorsed barrier was 'worry what the doctor might find (30%), least endorsed barrier was difficulty arranging transport (6%)</p>	<p>K: Lowest knowledge associated with lowest education, highest area income deprivation and unemployment for all symptoms (OR, p<0.001)***</p> <p>B: Strongest association for emotional barriers group (lower socioeconomic groups endorsed more emotional barriers): 'Too embarrassed' associated with most deprived quartile (postcode, OR 1.22, 99% CI: 1.08-1.39, p<0.001), lower education (OR 1.20, 99% CI: 1.09-1.33, p<0.001) and unemployment (OR 1.23, 99% CI: 1.11-1.35, p<0.001); 'too scared' associated with lower education (OR 1.24, 99% CI: 1.13-1.35, p<0.001) and unemployment (OR 1.15, 99% CI: 1.06-1.26, p<0.001); 'not confident to talk' associated with lower education (OR 1.39, 99% CI: 1.22-1.58, p<0.001) and unemployment (OR 1.30, 99% CI: 1.16-1.46, p<0.001); 'worry what the GP might find' associated with most deprived quartile (postcode, OR 1.12, 99% CI: 1.02-1.27, p<0.001), lower education (OR 1.16, 99% CI: 1.05-1.27, p<0.001) and unemployment (OR 1.13, 99% CI: 1.04-1.22, p<0.001)**** NR</p>	Good
Oliveria <i>et al</i> (1999)	Retrospective, Quantitative	255 men and women. Aged 18 years and over	US	Melanoma	Education, insurance	<p>K: Recognition (poor)</p> <p>SP: Mean time to symptom presentation (2 months)</p>	<p>K: NR</p> <p>SP: Education not associated with time to SP (statistics NR)</p>	Medium

O'Mahony and Hegarty (2009)	Retrospective, Quantitative	99 women. Mean age: 40 years	Ireland	Breast	Employment, education	K: Symptom interpretation PB: Competing life priorities, emotional reactions to symptom (afraid, scared, unsure) PF: Symptom disclosure, anxiety SP: Waited over 1 month to seek medical help (n=26)	K: NR PB: NR PF: NR SP: Higher education associated with longer time to SP (statistics NR)	Medium
O'Mahony <i>et al</i> (2011)	Retrospective, Qualitative	10 women. Mean age: 40 years	Ireland	Breast	Education, Employment	K: Most aware that a lump was a symptom B: Fatalism, curability of cancer, fear PB: Denial, competing life priorities PF: Symptom disclosure, good perceived access to GP, good relationship with GP SP: Sought medical help within 1 month (n=6)	N/A	Medium
Pedersen <i>et al</i> (2011)	Retrospective, Quantitative	901 men (n=423) and women (n=487). Mean age: 61.8 years	Denmark	All	Education	PF: Symptom disclosure, good partner support SP: Median interval: 12 days	PF: NR SP: NS association between education and time to SP: Lower secondary education and long SP (>55 days) (RRR 0.79, 95% CI: 0.36-1.74, p>0.05); tertiary education and long SP (>55 days) (RRR 1.30, 95% CI: 0.55-3.08, p>0.05)	Medium
Phillips and Taylor (1961)	Hypothetical, Quantitative	2000 women. Aged 20 and over	Canada	All	Occupation	K: Recall and recognition (best for 'lump') B: 'Cancer is the country's biggest killer'(44%); 'cancer is the most serious disease'(30%); 'cancer cannot be cured'(27%)	K: NR B: NR	Poor
Price (1993)	Hypothetical, Quantitative	500 men (n=250) and women (n=250) from disadvantaged backgrounds. Mean age: 59.9 years	US	Colorectal	Income, car ownership, type of dwelling, education	K: Recognition (poor, n=310; good, n=190) B: Curability of cancer ('incurable', 90%), perceived severity of cancer PB: Practical barriers	K: NS association between education and knowledge (p>0.05**) B: Lower education associated with perceiving cancer as more serious (p<0.05**) PB: NR	Medium
Quaife <i>et al</i> (2014)	Hypothetical, Quantitative	6965 men (n=4330) and women (n=2635). Aged 50 and over	UK	All	Education	K: Recognition (best for 'lump') PB: Poor access health services SP: Would wait 2+ weeks: (cough, n= 48.1%; breast change, n= 8.2%; rectal bleeding, n= 7.4%)	K: Lower education associated with lower recognition for all 3 symptoms (χ^2 , p<0.05**) PB: NR SP: Lower education associated with shorter time to SP for cough (OR 0.61, 95% CI: 0.54-0.68, p<0.001) and breast changes (OR 0.68, 95% CI: 0.52-0.89, p<0.001). NS association with education and time to SP for rectal bleeding (OR 0.83, 95% CI: 0.67-1.03, p>0.05) Higher education associated with longer time to SP	Good

Quaife <i>et al</i> (2015a)	Hypothetical, Quantitative	6965 men (n=2635) and women (n=4330). Aged 50 and over, mean age: 63 years	UK	All	Education	B: Beliefs about curability of cancer, treatment side effects, early diagnosis PB: 12% 'I would not want to know if I have cancer'	B: Participants with lower education less likely to endorse 'with cancer can expect to continue with normal activities' (OR 0.67, 95% CI: 0.45-0.98, p<0.05), 'going to the doctors quickly increases the chances of surviving cancer' (OR 0.31, 95% CI: 0.11-0.82, p<0.05). NS association with education and 'cancer can often be cured' (OR 0.78, 95% CI: 0.52-1.16, NS). Lower education more likely to endorse 'cancer is a death sentence' (OR 1.94, 95% CI: 1.43-2.63, p<0.001) and 'cancer treatment is worse than the cancer' (OR 2.64, 95% CI: 2.04-3.43, p<0.001) PB: Those with lower education more likely to endorse 'I would not want to know if I had cancer' (OR 2.66, 95% CI: 1.69-4.18, p<0.001)	Medium
Ramos <i>et al</i> (2010)	Retrospective, Qualitative	12 men (n=7) and women (n=5). Age range 45 to 82 years	Spain	Colorectal	Education, Occupation	K: Symptom interpretation PB: Fear PF: Changes to symptoms, persistence of symptoms, symptom disclosure, development of another health complaint (men only)	N/A	Medium
Rauscher <i>et al</i> (2010)	Retrospective, Quantitative	438 women. Age range: 30 to 79 years	US	Breast	Education, household income, health insurance status	PB: Poor general health service utilisation SP: Waited over 3 months to seek medical help (16%)	K: Lower income and education associated with more breast lump misconceptions (χ^2 , p<0.001**) PB: NR SP: Longer time to SP associated with lower education (χ^2 , p<0.05**) and lower income (χ^2 , p<0.05**)	Medium
Richard <i>et al</i> , (2000)	Retrospective, Quantitative	590 men (n=250) and women (n=340). Mean age: 51.2 years	France	Melanoma	Residence, social level, education	K: Symptom interpretation ('not serious', 34.8%) B: Fear PB: No symptoms, competing life priorities (work and family commitments) PF: Active encouragement from family SP: Sought medical help within 2 months (51.9%)	K: NS B: NS PB: Those with higher education more likely to self-detect melanoma (χ^2 , p<0.01**) PF: NR SP: NS association with and time to SP and socioeconomic group (statistics NR)	Medium

Rozniatowski <i>et al</i> (2005)	Retrospective, Quantitative	100 men (n=84) and women (n=16). Mean age: 57 years	France	Head and Neck	Education, occupation	PB: Low anxiety, poor general health service utilisation PF: Symptom disclosure, active encouragement from partner to seek help SP: The majority of patients waited over 1 week to seek medical help	K: NR PB: NR SP: NS association between socioeconomic group and time to SP (statistics NR)	Medium
Ristvedt <i>et al</i> (2014)	Retrospective, Quantitative	112 men (n=55) and women (n=57). Mean age: 59.3 years	US	Colorectal	Income, area of residence, education, health insurance coverage	K: Symptom interpretation (70.5% thought symptom serious within 13 weeks post onset) SP: Median time to symptom presentation (10 weeks)	K: NR SP: NS association between socioeconomic group (education and household income) and time to SP (statistics NR)	Medium
Ristvedt and Trinkhaus (2005)	Retrospective, Quantitative	69 men (n=42) and women (n=27). Mean age: 61.3 years	US	Colorectal	Education	K: Symptom interpretation ('not cancer', 71%) PB: Personality (low trait anxiety), poor health service utilisation SP: Mean time to symptom presentation (25 weeks)	K: NR PB: NR SP: Lower education associated with longer time to SP (Kaplan-Meier: median 15 weeks, 95% CI: 9.0-26.0*); higher education associated with shorter time to SP (Kaplan-Meier: median 8 weeks, 95% CI: 4.0-15.0*)	Medium
Robb <i>et al</i> (2009)	Hypothetical, Quantitative	2216 men (n=968) and women (n=1240)	UK	All	Education, occupation	K: Recall (poor, mean=2.2) and recognition (good, mean=7.2) PB: Emotional and service barriers most endorsed SP: Most would seek medical help within 2 weeks	K: Higher socioeconomic group (occupation) associated with highest knowledge (F(2,2015)=20.31, p<0.001) PB: Lower socioeconomic group (occupation) associated with more emotional barriers endorsed: 'worry what the doctor might find' ($x^2(1,1989)=17.08$, p<0.001), 'too embarrassed' ($x^2(1,1993)=20.74$, p<0.001), 'not confident to talk about symptom' ($x^2(1,1992)=4.77$, p<0.05), NS association with 'too scared' ($x^2(1,1977)=1.82$, p>0.05); Higher socioeconomic group (occupation) associated with more practical barriers endorsed: 'too busy' ($x^2(1,2005)=59.0$, p<0.001), 'other things to worry about' ($x^2(1,1996)=15.34$, p<0.001), 'difficult to arrange transport' ($x^2(1,2010)=11.13$, p<0.001); NS association between socioeconomic group (occupation) and service barriers:	Good

							<p>'difficult to make appointment' ($x^2(1,1983)=0.41, p>0.05$), 'worried about wasting the doctors time' ($x^2(1,1995)=1.44, p>0.05$), 'difficult to arrange transport' ($x^2(1,1938)=1.15, p>0.05$)</p> <p>SP: Lower socioeconomic group (occupation) associated with shorter time to SP for unexplained bleeding ($x^2(1,1991)=5.82, p<0.01$), difficulty swallowing ($x^2(1,1987)=28.41, p<0.001$), lump ($x^2(1,1988)=21.26, p<0.001$), change in mole ($x^2(1,1967)=24.24, p<0.001$), unexplained pain ($x^2(1,1965)=20.24, p<0.001$), sore that does not heal ($x^2(1,1977)=35.84, p<0.001$), change in bowel/bladder habits ($x^2(1,1982)=56.87, p<0.001$), cough ($x^2(1,1984)=48.32, p<0.001$), unexplained weight loss ($x^2(1,1963)=77.73, p<0.001$)</p>	
Rogers <i>et al</i> (2011)	Retrospective, Mixed	44 men (n= 26) and women (n=18)	UK	Oral and Pharyngeal		<p>K: Symptom interpretation ('serious', 13%)</p> <p>B: Fear</p> <p>PB: More than 1 barrier endorsed (46%), difficulty with access, difficulty getting an appointment, cost</p> <p>PF: anxiety, worry, the need to resolve uncertainty, active encouragement by someone else</p> <p>SP: Sought medical help within 1 month (n=29)</p>	N/A	Medium
Roncoroni <i>et al</i> (1999)	Retrospective, Quantitative	100 men (n=48) and women (n=52). Mean age: 65 years	Italy	Colorectal		<p>K: Symptom interpretation ('cancer', n=12)</p> <p>PF: Symptom disclosure</p> <p>SP: Mean time to symptom presentation (10.8 weeks)</p>	N/A	Medium
Rutier <i>et al</i> (2008)	Hypothetical, Quantitative	193 men (n=87 and women (n=106). Mean age: 49.2 years	Netherlands	All	Education	<p>K: Recognition</p> <p>SP: Well-known symptoms lead to best adaptive coping</p>	<p>K: NR</p> <p>SP: NR</p>	Poor

Samet <i>et al</i> (1988)	Retrospective, Quantitative	800 men (n=396) and women (n=404). Mean age: 72.2 years	US	All	Education, income	PB: Poor general health service utilisation, poor access SP: Most sought medical help within 2 months	PB: NR SP: Longer time to SP associated with lower income for breast and colorectal cancer (χ^2 , $p<0.05^{**}$) and lower education for all tumour sites (χ^2 , $p<0.05^{**}$)	Medium
Scanlon <i>et al</i> (2006)	Hypothetical, Qualitative	115 Irish (n=58) and white British (n=57) men (n=47) and women (n=70) in 25 focus groups	UK	All	Employment, housing, tenure, occupation	K: Recall (poor) B: Positive (early detection) and negative (silent cancers), fear, fatalism, shame, stigma, cancer should be hidden. PB: Machoism, denial, never talk about health concerns, poor access to health services, long waiting times, rushed appointments, worry about being perceived as a hypochondriac, cost	N/A	Medium
Schmid-Wendter (2002)	Retrospective, Quantitative	233 men (n=109) and women (n=124). Mean age: 54.5 years	Germany	Melanoma	Education	B: Fear PB: Lesion not visible, too busy SP: Sought medical help within 1 month (15.5%)	K: Higher education more likely to have knowledge about melanoma (χ^2 , $p<0.001^{**}$) B: NR PB: NR SP: NR	Medium
Scott <i>et al</i> (2007)	Retrospective, Qualitative	57 men (n=11) and women (n=46). Mean age: 54 years	UK	Oral	Education	K: Symptom interpretation ('cancer', 30%) PF: Persistence of symptoms, development of new symptom	N/A	Medium
Scott <i>et al</i> (2008)	Retrospective, Quantitative	80 men (30%) and women (70%). Mean age: 53 years	UK	Oral	Postcode Education	K: Symptom interpretation PB: Competing life priorities, poor access to health care SP: Mean time to symptom presentation, 71.2 days	K: NR PB: NR SP: NS association between education and time to SP (OR=0.55, 95% CI=0.23-1.36, $p>0.05$) longer time to SP for those living in deprived areas (OR=1.05, 95% CI=1.01-1.09, $p<0.05$)	Medium
Scott <i>et al</i> (2009)	Retrospective, Qualitative	57 men (n=11) and women (n=46). Mean age: 54 years	UK	Oral	Education	K: Symptom interpretation B: Benefits of early diagnosis PB: Not wanting to bother the doctor, watchful waiting, previous bad experiences with health care system, competing life priorities SP: Mean time to symptom presentation (71.5 days)	N/A	Medium

Shahid et al (2009)	Retrospective and Hypothetical, Qualitative	37 Aboriginal men (n=8) and women (n=29). Aged 30 years and over. Cancer diagnosis, (n=14), family members of people with cancer (n=16) and health service providers (n=7)	Australia	All	Area of residence	K: Symptom interpretation (poor) B: Cancer is a curse, fatalism, shame, fear, cancer is contagious, stigma PB: Mistrust in the medical system, use of traditional medicines	N/A	Medium
Sheikh and Ogden (1998)	Hypothetical, Mixed methods	Questionnaire: 400 men and women (Quantitative) Interviews: 20 men (n=6) and women (n=14). Age range: 17-70 years	UK	All	Education	K: Recognition (fair, lumps most recognised) B: Fear and fatalism PB: Embarrassment SP: Most timely for lumps/ thickening	K: NR B: NR SP: NR	Medium
Siminoff et al (2014)	Retrospective Mixed methods	252 men (n=132) and women (n=120). Mean age: 58 years (range 25 to 94 years)	US	Colorectal	Education, Employment, Income	K: Symptom interpretation (39.7% did not think symptom was serious) PB: Financial barriers (28.6%), fear of diagnostic tests (24.3%), embarrassment (11.9%) SP: Mean appraisal delay (4.8 months)	K: NR PB: NR SP: NS association between time to SP and socioeconomic group (statistics NR)	Medium
Simon et al (2010)	Retrospective, Quantitative	2208 men (n=968) and women (n=1240). 11.4% (n=236) had experienced a symptom in the past 3 months	UK	All	Occupation	K: Recognition (better knowledge if experienced a symptom previously) PB: Emotional and practical barriers	K: NS association between symptom interpretation and socioeconomic group (statistics NR) PB: NR SP: NS association between SP and socioeconomic group (statistics NR)	Good
Smith and Anderson (1985)	Retrospective, Quantitative	82 women. Age range: 20 to 54 years	US	Ovarian	Income, education, occupation	K: Symptom interpretation ('cancer', 10%) B: Fear PB: Previous benign disease SP: Median time to symptom presentation (4 weeks)	K: NS association between symptom interpretation and socioeconomic group (statistics NR) B: NR PB: NR SP: NR	Medium
Temoshok et al (1983)	Retrospective, Quantitative	106 men and women. Age range: 18 to 72 years.	US	Melanoma	Education, occupation	B: Melanoma not a serious disease PF: Lesion visible (face and neck) SP: Mean time to symptom presentation (4 months)	K: No association with knowledge and occupation (statistics NR) B: NR PF: NR SP: No association with time to SP and occupation (statistics NR)	Poor

Tod <i>et al</i> (2008)	Retrospective, Qualitative	20 men (n=12) and women (n=8)	UK	Lung	Occupation	K: Symptom interpretation (poor, symptoms usually interpreted as acute conditions) B: Fear, fatalism PB: If previously given up smoking (thought risk of lung cancer was nil), worry about the wasting doctors time, previous bad experiences with health system, blame, stigma, stoicism, poor health service utilisation PF: Active encouragement from family member SP: Range in time to symptom presentation (0 to 24 months)	N/A	Good
Tod and Joanne (2010)	Hypothetical, Qualitative	25 men (n=15) and women (n=10). Aged 50 years and over	UK	Lung		K: Recall (poor) B: Fear, fatalism PB: Expectation of symptoms to be extreme, stigma, blame, denial, self-medication, vague nature of symptoms, competing life priorities, too busy, don't like to bother the doctor, difficulty getting an appointment PF: Symptom disclosure, active encouragement from a family member	N/A	Medium
Tomlinson <i>et al</i> (2012)	Retrospective, Quantitative	87 men (n=56) and women (n=31). Mean age: 65 years	Canada	Colorectal	Education	K: Symptom interpretation PB: Self medication SP: Waited over 1 month to seek medical help (51%)	K: NR PB: NR SP: NS association between education and time to SP (χ^2 , $p>0.05^{**}$)	Medium
Trivers <i>et al</i> (2011)	Hypothetical, Quantitative	2991 women. 65% were aged 45 years and over	US	Gynaecological	Education, Income	B: Concern about developing gynaecological cancer PB: Being premenopausal SP: 50% of women would seek help for most symptoms	B: NR PB: NR SP: NS association between SP intentions and socioeconomic group (statistics NR)	Medium
Tyler <i>et al</i> (2005)	Retrospective, Quantitative	176 men (n=93) and women (n=83). Median age: 54 years	Canada	Melanoma		B: Benefits of early diagnosis PB: Previous misdiagnosis PF: Symptom disclosure, active encouragement by wife, cosmetic appearance of lesion SP: Median time to symptom presentation (4 months)	N/A	Medium
Van Osch <i>et al</i> (2007)	Hypothetical, Quantitative	459 men (49%) and women (51%) over the age of 55. Mean age: 68.6 years.	Netherlands	All	Education	K: Recognition (low to moderate, mean: 6.2) B: Benefits of early detection SP: Fair. Inconsistent for urgent symptoms, good for prolonged symptoms	K: NR B: NR SP: Lower education associated with shorter time to SP ($F(2,436) = 6.084$, $p < 0.01$)	Good

Waller <i>et al</i> (2009)	Hypothetical, Quantitative	1500 men and women from various ethnic minority groups	England	All	Occupation	<p>K: Recall (poor, mean: 1.2) and recognition (poor, mean: 4.7)</p> <p>PB: Worry what doctor might find (most endorsed)</p> <p>SP: African and Caribbean groups anticipated fastest time to symptom presentation</p>	<p>K: Higher socioeconomic group associated with higher recall (F(1,1487) =6.12, p<0.01) and higher recognition (F(1,1487)= 5.45, p<0.05)</p> <p>PB: NR</p> <p>SP: NR</p>	Good
Walter <i>et al</i> (2014)	Retrospective Qualitative	63 men (n=31) and women (n=32). Age range: 29-93 years.	UK	Melanoma	Education	<p>K: Symptom attributions (initially attributed to benign skin conditions or normal life changes)</p> <p>PB: Worry about wasting the doctors time, service barriers, competing life priorities, reassurance following symptom disclosure</p> <p>PF: Family history of melanoma, perceptions of high risk, symptom disclosure, symptom noticed by another person</p> <p>SP: Range 1-303 weeks</p>	N/A	Good
Whitaker <i>et al</i> (2014)	Retrospective Quantitative	1724 men (n=789) and women (n=921) over the age of 50 ^s . Mean age: 64.4 years.	England	All	Postcode, education, employment	<p>K: Symptom interpretations (2% thought symptom was cancer, highest interpretation for 'unexplained lump'), perceived seriousness of symptoms</p> <p>SP: Symptom experience (53% experienced at least 1 symptom in past 3 months). 59% contacted GP about symptom</p>	<p>K: Unemployment associated with higher perceived seriousness of pain (OR 2.26, 95% CI: 1.17-4.35, p<0.05), tiredness (OR 2.11, 95% CI:1.23-3.64, p<0.05), sore throat (OR 3.56, 95% CI: 1.10-11.45, p<0.05) and chest pain (OR 3.56, 95% CI: 1.10-11.45, p<0.05). Lower education associated with higher perceived seriousness cough (OR 2.25, 95% CI: 1.10-4.56, p<0.05), tiredness (OR 2.46, 95% CI:1.44-4.21, p<0.05), headaches (OR 3.80, 95% CI: 1.63-8.89, p<0.05), shortness of breath (OR 2.34, 95% CI: 1.11-4.97, p<0.05), sore throat (OR 4.16, 95% CI: 1.14-15.22, p<0.05) and chest pain (OR 4.16, 95% CI: 1.13-15.22, p<0.05)</p> <p>SP: NR</p>	Medium

Whitaker <i>et al</i> (2015c)	Retrospective Qualitative	48 men (n=23) and women (n=25) over the age of 50. Mean age: 64.4 years.	England	All	Education, employment	<p>K: Symptom interpretations (symptoms normalised or associated with cancer)</p> <p>PB: Stoicism, fear of diagnostic tests, worry about wasting doctors time, service barriers, negative attitudes towards HCPs, medical mistrust</p> <p>PF: Development of new symptoms, persistence of symptoms, symptom disclosure, fear</p> <p>SP: Varied per symptom: 33.3% contacted GP with 'persistent cough', 100% contacted GP with 'unexplained bleeding'</p>	N/A	Good
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K: Cancer symptom knowledge; **B:** Beliefs about cancer; **PB:** Perceived barriers to cancer symptom presentation; **PF:** Perceived facilitators to cancer symptom presentation; **SP:** Symptom presentation; **NS:** Non-significant; **NR:** Not reported; * p-value not reported; ** other statistics not reported; ***aggregate ORs not reported, see Table 2 in paper; ****see table 3 in paper for other aggregate statistics; *****p-value reported in Table 3 in paper; however, due to CI including 1, the quality of paper has been lowered; §reason for disparity between participant frequencies not reported.

3.5 Discussion

The present review was the first to systematically explore how knowledge, beliefs and barriers/facilitators to symptom presentation affect actual or anticipated cancer symptom presentation, across all tumour sites and in relation to socioeconomic group.

3.5.1 Summary of evidence

Poor knowledge of non-specific cancer symptoms such as fatigue and weight loss prolonged medical help seeking due to misattribution of symptoms to benign conditions such as stress or a cold. In contrast, lump and bleeding symptoms were most frequently recalled and recognised, and prompted the fastest symptom presentation. A knowledge gradient was observed, where poorer cancer symptom knowledge was associated with low socioeconomic group based on multiple indices. The combination of fearful and fatalistic beliefs about cancer was associated with prolonged symptom presentation. There was some evidence to suggest that those from a low socioeconomic group were more likely to hold fearful and fatalistic beliefs about cancer and less likely to endorse positive beliefs about the benefits of early diagnosis. In addition, emotional barriers to symptom presentation such as embarrassment or worry what the doctor might find were more likely to be endorsed in low socioeconomic groups. Such poor knowledge, prevalent beliefs and emotional barriers to symptom presentation might account for the long actual symptom presentation times and later stage cancers diagnosed in low socioeconomic groups. There was some evidence to suggest that social norms around symptom presentation behaviour were barriers to seeking medical help, particularly for vague and non-specific symptoms of lung cancer. However, when seeking medical help for a symptom was sanctioned by a family member or friend following symptom disclosure, this facilitated in the decision to seek medical help, although there was some evidence to suggest that symptom disclosure acted as a barrier in low socioeconomic groups.

3.5.2 Findings in the context of current literature

The findings of the current review confirm that failure to appreciate the seriousness of symptoms (Macleod *et al*, 2009; Mitchell *et al*, 2008) and non-disclosure of symptoms (Bish

et al, 2005; Macleod *et al*, 2009) lengthened time to symptom presentation, representing Capability in the COM-B model. Findings accord with previous studies in which negative beliefs (Quaife *et al*, 2015a), longer time to actual symptom presentation (Macleod *et al*, 2009) and low suspicion for cancer symptoms (Whitaker *et al*, 2015a) were associated with low socioeconomic group (Macleod *et al*, 2009). The current findings support Mitchell *et al*'s (2008) (Mitchell *et al*, 2008) review of colorectal cancer patients, in which fear of cancer either lengthened or shortened time to symptom presentation, representing Motivation in the COM-B model. Such findings might be explained by Type I and Type II information processing systems. Type I processing is a fast and automatic system, which represents an individual's 'gut reaction' to an event (automatic Motivation), whereas Type II is a slower, more thoughtful and deliberative system (Reflective Motivation) (Epstein, 1994). Whilst most people initially experience fear in reaction to a worrying symptom (Type I processing), cognitions during Type II processing may influence the decision to seek medical help since these are slower and may help someone to rationalise the situation (Epstein, 1994). If an individual has had time to reflect on the benefits of seeking medical help, and based upon their previous beliefs about early diagnosis, such beliefs may override the Type I fear response. There was evidence to suggest a higher prevalence of fearful and fatalistic beliefs in low socioeconomic groups and some evidence for fewer positive beliefs surrounding the benefits of early diagnosis in low socioeconomic groups. This suggests that Type I beliefs may not be overridden by Type II responses relating to the benefits of early diagnosis due to lower knowledge or higher emotive responses. As a consequence this may prolong symptom presentation. Findings relating to symptom disclosure suggest that people use the 'lay system' of healthcare (consulting family and friends) before making the decision to access formal healthcare (Edwards, 2013; Low *et al*, 2015; Pescosolido & Boyer, 1999) representing Opportunity in the COM-B model. However, among individuals from low socioeconomic groups, disclosing symptoms to someone with equally poor knowledge and Type I negative automatic beliefs about cancer may encourage false reassurance in the benign nature of symptoms and consequently no urgency to seek medical help.

3.5.3 Quality of studies

Most included studies were of medium quality. In many studies, socioeconomic group was measured but only reported for selected or none of the outcome variables. Most studies

only reported socioeconomic group differences for symptom presentation. Twenty-nine studies reported socioeconomic group differences for the other outcome measures: knowledge, beliefs and barriers/facilitators to symptom presentation. One poor quality study reported a statistically significant association between socioeconomic group and time to symptom presentation; however, because the confidence interval includes 1.0 the association should not reach statistical significance. Methodological limitations included a long duration between cancer diagnosis and participation in retrospective studies, and samples biased towards high socioeconomic groups. In some studies, socioeconomic variation was insufficient to perform statistical analysis on all outcomes.

There are methodological limitations associated with retrospective (actual symptom presentation) and hypothetical (anticipated symptom presentation) designs. Whilst retrospective studies are affected by recall bias, hypothetical studies rely on intentions which may not translate into actual presentation behaviour (Gollwitzer, 1993). This was observed in the variation between actual and hypothetical time to symptom presentation, where participants anticipated prompt symptom presentation but in reality reported longer symptom presentation times. Study designs exploring actual symptom presentation behaviour in a population sample are likely to reduce some of the limitations associated with retrospective and hypothetical symptom presentation study designs. In such study designs, participants disclose actual symptoms experienced in the past three months, usually prompted by a list (without any mention of cancer), and reasons for not consulting a doctor explored (Cockburn, 2003; Simon *et al*, 2010; Whitaker *et al*, 2015a; Whitaker *et al*, 2014).

3.5.4 Strengths and limitations of review

Checklists such as AMSTAR (A Measurement Tool to Assess Systematic Reviews; www.amstar.ca, accessed 08.02.2016) can be used to assess the quality of a systematic review. According to the AMSTAR checklist, the present review was of good quality because an 'a priori' design was used, studies for the present review were selected and data extracted by two independent reviewers, multiple databases were searched, studies were assessed for quality, and study characteristics were tabulated. Although appropriate methods (a narrative synthesis) were used to combine study findings, a meta-analysis was

precluded by the wide range of qualitative and quantitative data collection methods and outcome measures of included studies, and is a limitation of the review.

Other limitations of this review include problems relating to retrieval of studies and analysis of the evidence. Due to poor indexing of studies under the MeSH indexing in this topic area, a high proportion of studies (n=22) was found through hand-searching. Finally, other factors such as age, gender and ethnicity can affect symptom presentation (Hiom, 2015; Macleod *et al*, 2009). However, interactions between these domains and socioeconomic group was considered to be beyond the scope of this review.

3.5.5 Implications for policy and practice

Cancer awareness interventions should be carefully developed to target those who are most likely to present with advanced stage disease: low socioeconomic groups with low symptom knowledge and fearful and fatalistic beliefs about cancer. Development of interventions targeted at people living in socioeconomically deprived communities should aim to consider the wider societal influences on symptom presentation behaviour including social norms around medical help seeking. The results of this review suggest that it is important to highlight the significance of vague and non-specific symptoms as potentially indicative of cancer, along with advice on an appropriate time in which an individual should seek medical help and how to access such help (Dobson *et al*, 2014). This should be coupled with information outlining the benefits of early diagnosis and improved effectiveness of modern treatments for cancer, in an effort to counter negative beliefs surrounding cancer. The current results suggest that such an intervention could potentially utilise an individual's social networks to facilitate distribution of information (Rogers, 1983).

3.6 Conclusion

The present review found evidence to suggest the presence of poor cancer symptom knowledge (Capability), high negative beliefs about cancer and emotional barriers to cancer symptom presentation (Motivation) in low socioeconomic groups. These factors in combination are likely to explain prolonged cancer symptom presentation and later-stage disease at diagnosis in low socioeconomic groups; however, the quality of evidence was limited due to the lack of socioeconomic variation within study samples. Subsequent

chapters will explore knowledge, beliefs and barriers to cancer symptom presentation in low socioeconomic groups within Wales using qualitative methods. Such insight is essential to understand the barriers to symptom presentation in order to develop interventions to encourage more timely symptom presentation in socioeconomically deprived groups.

Chapter 4

Understanding the barriers to cancer symptom presentation among low socioeconomic groups: a qualitative interview study

4.1 Chapter overview

This chapter reports findings from a qualitative interview study with thirty participants over the age of 50 from low socioeconomic groups based on multiple individual and group level indicators (McCutchan *et al*, 2016). Cancer knowledge, beliefs about cancer, barriers to actual or hypothetical cancer symptom presentation, and the wider social and environmental factors influencing actual or anticipated cancer symptom presentation were explored. Data were analysed using a framework approach based around the COM-B model. This chapter reports findings from the study and how they were used to facilitate understanding of the barriers and facilitators to cancer symptom presentation among people from low socioeconomic groups. Implications for a cancer awareness intervention targeted at people from socioeconomically deprived groups and the usefulness of the COM-B model in this context will be discussed.

4.2 Introduction

As outlined in Chapter 1, people from low socioeconomic groups are more likely to prolong cancer symptom presentation and consequently receive a diagnosis of cancer in the later stages of disease where treatment options are limited and the chances of survival are reduced (Macleod *et al*, 2009; Lyratzopoulos *et al*, 2013). The reasons for prolonged cancer symptom presentation among low socioeconomic groups are not fully understood. An in-depth understanding of this phenomenon is essential for the development of targeted cancer awareness interventions to promote timely symptom presentation among people from low socioeconomic groups.

As outlined in Chapter 1, the updated National Awareness and Early Diagnosis Initiative (NAEDI) framework provides a descriptive framework for suggested reasons for prolonged symptom presentation including poor cancer symptom knowledge, negative beliefs about cancer, barriers to help seeking and difficulty accessing primary care (Hiom, 2015). In the most recent version, socioeconomic group was included as a risk factor for prolonged cancer

symptom presentation (Hiom, 2015). However, due to the descriptive nature of the NAEDI framework, it is unclear how knowledge, beliefs and barriers might contribute to the decision to seek medical help for a symptom of cancer in the context of socioeconomic deprivation. Findings from the systematic review in Chapter 3, provide support for the assumptions of the NAEDI framework, and begin to provide insight into which factors are most salient among low socioeconomic groups where poorer knowledge, higher negative beliefs, and emotional barriers such as fear of a diagnosis of cancer were more prevalent (McCutchan *et al*, 2015; Appendix 1). However, evidence regarding the influences of symptom presentation has mainly been restricted to quantitative methods, involving samples with low socioeconomic variation and often relying on a sole socioeconomic group indicator. In addition, studies have typically focused on individual barriers rather than taking into account the wider social and environmental factors on behaviour (McCutchan *et al*, 2015; Appendix 1). A detailed examination of the mechanisms underlying prolonged cancer symptom presentation in deprived communities is required. This will involve gaining insight into the formation of beliefs and knowledge of cancer and an examination of the wider contextual influences on symptom presentation behaviour. The use of qualitative interview methods enables a deeper understanding of how both individual and socioeconomic factors might lengthen time to cancer symptom presentation.

4.2.2 The COM-B model

As discussed in Chapter 2, the COM-B model offers a potentially useful insight into how the decision to present with a potential symptom of cancer might be influenced through the constructs of 'Capability', 'Opportunity' and 'Motivation' and their underlying theoretical domains (Michie *et al*, 2011). Where many other theories neglect the wider social influences on behaviour, the COM-B model takes these and other individual level constructs into account, and was selected to aid analysis and interpretation of the data. According to the COM-B model (Michie *et al*, 2011), in order for behaviour to occur, an individual must have the 'Capability' (physical or psychological capacity of a person to perform behaviour; having the knowledge and skills to direct the behaviour) as well as the 'Opportunity' (physical opportunities created by the physical environment or social opportunities created by the cultural environment). In addition, 'Motivation' to engage in the target behaviour must outweigh motivation to engage in competing behaviours (Michie *et al*, 2011). 'Motivation' may be automatic (Type 1 innate, unconscious processes e.g. habitual or emotional

responses) or reflective (Type 2 deliberative, slower processes e.g. conscious decision making) (Michie *et al*, 2011).

4.2.2 Qualitative methods

A qualitative methodology was selected to gain an in-depth understanding of how individual and socioeconomic factors might influence cancer symptom presentation, understand the formation of cancer knowledge and beliefs, and identify barriers to cancer symptom presentation. Through qualitative methods, the wider social and environmental influences on health behaviour can be explored, which as described in Chapters 2 and 3, are likely to affect cancer symptom presentation among low socioeconomic groups. A semi-structured topic guide was developed based on the results of Chapter 3 and guided by relevant theory identified in Chapter 2. However, issues of importance which emerge can be explored during the interviews due to the nature of qualitative research. Additional themes could be explored and the topic guide developed should they become salient. The findings were used to build upon the results of existing studies described in Chapter 3, attempting to understand how socioeconomic group factors influence knowledge, beliefs and barriers to cancer symptom presentation.

4.2.3 Aims of the qualitative study

To date, no study has sought to understand the barriers to cancer symptom presentation from an in-depth qualitative perspective with participants from low socioeconomic groups based on multiple individual and group indicators. This study aimed to explore cancer symptom knowledge, beliefs about cancer, the wider social determinants and barriers to cancer symptom presentation in a sample of participants from low socioeconomic groups using qualitative interview methods.

4.3 Methods

4.3.1 Interview topic guide

Development of the topic guide was guided by the results of systematic review findings and relevant theory outlined in Chapter 2. The systematic review described in Chapter 3 helped

to identify any gaps in the evidence base and guide which topics required further exploration, in order to understand the formation of beliefs about cancer. Theory was used to identify the constructs which could potentially determine intentions to perform behaviour.

The main topics covered at interview were: cancer knowledge, beliefs about cancer (e.g. treatments for cancer and survival outcomes), any barriers and/or facilitators to presenting with actual or hypothetical symptoms to a healthcare professional (HCP), any previous symptom experiences (including symptom attributions, if they sought medical help or not and any barriers/facilitators experienced), hypothetical symptom episodes (including whether the participant would seek medical help or not and why, anticipated barriers/facilitators), symptom disclosure (who they would or have previously spoken to about health concerns), a description of the community and suggestions for a cancer awareness intervention (see Appendix 4 for topic guide). In an attempt to gain insight into perceived community norms associated with all previous topics, questions such as *'thinking about people in your community, do you think they know the symptoms of cancer?'* were asked.

The topic guide was developed with lay involvement from a member of the Tenovus Cancer Care Patient Advisory Group, a group of lay members of the public who have previously been affected by cancer. In addition, the topic guide was presented to 12 qualitative researchers at the Division of Population Medicine qualitative research group meeting at Cardiff University. Amendments to the topic guide were made following comments, and piloted on two postgraduate students at Cardiff University.

Changes to the topic guide following these piloting activities included adaptation of wording to ensure simple language was used and leading questions were not asked. The topic guide was adapted for any participants who disclosed a previous diagnosis of cancer during the interview. The recruitment strategy originally intended to capture members of the public who had not received a diagnosis of cancer, because it was thought that a previous diagnosis of cancer might bias cancer knowledge and beliefs. On further reflection, it was considered unethical to terminate an interview immediately after an individual disclosed a previous diagnosis and to exclude that participant. Therefore, anyone who disclosed a previous

diagnosis of cancer was interviewed using additional questions in the topic guide (see Appendix 4), in which questions were based on actual symptom presentation experiences, any barriers/facilitators and community level norms.

4.3.2 Participant recruitment

Participants were initially recruited through the International Cancer Benchmarking Partnership (ICBP) Welsh database (Forbes *et al*, 2013) which is a database of people who took part in the ICBP study in 2011. The ICBP study was conducted in five high income countries with comparable health care systems and was designed to capture population level data on cancer knowledge, beliefs, barriers and intentions to seek help for cancer symptoms in people aged over 50 years using the Cancer Awareness Measure (Forbes *et al*, 2013). Demographic data including educational attainment and postcode were collected as measures of socioeconomic group (Forbes *et al*, 2013). Participants in the ICBP study were contacted by telephone using random digit dialling and invited to take part in the survey study over the phone (Forbes *et al*, 2013). At the end of the study, participants were asked if they would like to be contacted to take part in future research (Forbes *et al*, 2013).

Participants for the present study were initially recruited from the ICBP Welsh database if they consented to be contacted for future research studies at the time of the ICBP study. Participants were selected based on Welsh Index of Multiple Deprivation (WIMD) score and educational attainment to ensure that those from a low socioeconomic group were invited to take part in the current study. Those residing in the most deprived quartile (a WIMD score less than 496 based on postcode; WIMD, 2011) and those with the lowest educational attainment ('finished school before age 15' or 'no qualifications or left school at age 16') were invited to take part in the study. Due to low response rates, additional participants were recruited using snowball sampling or were identified through Communities First partners. Communities First is a Welsh Government initiative designed to tackle poverty by supporting people who live in the most deprived areas of Wales. They employ Communities First partners to help delivery of government initiatives and provide face-to-face support for those living in the communities.

The original aim of the present study was to capture the perceptions and beliefs of people who had not received a diagnosis of cancer in order to understand the barriers to

anticipated cancer symptom presentation. However, as previously described, some participants disclosed a previous diagnosis of cancer during the interview, whereas some participants reported previous symptoms which could indicate cancer, and others reported no previous cancer symptoms. All participants were included to allow insight into the barriers and facilitators to symptom presentation based on a range of symptom experience.

4.3.3 Procedure

Potential participants were introduced to the study via telephone using a script tailored to their recruitment method (Appendix 5 and 6). Those who expressed interest in taking part were posted an invitation letter and study information sheet tailored to recruitment method (Appendix 7 and 8). Potential participants were contacted by telephone a week later to answer any questions about the research study, and a time and date for interview was arranged for those who were interested in participating in the study. All recruitment materials and written information were developed with lay involvement from a member of the Tenovus Cancer Care Patient Advisory Group and were tested using a readability formula to ensure that information was easy to read. Upon request, written information was available in Welsh.

Participants were offered a face-to-face interview in their own homes or at a place of their choosing. Telephone interviews were offered to some participants due to geographical factors, suspicion associated with a researcher coming into their home to talk about cancer, or physical disability. At the time of interview, participants were offered the opportunity to ask any questions and completed a written consent form. Participants interviewed over the telephone were posted the consent form for completion to be returned in the post, and also verbally consented over the telephone prior to commencement of the interview. Upon completion of the interview, additional demographic data were collected: age, occupation, car ownership, home ownership. If the interview took place somewhere other than their home, participants were reimbursed for any travel expenses incurred. Response rates for taking part in research are usually lower among people from low socioeconomic groups, therefore participants were offered £10 in cash as an incentive to participate in the study.

Semi-structured qualitative interviews were conducted, informed by the topic guide to allow for additional topics to be explored using probes and prompts during interview. Interviews were audio-recorded with permission and transcribed verbatim.

4.3.4 Ethical issues

Ethical approval for this interview study was sought from Cardiff University School of Medicine Research Ethics Committee (ref 14/01; Appendix 9). Two amendments were submitted and approved for changes to participant recruitment methods, first for snowball sampling and second for recruitment through community partners. There were a number of ethical issues encountered before and during the interview study.

4.3.4.1 Talking about cancer

Cancer is an emotive subject and there were some ethical issues around discussing cancer with participants. Most participants could recall losing someone close to them to cancer and some participants became very upset recalling these accounts, especially as they had not spoken about it at such length before. In cases where the participant became upset during the interview, the recorder was stopped and permission was sought from the participant before recommencement of the interview and participants were reminded of their right to withdraw. In all cases, participants requested to carry on the interview and some participants described the process as cathartic. There are issues around recalling these memories, and although all participants were given the contact details for the researcher and a free helpline number for the cancer charity 'Tenovus Cancer Care', those who became very upset were encouraged to seek help via the helpline number. The Tenovus Cancer Care helpline is run by volunteers and offers a free support line for people to talk about cancer worries. The staff are trained to signpost people to other services such as counselling services if they need further support.

Building rapport and gaining the trust of participants, particularly when interviewing individuals about cancer, is imperative due to highly emotive and often personal topics. Once an individual agrees to take part in a qualitative interview, although strict confidentiality and data protection procedures are followed to ensure no one outside of the research team will know they took part in the study, an individual is no longer anonymous to

the researcher. They might feel vulnerable as they discuss personal and emotional topics with someone who is in effect a stranger. Therefore, the researcher must be flexible with regard to the topics discussed and remind participants that they do not need to answer questions which make them feel uncomfortable. The interview topic guide was carefully designed to start with more factual knowledge of cancer, using questions designed to encourage the participant to talk and feel comfortable in a qualitative interview scenario. The topic guide then progressed onto the more emotive and personal topics later on in the interview. In most interviews, participants brought up previous upsetting experiences of cancer within their social network therefore the interview was guided by the participant. Building rapport was particularly challenging for those interviews conducted via telephone; however, efforts were made to engage in general conversation with the participant before commencement of the interview. For face-to-face interviews, rapport building was easier where general conversational questions, such as how long they had lived in the community or talk about recent sporting events, were used to engage participants whilst making a drink before the interview. Prior to the start of the interview, participants were reminded of confidentiality and permission to audio record was obtained to build trust. Body language and listening skills were important to encourage the participant to feel comfortable and be able to talk openly.

4.3.4.2 Telephone interviews

Telephone interviews were offered to four participants in situations where a face-to-face interview was not possible for reasons of geographical distance, physical disability or suspicion around talking about cancer in their home. For example, one participant needed to be in a horizontal position due to disability and requested a telephone interview to enable participation in the interview study whilst lying in bed. Another participant reported superstition associated with talking about cancer at length in the house and requested a telephone interview. Following discussion with supervisors about the ethical implications of interviewing someone with such strong superstitions, it was considered acceptable to interview this participant over the phone as the participant had requested a telephone interview.

There are particular ethical issues associated with gaining informed consent over the telephone and difficulties building rapport in a telephone interview. Participants were

posted an information sheet and a consent form prior to the arranged interview time, asked to read both documents, fill in, and return the consent form in a pre-paid envelope. At the time of the interview, the researcher reminded the participant of what their participation in the interview involved and other ethical issues such as right to withdraw according to the information sheet. The researcher read through the consent sheet again to receive verbal informed consent over the phone. As previously discussed, it is more difficult to engage participants over the phone, when compared to a face-to-face interview. However, as the PhD researcher had spoken to the individual at least twice before the interview over the phone, making conversation to build rapport was easier, compared to speaking to someone for the first time.

4.3.4.3 Symptom advice

Participants were reminded at the start of the interview that the PhD researcher was not medically trained and therefore could not offer advice on symptoms, but could signpost participants. There were a few participants who disclosed worrying symptoms or asked advice on symptoms. All participants with symptoms were encouraged after the interview to seek help from their GP. A few participants requested more information about the symptoms of cancer as they were unsure where to get symptom information from, or their reason for taking part was to learn more about cancer. All participants who requested more information were posted a variety of Cancer Research UK leaflets containing advice about symptoms of various cancers.

One participant disclosed a diagnosis of early stage dementia and discussed committing suicide, including details of his suicide plan if his memory became worse as he did not want to burden anyone with advanced stage dementia. Immediately after the interview, the participant was encouraged to go to the doctor to discuss all of the issues raised. Follow up phone calls were made to the participant in the weeks following the interview to ensure he had been to the doctor to discuss concerns.

4.3.4.4 Researcher values and relationship to participants

In qualitative research it is important to reflect upon personal values of the researcher and the relationship between the researcher and the participant. The researcher should have an

awareness of these how these might influence responses and during an interview situation and interpretation of findings.

I am a white English middle class female with a good education. I have been given every opportunity to reach maximum potential socially and academically. I have an interest in the social determinants of health and believe we should live in a more equal society and that a society where people are living below the poverty line is unjust and barbaric, especially when the system fails to support those most in need. Although I made effort to understand the contextual factors in deprived communities, as I have not experienced living in a socioeconomically deprived community first hand I may never fully understand the wider social and environmental factors on behaviour.

Going into interviews, I was very conscious of my social standing as a middle class English female and how there was a potential for a power imbalance. I was aware of how this might influence rapport, trust and openness from the participant during the interview and made every effort to make the participant feel comfortable through dressing appropriately and engaging in conversation to break down any potential power imbalance. In addition, I was aware participants might be suspicious of someone from a university asking them to take part in research. For example, one participant during an interview disclosed the belief that the researcher was working undercover from the Government to assess his disability benefit and realised during the interview that I was actually a student from Cardiff University.

4.3.5 Analysis

Participants were interviewed until data saturation was achieved, to ensure that adequate data were collected and the views of the target population were represented. Data saturation was considered to have occurred when no new themes emerged for at least the final three participants (no new themes emerged from participant numbers 27 to 30). Transcripts were analysed using a framework approach (Richie and Spencer, 2002; Green and Thorogood, 2011 p.208) based around each of the COM-B model constructs (Capability, Opportunity, Motivation - Behaviour) (Michie *et al*, 2011). The Theoretical Domains Framework (Cane *et al*, 2012) was used to facilitate grouping of themes under the COM-B model constructs.

Each transcript was read and re-read and themes were generated from the transcripts (see Appendix 10 for coding framework). Themes were grouped under each of the COM-B model constructs according to the definitions outlined previously. Grouping of themes was double checked by another member of the research team to reduce potential bias, and amendments made accordingly. Data were managed using the qualitative analysis software package NVivo (NVivo, 10). Two other members of the research team double coded two transcripts (four in total were double coded). Discrepancies were resolved through discussion between the PhD researcher and coders. Discussing discrepancies was useful to reduce subjectivity associated with coding and to facilitate interpretation of findings.

Individual participant views were summarised and charted under each of the relevant themes of the COM-B model constructs, supported by Microsoft Excel (see Appendix 11 for an example of one charting spreadsheet). Data were analysed and charted according to reported cancer symptom experience and patient ID. Separate charts were produced for those who reported no symptom experience, previous cancer symptom experience or a previous diagnosis of cancer.

The primary focus of this PhD thesis was to understand the factors underlying prolonged cancer symptom presentation among low socioeconomic groups. The topic guide and interview findings reflect this. However, as the PhD evolved, lung cancer was selected as an exemplar of prolonged cancer symptom presentation and poor survival in deprived communities (see Chapter 1). For this reason, additional analysis was undertaken for findings associated with lung cancer and presented after each of the COM-B constructs.

4.4 Results

4.4.1 Response rate

Thirty participants were interviewed between June 2014 and March 2015. Face-to-face interviews (n=26) or telephone (n=4) interviews were conducted with 13 men and 17 women, with a mean age of 66 years (range 52 to 88 years). Three interviews were conducted with two people at the same time due to restrictions on space precluding the ability to interview participants in separate rooms. Interviews were between 45 minutes and 2.5 hours duration (mean 72 minutes).

Twenty participants were recruited from the ICBP Welsh database, eight participants were recruited through snowball sampling and two through Communities First partners (see Table 4.1). Of the 126 names and telephone numbers extracted in total from the ICBP Welsh database according to WIMD score, educational attainment and permission to be re-contacted, verbal contact was made with 84 potential participants to invite them to take part in the study. No verbal contact was made with the remaining 42 individuals either because they did not answer the telephone after multiple attempts (n=23), their phone line was disconnected (n=15), the number was incorrect (n=2) or the individual had died (n=2). Of the 84 individuals who were invited to participate after initial verbal contact was made, 20 participants consented to interview (24% response rate). Reasons for non-participation in the study were: did not want to talk about cancer (n=31), too busy to take part (n=29), too ill to take part (n=12), did not want to take part in research (n=9), recent death in the family (n=3). Response rate data was unavailable for participant recruitment through snowball sampling and community partners.

4.4.2 Sample characteristics

All participants were in the most deprived quartile based on WIMD score calculated using postcode data. As shown in Table 4.1, all participants were of low educational attainment. Most participants were employed or retired from low skilled manual occupations such as factory work, or were entitled to receive job seeker allowance or disability benefit. The majority of participants did not own their own car, and rented their house or lived in a council owned property or sheltered housing. Although six participants owned their own house, they had lived in their home or community their entire lives and had inherited the family home.

Five participants disclosed a previous diagnosis of cancer at interview, 16 reported a previous symptom episode during the interview and nine participants reported no prior cancer symptom experience.

Table 4.1: *Sample characteristics*

Characteristics	Participants
Recruitment source	ICBP Welsh database (n=20; 24% response rate calculated as a proportion of those eligible for the study after verbal contact was made) Snowball sampling (n=8) Communities First partners (n=2)
Gender	Female (n=17) Male (n=13)
Age	50-60 years (n=10) 61-70 years (n=13) 71-80 years (n=5) 81-90 years (n=2)
Symptom experience	Previous diagnosis of cancer (n=5) Reported cancer symptoms (n=16) No cancer symptom experience (n=9)
Educational attainment	Finished school before age 15 (n=15) No qualifications or left school at age 16 (n=15)
Main source of household income	Wages or salary (n=3) Pension (n=18) Benefits (n=8) Other (n=1)
Home ownership	Owns home (n=6) ¹ Privately rented housing (n=11) Housing association or sheltered housing (n=7) Council owned property (n=6)
Car ownership	Owns car (n=9) Does not own car (n=21)

¹These participants had inherited the family home, where they had lived their entire lives

4.4.3 Interview themes

Key themes identified are presented under each construct of the COM-B model, with quotes as examples. Square brackets within the quotes represent inserted text to allow for clarification of the topic content. Where irrelevant, text was removed from quotes and denoted by '...'.

4.4.3.1 Capability

Key themes relating to psychological capability were: cancer symptom knowledge, knowledge of the causes of cancer and communication with HCPs. No themes for physical capability were identified.

4.4.3.1.1 Cancer symptom knowledge

Knowledge for 'red flag' symptoms of cancer including blood in urine and lumps was good. Participants also thought that community level cancer symptom knowledge was restricted to lumps and sometimes bleeding. Knowledge for blood in stools was also good; however, most participants attributed blood in stools to benign causes such as piles in the first instance, therefore anticipated symptom presentation was prolonged. Most participants intended to seek immediate medical attention for a lump. This was reflected in those who had previously experienced actual lump symptoms describing how they sought medical help immediately. These participants were able to override any reported barriers to symptom presentation, seeking medical help immediately and usually requesting an emergency appointment. For bleeding, action planning was not quite as consistent, with the urgency to seek medical attention dependent on the source of bleeding. Bleeding from the bowels was often attributed to other causes, whereas blood in urine was considered much more serious:

"I think the knowledge is there about bleeding from your back passage, lumps that knowledge is out there for everybody... If you bleed through the back passage you [think] is it piles? I suppose you'd leave it go a week or two, but if it didn't stop you'd [go]... a lump you automatically [go]." (*Female, age 67, previous diagnosis of cancer*)

"If I see there's anything wrong with my prostate and there's blood coming in my pee, I will be straight down the doctors." (*Male, age 72, reported previous cancer symptom*)

A few participants knew of other, non-specific symptoms such as weight loss or fatigue. Knowledge for these symptoms was usually acquired from retrospectively recalling symptoms experienced by family members and friends in the lead up to a diagnosis of cancer. However, non-specific symptoms were often attributed to existing co-morbid

illnesses which were highly prevalent in this group such as diabetes, or participants were unaware that these non-specific symptoms could indicate cancer. There was no perceived urgency to seek medical help for non-specific symptoms and all of those with a previous diagnosis of cancer reported attributing symptoms to ageing or pre-existing comorbidities. These participants reported being surprised upon learning their symptoms were signs of cancer when they went to their GP to discuss their symptoms:

“I- When you were having your problems with going to the toilet a lot, did it ever cross your mind that it might’ve been cancer?”

P- Nuh, not in a million years because I never even heard of that there’s something wrong with your prostate, I didn’t even know what the prostate was...I was thinking about going to the toilet all the time?” *(Male, age 75, previous diagnosis of cancer)*

“All my symptoms, because I’ve got diverticulitis, that’s one of the things, I’ve got acid reflux that’s another thing so I mean to say all these things could say I’ve got cancer so if I thought that I’d be thinking ‘I’m gonna die every day’.” *(Female, age 66, reported previous cancer symptom)*

A minority of participants knew the rarer and more advanced stage symptoms of cancer, such as pancreatic cancer symptoms, which is likely to reflect the high prevalence of these types of cancer among low socioeconomic groups. There was a common misconception that cancer is always painful and is likely to reflect seeing people in the community with advanced stage cancer, therefore it is likely that painless symptoms are misattributed to other benign causes. Some participants expressed anxiety around the belief that some cancers were symptomless. A few participants wanted to learn more about cancer but were unsure where to seek information from and this often motivated participation in the study:

“The thing is how do you know when you’ve got [cancer] anyway? You know what I mean? You don’t know really, until it reacts with you know what I mean?” *(Male, age 80, reported previous cancer symptom)*

4.4.3.1.2 Knowledge of the causes of cancer

Most participants discussed potential causes for cancer that were beyond their control and therefore expressed a reluctance to change 'risky' behaviours due to a perceived lack of benefit. Many participants thought "we're all born with cancer in us" (*Female, age 62, no cancer symptoms reported*), lying dormant until trauma such as a bump, psychological stress, or chemicals used in food cans was required to "trigger [cancer] off" (*Female, age 66, reported previous cancer symptom*). Such beliefs were usually reinforced by people they knew who had previously received a diagnosis of cancer. Luck associated with developing cancer was discussed by many participants and is likely to contribute to the belief that cancer is beyond one's control. One participant requested a telephone interview for superstitious reasons, due to worry that he would jinx himself if the PhD researcher came into the house to discuss cancer at length. Some participants discussed family members or friends who received a diagnosis of cancer as "unfair" because the individual concerned was a "good person" (*Female, age 58, reported previous cancer symptom*):

"I think too much [cancer] is made of the food though, I really do, there are a lot of additives and stuff that are put in foods that can cause problems...They're spraying all these, it's definitely man-made I think with all the chemicals that's my way of thinking, definitely. I think it's food, I think it's in the air, and I also think it's caused by knocks, you know if you bump, give yourself a hard knock?...Now my cousin she swears that years ago when she was playing tennis, her opponent accidentally hit her with a tennis racquet on the shoulder and that shoulder she said "left her in pain" she always had pain with it and she swore [the cancer] came from that." (*Female, age 69, reported previous cancer symptom*)

"You can't stop [cancer], once it's in you, it's in you and everybody's got a little bit of cancer in them and it only takes something to knock you to trigger it, to start it off." (*Male, age 56, no reported cancer symptoms*)

"[Cancer is] in everything we eat...using different fertilisers to make [food] grow to keep the flies and that away...You read all this in the paper, eat this, eat that, it's healthy for you, but it's the sales patter to sell it I'm sure, because it's not doing anyone any good...I say "eat what you like, eat it, if you like it eat it"...[cancer is] in

what we eat, but you've got to eat, it's as simple as that." (*Male, age 72, reported previous cancer symptom*)

Most participants understood that smoking was a cause of cancer, although around a third were sceptical of the link between smoking and cancer. Current smokers and those who smoked throughout the interview tended to hold the latter belief that smoking was unrelated to cancer risk. Such claims were usually supported with examples of people they knew who had never smoked but were diagnosed with cancer. Some smokers recalled instances when they were 'told off by the doctor' for their smoking habit and perceived that HCPs used smoking to blame their symptoms rather than treating the health problem. This is likely to result in a reluctance to visit the doctor for symptoms in the future:

"Smoking don't cause cancer it doesn't do you any bloody good at all, they say it gives you cancer and that is a lie, it does not give you cancer." (*Male, age 65, previous diagnosis of cancer*)

"I disagree with you because they put [cancer] down to cigarettes and yes, it does cause a lot of problems in health and one thing and another, my mother died of [cancer] and never had a smoke, his mother never smoked, she had [cancer] and there's a lot of people in my family that don't smoke that have got [cancer]..." (*Female, age 57, no cancer symptoms reported*)

Some other participants who currently smoke were reluctant to give up smoking as they reported smoking to be the last piece of enjoyment left, although they fully understood the links between smoking and cancer:

"When I go down [to the doctor] and she'll say "I know you're not drinking, but how about smoking?" and I say "do you want me to cut my throat?"" (*Male, age 67, reported previous cancer symptom*)

4.4.3.1.3 Communication with Healthcare Professionals (HCPs)

Some participants perceived themselves as having the capacity to effectively communicate symptoms to a HCP, sometimes using prompts such as lists to facilitate discussion and aid

memory recall. In addition, they felt confident about actively participating in a discussion with a HCP around healthcare and treatment options or would present to their GP with their self-diagnoses. For these participants, effective communication was perceived as important for access to optimal healthcare provision:

“I used to go to the doctor, and I’d go to the doctor and I’d tell them and they’d tell me and I’d trust them, you know I’d think they know they’re the doctor at the end of the day. Now I don’t ask them anymore I tell them, because you’re wasting your time if you just sit there, you’re wasting your time.” (Female, 66, *reported previous cancer symptom*)

“Don’t be afraid of the GPs pooh-poohing you. Usually you know your body better than anyone else, so you know when it’s not right. Go to your GP, and don’t be pushed off with “oh just take this couple of tablets you’ll be alright”. If you don’t feel like that push and push and push and unfortunately with GPs a lot of them, you’ve got to do that today...I always say to people “when you go to the doctors, write a list, take it with you” because you’re in there and you come out and you think “oh I didn’t ask so and so, or I should’ve said so and so” - too late then.” (Female, age 68, *no cancer symptoms reported*)

“I’m the type of person, I question something, [my husband] will accept it more than I will, he’ll say “oh well I’ve been told, listen now they’ve told me and that’s the end of it” [I say] “no it’s not the end of it, you disagree with it or you don’t believe it, question it again.” (Female, age 57, *no cancer symptoms reported*)

Other participants preferred to take a more passive role in their healthcare, expressing frustration when invited to participate in a discussion with a HCP about a potential diagnosis and management for symptom(s). These participants perceived this approach used by doctors to engage patients in shared decision making or discussion about treatment options as disinterest in them as a patient, which is likely to put people off going to the doctors in the future. A passive approach to healthcare was perceived as the norm within the community, where people in the community preferred to present with symptoms and receive a diagnosis with little participation in discussion about potential causes. Some participants described a lack of confidence when communicating symptoms, getting to an

appointment and forgetting what to say, or struggling to ask questions during an appointment with a HCP. Problems with communication during an appointment were perceived as the norm within the community, and are likely to reflect literacy issues among low socioeconomic groups and/or a power imbalance where participants reported that people in the community were often “in awe of their GP” (*Female, age 52, no cancer symptoms reported*):

“[The doctors] say to you “what do you think?” and as I say to them, “I’m not the doctor how do I know?” If it comes to diagnosing yourself why bother going to them? You know, what’s the point?” (*Female, age 66, reported previous cancer symptom*)

“My brother insists that [my daughter] comes to the hospital with me, I don’t listen to the doctor I don’t, you know. Instead of me listening to him, she was there so she knew what he was saying.” (*Male, age 75, previous diagnosis of cancer*)

4.4.3.2 Motivation

Key themes relating to automatic and reflective motivation were: fearful and fatalistic beliefs about cancer, and beliefs about the treatments for cancer and early diagnosis, and emotional barriers to symptom presentation.

4.4.3.2.1 Fearful and fatalistic beliefs about cancer

When participants were asked for their initial, automatic reactions to the word cancer, their reactions were all highly emotive and fearful, where participants described cancer as “evil” or “terrible”. There was an overall fear of receiving a diagnosis of cancer. Participants reported fear of the treatments for cancer and fear of dying from cancer especially as they associated the treatments of cancer with unpleasant and nasty side effects, and pain during the end stages of cancer where death was often the outcome. A diagnosis of cancer was feared more than other life threatening conditions, such as heart disease, due to the belief that cancer was a slow and painful death. There was a perception that cancer was a “dirty disease” (*Male, age 80, reported previous cancer symptom*) which is likely to contribute to the stigma attached to cancer. Some participants expressed cancer specific fatalistic beliefs

such as the belief that death was inevitable after receiving a diagnosis of cancer. These participants believed that there was no cure for cancer and treatment was used to prolong life rather than cure cancer. Such beliefs were usually based on witnessing family members or friends who suffered, and in most cases died, from cancer or stories of celebrities who had died of cancer:

“I- How would you describe cancer as an illness?

P- ((sighs)) evil, terrible, terrible yes.” (*Female, 58, reported previous cancer symptom*)

“If you have cancer, you think you’re gonna die....don’t you? You know that, that’s the most, that’s what you think, I don’t care who you are, that’s what you’re gonna think, they might be a chance these days, it is remote that you’ll survive it, but that’s the first thing, if anybody has been told that they’ve got cancer, that’s the first thing that goes through their brain.” (*Male, age 80, reported previous cancer symptom*)

“All I know is that once you get it, that’s your lot, as far as I know there is no cure ...it’s a dirty disease isn’t it? That’s the description of cancer, it’s a dirty disease...you start thinking the worst and to be honest with you the worst is cancer! No one thinks of heart attacks, or fits, or strokes, the first thing is cancer. Phone the funeral director I’ve got cancer!” (*Male, 80, reported previous cancer symptom*)

For some participants, fear prompted immediate actual or anticipated symptom presentation for symptoms suggestive of cancer. This was usually when fearful beliefs were combined with an awareness of the benefits of early diagnosis of cancer. Fear of the consequences of a late diagnosis of cancer prompted or would prompt participants to seek help quickly, and those reporting actual symptoms (usually lump) often requested emergency appointments. For other participants, fearful beliefs about cancer - especially when combined with fatalistic beliefs about cancer - were the biggest barrier to cancer symptom presentation. This was perceived to be the norm within the community and some participants could recall people they knew who were too scared to go to the doctor with symptoms. One participant discussed a family member who entered the healthcare system as an emergency case and died in intensive care two days later from a brain tumour, but had not been to the doctor about his symptoms. It was reported that he “put his life in order”

(*Female, age 67, reported previous cancer symptom*) for his wife before his death as the participant thought he was aware his symptoms were cancer but was too scared to go to the doctor:

“It took me a long time to go [to the doctor] I know that, I was terrified...I was terrified of the answers...what I don’t know I can’t worry about can I?” (*Female, age 88, previous diagnosis of cancer*)

I – “What do you think is stopping people from going [to the doctor]?”

P- Afraid I think it is to find out the truth, they know there’s something wrong, they’re just afraid to actually hear the doctor come out and say the word ‘cancer’...They’re afraid to go to the doctor’s in case they actually say “yes, you have got cancer” and a lot of people are afraid to hear that word you know...so a lot of them will just sort of put it off until they’re so ill they’ve got to go.” (*Female, age 52, no cancer symptoms reported*)

“I had a lump under my arm I was straight to the doctors I was absolutely petrified, but it was only a blocked um oh tube...” (*Female, age 58, reported previous cancer symptom*)

4.4.3.2.2 Beliefs about treatments and early diagnosis for cancer

Most participants were fearful of treatments for cancer and some believed the treatments to be worse than the cancer itself. Side effects such as sickness and hair loss were the most prominent deterrents for accepting cancer treatment. Some participants would anticipate refusing treatment if diagnosed with cancer and/or recalled family members or friends who had refused cancer treatment in the past. Some participants believed that air getting to cancer from operations caused the cancer to spread, and gave accounts of people they knew who died from cancer shortly after an operation to investigate or remove the cancer. Beliefs about air causing cancer to spread could put people off receiving treatment for cancer. For some participants there was confusion between potentially curative treatments for cancer and palliative or end of life care, where participants often mistook pain relief such as morphine for an intervention to treat cancer. This could reflect the vicious circle of participants having been exposed to people in their social network who were diagnosed at a

late stage. They might therefore have received less effective treatment, and were then moved directly into palliative care, and failing to understand the negative correlation between cancer stage and treatment effectiveness. In addition, low health literacy in this group or problems associated with communication and comprehension of medical information are likely to contribute to misunderstanding of the difference between therapeutic options and contribute to negative beliefs about cancer treatment:

“My sister she had radio, whatever you call it....on her throat and that when she had the throat cancer and when we went to see her, she was burned inside and outside, and it makes them ill and sick and whatever. Well a lot of people with cancer would rather die from the cancer than go through the treatment.” (*Female, age 52, reported previous cancer symptom*)

“[My friend with cancer] said “I’m not, I’m not having treatment, I can’t cope with it” she said and within a week she was dead.” (*Female, age 57, reported previous cancer symptom*)

“It is horrendous I think for a woman, when your hair goes, it’s terrible, terrible and being sick, she used to have this injection on the end of the month, so right she had it at the end of the month, she’d be sick for 2 weeks after that, then she’d sought of have 1 week and she would be okay and then we’d go again oh! It was awful that was.” (*Female, age 68, reported previous cancer symptom*)

As each interview evolved, many participants appeared to understand the benefits of early diagnosis, even after expressing previous fearful beliefs about cancer. These participants understood that detecting cancer in the early stages through prompt medical help seeking could enable access to less invasive treatments and potentially cure “good” (*Female, 69 years old, reported previous cancer symptom*) cancers such as breast and prostate. These contradictory beliefs are likely to reflect a deep-seated fear of cancer. However, participants thought that people in the community were generally unaware of the benefits of early diagnosis. Beliefs about the benefits of early diagnosis were usually reinforced by people they knew in the community who were diagnosed and had survived cancer, or from news items. For those who understood the benefits of early diagnosis, the urgency to get cancer diagnosed quickly was a source of anxiety and as a consequence some participants were

hypervigilant about symptoms and worried about cancer as a probable cause of symptoms. For others, anxiety stemmed from the belief that certain cancers were asymptomatic in the early stages. This may reflect the high prevalence of cancers in the community which are harder to diagnose in the early stage and have worse outcomes, such as lung or pancreatic cancer. As a consequence, although these participants understood the benefits associated with a diagnosis of cancer in the early stages, they felt that early diagnosis was beyond their control:

“I suppose I know people who’ve survived it. I think it used to be, once you heard that somebody had cancer that was their lot, but I can’t say that these days you know and they reckon more people survive cancer now than, than, you know you’ve got a good chance of surviving now.” (*Female, age 69, reported previous cancer symptom*)

“It all depends on what cancer it is, if it was breast cancer I think you’ve got a good chance, if you got it early enough, bowel cancer is a good cancer to have if you’ve got to have cancer, cos they tend to be able to treat that.” (*Female, 69 years old, reported previous cancer symptom*)

“Well hopefully they can catch it at an early stage where it hasn’t spread and then you’ve got more, they can remove it...[my friend] was very lucky they just removed it, he didn’t even have to have any chemotherapy after it, because it hadn’t spread it was early stages, but then I know other people who have had it and theirs had already spread, it’s already started to spread so that it, the quicker you get it the better isn’t it? But there again how do you know when you’ve got it?” (*Female, 71, no cancer symptoms reported*)

In contrast, some participants believed there was no cure for cancer, and provided anecdotal accounts of family members or friends who died from cancer. A few participants believed that the government had found a cure but was withholding it in order to generate revenue for the NHS by keeping people who work in cancer services in employment. Some participants reported that they had seen press releases and campaigns about cures for cancer in the media, but struggled to believe them. This is likely to reflect repeated exposure to cancer-related death in the community where they saw little firsthand or ‘real’ evidence

of people in their community surviving cancer. This could contribute to or reinforce lack of trust and suspicion towards government and health services, where participants believed that cancer was being used as an ulterior motive:

‘You’ll never get rid of it and it’s just one of those things you know. They’re on about “we’ve got cures for this, cures for that”, I think it’s just a big money making thing to be honest, I think that it’s a case of they got it and “we ain’t sharing it because there’s too much money going in....These cancer things, like I said, nuh there’s never going to be a cure...I don’t know I don’t hear of many that are cured, what I suppose they do, I think they get an extension to their life, but I don’t think they actually get cured, no....” (Male, age 56, no cancer symptoms reported)

“As soon as you mention the ‘C’ word people will lie down and die, because they think there’s no cure me... what am I supposed to do?” (Female, age 70, reported previous cancer symptom)

4.4.3.2.3 Emotional barriers to symptom presentation

Some participants reported embarrassment associated with disclosure of symptoms to a HCP, particularly when an examination of an intimate area was required such as a breast lump or the participant was required to disclose symptoms such as blood in faeces. Participants perceived embarrassment as a key barrier to cancer symptom presentation in the community, particularly among men. Many participants reported denial as a barrier to cancer symptom presentation in the community. For some participants, denial was conceptualised as individuals who believe themselves to be at low risk for cancer and have the attitude that ‘cancer will not happen to them’ so are reluctant to seek help for symptoms or change ‘risky’ behaviour such as smoking. For some participants, denial of symptoms was conceptualised as complete ignoring and repression of symptoms due to a deep-seated fear of cancer and the belief that a diagnosis of cancer would be too much to cope with, thereby prolonging or completely inhibiting cancer symptom presentation:

“I think it depends where you think you’ve got cancer as well, some people are too embarrassed to go to the doctor aren’t they?” (Male, age 81, previous diagnosis of cancer)

“They think you know [cancer is] not gunna happen to them, I’m okay.” (*Male, age 64, reported previous cancer symptom*)

4.4.3.3 Opportunity

Key themes relating to physical and social opportunity were: facilitators to cancer symptom presentation, barriers to cancer symptom presentation, experience of cancer, a lay system of healthcare, and social environment.

4.4.3.3.1 Facilitators to symptom presentation

Some participants reported a good relationship with their GP, where they felt their doctor was interested in them as a patient, listened and was easy to talk to. These participants felt confident in presenting to their doctor with potential cancer symptoms to discuss concerns and perceived this as a key facilitator. Some participants had help from family members or friends to book an appointment or help with transportation to an appointment. In addition, some participants benefited from family members or friends who would accompany them to an appointment to help with communication and listening during an appointment, which facilitated symptom presentation:

“I’ve been lucky up till now because I’ve always had a lift down, there’s always been somebody that goes out of their way to take me, but, other than that no, [the surgery is] really difficult to get to.” (*Female, age 62, reported previous cancer symptom*)

“I’ve got a very good doctor...my GP walks on water...he makes out that he’s interested I you, you know what I mean?” (*Male, age 80, reported previous cancer symptom*)

“I think if you can get a good GP you’re half way there, you know? I really do think 90% it’s down to your GP. There’s some awful GPs out there and there’s some brilliant ones you know? I’ve got a good one here now in my practice...I would feel confident to go to him with any misgivings about anything.” (*Female, age 60, no cancer symptoms reported*)

4.4.3.3.2 Barriers to symptom presentation

Continuity of care was described as a barrier to symptom presentation because participants reported often seeing a different GP on every visit. Most participants reported a preferred GP within their practice; however they were required to book an appointment up to three weeks in advance to see their preferred doctor. Participants weighed up the problems with seeing a different doctor on every visit, where they were required to repeatedly explain the same problem against waiting two to three weeks for an appointment with their preferred doctor. Many participants thought the receptionist at the GP practice often played a gatekeeper type role, where perhaps the receptionists did not understand the seriousness of certain symptoms and refused to issue them with an earlier appointment. For some participants who worked unpredictable shift patterns, planning and scheduling an appointment was difficult especially when they were required to book in advance. In addition, loss of earnings due to attending an appointment during work hours was a barrier to cancer symptom presentation. For some participants, the practicalities of getting to an appointment were barriers to symptom presentation because of a lack of transportation, work commitments and physical disabilities. Potential loss of earnings and difficulty getting to an appointment are likely to prolong presentation with symptoms that are perceived as non-urgent, such as vague or non-specific symptoms:

“In fact the last 3 times I’ve been now I’ve seen 3 different doctors, but I’ve been going for results of blood tests and that you know. I suppose if I was prepared to wait uh I could see the same one like, cos you phone up and [say] “can I see Dr so and so...?” “Oh they’re not here this week they’re somewhere else”, so you see anybody then, you know.” (*Male, age 81, previous diagnosis of cancer*)

“Well they made an appointment you’ve got to wait 3 weeks! You’d be dead by then, and they say you go to them like me, I, I struggle down, you go down and what did they do? Nothing! No different to went you walked in, only annoyed.” (*Female, age 66, reported previous cancer symptom*)

“They don’t pay you to go to the doctor, you know you’ve got to clock in and clock out I mean I said “no I can’t afford to lose time off work” and I don’t drive for another thing, so I said “where it would take 10 minutes to get down to you, I’ve got to wait for a bus, get down on the bus, and then go back to work which would take

me an hour, which would only take somebody else I said 15 minutes.” (*Female, age 57, reported previous cancer symptom*)

Time limited appointments and ‘one appointment, one problem’ policies prohibited the disclosure of more than one symptom. This was frustrating for participants, especially when they took time off work, waited a few weeks for an appointment or overcame the challenges associated with getting to an appointment. Consequently, participants perceived there to be “little point” (*Female, age 66, previous cancer symptom experience*) in going to the doctor, which has the potential to stop or delay a future visit to the doctor. The pressure of a time limited appointment is likely to increase anxiety or prohibit full disclosure of symptoms for those who struggle with communication during an appointment. For participants with potentially embarrassing or worrying symptoms such as blood in stools, other symptoms or health complaints may be used to ‘test the water’, before disclosure of a symptom which might indicate cancer. Therefore, policies that preclude the disclosure of more than one health complaint may prohibit presentation of the cancer symptom:

“If you don’t specifically book a week before or fortnight in advance to see a certain doctor you get to see a locum which, when you go in there they say “I can only see you about 1 thing, I’ve got 5 minutes” and I just looked at her and I thought well it’s a waste of space I said “It is literally just a waste of space coming to see you...cos it’s all related” ...I just looked at her and I thought “oh forget it”, I just went out and I said, I told them exactly “she’s a waste of space, she’s useless.” (*Female, age 57, reported previous cancer symptom*)

“I went in there with a complaint and he’s seven minutes. I said I got something else and he said “you’ve already come for the one complaint, you’ll have to make another appointment to see me again.” (*Male, age 80, reported previous cancer symptom*)

4.4.3.3 Experience of cancer

To support beliefs about cancer or demonstrate knowledge of the symptoms and causes of cancer, participants almost exclusively drew upon anecdotal accounts of people they knew with cancer in the community, which were generally negative. Some participants reported

that their entire immediate family or many close family members had suffered and died from cancer, and were often involved in nursing them in the end stages. For some participants, recalling these details was upsetting and the interview was paused. One participant produced a list of 25 people in the local community who had recently died of cancer and other participants could recall numerous local community members or friends who had died of cancer. Such high exposure to death from cancer and seeing family members and friends suffer is likely to contribute to the formation of fearful and fatalistic beliefs about cancer:

“I’ve had 17 in the family die of it [cancer].” (Male, age 56, no cancer symptoms reported)

“[My father] died in agony. I was there and he was, I’ll never forget it on [date] I watched him die in agony, like I watched my wife [die from cancer], through incompetence you know...” (Male, age 72, reported previous cancer symptom)

Some participants knew one or two people in the community who survived cancer, but who had kept their diagnosis a secret due to perceived stigma, or perhaps due to fear of being treated differently or rejected by the community. In addition, the only cancer-related media coverage that most participants could recall was about celebrities who died from cancer. Some participants reported how TV soaps and films often use cancer to ‘kill characters off’ which is likely to further reinforce negative beliefs about cancer and its association with death. It is unlikely that this was the only media coverage about cancer that participants had seen; however, these were the most salient to participants and are likely to reinforce negative beliefs about cancer:

“[My friend] never said nothing [about his diagnosis of cancer]. All he just said was “I haven’t had a hard on because I had prostate cancer” and that’s all he said, and that’s the only way I know he had cancer...and as far as I know he’s cured.” (Male, age 80, reported previous cancer symptom)

4.4.3.3.4 Lay system of healthcare

Seeking advice for symptoms from family members or friends before visiting doctors was the norm for participants, usually from someone they perceived as ‘knowledgeable’ such as

someone with cancer or the local ambulance driver who, although had received no formal medical training, was perceived to be knowledgeable because of regular contact with the hospital. A lay system of healthcare was used to seek reassurance that an appointment with the GP was necessary. This is likely to reflect the various practical and service barriers previously mentioned, such as problems receiving or accessing an appointment with the GP. It is likely that symptom disclosure would act as a barrier or facilitator depending on the quality of advice given. Some participants discussed people within the community asking them for advice on symptoms, or recalled noticing symptoms in others and advising that they seek medical help:

“Well the first person I’d talk about [a symptom] to is my mate because she’s had a couple of scares and fortunately thank god she hasn’t got cancer and then the next person I would go and see is my doctor.” *(Female, age 70, reported previous cancer symptom)*

“If [my husband] had a fear or thought that he might have the cancer or anything like that, he would either keep it to himself or confide in me, but he wouldn’t be to the doctors.” *(Female, age 70, reported previous cancer symptom)*

“[My friend] had been complaining that she wasn’t well before Christmas but she’s so stubborn that she wouldn’t go to the doctors and we kept on saying to her “go <name of friend>, it’s not normal to lose this amount of weight in such a short time”, and she said “oh I’ll go now” and she did go now mind.” *(Female, age 57, reported previous cancer symptom)*

4.4.3.3.5 Social environment

For many participants, health was not perceived to be a priority. Instead, day-to-day problems took precedence such as finding money for food and heating the house. Maintaining a healthy lifestyle was challenging when financial resources were limited, for example eating the recommended five pieces of fruit and vegetables per day was difficult with limited income. It is likely that symptoms are potentially dealt with once they start to impact on daily life rather than when they are first noticed. This could reflect competing priorities associated with fulfilling daily basic needs such as eating and staying warm. There

was a perceived general lack of control over daily life where many factors were discussed as beyond their control. For example, participants discussed new housing developments within the community that were out of their control, and were concerned with the impact of new people coming in to the community on primary care and other health services that were perceived to be already overrun. Housing was also described as a problem for those who lived in council owned properties or social housing, where participants had little or no control over who their neighbours were:

“Your health goes because myself right, I need £10 for the gas and I’ve got £20 in my purse to last me the week, but it’s gonna cost me £15 to get fresh veg, meat and fruit. Then I would leave the fruit aside and the veg, to make sure that I’ve got my gas to keep warm.” *(Female, age 57, no cancer symptoms reported)*

“In this [housing association] block you keep yourself to yourself because there’s a bit unsavoury characters...[one] was having parties all hours of the morning. He wasn’t very pleasant- you’d keep out of his way because he’d be quite rude you know. Then downstairs in the next block there are always gangs of boys back and forth always and there always [drunk]...so I have put in for a transfer but I don’t know how long it’ll take. *(Female, age 52, no cancer symptoms reported)*

Many participants reported suspicion and a lack of trust associated with the government, reflected in statements about the government withholding the cure for cancer, or the government ‘playing God’ with cancer treatment postcode lotteries where access to certain cancer treatments was determined by the area of residence. Some participants discussed feeling victimised or forgotten by the government. Competing priorities, a lack of resources available for a healthier lifestyle and perceived lack of control over daily life are likely to impact on medical help seeking behaviours:

“They’re on about we’ve got cures for this, cures for that, I think it’s just a big money making thing to be honest, I think that it’s a case of they got it and we ain’t sharing it because there’s too much money going in....” *(Male, age 56, no cancer symptoms reported)*

“I get angry because they cut everybody else’s money back except the politicians and they get money and some of these have got three and four houses, cars, I’m thinking alright, why do you need all those houses?” (*Female, age 52, no cancer symptoms reported*)

“A government thing, yes they have cameras that watches the people coming in going out right...and when they wanted to take [her disability benefit] off her they right, they watched her coming in, and they watched her coming out.” (*Male, age 71, reported previous cancer symptom*)

4.4.3.4 Lung cancer and smoking behaviour

Lung cancer was described as a ‘bad’ cancer. Lung cancer was often described as a “cruel” (*Male, age 71, previous diagnosis of cancer*) and “painful” (*Male, age 71, reported previous cancer symptom*) type of cancer resulting in death, often soon after diagnosis. This perception was supported by people they knew who had been diagnosed with lung cancer. One participant described lung cancer as a “silent killer” (*Male, age 71, reported previous cancer symptom*), perhaps reflecting the belief that lung cancer is a symptomless disease due to the vague and non-specific symptoms in the early stages. Some participants referred to lung cancer as a male disease, which has implications for women with symptoms as they may perceive themselves at low risk for lung cancer:

“I think people are afraid of you know, it’s not a very nice disease like is it? Like I said, it’s a cruel disease, my father in law then he died with cancer as well, um, I think he had, he had uh, lung cancer and it was cruel.” (*Male, age 71, previous diagnosis of cancer*)

“You’ve got lung cancer, it’s death isn’t it, but which is the most painful?” (*Male, age 71, reported previous cancer symptom*)

Most participants understood that smoking was a major cause of lung cancer and discussed people in the community who were smokers with a diagnosis of lung cancer. However, this was often qualified with statements such as “but she was a heavy smoker” (*Female, age 66, reported previous cancer symptom*), potentially reflecting blame around smoking and stigma towards lung cancer. A few participants were unsure of the link between smoking and lung

cancer, giving examples of people they knew with a diagnosis of lung cancer who had never smoked or used to smoke, and demonstrating a lack of understanding of the risks associated with being an ex-smoker:

“One of my mates have died from [lung cancer], but he wouldn’t quit his drinking, or his smoking so it’s partly his fault....” (*Male, age 58, reported previous cancer symptom*)

“I used to smoke, but I used to think well she never smoked and she had cancer of the lungs, why do they say it’s always you know cigarettes that do it? I thought because they say I don’t know whether it’s true, it’s there in everybody, but it sort of it gives it something for it to come out a knock, or an illness, or something you know to bring it out in you, I don’t know whether that’s true, I don’t know whether that’s a myth? People say these things, but no that’s what I thought well, my father smoked up until he was 80, didn’t do him anything like that.” (*Female, age 58, reported previous cancer symptom*)

I – “Do you know what might have caused the lung cancer?”

P- With my mother we put it down, she was in an accident and they say it takes a knock to bring it out, but I honestly don’t really know what can cause it, they say it’s smoking I know, but I honestly, I’ve known people who have smoked you know, all their life and I mean they’re still going at 90 years of age, so I really don’t think they can put it down to just smoking I think it’s gotta be something else as well

I – Did your parents smoke as well?

P- They did, but my mother had given up and my father had given up. They’d given up for years and yet they both got it...” (*Female, age 62, reported previous cancer symptom*)

4.4.3.5 Suggestion for intervention

Participants suggested various interventions to encourage people in the community to visit the doctor with symptoms of cancer. Many participants suggested talks within the community at local coffee mornings, community centres, sheltered housing, in local clubs or schools. A few participants suggested leaflets containing cancer information or integrating a

storyline into a TV soap where one of the characters survives cancer to overcome fear associated with cancer as a death sentence. Participants thought the intervention should include information about the symptoms of cancer and to include information to overcome fear of cancer using positive language to “be careful not to frighten people” (*Female, age 60, no cancer symptoms reported*). A few participants suggested using someone who had been diagnosed and survived cancer as part of the intervention:

“I don’t know, leaflets? I would just say general symptoms, you only have to, you could put various types of cancer on a leaflet and put their symptoms down underneath them and that’s it, that could help.” (*Female, age 71, no cancer symptoms reported*)

“I don’t see why they shouldn’t have a community centre where once a month somebody came along to tell you about cancer. I think people would be interested in that, because they’d be treated to teas and coffee there and cakes and they’d say ‘I’m having a day out’.” (*Female, age 70, reported previous cancer symptom*)

“Just to talk about it, try to reassure people, try to reassure them... if you done one here and then send a few leaflets around and say we’re having a meeting in the centre in the coffee morning everyone is welcome to come and have a talk about it...I know my friend would turn up.” (*Male, age 58, reported previous cancer symptom*)

4.5 Discussion

This study was the first to explore cancer symptom knowledge, beliefs about cancer and barriers/facilitators to cancer symptom presentation using qualitative methods among people from a low socioeconomic group based on multiple indicators. There was evidence to suggest that knowledge of cancer (Capability), and fearful and fatalistic beliefs (Motivation), where participants associated cancer with inevitable death, were usually formed and reinforced by witnessing family and friends suffer and often die from cancer (Opportunity). The combination of fearful and fatalistic beliefs (Motivation) was reported to prolong cancer symptom presentation among low socioeconomic groups. In contrast, those who held positive beliefs about the benefits of early diagnosis (Motivation) could quickly overcome any reported practical and service barriers for ‘red flag’ symptoms following accurate

symptom appraisal (Capability). However, non-specific symptoms were not recognised by most participants as symptoms of cancer and were usually attributed to symptoms of other co-morbid illnesses (Capability). For those with non-specific symptoms, priorities such as work commitments (Opportunity) were often more influential on the individual's decision about whether to seek help with these symptoms, in turn prolonging symptom presentation. Using the lay system of healthcare (Pescosolido and Boyer, 1999) to discuss symptoms with family members or friends before visiting the doctor was the norm for participants, and was considered common within the community (Opportunity), to decide whether a medical appointment was necessary. Disclosure of symptoms could prolong or prompt symptom presentation, depending on the nature of advice received (Opportunity).

Findings from this qualitative interview study confirm those of previous studies which involved participant samples with varied socioeconomic characteristics reported in a systematic review in Chapter 3 (McCutchan *et al*, 2015; Appendix 1). In addition, findings from this study support the assumptions of the NAEDI framework (Hiom, 2015) and offer insight into how the factors identified by the NAEDI framework might influence the relationship between socioeconomic group and prolonged cancer symptom presentation. Poor knowledge of non-specific cancer symptoms (Low *et al*, 2013; Brain *et al*, 2014), fearful and fatalistic beliefs about cancer (McCaffery *et al*, 2003; Chonjnacka-Szwalowska *et al*, 2013) and emotional barriers to cancer symptom presentation (Robb *et al*, 2009; Simon *et al*, 2010; Low *et al*, 2013) were identified as more prevalent among low socioeconomic groups in the systematic review (McCutchan *et al*, 2015; Appendix 1) and are supported by the findings from this study. Through using qualitative methods, insight and possible explanations for these findings were gained by exploring the wider social context (Opportunity) that is specific to low socioeconomic groups, and how this might influence cancer symptom presentation. General fatalistic attitudes were common, with individuals believing themselves to have little control over daily life or their fate, and are likely to contribute to feelings of helplessness or disempowerment. Consequently, there was a reluctance to change risky health behaviours, and the potential for individuals to deny or ignore health problems. For some, this extended to cancer-specific fatalism in which symptom presentation was prolonged because cancer was always believed to be a fatal disease. Experiences of cancer in the community were more influential on the formation and maintenance of such beliefs than media items, despite campaigns and news items promoting advances in treatments and improved cancer survival. Witnessing poor cancer

outcomes among family members and friends in the immediate social environment which counter media claims, combined with mistrust of official information sources, may contribute to the prevalence of fatalistic beliefs in deprived communities (Lyrtatzopoulos *et al*, 2015a; Quaife *et al*, 2015a).

Lung specific findings suggest that lung cancer is conceptualised as a 'bad' cancer, where treatment options are limited and ineffective. Such beliefs are likely to contribute to fear of a diagnosis of lung cancer and reluctance to present to the GP with symptoms. Findings from a lung screening study suggested that smokers from a low socioeconomic group commonly hold the belief that the lungs cannot be removed, as they are a vital organ, and are therefore untreatable (Quaife *et al*, 2016a), which could explain findings relating to beliefs about treatment. There was evidence of the stigma attached to lung cancer, where a diagnosis of lung cancer was qualified with statements around smoking behaviour, suggesting diagnosis in smokers was self-inflicted. Stigma surrounding lung cancer is likely to prolong cancer symptom presentation (Chatwin and Sanders, 2013; Corner *et al*, 2005; Corner *et al*, 2006; Tod *et al*, 2008; Chapple *et al*, 2004). In addition, there was confusion about risk associated with smoking and lung cancer, where participants appeared to misunderstand that ex-smokers were at heightened risk for lung cancer, which has the potential to prolong symptom presentation.

Wider community influences on behaviour could indicate issues that are specific to low socioeconomic groups and have the potential to explain the disparities in cancer outcomes among socioeconomic groups through prolonged cancer symptom presentation. For instance, people from a high socioeconomic group are less likely to experience economic hardship in a similar way to people from a low socioeconomic group, such as choosing between heating the house and feeding the family. Competing priorities such as the stresses of day-to-day living and work commitments, particularly when employed on a zero hours contract where no pay can be received for sickness or going to the GP, are likely to be more salient among low socioeconomic groups. When symptoms are vague or dismissed as normal in the context of other pre-existing co-morbidities, these competing priorities are likely to take precedence over a visit to the GP.

Once an individual has overcome the barriers associated with getting to an appointment, there was evidence of further obstacles to full and effective disclosure of symptom concerns

at a service and organisational level. Not being able to communicate symptom concerns effectively (Capability) in a time limited appointment, and reported policies that preclude discussion of more than one symptom during a consultation (Opportunity), are likely to limit presentation of a cancer symptom. This is especially likely for those who present with another health complaint to 'test the water' before disclosure of a worrying or embarrassing symptom, potentially prolonging disclosure of symptoms (Andersen and Vedsted, 2015).

Findings relating to beliefs about cancer translating into either immediate or prolonged symptom presentation might be explained by Type I and Type II responses to symptoms (Khaneman, 2011; Epstein, 1994). All participants experienced an initial fearful, highly emotive response when asked to think about cancer as a disease (Type I response; Automatic Motivation), potentially reflecting a community wide response to cancer. However, after consideration, some participants expressed positive beliefs about the benefits of early diagnosis, which could represent participants using their slower, more conscious appraisal processes (Type II response; Reflective Motivation). The latter response may prompt symptom presentation, with fear of a late diagnosis of cancer and perceptions of self-efficacy around knowing what to do with a symptom and the ability to discuss concerns motivating the individual to seek medical help quickly (Robb *et al*, 2014). Consulting family and friends to discuss symptoms before visiting the doctor was perceived to be the norm in the community. A previous study found that those from lower socioeconomic groups were more likely to prolong cancer symptom presentation after disclosure of symptoms to a family member or friend (Li *et al*, 2012). There was evidence of poor knowledge and negative beliefs about cancer among low socioeconomic groups. Therefore it is likely that people from a low socioeconomic group who seek symptom advice from family or friends could receive poor quality advice and prolong symptom presentation.

4.5.1 The COM-B Model

The COM-B model (Michie *et al*, 2011) appeared highly applicable in the context of cancer symptom presentation behaviour, allowing exploration of how individual cognitive and affective processes and the wider social context influence behaviour. The model currently represents a bi-directional influence of Capability, Opportunity and Motivation on Behaviour and suggests that both Capability and Opportunity influence Motivation. However, this study also found that knowledge of the causes of cancer and symptoms of cancer (Capability) was influenced by the experiences of other people within their social network who have had

cancer (Opportunity) (Michie *et al*, 2011). This interaction is not currently represented in the COM-B model, and could be explored in future research into the social determinants of cancer help seeking behaviour.

As discussed in Chapter 2, although the COM-B model was selected as the most comprehensive of all the theories and models identified, it was not underpinned by the Common Sense Model of Illness Self-Regulation (CSM; Leventhal *et al*, 1980). Since the CSM is a model of illness representations, the COM-B model does not explicitly attempt to explain how symptoms are attributed and illness inferred, although the TDF domains underpinning the Capability construct of the COM-B model are implicitly linked to symptom interpretations. Therefore, analysis of symptom interpretations was potentially restricted and is a limitation of the model.

4.5.2 Strengths and limitations of the study

This study used in-depth qualitative interview methods which enabled a rich insight into the influences on cancer symptom presentation among people from low socioeconomic groups. In addition, this study used multiple individual and group level indicators of socioeconomic group to overcome some of the issues associated with reporting single group or individual level indicators. However, although participants in the present study were representative of a low socioeconomic group, they were sampled from a database of participants who had previously engaged in research about cancer and the study was framed around cancer. Therefore those who agreed to take part in the study may not be representative of a community who are fearful of cancer and more likely to prolong symptom presentation. To overcome these limitations, questions were asked about community norms to gain an understanding of knowledge, beliefs and barriers to symptom presentation from a community perspective. Eight participants were recruited through snowball sampling due to low response rates through the ICBP database. Snowball sampling is often criticised for problems associated with representativeness through selection bias (Van Meter, 1990), however it is commonly used as a method to engage 'harder to reach' populations (Faugeier and Sargeant, 1997). Snowball sampling and recruitment of participants through community partners were useful methods for engaging a group of individuals who might otherwise not have engaged in this research study. However, there were no data available for the numbers of individuals approached, therefore response rate or reasons for refusal are unavailable.

There are limitations associated with telephone interviews due to problems of building rapport and depth of analysis, since there was no opportunity to see the context in which

the participant lives. Interviewing two people at the same time also has its limitations, where certain information may be withheld by participants, particularly for a sensitive subject such as cancer, or one participant may dominate the interview (Kendall, 2009). However, telephone and dual person interviews were conducted only when necessary due to superstitions, disability, geographical distance or lack of space in the house. Without the flexibility of allowing individuals to participate on the phone or be interviewed as a pair, these individuals could not have been included in the study.

There are limitations in the use of retrospectively recalled barriers to cancer symptom presentation, where memory might bias recall, or hypothetically anticipated barriers, where intentions might not reflect actual symptom presentation behaviour. Study designs exploring barriers to symptom presentation in a community sample who disclose symptoms, without mention of cancer, could overcome these limitations (Low *et al*, 2015; Whitaker *et al*, 2015).

Finally, when approached to take part in the study, participants were unaware that they were being selected on the basis of socio-demographic group indicators. Following discussion with supervisors and ethical committee review, the decision to remove any information from study materials to indicate that participants were being selected because of area of residence and educational attainment was made. However, there are ethical implications associated for withholding information about why participants were being selected for the study, in relation to the extent to which participants can provide full informed consent.

4.5.3 Implications for a cancer awareness intervention

Findings from the systematic literature review (McCutchan *et al*, 2015; Chapter 3) and qualitative interviews (McCutchan *et al*, in press) have allowed a greater understanding of the barriers to cancer symptom presentation, aiding the development of a targeted intervention to encourage earlier presentation in people from deprived communities. An intervention targeted at low socioeconomic groups should take into account the wider influences on symptom presentation behaviour within social networks to encourage earlier cancer symptom presentation. Such interventions could use the strong social networks within the community to increase community wide knowledge about non-specific cancer symptoms, challenge negative beliefs surrounding cancer, and reinforce positive messages about the benefits of early diagnosis and advances in modern treatments. An intervention should seek to empower people, perhaps through offering strategies to overcome reported

barriers to symptom presentation and an aid for communication problems during a consultation. This could be delivered through a community based educational programme or leaflet based intervention.

4.5.4 Conclusion

Cancer symptom presentation behaviour among low socioeconomic groups is influenced by both individual and wider socio-environmental factors. Interventions which aim to improve symptom knowledge (Capability), modify negative beliefs (Motivation) and take into account the wider influences on behaviour (Opportunity) might be able to encourage earlier cancer symptom presentation behaviour among socioeconomically deprived groups. The following chapter will report findings from a focus group study with members of the public and local stakeholders who live or work in deprived communities. The study aims to provide additional insight into community norms and the wider socio-environmental influences on cancer symptom presentation behaviour.

Chapter 5

Factors influencing cancer symptom presentation in deprived communities: a focus group study with members of the public and local stakeholders

5.1 Chapter overview

This chapter reports the results of a focus group study with members of public and local stakeholders (healthcare professionals and community partners) who live or work in deprived communities. The focus groups explored the influence of the wider social environment and other factors which might influence timely cancer symptom presentation in deprived communities. In the public focus groups, a cancer symptom attribution task was used to understand in greater detail how symptom interpretations might influence an individual's decision to seek medical help. Findings from the focus groups and the implications for a cancer awareness intervention will be discussed.

5.2 Introduction

Understanding the factors which influence timely cancer symptom presentation is essential to developing effective interventions designed to overcome the barriers to symptom presentation and facilitate timely cancer symptom presentation, ultimately to promote earlier diagnosis of cancer. This is particularly important in socioeconomically deprived communities where cancer is often diagnosed at an advanced stage.

Findings from a systematic review (McCutchan *et al*, 2015, Appendix 1) and qualitative interviews (McCutchan *et al*, 2016) described in Chapters 3 and 4 support the assumptions of the NAEDI hypothesis outlined in Chapter 1. These studies begin to offer useful insights into how knowledge, beliefs, and barriers to symptom presentation influence the decision to present to the doctor with a symptom of cancer. In addition, the influence of socioeconomic factors on symptom presentation behaviour was explored in these studies to understand the factors underlying prolonged cancer symptom presentation among low socioeconomic groups. Lower cancer symptom knowledge, a higher prevalence of fearful and fatalistic beliefs about cancer, and barriers such as difficulty with communicating symptoms during a consultation and problems with getting to an appointment were found among low socioeconomic groups in the studies described in Chapters 3 and 4. These factors in combination were considered to prolong cancer symptom presentation in low socioeconomic groups.

In the qualitative interview study described in Chapter 4 (McCutchan *et al*, 2016), there was an indication that opportunities afforded by environmental circumstances in low socioeconomic groups were associated with the formation of knowledge and beliefs about cancer. In addition, there was evidence to suggest that environmental opportunity was likely to create some of the reported barriers to cancer symptom presentation such as lack of transport to an appointment. Furthermore, there was evidence to suggest that social networks had the potential to attenuate or facilitate the decision to seek medical help for a symptom, where discussing symptoms with family members and friends was the norm. Good advice was considered to prompt symptom presentation, whereas poor quality advice was likely to prolong symptom presentation. However, it remains unclear how symptoms are discussed within the community, what advice is given, and how the quality of advice might influence the decision to seek medical help. In addition, a broader understanding of the day-to-day environmental issues in deprived communities is required, and how these might influence symptom presentation among individuals living in deprived communities.

To date, all studies in this PhD have focused on symptomatic or asymptomatic individuals seeking medical help for actual or hypothetical symptoms. All papers included in the systematic review described in Chapter 3 were from the patient perspective, and the qualitative interviews described in Chapter 4 were carried out with members of public from low socioeconomic groups. Local stakeholders who work closely with people in deprived communities are likely to offer an alternative perspective and could confirm previous findings, or provide new insights and explanations for mechanisms underlying prolonged cancer symptom presentation behaviour. It was therefore considered useful at this stage to involve local stakeholders (healthcare professionals and community partners) who work in deprived communities reflecting on barriers to cancer symptom presentation. In addition, how symptoms are attributed and evaluated by members of the community and the speed at which medical help might be sought for symptoms is unclear. Therefore, members of the community were included to understand these and other factors influencing cancer symptom presentation in a focus group setting.

5.2.1 The Awareness and Beliefs About Cancer study

The focus groups were conducted as part of an aligned study funded by Cancer Research UK, the Awareness and Beliefs About Cancer study (ABACus; Smits *et al*, 2016). ABACus is an ongoing study at Cardiff University involving the development and evaluation of the Tenovus

health check intervention. The health check is a touch screen questionnaire, designed to modify cancer risk behaviours, raise awareness of the symptoms of cancer and pick up any cancer symptoms the individual may have. The health check asks a series of questions about lifestyle factors such as smoking and diet, followed by symptom questions such as 'Have you noticed any blood in your poo?'. Following completion of the health check, the individual is given their results both printed and verbally in a one-on-one session with a trained lay health check advisor. The individual is encouraged to visit the doctor with any reported symptoms and given information on what symptoms to look out for in future including advice on what to do should they have a symptom in the future.

Tenovus Cancer Care is a Welsh based cancer charity committed to supporting those with cancer in the community who are in greatest need and working with work communities to develop and deliver innovative cancer prevention programmes. Much of their work is focused in deprived communities in Wales, such as Communities First areas. The Tenovus health check is one example of this. Focus groups were conducted for the ABACus study with healthcare professionals and community partners working in deprived communities and members of the public living in deprived communities. The aim of the focus groups was to understand the influences on cancer symptom presentation in deprived communities and to offer feedback on the Tenovus health check. The PhD researcher supported the Research Associate on the ABACus study in the development of the topic guide for the local stakeholder focus groups (healthcare professionals and community partners) and co-moderated the local stakeholder focus groups. The PhD researcher developed and refined the topic guide for the members of public focus group, recruited participants into the members of public focus groups and lead moderated the members of public focus groups. All data were analysed by the PhD researcher independently of the ABACus study.

5.3 Focus group methodology

A focus group is designed to facilitate discussion around a certain topic in an informal manner, replicating an everyday conversation (Green and Thorgood, 2011 p.127). Typically, a group of six to twelve participants who have not previously met are selected according to inclusion criteria, and invited to take part in a focus group. During the focus group, a facilitator guides participants through a list of topics using open ended questions, prompting participants to discuss topics as a group. The facilitator should endeavour to create an

environment where everyone feels comfortable to participate in discussion. In health research, focus groups are most commonly used for evaluating health interventions, although they have been used as a method for understanding cultural norms around health-seeking behaviour (Larkey *et al*, 2001).

Whilst one-on-one interviews are useful to understand individual views and stories, particularly when discussing a sensitive topic like cancer, focus groups can be beneficial to gain insight into the views of multiple participants in a relatively short space of time. The overall aim of a focus group is to reach group consensus about a certain topic (Wilkinson, 1998), and can also be helpful to identify incongruent views within the group. Gaining multiple views and assessing the group dynamic through the extent to which participants agree or disagree with one another can be useful to understand the cultural norms of a group. Focus groups are considered one of the best methods for accessing and collectively teasing out shared group norms (Bloor *et al*, 2001, p.6), and can be used alongside qualitative interviews to clarify previously discussed topics. Therefore, focus groups were selected to build upon the findings from the individual qualitative interviews described in Chapter 4 to gain further insight and clarity regarding the factors affecting cancer symptom presentation in deprived communities.

Although there are benefits of using group discussion to understand group norms, there is the potential for discussion during a focus group to be dominated by a certain participant(s) within the group. When participants are from different socioeconomic groups, those from a higher socioeconomic group are more likely to dominate discussion (Green and Thorgood, 2011 p.137). Therefore, for this study, separate focus groups were conducted with healthcare professionals, community partners and members of public to facilitate a relaxed atmosphere and discussion among participants.

5.4 Method

5.4.1 Participant recruitment

Six focus groups were conducted across two health boards in South Wales (Cwm Taf and ABHUB). Focus groups were conducted with people living or working in deprived communities, defined as 'Communities First' area.

Three focus groups were conducted in each health board and were grouped by members of public (males and females over the age of 40 living in a Communities First area), healthcare professionals (General Practitioners, GP practice nurses, GP practice managers, community

pharmacists and public health consultants working in a Communities First area) and community partners (housing association workers, Communities First workers and other community-based workers working in a Communities First area).

Potential healthcare professional and community partner focus group participants were identified by two of the ABACus study collaborators working within in each of the health boards. Healthcare professionals and community partners who were interested in taking part in the study were contacted by telephone or email with information about the study, and were invited by the Research Associate to take part in the study. A date and time for the focus group was arranged for those who wanted to take part in the study.

Participants for the members of public focus groups were identified through the participants who took part in the community partner focus groups. Those who took part in the community partner focus groups were contacted by the PhD researcher and asked to identify potential participants to take part in the study. Recruitment procedure varied per community partner. Some community partners identified members of public and requested permission for their contact details to be passed on to the PhD researcher, where potential participants were contacted by telephone and invited to take part in the study. Written information was posted to those who were interested in taking part and a time and date for the focus group was arranged. Other community partners preferred to personally invite people to take part in the study according to the inclusion criteria using a pre-arranged date and time for the focus group. In this case, written information was posted to the community partner and they were asked to pass it on to potential study participants.

5.4.2 Procedure

The study was ethically approved by the National Research Ethics Committee (NRES) Research Ethics Committee (REC reference no 14/NW/1104, see Appendix 12). All participants provided written informed consent to take part in the study and were reminded about group confidentiality. All focus groups were audio-recorded with permission.

The first half of the focus group involved exploring the influences on cancer symptom presentation in deprived communities. In the second half, participants were given a demonstration of the Tenovus health check, and asked for their feedback on the health check. A semi-structured topic guide was used to facilitate discussion of similar topics across groups and allow issues of importance to emerge. The PhD researcher co-moderated the local stakeholder focus groups and lead moderated the member of public focus groups.

Participants were reimbursed for their time or were offered a high street shopping voucher to thank them for taking part in the study. All travel expenses were reimbursed. Following each focus group, a summary of the main points was sent to participants for approval (see Appendix 13 to 18 for summaries).

5.4.3 Topic guide

Topic guide development for the first half (influences on cancer symptom presentation) was guided by findings from the systematic review described in Chapter 3 and the qualitative interviews with people from deprived communities in Chapter 4 to identify which topics required further exploration. Focus group topics were aligned with each of the COM-B (Capability, Opportunity, Motivation Behaviour) model constructs (Michie *et al*, 2011) to facilitate analysis of data. Topics included: health and cancer as a priority in the community, cancer symptom presentation behaviour, barriers/facilitators to prompt cancer symptom presentation, symptom disclosure within the community and current cancer awareness campaigns in the community. Please see appendix 19 and 20 for topic guides.

For the local stakeholder focus groups, participants were asked to discuss each topic in relation to the local community. The topic guide was modified for the members of public focus group to reflect the focus on the individual rather than the community. In the members of public focus groups, participants were asked to collectively recall any symptoms of cancer they knew and their responses were written onto individual flash cards to be used later in the focus group for a symptom attribution task. During the symptom attribution task, participants were asked to rank the symptoms in order of how long it would take them to seek medical help for the symptom from the fastest to the slowest. Participants were asked to discuss why they would seek help in this time frame and what they might consider the symptom to be in the first instance. In the second half of the focus group, participants viewed a demonstration of the health check, and were asked for their feedback on the health check. The PhD researcher supported the development of the topic guide for the local stakeholder groups and initially developed and refined the topic guide for the members of public focus groups.

5.4.4 Analysis

Data relating to the health check intervention evaluation were not analysed as this was not directly relevant to the aims of the PhD. Data relating to influences on cancer symptom presentation behaviour among deprived communities in the first part of the focus group

were analysed using framework analysis (Ritchie & Lewis, 2003). Framework analysis was selected as most appropriate in this context due to the data charting stage and depth of analysis. Whereas other qualitative data analysis method such as thematic analysis do not include charting of data, framework analysis involves production of a matrix which summarises focus group data per theme, and was considered a key benefit to the PhD researcher to facilitate comparisons of data across focus groups. Furthermore, framework analysis provides a deeper level of analysis in comparison to thematic analysis which was useful for this study. In addition, the framework can be developed around existing theory, unlike other qualitative analysis methods which take a more inductive approach such as grounded theory (Charmaz, 2006, p.2). As discussed in Chapters 2 and 4, the COM-B model was identified as useful for understanding cancer symptom presentation among low socioeconomic groups, and will be used with the Behaviour Change Wheel to guide intervention development. Therefore, the analytical framework was based around each of the COM-B model constructs to aid interpretation of findings and intervention mapping using the Behaviour Change Wheel (Michie *et al*, 2011).

Themes were generated from the transcripts and grouped under each of the COM-B model constructs (Capability, Opportunity and Motivation) (see Appendix 21 for coding framework). The Theoretical Domains Framework (TDF; Cane *et al*, 2012) was used to provide a more granular level of understanding of each of the COM-B model constructs to facilitate grouping of themes. Once themes were grouped, supervisors checked the framework to ensure themes were placed under the appropriate COM-B model construct. Coding of data was managed using the qualitative analysis software package NVivo 10 (NVivo 10, 2012). Summaries of the content of each theme per focus group were charted under each of the COM-B model constructs, supported by Microsoft Excel (see Appendix 22 for an example). Framework analysis typically involves charting of data per participant; however, for this focus group study, data were charted according to focus group rather than for each individual participant. Data were charted in this way because themes were rarely discussed by all participants within the group; therefore, comparisons across groups rather than individual were considered to be most useful. In addition, the present study was concerned with understanding views across three different groups of individuals: members of public, healthcare professionals and community partners. Therefore, themes were summarised per focus group to facilitate analysis and interpretation of data analysis according to participant group.

5.5 Results

The focus groups were conducted between November 2014 and March 2015 and ranged from 64 to 82 minutes in length. A total of six focus groups were conducted in total: two with healthcare professionals (n=6 participants and n=8 participants), two with community partners (n=8 and n=6) and two with members of public (n=6 and n=8). See Table 5.1 for focus group characteristics.

Table 5.1 Focus group characteristics

Health board 1	Health Board 2
<p>Healthcare professionals (n=8) (3 GPs, 1 GP Clinical Director, 1 community pharmacist, 1 practice manager, 1 Public Health Wales Consultant, 1 nurse)</p>	<p>Healthcare professionals (n=6) (2 GPs, 1 Neighbourhood Care Network (NCN) lead, 2 Public Health Wales Consultants, 1 nurse)</p>
<p>Community Partners (n=6) (3 Housing Association, 2 Communities First health leads, 1 Public Health Wales Screening)</p>	<p>Community Partners (n=8) (2 Housing Association, 2 Communities First health leads, 2 Communities First staff, 1 Community development worker, 1 adult community learning project coordinator)</p>
<p>Members of public (n=8) (6 female, 2 male aged 40+)</p>	<p>Members of public (n=6) (4 female, 2 male aged 40+)</p>

Key themes are presented under each of the COM-B model constructs (Capability, Opportunity and Motivation), with quotes as examples. Themes included: symptom attributions, communicating symptom concerns, appointment policies, crisis point care, a lay system of healthcare, health norms and expectations, community interventions, fear and avoidance, and cultural barriers. Square brackets within the quotes represent inserted text to allow for clarification of the topic content. Irrelevant speech has been removed from the text for brevity, denoted by ‘...’.

5.5.1 Capability

5.5.1.1 Symptom attributions

A few of the members of public could not recall any symptoms of cancer and some participants only knew lumps and bleeding as symptoms of cancer. Other participants could

recall many symptoms of cancer. Rare or vague symptoms such as skin like orange peel and headaches were discussed in terms of family members or friends who had experienced these symptoms prior to a diagnosis of cancer. The healthcare professionals and community partners thought that knowledge in the community for the non-specific symptoms of cancer such as tiredness was poor and was often dismissed as nothing serious or completely disregarded, thereby prolonging symptom presentation.

Findings during the symptom attribution task reflect longer anticipated symptom presentation times for non-specific cancer symptoms (Figure 5.1), where lumps and bleeding were associated with the most prompt symptom presentation for both members of public groups. Non-specific symptoms such as headaches or tiredness were associated with the longest times to cancer symptom presentation. Discussion about these symptoms suggested that non-specific symptoms are often normalised and would be attributed to benign causes or other pre-existing co-morbidities such as diabetes or asthma. The members of public discussed rationalising symptoms and attributing them to acute conditions before considering more serious explanations. Symptoms which worsened or were completely unexplained were considered more serious and would prompt more timely presentation behaviour. Some of the symptoms associated with lung cancer were discussed by both of the members of public focus groups, but were discussed in terms of general symptoms for cancer rather than specific to lung cancer. The frequency and prevalence of coughs in the community was high, where having a cough is likely to be perceived as normal and was considered to be a symptom of other benign health problems, which is likely to prolong symptom presentation. Difficulty swallowing and coughing up blood were mentioned by one group and would prompt a visit to the doctor sooner, as these were perceived as more serious.

“Mod: A cough

P3- That’s low down too, most people cough on a regular basis.

P5- We get so many coughs don’t you, you live with it ...

P2- You would, if that’s the timeline it’s going to be 4 weeks before you bother isn’t it, so it’s going to be lower down. If I had difficulty swallowing I’d be more likely to go to the doctor quicker than I would if I coughed.” (*Health board 1, members of public*)

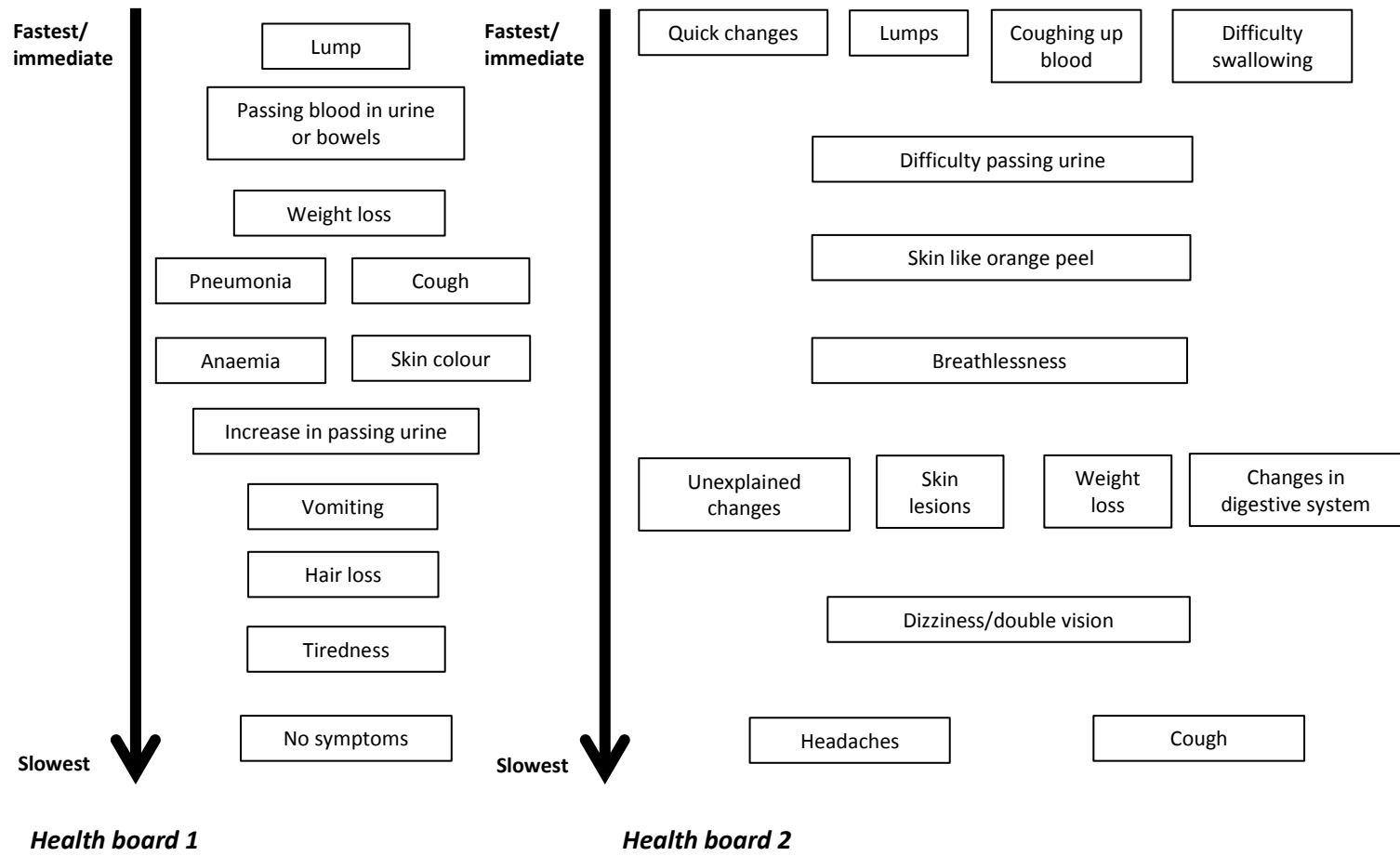


Figure 5.1 Symptom attribution task. Participants in the members of public focus groups were asked to rank the previously recalled symptoms of cancer in terms of the time in which they would anticipate seeking medical help for the symptom. Symptoms at the top of the figure are those which participants would anticipate seeking medical help most promptly for. Symptoms at the bottom of the figure are those which participants would anticipate seeking medical help slowest for.

Healthcare professionals and community partners thought that most cancer symptom knowledge was gained from people within the community who had been diagnosed with cancer, and a limited amount of cancer knowledge was gained from media cancer awareness campaigns. A community partner thought it was unlikely that people in their community were interested in watching TV programmes with cancer related content such as Panorama or the news, so cancer knowledge was almost exclusively gained through family members and friends in the community who in most cases died from cancer.

“If you are maybe an illiterate or virtually illiterate, you may have no interest whatever watching a news programme. A lot of this kind of stuff, what's good, what's bad, is linked to news programmes and Panorama, those kinds of week in, week out. And if you are not watching them, you might never realise.” (*Health board 2, community partner*)

5.5.1.2 Communicating symptom concerns

The healthcare professionals described that patients would rarely communicate concerns that their symptom might indicate cancer unless prompted to do so by the doctor. This was considered to reflect the patient's hope that they might seek reassurance regarding the benign nature of symptoms. Healthcare professional participants who were GPs reported that patients would usually present with a cancer symptom as part of another consultation, often disclosing their symptom as they were leaving the consultation. This was referred to as the 'door handle diagnosis'. It was felt that patients would present with another health complaint to assess whether they trust the doctor enough to disclose their cancer symptom at the end of the consultation. This reflects the community partners' observations, where they discussed that people in the community were worried they would not be taken seriously or dismissed by the doctor if they presented directly with cancer symptoms.

“P7- A few years ago, I had a gentleman come in with his blood pressure and we did a blood pressure review on him. Just as he was going, he said, "Can you just have a look at this on my back?" He had a massive lesion, a huge lesion, and it was only as a side thing and lots of them do that. They are worried underneath, but they just can't bring it out in the first bit.

P8- I think they're testing you out as well to see whether they can trust you with their more important concerns, so they test you out with something really quite simple to see what they think of you and whether they can trust you, I think, and

whether they want to then tell you more personal things or whether they'll save those for somebody else." (*Health board 1, healthcare professional*)

The community partners reported that people in the community found doctors difficult to talk to and struggled to communicate symptom concerns effectively, especially during a time limited appointment. They recalled occasions where they or their colleagues had previously offered to attend an appointment with members of the community to help communicate symptoms. Some of the members of public reported using prompts during a consultation with the doctor, such as lists, to aid memory for discussion of symptoms.

"[It's] ten minutes per consultation. Well, the reality is some people might need longer than that because perhaps...they might struggle to explain themselves or need longer and they don't have that time. So they feel rushed and pressured which I think has a bearing on things as well." (*Health board 2, community partner*)

5.5.2 Opportunity

5.5.2.1 Appointment policies

Some GP surgery appointment booking procedures made accessing an appointment challenging for some members of the community. Community partners reported that some people in the community do not own a phone or were busy taking the children or grandchildren to school around the time when you are required to ring to book an appointment. These issues and long wait times for an appointment with their preferred doctor were considered to prolong symptom presentation, especially for non-specific symptoms which were often perceived as not serious. Community partners reported occasions when they had phoned the GP surgery on behalf of someone in the community to book them an appointment or to get an appointment quicker than originally booked, and could reflect problems with communication when booking an appointment. GP surgeries which opened for one or two evenings a week were described as helping with scheduling of an appointment.

"P5- I think with the surgery I'm in, you've got to either be there or ring at 8.30 am. And I think a lot of our tenants, for whatever reasons, they won't be up and be in a position where they can be ringing in or visiting a surgery at 8.30 am to get an appointment. It's just not possible for some of them.

P4- Some of them don't have telephones.

P5- Exactly. They take the children to school or...

P4- Pr they can't get up in time or...

P5- It's very restrictive." (*Health board 1, community partner*)

Policies which preclude the discussion of more than one symptom during a consultation and time limited appointments were considered to prolong cancer symptom presentation for those who present with another health complaint to 'test the water' before disclosing a cancer symptom. These policies were also considered to inhibit disclosure of a cancer symptom for those who require an appointment with the doctor in order to receive their benefits, for example employment and support allowance (ESA). This is likely to take precedence over a symptom which might be perceived as nothing serious, and as a consequence it is unlikely these symptoms will be discussed.

"We've got very, very high levels of ESA [Employment and Support Allowance] and they tend to go to doctors just to make sure they stay signed off. So they go with the one issue. And as you said, you can't go with multiple issues. You've got that timeslot and you know, I'll be fine, kind of thing, until it all blows up." (*Health board 1, community partner*)

5.5.2.2 Crisis point care

Health was not perceived to be a priority or concern among the community, particularly for younger people, and was dealt with at the point of crisis. The healthcare professionals and community partners considered health in the community to be more about firefighting than prevention, where health problems are addressed in the short term once they become a problem, rather than through long term maintenance of health through lifestyle choices. The community partners discussed how health and maintenance of health is low in priority compared to some of the higher priority issues faced by people in the community, such as paying the bills, debt and housing problems. They suggested that people engage in unhealthy behaviours such as smoking to cope with the adversity of day-to-day living in deprived communities.

"P4- I think [for] most of the people, health is not a concern for a lot of the time unless it immediately becomes a massive concern...So a lot of the time we can struggle to get people to engage with their health and take responsibility about their health. It is frustrating quite often, their health is perhaps seen as not a problem or

is our problem...But then something will happen and all of a sudden, they will become very, very concerned.

P5- I think you also find we have a lot of them worried as well, so if anything is going on, they'll be the first to do it. But you often find the people you really want to target won't take anything on until there is something seriously wrong with them. But that's a big problem with us.

P3- I think there's a difference between maintaining health and when people come and see a doctor or a nurse, it's where they develop symptoms. So sometimes it's a bit too late for them...So as [name] was saying, there is a lot of worried well out there. But it's probably is driven by anxiety. "Oh, my mother had cancer of the ovaries. I've got it too." It's a lot of fear about that. So health in general, people are not maintaining health. They come in when they've got symptoms, sometimes when it's too late. And a lot are driven by anxiety, really.

P2- I'd agree with that. I think that it varies as well between different groups."
(Health board 2, healthcare professional)

"P1-I think a lot of people, health is at the bottom of the pile because actually paying the bills and the housing and all the other things come first and they don't realise how that impacts on their health. Do you know what I mean? For whatever reason.

P4- I think they deal with their health problems when it becomes a crisis rather than looking at prevention, than dealing with the problem, basically. Then look for assistance.

P3- And it's constantly firefighting, isn't it? It's not sort of saying, well, I need to go for a check-up. We don't see that happening very often in the community."
(Health board 1, community partner)

5.5.2.3 A lay system of healthcare

Consulting friends, family members and support workers for advice on symptoms before visiting the doctor was described as the norm in the community. Members of public reported seeking advice from individuals who were perceived as trusted and/or knowledgeable, such as elders or their spouse. The community partners and healthcare professionals suggested that this served the function of seeking reassurance about a symptom. They proposed that the quality of advice given was shaped by the advice givers' previous experiences within the health service, where negative past experiences such as

pain or embarrassment during diagnostic testing were relayed to the individual seeking advice, and in turn prolonged their symptom presentation. Positive experiences within the health service resulted in good quality advice, and pressure from family members and friends to seek medical help following symptom disclosure was thought to accelerate the help seeking process. Sometimes the advice giver would falsely reassure the individual that there was nothing to worry about in order to minimise anxiety about symptoms, so symptom presentation was prolonged.

“I'd say most of our tenants who've caught cancer early have been ones with support in place where there has been that support worker who's noticed subtle changes in behaviour... “Let me make an appointment for you, I'll come with you”...And that has pushed it along. I think left to their own devices, a lot of our tenants, particularly the men...particularly older gentlemen who don't have family around, are on their own. And quite often, I've found, in sheltered, is that they reach quite advanced stages of cancer before [diagnosis].” (*Health board 2, community partner*)

“Mod- Do you think there is anywhere else they go with concerns about potential symptoms, other than to the GP?

P- Their mother.

P- The family. Family and friends.

Mod- Do you think that people would go to family and friends and then call it a day there?

P- Sometimes.

Mod- And do you think that's a problem?

P- Yes. Because you always get the one member who always knows, whatever test “It was horrendous. Needle that big. They do this to you and they do that to you.” You never hear the people who had the tests or the operations, I came through it lovely. Had a good time. You always have eight or nine, had the most horrendous time. “I wouldn't do that, I wouldn't have that done. Not for the life of me. Because I know somebody who had it done and they haven't been right since”.” (*Health board 2, healthcare professional*)

5.5.2.4 Health norms and expectations

The community partners and healthcare professionals discussed that perceptions of health were likely to be influenced by the health of individuals in the community or the health norms of their community. Health among those living in the community was generally considered poor. If poor health is the norm, they suggested that members of the community are more likely to expect poor health or normalise adverse health or symptoms. The members of public discussed feelings of disempowerment, which were considered to contribute to poor health in the community.

“I think social networks, social norms are particularly pervasive in terms of people's health behaviours. And people's expectations of their own health and the health of their family depending on where they live. So living in an area where there is relatively low life expectancy, high levels of premature mortality, everyone that you know has got a chronic condition, that's probably what you expect yourself. So maybe there is a lack of motivation to make changes because it just seems, it's that external levels of control, you just think well, these things are outside of my control. That's how I'm going to end up. I think it's very difficult for people to change if you ignore the context in which they live their lives.” (*Health board 1, healthcare professional*)

5.5.2.5 Community interventions

The community partners and healthcare professionals discussed a range of health promotion campaigns and initiatives which had previously been implemented in the community. Stroke and diabetes campaigns were considered successful, but smoking cessation campaigns were much less successful. One of the health boards ran a cough campaign to encourage people who had a cough for three weeks or more to go to the doctor with limited success. Those who presented to the GP with symptoms following the campaign were generally low risk for lung cancer and represented the “worried well”. However, the healthcare professionals reported that some people did present with symptoms following the campaign who were at a higher risk and may not have previously sought help.

“We did a campaign...If you had a cough longer than three weeks, go to your doctor. I saw a huge number of people after that. I think that really made a big difference...there was a proportion of them were worried well, that the non-

smoking, healthy robust marathon running types who just had a bit of a tickle. But there was a few that came that wouldn't have otherwise and I think that that's a good thing." (*Health board 2, healthcare professional*)

"If you talk to people about smoking...they tend to put the barriers up." (*Health board 1, community partner*)

Community partners discussed a need for clearer guidance and advice on which symptoms to consult the doctor for and when. The community partners and healthcare professionals suggested using social networks to spread the messages, using a role model or someone who has previously had cancer as a health champion within the community. The healthcare professionals thought it was important to promote the benefits of early diagnosis and advances in survival and the treatments for cancer.

"If there were guidelines, say, for example, 'if you've got a mole and you know you should go to the GP, it's wider than X number of millimetres' or whatever, I think those kind of actual... You can put a clear measurement on them, that will make somebody more likely to go..." (*Health board 2, Community partner*)

5.5.3 Motivation

5.5.3.1 Fear and avoidance

Fear of a cancer diagnosis was considered a major barrier to presenting to the doctor with symptoms, particularly in the older members of the community. The community partners and health care professionals thought this reflected a deep-seated fear for cancer, where cancer was associated with death and unpleasant treatment side effects. Such beliefs were thought to reflect the high incidence of cancer related death in the community, where members of the public form an expectation of what cancer is supposed to be like based on experience, usually witnessing family members and friends suffer and die from cancer. Lung cancer diagnoses within the community were often diagnosed at late stage where palliative treatments were the only option, and as a consequence lung cancer was associated with fear in the community. The healthcare professionals thought that some people in the community understood some of the symptoms of lung cancer, but are too scared to present to the doctor with the symptom due to fear of a diagnosis.

“Most of our lung diagnoses that comes into us because I'm made aware of all the cancer diagnoses, most of the lungs go straight onto a palliative care register.”

(Health board 2, healthcare professional)

“I think particularly the elderly, they've seen [cancer] in the past, maybe 30 years ago people dying of cancer in really a horrific way and they've seen people not getting very good treatment and I think the elderly are really fearful of cancer and they'd rather not know.” *(Health board 1, healthcare professional)*

The healthcare professionals suggested that those who suspect but fear a diagnosis of cancer might prolong symptom presentation in order to allow time to process the consequences of being diagnosed with cancer. For some, a diagnosis of cancer would be too much to consider in the context of other accumulating life problems and circumstances such as housing or money problems, and could result in avoidance or denial of symptoms as a strategy for dealing with symptom concerns. Similarly, mental health problems such as anxiety and depression were discussed by community partners and members of the public as factors that are likely to facilitate denial or avoidance of symptoms, or exacerbate fear and worry about a diagnosis of cancer.

“If you live in an area where you've got housing issues and debt problems and employment, then a cancer diagnosis is almost too... You can't take that on as well, with all these wider social problems. Some people will almost put their head in the sand, ignore that, hope it goes away. Because they are dealing with just trying to survive, week on week. How am I going to pay the rent next week, I can't deal with a cancer diagnosis as well.” *(Health board 2, Healthcare professional)*

“And I think it's avoidance, isn't it? Not hearing things as well, not bothering, not going. Not dealing with it. Because I don't want to know the result. That it could be bad. And I think people put off going for checks. I know I do. Definite. And it's stupid.

P5- My brother was like that...“I don't want to go. I don't want to know. I'd rather not know.” It wasn't until we said, well, it could affect your children, because he's got two daughters. And then he went, oh okay then, I'll go.” *(Health board 1, members of public)*

5.5.3.2 Cultural barriers

The embarrassment associated with disclosure of symptoms and potential examinations and diagnostic testing was considered to be a barrier to symptom presentation. Healthcare professionals could recall asking patients about whether they had noticed symptoms such as blood in stools, but reported that only a minority of people check their stools for blood. These were considered to reflect cultural issues relating to embarrassment and could result in symptoms being missed by patients.

“I never fail to be amazed when I ask people who come with abdominal symptoms-suspected bowel cancer is where I'm leading to. And you ask them if they've seen any blood in their motions. And nobody ever seems to look at their motions when they go to the toilet. “Oh, I don't... I've got that blue stuff in the toilet doctor, I can't see. Oh, I never look at that.” You think, really? Do you not look at it?” (*Health board 2, healthcare professional*)

Mod- “Why was he put off going [for screening]?”

P5- The process, the camera, where they put the camera. You know?

Mod- Do you think that's quite a normal attitude? Would you say that people...?

P7- A lot of people think like that, don't they?” (*Health board 2, members of public*)

5.6 Discussion

This study aimed to gain further insight into the mechanisms underlying prolonged cancer symptom presentation among low socioeconomic groups through the perspective of local stakeholders and members of the community who live or work in deprived communities. The influences of the environment in which individuals live, symptom attributions, beliefs about cancer and how symptoms are communicated during a consultation were explored.

5.6.1 Summary of findings

Non-lump and bleeding symptoms of cancer were usually attributed to symptoms of pre-existing co-morbidities or other acute conditions, and consequently there was no perceived urgency to seek medical help. Health and maintenance of health were not considered a priority in deprived communities and were considered a problem at the point of crisis. Poor general health in the community was perceived to be the norm rather than the anomaly,

and addressing basic needs and day-to-day living such as paying the bills were prioritised over health-seeking behaviours. Fear of cancer and its association with inevitable death and unpleasant treatment side effects were based on witnessing people in the community suffer and in most cases die from cancer. Negative fearful and fatalistic beliefs about cancer were associated with the longest time to cancer symptom presentation and were discussed in terms of their contribution to denial and avoidance of symptoms, particularly for those with carer responsibilities or those with mental health problems. Symptoms were often discussed with family members or friends for advice on what to do or to seek reassurance, which could attenuate or facilitate the decision to seek medical help for a cancer symptom.

5.6.2 Findings in relation to previous research

Findings from the present focus group study confirm and extend those of previous studies which have reported associations between low socioeconomic groups and poor knowledge of the non-specific symptoms of cancer and low suspicion of their association with cancer (Capability) (Brain *et al*, 2014; Robb *et al*, 2009; Whitaker *et al*, 2015a), a high prevalence of fearful and fatalistic beliefs about cancer (Motivation) (Quaife *et al*, 2015), problems associated with effective communication of symptoms during a consultation (Capability) (Chapter 4; Mccutchan *et al*, in press) and prolonged symptom presentation following disclosure of symptoms to family or friends (Opportunity) (Li *et al*, 2012).

In this study, expectations of health were discussed in the context of what is perceived as normal in relation to the local community, where individuals compare their health against other members of the community and make assumptions about what is normal (Opportunity). According to the Common Sense Model of Illness Self-regulation (Leventhal *et al*, 1984), an initial unconscious assessment of whether a bodily change is normal or abnormal precedes a conscious assessment of the bodily change. If the bodily change is unconsciously assessed as abnormal, it is assessed consciously in relation to illness schemas, where the individual aims to seek a common sense explanation for symptoms (Leventhal *et al*, 1984). Perceptions of illness and symptoms are likely to be influenced by social and cultural factors. In a community with poor general health, where non-specific symptoms such as a cough are common, it is likely that such symptoms are interpreted in relation to the norms of the community and thereby dismissed as normal (Zola, 1966). For example, respiratory symptoms are more prevalent, but consultation behaviour is lower for respiratory symptoms among low socioeconomic groups, compared to high socioeconomic groups (Trinder *et al*, 1999; Trinder *et al*, 2000). It is possible that symptoms are perceived as

normal when judged against community norms rather than in isolation, thus considered to not require medical help (Trinder *et al*, 1999; Trinder *et al*, 2000). If symptoms are normalised in the context of symptoms which are highly prevalent in the community, symptoms could be misattributed and dismissed as normal (Capability), prolonging presentation of potential cancer symptoms.

Consulting family members and friends or support workers for advice about symptoms prior to a visit to the doctor with a symptom was the norm in the community (Opportunity). This is likely to reflect the problems associated with getting an appointment with the doctor or concerns about being taken seriously, and perhaps the need to seek reassurance about a symptom. Disclosure of symptoms to a family member or friend has previously been associated with longer medical help seeking among low socioeconomic groups (Li *et al*, 2012; McCutchan *et al*, 2016). The present study found evidence of the types of advice which might be given to individuals seeking help from lay members of the community, and how this advice might attenuate or facilitate the decision to present to the doctor with symptoms. Negative beliefs about cancer and previous negative experiences in healthcare were likely to influence the quality of advice given to individuals seeking advice on symptoms from a family member or friend and prolong cancer symptom presentation. Conversely, when good quality advice was given to an individual along with help booking an appointment and communicating symptom concerns during the appointment, symptom presentation was often accelerated and cancer was sometimes diagnosed in the early stages.

Healthcare professionals reported that patients would often present with unrelated symptoms and disclose a cancer symptom at the end of a consultation or as they were leaving. Perhaps this is related to worry about not being taken seriously by the doctor, perhaps due to fear of being perceived as a hypochondriac or embarrassment associated with disclosure of symptoms, where symptoms are disclosed only once they have established that they can trust the doctor. Policies which preclude the discussion of more than one symptom during a consultation are likely to inhibit presentation of symptoms for these individuals. Furthermore, time limited appointments were considered to be problematic for people in the community who struggle with communication during an appointment, as they may feel pressured to remember or discuss all symptom concerns.

Through the involvement of local stakeholders who work in deprived communities, additional insight into the day-to-day challenges faced by individuals living in deprived communities and how these might affect cancer symptom presentation behaviour was gained (Opportunity). Seeking help for symptoms perceived as not serious (Capability) was not considered a priority for people in deprived communities whose priorities included addressing debt, paying the bills and housing issues (Opportunity). Maslow's hierarchy of needs (Maslow, 1943) is a theory of human motivation to achieve certain needs and comprises of a hierarchy of five stages from the most basic needs (biological and physiological needs such as food, shelter and warmth) to the higher level needs (self-actualisation needs such as self-fulfilment and seeking personal growth). According to the theory, progression on to the higher needs is difficult when the basic needs at the bottom of the hierarchy are not met (Maslow, 1943). In this study, there was evidence to suggest that these basic needs were not fulfilled for some members of the community, and could explain why these take precedence over cancer symptom presentation and addressing other health concerns. In addition, this might facilitate understanding for why some individuals enter a state of denial or avoidance of symptoms, where they might perceive that they cannot cope with a diagnosis of cancer, especially when the most basic of needs are yet to be fulfilled.

The general struggles of day-to-day living were considered by local stakeholders to reflect the high prevalence of health damaging behaviours such as smoking in order to cope with the adversity of daily life, and reflect findings of previous studies (Wilkinson *et al*, 1997). Despite numerous efforts by local stakeholders to run smoking cessation and community campaigns to encourage people to quit smoking, these attempts were reported as unsuccessful or poorly attended. This is likely to reflect a general reluctance to quit smoking, therefore a cancer awareness intervention targeted at deprived communities should consider the exclusion of smoking cessation advice to encourage attendance.

5.6.3 The COM-B model

The analytical framework for this study was based on the COM-B model constructs (Michie *et al*, 2011). All COM-B model constructs (Capability, Opportunity and Motivation) were found to be applicable in the context of cancer symptom presentation behaviour, therefore the COM-B model provides a useful framework for understanding cancer symptom presentation behaviour among low socioeconomic groups. The model currently represents a bi-directional influence of Capability, Opportunity and Motivation on Behaviour and suggests that both Capability and Opportunity influence Motivation (Michie *et al*, 2011) which is

supported by the findings from this study. There was evidence from this study and the interview study previously described in Chapter 4 to suggest that Opportunity can influence Capability, for example previous experiences of witnessing people in the community influenced knowledge of cancer. This relationship is currently not represented in the model. In the context of cancer symptom presentation behaviour, the relationship between these two constructs (Capability and Opportunity) appears to be key and representation of this relationship should be considered in the model in this context.

Where many other theories neglect to include the influences of the environment (Opportunity) on behaviour, the COM-B model takes the role of the environment into account. The inclusion of Opportunity in this analytical framework facilitated exploration of the influences of the environment on cancer symptom presentation behaviour. In this context, there was a strong influence of environment on cancer symptom presentation behaviour and on the other constructs (Capability and Motivation). However, the constructs were overlapping in their nature, therefore there were some themes had the potential to fit under multiple constructs. Deciding which construct to group each theme under was in some cases challenging, for example, the theme 'health norms and expectations' which is discussed under the construct Opportunity could also represent Motivation.

5.6.4 Strengths and limitations of the study

The strong theoretical underpinning from the study design through to analysis and interpretation of the data in this study was a strength. The use of the COM-B model as an analytical framework and relevance of the COM-B model in this particular context of cancer symptom presentation behaviour will facilitate development of the intervention with the Behaviour Change Wheel. Through qualitative methods, the factors influencing cancer symptom presentation which cannot be explored in depth using quantitative measures were identified, particularly the influences of the contextual factors (Opportunity) on behaviour.

The inclusion of local stakeholders who work closely with members of the community was a strength of the study, since they were able to provide an alternative perspective on cancer symptom presentation behaviour in the community. There are methodological issues associated with obtaining proxy views from local stakeholders; however, findings were aligned with the members of public focus groups and confirmed findings in the interview study with members of the public described in Chapter 4. It could be considered paternalistic to include local stakeholders to gain their views on symptom awareness and

cancer symptom presentation behaviour for people in the community. However, through the inclusion of local stakeholders, a broader view of the influences on cancer symptom presentation behaviour such as the struggles of day-to-day living could be explored. In addition, local stakeholder could confirm previous speculations, for example it was speculated in the interview study that people who disclose symptoms at the end of a consultation do so to test the water. There was evidence from this study to confirm these speculations.

There are limitations associated with participant recruitment and potential generalisability of findings. Participants were recruited opportunistically, therefore those who took part in the study could have a particular interest in cancer and may not be representative of the general population. In addition, only two sites in South Wales were included in this study, therefore findings may not be generalisable to other deprived communities. For example, findings relating to appointment policies might be specific to communities in South Wales or UK context, where other countries and health care systems might have a different approach to appointment policies. However, there were some findings which are likely to reflect problems faced by deprived communities universally. For example, individuals living in deprived communities are likely to face economic hardship regardless of where they reside geographically. Therefore, findings associated with competing priorities and money worries taking precedence over medical help seeking behaviour are likely to be generalisable to all other deprived communities.

The members of the public were recruited through community partners, therefore there is the potential for selection bias where the community partners might select those in the community with a particular interest in cancer or were more motivated to take part. In addition, a focus group may attract individuals who are confident when speaking in a group or have particularly strong views; therefore, participants may not be fully representative of the general population. Recruitment of members of the public through community partners meant that there are no data on response rates or reasons for non-participation. In addition, the criteria for inclusion were over 40s who live in a Communities First area. No further demographic data were collected at the focus group, which has its limitations as only one area-level indicator of socioeconomic deprivation was used. Whilst Communities First areas are the most deprived communities in Wales, residence in these areas may not fully represent an individual's current socioeconomic circumstances.

Involvement in the ABACus study provided a good opportunity to gather data in a focus group setting to understand the mechanisms underlying cancer symptom presentation from people who live or work in deprived communities. As a consequence, the PhD researcher was restricted by the aims of the ABACus study, therefore lung cancer specific findings were limited and only half the focus group was dedicated to understanding cancer awareness and cancer symptom presentation behaviour.

5.6.5 Implications for intervention

Findings from this study provide additional support for the strength of social networks as an influence on cancer symptom presentation, therefore social networks could be used to disseminate information and facilitate good quality advice following symptom disclosure. Previous attempts at health related campaigns within the community suggest that information needs to be tailored to those who are most at risk, to reduce the number of 'worried well' presenting to the doctor with symptoms. Lessons learned from previous smoking cessation campaigns in the community suggest that the inclusion of smoking cessation advice in a lung cancer awareness intervention should be carefully considered, and perhaps excluded in order to increase attendance. Information on the significance of non-specific symptoms of cancer, paired with clear guidance on when to present to the doctor with symptoms and information about the benefits of earlier diagnosis for lung cancer, are important and should be included in the content of the intervention.

5.6.6 Conclusion

Poor knowledge for the non-specific symptoms of cancer or dismissal of symptoms as normal in the context of other co-morbidities and fearful and fatalistic beliefs about cancer can prolong cancer symptom presentation in deprived communities. The day-to-day problems faced by individuals living in deprived communities are likely to facilitate denial of symptoms and reduce the motivation to seek medical help for symptoms. More research is needed to understand the barriers to lung cancer specific symptom presentation. The findings from this focus group study and the previous two studies will be mapped to the Behaviour Change Wheel for intervention development. Prior to this, a scoping review of all available cancer awareness interventions targeted at low socioeconomic groups is required to understand what interventions have been implemented in deprived communities and which have been successful for prompting cancer symptom presentation.

Chapter 6

Scoping review of interventions to encourage timely cancer symptom presentation among low socioeconomic groups

6.1 Chapter overview

Findings from a scoping review of interventions designed to promote timely cancer symptom presentation among low socioeconomic groups across all tumour sites will be presented in this chapter. The types of intervention, their mode of delivery and content will be described. Where the interventions were evaluated and data are available, evidence will be presented regarding effects of the interventions on clinical outcomes, psychological/behavioural outcomes, intervention reach and cost-effectiveness.

Interventions with a lung cancer focus will be extracted and discussed in addition to findings from all interventions. The scoping review findings will be discussed in terms of which interventions appear most promising for encouraging timely cancer symptom presentation among low socioeconomic groups, and the implications for developing a lung cancer focused intervention.

6.2 Introduction

Cancer awareness interventions designed to shorten the patient time interval and encourage symptomatic individuals to visit their GP promptly to discuss symptoms have the potential to enable cancer to be diagnosed at an earlier stage where the chances of survival are greater. As outlined in Chapter 1, this is particularly important for individuals in low socioeconomic groups who report the longest patient intervals and who are more likely to be diagnosed with cancer at a late stage (Macleod *et al*, 2000; Macleod *et al*, 2009; Lyratzopoulos *et al*, 2013).

In 2009, a systematic review of interventions designed to increase cancer awareness and encourage timely cancer symptom presentation was conducted (Austoker *et al*, 2009). A total of 15 interventions were identified for analysis across a range of different cancer types, countries and participant demographics (Austoker *et al*, 2009). Two types of intervention were identified: individual-level interventions (n=5) and community-level interventions (n=10). Individual-level interventions were defined as those tailored or targeted at

individuals, for example a one-to-one interaction with a healthcare professional or a leaflet given or posted to a specified individual (Austoker *et al*, 2009). Community-level interventions were defined as interventions delivered to communities, such as media campaigns or leaflets distributed in a community setting or health club (Austoker *et al*, 2009).

All interventions in the Austoker *et al* (2009) review included an intervention evaluation. The review concluded that individual-level interventions were more effective for increasing cancer knowledge when information was tailored to the individual and when they were more intensive (Austoker *et al*, 2009). However, increases in cancer knowledge were not sustained long term (Austoker *et al*, 2009). There was no evidence for the effectiveness of individual-level interventions in promoting earlier cancer symptom presentation behaviour (Austoker *et al*, 2009). In contrast, community-level interventions showed limited effectiveness in increasing cancer knowledge, but there was evidence to suggest that community-level interventions could promote more timely symptom presentation and diagnosis of cancer (Austoker *et al*, 2009). However, due to limited evidence and heterogeneous evaluation methods, the authors concluded that it was unclear which type of interventions work best to increase cancer awareness and promote earlier cancer symptom presentation (Austoker *et al*, 2009).

The ABC-DEEP rapid review was conducted in 2014 for interventions designed to increase cancer awareness or promote timely symptom presentation (Campbell *et al*, 2014) and to update Austoker *et al*'s (2009) review. Forty-three cancer awareness interventions for a range of different cancer types and participant demographics, and those which included an evaluation, were identified from database and grey literature searches (Campbell *et al*, 2014). There was evidence of a short term effect of mass media campaigns such as TV and radio campaigns on symptom knowledge (Campbell *et al*, 2014). Interventions which adopted a multi-faceted approach, communicating intervention messages through various modes of delivery, were concluded to have the most potential benefit in terms of effectiveness, although there is a need for more robust evaluations to assess long term effects of interventions (Campbell *et al*, 2014).

Both reviews only included interventions that were formally evaluated (Austoker *et al*, 2009; Campbell *et al*, 2014), and the Austoker *et al* (2009) review was restricted by systematic

review methods. Systematic review methods limit the type of intervention included, for example smaller local community based interventions are unlikely to be published in academic journals, and would consequently not be identified by the review. Although the ABC-DEEP review included grey literature searches, the Austoker *et al* (2009) review did not include grey literature searches, potentially excluding unpublished and pilot studies. In addition, the reviews did not focus on interventions targeted at a particular demographic such as ethnic minority groups or low socioeconomic groups, where cancer outcomes are known to be poorer. Therefore it is unclear which interventions were implemented in these 'harder to reach' groups and which were most effective for promoting timely cancer symptom presentation behaviour.

To date, no review of cancer awareness interventions has focused solely on those targeted at 'harder to reach' groups. This PhD is concerned with promoting timely cancer symptom presentation among low socioeconomic groups. Therefore, this scoping review will focus only on interventions targeted at individuals within low socioeconomic groups defined by individual indicators such as educational attainment or area level indicators such as deprivation scores calculated from postcode data.

6.2.1 The Medical Research Council (MRC) framework

Intervention development for this PhD follows the MRC framework for the development and evaluation of complex interventions (Craig *et al*, 2008). As outlined in Chapter 1, four phases of development are outlined by the MRC framework including a development phase, which highlights the importance of identifying the existing evidence base for 'what is already known about similar interventions and the methods used to evaluate them' (Craig *et al*, 2008). In the absence of evidence from a review of cancer awareness interventions targeted at individuals in low socioeconomic groups, a scoping review was conducted and the findings used to contribute to intervention development reported in Chapter 7.

6.2.2 Aims and objectives

The present scoping review aimed to identify and describe interventions which seek to encourage timely cancer symptom presentation among low socioeconomic groups, irrespective of tumour site. There were three objectives of this review: (1) to extract data

according to who the intervention was targeted at, what type of intervention was used, how the intervention was implemented, and information regarding the content and delivery of the intervention; (2) where available, extract evaluation data regarding effectiveness in raising awareness of cancer, encouraging timely cancer symptom presentation, improving clinical outcomes and reaching those for whom the intervention was intended, and cost-effectiveness; and (3) describe and critically appraise intervention evaluation methods. Findings from this review will be used to inform intervention development for a lung cancer awareness intervention targeted at low socioeconomic groups, described in Chapter 7. Whilst the focus of the current intervention is lung cancer, interventions targeted at low socioeconomic groups for other types of cancers are included in the present review. The decision to include all cancer types was made in order to identify the types of interventions that have been used in low socioeconomic groups and, where possible, to extrapolate from evidence regarding their effectiveness in the reported outcome domains.

6.2.3 Scoping review methodology

A scoping review methodology was selected because many cancer awareness interventions, particularly smaller interventions at community level, were unlikely to be published in peer-reviewed academic journals. A scoping review involves the synthesis and analysis of a wide range of research and non-research material to map the existing evidence base (Davis *et al*, 2009). Although the evidence is systematically collected, a scoping review allows the identification of evidence from heterogeneous sources including academic databases in addition to grey literature searches, search engines and key websites to identify both published and unpublished findings (Cacchione, 2016).

Other review methodologies were considered too restrictive, for example a systematic review methodology involves searching databases for peer-reviewed and published articles only. In addition, a scoping review is less restrictive in terms of inclusion criteria and evidence is included regardless of quality to provide an overview of the current evidence base and identify gaps for future research (JBI, 2015; Arksey and O'Malley, 2005). Taking into account the aims of the present review, a scoping review was selected to allow inclusion of both unpublished interventions (such as smaller community based initiatives) and published interventions (such as larger media interventions), regardless of whether the intervention was evaluated. Informal quality assessments are reported in this review.

6.3 Methods

Scoping review followed the framework for conducting scoping reviews described by Arksey and O'Malley (2005). In their framework, five key stages are outlined: identification of the research question, identification of relevant information using search terms, intervention selection using an exclusion/inclusion criteria, data extraction/charting of data, and summarising/reporting of findings (Arksey and O'Malley, 2005). Each stage is outlined below:

6.3.1 Stage 1: identify the research question

The research questions were: what interventions designed to encourage timely cancer symptom presentation are available, and which of these are targeted at low socioeconomic groups? If evaluation data are available, how effective are these interventions? Effectiveness was defined in terms of improved outcomes within the following four domains:

- a. Psychological/behavioural domain
 - Symptom presentation behaviour (self-reported or GP read code data for actual symptom presentation, or self-reported hypothetically anticipated symptom presentation behaviour)
 - Cancer symptom knowledge (recall or recognition)
 - Barriers to cancer symptom presentation (reported actual or anticipated barriers to cancer symptom presentation)
- b. Clinical domain
 - Referral (number of urgent two week wait (2WW) referrals for suspected cancer to secondary care, number of GP requested diagnostic tests e.g. chest X-rays for suspected lung cancer)
 - New cancers detected (number of new cases of cancer detected)
 - Staging data (cancer stage shift observed, number of patients offered earlier stage treatments e.g. surgery)
- c. Intervention reach domain (outcomes relating to intervention messages reaching those for whom the intervention was targeted, such as whether the target group were aware of the intervention, and any changes in

psychological/behavioural or clinical outcomes observed specifically within the target group)

- d. Cost effectiveness domain (calculated in relation to clinical outcomes such as cost of intervention per new diagnosis of cancer, or quality-adjusted life-years).

6.3.2 Stage 2: identification of relevant interventions

Electronic database searches, reference list searches and online searches of key organisation and search engines were performed to identify relevant interventions up to and including April 2016. Terms related to 'cancer', 'awareness', 'symptom presentation' and 'intervention' were used to identify relevant interventions.

The electronic databases of MEDLINE, PsycINFO and EMBASE were searched for interventions and evaluations of interventions in peer reviewed papers and those published as conference abstracts. The de-duplicate function was used on Ovid and CINAHL before reviewing abstracts. Manual searches of reference lists of included papers were performed. Online searches of key organisation websites such as Cancer Research UK and the search engine 'Google' were used to help identify interventions using key words. If further information was required, the organisation, researcher or programme lead was contacted via email to obtain further information about the intervention. A reminder email was sent if the individual or organisation did not respond.

6.3.3 Stage 3: intervention selection

In order to identify relevant interventions for inclusion in the review, inclusion/exclusion criteria were applied to all search engine hits, interventions found through websites, and for articles found through databases and hand searching of reference lists. Criteria for inclusion were as follows:

- An intervention development or evaluation paper designed to encourage or prompt timely cancer symptom presentation among recipients
- An intervention targeted at low socioeconomic groups. A low socioeconomic group was defined as individuals who were in a low socioeconomic group according to individual socioeconomic group indicators (such as educational attainment i.e. low

educational attainment) or area level deprivation (such as an index of multiple deprivation i.e the most deprived quartile). The peer-reviewed paper or description of intervention gained from online searches or contact with co-ordinators or organisations must explicitly state that the intervention was targeted at a low socioeconomic group according to these criteria.

- Interventions with or without evaluation were included. Where the intervention was evaluated, all study designs were included and findings reported separately. If evaluation data were reported in a separate peer-reviewed paper or intervention report, these were included and referenced.
- Interventions implemented in high income countries classified by Organisation for Economic Co-operation and Development (OECD) membership (OECD, 2014) were included.

The exclusion criteria were as follows:

- Interventions which were not focused on cancer.
- Interventions targeted at people with a diagnosis of cancer such as cancer treatment intervention or quality of life interventions following a diagnosis of cancer.
- Interventions designed to promote healthier lifestyles to reduce individual cancer risk.
- Interventions designed to encourage participation in cancer screening. As previously discussed in Chapter 1, the barriers to cancer screening are similar to those of cancer symptom presentation. However, the process of recognising, appraising and seeking medical help for a symptom of cancer is different to attending a screening appointment after receiving a reminder letter, therefore screening interventions were excluded from this review.
- Interventions and papers not written in English.
- Interventions implemented in low or middle income countries, classified by OECD membership (OECD, 2014).

6.3.4 Stage 4: data extraction and charting

All available data were extracted into a table according to the following headings: name of intervention; location of intervention (country and city); cancer type and target symptoms,

and intervention type (target group, method(s) of delivery, duration of intervention, cost of intervention, intervention content, healthcare professional element). If the intervention included an evaluation, data were extracted into the table according to the following headings: method of evaluation (study design, data collection methods, outcome measures, participant characteristics and sample size) and key findings (behavioural/psychological outcomes, clinical outcomes, reach, cost-effectiveness). Interventions were ordered alphabetically according to intervention name (Table 6.1).

6.3.5 Stage 5: collating, summarising and reporting the results

Interventions were grouped according to intervention type. An overview of the content and delivery of each intervention type is presented. Where data were available, the findings in relation to intervention effectiveness for psychological/behavioural outcomes, clinical outcomes, reach and cost effectiveness are reported.

6.3.6 Quality Appraisal

Scoping review methodology does not include a formal assessment of intervention or study quality, therefore interventions included in this review were not formally assessed for quality before or after inclusion. However, quality assessments for intervention development and evaluation were considered important, and quality was judged informally in accordance with the MRC framework guidance for intervention development (Craig *et al*, 2008). Interventions which were developed in accordance with the guidance outlined by the MRC framework (Craig *et al*, 2008) and those which used appropriate evaluation methods were considered to be of higher quality. Quality appraisal is reported after findings from intervention evaluation studies.

6.3.7 Lung cancer interventions

Interventions of lung cancer were analysed in addition to findings for all included interventions, and reported after the main findings. These included interventions which focused solely on lung cancer or interventions targeting multiple types of cancer including lung cancer. Lung specific outcomes were extracted to provide insight into the types of

interventions previously carried out, and if data available how effective these interventions were to inform intervention development for this PhD.

6.4 Results

A total of 20 interventions or intervention programmes designed to encourage timely cancer symptom presentation among low socioeconomic groups were included in this scoping review. Some interventions reported outcome measures over a number of articles, therefore the number of studies or articles included in the review is higher than the number of interventions. The target groups were confirmed in the text of the intervention content documents, peer-reviewed papers or conference abstracts or in email correspondence to intervention managers. Interventions were identified through searches of academic databases and hand searching of reference lists (n=11), search engine searches (n=13) and key websites (n=5). After duplicates were removed, 20 interventions were included (Figure 6.1).

Nine interventions targeted multiple types of cancer, and 11 interventions focused on one type of cancer only: lung (n=5), oral (n=3), breast (n=2), bowel (n=1). Fifteen of the 20 interventions reported findings from an intervention evaluation. Nineteen interventions were carried out in the UK (England, n=15; Scotland, n=2; Wales n=2), and one intervention took place in the United States.

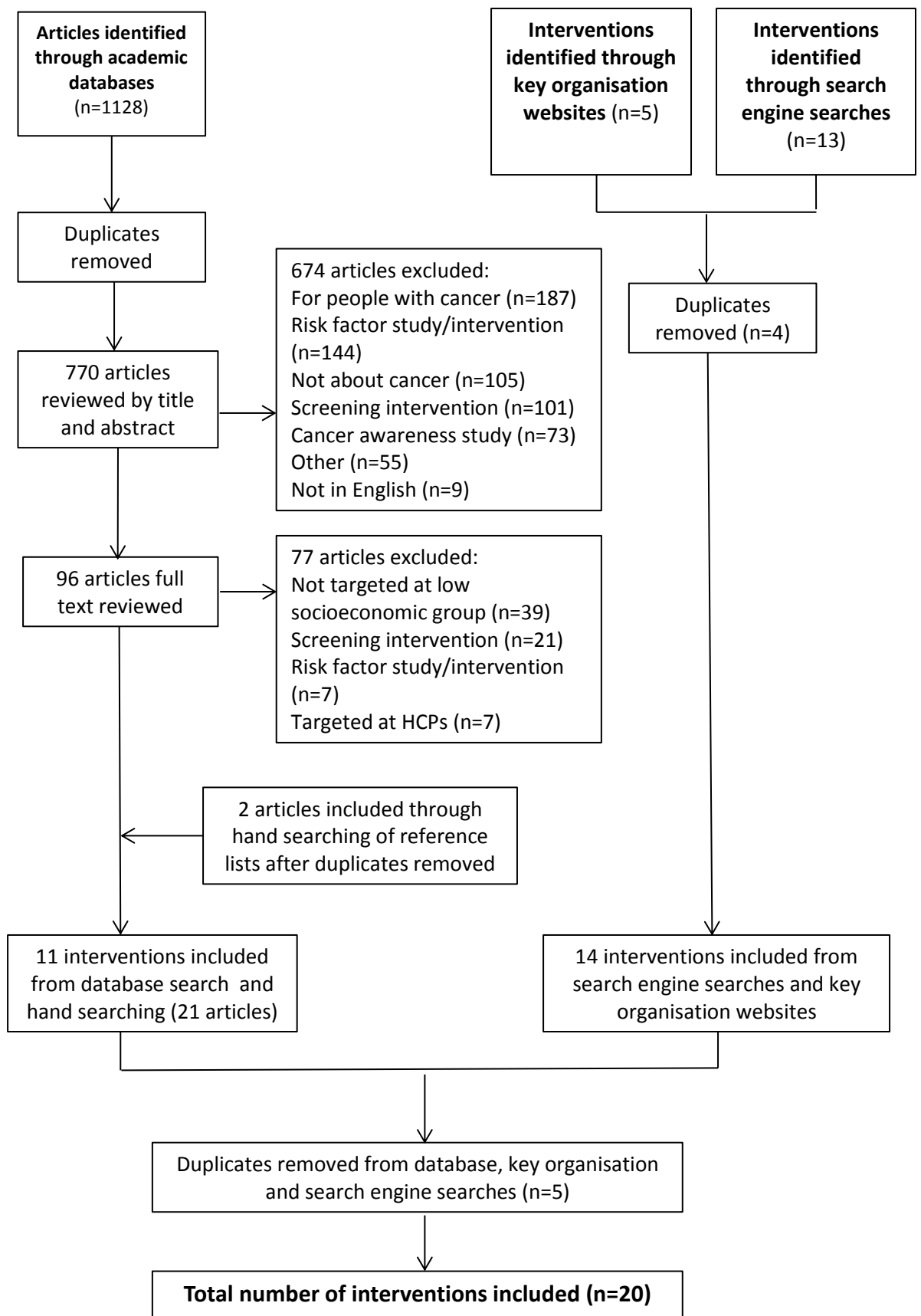


Figure 6.1 Flow chart of cancer awareness interventions included in the scoping review

6.4.1 Types of intervention

The interventions were categorised into five types: community based multi-faceted social marketing intervention (n=12); mass media intervention (n=3), health check intervention (n=2), educational intervention (n=2), and roadshow intervention (n=1). The type of interventions included, and the content and delivery of each intervention are described below.

6.4.1.1 Community based multi-faceted social marketing interventions

Twelve community based multi-faceted social marketing (CBMSM) interventions were identified. Seven interventions targeted multiple cancers (Detect Cancer Early Programme, East Sussex Downs and Weald PCT cancer awareness project, The Early Presentation of Cancer Symptoms Collaborative Programme, Early Presentation of Cancer Programme, The Healthy Communities Collaborative, NAEDI local projects, The Small “c” Campaign). Five CBMSM interventions focused on one type of cancer only: lung cancer (n=3; ‘Don’t be a cancer chancer’ campaign, The Early Lung Cancer Detection in Corby Project, Early Lung cancer Intervention in Doncaster), oral cancer (n=1; Lowry *et al*, 2009), breast cancer (n=1; Painting Stroud Pink). Most interventions were carried out in England (n=11), and one intervention was conducted in Scotland. Two interventions of lung cancer targeted persistent cough symptom (Small ‘C’ campaign, Early Lung Cancer Intervention in Doncaster). The remaining ten interventions did not report which specific symptom(s) were targeted in the intervention.

A CBMSM intervention incorporates multiple methods of intervention delivery to communicate a message to members of the public in a variety of ways. This intervention type typically involves media advertising such as local radio and television targeted to a specific geographical area, combined with poster adverts strategically placed in locations such as pharmacies or bus stops. The media aspects are usually supported by face-to-face local events such as cancer awareness stalls at supermarkets or public events, or talks in community venues such as community centres, hairdressers or mosques. A minority of interventions used a self-referral programme where individuals could refer themselves for diagnostic testing (n=2; The Early Lung Cancer Detection in Corby Project, and Lowry *et al*, 2009).

Six CBMSM interventions recruited lay members of the community to become 'cancer champions' or community volunteers (Small 'C' campaign, Painting Stroud Pink, NAEDI local projects, The Early Presentation of Cancer Symptoms Collaborative Programme, Early Presentation of Cancer Programme, East Sussex Downs and Weald PCT cancer awareness project, Early Lung Cancer Detection in Corby Project). Their role varied according to each intervention for example some volunteers or cancer champions were recruited to replenish leaflets and refresh poster boards in their area. Other interventions recruit volunteers or cancer champions to run cancer awareness events or talks within the community. Some interventions recruit volunteers or cancer champions to disseminate intervention messages within the community, and are trained to deliver opportunistic brief behaviour change interventions to encourage people in the community with symptoms to consult the GP. Volunteers and cancer champions were usually recruited through poster advertising within the community, or through clinical nurse specialists or cancer support groups. The length of training and time commitment expected of each volunteer or cancer champion varied according to their role. Volunteer and cancer champion training sessions varied from a few hours to two days, and time commitment required was usually around two days per month.

Eight of twelve CBMSM interventions were targeted at one specific geographical area (The Early Lung Cancer Detection in Corby Project; Don't be a Cancer Chancer intervention in Manchester; Early Lung Cancer Intervention in Doncaster; The Early Presentation of Cancer Symptoms Collaborative in North East Lincolnshire; East Sussex Downs and Weald PCT Cancer Awareness Project; Lowry *et al*, 2009 in Newcastle and Gateshead; Painting Stroud Pink in Gloucestershire; and the Small "c" Campaign in London). Three larger or national programmes allocated funding to leads within smaller target areas to develop tailored interventions in the most deprived areas within the larger geographical area. These include the Detect Cancer Early Programme in Scotland, The Improvement Foundation Healthy Communities Collaborative, and the NAEDI local projects which funded sixty projects at local level to support the larger mass media Be Clear on Cancer Campaigns.

The CBMSM approach repeats the intervention message to individuals through multiple channels of communication. This means that individuals are likely to receive the information from multiple sources and exposure to the message is increased to facilitate awareness of the intervention and information retention. In addition, these interventions are usually

culturally tailored or adapted to the target group or geographical area following research focus groups or interviews with people from the local area to ensure the message is communicated in most appropriate way to bring about behaviour change. For interventions which engaged lay members of the community in intervention development at the early stages, this was considered key in the success of these interventions. Furthermore, interventions which trained volunteers and cancer champions to help spread cancer awareness messages did so to create intervention sustainability as local people can learn and develop skills at little cost.

Seven CBMSM interventions employed 'push-pull' methods. The 'push' aspect refers to information to push people to go to the GP with symptoms and the 'pull' aspect involves a healthcare professional (HCP) educational element of the intervention. The HCP education usually involves reminding GPs of the referral guidelines for suspected cancer and/or an intervention in secondary care to help them prepare for increased caseload. For example, The Detect Cancer Early Programme in Scotland included a social marketing campaign to raise public awareness of cancer symptoms and screening programmes, alongside interventions with HCPs in primary and secondary care. In primary care, GP's were reminded of the guidelines for referral of suspected cancer. In secondary care, diagnostic services were helped to prepare for increased case load to ensure there was sufficient capacity to provide patients with appropriate diagnostic testing.

6.4.1.2 Mass media interventions

Three mass media interventions were included in this review, each targeted at three different types of cancer and various symptoms: oral cancer (n=1; ulcers, sores, red/white patch, spots, lump(s), persistent changes, change in tongue; The West of Scotland Cancer Awareness Project), bowel cancer (n=1; change in bowel habit, blood in faeces; Be Clear on Cancer bowel cancer campaign) and lung cancer (n=1; persistent cough; Be Clear on Cancer lung cancer campaign).

A mass media intervention involves the transmission of messages nationally or regionally through media channels such as television, radio or poster adverts, and is not specifically targeted at a particular smaller geographical area but is designed to reach larger audiences. Three mass media interventions were developed using wording and messaging targeted at

low socioeconomic groups and were therefore included in this review. These included two national 'Be Clear on Cancer' mass media interventions in England, one for lung cancer and the other for bowel cancer, and the West of Scotland Cancer Awareness Project, a regional mass media intervention for oral cancer in Scotland.

The Be Clear on Cancer campaigns were targeted at those over the age of 55 from a low socioeconomic group and utilised radio, television and poster adverts to increase awareness and promote earlier symptom presentation for lung and bowel cancer respectively. These interventions used GPs as part of their adverts in an attempt to overcome reported barriers associated with timely symptom presentation such as worry about bothering the GP. Push-pull methods were also used for both the Be Clear on Cancer campaigns to encourage individuals to go to the doctor with symptoms of cancer. The West of Scotland Cancer Awareness Project used radio, television, press, leaflets, mail drops and poster adverts to raise awareness of oral cancer symptoms and promote earlier symptom presentation for those aged 40-70 from a low socioeconomic group. The oral cancer intervention in Scotland adopted a testimonial approach using real cancer patients' stories to communicate intervention messages.

6.4.1.3 Educational interventions

Two educational interventions were included in this review: one intervention was a US based intervention with a focus on breast cancer (target symptoms not reported; Cardarelli *et al*, 2011), and the other was a UK based intervention with an oral cancer focus (target symptoms not reported; Scott *et al*, 2012b).

Educational interventions are designed to raise cancer awareness and encourage earlier symptom presentation in members of the public in a face-to-face setting, and delivered in a group or one-to-one. The US based intervention involved eight 1.5 hour group based educational sessions, where two sessions contained information designed to highlight the importance of early detection of breast cancer, the symptoms of breast cancer and encourage earlier presentation (Cardarelli *et al*, 2011). The remaining six sessions contained information about how to lead a healthy lifestyle, breast cancer prevention and screening, using breast cancer survivor stories to deliver intervention messages (Cardarelli *et al*, 2011). A UK based three arm randomised controlled trial (RCT) study evaluated a leaflet plus

intensive one-to-one educational intervention delivered by a trainee health psychologist compared with a leaflet only (Scott *et al*, 2012b). The one-to-one session lasted between five and ten minutes, and was designed to offer tailored information on how to spot the symptoms of oral cancer, a practical demonstration on how to perform mouth self-examination, and to address the barriers to early symptom presentation and encourage participants to seek medical help early in the event of symptoms (Scott *et al*, 2012b). The leaflet contained information on oral cancer symptoms and advice on when to seek medical help for symptoms (Scott *et al*, 2012b).

6.4.1.4 Health check interventions

Two Welsh based health check interventions were included in this review: the Tenovus health check and the 'Love Your Lungs' campaign. Health check interventions aim to identify symptomatic individuals and encourage them to seek medical help for their symptoms by signposting to the relevant HCP or providing individuals with a letter of referral. Health check interventions are often used as "teachable moments". Those who take part or are asymptomatic at the time of the health check are given information on what to look out for in the future and when to go to the doctor with symptoms.

The Love Your Lungs campaign advertised a free health check for members of public for three target symptoms of lung cancer (cough, wheeziness, breathlessness) (British Lung Foundation, 2014). For those who attended the health check event, individuals were assessed by a respiratory specialist to pick up symptoms, and a letter of referral was given to individuals who required further investigation to take to their GP (British Lung Foundation, 2014). Information leaflets were given to all individuals who attended the Love Your Lungs health check events (British Lung Foundation, 2014).

The Tenovus health check is a touch screen questionnaire, designed to identify any potential symptoms of common cancer (persistent cough, lump(s), skin changes, sore or ulcer which will not heal, change in bowel habit, blood in faeces, problems urinating, unexplained bleeding, difficulty swallowing, weight loss, unexplained tiredness, loss of appetite, bloating, pain) and prompt medical help seeking for symptomatic individuals (Smits *et al*, 2016). Advice is given in a tailored one-to-one results session with a trained health check advisor. The results session is also used a teachable moment to advise individuals to look out for

symptoms in future, offer advice on when to go to the doctor with symptoms and highlight the importance of early detection.

6.4.1.5 Roadshow

One UK based roadshow intervention was included in this review: the Cancer Research UK (CRUK) Cancer Awareness Roadshow (Smith *et al*, 2014). A roadshow intervention involves travel to specific communities to provide tailored cancer awareness information in an opportunistic setting. There are various formats of information and resources available at roadshow interventions such as leaflets and/or a nurse to answer specific queries and offer tailored advice, therefore no specific cancer type or symptoms were targeted in this intervention. The CRUK Cancer Awareness Roadshow is a mobile roadshow visiting deprived areas to offer tailored information on cancer awareness, promote the benefits of early diagnosis and encourage prompt cancer symptom presentation (Smith *et al*, 2014). A qualified nurse trained in cancer awareness and various leaflets were available for attendees (Smith *et al*, 2014).

6.4.2 Intervention evaluation

As shown in Table 6.1, fifteen of the 20 interventions included in this review were evaluated in relation to one or more of the following domains: (a) psychological/behavioural; (b) clinical; (c) reach; and (d) cost-effectiveness.

Six intervention evaluations employed both quasi-experimental and before and after study methodologies to assess intervention effectiveness. Before and after studies involve comparisons between outcome measures collected before the intervention to those during the intervention time period or after the intervention time period. Quasi-experimental methods comprise domain outcome data collections across multiple sites or communities, some of which were intervention target sites and received the intervention (intervention area) and other sites that were not targeted by the intervention and did not receive the intervention (control area). The control area(s) were often similar to the intervention area(s) on the basis of demographic characteristics of people living in the community and area level deprivation (Table 6.1).

Six intervention evaluations used before and after studies only. The time period of data collection varied according to intervention type and outcome measure. Clinical domain data were often collected yearly or monthly at various time points before, during and after the intervention using electronic records. Surveys were typically used to compare behavioural/psychological and reach domain data collected before and after the intervention. Time scales for data collection varied between immediately after the intervention up to one year post intervention (Table 6.1).

Two interventions used controlled methods to assess intervention effectiveness. One intervention used a two arm non-randomised design, collecting survey data at three time points (pre and post intervention, and eight week follow-up), and another intervention used a three-arm randomised controlled study (RCT) design collecting survey data from intervention and control groups at three time points (pre and post intervention, and one month follow-up). One intervention assessed intervention domain outcomes in a cross sectional survey study, conducted post intervention only. Participants were required to self-report perceptions of knowledge improvements following the intervention and symptom presentation behaviour (Table 6.1).

Four interventions did not report evaluation data and were all CBMSM interventions (East Sussex Downs and Weald PCT cancer awareness project; Early Presentation of Cancer Programme; Lowry *et al*, 2011; Painting Stroud Pink). The Tenovus health check intervention is currently undergoing evaluation, therefore evaluation data were not available at the time of reporting.

Intervention evaluation data analysed using statistical tests to assess whether the difference between time points, or control and intervention groups was statistically significant are reported where available. Where data were not analysed using statistical tests or significance levels not reported, percentage increases between time points, or control and intervention groups are reported.

6.4.2.1 Community based multi-faceted social marketing intervention (CBMSM)

Eight of the 12 CBMSM interventions reported evaluation data relating to the clinical (n=8), behavioural/psychological (n=4) and intervention reach (n=5) domains. CBMSM

interventions were evaluated using a combination of before and after and quasi-experimental studies (n=5) or before and after studies only (n=3).

(a) Clinical domain

Clinical outcomes data were available for all CBMSM interventions that included an evaluation.

Referral outcomes

Overall, a statistically significant increase in the number of two week wait (2WW) referrals for suspected cancer was observed for lung cancer (9%; $p < 0.01$) and bowel cancer (16%; $p < 0.01$) in the 60 local NAEDI project intervention areas pre to post intervention (Cancer Research UK, 2012). There were no clinical outcome data available for breast cancer. However, increases in 2WW referrals were also observed in the time periods pre to post local NAEDI project interventions in the control areas who did not receive the intervention for lung cancer (7%) and bowel cancer (13%). Increases in 2WW referrals reported in intervention areas compared to the control areas were therefore small and not statistically significant (Cancer Research UK, 2012).

The differences in referrals for each individual NAEDI local project intervention area in a before and after comparison study (data collected during intervention time period compared to the previous year) were extremely variable: 24 of the lung specific projects and 25 of the bowel specific interventions reported an increase in 2WW referrals, three lung specific and seven bowel specific interventions reported no change in referrals, and ten lung specific and one bowel specific interventions reported a reduction in the numbers of 2WW referrals in comparison to the previous year (Cancer Research UK, 2012).

The remaining CBMSM intervention evaluations reported increases in the numbers of 2WW referrals for suspected cancer, with the exception of breast cancer referrals for one intervention (Lyons *et al*, 2009). The Small "c" Campaign reported an increase in 2WW referrals for suspected lung and breast cancer of 44% and 22% respectively, pre to post campaign (Shankleman *et al*, conference poster). Time frames for the before and after study were not reported. The Improvement Foundation Healthy Communities Collaborative

reported statistically significant increases of 29.2% ($p < 0.01$) and 27.7% ($p < 0.001$) in 2WW referrals for lung and bowel cancers respectively in the first year of the intervention, in comparison to the same time period one year before the start of the intervention, (Lyon *et al*, 2009). The increase in breast cancer referrals was not statistically significant (Lyon *et al*, 2009). The 'Don't Be a Cancer Chancer' Campaign reported an increase of 51% in urgent referrals for suspected lung cancer during the intervention period in comparison to the previous year in a before and after study (Kane *et al*, 2009). The Early Presentation of Cancer Programme reported increases in 2WW referrals ranging from 25% to 67% across all targeted tumour sites in a before and after study (EPOC impact report, p.5).

The Early Lung Cancer Detection in Corby Project reported an increase of 63% during the intervention period in comparison to the previous year for chest x-rays performed following the intervention (Campbell *et al*, 2013). This was a statistically significant increase in comparison to control areas ($p < 0.001$). The Early Lung Cancer Intervention in Doncaster observed an increase of 27% in chest x-ray referrals from GP practices in the target areas at six weeks post intervention compared to the previous year (Athey *et al*, 2012; Suckling, 2008). This was a difference of 8% in comparison to control non-targeted practices area, which reported an increase of 19% referrals compared to the previous year, and represented a statistically significant increase in the number of chest x-rays ordered between intervention and control areas ($p < 0.001$) (Athey *et al*, 2012; Suckling, 2008). A statistically significant increase of 20% ($p < 0.001$) in chest x-ray referrals in comparison to the year before the Early Lung Cancer Intervention in Doncaster was maintained at one year post intervention (Athey *et al*, 2012; Suckling, 2008).

New cases of cancer

Findings for the number of new cancer diagnoses were variable for CBMSM interventions. The NAEDI local projects intervention reported overall non-significant increases of 4% and 6% respectively in the number of new lung and bowel cancer cases diagnosed respectively in the intervention areas during the intervention time period in comparison to the previous year across all of the 60 projects (Cancer Research UK, 2012). For each of the local NAEDI projects, the number of new cancers diagnosed per intervention area in comparison to clinical domain data from the previous year was variable: some projects reported an increase in new cancer diagnoses for both tumour sites (lung, $n=8$; bowel, $n=6$). Only one

project reported a statistically significant increase in new lung cancers diagnosed ($p < 0.001$), and there was no statistically significant increase at project level for new cases of bowel cancer diagnosed. Other local NAEDI projects reported no change in new cancer diagnoses (lung, $n=1$; bowel, $n=1$) and some intervention areas reported a reduction compared to the previous year (lung, $n=10$; bowel, $n=5$), of which two lung specific and one bowel specific projects reported a statistically significant decrease in new lung cancers diagnosed ($p < 0.05$) (Cancer Research UK, 2012). Individual area level data were unavailable for all of the 60 local projects (Cancer Research UK, 2012).

The Early Lung Cancer Intervention in Doncaster observed a statistically significant increase of 27% ($p < 0.001$) for new lung cancer diagnoses in comparison to the previous year (Athey *et al*, 2012; Suckling, 2008). The Improvement Foundation Healthy Communities Collaborative reported a statistically significant increase of 27.4% ($p < 0.05$) and 28% ($p < 0.01$) of new cancer diagnoses for bowel and lung cancer respectively after the first year of the campaign (Lyon *et al*, 2009). The 'Don't Be a Cancer Chancer' intervention reported forty new cases of lung cancer diagnosed during the intervention period in comparison to eight new lung cancer diagnoses in the same time period the following year (Kane *et al*, 2009). The Early Lung Cancer Detection in Corby Project reported two new cases of lung cancer detected through the walk in self-referral chest x-ray programme, both of which were advanced stage, representing 0.5% of the total number of individuals receiving walk in chest x-rays (Campbell *et al*, 2013).

Staging data

Most CBMSM interventions, such as The Early Lung Cancer Intervention in Doncaster (Athey *et al*, 2012; Suckling, 2008), reported no stage shift following the interventions. The Small "c" Campaign reported a 1% increase in the number of new lung cancers diagnosed at an early stage and a 4% decrease in the number of advanced stage breast cancer diagnoses before and after the intervention, although data collection time scales were not reported (Shankleman *et al*, conference poster). The Detect Cancer Early Programme reported a 6.5% increase in the third year of the campaign for the number of people diagnosed with Stage I breast, lung and bowel cancer in comparison to two years preceding the intervention (Information Services Division Scotland, 2015c), although it is unclear the extent to which these findings can be attributed to the patient component of the intervention.

(b) Psychological/behavioural domain

Psychological/behavioural domain outcome data were available for four CBMSM interventions.

Symptom presentation behaviour

The NAEDI local projects reported data for anticipated symptom presentation in before and after surveys involving various time scales, with little evidence of change (Cancer Research UK, 2012). Four NAEDI projects reported a statistically significant increase ($p < 0.01$) pre to post intervention in the number of participants reporting intentions to seek help within one week of noticing a symptom of lung, bowel or breast cancer (Cancer Research UK, 2012). Nineteen NAEDI local projects reported no change, and six projects reported a decrease in intentions to seek medical help for symptoms pre to post intervention, two of which reported statistically significant decreases ($p < 0.01$) (Cancer Research UK, 2012). The Early Lung Cancer Intervention in Doncaster reported a small significant 4% difference ($p < 0.01$) in intentions to visit the GP with lung cancer symptoms and a 12% non significant rise in the number of people from the intervention area reporting that they would request a chest x-ray from the GP pre intervention to 1 year post intervention (Athey *et al*, 2012; Suckling, 2008). Those in the intervention areas for The Early Lung Cancer Intervention in Doncaster were 1.97 times more likely to report intentions to visit the GP with lung cancer symptoms in comparison to the control areas in a post intervention survey study, which reached statistical significance ($p < 0.01$) (Athey *et al*, 2012; Suckling, 2008). The Early Presentation of Symptoms Collaborative reported an 11% increase in willingness to act on symptoms in the intervention areas pre to post intervention, although data collection time scales were not reported (EPOC impact report, p.5).

Symptom knowledge

For the NAEDI local projects, the percentage of respondents who correctly recalled symptoms of cancer was assessed. There was a small increase in cancer symptom knowledge (recognition) for lumps, bleeding and pain pre to post interventions, with an average project level increase of 1-2% symptoms correctly recognised following the NAEDI local projects (Cancer Research UK, 2012). The Small "c" Campaign reported an increase in recall and

recognition of breast cancer symptoms, but not lung cancer symptoms, in a survey study conducted three years before the intervention and one month after the intervention (Shankleman *et al*, conference poster). The Early Presentation of Symptoms Collaborative reported a 15% increase in confidence in the detection of early symptoms of cancer in the intervention areas pre to post intervention (time scales not reported; EPOC impact report, p5).

(c) Reach

Two CBMSM intervention evaluations explored intervention recall among the target group for whom the intervention was intended. Thirty nine percent of those surveyed in the target intervention areas could recall an aspect of the local NAEDI projects in their area (range 11-71% per project) (Cancer Research UK, 2012). However, socioeconomic group data were unavailable and it is unclear if those who completed the surveys were representative of a low socioeconomic group. The Early Lung Cancer Intervention in Doncaster reported that 21% of those who took part in the post intervention survey and lived in the target communities could recall an aspect of the intervention (Athey *et al*, 2012; Suckling, 2008).

The Small “c” Campaign evaluation reported that the intervention was effective at targeting those most at risk of lung cancer, however no further data were provided (Shankleman *et al*, conference poster). The Early Lung Cancer Detection in Corby project offered a free walk in chest x-ray and reported that 86% of those who attended were clinically eligible for chest x-ray, and 37% were current smokers (Campbell *et al*, 2013). One intervention evaluated clinical outcomes for the intervention target group. The ‘Don’t Be a Cancer Chancer’ campaign reported the largest rise in GP 2WW referral rates for suspected lung cancer for those in the most deprived areas compared to more affluent areas (Kane *et al*, 2009).

Summary of CBMSM interventions

Overall, clinical domain outcomes following CBMSM interventions appeared to be improved. There is evidence to suggest that CBMSM interventions were successful in increasing the number of 2WW referrals and new cases of cancer diagnosed, although staging data suggested that CBMSM interventions had little effect on the number of new cancers diagnosed at an earlier stage. There was mixed evidence for the effectiveness of CBMSM

interventions on psychological/behavioural domain outcomes. Trends towards more timely cancer symptom presentation behaviour were observed following CBMSM interventions. Some interventions reported small symptom knowledge improvements following intervention exposure, while others reported no change.

6.4.2.2 Mass media interventions

All three mass media interventions reported evaluation data for clinical (n=2), behavioural/psychological (n=3), intervention reach (n=3) and cost-effectiveness (n=2) outcome domains. The two national Be Clear on Cancer mass media interventions were evaluated using before and after methods. The West of Scotland cancer awareness project regional mass media intervention was evaluated using before and after/quasi-experimental methods, comparing intervention areas to control areas and data comparisons before and after the intervention time period.

(a) Clinical domain

Both the Be Clear on Cancer Campaigns for lung and bowel cancer were evaluated in terms of clinical domain outcomes.

Referral outcomes

Referrals via the 2WW pathway rose substantially by 59% ($p < 0.01$) during the Be Clear on Cancer bowel cancer campaign (Peacock *et al*, 2013) and 31.8% ($p < 0.001$) during the Be Clear on Cancer lung cancer campaign (Ironmonger *et al*, 2014) in comparison to two years before the campaign launch. The number of GP ordered chest x-rays increased by 18.6% ($p < 0.001$) during the lung campaign period compared to the previous year (Ironmonger *et al*, 2014).

New cases of cancer

The bowel campaign reported a non significant 2% reduction in the number of new colorectal cancers diagnosed following the intervention (Peacock *et al*, 2013), whereas the lung campaign reported a statistically significant 9.1% ($p < 0.001$) increase in the numbers of

new lung cancers diagnosed during the campaign period (Ironmonger *et al*, 2014) in comparison to the two years preceding the campaigns.

Stage shift

Following the lung campaign, there was a statistically significant increase of 3.1% ($p < 0.001$) for the number of individuals diagnosed with non-small cell lung cancer at Stage I and a statistically significant 3.5% decrease ($p < 0.001$) in the number of individuals diagnosed at Stage IV (Ironmonger *et al*, 2014) during the intervention period in comparison to the two years preceding the campaign. The number of surgical resections increased by 2.3% ($p < 0.001$) following the lung campaign compared to the pre-campaign time period (Ironmonger *et al*, 2014).

(b) Psychological/behavioural domain

Both the Be Clear on Cancer Campaigns for lung and bowel cancer were evaluated in terms of psychological/behavioural outcomes using the Cancer Awareness Measure (CAM; Stubbings *et al*, 2009) in before and after studies. The West of Scotland Cancer Awareness Project used a survey measure in a before and after/quasi-experimental study design over three time points (pre-intervention, seven and 12 months post intervention).

Symptom presentation behaviour

A statistically significant increase of 63% ($p < 0.001$) in the number of people presenting to the GP with a cough symptom was observed in the eight weeks during the Be Clear on Cancer lung campaign in comparison to GP read code data collected the previous year (Ironmonger *et al*, 2014). The West of Scotland Cancer Awareness Project mass media campaign reported that intentions to visit the GP with a symptom suspicious of oral cancer were highest among those in the intervention areas compared to control areas after the campaign, and were sustained at 12 month follow up among those in the intervention areas ($p < 0.001$) (Eadie *et al*, 2009).

Symptom knowledge

Public awareness for the symptoms targeted by both the Be Clear on Cancer Campaign interventions was improved after the respective intervention time period. Recall for a cough symptom rose by 11% ($p < 0.001$) and recognition of a cough symptom increased by 15% ($p < 0.001$) in the months following the lung campaign (Ironmonger *et al*, 2014) in comparison to survey data collected two years before the campaign. Recall and recognition for change in bladder/bowel habit increased by 20% ($p < 0.001$) and 4% ($p < 0.001$) respectively in a survey study in the months following the bowel campaign compared to survey data collected two years before the intervention (Power and Wardle, 2015). In the same study, non-significant increases of 2% and 3%, respectively, were observed for recall and recognition of unexplained bleeding after the bowel campaign (Power and Wardle, 2015).

The West of Scotland Cancer Awareness Project oral cancer campaign reported that awareness of ulcers and lumps was highest in the intervention areas seven months post intervention compared to control areas who did not receive the intervention (Eadie *et al*, 2009). However, improved symptom knowledge in the intervention areas was not sustained at 12 month follow up (Eadie *et al*, 2009).

Barriers to symptom presentation

No significant differences in the number of barriers endorsed by participants were observed in the survey studies conducted two years pre intervention and in the months following the respective Be Clear on Cancer bowel and lung cancer campaigns (Power and Wardle, 2015).

(c) Reach

Clinical and psychological/behavioural outcome data were evaluated in terms of reach for both Be Clear on Cancer Campaigns to examine their effects on cancer symptom knowledge, symptom presentation behaviour and referrals among the target group (over 55s from a low socioeconomic group) in before and after studies. For both interventions, knowledge for the symptoms targeted by the campaigns was slightly improved across all socioeconomic groups pre to post campaign (Power and Wardle, 2015; Moffat *et al*, 2015). However, the socioeconomic gradient for cancer symptom knowledge remained stable, where cancer

symptom knowledge decreases with increasing socioeconomic deprivation (Power and Wardle, 2015; Moffat *et al*, 2015). Therefore, although symptom knowledge overall improved, cancer symptom awareness remained poorest for those in low socioeconomic groups when compared to high socioeconomic groups post intervention.

In terms of clinical outcomes, analysis by socioeconomic group suggested that outcomes were most improved among high socioeconomic groups rather than low socioeconomic groups following the Be Clear on Cancer bowel campaign. There was evidence to suggest that secondary care services were accessed disproportionately by more affluent groups following the bowel campaign, even though the greatest increase in GP attendances for symptoms targeted by the intervention was observed among practices in the most deprived areas ($p < 0.001$) (Hall *et al*, 2015). In addition, although there was an overall increase of 59% for bowel cancer 2WW referrals during the bowel campaign, increases in the number of new bowel cancers diagnosed during or after the campaign were not observed (Hall *et al*, 2015; Peacock *et al*, 2013). Therefore the authors concluded that the “worried well” were more likely to present to the GP following the intervention (Peacock *et al*, 2013).

The greatest number of GP attendances for symptoms targeted by the Be Clear on Cancer lung campaign was reported in practices in the most affluent areas during the campaign time period ($p < 0.01$) (Moffat *et al*, 2015). Those from a low socioeconomic group were less likely than those from high socioeconomic groups to report recognising the Be Clear on Cancer lung ($p < 0.05$) and bowel ($p < 0.05$) adverts in a post intervention survey study (Moffat *et al*, 2015). The West of Scotland Cancer Awareness Project reported that awareness of the intervention was higher in the intervention areas compared to control areas, but further data on reach to low socioeconomic groups were not reported.

(d) Cost effectiveness

Two studies evaluated cost effectiveness for the Be Clear on Cancer bowel and lung interventions. Following the bowel cancer campaign, the cost per new cancer diagnosed rose from £7585.58 in the year before the intervention to £9662.72 during the intervention time period (Peacock *et al*, 2013). Mathematical modelling was used to assess cost-effectiveness of the lung campaign in terms of incremental cost-effectiveness ratios and costs per quality-adjusted life years (Hinde *et al*, 2015). An additional 178 quality-adjusted

life years were gained following the national campaign (Hinde *et al*, 2015). This was reported to represent an incremental cost-effectiveness ratio of £18,173 per quality-adjusted life year gained, which was below NICE's threshold for cost-effectiveness (Hinde *et al*, 2015).

Summary of mass media interventions

Clinical domain outcome data suggested that mass media interventions were successful at increasing the number of referrals for cancer via the 2WW pathway. However, improvements in the number of new cases of cancer diagnosed and a stage shift were only observed for lung rather than bowel cancer, although there was evidence to suggest that these outcomes were most improved among affluent groups. Psychological/behavioural domain outcome data suggested that mass media interventions prompted (or would prompt) cancer symptom presentation behaviour and increased awareness of the symptoms of cancer across all socioeconomic groups. However, there was limited evidence to suggest that knowledge improvements were sustained long term. There was evidence that mass media interventions were unsuccessful in terms of modifying barriers to cancer symptom presentation.

6.4.2.3 Educational interventions

Both educational interventions were evaluated using controlled methods to assess intervention effectiveness. The oral cancer intervention randomised participants into one of three arms (Scott *et al*, 2012b), and the breast cancer intervention allocated participants to one of two arms, but did not randomise (Cardarelli *et al*, 2011). Both educational interventions reported data for psychological/behavioural outcomes. Data were not available for clinical, reach or cost-effectiveness outcomes. This is likely to reflect group sizes which were too small to report population level clinical outcome data or cost-effectiveness. All individuals recruited into the educational interventions were selected based on predefined criteria for inclusion.

(a) Psychological/behavioural domain

Symptom presentation behaviour

In the three arm RCT for oral cancer, both intervention groups were significantly more likely to anticipate timely symptom presentation behaviour at one month follow-up compared to the control group ($p < 0.001$) (Scott *et al*, 2012b). There was no significant difference between intervention arms for anticipated symptom presentation behaviour post intervention (Scott *et al*, 2012b).

Symptom knowledge

Small but significant increases for cancer symptom knowledge of 0.72 points ($p < 0.01$) were observed for the intervention group following an intensive eight week group based breast cancer educational intervention compared to the control group (Cardarelli *et al*, 2014). In the three arm RCT, increased oral cancer knowledge was observed for both intervention arms in comparison to the control group at one month follow up ($p < 0.001$), although differences in symptom knowledge were not statistically significant for either intervention arm (Scott *et al*, 2012b).

Beliefs about cancer

A decrease in fearful and fatalistic beliefs about cancer was observed in both the intervention and control groups from baseline (before the first intervention session) to post intervention (after the final intervention session) ($p < 0.001$) (Cardarelli *et al*, 2011). Although awareness of the importance of early detection was measured, findings for this outcome were not reported (Cardarelli *et al*, 2011).

Summary of educational interventions

Psychological/behavioural domain outcome data suggested that educational interventions promoted more timely cancer symptom presentation behaviour, increased cancer symptom knowledge and reduced negative beliefs about cancer. There was evidence to suggest that both targeted and tailored interventions improved knowledge and behavioural outcomes.

6.4.2.4 Health check intervention

The 'Love Your Lungs' intervention health check reported data for psychological/behavioural outcome and reach domains in a cross sectional survey study conducted post intervention only (British Lung Foundation, 2014).

(a) Psychological/behavioural domain

The self-report survey given to participants after attending the 'Love Your Lungs' intervention included questions to evaluate perceptions of changes to cancer symptom knowledge and actual or anticipated cancer symptom presentation behaviour. Participants were asked to complete the survey immediately after attending the Love You Lungs health check or in a postal survey up to one month post intervention attendance (British Lung Foundation, 2014).

Symptom presentation behaviour

Eighty percent of those who attended the Love Your Lungs health check event agreed or strongly agreed that they would go to their GP with a symptom suggestive of lung cancer in the future (British Lung Foundation, 2014). Of the 463 individuals who attended the event and received the health check clinical examination, 133 (24%) were referred to their GP, of whom 22 reported going to their GP after the event with their referral letter (British Lung Foundation, 2014).

Symptom knowledge

Of those who attended the health check event, 62% agreed or strongly agreed that they knew more about the signs and symptoms of lung cancer than they did before the event (British Lung Foundation, 2014).

(b) Reach

Fifty-one percent of those who attended the free 'Love your Lungs' health check were non-smokers and 26% had previously worked in heavy industry. However, further socio-demographic characteristics were not reported, thus it is difficult to assess whether those who attended the event were representative of a low socioeconomic group.

6.4.2.5 Roadshow intervention

The CRUK roadshow reported evaluation data for psychological/behavioural domain outcomes and reach in a before and after study (Smith *et al*, 2016). A proportion of participants prior to attending the roadshow were selected by the roadshow staff to complete a pre-roadshow questionnaire survey (Smith *et al*, 2016). A different proportion of participants who attended the roadshow were asked to complete the same survey immediately after attending the roadshow (Smith *et al*, 2016).

(a) Behavioural/psychological domain

Symptom presentation behaviour

For those who disclosed a symptom of cancer to staff during the CRUK cancer awareness roadshow, 33.6% reported intentions to book an appointment with the GP after the roadshow to discuss the symptom (Smith *et al*, 2016).

Symptom knowledge

A small but statistically significant 0.3 point increase ($p < 0.001$) in cancer symptom knowledge (recognition) was reported pre to post roadshow intervention (Smith *et al*, 2016).

Barriers to cancer symptom presentation

Reductions in the number of barriers to symptom presentation endorsed were observed pre to post roadshow intervention (Smith *et al*, 2016). Those who completed the questionnaire after the roadshow were less likely to be worried about what the doctor might find

($p < 0.001$), less worried about wasting the doctor's time ($p < 0.001$), and more confident in reporting symptoms to the doctor ($p < 0.05$) (Smith *et al*, 2016).

(b) Reach

The authors concluded that the roadshow was attended by people from a low socioeconomic group (Smith *et al*, 2016). Employment status and home ownership data were reported; however, almost half of respondents owned their own house and were employed. Employment type was not reported, therefore it is unclear whether the sample was truly representative of a low socioeconomic group.

Roadshow intervention summary

Behavioural/psychological domain data suggested that the roadshow intervention prompted cancer symptom presentation behaviour and reduced perceived barriers to cancer symptom presentation. However, small increases in symptom knowledge were observed and reach data suggested that the roadshow intervention may not have engaged those truly representative of a low socioeconomic group.

6.4.2.6 Lung cancer interventions

Of the 20 interventions identified in the scoping review, 13 interventions included lung cancer information. Five interventions focused specifically on lung cancer and were of various types: CBMSM intervention ($n=3$); mass media intervention ($n=1$); health check intervention ($n=1$). Eight multiple cancer interventions included a lung cancer component, mostly targeting persistent cough symptom. Seven were CBMSM interventions, and one was a health check intervention. Of the 13 lung cancer interventions, ten included an intervention evaluation and reported outcomes for clinical ($n=7$), psychological/behavioural ($n=5$), reach ($n=3$) and cost effectiveness ($n=1$) domains. Lung specific findings relevant to each domain are summarised below.

(a) Clinical domain

Both mass media and CBMSM interventions were associated with improved referrals via the 2WW pathway for suspected lung cancer (Cancer Research UK, 2014; Shankleman *et al*, conference poster; Lyon *et al*, 2009; Kane *et al*, 2009) and increases in the number of GP ordered chest X-rays (Campbell *et al*, 2013; Athey *et al*, 2012; Suckling, 2014; Ironmonger *et al*, 2014). Increases in the number of new cases of lung cancer diagnosed were observed following both mass media and CBMSM interventions (Cancer Research UK, 2014; Athey *et al*, 2012; Suckling, 2014; Lyon *et al*, 2009; Ironmonger *et al*, 2014), where a higher percentage of new lung cancer cases was reported following CBMSM interventions (Athey *et al*, 2012; Suckling, 2014; Lyon *et al*, 2009; Cancer Research UK, 2014). Both intervention types reported small improvements for staging data, where a stage shift towards earlier stage lung cancer was observed following mass media and CBMSM interventions (Shankleman *et al*, conference poster; Information Services Division Scotland, 2015c; Ironmonger *et al*, 2014) and an increase in the number of surgical resections was reported following a mass media intervention (Ironmonger *et al*, 2014).

(b) Behavioural/psychological domain

Improvements in lung cancer symptom knowledge were observed for both recalled and recognised symptoms following a mass media intervention (Ironmonger *et al*, 2014), and there were reports of lung symptom knowledge improvements after attending a Love Your Lungs health check intervention (British Lung Foundation, 2014). Lung symptom awareness remained stable post CBMSM intervention (Shankleman *et al*, conference poster). CBMSM and health check interventions reported more timely anticipated presentation for lung symptoms post intervention (Athey *et al*, 2012; Suckling, 2008; Cancer Research UK, 2014; British Lung Foundation, 2014), and a large 63% increase in the number of individuals presenting to the GP with the targeted symptoms was observed during a mass media intervention (Ironmonger *et al*, 2014).

(c) Reach

There was evidence to suggest that a lung cancer mass media intervention was most successful for improving clinical outcomes for high socioeconomic groups rather than low

socioeconomic groups, and that people from low socioeconomic groups were the least likely to recall an aspect of the intervention (Moffat *et al*, 2015). Reach data from a CBMSM intervention suggested that this method of intervention was successful for prompting lung cancer symptom presentation behaviour among low socioeconomic groups (Kane *et al*, 2009).

(d) Cost-effectiveness

There was evidence to suggest that the mass media lung intervention was cost-effective in accordance with NICE threshold for incremental cost ratios and costs per quality-adjusted life years (Hinde *et al*, 2015).

Table 6.1 Table of included interventions

Name of intervention	Country (city)	Cancer type (target symptoms)	Intervention type Target group; delivery (method(s) of delivery, duration of intervention, cost); content (information included); HCPs .	Evaluation Study design; data collection methods (prospective/cross sectional, questionnaire, interviews); outcome measures used (psychological/behavioural, clinical, reach); participants (sample size, age, gender, socioeconomic group); Cost –effectiveness	Key findings Psychological/behavioural (symptom knowledge, actual or hypothetical symptom presentation); clinical (2WW referrals, number of new cancers detected, staging data; cost per new cancer diagnosis; surgical resection rate specific to lung cancer); reach (target group seen intervention; outcomes improved for target group)
Be Clear on Cancer Bowel Campaign	England (national campaign)	Bowel (blood in poo, looser poo)	<p>National mass media intervention.</p> <p>Target group: Individuals over the age of 55 from low socioeconomic groups.</p> <p>Delivery: Radio and TV adverts, posters, branded symptom cards, leaflets and referral cards, door drops. Used push-pull methods. Initial campaign ran for 8 weeks between February 2012 and March 2012. Reminder campaign between August 2012 and September 2012.</p> <p>Content: Information about the symptoms of bowel cancer and when to go to the doctor with symptoms to promote earlier symptom presentation. Included wording designed to overcome barriers to symptom presentation.</p> <p>HCPs: Helped primary and secondary care physicians to prepare for increased presentations.</p>	<p>Before and after study</p> <p>Psychological/behavioural: Participants given the CAM as part of the ONS survey in 2010 (pre campaign) and in 2012 (post campaign) [1]: <i>Symptom knowledge:</i> Recall and recognition (one question on change in bladder/bowel habit, one question on non-specific unexplained bleeding) [1]. Recall and recognition (two questions) [4]. <i>Barriers:</i> Ten questions for barriers to symptom presentation [1]</p> <p>Clinical data: <i>Referral data:</i> 2WW referrals 3 months pre and 3 months post campaign [2]. <i>New cases of cancer diagnosed:</i> Numbers of new cancer diagnoses 3 months before and 3 months post the campaign [2].</p> <p>Reach: Collected occupation and educational attainment in CAM survey study [1]. Door-to-door survey with a population representative sample of over 55's pre and post campaign using the Bowel CAM [4]. GP read codes from a sample of GP practices to examine the number of attendances for target symptoms [4]- collected socioeconomic group data (ABC1 or C2DE) for CAM and GP read codes [4]. 2WW referral data analysed according to socioeconomic group data- 3 months pre campaign, 3 months post the first campaign then 8 months after the reminder campaign [3].</p>	<p>Psychological/behavioural: <i>Symptom knowledge:</i> Recall and recognition increased for change in bowel/bladder habit pre to post campaign (recall: 21% pre-41% post, $p<0.001$; recognition: 87% pre-91% post, $p<0.001$). NS increase in recall and recognition for unexplained bleeding pre to post campaign (recall: 31% pre-33% post; recognition: 84% pre-87% post) [1]. Recall increased pre to post campaign for blood in stools (27% pre-42% post, $p<0.001$) and looser stools (10% pre-23% post, $p<0.001$) [4]. NS difference pre to post campaign for recognition of blood in stools, significant increase for recognition of looser stools from 17% pre-27% post campaign ($p<0.001$) [4]. <i>Barriers:</i> NS difference between targeted barriers pre to post campaign [1].</p> <p>Clinical: <i>Referral data:</i> An increase of 59% for 2WW referrals observed pre to post campaign ($p<0.01$)* [2]. <i>New cases of cancer diagnosed:</i> NS increase in the number of new bowel cancers diagnosed pre to post campaign [2].</p> <p>Reach: Low socioeconomic groups were less likely to report having seen the campaign adverts (47% for ABC1 vs 54% for C2DE; $p<0.05$) [4]. Symptom knowledge increased across all socioeconomic groups; however NS difference between groups [1,4]. Highest increase in the number of GP attendances with symptoms observed for GP practices in the most deprived quintile (72% vs 18%, $p<0.001$) [4]. However; secondary care services were accessed disproportionately by high socioeconomic groups with no increase in referrals among low socioeconomic groups [3].</p>

				<p>Cost-effectiveness: Performed a cost analysis for cost per new cancer diagnosed pre to post campaign [2].</p>	<p>Cost-effectiveness: The cost per new cancer diagnosed rose from £7585.58 to £9662.72 pre to post campaign [2].</p>
<p>Be Clear on Cancer Lung Campaign</p>	<p>England (national campaign)</p>	<p>Lung (cough for 3 weeks or more)</p>	<p>National mass media intervention</p> <p>Target group: Individuals over the age of 55 from low socioeconomic groups.</p> <p>Delivery: Radio and TV adverts, posters, branded symptom cards, leaflets and referral cards, door drops. Used push-pull methods. Ran for 8 weeks between May 2012 and June 2012</p> <p>Content: Information about the symptoms of lung cancer and when to go to the doctor with symptoms to promote earlier symptom presentation. Included wording designed to overcome barriers to symptom presentation. No mention of smoking.</p> <p>HCPs: Helped primary and secondary care physicians to prepare for increased presentations.</p>	<p>Before and after study</p> <p>Psychological/behavioural: <i>Symptom presentation:</i> GP read codes collected for target symptoms over the 8 weeks of the campaign compared to the previous year, no demographic data collected [5]. Participants given the CAM as part of the ONS survey in 2010 (pre campaign) and in 2012 (post campaign) [1]. A population sample of over 55's given the Lung CAM before and after the intervention [5]. Door-to-door survey with a population representative sample of over 55's pre and post intervention using the Lung CAM [4]: <i>Symptom knowledge:</i> Recall and recognition. CAM included one question on cough/hoarseness, one question on non-specific unexplained bleeding <i>Barriers:</i> 10 questions in CAM for barriers to symptom presentation</p> <p>Clinical: <i>Referral data:</i> Number of 2WW referrals to secondary care collected monthly from January 2010 to November 2012 [5]. The number of GP ordered CXRs and CT scans performed were collected from the intervention period and compared to the previous year [5]. <i>New cases of cancer:</i> The numbers of new diagnoses of lung cancer were collected in the 2 years preceding the campaign and the campaign period [5]. <i>Staging data:</i> Staging data and one year survival data were collected in the 2 years preceding the campaign and the campaign period [5].</p> <p>Reach: Collected occupation and educational attainment [4]. Collected socioeconomic group data (ABC1 or C2DE) [4]. GP read codes used to examine the number of attendances for target symptoms-collected socioeconomic group data by postcode [4].</p> <p>Cost-effectiveness: Mathematical modelling for cost-effectiveness ratio to costs per quality-adjusted life years [6].</p>	<p>Psychological/behavioural: <i>Symptom presentation</i> A statistically significant increase of 63% ($p<0.001$) for patients visiting their GP with a cough symptom was observed pre to post campaign [5]. <i>Symptom knowledge:</i> Recall of cough as a symptom of lung cancer increased pre to post campaign (54-64%, $p<0.001$), NS increase for recall of prolonged/persistent cough (12-15%), significant increase of recognition of prolonged/persistent cough (18-33%, $p<0.001$) [5]. Recall and recognition of cough/hoarseness increased pre to post campaign (recall: 18-26%, $p<0.001$; recognition: 67-78%, $p<0.001$) [1]. NS increase recall and recognition for unexplained bleeding pre to post campaign (recall: 31-33%; recognition: 84-87%) [1]. Recall of cough/hoarseness increase 41-50% pre to post campaign, recognition NS [4]. <i>Barriers:</i> NS difference between targeted barriers pre to post campaign [1].</p> <p>Clinical: <i>Referral data:</i> Number of 2WW referrals increased by 31.8% ($p<0.001$), GP ordered CXR referrals increased by 18.6% ($p<0.001$) and GP ordered CT scans increased by 15.7% pre to post campaign ($p<0.001$) [5]. <i>New cases of cancer:</i> Number of new lung cancers diagnosed increased by 9.1% ($p<0.001$) following the campaign. <i>Staging data:</i> A stage shift was observed where there was an increase of 3.1% ($p<0.001$) for the number of patients diagnosed with non-small cell lung cancer at stage one and a 3.5% decrease ($p<0.001$) in the number of patients diagnosed at stage four [5]. Number of surgical resections was increased by 2.3% ($p<0.001$) after the campaign [5].</p> <p>Reach: People from low socioeconomic groups were less likely to report having seen the campaign adverts (43% for ABC1 vs 49% for C2DE; $p<0.05$) [4]. Symptom knowledge increased across all socioeconomic groups; however NS difference between groups, therefore knowledge remained lowest among low socioeconomic groups [1,4]. Highest increase in GP attendances observed in the most affluent GP practice areas (67% vs 48%, $p<0.01$) [4].</p>

					Cost-effectiveness: An additional 178 quality-adjusted life years were gained following the national campaign [6]. This represents an incremental cost-effectiveness ratio of £18,173 per quality-adjusted life year gained [6].
Cancer Research UK Cancer Awareness Roadshow	England (Midlands, Northwest, Northeast England)	Common cancers (no specific symptoms)	<p>Roadshow</p> <p>Target group: Members of public in deprived areas.</p> <p>Delivery: Mobile roadshow which visits deprived areas. Qualified nurse trained in cancer awareness available at the roadshow to answer questions and offer individual tailored advice. Various leaflets available and given to members of the public attending the roadshow. Ongoing (since 2006).</p> <p>Content: Information about cancer including: cancer symptoms, cancer prevention, cancer screening and the benefits of early diagnosis. Designed to increase access to health services and prompt or encourage cancer symptom presentation, and reduce barriers to symptom presentation.</p>	<p>Before and after study</p> <p>Psychological/behavioural: Some participants approached prior to roadshow and asked to complete CAM, others approached immediately after the roadshow and asked to complete CAM [7].</p> <p><i>Symptom presentation:</i> Intentions to seek medical help for those who reported symptoms [7]</p> <p><i>Symptom knowledge:</i> Recall and recognition [7]</p> <p><i>Barriers:</i> Four barriers to cancer symptom presentation assessed [7]</p> <p>Reach: Demographics of those attending the roadshow (occupation) [7]</p>	<p>Psychological/behavioural:</p> <p><i>Symptom presentation:</i> 33.3% of those in the post roadshow questionnaire who disclosed a symptom intended to book an appointment with the GP to discuss the symptom**[7].</p> <p><i>Symptom knowledge:</i> The post roadshow group recognised 0.3 more symptoms than the pre-roadshow group ($p<0.001$; $\eta^2=0.014$) [7].</p> <p><i>Barriers:</i> Small improvements for barriers to symptom presentation observed between groups: the post roadshow group were less worried about wasting the doctors time (20.4% vs 23.1%; OR=1.66, 95% CI=1.28-2.14, $p<0.001$), were more confident in reporting symptoms (12.6% vs 17.9%; OR=1.54, 95% CI=1.10-2.15, $p<0.05$) and were less worried about what doctor might find (27.8% vs 38.1%; OR0.60, 95% CI, 0.47-0.87, $p<0.001$) [7].</p> <p>Reach: It was reported that the roadshow was well represented by low socioeconomic groups as assessed by occupation, however the majority of attendees were in employment and there is no data available for employment type [7]</p>
Cardarelli et al, 2011 [8]	US (Dallas)	Breast (target symptoms NR)	<p>Educational intervention</p> <p>Target group: African-American women from low income areas aged 40 and over. A lay health educator within the community was trained to help with recruitment.</p> <p>Delivery: Eight interactive sessions, each 1.5h long over 8 weeks. Group based educational sessions. The intervention group was compared to the control group who received written breast health information.</p> <p>Content: Information about breast cancer prevention, the importance of early</p>	<p>Two arm non-randomised trial</p> <p>Psychological/behavioural: Questionnaire data were collected at baseline (at the start of the first intervention session) and post intervention (week 8 of the intervention- the final session) from 59 women in the intervention arm and 60 women in the control arm [8].</p> <p><i>Symptom knowledge:</i> It is reported that data for breast cancer knowledge were collected. No further information [8].</p> <p><i>Beliefs:</i> It is reported that data for attitudes towards breast cancer were collected. No further information [8].</p>	<p>Psychological/behavioural:</p> <p><i>Symptom knowledge:</i> A significant 0.72 point increase ($p<0.01$)* in breast cancer knowledge was observed in the intervention group compared to the control group [8].</p> <p><i>Beliefs:</i> Decreases in fearful and fatalistic beliefs observed across both control and intervention groups between baseline and follow up ($p<0.001$)* [8].</p>

			<p>detection, and breast screening. Two sessions included information about symptoms and the importance of early detection. Breast cancer survival testimonies were used throughout the intervention to deliver intervention messages.</p>		
<p>Detect Cancer Early Programme</p>	<p>Scotland</p>	<p>Lung, breast and bowel (target symptoms NR)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Designed to target the 'unworried well' living in deprived communities.</p> <p>Delivery: Advertising (no further information), health stalls in shopping centres, pubs, bookies. Empowerment intervention ran between February 2012 and March 2012. Tumour specific interventions for completed December 2015.</p> <p>Content: Information designed to raise awareness of the benefits of earlier diagnosis of cancer, to tackle fear associated with going to the doctor, and prompt symptom presentation. The intervention used real stories from local people with cancer to communicate intervention messages. Key message: 'The earlier the better'.</p> <p>HCPs: GP's reminded of the guidelines for referral of suspected cancer. Diagnostic services in secondary care were helped to prepare for increased case load and to ensure there was sufficient capacity to provide patients with appropriate testing.</p>	<p>Before and after study</p> <p>Clinical: <i>Staging data:</i> Collected at baseline (2010 and 2011) compared to the third year of intervention (2013 and 2014) [9].</p>	<p>Clinical: <i>Staging data:</i> An increase of 6.5% for the number of people diagnosed at stage 1 for breast, lung and bowel cancer combined in year three of the intervention compared to baseline was observed** [9].</p>

<p>'Don't Be a Cancer Chancer' Campaign</p>	<p>England (Manchester)</p>	<p>Lung (target symptoms NR)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Members of public living in deprived areas.</p> <p>Delivery: Intervention materials advertised on billboards, local press, and football matches. Leaflets and stationary with intervention messages were distributed within the community in local venues such as community centres and hairdressers. Local events including an event at a football club, road show at local supermarkets and markets across the area to create noise. Key intervention message: "Catching it early could save your life". Ran January to June 2007 and again March to April 2009.</p> <p>Content: Information about the symptoms of lung cancer and information about when to go to the doctor to encourage earlier presentation of symptoms.</p>	<p>Before and after study</p> <p>Clinical: <i>Referral data:</i> The number of non-urgent and urgent 2WW referrals 1 year before the intervention, during the intervention and one year post intervention [10] <i>New cases of cancer:</i> The number of new lung cancers diagnosed 1 year before the intervention, during the intervention and one year post intervention [10]</p> <p>Reach: The number of 2WW referrals by socioeconomic group (area level- GP practice in deprived/affluent area) [10]</p>	<p>Clinical: <i>Referral data:</i> An increase in the number of non-urgent and 2WW referrals for lung cancer was observed during the intervention period compared to the previous year (non-urgent: 18.7% increase; 2WW: 51% increase)** [10] <i>New cases of cancer:</i> During the campaign, 40 new lung cancers were diagnosed, 8 new cases of lung cancer were diagnosed in the year after the intervention** [10]. Data not available for previous year</p> <p>Reach: Largest increase in 2WW referrals observed for those living in the most deprived areas [10].</p>
<p>The Early Lung Cancer Detection in Corby Project</p>	<p>England (Corby)</p>	<p>Lung (non-specific)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Over 50's from low socioeconomic groups with a cough lasting more than 3 weeks.</p> <p>Delivery: Intervention materials advertised on bus routes, beer mats, flyers, posters and pharmacy bags. Media events, outreach events used to deliver intervention messages. A walk-in chest x-ray (CXR) self-referral programme was available. Community health educators were trained to deliver intervention messages. Ran over a 2 month period (dates NR).</p>	<p>Before and after study/quasi-experimental methods</p> <p>Psychological/behavioural: Number of people attending the self-referral facility for CXR [11].</p> <p>Clinical: Comparison of intervention area to control area. Clinical data obtained from cancer registries and radiography services (1 year pre intervention and during intervention period) for: <i>Referrals:</i> The number of CXRs performed [11]. <i>New cases of cancer:</i> The number of new cases of lung cancer diagnosed [11].</p> <p>Reach: Demographics of the individuals attending the walk in CXR facility [11].</p>	<p>Psychological/behavioural: An initial large uptake of self-referred CXRs was observed when intervention was launched [11]. In total, 407 men and women attended the CXR walk in clinic [11]</p> <p>Clinical: <i>Referrals:</i> Number of CXRs performed increased in the intervention area by 63% in comparison to the year prior to the intervention (21% increase in the control area). Difference between intervention and control area was statistically significant ($\chi^2=212.94$, $p<0.001$) [11] <i>New cases of cancer:</i> Two new cases of lung cancer were diagnosed at walk in CXR clinic (both advanced stage) in intervention area (0.5% of x-rays taken, NS) [11]</p> <p>Reach: 86% of people attending the walk in CXR clinic were clinically eligible for CXR, mean age 64.7 and 37% were current smokers [11].</p>

			<p>Content: Information about the symptoms of lung cancer and messages designed to change fatalistic beliefs about cancer. Information encouraging target group to attend self-referral for CXR.</p>		
<p>Early Lung Cancer Intervention in Doncaster</p>	<p>England (Doncaster)</p>	<p>Lung (cough for 3 weeks or more)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Men over 50 who were current or ex smokers who worked in heavy industry and who live in communities in the most disadvantaged areas (C2DE). Six intervention communities identified by geo-demographic profiling software.</p> <p>Delivery: Intervention materials delivered through local press and radio advertising, adverts on beer mats, pharmacy bags and billboards. Coughing bus stops in target areas. Face-to-face events in the target areas. Ran over a 6 week period from March 2008.</p> <p>Content: Cancer was not specifically mentioned in the campaign. The intervention materials prompted those with a cough for 3 or more weeks should visit their GP and request a CXR. No smoking references were made.</p> <p>HCPs: Brief educational intervention for HCPs to help them prepare for increased referrals</p>	<p>Before and after/ quasi-experimental study</p> <p>Psychological/behavioural: Six intervention areas compared to 1 control area. <i>Symptom presentation:</i> Questionnaire data collected by telephone at baseline and 12 months post intervention to assess interventions to visit the GP with a cough symptom to request a CXR [12, 13]. Participants at baseline: 801 men and women over 50. Current smoker (18%), past smoker (51.5%), never smoked (30.5%). All low SES (group C2, D or E). 76% response rate. Participants post intervention: 800 men and women over 50. Current smoker (16.75%), past smoker (53.75%), never smoked (29.5%). All low SES (group C2, D or E). 76% response rate [12, 13].</p> <p>Clinical: Six intervention areas compared to 1 control area. <i>Referrals:</i> The number of CXR referrals 1 year before and after the intervention [12, 13] <i>New cases of cancer:</i> Number of new cases of lung cancer diagnosed 6 weeks before and 6 weeks after intervention [12, 13] <i>Stage shift:</i> Collected 3, 6 and 12 months after the intervention [12, 13]</p> <p>Reach: Number of individuals from intervention communities who could recall an aspect of the intervention [12, 13]</p>	<p>Psychological/behavioural: <i>Symptom presentation:</i> A small difference for intentions to visit GP between the intervention and control area was observed (intervention area 1.97 times more likely to report intentions to visit GP with a cough symptom compared to control area; 95% CI 1.18-3.31, p<0.01) [12, 13]. An increase of 4% pre to post intervention in the intervention area was reported those who would go to the doctor with a cough symptom and a 12% rise for the number of individuals who would request a CXR from their GP** [12, 13]</p> <p>Clinical: <i>Referrals:</i> A 27% increase in CXR referrals was observed pre to post intervention in the target areas (19% increase in the control areas)*. A 20% increase in CXR referrals was maintained 1 year post intervention in the intervention areas (a 2% fall in the control areas). There was a statistically significant increase in the number of CXR referrals over time between intervention and control areas (IRR 1.22 (95% CI 1.12-1.33, p<0.001) [12, 13]. <i>New cases of cancer:</i> An increase of 27% new cases of lung cancer diagnoses was reported pre to post intervention in the target areas. A 10% fall in the number of new cases of lung cancer was observed in control practices. Comparison of change in diagnosis rates between intervention and control areas over time was NS (IRR 1.42 (95% CI 1.83-2.43, p=0.119) [12, 13]. <i>Stage shift:</i> NS stage shifts (3m, 6m or 1 year), but increases in case loads were observed at all stages compared to the previous year [12, 13].</p> <p>Reach: 21% of those living in the target communities could recall an aspect of the intervention [12, 13].</p>

<p>East Sussex Downs and Weald PCT cancer awareness project</p>	<p>England (East Sussex Downs and Weald)</p>	<p>Prostate, lung, bowel (target symptoms NR)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Men over the age of 45 who were manual/routine workers, living in deprived areas.</p> <p>Delivery: Intervention messages delivered on posters, leaflets and toilet stickers. Intervention messages emailed to local workplaces. Health champions (members of the community) were recruited through focus groups and at work places. These tended to be key people in the community e.g. football coaches, pub landlords etc. and were trained to deliver cancer awareness sessions in the community and provide members of public with intervention information. Ran from April 2010- June 2010.</p> <p>Content: Information about the symptoms of bowel, lung and prostate cancer with clear messaging on when to go to the GP with symptoms and information designed to reduce the barriers to symptom presentation.</p> <p>HCPs: An adapted version of the cancer awareness training given to members of public was delivered to local GPs</p>	<p>No evaluation reported</p>	
<p>The Early Presentation of Cancer Symptoms Collaborative Programme</p>	<p>England (NHS North East Lincolnshire)</p>	<p>Core tumour sites: Bowel, Prostate, Gynaecological cancers, Lung. Temporary tumour sites:</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: People living in deprived communities.</p> <p>Delivery: Volunteers (cancer champions) from the community were recruited to deliver brief interventions opportunistically with members of the community (cancer champions received a 2 day brief intervention training). Leaflets</p>	<p>Before and after/quasi-experimental study</p> <p>Psychological/behavioural: Used the CAM in 2010 with members of public in the intervention area and control areas. Also conducted a post intervention study using the CAM. Time scale not reported: <i>Symptom presentation:</i> Willingness to act on symptoms (anticipated symptom presentation behaviour) [14] <i>Symptom knowledge:</i> Recall and recognition measured by CAM [14]</p> <p>Clinical:</p>	<p>Psychological/behavioural: <i>Symptom presentation:</i> Those in the intervention areas were more proactive in terms of seeking medical help for symptoms than those in the control areas (no further data reported) [14]. 11% increase in willingness to act up on cancer symptoms pre to post intervention**[14]. <i>Symptom knowledge:</i> Those in the intervention areas were more aware of the symptoms of cancer (no further data reported). 15% increase in confidence to identify early cancer symptoms pre to post intervention** [14]</p> <p>Clinical:</p>

		<p>Throat and Upper GI. (target symptoms NR)</p>	<p>and posters were available with intervention messaging from community venues such as pubs and community centres. Ongoing (started in 2007). Grant awarded to the programme: £50,000.</p> <p>Content: Intervention materials and cancer champions were used to tackle taboo around cancer in the community to help people talk more about cancer, provide information for the symptoms of cancer and encourage individuals to seek medical help quickly with symptoms.</p>	<p><i>Referrals:</i> 2WW referral data for gynaecological, bowel, prostate and lung cancer was reported at baseline (3 years preceding intervention) and during the intervention (reported monthly) [14]</p>	<p><i>Referrals:</i> A substantial increase in 2WW referrals for gynaecological, bowel, prostate and lung cancer was reported (between 25 and 67% increase in 2WW referrals) **[14].</p>
<p>Early presentation of Cancer Programme</p>	<p>England (Lincolnshire)</p>	<p>Breast, bowel, cervical, prostate and lung (target symptoms NR)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: People living in deprived communities</p> <p>Delivery: Full time paid development workers and trained lay volunteers recruited to communicate intervention messages and encourage people in the community to go to the doctor with symptoms (volunteers received a 10 hour accredited training course). Leaflets and posters in community venues e.g. workplaces, pubs. Included intervention messages and were replenished by lay volunteers. Some communities hosted cancer stalls at local markets, events at local community venues such as libraries or hairdressers; other communities ran awareness sessions. Symptom check lists given to members of the community to take to the doctors. Ran from 2009-2014.</p> <p>Content: Information about the symptoms of cancer and when to go to the doctor with symptoms to prompt more timely cancer symptom presentation. Messaging to reduce negative beliefs about cancer and to</p>	<p>No evaluation findings. It is reported that cancer awareness questionnaires were carried out at baseline and 6 month follow up. Contacted but no reply.</p>	

			<p>reduce stigma associated with cancer.</p> <p>HCPs: Worked with GPs to raise awareness of the symptoms of cancer and to increase the use of 2WW referrals.</p>		
<p>The Improvement Foundation Health Communities Collaborative Programme</p>	<p>England (20 Primary Care Trusts in 60 specific communities)</p>	<p>Lung, Breast, Bowel (target symptoms NR)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: People living in one of 60 deprived communities in England</p> <p>Delivery: Community nurses recruited to deliver locally tailored programmes in the area. Mode of delivery varied per area, examples include: symptom awareness games, face-to-face events in community centres, pubs, bingo halls. Posters in GP surgeries to encourage people to talk about symptom concerns. Ran from April 2002 to February 2010</p> <p>Content: Information designed to increase cancer symptom knowledge, information on when to seek medical help for symptoms, the benefits of early diagnosis and information to modify negative beliefs about cancer</p> <p>HCPs: Work with GP's to improve earlier diagnosis and increase referrals to secondary care</p>	<p>Before and after study</p> <p>Clinical: <i>Referrals:</i> Baseline (12 months before intervention) and 1 year into the intervention GP 2WW referrals to secondary care [15]. <i>New cancers diagnosed:</i> Number of new cases of cancer collected at baseline (12 months before intervention) and 1 year into the intervention [15].</p>	<p>Clinical: <i>Referrals:</i> A significant increase of 2WW referrals for bowel (27.7%; $\chi^2=22.193$, $df=1$, $p<0.001$) and lung (29.2%; $\chi^2=8.886$, $df=1$, $p<0.01$) cancer from baseline to during the intervention. A NS 7.3% increase for 2WW referrals for breast cancer [15]. <i>New cancers diagnosed:</i> The number of new cancers diagnosed increased significantly from baseline to during the intervention for bowel (27.4%; $\chi^2=4.687$, $df=1$, $p<0.05$) and lung (28%; $\chi^2=9.178$, $df=1$, $p<0.01$) cancer. A NS 3.5% increase for new breast cancers diagnosed [15].</p>
<p>Love your Lungs campaign</p>	<p>Wales (South Wales)</p>	<p>Lung (cough, wheeziness, breathlessness)</p>	<p>Health check</p> <p>Target group: Areas where incidence was highest for lung cancer, mainly areas of deprivation.</p> <p>Delivery: Three events offering a free lung health check to members of the public (spirometry test) by local respiratory HCPs. Event advertised through local GP practices and pharmacies in the target areas on flyers and posters and local press</p>	<p>Post intervention questionnaire</p> <p>Psychological/behavioural: Individuals who received a free health check were sent an evaluation form in the post (23% response rate); <i>Symptom presentation:</i> Self-report if they had been to the GP with their referral letter [16] <i>Symptom knowledge:</i> Self-report if they believed their knowledge of cancer symptoms had improved after attending the health check [16]</p> <p>Reach: Health check attendee demographics collected</p>	<p>Psychological/behavioural: <i>Symptom presentation:</i> 85% of those who returned the questionnaire and received a referral letter had been to see their GP [16] <i>Symptom knowledge:</i> 60% of those who were screened agreed or strongly agreed they knew more about lung cancer following the intervention**[16]. 62% of those who were screened agreed or strongly agreed that the event helped them to learn more about the signs and symptoms of lung cancer* [16].</p> <p>Reach: 72% of those screened were over 50. 51% were</p>

			<p>(local TV, local newspapers) and social media. Health check event dates in October 2014 and November 2014.</p> <p>Content: Event advertising contained information about the health check event with 3 target symptoms (cough, wheeziness, breathlessness), information about the benefits of early diagnosis and advice to get the symptoms checked by GP or go to the local event. For those who attended the event and received the health check, a referral letter was given to them to take to the GP if necessary and symptom awareness leaflets. Those who were not screened were given a leaflet with lung cancer symptoms and when to go the doctor with symptoms.</p>	(smoking status and occupation) [16]	non-smokers, 34% were ex-smokers, 15% were current smokers. 26% had previously worked in heavy industry. (no further demographics reported) [16]
Lowry <i>et al</i> , 2009; Lowry <i>et al</i> , 2011	England (Newcastle and Gateshead)	Oral (non-specific)	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Individuals from low socioeconomic groups who were over 40 and current smokers who drink more than the recommended allowance of alcohol and do not attend regular dentist check-ups.</p> <p>Delivery: Intervention messaging delivered through local press, regional TV news, radio, posters in pharmacy windows, medical practices and community centres. Free oral cancer screening service.</p> <p>Content: Information about the symptoms of oral cancer and the voucher based system for target group to receive a free oral cancer clinical examination.</p> <p>HCPs: Sent training DVDs to improve communication and clinical examination skills</p>	No evaluation data for the outcomes of interest available	

NAEDI local projects	England (109 PCTs)	Breast, bowel and lung (target symptoms NR)	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Defined areas within 109 PCTs across England. Most projects were targeted at over 50's. All projects were targeted at low socioeconomic groups.</p> <p>Delivery: Fifty-three individual projects. Most projects used high level advertising such as local TV, radio and press adverts to raise awareness. This was followed by more targeted face-to-face community outreach activities for specific sub groups. Most projects used information leaflets and posters combined with local events such as stalls or exhibitions in public spaces or supermarkets (34 projects), or talks in the community (29 projects). 29 projects trained and recruited local community volunteers/ cancer champions to run stalls, deliver brief opportunistic behaviour change interventions with people in the community or top up leaflets/ poster displays in the community. Ran between October 2010 and July 2011. Most projects ran for 6-8 weeks. Cost: £9,000,000 for all projects. Each project could bid for up to £100,000. Successful projects ranged from £22,750 to £100,000.</p> <p>Content: Local projects were designed to support the National Be Clear on Cancer campaigns at community levels and contained information about the symptoms of cancer and when to go to the doctor with a symptom. Most campaigns used the 'Be Clear on Cancer', 'Cough Cough' and 'Don't be a cancer chancer' materials. Some projects modified them to more relevant to the target community e.g. include local</p>	<p>Before and after/quasi-experimental methods</p> <p>Psychological/behavioural: Used the CAM or Early Diagnosis of Cancer (EDC) survey. Survey timings for each are varied, but each PCT conducted a pre and post intervention CAM or EDC with all age groups or only over 50's within their target area depending on PCT area: <i>Symptom presentation:</i> Anticipated symptom presentation behaviour [17] <i>Symptom knowledge:</i> Percentage of individuals correctly recalling symptoms (using an open question) [17]</p> <p>Clinical: Compared the 76 intervention PCTs to 73 PCT control areas for lung cancer. Compared the 77 intervention PCT areas to 74 PCT control areas for bowel cancer. No data available for breast cancer. Also collected before and after clinical data (intervention period compared to the previous year): <i>Referrals:</i> 2WW referral data [17] <i>New cases of cancer:</i> Number of new cases of cancer from 2WW referrals [17]</p> <p>Reach: Awareness of intervention content [17]</p>	<p>Psychological/behavioural: <i>Symptom presentation:</i> Intentions to visit the GP within 1 week of symptom experience remained stable pre to post intervention [17]. Four projects reported increased number of participants reporting intentions to visit the GP within 1 week of symptom experience (range 4-24%; statistically significant increase for all 4 projects $p<0.01$), 6 projects reported a decrease in intentions (range 1-10%; a statistically significant decrease for intentions was reported for 2 projects, $p<0.01$) [17]. <i>Symptom knowledge:</i> Symptom knowledge for lumps, bleeding and pain improved pre to post intervention (average changes of 1-2% more individuals recalling these symptoms post campaign)** [17].</p> <p>Clinical: <u>Lung cancer</u> <i>Referrals:</i> 9% increase in the number of individuals referred via the 2WW for suspected lung cancer ($p<0.01$) [17]. The control areas reported an increase of 7% in the number of individuals referred via the 2WW for suspected lung cancer [17]. At an area level, 24 projects reported an increase of 2WW referrals from intervention period to the previous year (range: 2-44%), 10 projects reported a decrease (range 2-17%), 3 projects reported no change [17]. <i>New cases of cancer:</i> A 4% increase in the number of new lung cancer diagnoses following 2WW referral was reported compared to the control area which reported a 1% increase [17]. At area level, 8 projects reported an increase in new lung cancers diagnosed (range 2-111%; statistically significant increase for one project, $p<0.001$); 10 reported a decrease (range: 3-31%; statistically significant decrease for two projects, $p<0.05$), 1 project reported no change [17]. Western Cheshire and Cheshire West reported the best clinical results in terms of number of new lung cancer cases diagnosed [17].</p> <p><u>Bowel cancer</u> <i>Referrals:</i> 16% increase in the number of individuals referred via the 2WW for suspected bowel cancer ($p<0.01$). In the control area a 13% increase in 2WW referrals was reported [17]. At an area level, 25 projects reported an increase in 2WW</p>
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			<p>statistics.</p> <p>HCPs: 96% of projects included activity targeted at GPs to inform them of the intervention activity and ask them to display intervention materials in their practice. Some projects updated GPs with the signs and symptoms of cancer and reminded them of referral pathways and ensured they had capacity to cope with the impact of the project (increased patient presentations).</p>		<p>referrals (range: 1-49%), 7 projects reported a decrease (1-33%) [17].</p> <p><i>New cases of cancer:</i> A 6% increase for the number of new diagnoses of bowel cancer was reported in the intervention PCTs compared to the control area PCTs which reported an increase of 0.6% [17]. At project level, 6 projects reported an increase in the number of people diagnosed with bowel cancer (range: 5-86%; NS), one project reported no change, 5 reported decreases in the numbers of new diagnoses (range: 1-57%; statistically significant decrease for one project, p<0.05) [17]. Great Yarmouth and Waveney was most successful in increasing number of new cancers diagnosed [17].</p> <p>Reach: For projects which assessed awareness of campaigns, respondent awareness ranged from 11-71%. On average 39% of participants reported seeing an aspect of the intervention [17]</p>
Painting Stroud Pink	England (Stroud, Gloucestershire)	Breast (target symptoms NR)	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Women from low socioeconomic groups.</p> <p>Delivery: Leaflets with intervention messaging. Pop up beauty salons called 'ladies lounges' to recruit volunteers and create buzz about the project. Recruited 32 volunteers from the community to help spread intervention messages through word of mouth, and run local and high street events (3 half day events). Ran from May 2010 to June 2010. Cost: £35,000</p> <p>Content: Information about early signs for breast cancer, when to go to the doctor with symptoms and to encourage others to go the GP if they have symptoms.</p>	No evaluation data available	

<p>The Small “c” Campaign</p>	<p>England (London :Tower Hamlets, Hackney, Newham, Waltham Forest)</p>	<p>Breast and lung (cough)</p>	<p>Community based multi-faceted social marketing intervention</p> <p>Target group: Residents living in areas of deprivation. For breast: women aged over 40 years old. For lung: smokers and ex-smokers over 50.</p> <p>Delivery: Launch event, local and regional newspaper advertising, local TV and press releases. Interviews with oncologists and cancer survivors. In two areas, GP practices identified target groups and mailed letters, information sheets and symptom checkers to individuals. Printed resources included leaflets in pharmacies and stickers for cough medicine bottles. Local staff and volunteers were trained to deliver brief interventions opportunistically with members of the public. Various organisations of places in the community held local events with information stalls or giving talks e.g. cafes, hairdressers. Ran from June 2011-March 2012. Cost £400,000</p> <p>Content: Information about the symptoms of cancer and the importance of going to see the doctor promptly with a symptom.</p> <p>HCPs: Pharmacists contacted to promote cancer awareness. GPs given information about the campaign, given health promotion materials and NICE guidelines reminders. Training and practice visits were performed.</p>	<p>Before and after/quasi-experimental study</p> <p>Psychological/behavioural: CAM survey before intervention (2010) and after the intervention (2015). <i>Symptom knowledge:</i> Recall and recognition [18]</p> <p>Clinical: Time periods for clinical data collection not reported <i>Referrals:</i> 2WW referrals pre to post intervention [18] <i>Staging data:</i> Staging data collected pre to post intervention [18]</p> <p>Reach: No explanation for how reach was measured [18]</p>	<p>Psychological/behavioural: <i>Symptom knowledge:</i> Increase in cancer symptom knowledge reported for the target communities [18]. 27% increase in recognition of breast cancer symptoms**[18]. NS difference in knowledge for lung cancer symptoms [18].</p> <p>Clinical: <i>Referrals:</i> Number of 2WW referrals for suspected lung and breast cancer increased by 44% and 22% respectively from pre to post campaign** [18] <i>Staging data:</i> 1% increase in the number of lung cancers diagnosed at an early stage reported, 4% decrease in the number of breast cancers diagnosed at advanced stage** [18]</p> <p>Reach: Reported that the intervention was effective at targeting those most at risk (no further data) [18]</p>
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<p>Scott et al, 2012b</p>	<p>England (London)</p>	<p>Oral (target symptoms not reported)</p>	<p>Educational intervention</p> <p>Target group: Smokers living in a deprived area. Aged between 45 and 65.</p> <p>Delivery: Three arm trial: Leaflet only vs 5-10 minute one-on-one session with trainee health psychologist and leaflet vs usual care.</p> <p>Content: Leaflet contained information about oral cancer symptoms, how to spot oral cancer and how to perform mouth self-examination (MSE). The one-on-one session assessed the individuals understanding of oral cancer symptoms, addressed individual barriers to help seeking, allowed the individual to practice MSE and encouraged timely cancer symptom presentation for symptoms.</p>	<p>Randomised controlled trial (leaflet vs leaflet & one-to-one session vs control)</p> <p>Psychological/ behavioural: Questionnaire data (Knowledge and beliefs about Mouth Cancer scale and the temporal measure of help-seeking. Participants: leaflet only (n=42), leaflet & one-on-one (n=46), control (n=24). Men and women, mean age: 54 years. All current smokers, 55% high alcohol dependency. Collected at baseline, post intervention and 1 month follow up to assess: <i>Symptom presentation:</i> Intentions to seek medical help with symptoms and confidence to seek medical help. <i>Symptom knowledge:</i> Recognition</p>	<p>Psychological/ behavioural: <i>Symptom presentation:</i> Both intervention groups were less likely to anticipate delay and reported higher confidence in seeking medical help post intervention [19]. Compared to the control group (45%), those in the leaflet group (5%; $\chi^2=14.88$, $df=1$, $p<0.001$) and those in one-on-one group (7%; $\chi^2=13.67$, $df=1$, $p<0.001$) were less likely to anticipate delay; however this was not sustained at 1 month (NS difference between intervention groups) [19]. <i>Symptom knowledge:</i> Knowledge in both intervention groups was significantly higher at follow up compared to control group (leaflet: $U=91.0$, $z=-4.9$, $p=0.00$; one-on-one: $U130.5$, $z=-4.4$, $p=0.00$) (NS difference between intervention groups) [19].</p>
<p>The Tenovus Health Check</p>	<p>Wales (evaluation in South Wales)</p>	<p>Common Cancer (persistent cough, lump(s), skin changes, sore or ulcer which will not heal, change in bowel habit, blood in faeces, problems urinating, unexplained bleeding, difficulty swallowing, weight loss,</p>	<p>Health Check</p> <p>Target group: Men and women, over 40's living in deprived areas in Wales.</p> <p>Delivery: Intensive face-to-face, one-to-one tablet based intervention and tailored consultation with a trained lay advisor. Ongoing, amended in 2015.</p> <p>Content: Questions to assess cancer-risk related behaviour and questions designed to identify current symptoms the individual has. In the one-on-one section, the individual is prompted to seek medical help for reported symptoms and given advice on what symptoms to look out for in the future and what to do if they experience a symptom. Information designed to reduce negative beliefs about cancer.</p>	<p>Evaluation ongoing.</p>	

		unexplained tiredness, loss of appetite, bloating, pain)			
The West of Scotland Cancer Awareness Project	Scotland (West of Scotland)	Oral (ulcers, sores, red or white patch, spots, lump(s), any persistent changes, change to the tongue)	<p>Regional mass media intervention.</p> <p>Target group: People aged 40-70 from low socioeconomic groups (C2DE)</p> <p>Delivery: TV and radio adverts, local and national press adverts, posters, leaflets and mail drops.</p> <p>Content: Oral cancer awareness, promote timely symptom presentation, early detection methods. Used a testimonial approach (using real people to tell their stories). Cost: £264,000</p>	<p>Before and after/quasi-experimental methods</p> <p>Psychological/behavioural: Comparison of target area and control area. Participants: men and women from low socioeconomic groups (C2DE); baseline, (n=922), 7 month (n=934), 12 month (n=944). Age range: 40-70 years. A 3-stage cross sectional tracking survey (baseline- before the campaign was launched, 7 month and 12 months post campaign). Face-to-face quantitative survey to assess: <i>Symptom presentation:</i> Intentions to seek medical help for symptoms targeted by the intervention [20] <i>Symptom knowledge:</i> Recognition of oral cancer symptoms targeted by the intervention [20]</p> <p>Reach: Awareness and recall of campaign materials.</p>	<p>Psychological/ behavioural:</p> <p><i>Symptom presentation:</i> At 12 month follow up, participants in the intervention group were more likely to report intentions to visit a GP with a symptom compared to control group (86% intervention area vs 77% in the control area; p<0.001)[20]. No difference in intentions to visit a dentist were observed between intervention groups [20]. <i>Symptom knowledge:</i> Awareness of ulcers and lumps as symptoms increased in the intervention group at both follow ups compared to control group (p<0.001). For other symptoms, short term knowledge was improved at first follow up compared to baseline in the intervention group, but this was not sustained at 12 month follow up [20].</p> <p>Reach: Awareness of the campaign was higher in the intervention group compared to control group. TV advertising accounted for the largest media coverage [20].</p>

[1] Power and Wardle, 2015; [2] Peacock *et al*, 2013; [3] Hall *et al*, 2015; [4] Moffat *et al*, 2015; [5] Ironmonger *et al*, 2014; [6] Hinde *et al*, 2015; [7] Smith *et al*, 2016; [8] Cardarelli *et al*, 2011; [9] Information Services Division Scotland, 2015c; [10] Kane *et al*, 2009; [11] Campbell *et al*, 2013; [12] Athey *et al*, 2012; [13] Suckling, 2008; [14] EPOC impact report; [15] Lyon *et al*, 2009; [16] British Lung Foundation, 2014; [17] Cancer Research UK, 2012; [18] Shankleman *et al*, conference poster; [19] Scott *et al*, 2012b; [20] Eadie *et al*, 2009; **NS:** Non-significant; *No further statistics reported; ** Statistics not reported

6.4.3 Quality of included interventions

In line with scoping review methods, intervention quality was not formally assessed using critical appraisal checklists such as the CASP tool. However, the quality of intervention development and evaluation was assessed in relation to the MRC framework for developing and evaluating complex interventions (Craig *et al*, 2008).

6.4.3.1 Intervention development

Interventions which conducted needs assessment studies prior to intervention development, in order to understand the processes underlying delayed cancer symptom presentation among those in the target group, were considered to be of higher quality. Needs assessments typically involved survey, interview or focus group studies to identify the barriers and facilitators to timely cancer symptom presentation and identify gaps in symptom knowledge among individuals in the target group or community. In addition, pre-intervention studies that co-produced new intervention materials or adapted existing materials with participants from the target community or group, in order to increase the relevance and acceptability of the intervention, were of higher quality. Most interventions conducted pre-intervention studies with members of the target group, and were therefore judged to be of higher quality. Three lower quality interventions bypassed the development stage due to time and budget restrictions. These interventions often used intervention materials which were previously reported as successful in other similar communities.

Interventions which explicitly identified and used relevant theory to develop the intervention were considered to be of higher quality. Five interventions reported intervention development using various theoretical frameworks such as Social Cognitive Theory (Bandura, 1991) and the Common Sense Model (Leventhal *et al*, 1980). One intervention used multiple behaviour change theories to underpin an oral cancer educational intervention (Scott *et al*, 2012b). These higher quality interventions provided a rationale for the choice of theory and a description of how theory was used to guide intervention development and content.

6.4.3.2 Intervention evaluation

Higher quality studies involved efforts to conduct either RCTs or pragmatic controlled evaluations with a control area and/or control time period for comparison. Two higher quality studies comparing intervention with control areas reported demographic data to ensure that comparisons between similar areas were conducted (Eadie *et al*, 2009; Athey *et al*, 2012). Eight higher quality intervention evaluations collected data at multiple time points including baseline, during the intervention and at follow up (usually 3, 6 or 12 months post intervention) to assess longer term information retention and/or behaviour change. Six lower quality interventions collected evaluation data at one time point, or included a short term follow up measure (immediately post-intervention, up to one month post intervention), precluding comparisons between different time points to assess intervention effectiveness or assessments of long term retention of information.

Questionnaire based intervention evaluations used a range of different measures, some of which were developed for the purposes of the study, therefore it was difficult to draw direct comparisons between interventions. Six higher quality evaluations used standardised measures such as the CAM (Stubbings *et al*, 2009). Two lower quality studies used methods of evaluation such as self-reported retrospective perceptions of symptom knowledge prior to the intervention, or did not collect or report follow up data regarding whether symptomatic participants made or attended an appointment with their GP. One lower quality evaluation compared questionnaire measure scores for a sample of participants who completed the measure before attending the Roadshow intervention, to a sample of participants who completed the measure after attending the Roadshow. One lower quality evaluation reported knowledge score increase; however did not report the total score or knowledge items assessed.

Six lower quality intervention evaluations did not report participants' socioeconomic or demographic characteristics, therefore it was unclear if those included in the intervention evaluation were representative of the target group or if the intervention was successful in terms of reach to low socioeconomic groups.

6.5 Discussion

The present scoping review aimed to identify interventions designed to encourage timely cancer symptom presentation among low socioeconomic groups. The review included twenty interventions that used various methods of delivery to disseminate intervention messages. The majority of interventions included information about cancer symptoms and/or advice on when to visit the GP with symptoms. Few interventions aimed to explicitly break down barriers to cancer symptom presentation through campaign messaging or to modify negative beliefs about cancer. Finally, some interventions used push-pull methods to pull symptomatic individuals into primary care and push individuals to secondary care through incorporating HCP education into the intervention to increase referrals to secondary care and help prepare HCPs for increased capacity. The majority of interventions adopted a CBMSM approach, delivering intervention messages to members of the public using multiple methods of communication to increase intervention awareness and facilitate retention of intervention messages.

CBMSM interventions and mass media interventions were successful for increasing the number of referrals for suspected cancer to secondary care, especially when push-pull methods were used. However, evidence for improvements in the number of new cases of cancer diagnosed and stage shift was mixed. Mass media interventions reported no or small increases in the number of new cases of cancer diagnosed and stage shift. Improved clinical outcomes were only observed among more affluent groups and there was evidence that the number of referrals was disproportionately biased towards more affluent groups (Hall *et al*, 2015). There was limited evidence of reach and improved clinical outcomes for CBMSM interventions, since data were only reported from an intervention evaluation that reported an increase in referrals among the most deprived practice areas (Kane *et al*, 2009). CBMSM interventions were most successful for increasing the number of new cases of cancer diagnosed. There was evidence to suggest that the most successful interventions employed multiple methods of intervention message delivery and used push-pull methods.

Evidence for improved psychological/behavioural outcomes was mixed, with small or no increases in symptom knowledge or anticipated symptom presentation reported across all intervention types. This could reflect the difficulties of measuring symptom presentation behaviour and the limitations associated with using proxy measures of symptom

presentation behaviour. CBMSM, educational and road show interventions reported limited success in improving cancer symptom knowledge, and there was evidence to suggest that knowledge was not sustained long term. Mass media interventions maintained the socioeconomic gradient for knowledge, where symptom knowledge remained poorest among low socioeconomic groups. There was evidence to suggest that the roadshow intervention reduced barriers to cancer symptom presentation, and that an educational intervention modified negative beliefs about cancer.

One explanation for why outcomes were more improved for certain types of intervention than others is that interventions which are not targeted to a specific group or geographical area, such as mass media interventions, engage the 'worried well' rather than the target group or those at higher risk for developing cancer. There is evidence from other non-cancer health interventions which adopt a mass media approach that such interventions are unreliable in reaching the most disadvantaged groups (Hill *et al*, 2005). In addition, a review of public health interventions found evidence to suggest that mass media campaigns increased health inequalities for a range of health behaviours (Lorenc *et al*, 2012). The same review concluded that educational interventions and multi-component school and community based interventions were equivocal in terms of reducing health inequalities (Lorenc *et al*, 2012). Mass media interventions may fail to bring about change amongst low socioeconomic groups because they ignore the wider socio-environmental influences on health, thus not supporting behaviour change among these groups (Bambra *et al*, 2009; Hawe *et al*, 2009). In the context of cancer symptom presentation, it is likely that providing information about the symptoms of cancer and when to go to the doctor is not sufficient to effect change among a group of individuals who may report emotional barriers, such as fatalism, fear of what the GP might find, and difficulties with communication about symptoms. Therefore, Motivational aspects of the COM-B model must be addressed alongside Capability. In addition, a lack of risk information could prompt symptomatic individuals who are at low risk for cancer to present to the GP with symptoms, therefore improvements in clinical outcomes such as new cases of cancer diagnosed are not observed. Interventions which are not developed based on a theoretical and practical understanding of the needs and preferences of the target audience (Craig *et al*, 2008), and those that do not include relevant risk information, are likely to engage and prompt symptom presentation amongst the worried well.

Face-to-face tailored and targeted interventions, such as educational or health check interventions, or interventions which are targeted at individuals within a specific community and deliver intervention messages through multiple channels, such as CBMSM interventions, are likely to be most successful for targeting low socioeconomic groups. Through face-to-face interventions, messages can be tailored to the individual to overcome specific barriers and offer practical tailored advice about how to overcome barriers. CBMSM interventions can also be targeted to be culturally relevant to a specific community, delivered in a way that is culturally acceptable and involving repetition of messages to increase retention and salience of intervention messages.

The use of volunteers or cancer champions to disseminate messages and deliver brief interventions with people in the community at local events is likely to be successful in offering tailored information, and has the potential to target those who are hardest to reach (Opportunity). Findings from Chapters 3, 4 and 5 suggested that social networks were a key barrier or facilitator to cancer symptom presentation, depending on the quality of advice given. There was evidence to suggest that seeking advice from family members or friends is the norm among participants, and can prolong cancer symptom presentation due to poor advice given as a result of poor knowledge, previous negative experiences in the health service or negative beliefs about cancer. Interventions included in the present review that used volunteers or cancer champions to deliver brief interventions tended to utilise opportunistic interactions with people at supermarkets or events, encouraging symptomatic individuals to visit the GP with symptoms. This strategy could be adapted to target harder to reach groups through their social networks through Opportunity, rather than opportunistically approaching them in the community. This peer educator approach has been used in various public health interventions to promote condom use among gay men in the United States and reduce smoking behaviour among school children in England and Wales (Hart and Elford 2003; Campbell *et al*, 2008). This approach was most successful for reducing smoking behaviour among school age children in the Welsh Valleys because of the strong social networks within the close-knit community (Campbell *et al*, 2008).

6.5.1 Strengths and limitations of the current review

The scoping review method was considered to be less restrictive than other review method such as systematic review, therefore allowing for the inclusion of interventions that would

otherwise be excluded. Although interventions from high income countries other than the UK were identified by the search, these were subsequently excluded because they focused on the whole population rather than low socioeconomic groups, harder to reach ethnic minority groups rather than specifically low socioeconomic groups, or screening uptake among low socioeconomic groups. Fewer smaller interventions of other high income countries were identified through search engine or key organisation websites. It is therefore possible that smaller interventions from other high income countries were not identified, since the search engine platform used was based in the UK. In addition, other social science academic database search engines were not searched, thus it is possible that further interventions were not identified by this review.

6.5.2 Implications for intervention

6.5.2.1 Content and mode of intervention delivery

A more strategic and innovative approach is required for engaging people from a low socioeconomic group in a lung cancer awareness intervention or delivering intervention messages to them. Information provision alone may be insufficient to bring about behaviour change through increased Capability in this group. Symptom and action planning information should be coupled with information designed to modify negative beliefs about cancer and emphasise the benefits of early diagnosis (Motivation), educate regarding who is most at risk for developing lung cancer (Capability), and provide strategies to overcome reported barriers to symptom presentation and empower individuals to seek medical help for symptoms (Opportunity). An intervention could utilise strong social networks by actively encouraging individuals to disseminate intervention messages within the community (Opportunity). Such a strategy has the potential for intervention messages to reach individuals who are unlikely to attend a cancer intervention, and potentially increase intervention sustainability.

6.5.2.2 Implications for intervention evaluation outcome methods and measures

There is a need for controlled evaluations that measure and compare outcomes at various time points: before the intervention, at short term follow-up (up to 1 month post intervention) and in the longer term (6 or 12 months and beyond). Intervention evaluation

at long term follow up is not feasible within the boundaries of the current PhD, therefore data collection over two time points (before and after intervention) should be considered for intervention user testing. In addition, a controlled evaluation is desirable, although out of remit for this PhD.

Choosing which domain outcome measure(s) to use to assess intervention effectiveness is complex and each measure has limitations. Interventions designed to target large audiences can measure clinical outcomes in a given community or area, assessing actual symptom presentation behaviour. Smaller scale interventions such as educational interventions which target few people in a community preclude the measurement of clinical outcomes, such as the number of new cancers diagnosed or actual symptom presentation behaviour through GP read codes, due to the relatively small number of cancer diagnosed per community. Instead, proxy measures which influence time to symptom presentation can be used to assess intervention effectiveness such as symptom knowledge, beliefs about cancer and barriers to cancer symptom presentation using standardised measures such as the CAM (Stubbings *et al*, 2009). These proxy measures can be used in combination with anticipated cancer symptom presentation behaviour, although there are limitations associated with measuring anticipated cancer symptom presentation where intentions may not accurately reflect actual behaviour. If the evaluation includes a long term follow up, self-reported actual symptom presentation behaviour can be measured.

Findings from the present chapter will be used in combination with findings from Chapters 3, 4 and 5 to develop an intervention designed to promote timely lung cancer symptom presentation among low socioeconomic groups. Intervention development will be guided by the Behaviour Change Wheel and MRC framework, described in Chapter 7.

Chapter 7

Development of a community based group educational intervention designed to encourage timely lung cancer symptom presentation

7.1 Chapter overview

This chapter aims to describe the development of a community based group educational intervention designed to encourage timely lung cancer symptom presentation. Findings from the intervention development process using the Behaviour Change Wheel to facilitate selection of the format and content of the intervention are reported. Finally, the Behaviour Change Wheel will be critically evaluated for its usefulness as a framework for intervention development in the context of behaviour change for cancer symptom presentation.

7.2 Introduction

In 2015 the need to improve lung cancer outcomes was prioritised by the Welsh Government where lung cancer was considered a national priority, and was high on the policy agenda (Welsh Government, 2015). In the absence of a national lung cancer screening programme, encouraging individuals to present to their primary care doctor promptly with symptoms suggestive of lung cancer is a potential strategy to improve survival outcomes through earlier diagnosis. The rationale is that better lung symptom awareness and more positive beliefs about lung cancer may shorten the patient interval, which currently accounts for the longest period of time in the pathway from noticing a symptom and the start of cancer treatment (Lyrtzopoulos *et al*, 2015).

Findings from Chapter 6 suggested that lung specific mass media interventions using TV, radio or posters to distribute intervention messages to a large audience are ineffective at targeting those from low socioeconomic groups and have the potential to widen socioeconomic inequalities in cancer outcomes (Moffat *et al*, 2015). In order to encourage people from low socioeconomic groups to present to the doctor with symptoms of lung cancer, more targeted and innovative methods such as community group based educational interventions could be used to engage this group.

Lung cancer incidence is highest among low compared to high socioeconomic groups (WCISU, 2015a; Riaz *et al*, 2011) and in individuals over the age of 40 (Malhotra *et al*, 2016). Smoking is the leading cause of lung cancer (Malhotra *et al*, 2016), accounting for approximately 86% of cases (Cancer Research UK, 2015e). Lung cancer risk increases with the quantity of cigarettes smoked and the duration that an individual has smoked (Doll *et al*, 2005; Pope *et al*, 2011). In comparison to never smokers, lung cancer risk is 39 times higher among individuals who smoke 42 cigarettes per day, and risk decreases as the number of cigarettes smoked per day is lowered (Pope *et al*, 2011). Although the risk of lung cancer is reduced for former smokers, they are still at increased risk in comparison to never smokers (Malhotra *et al*, 2016). Other non-smoking risk factors include working with occupational exposures such as asbestos and air pollutants such as coal fuelled fires in poorly ventilated houses in both smokers and never smokers (Malhotra *et al*, 2016). There is evidence to suggest that certain medical conditions which cause chronic inflammation, such as asthma or chronic obstructive pulmonary disease (COPD), increase lung cancer risk (Malhotra *et al*, 2016).

Intervention target group for this PhD were selected based the group of individuals for which lung cancer is most common (Malhotra *et al*, 2016) and the NICE guidelines for referral of suspected lung cancer (NICE, 2015). Although current or former smokers with pre-existing lung co-morbidity are most at risk for lung cancer, they are often already symptomatic and potentially engaged in clinical interventions. Therefore the decision to target the intervention at current smokers, former smokers or family members of smokers who over the age of 40, living in deprived communities in Wales was made. Family members of smokers were included in order to utilise social networks to facilitate spread of knowledge gained from the intervention through social networks, and will be discussed in more detail later in this chapter.

7.2.1 The Medical Research Council (MRC) framework

The MRC framework was used to guide intervention development (Craig *et al*, 2008). This PhD reports findings from the first two MRC phases: intervention development and feasibility and piloting. Chapters 2 to 6 reported findings from the development phase, with relevant theories identified in Chapter 2, and the remaining chapters reported data from primary and secondary sources to identify the evidence base and understand what is driving

symptom presentation behaviour in low socioeconomic groups. The present chapter will report the development of the intervention using the Behaviour Change Wheel process (Michie *et al*, 2011).

Whilst the MRC framework provides guidance on the processes which should be included at each stage of intervention development, there is little guidance within the framework on exactly how to develop and implement an intervention, how to select theory and what content should be included (Craig *et al*, 2008). Various checklists such as MINDSPACE (Institute for government, 2011) or frameworks such as intervention mapping (Bartholomew *et al*, 1998; Bartholomew *et al*, 2011) are available to support and guide intervention development. However, a systematic review of intervention development frameworks and checklists reported that most of the 19 included frameworks lacked comprehensiveness and/or coherence (Michie *et al*, 2011). Furthermore, few of the frameworks were underpinned by a model of behaviour and/or failed to involve adequate initial analysis of the target behaviour, which could explain the variable success of behaviour change interventions (Michie *et al*, 2011). In an attempt to overcome these issues, the Behaviour Change Wheel was developed from the existing frameworks and checklists to provide a comprehensive, coherent and theoretically grounded framework which can be applied to a wide range of behaviour change intervention contexts. The Behaviour Change Wheel provides a systematic framework for the development of behaviour change interventions, underpinned by a single model of behaviour created from 83 theories of behaviour change (the COM-B model; Michie *et al*, 2011).

7.2.2 The Behaviour Change Wheel

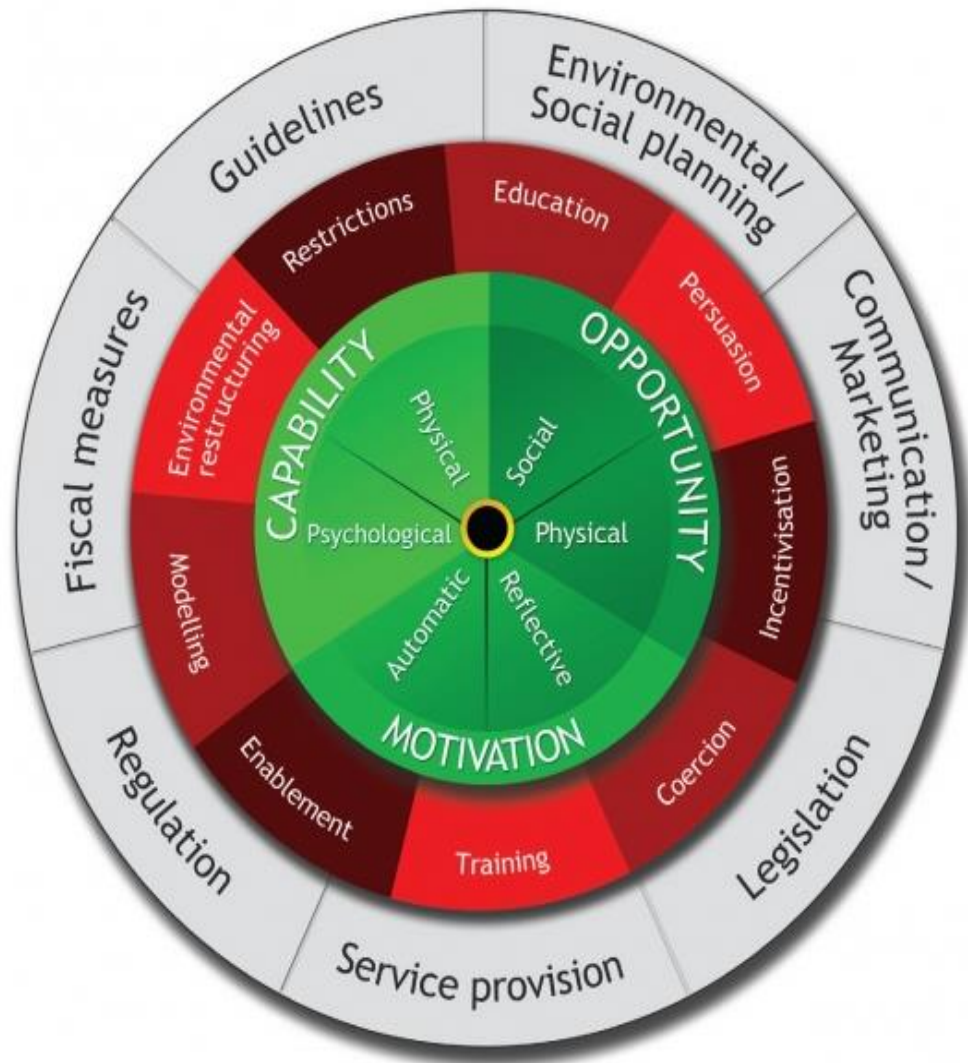
As discussed in Chapter 1, the Behaviour Change Wheel provides researchers with a suite of tools to facilitate intervention development in three key stages (Michie *et al*, 2011). The systematic framework and comprehensive theoretical underpinning of the Behaviour Change Wheel were considered to be benefits of using this approach to intervention development. Therefore, the Behaviour Change Wheel was selected to facilitate intervention development for this PhD.

7.2.3 Aims and objectives

This chapter aims to describe the development of a community group based educational intervention using the Behaviour Change Wheel in accordance with the MRC framework. There were three objectives: (1) to develop an intervention using the Behaviour Change Wheel and MRC framework; (2) to create intervention materials based on the results of the Behaviour Change Wheel intervention development exercise, and (3) to critically evaluate the Behaviour Change Wheel for its usefulness as a framework for intervention development in the context of cancer symptom presentation behaviour.

7.3 Intervention development using the Behaviour Change Wheel

There are three key stages in the intervention development process using the Behaviour Change Wheel (Figure 7.1). Each of the processes involved at each stage are outlined in Table 7.1.



- Sources of behaviour
- Intervention functions
- Policy categories

Figure 7.1 *The Behaviour Change Wheel for intervention development (Michie et al, 2014)*

Table 7.1 Stages of the Behaviour Change Wheel and processes involved at each stage

Behaviour Change Wheel stage	Processes involved at each stage
Stage 1: Sources of behaviour (inner most circle)	Identify target behaviour Understand the barriers and facilitators to the behaviour Map behavioural barriers and facilitators to TDF and COM-B model constructs
Stage 2: Intervention functions (middle circle to identify intervention type). Use Behaviour Change Techniques Taxonomy (Michie <i>et al</i> , 2013) to identify intervention content	Apply APEASE (Affordability, Practicability, Effectiveness and Cost-effectiveness, Acceptability, Side-effects/safety, Equity; Table 7.3) criteria to applicable intervention functions Apply APEASE criteria to relevant Behaviour Change Techniques Taxonomy (Michie <i>et al</i> , 2013)
Stage 3: Policy categories (outer most circle to identify how to implement the intervention and mode of delivery)	Apply APEASE criteria to applicable policy categories Apply APEASE criteria to all modes of delivery

Figure 7.1 is a pictorial representation of the Behaviour Change Wheel (Michie *et al*, 2011) and corresponds to each of the stages in Table 7.1. The researcher is required to start with the inner most circle (sources of behaviour) to identify the potential sources of behaviour. The researcher is then required to work their way out to the outer circle to identify intervention type (intervention functions) and finally how to implement the intervention (policy categories). The results from each stage determine which aspects are considered at the next stage. These will be outlined below alongside findings from each stage.

7.3.1 Stage 1: Sources of behaviour

A 'behavioural diagnosis', defined as an analysis of the target behaviour, was performed to identify the potential sources of behaviour and to understand what drives behaviour in the context of timely lung cancer symptom presentation among low socioeconomic groups. Behavioural diagnosis involved mapping barriers and facilitators to lung cancer symptom presentation to the TDF and COM-B model constructs. The TDF provides a more granular level to facilitate understanding of the COM-B constructs and mapping of barriers/facilitators to each COM-B construct. Findings from studies of the barriers and facilitators to cancer symptom presentation among low socioeconomic groups were used in this part of the Behaviour Change Wheel process. These included the systematic review (Chapter 3), and findings from qualitative interviews (Chapter 4) and focus groups (Chapter

5). Although the latter studies were not specific to lung cancer, lung-specific barriers and facilitators were extracted and used in the present intervention development study. All barriers and facilitators to lung cancer symptom presentation were listed and grouped under sub-headings, for example 'fear of a diagnosis of lung cancer' and 'shame associated with lung cancer' were grouped under the sub-heading 'emotional barriers' (see Appendix 23 for all barriers/facilitators). A total of 77 barriers and facilitators to the target behaviour (timely lung cancer symptom presentation among low socioeconomic groups) were identified through data sources (see Appendix 23). These were grouped under eight sub-headings (see Appendix 23).

All barriers and facilitators to behaviour were categorised as 'modifiable' or 'non-modifiable'. Modifiable barriers and facilitators were those which could be targeted during the intervention, for example a modifiable barrier might be 'poor knowledge of the symptoms of lung cancer' which can be addressed by provision of information about lung cancer symptoms. Non-modifiable barriers were those which were considered beyond the scope of the current intervention, for example 'interpersonal skills of GP' (see Appendix 23 and Table 7.2 for the modifiable barriers/facilitators). A total of 50 barriers/facilitators to the target behaviour were considered to be modifiable, therefore 27 barriers/facilitators were excluded (see Appendix 23 and Table 7.2).

Each modifiable barrier and facilitator to lung cancer symptom presentation was then individually mapped to at least one of the 14 domains in the TDF described in Chapter 2 (Cane *et al*, 2012) and the corresponding COM-B model construct (Michie *et al*, 2011), according to definitions provided in Chapter 2. For example 'fear of a diagnosis of lung cancer' was mapped to the TDF domains of 'emotion' and 'beliefs about consequences' and the COM-B constructs of automatic and reflective motivation, respectively. The mapping process was undertaken using a Microsoft Excel spreadsheet. No dual coding of barriers/facilitators was performed; however, supervisors checked findings once barriers and enablers were mapped to the TDF and COM-B constructs. The sources of behaviour refer to the modifiable barriers and enablers which have been identified under the TDF domains and corresponding COM-B model constructs (Table 7.2).

Frequencies of modifiable barriers/facilitators according to TDF domain headings were as follows: knowledge (n=16); skills (n=11); memory, attention and decision processes (n=16);

behavioural regulation (n=11); social influences (n=6); environmental context and resources (n=4); reinforcement (n=0); emotion (n=14); social/professional identity (n=1); beliefs about capabilities (n=7); optimism (n=1); beliefs about consequences (n=18); intentions (n=8); goals (n=1). For the corresponding COM-B construct, frequencies were as follows: Capability (n=57: psychological capability, n=57; physical capability, n=0), Opportunity (n=12: social opportunity, n=8; physical opportunity, n=4) and Motivation (n=51: automatic motivation, n=14; reflective motivation, n=37).

The findings suggested that psychological capability, social and physical opportunity, and automatic and reflective motivation are relevant sources of behaviour in the context of timely lung cancer symptom presentation, and could potentially be modified in order to bring about behaviour change (Table 7.2).

Table 7.2 *Modifiable barriers and facilitators to timely lung cancer symptom presentation behaviour and corresponding TDF domain and COM-B model constructs (sources of behaviour)*

Barrier/facilitator to timely lung cancer symptom presentation behaviour	TDF domain(s)	COM-B model construct(s)
<i>Individual characteristics</i>		
Smoking behaviour	Knowledge; Skills; Behavioural regulation	Psychological Capability
Stoicism	Social/professional identity	Reflective Motivation
<i>Cancer knowledge</i>		
Knowledge of the symptoms of lung cancer	Knowledge	Psychological Capability
Perceptions of symptom severity	Knowledge; Memory, attention and decision processes	Psychological Capability
Lack of pain associated with lung cancer symptoms	Knowledge; Memory, attention and decision processes	Psychological Capability
Belief lung cancer is symptomless	Knowledge; Memory, attention and decision processes	Psychological Capability
Number of symptom(s)	Knowledge; Memory, attention and decision processes	Psychological Capability
Worsening of symptom(s)/symptom(s) impacting on daily life	Knowledge; Memory, attention and decision processes	Psychological Capability
Duration of symptoms(s)	Knowledge; Memory, attention and decision processes	Psychological Capability
Symptom type (vague e.g. persistent tiredness vs specific e.g. haemoptysis)	Knowledge; Memory, attention and decision processes	Psychological Capability
Attribute symptom(s) to smoking habit	Memory, attention and decision processes	Psychological Capability
Attribute symptom(s) to co-morbidity	Memory, attention and decision processes	Psychological Capability
Attribute symptom(s) to age	Memory, attention and decision processes	Psychological Capability
Perceptions of the causes of symptoms	Knowledge	Psychological Capability
Perceptions of individual risk of developing lung cancer	Knowledge; Memory, attention and decision processes	Psychological Capability
<i>Self-efficacy/skills</i>		
State specific self-efficacy	Skills	Psychological Capability
Confidence when communicating	Skills; Beliefs about capabilities	Psychological Capability;

symptoms to the GP		Reflective Motivation
Listening skills during an appointment with the doctor	Skills; Beliefs about capabilities	Psychological Capability; Reflective Motivation
Ability to articulate symptom concerns	Knowledge; Skills; Beliefs about capabilities	Psychological Capability; Reflective Motivation
Knowledge of what to do when the individual experiences a symptom(s)	Knowledge; Skills; Memory, attention and decision processes; Behavioural regulation; Beliefs about capabilities	Psychological Capability; Reflective Motivation
Knowing how to book an appointment with the doctor	Knowledge; Skills; Beliefs about capabilities	Psychological Capability; Reflective Motivation
Health information seeking	Knowledge; Skills; Beliefs about capabilities	Psychological Capability; Reflective Motivation
Health service factors		
Concerns about wasting GP time	Skills; Social influences; Beliefs about capabilities	Psychological Capability; Social Opportunity; Reflective Motivation
Perception the GP cannot help/resolve the symptom(s)	Knowledge; Memory, attention and decision processes; Optimism	Psychological Capability; Reflective Motivation
Worry about being perceived as a hypochondriac	Social influences; Beliefs about consequences	Social Opportunity; Reflective Motivation
Worry about being told to stop smoking	Beliefs about consequences	Reflective Motivation
Beliefs about lung cancer/treatments		
General fatalistic beliefs about cancer (no cure, death sentence, bad luck)	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
The belief that lung cancer is a fatal disease	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
The belief that there is no treatment for lung cancer	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Fear of the treatments for lung cancer	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Beliefs about early diagnosis	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Community factors/competing priorities		
Using a lay system of healthcare/symptom disclosure	Skills; Memory, attention and decision processes; Social influences; Environmental context and resources	Psychological Capability; Social Opportunity; Physical Opportunity
Cultural messages to reduce GP consultation behaviour	Social influences; Beliefs about consequences	Social Opportunity; Reflective Motivation
Emotional barriers		
Shame	Emotion; Social influences	Automatic Motivation; Social Opportunity
Stigma associated with lung cancer	Social influences; Beliefs about consequences	Social Opportunity; Reflective Motivation
Fear of a diagnosis of lung cancer	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Worry about what the doctor might find	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Fear of diagnostic tests	Emotion; Beliefs about consequences	Reflective Motivation; Automatic Motivation
Embarrassment around disclosure of symptoms	Social influences; Emotion; Beliefs about consequences	Social Opportunity; Reflective Motivation; Automatic Motivation
Fear of the unknown	Emotion	Automatic Motivation
Responses to symptoms/behavioural response		
Avoidance	Behavioural regulation; Emotion	Psychological Capability; Automatic Motivation
Denial	Behavioural regulation; Emotion	Psychological Capability; Automatic Motivation
Watchful waiting	Memory, attention and decision	Psychological Capability;

	processes; Behavioural regulation; Intentions	Reflective Motivation
Self-management/self-medication	Behavioural regulation; Beliefs about consequences; Intentions	Psychological Capability; Reflective Motivation
Use of over the counter medicines	Behavioural regulation; Beliefs about consequences; Intentions	Psychological Capability; Reflective Motivation
Belief that the symptom will resolve on its own without medical intervention	Behavioural regulation; Beliefs about consequences; Intentions	Psychological Capability; Reflective Motivation
Use of traditional herbal medicines	Behavioural regulation; Beliefs about consequences; Intentions	Psychological Capability; Reflective Motivation
Appointment booked for another reason (piggybacking)	Behavioural regulation; Environmental context and resources; Intentions	Psychological Capability; Physical Opportunity; Reflective Motivation
Wait for another symptom/health complaint to appear	Behavioural regulation; Environmental context and resources; Intentions	Psychological Capability; Physical Opportunity; Reflective Motivation
Intention to act on symptom(s) (if symptom persists for three weeks)	Knowledge; Skills; Memory, attention and decision processes; Behavioural regulation; Social influences; Environmental context and resources; Emotion; Beliefs about consequences; Intentions; Goals	Psychological Capability; Social Opportunity; Physical Opportunity; Automatic Motivation; Reflective Motivation

7.3.2 Stage 2: Interventions functions and content

Stage 2 of the Behaviour Change Wheel process involves identification of the potential type and content of the intervention. The types of interventions considered at Stage 2 are determined by the findings at Stage 1 where according to the framework, certain types of interventions should be considered depending on which sources of behaviour are relevant in this context. The intervention functions matrix (Figure 7.2) was used to identify which of the nine intervention functions should be considered according to the sources of behaviour. Psychological capability, Physical Opportunity, Social Opportunity, Automatic Motivation and Reflective Motivation were identified as sources of behaviour (Table 7.2). The intervention functions ‘education’, ‘persuasion’, ‘incentivisation’, ‘coercion’, ‘training’, ‘restriction’, ‘environmental restructuring’, ‘modelling’ and ‘enablement’ were therefore considered (Figure 7.2, shaded boxes).

COM-B components	Intervention functions								
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	restructuring	Modelling	Enablement
Physical capability									
Psychological capability	x				x				x
Physical opportunity					x	x	x		x
Social opportunity						x	x	x	x
Automatic motivation		x			x		x	x	x
Reflective motivation	x	x							

Shading represents the intervention functions that were considered against the APEASE criteria based on findings at Stage 1. Each 'x' represents intervention functions considered most relevant in this context using the APEASE criteria.

Figure 7.2 Intervention functions matrix of links between COM-B and intervention functions (adapted from Michie et al, 2014, p116).

The APEASE criteria (Table 7.3) were applied to all potential intervention functions (Figure 7.2). This means that each intervention function type identified by the matrix was considered and a judgement made to assess the suitability of intervention type according to affordability, practicality, cost effectiveness, acceptability to relevant stakeholders, whether it would produce any unwanted side effects, and whether it would create disparities in health between different sectors in society.

Table 7.3 *The APEASE criteria and definitions (adapted from Michie et al, 2014, page 23-24)*

Criterion	Description
Affordability	An intervention is affordable if within acceptable budget it can be delivered to, or accessed by, all those whom it would be relevant or of benefit.
Practicability	The extent that the intervention can be delivered as designed through the means intended to the target population. E.g. an intervention may be effective when delivered by highly selected and trained staff and extensive resources, but in routine clinical practice this may not be achievable.
Effectiveness and cost-effectiveness	Effectiveness refers to the effect size of the intervention in relation to the desired objectives in the real world context. It is different from efficacy which refers to the effect size of the intervention when delivered under optimal conditions in comparative evaluations. Cost-effectiveness refers to the ratio of effect (in a way that has to be defined, and taking into account of differences in timescale between intervention delivery and intervention effect) to cost. If two interventions are equally effective then clearly the most cost-effective should be chosen.
Acceptability	The extent to which an intervention is judged appropriate by relevant stakeholders (public, professional and political). Acceptability may differ for different stakeholders. Interventions that appear to limit acceptability on the part of the target group are often only considered acceptable for more serious problems.
Side-effects/safety	An intervention may be effective and practicable, but have unwanted side-effects or unintended consequences. These need to be considered when deciding whether or not to proceed.
Equity	An important consideration is the extent to which an intervention may reduce or increase the disparities in standard of living, wellbeing or health between different sectors of society.

Incentivisation was considered unaffordable, impractical and not cost-effective. Coercion was considered to be not acceptable or practical. According to the APEASE criteria, therefore, it was considered that the intervention functions of education, persuasion, training, enablement, modelling and environmental restructuring could be used in the context of encouraging early lung cancer symptom presentation in low socioeconomic groups (Figure 7.2).

Intervention functions that were considered suitable according to the APEASE criteria were then used to identify potential intervention content using the Behaviour Change Techniques Taxonomy. The Behaviour Change Techniques (BCT) Taxonomy (Michie *et al*, 2013; Michie

et al, 2014, p259-283) is a list of techniques which can be used in interventions to bring about behaviour change. It is a separate tool developed from existing taxonomies and checklists (Michie *et al*, 2013), and is formally linked to the Behaviour Change Wheel through the intervention functions. Suggestions for which behaviour change techniques to consider are based on the intervention functions identified in Stage 2 of the Behaviour Change Wheel. The BCT Taxonomy lists the most frequently used behaviour change techniques for each intervention function. Potential behaviour change techniques for each candidate intervention function were considered against the APEASE criteria to assess suitability of that particular behaviour change technique in the context of promoting timely lung cancer symptom presentation behaviour.

Thirteen behaviour change techniques were identified which could be used in this context (Table 7.4). These were as follows: goal setting (behaviour), problem solving, action planning, self-monitoring of behaviour, monitoring of outcome(s) of behaviour by others without feedback, social support (unspecified), social support (practical), instruction on how to perform behaviour, information about health consequences, salience of consequences, information about social and environmental consequences, prompts and cues, and credible sources. For example, for 'action planning' information could be provided on when is an appropriate time to consult the doctor with a symptom. Table 7.4 displays each selected BCT and its corresponding intervention content.

7.3.3 Stage 3: Policy categories and mode of delivery

How the intervention could be implemented and its mode of delivery were considered in the final stage of the Behaviour Change Wheel (Michie *et al*, 2014). The policy categories considered at this stage were determined by the findings at stage 2. The policy categories matrix (Figure 7.3) was used to identify which policy categories should also be considered against the APEASE criteria (Table 7.3). The intervention functions of education, persuasion, training, enablement, modelling, and environmental restructuring were considered at stage 2 to be appropriate according to the APEASE criteria. Therefore, the policy categories 'communication/marketing', 'guidelines', 'fiscal measures' 'regulation', 'legislation', 'environmental/social planning' and 'service provision' (Figure 7.3, shaded boxes) were assessed for suitability against the APEASE criteria (Table 7.3).

Guidelines, regulation and environmental/social planning were considered impractical. Fiscal measures and legislation were considered impractical and unacceptable. The policy categories of service provision and communication/marketing could be used in this context (Figure 7.3). For example, information about lung cancer could be communicated to individuals; however, a mass media campaign would not be affordable and would not create equity in this context.

Policy categories	Intervention functions								
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	restructuring	Modelling	Enablement
Communication/ marketing	x	x						x	
Guidelines									
Fiscal measures									
Regulation									
Legislation									
Environmental/social planning									
Service provision	x	x			x			x	x

Shading represents the policy categories that were considered against the APEASE criteria based on findings at Stage 2. Each 'x' represents policy categories that were most relevant in this context using the APEASE criteria.

Figure 7.3 Policy categories matrix of links between interventions functions and policy categories (adapted from Michie et al, 2014, p.138).

The mode of delivery matrix was then used to guide how the intervention might be delivered (Figure 7.4). Each of the 13 suggested modes of delivery (Figure 7.4) were assessed by the APEASE criteria to decide which would be most suitable in this context (Table 7.3). Using the APEASE criteria at this stage takes into account funding constraints and findings from previous research, for example the potential for mass media interventions to increase socioeconomic disparities in lung cancer outcomes, and limited budget for the intervention.

All population level modes of delivery were considered not affordable for this PhD. Telephone (text and helpline) and computer programme modes of delivery were considered to be impractical and not affordable for this PhD, and are currently available through the Welsh based cancer charity Tenovus Cancer Care. Face-to-face individual and group intervention modes of deliveries were considered the most appropriate in the current context. Due to the potential cost effectiveness of targeting multiple recipients in one session, a group based face-to-face intervention was selected (Figure 7.4).

Mode of delivery				Does the mode of delivery meet the APEASE criteria (Table 7.3)?
Face-to-face	Individual			
	Group			x
Distance	Population-level	Broadcast media	TV	
			Radio	
		Outdoor media	Billboard	
			Poster	
		Print media	Newspaper	
			Leaflet	
	Digital media	Internet		
		Mobile phone app		
	Individual-level	Phone	Phone helpline	
			Mobile phone text	
		Individually accessed computer programme		

Shading represents modes of delivery that were considered against the APEASE criteria. The 'x' represents the mode of delivery that was selected to deliver the intervention in this context using the APEASE criteria.

Figure 7.4 Mode of delivery matrix (adapted from Michie et al. 2014, p.178).

7.3.4 Intervention design

The intervention was developed to reflect the results from each stage of the Behaviour Change Wheel. Intervention content was developed in accordance with the results from Stage 2, using findings from the intervention functions matrix, the Behaviour Change Techniques Taxonomy and the barriers to lung cancer symptom presentation highlighted in the previous studies and sources of behaviour matrix. The mode of intervention delivery was developed in conjunction with the results from the review of interventions described in Chapter 6 and the mode of delivery matrix. These helped to identify which intervention mode of delivery was most appropriate in this context. A draft intervention specification and protocol was then developed.

The findings of the Behaviour Change Wheel mapping and draft intervention specification were presented at the Healthcare Quality group weekly meeting comprising of a mixture of healthcare professionals and academic researchers with expertise in health psychology, social sciences and epidemiology. This meeting was used to gain feedback at an early stage regarding the concept and feasibility of the intervention, and intervention content. The intervention content was developed and amended following this meeting and discussion with supervisors. Intervention content was developed in accordance with the updated NICE guidelines for referral of suspected lung cancer (NICE, 2015) and information on key websites such as NHS Choices (www.nhs.uk, accessed 18.04.2016) and CRUK (www.cancerresearchuk.org, accessed 18.04.2016) to ensure that messaging was consistent with current guidelines. Intervention content was fact checked for clinical accuracy by a GP working in a deprived area and a secondary care respiratory physician. The near-final version was piloted with two lay members of the public. Adjustments were made accordingly to reduce the length of the intervention. The cancer charity Tenovus Cancer Care who funded this PhD approved the intervention and allowed their logo to be used on intervention slides and materials.

Format and target group

A community based “lung health information session” group educational intervention designed to encourage earlier lung cancer symptom presentation was developed. The intervention was intended to be delivered to up to ten attendees per session via a scripted PowerPoint presentation (see Appendix 24 for slides and corresponding script). The group size was limited to ten to ensure that the group was small enough for attendees to feel able to participate in the group, as a group larger than ten could be considered intimidating for participants.

As previously discussed, the intervention target group was selected to reflect the population in which lung cancer is most common. The intervention was targeted at individuals living in deprived communities in Wales, defined as individuals living in a Communities First area. Those who are over the age of 40 were eligible to take part in the intervention to reflect the NICE guidelines (NICE, 2015) for referral of suspected lung cancer. Current smokers, former smokers and family members of smokers were eligible to attend the intervention due to the increased risk associated with smoking and lung cancer. Smokers are a difficult group to engage in health interventions and are often more isolated (Hiscock *et al*, 2012; Rutten *et al*, 2011). In order to reach those most in need, usually in the “hardest to reach” contexts, social networks were used as a strategy to reach these people, therefore family members of smokers were included as part of this intervention.

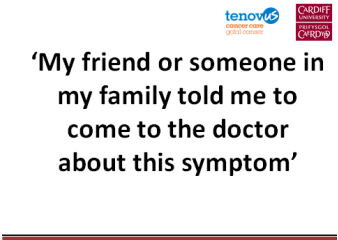
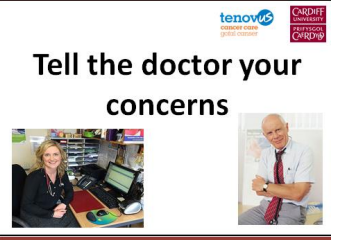







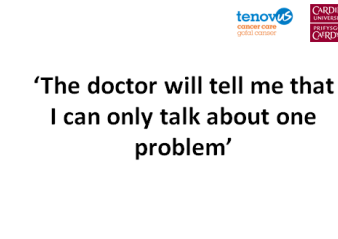
Content


















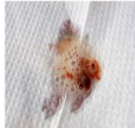





Intervention content was developed to reflect the behaviour change techniques identified from the Behaviour Change Wheel (Table 7.4). Intervention content included information about the basic biology of lung cancer, who is most at risk for developing lung cancer, information to combat negative beliefs about lung cancer, the benefits of early diagnosis, the symptoms of lung cancer, when to go to the GP with symptoms of lung cancer, information about what happens at primary care and secondary care, strategies to overcome reported barriers to symptom presentation, strategies to facilitate communication of symptoms during a consultation, how to notice symptoms of lung cancer other people in the community and what advice to give them. For example, ‘information about health consequences’ was selected as a behaviour change technique; therefore, the

intervention content was developed to include information about what to expect when an individual presents with symptoms of lung cancer at primary and/or secondary care, in addition to information about the importance of early diagnosis. Table 7.4 includes a full list of identified behaviour change techniques and corresponding intervention content and examples of slides.

At the end of the session, attendees were given a handout to take away with them which included information about the symptoms of lung cancer, when to go to the doctor and information about the benefits of early diagnosis (see Appendix 25). Attendees were encouraged to take this to their GP, if or when they were attending about a relevant symptom, to facilitate communication during a consultation. Information about smoking cessation was not included in the intervention content. It was felt smoking cessation information may act as a potential deterrent for participation in the intervention, following findings from the focus group study (Chapter 6) where people in the community were reluctant to give up smoking or attend smoking cessation sessions. However, acceptability of including information about smoking cessation was incorporated into the user testing focus group, and stop smoking service information was provided at the end of the session for those who requested it.

Table 7.4 Selected behaviour change techniques (adapted from Michie et al, 2014, p259-283) and corresponding intervention content with relevant intervention materials.

Behaviour Change Technique	Intervention content	Slides (Appendix 24 for corresponding script/ Appendix 25 for handout)
<p>1.1 Goal setting (behaviour) <i>Definition: set or agree a goal defined in terms of the behaviour to be achieved</i></p>	<p>-Set a goal for participants: to tell the doctor about symptom concerns at a consultation -Set a goal for participants: ask participants to advise others in the community to go to the doctor with a symptom(s) of lung cancer if they notice symptom(s) in others</p>	<div style="display: flex; justify-content: space-around;"> <div style="text-align: center;">  <p>'My friend or someone in my family told me to come to the doctor about this symptom'</p> </div> <div style="text-align: center;">  <p>Tell the doctor your concerns</p> </div> </div>
<p>1.2 Problem solving <i>Definition: Analyse or prompt the person to analyse factors influencing the behaviour and generate or select strategies that include overcoming barriers and/or increasing facilitators</i></p>	<p>-Highlight the difficulty associated with knowing when to present with vague symptoms (to overcome this give participants advice on how to know which and when symptoms need medical help e.g. knowing what is normal for you, multiple symptoms) -Suggest participants go to an appointment with the symptomatic family member/friend as a strategy to overcome barriers to symptom presentation -Present various strategies to overcome the commonly reported barriers to symptom presentation in the barriers section</p>	<div style="display: flex; justify-content: space-around;"> <div style="text-align: center;">  <p>Anything unusual</p>  </div> <div style="text-align: center;">  <p>Changes to current symptoms</p>  </div> <div style="text-align: center;">  <p>Any new symptoms</p>  </div> </div> <div style="display: flex; justify-content: space-around; margin-top: 20px;"> <div style="text-align: center;">  <p>What stops people going to the doctor?</p> </div> <div style="text-align: center;">  <p>'The doctor will tell me that I can only talk about one problem'</p> </div> </div>

		  <p>'I get into an appointment and forget what to say'</p>	  <p>'My doctor won't take me seriously- they will just fob me off and tell me I have a cold'</p>	  <p>'My doctor will tell me to stop smoking'</p>
		  <p>'I'm too scared to go to the doctor'</p>	  <p>What can you take with you to an appointment?</p> 	
<p>1.4 Action planning Definition: prompt detailed planning of performance of the behaviour (must include at least one of context, frequency, duration and intensity). Context may be environmental (physical or social) or internal (physical, emotional or cognitive)</p>	<p>-Clear information about when to go to the GP with a symptom on session slides and hand-out -Information on what advice participants might give someone with symptoms in the hypothetical scenarios, followed by appropriate advice (see script, Appendix 24)</p>	  <p><u>A cough</u></p>  <ul style="list-style-type: none"> -For 3 weeks or more -Or a change in normal cough <p><u>Go and see the doctor</u></p> 	  <p><u>Coloured or bloody phlegm</u></p>  <ul style="list-style-type: none"> -If you notice any blood in phlegm -A change in colour of phlegm <p><u>See the doctor straight away</u></p> 	  <p><u>Shortness of breath</u></p>  <ul style="list-style-type: none"> -Feeling as though you can't catch your breath -If gradual- see your doctor after 3 weeks. -If sudden- see your doctor straight away. 

Chest pain



-A pain in your chest
-Go and see the doctor straight away



Weight loss



-Losing weight but not meaning to for the past 3 weeks
-Can't explain why you've lost weight

Go and see the doctor



Loss of appetite



If you've noticed a loss of appetite for 3 weeks or more and can't explain why

Go and see the doctor



Feeling tired



-Feeling tired all the time for 3 weeks or more but can't explain why

Go and see the doctor



Activity: What advice would you give to these people?



Susan is 60, she is one of your neighbours. She has smoked for as long as you have known her. She has always had what she calls a 'smokers cough', but over the past few months you have noticed that this has got worse and that she keeps saying she is tired. When you asked her if she has been to the doctor, she said that she hasn't because it is 'just her smoker's cough' and she has 'had a lot on recently' which is why she is tired. What would you do in this situation?













You work with Aled. He is 25 and smokes. He has had a cough for a couple of months and hasn't been to the doctor. What would you do in this situation?





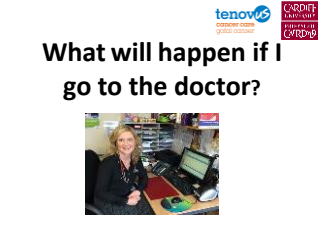



Ivor is 65 and used to smoke (he gave up a few years ago). Recently, he has had lots of chest infections. He keeps going to the doctor and they keep giving him antibiotics, which he is taking, but the chest infection has not gone or comes back quickly. He has asthma, so thinks it could be something to do with this. What would you do in this situation?



<p>2.3 Self-monitoring of behaviour</p> <p>Definition: Establish a method for the person to monitor and record their behaviour(s) as part of a behaviour change strategy</p>	<ul style="list-style-type: none"> -Encourage participants to understand what is 'normal' for them when talking about symptom detection (developing awareness of self and others) -Encourage participants to write a list of symptoms and duration of symptoms to take to the GP 	

<p>2.5 Monitoring outcome(s) of behaviour by others without feedback</p> <p>Definition: Observe or record outcomes of behaviour with the person's knowledge as part of a behaviour change strategy</p>	<p>-Information on how participants can monitor whether the symptomatic family member/friend they told to go to the GP with a symptom has been to the GP or not (see script for corresponding slides, Appendix 24)</p> <p>-Encourage participants to notice any changes to symptoms/new symptoms in symptomatic family member/friend in the community at two different time points (from when you first noticed symptoms to the next time the participant sees them)</p>	 <p>Changes to current symptoms</p>   <p>A chest infection which won't go away</p> 	 <p>Any new symptoms</p>   <p>A chest infection which won't go away</p> 	 <p>Anything unusual</p>   <p>A chest infection which won't go away</p> 
<p>3.1 Social support (unspecified)</p> <p>Definition: Advise on, arrange or provide social support (e.g. from friends, relatives, colleagues, buddies, or staff) or non-contingent praise or reward for performance of the behaviour. It includes encouragement and counselling, but only when it is directed at the behaviour.</p>	<p>-Information on when participants should encourage symptomatic family member/friends in the community to go to the doctor with a symptom(s)</p> <p>-Advice giving in the scenario exercise</p>	<p>Activity:</p> <p>What advice would you give to these people?</p> <hr/> <p>Ivor is 65 and used to smoke (he gave up a few years ago). Recently, he has had lots of chest infections. He keeps going to the doctor and they keep giving him antibiotics, which he is taking, but the chest infection has not gone or comes back quickly. He has asthma, so thinks it could be something to do with this. What would you do in this situation?</p>	<p>Susan is 60, she is one of your neighbours. She has smoked for as long as you have known her. She has always had what she calls a 'smokers cough', but over the past few months you have noticed that this has got worse and that she keeps saying she is tired. When you asked her if she has been to the doctor, she said that she hasn't because it is 'just her smoker's cough' and she has 'had a lot on recently' which is why she is tired. What would you do in this situation?</p>	<p>You work with Aled. He is 25 and smokes. He has had a cough for a couple of months and hasn't been to the doctor. What would you do in this situation?</p>

<p>3.2 Social support (practical) Definition: Advise on, arrange, or provide practical help (e.g. from friends, relatives colleagues, buddies or staff) for performance on behaviour</p>	<p>-Advise the participant to offer practical help to symptomatic family member/friends in the community to get to an appointment or accompany someone to an appointment (see script for corresponding slides, Appendix 24)</p>			
<p>4.1 Instruction on how to perform behaviour Definition: Advise or agree on how to perform the behaviour (includes skills training)</p>	<p>-Information on how to detect coloured or bloody phlegm -Advice on what to say during a consultation and what participants can take with them to aid communication -Advice on how to request an earlier appointment from the receptionist if particularly worried about symptom</p>			
				

5.1 Information about health consequences

Definition: Provide information (e.g. written, verbal, visual) about health consequences of performing the behaviour

- Information about early diagnosis and survival outcomes (throughout the presentation and during the true/false activity)
- Information about diagnostic testing for lung cancer and what to expect at primary and secondary care
- Information about the treatment for lung cancer
- Advise that being upfront about symptom concerns during a consultation with the GP can help in the longer term

Activity:
True or false?

'There is no treatment for lung cancer'

True or **false**?

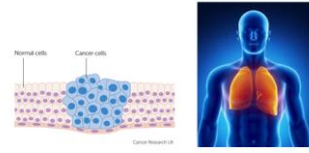
'If you catch lung cancer in the early stages it can be cured'

True or false?

'When air gets to cancer it can make the cancer spread'

True or **false**?

Lung cancer



What will happen if I go to the doctor?




Tell the doctor your concerns

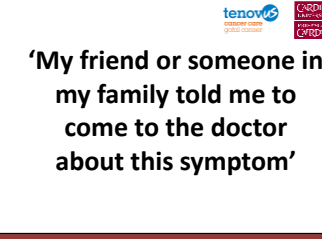
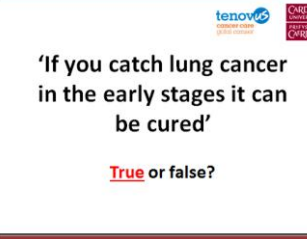
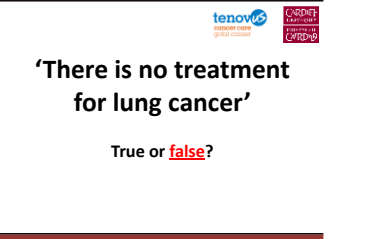
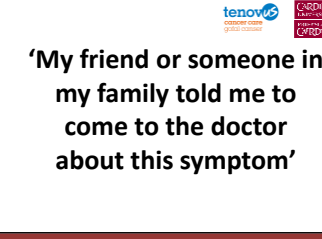
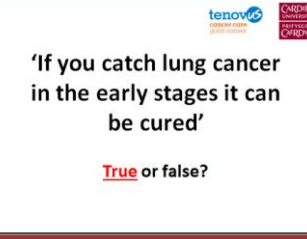




tenovus **CARDIFF**
cancer care **tenovus** **CARDIFF**
great cancer **tenovus** **CARDIFF**

If lung cancer is found early it is easier to treat and people are more likely to survive

Are you 40 or older and currently smoke or used to smoke?
If so, go and see your doctor if you have any of these symptoms. It could be nothing, but its best to get it checked out. Tell your doctor your concerns.

 <p>Have you had a cough for 3 weeks or more or has your cough changed? Go and see your doctor.</p>	 <p>Do you have blood in your phlegm or has it changed colour? Go and see your doctor.</p>
 <p>Do you have chest pain? Go and see your doctor.</p>	 <p>Have you suddenly been short of breath or have you noticed over the last 3 weeks you are short of breath? Go and see your doctor.</p>
 <p>Have you lost your appetite for 3 weeks or more and can't explain why? Go and see your doctor.</p>	 <p>Have you been losing weight without trying to for 3 weeks or more. Go and see your doctor.</p>
 <p>Have you been feeling tired for 3 weeks or more and can't explain why? Go and see your doctor.</p>	<p>Go to your doctor if you notice anything like any changes or a chest infection which won't go away.</p>

<p>5.2 Salience of consequences Definition: Use methods specifically designed to emphasise the consequences of performing the behaviour with the aim of making them more memorable (goes beyond informing about consequences)</p>	<p>-Similar to 'Information about health consequences' but more emphasis on earlier diagnosis to save their lives and later stage disease at diagnosis means a cure is less likely -Information about why it is important to go to the GP quickly with a lung cancer symptom and the consequences of early diagnosis (improved chances of survival and better access to treatment options)</p>			
<p>5.3 Information about social and environmental consequences Definition: Provide information (e.g. written, verbal, visual) about the social and environmental consequences of performing the behaviour</p>	<p>-Intervention content associated with a 'community responsibility' type intervention. Information about earlier diagnosis of lung cancer in the community can promote better lung cancer survival in the community and this can be achieved through noticing symptoms in symptomatic family member/friends in the community and encouraging them to go to the doctor with symptoms</p>			

<p>7.1 Prompts and cues</p> <p>Definition: Introduce or define environmental or social stimulus with the purpose of prompting or cueing the behaviour. The prompt would normally occur at the time or place of performance.</p>	<p>-Hand out with simple information on what symptoms to look out for and when to go to the doctor with these symptoms.</p>	
<p>9.1 Credible sources</p> <p>Definition: Present verbal or visual communication from a credible source in favour of or against behaviour</p>	<p>-Information and some pictures from CRUK, NICE or NHS website. Fact checking by clinicians. -Tenovus and Cardiff University logo on hand out and slides</p>	<p>All slides and handout created with credible sources</p>

Intervention delivery

Throughout the intervention session, information was delivered to attendees through various activities and verbal presentations of information. For example, attendees were asked to participate in a true/false activity which was designed to modify negative beliefs about lung cancer. Attendees were presented with a quote such as 'there is no treatment for lung cancer' and asked if they believed the statement to be true or false. This was followed by the correct answer and verbal information about why each statement is true or false. The session was designed to be as interactive as possible, and slides were developed with visual images and minimal text for participants who were likely to have low literacy levels.

The intervention content was delivered entirely in the third person as a community responsibility intervention. For example 'if you *know someone in the community* who has a symptom of lung cancer...' was used rather than 'if *you* have a symptom of lung cancer...'. Information was framed in the third person in an attempt to avoid placing any potential blame on the individual attending the intervention, particularly if they smoke or used to smoke, and to mobilise social networks. Findings from Chapters 3, 4 and 5 suggested that people utilise a lay system of healthcare before seeking medical help from their GP, which can be problematic among low socioeconomic groups if advice is sought from someone in the community with poor knowledge and negative beliefs about cancer. The intervention attempted to use these strong social networks to disseminate intervention messages within the community and ask attendees to encourage high risk individuals in the community to go to their GP with symptoms. This strategy was used in an attempt to prompt other symptomatic individuals who may not have attended an intervention about lung cancer to present to the GP with symptoms.

This follows the approach used by "gay hero" and ASSIST interventions, based around the diffusions of innovations theory (Rogers, 1983), where the most popular members of a defined community are recruited as peer educators (Hart and Elford, 2003; Campbell *et al*, 2008). The peer educators receive a training educational session designed to provide information about the dangers of unprotected sex and smoking and are asked to communicate these messages to peers within their network (Hart and Elford, 2003;

Campbell *et al*, 2008). For the school based ASSIST intervention, teachers are asked to identify who is the most popular in a given year group and for the safe sex intervention with gay men, the bartenders of a local gay bar are asked to identify who is the most popular (Hart and Elford, 2003; Campbell *et al*, 2008). It was considered unfeasible to identify a community champion from a Communities First area, since the geographical area is large and usually the number of people living in a given area is too big to take a percentage of those to recruit as peer educators. Therefore, the decision was made to engage higher risk individuals or family members of high risk individuals to deliver key messages in the community.

After attendees were given information about the symptoms of lung cancer and when to go to the GP with symptoms, the group was given three hypothetical scenarios which included information about symptomatic individuals, their age, gender and smoking status. Attendees were asked to discuss what information they would give each individual, followed by information from the facilitator about what the symptoms could indicate and what appropriate advice should be given. Two scenarios were designed to fit the NICE guidelines for referral (NICE, 2015) where symptomatic individuals were high risk, and one scenario was designed to not fit the NICE guidelines for referral where the symptomatic individual was low risk (the individual was age 25). The scenario exercise was intended to simulate what might happen in a normal situation and facilitate good, accurate advice to be given to people in the community.

7.4 Discussion

A community based group educational intervention was developed to encourage earlier lung cancer symptom presentation among low socioeconomic groups. Capability, Motivation and Opportunity were identified as influences on lung cancer symptom presentation behaviour among low socioeconomic groups. Based on these findings, the intervention functions of education, persuasion, training, enablement, modelling and environmental restructuring were considered most relevant to encouraging timely lung cancer symptom presentation behaviour. The intervention session content was developed in accordance with thirteen selected behaviour change techniques and contained information about lung cancer, who is most at risk for lung cancer, the symptoms of lung cancer, when to go to the GP with a symptom of lung cancer, information to combat negative beliefs about cancer and strategies

to overcome the barriers to lung cancer symptom presentation. PowerPoint slides and a corresponding script (Appendix 24) were created in accordance with the behaviour change techniques identified from the Behaviour Change Techniques Taxonomy (Michie *et al*, 2013). The intervention was scripted and framed in the third person in order to reduce stigma and remove any potential perceptions of blame away from the individuals attending the group, particularly if they smoke or used to smoke. In addition, the intervention was designed to utilise strong social networks within the community and was framed in the third person as a 'community responsibility' intervention to disseminate intervention messages (Rogers, 1983). This approach was selected in order for intervention messages to reach people in the community who are unlikely to attend such an intervention and encourage higher risk symptomatic individuals to present quickly to the GP with symptoms suggestive of lung cancer. However, it is possible that the third person approach could have unintended consequences. For example, those who attend the intervention may not relate to the intervention messages and consequently overlook symptoms. Alternatively, symptomatic friends and family may not be receptive to advice from those who attended the intervention with the intention of promoting a visit to the doctor.

7.4.1 The Behaviour Change Wheel as a framework for intervention development

The systematic nature of the Behaviour Change Wheel and strong theoretical underpinning of the framework were strengths. In addition, the inclusion of an analysis of the target behaviour using the COM-B model was a strength of the Behaviour Change Wheel due to the applicability of the model in this context as discussed in Chapters 2, 4 and 5. This enabled a broad and full range of behaviour change techniques, mode of delivery and intervention type to be considered for intervention development in the context of promoting timely cancer symptom presentation among low socioeconomic groups. The APEASE criteria were particularly useful when helping to narrow down the options identified at each stage of the Behaviour Change Wheel, facilitated by clear definitions of the criteria. In addition, the systematic process by which intervention components are selected or rejected using the APEASE criteria was useful. The APEASE criteria provided a framework for reporting rationale for the decisions for why certain components were included or excluded, increasing research rigour.

Although there were a number of strengths of the Behaviour Change Wheel, some limitations regarding usability of the framework were identified. The Behaviour Change Wheel was developed to be applied to all behaviour change interventions contexts, and as a consequence, many of the definitions and aspects of the framework were vague, similar or overlapping, which presented difficulty with mapping at each stage. Specifically, definitions for the Behaviour Change Techniques Taxonomy, policy categories and intervention function categories were short and often supported with only one example. In addition, many of the behaviour change techniques outlined in the Taxonomy were similar, and choosing between which behaviour change techniques to select for the intervention was challenging due to sometimes vague and overlapping definitions. Since its initial development, validation studies of Behaviour Change Wheel have highlighted 12 of the behaviour change techniques definitions which require further refinement and clarity in future revisions (Michie *et al*, 2015). Therefore, amended versions of the Behaviour Change Techniques Taxonomy are likely to overcome some of the problems experienced in the present intervention development study. Furthermore, studies suggest that formal training in the Behaviour Change Wheel can improve coder reliability (Michie *et al*, 2015). The PhD researcher did not undergo any formal training using the Behaviour Change Wheel, instead the researcher relied on the Behaviour Change Wheel book (Michie *et al*, 2014), published papers (Michie *et al*, 2011; Michie *et al*, 2015; Cane *et al*, 2015), and supervision in the Behaviour Change Wheel process in the boarder ABACus study. However, the ABACus intervention was not specific to intervention development for this PhD. Using the Behaviour Change Wheel resources presented difficulty at times as it was unclear how some of the stages linked with one another, since the written documents were challenging to follow and understand how they linked. For example, it was unclear at which point the Behaviour Change Techniques Taxonomy should be used.

Finally, mapping components and information at each stage of the Behaviour Change Wheel is subjective in nature. The researcher is required to make subjective assessments based on guidelines outlined in the Behaviour Change Wheel to guide selection of intervention components at each stage. As previously discussed, many of the definitions were vague which has implications for increased subjectivity during the Behaviour Change Wheel process. Future revisions of the intervention should seek to dual code each stage of the mapping process to reduce subjectivity.

7.4.2 Strengths and limitations

Intervention development followed the MRC framework and Behaviour Change Wheel which are both highly regarded frameworks for the development of interventions. When mapping the sources of behaviour, only the lung specific barriers and facilitators to timely symptom presentation were extracted from data sources that were not restricted or specific to lung cancer only. Therefore, it is possible that some of the barriers and facilitators specific to lung cancer could have been missed or some of the more general barriers were not specific enough in this context. Future research should explore lung specific barriers to cancer symptom presentation, particularly among smokers. In addition, dual coding was not performed at any stage of the Behaviour Change Wheel, which as previously discussed has potential implications for subjectivity and potential for miscoding. In order to increase rigour, each stage of the Behaviour Change Wheel should be dual coded. Finally, selection of relevant aspects at each stage of the Behaviour Change Wheel was carried out by the PhD researcher using the APEASE criteria. Local stakeholders could provide additional input with regard to which aspects of intervention format, delivery and content would be most appropriate. Future intervention development using the Behaviour Change Wheel should consider completing the process with local stakeholders.

7.5 Conclusion

The Behaviour Change Wheel was a useful framework for the development of a lung cancer awareness intervention targeted at smokers and former smokers from a low socioeconomic group. A community group based educational 'lung health information session' intervention was developed to increase lung cancer symptom knowledge, modify negative beliefs, offer practical strategies to overcome barriers to cancer symptom presentation and encourage timely symptom presentation by utilising strong social networks in the community. Intervention acceptability testing with a group of potential users will be reported in Chapter 8.

Chapter 8

Intervention acceptability testing with a group of potential users

8.1 Chapter overview

The 'lung health information session' was carried out with two groups of potential intervention users identified and recruited through community partners. Findings from the intervention acceptability testing study, which used a multiple methods approach, will be reported in this chapter. Implications and recommendations for the intervention in the future will be explored.

8.2 Introduction

The development of a 'lung health information session' using the Behaviour Change Wheel (Michie *et al*, 2014) in accordance with the Medical Research Council (MRC) framework guidance (Craig *et al*, 2008) was reported in Chapter 7. The group based educational session was designed to improve lung cancer symptom knowledge, modify negative beliefs about lung cancer and empower individuals to seek medical help for symptoms to promote timely lung cancer symptom presentation behaviour. In addition, a community responsibility aspect was integrated into the intervention to mobilise social networks and facilitate good quality advice following symptom disclosure or noticing of symptoms.

As discussed in Chapter 1, the MRC framework highlights the importance of conducting feasibility and pilot studies before controlled evaluation studies and/or implementation are considered. Feasibility studies require testing the intervention with potential users to gain views on the acceptability of the intervention format, content and delivery, and evaluation outcome measures used. In addition, feasibility studies can be used to highlight potential recruitment issues before further pilot studies and controlled evaluation are carried out.

This chapter presents findings from an intervention acceptability testing study with a group of potential users. As discussed in Chapter 7, the target group was defined as adults aged over 40 years living in socioeconomically deprived areas, who are current smokers or ex-smokers, or are family members of smokers. Potential users were recruited opportunistically via community partners to participate in the intervention session, and a multiple methods approach was used to assess intervention acceptability. Focus groups and observational

methods were used to gain views on the intervention format and content, and assess group attentiveness. An adapted version of the Lung Cancer Awareness Measure (CAM; Simon *et al*, 2012a) was selected as the quantitative measure to assess changes in outcomes measured pre to post intervention and acceptability of outcome measures. The Lung CAM is a validated tool designed to assess lung cancer knowledge, confidence in detecting a symptom and anticipated lung symptom presentation behaviour, and was selected because most of the items aligned well with the aims of the lung health information session. In the absence of relevant Lung CAM items, additional items adapted from the Awareness and Beliefs about Cancer Measure (ABC; Simon *et al*, 2012b) were included in the pre and post questionnaire measures in order to reflect intervention content designed to modify negative beliefs about lung cancer and provide information on how to detect symptoms in others. In order to reduce the burden on participants, items that were not directly relevant to the content of the intervention were removed (for example, environmental risk factors for lung cancer such as radon gas).

Lung CAM items to assess knowledge of lung cancer symptoms using both prompted recognition and unprompted recall remained in the adapted version were used for the current study. Although the intervention content was limited to nine potential lung cancer symptoms (NICE, 2015), all 14 Lung CAM symptoms listed in the recognition task were retained in order to measure change in knowledge of symptoms that were targeted by the intervention, as well as to observe potential response bias associated with those symptoms that were not targeted. In addition, some symptoms targeted by the intervention were specific, such as haemoptysis, and others were non-specific, such as persistent cough and tiredness. Non-specific symptoms of lung cancer are the most poorly recalled or recognised in comparison to specific symptoms (Crane *et al*, 2016; Simon *et al*, 2012a), and often are misattributed to other benign causes and medical help seeking prolonged (Carter-Harris, 2015; Tod and Joanne, 2010). It was therefore considered important to assess change in knowledge of both specific and non-specific lung cancer symptoms.

8.2.1 Aim and hypotheses

The aim of the present study was to test the lung health information session for acceptability with a group of potential users. It was hypothesised that recognition and recall of symptoms (both specific and non-specific) that were targeted by the intervention would improve after exposure to the intervention, compared to non-targeted symptoms. In addition, it was hypothesised that participants would report higher confidence in detecting

symptoms in themselves and others, and more positive beliefs about lung cancer, and that anticipated lung symptom presentation would be aligned with the NICE guidance and intervention messaging after exposure to the intervention.

8.3 Methods

8.3.1 Participants

The final version of the intervention (Appendix 24) was piloted with potential users to assess acceptability. Ethical approval was obtained from the School of Medicine Ethics committee (SMREC Ref 16/11, see Appendix 26). Community partners were contacted through existing Communities First links from the Awareness and Beliefs About Cancer (ABACus) focus group study, and via a GP and staff member in a local hospital Research and Development department. Community partners were contacted to request assistance with recruiting members of the community to take part in the study according to the following criteria: individuals living in a Communities First area, over the age of 40 and who were current or ex-smokers, or family members of smokers. As described in Chapter 7, these criteria were selected in order to identify participants who would be most likely to represent the intervention target group. Community partners were given study information sheets and flyers to distribute to potential participants with detailed information about the study (see Appendix 27 and 28). All participants were given a £15 shopping voucher to thank them for their time.

8.3.2 Procedure

After the community partner invited potential participants to take part in the intervention, the PhD researcher was notified of those who were interested in taking part. A mutually convenient time and date for the intervention user testing study was arranged. The community partner passed the time, date and venue details on to potential participants on behalf of the researcher. Intervention user testing took place in community centre venues within the community partners' area, to ensure that the study took place close to where participants lived. Conference or meeting rooms in the community centre were hired to conduct the intervention.

On the day of the study, participants provided written informed consent and were then asked to complete an adapted Lung CAM (Simon *et al*, 2012a) at baseline before the intervention session started, and directly after the intervention session (see Appendix 29 and 30). After completion of the baseline questionnaire, participants took part in the intervention session. After completion of the post intervention questionnaire and a break for lunch, participants took part in a focus group. All participants were fully consented and debriefed. Permission to audio record the intervention session and focus group was obtained.

8.3.3 Ethical issues

During the intervention introductory slides, participants were reminded that the facilitator was not medically qualified to provide advice for symptoms on an individual basis. Those who asked for advice on symptoms were signposted to the appropriate medical service. All participants were given the Tenovus Cancer Care phone number and PhD researcher's contact details should they have any further questions about cancer after the intervention. Individuals who appeared upset during the intervention were reminded that they could leave at any point.

8.3.4 Data collection

Three types of data were collected during user testing: questionnaire data, qualitative focus group data and group observational data.

8.3.5.1 Questionnaire measures

As previously discussed, the questionnaire was adapted from the Lung CAM (Simon *et al*, 2012a) to include questions that were targeted by the intervention (Appendix 29 and 30). The Lung CAM has shown good internal reliability (Cronbach's $\alpha=0.88$) and test-retest reliability ($r=0.81$, $p<0.001$) (Simon *et al*, 2012a). Two additional questions (seven statements in total) which were not previously included in the Lung CAM were included to assess confidence in detecting a symptom in others, and beliefs about lung cancer (Appendix 29 and 30). Measures included:

(a) Symptom knowledge

Participants were asked one open-ended question and a set of closed questions to measure lung cancer symptom awareness. The open-ended question measured symptom recall as follows: “*There are many warning signs and symptoms of lung cancer. Please name as many as you can think of*”. The closed question measured symptom recognition: “*The following may or may not be warning signs of lung cancer. We are interested in your opinion*”. Fourteen symptoms were listed, all of which are possible symptoms of lung cancer generated from a review of the literature and cancer websites (Simon *et al*, 2012a). Response options for each symptom were ‘yes’, ‘no’, ‘don’t know’. Each closed question response was dichotomised into *correct* (response ‘yes’) or *incorrect* (response ‘no’/‘don’t know’). ‘No’ and ‘don’t know’ responses were grouped together due to a small number of ‘don’t know’ responses. Responses to the open ended recall questions were recorded verbatim and analysed thematically, and grouped into 14 categories to accord with the 14 symptoms listed in the recall question. Responses were classed as *correct* or *incorrect* based on the NICE guidelines for suspected lung cancer and the symptoms listed in the recognition section. Correct responses for both questions were summed to create recall and recognition scores, respectively (total score range 0-14).

Nine of the 14 symptoms included in the questionnaire were targeted by the intervention: persistent cough, change/worsening of cough, shortness of breath, unexplained weight loss, chest infection that won’t go away, persistent tiredness or lack of energy, chest pain, loss of appetite, and coughing up blood. The remaining five symptoms were not targeted by the intervention: high pitched sound when breathing, painful cough, change in shape of fingers/nails, shoulder pain, and ache/pain when breathing. Correct responses were summed for both recall and recognition of targeted symptoms (score range 0-9) and non-targeted symptoms (score range 0-5).

Of the nine lung cancer symptoms targeted by the intervention, five were non-specific (persistent cough, change/worsening of cough, unexplained weight loss, persistent tiredness/lack of energy, loss of appetite), and four were specific (shortness of breath, chest infection that won’t go away, chest pain, coughing up blood). Correct responses were summed for recall and recognition of non-specific symptoms (score range 0-5) and specific symptoms (score range 0-4) to assess change pre to post intervention.

(b) Anticipated symptom presentation behaviour

Participants were asked one closed question to assess anticipated time to lung cancer symptom presentation: *“If you had a symptom which you thought might be a sign of lung cancer, how soon would you go to your doctor to talk about it?”* There were six response options: *‘I would go as soon as I noticed the symptom’*, *‘I would go within 1 week’*, *‘I would go between 1 and 2 weeks’*, *‘I would go between 2 and 3 weeks’*, *‘more than 1 month’*, and *‘I would not contact my doctor’*.

For analysis purposes, response options were grouped into categories that mirrored as closely as possible the advice given during the intervention, i.e. to seek medical help if a symptom persisted for three weeks or more. Since the Lung CAM response options were not directly aligned to intervention content, responses were grouped into three categories: *under two weeks* (including responses *‘I would go as soon as I noticed the symptom’*, *‘I would go within 1 week’* and *‘I would go between 1 and 2 weeks’*), *over two weeks* (*‘I would go between 2 and 3 weeks’* and *‘more than one month’*), and *I would not contact my doctor*.

(c) Confidence in noticing a symptom of lung cancer

Confidence in noticing a symptom of lung cancer was assessed using two closed questions: *“How confident are you that you would notice a symptom of lung cancer?”* and *“How confident are you that you would notice a symptom of lung cancer in someone else?”* There were four response options to both questions: *‘not at all confident’*, *‘not very confident’*, *‘fairly confident’*, and *‘very confident’*. Response options were merged to create binary variables reflecting *higher confidence* (*‘fairly confident’* or *‘very confident’*) and *lower confidence* (*‘not very confident’* or *‘not at all confident’*) in self and others, respectively

(d) Beliefs about lung cancer

Beliefs about lung cancer were measured using a list of six statements which were anchored to the question: *“For each statement below can you tell us how much you agree or disagree with each item”*. The six statements were: *‘Lung cancer can often be cured’*, *‘Most lung cancer treatment is worse than the cancer itself’*, *‘I would not want to know if I have lung cancer’*, *‘Going to the doctor as quickly as possible after noticing a symptom of lung cancer could increase the chances of surviving’*, *‘People who are important to me would want me to go to the doctor if I had a symptom of lung cancer’*,

and *'I have no control over whether or not I get lung cancer'*. Response options to each statement included: *'strongly disagree'*, *'tend to disagree'*, *'tend to agree'*, and *'strongly agree'*. Responses to each of the belief statements were dichotomised for purposes of analysis, where *'agree'* included responses *'tend to agree'* and *'strongly agree'*, and *'disagree'* included responses *'tend to disagree'* and *'strongly disagree'*.

(e) Demographic data

Demographic data including age and gender were collected post intervention only. Socioeconomic group was measured using three questions including educational attainment (*"What is your highest level of education?"*, six response options), home ownership (*"Please tick the box that best describes your home/living arrangement"*, six response options), and employment status (*"Are you currently"*, nine response options). See Table 8.1 for the full list of response options. Postcode data were used to derive Welsh Index of Multiple deprivation scores (WIMD, 2014). Smoking status was assessed by a closed ended question: *"What statement best describes your smoking status?"* There were four response options: *'I currently smoke'*, *'I used to smoke'*, *'I have never smoked'*, and *'Other (please specify)'*. Those who currently or used to smoke were asked to complete the number of cigarettes they smoke/d per day: *'0-9 per day'*, *'10-19 per day'*, *'20-29 per day'* and *'30 or more per day'*.

8.3.5.2 Observational data

Observational data were collected during delivery of the intervention session by one of the supervisory team via an observation sheet (see Appendix 31). The observational data were used to provide information on the group dynamics during the intervention and activities, note any questions people asked and comments during the group activities, and collect non-verbal information such as group attentiveness. The questions asked during the intervention were collated to inform potential additional information to be included in the intervention in the future, and to produce a list of frequently asked questions with suggested responses to complement the manualised content for future intervention facilitators.

8.3.5.3 Qualitative focus group data

The focus group was designed to explore acceptability and potential feasibility of the intervention. A semi-structured topic guide with probes was used during the focus group

(see Appendix 32). Topics included: perceived usefulness of intervention session, feasibility of intervention, content of intervention (including information about smoking cessation), comprehension of intervention content, delivery of the session, improvements for the intervention, and recruitment into the intervention.

8.3.6 Data analysis

Demographic characteristics of the sample were analysed using frequencies. Due to the small number of participants, questionnaire data including symptom recognition and recall (for targeted and non-targeted symptoms), anticipated symptom presentation, confidence and beliefs about lung cancer were analysed at baseline and post intervention using descriptive statistics (means and frequencies, as appropriate). Two participants entered the study half way through the intervention session, therefore it was not possible to collect baseline measures for these individuals. Assessment of change in outcomes was therefore only conducted for 12 participants who completed both pre and post intervention questionnaires. Item non-response, or when more than one response option was selected, were treated as missing. Responses for each measure were grouped into categories to facilitate data analysis and comparisons between participants.

Observational data collected during the intervention session were analysed thematically to identify recurrent questions, group attentiveness and engagement in the session. Focus group data were transcribed verbatim and analysed thematically to look for similar and disparate themes, supported by NVivo (NVivo 10, 2012).

8.4 Results

Eight community partners from Communities First areas in South Wales were contacted with information about the study and the study inclusion criteria to request help for study recruitment. Two of the six community partners forwarded the study details on to a total of 12 staff in their community area to facilitate study recruitment.

Fourteen members of the community were recruited in two areas to take part in the study according to the inclusion criteria (site 1, n=7; site 2, n=7). The remaining six areas were unsuccessful, mainly due to community partners being too busy to recruit people in the

community or not being able to find people to take part in the study. Reasons for members of the public not taking part in the study were reported by communities partners as not being resident in a Communities First area or being under the age of 40 years, and therefore not meeting the study inclusion criteria, or being unable to take part due to work commitments or childcare issues.

8.4.1 Sample characteristics

Participants from site 1 were all members of an existing mental health peer support group who met weekly at the community centre. They were approached by the Communities First partner and agreed that the study could take place instead of one of their weekly meetings. Participants from site 2 were recruited through an existing volunteer network in the community. Fourteen participants took part in the intervention in total across the two sites. As shown in Table 8.1, most participants were female and were ex-smokers, finished school at or before age fifteen, were retired, owned their house outright, and lived in the most deprived quartile. Thirteen out of 14 participants were over the age of 40.

Table 8.1 *Sample characteristics for acceptability testing with a group of potential users*

Variable	Number of participants (N=14)
Gender	Male (n=4) Female (n=10)
Age (years)	Mean: 63.5 (range 34-86)
Educational attainment	Finished school at or before age of fifteen (n=6) No qualifications/left school at age 16 (n=1) Completed CSEs, O-levels or equivalent (n=2) Completed A levels or equivalent (n=0) Completed further education but not degree (n=4) Completed a Bachelors degree/masters/PHD (n=0) Prefer not to say (n=0) Missing data (n=1)
Employment	Employed full-time (n=1) Employed part-time (n=1) Full-time homeowner (n=0) Retired (n=10) Unemployed (n=2) Self-employed (n=0) Still studying (n=0) Disabled or too ill to work (n=0) Prefer not to say (n=0)
Home ownership	Own outright (n=7) Own mortgage (n=0) Rent from local authority/housing association (n=6) Rent privately (n=0) Living with family/friends (n=1) Prefer not to say (n=0)
Deprivation quartiles	1 (Most deprived) (n=8) 2 (n=1) 3 (n=0) 4 (Least deprived) (n=0) Missing/incomplete data (n=5)
Smoking status	Current smoker (n=3) Former smoker (n=6) Never smoked (n=5)
Number of cigarettes smoked per day (current and former smokers)	0-9 (n=3) 10-19 (n=3) 20-29 (n=1) 30 and over (n=0) Missing data (n=2)

8.4.2 Questionnaire data

Symptom knowledge

As shown in Table 8.2, overall knowledge of the symptoms of lung cancer at baseline was good for both recall and recognition scores. For symptoms that were targeted by the intervention, recall and recognition scores were generally higher than those for symptoms not targeted by the intervention at both baseline and post intervention (Table 8.2).

Table 8.2 Symptoms correctly recalled and recognised at baseline and post intervention

Symptom	Baseline (n=12)		Post intervention (n=14)	
	Recognition	Recall	Recognition	Recall
Overall symptom knowledge, mean (range)	8.3 (4-13)	2.5 (0-4)	10 (8-14)	4 (0-7)
Targeted by the intervention, n				
Mean (range)	6.2 (3-9)	3 (0-8)	8.7 (5-9)	5 (0-10)
Persistent cough	10	8	13	10
Change/worsening of cough	8	0	14	1
Shortness of breath	8	4	11	5
Unexplained weight loss	8	1	14	7
Chest infection that won't go away	10	0	13	0
Persistent tiredness/lack of energy	7	5	13	5
Chest pain	6	4	11	7
Coughing up blood	12	5	13	6
Loss of appetite	5	0	11	4
Not targeted by the intervention, n				
Mean (range)	4.2 (2-7)	0 (0)	7.4 (2-12)	0 (0)
High pitched sound when breathing	6	0	8	0
Painful cough	7	0	11	0
Change in shape of fingers/nails	2	0	2	0
Shoulder pain	2	0	4	0
Ache/pain when breathing	4	0	12	0

For individual symptoms, the non-specific symptom 'persistent cough' was the most frequently recalled symptom at both baseline and follow-up, and was targeted by the intervention (Table 8.2). The specific symptom 'coughing up blood' was correctly recognised by all participants at baseline, whereas the non-specific symptoms of 'change/worsening of cough' and 'unexplained weight loss' were recognised by all participants post intervention (Table 8.2), and were all targeted by the intervention. A 'chest infection that won't go away' and 'change/worsening of cough' were poorly recalled symptoms at both baseline and post intervention (Table 8.2). None of the five non-targeted symptoms were correctly recalled at either time point. All five symptoms not targeted by the intervention, with the exception of 'ache/pain when breathing' and 'painful cough', were the most poorly recognised symptoms post intervention (Table 8.2).

In twelve participants who completed both questionnaires, an increase was observed pre to post intervention for both recall (two point increase) and recognition (three point increase) of lung cancer symptoms targeted by the intervention (Table 8.3). Recognition of symptoms not targeted by the intervention was also improved post intervention (two point increase), although no change was observed for recall (Table 8.3).

Table 8.3 Assessment of change for participants who completed both baseline and post intervention questionnaires

Measure	Baseline (n=12)	Post intervention (n=12)
Overall symptom knowledge, mean (range)		
Symptom recall	2.5 (0-4)	4 (0-7)
Symptom recognition	8.3 (4-13)	11 (8-14)
Knowledge of symptoms targeted by the intervention, mean (range)		
Recall of symptoms targeted by the intervention	3 (0-8)	5 (0-10)
Recognition of symptoms targeted by the intervention	6.2 (3-9)	9.2 (5-9)
Knowledge of symptoms not targeted by the intervention, mean (range)		
Recall of symptoms not targeted by the intervention	0 (0)	0 (0)
Recognition of symptoms not targeted by the intervention	4.2 (2-7)	6.2 (2-10)
Anticipated time to lung cancer symptom presentation, n		
Under two weeks	9	6
Over two weeks	2	5
Would not contact doctor	1	0
Missing/incomplete	0	1
Confidence in detecting symptom of lung cancer – self, n		
Higher confidence	5	10
Lower confidence	7	2
Missing/incomplete	0	0
Confidence in detecting symptom of lung cancer - someone else, n		
Higher confidence	5	10
Lower confidence	7	2
Missing/incomplete	0	0
Beliefs about lung cancer, n		
<i>'Lung cancer can often be cured'</i>		
Agree	4	10
Disagree	8	2
Missing/incomplete	0	0
<i>'Most treatments for lung cancer are worse than the cancer itself'</i>		
Agree	7	5
Disagree	3	5
Missing/incomplete	2	2
<i>'I would not want to know if I had lung cancer'</i>		
Agree	3	3
Disagree	9	9
Missing/incomplete	0	0
<i>'Going to the doctor quickly with a symptom of lung cancer increases the chance of survival'</i>		
Agree	10	11
Disagree	1	1
Missing/incomplete	1	0
<i>'People important to me would want me to go to the doctors with a symptom of lung cancer'</i>		
Agree	11	10
Disagree	1	2
Missing/incomplete	0	0
<i>'I have no control over if I get lung cancer or not'</i>		
Agree	6	4
Disagree	6	8
Missing/incomplete	0	0

For individual symptoms targeted by the intervention, recall and recognition were improved from baseline to post intervention for all symptoms (Figure 8.1 and Figure 8.2), with the exception of recognition of the specific symptom 'coughing up blood' due to a ceiling effect (Figure 8.1) and recall for the specific symptom 'chest infection that won't go away' and non-specific symptom 'persistent tiredness/lack of energy' (Figure 8.2) where no change was observed. The greatest improvements in symptom knowledge were observed for 'loss of appetite' and 'unexplained weight loss' (Figure 8.1 and Figure 8.2), both of which were targeted by the intervention and were non-specific symptoms. Three symptoms that were not targeted by the intervention were more likely to be recognised post intervention: painful cough, shoulder pain, and ache/pain when breathing (Figure 8.1).

Figure 8.1: Change for the number of individual symptoms correctly recognised pre to post intervention

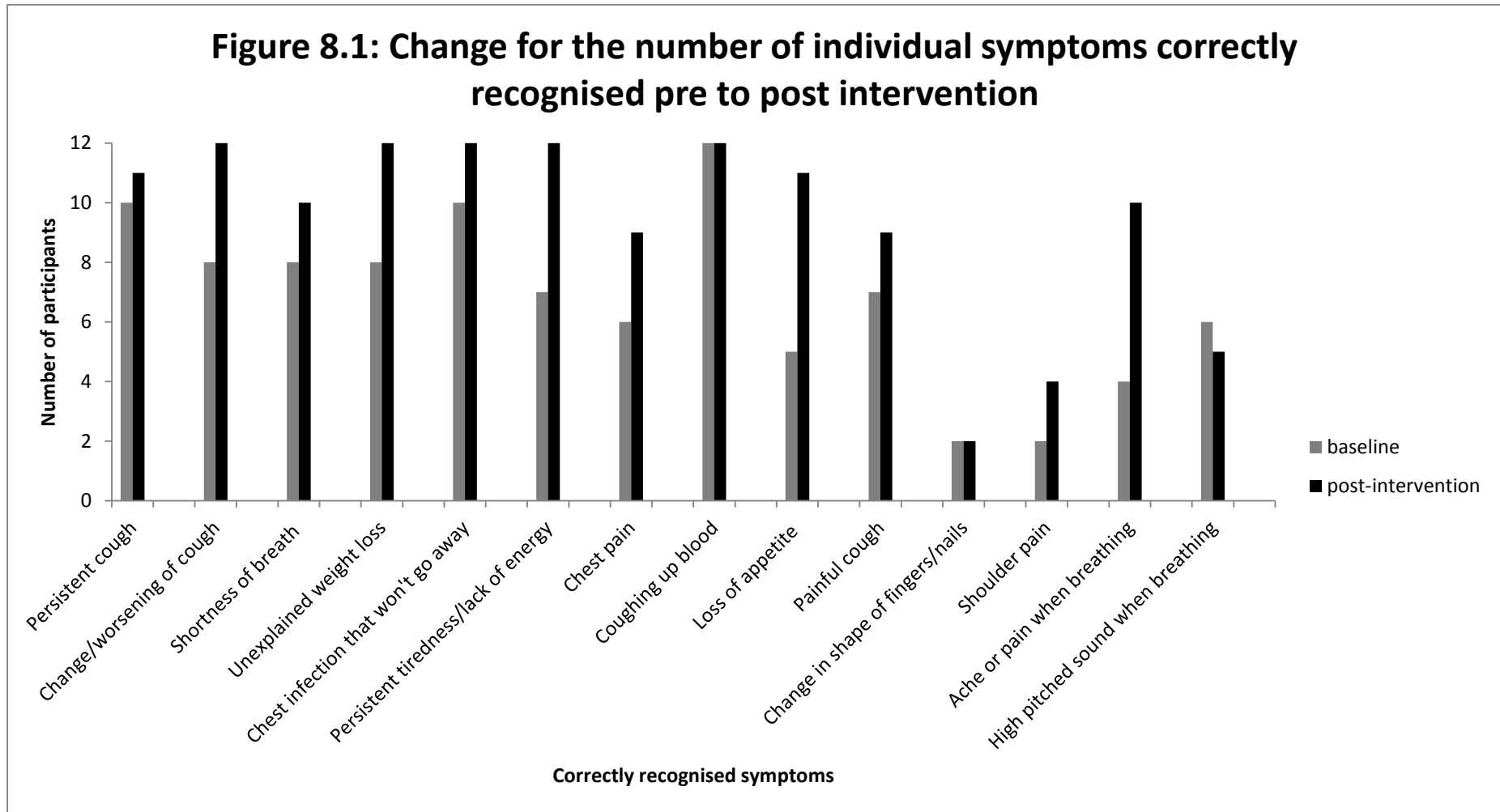
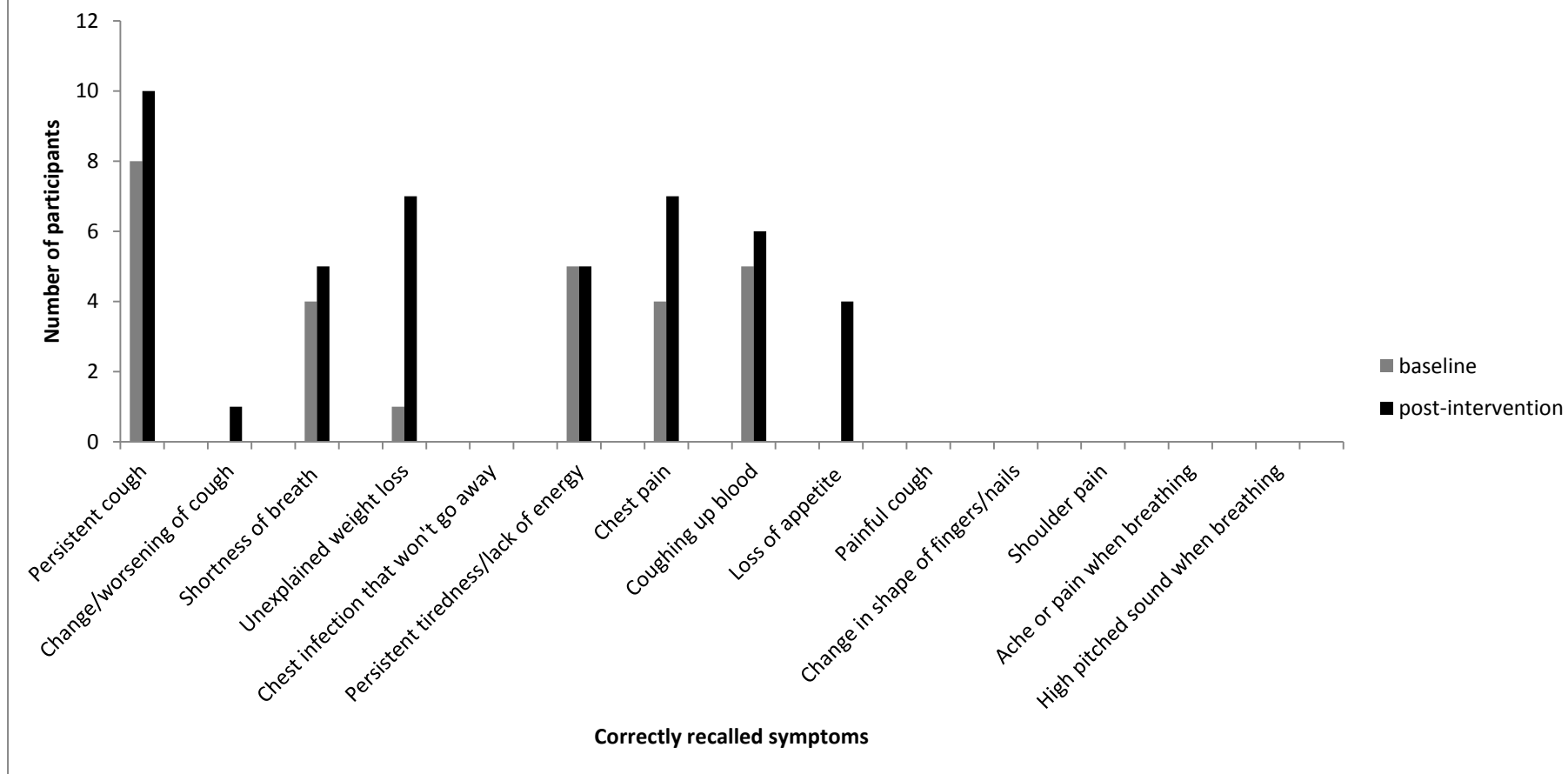


Figure 8.2: Change for the number of individual symptoms correctly recalled pre to post intervention



Anticipated time to lung cancer symptom presentation

Anticipated time to lung cancer symptom presentation varied at baseline, with most participants anticipating shorter time intervals (Table 8.4). For those who completed both questionnaires, the majority of participants anticipated shorter symptom presentation intervals at both time points. However, a shift towards lengthened, more appropriate anticipated symptom presentation times (in line with NICE guidelines for suspected lung cancer) was observed pre to post intervention (Table 8.3).

Confidence noticing a symptom of lung cancer

At baseline, most participants reported lower confidence in detecting symptoms in themselves and others (Table 8.4). Confidence to detect a symptom of lung cancer in themselves and others appeared to be improved pre to post intervention (Table 8.3). At follow-up, the majority of participants reported higher confidence that they could detect a symptom of lung cancer in themselves and others (Table 8.3).

Beliefs about lung cancer

At baseline, most participants endorsed the benefits of early diagnosis, thought that those close to them would want them to seek medical help for lung cancer symptoms, and would want to know if they had lung cancer (Table 8.4). Participants at baseline were more likely to hold negative beliefs about the treatments for lung cancer, and half of the sample perceived themselves to have no control over getting lung cancer (Table 8.4).

For the 12 who completed both questionnaires, small improvements towards more positive beliefs were observed pre to post intervention for four statements (Table 8.3). After the intervention, there appeared to a small shift towards participants endorsing positive beliefs about lung cancer curability and the benefits of early diagnosis, and fewer negative beliefs about lung cancer treatments and lack of control over getting lung cancer (Table 8.3). There was no change pre to post intervention observed for those wanting to know if they had lung cancer (Table 8.3). There was a small decrease in perceived social norms, where participants were less likely to agree that important others would want them to seek medical help for a symptom of lung cancer (Table 8.3).

Table 8.4 Anticipated time to presentation, confidence and beliefs at baseline and post intervention

Measure	Baseline (n=12)	Post intervention (n=14)
Anticipated time to lung cancer symptom presentation, n		
Under two weeks	9	7
Over two weeks	2	5
Would not contact doctor	1	1
Missing/incomplete	0	1
Confidence in detecting symptom of lung cancer – self, n		
Higher confidence	5	12
Lower confidence	7	2
Missing/incomplete	0	0
Confidence in detecting symptom of lung cancer - someone else, n		
Higher confidence	5	11
Lower confidence	7	3
Missing/incomplete	0	0
Beliefs about lung cancer, n		
<i>‘Lung cancer can often be cured’</i>		
Agree	4	11
Disagree	8	3
Missing/incomplete	0	0
<i>‘Most treatments for lung cancer are worse than the cancer itself’</i>		
Agree	7	7
Disagree	3	5
Missing/incomplete	2	2
<i>‘I would not want to know if I had lung cancer’</i>		
Agree	3	5
Disagree	9	9
Missing/incomplete	0	0
<i>‘Going to the doctor quickly with a symptom of lung cancer increases the chance of survival’</i>		
Agree	10	13
Disagree	1	1
Missing/incomplete	1	0
<i>‘People important to me would want me to go to the doctors with a symptom of lung cancer’</i>		
Agree	11	12
Disagree	1	2
Missing/incomplete	0	0
<i>‘I have no control over if I get lung cancer or not’</i>		
Agree	6	6
Disagree	6	8
Missing/incomplete	0	0

8.4.3 Observational data

Participants were a close-knit group who met weekly as a mental health peer-support group (site 1) and a group of volunteers in the community (site 2). Three participants became upset

talking about cancer, because they had previously experienced bereavement associated with cancer. Two participants arrived half way through the session, therefore they missed out on the beliefs and symptom section. However, they were given the handout which contained most of the information discussed in the first half of the session and helped them to participate in the second half of the session.

Participants were generally engaged throughout the intervention session and participated well in all group activities, particularly the symptom slides and barriers section, where participants could relate to most of the barriers discussed. Lack of GP access was key and discussed throughout the session, where getting an appointment to see the GP was described as challenging, and preclusion of discussion of more than one symptom was frustrating for participants. Participants appeared to understand the scenario section and would offer appropriate advice to each individual. The relationship with the person was perceived as most important, where participants would feel most comfortable giving advice to those closest to them and would in most cases not mention cancer as a possible cause of their symptoms. Two to three participants in each group tended to dominate discussion, however all participants engaged in discussion at some point throughout the intervention session. Questions from participants were mainly focused around lung cancer risk, particularly risk factors such as air pollution, breathing in secondary cigarette smoke, genetic risk factors and age. There was some discussion about the need for a lung cancer screening service and the safety of e-cigarettes.

With permission from participants, the community partner from site 2 who helped to recruit participants to take part in the session observed the intervention. Although the presence of the community partner in the session did not appear to affect participation from those who attended the session, the community partner was fairly disruptive throughout the session. The community partner was seated outside of the main group, and reminded not to participate in the session; however, the community partner asked questions throughout and told stories which were irrelevant to the intervention content.

8.4.4 Focus group data

Themes were generated from the data regarding intervention acceptability and feasibility in the community, format of the intervention as a 'community responsibility' intervention, intervention delivery, content, length and suggestions for changes to the intervention.

(a) Acceptability of the intervention

The intervention was well received by both groups and feedback for the intervention was generally positive. Participants described the intervention as "informative", particularly the symptom section, and thought that the intervention was pitched at the right level for the target audience. Participants found all elements of the intervention useful and would recommend lengthening the intervention session to include more information about risk factors for lung cancer, other potential causes of symptoms (rather than lung cancer only), and more images. Participants found the handout useful and would take it to their GP to aid communication of symptoms:

P2- "You've got to pitch it at the level of your audience really... It wasn't too simplistic but it was written in such a way that absolutely everybody could look and understand and take in what was written there" (*Site 1*)

Mod1- "What did everyone think about the session?"

P3- Very informative.

P2- Yes, I was just going to say that.

P4- Very interesting.

P6- A good help, yes.

P4- It was just straight to the point, telling us about different symptoms. Like some of them I didn't even know was the symptoms. So it was a big eye-opener for me on understanding the symptoms. Yes, so it was good.

Mod1- What were the stand out bits? Everyone's saying "yes, I liked it". Was there any stand out bits that you particularly liked?

Multi- Symptoms.

P3- Yes, symptoms, information, that was the main thing. (*Site 2*)

Mod1- "What do you think of the hand out that everyone got at the end?"

P2- Very good, something to take away and something to remind you.

P1- I would take it [to the doctors] myself if I thought I was in that condition or had problems, put it that way.

P3- It's a useful memory jogger, isn't it?" (Site 1)

(b) Intervention content

Participants understood the community responsibility aspect of the intervention. They described how they would feel comfortable advising people in the community to go to the GP with symptoms, but would not mention cancer as a potential cause of symptoms. Participants held mixed views on the inclusion of smoking cessation information. Some participants at site one thought there should be a small section at the end with information about how to stop smoking. The majority of participants thought that people had their "own way of quitting" and were sceptical about the inclusion of smoking cessation advice, especially as smoking cessation support services are already available in the community. Current smokers thought that signposting to stop smoking services was adequate, and some non-smokers discussed how smoking session information was irrelevant to them and could potentially disengage non-smokers in the session. Two participants reported asking family members who smoke to come along to the intervention but were reluctant to attend, although the reasons for this were unclear:

"P2- I don't think you need to be saying [symptoms could indicate lung cancer] but if they've got worrying symptoms, best advice is they need to go and get checked out with a GP. You don't need to give any other details.

P1- Yeah

P7-You don't have to say "I think you've got..."

P6- No, no

P7- Cos you're not a doctor are you?" (Site 1)

P4- "Well, obviously you did say about the non-smoking, and all you said was there is advice, if anybody needed advice afterwards then ask. I think you should just leave it at that, because there's quite a few stop smoking services. If they want to give up

they can go to their local GP, they can go to like support groups or whatever, and they can do it that way. So I think you should just leave it, like you've explained it.

P1- You're offering them extra literature and contacts, so I think that's enough.

P7- If interested, suggest that they come to the smoking session." (*Site 2*)

Mod2- "One of the things we deliberately didn't include was stop smoking advice because I suppose we were worried that it would just for smokers completely put them off.

P5- Yes, they don't want to know.

Mod2- I just wondered what you think about whether we should do that [include stop smoking advice?]

P2- You could do that at the end couldn't you?

P3- I think you've got a good balance at the minute

P4- Yeah" (*Site 1*)

(c) Feasibility of the intervention

Participants thought the intervention was something which would fit in with their community and that people in the community would attend. Participants thought the size of the group was good, and there was discussion about the benefits of having a group that was small enough to facilitate sharing of experiences and participation in group discussion. Participants at site one were happy with the intervention taking up one of their support group meeting sessions and suggested using similar groups to deliver the intervention. Other suggestions for advertising the intervention in future were via posters, on the community website or in doctors' surgeries. The importance of delivering the intervention in close proximity to their house in community centres or similar venues was discussed, reflecting difficulties with transportation for some members of the community. Holding the intervention at different times of the day was considered important, to give people who work the opportunity to attend. Participants reported that they would recommend the intervention to family and friends. There was discussion around adapting the intervention for delivery to school age children:

Mod1- "How do you feel about the size of the group we've had today here?

P1- I wouldn't have thought much more, because I think you could get lost in there.

Multi: Yes.

P2- I've enjoyed it today with us all giving like different opinions.

P3- I think it's comfortable for people here, because pretty much everybody knows everybody and, therefore, they're willing to share something that might otherwise be confidential to them. If you've got 500 people in a room there's often somebody who just will not speak when they've got a perfectly valid question, partly out of embarrassment, I suppose. And so I think smaller groups probably get a better response. A manageable size, I would say 10 to 12, that's my view." (Site 2)

P5- "I don't do evening things because the buses stop in this area, don't they? I won't get a bus on a Sunday.

P2- It only goes as far as the corner. Doesn't go up to the top of the valley does it?

Mod1- So it is important that [the session] is near to where you are?

P5- Yeah" (Site 1)

Some participants reported feeling apprehensive about attending a session about cancer, and for some this almost completely deterred participation in the session. These participants reported that others encouraged them to go to the intervention session. A few participants reported efforts to persuade family and friends to come with them to the session, but were reluctant to attend as talking about cancer was considered "daunting" (P4, site 2). "Word of mouth" (P7, site 2) was considered important, where positive feedback from others about the intervention session would increase and encourage attendance to future sessions:

P7- "Well, <name of other participant> , she phoned me about the [session], my words were, I'm not sure I want to go there, I said.

P2- That's right.

P7-And I said, I don't want people talking about cancer, didn't I?

P2- Yes, you did.

P7- I said, I'm not sure I can deal with it.

P2- And what did I say to you, I went to the last one and I found it really interesting.

P7- Yes, I know, but I still ...

Mod 1- So what would you say now if someone rang you up to say they were going to come to this session, would you recommend it?

P7- Yes, I think it was totally different to what I thought.

P1- It's informative and not gruesome, isn't it.

P7- That's right.

P6- That's right, yes, that's a good way of putting it, that, yes." (Site 2)

8.5 Discussion

Findings from feasibility testing with a group of potential users suggested that group education was an acceptable method of delivering information about lung cancer, and that the lung health intervention session could fit in with the local community. Participants appeared to understand the community responsibility aspect and described feeling comfortable about prompting someone close to them to go to the GP with symptoms, but would not usually mention cancer as a potential cause. Small improvements for lung cancer symptom knowledge, beliefs about cancer and confidence in detecting symptoms were observed post intervention. The greatest improvements for symptom knowledge were observed for symptoms targeted by the intervention and non-specific symptoms. Although some participants anticipated longer symptom presentation times after exposure to the intervention, intentions to seek help were more aligned to the NICE guideline of three weeks and to advice given during the session. This finding might be explained by background characteristics of the groups involved in acceptability testing. Site one was a group of individuals who were already engaged in a health peer support group. They may previously have been more comfortable about seeking medical help and therefore motivated to seek medical help as soon as they noticed something suspicious. Most symptoms included in the intervention were coupled with advice to seek medical help for symptoms if they persisted for three weeks or more. It is likely that following advice from the intervention, participants were more likely to anticipate monitoring symptoms to see if they persisted, rather than seeking medical help immediately.

Lack of GP access was a key barrier for participants. Although participants were given strategies to overcome reported barriers, there is a need for healthcare professional intervention at primary care level. In the review of interventions reported in Chapter 6, some interventions used 'push-pull' methods to 'push' symptomatic patients to primary care and 'pull' patients through primary care and secondary care using interventions delivered to healthcare professionals. Although out of the remit and budget of this PhD, a 'pull' strategy involving reminders of the NICE guidelines and preparations for increased case load could be considered for the intervention in future.

8.5.1 Limitations of the study

There was poor representation from current smokers at the intervention acceptability testing, therefore it is unclear if the intervention is acceptable to current smokers. Gaining views from current smokers is important since they are most at risk of lung cancer. Family members who attended the intervention reported efforts to encourage smokers within the family to attend. It is unclear why more smokers did not attend or why participants' family members who were smokers were not willing to attend. However, it is possible that this reflects smokers' reluctance to engage in lung cancer awareness interventions, perhaps due to the stigma associated with smoking and lung cancer. Engaging never-smokers or former smokers who have people within their social networks who are current smokers may be a potential strategy for delivering messages to smokers, or encouraging current smokers to attend intervention sessions in the community. Similar strategies have been used in other peer educator interventions (Kim *et al*, 2015). Kim *et al* (2015) used a friend nomination approach to identify people in the community to receive the intervention next, rather than identifying who is the most popular in the community. In this study, the intervention could run a few times within a given community and intervention attendees were asked to nominate someone within their social network to receive the intervention (Kim *et al*, 2015). Future pilot work could assess the feasibility of adopting the friend nomination approach in the context of the lung health information session.

The small sample size of 14 participants who were recruited over two sites to take part in intervention acceptability testing was a key weakness of the study, and limits the generalisability of study findings. It remains unclear whether community group based education is an acceptable method of intervention, and whether it could be scaled-up for delivery to a larger audience. In addition, although both groups met the criteria for inclusion, one group were already members of a peer support group who were accustomed to discussing health issues and may not be representative of a typical group of individuals within the community.

Both groups were recruited through community partners, with potential for selection bias where community partners choose participants to take part in the intervention study based on previous experiences of cancer, or a perception that the selected group had an interest in health and were therefore more likely to engage in the intervention. Furthermore,

recruitment through community partners meant that it was not possible to calculate response rates based on the number of people invited to participate in the intervention, and limited data were available regarding reasons for non-participation.

Future feasibility and pilot intervention testing should take place over multiple sites, preferably across various geographical sites such as deprived communities in Scotland and England. In addition, future pilot testing could explore appropriate alternative methods of recruiting people into the intervention such as work places or poster adverts in the community, with a particular emphasis on engaging smokers in the intervention.

8.5.2 Measures

An adapted version of the Lung CAM was used in the present study. There was minimal missing data, suggesting that the format and wording used in the questionnaire measure was acceptable. Missing data were most frequent for the postcode question used to derive WIMD score. It is likely that participants felt uncomfortable providing such personal information, suggesting that other measures of socioeconomic group may be more acceptable. In addition, most participants were retired thus it was not possible to gain an understanding of their current or previous social circumstances. Further revisions could measure occupation prior to retirement.

There were some problems associated with using a standardised measure. For example, the anticipated time to symptom presentation intervals did not match the messages used in the intervention. For most of the symptoms, the advice given to participants in the intervention was to seek medical help for symptoms if they persisted for three weeks or more. However, this was not reflected in the standard Lung CAM response options. In addition, three pain related symptoms that were not targeted by the intervention were more likely to be recognised post intervention, and could reflect response bias associated with recognition measures of symptom knowledge. Alternatively, it is possible that because 'chest pain' was included in the intervention content, participants were aware of 'pain' as a general symptom of lung cancer irrespective of the site of the pain.

8.5.3 Implications and recommendations for the intervention

The content, format and mode of delivery of the intervention were found to be appropriate and acceptable in the context of promoting timely lung cancer symptom presentation among low socioeconomic groups. Framing of the intervention from a third person 'community responsibility' aspect could be considered a low cost and sustainable method for disseminating intervention messages among the community. Findings suggest that the community responsibility aspect is an acceptable way of delivering intervention messaging and could be used as a method for disseminating information to smokers who are unlikely to attend an intervention about lung cancer, although this would be challenging to evaluate.

In an attempt to increase sustainability of the intervention and frequency of the intervention sessions, key members of the community such as a Communities First partner could be trained to deliver the intervention for future sessions and should be explored in future research. The intervention should be modified to include more images, more information about the risks associated with developing lung cancer and other potential causes of symptoms. The inclusion of a healthcare professional component to remind GPs of the referral guidelines for suspected lung cancer could be considered in future research.

In addition, there is potential for the intervention to be carried out with higher risk groups: current and former smokers with pre-existing lung co-morbidity such as COPD. As outlined in Chapter 7, this group are at increased risk for lung cancer in comparison to current or former smokers without lung co-morbidity, but are often already symptomatic and potentially under clinical intervention. Further research should seek to understand the barriers to lung cancer symptom presentation among this group to understand perceptions of new or changing symptoms with potential adjustments made to intervention content.

8.5.4 Reflections from user testing

Community partners are often trusted, key members of the community, and were valuable assets to facilitate participant recruitment for this user testing study, enabling access to groups of people who may otherwise not engage in research. Both community partners who successfully helped to recruit participants for the study were enthusiastic and supported the study, facilitating the planning and organisation of the session. However, there were some

challenges encountered during the study, where as previously discussed, one community partner observed the session, often discussing issues during the session which were irrelevant. This could potentially reflect perceptions of ownership of the session from the community partner, where they became involved with the session from an early stage. In addition, their involvement might also reflect almost paternalistic feelings towards the group of individuals who have agreed to take part in the session, where the community partner perceived themselves to have a certain amount of responsibility towards those who were recruited to take part in the session. Although community partner participation in the session did not appear to affect study participant responses, it was difficult to balance community partner involvement in a time limited session, especially considering their contribution to the session was often off-topic. In future, procedures should be clearly outlined for the inclusion of community partner, and boundaries clearly defined before the intervention. Alternatively, there is potential to harness this enthusiasm and train community partners to deliver the intervention.

8.6 Conclusion

A community based educational intervention to promote timely symptom presentation by utilising strong social networks in the community was tested for acceptability with a group of potential users. Group-based education was an acceptable mode of intervention delivery, and can be used to engage the target group in lung cancer early detection. Further pilot testing across multiple sites is required to explore feasibility and acceptability of the intervention in the future, including methods for engaging smokers.

Chapter 9

General discussion

9.1 Chapter overview

This chapter presents an overview of the PhD findings. A summary of how these findings were used in combination with findings from a scoping review study and intervention development exercise using the Behaviour Change Wheel is presented. Each phase of work is summarised and discussed in relation to existing evidence. The methodological strengths and weaknesses of the PhD are discussed, along with the future implementation and evaluation of the intervention.

9.2 Summary of thesis findings

This PhD aimed to (1) understand the barriers to cancer symptom presentation among people from low socioeconomic groups, and (2) develop a cancer awareness intervention targeted at people from a low socioeconomic group. Initially, it was envisaged that the intervention would have a generic cancer focus; however, in response to changes in policy regarding the need to improve lung cancer outcomes as a national priority (Welsh Government, 2015) the decision was made to focus the intervention solely on lung cancer symptom awareness.

There were five objectives of the PhD: (1) identify relevant theory for cancer awareness, beliefs about cancer and symptom presentation behaviour; (2) identify studies of cancer symptom knowledge, beliefs about cancer, barriers to cancer symptom presentation and actual or anticipated cancer symptom presentation behaviour using systematic review methods; (3) identify the factors influencing cancer symptom presentation among people from low socioeconomic groups using qualitative methods; (4) identify and review interventions designed to encourage earlier cancer symptom presentation among people from low socioeconomic groups; (5) develop an intervention to encourage earlier cancer symptom presentation among people from low socioeconomic groups and examine its acceptability with a sample of potential users. Each aim and objective will be addressed and discussed.

Objectives 1 to 3 contribute to the first aim of the PhD to understand the barriers to cancer symptom presentation among low socioeconomic groups. Theories and models considered relevant to cancer symptom presentation behaviour were identified in Chapter 2 (objective

1) and the COM-B model was presented as a potentially useful framework for understanding cancer symptom presentation behaviour (Michie *et al*, 2011). The COM-B model was used throughout this PhD thesis and provided a useful framework for analysing qualitative data to explore individual and socio-environmental influences on behaviour, and to guide understanding of these influences on cancer symptom presentation behaviour among low socioeconomic groups. A systematic review described in Chapter 3 was used to identify relevant literature relating to cancer symptom knowledge, beliefs about cancer, barriers to cancer symptom presentation, and actual or anticipated cancer symptom presentation behaviour (objective 2) (McCutchan *et al*, 2015; Appendix 1). The systematic review was useful to understand which of these factors could prolong cancer symptom presentation behaviour and which were most prevalent among low socioeconomic groups. Findings suggested that lower knowledge, negative fearful and fatalistic beliefs about cancer and emotional barriers to symptom presentation were more prevalent among low socioeconomic groups, and contributed to prolonged cancer symptom presentation. The systematic review helped to identify the need for a more in depth understanding of how these and other factors might influence symptom presentation among low socioeconomic groups, which was essential for the development of an intervention targeted at low socioeconomic groups and could be achieved through qualitative methods.

A qualitative exploration of cancer knowledge, beliefs about cancer and barriers as influences on cancer symptom presentation among low socioeconomic groups, using interview and focus group methods, was reported in Chapters 4 and 5 (objective 3). Findings were used to confirm those of previous studies, and to gain in depth insight into the barriers to cancer symptom presentation among low socioeconomic groups. The qualitative studies were useful for identifying and understanding the influences of both individual and wider social and environmental factors on cancer symptom presentation behaviour, highlighting the role of broader social determinants of health on behaviour. Social networks were identified as key to the acquisition and maintenance of cancer knowledge and beliefs and the decision to seek medical help. Symptom advice was often sought from family and friends prior to a visit to the GP, with the potential to prolong cancer symptom presentation following poor quality advice. Furthermore, the influence of organisational barriers such as GP policies and wider socio-environmental factors, such as the struggles of day-to-day living in a socioeconomically deprived community where health was not perceived as a priority, contributed to prolonged symptom presentation.

The final two objectives 4 and 5 relate to the second aim to develop a cancer awareness intervention targeted at low socioeconomic groups. A scoping review of existing cancer awareness interventions was presented in Chapter 6 (objective 4). The review was useful for understanding what types of interventions had previously been implemented and which interventions were most effective in terms of behaviour change among low socioeconomic groups. Intervention messages communicated through mass media channels were least effective, and more culturally targeted interventions such as community based multi-faceted or educational interventions were most effective. In addition, the scoping review helped to identify the most and least frequently included intervention content. Most interventions did not include any cancer risk information and/or information on strategies to overcome barriers to symptom presentation. This highlighted the need for more targeted, interventions that included factual symptom, belief and risk related information, and practical advice on how to overcome barriers to cancer symptom presentation to empower individuals from low socioeconomic groups to seek medical help for symptoms.

In Chapter 7, findings from an intervention development exercise using the Behaviour Change Wheel were reported (objective 5). The intervention was developed in accordance with the MRC framework for complex intervention development and findings from studies using primary and secondary data reported in Chapters 3 to 6. An intensive, community based group educational intervention was developed, containing information to combat negative beliefs about lung cancer, and to inform about the symptoms of lung cancer, when to go to the doctor with a symptom of lung cancer, who is most at risk for lung cancer, strategies to overcome barriers to symptom presentation, what advice to give other people in the community with symptoms, and what to expect from the GP and in secondary care if they present with symptoms. The intervention was tested for acceptability with a group of potential users who included current smokers, former smokers and family members of smokers over the age of 40 from socioeconomically deprived communities (objective 5). Overall, findings from the user testing study (Chapter 8), suggested that the intervention was an acceptable method for engaging members of the community in an intervention about lung cancer. Preliminary evidence suggested that the intervention may have the potential to increase lung cancer symptom knowledge, modify negative beliefs and increase confidence in detecting symptoms. However, there was poor representation from current smokers in the user testing studies, and the quantitative findings suggested that anticipated symptom presentation increased after exposure to the intervention. These limitations will be discussed later in the chapter.

9.3 Understanding the barriers to cancer symptom presentation among low socioeconomic groups

The NAEDI framework (Hiom, 2015) described in Chapter 1 was used to guide understanding of potential influences on cancer symptom presentation in this PhD. The NAEDI framework suggests that low cancer knowledge, negative beliefs about cancer, and barriers to symptom presentation contribute to prolonged cancer symptom presentation. In addition, socioeconomic factors are included in the NAEDI framework as a risk factor for prolonged symptom presentation (Hiom, 2015); however, due to the descriptive nature of the framework, it was unclear how these factors in combination with socioeconomic deprivation can prolong cancer symptom presentation. This PhD was concerned with exploring how the factors identified by the NAEDI framework and other factors might prolong cancer symptom presentation among low socioeconomic groups.

Findings from the systematic review reported in Chapter 3 supported the assumptions of the NAEDI framework (McCutchan *et al*, 2015, see Appendix 1). There was limited evidence to suggest that the influence of socio-environmental factors such as symptom disclosure could prolong cancer symptom presentation among low socioeconomic groups (Li *et al*, 2012). In addition, how socioeconomic factors could influence knowledge, beliefs, and barriers to cancer symptom presentation lacked clarity.

Qualitative findings from an in-depth interview study with people from a low socioeconomic group (McCutchan *et al*, 2016; Chapter 4) and a focus group study with people who live or work in deprived communities (Chapter 5) supported the findings of previous studies (McCutchan *et al*, 2015; Chapter 3) and the assumptions of the NAEDI framework (Hiom, 2015). There was evidence to suggest that cancer knowledge and problems of communicating of symptom concerns during a consultation (Capability) could influence cancer symptom presentation. Fear in combination with fatalistic beliefs about cancer, was associated with prolonged symptom presentation, whereas fear combined with positive beliefs about early diagnosis prompted symptom presentation (Motivation). The inclusion of members of the public from low socioeconomic groups helped to identify some of the personal issues faced by individuals, and to reveal social norms within their community network (Opportunity). Inclusion of local stakeholders who live or work in deprived communities facilitated insight into 'upstream factors' on behaviour, defined as wider social influences and social inequalities that contribute to poor health (Bharmal *et al*, 2015), where the broader issues and challenges of living in a deprived community such as unemployment

and housing problems were discussed (Opportunity). In addition, community level norms and barriers to cancer symptom presentation specific to low socioeconomic groups could be explored with local stakeholders (Opportunity). Through qualitative methods, the ways in which socioeconomic factors (Opportunity) could influence Capability and Motivation to potentially prolong cancer symptom presentation behaviour were identified. Social Opportunity was a key influence on Capability and Motivation, where previous experiences contributed to the formation of knowledge and beliefs about cancer. In addition, social Opportunity was found to influence symptom presentation through symptom disclosure and the quality of advice given. Physical Opportunity influenced symptom presentation through the wider social determinants of health, where the contextual factors associated with living in a deprived community such as lack of resources and competing priorities could prolong cancer symptom presentation behaviour.

There was evidence of poor knowledge for the non-specific symptoms of cancer and a high prevalence of negative fearful and fatalistic beliefs about cancer (Marcu *et al*, 2016; Quaife *et al*, 2015; Chonjnacka-Szwalowska *et al*, 2013; Grunfield *et al*, 2002; Marlow *et al*, 2014) among those from low socioeconomic groups. Using qualitative methods, a rich understanding was obtained regarding how knowledge and beliefs were acquired and maintained in the community, where experience of cancer within one's social network was most influential. There was evidence that cancer-related knowledge and beliefs were almost exclusively gained from exposure to people in the community who had died and in most cases suffered with cancer, which could explain the high prevalence of negative beliefs among low socioeconomic groups. Knowledge of non-lump symptoms and bleeding was often based on people with cancer known in the community, with participants often describing the symptoms of advanced stage cancer. In addition, non-specific symptoms of cancer such as tiredness were often misattributed to symptoms of pre-existing co-morbidities such as diabetes, which were common in this group (Rachelle *et al*, 2016). Two studies found that people from low socioeconomic groups hold lower suspicions than higher socioeconomic groups that their symptoms could indicate cancer (Whitaker *et al*, 2015a) or were more likely to down play the seriousness of symptoms (Marcu *et al*, 2016).

Misattribution to pre-existing co-morbidities could explain this finding, and has implications for seeking medical help for cancer symptoms (Carter-Harris *et al*, 2015; Ristvedt *et al*, 2014; Siminoff *et al*, 2014; Tod *et al*, 2008). These findings highlighted the need for an intervention to inform people in socioeconomically deprived communities about the symptoms of cancer,

explain the importance of multiple symptoms and changes to normal symptoms, and challenge negative beliefs about cancer.

In the qualitative interview study (McCutchan *et al*, 2016; Chapter 4), there was additional evidence regarding the influence of social networks on cancer symptom presentation behaviour through the quality of advice received following symptom disclosure to family members or friends (Li *et al*, 2012). The influence of norms around using a lay system of healthcare before a visit to the GP was confirmed in the focus group study (Chapter 5), where symptom advice was often sought from people deemed as 'knowledgeable', close to them or well respected within their social network (Edwards *et al*, 2013; Low *et al*, 2015; Pescosolido and Boyer, 1999). Although seeking symptom advice from family and friends is common (Pedersen *et al*, 2011; Whitaker *et al*, 2015a; Whitaker *et al*, 2014; Marlow *et al*, 2014; Kakagia *et al*, 2013), it is likely to be problematic for people from a low socioeconomic group. There is a potential to receive poor quality advice from someone who has poor cancer symptom knowledge, negative beliefs about cancer, or previous negative experiences in the health service which could deter or prolong cancer symptom presentation. Using strong social networks to educate and facilitate dissemination of intervention messages was identified as a potential strategy for promoting earlier cancer symptom presentation in the community (Hart and Elford 2003; Campbell *et al*, 2008; Rogers, 1983).

Both qualitative studies confirmed the existence of emotional barriers to cancer symptom presentation among low socioeconomic groups such as embarrassment and worry about what the GP might find (Niksic *et al*, 2015; Quaife *et al*, 2015a; Robb *et al*, 2009), and provided insight into how emotional barriers might prolong cancer symptom presentation. Embarrassment about undergoing intimate examinations and anticipating pain during diagnostic testing were discussed as barriers to cancer symptom presentation, and were usually gained from people in the community discussing negative experiences of such testing. Again, this highlights the significance of social networks for influencing symptom presentation behaviour. Fear of receiving a diagnosis of cancer and worry about what the GP might find were reported as key barriers to cancer symptom presentation in the community (Robb *et al*, 2009; Whitaker *et al*, 2015c; Waller *et al*, 2009; O'Mahoney *et al*, 2011). Fear and worry are likely to reflect perceptions of inevitable death after a diagnosis of cancer, based on experiences of cancer in the community. Findings from the focus group study suggested that, for some, a potential diagnosis of cancer was too much to cope with in the context of other day-to-day challenges, pushing these individuals into a state of denial and

prolonged symptom presentation. There appears to be a vicious circle associated with fear or denial of cancer based on previous experience, which acts as a barrier to cancer symptom presentation. These individuals might present with a late stage diagnosis of cancer, further reinforcing negative beliefs about cancer in the community. This highlights the importance of earlier cancer diagnosis to 'break the circle' and promote earlier symptom presentation, in order to provide 'real' first-hand evidence of cancer survival in the community.

Other barriers to going to the GP with a symptom of cancer that were identified in the qualitative studies highlighted the significance of the pressures of living in a socioeconomically deprived community as influences on symptom presentation behaviour. Exploration of the wider social environment was used to understand the struggles of day-to-day living in a deprived community (Steptoe and Feldman, 2001; Ellen *et al*, 2001), and how these might influence cancer symptom presentation behaviour. As outlined in Chapter 1, The Health Map (Burton and Grant, 2006) identifies multiple determinants of health both in the immediate environment and the wider physical, social and economic environment in which an individual lives. There was evidence from this PhD of the wider upstream determinants of health influencing cancer symptom presentation behaviour among low socioeconomic groups. For example, economic hardship meant that fulfilling basic needs day-to-day, such as finding money for food or heating the house, were prioritised over seeking medical help for symptoms, particularly when symptoms were perceived as non-serious.

Through qualitative methods, various barriers at an organisational level and problems with full and effective disclosure of symptoms during an appointment with the GP were identified. Some GP practice policies which preclude discussion of more than one symptom during a consultation (McCartney, 2014) and time limited appointments had the potential to prolong cancer symptom presentation and were considered to be a key barrier to disclosure of a cancer symptom, since patients rarely presented their cancer symptom first (Corner and Brindle, 2010; Andersen and Vested, 2015). Instead, other benign symptoms were often used to test the water and build trust with the GP, or appointments were used to discuss other non-health issues such as getting Employment and Support Allowance (ESA) forms signed off to ensure benefits were paid on time. In the context of socioeconomic deprivation, where individuals are struggling to live day-to-day with little money, getting ESA forms signed is likely to be perceived as more important than discussion of cancer symptoms.

A lack of confidence when communicating symptoms, especially during time limited appointments, was found to influence discussion of symptoms. There is evidence from non-cancer contexts that people from a low socioeconomic group are generally less likely than those from a high socioeconomic group to actively engage in a GP consultation (Willems *et al*, 2005). Studies suggest people from low socioeconomic groups more often spend time during the consultation discussing other non-health related issues and take a more passive approach to health care than those from a high socioeconomic group (Willems *et al*, 2005). In addition, those from low socioeconomic groups are more likely to perceive power imbalance between themselves and the GP, which can impair full disclosure of symptoms during a consultation (Scambler and Britten, 2001; Greenhalgh *et al*, 2015; Ward and Coates, 2006). These findings highlighted the need for an intervention to offer practical advice on strategies to overcome barriers to symptom presentation, providing individuals with the tools to effectively communicate symptom concerns during an appointment.

There were additional upstream social influences on behaviour, through which socioeconomic deprivation is likely to prolong cancer symptom presentation. Feelings of victimisation and suspicion towards authority and government were reported (Ward and Coates, 2006; van Ryan and Burke, 2000). There was a general sense of lack of control over day-to-day living, and general fatalistic beliefs such as the belief that everything is out of one's control were often reported including feelings of helplessness. These in addition to the stigma of being associated with a deprived community are likely to reflect feelings of disempowerment, which are linked to poor health and feelings of not being worthy (Marmot, 2015), and could impact on cancer symptom presentation behaviour. This highlighted the need for an intervention to empower individuals to seek medical help, and legitimise presenting to the doctor with symptoms of cancer. Furthermore, using a trusted and reliable source to endorse intervention material was considered important.

9.4 Theoretical underpinning using the COM-B model

In Chapter 2, the COM-B model (Michie *et al*, 2011) was identified as a potentially useful framework for understanding cancer symptom presentation among low socioeconomic groups. Where many other psychological theories neglect emotional factors and the wider social and environmental influences on behaviour, the COM-B model includes these and other individual factors, which were considered relevant to this context. The COM-B model was used throughout the PhD thesis to guide analysis for the qualitative studies, using a framework approach based on the COM-B model constructs. In addition, the COM-B model

underpinned the framework of the Behaviour Change Wheel, which was selected to guide intervention development. There are benefits associated with using the COM-B model as the basis for the framework analysis in the qualitative studies, as this facilitated exploration of the wider social environmental influences on behaviour. In addition, an in depth understanding of the COM-B model was beneficial when performing the analysis of the target behaviour around the first stage of the Behaviour Change Wheel.

Findings from the qualitative studies reported in Chapters 4 and 5 suggested that the COM-B model was useful for understanding how the constructs of Capability, Opportunity and Motivation influence cancer symptom presentation behaviour among low socioeconomic groups. As previously discussed, Opportunity was identified as a key influence on cancer symptom presentation behaviour in this context. Therefore, the inclusion of Opportunity was a strength of the model, considering that many other psychological theories do not include the wider social and environmental factors. Opportunity was found to directly influence behaviour, as well as indirectly influence behaviour through Capability and Motivation. For example, lack of transportation to get to an appointment with the GP and competing priorities such as work commitments directly influenced behaviour, where working to earn money or not being able to get time off work (Opportunity) prolonged symptom presentation (Behaviour). There was evidence to suggest that both Motivation and Capability influenced the relationship between Opportunity and Behaviour. For example, cancer knowledge (Capability) and beliefs about cancer (Motivation) were almost exclusively gained from seeing people in the community with cancer (Opportunity), and both poor knowledge and negative beliefs prolonged cancer symptom presentation (Behaviour). The influence of Opportunity on Capability is currently represented in the COM-B model. However, the influence of Opportunity on Capability is not represented in the model, and there was evidence to suggest the existence of this bi-directional relationship. Future revisions of the model should consider representing the relationship between Opportunity and Capability, where bi-directional arrows could represent the influence of Opportunity on Capability.

Basing the qualitative studies' framework analysis around the COM-B model could be considered reductionist and potentially limiting. As previously discussed, the COM-B model was chosen due to its breadth, which combined a range of theories of behaviour, to create a single model of both individual and environmental influences on behaviour. However, in order for the model to be applicable to various behavioural contexts, some of the definitions

for each construct were limited and vague. Vague definitions presented difficulty when assigning a theme to a construct, however; when used in combination with the Theoretical Domains Framework (TDF), sorting of themes under each of the COM-B model constructs became clearer, and any ambiguity was overcome through double checking of themes by supervisors. Two theories which did not formally underpin the COM-B model were identified in Chapter 2 as useful for understanding influences on cancer symptom presentation behaviour. This has the potential to exclude or limit analysis of factors identified in these theories as relevant to the context of cancer symptom presentation. For example, the Common Sense Model of Illness Self-Regulation (CSM; Leventhal *et al*, 1984) attempts to explain how illness is inferred, understood and acted upon, but was not used to underpin the COM-B model. Consequently, symptom interpretations are not explicitly represented in the COM-B model, but are important when deciding to seek medical help for a symptom (Noonan *et al*, 2014; Walter *et al*, 2012). However, the domains of 'knowledge' and 'memory attention and processes' in the TDF are implicitly similar to the construct of identity in the CSM; therefore, in both qualitative studies, symptom attributions were discussed under Capability in the context of symptom knowledge.

9.5 Study methodology strengths and limitations

9.5.1 Qualitative methods

Qualitative methods were selected to enable an in-depth examination of the barriers to symptom presentation among low socioeconomic groups. Qualitative methods were considered most appropriate in this context, since quantitative methods such as a questionnaire survey would preclude a detailed analysis. Two qualitative methods were chosen: qualitative interviews and focus groups. Face-to-face interview methods were used to facilitate in-depth exploration of the topic under investigation, providing a deep understanding of an individual's experiences, and examination of the wider environmental factors and how these might influence cancer symptom presentation behaviour. Focus group methods were considered most suitable for further exploration of themes that emerged from the interview study, to validate interview findings and to allow insight into shared group norms around symptom presentation behaviour, and to engage members of public participants in a group activity of symptom attributions.

Although qualitative methods were most suitable for understanding the wider social and environmental influences on symptom presentation behaviour, there are limitations. Qualitative methods are often critiqued for a lack of generalisability, where in depth

examinations of individuals on a case-by-case basis may not be generalisable to wider populations or other contexts. For example, GP appointment policies precluding the discussion of more than one symptom might be specific to a UK context or certain areas in the UK. However, it is likely that barriers related to economic hardship are universal to low socioeconomic groups regardless of geographical location. In addition, qualitative methods are often criticised for limitations associated with subjectivity during data analysis and the potential for influence of researcher bias or values on the interpretation of findings, although some argue that this is a strength of qualitative research (Ratner, 2002). Measures were taken to reduce potential subjectivity by involving the supervisory team in data analysis through double coding.

In addition, I was reflexive throughout data collection and analysis in terms of how the potential influences of my own values might influence on interpretation of findings. I made efforts to reduce any potential influences of my own social standing during interviews through rapport building and taking time to make the participant feel comfortable. During data analysis, I was aware of how my own experiences of growing up in an environment where I was given every opportunity to succeed might influence interpretation of findings. It is likely that I will never fully understand the day-to-day struggles and economic hardship faced by those who took part in the studies. Ethnographic methods could be considered in future to provide further insights into the complexities and issues of deprived communities. I would integrate myself fully into a community to understand the social and economic issues encountered by deprived communities.

9.5.2 Anticipated and actual symptom presentation behaviour

In the qualitative interview study (McCutchan *et al*, 2016; Chapter 4), participants were asked to recall actual cancer symptom presentation behaviour and any barriers to symptom presentation experienced, or to hypothetically predict cancer symptom presentation behaviour and potential barriers to symptom presentation. There are methodological limitations associated with both methods, where retrospective recall of symptoms and associated behaviour relies on memory and there is potential for recall bias. Conversely, hypothetical study designs require the individual to estimate behaviour and might be biased by good intentions, so predicted behaviour may not accurately reflect actual behaviour in the future. A prospective study, following individuals over a long period of time to wait for them to become symptomatic and then record actual symptom presentation behaviour, is unfeasible due to the prohibitively large sample that would be required. Instead, study

designs using a community sample of currently symptomatic individuals and inviting them to take part in a study without the mention of cancer, may overcome some of these limitations (Cockburn *et al*, 2003; Whitaker *et al*, 2015a; Whitaker *et al*, 2014). In such studies, symptomatic individuals would be asked to complete a questionnaire and/or interviewed about their symptom experience and perceptions and the reasons for seeking medical help or not would be explored.

9.5.3 Review methods

Two types of review method were used in the PhD thesis. Systematic review methods were used to identify studies relating to knowledge, beliefs, barriers to symptom presentation and symptom presentation behaviour, and was considered most appropriate due to the high amount of published articles in this context. Systematic reviews are considered to be the highest level of research evidence due to inclusion of good quality evidence, replicability and low bias through double coding at all stages. However, due to the wide range of outcomes measures and heterogeneous research methods used for the included studies, meta-analysis was precluded and is a limitation of the systematic review study.

A scoping review methodology was considered most suitable for the review of cancer awareness interventions in order to allow for inclusion of grey literature reporting interventions that had not been evaluated, interventions of lower quality, and community-level interventions that were not published in peer reviewed journals. There are some limitations associated with scoping review methodology. Double coding at each stage of the search, study selection and data extraction is not compulsory, therefore there is potential for subjectivity at each stage. In addition, scoping review methodology does not include a formal quality assessment of included studies. Without quality assessment in the study selection stage, there is potential for conclusions to be drawn based on methodologically flawed studies or untrustworthy evidence. This has implications when making intervention or policy recommendations if advice is based on evidence whose risk of bias is unclear. However, without the flexibility of scoping review methodology, as opposed to more rigorous methods such as systematic review, many of the smaller community based interventions would not be included in the review. Since the primary aim of the review was to identify all existing interventions targeted at low socioeconomic groups, a scoping review was useful and most appropriate in this context. Some of the intervention evaluation studies were of lower quality, and conclusions were drawn regardless of the quality of evaluation.

Analysis of intervention effectiveness by strength of evidence may have been more useful when drawing conclusions regarding intervention effectiveness.

9.5.4 Acceptability testing

A multiple methods approach was used for the intervention acceptability user testing study. Quantitative data were collected before and immediately after exposure to the intervention to measure knowledge, beliefs, anticipated symptom presentation behaviour and confidence in detecting symptoms. A qualitative focus group method was considered most appropriate for assessing acceptability of the intervention and suggestions for changes, and observational data were collected to record non-verbal feedback and group attentiveness. Using a multiple methods approach was beneficial to assessing intervention acceptability through qualitative and observational methods, in addition to quantitative measures to assess potential for change following participation in the intervention. However, there are limitations of assessing outcome measures directly after the intervention session. Using quantitative measures immediately after the intervention is likely to bias findings, potentially overestimating the potential for the intervention to improve the outcome measures of interest. In addition, immediate follow-up precludes assessment of information retention. A follow-up questionnaire at least one month post intervention, and ideally longer-term, would be desirable to assess retention of intervention messages. Limitations associated with sampling for the user testing study will be discussed.

9.6 Strengths and limitations of sampling methods

9.6.1 Qualitative studies

Using multiple individual and area level indicators to ensure that participants included in the qualitative interview study (Chapter 4) were representative of low socioeconomic groups, was a strength of this study. However, there were limitations associated with sampling participants through the ICBP Welsh database study who were individuals previously engaged in research about cancer. This has the potential to bias the sample towards people who were more motivated to take part in research or talk about cancer. In addition, framing the study around cancer might encourage people who were less negative about cancer, and more likely to seek medical help quickly with a cancer symptom, to take part in the interview study.

To overcome some of these limitations, community norms regarding knowledge, beliefs, barriers and cancer symptom presentation behaviour were elicited, although there are limitations associated with gaining proxy views. It is likely that an individual's perception of community norms may not accurately reflect reality, particularly when cancer is considered a taboo subject and is not often discussed with peers. In addition, opportunistic recruitment methods involving snowball sampling via community partners and previous participants recruited through the ICBP database were used to invite further participants to take part in the interview study. There are limitations associated with snowball sampling and it is often considered as a last option due to limitations associated with selection bias (van Meter, 1990). For example additional participants are often recruited through ones social network, which places limits of validity. However, in this context it was a useful method for gaining access to and engaging participants who may otherwise not have been included in the study (Faugeier and Sargeant, 1997).

In the focus group study (Chapter 5), community partners and healthcare professionals were able to provide insight into community level norms and the challenges of day-to-day living. This enabled insight to be gained into community and organisational level barriers of which members of the public may not be aware. Participants in the public focus groups were recruited through community partners, which was considered to be a good recruitment strategy, as they are a trusted source who are likely to provide access to people in the community who might not otherwise engage in research. However, there are issues regarding selection bias, where the community partner may select participants based on previous experiences of cancer, such as a losing a spouse to cancer. This is problematic as those who have particularly negative experiences of cancer or a higher knowledge of cancer in comparison to the rest of the community could be selected. In addition, data were unavailable on the numbers of individuals invited to take part or their reasons for refusal. Therefore, the response rate and reasons for non-participation in the focus group study were unknown. Finally, additional socioeconomic indicators were not collected at the time of the public focus group study. The only measure of socioeconomic group was residence in a Communities First area. Although those who live in a Communities First area reside in the most deprived areas of Wales, this may not accurately represent an individual's current socioeconomic circumstances (Galobardes *et al*, 2006b). Assessing additional individual level indicators such as education and employment are likely to overcome these issues (Galobardes *et al*, 2006a).

9.6.2 Intervention acceptability testing

The intervention was tested for acceptability on two small groups of potential users. Whilst the aim of the user testing study was to explore acceptability and feasibility of the intervention, there are limitations with using a small sample of individuals from two communities. Small sample size has limitations of generalisability and precludes inferential statistical analysis. Therefore, conclusions cannot be drawn regarding potential for change in the outcomes measured.

Both groups were recruited opportunistically through community partners and there is potential for recruitment bias. It is likely that those recruited to take part in the acceptability testing study were selected by the community partner based on an interest in health or were more active members of the community, which has implications for representativeness. One group was recruited through an existing peer support group for mental health, and the other group were mainly recruited from the volunteer network in the community. Those who attend a weekly peer support group may be more likely to engage in help seeking behaviour or feel able to discuss health concerns. This could explain the findings related to increased anticipated time to symptom presentation after completing the intervention. In addition, those who are members of a local volunteer network may be the more active, key or outspoken members of the community. Although piggybacking on similar existing groups is likely to be a useful method for recruiting individuals into an intervention session, such groups may not be truly representative of the target population. However, holding the intervention with a pre-existing group for the first time in a community, and subsequently running multiple sessions in the same area could be used as a strategy for encouraging participation. Encouraging future participation in the intervention will be discussed later in this chapter. Finally, recruiting people to take part in the intervention through community settings was time-intensive. This is likely to have implications for the intervention in future and evaluation due to the amount of time required to identify and invite individuals to take part in an intervention session, in addition to the time required to organise and co-ordinate a session.

9.7 Intervention development using the Behaviour Change Wheel

The Behaviour Change Wheel was used in accordance with the MRC framework to guide intervention development for this PhD and was useful in this context. The Behaviour Change Wheel was selected to guide intervention development due to its systematic framework and theoretical underpinning of the COM-B model and TDF. As previously discussed, the COM-B

model was identified as a useful model for understanding cancer symptom presentation behaviour among low socioeconomic groups (Chapters 2, 4 and 5). Therefore, using an intervention development framework underpinned by the COM-B model was a strength.

The Behaviour Change Wheel provides researchers with a step-by-step guide to intervention development, facilitating replicability and research rigour, and was a key benefit of the framework. Researchers are required to consider a broad range of intervention constructs (type, content and mode of delivery), using the APEASE criteria to narrow down construct selection. Starting with a wide and comprehensive range of intervention constructs was useful to consider all available options, thus at no point was the framework limiting. The APEASE criteria were particularly useful when choosing appropriate intervention constructs throughout the Behaviour Change Wheel process. Each of the six APEASE criteria was clearly defined, facilitating systematic selection of intervention components, ensuring the selection process did not rely on researcher preference. This process reduced potential bias when deciding which constructs were most suitable in the present context, enabling accurate reporting of the decision making process for why certain aspects were included or excluded. In future it could be beneficial to undergo the intervention development process using the Behaviour Change Wheel with local stakeholders. When applying the APEASE criteria to each stage, it would be useful to gain their views in relation to acceptability of certain aspects and ongoing local policy and initiatives in the community.

Although the breadth of the Behaviour Change Wheel was a benefit, its applicability to a wide range of behaviour change contexts posed limitations in the present intervention development study due to vague and overlapping construct definitions. For example, the intervention functions of training and education were similar, and the definitions provided for each intervention function did not overcome the ambiguity between the two intervention functions. Although the APEASE criteria were useful for systematic construct selection, fully understanding each intervention construct was challenging without comprehensive definitions.

The Behaviour Change Wheel textbook is designed to provide researchers with a step-by-step guide to the development of behaviour change interventions (Michie *et al*, 2014). However, the textbook guide lacked clarity in places with regard to how each of the Behaviour Change Wheel stages linked and personal judgement was required to understand the process. For example, it was unclear that the Behaviour Change Techniques (BCT) Taxonomy should be consulted after selection of the intervention functions. There were

additional problems encountered when using the BCT Taxonomy. Firstly, it was unclear if all the BCTs should be considered for intervention content or just the most frequently used BCTs as listed in the taxonomy. Secondly, although the BCT Taxonomy was created with the aim to provide researchers with a clear and simple standardised taxonomy, some definitions were vague, making selection of relevant BCTs difficult. Many of the BCTs outlined in the taxonomy were similar, with limited information in the definitions on the difference between the BCTs in practice, where often only one example of how the BCT could be used was provided. Often, limited examples did not reduce the ambiguity of the definition. For example 'information about health consequences' and 'salience of health consequences' were similar. The definition for 'salience of health consequences' in part states that this BCT 'goes beyond informing about health consequences' with little guidance on how to go beyond providing information about health consequences. A recent study suggests that other researchers have experienced similar problems when selecting 13 of the 93 BCTs (Michie *et al*, 2015; Abraham *et al*, 2015), which are likely to be resolved through further revisions of the framework and provision of formal training (Wood *et al*, 2016).

Finally, all stages of the BCW mapping process involve subjective assessments, which were complicated by imprecise construct definitions. Each definition is subject to potential bias through interpretation and selection bias of each component, potentially excluding key components at each stage. Although this can be reduced by using the APEASE criteria and reporting reasons for exclusion, additional steps can be taken to reduce subjectivity. Dual coding at each stage, followed by discussion between coders can limit any potential bias. However, dual coding was not performed as part of this PhD thesis which is a limitation.

9.8 Development of a community lung health intervention targeted at people from a low socioeconomic group

The initial aim of this PhD was to develop a cancer awareness intervention for common cancers. However, in response to changes in Welsh Government policy in 2015, the decision was made to focus the intervention on lung cancer. For intervention development, lung specific barriers identified in Chapters 3, 4 and 5 were extracted and mapped to the Behaviour Change Wheel. These studies were designed to understand the barriers to symptom presentation among low socioeconomic groups regardless of tumour site. Consequently, there are limitations associated with designing an intervention targeted specifically at lung cancer on the basis of preliminary work to understand the barriers and facilitators to general cancer symptom presentation. It is likely that some lung specific

barriers and facilitators were overlooked, and that some of the more general barriers/facilitators to cancer symptom presentation may not be applicable to lung cancer. For example, there is evidence to suggest that smoking habit can act as an additional barrier to symptom presentation. Smokers are more likely than non-smokers to prolong or not seek medical help for symptoms of lung cancer (Friedemann-Smith *et al*, 2016; Corner *et al*, 2006; Chatwin and Sanders, 2013). There is evidence to suggest that lung cancer symptom knowledge is equal for smokers and non-smokers (Simon *et al*, 2012a), therefore prolonged symptom presentation is likely to be a consequence of misattribution of symptoms and social factors such as stigma.

Lung cancer symptoms are often misattributed and dismissed as normal in the context of smoking habit (Corner *et al*, 2006; Chatwin *et al*, 2014; Birt *et al*, 2014a; Birt *et al*, 2014b). In addition, as smoking prevalence falls in higher income countries, the stigma attached to those who smoke increases (Stuber *et al*, 2008; Farrimon and Joffe, 2006). The association between smoking and lung cancer is commonly understood, leading to the stigmatisation of lung cancer as a self-inflicted or 'dirty disease' (Simon *et al*, 2012a; Marlow *et al*, 2015; Chambers *et al*, 2012; Chapple *et al*, 2004a). Smokers may report a reluctance to seek medical help for symptoms through feelings of blame and guilt associated with their symptoms caused by smoking habit, which in part can be due to the stigma attached to smoking (Quaife *et al*, 2016; Chatwin and Sanders, 2013; Corner *et al*, 2005; Corner *et al*, 2006; Tod *et al*, 2008; Chapple *et al*, 2004a). In addition, there is evidence to suggest that smokers prolong symptom presentation due to fear of being refused treatment or being judged by the healthcare professional (Tod *et al*, 2010; Corner *et al*, 2006).

Around a third of those who took part in the qualitative interviews (Chapter 4) were current smokers and there were no data available on smoking status for the focus group study (Chapter 5), therefore it is unclear how many of the sample currently smoked or used to smoke. Smoking related barriers to symptom presentation behaviour were only explored if mentioned by the participant. Therefore, the influence of smoking in the context of cancer symptom presentation behaviour was not fully explored, and certain smoking specific barriers potentially excluded from the intervention. On reflection, if the focus of this PhD had been on lung cancer from the outset, the interviews might only have been carried out with smokers or ex-smokers, and the topic guide adapted to focus in part on smoking related barriers to cancer symptom presentation. For example, this might include whether and how smoking habit influences symptom interpretation and the decision to seek medical

help. In addition, questions designed to understand how smoking status affected previous interactions in a healthcare setting would be asked. A more in depth understanding of lung specific symptom presentation barriers and facilitators among current and former smokers is required before further pilot testing or controlled evaluations are considered. In addition, an understanding of how smoking status and comorbid lung conditions such as COPD might influence interpretation of potential lung cancer symptoms is needed.

9.9 Future of the intervention

The secondary aim of this PhD was to develop an intervention to encourage timely lung cancer symptom presentation among low socioeconomic groups to promote early detection and diagnosis of lung cancer. An intensive community group based educational session intervention was developed, targeted at those who are most at risk for lung cancer. Family members of smokers were invited to take part in the intervention to utilise strong social networks in the community and promote good quality advice following symptom disclosure or noticing of symptoms in the community. The intervention contained information about the symptoms of lung cancer, when to go to the GP with symptoms, lung cancer risk information, information to modify negative beliefs about lung cancer, what to expect when presenting to primary and secondary care, and strategies to overcome barriers to symptom presentation.

The MRC framework for complex intervention development outlines various stages in the development of interventions before implementation (Craig *et al*, 2008). After intervention development, feasibility and pilot testing should be conducted before larger scale intervention evaluation and finally implementation. Acceptability testing with a small group of potential intervention users was conducted as part of this PhD, however further feasibility and pilot studies are required before a controlled evaluation and implementation is considered. This section will outline the future for the intervention, including suggestions for further feasibility and pilot testing, and evaluation, including potential implementation considerations and challenges. Finally, the potential role of the intervention will be discussed in relation to policy initiatives for lung cancer prevention and early detection.

9.9.1 Recommendations for further evaluation

9.9.1.1 Feasibility testing

Preliminary findings from a small user testing study suggested that the intervention is an acceptable method for delivery; however, further feasibility testing is required before pilot testing. The MRC guidance highlights the importance of conducting feasibility testing across multiple sites (Craig *et al*, 2008), so that the extent to which the intervention is acceptable and feasible in other communities can be evaluated. Therefore feasibility testing of the intervention should be carried out in socioeconomically deprived areas of the UK.

Feasibility testing should be conducted to estimate sample size for a larger study, and assess appropriate methods of participant recruitment. This would include estimates of the number of people in the community who are eligible for the intervention, and willingness of staff in the community to help identify participants to take part in the intervention study. In addition, the acceptability and suitability of questionnaire measures should be assessed. The distribution of incomplete or multiple responses to questions or statements would be observed, and a think-aloud method could be used for questionnaire completion with a proportion of participants to assess comprehension of questions and views on appropriateness of response options. Adjustments to questionnaire measures would be made accordingly. In addition, response rates to follow up questionnaires would be calculated to assess compliance. Finally, the time required to collect and analyse data would be recorded to estimate time scales for a larger study.

9.9.1.2 Pilot testing

Before scaling up to a controlled evaluation, pilot testing of the intervention is required across multiple sites (Craig *et al*, 2008). At pilot testing, the intervention study is designed to replicate a larger controlled trial on a smaller scale. Pilot testing is conducted to ensure the various components of the intervention study run as intended such as participant recruitment, randomisation, and completion of baseline and follow-up measures. In addition, pilot testing has the potential to offer preliminary insights into intervention effects. It is envisaged that the controlled evaluation would ideally take the form of a randomised control trial (RCT); therefore, participants at pilot testing would be randomised to one of three arms: an intervention arm where individuals take part in the lung health information session; a leaflet arm where individuals receive information such as the CRUK lung cancer leaflet, and a control arm where individuals receive no intervention.

Measures used for intervention pilot testing could include proxy measures of the factors which contribute to prolonged cancer symptom presentation. An adaptation of the lung Cancer Awareness Measure (CAM; Simon *et al*, 2012a) could be used to assess lung cancer symptom knowledge, beliefs about lung cancer, barriers to cancer symptom presentation and anticipated lung cancer symptom presentation behaviour. Intervention session observations and qualitative interviews can be used to explore intervention preferences. Measuring actual symptom presentation behaviour using GP read codes, number of new referrals to secondary care or numbers of new lung cancers diagnosed are not useful at pilot testing. This is due to relatively low numbers of new cases of lung cancer diagnosed in each community and small numbers from each community in each intervention session; however, these measures of actual symptom presentation behaviour could be used to assess intervention effectiveness for a larger scale RCT.

Preliminary acceptability testing from this PhD included a post intervention questionnaire directly after the intervention which precluded assessment of information retention. It would be preferable for post intervention follow-up questionnaires to be completed at least one month post intervention. Longer time periods for follow-up questionnaire such as six months would be desirable; however, due to time and funding restrictions, six month follow up may not be feasible, instead opting for a shorter follow up time of one, two or three months.

9.9.1.3 Controlled evaluation

Depending on the outcome from pilot and feasibility testing, a controlled evaluation could be considered if the intervention was acceptable and amendments were made to the intervention following pilot testing. This could take the form of a RCT where individuals are randomised into one of three arms outlined above. Measures collected during controlled evaluation might be similar to those at feasibility and pilot testing phase, and are likely to involve a survey based measure such as the Lung CAM at baseline and follow up. As previously discussed, depending on the scale of the intervention implementation, collecting clinical data such as two week wait referrals, GP read codes and new cases of lung cancer could be considered. If the intervention is effective, intervention implementation can be considered.

9.9.2 Intervention implementation: considerations and challenges

9.9.2.1 Encouraging participation in the intervention

Encouraging participation in the lung health intervention, particularly among smokers, is likely to present the greatest challenge for intervention implementation. This was reflected in the difficulties of recruiting people to take part in intervention user testing. Recruiting current smokers into an intervention about lung cancer was predictably challenging, and there was low representation from current smokers in the intervention user testing. There was evidence that current smokers were apprehensive about attending the intervention. In addition, some non-smokers who took part in the intervention reported unsuccessful attempts to persuade family members who smoke to attend the intervention.

There are two potential strategies which could be used to encourage smokers to attend the intervention or facilitate intervention messages to reach smokers. Firstly, the intervention could be repeated a few times in any given community on different days and at different times. At the end of the session, intervention attendees could be given a list of the additional intervention sessions and asked to tell family members or friends who currently smoke about the session and encourage them to attend. There was evidence to suggest that positive feedback through word of mouth is important, where attendees would recommend the intervention to family and friends in the future. Secondly, current smokers could be targeted through social networks using the current intervention strategy where family members of smokers attend the intervention and look out for warning signs by proxy, prompting high risk symptomatic individuals to go to the GP with symptoms. Social support and legitimisation of symptoms requiring medical help from family and friends has been found to prompt lung cancer symptom presentation in smokers (Birt *et al*, 2014b; Chatwin and Saunders, 2013).

Targeting individuals through social networks has the potential for intervention messages to reach individuals who might otherwise not engage in an intervention about cancer (Rogers, 1985). Giving people in the community information to facilitate good quality advice upon symptom disclosure or noticing symptoms could promote earlier symptom presentation. In addition, asking people to notice symptoms in others and prompt symptomatic individuals to seek medical help from their GP is likely to create intervention sustainability. Providing individuals with the skills and knowledge to notice symptoms in others and offer good

quality advice has the potential for the intervention messages to reach members of the community even after the intervention is no longer implemented.

Other reasons for non-participation which could be overcome included childcare issues and problems with timing. In addition, there was interest in taking part in the intervention from a younger age group and perhaps the intervention in future could explore reducing the age to the over 30s and run the intervention session at different times of the day to allow those who work to attend.

There were problems associated with engaging most of the communities contacted to help with recruitment for the intervention. As previously discussed, recruiting participants through community partners as a 'trusted source' was a good method to enable access to members of the community who may not usually take part in research. However, relying entirely on help for recruitment through community partners was problematic when community partners could not recruit participants because they were too busy, since finding people to take part was time consuming. Future pilot and feasibility studies should explore alternative recruitment methods, perhaps through social media groups or poster boards in the community, or snowballing through community partners in other areas.

9.9.2.2 A multi-level intervention approach

Findings from acceptability testing suggested that GP access was a key barrier to presenting promptly with symptoms. In Chapter 6, interventions which adopted a push-pull method were most effective in terms of behaviour change, pushing symptomatic individuals to go to the GP through intervention messaging and pulling individuals into secondary care using HCP interventions. It was beyond the scope of this PhD to develop an intervention for both HCPs and members of the public; however, the feasibility of combining this intervention with an intervention targeted at HCPs could be explored in future, adopting a multi-level approach to behaviour change. For example, since development of the intervention, there has been interest from a GP working in a Communities First area in South Wales who has developed an intervention targeted at HCPs. The intervention was designed to remind HCPs of the referral guidelines for suspected lung cancer and encourage them to refer patients with symptoms for chest x-ray.

In the context of upstream factors such as employment problems resulting in economic hardship which influenced symptom presentation behaviour, interventions targeted at the individual or community level may have limited impact. As outlined in Chapter 1, attempting

to modify the wider social determinants of health was beyond the scope of this PhD. Education at the community level was therefore selected as the focus of the intervention to promote behaviour change. Education was used to enable individuals to feel empowered to detect and report symptoms to the GP to promote earlier detection of lung cancer. Interventions at the individual level are most likely to be effective when local and national policy addresses the social determinants of health inequality through improvements in living and working conditions.

9.9.2.3 Policy considerations

Consideration of how the lung cancer intervention could fit with local and national policy on lung cancer early detection and prevention is important for implementation. The need to improve health outcomes, including cancer, in the most deprived communities is one of the strategic aims of Communities First, the Welsh Government initiative to tackle poverty. In addition, recent changes to policy where the need to improve lung cancer outcomes became a national priority (Welsh Government, 2015) support the need for interventions targeted at those who are most at risk to promote earlier lung cancer detection.

Promoting timely presentation with potential symptoms through cancer awareness interventions is one potential strategy for improving lung cancer outcomes through earlier detection. Based on the English Be Clear on Cancer lung cancer public awareness campaign, an eight week mass media TV and radio campaign was launched in July 2016 across Wales to encourage people with a cough symptom lasting three weeks or more to go to their GP. As reported in Chapter 6, mass media interventions are the least beneficial in terms of encouraging symptom presentation behaviour among low socioeconomic groups. However, mass media campaigns could be used in combination with targeted interventions such as the lung health information session developed in this PhD.

An alternative strategy for detecting lung cancer in the early stages is screening high risk individuals using low-dose computed tomography (LDCT). LDCT lung screening is currently undergoing implementation in the United States following the success of the National Lung Screening Trial, which reported a 20% reduction in lung cancer mortality (Aberle *et al*, 2011). Although not routinely available in the UK, trials are ongoing across Europe to assess feasibility, acceptability and effectiveness of LDCT screening among high risk groups (Brain *et al*, 2016; Field *et al*, 2015; van Klaveren *et al*, 2009). Based on these findings, the National Screening Committee will decide whether LDCT screening will become the standard of care

in the UK among high risk groups. Paradoxically, however, participation in lung screening trials is lowest among those at highest risk, including current smokers from a low socioeconomic group (Aberle *et al*, 2010; Hestbech *et al*, 2011). If stratified LDCT screening is introduced in the UK NHS, interventions targeted at those who are most at risk are essential to encourage participation. Studies suggest that smokers from a low socioeconomic group place lower value on the benefits of lung cancer screening, hold fatalistic beliefs about lung cancer as an untreatable disease, or report stigma as a barrier to screening participation (Quaife *et al*, 2016a; Aberle *et al*, 2011; Patel *et al*, 2012). Group education aimed at current or past smokers in the community setting could potentially be used to provide information about lung screening among high risk groups, providing information to modify fearful and fatalistic beliefs, minimise the stigma surrounding lung cancer, and emphasise the benefits of earlier diagnosis and treatment. Family members of smokers could be included to promote engagement with lung screening through social networks. In the primary care setting, an information leaflet mailed through GP practices inviting high risk individuals to attend a nurse led lung health check is currently undergoing evaluation as a potential strategy to engage individuals in lung screening (Quaife *et al*, 2016b).

As the main primary prevention option for lung cancer, smoking cessation advice is recommended for use in conjunction with LDCT screening (Moyer, 2014). Smoking prevalence is highest among low socioeconomic groups (Riaz *et al*, 2011; Hiscock *et al*, 2012), and despite an overall decline in smoking among developed countries, smoking rates have remained stable among low socioeconomic groups (Hiscock *et al*, 2012). There is evidence to suggest that people from low socioeconomic groups are just as likely as those from a high socioeconomic group to attempt to quit smoking, but less likely to be successful (Kotz and West, 2009), possibly due to social norms for smoking among low socioeconomic groups (David *et al*, 2010; Paul *et al*, 2010) and lack of social support required for a quit attempt (Fisher, 1997; Hiscock *et al*, 2012). In addition, stressful living environments and higher nicotine dependence are more likely to result in relapse (Baker *et al*, 2007; Tsoortos *et al*, 2008). Smoking cessation interventions which provide behavioural and pharmacological support and are targeted at individuals from low socioeconomic groups appear to show promising results, although further research is needed to understand how best to engage high risk groups (Hiscock *et al*, 2012; Bryant *et al*, 2011). Findings from intervention acceptability testing during this PhD suggested that integrating smoking cessation advice may deter engagement with lung cancer early detection strategies. Positive feedback of the intervention to family and friends in the community was discussed as

important for the future of the lung health intervention because recommendations would encourage other members of the community to attend the intervention. The inclusion of smoking cessation advice in a LDCT lung screening service should be carefully considered, and perhaps offered as an option to those who are motivated to quit smoking in order to minimise the potential for negative feedback through word of mouth of lung screening services in the community.

9.10 Conclusion

There is a complex interplay between individual factors (Capability and Motivation) and wider social and environmental factors (Opportunity) on cancer symptom presentation behaviour among low socioeconomic groups. Social networks (Opportunity) were most influential on the formation and maintenance of cancer knowledge (Capability) and beliefs (Motivation), and social networks had the potential to prolong or prompt cancer symptom presentation through symptom disclosure. The environmental factors associated with living in a deprived community were found to influence cancer symptom presentation (Opportunity). Specifically, competing priorities as a consequence of economic hardship took precedence over medical help seeking behaviour, especially when symptoms were perceived as not serious in the context of other pre-existing co-morbidities. A community group based educational intervention designed to empower high risk individuals to seek medical help for lung cancer symptoms was developed to encourage earlier lung cancer symptom presentation. This was considered by participants to be an acceptable method for intervention delivery, although further pilot and feasibility testing are required. There is potential for the lung health information session intervention developed for this PhD to fit with future policy initiatives to introduce LDCT lung cancer screening and integrated smoking cessation, creating a package of interventions to encourage earlier diagnosis and prevention of lung cancer among high risk groups.

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RESEARCH ARTICLE

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Influences of cancer symptom knowledge, beliefs and barriers on cancer symptom presentation in relation to socioeconomic deprivation: a systematic review

Grace M. McCutchan*, Fiona Wood, Adrian Edwards, Rebecca Richards and Kate E. Brain

Abstract

Background: People from lower socioeconomic groups have worse survival outcomes for cancer, which in part reflects later-stage disease at diagnosis. The mechanisms underlying delayed cancer symptom presentation in lower socioeconomic groups are not well understood.

Methods: Systematic review of studies of actual or anticipated symptom presentation across all tumour sites. Included studies measured socioeconomic group, symptom presentation and one or more of the following variables: cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation.

Results: A total of 60 studies was included. Symptom knowledge overall was lowest and actual presentation time was longest in lower socioeconomic groups. Knowledge for specific symptoms such as lumps and bleeding was good and encouraged timely symptom presentation, in contrast to non-specific symptoms which were not well recognised. The combination of fearful and fatalistic beliefs was typically associated with later presentation, especially in lower socioeconomic groups. Emotional barriers such as 'worry what the doctor might find' were more frequently reported in lower socioeconomic groups, and there was evidence to suggest that disclosing symptoms to family/friends could help or hinder early presentation.

Conclusions: Poor symptom knowledge, fearful and fatalistic beliefs about cancer, and emotional barriers combine to prolong symptom presentation among lower socioeconomic groups. Targeted interventions should utilise social networks to improve knowledge of non-specific symptoms, challenge negative beliefs and encourage help-seeking, in order to reduce avoidable delays and minimise socioeconomic group inequalities.

Keywords: Patient delay, Symptom knowledge, Cancer beliefs, Barriers to symptom presentation, Socioeconomic status

Background

Socioeconomic inequalities in cancer survival outcomes exist, but the reasons for this are not fully understood [1–3]. Survival differences are likely to reflect later-stage disease at diagnosis [2, 4, 5] partly as a consequence of delayed cancer symptom presentation in people from lower socioeconomic groups [6]. By eradicating socioeconomic inequalities at stage of diagnosis, it is estimated that 5600 patients in the UK annually could be diagnosed with earlier stage disease [7], and that 11 % of

deaths from cancer could be avoided if three-year survival in lower socioeconomic groups matched that in higher socioeconomic groups [1].

'Patient delay' is defined as the time between discovery of a cancer symptom and the initial visit to a healthcare professional. It accounts for the greatest proportion of delay time in the pathway from symptom discovery to the start of cancer treatment [8–10] and has been associated with socioeconomic deprivation [6]. Patient delay has been conceptualised in Walter et al.'s Model of Pathways to Treatment, with various stages involving an 'appraisal interval' during which the individual detects a bodily change, and a 'help seeking interval'

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in which the individual decides to seek medical help (see Fig. 1 [11]). Evidence suggests that knowledge of cancer symptoms is important during the appraisal stage, with potential misattribution of symptoms attenuating the decision to present [12, 13]. Beliefs about cancer are considered to be important in both the appraisal and help-seeking stages, where emotions such as fear might influence interpretation of symptoms [12] and the decision to seek medical help [6, 14–17]. Barriers such as competing life events and ease of getting a medical appointment are thought to delay symptom presentation during the help-seeking interval [11].

The contribution of socioeconomic and other demographic factors to delayed presentation has been highlighted in the Model of Pathways to Treatment, and more recently in the updated National Awareness and Early Diagnosis Initiative (NAEDI) framework designed to conceptualise the route from public awareness and beliefs about cancer to cancer survival outcomes ([18]). Empirical evidence supports associations between lower socioeconomic group and poor cancer symptom knowledge [19], fearful and fatalistic beliefs about cancer [20] and emotional barriers such as worry about what the doctor may find [19]. These findings

help to explain why people from lower socioeconomic groups tend to present with more advanced stage cancers, and hence have worse survival outcomes [1–5]. However, a more detailed understanding of psychosocial influences on the relationship between socioeconomic deprivation and cancer symptom presentation is essential to developing behavioural interventions designed to promote timely presentation and reduce socioeconomic inequalities in cancer outcomes.

Attempts to understand why people might delay seeking medical help for cancer symptoms have examined actual or anticipated symptom presentation behaviour, exploring perceived barriers to symptom presentation. Prospective study designs are difficult due to follow-up of a large sample, so studies frequently use retrospectively recalled or hypothetically anticipated symptom study designs. Previous reviews have focused on tumour site-specific delay factors [15, 16, 21] or common cancers only [6], or have been restricted to qualitative studies [17] and patients with cancer [6, 16, 17]. The purpose of the current systematic review was to explore how knowledge, beliefs and barriers/facilitators to symptom presentation affect actual or anticipated cancer symptom presentation in relation to socioeconomic group and across all tumour sites.

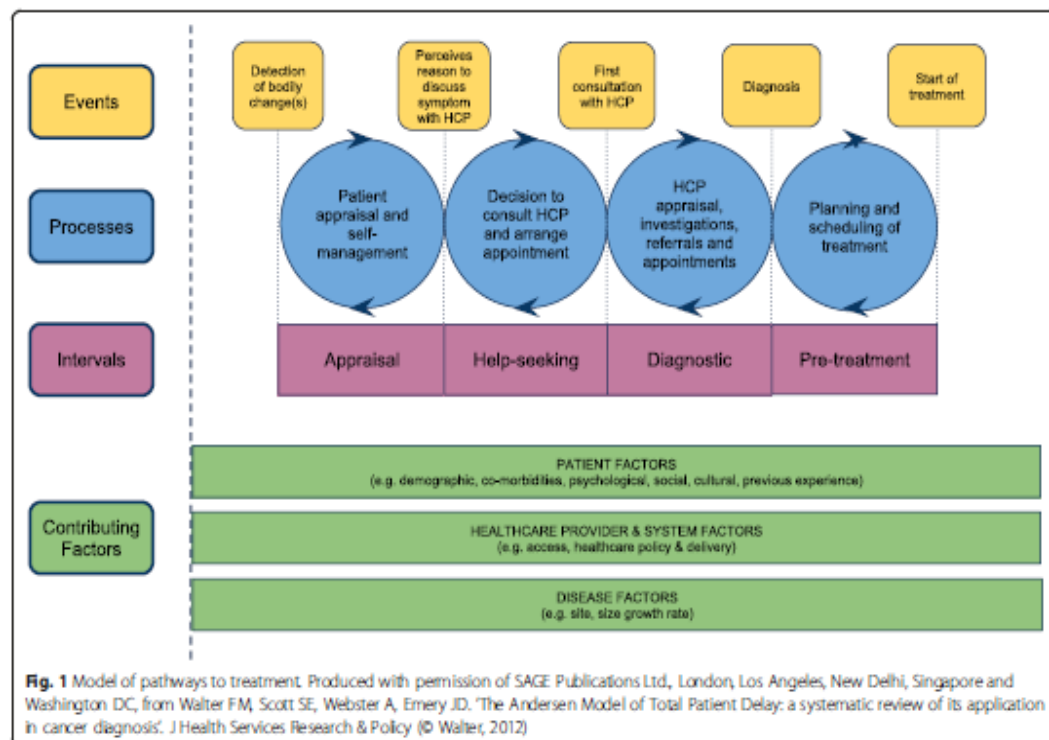


Fig. 1 Model of pathways to treatment. Produced with permission of SAGE Publications Ltd, London, Los Angeles, New Delhi, Singapore and Washington DC, from Walter FM, Scott SE, Webster A, Emery JD. 'The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis.' *J Health Services Research & Policy* (© Walter, 2012)

Method

Identification of included studies followed the PRISMA guidelines [22]. The protocol was registered on PROSPERO (CRD42014013220 [23]) and is available on the NIHR HTA programme website (www.hta.ac.uk). At all stages of the search, data extraction and quality appraisal, 10 % of studies were double checked for consistency by a second member of the research team (RR). All discrepancies were resolved through discussion.

Search strategy

The literature was searched up to July 2015 on the electronic databases of MEDLINE, PsychINFO, EMBASE and CINAHL. The de-duplicate function was used on Ovid and CINAHL before reviewing abstracts. Manual searches of reference lists of included studies were performed. A SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) search strategy tool was used for retrieval of studies (see Additional file 1: Appendix 1 [24]). Databases were searched using terms relating to *symptom presentation, cancer symptom knowledge, beliefs about cancer, perceived barriers and facilitators to symptom presentation* (see Additional file 1: Appendix 1).

Inclusion criteria

Publications that measured and reported data for symptom presentation and socioeconomic group were included. 'Symptom presentation' was defined as actual symptom presentation (retrospectively recalled) or anticipated symptom presentation (hypothetically estimated) measured as continuous (time to presentation) or binary (did/did not present) variables. 'Socioeconomic group' was defined in terms of individual level socioeconomic indicators including education, income, home/car ownership, occupation and employment, and/or area-level indicators based on postcode. In addition, publications were included if they measured and reported one or more of the following domains of interest:

- 'Knowledge': studies which assessed knowledge for the symptoms of cancer through recall e.g. 'What symptoms of cancer can you list?' or recognition methods e.g. 'Which of these are symptoms of cancer?' or through retrospective recall of symptom interpretation at the time of symptom discovery.
- 'Beliefs': studies which explored any positive (e.g. beliefs about the benefits of early diagnosis and curability) or negative (e.g. fear and fatalism) beliefs surrounding cancer.
- 'Perceived barriers/facilitators': studies which assessed any anticipated or actual barriers or facilitators to symptom presentation.

There were no restrictions on date of publication or study methodology. Only English language studies from high income countries as classified by Organisation for Economic Co-operation and Development (OECD) membership (OECD, 2014 [25]) were included.

Exclusion criteria

Studies that did not measure and report symptom presentation, socioeconomic group and one or more of the domains of interest were excluded. Studies not relating to cancer, and those examining screening behaviour, self-examination behaviour, efficacy of interventions, genetic risk, healthcare professionals' perspective, cancer prevention, treatments for cancer or living with cancer and studies involving children were excluded. Studies from low/middle income countries, not written in English, review papers or conference abstracts were excluded (Fig. 2).

Data extraction and synthesis

Data were extracted onto a template using the following headings: method, sample characteristics, tumour site, symptom presentation, knowledge, beliefs, perceived barriers/facilitators and socioeconomic group measure. A meta-analysis was precluded due to the heterogeneity of included studies and a narrative synthesis was performed [26].

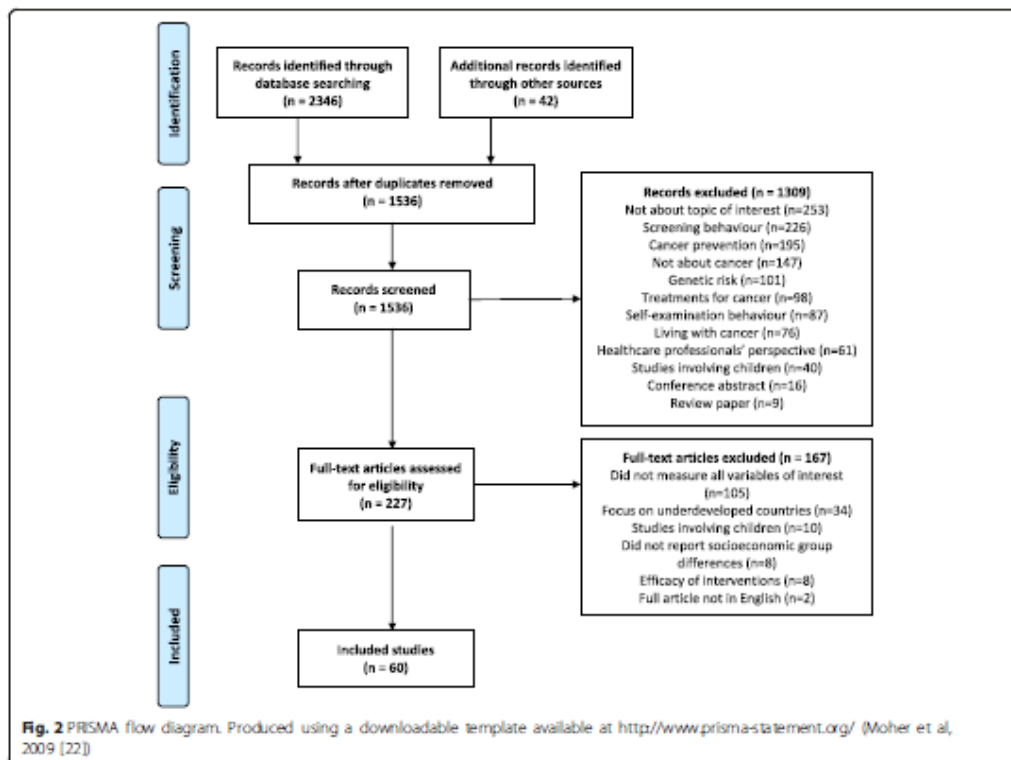
Critical appraisal

The methodological quality of all included studies was examined using the Critical Appraisal Skills Programme tool (CASP, 2014 [27]) appropriate for the study design. Quality was assessed according to each domain on the CASP checklists: rationale of study, methodology, design, recruitment, data collection, data analysis, ethical issues, reporting of findings and contribution to research. Overall quality was categorised as good, medium or poor.

Results

The search returned a total of 1536 studies after 810 duplicates had been removed. A total of 1309 studies was excluded based on title and abstract, leaving 227 studies to be read in full. A total of 60 studies met the inclusion criteria (see Fig. 2). Eleven of these studies were found through hand searching reference lists.

Included studies employed qualitative methods ($n = 15$), quantitative methods ($n = 42$) and mixed methods ($n = 3$). Quality of studies was good ($n = 18$), medium ($n = 37$) and poor ($n = 5$). Limitations of lower quality studies included measuring but not reporting socioeconomic group differences for all outcome measures, leaving a long period of time between cancer diagnosis and participation in the study and recruitment of samples biased towards higher socioeconomic groups. The overall combined percentage



agreement between raters (GM and RR) for inclusion/exclusion of studies, critical appraisal and data extraction was 87 %.

A total of 53 studies examined time to symptom presentation, seven studies reported presentation behaviour (if participants did or did not present or anticipate presenting to their doctor with reported symptoms), 45 studies measured actual symptom presentation, 15 studied anticipated symptom presentation, 46 studies assessed knowledge for cancer symptoms, 32 studies explored beliefs about cancer and 50 studies examined perceived barriers/facilitators to symptom presentation. The numbers of studies by tumour site were as follows: breast ($n = 22$), any cancer/multiple tumour sites ($n = 15$), colorectal ($n = 7$), skin ($n = 6$), oral and pharyngeal ($n = 3$), ovarian ($n = 3$), lung ($n = 2$), gynaecological ($n = 1$), and prostate ($n = 1$) (see Table 1). Results are presented according to domain headings.

Symptom presentation

Studies involving anticipated symptom presentation reported shorter time to symptom presentation compared

with studies that examined actual time to symptom presentation. In the former, most participants anticipated seeking medical help within one week [28–30] or within one month [19, 31, 32], in contrast to real-world studies where it was more common for patients to have waited over two months before seeking medical help [33–41]. The most prompt actual and anticipated symptom presentation was reported for lumps [32, 38, 42–47] or bleeding [19, 32, 48–53]. Studies examining participants who reported experiencing a potential symptom of cancer in the past three months found between 59 % and 75 % of participants had consulted a doctor about their symptom [49, 54, 55].

Disparity between actual and anticipated symptom presentation relating to socioeconomic group was observed. In five studies, shorter anticipated time to symptom presentation was observed in lower compared to higher socioeconomic groups [19, 28, 31, 32, 48]. Conversely, in two studies, longer anticipated time to symptom presentation was reported in those from lower socioeconomic groups compared with higher socioeconomic groups [56, 57].

Table 1 Table of included studies

Study	Method	Sample	Country	Tumour site	Socio-economic measure	Measures: Knowledge (K), Beliefs (B), Perceived barriers (PB), Perceived facilitators (PF), Symptomatic Presentation (SP)	Measure of association between variables of interest and socioeconomic indicator (qualitative studies not applicable)	Quality appraisal
Brain et al. (2014) [28]	Hypothetical Quantitative	1043 women. Aged 50 years and over	Wales	Ovarian	Postcode, education	K: Recognition (mean, 6.85 symptoms) B: Cancer worry PB: Emotional and practical barriers SP: Sought medical help in under 3 weeks (n = 898)	K: Lower education associated with lower knowledge ($F_{(2, 1003)} = 8.23, p < 0.001$); higher deprivation (postcode) associated with lower knowledge ($F_{3886} = 2.82, p < 0.05$) B: NR PB: NR SP: Higher education associated with longer time to SP, (OR = 2.64, $p \leq 0.001$); NS difference between deprivation by postcode and anticipated delay ($\chi^2_{(3)} = 6.73, p > 0.05$) NS	Good
Brouha et al. (2005) [76]	Retrospective Quantitative	189 men and women. Mean age: 59 years	Holland	Oral and Pharyngeal	Education, income	K: Symptom interpretation ('cancer', n = 2), misattribution of symptoms to dental problems delayed SP PB: Symptom did not interfere with daily life PF: Persistence of symptom, development of new symptom SP: Mean time to symptom presentation (pharyngeal, 45 days; oral, 28 days)	K: NR PB: NR PF: NR SP: Education and income not associated with time to SP (statistics NR)	Medium
Burgess et al. (1998) [45]	Retrospective Qualitative	185 women. Mean age: 54 years	UK	Breast	Occupation	K: Symptom interpretation (46 % thought their symptom indicated cancer) B: Fear PF: Symptom disclosure, appearance of new symptoms, appointment booked with GP for another reason SP: Waited over 3 months to seek medical help (19 %)		Medium
Burgess et al. (2000) [67]	Retrospective Qualitative	158 women. Mean age: 53 years	UK	Breast	Occupation	PB: Life events SP: Waited over 3 months to seek medical help (18 %)		Medium

Table 1 Table of included studies (Continued)

Burgess et al. (2001) [43]	Retrospective Qualitative	46 women. Mean age: 54.1 years	UK	Breast	Occupation	K: Symptom interpretation ('lump' most attributed to cancer) B: Consequences of treatment PB: Not wanting to bother the doctor, poor health service utilisation, competing life priorities PF: Symptom disclosure, change in symptom SP: Waited over 3 months to seek medical help (n = 31)		Medium
Cameron and Hinton (1968) [58]	Retrospective Quantitative	83 women	UK	Breast	Education, husband's occupation	K: Symptom interpretation B: Fear, worry SP: 61 % sought medical help within 1 month	K: NR B: NR SP: Higher education associated with shortest time to SP for lump symptoms ($\chi^2 = 6.6, p < 0.05$); Higher social group (husband's occupation) associated with shortest time to SP ($\chi^2 = 3.02, p < 0.01$)	Poor
Caplan (1995) [44]	Retrospective Quantitative	162 women	US	Breast	Income, education, employment	PB: Fluctuating symptoms, relationship with GP SP: Waited over 2 months to seek medical help (n = 27)	PB: NR SP: Lower socioeconomic group (various indices) associated with longer time to SP, but NS: High vs low income (OR 2.56, 95 % CI: 0.68-8.64*); High vs low education (OR 1.07, 95 % CI: 0.41-2.77*); Working vs non-working (OR 0.72, 95 % CI: 0.27-1.99*)	Poor
Carter-Harris et al. (2015) [69]	Retrospective Qualitative	11 men (n = 4) and women (n = 7). Age range: 40-76 years	US	Lung	Education, employment	K: Symptom interpretations (one participant was alarmed at symptoms) PB: Vague and intermittent nature of symptoms PF: Worsening of symptoms, good relationship with GP SP: Immediate (n = 1)		Medium
Chonjnacka-Szawlowska et al. (2013) [36]	Retrospective Quantitative	301 men (n = 186) and women (n = 115). Mean age: 42.3 years	Poland	All	Education	K: Recall, mean: 1.51 B: Fatalism and cancer curability SP: Mean time to symptom presentation: 6 months and 10 days; stage of cancer	K: NR B: NR SP: NS correlation between education and stage of cancer (statistics NR)	Medium

Table 1 Table of included studies (Continued)

Coates et al. (1992) [42]	Retrospective Quantitative	735 women (410 black and 325 white). Age range: 20 to 79	US	Breast	Education, occupation, poverty index (income/no of people in household)	K: Symptom interpretation B: Fatalism PB: Symptom disclosure, other comorbid conditions, appointment with doctor booked for another reason SP: Median time to symptom presentation (black women, 16 days; white women, 14 days)	K: NR B: NR PB: NR SP: Higher education associated with shorter time to SP (Mantel-cox 1.43, 95 % CI: 1.11-1.86, $p < 0.05$); Low deprivation (poverty index) associated with shorter time to SP (Mantel-Cox 1.24, 95 % CI: 1-1.54, $p < 0.05$)	Good
Cockburn et al. (2003) [54]	Retrospective Quantitative	1332 men (40 %) and women (60 %). Aged 40 years and over	Australia	Colorectal (Bowel)	Education	K: Recall (25 % could not recall any symptoms), symptom interpretation B: Benefits of early diagnosis SP: 306 had experienced a symptom, 31.9 % did not seek medical help	K: Higher education associated with higher K of symptoms (PR 0.93, 95 % CI: 0.89-0.96*) B: Higher education more likely to hold positive beliefs about the benefits of early diagnosis (statistics NR) SP: NR	Medium
Esteva et al. (2013) [70]	Retrospective Quantitative	795 men ($n = 489$) and women ($n = 291$)	Spain	Colorectal	Social class, education	K: Symptom interpretation ('not serious', 65.6 %) PF: Symptom disclosure, good relationship with GP (trust) SP: Median time to symptom presentation (19 days)	K: NR SP: NS association between social class and time to SP (statistics NR), NS association between education and time to SP (statistics NR)	Medium
Facione and Facione (2006) [59]	Retrospective Qualitative	28 women. Mean age: 42.34 years	US	Breast	Income, education, health insurance	K: Symptom interpretation B: Fear, fatalism, benefits of early diagnosis PB: Worry about losing relationship with partner if diagnosed with cancer PF: Symptom disclosure SP: Sought medical help after 3 months ($n = 15$)		Medium
Facione et al. (2002) [56]	Hypothetical Quantitative	669 women. Mean age: 46.95 years	US	Breast	Income, education, health care insurance	K: Recognition (10 % recognised all or all but one symptoms) B: Fatalism PB: Difficulties with access, prejudice in health care, concerns about deportation, use of alternative therapies SP: Likely to delay (23.7 %).	K: Higher education associated with higher symptom recognition ($F_{3,690} = 32.32$, $p < 0.001$) B: NR PB: NR SP: Lack of insurance associated with longer time to SP (Cramer's V = 0.187, $p < 0.001$); Lower education associated with longer time to SP (Cramer's V = 0.288, $p < 0.001$); Lower income	Good

Table 1 Table of included studies (Continued)

Facione et al. (1997) [84]	Hypothetical Quantitative	352 African American or Black women. Mean age: 38.6 years	US	Breast	Income, Education, Employment	B: Fear, fatalism PB: Poor health service utilization SP: 11.6 % = strong disposition to SP.	associated with longer time to SP (Cramer's V = 0.291, $p < 0.001$) B: NR PB: NR SP: Stronger disposition to SP associated with lower education ($r = 0.19$, $p < 0.01$) and lower income ($r = 0.32$, $p < 0.001$)	Medium
Facione and Dodd (1995) [83]	Retrospective Qualitative	39 women. Mean age: 49.6 years	US	Breast	Income, education	K: Symptom interpretation B: Fear PB: Competing life priorities PF: Appearance of new symptom, worsening of symptoms, symptom disclosure SP: 59 % sought medical help within 1 week		Medium
Fitzpatrick et al. (1998) [57]	Hypothetical Quantitative	280 men. Mean age: 53.7 years	Ireland	Prostate	Health insurance, occupation	B: Fear PB: Poor health service utilisation, dislike of doctors, embarrassment SP: 81 % would seek medical help if developed urinary symptoms	B: NR PB: NR SP: Non-manual social class associated with higher willingness to attend GP with symptoms (OR 1.8, $p < 0.05^{**}$)	Good
Forbes et al. (2011) [29]	Hypothetical Quantitative	1515 women from various ethnic groups (White, South Asian, Black). Aged 30 years and over	UK	Breast	Postcode (IMD)	K: Recognition (18 % recognised 5 or more non-lump symptoms) PB: self-efficacy, worry what the doctor might find, embarrassment, worry about wasting doctors time, difficulty getting an appointment SP: 73 % would seek help within 1 week	K: Differences between ethnic groups for cancer awareness not due to IMD score or lower level of education (statistics NR) PB: Differences between ethnic groups for PB not due to IMD score (statistics NR) SP: NR	Good
Forbes et al. (2014) [64]	Retrospective Quantitative	1999 men ($n = 1077$) and women ($n = 922$). Aged 50 or over	UK	All	Postcode	K: Symptom interpretation PB: 48 % of patients reported at least one barrier SP: Delay over 3 months ($n = 21$ %)	B: NR PB: NR SP: Lowest socioeconomic group associated with longest time to SP (1.51, 95 % CI: 1.18-1.88*)	Good
Freidman et al. (2006) [38]	Retrospective Quantitative	124 women. Mean age: 44.3 years	US	Breast	Employment, education	B: Fear PB: Worry what the symptom might be, difficulty getting an appointment, cost, denial	B: NR PB: NR SP: Lower education associated with longest time	Medium

Table 1 Table of included studies (Continued)

Goldsen et al. (1957) [61]	Retrospective Quantitative	727 men and women	US	All	Income, education and occupation	SP: Mean time to symptom presentation (9 months) K: Symptom interpretation (20 % thought symptoms indicated cancer) B: Cancer worry, fatalism PB: Poor health service utilization, symptom not noticed PF: Symptom disclosure SP: 51.3 % sought medical help under 30 days	to SP (Fishers Exact test, $p < 0.01^{**}$) K: NR B: NR PB: NR PF: NR SP: Lower income, education and occupation associated with longest time to SP (statistics NR)	Medium
Gould et al. (2010) [39]	Retrospective Qualitative	14 women. Aged range: 30 to 69 years	Canada	Breast	Education, employment, income	K: Symptom interpretation (poor for non-lump symptoms) B: Fear PB: Previous benign disease, watchful waiting, competing life priorities PF: Symptom disclosure, already have another appointment booked. SP: All women waited 8+ weeks		Medium
Grant et al. (2010) [82]	Retrospective Qualitative	15 men ($n=7$) and women ($n=8$). Aged 45 years and under	Scotland	Oral	Postcode	K: Symptom interpretation PB: Self-medication PF: Already had an appointment booked SP: Sought medical help within 8 weeks ($n=8$)		Medium
Greer (1974) [68]	Retrospective Quantitative	160 women with stage I or stage II cancer. Aged 70 years and under	UK	Breast	Social Class	K: Symptom interpretation B: Fear, fatalism PB: Embarrassment SP: 64 % sought medical help within 1 month	K: NR B: NR PB: NR SP: NS difference between time to SP and social class (statistics NR)	Poor
Hunter et al. (2003) [30]	Hypothetical Quantitative	546 women. Mean age: 47 years	UK	Breast	Occupation	K: Recognition (good, mean 6.65) B: Beliefs about treatment SP: 58.6 % would seek immediate medical help.	K: NR NR: NR SP: Socioeconomic group not associated with time to SP ($F_{(1,518)} = 0.29, p > 0.05$)	Medium
Kakagia et al. (2013) [34]	Retrospective Quantitative	513 men ($n=56.5\%$) and women ($n=43.5\%$). Mean age: 67.5 years	Greece	Skin	Education, ethnicity, area of residence	K: Symptom interpretation B: Fear, fatalism PB: Other serious comorbidities, poor health service utilisation, dislike of doctors and hospitals, transport issues, worry about	K: NR B: NR PB: NR PF: NR SP: Longer time to SP associated with lower socioeconomic group	Medium

Table 1 Table of included studies (Continued)

						wasting doctors time, embarrassment, competing life demands PF: Symptom disclosure, active encouragement to seek medical help SP: Mean time to symptom presentation (3.9 months)	(OR 1.89, 95 % CI: 0.9-3.8, $p < 0.001$) and lower education (OR 3.01, 95 % CI: 1.6-5.6, $p < 0.001$)	
Lam et al. (2009) [63]	Retrospective Qualitative	37 women. Age range 20-81 years	Hong Kong	Breast	Employment, education	K: Symptom interpretation B: fear, fatalism PB: Watchful waiting, poor general health service utilisation, cost, competing life priorities, embarrassment PF: Persistence of symptoms, appearance of new symptom, symptom disclosure, symptom interfering with daily life, appointment booked for another reason SP: Waited over 3 months to seek medical help ($n = 14$)		Medium
Li et al. (2012) [65]	Retrospective Quantitative	425 women. Mean age: 51.97 years	Hong Kong	Breast	Employment, education	B: Fear PB: Cost, gender of doctor, unsure where to seek medical help, competing life priorities, no history of breast problems, symptom disclosure PF: Symptom disclosure SP: Median time to symptom presentation (14 days)	B: NR PB: Symptom disclosure for women with lower education less likely to translate into immediate SP ($\chi^2 = 6.4$, $df = 2$, $p < 0.05$) PF: NR SP: Longer time to SP associated with higher education (OR 3.35, 95 % CI: 1.19-9.42, $p < 0.05$) and full time employment (OR 2.52, 95 % CI: 1.18-5.36, $p < 0.05$)	Good
Loehrer et al. (1991) [71]	Retrospective Qualitative	128 men ($n = 33$) and women ($n = 95$). Mean age: 63 years	US	All	Employment, income, education	B: Curability of cancer, cancer is contagious, surgery causes cancer to spread SP: Poor for non-specific symptoms		Medium
Low et al. (2013) [31]	Hypothetical Quantitative	1000 women. Mean age: 47 years	UK	Ovarian	Education, car ownership, home ownership	K: Recall (poor, mean 0.6) and recognition (good, mean 6.3) PB: Mean number of barriers endorsed (2.2), emotional, practical and service barriers SP: Varied by symptom, most	K: NR PB: NR SP: Higher socioeconomic group associated with longer time to SP (beta = 0.12, SE 0.05, $p < 0.001^{**}$)	Good

Table 1 Table of included studies (Continued)

Magarey et al. (1977) [72]	Retrospective Quantitative	64 women. Age in years: less than 40 (<i>n</i> = 13), 40-60 (<i>n</i> = 28), over 60 (<i>n</i> = 23).	Australia	Breast	Education	would seek help under 2 weeks PB: Denial, anxiety SP: Most sought medical help within 2 weeks (<i>n</i> = 35)	PB: NR SP: Education not associated with time to SP (statistics NR)	Poor
Marlow et al. (2014) [78]	Hypothetical Qualitative	54 women from ethnic minority groups living with a comparison of white women. Age range: 25-64 years	UK	Breast and Ovarian	Employment, education, living arrangement	K: Recall (good for lumps/bleeding, poor for other symptoms) B: Fear, fatalism, benefits of early diagnosis PB: Poor relationship with GP, emotional barriers, practical barriers, service barriers, competing life priorities PF: Symptom disclosure SP: Varied: days to months. All sought help within 3 months.		Medium
McCaffery et al. (2003) [50]	Hypothetical Quantitative	1637 men (<i>n</i> = 763) and women (<i>n</i> = 874). Age range: 16-74 years	UK	Colorectal	Education	K: Recall (poor) B: Fear SP: 92.8 % would anticipate seeking medical help if noticed blood in stool for more than 2 weeks.	K: Higher education associated with higher symptom recall ($\chi^2 [4] = 73.98, p < 0.001$) B: Lower education associated with most negative beliefs ($\chi^2 [4] = 74.96, p < 0.001$) SP: NS association with education and SP intentions (statistics NR)	Good
Meechan et al. (2003) [46]	Retrospective Mixed	85 women. Mean age: 38.9 years	New Zealand	Breast	Education	PB: Having a family member with cancer, low emotional response to symptom PF: High emotional response to symptom SP: Median time to symptom presentation (14 days)	PB: NR PF: NR SP: NS association between education and time to SP ($t (83) = -1.26, p > 0.05$)	Medium
Mor (1990) [74]	Retrospective Mixed	700 patients. Age range: 45 to 90 years	US	Lung, Breast and Colorectal	Education, housing, income, education	K: Symptom interpretation (best knowledge for breast cancer patients) B: Fear (16.8 % of delayers) PB: "thought it would go away" (60.5 % of delayers), too busy (8.4 % of delayers)	K: NR B: NR PB: NR SP: NS relationship between socioeconomic group and time to SP (statistics NR)	Medium

Table 1 Table of included studies (Continued)

Oliveria et al. (1999) [37]	Retrospective Quantitative	255 men and women. Aged 18 years and over	US	Melanoma	Education, insurance	SP: Waited over 3 months to seek medical help: lung (54.9 %), breast (56.2 %), colorectal (87.6 %) K: Recognition (poor) SP: Mean time to symptom presentation (2 months)	K: NR SP: Education not associated with time to SP (statistics NR)	Medium
O'Mahony and Hegarty (2009) [47]	Retrospective Quantitative	99 women. Mean age: 40 years	Ireland	Breast	Employment, education	K: Symptom interpretation PB: Competing life priorities, emotional reactions to symptom (afraid, scared, unsure) PF: Symptom disclosure, anxiety SP: Waited over 1 month to seek medical help (n = 26)	K: NR PB: NR PF: NR SP: Higher education associated with longer time to SP (statistics NR)	Medium
O'Mahony et al. (2011) [79]	Retrospective Qualitative	10 women. Mean age: 40 years	Ireland	Breast	Education, employment, insurance	K: Most aware that a lump was a symptom of cancer B: Fatalism, curability of cancer, fear PB: Denial, competing life priorities PF: Symptom disclosure, good perceived access to GP, good relationship with GP SP: Sought medical help within 1 month (n = 6)		Medium
Pedersen et al. (2011) [85]	Retrospective Quantitative	901 men (n = 423) and women (n = 487). Mean age: 61.8 years	Denmark	All	Education	PF: Symptom disclosure, good partner support SP: Median interval: 12 days	PF: NR SP: NS association between education and time to SP: Lower secondary education and long SP (>55 days) (RRR 0.79, 95 % CI: 0.36-1.74, p > 0.05); tertiary education and long SP (>55 days) (RRR 1.30, 95 % CI: 0.55-3.08, p > 0.05)	Medium
Quaife et al. (2014) [32]	Hypothetical Quantitative	6965 men (n = 4330) and women (n = 265). Aged 50 and over	UK	All	Education	K: Recognition (best for 'lump') PB: Poor access health services SP: Would wait 2+ weeks: (cough, n = 48.1 %; breast change, n = 8.2 %; rectal bleeding, n = 7.4 %)	K: Lower education associated with lower recognition for all 3 symptoms (χ^2 , p < 0.05**) PB: NR SP: Lower education associated with shorter time to SP for cough (OR 0.61, 95 % CI: 0.54-0.68, p < 0.001) and breast changes (OR 0.68, 95 % CI: 0.52-0.89, p < 0.001). NS association with	Good

Table 1 Table of included studies (Continued)

Rauscher et al. (2010) [66]	Retrospective Quantitative	438 women. Age range: 30 to 79 years	US	Breast	Education, household income, health insurance status	K: Breast lump misconceptions (20 % reported one or more misconception) PB: Poor general health service utilisation SP: Waited over 3 months to seek medical help (16 %)	education and time to SP for rectal bleeding (OR 0.83, 95 % CI: 0.67-1.03, $p > 0.05$) K: Lower income and education associated with more breast lump misconceptions ($\chi^2, p < 0.001^{**}$) PB: NR SP: Longer time to SP associated with lower education ($\chi^2, p < 0.05^{**}$) and lower income ($\chi^2, p < 0.05^{**}$)	Medium
Richard et al. (2000) [77]	Retrospective Quantitative	590 men ($n = 250$) and women ($n = 340$). Mean age: 51.2 years	France	Melanoma	Residence, social level, education	K: Symptom interpretation ('not serious', 34.8 %) B: Fear PB: No symptoms, competing life priorities (work and family commitments), melanoma not detected by participant PF: Active encouragement from family SP: Sought medical help within 2 months (51.9 %)	K: NS B: NS PB: Those with higher education more likely to self-detect melanoma ($\chi^2, p < 0.01^{**}$) PF: NR SP: NS association with and time to SP and socioeconomic group (statistics NR)	Medium
Rozniatowski et al. (2005) [73]	Retrospective Quantitative	100 men ($n = 84$) and women ($n = 16$). Mean age: 57 years	France	Head and Neck	Education, occupation	PB: Low anxiety, poor general health service utilisation PF: Symptom disclosure, active encouragement from partner to seek help SP: The majority of patients waited over 1 week to seek medical help	K: NR PB: NR SP: NS association between socioeconomic group and time to SP (statistics NR)	Medium
Ristvedt et al. (2014) [33]	Retrospective Quantitative	112 men ($n = 55$) and women ($n = 57$). Mean age: 59.3 years	US	Colorectal	Income, area of residence, education, health insurance	K: Symptom interpretation (70.5 % thought symptom serious within 13 weeks post onset) SP: Median time to symptom presentation (10 weeks)	K: NR SP: NS association between socioeconomic group (education and household income) and time to SP (statistics NR)	Medium
Ristvedt and Trinkhaus (2005) [9]	Retrospective Quantitative	69 men ($n = 42$) and women ($n = 27$). Mean age: 61.3 years	US	Colorectal	Education	K: Symptom interpretation ('not cancer', 71 %) PB: Personality (low trait anxiety), poor health service utilisation SP: Mean time to symptom presentation (25 weeks)	K: NR PB: NR SP: Lower education associated with longer time to SP (Kaplan-Meier: median 15 weeks, 95 % CI: 9.0-26.0*); higher education associated with shorter time to SP (Kaplan-Meier: median 8 weeks, 95 % CI: 4.0-15.0*)	Medium

Table 1 Table of included studies (Continued)

Robb et al. (2009) [19]	Hypothetical Quantitative	2216 men (n = 968) and women (n = 1240)	UK	All	Education, occupation	K: Recall (poor, mean = 2.2) and recognition (good, mean = 7.2) PB: Emotional and service barriers most endorsed SP: Most would seek medical help within 2 weeks	K: Higher socioeconomic group (occupation) associated with highest knowledge (F (2,2015) = 20.31, $p < 0.001$) PB: Lower socioeconomic group (occupation) associated with more emotional barriers endorsed: 'worry what the doctor might find' (χ^2 (1,1989) = 17.08, $p < 0.001$), 'too embarrassed' (χ^2 (1,1993) = 20.74, $p < 0.001$), 'not confident to talk about symptom' (χ^2 (1,1992) = 4.77, $p < 0.05$), NS association with 'too scared' (χ^2 (1,1977) = 1.82, $p > 0.05$); Higher socioeconomic group (occupation) associated with more practical barriers endorsed: 'too busy' (χ^2 (1,2005) = 59.0, $p < 0.001$), 'other things to worry about' (χ^2 (1,1996) = 15.34, $p < 0.001$), 'difficult to arrange transport' (χ^2 (1,2010) = 11.13, $p < 0.001$); NS association between socioeconomic group (occupation) and service barriers: 'difficult to make appointment' (χ^2 (1,1983) = 0.41, $p > 0.05$), 'worried about wasting the doctors time' (χ^2 (1,1995) = 1.44, $p > 0.05$), 'difficult to arrange transport' (χ^2 (1,1938) = 1.15, $p > 0.05$) SP: Lower socioeconomic group (occupation) associated with shorter time to SP for unexplained bleeding (χ^2 (1,1991) = 5.82, $p < 0.01$), difficulty swallowing (χ^2 (1,1987) = 28.41, $p < 0.001$), lump (χ^2 (1,1988) = 21.26, $p < 0.001$), change in mole (χ^2 (1,1967) = 24.24, $p < 0.001$), unexplained pain (χ^2 (1,1965) = 20.24, $p < 0.001$), sore that does not heal (χ^2 (1,1977) = 35.84, $p < 0.001$), change in	Good
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Table 1 Table of included studies (Continued)

							bowel/bladder habits (χ^2 (1,1982) = 56.87, $p < 0.001$), cough (χ^2 (1,1984) = 48.32, $p < 0.001$), unexplained weight loss (χ^2 (1,1963) = 77.73, $p < 0.001$)	
Samet et al. (1988) [62]	Retrospective Quantitative	800 men ($n = 396$) and women ($n = 404$). Mean age: 72.2 years	US	All	Education, income	PB: Poor general health service utilisation, poor access SP: Most sought medical help within 2 months	PB: NR SP: Longer time to SP associated with lower income for breast and colorectal cancer (χ^2 , $p < 0.05^{**}$) and lower education for all tumour sites (χ^2 , $p < 0.05^{**}$)	Medium
Schmid-Wendter (2002) [40]	Retrospective Quantitative	233 men ($n = 109$) and women ($n = 109$). Mean age: 54.5 years	Germany	Melanoma	Education	K: Previous knowledge of melanoma, symptom interpretation B: Fear PB: Lesion not visible, too busy SP: Sought medical help within 1 month (15.5 %)	K: Higher education more likely to have knowledge about melanoma (χ^2 , $p < 0.001^{**}$) B: NR PB: NR SP: NR	Medium
Siminoff et al. (2014) [35]	Retrospective Mixed methods	252 men ($n = 132$) and women ($n = 120$). Mean age: 58 years (range 25 to 94 years)	US	Colorectal	Education, Employment, Income	K: Symptom interpretation (39.7 % did not think symptom was serious) PB: Financial barriers (28.6 %), fear of diagnostic tests (24.3 %), embarrassment (1.9 %) SP: Mean appraisal delay (4.8 months)	K: NR PB: NR SP: NS association between time to SP and socioeconomic group (statistics NR)	Medium
Simon et al. (2010) [49]	Retrospective Quantitative	236 men ($n = 968$) and women ($n = 1240$). 11.4 % ($n = 236$) had experienced a symptom in the past 3 months	UK	All	Occupation	K: Recognition (better knowledge if experienced a symptom previously); symptom interpretation (worry symptom might be cancer) PB: Emotional and practical barriers SP: Symptom experience: 11.4 % experienced symptom in past 3 months (75 % consulted a GP about symptom)	K: NS association between symptom interpretation and socioeconomic group (statistics NR) PB: NR SP: NS association between SP and socioeconomic group (statistics NR)	Good
Smith and Anderson (1985) [51]	Retrospective Quantitative	82 women. Age range: 20 to 54 years	US	Ovarian	Income, education, occupation	K: Symptom interpretation ('cancer', 10 %) B: Fear PB: Previous benign diagnosis SP: Median time to symptom presentation (4 weeks)	K: NS association between symptom interpretation and socioeconomic group (statistics NR) B: NR	Medium

Table 1 Table of included studies (Continued)

Temoshok et al. (1983) [75]	Retrospective Quantitative	106 men and women. Age range: 18 to 72 years.	US	Melanoma	Education, occupation	K: Previous knowledge of melanoma B: Melanoma not a serious disease PF: Lesion visible (face and neck) SP: Mean time to symptom presentation (4 months)	PB: NR SP: NR K: No association with knowledge and occupation (statistics NR) B: NR PF: NR SP: No association with time to SP and occupation (statistics NR)	Poor
Tod et al. (2008) [80]	Retrospective Qualitative	20 men (n=12) and women (n=8).	UK	Lung	Occupation	K: Symptom interpretation (poor, symptoms usually interpreted as acute conditions) B: Fear, fatalism PB: If previously given up smoking (thought risk of lung cancer was nil), worry about the wasting doctors time, previous bad experiences with health system, blame, stigma, stoicism, poor health service utilisation PF: Active encouragement from family member SP: Range in time to symptom presentation (0 to 24 months)		Good
Tomlinson et al. (2012) [60]	Retrospective Quantitative	87 men (n=56) and women (n=31). Mean age: 65 years.	Canada	Colorectal	Education	K: Symptom interpretation PB: Self medication SP: Waited over 1 month to seek medical help (51 %)	K: NR PB: NR SP: NS association between education and time to SP ($\chi^2, p > 0.05^{**}$)	Medium
Trivers et al. (2011) [52]	Hypothetical Quantitative	2991 women. 65 % were aged 45 years and over.	US	Gynaecological	Education, Income	B: Concern about developing gynaecological cancer PB: Being premenopausal SP: 50 % of women would seek help for most symptoms	B: NR PB: NR SP: NS association between SP intentions and socioeconomic group (statistics NR)	Medium
Van Osch et al. (2007) [48]	Hypothetical Quantitative	459 men (49 %) and women (51 %) over the age of 55. Mean age: 68.6 years.	Netherlands	All	Education	K: Recognition (low to moderate, mean: 6.2) B: Benefits of early detection SP: Fair. Inconsistent for urgent symptoms, good for prolonged symptoms	K: NR B: NR SP: Lower education associated with shorter time to SP (F (2,436) =6.084, $p < 0.01$)	Good

Table 1 Table of included studies (Continued)

Waller et al. (2009) [53]	Hypothetical Quantitative	1500 men and women from various ethnic minority groups.	England	All	Occupation	K: Recall (poor, mean: 1.2) and recognition (poor, mean: 4.7) PB: Worry what doctor might find (most endorsed) SP: African and Caribbean groups anticipated fastest time to symptom presentation	K: Higher socioeconomic group associated with higher recall ($F(1,1487) = 6.12, p < 0.01$) and higher recognition ($F(1,1487) = 5.45, p < 0.05$) PB: NR SP: NR	Good
Walter et al. (2014) [41]	Retrospective Qualitative	63 men ($n=31$) and women ($n=32$). Age range: 29-93 years.	UK	Melanoma	Education	K: Symptom attributions (initially attributed to benign skin conditions or normal life changes) PB: Worry about wasting the doctors time, service barriers, competing life priorities, reassurance following symptom disclosure PF: Family history of melanoma, perceptions of high risk, symptom disclosure, symptom noticed by another person SP: Range 1-303 weeks		Good
Whitaker et al. (2014) [55]	Retrospective Quantitative	1724 men ($n=789$) and women ($n=921$) over the age of 50. Mean age: 64.4 years.	England	All	Postcode, education, employment	K: Symptom interpretations (2 % thought symptom was cancer, highest interpretation for 'unexplained lump'), perceived seriousness of symptoms SP: Symptom experience (53 % experienced at least 1 symptom in past 3 months). 59 % contacted GP about symptom	K: Unemployment associated with higher perceived seriousness of pain (OR 2.26, 95 % CI: 1.17-4.35, $p < 0.05$), tiredness (OR 2.11, 95 % CI: 1.23-3.64, $p < 0.05$), sore throat (OR 3.56, 95 % CI: 1.10-11.45, $p < 0.05$) and chest pain (OR 3.56, 95 % CI: 1.10-11.45, $p < 0.05$). Lower education associated with higher perceived seriousness cough (OR 2.25, 95 % CI: 1.10-4.56, $p < 0.05$), tiredness (OR 2.46, 95 % CI: 1.44-4.21, $p < 0.05$), headaches (OR 3.80, 95 % CI: 1.63-8.89, $p < 0.05$), shortness of breath (OR 2.34, 95 % CI: 1.11-4.97, $p < 0.05$), sore throat (OR 4.16, 95 % CI: 1.14-15.22, $p < 0.05$) and chest pain (OR 4.16, 95 % CI: 1.13-15.22, $p < 0.05$) SP: NR	Good

Table 1 Table of included studies (Continued)

Whitaker et al. (2015) [81]	Retrospective Qualitative	48 men (<i>n</i> = 23) and women (<i>n</i> = 25) over the age of 50. Mean age: 64.4 years.	England	All	Education, employment	K: Symptom interpretations (symptoms normalised or associated with cancer) PB: Stoicism, fear of diagnostic tests, worry about wasting doctors time, service barriers, negative attitudes towards HCPs, medical mistrust PF: Development of new symptoms, persistence of symptoms, symptom disclosure, fear SP: Varied per symptom: 33.3 % contacted GP with 'persistent cough', 100 % contacted GP with 'unexplained bleeding'	Good
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K = cancer symptom knowledge; *B* = beliefs about cancer; *PB* = perceived barriers to symptom presentation; *PF* = perceived facilitators to symptom presentation; *SP* = time to symptom presentation; *NR* = not reported; *NS* = not significant; **p*-value not reported; **other statistics not reported

Studies which measured actual time to symptom presentation reported the longest delays in symptom presentation among individuals with lower educational attainment [33, 34, 42, 54, 58–61], lower annual income [61, 62], lower occupation and employment [43, 61, 63] and those from deprived areas [64]. This effect was also observed in studies of actual symptom presentation where multiple socioeconomic indices were reported [34, 42, 44, 61, 65, 66]. Twenty-two studies found no group differences for socioeconomic group indicators and time to symptom presentation [30, 33, 35–37, 45, 46, 49, 50, 52, 60, 67–77].

Knowledge

Knowledge of symptoms based on recall methods was generally lower than in studies that used recognition methods. Lump symptoms were the most recalled and well-recognised potential cancer symptom [19, 32, 48, 50, 53, 56, 64, 78]. This was supported by retrospective studies where patients presenting with a lump were most likely to have attributed their lump symptom to cancer [39, 43, 45, 74, 79]. Knowledge was generally poor for non-specific symptoms of cancer. Symptoms such as fatigue or unexplained weight loss were poorly recalled or recognised as potential symptoms of cancer [28, 29, 31, 53, 78]. Poorer cancer symptom knowledge was associated with lower socioeconomic group when measured by educational attainment [28, 32, 40, 50, 54, 56], occupation [53] and multiple indicators [19, 28, 66]. These findings were consistent across site-specific and non site-specific studies, suggesting poor general cancer symptom knowledge in lower socioeconomic groups regardless of cancer type.

In retrospective studies, patients experiencing non-specific symptoms recalled attributing them to other benign causes or life stresses [35, 51, 55, 65, 69, 76, 80, 81] or not recognising the seriousness of their symptoms [9, 33, 35, 37, 40, 42, 43, 45, 47, 51, 54, 55, 57, 60, 65, 68, 76, 77, 81, 82] resulting in patients delaying symptom presentation [35, 39, 51, 76] or later stage at diagnosis [69].

Beliefs about cancer

In most studies, beliefs were formed from participants' past experiences of cancer, usually witnessing friends or family with the disease [36, 43, 47, 59, 78, 79]. Positive beliefs were identified in nine studies [30, 36, 43, 48, 54, 58, 78, 79] and tended to focus on the effectiveness of modern cancer treatments, where participants expressed trust in doctors and the medical system and endorsed the benefits of early diagnosis [30, 58, 59, 78] or acknowledged that cancer can be cured [78]. Such beliefs tended to encourage timely symptom presentation to a primary care physician [30, 58, 59, 78, 79]. One study

found that those with lower educational attainment were less likely to endorse positive beliefs about the benefits of early detection [54].

Negative beliefs tended to manifest in fear or fatalism regarding cancer. Fear was frequently reported across all studies examining beliefs. This included fear of diagnosis [34, 39, 58, 63, 74, 80, 81, 83], fear of treatment [30, 43, 57–59, 68, 78, 83] and fear of dying [59, 78, 83]. Fatalistic beliefs were a common theme throughout studies, but were expressed only by a minority of participants per study [34, 36, 42, 56, 59, 61, 78, 79, 84]. Fearful and fatalistic beliefs about cancer were more likely to be expressed by individuals from lower socioeconomic groups based on educational attainment [36, 50] or multiple indices [42, 71].

When considering time to symptom presentation, fearful beliefs about cancer appeared to operate at the two extremes of immediate or prolonged symptom presentation. For participants whose fearful beliefs encouraged immediate (actual or hypothetical) presentation to doctors [43, 45, 58, 59, 61, 74, 78, 79, 84], a visit to doctors was used to alleviate anxiety associated with the symptom [43, 47, 58, 59, 61, 77, 78]. This was usually coupled with the participant expressing trust in the medical profession and positive beliefs surrounding early diagnosis [43, 59].

For individuals whose fearful beliefs led to prolonged delays (sometimes years) [30, 34, 38, 39, 43, 47, 51, 61, 68, 74, 78, 79], denial of or ignoring symptoms initially alleviated anxiety associated with the symptom [38, 39, 47, 59, 68, 72, 76, 78, 79]. Such beliefs were usually combined with fatalistic beliefs such as 'cancer cannot be cured' [59, 61, 79], and were associated with the longest times to symptom presentation or were expressed by those with advanced stage disease [36, 56, 59, 84]. This is likely to reflect a lack of perceived benefit in presenting to doctors due to the belief that 'nothing can be done' [59, 78].

Barriers to symptom presentation

Some participants reported service barriers relating to concerns about wasting doctors' time [19, 29, 31, 34, 41, 43, 55, 80, 81], lack of continuity with primary care doctor [42, 81] or difficulties with accessing and making an appointment [29, 32, 34, 38, 53, 55, 56, 65, 78, 81]. For others, practical barriers such as being 'too busy to make an appointment' were reported and these delayed symptom presentation [31, 39, 40, 43, 49, 74, 77, 78]. Low general health service utilisation for acute or long term conditions lengthened time to cancer symptom presentation [9, 34, 42, 43, 57, 58, 61, 66, 68, 73, 77, 78, 80, 84]. Emotional barriers included embarrassment or fear associated with undergoing intimate diagnostic tests [19, 29, 31, 34, 35, 49, 57, 78, 81].

Practical barriers such as 'being too busy' were more frequently reported in high socioeconomic groups [19]. In countries where patients pay for their healthcare, those with lower annual income were more likely to report the cost of a consultation as a barrier to symptomatic presentation [38, 63].

Facilitators to symptom presentation

The most common facilitator of symptom presentation was disclosure of symptoms to a family member or friend [34, 39, 41, 43, 45, 47, 55, 61, 65, 70, 73, 76–79, 81, 84, 85]. In some cases, this reduced time to symptom presentation by half [36] or by six times [45]. The appearance of a new symptom [43, 69, 76, 83] or persistence of the current symptom [45, 69, 76, 81, 84] facilitated decisions to seek medical help. One study found that individuals from a lower socioeconomic group who disclosed their symptom to a family member or friend took longer to seek medical help compared to those from a higher socioeconomic group [65]. In five studies, participants waited until they developed another health complaint or tagged their cancer symptom on to the end of a consultation which provided an opportunity to disclose the cancer symptom during the consultation [42, 45, 68, 81, 82].

Discussion

This review is the first to systematically explore how knowledge, beliefs and barriers/facilitators to symptom presentation affect actual or anticipated cancer symptom presentation in relation to socioeconomic group, across all tumour sites. Poor knowledge of non-specific cancer symptoms such as fatigue and weight loss prolonged presentation due to misattribution of symptoms in lower socioeconomic groups. In contrast, lump and bleeding symptoms were most frequently recalled, recognised and prompted the fastest symptom presentation. A knowledge gradient was observed, where poorer cancer symptom knowledge was associated with lower socioeconomic group based on multiple indices. There was some evidence to suggest that those from a lower socioeconomic group were more likely to hold fearful and fatalistic beliefs about cancer and less likely to endorse positive beliefs about the benefits of early diagnosis. Such combinations of fearful and fatalistic beliefs were associated with prolonged symptom presentation. In addition, emotional barriers to symptom presentation such as worry what the doctor might find were more likely to be endorsed in lower socioeconomic groups. Such poor knowledge and prevalent beliefs might account for the long actual delays and later stage cancers diagnosed in lower socioeconomic groups. Disclosure of a symptom to a family member or friend was a key facilitator in the decision to seek medical help, although

there was some evidence to suggest that symptom disclosure acted as a barrier in lower socioeconomic groups.

Most included studies were of medium quality. In many studies, socioeconomic group was measured but not reported for all outcome variables. Most studies only reported socioeconomic group differences for symptom presentation. Twenty-three studies reported socioeconomic group differences for the other outcome measures: knowledge, beliefs and barriers/facilitators to symptom presentation. A further eight studies could have met the inclusion criteria, but were excluded due to non-reporting of any outcomes associated with socioeconomic group [14, 86–92]. Methodological limitations included a long duration between cancer diagnosis and participation in retrospective studies, and samples biased towards higher socioeconomic groups. In some studies, socioeconomic variation was insufficient to perform statistical analysis on all outcomes.

There are methodological limitations associated with retrospective (actual symptom presentation) and hypothetical (anticipated symptom presentation) designs. Whilst retrospective studies are affected by recall bias, hypothetical studies rely on intentions which may not translate into actual presentation behaviour [93]. This was observed in the variation between actual and hypothetical time to symptom presentation, where participants anticipated prompt symptom presentation but in reality reported longer delays. Study designs exploring actual symptom presentation behaviour in a population sample are likely to reduce some of the limitations associated with retrospective and hypothetical symptom presentation study designs. In such study designs, participants disclose actual symptoms experienced in the past three months, usually prompted by a list (without any mention of cancer), and reasons for not consulting a doctor are explored [49, 54, 55, 81].

The limitations of this review include problems relating to retrieval of studies and analysis of the evidence. Due to poor indexing of studies in this topic area under the MeSH indexing in this topic area, a high proportion of studies ($n = 11$) was found through hand-searching. Additionally, meta-analysis was precluded by the wide range of qualitative and quantitative data collection methods of included studies. Finally, other factors such as age, gender and ethnicity can affect symptom presentation [6, 18]; however, interactions between these variables and socioeconomic group were not addressed in the current review.

The findings of the current review confirm that failure to appreciate the seriousness of symptoms [6, 16] and non-disclosure of symptoms [6, 15] lengthened time to symptom presentation. Our findings accord with previous studies in which negative beliefs [20], longer time to

actual symptom presentation [6] and low suspicion for cancer symptoms [94] were associated with low socio-economic group [6]. The current findings support Mitchell et al.'s (2008) [16] review of colorectal cancer patients, in which fear of cancer either lengthened or shortened time to symptom presentation. Such findings might be explained by Type I and Type II information processing systems. Type I processing is a fast and automatic system, which represents an individual's 'gut reaction' to an event, whereas Type II is a slower, more thoughtful and deliberative system [95]. Whilst most people initially experience fear in reaction to a worrying symptom (Type I processing), cognitions during Type II processing may influence the decision to seek medical help since these are slower and may help someone to rationalise the situation [96]. If an individual has had time to consider the benefits of seeking medical help, and based upon their previous beliefs about early diagnosis, such beliefs may override the Type I fear response. We found evidence to suggest a higher prevalence of fearful and fatalistic beliefs in lower socioeconomic groups and some evidence for fewer positive beliefs surrounding the benefits of early diagnosis in lower socioeconomic groups. This suggests that Type I beliefs may not be overridden by Type 2 responses relating to the benefits of early diagnosis due to lower knowledge or higher emotive responses. As a consequence this may delay symptom presentation. Findings relating to symptom disclosure suggest that people use the 'lay system' of healthcare (consulting family and friends) before making the decision to access formal healthcare [13, 97, 98]. However, among individuals from low socioeconomic groups, disclosing symptoms to someone with equally poor knowledge and Type I negative automatic beliefs about cancer may encourage false reassurance in the benign nature of symptoms and consequently no urgency to seek medical help.

Cancer awareness interventions should be carefully developed to target those who are most likely to present with advanced stage disease: lower socioeconomic groups with low symptom knowledge and fearful and fatalistic beliefs about cancer. Such an intervention should utilise an individual's social networks to facilitate distribution of information [97], highlighting the significance of non-lump symptoms as potentially indicative of cancer, along with advice on an appropriate time in which an individual should seek medical help and how to access such help [99]. This should be coupled with information outlining the benefits of early diagnosis and improved effectiveness of modern treatments for cancer, countering negative beliefs surrounding cancer. Future research should evaluate the effectiveness of such interventions in lower socioeconomic groups.

Conclusion

Knowledge of potential cancer symptoms, beliefs about cancer and barriers to symptom presentation work in combination to influence symptom presentation: knowledge is necessary for accurate symptom appraisal, but beliefs about cancer and barriers to symptom presentation influence the decision to seek medical help or not. This is especially important in the context of socioeconomic deprivation, where lower knowledge, higher negative beliefs about cancer and perceived barriers may lead to avoidable delays, later stage of diagnosis and ultimately poorer survival outcomes. Targeted interventions should not only educate people about symptoms for cancer, but also work to break down unhelpful myths surrounding cancer survival and treatment options. They should address the barriers that people in lower socio-economic groups experience, and use social networks to raise awareness and support early symptom presentation.

Additional file

Additional file 1: Appendix 1. Search terms. (DOCX 13 kb)

Abbreviations

NAEDI: National awareness and early diagnosis initiative; SPIDER: Sample phenomenon of interest, design, evaluation, research type; CASP: Critical appraisal skills programme; OECD: Organisation for economic co-operation and development.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

GMM, KEB, AGE and FW were responsible for the concept and design and conduct of the study. AGE gave additional advice on methodology. GMM was responsible for collection of data and manuscript preparation. RR was responsible for double checking at all stages of the search. KEB, AGE and FW extensively reviewed and edited the manuscript drafts. All authors were involved in interpretation of results and approved the final version of the manuscript.

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Appendix 2: SPIDER search strategy

SPIDER	Description	Equation used for search
Sample	Adults (18+) male and female	Sample: "Adult" OR "18 and over" OR "over 18" OR "male" OR "female" OR "deprived area(s)" OR "socioeconomic status" OR "deprived", OR "NOT child"
Phenomenon of Interest	How cancer symptom knowledge, beliefs about cancer and barriers/facilitators to symptom presentation affect actual or anticipated cancer symptom presentation	<p>Cancer: "Cancer" OR "Malignancy" OR "Tumour" OR "Sarcoma" OR "Melanoma" OR "Disease"</p> <p>Knowledge: "Awareness" OR "Cancer awareness" OR "knowledge" OR "knowledge of cancer symptoms" OR "passive detection" OR "recognition" OR "recall" OR "appraisal" OR "appraisal of symptom*"</p> <p>Symptoms: "symptom" OR "cancer symptom" OR "cancer sign" OR "sign" OR "warning sign" OR "early warning sign" OR "suspected symptom*"</p> <p>Beliefs: "beliefs" OR "attitudes" OR "thoughts" OR "feelings" OR "negative beliefs" "negative attitudes" OR "fear" OR "anxiety" OR "worry" OR "concern" OR "Embarrass*" OR "fatalism" "positive beliefs" OR "positive attitudes" OR "hope" OR "optimism" OR "benefit" OR "spiritual"</p> <p>Perceived barriers: "barriers to present*" OR "service barrier*" OR "emotional barrier*" OR "practical barrier*"</p> <p>Symptomatic presentation: "help seeking behaviour" OR "help seeking" OR "health seeking behaviour" OR "health seeking" OR "early presentation" OR "late presentation" OR "presentation" OR "delay" OR "patient delay" OR "delay in help OR health seeking" OR "behaviour" OR "intentions" OR "intentions to seek help"</p>
Design	Both qualitative and quantitative methods	Study design: "questionnaire" OR "survey" OR "interview" OR "focus group" OR "case study" OR "observ*"
Evaluation	Outcome measures. Cancer symptom knowledge, beliefs about cancer, barriers/facilitators to symptom presentation and symptom presentation.	Outcome measures: "help seeking behaviour" OR "experinec*" OR "view" OR "opinion" OR "perce*" OR "belie*" OR "feel*" OR "know*" OR "understand*"
Research Type	Qualitative, quantitative or mixed methods	Methods: "qualitative" OR "quantitative" OR "mixed methods"

Appendix 3: Adapted CASP tool

Quantitative study design	Qualitative study design
<p>1. Was there a clear statement of the aims of the research?</p> <p>-Was the goal stated? -Why is this important? -How relevant is it?</p>	<p>1. Was there a clear statement of the aims of the research?</p> <p>-Was the goal stated? -Why is this important? -How relevant is it?</p>
<p>2. Is a quantitative methodology appropriate?</p> <p>-does the research aim to illuminate the characteristics/ demographics of participants or assess their opinions/attitudes?</p>	<p>2. Is a qualitative methodology appropriate?</p> <p>-Does the research aim to illuminate the characteristics/ demographics of participants or assess their opinions/attitudes?</p>
<p>Is it worth continuing? Yes/no</p>	<p>Is it worth continuing? Yes/no</p>
<p>3. Was the research design appropriate to address the aim of the research?</p> <p>-Has the research design been justified? -Was the timing of the study appropriate i.e. if study was conducted with participants with a diagnosis of lung cancer, 12 months post diagnosis would be inappropriate due to poor long term survival? -Was the study theoretically underpinned?</p>	<p>3. Was the research design appropriate to address the aim of the research?</p> <p>-Has the research design been justified? -Was the timing of the study appropriate i.e. if interview was conducted with participants with a diagnosis of lung cancer, 12 months post diagnosis would be inappropriate due to poor long term survival? -Was the study theoretically underpinned?</p>
<p>4. Was the recruitment strategy appropriate to the aims of the research study?</p> <p>-Has it been explained how participants were selected? -Has it been explained why participants were appropriate to provide answers to the research questions? -Has the researcher discussed response rate? -Has the researcher discussed how the control group was selected and why (if appropriate)? -Were demographic variables of respondents discussed? -Has the researcher discussed non-participation and their reasons for non-participation?</p>	<p>4. Was the recruitment strategy appropriate to the aims of the research study?</p> <p>-Has it been explained how participants were selected? -Has it been explained why the participants were appropriate to provide answers to the research questions? -Has the researcher discussed non-participation and their reasons for non-participation?</p>
<p>5. Were the data collected in a way that addressed the research issue?</p> <p>-Has the researcher considered their own role, potential bias and influence? -During formulation of research questions -During recruitment and data collection (if any data collected from p's through face-to face or telephone survey) -Has the researcher considered the implications of any changes in the research design and events during the study? -Were participants aware the study was about cancer? Symptomatic individuals without mention of cancer/ actual/anticipated study designs? -What measure of symptom awareness/beliefs/symptom presentation was used? Was it a standardised measure?</p>	<p>5. Were the data collected in a way that addressed the research issue?</p> <p>-Was the setting for the data collection justified? -Is it clear how data was collected? -Has the researcher made methods explicit? -Is the form of data clear? -Has the researcher discussed saturation of data? -Were participants aware the study was about cancer? Symptomatic individuals without mention of cancer/ actual/anticipated study designs?</p>

<p>6. Have ethical issues been taken into consideration?</p> <ul style="list-style-type: none"> -Were ethical standards maintained (if enough info provided)? -Have ethical approval been sought from ethics committee? -If disclosed symptoms during the study, what was the process of advising participants to seek medical help/not? 	<p>6. Have ethical issues been taken into consideration?</p> <ul style="list-style-type: none"> -Were ethical standards maintained (if enough info provided)? -Have ethical approval been sought from ethics committee? -If disclosed symptoms during the study, what was the process of advising participants to seek medical help/not?
<p>7. Was the data analysis sufficiently rigorous?</p> <ul style="list-style-type: none"> -Has an in-depth description of data analysis been provided? -Is it clear which statistical tests were used/ were the tests appropriate to answer the research question? -Is sufficient data presented to support the findings? -To what extent was contradictory data taken into account? 	<p>7. Has the relationship between researcher and participants been adequately considered?</p> <ul style="list-style-type: none"> -Has the researcher considered their own role, potential bias and influence? <ul style="list-style-type: none"> -During formulation of research questions -During recruitment and data collection (if any data collected from p's through face-to face or telephone survey) -Has the research considered the implications of any changes in the research design and events during the study?
<p>8. Is there a clear statement of findings?</p> <ul style="list-style-type: none"> -Are the findings explicit? -Is there adequate discussion of the evidence for and against the researcher's arguments? -Has the researcher discussed the credibility of their findings? -Are findings discussed in relation to other research? 	<p>8. Was the data analysis sufficiently rigorous?</p> <ul style="list-style-type: none"> -Has an in-depth description of data analysis been provided? -Is it clear how categories/ themes were derived (if used)? -Has the researcher explained how data extracts were selected? -Is sufficient data presented to support the findings? -To what extent was contradictory data taken into account?
<p>9. How valuable is the research?</p> <ul style="list-style-type: none"> -Has the researcher discussed the contribution his study makes to existing knowledge? -Does the researcher identify areas for further research? -Has the researcher discussed whether findings can be transferred to their populations or considered ways the research can be used? 	<p>9. Is there a clear statement of findings?</p> <ul style="list-style-type: none"> -Are the findings explicit? -Is there adequate discussion of the evidence for and against the researcher's arguments? -Has the researcher discussed the credibility of their findings? -Are findings discussed in relation to other research?
<p>Further comments</p>	<p>10. How valuable is the research?</p> <ul style="list-style-type: none"> -Has the researcher discussed the contribution this study makes to existing knowledge? -Does the researcher identify areas for further research? -Has the researcher discussed whether findings can be transferred to their populations or considered ways the research can be used? <p>Further comments</p>

Appendix 4: Interview topic guide

Prologue

1. Introduce myself, explain where I am from, ensure they are comfortable etc.
2. Check understanding of reason for meeting and give an opportunity for questions:
“Before we start, do you have any questions about the study or about what I’ve come to talk to you about today?”
Set the focus of the interview. Base this around the following script:
“Thank you for agreeing to take part in my study. Just to remind you, I am interested in what people from Wales think about cancer. At the end of the study, we aim to develop better cancer services for people living in Wales. There are no right or wrong answers to my questions, I am interested in what *you* think.”
3. After establishing what is understood about the study and answering any questions, explain that the interview will be recorded:
“I would like to record what you say as that saves me having to scribble when you’re talking, which means that I can concentrate on what you’re saying. The recording will only be heard by people who are working on this project. The interview will be typed, but your name and the name of any person, or places you talk about today will never be typed in any published work. Is that okay with you?”
4. Obtain consent for the interview and for the recording [go through the consent form with participant]. If not already done, set up and switch on the recording equipment while the participant signs the consent form.
5. Explain how the interview will work:
“I’ve planned some ideas about the sorts of things I’d like us to talk about today, and if it’s okay with you we’ll try and base our conversation around those points. Having said that, if you want to tell me about anything that I don’t ask about, please just tell me. Also, if you find a question difficult to answer or you don’t understand it, please say and we can move on or I can try to ask it in a different way. Of course, if you’d prefer not to answer a question, that is absolutely fine. There are no right or wrong answers to any of the questions I ask you, I am just interested in your own opinions and experiences. Does that all sound alright to you?”
6. Obtain demographic information:
“Before we start, I’d like to ask you some questions about yourself.....”

[Build rapport: ask questions about how long they have lived in the community etc]

Rationale: Establish what they know and how much the participant knows about cancer and its causes.

Knowledge of cancer

Q1: I'd like to get an idea about what you know about cancer. Can you tell me what you know about cancer?

Probes:

- How would you describe cancer as an illness?
- What do you think causes cancer?
- How do you think cancer compares to other illnesses like heart disease, diabetes etc.?
- Do think there anything people can do to stop them getting cancer?
- [If smoking comes up probe: why do you think smoking does/does not cause cancer?/ Smoking behaviour in the community]
- Can you think of any symptoms of cancer?
- Thinking about people in your community, do you think they know the symptoms of cancer?

Rationale: Participants attitudes and beliefs about cancer a treatments for cancer. Understand fast processing (initial reactions) vs slow processing (more deliberative) systems underlying attitudes and beliefs about cancer and treatments for cancer. Touch on fearful/fatalistic beliefs.

Attitudes and beliefs about cancer

Q2: I would like to know a little more about your feelings towards cancer. What comes to mind when you hear the word 'cancer'?

Probes:

- Can you tell me why you feel this way?/ Can you tell me more about that?
- Can you think of anything that has happened that might make you feel this way?
- Thinking about people in your community, how do you think they feel about cancer?
- Can you remember the first time you heard about cancer?
- Some people say that if you get cancer, there is nothing you can do to stop it. They say 'oh I was going to get it anyway'. What do you think about this?
- Can you tell me more about why you think this?
- Can you tell me what you know about the treatments for cancer?
- What do you think about the treatments for cancer?
- Do you think some treatments are better or worse than others?
- Some people think that there is 'no cure for cancer' whereas others think that you can cure cancer. What do you think?
- Do you mind me asking why you think that?
- What do you think people in your community think about the treatments/a potential cure for cancer?

Rationale: To clarify if they, themselves have had cancer and establish any 'first hand' experiences of cancer. To understand if/how such experiences have shaped their attitudes/beliefs about cancer.

P's might get upset here. If this happens suggest a break or move on to the next question. Ask if they would like to terminate the interview or carry on.

Personal experience of cancer

Q3: Have you ever had cancer, or had close family or close friends who have been diagnosed with cancer?

Or: Earlier you mentioned [person/people] [had/has] cancer, would you mind if I asked you some more questions about them?

[If participant discloses a previous diagnosis of cancer, go to Q7]

Probes:

- Would you mind telling me more about [that/them]?
- Can you remember what type of cancer they [have/had]?
- Thinking back to when [person] had cancer. Do you remember what was going on before they were diagnosed as having cancer?
Probe:
 - Had they been obviously unwell before being diagnosed?
 - Can you tell me about if/when they went to the doctor?
 - Can you tell me about any tests they had?
- Can you remember anything about their treatment, what happened to them during treatment?

Rationale: Perceived behavioural control over correctly appraising and acting on a symptom of cancer. Who they would go to, to seek help should they suspect they have a symptom of cancer. If they would confide in others before seeking medical help, who would they be and what would they advise.

Appraising and Acting upon a potential symptom of cancer

Q4: You mentioned earlier some symptoms which you think could be cancer, what would you do if you had one of these symptoms which you thought might be cancer?

Probes:

- How do you think you might feel?
- Would you mind telling me more about that?
- [If they say they would go to the doctor] How long do you think it would take for you to visit your doctor?
Probe:
 - Can you tell me a little more about why you would wait [length of time]?
- What do you think people in your community would do if they had a symptom which they thought might be cancer?

-[*If not previously mentioned*] Have you ever had a symptom which you think might be something like cancer?

Probe:

-Can you tell me more about it?

-What was the symptom/How long did you have the symptom for/ what did you think it was?

-How did you feel?

-What did you do?

-[*If went to the doctor*] Can you remember how long it took you to go to the doctor? Why did you decide to go [*period of time*]?

-Would/did you tell anybody about your symptom?

-Why would/did you tell this person?

-What do you think they would say if you told them you had a symptom that you thought was cancer?/ What did they tell you to do?

-Is this what you think your friends would do, or do you think they would do something different?

-[*if different*] What would they do?

-How confident would/did you feel noticing that something might be a symptom of cancer?

-Would/did you do anything to keep track of your symptoms?

Rationale: Explore the length of time in which people anticipate seeking help for a symptom of cancer, social norms around medical help seeking,

Medical help seeking: acting upon a symptom of cancer

Q5: I would like to know some more about your doctor. Are you registered with a doctor?

Probes:

-If you could describe your GP practice in a few words, what would they be?

Probes:

-What is it like getting an appointment?

-How often do you visit your GP?

-What is your GP like?

-How confident do you feel talking to your GP?

Rationale: Identify any barriers or facilitators to medical help seeking. Gain a deeper understanding of why participants have such barriers. Ask about anticipated regret.

Medical Help seeking barriers and facilitators

Q6: If you had a symptom that you thought might be cancer, can you think of anything that would make it hard for you to visit your GP?

Probes:

-What might make it easier?

-What might you do before going to the doctor e.g. search online, speak to someone from a charity?

- Some people say they are embarrassed about talking to the doctor with symptoms.
- What do you think about this?
- Can you tell me more about why you might feel this way?
- Can you tell me about how you might get to an appointment with the doctor?
- Probe:
 - If transport is a problem/ get help from family and friends
- Thinking about people in your community, can you think of anything which might be stopping them going to their doctor with a symptom of cancer?

[Go to Q8]

Rationale: Explore the length of time in which those with a previous diagnosis of cancer sought medical help

Participants with a previous diagnosis of cancer

Q7: You mentioned you had previously been diagnosed with cancer. Do you mind if I ask you some questions about your cancer?

- Can you take me through what happened before you were diagnosed with cancer?
- Can you remember what symptoms you had before you were diagnosed?
- At the time can you remember what you thought these symptoms were?
- Did you tell anyone about your symptoms?
 - [If yes] What did they say?
- Can you remember if you went to the doctor?
 - [If yes] Probes:
 - Can you remember how long it took you to go to the doctor from when you noticed your symptoms?
 - Can you tell me about what the doctor said to you?
 - Can you remember how many times you went to the doctor with this symptom?
 - Can you think of anything that helped you to go to the doctor quicker than usual?
 - Can you think of anything that stopped you going to the doctor?
- Can you tell me about what happened after that?
- Can you remember the point at which you thought you might have cancer?
 - How did this make you feel?
- Can you remember how your friends and family reacted to the news that you had cancer?
- Can you tell me about the treatment you had/are having for your cancer?
 - What was it like?

Rationale: Anything that stands out in memory. Details that should be avoided in the intervention/ details which might be useful when designing an intervention

Awareness campaigns

Q8: Can you tell me about any cancer awareness campaigns that you have seen? [describe what a cancer awareness campaign if they don't understand what this is]

- Did anyone tell you about a campaign they saw?

- How did they make you feel about cancer?
- Can you tell me what you thought was good about the campaign?
- Can you think of anything that was bad about the campaign?
- Do you have any ideas for a cancer awareness campaign in your community?

Description of community

Q9: Can you tell me what your community is like?

Future research

Q10: Finally, we might be doing future studies in this area. Would you like to be contacted again for this research?

Debrief:

'Thank you for taking part in this study. The purpose of this study was to understand what people who live in Wales think about cancer. Your thoughts have been very helpful in helping us to understand this and we hope the results of this study will help to develop better cancer services in Wales. Do you have any questions or concerns about the study? [*if yes: answer any questions. If no: continue*]. Here are my contact details in case you do have some questions in the future. Many thanks again.'

Appendix 5: Telephone script for study recruitment through the ICBP database

Hello, my name is Grace, I'm a researcher calling from Cardiff University on behalf of Tenovus, the cancer charity. Please may I speak to *[name]*.

If they are not there: I would like to invite *[name]* to take part in a research study. Do you know when would be a good time for me to ring back so I can speak to *[him/her]* about taking part in the study? *[Take time and date and thank the person on the phone. Ring back at a later date and follow script again]*

If they are on the phone: I would like to invite you to take part in a research study. You may or may not remember, as it was a couple of years ago, but you took part in a study over the phone, and my colleagues asked you some questions about cancer.

This was a national survey of people from across Wales who are aged over 50.

We are interested in speaking to you again because at that time you agreed to be contacted again for future research. Your responses from that study were very helpful, and we are carrying out some more research on this topic.

I would like to tell you a little bit about the study before you decide whether to take part or not. This will take a few minutes. Would you like me to continue? I can call back another more suitable time if you wish.

If no: Would you mind telling me why? *[enquire gently without insisting on an answer]* Thank the participant for their time.

If they would like a call back: No problem, when would be more suitable for me to ring you back? *[arrange a time and date for me to ring back, thank them for their time]*

If yes: Thank you. I will take you through some brief information now about the study and what it would involve, to help you decide if you would like to receive some more information about the study through the post. You don't need to decide today if you would like to take part or not.

Cardiff University and Tenovus would like to carry out some interviews to understand more about people's awareness and beliefs about cancer symptoms in some areas of Wales. The results of these interviews will help us develop better services and campaigns to increase early diagnosis of cancer in communities like yours.

If you do decide to take part I will come and visit you at a time and in a place that is best for you. I will ask you some questions about cancer, which will take around an hour in total.

To thank you for your time we would like to give you £10 cash.

Taking part is voluntary. This means it is entirely up to you whether you decide to take part or not. If you do decide to take part, you are still free to stop the study at any point and without giving a reason.

Do you have any questions? *[Answer any questions]*

Is this study something you might be interested in?

If yes: Before you decide to take part or not, I would like to send you some more information in the post about the study so you can have some time to decide whether to take part or not and discuss it with others, for example your family or friends.

[Ask for their name and address and say you will send them the information].

I will ring you again in about a week's time to answer any questions you have about the study. *[Arrange a date and time for ring back]*

When I phone, if you would like to take part I will arrange a date, time and place for us to meet that is best for you. This can be in your own home or another place of your choosing.

In the meantime, if you have any questions, here are my contact details *[give my contact details]*. These will also be on the information that I will send out to you today.

If unsure: Would you like me to send you some information in the post about the study so you can have a think about it and discuss it with family or friends? I can then ring you back in a week's time to answer any questions you have about the study. Then, if you would like to take part we can arrange a time and date to meet for the interview. *[Take postal details if they would like information]*

If no: No problem *[Thank the participant for their time]*

Appendix 6: Telephone script for study recruitment through snowball sampling/community partners

Hello, my name is Grace, I'm a researcher calling from Cardiff University on behalf of Tenovus, the cancer charity. Please may I speak to [*name*].

If they are not there: I would like to invite [*name*] to take part in a research study. Do you know when would be a good time for me to ring back so I can speak to [*him/her*] about taking part in the study? [*Take time and date and thank the person on the phone. Ring back at a later date and follow script again*]

If they are on the phone: I would like to invite you to take part in a research study. I was given your details by your [*friend/family member*], [*insert name*] as they thought you might be interested in taking part in this study.

I would like to tell you a little bit about the study before you decide whether to take part or not. This will take a few minutes. Would you like me to continue? I can call back another more suitable time if you wish.

If no: Would you mind telling me why? [*enquire gently without insisting on an answer*] Thank the participant for their time.

If they would like a call back: No problem, when would be more suitable for me to ring you back? [*arrange a time and date for me to ring back, thank them for their time*]

If yes: Thank you. I will take you through some brief information now about the study and what it would involve, to help you decide if you would like to receive some more information about the study through the post. You don't need to decide today if you would like to take part or not.

Cardiff University and Tenovus would like to carry out some interviews to understand more about people's awareness and beliefs about cancer symptoms in some areas of Wales. The results of these interviews will help us develop better services and campaigns to increase early diagnosis of cancer in communities like yours.

If you do decide to take part I will come and visit you at a time and in a place that is best for you. I will ask you some questions about cancer, which will take around an hour in total.

To thank you for your time we would like to give you a £10 voucher or cash, whichever you prefer.

Taking part is voluntary. This means it is entirely up to you whether you decide to take part or not. If you do decide to take part, you are still free to stop the study at any point and without giving a reason.

Do you have any questions? [*Answer any questions*]

Is this study something you might be interested in?

If yes: Before you decide to take part or not, I would like to send you some more information in the post about the study so you can have some time to decide whether to take part or not and discuss it with others, for example your family or friends.

[Ask for their name and address and say you will send them the information].

I will ring you again in about a week's time to answer any questions you have about the study. *[Arrange a date and time for ring back]*

When I phone, if you would like to take part I will arrange a date, time and place for us to meet that is best for you. This can be in your own home or another place of your choosing.

In the meantime, if you have any questions, here are my contact details *[give my contact details]*. These will also be on the information that I will send out to you today.

If unsure: Would you like me to send you some information in the post about the study so you can have a think about it and discuss it with family or friends? I can then ring you back in a week's time to answer any questions you have about the study. Then, if you would like to take part we can arrange a time and date to meet for the interview. *[Take postal details if they would like information]*

If no: No problem *[Thank the participant for their time]*

Appendix 7: Invitation letter and study information sheet for study participants recruited through the ICBP database



Dear [insert name],

I phoned you on [insert date] to talk to you about taking part in a study. The study is funded by Tenovus, the cancer charity. The aim is to help make better services for cancer in Wales.

The study involves an interview to find out what you think about cancer. The interview will take about 1 hour.

The next few pages tell you more about the study. This is to help you decide whether or not to take part. If you like, you can talk to members of your family or friends about the study.

If you do decide to take part, we would like to offer you £10 cash to say thank you.

I will phone you again on [insert date]. I will answer any questions and ask if you would like to take part in the study.

If you have any questions before then, please contact me on 02920 687639 or mccutchangm@cardiff.ac.uk.

[insert signature]

Grace McCutchan

What is the study all about?

I am from Cardiff University, and I want to find out what people think about cancer. This is a study funded by the charity Tenovus.

You took part in a study in 2011. This study found differences in how much people know about cancer and what they think about cancer. We would like to know more by asking you and other people some questions in an interview.

If you would like to take part in the study, I will arrange to come and talk to you at a time and place that is best for you.

Why have I been chosen and how did you get my details?

In 2011 you took part in a study over the phone to find out how much people know about cancer. At the end of the phone call, you said you would like to be contacted again for future studies- thank you!

Do I have to take part?

No. It is up to you to decide to take part in this study or not.

I will contact you on [*insert date*]. I will answer any questions you have and ask if you would like to take part.

This will give you some time to think about if you would like to take part. You can talk to your family and friends about this. They might be able to help you decide if you want to take part or not.

If you have any questions before, please contact me. My contact details are at the end of this letter.

Before the interview starts, you will be asked to sign a consent form. I will go through this form with you. This is to say that you agree to take part in the study.

If you do take part, you can stop the study at any time. You will not need to tell me why you would like to stop.

What will happen to me if I take part and what do I have to do?

I will ring you to arrange a date and time for us to meet. You can choose where the interview will take place. This can be at your home or somewhere else that you have chosen. If the interview takes place somewhere that is not your home, we will pay for your travel to that place.

The interview will take about 1 hour. I will ask you questions about cancer. This will include symptoms of cancer, your thoughts about cancer and visiting your doctor.

There are no right or wrong answers to the questions. I am just interested in what your thoughts are. All you need to do is talk about your thoughts and feelings about cancer.

If you feel uncomfortable with my questions, you can decide not to answer those questions. If it is OK with you, the interview will be recorded.

To thank you for your help, we would like to offer you £10 cash at the end of the interview.

What will happen after the interview?

After the interview, I will type what you said. This means we will be able to compare what people say in their interviews.

Your name will not be typed on any interviews. Some of what you say might be used in written research. No one outside of the research team will know you took part in the study.

The final results will be used to help make better services for cancer in Wales.

What happens to my personal details?

This study is carried out by a team at Cardiff University. Your name and contact details will be stored on secure, password protected university computers. Your name and contact details will only ever be seen by members of the research team.

Your details will not be used for anything other than contacting you as part of this study.

Anything you say in the interview will be confidential. This means no one outside of the research team will know that you were in the study. Your name will not be linked to anything you have said in the interview.

What are the potential risks or disadvantages in taking part in the study?

This study involves talking about cancer. It is possible that some of the things we talk about may be upsetting. If you are upset during the interview please talk to the researcher about this.

You can also stop the interview at any point without giving a reason.

If you want to talk to someone else, you can contact Tenovus on the number at the end of this letter.

How can I take part?

I will phone on [insert date] to answer any questions. I will also ask if you would like to take part in the study.

Contact for further information

Grace McCutchan
PhD researcher
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS
Phone: 02920 687197
Email: mccutchangm@cardiff.ac.uk

If there are any issues that I have not been able to resolve, please contact:

Dr Kate Brain (supervisor)
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS

The research is funded by the charity 'Tenovus' through Cardiff University

Helpline

Tenovus cancer support line

0808 808 1010

The support line is open 8am-8pm, 7 days a week.

This is a free number from BT landlines. From mobiles, your network may charge.

Website: www.tenovus.org.u

Appendix 8: Invitation letter and study information sheet for study participants recruited through snowball sampling or community partners



Dear [insert name],

I phoned you on [insert date] to talk to you about taking part in a study. The study is funded by Tenovus, the cancer charity. The aim is to help make better services for cancer in Wales.

The study involves an interview to find out what you think about cancer. The interview will take about 1 hour.

The next few pages tell you more about the study. This is to help you decide whether or not to take part. If you like, you can talk to members of your family or friends about the study.

If you do decide to take part, we would like to offer you £10 cash to say thank you.

I will phone you again on [insert date]. I will answer any questions and ask if you would like to take part in the study.

If you have any questions before then, please contact me on 02920 687639 or mccutchangm@cardiff.ac.uk.

[insert signature]

Grace McCutchan

What is the study all about?

I am from Cardiff University, and I want to find out what people think about cancer, so we can improve cancer services in Wales. This is a study funded by the charity Tenovus.

If you would like to take part in the study, I will arrange to come and talk to you at a time and place that is best for you.

Do I have to take part?

No. It is up to you to decide to take part in this study or not.

If you have any questions please ring me on 02920 687639.

You can talk to your family and friends about the study. They might be able to help you decide if you want to take part or not.

Before the interview starts, you will be asked to sign a consent form. I will go through this form with you. This is to say that you agree to take part in the study.

If you do take part, you can stop the study at any time. You will not need to tell me why you would like to stop.

What will happen to me if I take part and what do I have to do?

I will come to you to interview you on [date].

I will ring you to arrange a date and time for us to meet. You can choose where the interview will take place. This can be at your home or somewhere else that you have chosen. If the interview takes place somewhere that is not your home, we will pay for your travel to that place.

The interview will take about 1 hour. I will ask you questions about cancer. This will include symptoms of cancer, your thoughts about cancer and visiting your doctor.

There are no right or wrong answers to the questions. I am just interested in what your thoughts are. All you need to do is talk about your thoughts and feelings about cancer.

If you feel uncomfortable with my questions, you can decide not to answer those questions. If it is OK with you, the interview will be recorded.

To thank you for your help, we would like to offer you £10 cash at the end of the interview.

What will happen after the interview?

After the interview, I will type what you said. This means we will be able to compare what people say in their interviews.

Your name will not be typed on any interviews. Some of what you say might be used in written research. No one outside of the research team will know you took part in the study.

The final results will be used to help make better services for cancer in Wales.

What happens to my personal details?

This study is carried out by a team at Cardiff University. Your name and contact details will be stored on secure, password protected university computers. Your name and contact details will only ever be seen by members of the research team.

Your details will not be used for anything other than contacting you as part of this study.

Anything you say in the interview will be confidential. This means no one outside of the research team will know that you were in the study. Your name will not be linked to anything you have said in the interview.

What are the potential risks or disadvantages in taking part in the study?

This study involves talking about cancer. It is possible that some of the things we talk about may be upsetting. If you are upset during the interview please talk to the researcher about this.

You can also stop the interview at any point without giving a reason.

If you want to talk to someone else, you can contact Tenovus on the number at the end of this letter.

Contact for further information

Grace McCutchan
PhD researcher
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS
Phone: 02920 687197
Email: mccutchangm@cardiff.ac.uk

If there are any issues that I have not been able to resolve, please contact:

Dr Kate Brain (supervisor)
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS

The research is funded by the charity 'Tenovus' through Cardiff University

Helpline**Tenovus cancer support line**

0808 808 1010

The support line is open 8am-8pm, 7 days a week.

This is a free number from BT landlines. From mobiles, your network may charge.

Website: www.tenovus.org.uk

Appendix 9: Ethical approval 1

School of Medicine
Dean Professor John Bligh BSc MBChB MA(Lit) MMed MD FRCGP HonAcadMed
Ysgol Meddygaeth
Dean Yr Athro John Bligh BSc MBChB MA(Lit) MMed MD FRCGP HonAcadMed



Cardiff University
School of Medicine
Heath Park
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meddeen@cardiff.ac.uk
Prifysgol Caerdydd
Ysgol Meddygaeth
Parc Myrddal Bychan
Caerdydd CF14 4XN

Thursday 23rd January 2014

Grace McCutchan
Institute of Primary Care
& Public Health
School of Medicine
Heath Park
Cardiff CF14 4YS

Dear Grace,

Re: Developing a targeted cancer awareness intervention for people from deprived areas of Wales.

SMREC Reference Number: 14/01

This application was reviewed by the Committee on Wednesday 22nd January 2014.

Ethical Opinion

On review, the Committee have granted ethical approval for this project provided that:

1. The phrase "deprived area" is removed from the title and all other documentation as the Committee felt that this could potentially lead to participants feeling stigmatised.
2. You consider simplifying some of the sentences in the Information Sheet.
3. You provide a copy of the Interview Schedule once it has been finalised for our records.

Please send any revised documentation to the Committee Secretary, Miss Claire Batten.

Conditions of Approval

The Committee must be notified of any proposed amendments to the methodology and protocols outlined in your submission. Also, any serious or unexpected adverse reactions that may arise during the course of the study must be reported to the Committee.

Documents Considered

Document Type:	Version:	Date Considered:
Application Form	V1 09/01/14	22/01/14
Project Description	V1 09/01/14	22/01/14
Participant Information Sheet – Focus Group	V1 13/01/14	22/01/14
Consent Form	V1 09/01/14	22/01/14
Script for introducing the study to potential participants over the phone	V1 09/01/14	22/01/14
Covering Letter & Information Sheet	V1 09/01/14	22/01/14
Consent Form	V1 09/01/14	22/01/14
Interview Schedule	V1 09/01/14	22/01/14

With best wishes for the success of your project.

Yours sincerely,

Dr Andrew Freedman
Chair, School of Medicine Research Ethics Committee

Appendix 10: Coding framework 1

Coding framework onto COM-B

Capability		
Both the physical and psychological capacity of a person to perform behaviour		
Physical (includes skills, strength, stamina) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
No codes		
Psychological (having the knowledge and the skills to perform the behaviour and the capacity to engage and direct behaviour) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
Knowledge of the symptoms of cancer	Identification of what the participant thinks are the symptoms of cancer (correct or incorrect) or if they think there are no symptoms/ say they don't know symptoms. Also code here if in the context of symptoms they themselves have had or in other people with cancer/ cancer scare. When they talk about how this knowledge was acquired, use the code 'acquisition of knowledge'. If they are speculating about community knowledge, double code under 'community'.	'A lump is a symptom of cancer' 'Yeah there are symptoms you look for lumps and you get blood but, when you've got bowel cancer, if you haven't got the symptoms what, and like if it's in the oesophagus what do you look for?' 'I coughed and spit into a handkerchief, uh toilet roll to see if there was blood there, thinking it was cancer'
Knowledge of the types of cancer	Any knowledge of the different types of cancer (tumour sites). Also code here when the participant describes a person they know with cancer- only code the part that they say what type of cancer they had as it shows knowledge of the different types of cancer.	'I have heard of breast cancer' 'Well I know it can attack every part of the body' 'My friend's husband had bowel cancer'
Knowledge of the biology of cancer	Knowledge of the biology of cancer (correct or incorrect). Include here when they talk about cancer spreading. Include any knowledge about secondary cancers.	'From what I understand, it is when your cells go wrong' 'It can spread so quickly can't it?' 'I think they can become secondary can't they?' 'it's a bloody nuisance disease it's get's there it kills your immune system... well it kills your metabolism, it kills your body function...'
Knowledge of the causes of cancer	Knowledge of what causes cancer (correct or incorrect). If talking about someone else with cancer and they speculate what caused their cancer, double coded here with 'experience of cancer (knowing someone with cancer)'. Code here when they say about genetic causes of cancer. If they talk about their familial risk being high or low for cancer, code under 'personal perceptions of cancer risk'	'It is the chemicals in our food that cause cancer' 'my father died of stomach cancer because he was attacked and he was on the bus and he had those, big bus ticket issue machine, that went though his stomach and that actually caused the cancer' 'I know you can get a cancer of the throat from drinking' 'But with smoking I don't think it's anything to do with cancer'

Knowledge of treatments for cancer	Knowledge of the types of treatments for cancer available. If talking about someone else with cancer double code what treatment that had with 'experience of cancer (knowing someone with cancer)'. If they express an opinion about the treatments for cancer, code under 'beliefs about treatments'	'Chemotherapy, and what's the other one, radiotherapy, and tablets, that's all I know, operations obviously to cut things out' 'He's taking medication because there was something to do with they didn't want to operate so they medicated him'
Self-examination behaviour or checking for symptoms	Knowledge of self-examination behaviours. Code here when the participant says that they do or don't check or themselves for symptoms or they self-examine or look out for symptoms. If talking about someone else, double code under 'community'	'I do check myself you know. In the shower every now and again you know' 'I think you know we're all keen on checking your breasts'
Communication with Health care professionals	When they mention anything about how they communicate with their GP or any other HCPs. Include any dialogue between themselves and HCPs. Include any strategies people use to aid communication with HCPs. Double code under 'community' if talking about someone else.	'I just push push push until I get the answer I want' 'And she'd say, "well what do you want us to do about it?" and I'd go "well it's not up to me to tell you what I want you to do about it, it's what you think isn't it"
Screening behaviour and diagnostic testing (performance of)	Any mention of taking part or not taking part in screening behaviour in primary care or diagnostic testing in secondary care. For emotional reactions to screening or experiences of screening, code under 'emotional experiences screening'. Double code under 'community' if talking about someone else.	'I do those kits they send through the door, for your bowels you know' 'I go for regular smears as well' 'She's gotta go for another scan now, but they've had, they've given her an internal'
Hypothetical symptom experience	When the interviewer asks the participant what they would do if they found a symptom which they thought might be cancer. For potential emotional reactions to the symptoms, code under 'Emotional reactions or impact of people who have cancer and emotional reactions to an actual or potential cancer diagnosis' When they offer an action plan for a certain symptom without prompting for intentional behaviour, code under 'knowing what to do with a symptom of cancer' Double code under 'community' if talking about someone else.	'Straight away you would think, cancer' 'I'd think about it for a while and then if it didn't go away I'd go to the doctor' 'It would be scary, all you can think of is how will I tell the kids'
Knowledge as a barriers	Any mention of if/how cancer knowledge is/was a barrier to medical help seeking e.g. code here when they mis-attribute symptoms for other benign causes/ co-morbid conditions or hope the symptom will go away. If the doctor diagnoses the symptom as benign or says it is another condition, code under 'service barriers' Double code under 'community' if talking about someone else.	'I should have gone back sooner shouldn't I?...I accepted that HRT was God' – lady with kidney cancer who was put on HRT for 11 months. 'Diabetes, diabetes...that's a symptom of diabetes as well weight loss'

Knowledge as a facilitator	Any mention of how knowledge for cancer or other health problems acts as a facilitator to medical help seeking. Code under 'emotional facilitators' when the participant talks about going to the doctor because their fear it might be cancer facilitates help seeking. Also code here when they talk about 'knowing their body' Double code under 'community' if talking about someone else.	'He was having prostate problems, they kept saying nothing was wrong with him so he found it in the newspaper, the symptoms and he took it to the doctor and said "that's what I've got"
Opportunity All factors extrinsic to a person that either prompt the behaviour or allow enactment of the behaviour		
Physical opportunities (created by the environment e.g. time, financial resources, access and cues) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
Practical/physical barriers to medical help seeking (general or cancer specific)	Anything that acts as a practical or physical barrier to help seeking behaviour (HSB). E.g. being too busy, not being able to get to an appointment, disability Double code under 'community' if talking about someone else.	'I got work and a family, I don't have time to be making an appointment to go down the GP' 'I've got to wait for a bus, get down on the bus, and then go back to work which would take me an hour, which would only take somebody else I said 15 minutes'
Practical/physical facilitators to medical help seeking (general or cancer specific)	Any practical or physical facilitators to HSB e.g. someone going with them to the doctors or the participant themselves took someone else to the doctors, having regular contact with GPs, home visits Double code under 'community' if talking about someone else.	'The doctor, he came to the house' 'I do give an offer and say "well I'll come with you if you want me to"
Service barriers to medical help seeking (general or cancer specific)	Anything that acts as a barrier to HSB is to do with the health service. E.g. not being able to get an appointment, perceptions of not wanting to waste the docs time, 1 appointment 1 problem, time limited appointments, not liking a specific doctor. If it is about a general dislike for doctors, code under 'cultural barriers' Double code under 'community' if talking about someone else.	'You have to wait 3 weeks if you want to see a specific doctor' 'If you don't specifically book a week before or fortnight in advance to see a certain doctor you get to see a locum which, when you go in there they say you've got 5 minutes to see them, I thought what 5 minutes?'
Service facilitators to medical help seeking (general or cancer specific)	Anything that acts as a facilitator to HSB that is to do with the health service e.g. knowing they can ask for a different doctor, knowing that they can take the emergency appointments, piggy backing symptom, requesting an appointment earlier than the one given, liking their doctor. Double code under 'community' if talking about someone else.	'Well my GP is brilliant, he listens to everything I say, so I feel OK about going to him you know'

Description and comments about GP	Descriptive information about their GP surgery or staff. Comments which describe their GP or GP practice in a positive or negative light. Double code if they mention that anything to do with their surgery is a barrier or facilitator to HSB	'It is just up the road and has 3 doctors' 'My doctor is fantastic' 'They are very good actually, I have a good GP' 'Well I don't know about them really, I have never been to this new one, I didn't like my old surgery'
Description and comments about other healthcare services (not GP)	Any mention of other services used e.g. secondary care services, pharmacy, community care services, care homes, practice nurses. Any comments positive or negative about the NHS. This usually about the level of service provided or about drugs not being available on the NHS etc. If they mention anything about funding cuts or higher level organisational problems etc., double code under 'comments about politics or government'	'health care at home was used to help people stay at home if they were ill' 'My pharmacist is brilliant, I ask him about everything before going to the doctor' 'the problem with the NHS is there is are people making decisions who are not on the ground'
Current awareness campaigns	When the participant mentions any cancer awareness campaigns or if they have not seen anything. For how these campaigns made them feel code under 'emotional reactions to awareness campaigns'	'I saw an advert about coughing' 'no I can't really say I have seen anything'
Current places to talk about cancer	Anywhere people can currently ring or go to talk about cancer concerns or if there is nothing available. This can include any counselling service available for people who have been affected by cancer.	'there is this phone line you can ring'
Comments about government or politics	Anything that is political or when the participant talks about the government. This can be in relation to health or not. Also include information on policy etc. This is usually mentioned in the context of money, or participates refer to 'they' or 'them'. Code here any superstition about withholding cures for cancer etc.	'I seen my sister on the Tamoxifen which we can't really afford in our country now' 'They're on about we've got cures for this, cures for that, I think it's just a big money making thing to be honest, I think that it's a case of they got it and we aint sharing it because there's too much money going in....'
Cancer in the media	Any mention of cancer related articles or pieces in the media. E.g. news items, celebrities with cancer, newspaper articles on cancer risk etc. For social media, code under 'comments about social media'	'I mean you read the newspapers and this week they're telling you for example, that vinegar is excellent for you..."you must use vinegar, there's this, this, and this in it and it's good for you, vitamin marvellous" 3 weeks later, "don't have so much vinegar because..." and this is happening continually isn't it?' 'It's like Linda Bellingham isn't it she died this morning didn't she?'

Acquisition of cancer symptom knowledge	Any mention of knowledge for how cancer symptom knowledge was acquired e.g. because they knew someone who had the symptoms, looked don the internet, campaigns etc	'I do read about it you know' 'Going over the past that I've seen with my parents and 2 late brothers and my wife, you know late wife you know all the signs' 'I know you can get stuff of the internet and all that'
Other health in the media	Any other mention of health related issues in the media- this can be anything else health related e.g. heart problems,. Include celebrities with health problems	'I read these things because half of it I don't believe, you know I think oh...you know they'll say like I'm on cholesterol tablets now a couple of times they're claiming they make...oh they make your bones ache'
Comments about social media	Any mention of social media (Facebook or twitter). Code what they think of it/ if they use it or don't use it and how they use it. If they say that people put their cancer diagnosis on Facebook, double code under 'talk about cancer within the community'	'My wife uses facebook, I don't use Facebook'
Barriers to changes in risk behaviour	Any barriers to changes in health risk behaviours e.g. changes in healthy eating might be due to a lack of availability in healthy foods or the inability to afford it. Include personal barriers but also the wider societal barriers to changes in risk behaviour e.g. school provision. Double code under 'community' if not about the participant.	'I had myself, right, I need £10 for the gas and I've got £20 in my purse to last me the week, but it's gunna cost me £15 to get fresh veg, meat and fruit, then I would leave the fruit aside and the veg to make sure that I've got gas to keep me warm'
Social opportunities (created by cultural environment) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
Symptom disclosure	When the participant is asked or says that they would tell anyone about a symptom. Code all aspects of the interaction: who, why and advice given. Also code here when they say they would not disclose a symptom.	'I told my wife about when I found some blood in my pee'
Symptom disclosure (recipient)	When the participant says they have been asked for advice by another person about a symptom or when the participant has noticed someone's symptoms and they give them advice on what to do (e.g. go to docs). Code all aspects of the interaction: who, why and advice given. Also code here when they say people don't ask them about symptoms.	'I always tell them to go straight to the doctor' 'I'm like the hospital, people come to me with everything heath related'
Symptom disclosure (3rd party)	When the participant describes an incidence of someone they know disclosing symptoms to another person they know or when another person notices their symptoms. Code here who, why and what was said.	'He begged her to go to the doctor, her daughter begged her to go to the doctors'

<p>Experience of cancer (knowing someone with cancer)</p>	<p>There is a lot of coding and double coding here. Code all information gathered a person they know who had cancer. E.g. type of cancer, treatments, descriptions of the side effects of treatment, the symptoms they experienced and other information about their cancer journey.</p> <p>For actual HSB when they noticed symptoms, double code under 'symptom experience family and friends'.</p> <p>For anything about how this experience has influenced how they think about cancer or how the individual reacted to their diagnosis of cancer, code under 'Emotional reactions or impact of people who have cancer and emotional reactions to an actual or potential cancer diagnosis' .</p>	<p>'He had cancer of the stomach'</p> <p>'He had a cough for ages, I kept saying you need to go to the doctor, but he wouldn't. Eventually he did and the doctor sent him away for tests'</p>
<p>Concentric circles/ social networks</p>	<p>When p's are asked about their social networks using the concentric circles. Code all aspects under this code and double code under 'symptom disclosure' or 'symptom disclosure (recipient) for the parts when they talk about who in their circle has come to them with a symptom or who they would go to with a symptom.</p>	<p>'I – okay so first off I'd just like to get to know you, a bit more about you what I've been doing with people is saying "imagine this is you in the middle" and this is your closest circle of friends or family. These are people you talk to most or you see most and you just feel the closest to. Who do you think you'd put in your circle here? EH.DS2 F – well I got family and friends...'</p>
<p>Cultural BARRIERS</p>	<p>Anything that might act as a cultural barrier (things afforded by the environment) e.g. being male (stoic), a general dislike of doctors, having low general trust in doctors, age as a barrier (feeling too old to seek help), societal norms around medical help seeking.</p> <p>When they talk about communication with doctors code under 'Communication with HCPs' or if it is a barrier, double code under 'Service barriers'.</p> <p>Double code gender differences under 'gender differences'</p> <p>Double code under 'community' if talking about someone else.</p>	<p>'but a man won't [go], they tend not to think it's me, it'll go, but it doesn't'</p> <p>'nothing, I've got no faith in doctors at all'</p>
<p>Cultural facilitators</p>	<p>Anything that might as a cultural facilitator (things that are afforded by the environment) e.g. being female (more likely to discuss health problems), seeing people in social environment with cancer, having general good trust in doctors</p> <p>If they talk about liking a specific doctor code under 'service facilitator'</p> <p>Double code gender differences under 'gender differences'</p> <p>Double code under 'community' if talking about someone else.</p>	<p>'local people dying from it will make others think oh I'd better go and see about it'.</p>

<p>Talk about cancer within the community</p>	<p>Any mention of how people within the community talk about cancer to one another, or if they don't want to talk about cancer. This can be face to face talk about cancer or talk about cancer on social media etc. Code what is said and why.</p> <p>Also code here if they talk about keeping their cancer diagnosis a 'secret' or telling other people about their cancer diagnosis in the community.</p> <p>If social media is mentioned, double code under 'comments about social media'. When they talk about cancer within the mass media, code under 'cancer in the media'</p> <p>Double code for the latter under 'experience of cancer (knowing someone with cancer)' as well.</p> <p>Double code under 'community' if talking about someone else.</p>	<p>'I – why do you think people don't like talking about it? P – it's never going to happen to me hopefully' 'they sort of hide cancer don't they, you know what I mean? It's something "oh don't talk about it" you know you mean, I wouldn't normally talk about it like I have with you, you know what I mean'</p>
<p>Gender differences</p>	<p>Anything about gender differences relating to talk about cancer/ health etc.</p>	<p>'It's very depressing for the men innit? ((laughs)) I – ((laughs)) men don't really like talking about cancer do they? No, they don't'</p>
<p>Motivation</p> <p>The processes in the brain that energise and direct behaviour. This includes conscious decision making and habitual processes, emotional responses or processes involving analytical decision making.</p>		
<p>Reflective processes (involving evaluations and plans) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'</p>		
<p>Personal perceptions/ Perceptions of cancer risk</p>	<p>When the participant mentions how far they believe themselves to be at risk of getting cancer or not at risk of getting cancer. This might be discussed in terms of familial risk.</p> <p>They might talk about other people they know and their perceptions of risk, code here and double code under 'community'</p> <p>If they worry about their risk of getting cancer, double code under 'cancer worry'</p>	<p>'Cancer is my side, heart is his side, it does worry me thinking am I gonna be alright, is it going to happen to me?' 'they want to block it out and say "well it's not gonna happen to me" 'I asked was it sort of hereditary because my brother had prostate cancer, would I have it? And they said "there's a possibility that you could develop it" touch wood, I haven't.'</p>
<p>Symptom tracking and evaluations</p>	<p>Anything the participant has done or would do to keep track of their symptoms before going to visit the doctor e.g. looking on the internet, keeping a symptom diary Double code under 'community' if talking about someone else.</p>	<p>'I get on the internet have a look' 'I mean most people have got computers today you can google...your symptoms so it will come up'</p>

<p>Beliefs about early diagnosis</p>	<p>Any beliefs about early diagnosis of cancer. E.g. some participants might highlight the importance of diagnosing cancer early, others might say it doesn't make a difference. Code here when participant talk about 'going to the doctors early/ straight away', 'catching cancer early'.</p> <p>For anything about cancers 'spreading' in relation to late diagnosis, double code under 'biology of cancer'</p> <p>If in relation to knowing someone with cancer, double code under 'experiences/ knowing someone with cancer'</p>	<p>'The earlier you get cancer diagnosed, the more likely to you are to survive'</p> <p>'If it is not found early it spreads to other organs with terrible results'</p> <p>'If you've got cancer and you don't get it looked at straight away because it can, it can happen where they don't diagnose it straight away, it can spread so quickly can't it'</p>
<p>Beliefs about treatments for cancer</p>	<p>The participants opinions about the treatment for cancer e.g. any language used to describe what they think are the side effects of cancer treatments, how effective treatments are.</p> <p>When p's talk about cancer being 'treatable' or 'curable', code under 'beliefs about curability of cancer'</p> <p>For knowledge of the types of treatments for cancer, code under 'knowledge of the treatments for cancer'</p> <p>If in relation to knowing someone with cancer, double code under 'experiences/ knowing someone with cancer'</p>	<p>'The treatments can make you very ill, sometimes the treatment is worse than the cancer'</p>
<p>Beliefs about curability of cancer</p>	<p>The p's opinions and beliefs about the curability of cancer (if it can or can't be cured) e.g. how treatable cancer(s) are or if they believe they can be cured.</p> <p>A lot of p's talk about how the mind can help curability of cancer (being determined, fighting cancer, staying positive)- code these here.</p> <p>When they use language relating to how early diagnosis can aid curability of cancer, double code under 'beliefs about early diagnosis of cancer'.</p> <p>If in relation to knowing someone with cancer, double code under 'experiences/ knowing someone with cancer'</p>	<p>'Look on the bright side, there is a cure out there somewhere'</p> <p>'Because a lot of cancers today are treatable thank goodness'</p> <p>'Well once you've got it it's like a death sentence isn't it really then it's very rare someone having cancer and beating it'</p> <p>'He don't think they'll ever find a cure [for cancer]'</p>
<p>Knowing what to do with a symptom of cancer</p>	<p>This is different to 'hypothetical symptom experience' as they are <i>asked</i> what they would hypothetically do if experiencing a symptom. For this code, the participant lists off almost a set of rules (or action plans) about what one should do when faced with a symptom- like an action plan rather.</p> <p>Double code under 'community' if talking about someone else.</p>	<p>'Bleeding is another sign of it and you must go straight to the doctor and sort it'- she was not prompted or asked what she would do if experiencing bleeding from the bowels, instead she demonstrated symptom knowledge and then what you should do if experiencing that symptom</p>

Smoking behaviour	Any detail about smoking behaviour (or lack of smoking behaviour) from the participant or members of the community. E.g. why they or people in the community smoke even if they know the risk associated with smoking, descriptions of how many people smoke, insight into why people take up smoking, stop smoking, general information about smoking behaviour. When they explicitly say if they think smoking causes cancer or not, code under 'knowledge of the causes of cancer'. If they talking about people in the community, double code under 'community'	'I – why do you think people still smoke even though they know the risks P- there's a certain intellect of people whatever you tell them about anything they won't accept it'
Motivation to learn more about cancer or health	Any mention of motivations to know or learn more about cancer symptoms/ cancer or general health. When they talk about how acquire the information, code under 'acquisition of knowledge' If the motivation to learn more is because of seeing people with cancer, code under 'experiences/knowing someone with cancer'	'I'm learning all the time and this is why with health, I'm more into that than anything else, because seeing what's happened in the past to me'
Automatic processes (emotions and impulses that result from innate dispositions or associative learning) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
Beliefs about cancer	Any language used to describe cancer and what they think about cancer as a disease. e.g. attitudes or beliefs towards cancer, folk beliefs, fearful beliefs and fatalistic beliefs. For beliefs about the curability of cancer, treatments for cancer or early diagnosis, code under relevant codes above under 'reflective processes' or double code if it such beliefs relate to how they think about cancer as a disease.	'It is a horrendous disease' 'it is it's a dirty disease isn't it? That's the description of cancer, it's a dirty disease, and once you've got it that's your lot, isn't it....'
Emotional barriers to medical help seeking (general or cancer specific)	Anything that acts as a barrier to symptom presentation that is emotive. These might be quite similar to beliefs or cancer worry, but only code here when the participant explicitly states that these emotions will act as a barriers to their or others HSB. E.g. fear and worry of what they symptom might be, embarrassment. Double code under 'community' if talking about someone else.	'I think for him perhaps fear, I think perhaps might be a lot to do with some people, fear. Fear of the unknown isn't it?' 'I think a lot of them are too terrified to see about it mind, I used to be anyway....'
Emotional facilitators to medical help seeking (general or cancer specific)	Things that make it easier for the person to seek medical help that is emotive. E.g. their fear motivates a visit to the doctor, anxiety, help seeking for reassurance Double code under 'community' if talking about someone else.	'What's the point in worrying about it, go and get it checked out- put's your mind at rest' 'You just go down there [to the doctors] hoping he would tell you "go away all you've got is a cough" 'I'd be afraid to leave it you know and I wouldn't hesitate in going to my GP'

Cancer worry	How much the participant or people in their community worries about getting cancer or does not worry about getting cancer Double code under 'community' if talking about someone else.	'yeh it do worry me, it's not good saying it don't' I'm afraid of long term infection of the chest that could cause cancer right' 'The cancer I must be honest it never worried me'
Cancer compared to other life threatening diseases	Some participants described cancer compared to other diseases e.g. diabetes, heart disease etc. Code here what their opinions and comparisons.	'You can't compare them, cancer is just terrible, it's like death, others you can live with' 'To be honest with you out of all the disease I would prefer cancer believe it or not...because I'm suffering from memory loss'
Difference between cancer now and in the past	Comments about the difference between cancer in the past and now. Can be anything to do with survival, attitudes, treatments etc- double codes under relevant codes if about these e.g. if about differences in treatments for cancer, double code under 'beliefs about treatments for cancer'. For differences in how people talk about cancer nowadays, double code under 'talk about cancer in the community'	'I don't think the word cancer was ever used when I was...I can't remember if they ever used it' 'Years ago it was the big "C" they'd whisper the word or mouth the word, not for anybody, you know...but to day they put it on Facebook' 'I mean they're coming up with different things all the time if there is a chance, there is more survival rates now than it was going back 10 years ago'
Religious beliefs and cancer	Any religious views and how they change beliefs or form the basis of beliefs about cancer	'I don't think God has got anything to do with it'
Emotional reactions or impact of people who have cancer and emotional reactions to an actual or potential cancer diagnosis	How someone would react or has reacted to someone having cancer and how a diagnosis of cancer has impacted the family/ participant. Also code here if the p has/had cancer and they are talking about the impact of their cancer on family members or friends or how they felt about their cancer diagnosis e.g. accepting the diagnosis of cancer, the family not being able to cope, offering support, people pussyfooting around the person etc. Also code here when the p talks about emotional reactions to a potential cancer diagnosis. Double code under 'community' if talking about someone else. If they describe their own cancer, code under 'description of their cancer' or if they describe someone else who has cancer code under 'experiences/knowing someone with cancer'.	'support, support as much as they want' 'Oh it was terrible [when he got cancer]' 'he do joke about it, he do say "well I can have a false ball if I want" 'you don't know what to say you're um, you're dumbstruck, and that's it...yeah, you don't know how to react'

Emotional reactions to screening/ diagnostic tests	Any opinions thoughts on screening programmes, emotional reactions to taking part or not taking part in about screening, details of positive or negative experiences for screening or diagnostic testing.	'I went for a smear once and I have never been again, the whole experience was just awful'
Emotional reactions to awareness campaigns/ in the media	Any emotional reactions or opinions about any campaigns to raise cancer awareness or how any reporting of cancer related info in the media has made them feel e.g. cancer in the news or on TV.	'I think they ones on TV are very scary, they scare people away from thinking about it'
Emotional reactions to actual or hypothetical cancer symptoms	How the participant reacted to an actual symptom experience- even if the diagnosis was benign. Also code here if they predict how they would feel for a hypothetical symptom.	'I went home very upset, cus when he said "lump" you automatically think cancer'
Behaviour		
Performance or intentions to perform a behaviour		
Actual symptom experience	When the participant experiences a symptom of cancer. Code the description of the symptom, what they did and any symptom attributions made. Code here even if they don't explicitly say they thought could be cancer. For general descriptions of their cancer double code under 'description of their cancer'. For emotional reactions to symptoms code under 'Emotional reactions or impact of people who have cancer and emotional reactions to an actual or potential cancer diagnosis'. For symptom experience in another person, code under 'symptom experience for friends and family'. For any barriers or facilitators to HSB, double code under relevant codes. For anything about communication symptoms to HCPs, double code under 'Communication with HCPS'	'Well I went short of breath, no other illness just short of breath. I went to the surgery and he sent me for a chest x-ray'
Symptom experience for family and friends	Any information about symptom experience in someone else. Code the description of the symptom, what they did and any symptom attributions made. Code here even if they don't explicitly say they thought could be cancer. If they report that they experienced any barriers or facilitators to help seeking, double code under appropriate codes and double code under 'community'. For anything about communication symptoms to HCPs, double code under 'Communication with HCPS'	'She lost a tremendous amount of weight, and she really wasn't well she just kept on saying "I can't eat, I can't swallow" and he just said to her "it's a virus, it's to do with your throat" she said have I really?'
Changes in risk behaviour	Any disclosure that the participant or someone else has stopped or attempted to stop risky health behaviours e.g. smoking or has made changes to their lifestyle in order to reduce their risk of cancer. Also code here if they express or reluctance to give up behaviours that increase the risk of cancer and what it was like to change risk behaviour. If about smoking behaviour, double code 'smoking behaviour'. Double code under 'community' if talking about someone else.	'I said we try and eat healthy you know and all these different vitamins and things like that 'My son he smokes and he's 52 he's smoked since he was 14 that I know of, right he stopped smoking 12 months ago'

Medical help seeking for non-cancer symptoms	Any mention of medical help seeking for symptoms that are not related to cancer or other medical health conditions e.g hip replacement or diabetes. Code a description of the condition, who they went to, symptom attributions etc. When they disclose that they have a co-morbidity or health condition, double code under 'information about the participant'. For anything about communication symptoms to HCPs, double code under 'Communication with HCPS'	'I knew you know my throat wasn't right, and then they sent me for a test, "no it's fine" and then they said to me then "oh yes it is, you have got underactive thyroid, so we'll put you on tablets now" you know'
Other codes that do not fit under COM-B		
Community	Code here when the participant has been asked to imagine what their friends/ family/ community know or believe about cancer or what they would do if they experienced a symptom. These questions were used to get a feel of the social norms in the community surrounding knowledge and beliefs about cancer. When using this code, double code under the relevant other code. E.g. symptom knowledge	
Description and comments about community	When the participant is asked to describe the community they live in or the facilities available in their community. Or any stories about the community or neighbours that live in their community.	'It's very close knit, everybody knows everybody' 'It's mainly Asians down there now...and their line broke...So I made a line for these people'
Community health	Any description about the status of health in members of the community in which they live in or friends and family and how people talk about health within the community or if health is a priority etc. also code if they talk about health habits (not cancer related) of friends and family	e.g. 'no its vascular stuff she got', '2 days after that my sister died'
Suggestion for an intervention	When the participant is prompted to generate any ideas for an intervention to encourage more timely symptom presentation. Or any suggestions for interventions that they don't think would work.	'You could try doing a talk in the community centre'
Information about the participant	Any demographic information and information about general health. Also code here any contextual information about family.	I'm 76 now' My memory is terrible, its just getting worse' 'My grandson is 23 and uh he is old enough for me to want him to have a job'
Talk not related to topic of interest	Code anything here that is not related to anything the interviews are trying to capture.	'is it raining? Yeh let the dog in then'

Description of their cancer (or benign cancer diagnosis)	Code anything here about the participant if they, themselves had cancer or was referred for cancer tests and it turned out to be benign. Any info they give about having cancer/ cancer journey. If they talk about how they were diagnosed and went to seek medical help etc, double code under 'actual symptom experience'. For any barriers and facilitators to medical help seeking, double code using appropriate barrier and facilitator codes. When they talk about any emotional reactions to their cancer or potential cancer diagnosis, code under 'Emotional reactions or impact of people who have cancer and emotional reactions to an actual or potential cancer diagnosis'	
Talk about charities	Any talk about charitable organisations. Include any talk about them giving to the charity or the work a charity does etc. Or any talk about the community raising money for charities	'It's very important that people keep giving, because where would we be without the voluntary, the McMillan'
Comments about euthanasia	Any mention of euthanasia and their opinions surrounding it	'I don't know whether I'm for euthanasia or against it'
Taking part in future research	If the participant says that they do or don't want to take part in future research	

Appendix 11: Charting of data 1. Example: psychological capability- participants with a previous diagnosis of cancer

Previous diagnosis of cancer	Theme (Psychological Capability)		
Participant ID	Knowledge of the symptoms of cancer	Knowledge of the types of cancer	Knowledge of the biology of cancer
1	Aware of lump as a symptom of cancer and weight loss.		Aware that cancer is when the cells in the body 'go wrong'.
9	Aware of shortness of breath and vomiting as symptoms of cancer. Believes cancer to be painful. Lack of pain and vomiting for symptoms prior to diagnosis therefore cancer was not considered a probable cause of symptoms.	Aware of multiple types of cancer- lists bowel, lung, breast and pancreas. Says you can get cancer anywhere.	Did not tell anyone about his cancer diagnosis because he thought people in the community might think he was contagious and they would refuse to sit next to him/come and see him.
10	Thinks that people in the community are unaware of the symptoms of cancer.		
18	Symptoms prior to diagnosis were frequency of going to the toilet- was unaware this was a symptom of cancer and was surprised to receive a diagnosis of cancer. Was surprised the symptoms were painless. Aware of weight loss as a symptom of cancer but thinks some cancers are symptomless.	Had never heard of prostate cancer until diagnosed with prostate cancer. Aware of pancreatic cancer because father was diagnosed with pancreatic cancer. Also aware of breast and lung cancer.	Aware that the cancer can spread to other parts of the body
27	Was surprised to receive a diagnosis of cancer as were unaware that the symptoms could indicate cancer. Expected cancer to be painful.	Aware you can get cancer in any part of the body	

Previous diagnosis of cancer	Theme (Psychological Capability)		
Participant ID	Knowledge of the causes of cancer	Knowledge of the treatments for cancer	Self-examination behaviour/checking for symptoms
1	Thinks there is an increase in the prevalence of cancer. Attributes this to chemicals used in food- from the chemicals used in the food for animals (so they are ingesting the chemicals) and chemicals used to grow food crops- so humans ingest these chemicals which causes cancer. Aware that smoking is a major cause of cancer.		Self-examines but could not self-examine to find her tumour.
9	Could not cite any potential causes of cancer- unaware of the causes of cancer	Aware of chemotherapy, radiotherapy and surgery as treatments for cancer.	
10	Could not cite any potential causes of cancer- unaware of the causes of cancer	Aware of hormone tablets as treatments for cancer.	
18	Aware of the link between smoking and cancer, but slightly sceptical because he could think of some people in the community with a diagnosis of cancer who did not smoke. Thinks other people in the community are sceptical of the link between smoking and cancer.		Reminds his family to check themselves for cancer regularly- think self-examination is very important.
27	Believes cancer 'lies dormant' in everyone, and that a physical hit or psychological trauma i.e. death in the family will 'shock start it off'. Thinks smoking does not cause cancer- says that this is an excuse the medical profession use to blame symptoms on smoking habit. Knows some people who smoked their whole life and never received a diagnosis of cancer. Does not believe what the media report about the link between a poor diet and cancer- says this link has 'never been proven'.	Aware of four different treatment options because he was offered these- surgery, radiotherapy injection, hormone injection, radiotherapy	

Previous diagnosis of cancer	Theme (Psychological Capability)					
	Participant number	Communication with HCPs	Screening behaviour (performance of)	Hypothetical symptom experience	Knowledge as a barrier	Knowledge as a facilitator
	1	Thinks the problem people in the community have with communicating with the doctors is that they get a telling off about their diet and weight so they don't listen to the doctor.	Up to date with regular screening, but needs to 'nag' husband to do screening. Reports that he refused to do the bowel screening test and thinks this is typical for men- they won't engage with screening.	N/A Previously diagnosed with cancer.	Unaware symptoms could indicate cancer, therefore did not seek medical help for 11 months.	
	9		Has regular colonoscopy. Used to be embarrassed but is used to it now.	N/A Previously diagnosed with cancer.	If attributed symptom to cancer he would have gone to the doctors sooner	
	10	Finds asking the doctor questions difficult.		N/A Previously diagnosed with cancer.	Aware symptom (lump) could indicate cancer so prolonged symptom presentation	
	18	Finds it difficult to listen to the doctor during a consultation. Member of family accompanies the participant to appointments to help with listening.	Aware that blood tests and MRI scans can be used to screen for cancer.	N/A Previously diagnosed with cancer.	Didn't attribute symptoms to cancer otherwise would be to the doctor sooner	
	27	Participant is passive when talking to HCPs, wife more proactive.	Found his first colonoscopy very painful and embarrassing.	N/A Previously diagnosed with cancer.	Unaware symptoms were cancer otherwise would have sought medical help quicker	Would go straight to the doctor in future if attribute symptom to cancer

27 August 2015

Dr Kate Brain
Reader
Cardiff University School of Medicine
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Heath Park
Cardiff
CF14 4YS

Dear Dr Brain

Study title: Development and pilot evaluation of the Tenovus health check: a targeted cancer awareness intervention for people from deprived communities (ABACus Phase 2)
REC reference: 15/WM/0292
Protocol number: SPON 1445-15
IRAS project ID: 184214

Thank you for your letter of 27th August 2015, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Assistant, Tad Jones, nrescommittee.westmidlands-solihull@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Interview schedules or topic guides for participants [2b Interview topic guide v1.0 15.04.15]		
IRAS Checklist XML [Checklist_31072015]		31 July 2015
IRAS Checklist XML [Checklist_27082015]		27 August 2015
Letter from funder		
Letter from sponsor		
Non-validated questionnaire		
Non-validated questionnaire [2a Prospective Q_draft follow up v1.0 30.07.15]		
Non-validated questionnaire [2a Prospective Q_draft baseline v1.0 30.07.15]		
Other [Cover Letter response to provisional opinion]	1.0	21 August 2015
Participant consent form [2b Interview_consent form_v1.0 15.04.15]		
Participant consent form [2b Observation_consent form_v1.0 15.04.15]		
Participant consent form [2a Prospective Q_consent form_v1.1 18.08.15]	1.1	18 August 2015
Participant information sheet (PIS) [2b Interview_information_v1.0 15.04.15]		
Participant information sheet (PIS) [2b Observation_information_v1.0 15.04.15]		
Participant information sheet (PIS) [2a Prospective Q_information_v1.1 18.08.15_ab]	1.1	18 August 2015
Participant information sheet (PIS) [2a Prospective Q_information_v1.1 18.08.15_ct]	1.1	18 August 2015
REC Application Form [REC_Form_31072015]		31 July 2015
Referee's report or other scientific critique report		
Research protocol or project proposal [ABACus y2 research protocol V2.0 14.07.15]		
Summary CV for Chief Investigator (CI)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WM/0292	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Rex J Polson
Chair

Email: nrescommittee.westmidlands-solihull@nhs.net

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Dr Stephanie Smits*

Appendix 13: Focus group summary 1

Healthcare professional focus group Site 1

Overall, the Tenovus health check was viewed positively as a useful tool for encouraging people living in Communities First areas in [place] to engage with their health. However, weaknesses and areas for improvement were also discussed. A number of barriers and facilitators to cancer awareness and early help-seeking were also highlighted.

Barriers to timely GP presentation

The group discussed that people in Communities First areas are aware of cancer, but tend to be less aware of the risk factors for cancer. There was a view that many people in the community do not have an accurate perception of personal risk and do not understand that engaging in risky behaviours (smoking, poor diet, lack of exercise etc) influences their risk of cancer.

Long-term health was perceived not to be a priority for many people in the local community. The group felt that people often come to see the GP once health problems have been experienced for a while and reach a point where they can no longer be avoided. GP practices were described as playing a 'firefighting' role, with only a small amount of work being about prevention.

Negative beliefs and fears about cancer were thought to be widespread within the community, with cancer perceived as a non-treatable disease that is a death sentence. These beliefs were thought to be particularly prevalent in older people, who also have concerns about bothering the doctor.

Facilitators of timely GP presentation

People living in Communities First areas were thought to be receptive to large scale cancer awareness campaigns, with discussions about increases in concerned patients following such campaigns. However, the group was concerned that such campaigns may result in increased visits by the 'worried well' rather than those who are most at risk.

Discussing symptoms with family members was considered by the group to be a prompt for people in the local community, with family members often encouraging people to visit the GP and in some cases ringing to make the appointment.

Health check content

The Tenovus health check was described as comprehensively covering a wide range of cancer symptoms and risk factors. The health check was considered to be easy to use and understand, with the traffic light system praised for making the results clear. The printability of the condensed results section was viewed positively, as was the prominence of the helpline number throughout the health check.

The group agreed that the health check could be strengthened by making the questions more specific, especially the diet and family history related questions. It was felt that the answer options were too restrictive, with the potential for inaccurate results. The results section was viewed as being negative, overwhelming and lacking a motivational tone. It was suggested that the results section could be improved by priming the positive results and by including more motivational language. The advantages of motivational interviewing techniques were discussed, with the group expressing that the results could be improved if they encouraged people to make plans and set goals to change one or two behaviours. Diagrams and graphs could also be utilised in the results section to break up the text.

Suggestions were made to include a statement at the end of the health check informing people when they should re-do the health check, with consideration given to what would be an appropriate time frame. It would also be beneficial to add a statement informing people that the health check is not exhaustive, and that results do not give the 'green light' for all aspects of health.

How to conduct the health check

Overall, involving a trained advisor was considered preferable to people doing the health check alone because it would allow hands-on support, advice and signposting to relevant services. Signposting to relevant services was considered very important, and the advisor could help to ensure that the individual is aware of the appropriate places to go for help and support.

Places to conduct the health check

It was thought that the health check could be carried out in a range of community venues including supermarkets, shopping centres, sports venues, job centres, gyms, and local events such as healthy living days. Communities First was mentioned as a potential way to implement the health check via health and wellbeing events in the local community.

Community pharmacies and GP practices were also described as good locations for providing a 'captive audience' who could complete the health check whilst waiting. Lack of privacy was considered an issue in these environments, but could be overcome by booking a room for an afternoon and conducting an advertised afternoon drop session.

Implementation and sustainability of the health check

Media campaigns (newspapers, TV, radio) were considered important for the implementation and take up of the health check, as GPs had noticed increases in presentations following similar media campaigns. If such an approach is used, consideration needs to be given to how to identify the target audience to ensure that the correct people are presenting.

The pathways to presentation and signposting to relevant services needs to be clarified in the health check, in order to help people access the right services at the right time and reduce the number of people incorrectly presenting to the GP.

Practice nurses and community pharmacists are frequently involved with health promotion, so the health check could be promoted through these existing channels with further signposting to the GP where relevant.

Involving and engaging health professionals in development and implementation processes was considered key to successful uptake and impact of the health check (e.g. going through a local medical committee). This will be particularly useful for GPs as it will help increase awareness of the health check and prepare them for potential consultations where patients present after completing the health check.

Appendix 14: Focus group summary 2

Healthcare professional group Site 2

The Tenovus health check was discussed as a tool for encouraging people living in Communities First areas in [place] to engage with their health. Many weaknesses of the health check and areas for improvement were discussed. A number of barriers and facilitators to cancer awareness and early help-seeking were also highlighted.

Barriers to going to the GP

Anxiety over symptoms and what might happen as a result of a medical consultation were perceived by the group to discourage people in the local community from going to see the GP. The group also felt that patients often feel uncomfortable talking about their symptoms, with embarrassment about intimate symptoms quite common.

The group felt that people often come to see the GP once health problems have been experienced for a while and it has got to a point where it can no longer be avoided. Long term health was perceived not to be a priority for many people in the local community.

The group discussed how they think that people in local Communities First areas are aware of cancer, but tend to be less aware of the risk factors for cancer. There was a view that many people in the community do not have an accurate perception of personal risk and do not understand that engaging in risky behaviours (smoking, poor diet, lack of exercise etc) influences their risk of cancer.

Negative beliefs and fears about cancer were thought to be widespread within the community, with cancer perceived as a non-treatable disease that is a death sentence. These beliefs were thought to be particularly prevalent in older people, who also fear being told what to do and having their independence taken away.

Facilitators to going to the GP

People living in Communities First areas were thought to be receptive to large scale cancer awareness campaigns, with discussions about increases in concerned patients following such campaigns. However, the group was concerned that such campaigns may result in increased visits by the 'worried well' rather than those who are most at risk.

The group felt that social networks were very important for people in the local community. People in the community often discuss symptoms with family members and friends, with

advice from these people often taken on board. The group discussed how people often base their own health concerns on experiences of disease in family or friends.

Health check content

The Tenovus health check was considered to be easy to use and understand, with the traffic light system praised for making the results of the health check clear. The content of the 'green' results was particularly praised for highlighting the good things that people are doing, and explaining why these are good things.

The group agreed that the health check could be strengthened by making the questions more specific, especially the diet and family history related questions. The group thought that some answer options were too restrictive and do not allow people to accurately answer questions, with this leading to inaccurate results. The terminology in the health check was questioned, with words such as 'history' and 'positive results' examples of words that could be misunderstood.

Questions were also raised by the group over the need to capture personal identifying information (e.g name and telephone number) at the start of the health check, and again before results are revealed. The group agreed that gender and age information was useful, but that the other information may put people off using the health check.

Overall, the health check content was considered to be too broad, with the length of the health check too long for an intervention that is trying to get people who would not normally think about their health to do so. The group likened the health check to a full medical history, with this viewed as excessive and not necessary for such a health intervention. Whilst the content of the health check was viewed by the group as credible, it was perceived to be too long and containing questions that were irrelevant or non-pertinent. Focusing the health check so that it contains fewer questions will help to get across the key messages. Streamlining was also deemed to be beneficial in terms of uptake, as the group felt more people would complete the health check if it was shorter.

How to conduct the health check

The group raised questions over how the health check was intended to work, and whether it was supposed to be completed by people opportunistically online, or whether it would be taken out in to communities. Both avenues were deemed acceptable, but it was felt that the

health check would need to be adapted and strengthened for either approach to be successful.

For online completion, the group thought that the health check would need to be shorter and more visually appealing. Social media was discussed as a way to promote the online version of the health check. The group viewed the online version as a potential way to make people think about their health and then encourage them to do something about it.

However, in order for this to be achieved, changes outlined above would need to be made. Whilst the internet was considered a way to engage some people, the group also discussed that this medium may not target the people who are most at need of such an intervention. Older people are an example of a group of people who would be less likely to engage with the health check in this format.

Taking the health check out to the community and having a trained advisor to help people complete the health check was also discussed. The group discussed how, if done in the right settings, this could lead to people engaging with their health who would not usually do so. The support and signposting offered by an on hand advisor was viewed positively, especially for potential anxiety or concerns over results. However, the sustainability and the ability to demonstrate public health impact via this method was questioned, due to the large number of people who would need to complete the health check in order demonstrate impact.

Places to conduct the health check

The group felt that the health check would not be best placed in supermarkets or shopping centres, as people would not be willing to give up their time to complete a health check in such places. Places where people already spend a lot of time were viewed as better alternatives, such as the work place or community events. Drop in sessions in community venues were also discussed as a way of engaging people.

Conducting the health check in places such as the pharmacy or GP waiting room were also discussed by the group, but it was felt that people do not want to extend their time in such places and would not be particularly willing to conduct the health check.

Implementation and sustainability of the health check

In order for the health check to be implemented successfully, the different dissemination pathways (internet and in person with an advisor) need to be given some more thought and

clear marketing strategies should be considered. The target audience (e.g age, ethnicity) also needs to be defined, as this will help guide decisions about content and marketing.

Primarily, the content of the health check needs to be re-considered, as the group felt that it is too long and too broad in its current form. Streamlined content could lead to a more user friendly and approachable intervention.

Appendix 15: Focus group summary 3

Community partner focus group Site 1

Overall, the Tenovus health check was viewed positively as a useful tool for encouraging people living in community first areas in [place] to engage with their health. A number of barriers and facilitators to cancer awareness and early help-seeking were discussed.

Barriers to going to the GP

The group discussed the extent to which cancer is seen as a health priority for people in the local community. It was felt that people deal with their health when it becomes a crisis, rather than looking to prevention or seeking medical help early in the symptom experience.

Concerns and priorities of the people in the community were also discussed, with concerns about bills, children and food the main priority and therefore potential barriers to prevention and early help-seeking.

Difficulty getting an appointment to see the GP was discussed as a barrier to early presentation in the community. Sometimes people are required to ring GP practices at 8.30am to get appointments, and for many this is not possible.

Some people in the community are not registered with a GP. In these cases, it is hard to get people to register with a GP, and even harder to get them to make an appointment.

Length of time in GP appointments was also mentioned as a barrier to discussion about health concerns. People feel they do not have enough time in appointments to explain their problems, and also feel that they can only go to the GP with one health concern, as opposed to multiple health problems. The 'door handle' diagnosis was also discussed, with this reflecting that many people wait until the end of the consultation to mention their real concern.

There are also many negative beliefs about cancer that are held within the community, with cancer feared and considered a 'death sentence'. These beliefs can lead people to think there is nothing they can do to prevent cancer, and may be particularly prominent in older members of the community, who would rather not know what is wrong with them.

Facilitators to going to the GP

People in the community have often had experience of cancer in friends or family, which may help to raise levels of awareness. Cancer is now much more in the open, with cancer discussed in community places, such as clubs, as well in newspapers and on TV shows.

Building relationships with community partners who they see regularly, such as tenancy support workers, can help people become more aware and engaged in their health by making it easier to disclose health issues, or for others to pick up on potential changes in the individual that are indicative of health problems. In these situations, people can get support and be encouraged to visit their GP. Sometimes it can be easier for people to talk to support workers than friends or family.

Making GP practices more accessible with home visits and evening opening times was viewed as making easier for people to discuss their health concerns with a GP. Past experiences with sympathetic GPs can also help people re-engage with their health and help them feel confident and comfortable in presenting to the GP with concerns.

Health check content

The Tenovus health check was viewed favourably in comparison with other tools such as the Welsh Government's 'Add to your life' online check, due to its brevity and efficiency.

The group agreed that the health check could be strengthened by including information on recommended cancer screening. If people in the community were aware of and engaged with screening it may help problems to be picked up earlier, with early diagnosis a priority for better outcomes. It was felt that the screening information would be particularly relevant to the people who received 'amber' results, as this would emphasise that while there may not be an immediate risk of a health problem, it would good to signpost them to age/gender appropriate screening.

Literacy levels were also discussed, with suggestions made to reduce the text and increase the number of pictures in the health check to make it more accessible and understandable. Questions were also asked about the use of the health check with people who are visually impaired or who speak other languages.

The traffic light system was viewed positively as it was considered a clear way to show people their results. The use of tablets as a platform for the health check was viewed favourably and were seen as easy and intuitive to use.

The ability to print off the results of the health check was praised, and the printouts could be useful for people to take along with them to GP appointments.

How to conduct the health check

Overall, involving a trained advisor was considered preferable to people doing the health check alone because it would allow on hand support and advice to be provided, especially for people who receive 'red flag' traffic light results.

It was thought that the opportunity to complete the health check alone should be available for those that want it, with the advisor available to answer questions and to discuss the results if needed.

Places to conduct the health check

It was thought that the health check could be carried out in various places, such as rugby clubs, coffee mornings, church mornings and local events, such as healthy living days.

Introducing the health check into 'safe' environments that people are familiar with may make them more likely to complete the health check.

The length of the health check was viewed as lending itself to being conducted at the end of other sessions, such as housing discussions or other one-to-one meetings with community partners.

Ways in which the health check could fit with current local initiatives was discussed, and could be maximised by training local community partners. This would remove the barrier of having to wait for a Tenovus health check Advisor to carry out the health checks, and could facilitate increased use and spread.

Appendix 16: Focus group summary 4

Community partner focus group Site 2

Overall, the Tenovus health check was viewed positively as a useful tool for encouraging people living in community first areas in [place] to engage with their health. A number of barriers and facilitators to cancer awareness and early help-seeking were discussed.

Barriers to going to the GP

The group discussed that people in community first areas are aware of cancer, but tend to think 'it won't happen to me'. People may turn to family members or elders about health concerns instead of going to visit their GP.

The similarity of many cancer symptoms to symptoms for other illnesses was described as making it harder for people to attribute symptoms to cancer. This can sometimes lead to people minimising their symptoms and attributing the symptoms to something else.

Difficulty getting an appointment to see the GP was discussed as a barrier to early presentation in the community. In many cases, unless it is an emergency, people have to wait around 2 weeks to get an appointment, with this discouraging people from going to see the doctor. Length of time in GP appointments was mentioned as a barrier to discussion about health concerns. The amount of time for appointments may not be long enough for the patient to explain themselves, with this leading to feelings of being rushed and pressured.

The cultural diversity of the community was discussed, with some people not aware of the GP service as a place to discuss health concerns. If people have come from countries where they previously didn't have a doctor, or had to pay lots of money to see a doctor, they often assume it is the same in this country. People therefore need to be made aware of the services that are available to them. There are also language barriers as a result of cultural diversity.

There are also many negative beliefs and fears about cancer within the community. People are also concerned about bothering the doctor and wasting the doctor's time. These feelings are particularly prominent in older members of the community. In some cases, people fear being taken seriously by the doctor.

Facilitators to going to the GP

People in the community have often had experience of cancer in friends or family, which may help to raise levels of awareness. Experience of cancer in friends or family, and discussions with friends and family were thought to contribute to people's knowledge about cancer. Cancer is now much more in the open, featuring more frequently in the media and on TV. This is especially the case for the more well publicised cancers, such as breast and testicular. It was felt that there is a lot to be gained through early diagnosis of cancer, and awareness of the different types of symptoms could help people make decisions to present to the doctor.

Provision of clear information or guidelines on when to seek help would help people know when to go and see their doctor. For example, if people were told to seek help after coughing for X amount of weeks, or if a mole had grown X millimetres.

Building relationships with community partners or other people in the community can help people become more aware and engaged in their health by making it easier to disclose health issues. People find it easier to discuss health with people that they trust, with this especially the case for the BME community. People are often receptive to the advice and support given to them by the trusted person (e.g. friend, family or elder), and therefore if this person suggests going to see the doctor with the health problem, they may be more likely to go. It was discussed that sometimes people seek reassurance from others to help legitimise the decision to go the doctor and to avoid feelings of being a troublesome patient.

If people were aware that they could take someone along to their medical appointment it may encourage them to visit the GP. Having a partner, family member or friend attend the appointment can increase confidence and help with questions and explanations.

Health check content

The Tenovus health check was viewed favourably in comparison with other tools such as the Welsh Government's 'Add to your life' online check, due to its brevity and efficiency. It was felt that the health check 'delves a bit deeper' than other health checks, and provides information on real symptoms of cancer.

The group agreed that the health check could be strengthened by including questions on emotional wellbeing, as well as questions about ethnicity. These questions would enable tailored advice and support to be given to people. Having a 'live chat' option is something

that features on many websites, and could be a useful way for someone to directly talk to an advisor about any concerns.

It was also thought that including further response options would strengthen the health check, as the 'yes'/'no' options do not allow people to accurately answer some questions. Some questions were also raised about the applicability of the questions to all people, for example, the bleeding/menopausal questions will not be relevant to all women.

The results section was praised as providing people with positive reinforcement, as well as providing people with links to seek more help. The ability to print the results of the health check was thought to be a useful way of helping people to reflect on their results.

How to conduct the health check

Overall, involving a local trained advisor was considered preferable to people doing the health check alone because it would allow hands-on support, advice and signposting to relevant local services. Training trusted members of the local community may encourage people to complete the health check. Completing the health check with an advisor was considered to be more engaging than just reading information.

Access to IT and privacy issues were raised as concerns about conducting the health check. However, it was thought that these issues could be resolved by taking the health check out to the community, and by trusted community members acting as the health check advisor.

Places to conduct the health check

It was thought that the health check could be carried out in a range of venues including community housing, job centres, mosques, and local events such as healthy living days. It was discussed how the health check would be most effective if taken to communities, thereby encouraging people to complete the health check who wouldn't normally access it. Schools were also mentioned as a potential place to conduct the health check, as many older BME members of the community get their information from their children.

The length of the health check was viewed as lending itself to being conducted in places where people already come for support, such as housing discussions or other one-to-one meetings with community partners or advisors.

Social media was considered an important tool for the implementation and take up of the tool, as members of the community frequently interact with such media. Endorsement of

the health check at strategic organisational level was also considered an important motivator for staff providers implementing the health check.

Appendix 17: Focus group summary 5

Member of the public focus group Site 1

Overall, the group liked the Tenovus health check and thought it could be used with lots of different age groups. There were lots of ideas for places where people could do the health check. The group talked about the symptoms of cancer and the sorts of things that might put people off going to the doctor, as well as things that could make it easier to go to the doctor.

Symptoms of cancer

The group came up with a long list of symptoms that could be cancer and then put these in order of how long it would take to go and see the doctor.

Some people in the group said they would go straight to the doctor, whereas others said they would ask someone for advice, look on the internet or try to block it out. If the group asked someone else for advice, they would pick someone who they think knows a lot about cancer. This might be a family member or friend who has some medical training (e.g. a nurse) or someone who has had cancer before.

Things that make it harder to go and see the doctor

The group talked about the sorts of things that would put them off going to see the doctor with a symptom of cancer. This could be things like embarrassment about the tests doctors use to diagnose cancer, fear of the unknown and fear of dying.

Most of the group felt that some doctors don't listen to what they have to say and try and rush appointments. Some of the group would be worried about wasting the doctor's time. The group also talked about the receptionists in the doctor's surgery. Some of the group felt that they were like gate keepers and will not give you an appointment quickly. The group thought this was because they did not know that some symptoms need to be seen quickly.

Things that make it easier to go and see the doctor

Some of the group could think of doctors that take lots of time and listen to what you have to say. Having a doctor like this makes it much easier to go with a symptom of cancer.

Health check likes

The group thought that the health check was easy to understand with not too many questions. The group also liked how you could pick if you wanted to do it on your own or with someone else. The group liked the traffic light system. They thought this would help people to pick the most important things that they need to change. The group also thought doctors might take people more seriously if they had done the health check.

Health check dislikes

The group thought that there should be more information on how to look out for symptoms of cancer. They thought that there could be more information about asking for help from other health care professionals rather than just doctors.

Places to do the health check

The group came up with lots of ideas for places to do the health check. These were: drop in centres, a mobile van, community centres, GP surgeries and colleges. The group thought that the best people to give the health check would be people who have had cancer before.

Appendix 18: Focus group summary 6

Member of the public focus group Site 2

Overall, the group liked the health check. The group came up with lots of ideas for how the health check could be improved. The group talked about the symptoms of cancer and the sorts of things that might put people off going to the doctor, as well as things that could make it easier to go to the doctor.

Symptoms of cancer

The group came up with a long list of symptoms that could be cancer and then put these in order of how long it would take to go and see the doctor.

The group said they would either go straight to the doctor or speak to a nurse if they had a symptom which could be cancer. Some of the group would not tell anyone else about their symptoms. Others would tell to someone close to them e.g. wife before going to see the doctor or nurse.

Things that make it harder to go and see the doctor

The group talked about the sorts of things that would put them off going to see the doctor with a symptom of cancer. They felt that some doctors don't listen and that the appointments are sometimes rushed. Other things that put the group off going to see the doctor were seeing a different doctor every visit and having to wait a long time to get an appointment. The group also talked about fear of the unknown and anxiety about cancer.

Things that make it easier to go and see the doctor

Some of the group said that making a list of things they need to talk about before going to see the doctor helps. The group talked about how people seem to be less embarrassed and are more able to talk about cancer now compared to the past.

Health check likes

The group thought that the health check was a good idea. They thought the length was good and liked how anyone could be trained to do the health check with people. The group liked that there is a free helpline number in case people were worried when doing the health check.

Health Check dislikes

The group thought that there was too much information at the end. They thought that some people might find it scary and that some people e.g. people with learning disabilities might not understand it. The group suggested that the information could be shorter with more pictures or videos. The group also thought that pictures and pop-up definitions in the question section of the health check could be used.

The group thought that the health check should be available in more languages. The group felt that there should be some information to say that it is a secure site as they were worried about their personal details.

Places to do the health check

The group came up with lots of ideas for places to do the health check. These were: libraries, community centres, GP surgeries and schools. The group really liked how Tenovus would come to communities and do the health check with people.

Appendix 19: Topic guide for member of the public focus group

Topic guide members of the public focus groups

PUBLIC FOCUS GROUP TOPIC GUIDE

BACKGROUND

- Welcome and thanks; introduce the researchers.
- Brief background on purpose of the focus group (setting the scene in terms of what is known about influences on cancer awareness and help-seeking, but that research is needed to understand the needs of deprived communities & develop targeted interventions such as the health check).
- Explain what will happen in the focus group; etiquette (there are no right or wrong responses, everyone is entitled to their own opinion, respect for other people's opinions / try not to talk over).
- Round of introductions from the participants (name, where you come from and what you do/ something about yourself).

Rationale: to gain views on (a) factors influencing cancer awareness and help-seeking in the local community, (b) ways in which the health check might facilitate. Aligned with Capability (knowledge, psychological skills, attention, behavioural regulation), Opportunity (environmental context/resources, social influences) & Motivation (emotions, beliefs about capabilities/consequences, intentions and goals).

PART 1: INTERVENTION CONTENT

A. INFLUENCES ON CANCER AWARENESS AND HELP-SEEKING IN THE COMMUNITY

1. Is health a priority for you? Is health a priority for people in your community?

Is cancer a concern for you? Is cancer a concern for people who live in your community?

How do you think cancer compares to other diseases e.g. diabetes or heart disease?

What do you think about the treatments for cancer?

Activity (write responses to the following question on individual cards): Can you think of any symptoms of cancer? *Can you remember how you found out that these were symptoms of cancer?*

2. What would you do if you noticed a change in your body that you think might be cancer?

Would you tell anyone? Why would you tell this person? What do you think they would say?

What would influence you in deciding what to do?

Has anyone ever asked you for advice about a symptom? What advice did you give? Why do you think they came to you for advice?

What do you think other people who live in your community would do if they noticed a symptom that they think might be cancer?

Do you ever consciously look out for symptoms of cancer?

3. Thinking about health care professionals e.g. doctors, nurses, pharmacists etc, who would you go to first if you thought you had a symptom of cancer?

4. Is there anything that would stop you going to see your doctor with a symptom of cancer?

If you had a symptom that you think might be cancer, what would you say to your doctor? Would you go just for this symptom or for something else and then tell them about this symptom?

What might encourage you to go?

Probes can be barriers from BCW: knowledge, confidence, fear etc i.e. Do you think things like fear would stop you going to the doctor with a symptom of cancer?

5. If you needed to go to the doctor, how easy would it be for you to go and see them?

What is it like getting an appointment? How easy do you find it to talk to the doctor? Is distance/travel a problem? Do you feel confident talking about symptoms with your doctor? Are there other things that get in the way when going to see the doctor? Probe – attitudes, awareness, beliefs... i.e. What about your relationship with the doctor?

Do your family members or friends influence your decision to go and see the doctor? Do you take anyone with you when you go to the doctors? Has experience of cancer in friends or family influenced your thoughts about cancer?

What are the most important things influencing your decision to see the doctor?

Activity: Look at the symptoms on the individual cards (previously generated from earlier activity). Ask participants to rank the symptoms in terms of how quickly they would make an appointment with their doctor.

B. THE TENOVUS HEALTH CHECK

- **Now let's talk about the Tenovus Health Check.....** Demonstration of the health check by the researcher (orientating to its cancer symptom awareness / early diagnosis functions).

1. What do you like about the Health Check? What do you dislike?

Pros and cons of content, format.

What do you think about the information section at the end?

2. What do you think are the benefits of using the Health Check?

Do you think the health check will help you to know more about the symptoms of cancer?

Do you think the Health Check will help you to know what to do if you had a symptom of cancer?

If someone offered to do the Health Check with you, what would you do/say? What about other people in your community?

What do you think about the questions in the health check about cancer symptoms?

(Orientate and remind participants about which questions these are)

Can you think of any problems with using the Health Check?

3. Do you think anything else could be included in the Health Check to encourage people to go to their doctor quickly?

For example, inclusion of additional cancer symptoms, links to age-appropriate screening recommendations, use of positive messaging to change beliefs, social encouragement/support, action planning (define).

Can you think of anything else that you would like to see included in the Health Check?

4. Can you think of places where would it be good to have the health check?

For example GP practice, Tenovus mobile unit, community centre, libraries, local pharmacy, sports clubs?

Probe issues of confidentiality, embarrassment, stigma etc

Can you think of ways we could advertise the health check?

What do you think about having the health check online?

What do you think about going through the Health check with a trained health check advisor? Who would you be most comfortable doing the health check with?

5. Have you done anything like the Health Check before?

How does it compare?

NEXT STEPS

We will now write up what we have talked about today, and we will email you a summary of what we have talked about- **by post or email?**

Once we have completed a few more focus groups we will also be inviting people to take part in a follow-on workshop to gain feedback on ideas for modifying the health check and to test the evaluation study recruitment materials. It would be great if some of you would like to be involved with this, and we will send you an email to tell you more about this when the time comes.

DEBRIEF

Summary, address any questions or concerns, thanks.

Hand out flyers for public focus groups.

Housekeeping – travel expense & honorarium claim forms; ensure consent forms have been signed.

NOTES: CAM symptoms: Lump or swelling, unexplained bleeding, unexplained pain, unexplained weight loss, change in a mole, change in bowel/ bladder habits, persistent cough, sore that does not heal, difficulty swallowing.

Health check symptoms:, appetite change/weight loss , bowel change/blood in stool ,skin changes/moles , persistent cough, lumps and bumps , frequent urination , pain during sex/irregular bleeding (health check also covers: family history, BMI , Age, Exercise, Smoking , Alcohol, Diet, Sunburn)

Welsh screening: Bowel: aged 60-74 every two years. Breast: aged 50-70 every 3 years. Cervical: aged 25-49 every 3 years. aged 50-64 every 5 years.

LOCAL STAKEHOLDER FOCUS GROUP TOPIC GUIDE

BACKGROUND

- Welcome and thanks; introduce the researchers.
- Brief background on purpose of the focus group (setting the scene in terms of what is known about influences on cancer awareness and help-seeking, but that research is needed to understand the needs of deprived communities & develop targeted interventions such as the health check).
- Explain what will happen in the focus group; etiquette (there are no right or wrong responses, everyone is entitled to their own opinion, respect for other people's opinions / try not to talk over).
- Round of introductions from the participants (name, where you come from and what you do, what community initiatives you are involved in).

PART 1: INTERVENTION CONTENT

B. INFLUENCES ON CANCER AWARENESS AND HELP-SEEKING IN THE COMMUNITY

1. Is health a concern for people in your community?

Is cancer a concern? How concerned are people in your community about cancer compared to other diseases?

Do you think people in your community know much about cancer symptoms?

How do people in your community find out about cancer symptoms?

What do people in your community think about cancer / cancer treatment?

2. What do you think people in your community would do if they had a potential cancer symptom? Would they tell someone, go to the doctor, go somewhere else?

What influences them about what to do? How much experience from others is there? Or personal?

3. How easy is it for people in your community to go and see the doctor?

How easy is it for people in your community to get an appointment / talk to the doctor? Is distance/travel a problem?

Is going to the doctor with symptoms something that people in your community usually do?

Are there other things that get in the way? Probe – attitudes, awareness, beliefs...

To what extent do family members or friends influence decisions about going to see the doctor?

What do you feel are the most important influences?

4. Can you think of anything that could put people in your community off going to see their GP to discuss concerns about cancer symptoms?

What could encourage them to go?

Probes can be barriers from BCW: knowledge, confidence, fear etc

Rationale: to gain views on (a) factors influencing cancer awareness and help-seeking in the local community, (b) ways in which the health check might facilitate. Aligned with Capability (knowledge, psychological skills, attention, behavioural regulation), Opportunity (environmental context/resources, social influences) & Motivation (emotions, beliefs about capabilities/consequences, intentions and goals).

B. THE TENOVUS HEALTH CHECK

- **Now let's talk about the Tenovus Health Check.....** Demonstration of the health check by the researcher (orientating to its cancer symptom awareness / early diagnosis functions).

1. What do you like about the Health Check? What do you dislike?

Pros and cons of content, format.

2. What do you think the benefits of people using the Health Check are?

Do you think the health check will help people know more about the symptoms of cancer and what to do?

Is the health check something that you think could fit in with your community or not?

Can you think of ways to support or promote the health check?

Can you think of any problems with the health check being used by people in your community?

3. Do you think anything else could be included in the Health Check to encourage people to go to their doctor quickly?

For example, inclusion of additional cancer symptoms, links to age-appropriate screening recommendations, use of positive messaging to change beliefs, social encouragement/support, action planning (define).

4. Where would it be good to have the health check?

Can you think of places where it would be good to have the health check? For example GP practice, Tenovus mobile unit, community centre, libraries, local pharmacy, sports clubs?

Probe issues of confidentiality, embarrassment, stigma etc

5. Is using the Health Check alone something that you think could fit in with your community or not?

How easy is it for people in your community to read and understand health information alone?

To what extent will resources (internet access) hinder people in your community doing the health check alone?

What do you think about the health check being done electronically rather than on paper?

Do you think people in your community would want to do the health check with a health check advisor?

Are there any groups of people within your community that you would be particularly concerned about using the Health Check? For example, older age groups?

6. Are you aware of any other cancer awareness initiatives/tools? How do they compare to the Health Check?

Rationale: to gain views on suitable methods of engaging people in the study in terms of identifying, approaching, recruiting and keeping people in the study (and future trial).

PART 2: INTERVENTION EVALUATION METHODS

The next part of the research project will involve people completing the Health Check and then talking to us about their experience of using it.

If we were trying to find people in your community to complete the Health Check, where would be best to find them?

Can you think of any ideas to try and get people involved in the study?

Are there incentives we could use to get people involved in the research project? (Reinforcement)

Can you think of ways we could promote the health check so that people know about it? (Advice on recruitment materials.)

If we were to trial the health check, do you think people in your community would accept being randomised to a 'no health check' control group? (Explore whether delaying access to the health check, at the end of the study period, would be problematic.)

NEXT STEPS

We will now write up what we have talked about today, and we will email you a summary of what we have talked about.

Once we have completed a few more focus groups we will also be inviting people to take part in a follow-on workshop to gain feedback on ideas for modifying the health check and to test the evaluation study recruitment materials. It would be great if some of you would like to be involved with this, and we will send you an email to tell you more about this when the time comes.

DEBRIEF

Summary, address any questions or concerns, thanks.

Hand out flyers for public focus groups.

Housekeeping – travel expense & honorarium claim forms; ensure consent forms have been signed.

NOTES: CAM symptoms: Lump or swelling, unexplained bleeding, unexplained pain, unexplained weight loss, change in a mole, change in bowel/ bladder habits, persistent cough, sore that does not heal, difficulty swallowing.

Health check symptoms:, appetite change/weight loss , bowel change/blood in stool ,skin changes/moles , persistent cough, lumps and bumps , frequent urination , pain during sex/irregular bleeding (health check also covers: family history, BMI , Age, Exercise, Smoking , Alcohol, Diet, Sunburn)

Welsh screening: Bowel: aged 60-74 every two years. Breast: aged 50-70 every 3 years. Cervical: aged 25-49 every 3 years. aged 50-64 every 5 years.

Appendix 21: Coding framework 2

Coding framework for focus groups onto COM-B (focus groups)

Capability		
Both the physical and psychological capacity of a person to perform behaviour		
Physical (includes skills, strength, stamina) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
No codes		
1.Psychological (having the knowledge and the skills to perform the behaviour and the capacity to engage and direct behaviour) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
1.1Cancer symptom knowledge	Identification of potential cancer symptoms. Also code here when HCPs and CPs speculate on symptom knowledge in the community. When they talk about how this knowledge was acquired, use the code 'acquisition of knowledge'.	'Changes in digestive processes, anything dramatic, anything that's sort of different'
1.2Symptom attributions	Any discussion around potential cancer symptom attributions. Code here when symptoms might be attributed to other benign causes, which acts as a barrier to symptom presentation (SP).	'It depends when I say headache....what sort of headache, a debilitating headache or, I've not had much sleep headache...'
1.3Knowledge of the causes of cancer	Knowledge of what causes cancer or increases your risk for cancer (correct or incorrect). Also code here when HCPs and CPs speculate on community level knowledge of causes of cancer.	'They said my husband's [cancer] was from because he was a steel worker'
1.4Communication with Health care professionals	When they mention anything about how public communicate with their GP or any other HCPs or vice versa. Also code here is communication is perceived as a barrier and any strategies used to aid communication such as the use of lists.	'I- Do you think there is anything that would be preventing them from actually going to the consultation or talking to the GP? P- confidence to be able to talk'
Opportunity		
All factors extrinsic to a person that either prompt the behaviour or allow enactment of the behaviour		
2.Physical opportunities (created by the environment e.g. time, financial resources, access and cues) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
2.1Practical/physical barriers to medical help seeking	Anything that acts as a practical or physical barrier to SP. E.g. being too busy, not being able to get to an appointment, disability	'I think mental health is an issue. Because I think people suffer from either depression or anxiety, seeing a GP [is difficult]'
2.2Practical/physical facilitators to medical help seeking	Any practical or physical facilitators to SP e.g. someone going with them to the doctors or the participant themselves took someone else to the doctors, home visits etc.	[the CP says] 'let me make an appointment for you, I'll come with you, you know? And that has pushed it along'

2.3Service barriers to medical help seeking	Anything that acts as a barrier to SP that is to do with the health service. E.g. not being able to get an appointment, perceptions of not wanting to waste the docs time, '1 appointment 1 problem' policies, time limited appointments, not liking a specific doctor.	'Sometimes when you go in about something there might be other things on your mind as well and you think I can't mention too many things because they've only got 5 minutes'
2.4Service facilitators to medical help seeking	Anything that acts as a facilitator to SP that is to do with the health service e.g. knowing they can ask for a different doctor, knowing that they can take the emergency appointments, piggy backing symptom, requesting an appointment earlier than the one given, liking their doctor.	'I've got a good GP'
2.5Current awareness campaigns	When the participant mentions any cancer awareness campaigns or if they have not seen any campaigns. Also code here when the HCPs talk about campaign effects on presentation rates and reach.	'To be honest there's some really good advertising campaigns for them. You know? Like more people survive cancer than die from it now.'
2.6Cancer in the media	Any mention of cancer related articles or pieces in the media. E.g. news items, celebrities with cancer, newspaper articles on cancer risk etc. Also code here how such items in the media affect cancer awareness or presentation behaviour.	'When they did Eminem on the television, men shouldn't be embarrassed to check their testicles and he had a t-shirt to say he checked his, and I think that was good because the awareness is obviously raised.'
2.7Acquisition of cancer symptom knowledge	Any mention of knowledge for how cancer symptom knowledge was acquired e.g. because they knew someone who had the symptoms, looked on the internet, campaigns etc.	'They know somebody who has similar symptoms. They think oh, I've got that aswell'
3.Social opportunities (created by cultural environment) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
3.1Health as a priority /concern	Any comments about whether they think health is a priority in deprived communities or if health is a personal priority or concern.	'99% is fire fighting and 1% is prevention....short term health is a priority, long term is not'
3.2Lay system of health care	When the participant is asked or says that they would tell anyone about a symptom or when HCPs/CPs talk about how symptoms are discussed with other members in the community. Code all aspects of the interaction: who, why and advice given. Also code here when they say they would not disclose a symptom. Also code when CPs say they notice symptoms in people in the community.	'I would tell my wife [about a symptom] because I would be seeking reassurance and possibly her saying to me don't be silly or get yourself to the doctor'

3.3 Cultural barriers to medical help seeking	When the participant talks about how culture acts as a barrier to SP e.g. cultural beliefs about not seeking medical help, only seeing the same gender doctor, stoicism etc.	'Culturally, where women are concerned, they will go to an elder and even if they were encouraged to go to a doctor at that point, they wouldn't go to a male doctor. They would have to go to a female doctor'.
3.4 Experience of cancer (knowing someone with cancer)	Any description of people they know with cancer. Code all details including symptom presentation behaviour, treatments etc.	'My brother is currently dying of cancer he had Barretts disease which is cancer of the oesophagus'
3.5 Social context/ environment	Any description of the social environment in which people from deprived communities live in. Code here when the social opportunity affects health. Also code here for any comments about lack of trust associated with government.	'people's expectations of their own health and the health of their family depending on where they live. So living in an area where there is low life expectancy, high premature mortality, everyone that you know has got a chronic condition, that's what you expect yourself. So maybe there is a lack of motivation.'
3.6 Talk about cancer within the community	Any mention of how people within the community talk about cancer to one another, or if they don't want to talk about cancer e.g. taboo around discussion of cancer	'Its just not talked about is it?'
3.7 Gender differences	Anything about gender differences relating to cancer or health e.g. presentation behaviour, self-examination behaviour, discussion of health issues.	'men tend to be too macho to go to the doctor'
3.8 Age differences	Anything about age differences relating to cancer or health e.g. presentation behaviour, self-examination behaviour, discussion of health issues.	'With younger people, to show the other side of the spectrum, is massive embarrassment. They don't want to bear all to the doctor.'
Motivation		
The processes in the brain that energise and direct behaviour. This includes conscious decision making and habitual processes, emotional responses or processes involving analytical decision making.		
4. Reflective processes (involving evaluations and plans) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
4.1 Beliefs about cancer (treatments, cures, early diagnosis)	Any beliefs about cancer relating to early diagnosis of cancer, beliefs about treatments and beliefs about cures for cancer. E.g. They highlight the importance of diagnosing cancer early, comments about the side effects of treatments, beliefs about effectiveness of treatments, beliefs about curability (or not) of cancer.	'Years ago, if you had cancer, you more than likely died anyway. Now, you don't. There's lots of advances.'

4.2 Cancer compared to other diseases	Any comparisons made between cancer and other life threatening diseases such as heart disease.	'There is more anxiety about cancer then say about strokes or heart attacks'
4.3 Smoking behaviour	Any detail about smoking behaviour (or lack of smoking behaviour) from the participant or members of the community. E.g. why they or people in the community smoke even if they know the risk associated with smoking, descriptions of how many people smoke, insight into why people take up smoking, stop smoking, general information about smoking behaviour.	'Young people smoking, they never think they are going to come to any harm by it'.
5. Automatic processes (emotions and impulses that result from innate dispositions or associative learning) When the participant mentions any of the following for friends/ family/ other people in the community, double code under 'community'		
5.1 Fearful and fatalistic beliefs about cancer	Any mention of fear associated with cancer or fatalistic beliefs about cancer. For fatalistic beliefs associated with 'no cure for cancer', double code under 'Beliefs about cancer (treatments, cures, early diagnosis).	'If you mention cancer, it's almost like a death sentence'
5.2 Emotional barriers to medical help seeking	Anything that acts as a barrier to symptom presentation that is emotive. These might be quite similar to beliefs or cancer worry, but only code here when the participant explicitly states that these emotions will act as a barriers to their or others HSB. E.g. fear and worry of what they symptom might be, embarrassment.	'I think there is the fear of what they might be told...some people just wouldn't go because they don't want to hear it.'
5.3 Emotional facilitators to medical help seeking	Things that make it easier for the person to seek medical help that is emotive. E.g. their fear motivates a visit to the doctor, anxiety, help seeking for reassurance	'you just cant take a chance, if you've got a concern, see the doctor'
5.4 Cancer concern/ worry/ denial	How much the participant or people in their community worries about getting cancer. Also code here when they avoid cancer with denial.	'It's [cancer] at the back of your mind all the time'
6. Behaviour Performance or intentions to perform a behaviour		
6.1 Symptom presentation	Any discussion around actual SP behaviour of the public or when CPs/HCP talk about actual presentation behaviour in members of the community/ patients in their surgery. Also code here any discussion around timelines or time scales for presenting with symptoms in the public FGs using flash cards.	'if you had a lump, you'd go now wouldn't you?...I'd be on my way, for me a lump is quite important.'
6.2 Community health behaviours	Anything discussion around changes in health behaviour. Also code here for reluctance to change health related behaviours.	'We are very active, I try to eat sensibly'

7. Other codes that do not fit under COM-B		
7.1 Suggestion for an intervention	When the participant generates any ideas for an intervention to encourage more timely symptom presentation. Or any suggestions for interventions that they don't think would work.	'if there were guidelines, say, for example, if you've got a mole and you know you should go to the GP if it's wider than X number of millimetres...that will make someone more likely to go'
7.2 Information about the participant	Any demographic information about the participant.	'I'm [name], I am the housing manager for [name]'
7.3 Talk not related to topic of interest	Code anything here that is not related to what the focus groups are trying to capture. Also code the health check section here.	

Appendix 22: Charting of data 2 (Focus groups)

	Theme (Social Opportunity)	
Focus group	Health as a priority/ concern	Lay system of health care
Community Partner (site 2)	People in the community do not take their health seriously enough- they think cancer is never going to happen to them so people in the community don't try to reduce the risk factors.	In BME communities people speak to elders or family members about symptom because they do not trust doctors. They also get advice from elders about good/ bad experiences in health care- if they have had a bad review then they are put off going to the doctor. If people go to the community partner about symptom they suggest they go to the doctor about it.
HCP (site 1)	Health is 99% firefighting, 1% prevention- short term health is a priority, long term health is not.	People in the community speak to family members/friends about symptom before going to see the HCP- they described times when people come in with family members with symptoms. They often have people phoning up to book someone else an appointment for them or people saying they are coming in because someone else made them go to the doctor.
Public (site 1)	P's felt that health was a priority for them, but for younger people in the community health is not a priority- the younger generation think they are invincible. They feel that it is all about avoidance- ignoring health so they don't have to deal with problems and just put off getting checks etc.	One participant recalled someone approaching to him with a lump symptom- he suggested that he should go to the doctor and the person was diagnosed with cancer. The individual was scared that his testicles would be removed, so he was asking the participant for advice on what to do. Another said she forced her husband to go to the doctors. Another participant would ask his partner for advice because she has had cancer.
HCP (Site 2)	Concern about health in the community is massively variable- for most health is not a concern until it becomes a problem. People struggle to take responsibility for their health. There was a perception that health in the community is not their problem, but the doctors problem. People don't seem to want to maintain health, they just deal with problems when they become a problem. People who come in with symptoms tend to be driven by anxiety.	Patients tend to go to family members/friend/google to seek advice before going to see the doctor. Then they talk about bad experiences with tests/operations which can potentially put them off going. They worry that the loss of the traditional family structure is going to change the way in which advice is sought.
Community Partner (site 1)	People in the community don't see health as a concern- health is at the bottom of a pile of more important issues- e.g. paying the bills are more important. Health is dealt with at crisis point in a firefighting type role. Priorities are paying the bills- bad health behaviours e.g. smoking. is a way of dealing with daily life problems. Talking about health in the community is a taboo subject.	People in the community ask support workers or family and friends for advice on symptoms. But talking about health in the community is a taboo. It tends to be that those who are diagnosed with early stage cancer, the support workers has noticed a symptom and suggested to go to the doctor/ accompanied them to an appointment.
Public (site 2)	As people get older health becomes more of a concern	People would tell family members/ friends about symptoms first to seek reassurance. Some would offer poor advice as they would not want to worry them.

	Theme (Social Opportunity)		
Focus group	Cultural barriers to HSB	Experience of cancer (knowing people in the community with cancer)	Social environment/ context
Community Partner (site 2)	BME community- medical help seeking is not the norm- it is perceived as a sign of weakness and taboo to seek medical help, so they tend not to seek help. Language barriers are also a problem. Self-examination behaviour is not a cultural norm.		Lots of mistrust of the government and fear of authority in the community- they feel as though the government has an ulterior motive. They discussed the important of social networks and norms for health behaviours, therefore they suggest we study the social context of behaviours. They discussed lots of other problems with debt, housing- a cancer diagnosis is just too much for people in the community to deal with.
HCP (site 1)	The elderly population have seen lots of people dying from cancer. Therefore they are fearful of cancer. Fear is a big barrier. In addition, older generations tend to not want to bother the doctor.		People go to the doctors to make sure they get signed off because there is high levels of unemployed (ESA)- this generally takes up the whole consultation timeslot- they will prioritise this and not discuss worrying symptoms.
Public (site 1)		Most participants know a few people with cancer- generally relatives or spouses, some of whom had died. Described instances when cancer had been detected by accident or cancer detected too late.	People in the community feel disempowered.
HCP (Site 2)	A cultural issue is that people don't want to check their stools for blood- they come in with certain symptom and are asked if they have any blood in their stools but they say they don't look at their stools so they are unsure. Social problems with housing and debt problems mean people in the community simply can't cope with a cancer diagnosis- it would just another thing so they just don't deal with it and ignore symptoms.	People have certain expectations of what cancer is supposed to be like based on the people they know within the community with cancer. They form beliefs based on this and when they ask for advice on symptoms from family members/ friends they usually get told about all the negative things that happen during tests/treatment.	
Community Partner (site 1)		People in the community know lots of people with cancer, usually with fatal circumstances.	
Public (site 2)		Knew lots of people who have had cancer- mainly spouses who died from cancer or are currently diagnosed with terminal cancer. They are aware of lots of nasty treatment side effects because participants tend to nursed their spouses.	

	Theme (Social Opportunity)		
Focus group	Gender differences	Talk about cancer in the community	age differences
Community Partner (site 2)	Women are more likely to go to the doctors than men		Older members of the community tend to not want to bother the doctor.
HCP (site 1)			Younger patients tend to be the worried well- younger people in the community seem to be more aware of the red flag symptoms. The elderly see a lot of people dying of cancer and form negative beliefs about cancer.
Public (site 1)	Women more likely to do go to the doctors because they are more used to being in contact with health services and are less embarrassed to seek help. Men tend to put off going to the doctor.		Younger people in the community think they are invincible
HCP (Site 2)		Unsure know how to react to people in the community who have cancer.	Younger people in the community engage in harmful health behaviours such as smoking as they think they are invincible and will not become ill.
Community Partner (site 1)	Men are worse at seeking help, they usually present when in the advanced stages.	They think doctors don't even use the word 'cancer'- they use different words to avoid using the word cancer to minimise distress	The older generation are in more denial- have the attitude of they are going to die of something anyway so don't need to be aware of symptoms/seek medical help.
Public (site 2)		They think people are much more open about cancer now and talk about it more than they used to	

Appendix 23: All barriers and facilitators to behaviour

Non-modifiable barriers/facilitators to prompt lung cancer symptom presentation	Modifiable barriers/facilitators to prompt lung cancer symptom presentation
<p><i>Individual characteristics</i></p> <ol style="list-style-type: none"> 1.Age 2.Gender 3.Pre-existing co-morbidity 4.Living alone 5.Ethnicity 6.Disability 7.Previous health service utilisation 8. Mental health 	<p><i>Individual characteristics</i></p> <ol style="list-style-type: none"> 28.Smoking behaviour 29.Stoicism
<p><i>Cancer knowledge</i></p> <p>N/A</p>	<p><i>Cancer knowledge</i></p> <ol style="list-style-type: none"> 30.Knowledge of the symptoms of lung cancer 31.Perceptions of symptom severity 32.Lack of pain associated with lung cancer symptoms 33.Belief lung cancer is symptomless 34.Number of symptom(s) 35.Worsening of symptom(s)/symptom(s) impacting on daily life 36.Duration of symptoms(s) 37.Symptom type (vague e.g. persistent tiredness vs specific e.g. haemoptysis) 38.Attribute symptom(s) to smoking habit 39.Attribute symptom(s) to co-morbidity 40.Attribute symptom(s) to age 41.Perceptions of the causes of symptoms 42.Perceptions of individual risk of developing lung cancer
<p><i>Self-efficacy/skills</i></p> <ol style="list-style-type: none"> 9.Trait self efficacy 	<p><i>Self-efficacy/skills</i></p> <ol style="list-style-type: none"> 43.State specific self-efficacy 44.Confidence when communicating symptoms to the GP 45.Listening skills during an appointment with the doctor 46.Ability to articulate symptom concerns 47.Knowledge of what to do when the individual experiences a symptom(s) 48.Knowing how to book an appointment with the doctor 49.Health information seeking
<p><i>Health service factors</i></p> <ol style="list-style-type: none"> 10.One appointment one problem policies 11.Time limited appointments 12.Not being able to get an appointment with the GP quickly 13.Relationship with GP 14.Interpersonal skills of GP 	<p><i>Health service factors</i></p> <ol style="list-style-type: none"> 50.Worry about being told to stop smoking 51.Concerns about wasting GP time 52.Perception the GP cannot help/resolve the symptom(s) 53.Worry about being perceived as a hypochondriac

<p>15.Receptionist at the GP 16.Lack of trust in the healthcare system 17.Unable to get an appointment with preferred doctor 18.Appointment booking policies</p>	
<p>Beliefs about lung cancer/treatments N/A</p>	<p>Beliefs about lung cancer/treatments 54.Beliefs about early diagnosis 55.General fatalistic beliefs about cancer (no cure, death sentence, bad luck) 56.The belief that lung cancer is a fatal disease 57.The belief that there is no treatment for lung cancer 58.Fear of the treatments for lung cancer</p>
<p>Community factors/competing priorities 19.Work commitments 20.Family commitments 21.Media influences 22.Previous experience of cancer 23.Lack of transportation 24.Proximity of GP practice to house 25.Financial commitments/worries</p>	<p>Community factors/competing priorities 59.Using a lay system of healthcare/symptom disclosure 60.Cultural messages to reduce GP consultation behaviour</p>
<p>Emotional barriers N/A</p>	<p>Emotional barriers 61.Fear of the unknown 62.Shame 63.Stigma associated with lung cancer 64.Fear of a diagnosis of lung cancer 65.Worry about what the doctor might find 66.Fear of diagnostic tests 67.Embarrassment around disclosure of symptoms</p>
<p>Responses to symptoms/behavioural response 26.Under frequent review for other health problems 27.Previously presented with a symptom and told was not serious</p>	<p>Responses to symptoms/behavioural response 68.Use of traditional medicines 69.Avoidance 70.Denial 71.Watchful waiting 72.Self-management/self-medication 73.Use of over the counter medicines 74.Belief that the symptom will resolve on its own without medical intervention 75.Appointment booked for another reason (piggybacking) 76.Wait for another symptom/health complaint to appear 77.Intention to act on symptom(s) (if symptom persists for three weeks)</p>

Lung health information session

Welcome and introductions myself and observers. Group introductions.
Structure of the morning. Right to withdraw etc. “Can everyone hear me and see the screen?”

Asthma

Emphysema

Lung cancer

COPD

Pneumonia

“There are **lots of different types of lung diseases**, for example asthma, emphysema, COPD, pneumonia and lung cancer. Today we are going to talk about lung cancer. By the end of the session, **we will have talked about the signs and symptoms** for lung cancer, and **what to do** if people in the community have these symptoms. We will talk about **why it is important for people in the community to go to the doctor quickly** with these symptoms. I will give you some advice on how prepare yourself for an appointment with the doctor, some **tips on what people can take with them** and how to tell the doctor about symptoms.”

What today is not about

“I’m not a doctor, so I can’t give you any specific advice on a symptom, but I can tell you where you can get help from. Also, this is **not a smoking cessation session**. I will not talk about how to quit smoking, it is not the aim of this session. If you would like some advice on how to quit smoking, then I have some leaflets and phone numbers of services that can help you quit. Please let me know at the end of the session. **Today is all about lung cancer only**. If you would like some information leaflets from Cancer Research UK on other cancers, please let me know and I can send you some more information in the post.”

Activity: True or false?

“To start, I’m going to show you some of the **things I often hear people say about lung cancer**. I’d like to know if you think they are **true or false**, then I will tell you the answer.”

‘There is no treatment for lung cancer’

True or false?

True or false: ‘There is no treatment for lung cancer’. Who thinks this is true? Who thinks this is false? Who is not sure?

‘There is no treatment for lung cancer’

True or false?

“False. There are lots of treatments available for lung cancer. If lung cancer is caught in the **early stages, there are more treatments** available and they are better and more effective. For example, when lung cancer is in the earliest stage, so if found quickly, patients can have an **operation to take away the cancer**. This is offered to about 20% of people with lung cancer. Scientists are constantly working to develop more treatments for lung cancer. So the **treatments for lung cancer are getting better and more effective.**”

‘If you catch lung cancer in the early stages it can be cured’

True or false?

True or false: ‘If you catch lung cancer in the early stages it can be cured’. Who thinks this is true? Who thinks this is false? Who is not sure?

‘If you catch lung cancer in the early stages it can be cured’

True or false?

“**True. Lung cancer can be treated and it can be cured if the cancer is found quickly.** If lung cancer is found in the **early stages**, there are **more treatments available** and it is possible that **lung cancer can be cured**. Unfortunately today, lung cancer is often diagnosed in the later stages, where a cure is less likely. **Currently, there is no screening service** for lung cancer like there is for breast, bowel and cervical cancer. **This means we need to get people to be aware of symptoms of lung cancer and go to the doctor quickly if they notice anything unusual. The quicker people to go to their doctor, the more likely lung cancer will be diagnosed in the early stages.** We will talk later about **what to look for** and the types of **advice** you can give people on when to go to the doctor.”

**‘When air gets to cancer
it can make the cancer
spread’**

True or false?

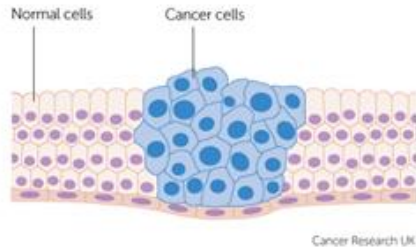
True or false: ‘When air gets to cancer, it can make the cancer spread’. Who thinks this is true? Who thinks this is false? Who is not sure?

**‘When air gets to cancer it
can make the cancer
spread’**

True or false?

“False. I hear this quite a lot, and it is probably one of the things that puts people off going to the doctor to get help or treatment for cancer. There is no scientific evidence that an operation or the air getting to cancer can cause cancer to spread.”

Lung cancer



“**So what is cancer?** We have millions of cells in our body. Sometimes we can get abnormal cancer cells. If they **multiply and grow, they can cause a tumour** or cancer in any part of the body.

Today we will be talking just about lung cancer. **Your lungs are here** [point to picture]. To diagnose lung cancer, the doctor sends the person to the hospital for an x-ray (a picture to look inside the lungs). It doesn't take long and it doesn't hurt. Once lung cancer is diagnosed the medical team will decide which is the best treatment for the person with lung cancer.”

Who is most at risk for lung cancer?



“It is important to understand who is most at risk for lung cancer. This means the types of people where lung cancer is most common. This is because a lot of the signs and symptoms for lung cancer are similar to other things like a cold or asthma etc like a cough that won’t go away. We will talk more about these in the next section. Obviously **the doctor cannot send everyone** who has a cough **for further tests**, so the doctor will **send those who are most at risk** and also have signs and symptoms of lung cancer.

People who are over the **age of 40 and who currently smoke or used to smoke** are more at risk for lung cancer. Some people who have given up smoking think their risk for getting lung cancer is zero. It is really good that they have **given up smoking because their risk for getting lung cancer and other cancers is lower** than if they were still smoking, but they are still at increased risk compared to people who have never smoked. So **ex-smokers** need to look out for some of the signs and symptoms of lung cancer too and go to the doctors if they have any of them and tell the doctor that they used to smoke.

It is much **more unlikely you will get lung cancer if you have never smoked**, but it is possible. For example, people who breathe in other peoples smoke or used to work in mines or used to work with asbestos are at increased risk for lung cancer. So it is important that these people look for these symptoms and tell their doctor.”

What are the signs and symptoms of lung cancer?

“In this section I will tell you about some of the **signs and symptoms of lung cancer**. These are the sorts of things you should look out for in others and when they should go to the doctor. I have a hand-out to give you at the end of the session for you to keep. This has information on what to look for and when to go to the doctor.

A cough

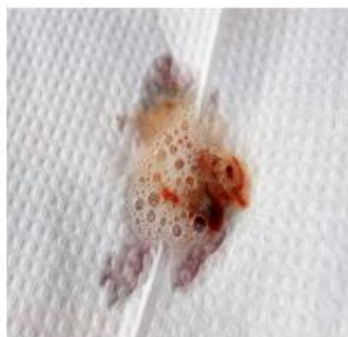


-For 3 weeks or more
-Or a change in
normal cough

Go and see the doctor

“A **cough for 3 weeks or more** or you notice a change in someone’s normal cough. Coughs often come and go. **A cough can be a sign of lots of things**, they might have always had a cough, especially if they smoke or it could be a sign of something like a cold. If someone has had a cough for 3 weeks or more, they should go and see their doctor. If someone else says that they have ‘always had a cough’, the **important things to look out for are any changes in the cough or anything unusual**. Also, if someone has a cough in combination with any of the other following symptoms they should go and see their doctor. **A cough can be due to many things, but it is best to get it checked out.**”

Coloured or bloody phlegm



- If you notice any blood in phlegm
- A change in colour of phlegm

See the doctor straight away

NICE
National Institute for
Health and Care Excellence

“Coloured or bloody phlegm. If someone is coughing up phlegm and it has **blood in it or it has changed from its normal colour**, especially if it is **greeny in colour**, they should go and see their doctor straight away. If they are unsure if their phlegm is coloured or bloody, just ask them to check the tissue next time to see if there is any blood in it or if it is green in colour. They should go to their **doctor straight away**. It could be nothing, but it’s best to get it checked out.”

Shortness of breath



- Feeling as though you can’t catch your breath

-If gradual- see your doctor after **3 weeks**.

-If sudden- see your doctor **straight away**.

NICE
National Institute for
Health and Care Excellence

“Shortness of breath. If you know someone who feels like they **just can’t catch their breath when doing normal tasks**. If this has happened slowly they should go and see their doctor if it lasts for **3 weeks or more**. If this happens suddenly and they **feel very short of breath very quickly**, they should go and see their **doctor immediately**. It could be nothing, but it’s best to get it checked out.”

Chest pain



-A pain in your chest
-Go and see the doctor straight away

“Chest pain. If someone you know has chest pain, they should go and see their doctor **straight away**. It could be nothing or something else, so it’s best to get it checked out.”

Weight loss



-Losing weight but not meaning to for the past 3 weeks
-Can't explain why you've lost weight

Go and see the doctor

“Weight loss. Weight tends to go up and down slightly. But if you notice that someone has been **losing weight without trying to especially over a short period of time** or they can't explain why they've been losing weight, for example you have noticed their **trousers are too big or they have gone down a notch on their belt**, they should go and see their doctor. If they have not been dieting, they should go and see the **doctor after 3 weeks**. It could be nothing, and there is lots of different reasons for weight loss, but it's best to get it checked out, especially if they've had some of the other symptoms.”

Loss of appetite



-If you've noticed a
loss of appetite for 3
weeks or more and
can't explain why

Go and see the doctor

NICE
National Institute for
Health and Care Excellence

“**Loss of appetite.** Everyone has changes in their appetite at times. There are lots of different reasons why appetite can change. If there is a **persistent change in appetite**, so if you know someone who has been **wanting to eat less for 3 weeks or longer** and can't explain why, they should go and see their doctor. There are lots of reasons for a loss of appetite, but it's best to get it checked out especially if they've been losing weight.”

Feeling tired



-Feeling tired all the
time for 3 weeks or
more but can't
explain why

Go and see the doctor

NICE
National Institute for
Health and Care Excellence

“**Feeling tired.** If you know someone who been feeling **tired or say they have no energy all the time for 3 weeks or more and can't explain why**. They should go and see the doctor after 3 weeks. There are lots of reasons for being tired, but it's best to get it checked out especially if they've had other symptoms.”



“The problem with a lot of the signs and symptoms of lung cancer is that **they can be other things like a cold or symptoms** of other health problems we have. Here are some other things to consider or think about if you notice someone has one of the symptoms we have talked about.



Anything unusual



“Anything unusual. It is **important to know what is ‘normal’ for someone.** If you notice something which seems unusual or different for someone you know, you should tell them to go and get it checked out. The next time you see them you could ask them if they have been to the doctor about it or if they have made an appointment. This sometimes gets people to go to the doctor quicker”



Changes to current symptoms



Any changes to current symptoms. Again it is important to know what is ‘normal’ for someone and **notice any changes to what is ‘normal’**. For example, someone you know may have had a cough for a long time. If you have noticed the cough has changed from the last time you saw them or you ask them and they think their cough has changed, they could suggest that they go to the doctor and get it checked out.



Any new symptoms



“If you have noticed that someone has a **new symptom** that you’ve not previously noticed. For example, recently might have been saying they’ve had chest pain or you have noticed they get short of breath on tasks which they used to be fine with. You could suggest that they go to the doctor and get it checked out.”



Multiple symptoms e.g.



“If you notice that someone has a **couple or a few of the symptoms** that we have talked about, then you should **suggest that they go and get these checked out**. For example, if they have had a cough for 3 weeks or longer and have been feeling tired all the time.”



Multiple symptoms e.g.



Or if they are having chest pain, shortness of breath and have noticed that they have lost their appetite. They should go and get these checked out.”



A chest infection which won't go away



“If you know someone has had a **chest infection for a while** which **won't go away**. Even if they have taken lots of medicines for it, they should go back to the doctor and get this checked out. **They should tell the doctor that the medicine they or another doctor gave them is not working.** You could suggest that they write down how long the chest infection has lasted, how many medicines they have taken and that they are not working. They could take this list along to the doctor.”

tenovus
cancer care
gofal cancer

CARDIFF
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PRIFYSGOL
CAERDYDD

Tell the doctor your concerns



“If it is you going to the doctor or you go along with someone, the doctor might ask what you think the symptom is, or say something like ‘**what are you worried about?**’ **This is normal.** They are trying to work out what is wrong and find out more about the problem so they can treat you better. **You should be prepared to tell them about your concerns and expectations.** Or you could **be upfront** from the start with your concerns- what you think your symptoms could be. They won't think you are wasting their time or are a hypochondriac. You can take the piece of paper that I will give you at the end of this session to show the doctor to help.”

Any questions?

Comfort break and ask if anyone has any questions.

‘My friend or someone in my family told me to come to the doctor about this symptom’

“**My friend or someone in my family told me to come to the doctor about this symptom’**. I **hear this a lot**. In our research, we found that when people tell family members or friends to go to the doctor it **makes people much more likely to go to the doctor** and **makes them go quicker**. Remember earlier we talked about the **importance of going to the doctor quickly** with a symptom of lung cancer. This is because the treatments for lung cancer are better and someone is **more likely to survive lung cancer the earlier the cancer is found**. So after today, if someone tells you about a symptom or you **notice that someone has a sign or symptom of lung cancer**, it would be great if you could tell them to go to the doctor. **Together we can try and get lung cancer diagnosed earlier in the community.**”

Activity: What advice would you give to these people?

“Activity. I’m going to read you some scenarios. They are also on the pieces of paper in front of you. I’d like to know what advice you would give each of these people.”

Susan is 60, she is one of your neighbours. She has smoked for as long as you have known her. She has always had what she calls a ‘smokers cough’, but over the past few months you have noticed that this has got worse and that she keeps saying she is tired.

What would you do in this situation?

Read the slide

Advice:

-Susan should go and talk to her doctor about her cough that has got worse and also about her tiredness. Because she is over 60 and is a smoker, she should go and talk to her doctor to find out what is wrong. **It could turn out to be nothing, but it is best to get it checked out.** The next time you see her, you could ask her if she has been to the doctor yet. If she hasn’t, you could offer to go with her. Sometimes this helps people to know that someone else is there.

You work with Aled. He is 25 and smokes. He has had a cough for a couple of months and hasn't been to the doctor. What would you do in this situation?

Read the slide. Advice:

-As Aled is 25, it is unlikely that his cough is something more serious. Earlier we talked about the people that are **most at risk being** over 40, who are smokers or ex-smokers. You could tell him to keep an eye on his cough and if it gets worse or changes to go to the doctors as it could be a chest infection. You could ask him if he has seen any blood in his cough and tell them to go to the doctors if he has blood.

Ivor is 65 and used to smoke (he gave up a few years ago). Recently, he has had lots of chest infections. He keeps going to the doctor and they keep giving him antibiotics, which he is taking, but the chest infection has not gone or comes back quickly. He has asthma, so thinks it could be something to do with this. What would you do in this situation?

Read the slide. Advice:

-It **sounds like the antibiotics are not working**, so the doctors may need to do some more tests to find out what the problem is. You should **encourage Ivor to go back to the doctor** and tell the doctor that the antibiotics are not working. You should tell him that he needs to tell the doctors that he has had lots of antibiotics for the same problem but they are not working. You could offer to go with him to the doctor, sometimes this helps people to know that someone else is there. **You or he could take the handout that I've got for you at the end of the session to show the doctor.**

What stops people going to the doctor?

“I’m going to show you some of the most common things I hear people say which stops them going to their doctor with symptoms. If you are telling people to go to their doctor, then you might hear some similar things. I will give you some advice on possible solutions for these and the sorts of things you can say to someone if they say this.”

‘The doctor will tell me that I can only talk about one problem’

[read this] ‘The doctor will tell me that I can only talk about **one problem**’

“Does anybody have this problem?”

Following discussion say: “**Different doctors have different appointment policies.** Some doctors will only allow you to **talk about one problem** during an appointment. For example, you won’t be able to talk about your both your cough and knee pain. **Make sure you tell the doctors about the thing you are most worried about first and the thing that is most urgent.** Or you can **write a list before** and ask the doctor to help you know which is the most important problem. Remember the **earlier cancer is diagnosed the better**, so make sure you tell the doctor about a symptom which are most worried about first. Make another appointment for the other, less urgent problem. In some doctors, you can make a **double appointment**, so if you have a few things you want to talk about ask the receptionist to make two appointments.

Also, different doctor surgeries have different appointment booking systems, so it is worth **checking with your surgery how they book their appointments.** Some of them you need to ring early in the morning. Others you can ring anytime to make an appointment, but you might not be able to get an appointment for 2 or 3 weeks. Sometimes if you are really worried about something they can fit you in a little bit quicker. Tell the receptionist when you book your appointment.”

'I get into an appointment and forget what to say'

'I get into an appointment and forget what to say'

"Does anybody have this problem?"

Following discussion say: "This is **very common and happens to lots of people**. You could tell someone to **write down what they want to talk** about and the sorts of symptoms they have been having before the appointment and suggest they take this with them. You can also **offer to go with someone to an appointment** to help them tell the doctor about their symptoms."

‘My doctor won’t take me seriously- they will just fob me off and tell me I have a cold’

[read this] ***‘My doctor won’t take me seriously- they will just fob me off and tell me I have a cold’***

“Has anyone felt like this before?”

Following discussion say: “A lot of people worry about their doctor thinking they are a **hypochondriac or that the doctor won’t take them seriously**. The doctor **does want to see** you and if someone has any of the symptoms which we have previously talked about and they go to the doctor in the times we talked about, then the doctor shouldn’t ‘fob them off’. They can take the **hand out from this session with them** to show the doctor, this will help. You should tell the **person to be upfront with what you think is wrong**. You could offer to go with them to help talk to the doctor.

The doctor **might prescribe some antibiotics** or other medicines to see if these help before sending them for an xray. Symptoms can be because of lots of different things, so they might not get to the bottom of what is going on the first time around and **you may need to go back after trying some other things like medicines**. If they do this, make sure you tell the person to ask the doctor **when they should make an another appointment to see the doctor** if your symptoms don’t go away or get worse. The doctor hasn’t ‘fobbed them off’, the doctor is just wanting to make sure the symptoms are not something else.”

'I'm too scared to go to the doctor'

[read this] *'I'm too scared to go to the doctor'*

"Has anybody felt like this before?"

Following discussion say: "**Anything to do with cancer is scary, but finding cancer early is really important.** If cancer is diagnosed in the early stages, there are much better treatments available and your chances of surviving lung cancer are better. The symptoms could be something else, not necessarily lung cancer so it's best to get them checked out. If someone is scared, you could offer to book them an appointment and go with them"

'My doctor will tell me to stop smoking'

'My doctor will tell me to stop smoking'

"Has this happened to anyone before?"

Following discussion say: "If they smoke, the doctor could tell them to stop smoking. You could suggest that they **explain to the doctor that the reason you are here is to talk about symptoms and not smoking.**"

"Have I missed anything? Has anyone experienced anything else that might stop them going to the doctor?"

What can you take with you to an appointment?



“We’ve already talked about a few of things you can take with you to help talk to the doctor. You can take a list of symptoms to help remember. You can take the hand out that I will give to you in a minute. And you can take someone else with you to help you talk about symptoms”

What will happen if I go to the doctor?



“When you **phone the doctors** to make an appointment they might ask you if you need an appointment urgently. **If you are worried then you can ask for a quicker appointment.** You don’t need to tell the receptionist what you think is wrong. When you are in the appointment with the doctor, the **doctor will ask about the sorts of symptoms** you have been having. **You can take a list with you to help you remember.** They might **listen to your chest or ask you to breathe into a small device** called a spirometer. This is just to see how much air you breathe in and out. **It doesn’t take long and it doesn’t hurt.** They might then send you to the hospital for an **X-ray** which is a photograph of the inside of your lungs. It doesn’t take long and it **won’t hurt.** They might take some **blood and some phlegm samples** which they will send to the hospital for testing. If the tests do find lung cancer then the medical team will help the person to decide which treatment is best for them.”

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If lung cancer is found early it is easier to treat and people are more likely to survive

Are you 40 or older and currently smoke or used to smoke?
If so, go and see your doctor if you have any of these symptoms. It could be nothing, but it's best to get it checked out. Tell your doctor your concerns.

 <p>Have you had a cough for 3 weeks or more or has your cough changed? Go and see your doctor.</p>	 <p>Do you have blood in your sputum or has it changed colour? Go and see your doctor.</p>
 <p>Do you have chest pain? Go and see your doctor.</p>	 <p>Have you suddenly been short of breath or have you noticed over the last 3 weeks you are short of breath? Go and see your doctor.</p>
 <p>Have you lost about 10% of your weight for 3 weeks or more and can't explain why? Go and see your doctor.</p>	 <p>Have you been told you have clubbing of your fingers? Go and see your doctor.</p>
 <p>Have you (or someone you know) tried to stop smoking for 3 weeks or more and can't explain why? Go and see your doctor.</p>	<p>Go to your doctor if you notice anything new, any change in a chest infection which won't go away.</p>

“Today we have talked about some of the **signs and symptoms** of lung cancer. **What to do** if you or someone else has one of these symptoms and some tips on how to overcome some of the **barriers to going to the doctor**. Finally we have talked about how **important it is to diagnose lung cancer early**. The earlier lung cancer is found, the more likely it is to get cured because there are more effective treatments for lung cancer in the early stages. **Here is a hand-out to go away with**. It contains all the signs and symptoms to look for and when to go to the doctor with these symptoms. **You can take it with you to a doctor’s appointment.**”

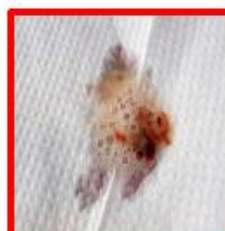
If lung cancer is found early it is easier to treat and people are more likely to survive

Are you 40 or older and currently smoke or used to smoke?

If so, go and see your doctor if you have any of these symptoms. It could be nothing, but its best to get it checked out. Tell your doctor your concerns.



Have you had a cough for 3 weeks or more or has your cough changed? Go and see your doctor.



Do you have blood in your phlegm or has it changed colour? Go and see your doctor.



Do you have chest pain? Go and see your doctor.



Have you suddenly been short of breath or have you noticed over the last 3 weeks you are short of breath? Go and see your doctor



Have you lost your appetite for 3 weeks or more and can't explain why? Go and see your doctor.



Have you been losing weight without trying to for 3 weeks or more. Go and see your doctor.



Have you been feeling tired for 3 weeks or more and can't explain why? Go and see your doctor.

Go to your doctor if you notice anything new, any changes or a chest infection which won't go away.

Appendix 26: Ethical approval 3

School of Medicine
Dean Professor John Bligh BSc MBChB MA(Lit) MMed MD FRCGP HonFAcadMed
Ysgol Meddygaeth
Deon Yr Athro John Bligh BSc MBChB MA(Lit) MMed MD FRCGP HonFAcadMed



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Monday 13th June 2016

Grace McCutchan, Kate Brain,
Adrian Edwards, and Fiona Wood
3rd Floor, Neuadd Meirionnydd
Heath Park
Cardoff
CF14 4YS

Dear Grace,

Re: Development of a lung cancer awareness intervention in deprived communities in Wales

SMREC Reference Number: 16/11

This application was reviewed by the Committee on Thursday 28th January 2016. Further revised documents were reviewed on Monday 14th March 2016. An amendment request was reviewed and granted on Monday 13th June 2016.

Ethical Opinion

On review, I can confirm that ethical approval has been granted for this study.

Conditions of Approval

The Committee must be notified of any proposed amendments to the methodology and protocols outlined in your submission. Also, any serious or unexpected adverse reactions that may arise during the course of the study must be reported to the Committee. As a condition of this approval, the Committee retains the right to audit and review the study for our own records.

Documents Considered

Document Type:	Version:	Date Considered:
Application	Signed 18/12/2015	28/01/2016
Supporting Document	V1 19/01/2016	28/01/2016
Lung health information session	V1 19/01/2016	28/01/2016
Draft baseline questionnaire	V1 19/01/2016	28/01/2016
Draft post intervention questionnaire	V1 19/01/2016	28/01/2016
Draft topic guide	V1 19/01/2016	28/01/2016
Consent Form	V1 19/01/2016	28/01/2016
Letter and Participant Information Sheet	V1 19/01/2016	28/01/2016
Email	22/02/2016	14/03/2016
Draft baseline questionnaire	V1.1 22/02/2016	14/03/2016
Email (Amendment Request)	20/05/2016	13/06/2016
Flyer	V1 20/05/2016	13/06/2016

With best wishes for the success of your study.

Yours sincerely,

Dr Jonathan Hewitt
Chair, School of Medicine Research Ethics Committee

Appendix 27: Information sheet (acceptability testing)

What is the study all about?

I am from Cardiff University, and I want to find out what people think about a lung health information session in the community. The results of the study will help to make the session better. This is a study funded by the charity Tenovus Cancer Care.

Do I have to take part?

No. It is up to you to decide to take part in this study or not. If you have any questions please ring me on 02920 687639.

You can talk to your family and friends about the study. They might be able to help you decide if you want to take part or not.

Before the interview starts, you will be asked to sign a consent form. I will go through this form with you. This is to say that you agree to take part in the study.

If you do take part, you can stop the study at any time. You will not need to tell me why you would like to stop.

What will happen to me if I take part and what do I have to do?

If you would like to take part in the study, I will ring you to arrange a time for you to take part in the session. I will give you information about where the session will take place. We will pay for your travel to that place.

You will take part in the lung health information session. This part will take about 1 hour. Before and after the information session, I will ask you to fill in a short questionnaire. I will then ask you questions as a group about what you thought of the session. This is called a focus group, and this part will take about 1 hour. We will have a short break in between the information session and focus group.

There are no right or wrong answers to my questions. I am just interested in what your thoughts are. All you need to do is tell me what you think of the session.

If you do not want to answer any of my questions, just let me know and we can move onto the next one. If it is OK with you, the interview will be recorded.

To thank you for your help, we would like to offer you £15 shopping voucher.

What will happen after the interview?

After the focus group, I will type up what you said. Your name or anything that could identify you will not be typed on any interviews. Some of what you say might be used in written research. No one outside of the research team will know you took part in the study.

The final results will be used to see if the session is a good idea or not and to improve the session.

What happens to my personal details?

This study is carried out by a team at Cardiff University. Your name and contact details will be stored on secure, password protected university computers. Your name and contact details will only ever be seen by members of the research team.

Your details will not be used for anything other than contacting you as part of this study.

Anything you say in the interview will be confidential. This means no one outside of the research team will know that you were in the study. Your name will not be linked to anything you have said in the interview.

What are the potential risks or disadvantages in taking part in the study?

This study involves talking about cancer. It is possible that talking about cancer may be upsetting. If you are upset during the interview please talk to the researcher about this. You can also stop the interview at any point without giving a reason. If you want to talk to someone else, you can contact Tenovus Cancer Care on the number at the end of this letter.

Contact for further information

Grace McCutchan

PhD researcher
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS
Phone: 02920 687197
Email: mccutchangm@cardiff.ac.uk

If there are any issues that I have not been able to resolve, please contact:

Dr Kate Brain (supervisor)
Institute of Primary Care and Public Health
3rd floor, Neuadd Meirionydd
University Hospital of Wales
Cardiff
CF14 4YS

The research is funded by the charity 'Tenovus Cancer Care' through Cardiff University

Helpline

Tenovus cancer care support line: 0808 808 1010

The support line is open 8am-8pm, 7 days a week. This is a free number from BT landlines. From mobiles, your network may charge.
Website: www.tenovuscancer.org.uk



Would you like to take part in a study?

Are you over 40 and smoke, used to smoke or have a family member who smokes?

If so, we want to you know what you think about a lung health information session.

There will be a free lunch and a £15 shopping voucher for everyone who takes part. We will pay for your travel to and from the study.

If you would like more information, please contact Grace on:

Phone: 02920 687639

Email: mccutchanGM@cardiff.ac.uk

If you would like to take part, we will arrange a time and date for the study that is best for you. The study will take about 2½ hours in total.

Appendix 29: Pre intervention questionnaire

1. There are many warning signs and symptoms of lung cancer. Please name as many as you can think of:



2. The following may or may not be warning signs for lung cancer. We are interested in <u>your</u> opinion:			
	Yes	No	Don't know
Do you think that unexplained weight loss could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a chest infection that won't go away could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a cough for three weeks or more could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent shortness of breath could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent tiredness or lack of energy could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent chest pain could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent shoulder pain could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that coughing up blood could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that an ache or pain when breathing could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that loss of appetite could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a painful cough could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that changes in the shape of your fingers or nails could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that developing an unexplained loud, high pitched sound when breathing could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a change in an existing cough or a cough getting worse could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. If you had a symptom that you thought might be a sign of lung cancer how soon would you go to your doctor to talk about it? (Please tick one)

I would go as soon as I noticed the symptom	<input type="checkbox"/>
I would go within 1 week	<input type="checkbox"/>
I would go between 1 and 2 weeks	<input type="checkbox"/>
I would go between 2 and 3 weeks	<input type="checkbox"/>
More than 1 month	<input type="checkbox"/>
I would not contact my doctor	<input type="checkbox"/>

4. How confident are you that you would notice a symptom of lung cancer?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. How confident are you that you would notice a symptom of lung cancer in someone else?

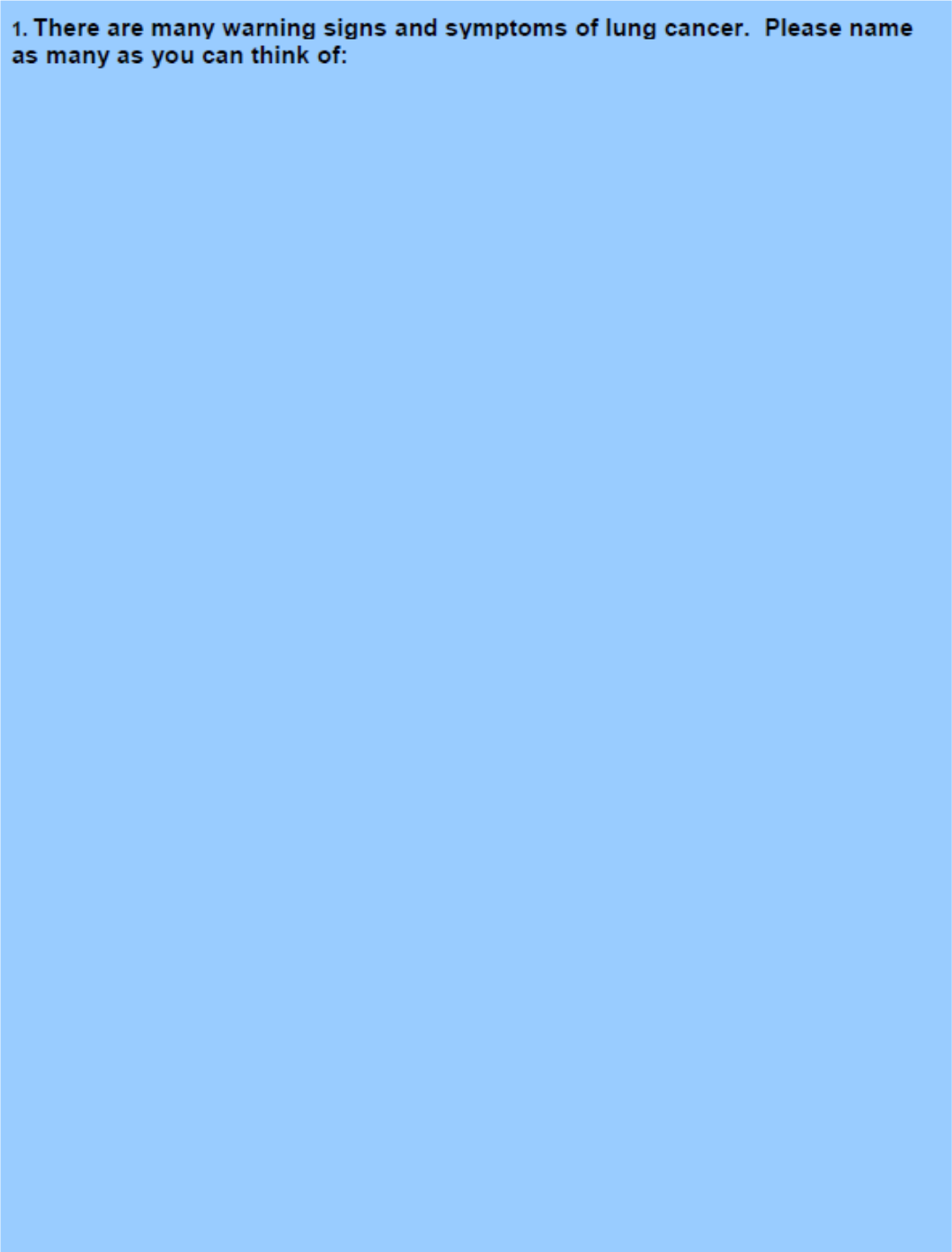
Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. For each of the statements below can you tell us how much you agree or disagree with each item

(Tick one box from each row)	Strongly disagree	Tend to disagree	Tend to agree	Strongly agree
Lung cancer can often be cured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most lung cancer treatment is worse than the cancer itself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would not want to know if I had lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to the doctor as quickly as possible after noticing a symptom of lung cancer could increase the chances of surviving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People who are important to me would want me to go to the doctor if I had a symptom of lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have no control over whether or not I get lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 30: Post intervention questionnaire

1. There are many warning signs and symptoms of lung cancer. Please name as many as you can think of:



2. The following may or may not be warning signs for lung cancer. We are interested in <u>your</u> opinion:			
	Yes	No	Don't know
Do you think that unexplained weight loss could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a chest infection that won't go away could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a cough for three weeks or more could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent shortness of breath could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent tiredness or lack of energy could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent chest pain could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that persistent shoulder pain could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that coughing up blood could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that an ache or pain when breathing could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that loss of appetite could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a painful cough could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that changes in the shape of your fingers or nails could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that developing an unexplained loud, high pitched sound when breathing could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think that a change in an existing cough or a cough getting worse could be a sign of lung cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. If you had a symptom that you thought might be a sign of lung cancer how soon would you go to your doctor to talk about it? (Please tick one)

I would go as soon as I noticed the symptom	<input type="checkbox"/>
I would go within 1 week	<input type="checkbox"/>
I would go between 1 and 2 weeks	<input type="checkbox"/>
I would go between 2 and 3 weeks	<input type="checkbox"/>
More than 1 month	<input type="checkbox"/>
I would not contact my doctor	<input type="checkbox"/>

4. How confident are you that you would notice a symptom of lung cancer?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. How confident are you that you would notice a symptom of lung cancer in someone else?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. For each of the statements below can you tell us how much you agree or disagree with each item

(Tick one box from each row)	Strongly disagree	Tend to disagree	Tend to agree	Strongly agree
Lung cancer can often be cured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most lung cancer treatment is worse than the cancer itself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would not want to know if I had lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to the doctor as quickly as possible after noticing a symptom of lung cancer could increase the chances of surviving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People who are important to me would want me to go to the doctor if I had a symptom of lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have no control over whether or not I get lung cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. How old are you? _____ years

8. I am (circle one) Male Female

9. What is your highest level of education? Please tick one option.

- Finished school at or before age of fifteen
- Completed CSEs, O-Levels or equivalent
- Completed A levels or equivalent
- Completed further education but not degree
- Completed a Bachelors degree/masters/PHD
- No qualifications/ left school at 16
- Other (please specify) _____
- Prefer not to say

10. Are you currently:

- Employed full-time
- Employed part-time
- Full-time homeowner
- Retired
- Unemployed
- Self-employed
- Still studying
- Disabled or too ill to work
- Prefer not to say

11. Please tick the box that best describes your home/living arrangement:

- Own outright
- Own mortgage
- Rent from local authority/housing association
- Rent privately
- Living with family or friends
- Prefer not to say

12. What is your postcode?

13. Which statement best describes your smoking status?

- I currently smoke
- I used to smoke
- I have never smoked
- Other (please specify)

13a. If you currently smoke or used to smoke:

- 0-9 per day
- 10-19 per day
- 20-29 per day
- 30 or more per day

Appendix 31: Observation sheet

Lung health intervention observation

Name of observer:

Date of observation:

Purpose: To observe the group dynamic, note any questions participants ask, note any reactions participants had to the intervention

Intervention section	Topics/ questions	Notes
True/false activity	<p>-Note the numbers of people who say true or false to each statement</p> <p>-Was anyone unsure?</p> <p>-Note any comments participants said about each statement</p>	<p>Lung cancer treatment statement: True n= __ False n= __</p> <p>Catch lung cancer early statement: True n= __ False n= __</p> <p>Air getting to cancer statement: True n= __ False n= __</p>

<p>Lung cancer and risk slides</p>	<p>-Note any comments participants said during these slides</p> <p>-Did any one react to the smoking/risk slides?</p>	
<p>Symptom slides</p>	<p>-Did anyone disclose a symptom during these slides?</p> <p>-Did anyone say they know someone with any of these symptoms?</p> <p>-How did participants react to the symptom slides?</p>	

Questions/ break	What questions were asked at this point? Did anyone comment about the intervention during the break? What did they say?	
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Community responsibility aspect	<ul style="list-style-type: none">-How did the group interact with one another during this task? -Did anyone discuss what they think the symptoms might be? i.e. cancer, a cold etc. -How did the group come to a decision about what advice to give the individual e.g.<ul style="list-style-type: none">-Was their 'relationship' with the individual important? i.e. If they were good friends would they be more likely to tell them to go to the doctor?-Was the age and other risk factors such as smoking status important?-Were the symptom(s) important?-Any other aspects important? -Any other observations?	
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<p>Barriers to symptom presentation section</p>	<p>-Did participants say they had experienced any of the barriers?</p> <p>-How much discussion around each barrier was there i.e. was it manageable or was it difficult to bring it back to the slides if everyone wanted to share their story?</p> <p>-Did anyone come up with any other barriers? If so, what barriers did they mention?</p>	
<p>What will happen at the doctors?</p>	<p>Any comments or questions from participants</p>	

Group management/ group dynamics	-Was the group easy or difficult to manage? -Did they go off topic at any point? -Was there a few dominant people in the group or did everyone get a chance to speak?	
Hand out	Did anyone comment on the hand out? If so what did they say?	
What questions were asked during the session?	Please note any questions asked by participants during the session. Either in this box or in the corresponding box for the session.	

Any other notes/ comments/ observations

Appendix 32: Topic guide for intervention acceptability testing study

Topic guide:

Lung cancer awareness intervention user testing

Aims:

To present the pilot lung cancer awareness intervention to participants. A focus group following participation in the pilot intervention will provide the opportunity to see if the intervention is 'fit for purpose' and gain insight into the acceptability and feasibility of such an intervention.

Interviewer note:

The interviewer should stress that:

- The focus group is not a test, we are seeing what participants' opinions of the intervention are to see if it is something that could work in their community or not.
- All comments including criticisms are welcomed.

Prologue:

'Before we start, I need to give you some information about why we are doing this study and what you have to do.

I would like to see what you think about a group session about lung health. At this stage, I am testing it to see what people think before it is finalised. So I am interested in what you think: both positive and negative.

It is completely up to you whether you decide to take part or not. Taking part is voluntary. If you decide you don't want to take part anymore, just let me know. You can stop the focus group at any point and you don't need to give me a reason. If you don't want to answer any of my questions, that is fine, just let me know and we can move onto the next one.

If it is OK with you, I will record the group session and focus group. After the focus group we will type up what you said, but anything that could identify (your name etc.) you will be taken out. No one outside of the research team will know that you have taken part in the study.

I have planned a few questions and things for us to talk about, but if you have anything else you want to say or add at any point, please feel free to do so.'

[Verbally go through consent form with participants. Ask participants to sign consent form if they agree to take part. Give participants the baseline questionnaire. Set up audio-recorder]

[Deliver pilot intervention to participants]

[Give participants the post intervention questionnaire. Break for lunch]

[Before starting the focus group, remind participants about confidentiality and ask participants not to talk over each other. Go around the circle and ask participants to introduce themselves for the transcription]

1. Usefulness of intervention:

What do you think of the session?

- What did you like?
- What did you dislike?

What part of the session would you find most useful?

What part of the session would you find least useful?

- Was there anything that you thought was not relevant to you?

What do you think of the hand out sheet with symptoms?

2. Feasibility of intervention/ Reach:

What do you think people in your community would think about the session?

- Why do you think they would feel this way?

Do you think people in the community would come to the session?

- Who do you think would come to it?
- Why do you think people would not come to the session?

3. Content/understanding:

What did you think of the subjects covered in the session?

- Do you think anything has been missed out?
- Do you think there is anything in the session that should be taken out?

What do you think the key messages from the session are?

- What was the one thing you took away from this session?

What do you think about including stop smoking (smoking cessation) information in the session?

- How do you think smokers might react to including this information?

What did you think about the whole session being about other people in the community?

What do you think about noticing symptoms of lung cancer in other people in the community and asking them to go to the doctor?

- What would you say to them if they had a symptom?
- Would you feel comfortable doing this?
- How do you think they would take the advice?

4. Delivery of session:

What do you think about the PowerPoint? Do you think the session should be delivered in a different way?

Who do you think would be best to deliver the session?

- What do you think about someone from Communities First delivering the session?
- Can you think of anyone else who could deliver the session?
- Is there anyone who should definitely not deliver the session?

Where do you think would be best to have the session?

- Is there anywhere we should avoid doing the session?

What do you think about the length of the session?

- Do you think it should be longer/shorter?
- What could we take out of the session?

What do you think of the hand out at the end of the session?

- Would you take it the doctor?

5. Improvements:

Can you think of anything else that could make the session better?

Is there anything in particular that hasn't been included, that you think should be?

6. Recruitment

How could we encourage people to come to the session?

- Can you think of any other ways we can encourage people to come to the session?

How could we advertise the session in your community?

Debrief

'Thank you for taking part in this study. We are interested in what people think of a lung cancer information session. The results will help us to make changes to the session to make it better. Anything you said will be treated as confidential. The voice-recoding will be stored securely. Any quotes used in published research will not have your name or anything that could identify you. Do you have any questions? *[answer any questions]* Here are my contact details if you have any further questions.'