Using significant event analysis and individual audit and feedback to develop strategies to improve recognition and referral of lung and colorectal cancer at an individual general practice level

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Abstract

Introduction: The lifetime risk of developing cancer is 50%. Whilst cancer survival rates are increasing, data suggests UK survival is lower than comparable countries. There is a growing evidence base to suggest cancer survival is linked at least in part, to the early recognition and referral of symptoms in primary care. The role of primary care is vital with 85% of cancers diagnosed following presentation to primary care. Significant event analyses (SEAs) are an effective tool to learn detailed lessons about the primary care interval and SEA research completed so far highlights the importance of safety netting.

Method: The research within the thesis was informed by two theories of behaviour change, the Behaviour Change Wheel and Normalisation Process Theory. The methods were split in to three distinct sections. Firstly, a scoping review of safety netting was undertaken. Secondly, the recognition and referral of lung and colorectal cancer symptoms in primary care was investigated using SEAs. Finally, the SEA data generated was used in an audit and feedback intervention to develop a series of action plans.

Findings: The definition and content of safety netting was developed. SEAs demonstrated the importance of safety netting in improving the primary care interval, but also highlighted the role of investigations, patient factors and comorbidities. SEA data was used to develop interventions which were accepted by primary care staff. Result synthesis showed the importance of safety netting and led to the development of a model.

Discussion: The importance of safety netting has been highlighted throughout the thesis. Further research is needed to evaluate the model developed. Opportunities for improving the primary care interval were highlighted. Developing interventions through audit and feedback with SEAs is feasible, and is accepted by primary care staff. The thesis has left multiple unanswered questions and could pave the way for a larger, more robust study based on the methods and techniques demonstrated.

Table of Contents

List of Figures

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Chapter 1: Introduction to cancer in primary care

The lifetime risk of developing cancer in the UK is estimated to be 50%. There is increasing emphasis on the role of primary care in the recognition and referral, as well as the prevention, of cancer. Whilst this focus is being driven by political and public opinion, there is little doubt that earlier diagnosis improves survival. In the UK around 85% of cancer diagnoses are preceded by primary care input, but cancer survival in the UK compared with similar countries is poor. As a result much of the focus on improving cancer survival has concentrated on primary care and improved recognition and referral of potential cancer symptoms.

This chapter will highlight the growing burden of cancer, and consider comparisons between different countries in terms of cancer survival. The process and complexity of diagnosing cancer in primary care will be discussed. Finally, as this thesis will predominantly consider the role of the primary care practitioner (PCP), the importance of the gatekeeper role of primary care in the UK will be discussed. The term primary care practitioner will be used throughout this thesis to describe health care professionals who consult with patients in primary care. This will most often refer to general practitioners (GPs), but increasingly the primary care workforce includes other professionals such as nurse practitioners, physician associates, pharmacists and paramedics who may consult with patients in primary care. The term GP will be used if a study or guideline involved specifically GPs.

1.1 Cancer Burden

The lifetime risk of developing cancer in the UK is now estimated to be 50% (1). In 2015 there were 359960 new cancer diagnoses in the UK and 163444 deaths due to cancer. Since 1975 the incidence of cancer has increased by 23% in males and 43% in females (see Figure 1) (2). A large study in 40 European countries reported 3.4million new cancer cases in 2012. The most common cancer site was breast (13.5%), followed by colorectal (13%), prostate (12.1%) and lung cancer (11.9%) (3). Cancer incidence is thought to be increasing as a result of lifestyle and environmental factors as well as the fact that people are living longer (4).

Cancer survival in the UK is also increasing, with 50% of patients now surviving 10 years or more. In the last 40 years cancer survival in the UK has doubled. Five year survival has increased from 25% in 1971 to 49% in 2011 for men, and from 34% to 59% over the same period for women (see figure 2) (2). As cancer survival increases, the number of patients living with cancer, and the after effects of the disease, will also increase. The Dutch Cancer Society estimates that between 2010 and 2020 the number of cancer survivors in Holland will increase by 61% (5). In the UK approximately 2 million people are cancer survivors and this is expected to rise to 4 million by 2030 (see figure 3) (6).
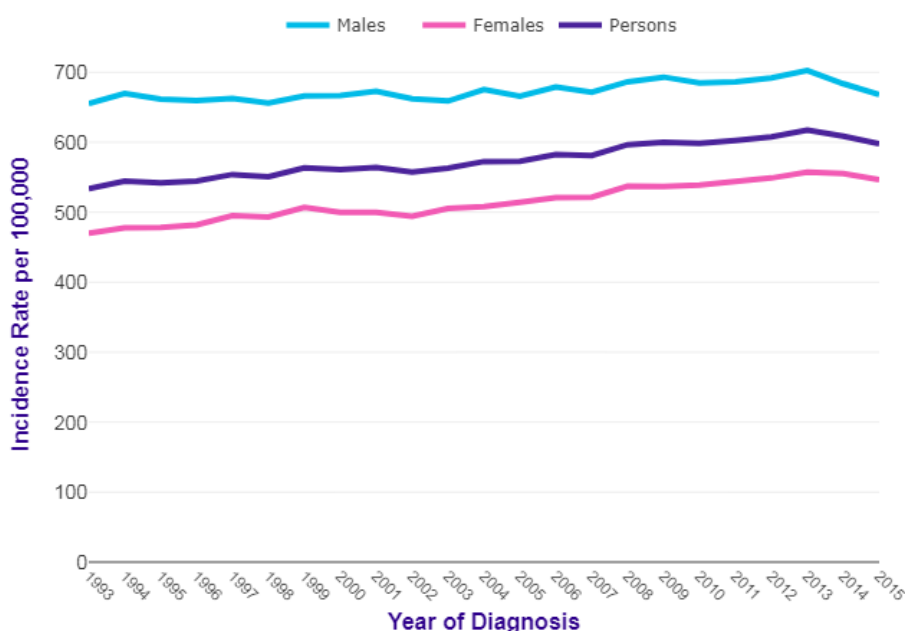
Figure 1: Age Standardised UK Incidence Rates of All Cancers Excluding Non-Melanoma Skin Cancer, 1993-2015 (2)
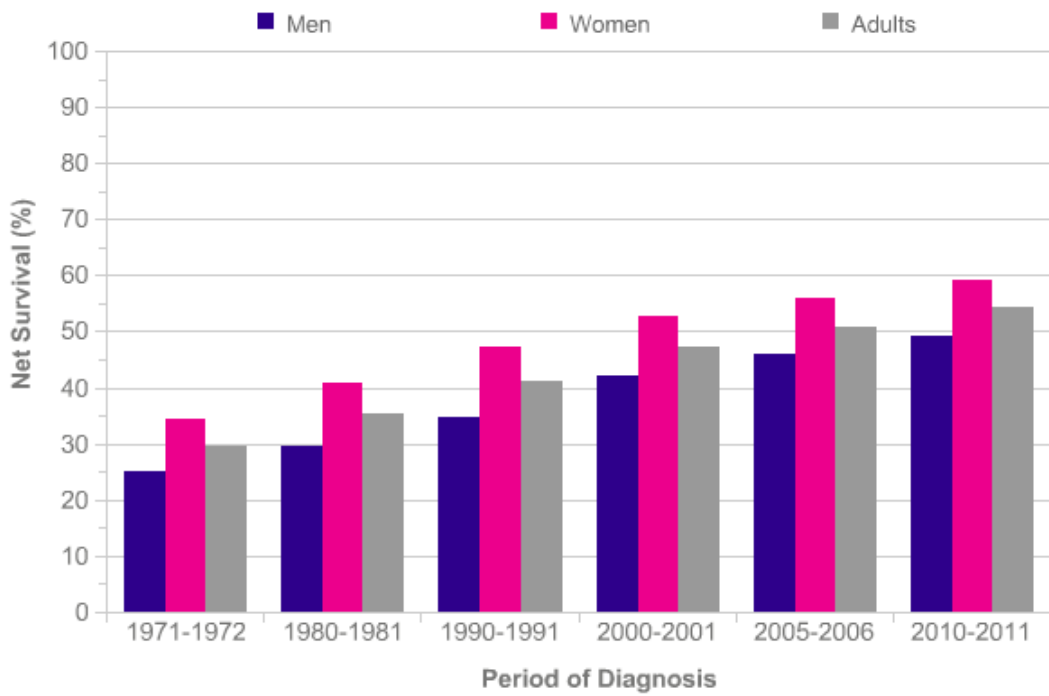
Figure 2: Age Standardised Five Year UK Net Survival For All Cancers
Excluding Non-Melanoma Skin Cancer, 1971-2013 (2)
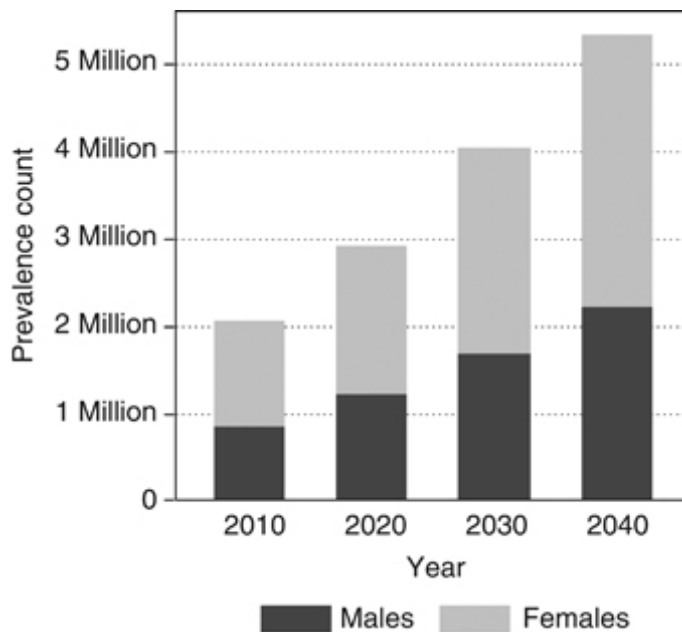
Figure 3: Projected Total Number of UK Cancer Survivors 2010 to 2040 (6)

1.2 UK cancer survival comparisons

The European cancer registry (EUROCARE) has been collecting data on
cancer survival across Europe since 1989. The registry published its fifth
report in 2014. It includes data from 29 countries and provides information on

21 million cancer diagnoses from 107 cancer databases. The report finds overall five year survival is increasing over time across Europe. However, as previous EUROCARE reports have also found, the UK consistently lags behind similar European countries (see figure 4) (7). Abdel-Rahmen et al. estimates that if cancer survival in the UK were comparable with the European average, 5000 deaths within the first five years of diagnosis would be avoided each year (8). Further work has been undertaken using data from the International Cancer Benchmarking Partnership (ICBP). This also found lower survival at one and five years in the UK compared with Australia, Canada, Norway and Sweden (see figure 5) (9).

The EUROCARE studies have been instrumental in demonstrating survival differences between comparable countries. They are updated regularly and are based on routinely collected data from each country, ensuring the findings are applicable to each of the included countries or regions. The data used are up to date and the findings of the studies are relevant to the UK context and to the work of this thesis. However, survival comparisons between countries have been controversial and criticised for being difficult to interpret. Differences in statistical methods used to control for mortality from other causes, differences in case recognition, and completeness of follow up are among the main limitations of the EUROCARE studies (10). Some countries do not have national cancer databases (France and Germany for example have only 23% of the population included in a cancer registry) and others have incomplete follow up, with deaths not adequately recorded. It has also been suggested that migration may have an effect on survival statistics with patients being diagnosed in one country but returning to another, perhaps to be closer to family for end of life care (11). However, despite the problems with EUROCARE it is widely accepted that its

limitations alone cannot explain the UK's poor cancer survival statistics.
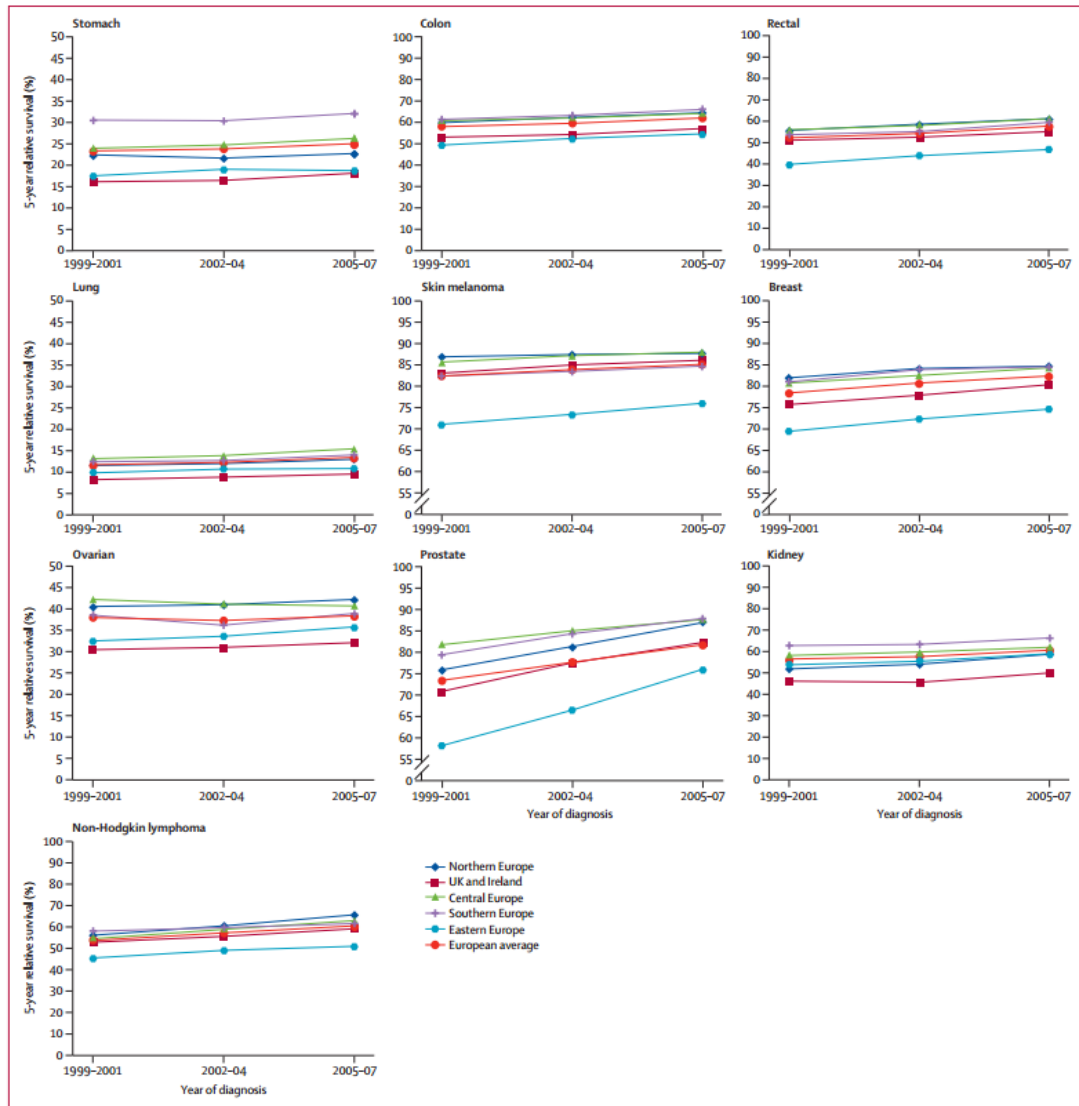
Figure 4: Age-specific 5-year relative survival for adults with cancer diagnosed in 2000–07 by cancer type and region (7)

ICBP Module 1 - survival differences

Colorectal Cancer 1yr Relative Survival

Lung Cancer 1yr Relative Survival

Breast Cancer 1yr Relative Survival

Ovarian Cancer 1yr Relative Survival
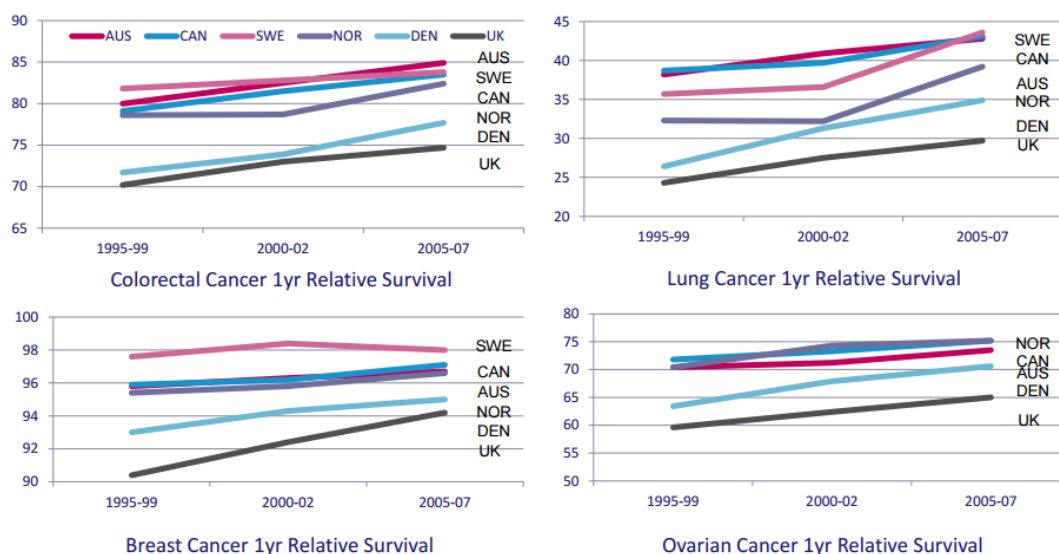
Figure 5: Age-standardised 1-year relative survival trends 1995–2007, by cancer and country (9)

1.3 Diagnosing cancer in primary care

1.3.1 Overview of the role of primary care

Primary care plays a vital role in the pathway to a new cancer diagnosis with evidence suggesting around 85% of cancers in the UK are diagnosed following symptomatic presentation to a PCP in primary care (4). This section will consider the importance of primary care and review the factors which influence this part of the diagnostic pathway such as the use of referral guidelines, the assessment of patients within general practice and the effect of the gatekeeper role.

Primary care is defined by the WHO as "first-contact, accessible, continued, comprehensive and coordinated care" (12). It is typically provided by clinicians who are generalists and is most often delivered as part of a multidisciplinary team.

As a result of this, primary care plays a vital role in the diagnostic pathway for cancer. Primary care is often a patients' first contact on recognition of a new symptom. In order to minimise delay in diagnosis, patients must present promptly to primary care with symptoms suggestive of cancer, and PCPs must respond appropriately to these symptoms by arranging further investigations or referring to secondary care (13). There are other ways in which a diagnosis of cancer can be made without prior primary care

involvement, such as through screening or emergency presentations to secondary care. Both these pathways are important and the subject of ongoing research, however this thesis will focus on the pathway to diagnosis which includes a primary care interval. The primary care interval is one step in the pathway to diagnosis models discussed below. It is the time from first presentation with a PCP to referral to secondary care.

1.3.2 Diagnostic pathways

The diagnostic pathway for cancer has been successfully described, and broken down into component parts. An early attempt to do this was by Nichols et al. who describe three stages in the diagnostic journey. The three stages include patient delay (the interval between first noticing a symptom and first consulting a doctor), practitioner delay (the interval between first consultation with a doctor and referral) and finally hospital delay (the time between referral and diagnosis) (14).

Early research on the pathways to cancer diagnosis were described by Neal as being mixed and confusing, partly due to differing ways of measuring delays and outcomes (15). This was recognised by Weller et al. who stated that research in to pre-diagnostic patient pathways "lacked consistent definitions and methods". The Aarhus statement has provided a solution to this problem by developing a guideline on conducting studies on the early diagnosis of cancer and by defining the diagnostic process and its component parts (see figure 6) (16, 17).

In addition to the Aarhus framework, a theoretical model of pathways to diagnosis was developed by Anderson et al. (18) and then refined by Walter et al. (19). This model of total patient delay complements the Aarhus statement and provides a theoretical framework. It describes five possible stages of delay and includes four 'intervals' (appraisal, help seeking, diagnostic and pre-treatment). The model also describes contributing factors, split into patient, healthcare and disease causes (see figure 7).

The Aarhus framework and the Walter et al. model show the importance of multiple intervals and stages in the pathway to diagnosis. The patient interval for example is vital to ensuring a reduced time to diagnosis, and improving this interval requires interventions from public health which could include mass media and education campaigns. However, this thesis will focus on the primary care interval and as a result the remainder of the introduction will focus on the important literature in this area. Both the Aarhus framework and the pathways to treatment model have been widely accepted and used in

further research. They were based on conceptual models and build on existing work. However they could be criticised for being over simplistic. One could question if the entire process within the primary care interval from first presentation to referral be explained by one step / box? This interval could include multiple presentations and the use and interpretation of investigations. Another potential criticism of the models is the lack of insight into how the patient interacts and plays a part in all stages of the diagnostic journey. In the Aarhus statement, the patient is only mentioned in the very first stage of the model, but in reality the patient may present to primary care, then refuse investigations, not return for follow up or miss secondary care appointments. The model of pathways to treatment acknowledges patient factors as a contributing factor but again could be more specific in its description of these factors. Work by Parsonage et al. looked at patient perspectives on delays in diagnosis and treatment of cancer and found multiple patient 'barriers and facilitators' which present at each stage of the diagnostic pathway. They conclude that work such as this shows how the models can work in practice (20).
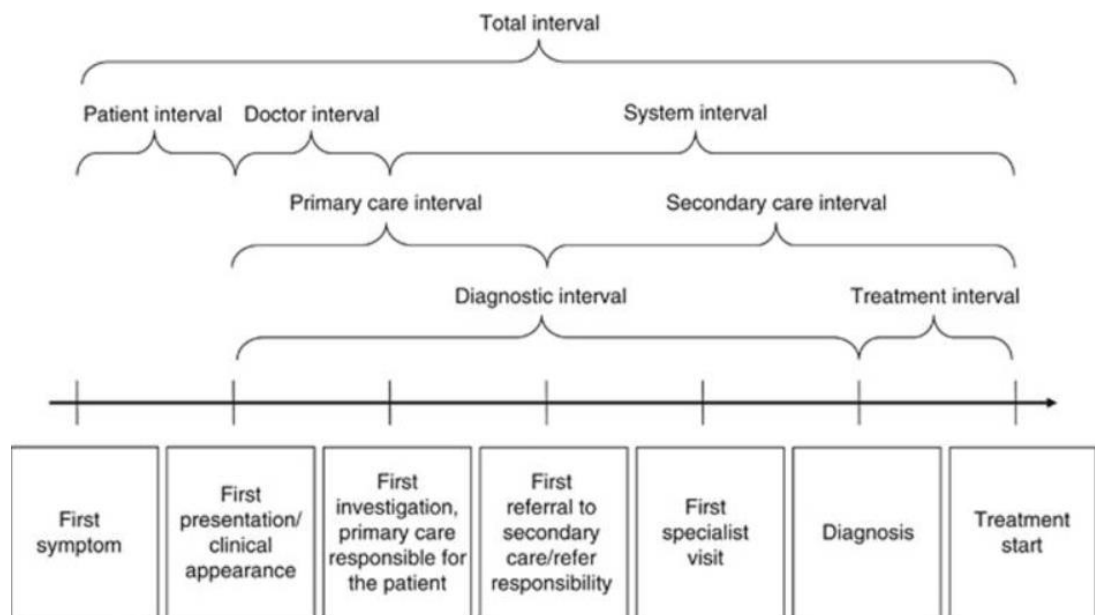
Figure 6: An illustration of the overall milestones and time intervals in the route from first symptom until start of treatment. Developed by Oleson et al. (17) and included in the Aarhus statement (16).
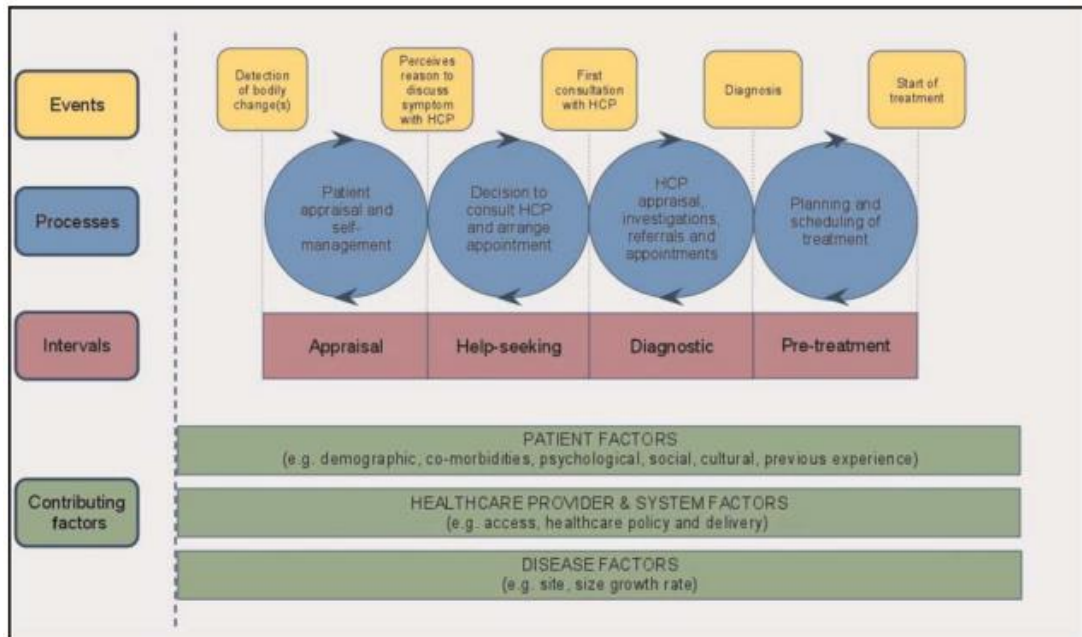
Figure 7: Model of pathways to treatment (19)

1.3.3 Cancer referral guidelines

In UK primary care, PCPs are guided by recommendations on the recognition and referral of cancer provided by the National Institute for Health and Care Excellence (NICE). The timely diagnosis of cancer has been a priority for the NHS since the Department of Health white paper entitled "The New NHS: Modern Dependable" (21). This paper made cancer diagnosis one of four key themes stating "we will improve prompt access to specialist services so that everyone with suspected cancer will be able to see a specialist within two weeks of their GP deciding they need to be seen urgently and requesting an appointment." This was the 'birth' of the two week wait (2ww) referral pathway still in use today. In 2005 NICE developed guidance on urgent referrals for suspected cancer which updated the Department of Health guidelines published with the commencement of the 2ww pathway in 2000 (22). These guidelines recognised that the diagnosis of cancer on clinical grounds alone was difficult, but urged GPs to be aware of the typical presenting features of cancer, whilst recognising that these same symptoms are commonly associated with benign conditions. The guidelines advise that GPs must be alert to the possibility of cancer when confronted by unusual symptom patterns and recommend discussion with specialists if there is any uncertainty. The guidelines then give evidence based recommendations on which symptoms and signs should warrant a 2ww referral for suspected

cancer. The publication of these guidelines raised awareness of the 2ww referral pathways as primary care trusts, who oversaw the work of GPs, were monitored on the use of the NICE guidance (23, 24). The guidelines were updated in 2015 and entitled "Suspected cancer: recognition and referral" (25). The updated guidelines amend some of the recommendations for suspected cancer based on new evidence, provide information on symptoms in children and young people, information and support needed and also provide advice on safety netting. Safety netting is a process undertaken by PCPs in primary care to ensure there is a 'safety net' for patients should things not go as planned. It could include advice given to patients or systems to ensure follow up of results of investigations. Safety netting is discussed in detail below.

1.3.4 Assessment of symptoms in general practice

The major challenge for PCPs is that the symptoms suggestive of cancer are also common in benign disease and the prevalence of cancer in primary care is low. Evidence suggests that a typical PCP, despite consulting with 20 to 40 patients a day, will only see one new case of colorectal, lung and prostate cancer each year and perhaps only one rare cancer in their lifetime (4).

The CAPER series of studies demonstrate the difficulties PCPs face. These studies have shown the low positive predictive value (PPV) of the symptoms of possible cancer listed in the NICE guidelines. This is due in part to the low prevalence of cancer and the high incidence of these symptoms in benign disease (26). Rectal bleeding for example is a worrying symptom and one that may raise suspicion of colorectal cancer. However, rectal bleeding is commonly caused by benign conditions such as haemorrhoids and anal fissures. The PPV for rectal bleeding in colorectal cancer is low at 2.4 and other markers, which possibly raise suspicion of colorectal cancer, such as constipation or diarrhoea are even less helpful with PPVs of 0.42 and 0.94 respectively (see figure 8) (27). Very common symptoms such as cough, tiredness and vague chest pains may be present in patients with lung cancer, but the vast majority of patients who present with these symptoms will not have cancer. In addition to this, other factors such as co-existing medical problems can make diagnosis difficult. The majority of lung cancers for example occur in long term smokers, but these patients could have a 'smokers cough' and may have a diagnosis of chronic obstructive pulmonary disease (COPD) which commonly causes breathlessness. As a result, symptoms which may be the early signs of lung cancer could easily be attributed to COPD, and an opportunity for early diagnosis could be missed.

Constipation	Diarrhoea	Rectal bleeding	Loss of weight	Abdominal pain	Abdominal tenderness	Abnormal rectal exam	Haemoglobin 10–13g dl⁻¹	Haemoglobin <10g dl⁻¹	
0.42 0.3, 0.5	0.94 0.7, 1.1	2.4 1.9, 3.2	1.2 0.9, 1.6	1.1 0.9, 1.3	1.1 0.8, 1.5	1.5 1.0, 2.2	0.97 0.8, 1.3	2.3 1.6, 3.1	PPV as a single symptom
0.81 0.5, 1.3	1.1 0.6, 1.8	2.4 1.4, 4.4	3.0 1.7, 5.4	1.5 1.0, 2.2	1.7 0.9, 3.4	2.6	1.2 0.6, 2.7	2.6	Constipation
	1.5 1.0, 2.2	3.4 2.1, 6.0	3.1 1.8, 5.5	1.9 1.4, 2.7	2.4 1.3, 4.8	11	2.2 1.2, 4.3	2.9	Diarrhoea
		6.8	4.7	3.1 1.9, 5.3	4.5	8.5	3.6	3.2	Rectal bleeding
			1.4 0.8, 2.6	3.4 2.1, 6.0	6.4	7.4	1.3 0.7, 2.6	4.7	Loss of weight
				3.0 1.8, 5.2	1.4 0.3, 2.2	3.3	2.2 1.1, 4.5	6.9	Abdominal pain
					1.7 0.8, 3.7	5.8	2.7	>10	Abdominal tenderness

Figure 8: Positive predictive values for colorectal cancer shown in a Risk Assessment Tool (27).

PCPs aim to identify patients who they deem to be at high risk of serious disease so that further tests can be arranged or referral to secondary care organised. This process is done based on the patient's clinical history, examination and investigations, using the PCP's clinical experience. In the consultation, the PCP may know some background about the patient, either from the medical notes or prior consultations. The PCP will then build on this information, asking about and examining for other signs or symptoms that will increase or decrease a patient's risk of serious disease (4, 28). If the patient is judged to be at low risk of serious disease, he or she may be reassured, given safety netting advice (discussed in chapter 2.5) and a policy of watchful waiting used. If patients are at high or intermediate risk, further tests may be organised or urgent referral to secondary care may be arranged.

A number of factors including knowledge of local guidelines and referral pathways, PCP experience, practice workload and recent experience seem to influence a PCP's readiness to refer or investigate patients' symptoms. A study using clinical vignettes of fictitious patients with low, moderate and high

risk of lung cancer was undertaken using a national sample of 227 GPs. In each vignette the GP was asked to take a history and decide on whether or not to refer / investigate. The study found variations in GPs readiness to investigate symptoms and that different patients with the same symptoms were not investigated equally. The authors concluded that insufficient data gathering could be responsible for some delay in diagnosis (29). The study used vignettes on an interactive website which may lack validity, the GPs had to type questions and constraints on the language system meant that on some occasions the website could not answer the GPs questions, leading some of the GPs to report frustration with the system. The process of typing questions may also have affected clinical reasoning. However this novel study did find some evidence for reasons for possible prolonged primary care intervals.

1.3.5 The PCPs role as a gatekeeper in cancer diagnosis

In healthcare, a gatekeeper may be defined as "a point of entry each time care is needed for a health problem" (30). In some health care systems a PCP is responsible for the role of gatekeeping though the process of referral into secondary care. The use of gatekeeping in healthcare is supported by three key arguments; the need to ensure patients receive appropriate care, the need for cost effective care and the need for justice in distributing care (30). The need for appropriate care and justice is cleverly discussed in the 1989 BMJ 'fairy tale' the gatekeeper and the wizard. This work argues that gatekeepers are better at spotting those who are well and wizards (hospital specialists) better at spotting those who are ill. Stopping those who are well from accessing hospital (wizard) care optimises the efficiency of the whole system (31, 32).

With financial constraints on the NHS growing, it is thought that gatekeeping may help the NHS use its resources efficiently. However this may come at a cost, with some evidence suggesting that gatekeeping is associated with delayed diagnosis and poor outcomes (33). This seems to be the case with cancer diagnosis. Studies show that European countries with strong gatekeeping principals having lower cancer survival (34). However, other studies including a systematic review on gatekeeping suggest that health outcomes and quality of life do not differ in countries with strong gatekeeper systems (33, 35). It is felt that a balanced gatekeeping system that meets clinical need, patient choice and system constraints is difficult to achieve. The NHS' gatekeeper model needs to be taken into account when

researching cancer in primary care, and when drawing comparisons with other countries.

To suspect cancer and make a diagnosis, GPs must assess the patient using history and examination; judge the patient's risk factors and the diagnostic probability of them having cancer and initiate further testing or referral as appropriate. The challenge comes in balancing the risk; referring too many patients would overload the hospital system, increasing health care costs. In addition the referral process may cause unnecessary anxiety for patients. Referring too few patients may cause delay in diagnosis which, as discussed above, is associated with poorer clinical outcomes, as well as a worse patient experience (36, 37).

PCPs, particularly in systems with a strong gatekeeper system such as the UK and Denmark, are aware of the balance between the benefits and harms of referral and diagnostic testing. An interview study of UK GPs perceptions of cancer diagnosis found that most GPs valued the gatekeeper role. They felt that the ability to identify which patients require further investigation and which can be managed with watchful waiting or reassurance was a key GP skill. GPs felt that their ability to act as gatekeeper was dependent on the quality of the GP/patient relationship and the GP's role as patients' advocate (38).

However, a Danish study looked at attitudes to risk taking, in a sample of 568 GPs. The study found huge variations in anticipated cancer risk (between 5% and 80%) and found some GPs had an unacceptably high tolerance for ambiguity and low levels of referral. They conclude that 'tolerance for ambiguity' should be included in education for GPs (39). As such, some GPs acting as a gatekeeper to services in Denmark, may be contributing to this country's comparably low levels of cancer survival. An earlier study supports the findings of the Danish research. Using EUROCARE data, a study found significantly lower one year cancer survival in countries with primary care based gatekeeping. They conclude that the use of a primary care gatekeeper, the use of patient lists and primary care being the first point of contact may have an adverse effect on survival (34).

1.3.6 Decision support tools

Evidence suggests that PCPs may not explicitly consider the process of in terms of a numerical estimation of risk (4). However potential cancer symptoms have been recently considered in terms of a numerical risk threshold. NICE suggested this risk level be reduced from 5% to 3% in their

2015 guidance (25) and a study published in 2014 used clinical vignettes to question patients on their preferred level of risk and found that the majority of patients preferred a risk threshold of 1% (40). To help aid the assessment of cancer risk, tools such as QCancer have been developed. QCancer is an online risk assessment tool based on algorithms from routinely collected data from thousands of UK general practices who contribute to the QResearch database. The research behind the data was extensive, with testing and validating of data from 22,251 cancers in 1,263,071 males and 23,216 cancers in 1,240,864 females (41, 42). The QCancer calculator allows PCPs to estimate a patient's risk of having cancer from a number of demographic and tick box symptoms which could be filled in with the patient present or after the consultation. Alternatively 'risk assessment tool' (RAT) was also developed by Hamilton et al. following the CAPER studies. This tool provided cancer risk scores based on combinations of symptoms which were then colour coded for high and medium risk. The CAPER studies, and the research behind Qcancer have several strengths and weaknesses. A key strength is the amount of data used. Using research databases gave access to large numbers of real patient data which suggests the data is likely to be generalisable to the UK population. The RATs were extensively evaluated using a cohort and nested qualitative study which looked at the use and acceptability of the tools over a six month period at 165 general practices. The study showed the tool was widely used, and in interviews GPs stated that RATs helped to confirm a need for investigation as well as allowing reassurance when investigation was not needed (43). However the decision support tools do have some problems. Practically, the tools have been criticised by some for not allowing the consideration of other factors. Whilst QCancer takes into account demographic information, neither allow the addition of examination findings or results of tests or screening. Both the CAPER studies and Qcancer were developed using summaries of the GP record based on Read coded data. Read codes are described as a coded thesaurus of clinical terms which provides a standard vocabulary to record patient findings and procedures in GP records. It is possible to search for Read codes and use them in research. However the use of research databases based on Read coded data is dependent on the information being coded by the PCP. PCPs often document most of the consultation information as free text meaning that important information from the PCPs free text notes may have been missed (44).

1.3.7 Optimal lung and bowel cancer diagnosis pathway

Patients generally receive a diagnosis of cancer in secondary care. Whilst this sometimes follows an emergency admission, most patients are referred from primary care. This section will describe the optimal pathway to lung and bowel cancer diagnosis in Hull and the East Riding of Yorkshire in the UK (the area in which this research took place).

For a lung cancer diagnosis, the following steps would normally take place. Following a presentation to primary care with symptoms which suggest a diagnosis of lung cancer the PCP would request a chest x-ray (CXR) by filling out a paper form. In Hull and the East Riding the PCP gives the patient this form requesting a CXR, which they can take to one of several locations for a 'walk in' CXR without a prior appointment at a time to suit them. Following the CXR the PCP receives a report usually within 48 hours. If the CXR is suspicious for lung cancer, the radiologist writing the report automatically requests a CT scan and informs the PCP. The PCP must then inform the patient and send a 2ww referral to secondary care. This referral is done using a specially designed form which can be sent electronically or faxed to an appointments team within the hospital. The patient should then receive appointments for a scan and secondary care consultation in the post. The patient should have the CT scan and the report from this should be available when the patient attends an appointment with a lung specialist within two weeks of the referral. At this appointment a diagnosis may be made or further tests such as bronchoscopy performed or organised.

For bowel cancer, following a patient presentation with symptoms suggestive of bowel cancer a patient could be referred using a 2ww form as described above. However the form states that for some symptoms such as change in bowel habit, patients symptoms should persist for six weeks prior to sending a referral. In this case the PCP may request blood tests, or use a period of watchful waiting prior to a referral. At the appointment in secondary care, the patient is seen and examined by a specialist, then if necessary further tests such as colonoscopy or CT scan are performed.

1.4 Summary

This chapter has highlighted the growing burden of cancer worldwide, showing that cancer is and will continue to be an extremely important area of research. The data on cancer survival has been reviewed and has identified a problem. The cancer survival statistics for the UK are lower than for

comparable countries. This seems to be confirmed in numerous studies, with different cancer sites and despite some concerns about the recording of statistics in some countries, is regarded as accurate data. The importance of primary care has then been discussed highlighting the expanding role of primary care in the recognition and referral of cancer symptoms. The impact of national guidelines, the management of risk and uncertainty by PCPs, and the structure of primary care has been discussed. Finally to provide context to the following research, the current optimal pathway to lung and bowel cancer is described. It is possible that interventions targeted in primary care may help improve cancer survival. The following chapter will consider the cancer diagnostic pathway in more detail.

Chapter 2: Investigating the pathway to cancer diagnosis

This chapter investigates the pathway to cancer diagnosis and potential delay in this diagnosis. The areas covered include the definition of delay, the benefits of a timely diagnosis, potential reasons for delay, and attempts to study and reduce delay. The research within this thesis focuses on the role of primary care in the pathway to lung and bowel cancer diagnosis. As a result, much of the existing literature considered in this chapter focuses on these areas of interest.

2.1 Definition of delay

Most of the models of pathways to diagnosis discussed in the chapter above use the term 'delay' to denote the various stages in the diagnostic pathway (14, 16-19). It has been argued that the use of the term delay is problematic for many reasons. Firstly, the term delay could be thought to attribute blame. This may be particularly important when discussing patient delay (45). It has been argued that terms such as the 'appraisal interval' or 'time to presentation' are less stigmatising than 'patient delay' (46). Secondly, there is the issue of what is normal or expected. In every cancer diagnosis, there will be a time from a patient first presenting to primary care with a symptom, to referral to secondary care by a PCP. This time could be anything from a few minutes, to weeks or months. In many cases this time will be appropriately short. Is it right then that this time period is called a delay?

Dobson et al. argues that the term interval would be best used for describing the individual time periods, and the term delay is used if this interval is deemed to be prolonged (46). This distinction helps to differentiate those with and without 'delay' and would allow further study of patients or patient groups with delay. Other researchers and studies have used a similar approach, but have used the term 'missed opportunities' rather than delay (47, 48). Dobson recommends stratifying time intervals into those with and without prolonged delay (46). Throughout this thesis, the term interval is used to describe time periods in the path to diagnosis and 'delay' to highlight any prolonged intervals. It is important to recognise however that there is little guidance on what constitutes a prolonged interval, with different studies using a range of definitions, most of which rely on a subjective judgement.

2.2 Benefits of a timely diagnosis

There is a growing evidence base to show the shorter the time to diagnosis for cancer, the more options there are for treatment and the greater the chance of survival. Cancer Research UK (CRUK) data shows that for colorectal, breast, prostate, ovarian and lung cancer the lower the stage of cancer at diagnosis, the greater the chance of survival. The differences in survival are stark; 83% of patients diagnosed with stage I lung cancer survive for one year compared to only 17% of patients diagnosed with the most advanced stage of the disease (49). Further analysis of National Cancer Registration Service (NRES) data by McPhail et al. showed for lung cancer, there is a substantial decrease in survival for each increase in stage of disease (50).

Advanced cancer stage at diagnosis, and poorer cancer survival, may be solely due to the biological properties of the tumour, either by growing and metastasizing quickly, or by not producing symptoms until the cancer is advanced. However cancer diagnosis may be prolonged due to patients not presenting with symptoms to general practice, delays in recognition and referral of symptoms in primary care or diagnostic delays in secondary care (51).

There had been some debate as to whether or not diagnosing cancer quickly improved survival. In 2009 Neal et al. asked "do diagnostic delays in cancer matter?" (15). Early reviews considering the effect of delays in diagnosis on survival for colorectal, lung, prostate, bladder, head and neck and paediatric cancers showed no benefit from fast diagnosis (52-56). In addition to this, Esserman highlighted the potential harms of over diagnosis, and with it over treatment, without increasing survival (57). In 2015 a large systematic review on the effect of time to diagnosis of cancer on survival was conducted by Neal et al. This review included 209 studies and found that shorter times to diagnosis increased survival for melanoma, breast, colorectal, head and neck and testicular cancers (56). The review also found benefits for shorter times to diagnosis from smaller studies for pancreatic, prostate and bladder cancer, with equivocal findings for other cancers. On lung cancer the study states there were mixed findings, with similar numbers of studies reporting positive and negative associations. The review concludes "that efforts to expedite the diagnosis of symptomatic cancer are likely to have benefits for patients in terms of earlier-stage diagnosis, improved survival and improved quality of life" (56). This large review is subject to some limitations. Firstly the studies included in the review were of mixed quality with some not reporting

the representativeness of the sample, and few undertaking confounder adjustment, prognostic adjustment or attempted bias minimisation. As with most studies on the diagnosis of cancer, measurement of outcome is difficult. Mortality or survival is the most objective outcome, but most studies in the review reported stage at diagnosis or another proxy measure. Cancer stage is subject to a variety of characterisations, again making comparisons and conclusions difficult. Despite these limitations, this review was well conducted, provided an assessment of study quality, and is the most comprehensive review of diagnostic delay conducted to date.

A retrospective study based in primary care in Denmark looked at the association between time to diagnosis and mortality in patients with colorectal cancer. This study found mortality decreased with diagnostic intervals from one to five weeks after which mortality increased with increasing diagnostic intervals (see figure 9) (58). This is an example of the 'waiting time paradox' which was first noticed in 2002 in a study considering treatment delay and survival of women with endometrial cancer (59), and in a systematic review of children and young adults with brain and non-rhabdomyosarcoma tumours (60). The waiting time paradox may seem counterintuitive; patients with a short time to diagnosis having poorer survival than those diagnosed over a longer period of time. There are several possible explanations for this. Firstly it is possible that in patients with a short time to diagnosis, PCPs are able to recognise symptoms of advanced disease and patients are referred after the first consultation. Whereas patients with vague symptoms are less likely to have aggressive disease and may be managed with watchful waiting in the first instance which increases the time to diagnosis, but the patient is diagnosed with less advanced disease. Secondly, it could be that patients presenting unwell or with alarm symptoms are prioritised by the PCP; they may be seen quicker and a referral may be expedited by phone calls to secondary care or by immediate or emergency admission (4). Finally, the paradox may be due to the disease itself. The cancer may grow rapidly or may cause a large disease burden before the patient recognises symptoms. This important retrospective study is subject to some limitations due to selection and information bias. 16% of the population could not be included in the study due to non-participation of the PCP. It is possible that these PCPs chose not to take part because they believed their patients were subject to increased delays. Secondly data were submitted by individual PCPs, who could have made errors regarding the length of the diagnostic interval. The authors suggest that PCPs may be likely to understate the length of the diagnostic interval for their patients.

Despite these limitations the study consistently found evidence of the waiting time paradox and this phenomenon has been demonstrated in other independent studies.
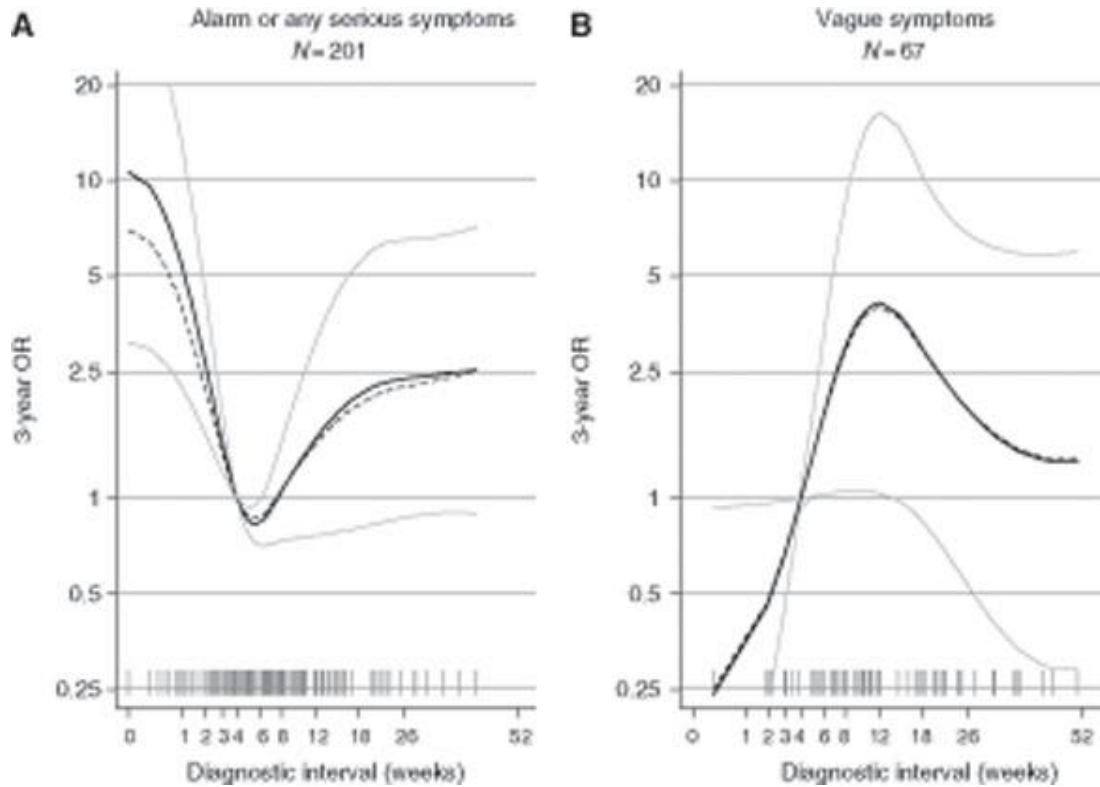
Figure 9: Estimated three year mortality odds ratios (OR) for patients with colorectal cancer by diagnostic interval (58).

In summary, it is thought that, despite some early doubt, the quicker cancer can be diagnosed, the better the outcome for the patient (56). However when researching and studying cancer diagnosis, one must be aware of the waiting time paradox described and demonstrated by Torring et al.'s large cohort study (58) which supported earlier work by Crawford et al. (59).

2.3 Reasons for increased time to cancer diagnosis

Considerable research has looked at the reasons for increased time to diagnosis of cancer and potential factors that predispose to slower referral from primary care. Much of this research has used vignettes to try to understand the decisions made by PCPs, or retrospective analysis of pathways to cancer diagnosis to learn about factors which cause delay.

A systematic review on the patient and primary care interval aimed to understand the risk factors associated with an increased time to presentation. The review found a strong association between increased patient interval and age, socioeconomic status, education level and having a fear of cancer . The review also looked at risk factors for increased primary care interval following presentation. The results showed misdiagnosis, inadequate examination, inappropriate use of tests and failing to follow up inconclusive or negative results were important risk factors for primary care delay (13). This important review found that both patient and practitioner factors played a role in delayed diagnosis. The study concludes by stating that the reasons for delay are complex and multifactorial but highlights the need for effective use of referral guidelines and better use of and access to diagnostic services. The findings of this review suggest that interventions targeted at the primary care workforce may help to reduce diagnostic delay.

In 2005, Allgar & Neal looked at the pathway to diagnosis of cancer, using data from the National Survey of NHS patients. They found that the majority of patients with cancer had presented to primary care with a symptom that could have been due to cancer before diagnosis. The analysis found that the patient and primary care interval contribute at least two thirds of the total time to diagnosis compared to the secondary care interval (61). This undertaken using a self report questionnaire. The self-report questionnaire leaves the results open to recall bias particularly regarding dates of diagnosis and presentation to general practice. However, the study sampled all 172 NHS trusts and had a data set of 65337 patients, which means that the results are likely to be generalizable.

A study of 41299 patients with 24 different cancers found variation in the number of times patients visit their GP before being referred to secondary care for suspected cancer. Patients with multiple myeloma, pancreatic cancer, stomach cancer, lung cancer, Hodgkin's lymphoma, colon cancer, and ovarian cancer were substantially more likely to have visited their GP three or more times before hospital referral (see figure 10) (62). This study concludes that the findings could be used to better target awareness campaigns and help to prioritise early diagnosis initiatives and research.
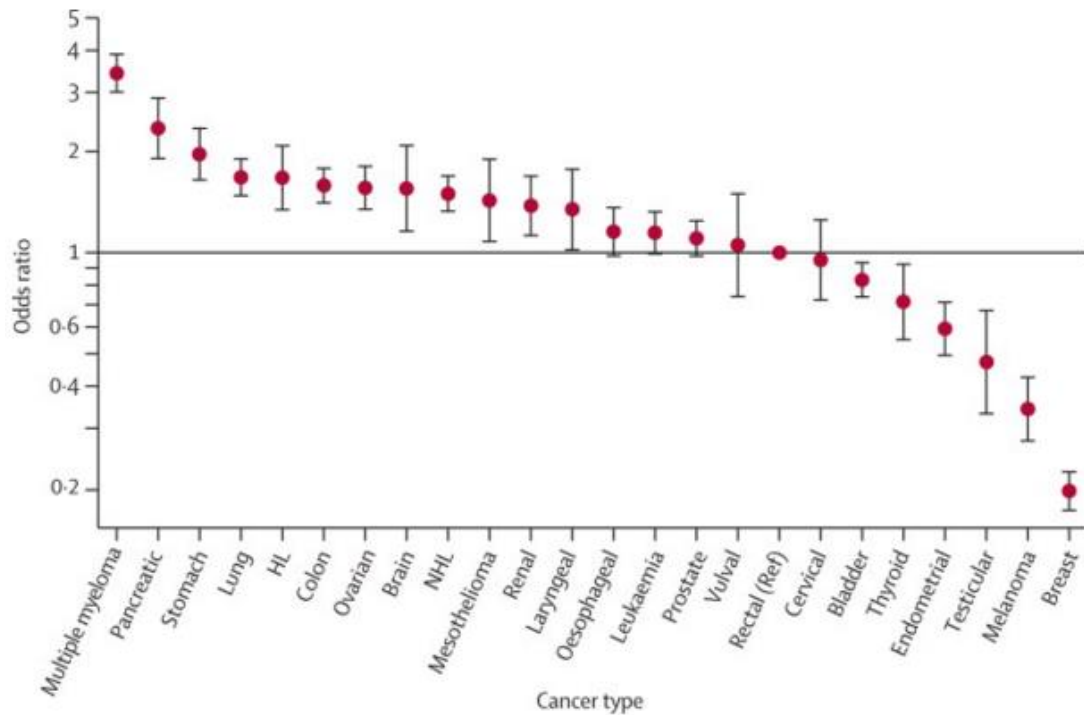
Figure 10: Odds ratios for three or more GP consultations before hospital referral by cancer type (62)

Primary care vignettes have been used to try to explain the variations in cancer survival found in the ICBP study. In one study a questionnaire was completed by 2795 primary care doctors in the ICBP group. The authors found a correlation between a GP's readiness to investigate or refer for suspected cancer and the cancer survival statistics in that GP's local area. The authors suggest that a doctor's 'readiness to act' consists of personal attributes of the doctor (which may include knowledge and attitudes about cancer) and system factors such as guidelines and the availability of diagnostic tests (51). Another study using 'video vignettes' was undertaken in Australia. This study asked GPs to review 24 GP records and video vignettes and indicate what action they would take. In the study all cases warranted referral for suspected cancer based on national guidelines. The study found that in one in eight cases the patient was not referred despite the GP having access to diagnostic tests (63). These studies both used vignettes to study GP behaviour. It could be argued that the use of vignettes lacks validity and that GPs may act differently when faced with real life patients. However Rose et al. argue that the vignettes did have face validity and have since been adopted into UK general practice training (51). As with all ICBP studies there is significant variation in response rate in different

jurisdictions which ranged from 5.5% to 18.7%. This may affect the interpretation of the results. Like the studies discussed earlier, these two vignette studies suggest that some delays in diagnosis may be due to the actions or the readiness of GPs to act on symptoms. Interventions which aim to change GPs behaviour may be important.

Retrospective analysis of cancer diagnosis has been used to discover patterns of 'missed opportunities' for earlier diagnosis and the factors that influence this (47). Missed opportunities were defined by Singh as "instances in which *post-hoc* judgement indicates that alternative decisions or actions could have led to a more timely diagnosis" (64). A review characterises missed opportunities in cancer diagnosis into three areas. Firstly, the initial diagnostic assessment, in which rigid consultation norms, inadequate history and examinations, language barriers, cognitive factors and access can cause delay. Secondly, diagnostic testing, in which missed opportunities can occur due to complex diagnostic testing processes, patient non adherence to recommended tests and inadequate testing. Finally, diagnostic follow up and coordination in which patient factors, such as lack of patient empowerment, over reliance on patients to 'call back' and a lack of appreciation or follow up of abnormal test results can lead to missed opportunities for earlier diagnosis (47). In a similar study Jenson et al. looked at 'quality deviations' in cancer diagnosis in Denmark. A quality deviation was defined as "an event that should not have happened and that you do not want to happen again". This study looked at all new cancer diagnoses in a four month period and sent a questionnaire to the patient's GP four months after diagnosis, which they were expected to complete on the basis of the patient's medical record. The study found that quality deviations were present in 30.4% of cases; the most common issues being sub optimal clinical decisions, communication problems and patients failing to return for follow up (65). These retrospective studies highlight the importance of both patient and GP factors in cases with longer time to diagnosis. These studies provide a helpful insight into areas in which GPs can speed up the diagnosis of cancer and again suggest that interventions targeted at GPs may improve cancer diagnosis.

In summary, multiple studies have looked at possible reasons for prolonged time to cancer diagnosis. Socioeconomic status, age, education level and type of cancer are patient factors which can influence the time to diagnosis. When focusing on the primary care interval, multiple factors appear to contribute to delay, including history and examination skills and clinical decision making of the PCP, and the use of, availability and complexity of

diagnostic testing. Finally poor follow up, doctor-patient communication and the management of investigations, have also been shown to lead to delays in diagnosis. The majority of studies which considered reasons for increased time to diagnosis used retrospective data such as those by Singh (64), Jenson (65) and Lyratzupolous (47). These studies used data from large cancer registries and GP records. These studies have the advantage of having relatively easy access to large numbers of patients and patient data, meaning they are more likely to be generalizable to other populations. However they often rely on retrospective data leading to recall bias, and are dependant of the quality of the data being recorded. General practice database studies are often criticised for relying on the use of Read codes, which are used in different ways by individual PCPs and often result in a loss of detail.

Vignette studies were also used to consider reasons for delay. Vignette studies are often criticised for lacking face validity, with some arguing that hypothetical vignettes cannot simulate real life clinical practice. However, the authors argue the vignettes used directly reflected clinical practice and have since been adopted for GP training in some areas suggesting they may better reflect real life decisions. In addition to this, vignette studies are dependent on PCPs taking part. In the ICBP study by Rose et al. response rates were as low as 5.5% in some jurisdictions which is unlikely to be representative of the population (51). One could argue that the GPs taking part in the study would be more motivated and interested in the diagnosis of cancer and hence provide a biased sample. Whilst these limitations must be taken in to account, the studies are helpful in identifying possible reasons for delay and help to target future research efforts. The studies were conducted in the UK, Denmark, Australia and USA. Denmark has a very similar healthcare structure to the UK with PCPs which act as gatekeepers to secondary care services. Australia and USA do have PCPs which provide a primary care service but patients are able to bypass this and consult directly with secondary care. However it could be argued that missed opportunities regardless of location or healthcare setting are relevant to the study of cancer recognition and referral. All the studies discussed above included either lung or colorectal cancer patients, with some considering all cancers. Therefore the studies are applicable to the aims of this thesis.

2.4 Use of audit tools in general practice to understand cancer diagnosis

Information on the primary care interval can be provided by audits using GP records. Two examples of these are the National Cancer Diagnosis Audit (NCDA) and significant event analysis.

2.4.1 National Cancer Diagnosis Audit

The first NCDA was undertaken in 2009 as part of the National Awareness and Early Diagnosis Initiative (NAEDI) (discussed in chapter 2.6) in collaboration with the Royal College of General Practitioners (RCGP) (66). This audit was updated in 2016 by the RCGP and CRUK. In this study all general practices in England were invited to take part. The study was promoted by the RCGP and through CRUK and Macmillan primary care engagement teams. Once registered, PCPs could enter data on patients diagnosed with cancer. The data included "patient characteristics, place of presentation and symptoms presented, primary care-led investigations, the number of pre-referral consultations, the referral pathway, whether there was evidence of safety netting, and any diagnostic delays incurred". The most recent audit collected data on 17042 patients at 439 practices. The data was analysed and information gained on the patient and practice demographics, presentation and referral data, and time intervals. Information was also collected on avoidable delay. The audit found one in four lung and colorectal cancer diagnoses had an avoidable delay. When considering safety netting, the audit found that only 44% of cases had documented advice in the medical record. The study concludes that the findings can act as a benchmark to which further studies can be assessed against (67, 68). The results show the benefit of a national audit as a tool to provide detailed information on the pathway to diagnosis in primary care.

2.4.2 Significant event analysis

Significant event analysis (SEA) can be used to understand the diagnosis of cancer. Mitchell et al. first used SEA to understand the diagnosis of lung cancer in primary care (69). SEA is a quality improvement tool specifically developed for UK general practice. It was first discussed in an RCGP occasional paper in 1995 (70) and has since been developed by the National Patient Safety Agency (NPSA) (71). SEA is described as a "qualitative method of clinical audit that is based on the synthesis of traditional case

review and the research principals of the critical incident technique" (72). SEAs should attempt to answer the following questions:

- What happened?
- Why did it happen?
- What can be learned?
- What should be changed?

SEA is now compulsory for individual GPs and health care teams who must provide documentary evidence of SEA participation as part of professional, contractual and clinical governance obligations (73, 74)

SEA involves an in-depth structured analysis of an event identified by the health care team as significant. A review of the evidence for SEA found that it was "a valued multidisciplinary quality improvement mechanism with strong support among healthcare teams". However the review also found that topics for SEA were "highly selective", there was a lack of training and no standard structured SEA method which could make the process subjective and superficial (75). Evidence seems to suggest that SEAs could help to improve patient care. A small study of GPs views using semi structured interviews found that SEA was acceptable and had positive educational outcomes (72). A review of 191 SEAs submitted from GPs in Scotland found that learning opportunities were identified in 95% of cases with 80% of analyses describing self-reported actions taken to improve practice systems or professional behaviour (73). A similar review in North West England reviewed 337 SEA reports with 89% of them identifying learning points and in 74% of cases, action plans had been developed or initiated. The report concludes that SEA is a valuable educational tool with potential patient safety benefits (76).

In the Mitchell et al. paper discussed above, a standard electronic SEA template was used to collect data on the diagnosis of lung cancer. GP practices were asked to undertake a SEA of the most recent diagnosis of lung cancer. 132 SEAs were analysed using qualitative methods. The study found that most SEAs demonstrated exemplary practice with timely recognition and referral of possible cancer symptoms. Cases with prolonged primary care intervals were reviewed in more detail. In these few cases a common theme was long delays between patients initially presenting with symptoms that may be due to cancer and then returning for subsequent review. In the reflections, practitioners described the importance of safety netting with some practitioners using the term explicitly in their narratives, commenting on its importance as part of the consultation (69).

The RCGP developed an improving cancer diagnosis toolkit in which 313 SEAs were analysed for lung, ovarian, upper gastro-intestinal and teenage and young adult cancers. This report states that "many of the learning points focused on consultation-based activities, including the importance of safety netting, and the need to ensure that steps are taken to fully consider what is currently happening with the patient, and to plan for what will happen next" (77).

Both the cancer audit and work on SEAs provide a detailed window into the primary care interval, giving information on multiple aspects of that interval including the use of investigations and safety netting. All the studies were conducted in the UK in primary care. The NCDA included all cancers, whereas the SEA work was conducted on lung cancers, with follow up work on ovarian cancer, upper gastrointestinal cancer, young adult cancers and cancers diagnosed via an emergency admission. As a result the findings are applicable to the work undertaken in this thesis. The studies are subject to important limitations which should be taken in to account when considering this research method. By definition, they depend on retrospective data from the GP record and the PCP memory of the case in question. This data is recorded at the time of the consultation, but then requires interpretation at the time of conducting the audit or SEA. Secondly these studies are subject to selection bias, both in the PCPs which take part and the cases submitted. The NCDA only included 6% of GP practices nationally. It is possible that the PCPs involved are more interested in cancer diagnosis and may be better performing than practices not included.

2.5 Safety netting and cancer symptoms

The retrospective analyses of cancer diagnosis discussed above often highlight the potential role of "safety netting" to prevent delay in cancer diagnosis. Safety netting is a part of the consultation performed by the PCP which patients may be unaware of. The term safety netting was first introduced by Neighbour who considered it to be a key component of the consultation (78). In his book The Inner Consultation he describes safety netting from the PCP point of view as answering three questions:

1. If I'm right, what do I expect to happen?
2. How will I know if I am wrong?
3. What would I do then?

The use of safety netting is recommended in several guides to consultation skills. One such guide, the Calgary-Cambridge model, states that doctors should: summarise likely symptoms which may be experienced, provide a time frame for resolution of symptoms, communicate uncertainty, give advice about potential alarm symptoms and when and where to consult in that event and finally suggest a time frame for follow up (79).

Safety netting is explicitly mentioned in the NICE guidelines which state "consider a review for people with any symptom that is associated with an increased risk of cancer, but who do not meet the criteria for referral or other investigative action. The review may be planned within a time frame agreed with the person or patient-initiated if new symptoms develop, the person continues to be concerned, or their symptoms recur, persist or worsen" (25). The importance of safety netting in cancer recognition and referral is increasingly being recognised. It is frequently highlighted as a potential solution to delays in cancer diagnosis and has formed the mainstay of a CRUK grant application call (80). Chapter six of this thesis reports on a scoping review undertaken in order to better understand the role of safety netting in healthcare consultations.

2.6 Interventions to reduce delay in cancer diagnosis

Many interventions have been developed and tested with the aim of reducing the time to cancer diagnosis. Some of these interventions and policy changes are discussed below.

The NAEDI Initiative was launched in 2008 as a public sector/third sector partnership led by CRUK, the Department of Health and Public Health England (81). An article in the British Journal of Cancer describes the aim of NAEDI "to address poor cancer survival by reducing the number and proportion of cancers diagnosed and treated at a late stage, mainly concentrating on symptomatic presentation and improvements across the diagnostic pathway" (82). The original NAEDI paper in 2009 described the 'NAEDI hypothesis' which has since been updated. This hypothesis shows the complex and multifactorial path from onset of symptoms to diagnosis and treatment and all the possible factors that could influence or cause delay in the pathway (see figure 11) (81). NAEDI had multiple initiatives; this included funding research projects, directing the public awareness 'be clear on cancer' campaign, and developing the National Cancer Intelligence Network.
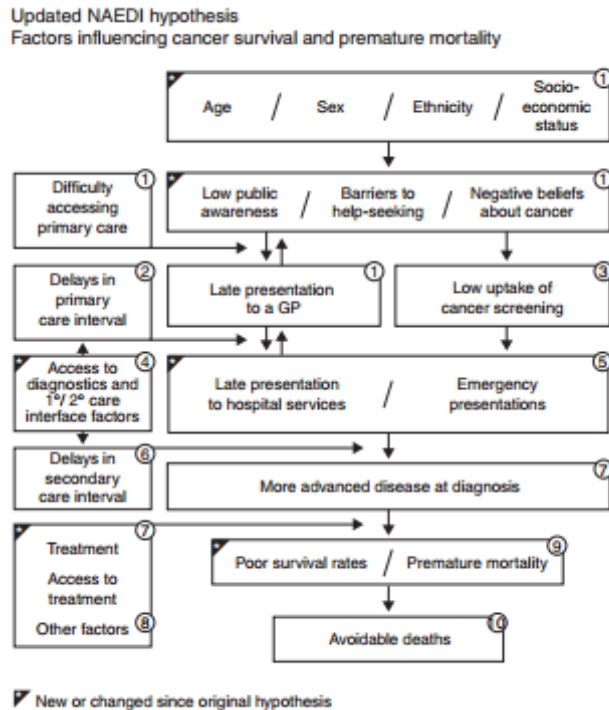
Figure 11: The updated NAEDI hypothesis showing factors influencing cancer survival (66).

A major intervention to reduce time to cancer diagnosis was the 2ww referral system discussed in chapter 1.3. The aim of the 2ww system was to speed up the time from suspicion of cancer to diagnosis. Since its implementation, the 2ww system has undergone extensive evaluation. Patients referred using the two week wait pathway have an 11% risk of being diagnosed with cancer (83), whereas case control studies show the risk of having cancer related to each alarm symptom is between 3-8% (26). This suggests the scheme may be effective. However, work looking at the 'routes to diagnosis' of cancer in the UK show that less than 25% of all cancer diagnosis were made via a 2ww referral, with a similar number diagnosed following routine referrals (84). In addition to this a review of the 2ww rule showed that audits were not well reported and had inconsistent findings (85).

Denmark has implemented an alternative pathway for the diagnosis of cancer which, the authors state, more accurately reflects the reality of symptoms presenting to primary care. This pathway is described as 'the Danish three legged strategy' and involves three separate referral or diagnostic options available to PCPs. Firstly, patients with symptoms suggestive of a specific cancer can be referred through an urgent referral pathway similar to the UK's two week wait system. Secondly, for non-specific, but serious symptoms patient can be referred to 'diagnostic centres' for cancer investigations. Finally, for patients with common symptoms, but

where cancer remains a possible diagnosis, there are yes/no clinics (86). This project is awaiting evaluation but is backed by strong evidence and may be an effective way of decreasing diagnostic delay in primary care. Research conducted in Denmark provides a helpful comparison to research in the UK. Whilst the population and size of Denmark is much smaller than the UK, the structure of healthcare is similar with list based primary care providing a gatekeeper role to secondary care investigations and treatment. Hence successful strategies implemented in Denmark could be applied to the UK context.

Other interventions to reduce the primary care interval in cancer diagnosis were the subject of a systematic review by Mansell et al. This review included 22 studies often focusing on a single cancer, with skin cancer being the most common. Five types of intervention to reduce delay were identified including education, audit and feedback, decision support software and guideline use, diagnostic tools, and other specific skills training. This review concludes that no study directly reduced primary care delay but that complex interventions including audit and feedback have the potential to do so (87). The authors go on to state that this finding correlates with existing literature which also supports the use of continuing medical education and audit and feedback (88-90). This review included studies from the UK, Australia, USA, Canada, Egypt, Tunisia, and Pakistan. Skin was the most frequently studied cancer, with only two studies considering colorectal cancer. As a result the findings may not be entirely applicable to this thesis. In addition to this, none of the included studies use reduction in primary care delay as the primary outcome. Instead, proxy measures of delay were used including improved knowledge, observational skills, diagnostic accuracy or improved referral rates. In addition to this, only 6 of the 22 studies were reported as high quality. Despite these limitations the review is helpful in identifying possible interventions to improve the recognition and referral of cancer symptoms.

A review of educational interventions for PCPs to promote early diagnosis of cancer included 21 studies in which audit and feedback was the most frequently used intervention, often combined as part of a package of education. The review concludes that interactive education, computer reminder systems and audit and feedback may significantly increase several cancer detection measures and promote earlier diagnosis of cancer (91).

Another potential intervention to improve the recognition and referral of cancer by PCPs is continuing medical education (CME). A systematic review including 11 studies looked at online CME for PCPs. They found 72.7% of

studies reported a significant improvement in at least one of the following outcomes: satisfaction, knowledge or practice change. There was little evidence for the impact of online CME on patient outcomes (92).

Toftegaard et al. reviewed the impact of a CME intervention in early cancer diagnosis on 831 GPs in Denmark. Only 24.3% of GPs undertook the CME learning and the study found the effect on knowledge about cancer diagnosis and their attitude towards their own role in cancer detection was limited. No effect was found on the GPs' readiness to investigate (93). The major limitation of this study is the response rate which could lead to selection bias. Indeed the authors recognise they found evidence of selection bias in the results. In addition to this the low response rate may suggest that CME is not an acceptable method of learning for all GPs, or that the workload in general practice is such that there is not time to undertake the CME online.

The same study group looked at the impact of a CME meeting on the use and timing of urgent cancer referrals in primary care. 396 general practices in Denmark were invited to take part and 40% of the practices participated in the CME meeting. This study found benefits in terms of reduced number of consultations prior to referral but found an increase in the primary care interval in the practices who attended the CME meeting. The authors suggest this may be due to raised awareness of non-specific cancer symptoms, which could cause the PCP to register an earlier date of first symptom presentation (94). The low response rate again is a significant limitation of this study. 40% of practices took part, and on further evaluation there were significant differences between practices which did and did not take part suggesting that any comparisons between the groups in the outcomes may be biased.

Whilst much research has been undertaken to try to understand the reasons behind delay in cancer diagnosis, relatively little work has attempted to reduce this delay. Much of the work which has been undertaken has used proxy measures of delay and were judged to be of low methodological quality. Despite these problems, which are common to much of the literature on early diagnosis, the studies have been conducted in either the UK or Denmark hency are applicable to the UK context and included lung and colorectal cancer often as part of education on the early diagnosis of all cancers. It seems that based on the evidence reviewed, audit and feedback is potentially a promising approach to change PCP behaviour in primary care and improve cancer recognition and referral.

2.7 Summary

This chapter has considered how a delay in cancer diagnosis is defined, as well as the benefits of early diagnosis and the potential reasons for delay. The use of SEA to discover the reasons for delay has been introduced as well as a summary of interventions tested to attempt to improve cancer recognition and referral. It is possible that there is potential to improve the primary care interval in the diagnostic pathway perhaps by improving the recognition and referral of cancer symptoms in primary care. This thesis will focus on the primary care interval with the aim of improving the recognition and referral of cancer by PCPs. Audit and feedback does have potential to improve the recognition and referral of cancer in primary care. SEAs have so far been used to investigate potential reasons for delay, and highlight the importance of safety netting in the recognition and referral of cancer symptoms in primary care. As well as showing the importance of safety netting, this chapter has shown there is potential for SEAs to be used as the 'audit' section of an audit and feedback intervention. This is a novel idea and one which will be explored in more detail in the section below.

2.8 Aims

As discussed in chapters one and two, cancer survival is linked at least in part, to the early recognition and referral of potential cancer symptoms by PCPs in primary care. SEAs have been shown to be an effective tool to learn detailed lessons about the primary care interval in new cancer diagnoses and SEA research completed so far highlights the importance of safety netting. The overall aim of the thesis is to investigate ways in which the primary care interval in the diagnosis of cancer could be improved by exploring the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer symptoms by PCPs in primary care.

This overall aim is addressed through the following specific objectives.

1. To understand the role of safety netting in the recognition and referral of cancer symptoms by scoping the available evidence on safety netting in any primary care setting and to use this information to update the definition of safety netting and develop guidelines on its use

2. To investigate opportunities to improve the recognition and referral of cancer symptoms in primary care using the technique of SEA

3. To explore the feasibility of using the data gathered, and presented through SEAs (i.e. audit and feedback) to develop a series of action plans with the aim of improving the recognition and referral of cancer in primary care

4. To explore the feasibility of implementing and assessing the action plans developed, using repeat SEAs and practice staff interviews

5. To gain insights into the use of audit and feedback and action planning as a technique to improve the recognition and referral of cancer symptoms in primary care

Chapter 3: Audit and feedback and action planning

This research aims to investigate ways in which the primary care interval in the diagnosis of lung and bowel cancer could be shortened. In order to achieve this, two specific objectives include:

1. Using SEAs to investigate opportunities for improved recognition and referral of cancer symptoms

2. Developing a series of action plans through the use of audit and feedback.

Chapter two showed the potential that SEA has to study the recognition and referral of cancer in primary care and went on to consider interventions which have been tested to reduce delay in primary care. SEA has been used to successfully study the primary care interval in both lung cancer diagnoses (69) and diagnoses of cancer following emergency presentations (95). Perhaps SEAs can be used as the 'audit' in an audit and feedback intervention for PCPs. In order to develop action plans, action planning will be used following the presentation of SEA findings in an educational meeting. This chapter will therefore explore the evidence behind audit and feedback, educational meetings and action planning.

3.1 Evidence for audit and feedback

The World Health Organisation (WHO) describes audit and feedback as "any summary of clinical performance of health care over a specified period of time aimed at providing information to health professionals to allow them to assess and adjust their performance" (96). Audit and feedback is widely used to improve professional practice (89). A Cochrane review of audit and feedback included 140 randomised controlled trials making it one of the most widely studied healthcare quality improvement interventions (89, 97). This review defined audit and feedback as "a summary of the clinical performance of healthcare providers over a specified period of time". It is thought that audit and feedback works in a number of ways to change behaviour including changing awareness and beliefs about current practice. It is reported that the technique may overcome a GP's limited ability to self-assess accurately (97, 98). The Cochrane review concludes that audit and feedback leads to potentially important improvements in professional practice. The results of

the review found a small positive overall result in "desired practice outcomes" compared to a control group. The study found a 4.3% absolute increase in the mean adjusted risk difference. However there was a wide variation with an interquartile range between 0.5% and 16%. Foy et al. argue that differences in the outcome of audit and feedback interventions vary due to variation in different aspects of the intervention such as whether the feedback is comparative or not, anonymous or not, the intensity of the feedback, the duration of feedback and the care setting (99).

The Cochrane review provides some advice on how best to conduct an audit and feedback intervention. However, when using the review to develop an audit and feedback intervention for diabetes mellitus, Foy et al. found problems with the recommendations given in the Cochrane review. Foy et al. noted that the review included only five head to head comparisons of methods on giving feedback and that generalisable lessons on how audit and feedback work are difficult to extract. As a result, Foy et al. argue that audit and feedback should be used within a conceptual framework in order to identify the features that systematically influence the effectiveness of interventions (100). Foy et al. suggest five stages for conducting an audit and feedback intervention including preparing for audit, selecting criteria, measuring performance, making improvements, and sustaining improvement (100). Practical considerations are then given for each stage as shown in table 1.

Stage	Recommendations
Preparing for audit	Securing stake-holder interest and involvement (e.g. professionals, patients or carers)
	Selection of appropriate topic, according to whether:
	• Topic concerned is of high cost, volume, or risk to staff or users
	• Evidence of a serious quality problem
	• Good evidence available to inform quality standards
	• Amenability of problem to change
	• Potential for involvement in a national audit project
	• Topic is pertinent to national policy initiatives
	• Topic is a priority for the organisation
	Clear definition of purpose of audit, e.g. to improve or ensure the quality of care
	Provision of necessary support structures, i.e.
	• Structured audit programme (committee structure, feedback mechanisms, and regular audit meetings)
	• Sufficient funding (audit staff, time of clinical staff, data collection, feedback)
	Identification of skills and people needed to carry out the audit
Selecting criteria	Definition of criteria (structure, process and outcome)
	Validity and potential to lead to improvements in care
	• Evidence based
	• Related to important aspects of care
	• Measurable
Measuring level of performance	Planning data collection
	• Definition of user group (and exceptions)
	• Definition of healthcare professionals involved
	• Definition of time period over which criteria apply
Making improvements	Identification of barriers to change
	Implementing change
	• Establishing the right environment (at individual, team and organisational levels)
	• Considering external relationships (e.g. with patients or other agencies)
	• Use of other supporting interventions (e.g. educational outreach, reminders) and / or multifaceted interventions
Sustaining improvement	Monitoring and evaluating changes, e.g. continuing audit cycle, use of performance indicators
	• Appropriate organisational development (e.g. cultural change, adequate training)
	• Use of existing strategic, organisational or clinical frameworks
	• Leadership

Table 1: Stages for conducting an audit and feedback intervention

Audit and feedback has been used in the field of early cancer diagnosis. A systematic review of interventions to improve the diagnosis of cancer included three audit and feedback intervention studies (87). All studies included an educational intervention with a 'before and after' audit. Outcome measures for the three studies included 'improved guideline adherence', 'recording of clinical diagnosis on pathology request forms' and 'improvement in ratio of benign versus malignant melanocytic lesions' (87, 101-103). One of the studies was a randomised controlled trial in which an audit and feedback intervention was undertaken in a group of GPs comparing clinical and histological diagnosis of skin lesions. The control group received no

intervention. This study reported an improvement in the recording of clinical information, but not in diagnostic accuracy in the intervention group compared to the control group (103). The other two studies on audit and feedback included in the review were uncontrolled before and after studies. Whilst both showed a significant improvement with audit and feedback, they were judged to be low quality, with no control group, small sample size, high dropout rates and little information on the content of the intervention (101, 102).

Given that SEA has been used to study the recognition and referral of cancer in primary care and is recommended by the RCGP in the primary care cancer toolkit (69, 77, 95) it is possible that practice SEAs could be used to 'audit' individual practice behaviour. As a result, this thesis will include an audit and feedback intervention using SEAs to stimulate behaviour change in PCPs in primary care. Using SEAs will enable the investigation of past cancer diagnoses to identify opportunities to improve the recognition and referral of cancer.

In order to obtain detailed information on the primary care interval for specific practices in the Hull and East Riding, SEA may be the best research method. Other options for auditing cancer recognition and referral at a practice level could have included using the NCDA which is discussed above. However, this relies on the practice completing the audit themselves and provides mostly quantitative data. Even if access to the data was granted, the NCDA would not have provided the same depth of information. It was felt that SEAs allowed for detailed in depth analysis at a patient, PCP and practice level and would be the most useful form of audit and feedback for PCPs.

Foy et al. suggest that audit and feedback interventions should be based around a conceptual theory (100). One such theory suggested was normalisation process theory (NPT). Johnson and May undertook an overview of systematic reviews of behaviour change interventions using NPT for evaluation (104). The interventions were categorised and mapped to the NPT constructs and mechanisms described below. The review found that both audit and feedback and educational outreach acted across the greatest number of constructs and were among the most effective interventions assessed in the review. The review concluded that interventions based on action such as audit and feedback were more likely to change professional behaviour than other methods, such as those based on persuasion (104). This overview of systematic reviews is subject to a number of limitations. The interventions included were homogeneous, complex and non-standardised

resulting in a large variation in effect size and difficulty in drawing definitive conclusions on effectiveness. However, despite these limitations this review suggests that audit and feedback may be effective in changing professional behaviour and fits well within NPT which will be discussed in Chapter 4 to inform the audit and feedback intervention.

The feedback in this thesis will be an educational meeting between the student and staff at each of the practices involved. A Cochrane review has considered the effects of educational outreach visits (EOV) on professional practice and health care outcomes (105). This review defined an EOV as 'a personal visit by a trained person to healthcare professionals in their own settings'. The review included 69 RCTs of EOVs and concluded that EOVs can provide 'small to moderate' improvements in professional care with a median adjusted risk difference in compliance with desired practice of 5.6%; similar to the findings of the review on the effect of audit and feedback. The review authors state that due to considerable variation in the interventions it was difficult to explain the differences in effect on professional practice. As a result the authors do not give many recommendations on the most effective method of EOV. The authors suggest a social marketing approach but go on to state that it was unclear to what extent a social marketing approach had been used in the interventions or if the approach contributed to the effectiveness of the EOV. Similarly the authors were not able to give recommendations on the frequency or number of visits. The authors did give recommendations on the type of visitor. One study included a questionnaire of GPs on the most appropriate visitor, with seventy-two percent of respondents indicating that another GP (either working clinically or academically and clinically) was the most appropriate visitor. One other study compared a peer vs non peer visitor and found a peer visitor was most effective.

3.2 Action planning theory

One of the key aims of this thesis is to explore the feasibility of using the data gathered, and presented through SEAs (i.e. audit and feedback) to develop a series of action plans with the aim of improving the recognition and referral of cancer in primary care.

Action plans have the potential to help change professional behaviour and could form the basis of the interventions planned in this thesis (106). Sniehotta et al. describe how planning can help to achieve a desired

behaviour. The authors state "by planning, persons develop a mental representation of a suitable future situation ("when" and "where") and a behavioural action ("how"), which is expected to be effective for the goal pursuit to be performed in that situation" (106). Sniehotta et al. go on to explain that action planning is the process of linking goal-directed behaviours to certain environmental cues by specifying when, where, and how to act. These cues can trigger the initiation of action without conscious intent. Gollwitzer & Oettingen provide many examples of the powerful benefits of action planning and state that their analysis strongly suggests that people can derive additional volitional benefits from planning (107). Evidence suggests that action planning can help patients change behaviour in many areas of life including physical activity (108), fruit and vegetable intake (109), snacking (110), childhood obesity (111), smoking (112) and rehabilitation (113).

Action planning has also been shown to be effective for changing behaviour of health professionals. A systematic review of interventions to promote change in health professionals behaviour concludes "This theory-led overview of systematic reviews has demonstrated that interventions based on action tend to be more likely to successfully change professional behaviour than those based on persuasion, such as local consensus processes and opinion leaders" (104).

In order to stimulate change following the audit and feedback intervention, action planning will be used when discussing ways in which the recognition and referral of cancer can be improved in each practice. This will meet the aim of the thesis to develop action plans to improve cancer recognition and referral. This will require a knowledge of behaviour change theory in order to inform and analyse the action plans. A summary of three models of behaviour change are discussed in the following chapter.

3.3 Summary and application of theory

This chapter has looked at the potential of audit and feedback and action planning to improve healthcare and has shown a statistically significant benefit from audit and feedback interventions in a systematic review. The systematic review by Ivers et al. suggests that audit and feedback could potentially change physician behaviour and improve performance across a variety of healthcare settings. In addition three small studies show some potential to improve the recognition and referral of cancer symptoms using

audit and feedback. Ivers et al. give five recommendations based on the review to ensure that audit and feedback is as effective as possible (97). The authors recommend audit and feedback may be most effective when: the health professionals are not performing well to start out with; the person responsible for the audit and feedback is a supervisor or colleague; it [the feedback] is provided more than once, both verbally and in writing; and includes clear targets and an action plan. These recommendations were further developed by Foy et al. who, as discussed above, suggested five stages for conducting an audit and feedback intervention with multiple recommendations in each stage, as well as suggesting any audit and feedback intervention should be based around a conceptual theory (99).

The evidence discussed above has helped to design the audit and feedback intervention planned in this thesis. When considering the topic, Ivers et al. suggests audit and feedback is most effective when health professionals are not performing well to start with (97). In preparing for the audit, Foy et al. suggest choosing a topic which is of high cost or risk to staff or users, where there is evidence of a serious quality problem, which is pertinent to national policy initiatives and a priority for the organisation (99). The recognition and referral of cancer symptoms seems to fulfil all these criteria. Chapters one and two showed that the UK performs poorly when compared to similar countries or regions in terms of cancer survival (7) and the early diagnosis of cancer is a priority both nationally and for individual GP practices (114).

When planning the audit and feedback, Foy et al. give further recommendations, including having a clear definition of the purpose of the audit and provision of necessary support structures including a structured audit programme. When introducing the topic to PCPs the purpose of the audit, and a background summary of the literature will be provided to practices to ensure a clear definition of the purpose of the audit. It was hoped that by using a validated SEA template and practice organised educational meetings, this thesis could work within a structured audit programme as recommended by Foy et al. (99).

Whilst Ivers et al. do not give advice on conducting the audit part of the intervention, Foy et al. suggest selecting evidence-based and measurable criteria which relate to important aspects of patient care (99). When measuring the level of performance, Foy et al. suggest clearly defining the user group, the PCPs and the time period involved. These recommendations were incorporated into design the audit and feedback intervention. The user

group, PCPs and time period have been clearly defined and the reasons behind these choices justified in chapter 7.1.

Advice was given by Ivers et al. on the delivery of the feedback. Ivers et al. recommend that feedback is most effective when given by a supervisor or colleague, when it is given more than once and when it is provided both verbally and in written form (97). Based on these recommendations, the feedback in this thesis will be given in an educational meeting and via a written email summary to ensure it is provided more than once and in verbal and written form. However as will be discussed in the limitations the PhD student is both a GP trainee (registrar) or newly qualified GP throughout the research period. As a result the feedback will not meet the recommendation by Ivers et al. that feedback is given by a supervisor or colleague. However the Cochrane review on EOV discussed above suggested a 'peer' and a 'GP' were the most appropriate visitors. The problems with the use of a GP registrar visitor and possible alternatives are discussed in chapter 11.3.3.

The final recommendation by Ivers et al. was that the feedback should include clear targets and action plans. This final recommendation formed the basis of the second part of the thesis, to develop action plans which could be put in place in each of the nine practices. Foy et al.'s final two stages give further advice on making and sustaining improvement which include identifying barriers to change and considering the environment in which the change is to be made. It was felt that within each practice included in the study the environment and barriers to change will be different, and that the practice staff would be best placed to be aware of these barriers. As a result a plan was made to discuss these potential barriers at each practice, following the educational meetings.

Both Ivers et al. and Foy et al. give little information on the detail of action planning. As a result additional research on action planning was considered. Sniehotta et al. suggest that action planning should include a representation of a future situation, the 'where' and 'when' together with a behavioural action which he called the 'how' (106). This clear structure of action planning will be followed during the audit, feedback and action planning in the thesis. It is hoped the plans will be developed by the practice staff but where possible the student will aim to ensure the plans have a where, a when and a how as recommended by Sniehotta et al. (106).

Foy et al.'s final recommendation is a clear one, forming the final line of the published paper. The authors state "conceptualising audit and feedback within a theoretical framework offers a way forward" (99). The next chapter

will explore behaviour change theory in order to provide a theoretical framework.

Chapter 4: Behaviour change theory

The aim of this thesis is to explore the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer. In order for audit and feedback followed by action planning to be successful, new behaviours and practices will have to be implemented and evaluated. As discussed in chapter three, Foy et al. highlight the importance of basing an audit and feedback intervention around a conceptual theory (99). In addition to this, Davies et al. conducted a systematic review to consider the use of theory in the design of guideline dissemination and implementation strategies, as well as in the interpretation of the results of evaluations (115). The review examined the use of theory in 235 studies that were identified in an earlier review by Grimshaw et al. (116).

The review found that only 53 (22.5%) of the 235 studies used theories of behaviour or behaviour change, and of these only 14 did so explicitly. In total 25 different theories were used, but the authors state that a small number of theories accounted for the majority of theory use. These theories included PRECEDE (Predisposing, Reinforcing, and Enabling Constructs in Educational Diagnosis and Evaluation), diffusion of innovation, information overload, and social marketing (academic detailing). The review also reports that there was poor reporting of the rationale for using specific theories (115).

The major limitation with the review is that the original systematic review used as the basis for this assessment included studies published up to 1998. The authors recognise this limitation and acknowledge that much of the discourse around the role of theory in implementation research has taken place in the last five years. Despite this, the authors highlight that greater use of explicit theory to understand barriers, design interventions, and explore mediating pathways and moderators is recommended (115). The authors go on to recommend that researchers give careful consideration to the choice of theory and have a clear rationale of how the theory is to operate within the study. Finally the authors state, 'the way in which the theory is proposed to explain that to which it has been applied should be clearly stated, as should methodological detail relating to the way in which the theory has been operationalised and analysed' (115). This chapter will explore the use of theory in behaviour change in order to inform the development of interventions through the use of audit and feedback to improve the recognition and referral of cancer symptoms.

The use of theory in research, especially when developing interventions is important. Theory is defined by Michie and Abraham as "a system of ideas or statements held as an explanation or account of a group of facts or phenomena" (117). The Medical Research Council (MRC) highlight the identification of relevant theory as a major step in developing complex interventions (118). The report states "a vitally important early task is to develop a theoretical understanding of the likely process of change, by drawing on existing evidence and theory". Several other papers also highlight the importance of theory when using qualitative methods. Reeves et al. state that theories provide complex and comprehensive conceptual understandings of things that cannot be pinned down such as why people interact in the way they do. The authors go on to state "theories give researchers different "lenses" through which to look at complicated problems and social issues, focusing their attention on different aspects of the data and providing a framework within which to conduct their analysis" (119-121). Foy et al. highlight the importance of using theory when developing interventions to improve patient safety and implement change. The authors argue that theoretical models can provide a basis or vocabulary in order to describe key features of target behaviours, contexts and interventions. They also suggest that "generalisation through theory offers a much more efficient method of generalisation than multiple study replications in different settings" (99). Michie and Prestwich showed that theoretically informed interventions lead to better outcomes (122).

As the evidence presented in chapter two has shown, there is significant benefit in diagnosing cancer earlier, and some of the delay in cancer diagnosis seems to occur in the primary care interval. There is potential to improve the recognition and referral of suspected cancer by changing the behaviour of PCPs. Research suggests that PCP behaviour often differs from best practice, evidence and guidelines (123) and that embedding research findings into everyday practice is 'notoriously difficult' (104, 124). A secondary analysis of survey data was undertaken from the ICBP study in which PCPs were presented with five clinical vignettes relating to lung, colorectal and ovarian cancer in nine jurisdictions. The study found adherence to cancer guidelines ranged from 20% to 82% with the UK having a lower adherence than the other jurisdictions (125). However, there was no link between guideline adherence and one year survival in this study. The study does have some limitations, reporting a response rate of 12%, (only 5.5% in the UK (51)) meaning there is a risk of selection bias. In addition to this, the original ICBP paper noted the survey responders were not

representative of PCPs in all areas. The researchers also had to interpret each jurisdiction's cancer guidelines which could have led to misinterpretation.

The challenge of embedding research evidence into everyday practice has been the subject of international research over many years. A large systematic review of 102 studies concluded there were "no magic bullets" of interventions to improve professional practice, but did report that if used appropriately, a wide range of interventions had the potential to improve care (126). Sandars, a professor of primary care with an interest in understanding and improving the impact of educational interventions on health agrees. He states that in the past there was a naïve assumption that guideline production will automatically influence practice. Sandars argues that the growth of movements such as implementation science have tried to change this but states "there is a common theme which recognises the enormous challenge of ensuring that explicit knowledge can be usefully applied to inform change in practice" (127).

Grol et al. recognised the importance of theory in behaviour change research with respect to health professionals and summarised multiple theories relating to behaviour change, highlighting the huge difference in focus, perspective and underlying paradigms of different theories (128). Much of the early research into behaviour change focused on patients and the general public. It had been assumed that PCP's behaviour was based solely on medical knowledge and therefore beliefs and behaviours would be similar in clinical situations, with any deviations thought to be due to a lack of knowledge (129). Marteau argued that health professionals had been neglected by psychologists and suggested that several models could be used to understand, predict and change the behaviour of PCPs, including cognitive and behavioural models such as information processing theories, attribution theory and subjective expected utility models (130).

As discussed above, Davies et al. found that in implementation research conducted before 1998 only 22.5% of studies had used behaviour change theory (115). Cane et al. highlight that theory selection is difficult, stating there is a risk of missing relevant theoretical constructs or including irrelevant ones (131), as well as basing interventions on several theories with overlapping theoretical constructs. One attempt to solve this dilemma was the theoretical domains framework (TDF) which aimed "to simplify and integrate a plethora of behaviour change theories" (132). Frameworks such as the TDF have strengths as well as limitations. As suggested by Cane et

al. it is likely that by using a framework based on multiple theories the risk of missing important constructs is reduced (131). Cane et al. also highlight the TDF has proved useful across a number of healthcare systems to improve implementation and bring about behaviour change. However in an interview study of researchers who had used the TDF it was criticised for being time consuming and resource intensive, difficult to understand and requiring a background understanding of psychology (133).

In order to inform the empirical work presented in this thesis, a decision was made to focus on three theories of behaviour change; the theory of planned behaviour (TPB) (134), the behaviour change wheel (BCW) (135) and the normalisation process theory (NPT) (136). These theories focus on professional behaviour change. The reason for this choice is that many of the objectives of this work will depend on changing the behaviour of the PCPs at each practice. The three models of behaviour change are summarised below. It is hoped that these three theories will provide a knowledge base by which to both design and evaluate the action plans in this research. The TPB was chosen as it is based on social cognitive theory and as a result may provide an insight which, health professional based models could miss. The BCW and NPT were chosen as they specifically focus on behaviour change in healthcare. They are both widely used for looking at PCP behaviour change and have a growing evidence base in primary care research. The BCW maintains a focus on social aspects such as motivation and attitudes, whereas NPT focuses on the implementation of interventions. As such, both theories may be helpful when designing the audit and feedback intervention. The advantages and limitations of each theory will be considered before a decision is made on a theory to help inform the design and guide the analysis of the interventions used in this thesis.

4.1 Theory of planned behaviour

Early research on behaviour change focused on social cognitive theories such as the theory of reasoned action and the TPB developed by Ajzen & Fishbein (134, 137). These theories aimed to understand voluntary behaviour, and state that each behaviour is preceded by an intention to perform the behaviour and that this intention is influenced by the person's attitude to the behaviour, and the subjective norm. Intention was defined by Ajzen as "indications of how hard people are willing to try, of how much effort they are planning to exert in order to perform a behaviour" (134). The model is a linear one, in which 'attitude', 'subjective norm' and 'perceived

behavioural control' interact with each other and influence 'intention' which then leads to a behaviour. Attitude was described as the person's evaluation of the behaviour of interest. Subjective norm relates to the individual's beliefs on what their peers and people important to them think about the behaviour. Finally perceived behavioural control describes the degree to which the individual believes they can control any given behaviour and the perception of the ease or difficulty in performing the behaviour.
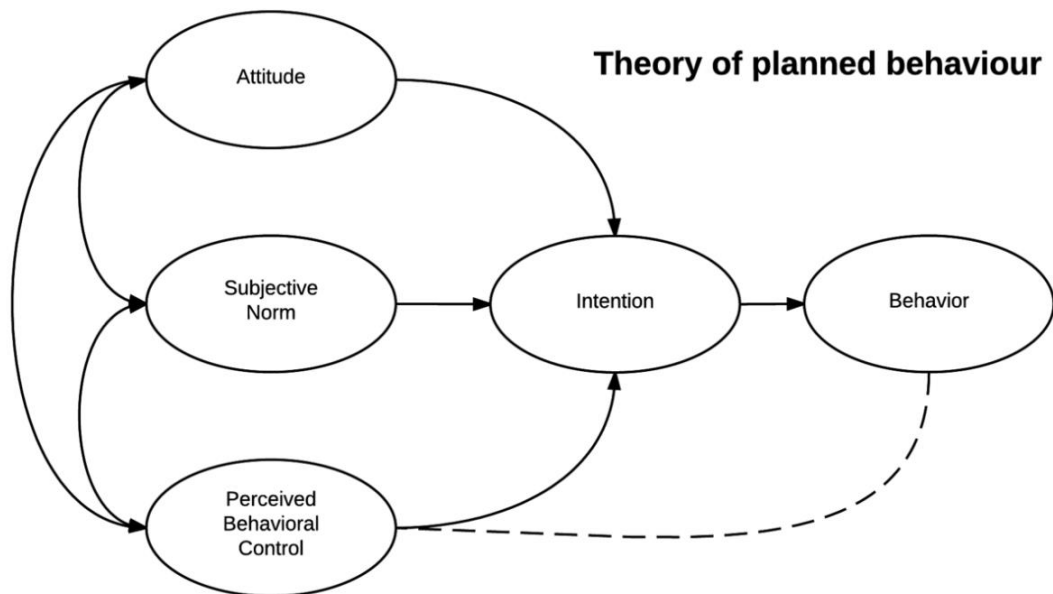
Figure 12: The theory of planned behaviour (134)

The TPB has been extensively researched and the link between intention and behaviour studied. A large meta-analysis including 185 tests of the TPB found support for the theory as a means of predicting intentions and behaviour (138). This finding was supported by earlier reviews by Hausenblas et al. (139) and Godin and Kok (140). The TPB has been used to understand health professionals intentions to use clinical guidelines. A study by Kortteisto et al. concluded that "the theory of planned behaviour is a suitable theoretical basis for implementing clinical guidelines in healthcare practices (141). A systematic review by Godin et al. considered healthcare professionals' intentions and behaviours using social cognitive theories and, similarly to Kortteisto et al., concluded that the TPB is an appropriate theory to predict behaviour in health professionals (142). A further systematic review by Eccles et al. found 10 studies which considered the relationship between intention and behaviour in health professionals. The behaviours studied included hand washing, patient education, clinical record keeping and prescribing. The review found a similar correlation between intention and

behaviour in PCPs compared with studies of the general population, of around 15% to 40% (143). The authors highlight a number of methodological problems with the review including difficulty measuring behaviour and differences in the reporting of studies.

This research suggests that whilst there is a link between intention and behaviour, it is not perfect and there is an 'intention behaviour gap' which has been the subject of further research. One approach to investigate the intention behaviour gap was to focus on 'post intentional processes' which may include a motivational phase (144) and subsequent volition phase (145). The motivational phase is influenced by perception of risk, expectations about the outcome and perceived self efficacy. The volition phase includes the planning, initiation and maintenance of behaviour, with action planning, self efficacy and action control thought to be important (106). Focusing on post intention mediators may help individuals to minimise the intention behaviour gap.

Like all theoretical models, the TPB has strengths and limitations. The strengths of the TPB include the use of social norms and perceived behavioural control to explain an individual's social behaviour and the strong evidence base behind the link between intention and behaviour, supporting the theory. As discussed above, the link between intention and behaviour is shown in a number of studies in both the general population and health professionals and the use of the model to predict behavioural intention is possible. The model helps to explain the link between intention and behaviour through perceived behavioural control. However the model is subject to some limitations. Firstly the model has been criticised for failing to take into account context and the person's needs, opportunities and resources in order to perform a certain behaviour. It has been argued, that whilst social cognitive models such as the TPB are widely used, they fail to address many other factors in decision making, such as impulsivity, habit, prior experiences, mood and emotional processing (146, 147). When considering PCPs, social cognitive models have been criticised for failing to address the complexity of clinical decisions undertaken by PCPs which could be affected by the type of health condition, the relationship between PCP and patient, multimorbidity and the acceptability of the treatment to the patient (142). Schaalma argues that using multiple theories allows the researcher to fully understand the complexity of behaviour change interventions. Whilst the focus of that work was the general population, the same approach could be used in PCPs (148).

4.2 The behaviour change wheel

The BCW was developed by Michie et al. following a review of existing behaviour change frameworks. The review compared the 'usefulness' of 19 frameworks using an established criteria of comprehensiveness, coherence and links to an overarching model of behaviour. The review found that none of the existing frameworks were comprehensive; only three were ranked as coherent and seven of the 19 were linked to an overarching model of behaviour (146). The review authors developed a framework for understanding behaviour entitled the COM-B system in which capability (the individual's psychological and physical capacity to engage in the activity concerned), opportunity (all the factors that lie outside the individual that make the behaviour possible or prompt it) and motivation (brain processes that energize and direct behaviour) interact to generate behaviour which then in turn can influence the components. This is shown in figure 13. The BCW was then developed by tabulating the intervention categories identified and linking them to the COM-B system described in figure 14. Once a target behaviour has been established, the red middle circle provides nine evidence based interventions which are each defined. The outer layer of the BCW identifies policy categories which apply more to changes targeted at an organisation or population level (149). The BCW was tested on the 2010 English Tobacco Control Strategy and the NICE Obesity Guidance showing high inter-rater agreement (146).

The BCW has been developed following an extensive review and was tested for reliability. It incorporates context by including 'opportunity' as one of the three main components of the behaviour system, and establishes that a target behaviour can arise as a result of multiple variables. Michie et al. recognise the importance of context, which the authors state, is key for effective design and implementations of interventions. A strength of the BCW is that through the opportunity section of the BCW, context can be included and can be the starting point of intervention design. This context is often missed in other theories such as the TPB which focuses on the individual and their cognitive processes, rather than the context around them.

The BCW was developed following a systematic review of behavioural change frameworks as discussed above. This method is subject to some limitations. It is possible that during the searching process important frameworks were missed, which could lead to the BCW being incomplete, or other behaviour or policy functions being available but not being included. Following on from this, when the review had been completed, the

interpretation and conceptualisation of the frameworks was subject to the author's individual judgement and as a result the BCW may not be the most optimal way of combining all the relevant data.
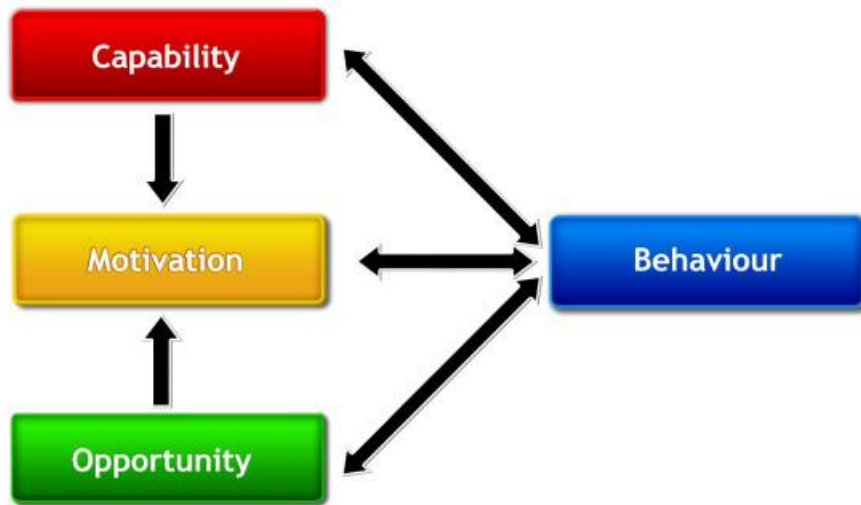
Figure 13: The COM-B model (146)
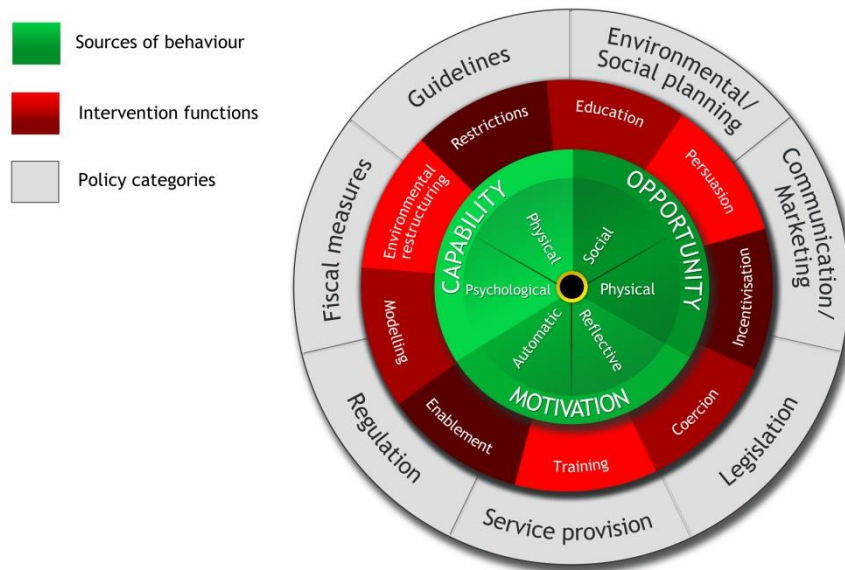
Figure 14: The behaviour change wheel (146)

4.3 Normalisation process theory

The final behaviour change theory considered is NPT. NPT was introduced by May and Finch in 2009 (150) and focuses on implementation and action. Rather than studying the beliefs, attitudes and intentions of people, NPT looks at what people do when they enact a behaviour or change practice.

NPT aims to understand and explain "the social processes through which new or modified practices of thinking, enacting and organising work are operationalised in healthcare and other institutional settings" (151). NPT identifies factors that promote or inhibit the incorporation of interventions into everyday practice and focuses on the work that individuals and groups do to enable an intervention to become embedded into everyday practice (normalised) (136). The three key problems NPT aims to understand are implementation (the social organization of bringing a practice or practices into action), embedding (the processes through which a practice or practices become routinely incorporated in everyday work of individuals and groups) and integration (the processes by which a practice or practices are reproduced and sustained among the social matrices of an organization or institution) (151). NPT contains four social mechanisms which help to understand the processes through which behaviour change interventions are enacted. The four mechanisms are: *coherence* (what users do to make sense of new practices); *cognitive participation* (what users do to engage with new practice); *collective action* (what users do to enact a new practice); and *reflexive monitoring* (what users do to appraise the effects of a new practice). Each of the four mechanisms, has four constructs which can be viewed in the referenced paper (151).

NPT offers a theory for understanding and evaluating behaviour change in a wide range of clinic settings with a diverse range of complex interventions. A review of studies which had used NPT reported that very little data fell outside of the theory. However some studies reported difficulties due to potential overlap in the NPT constructs and difficulty discerning the difference between constructs. Despite these limitations, the review concluded that 15 of the 20 included papers gave a "strong endorsement" for NPT, largely as a result of "providing an explanatory theoretical framework for identifying factors that promote and inhibit implementation of complex interventions" (152).

4.4 Summary

This chapter has explored three different theories of behaviour change relevant to the aims of this thesis. Ogden argues that whilst theories are useful for providing definitions which allow for clarity and replications, that they do not allow for variability (153). Ogden states this may not be variability for type of behaviour, intervention or even patient, but variability according to how the individual patient may feel, look, think, behave or respond at any

given time (153). Peters argues that large overarching theories of behaviour change diminish the existing variability in other theories which may be to the detriment of the efficacy of behaviour change science and its ability to progress (154).

All three theories discussed above have strengths and limitations, and some authors have suggested a combination may be the most effective way of studying behaviour change (148). A decision was made to use the BCW and NPT to inform the design of the research in this thesis and to help guide the analysis and interpretation of the findings.

As discussed above, at the centre of the BCW is the COM-B system. This suggests that behaviour is influenced by capability, opportunity and motivation. The COM-B system was at the heart of the design of the audit and feedback intervention planned for this thesis. By allowing the student to conduct the SEAs, collate and analyse the data produced, it was hoped the PCPs would be more likely to have the capability to engage with the findings and enact the subsequent action plans. It was thought by conducting the work on behalf of the practice workload could be reduced, improving capability. By allowing practice staff to listen to the findings of the SEAs, to discuss the findings as a group and to develop their own action plans, it was thought that both capability and opportunity would be improved. PCPs and practice staff were ideally placed to be aware of the potential barriers and facilitators to behaviour change in their individual practices and could use this knowledge to develop action plans which are more likely to change behaviour. Finally, it was hoped that motivation could be improved by conducting a SEA of the PCP's own patients and including examples of the PCP's own care and effects on the patients they are responsible for, motivation for change would be improved.

Whilst the aim of the action planning was to allow the practice staff to develop their own interventions based on the findings of the SEA audit, the policy and intervention categories of the BCW were used in both the development and analysis of the action plans. Whilst being developed and planned by the practice staff, the action plans were categorised using the policy and intervention functions described by Michie et al. which also helped in the analysis of the plans discussed in chapter nine.

The other theory chosen for use within this thesis focuses more on implementation and action, looking specifically at how behaviours are changed. NPT contains four social mechanisms which help to understand the processes through which behaviour change interventions are enacted. The

first two mechanisms, *coherence* (what users do to make sense of new practices) and *cognitive participation* (what users do to engage with new practice) were helpful when designing the audit and feedback intervention used within this thesis. The construct of *coherence* enabled the development of the educational meeting introduction in which the importance of early cancer diagnosis was introduced. The decision to conduct an audit of each practice's own patients was strengthened by the construct of *internalisation* which highlights the need to demonstrate the value, benefits and importance of a set of practices. If the PCPs could see the benefit of the project to their own patients, it may be more likely the new behaviours are enacted.

By enabling practice staff to develop their own action plans, the NPT core construct of *cognitive participation* may be strengthened. NPT suggests that for a new behaviour to be enacted, a community of practice around the new behaviour must be built and sustained. Through the development of action plans in an educational meeting with a range of practice staff it was hoped that staff could collectively contribute to the development and reorganisation needed to enact a new behaviour.

During the analysis of the action plans in chapter nine, all of the core constructs of NPT were used to try to understand the reasons for the potential success or failure of implementation of the action plans. The figure below shows how the theories chosen will fit into and inform the planned research. How each theory fits into this research will be discussed in the methods and results section of the results chapter.

The action plans were developed solely by the practice staff who may not have had any knowledge of the theories of behaviour change. As a result, the design of the interventions may not have been influenced by the BCW or NPT. It may have been possible to use some of the time in the educational meeting to provide an overview of the theories of behaviour change which could have influenced the design of the interventions. However, as discussed in the limitations of this thesis in chapter 11.3, time was often limited in the educational meetings therefore it was decided the time would be better spent conveying the findings of the audit.
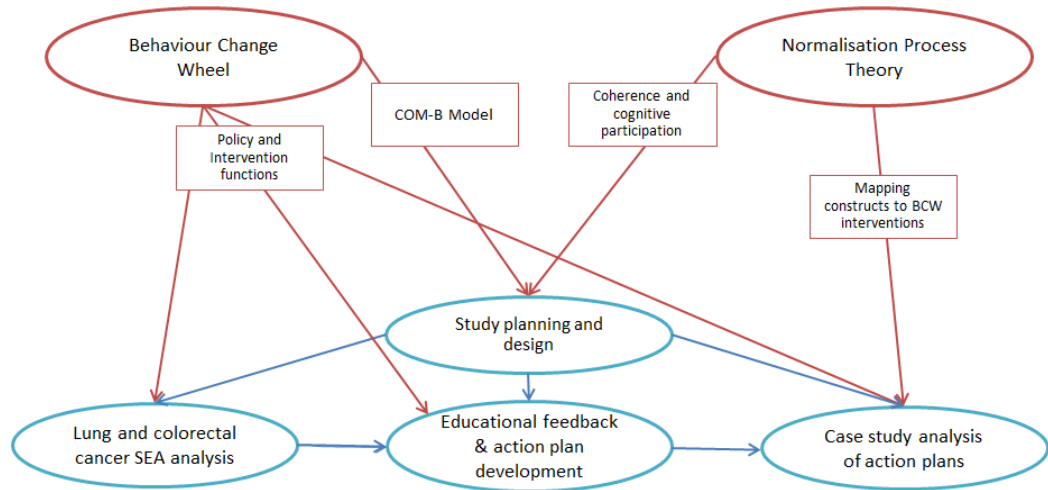
Figure 15: The research methods and the theories of behaviour change

Chapter 5: Research Methodology

This chapter provides an overview of the methods used within the thesis, the reasons behind the chosen methods, other potential methodological options that could have been used, and a justification of the chosen methods. The detailed methods used in each part of the thesis can be found within the results chapters below.

5.1 Study design

In order to meet the aims and objectives of the research, the thesis was split into three distinct sections. Firstly, in order to understand the role of safety netting, a scoping review was undertaken. The second part of the research aimed to investigate opportunities to improve the recognition and referral of cancer symptoms in primary care using SEAs by investigating the GP record of patients diagnosed with lung or colorectal cancer. Finally, the SEA data were used in an audit and feedback intervention to develop a series of action plans to improve care. This was achieved through the use of SEA and individual audit and feedback. The action plans were assessed using case note review and interview data coded using thematic analysis (TA) and NPT. Figure 16 shows how each component of the thesis met the aim and objectives of the research.
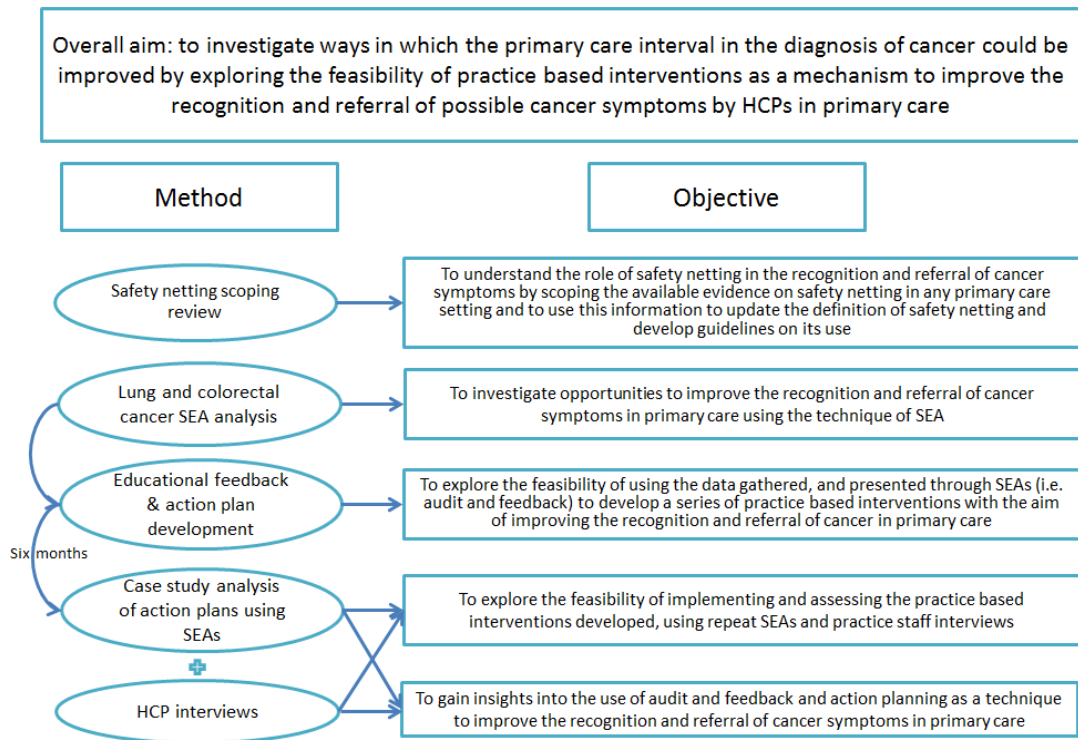
Figure 16: How the research methods met the aims and objectives

5.2 Methodological theory

As discussed in chapter four, the intervention in this study is based on two theories of behaviour change; the BCW (149), and NPT (151). The rest of this chapter considers other theory related to the design of this research.

5.2.1 Case note review

This research focused on the primary care interval of the pathway to cancer diagnosis using SEAs, and investigated encounters between PCPs and patients. As discussed in chapter two, SEAs are a form of detailed case review. In this study, the student completed an SEA template using data from anonymous computer medical records. The multiple SEAs collected at each GP practice were analysed qualitatively using an interpretive matrix and coded using TA.

Case note review methodology has been documented in medical literature for over 100 years with much of the case review methodology developed in the 1970s by Peer Review Organisations in North America. Case note review methodology has been divided into holistic or criterion based reviews (155, 156).

Holistic case reviews consider the patient documents or case as a whole to inform a judgement on quality of care. Holistic case reviews rely on professional judgement and are therefore dependent on the reviewers personal knowledge and perspective which is subjective and difficult to replicate. Holistic case reviews can be used to study any aspect of care and can be applied to any condition. They have the advantage of not requiring a detailed knowledge of each individual case (155, 156)

Criterion based case note reviews allow for a comparison of the quality of care in a given case with pre-defined standards such as national clinical guidelines. This method is thought to be more objective, and can be reproduced but means that only predefined criteria or questions can be addressed. This could mean that unexpected factors contributing to quality of care are missed (155, 156).

The SEA template which will be used in this case note review allows for a holistic case note review, with free text boxes to document the case and to reflect on the quality of care. However the template also has specific guidelines in each section to structure the SEA and ensure the correct level of detail is recorded. For example in the "why did it happen?" section the template suggests considering "whether appropriate diagnostic services were used". These suggestions allow for comparison between SEAs and help to ensure they are reproducible when completed by different PCPs or researchers.

Previous SEA research has required the clinical team involved in the patient's care to complete the SEA document. In this research all of the SEA data collection was conducted by the student (who is a GP and PhD student). This approach has both strengths and weaknesses and these will be discussed in chapter 11.3. The analysis of documents which are produced as part of the research process is a well-established technique. As Rapley states: "documents may exist prior to the research, such as acts of parliament, minutes of meetings or books, or they may be generated through the research, such as diaries, biographies and field notes" (157).

5.2.2 Epistemological standpoint and analysis method

The completed SEA documents will be analysed using TA. TA is described by Braun and Clarke as a qualitative method of analysis which can be applied across a range of theoretical and epistemological approaches. The authors define TA as a method for identifying, analysing, and reporting patterns (themes) within data. TA can be used as both an essentialist, or

constructionist method which can work to both reflect reality and to unpick the surface of reality. Braun and Clarke recognise that any theoretical framework will include a number of assumptions about the nature of the data and, whilst this is inevitable, good TA will make these assumptions transparent (158). It was felt that TA would better suit the analysis of this thesis due to the position of the student as a GP. In comparison with interpretative phenomenological analysis (IPA) which requires that the preconceived ideas the student may have about the data are ignored, TA recognises these assumptions may be present and advises that the student makes these transparent.

IPA as an analytic strategy was considered, as it was thought this project could also be suited to a phenomenological approach. Phenomenology was developed by Husserl and looks at the way things appear to individuals in their experience (159). Phenomenological studies consider people's description and experience of events rather than simply describing them in a standardised way (159). This would fit well with the aims of this thesis which will consider the phenomenon of the PCP consultation and the primary care interval. This research offers insights into how a PCP makes sense of a patient's 'story' or a set of symptoms and chooses to refer or not to refer based on their own ideas and interpretation of that story. Similarly, after the presentation of the findings at the educational meeting the PCP must make sense of the findings and develop an action plan based on them.

Both Barbour (160) and Larkin et. al. (161) give advice on analysing data from an IPA stance, stating that analysis often starts from the bottom up, generating codes from the data, without pre-conceived ideas around what may be found. Barbour goes on to discuss that IPA analysis starts with a detailed examination of one case until some outcome or 'closure' has been achieved before moving on to a second and then third case.

However as Barbour and Larkin suggest, in order to analyse data using IPA, the researcher cannot have pre-conceived ideas around the causes of early cancer diagnosis (160, 161). As a GP, it was difficult for the student not to have preconceived ideas and as such TA was a more appropriate way to analyse the data. However the TA approach adopted was a social constructionist one and therefore, whilst a different analytic strategy to IPA, the underlying epistemological standpoint, that of interpretivism, was similar.

5.2.3 Case note review analysis

The SEA documents produced during the thesis were analysed using the methods described by Mitchell et al. whose paper, described in chapter two, was the first to use SEAs to study the recognition and referral of lung cancer in primary care (69). Mitchell et al. describes the analysis of SEAs using a modified framework approach in which SEAs were read and re-read and coded using a thematic coding framework. In this study QSR Nvivo 10 was used to facilitate coding and organise the data. Following familiarisation with the data, initial codes were generated, as recommended by Braun and Clarke (158). These codes were generated by the student based on both knowledge of the data and the existing theory. A coding framework was developed following this which included a list of the codes as well as a plain English summary of what was meant by each code. A selection of SEAs, approximately 10%, were double coded by DJ and UM to ensure consistency. This coding allowed the "why did it happen" section comments to be analysed together and to spot common themes in the data set.

Following this an interpretive matrix was developed as described by Mitchell et al. by extracting relevant data from each SEA into a thematic chart in order to identify common and unique aspects of the diagnostic pathway. In each case data were extracted from each SEA in turn using the pre specified thematic chart which was created using Microsoft excel, and was based on the matrix developed by Mitchell et al. in their earlier work using SEAs. Data were extracted on demographic information on each case such as age, sex, whether the patient was alive or dead and any comorbidities. In addition to this, important dates were recorded including the date of first presentation (referred to as the index presentation throughout the analysis), referral, diagnosis and death. Presenting symptoms, PCP examinations and actions were also recorded as well as the results of any investigations. The total number of consultations, type of referral (routine / urgent / 2ww) and the reason for referral was documented as well as the date the patient would have met the 2ww referral criteria according to the NICE guidelines (22, 25). The statistics programme SPSS was used to calculate the time between index presentation and referral and index presentation and diagnosis as well as the time between meeting the 2ww criteria according to NICE and actual date of referral.

5.2.4 Interview methodology

The final part of the research involved interviews with PCPs at the practices in which the SEA data were collected. These interviews aimed to provide an insight into the use of audit and feedback and action planning from those 'at the front line', who were seeing patients and making decisions about investigations, referrals and diagnosis. The interviews aimed to inform the evaluation of the audit and feedback part of the project, providing insights into the barriers to implementing action plans, and feedback on how the educational meetings may be improved to further develop this method of behaviour change.

It was recognised that a qualitative research method would be most appropriate to gain insights into early cancer diagnosis and to evaluate the action plans. The student considered the use of interviews or focus groups with PCPs as the best method to collect this data. Questionnaires were also considered but it was thought this method would not provide the opportunity for PCPs to provide their own detailed thoughts on the diagnosis of cancer.

Interviews have been regarded as "the gold standard of qualitative research" (162) and are the most commonly used qualitative research method (160). Mason states that all interviews have four 'core features' in common: an interactional exchange of dialogue, an informal style, a thematic, topic-centred, biographical or narrative approach and the construction or reconstruction of knowledge (163).

Focus groups were thought to be a feasible alternative to interviews. Focus groups were described by Kitzinger as "a form of group interview that capitalises on communication between research participants in order to generate data" (164). Like interviews, Kitzinger argues that focus groups are useful for exploring people's knowledge and experience, and not only what they think, but how and why they think that way. Focus groups have some advantages over interviews. Focus groups may encourage participation from those who are reluctant to be interviewed, or may be intimidated by a 'one on one' interview, and could encourage contributions from participants through group discussion (164). Morgan argues that when exploring complex behaviours and motivations (such as the diagnosis of cancer) focus groups may be more beneficial than individual interviews. Morgan argues that this is a result of the participants in the group being able to explain themselves to other members of the group (165). However, there are disadvantages of focus groups. It has been argued that the moderator can more easily affect the outcome in focus groups (166), and studies suggest focus groups may be

less efficient (167). Practically, interviews were thought to be more feasible, due to the current workforce crisis in UK general practice (168). It was thought to be easier to arrange one on one interviews rather than focus groups which would require multiple PCPs to be able to meet at one time. In addition to this, it was noted that interviews had already been successfully used in a study exploring the insights of GPs into cancer diagnosis by Green et al. (38) and one could question whether or not PCPs would be happy to discuss potential 'missed opportunities' in a group setting. Interviews were audiotaped and transcribed verbatim. TA was undertaken using QSR Nvivo to organise and structure the interviews. To ensure rigour a proportion of the interviews were double coded by PhD supervisor (UM). Disagreements in coding were resolved by discussion between the student and UM. This process was a helpful one, whilst the student and supervisor agreed on most of the coding gaining the input from more than one perspective helped to clarify the analysis of the interview data and develop the coding framework. The fact that coding was consistent increases rigour and consistency and means that research bias is less likely (169).

5.2.5 Summary

The intervention in this thesis as a whole, using SEAs to gather data as part of an audit and feedback educational meeting with the development of action plans, was based on the models of behavioural change discussed above, with the qualitative analysis of the SEAs and PCP interviews undertaken using TA. Case note review was used to assess the implementation of the action plans, six months after their development and implementation. PCP interviews were also used in the assessment of the action plans where NPT helped to guide the analysis. The NPT online handbook and toolkit gives recommendations on how to incorporate NPT into the coding of qualitative data (170).

A detailed description of the methods used in each part of the thesis can be found in the individual chapters six, seven, eight and nine.

5.3 Setting

The SEA data collection, feedback meetings and PCP interviews took place in nine general practices across Hull and the East Riding of Yorkshire in the UK. The area studied has large rural areas as well as inner city and coastal areas. The area is served by two clinical commissioning groups (CCGs) and one acute trust. There is wide variation between areas studied in terms of

deprivation and health. Government statistics show Hull CCG is ranked 12th most deprived area out of 210 CCGs for deprivation, compared with East Riding CCG which is ranked 158th. In terms of health there are also stark differences, with Hull CCG ranked 27th least healthy, compared to East Riding which is ranked 161st (171). More detailed practice profiles and details on practice recruitment are presented in chapter seven.

5.4 Ethical approval

Ethical approval is important for all research studies and appropriate ethical approval was sought for each part of this PhD research. Below is a summary of the important ethical issues, followed by an explanation of the process of obtaining ethical approval.

5.4.1 Ethical issues

The scoping review on safety netting involved a review of the literature only; as a result no ethical approval was required for this part of the research project.

The section on the use of SEA to identify opportunities to improve recognition and referral of lung and colorectal cancer symptoms had a number of ethical issues. These included access to medical records, confidentiality, consent, data protection and the process of recruitment of practices and staff.

5.4.1.1 Access to medical records and patient consent

Collecting the data for the SEAs involved reviewing the notes of patients with a past cancer diagnosis and completing an anonymous audit form, with the aim of recording the events leading up to the diagnosis of cancer. The 1998 Data Protection Act aimed to protect an individual's right to confidentiality and stated that no identifiable data on living individuals should be handled or disclosed without the explicit consent of the subject (172). In addition to this, section eight of the Human Rights Act includes medical records in an individual's right to privacy (172). However, historical case note review is an important tool to monitor performance and learn from past cases. The Data Protection Act could have potentially prohibited any review of this kind without patient consent, which may be difficult to obtain years after medical treatment. Section 33 of the Data Protection Act contains a clause which allows historical records based research provided certain conditions are met. These include not causing distress, and not identifying individuals in results

or publications (172, 173). Finally, the Data Protection Act and the Information Commissioner state that in the absence of consent, all identifiers should be removed "so as not to act unfairly with regard to the individual"(172).

In response to security concerns about patient records, the Caldicott report was released in 1997. This included six key principals and 16 recommendations for handling patient data (174). This introduced the concept of direct care and the direct care team. The student is a GP, bound by the General Medical Council's (GMC) good medical practice and confidentiality guidelines (175). It was thought that as the study could improve the safety and quality of care for patients with suspected cancer at each practice, the Caldicott guidelines would define the student as a member of the direct care team (174). However, the Health Research Authority (HRA) confidentiality advisory group (CAG) defines the care team as "health professionals involved in the diagnosis, treatment or care of a patient" (176). This definition suggested that the student would not be classed as a member of the care team.

The protection of patient's privacy and confidential information is of the utmost importance, but the guidance surrounding the access to patients notes is somewhat confusing. The process to obtaining access is discussed in section 5.4.2

5.4.1.2 Storage of data

Once collected, data was stored securely to protect patient confidentiality. No confidential information was taken away from the practice. The SEA template provides very basic demographic details such as age and date of diagnosis and is felt adequate to provide anonymity. Anonymous SEA forms were completed at the practice and stored on a password protected memory stick.

5.4.1.3 Recruitment

The 'participant' in the study is the GP practice. Individual GP practices were contacted by the student. Contact was made with the practice manager or senior GP partner who was sent a research information sheet. This approach is subject to some limitations which are discussed in chapter 11.3.

5.4.1.4 Staff interviews

The final part of the thesis to be considered was the planned interviews. The ethical issues in this section centred on recruitment of participants, informed

consent and data use and storage. Recruitment was undertaken from the pool of practices that were recruited for the SEA study. Staff at each practice were invited by email which contained a participant information sheet. The aim was to interview between one and three PCPs at each practice. Informed consent was taken from staff members who agreed to be interviewed. The consent form included consent for interviews to be audiotaped and for quotes to be used in the analysis. These recordings were immediately transferred to password protected memory sticks. The records and subsequent transcriptions were anonymised.

5.4.2 Obtaining ethical approval

As with all studies, the research within this thesis required ethical approval. In the UK, the HRA oversee the ethical approval process. The first step is to establish if, according to their criteria, the study is classed as a research project or a service evaluation. This was an important decision as correct and thorough ethical approval is required in order to protect patients. The HRA has developed guidelines to help authors define research. These guidelines entitled "defining research" describe four key discriminants to help determine between research and audit or service evaluation (177).

In addition to these guidelines, the HRA in collaboration with the Medical Research Council (MRC) have developed a decision tool determine if the study is classed as research (178). This decision tool asks three questions based on the discriminants above.

1. Are the participants in your study randomised to different groups?
2. Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
3. Are your findings going to be generalisable?

The SEA project in this thesis did not involve the randomisation of participants and does not involve changing the treatment or care of patients. The difficult question surrounded the generalisability of the findings. The main aim of the SEAs was to use the findings to develop an educational meeting to be used as feedback for the PCPs at each practice involved. It was hoped that this could improve the diagnosis of cancer at each practice and therefore improve cancer survival of patients at each practice. This means that the outcome of the study was only of interest to the local area involved in the research. By this definition the SEA work was not generalisable. HRA state in the "Defining Research" guidelines, that studies may have more than one intent. A secondary aim of the SEA research in this

study included the development of new findings as a result of the SEAs conducted.

The HRA decision tool was completed and following discussion with supervisors a full research ethics committee form was submitted to the HRA. It was decided the project should be classed as a service evaluation for the purposes of HRA classification. Institutional ethical approval from Hull York Medical School (HYMS) would be required. A copy of the outcome of the HRA decision tool can be found in appendix A.

Ethical approval for the SEA study was obtained from HYMS and the study was discussed with the local research and development team, who despite not being required to authorise the study, were helpful in further clarifying and supporting the decisions made by the student. The HYMS ethical approval can be found in Appendix B.

The issue of accessing medical records required the input of a separate branch of the HRA entitled the confidentiality advisory group (CAG) which provides independent expert advice on the control of patient information for studies classified by the HRA as both research and non-research. The CAG has produced a pre-application checklist in order to assess the need for CAG approval for research studies. This checklist can be viewed in appendix C. The key question in the checklist for this study is question nine which asks "can de-identified information be used?" After seeking help from colleagues skilled in the electronic GP record systems, it was established that it was possible for a student to view the medical record without viewing confidential data. The GP computer records systems EMISweb and SystmOne both allow the patients identifiable details to be hidden. This safeguard meant the student would not be able to view any documents from secondary care which may mean that information regarding the diagnosis and attendances at accident and emergency, out of hours and other hospital clinics may be lost. It did however secure the anonymity of patients and satisfied the requirements of the CAG (176).

Finally, in order to interview staff members at the practices HRA R&D approval and HYMS ethical approval was obtained.

Chapter 6: Safety netting in healthcare consultations: a scoping review

Chapter 2.5 introduces the importance of safety netting in the pathway to cancer diagnosis. Detailed studies on the primary care interval such as SEA work by Mitchell et al. (69, 95) have shown that a lack of safety netting can have a negative impact on time to diagnosis. This chapter will describe the method and results of a scoping review which aimed to better understand the role of safety netting in the recognition and referral of cancer symptoms.

Safety netting is a consultation tool used by PCPs to ensure that patients know what to do if things do not go as anticipated. It could potentially improve patient safety within primary care by providing information for patients, empowering them to spot signs of serious illness and/or know when to re-present. Although safety netting activities are likely to have been around for longer, the practice was formally identified nearly 30 years ago by Roger Neighbour (78) who described it from the point of view of the PCP answering three questions: "*If I'm right, what do I expect to happen? How will I know if I am wrong? And what would I do then?*". Safety netting is considered best practice and an essential component of the consultation (179). It is included in several consultation models (79, 179, 180) and is recommended in national guidelines, including NICE guidance on the recognition and referral of suspected cancer (25), management of feverish children (181), meningitis (182), gastroenteritis (183) and self-limiting respiratory tract illnesses (184).

Current research on safety netting has concentrated on consultations with children, and on the early diagnosis of cancer. As a result, CRUK (185), Macmillan Cancer Support (186) and the Royal College of Paediatrics and Child Health (187) have issued safety netting guidelines. This has resulted in an increasing number of definitions of safety netting and variation in its constituent elements, along with calls for more research on what recommended safety netting advice should incorporate (188).

Bankhead et al. were among the first to attempt to provide recommendations for safety netting in primary care. They aimed to identify the components of safety netting relating to cancer diagnosis (189). The aim of this review was to build on the work by Bankhead et al. to collate and summarise the evidence on safety netting for all patients. Specific objectives were to (i)

identify definitions of safety netting and develop a summary to provide conceptual clarity, and (ii) propose a common approach to safety netting for all consultations including when safety netting is required and the information it should include.

6.1 Scoping review method

The concept of safety netting is broad. It can be used in different patient groups, in a wide variety of clinical settings and may include different actions. In order to collate the evidence on such a broad and poorly defined topic, a scoping review methodology was chosen with the aim of mapping the body of literature on safety netting.

As an alternative, a systematic review methodology was also considered. A systematic review was thought to have several advantages over a scoping review, including improved perceived rigour (190), an established and widely used guideline on the conducting and reporting of the review (191) and an opportunity to assess the quality of included studies. However, despite these advantages, a scoping review methodology was chosen for the following reasons. It was felt that the broad and ill-defined concept of safety netting would be better suited to a scoping review. As Mays et al. suggest in their article, scoping review methodology may be appropriate "especially where an area is complex or has not been reviewed comprehensively before" (192). In addition to this, much of the available literature on safety netting seemed to be published in guidelines and educational articles. As such a scoping review, aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting and synthesizing existing knowledge (193), seemed more appropriate. It was hoped that a scoping review would provide a base of information in order to conduct a systematic review at a later date.

The first methodological framework for conducting scoping reviews was published in 2005 by Arksey and O'Malley (194). Arksey and O'Malley give four reasons for undertaking a scoping review which include: to examine the extent, range and nature of research activity; to determine the value in undertaking a full systematic review; to summarise and disseminate research findings and to identify gaps in the existing literature. They argue that if a scoping review aims to summarise and disseminate research findings and to identify gaps in the existing literature, then it should be considered a method

in its own right and present a methodological framework for undertaking a scoping review (194).

The framework developed by Arksey and O'Malley has five stages as listed below.

1. Identify the research question
2. Identify relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting the results

When identifying a research question the framework suggests "maintaining a wide approach in order to generate breadth of coverage". By focusing on all aspects of safety netting within the consultation in any health care setting the scoping review was kept broad as per the guidelines, and therefore reduced the likelihood of missing relevant articles. Next, the authors suggest maintaining a broad scope within the search strategy and developing clear inclusion and exclusion criteria based on the specific research question. The final stages are the charting of the data and summarising and reporting of the data (194). Data extraction forms were developed to collect data from the papers, and tables of included studies and results tables were used to collate and summarise the data.

In 2010 Levac et al. published a paper aiming to advance the methodological framework developed by Arksey and O'Malley (194). When designing the search strategy Levac et al. emphasises the need to balance the breadth and comprehensiveness of the review with the feasibility of resources. When selecting studies and charting the data, Levac et al. suggests using an iterative team approach. Finally when reporting the findings, Levac et al. suggests providing numerical summaries, as well as qualitative thematic analysis and recommends considering the implications of the study in terms of future research and policy. Levac et al. also suggests including a sixth stage in the conducting of a scoping review. The authors recommend a consultation process in which consumer and stakeholders may suggest additional references and provide further insights beyond those in the literature (195).

There is considerable debate around the omission of a quality assessment in scoping reviews. Arksey and O'Malley were clear in their influential framework that scoping reviews should not include an assessment of quality (194). This view was supported by Levac et al. and more recently by Colquhoun et al. who recognised the considerable challenges in assessing

quality among the vast range of published and grey literature that may be included in scoping studies (193, 195) . However Daudt et al. disagree in their methodological update of scoping reviews. They argue that "assessing for quality is a necessary component of scoping studies if they are to provide research that in itself can be disseminated to others in a way that is useful to practice or policymaking and for future researchers" (196). Pham et al. conducted a scoping review of scoping reviews and found that a quality assessment was included in only 22% of studies (197). It was anticipated that the scoping review on safety netting would include a wide variety of papers including reports, books, letters and educational articles. As a result a decision was made not to include a quality assessment in the review. A detailed description of the search strategy and inclusion / exclusion criteria is documented below.

6.2 Inclusion criteria

The aim of this part of the research was to understand the role of safety netting in the recognition and referral of cancer symptoms, to identify different definitions of safety netting and to propose a common approach to safety netting. As a result, citations were included if they focused on patients, carers, or PCPs and provided information on safety netting for any patient group in any healthcare setting written in English. Studies using any research design were included. Educational articles and opinion pieces were included if the main focus of the article was consultation skills or patient safety, and specific information on safety netting was provided.

6.3 Search strategy

A database search using Medline, PsycInfo, CINAHL, EMBASE, The Cochrane Library, Web of Science Core Collection, and Google Scholar was undertaken from commencement to April 2018. The search strategy solely included search terms around the theme of 'safety netting' in order to capture as much of the relevant literature as possible. There were no MeSH terms for safety netting and Bankhead et al. in their literature review on safety netting for early diagnosis of cancer noted that adding the specific term 'safety net*' to their exsisting search around the early diagnosis of cancer, yielded no results (189). As this scoping review aimed to consider safety netting in any clinical setting, search terms around theme of safety netting such as 'safety net*' as described by Bankhead et al. were used. An information specialist

was not consulted due to the relative simplicity of the search which aimed to be deliberately broad. Searches of the grey literature database openGREY and websites including the Department of Health, NICE, the NPSA, NAEDI, the National Cancer Registration and Analysis Service were conducted to identify relevant unpublished work. Citation searches of all included papers were also undertaken. The search strategy can be viewed in appendix D.

In order to improve rigour and meet good practice requirements the student enlisted additional support in conducting the review all based at HYMS. Laurie Dunn (LD) is a post-doctoral researcher. Elizabeth Mitchell (EDM) is a senior lecturer in primary care research. Una Macleod and Ian Watt are PhD supervisors for this project and professors of primary care. LD provided assistance with search result screening. Approximately 10% of search results were independently screened by the student and LD to ensure consistency. The full text of any potentially relevant study was obtained and independently assessed for eligibility by the student and one of two other colleagues (LD or EDM). Disagreements were resolved by the student's supervisors (UM or IW). Data were extracted by using a standardised data extraction form. Information was collected on study setting, design, population, the definition of safety netting used, the components included, and recommendations as to the timing and circumstances under which it should be used. This information was then used in the analysis of the papers, which was undertaken using a narrative analysis approach.

As the focus of this review was to explore varying definitions and content of safety netting, a narrative synthesis was conducted. A narrative analysis was used as the types of papers identified were heterogeneous and primarily qualitative so therefore did not lend themselves to numeric synthesis such as a meta-analysis. Information from the papers on safety netting definitions, use and content were developed into categories. These categories were added to as more papers were reviewed.

6.4 Results

The search strategy retrieved 9949 papers, with 106 full text papers undergoing detailed review. After excluding papers that were not about safety netting (n=21), papers which were not available (n=11), papers not in English (n=2) and those that mentioned safety netting but did not provide any related information (n=25) a total of 47 studies were included in the review. The majority were from the UK with the remainder from Australia, Belgium,

The Netherlands, Sri Lanka and USA. All the papers included discussed safety netting in a 'first patient contact' setting, which was most often in primary care, the emergency department (ED) or an out of hours (OOH) setting. All patients were included in the majority of papers. Some focused on consultations with children whereas others dealt with specific conditions or symptoms such as melanoma, or fever. Figure 17 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses

(PRISMA) diagram. Appendix E contains further information on the included studies.
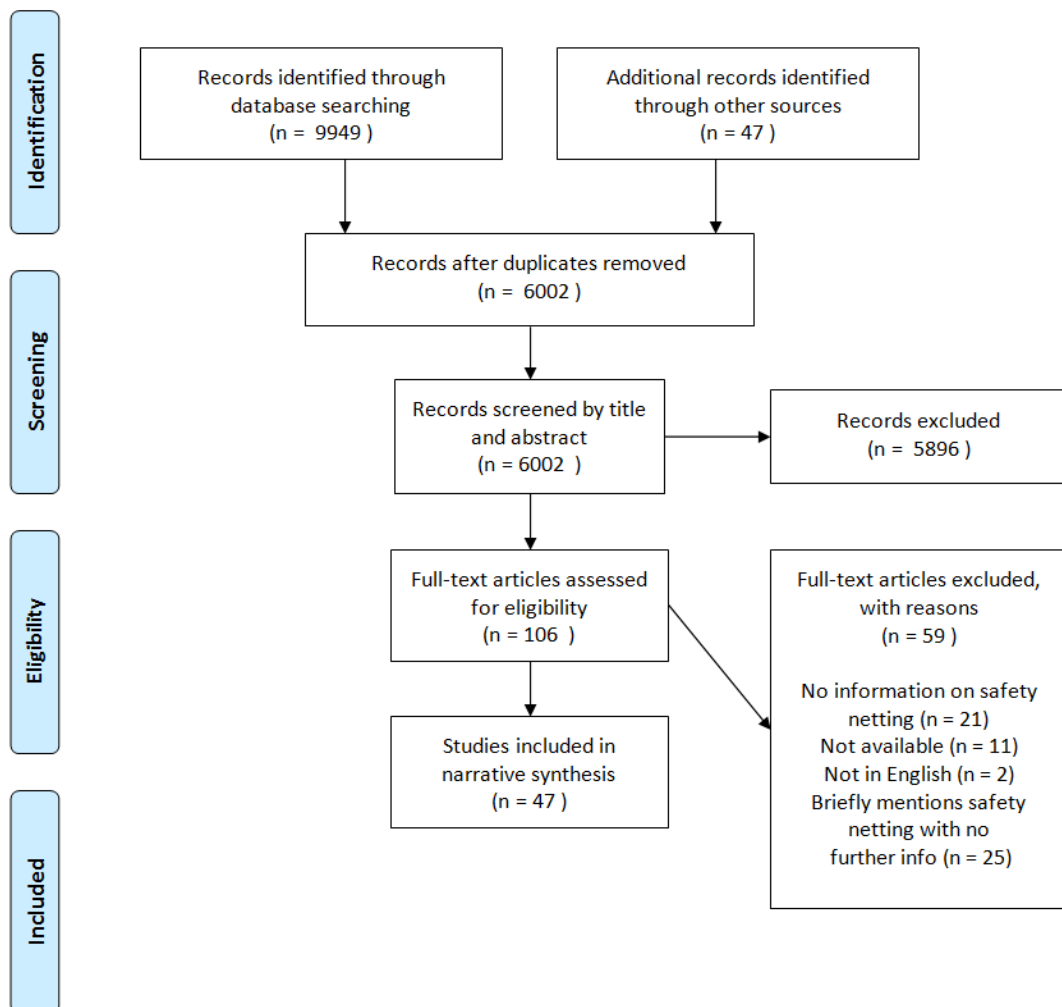
Figure 17: PRISMA diagram for scoping review

6.4.1 Current definitions of safety netting

Thirty of the included citations offered a definition of safety netting (25, 66, 69, 78, 179, 181, 185, 186, 188, 189, 198-217). Whilst this differed among included papers, several themes were common throughout the literature. This data is presented in table two.

DEFINITION \ CITATION	Ablett-Spence 2013	Almond 2009	Balla 2012	Bankhead 2011	Berthelot 2016	Buntinx 2011	Campion-Smith 2014	CRUK 2016	Chafer 2003	de Vos-Kikhof 2015	Hirst 2017	Jones 2013	Jones 2014	Kaufmann 2008	McKelvey 2010	MDDUS 2016	MDU 2018	Mitchell 2013	Morgan 2015	NPSA 2010	Neighbour 1987	NICE 2015	NICE 2013	Nicholson 2016	Pearson 2007	Rees 2017	Roland 2014	RCGP 2011	Singh 2010	Walter 2014
A consultation technique				●	●			●	●						●	●					●					●	●		●	
A tool to manage diagnostic uncertainty		●	●	●	●	●		●	●					●	●		●	●	●		●					●	●			
A mechanism to inform patients of red flag symptoms		●			●						●				●	●					●					●	●	●		
A contingency plan or patient review	●	●		●	●	●		●	●		●	●	●	●		●		●			●	●	●		●	●	●			●
The provision of information to ensure patients re-present	●			●	●			●		●	●		●			●	●				●				●		●	●	●	●
A means of empowering patients															●					●					●				●	●
Observation for/following potentially serious illness				●						●	●									●				●	●					
The active monitoring of patients	●	●		●				●												●		●	●		●		●			
The follow-up and monitoring of investigations				●			●	●														●		●		●				
The follow-up and monitoring of urgent referrals				●			●	●														●		●		●				
An administrative process				●			●	●																●						
Medicolegal protection for doctor		●	●	●																●										

Table 2: Safety netting as defined in the literature

The management of uncertainty was frequently mentioned, suggesting that safety netting may act as a contingency plan by providing patients with information on prognosis and ways of organising follow up. CRUK state that safety netting can be used to support the management of diagnostic uncertainty, helping to ensure patients are re-evaluated in a timely manner (185). Follow up and review are also considered to be important aspects of safety netting. Hirst et al. state "one of the main safety netting approaches is to ask patients to return if symptoms persist (214). Similarly, a model of the consultation introduced by McKelvey, states "*an agreed follow-up or review date is set*" (202). Safety netting was also discussed in terms of providing medico-legal protection to PCPs. The Medical Defence Union (MDU) state that if a complaint is received the doctors actions will be scrutinised (216).

Other definitions highlighted the need to review and act on results of investigations as an essential part of safety netting. This was described in definitions as 'active monitoring of patients', the 'follow up and monitoring of investigations and urgent referrals' and an 'administrative process' (25, 185, 212). This important aspect of safety netting was not originally discussed by Neighbour, but would seem to be a vital aspect of good patient care. It is suggested that this administrative aspect of safety netting should be included in further definitions. Box 1 provides a possible definition of safety netting following the scoping review.

Box 1: A proposed new definition of safety netting:

 "Safety netting is an essential process to help manage uncertainty in the diagnosis and management of patients by providing information for patients and organising follow up after contact with a health professional. This aims to empower patients and protect health care professionals. Safety netting may be performed at the time of the contact between health professional and patient, or may happen after the contact through active monitoring and administrative systems to manage results and referrals."

6.4.2 Timing and recipients of safety netting

Twenty-four of the included citations provided advice on when safety netting should be used (25, 69, 77, 185, 187-189, 199, 201, 203, 209-212, 214, 217-225). Safety netting was recommended when there is diagnostic uncertainty and the differential diagnosis includes serious illness or illness which may progress rapidly. The MDU state "safety netting is important where a patient may have risk factors for a specific disease or where specific complications are recognised as part of the illness" (216). The use of safety netting when managing children was frequently noted to be important, as a result of often early and non-specific presentations of acute illness in children and the small proportion of children with serious illness (220). Other patient factors such as old age, multimorbidity, or mental health problems may increase the risk of the illness being or becoming serious and therefore were felt to need careful safety netting (188). Three papers stated that safety netting should be done at each and every contact between a health care professional and patient. It was also acknowledged that safety netting is particularly important in acute settings, such as in ED, OOH centres and when using telephone consultations (189, 217, 225).

6.4.3 Information and actions included in safety netting

Two-thirds of studies in the review (n=38) provided suggestions for what safety netting advice should include (25, 66, 69, 78, 79, 95, 179-181, 185, 186, 188, 189, 198-202, 204-209, 211-217, 225-231) (Table 3). The most commonly recommended components are discussed below in order of frequency. They included (i) how and when to seek further medical care; (ii)

arranging planned follow up; (iii) potential red flags (symptoms or signs that may suggest serious illness); (iv) the time course of the illness; (v) communicating uncertainty; (vi) an explanation of investigations; (vii) organizational components. Table three shows the frequency of the recommendations.

Table showing components of safety netting (COMPONENT) against CITATION columns: Ablett-Spence 2013, Almond 2009, Bankhead 2011, Berthelot 2016, Buntinx 2011, Cabral 2014, Campion-Smith 2014, CRUK 2016, Chafer 2003, De Bont 2017, de Vos-Kirkhof 2015, Eden 2010, Hirst 2017, Jones 2013, Jones 2014, Kaufmann 2008, Kurtz 1999, McKelvey 2010, MDDUS 2016, MDU 2018, Mitchell 2013, Mitchell 2015, Morgan 2015, NPSA 2010, Neighbour 1987, NHS Healthy London 2016, NICE 2015, NICE 2013, Nicholson 2016, Pearson 2007, Rees 2017, Roland 2014, RCGP 2011, Schiff 2012, Singh 2010, Van Galen 2018, Walter 2014, Young 2010.

Components:

Consultation activity
- Discuss how and when to represent / seek further help
  - Cover who should make a follow-up appointment
  - Outline actions if symptoms persistent / recur
  - Legitimize repeat visits
  - Signpost to additional services
- Arrange planned follow-up
- Discuss red flag symptoms or signs to look out for
- Suggest time course for symptom resolution
- Communicate uncertainty
- Provide verbal or written information
- Check patient's understanding
- Document safety netting advice in the notes

Diagnostics
- Explain reasons for tests
- Follow-up investigations or referrals

Practice administration
- Follow-up missed appointments
- Ensure current contact details for patients
- Liaising with other care providers e.g. OOH

Table 3: Components of safety netting in primary care

6.4.3.1 How and where to seek further medical care

Patients need to know how and where to seek further medical care if symptoms persist or red flag symptoms present. This element of safety netting was the most frequently included component.

This element of safety netting included signposting to other services such as OOH, or the ED (205, 206), advice on how to make a follow up appointment if needed, and who should do this (179, 212), and legitimising repeat visits so that patients felt able to return if symptoms persist or worsen (208).

The key element of this component of safety netting ensures patients know how to, and where to seek help if things do not go as planned or expected. This was felt to be a separate component to planned follow up advice which is discussed below and may not be needed in every situation. For example Bankhead et al. described this component as "specific information about when and how to re-consult if symptoms do not resolve in the expected time course" (189). Buntinx et al. state safety netting should include "clear information and advice on re-contacting the HCP in specific situations" (201).

6.4.3.2 Arrange planned follow up

As well as advising patients on how to seek help should things not go as expected, arranging planned follow up may be a part of safety netting. This was felt to be a distinct element to safety netting and would normally involve a review in a similar setting often with the same PCP. The NICE suspected cancer guidelines make this distinction clear, stating reviews may be planned, or patient initiated if new symptoms develop (25). Planned follow up may be encouraged after having investigations (discussed below), or in groups of patients who may be less likely to re-present without planned follow up. In their safety netting advice, Morgan et al. state "arranging appropriate follow up for patients is an essential element of the consultation . . . We encourage having a low threshold for asking patients to return for a review." (211). Similarly Macmillan's safety netting leaflet advises the following: "if you feel a patient needs to be reviewed, offer to make an appointment for them, rather than asking them to do it" (186).

6.4.3.3 Advice on worrying symptoms and 'red flags'

In order to know when to represent or seek further medical care, it is necessary for patients to know the 'red flag' or worrying symptoms they should look out for.

This component of safety netting was described well by Almond et al. who stated that "if there is a recognised risk of deterioration or complications developing then the safety-net advice should include the specific clinical features (including red flags) that the patient (or parent/carer) should look out for" (188).

This could include a description of symptoms of serious illness such as meningitis in an unwell child (206), or signs which may by suggestive of cancer in a patient presenting with non-specific symptoms (e.g. a patient may be warned about PR bleeding or diarrhoea if they present with unexplained vague abdominal pain).

6.4.3.4 The likely time course of the illness

Persistent or non-resolving symptoms may warrant further investigation or consultation. In order to know when a symptom is persistent or non-resolving, PCPs need to communicate a likely time course of the acute illness to patients. However, Almond et al. recognise that this information may not be known for all presentations and state that this should not delay help seeking if the patient or carer has concerns (188). For example a large

systematic review found that acute cough in children could last up to 25 days (232). Safety netting advice could inform parents of this likely time course but should also discuss red flags and worrying symptoms, such as a rash or worsening fever, to prompt an earlier review if needed.

6.4.3.5 Communicating uncertainty

A discussion with the patient around uncertainty was highlighted as an element of safety netting. Almond et al's Delphi study described this well, stating "if the diagnosis is uncertain, that uncertainty should be communicated to the patient (or parent/carer) so that they are empowered to re-consult if necessary" (188). Similarly, in his advice to GP registrars, Singh states "If you are not sure of the aetiology, explain this to the patient. This reduces the risk of false reassurance and most patients appreciate the honesty" (205).

This component of safety netting is a necessary step before the other components of safety netting discussed below are introduced in the consultation. In order to ensure patients are able to look out for further worrying or red flag symptoms and know where and how to seek help should symptoms worsen, one could argue that patients need to understand the uncertainty that is inherent in medical care.

6.4.3.6 Safety netting and investigations

An explanation of the purpose, undertaking and follow up of investigations was included in several papers. Much of the safety netting advice around cancer diagnosis focuses on investigations. The NPSA state that patients should be "enabled to follow up test results relating to their own care" (207). The NICE suspected cancer guidelines state in their safety netting advice that results of investigations should be reviewed and acted upon appropriately (25). Nicholson et al. also highlight that patients often assume 'no news is good news' following investigations and suggest that PCPs retain responsibility for reviewing and acting on the results of investigations they have requested (212).

6.4.3.7 Organisational components

In addition to the contents listed above, included papers gave advice on other actions as part of safety netting. This included a recommendation to document safety netting advice in the patient's notes (189), have administrative systems in place to ensure abnormal results are dealt with

(186), and ensuring patients contact details are up to date (185). Written safety netting instructions were suggested (186, 233).

6.5 Summary

Safety netting was described as an essential component of the consultation in 1987 (78), and it continues to be advocated by national guidelines. In 2015 NICE introduced safety netting advice into its updated guidance on the recognition and referral of cancer symptoms (25). Following the publication of these guidelines there has been increased debate in the literature on the role of safety netting. CRUK released safety netting guidance aimed at primary care (185), as did 'the healthy London partnership' however NICE noted their safety netting advice was not based on any available evidence (221). Since then in a section entitled 'uncertainties' Nicholson et al. asked 'can safety netting improve cancer detection in patients with vague symptoms?' They state their 'broad search' found no systematic reviews or trials of safety netting interventions. The scoping review in this thesis has included 41 studies on safety netting with the aim of clarifying the concept, use and content of safety netting (212). It is clear from the literature that the definition of safety netting has moved on from that first described by Neighbour (78), and should include organising repeat appointments, following up on blood tests and other investigations, monitoring referral pathways and even medico-legal protection for the PCP. Safety netting should address administrative and organisational issues as well as advice to patients within the consultation.

The most recognisable part of safety netting ~ managing uncertainty ~ still occurs within the consultation, and whilst this may centre on the diagnosis as Neighbour suggested, it may now also include prognostic and management uncertainty (78). This uncertainty can be overcome by providing information to patients and organising, or legitimising, a follow up visit. The findings of this review suggest that safety netting goes beyond the consultation to include systems to track patients and manage referrals and the results of investigations.

Safety netting has been advocated at every consultation between clinician and patient. However, it may be of particular importance in patients with potentially serious illness, children, the elderly or patients with multiple comorbidities. These patients are more likely to present with acute illness, may deteriorate rapidly and, in the case of multimorbidity, may wrongly

attribute new or worsening symptoms to already diagnosed chronic illnesses. There are also certain clinical settings where safety netting is likely to be more important, such as in ED and OOH contacts. The higher proportion of acute illnesses dealt with in these settings, as well as reduced access to past medical notes and lack of continuity of care, make patients (and PCPs) understanding of any follow up plan important.

Safety netting should include information on the time course of the illness, when to seek help, red flags or signs of serious illness to look out for, how and where to seek help and an honest discussion on uncertainty in diagnosis. It may also contain a summary of symptoms, signposting to other services, written information and a discussion on how to follow up test results and referrals.

<u>Implications for practice</u>

This review has found advice within the consultation as Neighbour suggested is one part of a larger array of actions which safety netting may include. The included evidence suggests that safety netting, while still perceived to be an essential process to help manage uncertainty in diagnosis, should also include dealing with uncertainty in management of symptoms by providing information for patients and organising follow up after contact with a health professional. It aims to empower patients to recognise serious illness and seek timely and appropriate continued healthcare. The features of optimal safety netting include advice on how and where to seek help, red flags, the organisation of follow up, and the natural history or time course of an illness. It may be performed at the time of the contact between the health professional and the patient, or may occur after contact, through active monitoring and administrative systems to manage results and referrals.

Chapter 7: Using significant event analysis to identify opportunities to improve recognition and referral of lung and colorectal cancer at an individual general practice level

Chapter two showed the potential for SEA to provide detailed information on the primary care interval in the pathway to a diagnosis of cancer. Research published to date using this method has used PCP completed SEA forms which were analysed thematically by researchers and published with the aim of learning more about the primary care interval. However, what effect the SEA data has at practice level, and what changes or improvements in care occur as a result are largely unknown. In addition, given the current strain on primary care services and high workload in general practice, SEAs conducted by independent researchers or auditors could be more feasible and may still provide opportunities for learning.

The second objective of this research was to investigate opportunities to improve the recognition and referral of cancer symptoms in primary care using the technique of SEA. This chapter presents the findings of SEAs collected by the student for the purposes of this thesis. The SEAs were collected across a selection of practices in Hull and East Riding of Yorkshire in order to identify potential opportunities to improve the recognition and referral of lung and colorectal cancer.

7.1 Significant event analysis study method

This part of the research study involved the completion of SEAs for all patients with a new diagnosis of lung or colorectal cancer across a number of GP practices in Hull and the East Riding of Yorkshire, with the aim of investigating opportunities to improve the recognition and referral of cancer symptoms in primary care using the technique of SEA. The data from these SEAs were analysed and summarised into a presentation for a PCP educational meeting in each participating practice. The analysis of SEAs and their presentation formed an 'audit and feedback' intervention and PCPs were encouraged to develop an action plan to improve cancer diagnosis in their practices following the meeting. This is discussed in chapter eight.

A decision was made to focus on lung and colorectal cancer for two reasons. The first reason was to ensure enough SEAs were generated to allow for an in-depth analysis. Lung and colorectal cancer are among the most common

cancers in the UK. In Hull, part of the area in which the study was undertaken, the rates of lung cancer are among the highest in the country, with high levels of smoking and poor survival. The second reason for the choice of lung and colorectal cancer was that both cancers usually present with symptoms which require a period of investigation and/or assessment in primary care prior to referral. This is in contrast to breast cancer, for example, where in most cases a patient presenting with a breast lump would be immediately referred on a 2ww pathway. Finally, previous SEA work by Mitchell et al. showed the potential for learning from SEAs on lung cancer diagnosis (69). The decision was made to study all cases over a period of two years to ensure there were enough cases for analysis, whilst still ensuring the data relevant to the clinicians involved. Choosing to study all cases ensured no selection bias from the student.

An introduction to SEA and audit and feedback as well as its use for research into early cancer diagnosis has been included in chapters two and three. SEA is a quality improvement tool designed for general practice and is described as a "qualitative method of clinical audit that is based on the synthesis of traditional case review and the research principals of the critical incident technique" (72). SEA is embedded in general practice, being recommended as part of the Quality and Outcomes Framework, a GP's yearly appraisal and Care Quality Commission recommendations. It is a technique that GPs understand and engage with. This was thought to be helpful when presenting findings to practices.

In association with the RCGP, the NPSA have developed a guide to conducting a SEA with seven key stages (71). The stages include finding an appropriate event, which for the purpose of this thesis was a new diagnosis of lung or bowel cancer in the last two years, and information gathering on the case from written records. The analysis of the significant event then follows the format suggested by the RCGP and is discussed in chapter 7.1.3 (234).

7.1.1 Practice recruitment

A formal sample size calculation was not thought to be practical or appropriate for this research. Instead a pragmatic decision was made to maximise the number of practices recruited in order to gain as many SEAs as possible within the time frame and resource of the PhD. It was thought that including six to eight practices would be a reasonable target for recruitment, as well as providing a large number of SEAs and an opportunity

for a variety of feedback meetings and action plan development. A pilot search was undertaken at an average sized practice with four GPs and 7100 patients. This search found 14 new diagnoses of lung cancer and nine new colorectal cancer diagnoses in the last two years. Based on this pilot search it was thought possible to analyse between 150 and 200 SEAs.

A variety of practices were recruited, including both inner city and rural practices, training and non-training practices, of varying sized patient lists and GP numbers. Practice recruitment was undertaken by gathering a list of practices known to be interested, or engaged in research. This was determined by discussing the research with local academic GPs. In total 11 practices were contacted by emailing the practice manager or GP partner throughout April 2016. Practices were sent details of the research in the form of a practice information sheet and the contact details of the student and supervisor. Practices who failed to respond were sent one additional reminder email.

7.1.2 Electronic medical records searching

At each practice which agreed to take part in the study, a patient search was undertaken by practice administration staff using a set of predefined Read codes to find patients diagnosed with lung or colorectal cancer in the last two years.

Read codes are a coded thesaurus of clinical terms used to standardise the patient electronic medical record nationally. These codes can be searched for using tools within the medical records. The Read codes used can be viewed in appendix F

7.1.3 Data collection

Following the Read coded search the administrative team provided the student with a list of NHS numbers for patients who met the search. The medical record could then be viewed anonymously using a user profile which could hide patient identifiable information, or a letter template in which only consultation data was included. This depended on the electronic medical record system used by each practice. The SEA forms were completed at each practice at a time and place to suit the practice. This was within GP working hours and either in a free consultation room or desk in the administration office.

Data were collected using a standardised SEA template which had been developed for the RCGP's early cancer diagnosis toolkit (77). A copy of the

template can be viewed in appendix G. This template contains limited demographic information to ensure patient anonymity, but has space to record the patient's diagnosis, age, sex, date of diagnosis and whether or not the patient was alive. The next section is a free text box with the title "what happened?" This section allows a detailed description of the events leading up to the diagnosis including dates of consultations, which PCP was present, the patients presenting symptoms, examination findings and management plans. Other specialty input such as secondary care clinics and OOH / ED attendances can also be noted. This section takes the form of a timeline from initial consultation to referral and diagnosis. An example timeline can be seen in box 2. The third section of the SEA is a free text box which asks "why did it happen?" This section allows for a reflection on the process of diagnosis and asks if the timeline to diagnosis was as good as it could have been? How often was the patient seen? What safety netting or follow up was used? And was there any delay in the diagnosis?

Usually when SEAs are completed, the member of the clinical team conducting the SEA would reflect on his or her own clinical judgement and specific decisions regarding the management of their patient. In this research, this space was used to begin to immediately comment on and analyse the events discussed in the SEA. This was guided by the questions in the SEA template. This section provided the opportunity to document a commentary to the timeline.

The final section completed for the purpose of this research project was entitled "what has been learnt?" in which several key learning points were compiled for each case. Each SEA took between 20 minutes to one hour to complete and data were collected at the eight practices over a six month period.

Box 2: An example SEA timeline:

8/5/14 – Consult with Dr 1 (GP) presents with 7 day history of PR bleeding. No abdominal pain. Had piles in past. No change in bowel habit but reports occasional bloating. No dyspepsia. Weight not documented. Examination soft abdomen PR NAD. Plan states treat for haemorrhoids. Bloods for FBC and ferritin. States "if persists needs proctoscopy"

21/5/14 – Bloods taken haemoglobin normal ferritin low – check by Dr 1 Plan states asked to come in

4/6/14 – Consult with Dr 2 (GP) Rectal bleeding continues including darker blood. Also change in bowel habit from 1 a day to three times a day and loose. States has been like this for one year (last consult states no change) Low ferritin noted and 2ww colorectal done. Plan stated "needs 2ww"

4/6/14 – Admin note to say 2ww sent

7.1.4 Diagnostic intervals

In this study the index presentation was determined by the student. As a GP the student used his clinical judgement to determine the index presentation. This was often the first presentation of a symptom that could be due to cancer, the first presentation after a period of time not attending the doctor or the start of a series of consultations which led to the diagnosis. This method may be more inclusive than other described methods by Hamilton et al. (26) or Neal et al. (23) who used trained research assistants and electronic record searching by symptom to establish the index presentation. Electronic searching requires PCPs to use codes in the medical notes. This may miss earlier presentations and diagnoses if the PCP uses free text in the medical record which cannot be searched. The index presentation can be difficult to identify, which is discussed in the research limitations in chapter 11.3.

The date of referral was determined as the day the referral letter was sent to the secondary care provider. Whilst most studies just consider the time to diagnosis, by using detailed SEA analysis it is possible to record time to referral. This helped to distinguish between the primary care and secondary care components of the diagnostic interval.

The date of diagnosis was recorded as the date the diagnosis was documented in the medical record. This is normally documented following correspondence from secondary care confirming the diagnosis. This was done in exactly the same way as Neal et al. (23), Hamilton et al. (26) and Torring et al. (235) and is in line with the Aarhus statement (16). This enabled direct comparison with the other literature on diagnostic intervals.

7.1.5 SEA analysis

The differing sections of the SEAs were analysed in several ways, being guided by the methods described by Mitchell et al. who first used SEAs for the purpose of understanding the pathway to lung cancer diagnosis (69). A detailed description of the analysis is documented in section 5.2.3.

7.2 Significant event analysis study results

Eight practices were successfully recruited to take part in the study. However, one practice split during the study, with both new practices agreeing to remain part of the study. It was possible to separate the SEAs for each practice which resulted in nine audit and feedback meetings taking place. The rest of the thesis will refer to the nine practices separately. Four of the practices were based in the more rural East Riding of Yorkshire, with the other five practices based in Hull.

The practices varied in size both in terms of number of GPs and patients. The number of GPs at each practice ranged from 3 at the smallest, to 19 at the largest practice. The smallest practice had 7163 patients and the largest had 26808 patients. There was an average of 12114 patients per practice. Eight of the nine practices included in the study were training practices. Whilst data on the number of training practices across the UK is not publically available, the proportion of training practices in this sample is unlikely to be representative and should be taken in to account when interpreting the results. This is discussed in chapter 11.3. Index of multiple deprivation (IMD) scores were available for each practice and there was significant variation between the practices included, with one practice having a score of seven making it among the top 10% least deprived areas in the UK. Another practice had a score of 59.1 making it among the top 10% most deprived practices in the UK. Table four shows the demographics of each practice.

Practice	Number of GPs	Number of Patients	Training practice	Location	Deprivation score
1	19	26808	Y	East Riding	7.0
2	10	12088	Y	Hull	29.2
3	8	11736	Y	East Riding	13.8
4	9	11998	Y	East	14.2

				Riding	
5	9	12426	Y	East Riding	22.0
6	4	7163	Y	Hull	48.3
7	9	9563	Y	Hull	33.5
8	3	8505	N	Hull	59.1
9	4	8747	Y	Hull	49.8

Table 4: Practice demographics

In total 192 SEAs were completed across the nine practices. This included 74 bowel cancer SEAs and 118 lung cancer SEAs.

7.2.1 Bowel cancer

In total 74 cases of bowel cancer were collected using the SEA template. Two practices had only four cases of bowel cancer in the last two years (practice 6 and practice 7), whereas 20 cases came from one practice (practice 1).

The age ranged from 36 to 96 years old. The mean age was 71.36 with a standard deviation of 12.09. The age of five patients was unknown due to errors in data entry. 46 (62%) patients were males and 24 females with 4 unknown due to errors in data entry.

The most common presenting symptom was loose stools, which was mentioned by 34 (46%) patients. This was followed by abdominal pain and PR bleeding in 31 and 29 patients respectively. Other common symptoms included weight loss, anaemia, appetite loss, constipation and bloating. A graph showing the frequency of all symptoms is shown in figure 18.
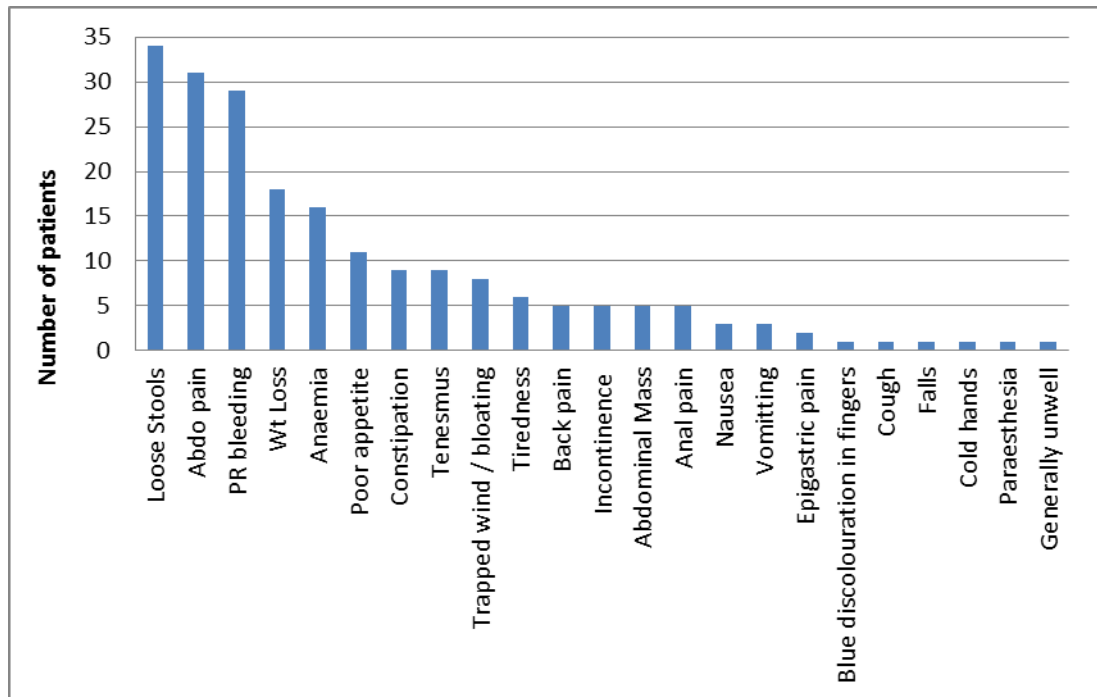
Figure 18: The frequency of presenting symptoms in the colorectal SEAs

When patients were referred, 44 (59%) patients were referred using the 2ww suspected colorectal cancer referral pathway. 16 (22%) of patients were referred routinely to the colorectal surgeons. Five patients were referred using the 2ww suspected upper gastrointestinal cancer referral pathway. Only three (4%) patients were diagnosed following an emergency admission.

The number of consultations between first presentation and referral could be calculated using the SEA data, which is shown in figure 19. The median number of consultations was two. The mean was 2.67 with a standard deviation of 1.78. One patient was seen 10 times between first presentation and diagnosis. 33 (45%) patients had three or more consultations prior to referral.
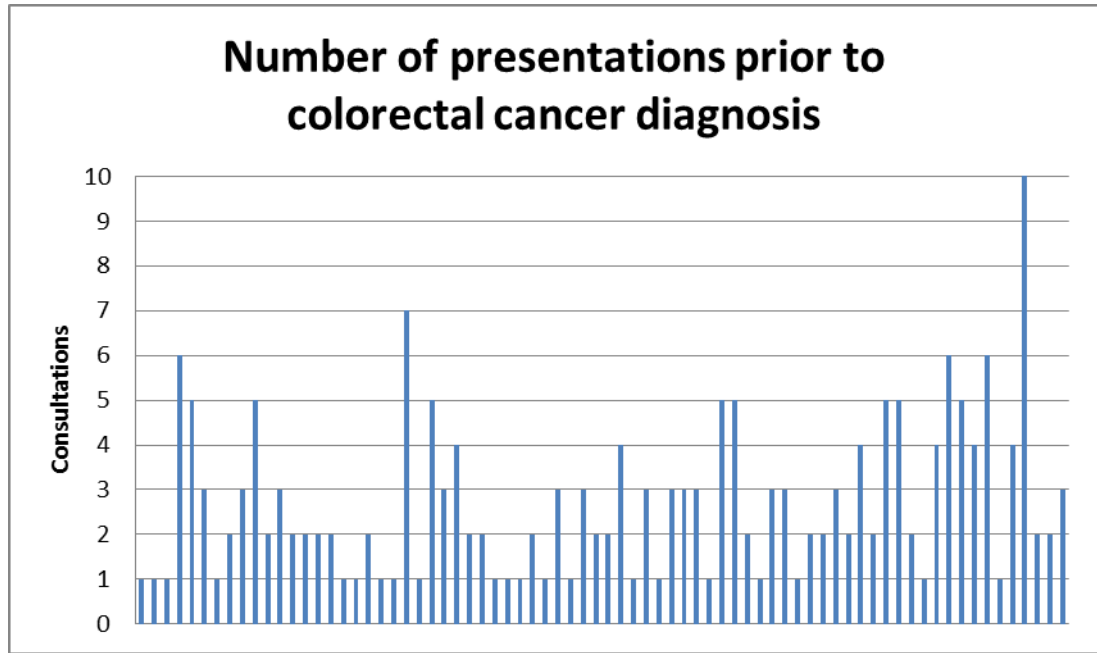
Figure 19: Number of presentations to general practice prior to referral

The length of time from first presentation to referral and to diagnosis could be calculated from the SEAs. For colorectal cancer, the number of days from first presentation to referral ranged from 0 to 345 days. The mean number of days was 57.2 with a standard deviation of 78.6 days. The time from first presentation to diagnosis ranged from 7 to 507 days with a mean of 120.4 and standard deviation of 111 days.

From the SEA reports it was possible to calculate the time from a patient meeting the referral criteria documented in the NICE guidance on the recognition and referral of cancer (22, 25) to being referred. This time could be considered as the time of missed opportunity in primary care. It could be argued that any time here has delayed the diagnosis and is significant. For the purpose of looking for the predictors of delay, from meeting the 2ww referral criteria to being referred, the SEAs were categorised as 0-6 days, 7-30 days and >30 days. 48 (65%) patients had no or minimal (0-6 days) delay; 11 (15%) patients has a moderate delay (7-30 days) and 15 (20%) patients had a significant delay (>30 days).

7.2.2 Lung Cancer

In total 118 cases of lung cancer were studied. One practice had only three cases of lung cancer in the last two years (practice 2), whereas 26 cases came from one practice (practice 7).

The age ranged from 45 to 95 years old. The mean age was 71.30 with a standard deviation of 10.77. The age of three patients was unknown due to errors in data entry. 59 (50%) patients were males and 59 were females.

The most common presenting symptom was cough which was mentioned by 83 (70%) patients. This was followed by shortness of breath and chest pain in 50 and 49 patients respectively. Other common symptoms included increasing sputum, weight loss, loss of appetite, wheeze, haemoptysis and feeling generally unwell. A graph showing the frequency of all symptoms is shown in figure 20.
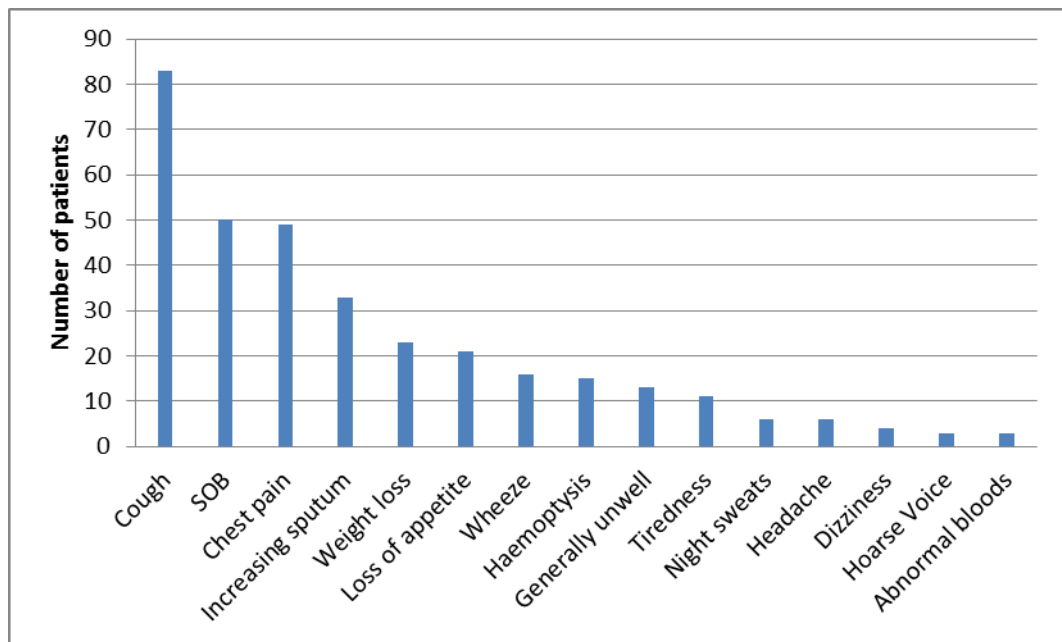
Figure 20: The frequency of presenting symptoms in the lung SEAs

Of the CXRs that were organised during each patient's investigation, 21 (18%) patients had a normal CXR and 16 (14%) were inconclusive and suggested a repeat after a period of time. In almost all of these cases the time to referral and diagnosis was prolonged.

When patients were referred, 81 (69%) patients were referred using the 2ww suspected lung cancer referral pathway. 24 (20%) of patients were diagnosed following an emergency admission. Four patients were referred routinely to the lung specialists, and other patients had 2ww referrals to upper GI, breast, colorectal and brain. One patient was not referred and was treated palliatively in primary care.

The number of consultations between first presentation and referral could be calculated using the data obtained from practice records. The median

number of consultations was three. The mean was 3.46 with a standard deviation of 2.47. One patient was seen 15 times between first presentation and referral. 67 (58%) patients had three or more consultations prior to referral.

The number of days from first presentation to referral ranged from 0 to 899 days. The mean number of days was 66.3 with a standard deviation of 116.2 days. The time from first presentation to diagnosis ranged from 0 to 899 days with a mean of 97.4 and standard deviation of 124.1 days. The median time to referral was 27 days and median time to diagnosis was 55.5 days

From the SEA reports it was possible to calculate the time from meeting the referral criteria documented in the NICE guidance (22, 25) to being referred as well as the time between the NICE guidelines recommending a CXR and the patient having a CXR. These two times could be considered delay due to missed opportunities in primary care. For the purpose of looking for the predictors of delay, from meeting the 2ww criteria to being referred or investigated, delay times were categorised as per the bowel cancer data above. Data on time lost was available for 100 patients. Of these 52 (52%) patients had no or minimal (0-6 days) delay; 26 (26%) patients has a moderate delay (7-30 days) and 22 (22%) patients had a significant delay (>30 days).

7.3 Qualitative analysis of the "why did it happen?" section of the SEAs

As described above, the student made a contemporaneous analysis of each case included in the SEA by completing the second section of the SEA template entitled "why did it happen?" Each analysis was specific to that case and was written contemporaneously with a review of the case notes. This section of the SEA provided a narrative to each case and highlighted the most important factors in the diagnostic pathway. When considered together, the contemporaneous analyses provided an opportunity for learning about cancer diagnosis in primary care and how recognition and referral of cancer symptoms could be improved.

The contemporaneous notes were analysed qualitatively using QSR NVivo software. A TA approach was used and a coding framework developed. The coding framework was used to draw common themes from the notes and provide an insight into both what was done well and what could be improved in the recognition and referral of suspected cancer in primary care. The most

common themes are discussed below. As many of the themes are common to both lung and bowel cancer, they were considered together in this section.

7.3.1 The effect of safety netting on the primary care interval

Safety netting was one of the most commonly coded themes throughout the cases. Guided by the earlier scoping review, safety netting could include advice on red flag symptoms, advice on follow up and when to return or how to seek extra help. Safety netting may also include advice or information around referrals or investigations, such as how and when to get the results of tests or imaging, when to expect appointments and what to expect in secondary care following the referral.

In this SEA analysis, the presence or absence of elements of safety netting was commonly discussed as well as any affect this had on the case. The analysis showed cases in which elements of safety netting were documented and those where it was not. Chapter six has shown the multiple possible elements of safety netting which were considered when analysing the data. When safety netting was documented there was a distinction between what the student termed 'poorly documented safety netting' which often included a single sentence at the end of the notes along the lines of "return if no better" or "see if symptoms persist". This was compared to 'detailed safety netting', in which there were planned review dates documented or appointments made, or thorough documentation of a discussion regarding the next steps in the patients care. Whilst it would have been helpful to characterise the baseline safety netting behaviours of practices included in the research, this proved difficult. None of the practices employed any specific interventions to aid safety netting advice or documentation prior to this research. It was clear when conducting the SEA analysis that, as with all aspects of medical note making, safety netting documentation was dependant on the individual PCP documenting the advice. Due to the relatively small number of SEAs analysed and the numbers of PCPs working in each practice safety netting documentation varied within each practice.

When safety netting was documented, there were examples of rapid time to referral and diagnosis, with patients returning for planned reviews or having timely investigations. Some examples of this are documented below and include patients being given clear instructions on when and how to return to see the PCP, planned follow up and safety nets for the review of investigations. These examples meet the requirements of safety netting

found in chapter six and suggest that detailed safety netting documentation is possible within the time constraints of the consultation.

- A doctor who was going away asked a colleague to 'chase up' a CXR result in a patient with weight loss they were worried about.
- A PCP who specifically requested to the patient and daughter to call the PCP for an update even if improving in an elderly lady with breathlessness.
- A patient treated with antibiotics, with clear documentation stating the patient "knows to come back in 10 days if no better".

However, there were also cases in which despite good safety netting documentation, the patient was lost to follow up. Examples of cases where this happened are discussed below

- An elderly man was seen with a short history of PR bleeding. Investigations were arranged and a plan was documented as being discussed with the patient if symptoms continue or investigations were abnormal. Despite this the patient does not have the bloods done and is not seen again for nine months, leading to a significant delay in diagnosis.
- A housebound ex-smoker with a chest infection had good safety netting documented following a home visit, with a review planned via telephone the next week. However when the telephone follow up was attempted the patients number was incorrect, leading to a delay in diagnosis.
- A patient with a cough was advised to have a CXR and a plan documented to 'review the results with me [PCP]'. However, despite this follow up plan the patient did not have the CXR and did not return for 6 weeks. When the patient did have the CXR it confirmed the diagnosis of lung cancer.

These cases suggest that safety netting is not a binary variable which can be said to have occurred or not occurred. As chapter six shows, the elements of safety netting may represent a continuum – and depend on the time the clinician has to apply to it – and where patient responsibility starts and ends. The question of responsibility is a difficult one. Is it the PCP's responsibility to chase patients up and ensure follow up? Or is it the patient's responsibility to listen and adhere to the advice given by the PCP? In some of the examples above, it could be argued the responsibility lies with the PCP. For example more careful arrangements are needed in patients with memory problems, and if telephone follow up is arranged, the patients phone number should be confirmed by the PCP. However in other cases, when clear follow up plans are discussed and documented, but not followed by the patient, it could be argued that the PCP has done all they can.

In some cases there are examples of poor documentation of safety netting. As the SEAs were completed using medical records alone, it is difficult to

know what exactly was said to patients in these cases. Safety netting advice such as 'come back if no better' may leave doubt in the mind of the patient about how soon to return and could therefore lead to delay. However, this sort of documentation may be all that is documented in the patient's medical notes following a much longer discussion about when and how to return for follow up. There are examples in the SEAs where this advice to "come back if no better" was adequate, and patients have presented for a timely review. However there are other cases where this safety netting documentation seems to have been inadequate, or not followed by the patient.

In many cases no safety netting instructions were documented. It is possible that safety netting advice was given and not documented, due to restrictions on time for example. However, this lack of documented safety netting did seem to affect the time to diagnosis in a number of cases, such as the two examples below..

- A patient with non-specific abdominal symptoms had bloods organised which showed anaemia. The bloods were marked as "repeat with haemotinics." However the patient did not return. It is not clear if the patient was contacted, but this oversight may have been compounded by a lack of safety netting. This led to a significant delay in diagnosis.
- A patient with a persistent cough was referred to ENT but at the same time was advised to have a CXR. No safety netting advice was documented. The patient did not have the CXR and was not followed up. After a normal examination by ENT, the patient represented to primary care two months later and did have a CXR which was abnormal.

In other cases there was a lack of documented safety netting at the time of referral. Evidence from the safety netting scoping review in chapter six suggests it is helpful to explain to patients the reasons for referral, when the patient should receive an appointment and what to expect at the specialist consultation. There were SEAs in which it seems this was not done, leading to delays in diagnosis.

- Three patients at a practice had cancelled colonoscopies which were organised as part of the 2ww referral, all of which led to a delay in diagnosis
- A patient's 2ww referral was not received by the hospital. Despite not getting an appointment, the patient waited four weeks before returning to general practice where the referral was re-sent

Finally there were some cases in which no safety netting seemed to have been documented, but despite this, the patient has returned when needed to or attended referral appointments. This suggests that perhaps more information is given to patients than is documented in the notes, or maybe

explained by the fact that some patients and carers are more proactive than others in seeking healthcare.

This analysis has suggested the potential importance of safety netting in the recognition and referral of cancer symptoms. There has also been some suggestion of how a lack of, or poorly documented safety netting advice can adversely affect the recognition and referral of cancer symptoms. These results support the growing evidence of the importance of safety netting. In their analysis of lung cancer SEAs, Mitchell et al. highlighted the importance of safety netting stating "It is important for practitioners to use appropriate 'safety-netting', and to agree follow-up plans with patients, even those who are presenting with their first recent infective episode" (69). More recently, safety netting has been included in the NICE recognition and referral of cancer guidelines and was highlighted by CRUK and Macmillan as an important step in the referral of cancer symptoms in primary care (25, 185, 186). The findings of this SEA analysis give support to the conclusions of Mitchell et al. and the increased weight being given to safety netting by other organisations.

7.3.2 The impact of chest X-rays on the primary care interval

The use of and impact of investigations on the pathway to the diagnosis of lung cancer was frequently highlighted in the analysis.

The main investigation in the diagnosis of lung cancer is the CXR. The impact of a normal CXR during the diagnostic period in the pathway to diagnosis was stark and relatively common. In total 37 (31%) patients had a CXR which was negative for lung cancer as part of the diagnostic work up from index presentation to diagnosis of lung cancer. Of the negative CXRs, 22 (19%) were normal and 15 (13%) showed consolidation and suggested a repeat after a period of time.

Having a negative CXR significantly delayed both time to referral and time to diagnosis (P < 0.001). Patients with a positive CXR, suggestive of lung cancer, had a median time to referral of 16 days (IQR 4-46), patients with a normal CXR had a median time to referral of 84 days (IQR 53-190) and those with a CXR which was inconclusive and needed repeating had a median time to referral of 74 days (IQR 54-122). Patients with a positive CXR had a median time to diagnosis of 44 days (IQR 28.5-68.5), patients with a normal CXR had a median time to diagnosis of 121 days (IQR 83-248) and those with a CXR which was inconclusive and needed repeating had a median time to diagnosis of 106 days (IQR 89-162). Patients with a positive CXR had an

average 2.68 consultations between first presentation and referral whereas those with a negative CXR had an average of 5.14 consultations.

It was clear that a normal CXR often diverted the PCPs focus away from the possibility of cancer towards other causes of symptoms such as COPD or ENT problems.

CXRs which showed consolidation were often reported by the radiologists as requiring a repeat after a certain period of time (often six to eight weeks). This was highlighted in many of the reflections on the SEAs and in many cases led to a delayed diagnosis. In some cases there was a delay in contacting patients about the need to repeat, and even if the investigation was repeated as suggested, it always caused delay. Examples of this are shown below

- A smoker with a persistent cough was sent for a CXR which showed consolidation suggesting infection. The CXR report suggested treating with antibiotics and repeating the CXR in four to six weeks. However the patient was not seen for two weeks following the CXR, leading to delay in starting antibiotics and delay in repeating the CXR.
- A patient with COPD presented with chest pain. The subsequent CXR suggested infection and a repeat, the patient was seen and informed of the plan but did not attend the repeat CXR. This practice automatically checks each CXR request so chased the patient up and the repeat CXR suggested cancer.

The problem of consolidation on the CXR is not a new one but guidelines consistently recommend a repeat CXR in cases of consolidation in order to ensure a malignancy is not missed (236). Evidence suggests a repeat CXR is the correct investigation in these patients Macdonald et al. found only 2% of all patients undergoing repeat CXR following consolidation had a malignancy (237). However in this thesis, a significant proportion of patients experienced delay in diagnosis as a result of having consolidation on their CXR. It is possible that this problem could be improved by stressing the importance of treating the patient, not the x-ray. The PCP must use their knowledge of the patient when deciding what to do following a CXR showing consolidation. For example, a heavy smoker with weight loss and a cough, and consolidation on a CXR should perhaps be referred on a 2ww even if the report suggests a repeat CXR after a period of time, whereas a younger patient who presents with fever and a cough is much less likely to have a malignancy and a repeat CXR after a period of time may be justified. There is no comment in the literature as to whether this approach would be effective or cost effective, and one must bare in mind the 2% positive rate found by

Macdonald, but pragmatically this approach may prevent a delayed diagnosis in some patients.

The need to have a low threshold for organising CXRs in primary care, and possible delays caused by not requesting a CXR when NICE guidelines suggest, was highlighted in a number of cases:

- An ex-smoker presented on three occasions with worsening breathlessness and cough, however he had a history of cardiomyopathy. As a result several attempts were made to correct possible heart failure before a CXR was done which suggested lung cancer.
- A current smoker presented on four occasions with new chest pain, which was thought to be muscular and was treated with physiotherapy, analgesia and reassurance on three occasions before a CXR was organised.

A randomised controlled trial is currently underway considering the benefits of earlier CXR in the UK. A feasibility trial suggested the intervention is feasible although uptake from eligible patients was lower than expected (238).

Finally, the positive aspect of getting a CXR early in a patient's diagnostic pathway was seen on many occasions. NICE state that a CXR should be ordered in current or ex-smokers if they present with just one of the symptoms suggestive of cancer, suggesting that PCPs should have a low threshold for organising CXRs. This guidance seems to have been followed in many cases, with a CXR being ordered at the first presentation in 47 of the 118 cases analysed, often leading to a rapid diagnosis. There were several other cases where a PCP has documented 'consider CXR' or '?CXR' but had opted to wait. The findings suggest PCPs should have a low threshold for CXR and even if a PCP briefly considers doing a CXR, particularly in current or ex-smokera, they should request one.

A key finding from the SEAs analysed is that the CXR is important in the diagnosis of lung cancer but can also potentially be a cause of diagnostic delay. The SEAs included examples of rapid recognition and referral of lung cancer as a result of having a low threshold for requesting and organising the investigation. However there were also multiple cases in which CXRs were not requested as early as could have been. A diagnostic challenge is presented when the CXR is either normal or shows consolidation. In the SEAs considered, a CXR which was negative for lung cancer increased the primary care interval fivefold. It is possible this potential delay could be prevented if the PCPs were aware of the frequency of normal CXRs in patients with lung cancer and the need to treat the patient rather than the

CXR report by having a low threshold to arrange further tests or referrals if there is a high suspicion of cancer.

7.3.3 The management of anaemia and its impact on the primary care interval

25 (34%) of the patients diagnosed with bowel cancer had blood tests arranged during the primary care interval. Of these 17 were abnormal (low haemoglobin or ferritin), five were normal and three had other abnormalities such as raised inflammatory markers. In other cases anaemia was found incidentally; on routine blood tests, or bloods done for other reasons. SEA analysis included some cases in which a request for blood tests may have delayed the diagnosis, through either a delay in having the blood tests, a lack of follow up of results or the patient simply not having the requested blood tests. Some examples are discussed below.

- It was suggested that a patient with vague abdominal symptoms have bloods and a routine USS scan. The patient did not have the bloods as suggested, which when done found iron deficiency anaemia (IDA). This led to a delay of over one month.
- A patient with three months of altered bowel habit was advised to have bloods and then 'review for scope'. The patient had bloods three days later which showed IDA. These were marked 'to discuss'. However the patient was not seen following this for two months regarding the bowels, despite one telephone consult regarding cataracts.
- A patient with a short history of abdominal pain and loose stools was booked for blood tests and a review in two weeks. The bloods came back the next day and showed mild anaemia and raised inflammatory markers. The bloods are marked as "has follow up", however the patient was not followed up and was not reviewed in two weeks as planned.

There were other cases in which blood results were ambiguous, which led to further testing or referral to other specialties, which also led to a delay in a number of cases.

- A patient presented with incidental IDA at routine new patient blood tests, however this was mild. This caused some delay whilst blood tests were repeated, a vitamin B12 injection was given and the case was discussed with haematology prior to referral.
- A patient had bloods showing mild anaemia which were repeated six times over a six month period without any change in management plan or further investigations.

In other cases, more than one test result was abnormal, often resulting in the anaemia being missed.

- A patient presented on two occasions with generalised abdominal pain, increase in stool frequency and an abdominal lump. Bloods were organised and done quickly. They showed a normal haemoglobin level and a low iron which may have increased the chance of serious pathology. However the patient also had bloods done for B12 and diabetes which showed newly diagnosed diabetes. In a follow up appointment for the bloods it seems the diagnosis of diabetes was discussed rather than the low iron.

There were cases in which IDA was not managed according to the guidelines. The NICE guidelines are clear in the fact patients with IDA should be referred using the suspected cancer referral pathway to the colorectal cancer team. However, in some cases reviewed this did not happen, leading to a delay in diagnosis.

Finally, on some occasions patients presented with red flag bowel symptoms which could have been referred for suspected cancer. However blood tests organised as part of the investigation came back normal, providing false reassurance.

- A patient with a long history of change in bowel habit had a normal full blood count seemed to have been falsely reassuring in a patient with red flag symptoms.
- A patient presented three times with abdominal pain and PR bleeding. Bloods were done which were normal and the patient was treated for haemorrhoids, despite not finding piles on PR.

These results have shown numerous ways in which investigations can adversely affect the recognition and referral of bowel cancer. Studies consistently show the importance of IDA in diagnosing bowel cancer. A 2008 case control study by Hamilton et al. showed that IDA had a PPV for bowel cancer in men over 60 of 13.3% (239). The high PPV has been confirmed by other more recent studies (26, 240). There were many examples of IDA being managed appropriately via a 2ww referral, but also as shown above, cases in which IDA was not referred. Similarly there were cases in which despite the presence of other red flags for bowel cancer a patient was not referred on the basis of normal bloods.

The management of anaemia is complex. The 2015 NICE guidelines are clear that in the over 60's, a 2ww referral should be sent for all patients with IDA. In younger patients even the NICE guidelines are unclear. A faecal occult blood test was recommended in some, but is often not available from

UK hospitals. More recently faecal immunochemical tests are being recommended but again this test is not yet widely available (241). Another question lies in how to manage patients with mild anaemia, low ferritin alone or chronic anaemia. Some of the cases above suggested that normal blood tests could be providing false reassurance. In these situations the guidance is clear that red flag symptoms should warrant a 2ww referral, regardless of blood test results.

Safety netting also plays a role in the management of blood results, as many of the examples above highlight delays due to lack of or inadequate follow up of blood results. CRUK and NICE both recommend having systems in place to ensure results are followed up carefully and RCGP quality improvement initiatives have focused on the complexity of organising and managing blood results in general practice (25, 185, 242). Again, the problem of patient responsibility is important as in some cases, delays occurred as a result of the patient not attending for blood tests. There needs to be some onus on the patient to have the tests if recommended by the PCP.

7.3.4 The role of patient factors on the primary care interval

Patient factors played a role in the pathway to diagnosis in many of the cases. One of the most common patient factors noted in the SEAs was patients attending late with new symptoms. This is known in the Aarhus statement as the patient interval and may involve the detection and interpretation of bodily changes and self- management before a decision is made to seek medical help. At a practice level the patient interval is difficult to reduce as it occurs before the patient sees a PCP. Much of the work on the patient interval has focused on the use of mass media education campaigns. Some examples of prolonged patient intervals are shown below.

- An ex-smoker presented to general practice with a six month history of a cough. A CXR was requested immediately and suggested a diagnosis of lung cancer.
- An elderly lady presented with a three month history of PR bleeding. She was referred immediately and a diagnosis of colorectal cancer was made at colonoscopy.

Other ways in which patient factors may have affected the time to referral and diagnosis included presenting with multiple problems and normalising symptoms. These are difficult scenarios to manage. If a patient presents with multiple problems there are a range of potential ways the PCP could respond. The PCP may manage the situation effectively, by booking further appointments and prioritising the patients problems. However, it is possible

that in a 10 minute consultation, shortcuts or errors could be made by the PCP. A possible example of this is seen in one case below in which a patient was not examined.

If a patient mentions a symptom which could be suggestive of cancer the PCP should investigate them fully. However if the patient normalises the problem or provides a valid alternative explanations such as below, it may be difficult for the PCP to justify a referral for invasive investigations. Examples of these are shown below

- A patient presented with red flag symptoms as well as vague abdominal pain and consistently blamed his work manoeuvring boats. There was no examination documented. It is possible that this explanation was accepted by the PCP resulting in a delay.
- In one case a patient was noted to have IDA after routine bloods. The patient attended a planned review however refused any investigations stating he was 'always anaemic'.

Finally patients often refused referral or investigations. This is within the patient's right to choose what treatment and investigations they would like, but could lead to delay in diagnosis.

- One patient attended with a six week history of PR bleeding, an urgent referral was suggested but the patient refused, stating it was just piles. The patient presented twice more before accepting referral.

As discussed above, some of the problems of delayed presentation and prolonged patient intervals cannot be resolved by individual GP practices. This requires patient education and mass media campaigns such as the "*be clear on cancer*" initiative to ensure that patients are aware of potential symptoms of cancer and present in a timely manner. GP practices could facilitate this by providing information at surgeries either in the form of posters or videos and improving access to PCP appointments. Within the consultation, opportunistic education can take place when patients present with other symptoms. One example of this may be providing ovarian and breast cancer information during a patient's smear test appointments.

7.3.5 The impact of patient comorbidities on the primary care interval

Patient comorbidities often affected the recognition and referral of cancer symptoms. Some examples of this are shown below. Patients with memory problems were highlighted on a number of occasions, often presenting with vague histories, and failing to attend for follow up appointments or

investigations. In other cases, new symptoms or results of investigations were incorrectly explained by existing diagnoses or medication.

- Patients found to have IDA which was thought to be due to recent surgery, rheumatoid arthritis and anti-platelet medication
- A patient with diarrhoea thought to be due to diverticular disease
- Patients with new coughs thought to be due to blood pressure medication.
- Two patients with worsening breathlessness suffered delays in diagnosis as their symptoms were thought to be due to worsening COPD in one case and worsening heart failure in another.

With an aging population, the issue of multimorbidity is growing in importance as is the evidence base on the effect of multimorbidity on cancer diagnosis, treatment and survival (243). Further work is planned, including a large database study in Scotland looking at the effects of multimorbidity on all aspects of cancer care (244). It is widely accepted that PCPs are ideally placed to recognise and manage multimorbidity (245). As a result it is important for PCPs to have an open mind to avoid missing important diagnoses and to have a low threshold for organising investigations. However it is also possible that patients with comorbidities may be frail and unable to tolerate invasive investigations such as colonoscopy, meaning there is also a danger in over investigation. Using safety netting in these patients is important but needs to be individually tailored particularly in the case of patients with memory problems who may require proactive follow up by the PCP.

7.3.6 Communication between primary and secondary care and the primary care interval

There were missed opportunities and possible increases in the primary care interval in some of the cases due to poor communication between primary and secondary care. There were many examples of this, which are highlighted below. After reviewing these cases it was thought to be important to communicate any worsening symptoms in patients awaiting investigations, but also to ensure the urgency of tests and referrals is changed if needed.

- A patient was referred on a 2ww referral and had a normal flexible sigmoidoscopy. The patient was then referred for a CT scan but whilst waiting, attends the PCP three times and ED twice with worsening symptoms. There was no attempt to communicate this worsening of symptoms with the surgeon in secondary care and the patient was eventually diagnosed with colorectal cancer via an emergency admission.
- A patient was admitted to the vascular ward for surgical procedure. The discharge letter stated that the patient's haemoglobin was low and that a transfusion was

given. It was not clear from this letter if the low haemoglobin was due to the surgery or was an incidental finding which may have suggested cancer. No action was taken at that time. When the patient was seen again two months later, he was generally unwell and blood tests showed low haemoglobin again. He was then referred to the colorectal surgeons and was diagnosed.

There were some examples of good communication between primary and secondary care leading a rapid diagnosis. These cases highlight the benefit in involving other specialities where possible.

- A patient attended the INR clinic to have his blood checked and mentioned to the nurse he is worried about 'rapid weight loss' and cough. The nurse at the clinic advised the patient to see the PCP urgently.
- A patient with fever of unknown origin was discussed with the infectious diseases team, they suggested several investigations including a CT scan which found the diagnosis.

These cases show that communication between primary and secondary care is important in managing patients with potentially serious illness. Efforts should be made to make communication as easy as possible, ensure hospital discharge letters are clear and allow PCPs to easily update specialists on the health of patients under their care. Work to facilitate this may be needed by local CCGs or GP cancer leads to develop links between PCPs and and secondary care colleagues.

7.3.7 Examples of good practice during the primary care interval

Good practice was defined for the purpose of coding as "any mention of good clinical care, diligence or awareness from any member of the primary care team".

There were many examples of good practice which led to a rapid diagnosis with no opportunities for improvement. The objective of the SEA was to investigate ways to improve cancer recognition and referral, and the examples of good practice provide excellent opportunities for learning. Examples included:

- Evidence of teamwork between different members of the practice leading to rapid diagnoses
- PCPs being vigilant for potential serious symptoms in other clinical scenarios such as annual reviews.
- PCPs being thorough and careful with investigation requests and referrals. A good example of this was shown in a patient who was seen with a short history of severe SOB. A CXR was done the same day which showed a suspicious lesion, however the breathlessness had worsened resulting in hospital admission. Despite this

admission to hospital the PCP stated a 2ww referral was done anyway 'for completeness'.

A common example of good practice involved other members of the healthcare team showing diligence, vigilance and good communication skills by recognising red flag symptoms in patients in other settings such as annual reviews or blood test appointments and seeking advice from PCPs. These actions should be actively encouraged, perhaps through discussion at team meetings or through the organisation of PCP appointment lists or any 'on call systems' to ensure other members of the health care team feel able to freely discuss cases with clinicians.

It is helpful to recognise the good practice shown in the SEAs. The information formed much of the learning points discussed below and was also useful when informing PCPs in the education meeting of areas of care which were done well. Positive feedback is also discussed by Michie et al. as a potential behaviour change technique (135). By recognising areas of good practice the behaviour can be promoted and adopted by other members of the primary care team.

7.3.8 Patient behavioural red flags during the primary care interval

It is possible that as well as the specific symptoms and signs of cancer described by NICE, the way in which patients present to general practice, as well as certain patient behaviours, may help to highlight potential serious disease to PCPs. These possible diagnostic factors are referred to by the student as 'behavioural red flags' and included presentations to ED or the OOH service during the diagnostic period, multiple presentations with the same problem, home visit requests in normally ambulant patients, and patients becoming angry, upset or emotional. There are some examples of these sorts of indicators already in the medical literature. For example, work by the Nuffield trust has shown that ED attendances and non-elective admissions to hospital rise significantly prior to a cancer diagnosis (246). It is also known that the number of primary care attendances increases prior to diagnosis, and that the number of attendances varies significantly by cancer type (62).

When analysing the SEAs in this project, possible patient behaviours that may suggest a serious diagnosis such as cancer were coded and analysed. These behaviours are discussed below.

As already mentioned in the medical literature, patients attending ED or OOH during the diagnostic period were frequently noted in the SEAs. This

supports the findings of the Nuffield trust work discussed above and suggests that PCPs should consider documenting and discussing ED attendances with patients. However this may not be feasible, given the current workload and recruitment problems in UK general practice. Examples of this in the SEAs include:

- An 80 year old ex-smoker presented with a few months of cough and new haemoptysis. The patient had a CXR which was normal and attended ED with the haemoptysis before re-presenting to general practice where a 2ww referral was done.
- A 78 year old man presented with loose stools, abdominal pain and weight loss and a 2ww referral was done. The patient had a normal colonoscopy so a CT scan is arranged. The patient had a long wait for this scan and attends ED twice during time with worsening symptoms, each time he is discharged with a note to his PCP but the colorectal team were not informed.

Patients who previously were infrequent attenders and then present to primary care were frequently highlighted in the SEA analysis. These patients had attended less than three times in the past year or had not presented in the last six months. It is possible that these patients are more likely to present with serious illness or to have had a longer patient interval prior to diagnosis. Similarly, it is possible that patients who are infrequent attenders may be less likely to represent with ongoing symptoms or attend planned reviews, which may increase the primary care interval. Examples of infrequent attenders affecting time to referral are shown below

- A 77 year old man with diabetes was found to have IDA on bloods following a routine operation at the hospital. The bloods were marked as 'to come in'. The patient did attend but it seems a diabetic review was done. Following this the patient did not attend for eight months before being admitted as an emergency and being diagnosed with colorectal cancer.
- An ex-smoker who had not presented in the last two years, presents on two occasions with chest pain and a cough. At the second visit a CXR was organised which led to the diagnosis.
- An ex-smoker who in the past two years had only presented for an annual diabetic review, presented twice in ten days with chest symptoms. A CXR was organised at the second presentation which suggested lung cancer.

Patients presenting multiple times with similar symptoms could also suggest potential serious illness. This was noted in a Delphi study on safety netting which suggested a 'three strikes and refer' rule for use in general practice. This rule suggested that if patients present on three occasions with similar symptoms without explanation, an automatic referral to secondary care was recommended (189). There were many examples of multiple presentations

within the SEAs which suggest both patient worry and possible serious illness.

- A 77 year old ex-smoker with COPD had three appointments, one telephone consultation and a home visit with worsening chest symptoms. The diagnosis was complicated in this case by a normal CXR but the patient continued to present. A CT was requested on the fourth visit which confirmed the diagnosis.
- A 76 year old ex-smoker was seen four times in 10 days with worsening chest symptoms. Due to poor mobility a CXR was delayed until the fourth presentation which was then suspicious for lung cancer.

7.4 Significant event analysis learning points

Following the completion of each SEA, the student recorded a number of learning points based on the events of that SEA. Learning points were documented in each case and may represent examples of care which led to a rapid diagnosis as well as examples of learning where there may have been missed opportunities. The learning points for both colorectal and lung cancer were collated and are discussed below.

7.4.1 Bowel cancer learning points

The importance of safety netting was highlighted in 39 of the SEAs (53%). As discussed in the scoping review in chapter six, this included safety netting when seeing patients with red flags, but also when arranging investigations and organising hospital referrals. There were many examples of effective safety netting in the SEAs reviewed which allowed patients to return, or have organised follow up and be referred quickly.

The need to be aware of relevant guidelines, and red flag symptoms suggestive of bowel cancer was reflected in learning points in 26 (35%) of the cases. This was often highlighted when the guidelines were followed and this led to rapid investigation and referral. However there were some cases in which patients with red flags were not investigated or referred as suggested in the guidelines. As discussed in section 7.3.3 the management of IDA is complex and this was highlighted in the learning points. IDA was often picked up incidentally in asymptomatic patients and was managed variably in different cases, leading to missed opportunities in some cases.

The need to have a robust system to manage investigation results was highlighted in 17 (23%) learning points. This included having clear systems in place for the filing and repeating of blood results, taking into account trends over time. If bloods need to be repeated or a patient seen to discuss a result,

there should be a system in place to ensure patients are not missed. In addition to this, there was a need to be aware of possible false reassurance from normal blood results which was highlighted in a further three learning points.

The importance of noting patients presenting multiple times or presentations in normally infrequent attenders should be taken into account when assessing patients and considering possible serious illness. This was highlighted in 12 (16%) learning points. Finally, difficulties in the diagnosis of patients with multiple comorbidities was reflected in six learning points highlighting the possible difficulties in assessing patients with multimorbidity. Table 5 shows the learning points from the 74 colorectal cancer SEAs.

Learning point	Frequency
Safety netting is important when managing patients with red flag symptoms, arranging investigations and sending referrals	39
Know the NICE guidelines on the recognition and referral of cancer and the red flags	26
Have a robust system for dealing with the results of investigations	17
A careful examination should be undertaken and documented in patients presenting with abdominal symptoms	15
Patients presenting multiple times with similar symptoms should be monitored	6
Have a low threshold for investigating patients who present infrequently	6
Patients with significant comorbidities may present late or have new symptoms labelled as part of their existing disease	6
Investigate patients with iron deficiency anaemia and know the local referral pathway	4
Good communication with secondary care can improve diagnosis times	3
Do not be reassured by normal blood results when a diagnosis of colorectal cancer is suspected	3
Ensure patient contact details are correct when organising investigations and referrals	2

Table 5: Colorectal cancer learning points by frequency

7.4.2 Lung cancer learning points

The most frequently recorded learning point was around the importance of safety netting, which was highlighted in 41 (35%) of the SEAs.

The need for a low threshold for CXR was highlighted in 34 (29%) of the SEAs. This was often recorded when a CXR was requested early in a patients presentation and resulted in a quick diagnosis, but there were also cases in which patients presented multiple times with chest symptoms before a CXR was requested. This seemed to happen more frequently in patients with symptoms of recurrent chest infections, or chest pain.

The need to have a good awareness of relevant guidelines for cancer recognition and the red flags of lung cancer was highlighted in 22 (19%) of the SEAs. This was frequently noted in patients who presented with haemoptysis, in whom the guidelines suggest a 2ww referral, but frequently a CXR was organised first. Another missed opportunity in this learning point were patients who were smokers and had one chest symptom, in which guidelines would suggest a CXR following that visit to the PCP.

Other learning points included being aware of patients presenting multiple times with similar symptoms, especially if they were previously infrequent attenders; the need to have a system in place to deal with investigation results and ensure this system is robust; and the dangers of a normal CXR in the period leading up to the diagnosis. A table showing the learning points and their frequency within the SEAs is shown below.

Learning point	Frequency
Safety netting is important when managing patients with red flag symptoms, arranging investigations and sending referrals	41
Have a low threshold for requesting CXRs, particularly in current or ex-smokers	34
Know the NICE guidelines on the recognition and referral of cancer and the red flags	22
Patients presenting multiple times with similar symptoms should be monitored	19
Have a robust system for dealing with the results of investigations	17
Be aware that CXRs can be negative even in patients with cancer	14
Patients presenting to ED or OOH should be monitored and reviewed as needed	11
Have a low threshold for investigating patients who present infrequently	9
A careful examination should be undertaken and documented in patients presenting with chest signs	7
Have a system in place to monitor investigations that have been requested and to chase up patients who do not	6

attend	
Good communication with secondary care can improve diagnosis times	6
Document and record smoking status in patients presenting with chest symptoms	3
Patients with significant comorbidities, may present late or have new symptoms labelled as part of their existing disease	2
Ensure patient contact details are correct when organising investigations and referrals	2

Table 6: Lung cancer learning points by frequency

7.5 Summary

This chapter has described the use of independently collected SEA data to identify opportunities to improve the recognition and referral of lung and bowel cancer.

The SEAs have shown how difficult the recognition and referral of bowel and lung cancer can be. Some of the symptoms reported to the PCPs in the SEAs, such as poor appetite, nausea, vomiting and epigastric pain would suggest an upper gastro-intestinal problem and may lead PCPs and patients away from considering bowel cancer, or may prolong the diagnosis due to possible referral to upper gastrointestinal specialists. Other, albeit less common symptoms in the colorectal cases such as blue discolouration in fingers, falls, paraesthesia and cold hands, presented without any classical symptoms and would not normally suggest a diagnosis of bowel cancer. For lung cancer, most of the symptoms are common in smokers such as cough, shortness of breath, increasing sputum and wheeze. These symptoms may be as a result of smoking itself, COPD or chest infections. Other symptoms, such as chest pain, feeling generally unwell, tiredness, night sweats and headache would not normally suggest lung cancer and may lead to PCPs organising bloods or watchful waiting which could lead to potential delay. Although one could argue a CXR may be a reasonable response to complaints of chest pain, night sweats and feeling generally unwell.

The SEAs completed have provided a wealth of information on the primary care interval in the pathway to lung and colorectal cancer diagnosis at nine practices across Hull and East Riding of Yorkshire. This chapter has highlighted several important areas in the diagnosis of lung and colorectal cancer which have the potential to improve the primary care interval including

safety netting, the organisation and management of investigations, communication with secondary care. In addition the SEA analysis highlighted examples of good practice which are equally important to learn from. This information will be used to develop an educational intervention for each participating practice.

In addition to this outcome, the research is the first time SEAs, not completed by the clinical team involved in the care of the patient, have been used in research. The findings suggest that SEA data collected by independent auditors could be an alternative to GP collected data. This could assist in future SEA research by allowing other members of the healthcare team to complete the SEA. It is important to note that in this research, the 'auditor' was still a clinician and it is unknown whether non clinical team members could successfully complete the SEA. The next chapter will discuss how the SEA data were presented to practices with the aim of developing practice action plans.

Chapter 8: Feedback meetings and action planning

This chapter considers the content, discussion and outcomes of the educational feedback meetings that occurred following the collection and analysis of SEA data from each practice. The process and detail of the feedback meeting is discussed in chapter 8.1. The discussion between practice staff present at the meeting following the presentation and the development of action plans for each practice form the results of this chapter in section 8.2. These action plans aimed to improve the recognition and referral of cancer symptoms in each practice.

8.1 Method

8.1.1 Audit and Feedback

The SEA data collected and analysed in each practice (discussed in chapter seven) were presented in an educational feedback meeting to staff in each practice using the techniques and recommendations discussed in the introduction to audit and feedback presented in chapter three. The work by Ivers et al., Foy et al., and Sniehotta et al., informed the design of the feedback meeting (97, 99, 106). This process is described in chapter 3.3. The aim was that the audit and feedback of cancer diagnoses for each practice could stimulate action planning and develop interventions which could change behaviour and improve future cancer diagnoses. There are multiple theories on how behaviour change may be achieved using audit and feedback. Three of these theories are introduced in chapter four. It is thought that the technique of audit and feedback may work in multiple ways including by changing beliefs about current practice, affecting self-efficacy and directing behaviour to a specific set of skills (97).

8.1.2 Educational feedback meeting demographics

The recipients of the feedback included a mixture of GPs, nurses, administration staff and allied health professionals, such as pharmacists, in a face to face group format on just one occasion, as soon as possible after completion of the SEAs. The meetings were better attended if they were part of a regular practice education meeting. The breakdown of the attendance of each meeting can be seen in table seven.

Practice	GPs	Nurses	Administration staff	Allied Health Professionals	Practice Managers	Total
1	4	1	1	0	0	6
2	4	1	1	0	0	6
3	7	1	0	0	0	8
4	6	0	1	0	1	8
5	5	2	0	0	0	7
6	5	3	3	2	1	14
7	4	2	0	0	0	6
8	3	1	0	0	1	5
9	4	2	0	1	0	7

Table 7: Attendance at educational feedback meetings by staff type

8.1.3 Educational feedback meeting design and content

The Cochrane review by Ivers et al. on audit and feedback gave recommendations on the most effective features of educational meetings (97). These recommendations were supplemented by work by Foy et al. (99). In addition to this the Cochrane review on educational outreach visits for PCPs was considered. The feedback in this thesis aimed to meet as many of the recommendations as possible. This research is discussed in chapter 3.3.

In addition to these recommendations, the RCGP SEA toolkit provided evidence based advice on using the SEA in an educational meeting which were developed using a "train the trainer" approach (77). Whilst this template aimed to teach PCPs how to use SEAs, and complete their own SEAs there was some focus on learning from SEAs already completed and three example SEAs were provided in the RCGP toolkit. As such, some of the RCGP SEA toolkit could be applied to the feedback meetings undertaken in this thesis. The RCGP toolkit recommends starting the educational meeting with introductions, followed by a background which should include figures on the early detection of cancer, the history of SEA use and an introduction to the cancer SEA template. The main part of the educational meeting concentrated on reviewing the three example SEAs, focusing on the 'why did it happen' reflective section of the SEA and the themes generated. The format of the educational meeting used for this thesis followed the same simple structure described below.

The format of the meeting was similar in each case, starting with an introduction to cancer diagnosis in primary care, highlighting some of the

issues surrounding early cancer diagnosis and the international comparisons in terms of survival. Following this, demographic information on the SEAs was presented, then the common themes in the case analysis were highlighted, demonstrated by some actual cases from each practices SEAs. This was done with individual practice data making the feedback specific to that team. Finally, a summary of the learning points was discussed. It became obvious as the student conducted the meetings, that the practice staff were most interested in looking at actual cases. As a result more of these were used as the feedback meetings were conducted. This was an interesting finding in itself, but one which was supported by the RCGP SEA toolkit and which is well documented in the medical literature. This is discussed in chapter 8.3.2 (247-249).

Having addressed the recommendations discussed above for audit and feedback and action planning research, a template for the educational meeting was developed. This is presented below. The next section will explain how this fits with the theories of behaviour change outlined in chapter four.

Template of an educational meeting for the feedback of audit data in primary care

Initial considerations
Choice of topic – Choose a topic which is of high cost or risk to staff or users, where there is evidence of a serious quality problem, which is pertinent to national policy initiatives and a priority for the organisation
Choice of educator – Consider a supervisor / colleague, a peer or a general practitioner
Frequency of meetings – Evidence suggests feedback given more than once is more effective

Introduction
A clear definition of the purpose of the audit, a background summary of the literature and use of the audit tool, a context such as local figures on performance

Audit findings
A summary of the audit findings presented as key themes
Use example individual cases to highlight these themes

Improving future performance
Identify barriers to change
Establish the right environment for change considering relationships within the team and with other groups such as patients and external agencies
Consider use of other interventions e.g. reminders
Set clear targets and consider an action plan
Ensure action plans have a clear 'where, when and how'

Figure 21: Template for the educational meeting developed by the student

8.1.4 The use of behaviour change theory in the educational meeting and action planning

Chapter four introduces theories of behaviour change and explains how the BCW and NPT will be used within this thesis. This section explains how the BCW and NPT informed the design of the educational meeting and aided the development of action plans. As discussed in chapter four, the COM-B model fits at the centre of the BCW. The COM-B model states that capability, opportunity and motivation all interact to generate behaviour. Thus, when designing the educational feedback meeting it was important that the PCPs capability, opportunity and motivation were considered. Motivation and opportunity could be enhanced by providing a clear background to the audit, including information on the recognition and referral of cancer symptoms in the UK as well as comparisons in cancer survival between the UK and comparable countries. Foy et al. recommend establishing the barriers to implementing change and establishing the right environment for this behaviour change (99). Within each practice, it is likely the practice staff are best placed to be aware of the barriers to implementation. By allowing practice staff to develop the interventions themselves, plans were more likely to be feasible and practical within each organisation. The specific method of using audit and feedback of the PCP's own patients before allowing the PCPs themselves to develop action plans fits well with the COM-B model. The COM-B model highlights the importance of capability and opportunity in generating a behaviour change, and the PCPs were perfectly placed to be aware of their own capability and opportunity within their own practice. For example, if the reception staff at a particular practice were already feeling overworked and stressed, there may not be the opportunity to implement an action plan to ask them to ring all patients who did not attend hospital appointments.

It was hoped that by allowing PCPs to develop their own action plans, using audit and feedback of their own patients and care, motivation for the behaviour change was strengthened. The COM-B model splits motivation into reflective and automatic motivation. Reflective motivation is affected by risks, expectations and self-efficacy whereas automatic motivation is affected by desires, reactions, impulses and reflex responses (149). By allowing staff to develop their own action plans they were able to take into account perceived risks and their own expectations. Automatic motivation may be improved by the PCPs inbuilt desires to improve their patient care.

NPT aims to identify factors that promote or inhibit the incorporation of interventions into everyday practice. It focuses on the work that individuals and groups do to enable an intervention to become embedded into everyday practice (normalised). The first component of NPT is *coherence* which focuses on sense making. By introducing the educational meeting with a clear definition of the purpose of the audit, a background summary of the literature, the use of the audit tool and a context, in this case UK cancer survival figures it was hoped that *coherence* will be improved. As much of NPT focuses on implementation, the theory will be key when developing action plans. It was thought that the NPT components of *coherence*, *cognitive participation* and *collective action* would be improved if staff developed action plans they all agreed upon, developed with their personal knowledge of their own practice and how the staff work together. The NPT framework askes in the *coherence* section; "do the participants [in this case the practice staff] have a shared sense of the intervention's purpose?" This was more likely to be the case if the staff had developed the intervention themselves. Similarly, in the *cognitive participation* section, the framework asks "Will they [the practice staff] be prepared to invest time, energy and work in the intervention?" Again it was thought that by developing their own interventions this part of *cognitive participation* could be improved (136). By identifying barriers to change, establishing the right environment for change, setting targets and having structured action plans based on Sniehotta et al.'s work on 'when, where and how' it is hoped that the NPT constructs of *cognitive participation* and *collective action* would be met (106).

8.1.5 Analysis of post educational meeting discussions

The discussion on the findings of the SEAs and the action plan development with practice staff was audio recorded to facilitate dissemination of the action plan to the staff via email. The Cochrane review on audit and feedback advised that the feedback is most effective when it is given both verbally and in writing and when it includes clear targets and action plans (97). By contacting the staff again following the meeting with an email summary, it was hoped action plan effectiveness would be improved.

Where necessary, the student offered his help in carrying out the action plans such as developing leaflets and electronic medical record templates. This help was specific to each practice but may limit the generalizability and ability to replicate the study. This is discussed in chapter 11.3.3. The aim of the discussion was to develop action plans which could be put into practice over the months following the meeting, to improve the recognition and

referral of cancer. Following each educational meeting, the student made field notes, and reflected on how the meeting had gone, what went well and what could be improved for the next meeting. These reflections are discussed throughout the chapter and in section 8.3.

The analysis in this chapter is based upon the audio recordings from the staff discussions following the educational feedback meeting, and the field notes made during and immediately after the meetings by the student. This data were assessed using the computer software NVivo and analysed using TA as discussed in chapter five. The analysis used themes based on the content of the discussion such as safety netting or continuity of care. The overriding themes drawn from the data will be discussed in the results below together with a summary of the action plans developed by each practice.

8.2 Results of practice discussions and action plan development

This results section will present the findings and analysis of the discussions which took place in the educational meeting in each practice followed by the practice action plans. A summary of the discussion points, and action plans developed is presented in table eight.

Practice	Key discussion points	Action plan	Intervention
Practice 1	Emergency appointments - The practice has a system of emergency five minute appointments booked on the day for acute problems, it was recognised that this could result in missed opportunities if used inappropriately	Use PCP booked follow up following emergency appointment if the patient needs more time / further investigation	Learning point agreed by PCPs in educational meeting with email reminder
	Safety netting - Staff recognised that whilst they do safety netting in their consultations, their advice could be more specific	Use the four steps of safety netting highlighted in the literature (Bankhead et al.)	Learning point agreed by PCPs in educational meeting with email reminder

	Multiple presentations - A number of cases demonstrated patients who had attended several times over a period of time with similar symptoms	Treat multiple attendances as a red flag and always review notes prior to seeing each patient	Learning point agreed by PCPs in educational meeting with email reminder
Practice 2	Multiple presentations - In several cases, patients often with multimorbidity, presented several times with similar symptoms	Use the three strikes and refer rule discussed by Bankhead et al. Review notes prior to seeing patients to spot infrequent attenders or those with multiple presentations	Learning point agreed by PCPs in educational meeting with email reminder
	Safety netting - The group highlighted the importance of documenting safety netting and ensuring patient attend for review	Ensure all staff document safety netting, keep up good work with safety netting	Learning point agreed by PCPs in educational meeting with email reminder
	CXR - A number of SEAs showed the dangers of a normal CXR in the time from first presentation to diagnosis and the importance of having a low threshold for requesting a CXR in smokers and ex-smokers	Ensure CXR are requested early as per the NICE guidelines. Refer on a 2ww if a patient has a normal CXR but there is suspicion of cancer	Email sent to staff with SEA findings and a discussion from local chest physicians on the management of patients with a normal CXR
Practice 3	Blood results - There was occasions where delay occurred when patients did not return for blood tests and results or waited a significant length of time before attending the surgery again.	When checking blood results comment as urgent if needed with a time frame for review	Learning point agreed by PCPs in educational meeting with email reminder

	2ww referrals - In a couple of cases patients did not attend 2ww referral appointments or did not get an appointment scheduled	Use the patient self booking system when doing a 2ww referral	Self booking leaflet created for patients. New starters and locum to have information on self booking included in 'starter pack'
	Patient follow up - It was recognised that patients could be lost to follow up and due to workload PCPs found it difficult to keep track of patients they had seen	Use a Read code to enable follow up of patients the PCPs are concerned about	Laminated poster created for each consultation room with the Read code on.
	Normal CXR - A number of patients had a normal CXR between presentation and diagnosis which resulted in delay	Discussion with local chest physicians regarding the management of this	Student to contact local chest physicians and feedback a plan
	Safety netting - Staff felt that whilst safety netting was frequently documented it was often not specific leading to patient and admin staff confusion	When documenting safety netting, write a time frame for follow up in the notes	Learning point agreed by PCPs in educational meeting with email reminder
Practice 4	Blood results - A number of cases demonstrated delay in review / further investigation as a result of patients not getting blood test results promptly	Encourage phlebotomists and nursing staff to safety net patients	Meeting with nursing staff. Development of protocol. Development of blood test safety netting leaflet
	Follow up - In several SEAs patient attended with potentially worrying symptoms but did not re attend for review.	Use a Read code to enable follow up of patients the PCPs are concerned about	Learning point agreed by PCPs in educational meeting with email reminder
	2ww referrals - SEAs were discussed in which the patient did not attend the 2ww appointment or attended but then	Use a 2ww referral information leaflet when referring, encourage self booking	A leaflet was developed by the student and paper and electronic copies distributed to the staff.

	refused further investigation		
	Referrals - Patients not attending hospital appointments led to delays in cancer diagnosis	Admin staff to check all DNA letters and contact patients if necessary	Learning point agreed by PCPs in educational meeting with email reminder
Practice 5	"To come in" letters - Patients had been sent a letter asking them to book an appointment because of abnormal blood results, however patients often thought the appointment was for other reasons	Admin staff to make the 'to come in letters more specific'	Learning point agreed by PCPs in educational meeting with email reminder
	Qcancer - This software was introduced by one of the team members, it was suggested it would be helpful if PCPs were unsure whether to refer or not, or to which specialty to refer to	Use the in-built Qcancer risk calculator in the computer system to aid referral	Learning point agreed by PCPs in educational meeting with email reminder
	Iron deficiency anaemia - Staff felt the current IDA guidance was ambiguous regarding cut off values and ferritin as an acute phase protein	Develop an anaemia pathway with secondary care input	Practice staff were to develop a pathway and implement the changes
	Examination - Staff highlighted that in some cases the patients had not been weighed, even when presenting with weight loss	Ensure patients are weighed at every opportunity	Learning point agreed by PCPs in educational meeting with email reminder
Practice 6	Examination - Staff highlighted that in some cases the patients had not been weighed, even when presenting with weight loss	Nursing staff asked to weigh patients at every opportunity for example, health checks and blood tests	Learning point agreed by PCPs in educational meeting with email reminder

	Safety netting - The need to improve safety netting advice and documentation was discussed	Develop a safety netting leaflet to give patients, with red flags and follow up advice	A safety netting leaflet was developed by the student with input from practice staff and disseminated in paper and electronic forms
	Safety netting - The need to improve safety netting advice and documentation was discussed	Develop a safety netting template to better document advice	Student developed an electronic template for safety netting
	Continuity of care - It was noted that in many cases there had been no continuity of care with the patient seeing a different PCP at each consult. It was unclear if this had caused delay but the group felt that follow up with the same PCP would be helpful	Admin staff were requested to ask the patient which PCP they would like to see. PCPs are encouraged to book own reviews	Learning point agreed by PCPs in educational meeting with email reminder
	Follow up - Following on from the safety netting discussion there was a thought that the computer record should allow easier follow up	Use a telephone appointment list on the appointment screen to aid follow up	PCPs to add patients to telephone list to enable follow up
Practice 7	CXR - Several SEAs included a normal CXR in the time from first presentation to diagnosis, this resulted in delayed referral	If worried about the patient refer irrespective of the CXR findings. Review the literature regarding consolidation on the CXR	Email to practice staff reinforcing the problems of CXR and a paper published in the BJGP
	Follow up - One case was discussed in which delay occurred as a result of a previous worrying presentation not being followed up	Put an alert on the patients record to let others know if previous notes need to be reviewed prior to the consultation	Learning point agreed by PCPs in educational meeting with email reminder

	Safety netting - This was recognised as important in the group and it was felt that safety netting should be undertaken at every opportunity	Practice staff to make a commitment to better document safety netting advice.	Learning point agreed by PCPs in educational meeting with email reminder
Practice 8	Iron deficiency anaemia - There were examples of delay due to IDA not being investigated as per the NICE guidelines	Always refer new IDA using the 2ww colorectal referral	Learning point agreed by PCPs in educational meeting with email reminder
	Weight loss - The practice staff discussed the importance of investigating weight loss thoroughly. Like others this centred around one case involving a normal CXR	Ensure patients presenting with abnormal weight loss are thoroughly investigated	Learning point agreed by PCPs in educational meeting with email reminder
	CXR - A number of SEAs showed the dangers of a normal CXR in the time from first presentation to diagnosis and the importance of having a low threshold for requesting a CXR in smokers and ex-smokers	Ensure CXRs are requested early as per the NICE guidelines. Refer on a 2ww if a patient has a normal CXR but there is suspicion of cancer	Learning point agreed by PCPs in educational meeting with email reminder
	Referrals - Patients not attending hospital appointments led to delays in cancer diagnosis	Admin staff to check all DNA letters and contact patients if necessary	Learning point agreed by PCPs in educational meeting with email reminder
Practice 9	Iron deficiency anaemia - Many of the bowel cancer cases presented with IDA.	Improve the management of iron deficiency anaemia	Learning point agreed by PCPs in educational meeting with email reminder
	CXR - Several SEAs included a normal CXR in the time from first presentation to diagnosis, this resulted in delayed referral	Refer on a 2ww if a patient has a normal CXR but there is suspicion of cancer	Learning point agreed by PCPs in educational meeting with email reminder

	Multiple presentations / infrequent attenders - A number of cases demonstrated patients who had attended several times over a period of time with similar symptoms, or patients who had not presented for some time before presenting with red flag symptoms	Treat multiple attendances as a red flag and always review notes prior to seeing each patient	Learning point agreed by PCPs in educational meeting with email reminder
	Education - Staff felt it would be helpful to have a further educational meeting on the new cancer referral guidelines	Improve knowledge of 2ww referral guidelines	Educational session delivered by student

Table 8: Summary of discussion points and practice action plans

The approach to the discussions was similar in practices one to seven. In each of these practices the discussion started with comments from a lead GP, before others made comments and discussed the findings. In practice eight, which was a small meeting, the team interrupted the presentation to ask questions and discuss the findings which meant the audiotaped discussion at the end of the meeting was limited.

Whilst the discussion following the feedback was different in each practice, there were some common themes discussed in each meeting before the development of individual action plans. The most common themes in the discussion largely matched those found during the analysis of the SEAs in chapter seven. The common themes in the practice discussions included the role of safety netting and follow up, the use of investigations, referrals, the management of patients with comorbidities and multimorbidity, problems with administration and finally consultation based activities. Figure 21 shows action plans by theme. Each practice developed between three and five action plans.

Safety netting and follow up action plans

- Improve safety netting advice and documentation of a follow up plan
- Use a Read code to enable follow up patients the PCPs are concerned about
- Develop a safety netting leaflet to give patients, with red flags and follow up advice.
- Develop a safety netting template to better document advice
- Use a telephone appointment list on the appointment screen to aid follow up

Managing investigation action plans

- Ensure CXRs are requested as per the NICE guidelines. Adopt guidelines to refer on a 2ww if a patient has a normal CXR but there is suspicion of cancer.
- Improve the management of patients with a normal CXR. Student to contact local chest physicians to develop guidelines
- Encourage phlebotomists and nursing staff to safety net patients through the development of a protocol and leaflet
- Communicate urgency when checking blood results
- Admin staff to make the 'to come in letters' more specific
- Develop an anaemia pathway with secondary care input
- Improve the management of IDA

Referral action plans

- Use the patient self booking system when doing a 2ww referral aided with a self booking leaflet created by student
- Admin staff to check all DNA letters and contact patients if necessary

Continuity of care action plans

- If patients attend in an emergency five minute appointment and need more time or further investigation, PCPs should book appropriate follow up.
- Recognise that multiple attendances may be a red flag.
- Admin staff are requested to ask the patient which PCP they would like to see. PCPs are encouraged to book own reviews
- Put an alert on the patient's record to let others know if previous notes need to be reviewed prior to the consultation

Consultation based action plans

- Use the in-built Qcancer risk calculator in the computer system to aid referral
- Ensure patients are weighed at every opportunity
- Ensure patients presenting with abnormal weight loss are thoroughly investigated

Education

- Improve knowledge of 2ww referral guidelines

Figure 21: Action plans developed by theme

8.2.1 Discussion theme 1: Safety netting and follow up

Safety netting and methods of ensuring follow up were commonly discussed leading to nine separate interventions. As discussed in the scoping review on safety netting in chapter six, safety netting and follow up are often used interchangeably and safety netting should include a plan for follow up. However in the discussions, safety netting was seen as the advice given by PCPs, whereas follow up was used to define ways of seeing patients again or keeping track of patients. Safety netting was discussed in the feedback meeting in six of the nine practices.

8.2.1.1 Safety netting quality

The discussion on the quality of safety netting varied between practices. In practice two, the SEAs showed evidence of safety netting being documented and patients attending for blood results and review appointments as planned. As a result the staff felt that safety netting advice was a strength of their work and planned to continue this. In other practices it was recognised that safety netting was likely being done, and perhaps the problem was more with documentation than actually giving out the advice.

8.2.1.2 Safety netting documentation

Following a discussion on safety netting in practice six, the practice pharmacist suggested the possibility of a safety netting leaflet. Some difficulties were recognised with this approach as it was felt that the advice may need to be different in each patient, and too much time may be lost in the consultation by filling in a form and adding this to the medical notes. Below is a quote from the practice pharmacist

"What about producing a leaflet that we can give and it doesn't matter, who sort of gives it, it doesn't matter if they keep getting the same leaflet, there is a fact isn't there something like you only remember 25% of what you are told but you remember 40% of what you see and if you have got a leaflet you are actually giving them the talk, but also this is something to refer to, to say I have given you a lot of information today but if you are not well . . . ".

However, one of the GPs was worried about this, stating: *"I guess the worry would be if it is a generic leaflet, sometimes you have more of a suspicion than others, and you would want to change that advice wouldn't you?"* Another GP in the same meeting felt a leaflet was a good idea and

commented that *"I think the difficulty with safety netting is, what is recorded on screen probably only reflects 10% of the conversation you've had".*

A similar discussion on safety netting was had in a separate meeting in practice three. In this meeting there was a discussion around the conversations PCPs had with patients when doing urgent or 2ww referrals. One doctor describes herself as a 'control freak' as an explanation for booking the patient's urgent appointment via an online system called choose and book. In response to this a colleague states

"I do always say to the patient, I say "if you don't hear anything this week, ring me back and let me know because you should have an appointment within two weeks, so you should hear within the next few days."

In response to this another GP asked if she documents that and also postulates *"how much time can we spend documenting?"* A fourth GP agreed, saying *"If I write if persists or worsens, I will have said to them come back in 2 weeks or come back in three weeks or, you can't write everything down".*

This exchange between a group of GPs highlights the difficulty with safety netting and documentation in the medical notes. It seems the GPs claim to be giving safety netting advice when making referrals. However they suggested that there is not time during a 10 minute consultation to write down everything that is said.

Finally, practices three, six and seven recognised there was room for improvement in the safety netting advice given. Much of the discussion in practice seven was led by one GP who had an interest in cancer. Following a discussion on a patient who had not attended a review appointment about abnormal blood results, the GP leading the discussion highlighted a recent BMJ paper he had read on safety netting. The GP explained that the impression he had got from the article was that safety netting should be documented, to protect the doctors and should include the management of blood results.

8.2.1.3 Safety netting content

There were discussions on what should be written down about safety netting advice and how best this could be documented. The time frame was felt to be important in order to allow administration staff to know when to book patients in, and when to use 'urgent or emergency appointments'. Following a discussion on continuity of care at practice six the administration staff

suggested it could be difficult to know if a doctor wants to see the patient again. One member of the administration staff stated that a time frame could help them. "*I think that then helps reception staff because a lot of the calls are, "the doctor has asked me to come back in a week" and you look back in the consult"*. A doctor at another practice echoed these thoughts. Following a discussion about potentially using tick boxes to quickly document safety netting, the GP felt that the important part of safety netting was the time frame. This GP stated *"maybe instead of writing if not better to come back, maybe we should write "If cough persists for more than four weeks needs to come back. Not everything because you can't do everything, but like change in bowel habit if you see somebody at three weeks maybe we should document if this goes on for another three weeks."* As an observer, it felt as though the time frames suggested by this GP were just examples, but the PCPs recognised that sometimes in the NICE guidelines there was the need to wait for symptoms to become persistent. Therefore documenting a time frame would help to manage these patients. This was demonstrated later on in the same conversation on time frames in this practice when another GP stated *"like we do with the persistent sore throats"*. This GP recognised that a sore throat is common but a persistent sore throat may be a sign of head and neck cancer, so informing the patient and documenting this is an important part of safety netting.

8.2.1.4 Follow up

As discussed at the start of this section, it seemed the groups made a distinction between follow up and safety netting. A number of groups had a discussion on whose responsibility follow up was, particularly regarding the follow up of DNAs. With most other topics of discussion the practices showed shared values and opinions. However this was one area where there were both disagreements between and within practice meetings, with some members of staff feeling that patient's needed to take responsibility for their health, but others feeling that PCPs should actively follow up patients.

The PCPs in practice three seemed unsure about how much patients should take responsibility for attending blood and CXR appointments if they have been recommended by the PCP. Following a discussion on referrals for tests and in particular CXRs, one of the GPs stated *"Patient responsibility comes up a lot with the safety netting doesn't it and that is interesting, it is difficult to know how much responsibility we should take as opposed to expecting patients to".* In response to this, in the same meeting another GP argues *"if you don't trust them when you give them the form to get it done [CXR], then*

when do you trust them?" A third GP again in the same meeting agrees *"I mean I even give them maps of where they are, to help them find it, you know, if you do all that and they don't turn up, they have chosen not to go, to a certain extent".* So whilst one GP was unsure about patient responsibility, others felt there was only so much you could do for the patient in each case.

In practice three, a case was highlighted in which an elderly patient presented with PR bleeding and the GP advised blood tests then a review before urgent referral. Sadly in this case the patient did not have the blood tests and did not attend for another nine months before eventually being diagnosed with colorectal cancer. Reflecting on this case which came up in the SEA feedback, the GP felt he could have done more. *"You might remember the odd one but, I personally don't keep a list of every patient I have sent for results and chase them up. And I wished I had with the bowel cancer chap because, he didn't come back for nine months, but I thought at the time this is suspicious but I need some more information before I can two week wait him, but he never came back and you just forget."*

After discussing this case the GPs recognised that they already use a system to keep track of radiology investigations they request and suggested this could be developed to keep track of patients too. A GP suggested, *"What about using a Read code to monitor patients we are worried about? Then that could be something that the receptionists could just run off, we already have a search set up for when we organise imaging, MRI, USS so we do know if we haven't had the CXR result back. So actually that [searching for a read code] would be a fairly easy search to do.*

Many of the problems with follow up came down to PCP time and workload, with many PCPs feeling they didn't have the time or resources to follow patients up. In practice five, after discussing a patient who did not attend a follow up appointment for abnormal bloods the GPs and nurses discussed if it was possible to keep track of patients who have abnormal results. One GP trainer stated, *"I know a registrar that I used to work with who used to record every result she sent someone for and every referral she did, and then sat and looked through them every week. But that was taking her two hours a week, and we don't have that time"*

When discussing follow up, using the GP record and computer technology to 'keep track of patients' was discussed in practice four. Ways of doing this included using searchable Read codes in the patient's notes or the computers 'diary follow up' system as a way of keeping track of patients the GPs were worried about. It was recognised that this would be a simple

intervention for PCPs to do when typing the consultation notes. It would however require a search of Read codes to be done every so often either by the PCP or a member of the administration team in order to follow up the patient. After discussing ways to keep track of patients, one of the reception staff involved in patient recall for chronic disease stated, *"There is a follow up button on EMIS, where you can do follow up and that can ping up but I just don't know how it works properly, maybe we need to explore that more. You can put in an exact date and it brings up people that go overdue."*

After discussing the idea of the safety netting leaflet in practice six, the practice explored using 'admin' lists or personal telephone lists to keep track of patients. A nurse in the practice stated, *"Well I'm not on as big a scale as you guys, but if I have got a patient I want to follow up I will book a telephone consultation with myself for when I know the bloods are going to be back so then that morning I will come in and I will check that the bloods have come back so then I can speak to a GP before I actually start and see what I need to do with that patient."*

8.2.1.5 Safety netting and follow up action plans

Following these discussions, interventions on the theme of safety netting and follow up were developed and included in the action plans in six of the nine practices.

Practice one: Improve safety netting advice.

Their plan included having a poster of the safety netting guidelines produced by Bankhead et al. (189) which could be placed in each consultation room.

Practice two: Continue to give and document safety netting advice to patients.

Practice three and four: Use a Read code to keep track of patients they were worried about.

This practice chose a Read code in the meeting (Patient awaiting investigation) and asked the student to develop a poster to remind all staff of this in their consulting room (this poster can be viewed in appendix H). The GPs in practice four felt it would be more helpful for each GP to choose a code for themselves and follow up as they saw fit.

Practice six: Develop a safety netting leaflet to give patients, with red flags and follow up advice

This would be developed by the student with feedback and input from the PCPs at the practice.

Practice six: Develop a safety netting template to better document advice

To aid documentation in the medical notes the student was asked to develop an electronic template to easily document safety netting advice in the notes

Practice six: Use a telephone appointment list on the appointment screen to aid follow up

To improve follow up practice six added a 'telephone list' on to the daily appointment system to which all PCPs could add patients they wanted to check up on

Practice seven: Improve safety netting advice

This was a non-specific 'learning point' to improve the quality of the advice given based on the findings of the review in chapter six.

8.2.2 Discussion theme 2: Investigations

Problems with, and delays as a result of, investigations were discussed in many of the SEAs and specifically in six of the nine practice meetings. Follow up after investigations as well as the management of anaemia and the use of CXRs formed much of the discussions.

8.2.2.1 When to request CXRs

Discussions on the use of CXRs particularly focused on the dangers of a normal CXR and on having a low threshold for organising a CXR in the first place.

In practice nine, there were some SEAs in which CXRs could possibly have been requested earlier. In this meeting, the discussion started with each member of staff being encouraged to state a key learning point. On having a low threshold for CXRs, one nurse stated, *"I think the one that stands out for me as a learning point is if the patient hasn't had an xray and they are still coming with symptoms, I will be aware of that."* There seemed to be a general agreement around this by all the practice staff at this meeting. So much so that a foundation year two doctor asked if it would be appropriate to get the receptionists to organise CXRs before the patient was seen. He stated, *"given the amount of time it takes for a patient to get an appointment, if we are being that liberal with CXRs, say anything more than 3 weeks, can we not have the girls at the desk pick those up and get a CXR before we see*

the patient?" Whilst the more experienced GPs recognised that administration staff would not be able to request CXRs without GP input, the question showed the degree to which the group felt they should have a low threshold for requesting CXRs. In practice two, a case was discussed in which the patient who was a smoker presented multiple times with chest pain which was thought to be musculoskeletal before being diagnosed with lung cancer as an emergency. The group reflected in this case that the guidelines would have suggested a CXR in the first instance of a smoker with chest pain.

8.2.2.2 Managing normal CXRs

As well as discussions about when to request CXRs, there were discussions on how to manage patients with normal CXRs. As discussed earlier, a normal CXR seemed to falsely reassure PCPs in the SEAs. In the discussions there was a general agreement across the groups as a result of the feedback that PCPs would be less reassured by a normal CXR. A nurse practitioner said, *"I think I will not be falsely reassured by a normal CXR and again probably have a low threshold for CXRs and er . . if a patient is coming back with the same symptoms, I would have a low threshold for even referral, because I think, you know there is something going on."* This lead to a discussion on normal CXRs and a GP followed up this learning point by stating that perhaps they need to be aware of the 'danger' of a normal CXR when dealing with paperwork. He stated *"the other thing is I'm also thinking about is, normal CXR you know we are looking at 100s of paperwork every day and CXR normal is a quick thing you know, you just file normal and put it aside, but taking the time to go back to the consultation and see, why this patient had a CXR and even communicate some other follow up safety netting plan, like please come back your CXR is normal, yet you were a smoker and you had weight loss and all this, to relate reports, rather than just blindly file reports".* A second nurse practitioner agreed, stating that they should not base decisions on just the CXR alone: *"We are over reliant on CXRs so actually, you've got a patient with a normal CXR but loads of signs and red flags ticking off, just do a two week wait anyway because that's what they do at the other end isn't it they would do a CT scan for us."*

Practice three had a very similar debate around the normal CXR. This practice first discussed when CXRs should be repeated if symptoms persist, with one GP questioning if they had a CXR nine months ago, should that be reassuring? In response to this, another GP asked if they would do a CT scan instead of repeating the CXR, However there was some debate and

confusion regarding what to do should a CXR be normal. One GP asks: *"Is there any research or guidelines about when you should do a CT scan with a normal CXR?"*

After discussing the possibility of doing more CT scans, particularly in patients with recurrent infections, the GP who asked about the guidelines above, stated *"It sounds like there is not much evidence to support that though is there?"*. It was decided in this group that the student would aim to review the literature on normal CXRs and contact local secondary care physicians for advice on how to manage patients with a normal CXR.

Practice two had a very similar debate following the presentation of a case which was delayed by a normal CXR. In this meeting the PCPs were also unsure about what could have been done differently, also commenting on the lack of awareness and guidance on this issue. The case was discussed for quite some time and there was an agreement that despite the delay due to the normal CXR, the nurse practitioner and GPs who had managed the case had acted appropriately. The staff in the meeting also asked if the student was aware of any advice or guidelines and the information obtained above for practice three was shared.

In practice seven, two of the 15 lung cancer cases were delayed by a normal CXR. This was discussed in the group, and whilst one of the GPs was aware of the data regarding normal CXRs stating, *"isn't it something like one in five CXRs will miss a cancer?"*, many of the other GPs and nurses were not aware of this and the statistic was met by some surprise. One of the nurses asked, *"is it really that many?"* and in response to this another GP asked why we do not do more CT scans. The group felt if there was any possibility of cancer they should refer the patient regardless of the CXR findings.

The discussions above highlight the difficulties with diagnosing lung cancer in primary care. It seemed that the PCPs ruled out a possible lung cancer as a result of a normal CXR. Most of the PCPs seemed unsure of what to do next with a patient presenting with chest symptoms, and discussed requesting more CT scans or doing more urgent referrals. Whilst some of the PCPs knew about the high number of false negatives associated with CXRs, many others did not. As a result of the findings of the SEAs, many practices developed interventions on the role of CXRs. These are discussed at the end of this section.

8.2.2.3 Anaemia

The use of full blood count blood tests and the management of anaemia in cases of suspected bowel cancer were discussed in three of the practices. It was felt by practices five and eight that the NICE guidelines were vague in this area. No cut off values for anaemia are given by NICE, yet local 2ww referral forms did have a cut off value for haemoglobin (<11g/L) and ferritin levels (<20µg/L). A GP at practice five felt that referral guidelines locally were confusing given the use of cut off values which seemed not to be present in the NICE guidance. There were also discussions about patients who seemed to have chronically low haemoglobin levels and those with anaemia but normal iron. It seemed at first during this discussion the GPs felt unable to challenge the hospital referral process and were somewhat resigned to the problems remaining. At one point a GP joked, "*If you [student] can improve the hospital anaemia clinic [laughs]*" however, others felt there was potential for improvement. After the GP had made the joke about the hospital clinic another GP asked, "*what we perhaps need to know is how often do you have to investigate iron deficiency anaemia? Because lots of people get it recurrently don't they*". A third GP in the meeting agreed and also added, "*we also need to know if a downward trend should be referred. Even if their results are within normal range*". In the end a plan was made for the practice to develop their own anaemia guideline to ensure that within their practice they were all acting in the same way. It was hoped that this could be discussed with secondary care colleagues.

In practice eight, following a discussion on the need to wait for patients to have persistent symptoms prior to referral, a GP suggested that bloods may be done whilst waiting and that these bloods may also be falsely reassuring. The GP stated, "*If you have got someone with change in bowel habit, red flag, and then your bloods come back completely normal, no iron deficiency anaemia, then you're reassured aren't you?*" In the meeting, it seemed as though everyone agreed with this comment, despite the NICE guidelines suggesting that even in the absence of anaemia, persistent symptoms should be referred. The same GP added that in the presence of normal bloods he would think "*Oh there was a pile, that must be where the bleeding was coming from*". This discussion highlights the difficulties faced when diagnosing bowel cancer in primary care but also perhaps confusion or a lack of knowledge around the NICE guidelines. There is an acknowledgement that PCPs cannot refer everyone, and the incidence of serious disease is low in primary care. As a result, it seems the PCPs in this practice were using the

normal bloods as reassurance. This approach does seem to go against the NICE guidelines on cancer referral and may be questioned by other clinicians. Perhaps when used with safety netting advice to ensure patients do return if symptoms persist, it could be considered safe.

In practice nine, the importance of IDA was a key learning point: *"When we file results showing anaemia, I will look more closely to see whether it is a microcytic anaemia and look at trends in them and obviously I will recall them if an examination has not been done."*

In this practice there was the impression that some of the PCPs were not aware that iron deficiency alone should warrant a 2ww referral for suspected colorectal cancer. This may have led, at least in part, to the action plan to have an educational meeting on the new NICE guidelines.

8.2.2.4 Managing results

In addition to the management of CXRs and anaemia, practices three, four and five highlighted more generic problems with the management of results.

Practice three discussed the importance of communicating urgency, both when arranging investigations and how quickly patients should be seen again with abnormal blood results. One GP asked, *"One of the things you picked up on is about the sort of delay between either getting investigations done or coming back to discuss results wasn't it?"* The GPs agreed but it was felt that problems of increased capacity and workload were contributing to this problem. The GP stated what usually happens when they [the GPs] look at abnormal results *"We will send a message to reception and say: "Ooo get this person in to talk about results" and then reception say "hmmm that's fine but you need to ring the next day because there are no appointments to book".* In response to this a second GP states: *"I think we are probably not that good at differentiating for reception, because if reception don't know its urgent, then they won't book it as urgent. And equally, when we request investigations in the first place, the reception automatically assume its routine unless we say otherwise, and I think we are not that good at saying, "urgent"."* In response to this the first GP suggested *"one of the things we have already started to look at is when an urgent response is needed, we need to highlight that to reception, to say "this is an urgent review that's needed."*

This discussion in practice three highlights multiple problems in the management of results of investigations. Firstly, it is clear there are a number of different steps in the management. The GP first looks at the results and, if

needed, asks the reception staff to book an appointment. It seems in this practice the GPs feel there is a need to inform reception staff if this is urgent or not. Then following this, the reception book the patient an appointment, or according to the quote above, may sometimes ask the patient to phone back when appointments are available. There are potential delays in each of these steps. In addition to potential human error, there could be delays due to capacity and workload and also due to poor communication between members of staff or between practice staff and the patient.

A case reviewed in practice five also highlighted a potential problem with the management of results. In this case a patient had worrying blood tests and received a letter inviting him to see the GP. However when he arrived the patient thought this appointment was for a diabetic check, leading to a delay in diagnosis. This case was discussed by the staff in the practice meeting. One GP stated, *"When patients get 'to come in' letters, the patients don't always know why they are coming in."* A nurse agreed saying "*Yeah the patients don't always understand the letters do they?".* The GP responds stating *"But you can see why it would be confusing for patients, we feel like we have sent a letter, and then they feel like they have come in, so everybody thinks the follow up has happened."*

This case resulted in a plan to make these letters more specific. This case shows how something as simple as writing to patient can cause delays in diagnosis. It seemed that the PCPs could see how the confusion could happen, but it took an SEA which resulted in a delayed diagnosis to highlight the problem and plan a change.

The final discussion around investigations took place in practice four, in which it was noted there were delays in patients attending for review following blood tests, much like the findings in practice three discussed above. This practice felt that there was an opportunity for nurses and phlebotomy staff to provide a safety net, and additional information to patients going for blood tests. The group discussed what they usually said to patients when suggesting they have bloods. This varied from usually giving no information at all on getting results, to some GPs who advised all patients to call for results. It was recognised that these differences could lead to delays where patients had not re-attended when requested for abnormal results. The group felt that getting phlebotomy staff to provide patients with information on the tests they were having and how to get the results, could prevent possible delays.

8.2.2.5 Investigation action plans

Practice two and eight: Have a low threshold for ordering CXRs

This was based on the discussions above and was disseminated by email to all staff in each of the practices, together with the relevant section of the NICE guidelines and case examples from the SEAs for each of the practices.

Practice two, three, seven, eight and nine: Improve the management of patients with a normal CXR

Practice three suggested the need for guidelines or a consensus on what action should be taken should a CXR be normal but there is still a suspicion of cancer. The same practice also questioned how long a normal CXR should be reassuring for, especially if symptoms continue. It was agreed that the student would contact local secondary care colleagues to provide guidance on this issue. This guidance was requested by and sent to the other four practices above.

Practice three: When checking blood results comment as urgent if needed with a time frame for review

This plan aimed to ensure both patients and admin staff knew if a planned investigation was urgent or not, by specifically telling patients (and documenting) if a test needed to be urgent. When viewing blood results and commenting on the results, they aimed to ensure if a test needed repeating or additional tests organising as a result that these are marked urgent. This was actioned by emailing all staff and the administration team with the plan to change the way blood results are booked and actioned

Practice four: Encourage phlebotomists and nursing staff to safety net patients through the development of a protocol and leaflet

A plan was made for the student to meet the phlebotomists at one practice to discuss how this should practically be done. Following this a protocol and leaflet was developed with the help of the phlebotomists.

Practice five: Develop a practice anaemia pathway

It was agreed the practice staff would develop an anaemia pathway and share this with all colleagues.

Practice five: Make 'to come in letters' more specific

Rather than just a generic letter, the new to come in letter explains the reason for making an appointment with the GP.

Practice eight and nine: Improve the management of IDA

This was to be achieved through clear plans to refer all patients on a 2ww referral if they have IDA, or just a 'mental note' to be aware of IDA or dropping blood counts. These interventions were emailed to all members of staff with the learning points and the rationale behind this.

8.2.3 Discussion theme 3: Referral

Problems with the referral pathway between primary and secondary care were highlighted in the SEAs and feedback meetings leading to four interventions from three practices. The main themes discussed included the management of 2ww referrals, the referral of vague symptoms, what to do when patients do not attend planned investigations or hospital appointments and the use of patient information sheets and self booking options.

8.2.3.1 Two week wait referrals

Much of the discussion on 2ww referrals centred on the doctor / patient discussion before the referral. This included advice to ensure patients know they should be seen within two weeks. Practice three discussed the advice given when making referrals after a discussion on safety netting and patients taking responsibility for their own care. The PCPs felt they did not have the time or capacity to keep track of all referrals and investigations they arrange. However they did feel they could give patients advice. One GP stated, *"even for a normal referral we could say if you haven't heard anything in a month please let us know and someone will chase that up for you. And, for a two week wait, say "this is called a two week wait, because you will get an appointment in two weeks and if you haven't, we need to know"*. It seemed clear from the meeting that the PCPs were aware of problems with the 2ww referral system. One doctor told of a patient who did not receive an appointment due to a lost fax. *"I saw I patient last week who was 12 days after being referred on a two week wait, you know it was 12 days and the hospital has lost the fax. So we had to re send the form and I have never known that happen before but they had lost the fax. And we have the fax receipt, so we know it was sent."* Since the audit, the use of electronic referrals has replaced faxes. However all the staff seemed to agree that careful safety netting could help prevent possible delays in referral.

Practices three and four also felt that encouraging patients to self book appointments could act as an additional safety net. Practice three discussed this straight after the discussion on safety netting for 2ww referrals. One GP asked *"Is everyone using the self booking?"*. It transpired in the meeting that not all staff were aware of the self booking system and that there had been

no system to inform the nurse practitioners, locums or GP trainees about the self book system. The same GP stated *"the big safety net is that you get the patients to self book, because I've had it where maybe three days after I sent the form, the appointments are ringing me and saying, where is your patient? They have not rung up yet? So they have a system at their end obviously to pick up on non contact."* The group discussed ways to get everyone to use the self booking system and involved the student in this plan. In these two practices, it seemed unanimous that the use of the self booking system was a positive way in which to ensure patients got an appointment which would suit them and which they were more likely to attend.

8.2.3.2 Did not attend letters

The management DNA letters was discussed by practices four and eight. In practice four there were some similarities with the discussions of safety netting, with some of the GPs feeling it was the patient's responsibility to attend appointments and the practice staff were too busy to chase up all DNAs. However other members of staff including the two nurse practitioners felt the PCPs had a responsibility to act on DNA letters. One GP in practice four stated *"I have had some where patients never received it [the appointment letter] where patients moved address or the address was not updated so we had all sorts of problems, you know this was a bit sad because the patient wanted to go but did not receive the letter . . . I think we need to set a system in place of how we action DNA letters, you know we could collect and check all DNA letters and one doctor check quickly relate to the consultation and look and act on it, rather than dismiss it, because someone has taken the action to inform us".* There were nods of agreement following this. The PCPs could obviously see how having the wrong address for the patient could prevent a patient going to an important appointment, and that the process of checking DNA letters could mostly be done by administration staff. In addition to this the staff at practice four felt that a 2ww information sheet given to patients at the time of referral may help to encourage patients to attend their appointment. Practice eight had considered checking DNA letters prior to the meeting and made a commitment to do this for every letter following an SEA in which a patient did not attend for a colonoscopy appointment leading to delay in bowel cancer diagnosis. The discussion around this was a quick one as it was an intervention the staff had already been planning. The DNA letter checking and discussion with patients was to be done by the administration staff.

8.2.3.3 Referral action plans

Practice three and four: Use the patient self booking system when doing a 2ww referral aided with a self booking leaflet created by student

These practices felt the use of the patient self booking service would provide an extra 'safety net'. Both practices asked for help from the student to develop a self booking information sheet for the PCPs to give to patients. This was developed by the student with the help of the practice staff. This included details on the 2ww referral scheme, the number to call and a place to write the time and date of the appointment. An example leaflet is shown in appendix I.

Practice four and eight: Admin staff to check all DNA letters and contact patients if necessary

These practices made a plan to ask administration staff to check what appointment was missed by the patient and to contact the patient in each case to discuss the DNA and the reason for missing the appointment.

8.2.4 Discussion theme 4: Continuity of care

The theme of continuity of care and the management of multiple presentations was discussed in four of the nine practice meetings.

8.2.4.1 Continuity

Staff in practice six felt that continuity aided safety netting and follow up, was helpful for spotting changes in patients over time and was liked by patients. However it was recognised that due to the rise of portfolio working for GPs, the use of locum GPs and problems with access to appointments, continuity was difficult to achieve at times. The topic of continuity followed a discussion on safety netting and follow up. The lead GP partner in this practice stated: *"I am big on continuity and always tell my patients, if I think it's really important to say, come and see me, or I find a way to remind myself."* In response to the comment above, a receptionist added *"one thing I want to bring up was consistency with the doctor"*. It seemed from the meeting that all staff felt continuity was important, but it had been difficult to achieve at this practice as they had a lot of 'book on the day appointments'.

8.2.4.2 Multiple presentations

The issue of multiple presentations was discussed in several meetings. In practice one it was felt that continuity of care may help to spot patients who

present multiple times and this may help to recognise patients with worrying or prolonged symptoms. When discussing a difficult diagnosis of lung cancer in a patient with COPD a GP at practice one stated, *"I think one of the patients was a COPD patient that had been seen umpteen times with exacerbations and I think that one of the problems there is that actually if you look you would probably see, he had seen seven different people"* The same GP goes on to recognise, *"the problem is you see them independently don't you and you don't necessarily read back and see that actually it's the fourth consultation in 12 months with the same thing"*. Practice one also had a system of emergency five minute appointments for people calling up on the day. It was recognised that these were potentially risky consultations, as there was not enough time to read past notes and this may lead to missed opportunities. It was felt the GPs should be aware of this and book patients in to routine appointments in the future if they feel more time is needed.

In practice nine both nurse practitioners highlighted the need to spot multiple presentations. The first stated, *"well I'll be totally honest, it scares you, you know which is a good thing, it makes you more vigilant and it actually makes you take a step back and look at a patient more holistically, you know because with a 15 min consultation it can be quite difficult and you take it as they come in on that day and sometimes you have to just look back a bit further"*. The second nurse practitioner agreed, *"certainly for me looking at the investigations and then getting the history and looking at how many times they have presented, because it is a bit scary as (NP1) said"*. It was perhaps surprising that both nurse practitioners felt the SEA findings were 'scary'. These comments show that the SEA audit and feedback had changed the nurse practitioners perceptions and the finding of patients presenting multiple times had struck them as important.

Finally practice two also discussed a case in which a patient presented multiple times with vague abdominal pain, prior to being diagnosed with colorectal cancer. In this discussion earlier the group had looked at the safety netting advice given by Bankhead et al. (189). They discussed using the 'three strikes and refer' rule for patients such as this in which they would be 'automatically' investigated or referred if they presented three times with similar unexplained symptoms. The GPs in the group were undecided about this. They were worried that this would result in over investigation and referral whereas others thought it would be a helpful 'rule of thumb' to remind GPs to try to identify patients presenting multiple times. In the end it was felt that if the three strikes and refer plan was used more as a guide, than a rule,

it may be helpful to spot and potentially refer patients who present multiple times.

8.2.4.3 Continuity of care action plans

Practice one: If patients attend in an emergency five minute appointment and need more time or further investigation, PCPs should book appropriate follow up.

This was agreed by all practice staff present in the meeting and disseminated via email.

Practice one and nine: recognise that multiple attendances may be a red flag

This was agreed in the meeting and a plan disseminated to all staff using staff email.

Practice two: Recognise that multiple attendances may be a red flag, use the 'three strikes and refer rule'

An explanation of the rule and the rationale behind adopting was emailed to all PCPs at the practice

Practice six: admin staff to ask the patient which PCP they would like to see and PCPs to book own reviews

This was agreed in the meeting and a plan disseminated to all staff using staff email.

Practice seven: put an alert on the patient's record to let others know if previous notes need to be reviewed prior to the consultation

8.2.5 Discussion theme 5: The consultation

8.2.5.1 Measuring weight

In practices five and six, several of the SEAs highlighted patients who presented with weight loss. It was noted that in some SEAs patients had not been weighed. This was recognised as a missed opportunity, and the benefit of monitoring weight over time was highlighted. In practice five, one of the GPs highlighted the issue of weight loss. He stated, *"I think recording weight is very important isn't it, it's very easy to ask someone if they have lost any weight, but actually jotting it down then you can look back if they come back later on and you can look for objective weight loss."* The nurses and GPs in

the group agreed with him, and whilst there was no further discussion, the group made a plan to record weights as often as appropriate.

In practice six, the discussion started with the lead GP highlighting the opportunity to monitor weight in primary care. *"I guess one of my thoughts is, weight loss is quite a common symptom isn't it, in most cancers, and I wonder if we actually started documenting weights more frequently . . . Then we will have a good objective kind of sign that might just actually get you thinking, 'actually is there something going on?' Trends are really good in principal for these kinds of patients aren't they?"* A plan was made to consider all opportunities to weigh patients, such as at blood tests and new patient health checks.

8.2.5.2 Investigating weight loss

In practice eight weight loss was also discussed. This discussion occurred after an SEA was presented in which a smoker, eventually diagnosed with lung cancer, presented with weight loss, but had a normal CXR which resulted in a delay. This case was recognised as being a difficult one, but there was a recognition that perhaps more could have been done to investigate the weight loss. A plan was made in future to investigate weight loss thoroughly.

8.2.5.3 The use of Qcancer in the consultation

In practice five, after a discussion about the difficulty of deciding when and to whom to refer patients with vague symptoms, a PCP suggested using Qcancer within the consultation. *"What do you think of the Qcancer? I use it quite a lot. I don't find it that hard. For example a patient came in with PR bleeding, and I wasn't sure if this was anything, but when I did the Qcancer, it came up, over 3% for colorectal so I did a 2ww rather than a routine. We have got it on our templates for EMIS web, so it fills in some of the details for you, if it's been coded, so you don't necessarily have to fill in all the details."* The rest of the GPs and nurses seemed to be unaware of Qcancer and asked for more information about it. The GP went on to describe how to use it in the consultation and the student suggested he could send papers on the theory behind Qcancer together with the action plan on how to use it.

8.2.5.4 Consultation action plans

Practice five and six: Ensure patients are weighed at every opportunity

Practice five simply agreed to try collectively to weigh patients more in the consultation to achieve objective measures of weight loss. Practice six planned to ask nursing staff to weigh patients at every routine health check, so that trends in weight over time could be recorded.

Practice five: Use the in-built Qcancer risk calculator in the computer system to aid referral

The evidence base behind Qcancer was sent by the student as well as instructions on how to access the calculator in the EMIS GP record.

Practice eight: Ensure patients presenting with abnormal weight loss are thoroughly investigated

8.2.6 Discussion theme 6: Education

Following a discussion about the management of anaemia, practice nine felt they needed to be updated on the new NICE cancer guidelines. The GPs at this practice felt this was a learning need and requested the student to re-attend the practice to give this talk. Whilst this was not discussed specifically as an action plan in the meeting, the student was contacted following the feedback meeting and this further educational session was planned.

8.3 Student reflections on presenting at educational meetings

At the end of every educational meeting, the student (referred to in the first person in this section) reflected on how the meeting went. A summary of these reflections is documented below.

8.3.1 Planning the meetings and the initial fears of presenting

On initially planning the research, I knew that the feedback or action plan meetings would be a crucial part of the work. The next stage of the project to develop and test action plans would prove difficult if the meetings were done badly, if team members at each practice didn't attend or didn't engage. I knew from the Cochrane review on audit and feedback, that feedback works best when it is provided by a supervisor or colleague. In some senses as a clinician and GP registrar I could be considered a colleague, but I was certainly more junior than the GPs I was to feedback to, with much less experience of seeing patients and diagnosing cancer. As I prepared for the meetings, it was this feeling of being junior to the doctors I was presenting to, which caused most of my anxiety. I had been in this situation before. As a

GP registrar I had given a talk on lung cancer to 250 GPs in West Yorkshire, which brought about similar thoughts and feeling of not being experienced enough to 'teach' experienced GPs. Prior to that meeting I told myself that whilst I may not have the experience of the GPs in the audience, I did have the knowledge, having spent the last 2 years learning and reading the literature on the diagnosis of lung cancer in primary care. In the SEA meetings, I had similar thoughts, having spent weeks reviewing all the practices cancer patients. This provided me with some confidence as I went in to the meetings. I felt that during the feedback my knowledge of the early diagnosis literature was helpful. I was able to provide summaries of recent papers and discuss comparisons to the findings in each practice with the national literature.

8.3.2 The use of case studies

As discussed in chapter 8.1, it became clear that the staff in the education meetings were more interested in actual case studies of the individual patients than they were in the overall findings and summaries from the SEAs. This resulted in a change to the structure of the meetings after the third meeting to include more cases. The cases were carefully chosen to demonstrate the same findings as the summary. Whilst this is an interesting finding, it is perhaps not surprising with evidence suggesting case studies have been used for clinical education for many years (247-249). Research has shown 'storytelling' can improve sense making (250), improve learning (249), and develop clinical reasoning (251, 252). It has been used in medical school lectures, but also on the wards and in general practice training (253). A literature review on the effectiveness of storytelling in adult education concludes that story telling is an effective part of the adult learning process and in particular states that case studies can promote realism, and help students to connect knowledge with practical situations (254). In the educational meetings organised as part of this thesis, all of the data and information given was taken from SEAs or case studies of the practices own patients, but despite this, the staff in the meeting still seemed to take more notice of an individual case, which fits with the research above. Allowing the PCPs to connect the findings of the SEAs to a particular patient story may help them to remember and relate to it better.

8.3.3 Identifying harm and discussing the benefit of hindsight

The very nature of case note review is likely to identify opportunities for improvement and possible patient harm. This is to be expected and the

important part of identifying the possible harm is to enable learning and stimulate behaviour change, so that patient care can be improved. This was difficult to manage when presenting findings to the practice staff in the educational meetings. I wanted to show areas for learning and cases in which there were missed opportunities, but I also did not want to seem critical of the care provided by the team at each practice and I did not want to be too negative. I managed this by carefully stressing the benefits of hindsight and the difficulties faced by GPs trying to find 'the needle in the haystack' in terms of a diagnosis of cancer. I recognised it was easier for myself reviewing the cases, knowing that the outcome was cancer, to find potential areas for improvement and possible harm, This had differing reactions in each practice. It seemed as though the majority of the practices accepted the intentions of the research, that I was not trying to criticise their work and all the points made during the meeting were with the aim of improving care for future patients. However in one practice the atmosphere felt different, instead of trying to learn from the SEAs and possible missed opportunities, the group seemed 'defensive' and made excuses or reasons why care had been different on each occasion.

8.3.4 Educational meeting time

There was a lot of information to potentially get across in a short period of time. Many GP practices already do significant event meetings. I have been to a couple myself in the practices I have worked in, and in an hour long meeting, normally they would discuss five or six cases maximum. I had to get across the messages from sometimes 20 to 30 cases in the same length of time. I knew that I had to provide a summary of all the cases, but looking at some real cases in which there were missed opportunities would perhaps have the most benefit for the PCPs attending the meeting. In one practice there was a practice meeting following my talk which only left me 45 minutes to present the findings, where as in others I was given 1 hour 45 minutes over two meetings to present. I know that general practice is under pressure at the moment, with a workload crisis and increased patient demands, I wanted to fit around the GPs busy schedule but even whilst doing this there were some meetings in which doctors entered late or had to leave half way through. In one particular reflection I wrote "it was a busy day at the surgery and the meeting started late with both GPs looking stressed on first appearance".

8.3.5 Comparisons and 'what did they do?'

Whilst undertaking the feedback sessions I was asked frequently about how the research was going and which other practices I had been to. This naturally led on to questions from the PCPs on what I had found, what action plans had come out of the work so far and how they were doing compared to other practices I had been to. I tried to manage this by explaining, that it would break confidentially if I were to discuss the findings of other practices. In addition it would compromise the research if I divulged information on the action plans of others. When asked for comparisons on performance I explained that this was not the purpose of SEAs, that they were qualitative accounts of a single diagnosis and as numbers were so small it would be difficult to give accurate comparisons. The PCPs seemed to accept these responses and did develop their own action plans. The focus of this research was to develop individual practice level interventions. As a result the plan was that each practice would develop their own action plans based on their experiences in their practice and the SEAs on their patients. By sharing interventions from other practices, the PCPs may not develop their own action plans or may focus on the pros and cons of other practices interventions. The only time information was shared was the expert opinion on the normal CXR which was obtained at the request of practice three. This was shared only when other practices recognised the problem of diagnosing lung cancer in patients with a normal CXR and planned to consult the literature or discuss with colleagues to improve the management of these patients. As a result it was felt the practice had developed the plan individually therefore providing the solution / opinion in this case felt appropriate.

8.3.6 Action plans or learning points

I was concerned after the first few meetings that whilst the PCPs were listening and learning from the educational meeting, that most of the action plans were actually learning points without much in the way of changes in the ways things were done. I reflected at the end of one meeting that "the difficult part in this situation was trying to discuss and come up with an action plan from the meeting. The GPs and practices nurses had come up with some points during the talk but during discussion at the end of the meeting they could not add to their initial thoughts, or think of any concrete plan to change things". However as time went by I became less concerned by the difference between learning points and action plans. I felt that most of the learning points could result in changes of behaviour and positive changes in the

recognition and referral of cancer. By agreeing to remind and reinforce the learning points through staff emails I felt there was the potential to improve care.

8.3.7 Leadership and practice dynamics

The group dynamic and the ability of all members of staff to voice their opinions seemed to vary significantly between practices. It was clear in some of the practices that a small group of GP partners made a lot of the decisions. Naturally, during the discussions these partners facilitated the meetings and often made the decisions. Whilst this may be a positive in some practices, (these partners will have the most experience, will have been working in the practice the longest and may have the most experience when dealing with changes in practice behaviour), in others, it may have prevented other members of the healthcare team such as nurses and administration staff from providing their input and ideas. I wanted to ensure all staff felt they could contribute. I felt that as so many of the patients in the SEAs had had involvement from the nursing staff and the role of paperwork and administration came up so frequently in the reflections, that the input of the whole practice team was important. However, this was often difficult to achieve and may have resulted in important or novel ideas being missed. The importance of group dynamics in learning and teaching is widely recognised in the medical literature (255-257). A BMJ article on group problem based learning states that groups need to be together long enough to allow for positive group dynamics to develop but also recognise that groups may need to be changed if "personality clashes or other dysfunctional behaviour emerges" (255). The same BMJ article advises on the role of the tutor to help maintain group dynamics. This task could be easier for a medical school 'tutor' in a position of authority within a group of students, than for a GP trainee, in a new group of GPs as I was during the meetings.

8.3.8 Positive feedback for the meetings

Much of the reflections I made after the meetings were positive. I noted after one meeting "The GPs and nurses listened carefully and made helpful suggestions as I went through the presentation and some of the more interesting cases where there were learning points. The atmosphere, I felt, was friendly with the three members of staff appreciating the opportunity for learning and accepting that in some cases, things could have been done differently". At the end of a different reflection I wrote "It was a very positive

and friendly meeting and the staff present thanked me for the hard work and the learning opportunity".

8.3.9 Student debriefing

This research involved the case note review, analysis and discussion of cases of real patients diagnosed with cancer and as such involved working in an emotive context with sensitive data. I was aware that the whole process, from data collection, to presentation of audit findings could be potentially stressful and upsetting. I knew I had the opportunity to debrief with my PhD supervisors who were always open and available to discuss problems with. Similarly I had a mentor at a different institution had I felt I needed an independent discussion. Thankfully I felt I managed the difficult situations satisfactorily and did not need to debrief during the research process.

8.4 Summary

This chapter has looked at the development of action plans following presentation of data from practice patients in the form of SEAs. Following the educational meeting, practice staff were encouraged to discuss the findings of the SEA analysis and develop action plans based on those findings. The discussions generated a useful insight into the way in which practice behaviour change can be generated through audit and feedback. The action plans developed as a result have been explained. Following the feedback meeting and the development of action plans, practice staff were left to put the plans into action. Any help the staff had requested from the student was done and disseminated via email and by practice visit. The work requested included the development of leaflets, posters, patient information sheets, protocols and electronic templates. A significant amount of work was undertaken by the student in supporting the practices, which allowed the action plans to be implemented more easily. However this may affect the replicability and generalizability of the findings. A discussion on the role of the student can be found in 11.3.3.

Chapter 9: Assessment of practice action plans feasibility and potential to improve the recognition and referral of cancer symptoms

The aim of this chapter is to explore the feasibility and potential impact of implementing the action plans which were developed and explored in chapter eight. Further SEAs and staff interviews were used to give an insight into the feasibility and practicality of implementing the action plans. The findings from the interviews are presented with the SEA data to gain further insight into the feasibility of the interventions.

9.1 Method

Following the educational meetings, and staff discussion, the action plans were implemented. As discussed in chapter four, the audit and feedback intervention was developed using two evidence based theories of behaviour change. Both the COM-B model at the centre of the BCW and the NPT core constructs of *coherence* and *cognitive participation* were central to the design of the intervention in this thesis. The intervention was designed to ensure that practice staff had the motivation, opportunity and capability to implement the action plans, but also understood their roles and the barriers to implementation. This ensured the plans could be implemented as successfully as possible.

All the action plans developed were categorised according to the BCW policy and intervention categories, which helped to provide an evidence base with which to implement the plans. NPT was particularly helpful when considering implementation, as it focuses on the implementation and integration of new systems of practice in health care settings. The third core construct of NPT is *collective action* which considers the operational work needed to enact a set of practices. The components of *collective action* were considered when implementing the plans, however as the student was primarily involved in organising the implementation of the action plans, there was limited opportunity for *collective action*. This will be discussed when considering the individual plans below and in chapter 11.3.

At each practice, after the educational meeting the student helped to implement the plans developed and agreed upon by the practice staff. In each practice this started with an email confirmation and summary of the

plans, together with the rationale behind each plan. As discussed in chapter four, audit and feedback was thought to be more effective when written, as well as verbal, feedback was provided. The email also contained an offer of help from the student to the practices with the aim of implementing the action plans successfully. This offer was taken up by a number of the practices with the student then helping design GP record templates, leaflets for patients, posters for consultation rooms and protocols with nursing staff. It was felt that as practice staff were best placed to know the facilitators and barriers to implementation of the individual plans they had developed, most of the implementation of the plans was left to the individual practices.

Following this implementation, six months after the audit and feedback meeting described in chapter eight, the student re-visited each practice with the aim of assessing the feasibility, acceptability and potential impact of the action plans. At this stage a patient search was undertaken by administrative staff using identical methods to those used in the original SEAs described in chapter seven. The search was undertaken for patients diagnosed with lung or colorectal cancer in the six months following the educational meeting. In order to assess the impact of action plans and any potential change in the recognition and referral of cancer, other elements were included in the search strategy. The same Read codes listed in appendix F were used to search for new cases of lung or colorectal cancer. In addition to this the Read codes used when 2ww referrals are completed and other Read codes which may be used as a result of the action plans were searched for. These Read codes included those used to follow up patients as suggested by practices three and four, Read codes used in the safety netting template developed by practice six and the Read code generated by the use of Qcancer.

In addition to the repeat SEAs, in eight of the nine practices involved in the research, PCPs agreed to be interviewed by the student in order to gain further insight into action plan development and to help to assess the feasibility and practicality of the action plans. Interviews were conducted with 13 PCPs in the time between the educational feedback meeting and the practice revisits. The interviews included one nurse practitioner and 12 GPs. Interview content included a discussion around cancer recognition and referral in primary care as well as a focus on the action plans developed. The interviews were conducted at a time and place to suit the PCP and lasted from 17 to 43 minutes. Only one practice did not have anyone available for interview and in five practices, two PCPs were interviewed. It

was recognised that any unintended consequences of the action plans such as increased staff workload or patient anxiety may not be picked up in the repeat SEAs. However it was felt that this would come up in the staff interviews and that this method could be used to identify potential negative aspects of the action plans

As in the first round of SEAs, an interpretive matrix was used to analyse and manage the large amount of data from the SEAs. Individual SEA examples were used to assess feasibility and any potential impact. The use of the term 'impact' was not intended to suggest any definite change, or cause and effect, but more to demonstrate any potential evidence of the action plan having an effect in individual cases.

It was beyond the scope of this thesis to assess if any of the action plans developed would improve the recognition and referral of cancer symptoms. Cause and effect could not be established due to the lack of a control group and the before and after study design. However it was felt the SEAs and practice interviews could give clues to the potential impact of the action plans through individual case studies possibly showing change through use of the intervention planned.

As described in chapter four NPT was used as a theoretical framework in order to consider the reasons behind the feasibility and impact of individual action plans. Interview data was audio recorded and transcribed using nVivo software, then coded and analysed using thematic analysis as described by Braun and Clarke (158).

For the purposes of analysis, action plans will be grouped by the discussion themes highlighted in chapter 8.2. This will enable the specific plans to be assessed according to which area of opportunity to improve patient care they were designed for.

NPT was used to provide an insight into the possible reasons for action plans being implemented or not. This assessment was based on the work of Johnson and May who undertook an assessment of interventions to promote professional behaviour change in healthcare using a theory led overview of systematic reviews (104). When assessing professional behaviour change interventions using NPT, Johnson and May classified the interventions using the Cochrane collaborations' Effective Practice and Organisation of Care (EPOC) classification, then mapped the EPOC categories to the constructs and mechanisms of NPT (104). The paper by Johnson and May gives no detail on how this mapping was undertaken, only stating that it was done by

both authors. In this thesis, using the mapping undertaken by Johnson and May as a guide, the BCW interventions and policies were mapped to the NPT constructs by the student to allow an assessment of the action plans using the NPT framework. This mapping could be considered to be subjective, dependant on the decision of the student alone, however the widely referenced and peer reviewed paper by Johnson et al. was used throughout to guide this process (104). The reliability of this approach could be considered a limitation of the analysis and will be discussed in chapter 11.3

9.2 Results

Across the nine practices in the six months following the educational meeting the Read code search revealed 23 new bowel cancer diagnoses (range 0-9), 37 new lung cancer diagnoses (range 2-9), 197 suspected bowel cancer 2ww referrals (range 9-44) and 84 suspected lung cancer 2ww referrals (range 0-21) leading to a total of 341 SEAs which were analysed. Below, the action plans are discussed in more detail, followed by case studies highlighting aspects of the intervention and interview data.

9.2.1 The assessment of safety netting and follow up action plans

Action plan: improve safety netting advice and documentation of a follow up plan

Four practices made a plan to improve safety netting in consultations and to document this in the notes. This plan was agreed in the educational meeting and communicated to all staff via an email from the student with the rationale behind the plan. This plan was considered to be an educational intervention in the BCW and no further steps were taken by the student to implement the action plan

Six months following the implantation of the action plan evidence for any change in behaviour was mixed. In the original SEAs the student noted it was difficult to classify practices in terms of baseline safety netting documentation, as this seemed to vary significantly even between practitioners at the same practice. Similarly in the SEAs six months following the action plan implementation, there were some case reports which showed safety netting advice and documentation, but still others which did not. Three cases are highlighted below.

A 73 year old man with no past medical history, presented feeling generally unwell. Bloods and review were arranged at the first consultation. The bloods showed a mild anaemia and low ferritin, but on review the patient felt well and was asymptomatic. As a result the patient was given iron replacement and careful safety netting with a plan to repeat bloods in three months. It was documented that 'patient is aware to report any symptoms and will need investigating'. The patient did attend as planned for repeat bloods which had worsened and he was referred on a colorectal 2ww referral pathway.

A 62 year old patient presented with a change in bowel habit. The patient had no other symptoms and no red flags. The patient thought the symptoms may be due to a new medication. A plan was made and documented in the medical notes to stop the medication and to review in one month, a discussion about the likely next steps was also documented. The patient presented one month later and reported being slightly better, and as a result a plan was made to review in one month again. The patient presented almost exactly one month later and had ongoing constipation with some diarrhoea. A full examination was normal but she was referred on a 2ww pathway with safety netting advice about the referral.

A 71 year old ex-smoker with a cough was referred for a CXR but no follow up plan was documented, in this case the CXR result was actioned four days later and a 2ww referral sent, no delay resulted as a result of this case.

Two cases demonstrate examples of successful patient follow up and documentation of safety netting. The cases suggest the intervention was implemented and could have an impact on patient care. However, the third case summarises others in which safety netting was not documented as planned. It is unclear whether or not safety netting was discussed in this case and as a result it could be questioned whether the intervention was successfully implemented.

PCPs from each of the practices aiming to improve safety netting were interviewed and were asked about safety netting, as well as how they had gone about improving safety netting following on from the action plan developed. It was agreed that safety netting is important and multiple reasons were given for this in the interviews. This suggests that the *coherence* mechanism of NPT is strong; both individually and collectively there is a sense that good safety netting can improve the recognition and referral of cancer. A GP in practice seven stated, *"I think safety netting is a good opportunity for the GP to set very clear parameters to the patient"*. In practice two, the GP interviewed discussed the importance of safety netting, and when asked about documentation stated, "I write something along the lines of, erm, something like standard, standard safety netting advice given advice to see me in two weeks". In practice one the GP interviewed stated,

"I'd always safety net as well. I think we're taught quite well now as registrars coming through to safety net, erm, so I would say if there's been a two week history, look, we're not quite sure what's going on, don't think there's anything nasty but I think if this is ongoing for six weeks you definitely need to come back and I'll make a note of that". However, some difficulties were discussed and noted in the interviews. In practice three the GP suggested that safety netting may mean different things to different groups. This suggests that the NPT construct of *individual specification* may not be as strong as first thought, but also may be a difficult construct to meet as there could be a lack of accountability and confidence in the GP's safety netting advice.

Action plan: use a Read code to enable follow up of patients the PCPs are concerned about

To improve follow up, practices three and four planned to use a searchable Read code to highlight any patients they were worried about or wanted to be reviewed. Practice three chose a Read code in the educational meeting. An email was sent to all staff with the plan and the student created a poster for each of the consultation rooms to act as a reminder for the PCPs. In practice four a similar plan was made but the group of PCPs opted to choose their own Read code. To aid this, a selection of possible Read codes was sent from the London Cancer Alliance Read code advice via email to all the PCPs (221). In both practices this action plan was developed and agreed upon in the meeting and was simple to implement. In practice three both electronic and laminated posters highlighting the Read code and its purpose were delivered to the practice. This plan was simple and feasible to assess. The use of Read codes meant that searching for its use was possible using the GP computer record. This plan was considered to be an environmental restructuring intervention in the BCW.

At practice three, a search for the Read code found it had been used only six times in the six months since the feedback meeting, all of these were in the first month following the meeting and by the same GP. In these six cases the Read code was added for patients who presented with red flag symptoms and in each case the patient was followed up, investigated and referred without any delay. The presentations in which the Read code had been used included change in bowel habit, weight loss, thoracic back pain, abdominal pain and hoarse voice. In all of the cases the Read code was added when further reviews, or investigations were planned prior to referral.

At practice three whilst there is some evidence from the case studies that the use of a Read code to aid follow up may have some potential, overall the intervention was not sustained and did not have the desired impact. In contrast, in practice four a Read code was used by several of the GPs and a nurse practitioner throughout the six months since the meeting. In total their Read code was used 51 times and was used in various scenarios including possible cancer symptoms, but also to follow up other investigations, monitor blood pressure and titrate cardiac medication. As with practice three, when this Read code was used, the patient was always followed up either by telephone or a further appointment.

In practice four no Read code was agreed in the meeting and instead of administration staff searching for the Read code, the PCPs were encouraged to check their own Read codes. This required much less input from the student, and was easier to organise. It could be argued that the use of the Read code does have the potential for success, as when it was used there was some evidence of improved follow up and patient care. The plan had also been adopted in other parts of the country, with the London Cancer Alliance advocating a similar idea (221). The plan was also simple to assess using the GP computer record searching. However it was not fully adopted by the PCPs in either practice. Further work may be needed to understand the reasons behind this and improve the potential use of this intervention.

One GP interviewed in practice three struggled with the use of Read codes. The GP stated, "I'm not sure about the codes, I'm not sure I am very good at doing that side of it". He argued that detailed safety netting was more important, stating "I try and lay on the safety nets quite thick and if I've got a plan of action in mind or, you know, erm, follow-up that I want the patient to do, I'd just keep reiterating it to them in that consultation, I've got them in and hope that they then follow that up." It seemed for this GP, that the NPT construct of *individual specification* may have been lacking. A second GP was also interviewed in practice three. When asked about the use of Read codes, this GP felt that lack of time was a barrier to use of codes, and argued that when he was rushed he didn't remember to add the Read code. The GP stated, "looking back at times when a GP or, or I think my performance hasn't been as good as it might be, often the reason isn't because of lack of knowledge, it's because of, sometimes lack of time to do it, you are just a little bit rushed and so you don't perform to the best of your ability". This led on to an interesting discussion about the use of computer reminders in general, with the GP arguing that finding ways to provide GPs

with more time in the consultation, would be more effective than developing electronic reminders as they are generally ignored when the GP is rushing. This suggests the NPT construct of *interactional workability* may be lacking, as the action plan seems not to have been operational in every day settings.

In practice four the GPs interviewed had differing views on the use of Read code follow up. One GP stated, following a discussion on safety netting that he used codes to make a note of patients he had told to come back. This suggests this GP was using the Read codes and did find it helpful. However another GP interviewed at practice four, agreed with the sentiments of the GP in practice three that perhaps safety netting is more important than Read code follow up. This GP stated, *"We don't have a system, sort of following that up but you've got to leave that I think with the patient and if you explain carefully but sort of explicitly that they need to, to come back and why you're concerned, I think that's enough to safety net."*

Action plan: develop a safety netting leaflet to give patients, with red flags and follow up advice

Practice six developed an action plan to use a leaflet to give to patients containing safety netting advice. This leaflet was developed by the student with discussions and amendments made by the PCPs at the practice. The finished leaflet was sent to all PCPs in electronic format and paper copies were put in consultation rooms.

The use of the finished leaflet was difficult to establish. None of the cases reviewed in the practice re-visit mentioned the safety netting leaflet in the notes, no Read code was associated with its use and as such it has been difficult to assess the impact of the intervention from the SEA analysis. The leaflet was discussed with a GP and nurse practitioner in practice six. When asked about the leaflet the nurse practitioner was positive about its use, stating; *"I am in favour of this, I give them something at the door, you know, saying that any change in symptoms, any continuation of symptoms that are not improving, carrying on then come back"*. However the nurse did recognise potential problems of increased work in completing the leaflet but felt this increased work would be worthwhile, if patients with potential cancer could be referred early. Finally the nurse felt that the leaflet may act as an aide memoir and perhaps the list of possible red flags was the most important issue. *"I think it would, I think it would be helpful I think because they [patients] walk out the door and two minutes later they're knocking to come back, what did you say?"* A GP working at the same practice had several reservations about the use of the leaflet, feeling that it may increase

patient's anxiety, be difficult to understand and might be ignored. The GP stated, *"I mean obviously if you've got someone who's very, very anxious, to be given something like that might actually increase their, their anxiety levels, whereas if you're talking to them you can moderate it to, to fit that patient, erm, so we've got to take into account there might be people who can't read or understand what you're doing, so, and some people, if they do like they do with a lot of leaflets is they just stick it in their bag and never look at it, so I don't know."*

When considering this interview data using NPT, it is clear that many of the constructs were lacking. The interviews suggest that the *coherence* constructs of *individual specification* and *internalisation* may not be met. The GP interview suggests there is a lack of sense making about the role of the leaflet as well as the value and benefit of using it. The nurse practitioner interviewed, who was largely supportive was concerned it may increase workload which may limit the NPT construct of *systematisation* and *contextual integration* as the use of resources and effectiveness of the leaflet remain in doubt.

The use of a safety netting leaflet was classed as communication and marketing under the BCW. Johnson and May showed that marketing could help to meet the NPT construct of *communal specification* and therefore help PCPs to work together to build a shared understanding of the aims, objectives and benefits of a new set of practices (104). Through the development of the leaflet, there was good evidence of *communal specification*, with multiple members of staff involved in designing the content and layout of the leaflet. The problem with this intervention may have been the lack of the NPT constructs of *activation*, *interactional workability* and *relational integration*. These three constructs allow an action plan to be sustained, operationalised into everyday settings and to build and maintain confidence in the intervention. It seems as though this intervention was not sustained, or put in to everyday use and information from one of the PCP interviews raises concerns about the use of the leaflet. In order to improve its future use, the leaflet needs to be more widely accepted and perhaps developed further to improve its integration into everyday settings.

Action plan: develop a safety netting template to better document advice

Practice six developed several interventions to improve safety netting including the use of an electronic template to document safety netting advice

in the notes. The electronic template was developed by the student and allowed safety netting advice to be documented in the patient's notes using just a few clicks. Once set up, an email was sent to practice PCPs to explain how to use the template. The use of the template was simple to assess, as like all electronic templates they are based on Read codes, which can be searched for using the GP record.

There was some evidence from the case study analysis that the electronic template was being used to better document safety netting in the notes.

> *A 67 year old male ex smoker presented with haemoptysis and a feeling of a tight chest. Examination was normal and there was a plan to request bloods and a CXR and a review planned for one week. Safety netting advice was documented in the patients notes using the template. The patient attended the next week as planned and despite a normal CXR was referred as per the NICE guidelines.*

> *Another case showed that safety netting is not just important when suspecting cancer. An 18 month old baby was seen by the paramedic employed by the practice. His parents gave a history of three days of worsening fever, productive cough and being generally unwell. The child was examined and treated for a chest infection with antibiotics. The safety netting template was used during this consultation to document red flags, an OOHs management plan and expected time course. In this case the plan stated to return or seek OOH help if the patients symptoms did not improve. The patient was not seen again suggesting the antibiotics had been successful.*

These cases demonstrate the potential benefit from the use of a safety netting template when seeing patients and suggests that this may be a helpful intervention to better document safety netting advice in the medical notes. The Read codes used in the template were also specifically searched for using the GP record. This found that the template had been used 67 times in the six month period by a number of staff including nurse practitioners, a practice paramedic and three of the four regular GPs. This suggests that the template was used by different members of the medical team. However, it could be argued that the template could have been used many more times. This is especially true given the findings of the scoping review of safety netting in chapter six of this thesis, which argues that safety netting should be undertaken in all consultations. It is possible that the template was only used in cases in which the PCP was worried about a patient or wanted to ensure they had documented the advice carefully.

In practice six a GP and nurse practitioner were interviewed about the use of the safety netting template. Both PCPs were largely supportive of the

template, stating it acted as a reminder to chase up CXRs and document safety netting advice. Both stated they used the template and that it saved time by avoiding typing. The GP stated, *"Those templates . . . I think it has been useful, erm, it prompts us, maybe makes us think about it . . . so I do sort of follow the prompts and things that are on there anyway and would use them, so I think it has helped, I think it's made us all think a little bit more, so I've used them".* On saving time the GP stated, *"It just saves you sometimes typing all those things that you would have put in, you can discuss it with the patient and code it as in one thing you've, you've discussed the red flags, you've told them how to come back if they need to come back, if you've done a chest xray or anything, it's there and, so yeah, we do use it".* The nurse practitioner stated the template served as a reminder particularly for chasing up CXRs, "*I do a lot of chest xrays and I access the, the template for that to, to remind me that, yeah, chest xray has been requested and to be followed up, so I, I tap into it quite a lot".* However there were problems with the template, which relate to 'pop up fatigue'. The GP felt that sometimes the template pops up when clearly not relevant and asked if there could be a way to skip the template. The GP said, *"if there was like a button which was, if it's not relevant you could just click that and it wouldn't go through the whole process, whether you could bypass a process".* Considering the interview findings using the NPT constructs, the data suggests that PCPs have made sense of the benefits and can see the advantages and value of the template, suggesting that the mechanism of *coherence* could be met. However, *interactional workability*, which refers to the use of the template in everyday settings may need development as the interviews suggest that the template was not relevant in some settings and needed to be bypassed or stopped. In order to improve this intervention, further work may be needed to enable the template to be more useful in everyday settings.

Action plan: use a telephone appointment list on the appointment screen to aid follow up

Practice six developed an action plan following a discussion on using the computer record to aid follow up. Each of the regular GPs at this practice do 'on call' days in which they have a telephone list for urgent problems, rather than a usual doctors surgery. It was decided that this list could be used to aid follow up. The plan involved PCPs themselves, but also other staff adding patients to the telephone list, if they wished for the patient to be followed up. At this practice, the plan was simple to set up due to the way the 'on call' system was set up. It required a 'restructuring' in the way this list was used

by all members of staff in order to use the list for follow up. Case study analysis revealed only one clear example of this being used in the 2ww referral SEAs. This case is documented below.

> *An 88 year old man with COPD and pancreatitis was asked to see the GP due to a drop in his haemoglobin. At the GP appointment he was asymptomatic but has lost some weight. A plan was made to repeat the bloods and look for other causes of weight loss. The plan states "added to my telephone list for follow up in 48h". The patient was seen called 48 hours later, he had low ferritin and was referred on a 2ww colorectal referral.*

This case shows how the action plan could potentially be used successfully. The patient had red flag symptoms and needed follow up after further investigation. The telephone list was used as planned, to serve as a reminder to the PCP to follow the patient up. However the analysis, using SEAs of cancer diagnosis and 2ww referrals was not an effective way of assessing this plan. It was difficult to specifically search for evidence of this plan working through the SEAs. A telephone appointment list was present every day, but resources were not available to tell if the list contained patients requiring follow up as per the action plan, or solely the usual urgent medical phone calls. In order to better assess the impact of this plan, alternative methods of assessment are needed. With better access to patient notes it is possible to see which member of staff booked an appointment and when. Alternatively, a Read code may help to track the use of the list for follow up, or having a separate follow up list would help in assessment, but having two lists could cause confusion for the PCP and potentially cause patients to be missed.

The five action plans above all aimed to improve safety netting and follow up. The plan utilised several BCW policy and intervention categories and were all successfully implemented. Assessing evidence of behaviour change was difficult, however the safety netting template and the use of the Read code showed some potential, being used multiple times over a sustained period. The interviews suggest that whilst some NPT constructs were met by the interventions, others may be lacking or could be improved. This will be discussed in more detail at the end of this chapter.

9.2.2 The assessment of action plans involving investigations

Action plan: ensure CXRs are requested as per the NICE guidelines

Practices two and eight developed a plan to have a lower threshold to request CXRs and planned to use the NICE NG12 guidelines in order to guide their CXR requests (25). This action plan was agreed by the staff in the

educational meeting and was feasible to implement with an email sent to all PCPs at the practice.

There were multiple cases in which CXRs were ordered at the first presentation, and a search of the lung cancer diagnoses, and 2ww referrals since the educational meeting did not find any cases in which a CXR was ordered late, or not requested when needed. All patients reviewed in practice eight received a CXR as per the NICE guidelines.

The GP interviewed in practice two seemed to fully support the plan to have a low threshold for requesting a CXR, stating *"in Hull getting a chest xray is easy as the patient can just walk in, there is no problem with accessing chest xrays"*. The GP in practice two felt that smokers or ex-smokers with lung symptoms should have a CXR at the first opportunity, stating the GP would always do a CXR "at the same time" as treating symptoms. This interview suggests that the NPT components of the *coherence* construct *individual specification* and *internalisation* were met, as well as the components in the *cognitive participation* construct. However, there may be problems with *collective action* and particularly the component of *relational integration* as the GP interviewed seemed worried about accountability as it was difficult to know if patients had attended for the test or not.

Action plan: improve the management of patients with a normal CXR

In total five practices made a plan to improve the management of patients with a normal CXR. The first practice feedback meeting arranged was with the staff at practice three. This practice recognised the difficulty of normal CXRs when diagnosing lung cancer, but noted there were no guidelines or advice on what to do with patients who had a normal CXR. The practice asked for the student to look for evidence and develop guidelines for the practice staff to use.

Following this educational meeting, the student contacted two local chest physicians with the help of his supervisor (UM) and advice was successfully sought and distributed on how to manage a patient with a normal CXR. This advice, which included suggestions to repeat CXRs which were older than three months and have a low threshold for referral, can be viewed in appendix J. Following this, when the problem of normal CXRs was discussed at other feedback meetings in practices two, seven, eight and nine the advice from the chest physicians was shared and the enacting of this advice formed the basis of the action plans in five practices.

The results from the SEA case study analysis were mixed. Two cases below show examples of normal CXRs in patients with persisting symptoms who were referred as per the local specialist advice. However the third case demonstrates a normal CXRs which still caused significant delay.

> *A 79 year old female smoker presented with thoracic back pain and morning stiffness, without any chest symptoms. A thoracic spine xray and bloods were arranged. The bloods showed raised inflammatory markers but the spine xray was normal, the symptoms continued and she developed a cough and breathlessness. In the next consultation a CXR was organised and she was given antibiotics. The CXR came back normal, but the patient's symptoms persist and she returned again, at this point she was noted to have finger clubbing and a 2ww lung referral was sent just ten days after the initial referral and lung cancer was diagnosed.*

> *A 73 year old lady with COPD presented on two occasions over a four week period with cough, wheeze and shortness of breath. She was treated with antibiotics and on the second occasion a CXR was requested which was normal. Two weeks after the CXR the patient presented again with worsening symptoms and further antibiotics were prescribed. Four weeks later the patient presented again still with shortness of breath. At this point the PCP documented the previous normal CXR and organises a CT chest which revealed lung cancer.*

> *The 66 year old ex smoker had a normal CXR after presenting with a 4 week history of a cough. Following this the patient was sent for spirometry and was seen five times over a six month period with ongoing cough before a repeat CXR was arranged which suggested lung cancer.*

Whilst this plan was feasible to implement, it possibly created another unintended consequence in practice nine. It was noted when reviewing the 2ww referrals at this practice, that one nurse practitioner had sent significantly more 2ww lung referrals than anyone else and over half of these were made without doing a CXR prior to referral. It could be argued that in all eight of these cases the NICE guidance had not been followed. Possibly as a result of the feedback meeting and the subsequent information from the expert opinion, the nurse practitioner felt that CXRs were not helpful in the diagnosis of lung cancer. This PCP seemed to be using the 2ww pathway if there was any suspicion of possible lung cancer. All the patients referred were fully assessed following the 2ww referral regardless of the fact they did not meet the referral criteria. Given that evidence suggests CXR misses around 30% of lung cancers, perhaps the nurse practitioner in this case was right to send more 2ww referrals. The nurse could argue that she was justified, as all referrals were investigated further in the hospital setting.

However, if all PCPs acted in this way the hospitals may struggle to meet demand, and in the eight cases referred on a 2ww without a CXR, none were diagnosed with cancer.

In the PCP interviews when discussing normal CXRs a number of themes were raised, including the management of risk in primary care, problems of capacity in secondary care, exposure to radiation for patients, and the worry of perceived unjustified referrals to secondary care. A GP in practice three stated, *"I think it's actually quite scary for us I think as to how poor some of our diagnostic tests that we rely on are"*. The GP goes on to state, "*if you look at the actual studies and the statistics quite a lot of early lung cancers won't show up on a chest xray, so then you're faced with how much you share that uncertainty with the patient and how ready you are to get them back and repeat an examination that's only been done perhaps a few months earlier"*. This GP was aware of the problems with normal CXR and had considered the expert advice to consider repeating CXRs in patients with persisting symptoms, suggesting that the sense making components of NPT were met. However the possibility of organising further tests in primary care was met with concern from this GP who was worried about capacity in secondary care and extra exposure to radiation if GPs began requesting CT scans. The GP stated, *"I think there are capacity issues. I think as soon as you start talking about CTs of more solid tumours and that leads on to the whole problem of screening really, then you're talking about a far more significant dose of, of radiation"*. A GP at practice seven stated, *"I do I think we are lucky with the walk in CXR but CXR is far from ideal and yet you want to be careful not to be putting every patient through a CT scanner or anyone with chest signs you know its common and fairly innocuous finding in many cases, erm I don't really know how you optimise that"*. This GP highlighted problems with the NPT construct of *relational integration* and *skill set workability*, suggesting that secondary care may not have the resources to operationalise the plan. A second GP in practice seven was concerned about being perceived to be sending too many 2ww referrals and being judged by secondary care as not being a good practitioner. As a result he was concerned about the expert opinion to send patients on a 2ww if concerned about lung cancer. The GP stated, "*they might just say "oh he's just sending everybody here" I feel it [gut instinct] might not be recognised and there might be more of an impact later on, kind of thinking, he is not a good GP, kind of sending everybody in, you know you might spoil your name and that maybe I should do further investigations before I send the patient through on a 2ww"*.

In summary it seems that GPs in this study were aware of the issue of normal CXRs, but were also concerned about the implications of acting on this, particularly in terms of increased exposure to radiation from CT scans and overloading secondary care with referrals which the GPs worry may not be justified. It seems the NPT mechanism of *coherence* is largely met. The PCPs being interviewed understood the problems with normal CXRs from the audit and feedback meeting. When enacting the plan the first steps were undertaken by the student to obtain information from the secondary care specialists on how to manage normal CXRs, which would help the construct of *initiation*. However the constructs of *legitimation*, *activation* and all the constructs in the mechanism of *collective action* may be difficult to meet due to the PCPs worries of over investigation, radiation exposure and referrals to secondary care. In order to improve the action plan further, more detailed discussion between primary and secondary care may help in order for both sides to agree on the best course of action. By simply relaying information from secondary care specialists to the PCPs, an opportunity may have been missed to allow the PCPs to ask further questions or clarify any doubts they may have had.

<u>Action plan: improve the management of iron deficiency anaemia</u>

Two practices made educational action plans to improve the management of IDA. The two cases below show prompt 2ww referral of patients with IDA.

> *An 80 year old man with COPD saw the nurse for a COPD review and had routine bloods done at this appointment. These bloods showed new anaemia and were checked and marked by the doctor to 'check ferritin'. The patient attended the next week for further bloods which confirmed IDA. The patient was seen four days later and a 2ww referral was sent and explained to the patient.*

> *A 40 year old lady with no past medical history presented with swollen ankles and a plan was made for blood tests and review. The bloods showed new microcytic anaemia. They were seen and marked by a doctor stating "suggests IDA please check haemotinics and review with doctor". The bloods done 12 days later showed low ferritin, the patient attended one day after this accompanied by her husband, the IDA was explained and 2ww referral sent.*

The aim of this action plan was to ensure that PCPs were aware that IDA was a red flag and should be referred urgently. Both GPs interviewed in practice nine recognised the difficulty with managing IDA. The first GP discussed two ways of managing patients with 'borderline anaemia', by booking follow up, or referring on a 2ww even if the guidelines are not met.

The GP said: *"I've had a few colorectals that I do, erm, very non-specific, with borderline anaemia, I'll diary them and review them and go from there, particularly seventy year old blokes who don't really fit in, you know, I'd probably do, but I do use time"*. The same GP goes on to state, *"I will, for iron deficiency and things for colorectal, I'll just, even if they don't meet the criteria I'll just tick and fudge it, even if they are, it's clear it's not, but in the covering letter I'd probably mention something"*. A second GP in practice nine agreed that in most cases he would err on the side of caution and refer patients even with mild symptoms. This GP stated, *"It's difficult with a mild drop in anaemia and I think we haven't got a clear guideline to work with, I think I refer more really because, that is all you can do"*. This data from the interviews seems to support the findings from the SEAs that the educational action plan may have some impact. The GPs interviewed showed that the NPT mechanisms of *coherence, cognitive participation* and *collective action* could potentially be met by this action plan. It seemed the GPs were aware that IDA was a red flag for colorectal cancer, but that also it posed diagnostic challenges when 2ww referral cut offs for IDA were not met. The GPs had both dealt with this by having a lower threshold for referral. It is possible that this could lead to over investigation, though this was not discussed in the interviews. It seemed from the interviews that the plan had been operationalised in to everyday settings and that the GPs had confidence in the new set of practices thus potentially meeting the constructs of *interactional workability* and *relational integration*.

Action plan: communicate urgency when checking blood results

Practice three made a plan to ensure blood results were appropriately marked as urgent to allow reception staff to book patients in quickly when needed. This was a difficult plan to assess at the six month practice re-visit. Many cases had blood tests done as part of their primary care investigation but most did not have any comment in the notes on the urgency of the appointment. As a result follow up SEA analysis was unable to assess whether the plans had any impact because the necessary data was not available to the student conducting the SEA analysis.

A GP at practice three was interviewed and asked about the management of blood results. The GP felt that when blood results came back as abnormal the surgery has to have a safe way of ensuring the patient is informed and seen. The GP stated, "*I think that it's definitely our responsibility if we turn up an abnormal test to make sure the patient gets the result, I think the inexcusable thing is when, as I have had happen, when you get a definite*

abnormal result and the patient is never told about it". The interview data suggests that the NPT constructs of *coherence* and *cognitive participation* were strong and that the GP understood his roles and responsibilities regarding the results of the blood tests. However it is unclear as to whether this was a result of the educational meeting or action plan.

<u>Action plan: encourage phlebotomists and nursing staff to safety net patients through the development of a protocol and leaflet</u>

Practice four developed a novel plan to improve the follow up of blood results by developing a protocol and leaflet to encourage the phlebotomy and nursing staff to provide safety netting advice. A meeting was organised between the student and the nursing staff in which the purpose of the action plan and the details behind it were discussed. It was found at this meeting that the nursing staff were anxious about giving any advice which wasn't documented in the notes by the doctor. As a result they felt that a standard leaflet may be most appropriate. Following this the student liaised with the lead nurse to develop a protocol for the nursing staff and a leaflet to give out when taking blood. These resources can be viewed in appendix K. This action plan was feasible to develop and set up. Following the feedback meeting there was good engagement with the nursing staff and resources were developed with input from the lead nurse. The resources developed were generic and could be used by different practices in a larger scale study.

However, like the safety netting leaflet developed for practice six discussed above, this action plan was very difficult to assess through the new cancer and 2ww referral SEAs. There was no evidence that the nurses or phlebotomists had used the protocol and leaflet in any of the cases. In addition to this, the nursing staff declined to be interviewed about the intervention. As a result it is impossible given the information available to judge any potential change in behaviour or benefit of this intervention. Whilst it was disappointing not to be able to gain any insight into the use of this action plan and its potential to change PCP behaviour, it could be argued that the process of developing resources and working with the nursing staff showed the intervention was feasible and could be worth pursuing if a more suitable evaluation could be planned. Some of the NPT components were met through the development of the protocol and leaflet including improving sense making with the nursing staff and *collective action* through a team approach to the intervention development.

<u>Action plan: admin staff to make the 'to come in letters' more specific</u>

Practice five suggested an action plan to make the letters they send to patients, known as 'to come in letters' more specific as a result of the findings presented at the audit and feedback meeting. It was noted that there was previously a potential for error here as patients who received letters, often did not know what they were being asked to come in for. Implementing this plan involved a discussion with administration staff with the findings of the SEAs and the need to change the letters. This plan was simple and feasible to set up. Administration staff understood the potential for missed opportunities as a result of vague 'to come in' letters and were keen to make the changes. The NPT constructs of *coherence* and *cognitive participation* were met following a discussion with the admin team who could appreciate the potential benefit from the action plan.

On review six months later, the staff confirmed they had changed the 'to come in letters' which now stated the reason for the letter such as diabetic review, blood tests, and results of investigations for example. There was only one case in the case study analysis which demonstrated this change in the practice policy.

> *A 69 year old current smoker with COPD presented with a two week history of SOB, wheeze and chest tightness. A plan for steroids, COPD review and a CXR was made. The CXR showed an opacity and a CT scan was arranged immediately for the patient by the radiologist. The patient required a kidney blood test prior to the scan and had not answered his phone. A letter was sent to the patient asking him to come in for blood tests and to discuss the CXR result. He did attend for bloods and review, had the CT scan as planned as was diagnosed with lung cancer.*

In this single case the patient needed two appointments, to explain the results, and plan for the CT scan. A generic 'to come in' letter may have led to the patient only booking one appointment, which may in turn have delayed the CT scan. Whilst evidence of its effectiveness was limited from the SEAs, administration staff confirmed it had resulted in a change to the letters.

Action plan: develop an anaemia pathway with secondary care input

Practice five noted a difficulty with the management of IDA. They made a plan to develop a pathway with input from secondary care with the aim to standardise the practice's management of IDA. This plan required no input from the student. PCPs present at the meeting implemented the plan which followed the feedback meeting.

When reviewing the SEAs, five of the six cases with anaemia were managed appropriately according to NICE guidelines. However the final case had a

prolonged primary care interval, due to mild unexplained IDA without any other symptoms. The patient was referred routinely to an 'anaemia clinic' which the patient waited over two months for, before returning to the GP with worsening symptoms and being referred on a 2ww pathway. This final case still highlights some of the difficulty of managing IDA shown in the original SEAs. The patient had no risk factors, was well and had only presented originally for mild ankle swelling.

When discussing IDA during the interview with a GP at practice five it was clear that despite the development of a protocol to help manage IDA, there were still challenges. The GP went on to say, *"I'm thinking about the ones who sort of have a long-standing anaemia and you're trying to work out whether or not it's, it is significant or whether or not it is because they've got other pathologies going, they've got chronic health issues, I think it does make it much more difficult to assess them"*. This suggests that even in the presence of a protocol, there were challenges to the management of IDA. As such the NPT construct of *contextual integration* is important in order to allocate resources to aid the execution of protocols.

Seven action plans were developed with the aim of improving the use and management of investigations. These included educational and environmental restructuring interventions from the BCW. All of the plans were feasible to implement and were able to meet many of the constructs of NPT. However many of the plans were difficult to assess using SEA analysis and interviews and evidence of any behaviour change was limited.

9.2.3 The assessment of action plans aiming to improve referrals

<u>Action plan: use the patient self-booking system when doing a 2ww referral aided with a self-booking leaflet created by student</u>

Practices three and four both recognised the potential extra safety net possible through the use of the patient self-booking system for 2ww referrals. In both practices the plan was similar and a learning point from the meeting was that staff should use the 2ww self-booking system at every opportunity. In addition to this the student was asked to create a self-referral form for the PCPs to give to patients. This form is available in appendix I.

The assessment of this action plan was difficult using SEAs. It was very difficult to determine the frequency of use of the self-booking system and information sheet developed by the student. There was no specific Read code documented when the self-booking system was used. It was marked on the referral form filled in by the GP, but due to confidentially the student was

not able to view these. In total there were 12 cases in which the PCPs making the referral had specifically documented the use of the self-booking system in the patient's notes, an example of this is shown below.

> *A 61 year old man with chronic back pain presented with PR bleeding and pain when passing stool. The patient was examined and was thought to have an anal fissure. Treatment was given as well as laxatives and a plan made to review if no better. The patient returned two weeks later with further PR bleeding but also some diarrhoea and tenesmus. The plan documented in the patients notes stated "advised 2ww, explained referral and need for it. Booking info given, advised to call in the morning".*

Overall, it is likely that the self-booking system was used in more than the few cases in which it is specifically mentioned in the free text plan, especially given that in practice three, some of the GPs were already using the system. However, its use was only documented in twelve cases and of those, two patients still had some delay as a result of cancelling appointments themselves. This suggests that whilst the plan was simple and feasible to implement, because the use of the self booking system was not documented, it was difficult to assess any impact. Perhaps in order to better assess this action plan, information could be sought from the hospital booking centre, or PCPs or practice secretaries could be encouraged to document the use of the 2ww self-booking.

The NPT construct of *coherence* seems to have been met in this action plan. The practice staff understood the self referral system and could see the benefit of an extra safety net when organising 2ww referrals. However the constructs of *collective action*s and *cognitive participation* are more difficult to meet in this plan.

Action plan: administration staff to check all DNA letters and contact patients if necessary

Practices four and eight made a plan to check all DNA letters and attempt to contact patients if necessary. This action plan seemed feasible to set up and implement. It was agreed that a change in practice was required following cases discussed at the audit and feedback meeting. The change in practice, which included either PCPs or administration staff checking DNA letters and contacting patients, was agreed and the plan and rationale behind the plan was emailed to staff. However, there were no examples in the SEAs completed following the action plan development which demonstrated any potential change in practice. On discussing this in the interviews, a PCP at practice four stated that they were checking DNA letters, but there was also

an interesting discussion on the role of patient responsibility and whether PCPs, GP practices or even hospitals should take responsibility for patients not attending appointments. The GP stated that he felt he had a responsibility to close the loop if a patient had had tests and did not attend follow up in primary care. However with regards to patients not attending hospital appointments the GP stated, *"I think that's also a duty of care that the hospital have, so I think that if someone is referred and DNAs then I think there is an obligation on the hospital to just try and find out why"*.

The two referral action plans both involved environmental restructuring. Both action plans were simple and feasible to implement, but both had very little evidence from the SEA analysis of any change of behaviour. Both plans seemed to meet the NPT core construct of *coherence* but may lack the required actions in the construct of *collective action*. This will be discussed in more detail below.

9.2.4 The assessment of action plans aiming to improve continuity of care

Action plan: if patients attend in an emergency five minute appointment and need more time or further investigation, PCPs should book appropriate follow up

Practice one made a plan to be aware of potential pitfalls with their emergency five minute, on-the-day appointment system. The PCPs aimed to use 'planned follow up' if they felt they could not manage the patients symptoms in the emergency surgery. However, when assessing this plan, like the management of blood tests above, the notes did not always state whether or not the appointment was an emergency one, meaning data was not available to be able to gain an insight into the impact of this plan.

An example described below suggests the action plan could have had an impact, with careful management of potentially red flag symptoms that eventually led to new diagnosis. It is not possible to say that the management of this case was altered as a result of the intervention. There were no examples of the emergency appointment being detrimental to the recognition and referral of suspected cancer symptoms in this practice.

> *A 76 year old female smoker attended A&E with a chest infection and haemoptysis. The patient had a CXR in A&E which the patient said showed infection and was discharged with antibiotics. The next day the patient attended the emergency surgery with a suspected allergy to the antibiotics given in A&E. In this appointment, alternative antibiotics were given but the patient was also told that if she has further haemoptysis she should represent for a*

CT scan. The patient did represent to a routine appointment a few weeks later where a scan was organised and the diagnosis of lung cancer was made.

In the case above, the patient presented to the emergency five minute on-the-day surgery organised by the practice. In the first round of SEAs these surgeries created missed opportunities, most likely as a result of not having enough time in each appointment. On this occasion the patient's immediate need (different antibiotics) was dealt with in the five minutes, but in addition to this, risk factors for possible cancer were recognised, and instructions on follow up discussed with the patient to ensure they were seen again if needed. The case suggests the action plan could have had an impact, however the assessment as a whole found too few cases to effectively assess the action. An alternative method of assessment would be needed should this action plan be implemented on a wider scale. It may be possible to record repeat appointments following an emergency appointment using an electronic template or Read code, in order to better assess its impact.

The GP interviewed in practice one was asked about the importance of time in the consultation and the use of follow up in this action plan. The GP felt that adequate consultation time was one of the main barriers to recognising cancer in primary care. In the five minute consultations the patients are given a card informing them of the use of an emergency appointment for one issue. The GP worried that as a result of this *"not many people come out with all the symptoms they are experiencing, especially more vague stuff like pain for example, I think though we always ask people red flags, there could be so much more than this."* The issue of consultation time came up a second time in the interview, during a discussion on ways to help improve the recognition and referral of cancer symptoms the GP stated that *"more time in the consultation"* was a key factor. The GP recognised that follow up could help with this stating that she always told patients to return if symptoms persisted. As such the NPT core construct of *coherence* seems to have been met. These interview findings echoed the findings of the discussion meeting on this issue. The GP felt that not having enough time for adequate history taking could negatively affect the PCPs ability to recognise cancer symptoms but agreed that using planned follow up could be one solution to this.

Action plan: recognise that multiple attendances may be a red flag.

A plan was made by three practices to be aware of multiple presentations and treat them as a possible red flag. Practice two planned to adopt a 'three

strikes and refer rule' but also to be aware of a change in presentations, for example if a previous infrequent attender, presents on a couple of occasions. No specific measures were undertaken to implement these educational action plans, but they were emailed to all PCPs explaining the plan and the reasons for it. Like the other educational action plans, it was easily set up and feasible to replicate on a larger scale, an email reminder was the only intervention needed following the audit and feedback meeting.

In all three practices there were mixed results, with some cases suggesting referrals were being made in patients who presented multiple times, however each practice also had cases in which patients were seen numerous times prior to referral. This seemed especially common in patients with exacerbations of COPD. The cases below highlight the mixed outcomes seen in the case study analysis.

> *A 71 year old man with a previous history of a stroke, presented three times over a one month period with bowel symptoms including loose stools. On the first presentation the symptoms were thought to be due to medicines, so these were altered. In the second, safety netting and reassurance was given. At the third consult, the symptoms had not changed and the patient was concerned. As a result a 2ww colorectal referral was made, with a note highlighting the other consultations, and patient worry.*

> *A 66 year old ex smoker presented five times over an eight month period with a cough and sputum production. The case was complicated by a normal CXR after the first presentation but following this, the patient was investigated with spirometry, blood tests, a change of inhalers and reassurance before a second CXR suggested a suspicious lesion.*

The interviews suggested that the audit and feedback intervention may have had some impact on the PCPs views of multiple presentations. In the interview with a GP in practice one, during a discussion on clues to help PCPs recognise cancer symptoms this action plan and the importance of recognising multiple presentations was discussed. The GP stated that *"repeated reviews with the GP are a red flag that PCPs should be aware of"* and goes on to say that *"I always look for repeated presentations"*. In Practice two, during a discussion on continuity of care the GP stated, *"sometimes I'll just keep an eye on them depending on how convinced I am that something else is going on . . . and sometimes I will bite the bullet and refer anyway and just say could you have a look?"* In practice nine the GP states: *"recurrent presentations of, erm, some diagnosed symptom, I think, three strikes you're out, come for the same thing three, three times for three different, yourself or three different doctors it could be something, generally needs to be investigated or somebody else to look at that"*. Again it seems

that the NPT construct of *coherence* was met, but the results of the SEAs found mixed results in terms of changes in behaviour. This will be discussed in the summary below

<u>Action plan: administration staff to ask the patient which PCP they would like to see. PCPs are encouraged to book own reviews</u>

This action plan was developed by the PCPs in practice six who felt that continuity of care could improve the recognition and referral of cancer symptoms. This plan was simple to set up and seemed feasible. Following the audit and feedback meeting, the plan was agreed and an email was sent to all PCPs and administration staff to explain the plan and the reason for it.

At the SEA review there were only three cases where it was clear from the medical notes that the PCP had ensured he or she would see them again. An example case is discussed below.

> *A 59 year old lady with previous heart disease presented to the PCP with abdominal pain and weight loss. Examination was normal so bloods and an USS were arranged. The plan states review with me with the results. The bloods showed new IDA and a different PCP checking the blood results booked an appointment for the patient with the original PCP. At this appointment the patient's symptoms had improved slightly. A plan was made to repeat the bloods, await the USS and "review with me". The notes also state if USS normal ?investigate bowel. The USS was done but marks an area of possibly abnormal bowel. The patient saw the same PCP again and a 2ww colorectal referral was made.*

In this case the same PCP followed the patient up from first presentation to referral, through several different investigations. Plans for review with the same PCP were made in the notes.

During the interviews in practice six both the GP and nurse practitioner recognised the benefit of continuity of care, and thus, actions aimed at improving this were welcomed. The GP stated, "*I think if you're seeing the same people, you build up a relationship with that person, you know their history or, about, about that person. Plus when it comes to like you making your records and things, it, you know where you're thinking is going*". Similarly the nurse practitioner stated he liked to book patients in for review with him *"I tend to bring a lot of patients back, I tend to book them back in a week, two, three, four weeks down the line, I tend to do that a lot and just my, my, I think my safety nettings, you know, reasonably, reasonably sort of good"*. This data suggests that the *coherence* mechanism of NPT in this plan was met. The PCPs understood the purpose of and the value and benefit in seeing patients again and having continuity of care. However the GP did not

discuss the use of the telephone list system and the nurse practitioner provided continuity of care by booking his own follow up. Similarly there was little evidence from the SEAs or interviews of the administration staff assisting with continuity of care. This suggests that the NPT mechanisms of *cognitive participation* and *collective action* may not have been met in this particular plan. It seems that whilst continuity was felt to be important, the PCPs may have had their own way of ensuring this happens. As a result one could question whether these action plans helped to improve continuity and perhaps further discussion with the team to consider other ways of ensuring continuity of care would be helpful.

<u>Action plan: put an alert on the patient's record to let others know if previous notes need to be reviewed prior to the consultation</u>

Practice seven felt that the 10 minute consultation did not always allow for a thorough review of the patient's past notes. The practice staff felt that by adding a dated alert to the notes of patients they were concerned about, other PCPs would be informed of previous, possible red flag presentations. This plan was feasible to implement, it was agreed by all PCPs in the audit and feedback meeting and the plan and it's rationale was emailed to all practice staff.

This was a difficult action plan to assess in the SEAs reviewed. None of the cases had a pop up alert, and it was not mentioned in the free texts of any of the cases. When interviewed the PCP at this practice had not been aware of any of the other PCPs adding alerts and had not seen any alerts on patients he had reviewed. It is possible that this plan was being undertaken by other members of the PCP team and the SEAs and PCP interviewed did not pick this up. In order to assess any potential benefit of this plan, more staff interviews or focus groups would be helpful.

On the evidence available, it seems that this action plan had not been successfully implemented. There are multiple possible reasons for this. For example, the alert system is in a different section of the medical notes, as a result the PCP would have to finish writing the consultation, then go to a different section of the medical record to add an alert. It is possible there was not enough time for this within the consultation. In addition to this, there is well documented 'pop-up fatigue' in which the frequency of alerts and pop-ups within the GP medical record when prescribing and documenting history and examination findings mean that they can be ignored or not used by the PCPs. Whilst this plan seemed feasible, it does not seem to have been

implemented and from interview data seemed to have no impact on behaviour. This could have been caused by a failure in a number of different areas of NPT. The core construct of collective action requires practices to be operationalised in everyday settings. It is possible that due to the need to go in to a different section of the notes and the problems with 'pop-up fatigue', the components of collective action were not met. The potential barriers to implementation will be discussed in the summary below.

9.2.5 The assessment of action plans aiming to improve elements within the consultation

<u>Action plan: ensure patients are weighed at every opportunity</u>

Practices five and six made a plan to weigh patients more frequently, after the importance of detecting weight loss in the consultation was discussed in the educational meetings. In both practices staff agreed to try to weigh patients at every opportunity.

Following the development of the intervention, practice five had five cases in which the patient reported weight loss. In all of these cases the patients were weighed during the consultation. Practice six had 20 cases in which weight loss was mentioned as part of the patient presentations. Reviewing the examinations in each case showed that patients were weighed in 11 of the 20 cases. The cases below show how patients presenting with weight loss were managed in the two practices.

> *A 66 year old smoker with a history of previous breast cancer was seen twice in the previous month with signs of a chest infection. She presented a third time with ongoing chest symptoms but also with weight loss. The patient was weighed and weight loss was compared with an older measurement. Tests were arranged to try to establish the cause with bloods, USS and CXR arranged. The CXR showed a lung mass and a 2ww was sent.*

> *A 85 year old man with type two diabetes and COPD presented with weight loss and diarrhoea. On examination he was weighed, had lost weight and was noted to look cachectic. His chest was wheezy and a CXR was arranged with a clear plan to arrange colonoscopy if CXR normal. The CXR showed a lung mass and the patient was referred on a 2ww lung pathway.*

The above examples demonstrate two cases in which weight loss was documented and patients were investigated and referred quickly. However it could be argued that as these patients were presenting with red flags anyway, they may have been investigated or referred irrespective of the

patient's weight. There were no examples in the cases reviewed of weight loss being found incidentally as a result of weighing patients more frequently.

Action plan: ensure patients presenting with abnormal weight loss are fully investigated

Practice eight made a plan to ensure that all patients presenting with weight loss were fully investigated. No formal investigation plan or guideline was suggested and the method of investigation was left to each PCP meaning there was little opportunity for *collective action*. In this practice, three patients presented with weight loss and each had further investigations or were referred at the first presentation. An example case is shown below.

> *A 70 year old female smoker with COPD who rarely attended the surgery, presented with her family concerned about recent weight loss. The patient had no other symptoms and chest and abdominal examination were normal. A plan was made to organise a CXR and blood tests to investigate the weight loss. The patient was seen the next day, she had a pleural effusion on a CXR and a raised Ca125 blood test. As a result two 2ww referrals were made to lung and gynaecology.*

This case shows a thorough investigation of a patient presenting with weight loss. In this case two referrals were made to two different specialities, which could have reduced the primary care interval in this case.

Action plan: use the in-built QCancer risk calculator in the computer system to aid referral

Practice five felt that using QCancer in the consultation would help with referral decisions. The background and evidence behind QCancer is discussed in chapter 1. It was felt the software may help the PCPs in practice five to decide if they should refer a patient or not and if so which specialty to refer to. This intervention was simple to implement, needing only a discussion at the practice meeting and an email to practice staff explaining how to use and how to access the calculator.

There was evidence that QCancer had been used prior to referral in the SEA analysis. In each case the risk assessment tool was used prior to a colorectal 2ww referral when symptoms were vague or examinations were normal.

> *In one case a 76 year old with loose stools and abdominal pain was seen on one occasion. Examination including PR was normal. A QCancer risk score was done showing a colorectal cancer risk of over 6%. Based on this risk, the patient was referred using a colorectal 2ww referral.*

Overall, there is some evidence this action plan was feasible and the case above suggests that the QCancer risk calculator can be used within the consultation. However the tool was only used nine times in total in the six months following the feedback meeting, albeit by several different clinicians. One may have expected there to have been more cases in the six month period. In order to improve the uptake of the risk calculator, further encouragement or education around QCancer may help to fully make use of the intervention.

In the interview with a GP in practice five, the GP did not find Qcancer helpful and stated, *"I tend not to use those".* When this was discussed in more detail the GP recognised they could act as a memory aid but found the tick box structure unhelpful. The GP stated, *"I find them a bit restrictive, it's just like a list, sort of like a list of things and you're ticking a box, I, I personally prefer to just go on the judgement from what information I've got. I think they can be useful because it can prompt you to ask things that you might have forgotten or, erm, it might highlight something that you need to be aware of, that you might not be aware of but I've never really used them".* This GP feels QCancer would not be of benefit due to being restrictive suggesting the NPT mechanism of *coherence* is not fulfilled in this case. If this action were to be taken forward perhaps further training on the use and benefits of the risk assessment tool would be helpful in order to improve *coherence*.

9.2.6 The assessment of education action plans

<u>Action plan: Improve knowledge of 2ww referral guidelines</u>

The PCPs in practice nine felt there was a training need around the new NICE recognition and referral of cancer guidelines. The PCPs requested that the student return for another educational meeting to present the changes in the recently updated guidelines.

Due to staff availability, the interviews with the two GPs in practice nine took place before the educational meeting. Whilst they could not give feedback on the meeting itself, both mentioned difficulties with using the NICE recognition and referral of cancer guidelines. The GP interviewed felt that the PCPs within the practice had both different thresholds for referral in the first place, and in the type of referral they do, suggesting that some GPs may do more 'urgent' rather than 2ww referrals which may affect time to diagnosis. The GP stated, *"There are obviously issues, even when they do present, what is our threshold, depending on experience, as clinicians, and using the cancer*

guidelines and referring them appropriately, so there are a lot of issues there, not all of us [GPs] will necessarily have the same threshold and that can lead to delay, some cases more than others. Erm I think there is also a challenge, even when we have done the referral, depending on what type of referral we do, sometimes we might do urgent, or routine referrals and this may delay things". The GP supported the plan to have a further educational meeting on the guidelines.

The data from this interview suggests the plan to provide further education to the staff, meets the NPT mechanism of *coherence*. The GP had made sense of the plan and recognised the potential value, benefits and importance of the plan. It was not possible to gauge from the interview any of the other mechanisms of NPT in this case as the interview took place before the educational meeting.

The student developed a presentation on the new guidelines and presented in a well-attended educational meeting. The student focused on the changes in the guidelines as well as where the PCPs could get more user friendly or easily accessible information for use within the consultation.

The meeting was feasible and easy to set up, the PCPs were keen to attend the meeting and already ran a regular educational meeting. Feedback from the meeting was positive and the student was thanked for his time.

There were no outcomes from this educational meeting and it was not possible to know if any of the case studies reviewed were impacted by the training. In the BCW Michie et al. describe training as "imparting skills" (149). Johnson and May suggest that participating in lectures or workshops can help to meet the NPT constructs of *communal specification*, *enrolment* and *skill set workability* (104). As such the training provided by the student could potentially improve the recognition and referral of cancer symptoms by allowing the team to build a shared understanding of the aims, objectives and expected benefits of the NICE guidelines. Thus allowing the PCPs to organise themselves and allocate work to meet the demands of the guidelines and ensure they are operationalised in everyday practice.

9.2.7 Overall assessment of action plans

9.2.7.1 Were the plans feasible and was implementation possible?

The SEA and interview data suggests that the majority of the action plans were feasible and were initially implemented successfully. All of the plans were developed by the practice staff who, as described in chapter four,

should have an understanding of the facilitators and barriers to implementation in their practice. As a result it was hoped all the actions plans would be feasible. In many cases the action plan required only an email summary sent to practice staff with the rationale for the action plan and a summary of the audit and feedback findings . When further work was required to implement the plan by the student this was undertaken with support from the practice.

Assessment of actual implementation was difficult using the SEA and interviews undertaken, with some plans showing no evidence of implementation using these methods of assessment. For example, one action plan to encourage phlebotomists and nursing staff to provide safety netting advice showed no evidence of implementation in the SEAs and none of the nursing staff were available for interview. As such it was unclear if the plan had been implemented. However, it was possible to engage with the nursing staff and a protocol and patient leaflet was developed following a meeting with the nursing staff involved. The meeting with the staff was positive and there seemed to be enthusiasm regarding the plan. It could be argued then, that the plan was feasible and could have been implemented. Perhaps, with better evaluation or more detailed record keeping an evaluation would have been possible.

Assessment of implementation of the action plans using SEA analysis and staff interview was possible in some action plans but difficult in others. When plans included the use of a Read code, for example the use of a Read code to track patients, Read codes within a safety netting template and the use of Qcancer, there was evidence in the SEAs that they were being used within the consultation. However, even between similar action plans using Read codes there seemed to be differences in how and if they were implemented. For example, the use of a Read code to track patients showed much more potential in practice four, being used multiple times over the six month assessment prior, but was barely used in practice three.

Plans such as using telephone lists for follow up, and the use of a pop up alert if patients required following up showed no evidence of being used in the SEA analysis, and interviews suggested some doubt about the success of the plans. It is unknown in these cases if the plans were simply not implemented and if so why not, or if there was a failure in the methods applied to measure implementation.

9.2.7.2 Were the plans acceptable to practice staff?

The acceptability of the intervention as a whole (including the initial SEA case note review, educational meeting, action plan development and implementation) to practice staff and PCPs was important to consider. It was felt that the intervention had to be acceptable to staff if the findings were to be useful for future research.

The importance of acceptability is increasingly recognised and has become an important consideration in the design, implementation and evaluation of healthcare interventions. The first edition of the Medical Research Council (MRC) guidance documents for researchers and research funders for designing and evaluating complex interventions published in 2000 did not mention acceptability. The third edition published in 2015 mentions acceptability 14 times but fails to define or give instructions on assessing acceptability (258). Throughout the medical literature, definitions of acceptability vary considerably suggesting the concept is ambiguous. Acceptability is highlighted in the BCW as part of the APEASE criteria (Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects and safety, Equity) (149). Acceptability is not specifically mentioned but could also be considered to be important, and contained within, several constructs of NPT including *internalisation*, *relational integration* and in i*ndividual* and *communal appraisal.*

An overview of systematic reviews published in 2017 identified 43 reviews which claimed to define, theorise or measure acceptability in healthcare interventions (259). The authors found that none of the systematic reviews explicitly theorised or defined acceptability. When considering the assessment of acceptability, several methods were used. These included behaviour measurements such as withdrawal or dropout rates and self-reported measures such as reports of individuals on their perceptions of, and experiences with, the intervention, using opened-ended interview questions. None of the 43 included reviews specified a criteria or threshold for when a measure would be considered acceptable or not. This overview confirms that the measurement of acceptability is difficult and as yet, poorly defined.

In this thesis acceptability was judged through the interview data with practice staff and through an assessment of whether or not the plan had been successfully implemented. However as discussed in the section above the availability of PCPs for interview and quality of the interviews in the short time available proved very difficult in this study, which was at least in part thought to be due to the current demands on PCPs in UK primary care. This

meant that whilst the interviews gave some insight into acceptability, an overall assessment was difficult. This was compounded by the finding that evidence of implementation or failure of implementation was also lacking, which as discussed above maybe in part to the decision to use repeat SEAs for the assessment. As such, whilst there was a general feeling of enthusiasm around the project from practice staff, good attendance and feedback from the educational meeting and discussions which generated a number of novel action plans, it was difficult to conclusively assess the acceptability of the intervention. If the work within this thesis is to be taken forward or built upon, a more thorough assessment of acceptability would be important.

9.2.7.3 Did the action plans show any evidence of impact or behaviour change?

Assessing any potential impact of the action plans was difficult. It is important to note that given the small numbers of repeat SEAs in each practice it was not possible to assess any impact of the action plans. In all cases the links between the action plan and outcomes of the SEAs were circumstantial and the lack of a control group or a definitive before and after study meant the impact of any of the plans cannot be proven. It is possible that the cases highlighted in the discussion, and others considered in the SEA analysis, would have been managed in the way they were, regardless of the audit and feedback and intervention developed. A variety of explanations and scenarios are possible and more definitive research is needed to investigate effectiveness and mechanisms. In addition to this, as will be discussed in chapter 11.3.4, by looking at the 2ww referrals alone it is possible that cases were missed in which patients were not managed appropriately and the cases reviewed could provide a positively skewed view of their management. It is possible that any suggestion of potential action plan impact may be misleading.

As discussed in the analysis of individual plans above, there were some instances in the SEA case reports in which the action plan was followed and there was evidence of good patient care. The plan involving the use of an electronic safety netting template is one such example. The template was widely used and seemed to be effective in documenting safety netting advice In addition to this it was widely praised by the two members of staff interviewed about the template. Patients with whom the template was used were managed effectively with no delay. However it still remains difficult to conclude that any change in practice or patient care was due to the plan.

Safety netting advice may have been adequate in each patient if the template was not available. This difficulty in assessing impact could be due to a failure in study design or assessment.

9.2.8 Assessing the action plans using theories of behaviour change

Whilst there was difficulty in assessing the acceptability and impact of the action plans in this thesis, it is possible to consider the design and implementation of the action plans using the BCW and NPT. Below the action plans will be categorised using the BCW with NPT then being used to assess the barriers to implementation.

9.2.8.1 Categorising action plans using the BCW

As discussed in chapter four, the BCW has the COM-B model at its centre, which is then surrounded by the nine intervention functions and seven policy categories. The interventions developed by the practices in this thesis can be divided into the BCW's interventions and policy sections. This classification described below was helpful when comparing the possible feasibility of the interventions. Figure 22 shows action plans by BCW policy or intervention category.

Education – "increasing knowledge or understanding"

- Improve safety netting advice and documentation of a follow up plan
- Improve the management of IDA
- Recognise that multiple attendances may be a red flag
- Communicate urgency when checking blood results
- Ensure patients are weighed at every opportunity
- Ensure patients presenting with abnormal weight loss are thoroughly investigated
- If patients attend in an emergency five minute appointment and need more time or further investigation, HCPs should book appropriate follow up
- Improve knowledge of 2ww referral guidelines

Environmental restructuring – "a change in the physical or social context"

- Use a Read code to enable follow up patients the HCPs are concerned about
- Develop a safety netting template to better document advice
- Use a telephone appointment list on the appointment screen to aid follow up
- Admin staff to make the 'to come in letters' more specific
- Use the patient self-booking system when doing a 2ww referral aided with a self-booking leaflet created by student
- Admin staff to check all DNA letters and contact patients if necessary
- Admin staff are requested to ask the patient which HCP they would like to see. HCPs are encouraged to book own reviews
- Put an alert on the patient's record to let others know if previous notes need to be reviewed prior to the consultation
- Use the in-built Qcancer risk calculator in the computer system to aid referral

Communication / marketing – "using print, electronic, telephonic or broadcast media"

- Develop a safety netting leaflet to give patients, with red flags and follow up advice

Guidelines

- Ensure CXRs are requested as per the NICE guidelines
- Improve the management of patients with a normal CXR. Student to contact local chest physicians to develop guidelines
- Encourage phlebotomists and nursing staff to safety net patients through the development of a protocol and leaflet
- Develop an anaemia pathway with secondary care input

Figure 22: Action plans by BCW intervention or policy category

Actions plans categorised as education

These interventions consisted of a GP learning point which was communicated to the rest of the PCPs via a summary email. The intervention in these examples came as a result of the educational meeting itself and was reinforced and relayed to other members of the healthcare team through emails. One intervention developed by a practice involved the delivery of a NICE cancer referral guideline talk from the student for the PCPs in the practice. The NICE guidelines on cancer recognition and referral were presented in a PowerPoint presentation delivered by the student at a separate meeting and was well received by practice staff.

<u>Actions plans categorised as environmental restructuring</u>

In each of these examples the intervention was implemented following the action planning meeting and involved adding to the practice computer system or encouraging PCPs to use new Read codes as discussed in the educational meetings. Some of the interventions, such as following up on 'did not attend' hospital letters could be classed as a mixed educational and environmental restructuring intervention. These interventions involved changing behaviour through the use of the GP computer record or the use of other systems of referral or dealing with paperwork. The intervention in each of these cases was an email to all staff with the action plan and rational behind it and in many cases work by the student to aid in the environmental restructuring.

<u>Actions plans categorised as communication and marketing</u>

These action plans overlap with environmental restructuring and education and included posters and leaflets that were developed by the student following the educational meeting, then shared with the practice, with both paper and electronic copies being made available.

<u>Actions plans categorised as guidelines</u>

Two interventions involved the development of guidelines, firstly on management of patients following a normal CXR and secondly on how to manage IDA. After a discussion in practice three, the student contacted two local chest physicians with the help of his supervisor (UM) and advice was successfully sought and distributed on how to manage a patient with a normal CXR. The management of IDA was thought to be a problem due to vague national guidelines without specific cut offs for haemoglobin and ferritin levels. The practice in this case opted to develop an anaemia pathway themselves.

A further guideline intervention involved training nursing and phlebotomy staff to give out safety netting advice when taking blood. This involved developing a protocol and policy document. This intervention started with a meeting with the nursing and phlebotomy staff at the different practices led by the student. It involved a discussion and training on safety netting before the development of a protocol and guideline to help the staff deliver safety netting to patients.

9.2.8.2 Mapping the BCW categories to the components of NPT

As discussed in chapter 4, both the BCW and NPT are able to provide insight into the development and analysis of action plans with the aim of changing PCP behaviour. Where the BCW focuses more on the factors which influence behaviour through the COM-B model, NPT looks at the way in which new practices are 'operationalised' in healthcare, and other settings. As such NPT will be helpful when evaluating the potential feasibility of action plans developed in this thesis but can also be used to consider how the action plans were developed.

NPT contains four social mechanisms, which each contain four constructs. The first of which is *coherence* which is described as what users do to make sense of new practices. Johnson and May demonstrated that professional interventions can be mapped to the NPT mechanisms and constructs (104). Johnson and May categorised behaviour change interventions using the Cochrane Effective Practice and Organisation of Care (EPOC) checklist, but the same principal can be used in this thesis using the BCW list of policies and interventions.

The components of NPT were mapped to the BCW policy and intervention categories used in the action plans in order to better assess the action plans against the NPT criteria. This was undertaken using the theory led overview of interventions to promote behaviour change by Johnson and May as a guide (104). Like Johnson and May, two NPT constructs were excluded from the analysis all together: *differentiation* and *reconfiguration*, because the first is a precondition for an experimental intervention and the second is a normal requirement of an intervention study (104). The NPT constructs were mapped to the four BCW policy and intervention categories using the student's judgement and the review article by Johnson and May to guide the process.

Mapping action plans to the construct of coherence

The first core construct of NPT is *coherence*, which is the sense making work done to operationalise a new behaviour or action plan. *Coherence* has three components for use in this mapping process. It was felt that, as a result of the audit and feedback and the educational meetings all the action plans met the constructs of *communal specification* and *internalisation*. The educational meeting allowed practice staff to see the impact of current care on their own patients and the discussion following the meeting would have allowed the group to build a collective of the aims, objectives and expected benefits. As all of the work was done in a group setting, there may have been less of an opportunity for *individual specification*.

All four BCW policy and intervention functions used within the action plans were judged to have met *communal specification* and *internalisation* but not to have met *individual specification*, mainly due to the design of the audit and feedback intervention and the practice educational meeting.

This may explain at least in part, the findings above of the educational action plan to improve safety netting documentation in practice one. As discussed above, two regular PCPs in this practice consistently failed to document safety netting advice, but their patients represented appropriately. This could be explained by a failure in *individual specification*, as the PCPs may not have made sense of the importance of documenting the safety net advice. It is possible that these PCPs felt the verbal advice they gave to patients was enough to ensure the patients returned if necessary. The need to spend vital consultation time documenting safety netting may not have made sense and as a result the PCPs in these case studies did not follow the action plan.

Several of the action plans required strong *communal specification*, such as the guideline action plans of developing a practice anaemia pathway, and encouraging phlebotomy staff to safety net at the time of taking blood. These plans required practice staff to make sense of the aims, objectives and expectations of the new guidelines, but also to have an understanding of their role within the guideline development.

Mapping action plans to the construct of cognitive participation

The second core construct is *cognitive participation* which is the relational work done to build and sustain a community of practice around a new technology. The four components of *cognitive participation* were more difficult to meet using the methods employed in this thesis. In the majority of the environmental restructuring, communication / marketing and guideline action plans, the initial work in implementing the plans was undertaken by the

student. Whilst this was felt practically to be the best option, as the PCPs in the practice were busy, it may have limited *cognitive participation*.

One action plan described above involved the production of an electronic safety netting template. By designing a template for safety netting without staff input, the student may have failed to add all the elements of safety netting the practice staff hoped the template may cover, or it may not be as easy to access as they hoped. This may have limited the *enrolment* and *activation* components of NPT.

Activation seems to have been a problem with a number of the action plans. For example, one environmental restructuring action plan was to use QCancer to aid decisions about referral. It is possible as the QCancer tool is not something which is needed 'everyday' in general practice, that participants were not able to collectively define what was needed to effectively sustain a practice. Similarly, the action plan to recognise that multiple attendances may be a red flag is a complex one, involving a number of different PCPs over a long period of time. In order for the action plan to be a success, each time a patient attends, the PCP needs to review previous medical notes thoroughly and recognise the reasons for previous attendances. During history taking the PCP and patient need to understand this new presentation may be the same illness / symptoms persisting over time. Finally the PCP needs to recognise that these multiple presentations may be a 'red flag'. This process needed sustained involvement from multiple PCPs over a period of time, therefore the lack of the NPT construct of *activation* which may explain the mixed findings in the SEA analysis.

The practice staff developed the educational and guideline action plans following an assessment of their own patient care, and own educational needs. As a result it was felt that the educational and guideline action plans could meet the component of *legitimation* as the practice staff must feel they could contribute to the implementation of learning they decided upon.

Mapping action plans to the construct of *collective action*

The third core construct of NPT is *collective action* which is the operational work done to enact a set of practices. As most of the work done to implement the plans following the educational meeting was done by the student, there may have been limited opportunity for *collective action*. For example, the component of *interactional workability* requires knowledge of how the new action plan will affect other parts of day to day work in each practice, something the student may have been unaware of. Similarly, the

student could not undertake the division of labour or the allocation of resources required for *skill set workability* and *contextual integration*.

Relational integration refers to the work done to build accountability and maintain confidence in a set of practices. It was felt that the guideline action plans could achieve this, as guidelines are designed to enable work and practices to be accountable to the guidelines themselves and to provide confidence in the work done. Similarly, the communication / marketing action plan is based on evidence from the safety netting review documented in chapter six which should help to provide confidence in the practice.

However, it was thought that *relational integration* may be lacking in the environmental restructuring action plans. When sending suspected cancer 2ww referrals, it is vital that PCPs feel they have confidence and accountability in the system. It is feasible that in 'handing over responsibility' to the patient in the plan to use the self booking system, that the PCP lost this confidence and as a result the action plan was not followed. Perhaps over time, through increased use of the self booking system, the PCPs confidence in the system will improve and accountability will be developed. However, even if confidence does increase in the system there is little that can be done about patients who cancel or DNA urgent appointments and the discussion around who takes responsibility for this, the patient or GP, continues.

Mapping action plans to the construct of reflexive monitoring

The final core construct of NPT is *reflexive monitoring* which is the appraisal work done to assess and understand the way that a new set of practices affects them. It was thought that both individual and communal appraisal and systematization would be possible in all the action plans developed. As the action plans were developed at a practice level, it was possible for the staff to evaluate the worth of the new practices both in a team and individually, similarly either formally through audits and case note reviews or informally through reflections on individual cases.

9.3 Summary

This chapter has considered the outcome of the re-visit to practices six months following the audit and feedback based educational meeting and the development of action plans. The feasibility, ease of implementation, and acceptability, as well as potential impact of each action plan has been discussed.

The action plans could be considered feasible as all the plans were developed in conjunction with practice staff with the aim of improving care for their patients. In each action plan the student helped to implement the action plan and where necessary, met practice staff or worked to support the implementation. The student had no difficulty implementing any of the action plans and received full support of the practice staff. As a result it seems that audit and feedback and action planning in education meetings is potentially a helpful way to support PCPs to bring about change. This finding is supported by the theory of the COM-B model of the BCW. There was an assumption that staff in each practice were aware of their own capability and opportunity, and as discussed above, by providing feedback on the PCPs own patients, motivation for behaviour change to improve care was potentially improved.

The BCW and NPT were used to provide some explanation of the findings. Using the framework developed by Johnson and May it was possible to map the action plan interventions planned as part of this thesis to the NPT constructs (104). This allowed for gaps in the NPT constructs to be considered and possible methods to improve the action plans could be developed. The process of audit and feedback and educational feedback meetings helped to satisfy the NPT constructs of *coherence* and *reflexive monitoring*, but due to the way the action plans were implemented often solely by the student, there was little opportunity for *cognitive participation* and *collective action*. In addition to this, other elements of the action plans helped to meet further NPT constructs whilst in some areas of the NPT framework, gaps consistently remained.

	Coherence			Cognitive participation				Collective action				Reflexive monitoring		
	Individual specification	Communal specification	Internalisation	Initiation	Legitimation	Enrolment	Activation	Interactional workability	relational integration	Contextual integration	Skill set workability	Systematisation	Individual appraisal	Communal appraisal
Educational		▓	▓		▓							▓	▓	▓
Environmental Restructuring		▓	▓									▓	▓	▓
Communication / marketing		▓	▓						▓			▓	▓	▓

Guidelines			▓	▓		▓				▓			▓	▓	▓

Table 12: Mapping the action plan BCW intervention and policy groups to NPT constructs

Table 12 shows how the BCW interventions and policies used to group the action plans in this research met the NPT constructs with areas in grey showing that the BCW intervention or policy met the NPT construct. It can be seen from this table, that most of the *cognitive participation* and *collective action* NPT constructs were not addressed through the action plans developed. However the *coherence* components of *communal specification* and *internalisation*, and the *reflexive monitoring* core constructs were met. This could help to explain why most of the action plans seemed to be feasible and were initially implemented across the nine practices due to opportunities for strong *coherence*. It is possible that the action plans developed showed little evidence of impact in the assessment due to a lack of *cognitive participation* and *collective action*.

The assessment of implementation, acceptability and any impact was difficult using the methods described in this chapter. This made it difficult to conclude if the action plans were not effective, if there was a failure of implementation or simply a failure to document the use of action plans in the patient's notes. Certainly a lack of documentation could play a part in the difficulty assessing the action plans. Using SEA analysis relies on the PCP or practice staff involved in care to not only document the change in behaviour as a result of the action plan, but also to do so in a way which allows the student to search for the change. As discussed throughout this thesis, SEA analysis has many advantages when looking in detail at individual cases and actions leading up to a diagnosis and in some cases was an excellent method for the action plan chosen. For example the action plan in which a template was developed for documenting safety netting advice was ideally suited to analysis via SEAs. It was possible to search for the template using Read codes, and using SEAs allowed the circumstances of each use to be considered in detail. In contrast, the action plan to put an alert on patients records to highlight when past consultations needed to be viewed was not suited to evaluation through SEA analysis, as this did not involve the use of searchable codes and was not a frequent enough action to be seen in the search of new cancer diagnoses. During the assessment of the action plans

it was noted that most did not have any evidence of their use documented in the medical notes. This included most of the educational, and guideline action plans as well as some of the environmental restructuring action plans.

Some of the action plans had to be documented in the medical notes if they were being used, such as the use of a Read code to track patients. In one practice this plan was implemented and seemed to be effective, but in another it was not used. In some of these cases, interview data can help to provide clues to the acceptability of action plans. Regarding the Read code action plans, interview data suggested that the PCPs in that practice did not use the Read codes and had other methods for following up patients, suggesting this plan in that particular practice was not effective. However in a significant number of the action plans assessed there was no data available from the SEAs or the staff interviews to accurately assess the plans. As a result in many cases it is not known if the plans were not implemented, not effective or were simply not documented in the notes. Interview data in some cases can provide a clue to the acceptability and feasibility of plans which were not able to be assessed using the SEAs, but as described above the interviews were limited by the availability and time of the PCPs, making assessment difficult.

Chapter 10: Synthesis of thesis results

The results of this thesis are separated into four chapters. Each chapter presents the findings of a separate component of the results. This chapter will briefly summarise the four chapters and attempt to synthesize the results around the overarching concept of safety netting.

10.1 Brief summary of results chapters

Chapter six contains the results of a scoping review on safety netting. The scoping review helped to develop a definition of safety netting, give recommendations on when it should be used and highlight what information safety netting should contain.

Chapter seven reports on the findings of a significant event audit of all lung and colorectal cancer diagnoses across nine practices in Hull and the East Riding of Yorkshire over two years. The data provides insights into the diagnosis of lung and colorectal cancer in primary care and highlights factors influencing the primary care interval which include safety netting, the role of investigations, patient factors, comorbidities and communication between primary and secondary care.

Chapter eight highlights the steps taken in the development of practice action plans. Following the presentation of individual practice SEA data from chapter seven by the student, practice staff were encouraged to discuss the results and develop an action plan in order to improve the recognition and referral of cancer. The content of the practice discussions are presented in chapter eight in themes which were generated using thematic analysis of audio tapes and student field notes. The themes included in the practice discussions were safety netting, investigations, referrals, continuity of care and the consultation.

Finally chapter nine reports on the feasibility and potential impact of the 35 action plans developed by the nine practices following the educational meetings.

The figure below shows how the results from each chapter are linked, with the findings of the scoping review in chapter six guiding the audit and feedback parts of the thesis.
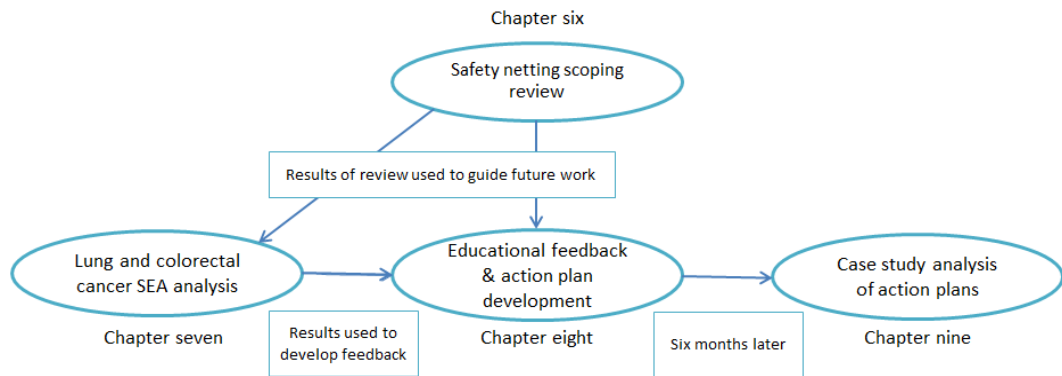
Figure 23: Diagram showing links between component parts of research project

10.2 Results synthesis

Strike and Posner define synthesis as an activity in which separate parts are brought together to form a whole (260). They go on to state that the construction of the whole is characterised by some degree of innovation so that the result is greater than the sum of its parts. Noblit and Hare used this definition in their development of meta-ethnography in which they aimed to answer the question of how to put together written interpretive accounts (261). Meta-ethnography can include a process of reciprocal translational analysis (RTA) in which concepts are translated from individual studies to create overarching concepts, and lines-of-argument (LOA) synthesis which involves building up a picture of the whole from studies of its parts (261). More recently Sandelowski & Barroso discuss how RTA can be modified to allow the integration of findings instead of comparing them. This change could involve considering if the same concept or theory could exist in different studies (262).

In this thesis, the concept of safety netting features throughout the four results chapters and appears to be an important concept in the recognition and referral of cancer symptoms.

In chapters one and two the potential increasing importance of safety netting in the recognition and referral of cancer became clear. Safety netting was included in the NICE suspected cancer guidelines for the first time in the 2015 update (25) and Nicholson et al. asked "can safety netting improve cancer detection in patients with vague symptoms?" (212). The importance of safety netting was particularly clear in early SEA work on lung cancer and emergency diagnoses conducted by Mitchell et al. (69, 95), and in the NCDA

which noted substantial variation in safety netting by cancer site (68). Despite this there appeared to be very little information in the medical literature on what safety netting was, when it should be used and what it should contain. As a result of this, in order to guide the next steps of the thesis including the further use of SEAs and practice educational feedback, it was thought to be helpful to have a thorough understanding of safety netting and as a result the scoping review on safety netting is presented in chapter six.

In chapter seven, the most common theme in the analysis of the SEAs was safety netting, which as a result formed a large part of the feedback and subsequent discussion by practice staff in the educational meetings. Following on from this many of the interventions developed by the practices had a role in safety netting, from simple 'learning points' to improve safety netting advice and documentation, to more formal methods of documentation and follow up such as electronic templates and the use of Read codes for following up patients. Whilst there were other themes that ran through each part of the thesis, safety netting was the most frequent. Even in other themes, such as the management of investigations and referrals, safety netting played a role. For example, ensuring blood results are looked at and dealt with effectively, and patients who do not attend hospital clinics are followed up.

Looking at the four component results chapters of the PhD as a whole reveals a number of novel points to consider about safety netting. These points are discussed below.

10.2.1 Safety netting includes more than consultation advice

Safety netting was first described by Neighbour as a part of the consultation between a doctor and patient which prepares for the event that "things do not go as planned". It was advice given by the doctor to the patient in the consultation. This was supported by other 'models' of the consultation (202) (79). Bankhead et al.'s Delphi study of safety netting was the first to suggest that safety netting may have a role outside of the consultation. The authors suggest safety netting may include the management of tests or investigations, the use of referrals and the documentation of safety netting (189). More recent citations support Bankhead et al.'s suggestion. The NICE suspected cancer guidelines state that safety netting should include recommendations to ensure that results of investigations are reviewed and acted upon (25). Nicholson et al. agree and provide further suggestions for

what safety netting may include such as ensuring patient contact details are up to date, and that patients with recurrent unexplained symptoms are highlighted (212).

This shift in the definition of safety netting is apparent throughout the results of this thesis. As can be seen in chapter 6.4.1 and in particular table two, it is clear that whilst most citations do still include 'a consultation technique' or 'the provision of information to patients' in their definition of safety netting, many also include 'the follow up and monitoring of investigations and results', 'an administrative process' and 'the active monitoring of patients'. These aspects all occur outside of the consultation, but are likely to be important in ensuring both patient safety and effective recognition and referral of cancer symptoms.

Chapter 7.3.1 highlights the role safety netting played in the pathway to lung or colorectal cancer diagnosis in the 192 SEAs completed and many of these cases included examples of safety netting outside of the consultation, such as a GP who requested a colleague to 'chase up' a CXR result in a patient. There were also examples of safety netting in referrals, such as a patient who had multiple red flags for lung cancer but was admitted as an emergency for breathlessness. It was very likely in this case the patient would be diagnosed via this emergency admission but the GP also sent a 2ww lung referral 'for completeness' thereby adding a safety net.

In chapter eight, the discussions by practice staff following the intervention are presented and safety netting was the most commonly discussed theme. In chapter 8.2.1.3 the discussions on the content of safety netting are presented in which the role of administration staff in follow up and the management of blood tests, CXRs and referrals is discussed. These discussions support the theory that safety netting could occur both in the consultation but also around the consultation and afterwards, particularly with patient follow up and the management of test results.

10.2.2 Safety netting may differ depending on the outcome of the consultation

It is possible that safety netting advice may need to be altered depending on the situation that it is used. In chapter 6.4.2 the components of safety netting developed from the citations in the scoping review are presented in table 3. The most common elements of safety netting may be similar in all consultations such as; discussing uncertainty, highlighting red flags, suggesting a time course and arranging follow up. However, explaining the

reasons for tests would only be needed if tests were part of the investigative plan. Similarly if patients were being referred, further advice on the referral and missed appointments may be needed.

These differences were clear from the scoping review, but were also seen in the SEA work in chapter seven. In chapter 7.3.1 there were examples of prolonged primary care intervals despite some safety netting being undertaken. In one example, a patient was advised to have a CXR and safety netting advice was to 'review with results with me [GP]'. However the patient did not have the CXR or return for a review. Similarly, a patient was advised to have blood tests after presenting with PR bleeding with a plan to review if tests were abnormal, however the patient did not have the tests as planned and did not return. It is possible that the follow up of investigations, suggested by the safety netting advice in the NICE guidelines and other citations in chapter six such as those by the NPSA, could have prevented these examples of prolonged primary care intervals. In chapter 7.3.4 there were examples of what were classed as 'patient factors' in which patients failed to attend or cancelled 2ww referral appointments or investigations. Perhaps this could be avoided if safety netting advice in the consultation explained the importance of the referral and what to expect at the hospital appointment.

These potential differences in safety netting advice by consultation outcome were also highlighted in chapter eight during discussions following the educational feedback meeting. The themes included "investigations" and "referrals", which are discussed in chapters 8.2.2 and 8.2.3. Whilst much of the discussion in chapter 8.2.2 focused on the management of different investigations, such as CXRs and anaemia, there were also discussions on the management of results which again highlighted a potential role for safety netting. For example, by ensuring patients know how to find out their results and a discussion on the potential role of further safety netting at the time of blood taking. Finally, ensuring the patients do not assume 'no news is good news' was discussed in terms of safety netting and follow up. Discussion points in chapter 8.2.3 were on the theme of referral, and again safety netting ran through much of these discussions, including the management of patients who do not attend secondary care appointments or follow up and the use of patient information sheets and patient self booking for referral to add another 'safety net'.

This finding is novel. All previously published safety netting work has proposed a single set of actions regardless of consultation outcomes.

However the evidence from this thesis suggests that safety netting advice may need to be adapted depending on the actions or outcomes of each consultation.

10.2.3 Changing safety netting by patient group may be helpful but needs further research

The scoping review commented on the potential recipients of safety netting in chapter 6.4.2. Whilst many papers suggested safety netting should be done at every contact regardless of patient group, other citations suggested there were certain groups of patients in which safety netting was more important. These groups included children, patients with multimorbidity or mental health problems and patients who present with symptoms in which the differential diagnosis includes serious illness. None of the papers suggested how safety netting should be adapted in these patient groups, just that it may be more important for them.

These suggestions in chapter six were supported by the findings of the SEA work in chapter seven. For example the suggestion that safety netting may be important in patients with multimorbidity was supported by a number of cases discussed in chapter 7.3.5 in which patients' symptoms were wrongly attributed to co-existing medical problems. If these patients had been given safety netting advice perhaps they would have returned and been referred earlier. Similarly there were examples of patients with memory problems failing to attend follow up appointments or investigations. One could question if these patients require alternative or more thorough safety netting to ensure they remember the proposed plan.

Despite these findings in chapters six and seven, there was limited discussion on chapter eight on the role of multimorbidity and different patient groups on safety netting advice, and none of the action plans aimed to cover this area. In addition to this, the content and definitions of safety netting found in the scoping review in chapter six did not include variations depending on patient group. Even the safety netting work done by the Acutely Sick Kid Safety Netting Interventions For Families (ASK SNIFF) research group, which specifically focused on children and is discussed in chapter six, suggested very similar safety netting advice for children as for adult patients. So whilst safety netting advice may be more important in certain patient groups and presentations, perhaps the required content of safety netting is the same. More research is needed on the role of safety netting in different patient groups such as those with memory problems.

10.2.4 Actions plans to improve safety netting are feasible but need further testing

The scoping review in chapter six, the SEA work in chapter seven and educational meetings and discussions highlighted in chapter eight all had a theme of safety netting running through them. It is unsurprising therefore that many of the action plans discussed in chapter nine focused on the role of safety netting.

Chapter nine comments on the feasibility and impact of each plan. It is clear that most of the plans were feasible, having been implemented and accepted by each of the practices. The SEA discussions and the method of developing action plans highlighted in chapter eight may have contributed to the feasibility and acceptability of the interventions by allowing practice staff to develop them, incorporating their knowledge of their own practice and ways of working. Similarly by presenting information from SEAs based on their own patients, as highlighted in chapter seven, it is possible that motivation to change was improved, again contributing to the acceptability of the plans. However the potential impact of most of the plans was difficult to assess using the method of repeat SEA and staff interview. Chapter nine shows that whilst plans to improve safety netting advice are possible, further research is needed to test the potential impact and effectiveness.

10.3 A model for safety netting

The scoping review and the synthesis described above, suggests that the concept of what safety netting is and what it should include has been developed since the term was first introduced over 30 years ago by Neighbour. More recent citations describing safety netting highlighted in chapter six, and the practice discussions and action plans described in chapters eight and nine suggest that safety netting includes much more than consultation advice. Safety netting also could include actions around the consultation including the organisation of follow up and the management of investigations. The synthesis has helped to emphasize that the content of safety netting advice may differ depending on consultation outcome. Finally, whilst it may be reasonable to argue that safety netting advice may differ by patient group, more research is needed on this area, and it may be that the same advice is simply more important in different groups of patients.

This process of synthesis has allowed for the development of a safety netting model using the findings from this thesis. The model for safety netting is

shown in figure 24. The model aims to identify outcomes of the consultation in which safety netting could be used and suggests components of safety netting related to each outcome of the consultation. Most of the elements of safety netting used within the model were identified following the scoping review of safety netting identified in chapter six and were confirmed following the SEA analysis described in chapter seven which identified it's importance in the recognition and referral of cancer symptoms. The action plans developed in chapter eight and tested in chapter nine included different elements of safety netting such as following up DNA letters, and using 2ww referral self booking systems. The action plan development helped to confirm the elements of safety netting used in the model. The model is circular, including different consultation outcomes followed by a list of relevant safety netting actions depending on the consultation outcome. Use of this model in practice could allow practitioners to identify specific safety netting advice, depending on the content and outcome of the consultation.

This novel model of safety netting will require further research in order to assess it's utility and effectiveness. This research could include focus groups and interviews with practitioners who may potentially use the model and tests of its use in practice.
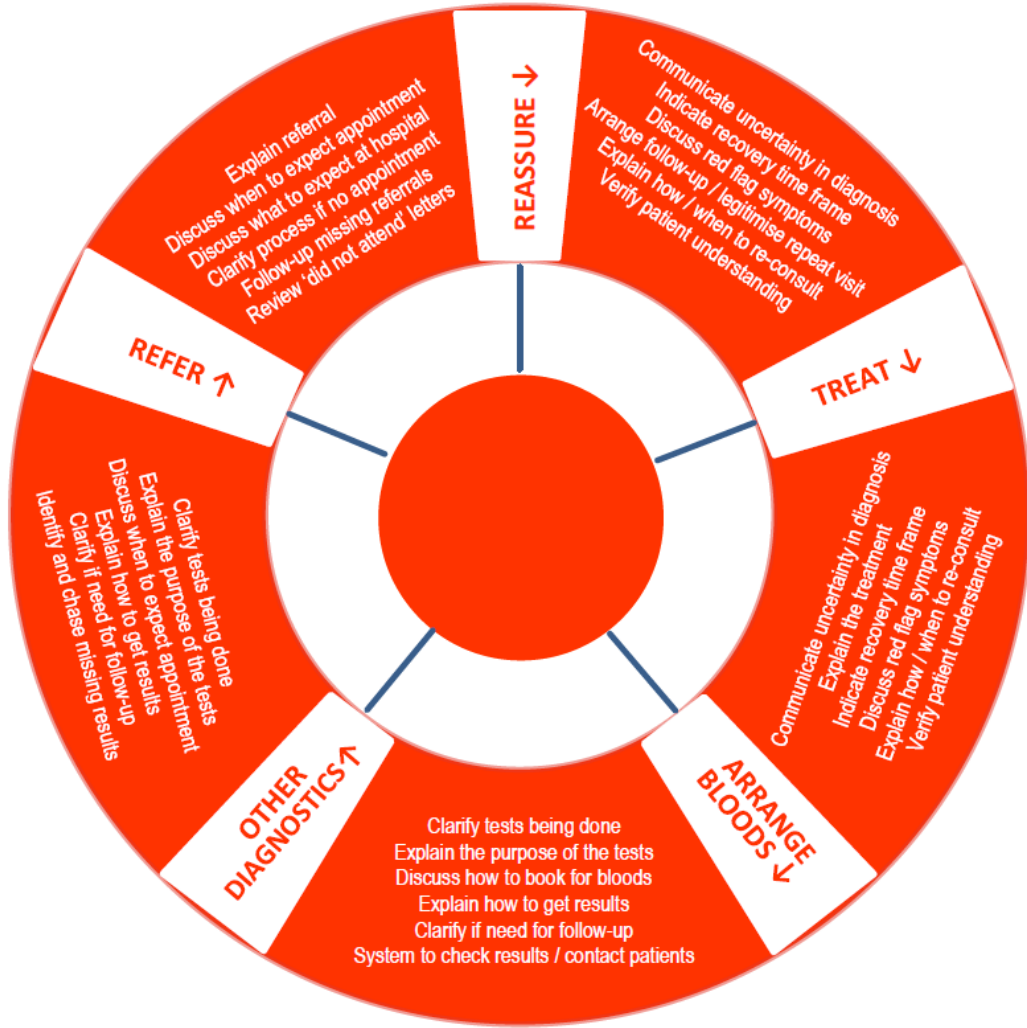
Figure 24: The lifebuoy model of safety netting developed as part of the scoping review

Chapter 11: Discussion

This chapter will explore the key findings of the thesis and how the results compare with other existing literature. This chapter will explore the potential limitations of the research conducted and finally will consider the implications of the research, including the use of this method in future research and how the findings could impact on current practice.

11.1 Comparison with existing literature

The first part of the discussion considers the ways in which the results of this thesis compare with existing literature in order to identify gaps in the existing evidence base and highlight potentially important areas for policy makers and researchers.

11.1.1 Safety netting

Little research has sought to define and assess safety netting prior to the review of safety netting in chapter six. The ASK SNIFF research programme has undertaken a number of research projects looking specifically at safety netting in children and relevant published work from this programme was included in the scoping review (199, 206, 208). More recently, the role of safety netting in the diagnosis of cancer has been the subject of research by a group in Oxford and again this work is included in the review in chapter six (189, 212).

Whilst the findings of this thesis largely support the existing literature on safety netting, particularly with regards to the elements of safety netting within the consultation, the synthesis of results presented in chapter 10 have developed and built on the concept of safety netting. The results of the thesis show that safety netting is not just important within the consultation, but also in the activities around the consultation and may differ depending on the outcome of the consultation. This development to include other aspects of medical care in safety netting seems to have begun with the Delphi study conducted by Bankhead et al. (189) and was supported by further guidance published by NICE (25), CRUK (185) and the NPSA (207). The model of safety netting developed as a result of this thesis, discussed in chapter 10.3 is novel, and the first to consider the differences in safety netting by consultation outcome. The utility and validity of the model needs to be

assessed in further research and could be developed further. A range of research methods, in consultation with those likely to use the model, could be used to allow the model to be implemented into the teaching of PCPs and into consultations with patients.

11.1.2 Opportunities to improve the recognition and referral of cancer symptoms

Chapter seven of this thesis aimed to explore potential opportunities to improve the recognition and referral of cancer symptoms in the nine practices involved in the study. As explained in chapter seven, this was done using SEAs of recent cancer diagnoses at each practice. Whilst the original purpose of this section of the thesis was to gather the data in order to conduct the audit and feedback intervention for the nine practices involved, the findings of the SEA analysis demonstrated some novel learning points which could improve the recognition and referral of cancer more widely.

The key themes arising from the SEA research presented in chapter seven include

- Safety netting

Safety netting findings included examples of when safety netting was documented carefully in the medical notes and examples of safety netting use outside of the consultation such as the follow up of investigations.

- The use and management of CXRs

The high frequency of normal CXRs in the patients diagnosed with lung cancer and the effect this had on the primary care interval was highlighted in many of the SEAs. In addition to this, the need to have a low threshold for requesting CXRs in line with the NICE guidelines was also shown.

- The investigation of anaemia

The difficulty and ambiguity of the investigation and management of anaemia was shown throughout the SEAs Often patients had mild drops in haemoglobin or normal iron levels which led to prolonged primary care intervals.

- Patient factors

Patient factors often included late presentation with red flag symptoms, but also presenting with multiple symptoms, normalising problems or refusing further investigations or referrals. It was felt that safety netting could help to

mitigate some of these problems but others were more difficult to manage and required the use of media campaigns or mass education.

- Communication between primary and secondary care

This included the management of letters and documentation sent by secondary care, including DNA letters, as well as the need to report further presentations or worsening of symptoms to secondary care colleagues if patients are awaiting investigation or treatment.

- Examples of good practice

There were multiple examples of good practice such as teamwork between members of the primary care team and vigilance for red flag symptoms from nursing colleagues and junior members of staff.

As discussed in chapter two SEAs have been used to study the recognition and referral of cancer in primary care. Two studies by Mitchell et al. considered the diagnosis of lung cancer and cancer diagnosis by emergency presentations using SEAs (69, 95). Several of the key findings presented by Mitchell et al. support the findings of this SEA work. Mitchell comments on the importance of safety netting, the role of the CXR, patient factors and complex presentations as factors which could affect the primary care interval (69, 95). All of these factors were also identified in the SEA work done in this thesis suggesting these elements are key in the recognition and referral of cancer symptoms.

Chapter 2.3 explores the literature around reasons for increased time to cancer diagnosis in primary care, which when compared with the results of this SEA work shows several similarities. Chapter seven reports on the difficulty in managing the results of investigations, particularly the normal CXR and anaemia which may be mild or present without low iron. A systematic review considering factors associated with a longer time to referral found that inconclusive or negative results were a risk factor for prolonged diagnosis but also highlighted the role of patient factors (13). A retrospective review of cancer diagnoses by Singh et al. found that complex diagnostic testing and a lack of follow up or coordination of care often lead to 'missed opportunities' (48). This fits with the findings of chapter seven of this thesis, particularly the sections on safety netting and investigations in chapters 7.3.1 to 7.3.3.

As discussed in chapter 2.4 the NCDA is a national audit of cancer diagnosis first undertaken in 2009 (66) and updated in 2016 by the RCGP and CRUK.

The audit looked at primary care delays and the reasons for them. The audit found delays were attributed to the patient in 26% of cases and to system factors in 34%. The importance of safety netting is also discussed in the NCDA report. The results of this audit are comparable to the findings of the SEA research reported in this thesis, suggesting the findings are representative. In addition, the reasons behind delay including comorbidities, patient and system factors, reported in the NCDA are also found in the analysis of the SEAs in this thesis. This may suggest these areas are ones which should be targeted in future interventions.

Comparing the existing literature on opportunities to improve the primary care interval with the findings of this thesis shows some similarities, particularly around the use of safety netting and follow up, the management of investigations and patient factors. Whilst complex diagnostic testing and inconclusive or negative results were mentioned in the literature, the specific effect of a normal CXR and the impact this had on the diagnostic pathway was an important finding, suggesting that a negative CXR often led the PCP away from a suspected cancer diagnosis even in the presence of red flag symptoms. The impact of communication between primary and secondary care was shown in a number of the SEAs and showed the importance of updating secondary care colleagues of worsening symptoms and carefully managing letters from secondary care. These factors affecting the primary care interval have not been highlighted in other work. Finally whilst some patient factors, particularly late presentation, have been discussed in the existing literature (and has a separate interval in the Aarhus model) (16), other patient factors such as presenting with multiple problems and normalising symptoms have not been discussed in other literature.

The similarities with existing work and novel findings within the thesis highlights the important aspects of the primary care interval which should be targeted with further research and possible changes in policy in order to speed up this interval. It is worth noting that some of the research presented in chapter 2.3 which looks at the reasons behind prolonged primary care intervals was published in 2009, with similar findings to the work conducted in this thesis. This could suggest that the medical community, researchers and policy makers have so far failed to address these opportunities for improvement in patient care or that the problems may be difficult to change due to the structure and organisation of primary care.

11.1.3 Interventions to improve the recognition and referral of cancer symptoms

Following the identification of opportunities to improve the recognition and referral of cancer symptoms in primary care, the next objective of the thesis was to explore the use of audit and feedback to develop interventions to meet these opportunities.

In this study, audit and feedback was combined with an educational meeting with the aim of developing action plans to improve the recognition and referral of cancer symptoms. As discussed in chapter nine, this seemed to be feasible and was accepted by the PCPs at each practice. However evidence for any impact was difficult to assess within the scope of this thesis. Several other studies have aimed to develop interventions to improve the recognition and referral of cancer symptoms which are presented in chapter 2.6. In Mansell et al's systematic review, the problem of measuring outcomes effectively was also highlighted, of the 22 studies included, none used reduction in the primary care interval as the primary outcome (87). Instead, proxy measures of delay were used including improved knowledge, observational skills, diagnostic accuracy or improved referral rates, suggesting that the difficulty in measuring impact may not be confined to this thesis. Despite the problem of directly measuring effect, Mansell et al. concluded that complex interventions including audit and feedback have the potential to improve the primary care interval (87). The authors go on to state that this finding correlates with existing literature which also supports the use of continuing medical education and audit and feedback (88-90). The findings of this thesis go some way to support the findings of Mansell by showing the feasibility of using audit and feedback with the aim of improving the diagnosis of cancer at practice level by developing actions plans to improve process and governance. However, the effectiveness of this approach needs formally evaluating.

A second review by Schichtel et al. considered educational interventions for GPs to promote early diagnosis of cancer. A total of 21 studies were included in which audit and feedback was the most frequently used intervention, often combined as part of a package of education. The review concluded that interactive education, computer reminder systems and audit and feedback may significantly increase several cancer detection measures and promote earlier diagnosis of cancer (91). The findings of this thesis support the conclusions of the review by Schichtel et al.. The audit and feedback intervention in this thesis was used in an educational setting, which following

the development of action plans, showed some potential to improve the recognition and referral of cancer symptoms.

The literature on audit and feedback is discussed in chapter 3.1. A Cochrane review of audit and feedback included 140 randomised controlled trials making it one of the most widely studied healthcare quality improvement interventions (89, 97). The review concluded that audit and feedback leads to potentially important improvements in professional practice. The results of the review found a small positive overall result in "desired practice outcomes" compared to a control group but with a wide variation in outcome effect size. This variation was thought to be due to variation in many different aspects of the intervention such as whether the feedback was comparative or not, anonymous or not, the intensity of the feedback, the duration of feedback and the care setting (99). In this thesis, chapter eight considers the outcome of the audit and feedback intervention used to develop action plans. The results from chapter eight provide some evidence for the use of audit and feedback. The educational meeting resulted in in-depth discussion between members of the healthcare team in each practice and the development of a large number of action plans. The aim of this thesis was to explore the feasibility of acceptability of an audit and feedback approach to develop action plans. The fact that the audit and feedback intervention generated discussion within the healthcare team, and resulted in action plans which could potentially change practice, suggests intervention was feasible, acceptable and does have the potential to have a positive impact on patient care.

11.1.4 Behaviour change theory

Chapter four provided an overview of three theories of behaviour change and resulted in a strategy to use both the BCW and NPT in the design and assessment of the research. Multiple studies have assessed the use of the BCW to change behaviour, and whilst most of these have focused on patients and the public, some have focused on health professionals. The theory has been successfully used to consider delayed antibiotic prescribing (263), blood test ordering (264), the implementation of an electronic prescribing aid (265) and in the management of vertigo (266). In this research the BCW successfully aided the design of an audit and feedback intervention which seemed both acceptable to the participants and a feasible technique in order to develop action plans and stimulate behaviour change. This supports the results of the other examples of BCW use discussed above.

NPT was also used in the design and analysis of this research. A NPT led systematic review of interventions to promote professional behaviour change successfully used NPT theory to assess various interventions including both educational outreach and audit and feedback (104). This review successfully used NPT in the analysis of the interventions and was able to highlight NPT constructs which tended to result in more positive outcomes. Similarly NPT has successfully been used to evaluate complex interventions aimed at health professionals including the use of a pre surgical checklist (267), a pathway to care for dying patients (268) and the use of a family violence screening tool (269). Like these studies, NPT seems to have been successfully used in this research project to both design and assess an intervention aimed at changing health professional behaviour which seemed to be acceptable and feasible and may have some potential for improving the primary care interval.

11.1.5 Summary

A key finding of this thesis is both the importance of safety netting in the recognition and referral of cancer symptoms, but also the development of safety netting to include a variety of actions both within and outside of the consultation. The existing literature supports this finding as well as the potential role of safety netting in managing investigations and referrals. However the existing literature suggests safety netting is a standard set of actions or advice to patients applicable in all settings. This PhD has shown for the first time that safety netting advice and actions taken may differ depending on both the outcome of the consultation, the onward plan and patient group involved.

Whilst existing literature had documented the difficulties with ambiguous or normal investigations, this PhD has shed further light on the potential pitfalls in the management of patients with symptoms suggestive of lung cancer, but with a normal CXR and in patients with new or worsening anaemia. This thesis has considered how PCPs managed patients with normal CXRs and the affect this had on the primary care interval. Whilst earlier work had sought to quantify the number of patients with lung cancer who had a normal CXR such as Stapley et al. (270), this is the first study to report on the actions of PCPs following a normal CXR in patients who were diagnosed with lung cancer. In this study, local experts were contacted to guide PCPs on the management of these patients but further research is needed into the use of CXR in the diagnosis of lung cancer. Particularly as current research is

exploring the use of low dose CT scanning as an approach to 'case finding' in primary care (271).

In addition to this, novel interventions to improve safety netting using audit and feedback and practice action plans have been shown to be acceptable and feasible and have the potential to improve the recognition and referral of cancer symptoms.

11.2 Assessment of research against quality criteria

Multiple research methods were used throughout this thesis including scoping review methodology, audit and feedback and qualitative interviews. The use of researcher derived SEAs to undertake an audit and feedback intervention to provide educational data on performance to drive behaviour change for individual PCPs or GP practices is novel and has not been done before. As a result of this it is important to consider the trustworthiness and quality of these methods.

The SEAs used in the audit and feedback intervention were analysed qualitatively, with the resulting data used to develop feedback in the form of educational meetings. Despite qualitative research methodology being well established in health care research, it has been criticised in the past for lacking rigour and transparency during data collection and analysis which potentially leads to a lack of integrity in the results. As a result, the issue of quality in qualitative research has been widely discussed (272-274). One of the most popular methods for ensuring the quality of qualitative research was proposed by Guba (275) and developed by Lincoln and Guba (276). Guba proposed four criteria which qualitative research should meet in order to be trustworthy. These criteria include credibility, transferability, dependability and confirmability. Each of the four criteria includes a number of different recommendations in order to ensure validity. An overview of the four criteria are described below.

<u>Credibility</u>

Credibility is described as "how congruent the findings are with reality" (277), or the confidence in the truth of the findings. This is comparable with the quantitative construct of internal validity. According to Lincoln and Guba, methods to improve credibility may include adopting established research methods, developing a familiarity with the culture of participating organisations, random sampling, triangulation and frequent debriefing

sessions (277). Lincoln and Guba stressed the importance of prolonged engagement and persistent observation to ensure credibility (276).

In this research, a combination of methods were used including a scoping review, audit and feedback, case study analysis and qualitative interview. All elements of the study have a good evidence base as discussed in chapter three and have been used to investigate the recognition and referral of cancer in the past. Therefore one could argue that established research methods have been used, as suggested by the Lincoln and Guba quality criteria. In addition, as recommended by Lincoln and Guba, the student had familiarity with the participating organisations having worked as a GP and GP registrar in or around many of the practices involved. Whilst practices were not sampled at random, as suggested by the quality criteria, previous research has postulated which practice factors may play a role in affecting cancer diagnosis (13). A range of practice characteristics including rurality, CCG, practice size, training status, number of patients and PCPs were sampled. Finally the context of the study and study methods have been described in the study methods (chapter five) as recommended by Lincoln and Guba.

As such many of the elements of research design Lincoln and Guba suggested to ensure credibility or internal validity were met by the design of the research within this thesis. This suggests that the credibility or internal validity of the thesis is high.

Transferability

Transferability is described as the extent to which the findings of one study can be applied to other situations (277). This concept is similar to the terms external validity or generalizability used in quantitative research. Lincoln and Guba argue that it is the job of the reader to determine if the research applies to their population and as such the role of the researcher is solely to provide sufficient contextual information to enable the reader to make this decision.

In this research, the student has attempted to provide sufficient information on both the context and the methodology in order to allow the reader to decide if the findings of the thesis can be applied to other populations. Maxwell et al. suggests that transferability may be demonstrated through generalizable theory (278). In this thesis behaviour change theory is used to help understand and explain the findings of the research. Behaviour change theory can be generalised to many other settings, both with health professionals and patients and therefore can support the transferability of the

research as suggested by Maxwell et al. (278). The aim of this thesis was to explore the acceptability and feasibility of an audit and feedback intervention at an individual practice level, hence the generalizability of the findings were thought to be less important. However, it was recognised that if the study is to be useful, the findings have to have some relevance to the rest of general practice. As described in chapter 5.3 the area of Hull and the East Riding of Yorkshire was chosen for multiple reasons. Most importantly though it was felt the area had a variety of settings, practices and patient populations. Through the recruitment of a variety of practices, both rural and urban, small and large, it was hoped the findings could be generalised to other settings or practices.

Dependability

Dependability or reliability is described as the extent to which if the study was repeated with the same context, participants and methods, that the same result would be obtained. This criteria is the subject of debate, with some qualitative researchers suggesting that outcomes are tied to the situation of the study (279). Lincoln and Guba argue that dependability is closely linked to credibility and if credibility is ensured then dependability will follow. Their criteria state that triangulation, though the use of overlapping methods will go some way to ensuring both credibility and dependability. In addition to this they recommend an in-depth documentation of the research design and its implementation, data gathering and a reflective appraisal of the project (276).

In this research the use of triangulation in the outcome assessment with both case note review and participant interview helps to ensure both credibility and dependability. In addition to this, an in depth description of the research design is included as Lincoln and Guba suggest. In this thesis, much of the process was dependent on the general practices involved. This affects both the findings from the SEAs, the discussions in the educational meetings and the action plans developed, however the overall method can be replicated in all primary care settings.

Confirmability

The final criteria is confirmability which refers to the accuracy and neutrality of a study (i.e. the findings are a result of the participants ideas and experiences rather than the researchers' biases). Triangulation is important here as the use of overlapping methodology can reduce the effect of investigator bias (277). In addition Miles and Huberman advise the use of a researchers reflective commentary to demonstrate the researchers

awareness of their own prejudices (280). However as discussed in chapter 11.3.2.2 the student does have a vital role in all stages of this thesis – as such the work could be subject to bias. Chapter 11.3 discusses this in more detail as there are both pros and cons to the studies. One must be aware of the student role and the potential biases both known and unknown when interpreting the results of this thesis

11.3 Study limitations

11.3.1 Scoping review search strategy

This is the first scoping review to consider safety netting in all age groups and settings and brings together information on safety netting from a variety of different sources. Given the largely undefined nature of safety netting, compiling a comprehensive search strategy was difficult. It was decided to limit the search to papers which used the term 'safety net or safety netting' rather than searching for all the possible components of safety netting. This approach relied on the term safety net or safety netting being used in the title or abstract of the included papers meaning that important studies could have been missed. Grey literature and citation searching was undertaken to minimise this risk. It was also felt that as part of the aim of this review was to identify the component parts of safety netting it was not possible to have developed a comprehensive search strategy including all the component parts of safety netting prior to conducting this review.

Despite the limited search strategy used in this scoping review, relevant citations were included. The results of the review can be used to guide the development of a larger and more comprehensive search strategy which could be used to develop systematic reviews on other aspects of safety netting such as efficacy.

11.3.2 Conducting SEAs

11.3.2.1 Practice recruitment

The next part of the thesis required general practices in Hull and the East Riding of Yorkshire to be recruited to take part in the audit and feedback study. The study was discussed with local academic GPs who suggested practices known to be engaged in or undertaking research. These practices were contacted by email, with the student aiming for a mixture of inner city and rural practices, of varying size, deprivation and training status. Whilst

this method was simple, and well suited for the purposes of this thesis it does have some limitations when reviewing the results. Most of the issues surrounding practice recruitment affect the possible generalizability of the thesis. It should be noted however that the issue of generalizability in qualitative research is controversial. This research, like much qualitative research, considers a specific issue in a certain population within a defined locality and therefore, perhaps generalizability is not an expected attribute of a study. As discussed above, Lincoln and Guba argue that it is the job of the reader of research to decide if its findings are applicable to their population (276). However with the use of knowledge synthesis in qualitative work through meta-synthesis or meta-ethnography the issue of generalizability becomes more important.

Firstly, as the practices were recruited following discussions with local academic GPs, it is likely these practices are more interested or engaged with research. This may affect the external validity or generalisation of the findings of the SEAs and the impact of the educational meeting and action planning. However one study suggests this may not be the case. A cross sectional survey of 973 practices from one area of England compared research active vs non research active practices. The study found that research active practices were larger, had a younger patient demographic, were in more deprived areas and had similar disease prevalence. Quality scores for both clinical and non-clinical markers were 'modestly higher' for research active practices, but despite the differences in quality scores being statistically significant the authors conclude that results of research from research active practices is likely to be generalizable as the absolute differences were small and unlikely to have any clinical impact (281).

Secondly, whilst the practices were varied in many aspects, only one 'non-training' practice was recruited. Training practices have GPs who have undergone further education to become 'trainers' and as a result are able to employ and teach GP registrars. It is possible that there are differences in the organisation and philosophy of training practices which may affect the outcome of this thesis. No studies have been undertaken in the UK considering the effect of training status on care. Research was available from France and Holland which both have different healthcare systems. A French study compared GP trainers with non-trainers and found GP trainers have a heavier workload in terms of office visits and on-call duties but tend to have better clinical performance (282). A study in Holland, albeit with smaller numbers reported similar findings, with trainers and training practices scoring

higher in all but one aspects of practice organisation. The study concludes that trainers (and training practices) provided more diagnostic and therapeutic services, made better use of team skills and scored higher on practice organisation, chronic care services and quality management than non-training practices. They also state that trainers reported more job satisfaction and commitment and less job stress than non-trainers (283). Several older studies also seem to support these findings (284, 285). Given that eight of the nine practices recruited in this thesis were training practices, it is possible that the results may not be generalizable to non-training practices or may be positively skewed towards seeming feasible due to the set up and organisation of training practices.

Overall however, it was felt that a wide range of practices were selected and that this would allow the findings to be generalised to other practices in the UK. This is supported by the discussion in chapter 11.1 which reports similarities between the data gathered in the nine practices in this thesis and national and international data.

11.3.2.2 Role of the student

A large part of this thesis involved work by the student in individual general practices which has implications for the findings and generalizability of the work.

The first role of the student was to conduct the SEAs at each of the practices. In other SEA work published to date, the SEAs have been conducted by PCPs involved in the case, for research purposes these anonymous SEAs were then sent to a researcher who analysed the findings (69, 77, 95). This method has several advantages. The PCPs involved in the care can easily access all the notes and documentation surrounding the case, may remember aspects of the patients care and can reflect directly on individual learning points. As a result the PCP will have access to all the relevant information in order to conduct a thorough SEA. By having individual practitioners each conducting a single SEA a wide variety of learning points will be gained from many different practitioners, all with different levels of experience and backgrounds which will result in more generalizable, and varied results.

However this approach is subject to some limitations. Mitchell et al. writes in their SEA work on lung cancer that "although practices were asked to report on their most recent lung cancer diagnosis to guard against self-selection of the 'best' cases, it was not possible to confirm that this was always done",

suggesting that the results may not be valid if the cases analysed were 'handpicked' (69). As well as this, whilst Mitchell et al. do not comment on this in their report, there is likely to be variation in the detail and quality of SEAs undertaken by PCPs in practice. Finally, this approach would have been difficult to achieve for the purposes of this thesis, in most other SEA work, the PCPs were incentivised for conducting the SEAs. No funds were available for this thesis which meant encouraging PCPs to conduct SEAs would have been difficult, particularly with the current workforce crisis in UK general practice (168). This need for incentivisation, and lack of clinical time to undertake SEA work, has implications for the wider application of the findings of this thesis. This will be discussed in more detail in chapter 11.4.

As described above in this thesis, in contrast to the other SEA work conducted so far, the student attended the practice and conducted all the SEAs independently. This method has pros and cons. Having one independent student conducting all the SEAs ensures that they are all of consistent quality and the problems discussed by Mitchell et al. of case selection can be avoided. In addition to this, the SEAs were conducted without any extra input being required from the PCPs working in the practice. This likely improved practice recruitment to the study and ensured that data collection went smoothly. The main problem with this method is the fact that SEAs are undertaken from the view of a single person, thereby losing the insights from different reflections and learning points. As well as this, through the process of data collection the student's views maybe altered or influenced by previous cases which could have affected the validity of the results. Finally, the part of the SEA entitled 'why did this happen?' was used by the student to comment on the pathway to diagnosis. This was done by the student based on the notes and guidance in the early diagnosis toolkit but again was subject to the student's own prejudice and interests.

11.3.2.3 Index presentation

When conducting SEAs, a difficult first step is determining the first presentation of the patient which could be due to the eventual cancer diagnosis. In this study the index presentation was determined by the student who used his clinical judgement to determine the index presentation which was often the first presentation of a symptom that could be due to cancer, the first presentation after a period of time not attending the doctor or the start of a series of consultations which led to the diagnosis. A strength of this method is that it may be more inclusive than other methods described by Hamilton et al. (26) or Neal et al. (23) who used trained research assistants

and electronic record searching by symptom to establish the index presentation, which relies on the symptoms being coded. However the method in this thesis may result in SEAs showing a longer time to referral and diagnosis than other studies, as the first presentation of a symptom may not be coded by the clinical team. This made comparisons with other research difficult. In addition the decision on which presentation was the index presentation was a difficult one, particularly in cases of patients who had non-specific abdominal pain or recurrent infective exacerbations of COPD. As a result, time to diagnosis or referral data may be inaccurate.

11.3.2.4 Case review analysis

The SEAs were completed using only anonymised data from the electronic medical record. The use of documents has some strengths, because the notes are generally made at the time of the consultation, or immediately after, there is no recall bias, and the data is likely to be accurate. However, for many reasons often the documented notes do not contain everything discussed in the consultation. Conversely, it is possible that information written in the patients notes actually isn't said or discussed or remembered by the patient. If safety netting is used as an example, often "return if not better" is documented in the notes. It is possible this could be 'shorthand' for a much longer discussion on multiple aspects of safety netting, however it could also be written automatically by the PCP without any discussion with the patient. In order to better assess the presence or absence of safety netting advice or, more importantly, what patients remember of that advice, recorded consultations or interviews with patients and staff would be a more effective method of data collection.

11.3.3 Audit and feedback meetings

11.3.3.1 The position of the student

The Cochrane review on audit and feedback conducted by Ivers et al. included over 140 studies and concluded that an audit and feedback intervention is most effective when the source of the feedback is a supervisor or colleague (97). This was compared to studies in which the source of the audit and feedback was the employer or the investigators. In this thesis the audit and feedback was conducted by the student who was a GP registrar or newly qualified GP during the meetings. As a result the feedback was given by a colleague, but a junior colleague, who was also acting the investigator. It was possible that the intervention could have been more effective if the

feedback was given by a more senior colleague or supervisor, but perhaps this source of feedback is more effective than an employer. Due to the design and nature of this thesis, it was difficult to conduct the audit and feedback intervention in any other way, but this unusual combination of researcher and junior colleague feedback should be taken into account when considering the findings of this intervention.

11.3.3.2 Development of action plans

Following the presentation of the feedback at the educational meetings, staff were encouraged to develop action plans. Whilst evidence discussed in chapter 3.2 suggested action planning can be effective, there is very little evidence on how to best design and implement action plans. When designing the study and encouraging the development of action plans, work by Sniehotta was used as a guideline (106). This work suggests action plans should include a when, where and how and recommended the SMART (specific, measurable, achievable, realistic and timely) framework (106). However, practices were encouraged to develop their own individual plans with little input from the student as it was felt the practice staff would have a better understanding of their own practice organisation and what would be feasible / acceptable. This method had pros and cons. It gave the staff the opportunity to develop and suggest novel ideas which may help to improve the recognition and referral of cancer as well as providing the opportunity for multiple plans to be developed. However it often left some plans unstructured, and without the framework suggested by Sniehotta. Some 'plans' were simple learning points, and things 'to be aware of' for future care of patients, rather than a specific strategy to improve care.

11.3.4 Assessment of action plans

11.3.4.1 Using SEAs and case note review

In order to assess the potential feasibility of the action plans developed in this thesis, a method of triangulation using case note review and staff interviews was used. Case note review has several benefits and has a long history of use within medical education. Case studies provide detailed insights into aspects of patient care which can then illustrate broader lessons for clinical care. They are often used when (as in the case of this study) other research methods may not be appropriate. They also provide 'real life context' in which to place the research findings. However case review methodology is criticised for not being generalizable and for lacking scientific

rigour. Generalisability can be improved by using a varied sample. In this thesis the practices involved were varied in terms of size and demographics. In addition to this by conducting case studies on 341 cases of new cancer diagnoses or 2ww referrals means that hopefully the sample is large enough to have some generalizability.

11.3.4.2 SEAs for action plan assessment

As discussed in chapter 9.3, the method of using SEAs to attempt to assess the feasibility of the action plans was subject to some limitations. Firstly, despite the large number of SEAs conducted at the six month review point, the actual number of SEAs which addressed the potential feasibility of some of the action plans were small, with some providing no data in the form of SEAs. It is possible that the problem in these cases was a failure to document a change in practice in the medical notes, but as a result it is not possible to conclude that the interventions has any impact on the recognition and referral of cancer symptoms. The findings of this thesis make it difficult to conclude if the action plans had failed, were not implemented or were simply not documented in the medical notes. This finding suggests that for some of the action plans, SEA was not the best way to assess feasibility and impact. During the design of the research for this thesis, it was felt SEAs would be an effective method for assessing plans and may allow a comparison with the original SEAs. It was felt that staff interviews would provide another assessment of the action plans for the people who were using them. If further time and resources were available, more rigorous methods of assessment could be considered such as RCTs or case control studies. In addition further qualitative work, particularly further staff interviews, considering the potential benefits and the barriers to implementation of each action plan. However, as discussed in this thesis, this needs to be done ensuring appropriate time and availability of PCPs. When designing action plans, it may be helpful to consider more closely the potential barriers to successful assessment of the plan and alternative methods of assessment. Due to the difficulty in assessing the action plans using SEAs and the lack of availability of practice staff for interview, it was difficult to definitely assess the acceptability and impact of most of the action plans. As discussed in chapter nine, the intervention as a whole, involving audit and feedback and the use of staff discussions to generate action plans did seem to be acceptable, was well received by practice staff and generated multiple novel action plans. However the assessment of these plans was

difficult, resulting in questions surrounding their acceptability, feasibility and impact.

A second difficulty with the method of assessment was the low number of new cancer diagnosis in the six months following the educational meeting. To try and resolve this SEAs were also conducted on the 2ww referrals for suspected lung and bowel cancer. This generated many more cases for analysis but did cause some problems when attempting to assess any potential impact of the practice action plans. As discussed in chapter 9.2 there were several instances where the 2ww SEAs could have potentially provided a 'skewed' view of the practice behaviour. This was a result of the inability to electronically search for other outcomes. For example, when looking at the management of IDA, the correct action in many cases would be a 2ww colorectal referral. Therefore by searching for 2ww referrals in the GP record, rather than IDA, only the cases managed correctly could be found in the search. It is possible that the search has missed cases of IDA that were not referred, thereby potentially delaying the recognition of cancer symptoms. Similarly it was not possible to search for normal CXRs, as using a search for 2ww lung cancer referrals only found the cases in which a normal CXR eventually led to a 2ww referral.

The aim of the PhhD was to investigate ways in which the primary care interval in the diagnosis of cancer could be improved by exploring the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer symptoms by PCPs. An assessment of feasibility and implementation of the interventions was possible and so, in the context of this thesis perhaps it could be argued that the use of SEA was acceptable. The decision to use repeat SEAs and conduct a 're-audit' was made for a number of reasons. As this study was conducted as part of a PhD study by one student, there were limited time and resources in which to complete the work. If this work were to be repeated with more resources, alternative methods of assessment would be more appropriate. This could include RCTs of action plans with quantitative methods of assessment such as primary care interval time or time to diagnosis in order to determine any definite behaviour change and impact on the recognition and referral of cancer symptoms. In an ideal world the outcome measure of choice would be cancer survival statistics, but on small scale primary care studies this outcome measurement is not feasible.

11.3.4.3 Interviews

In order to improve the assessment of the practice action plans, interviews were used as a method of triangulation. The aim of the interviews was to consider the views of PCPs on the methods used, the audit and feedback, and what worked / did not work in the practice action plans. However there were problems with the interviews, mostly as a result of the current workload in general practice and the time constraints on busy PCPs. The student struggled to arrange a time to interview the PCPs and when interviews did take place, they were often rushed and interrupted. In one practice, the student was unable to find anyone willing to be interviewed, and in another, a couple of the action plans heavily involved nursing staff who also refused interview.

This meant the interviews were not as helpful as they could have been in interpreting the feasibility of the audit and feedback intervention, development of the action plans and the outcome measures and much of the analysis relied on the SEAs. Despite this, 13 PCPs across eight practices agreed to by interviewed and useful information on some of the action plans was obtained.

11.3.5 The student as an active participant in the research

Throughout each step in this study the student played an active role in the organisation and delivery of the research. The student recruited each practice to the study, conducted all the case reports and analysed the SEAs. The student developed the educational meeting and presented the findings to the practice staff. Following the development of action plans, the student offered help implementing and developing the plans, which was taken up in a number of cases.

This involvement by the student in the project has strengths and weaknesses. As described in chapter 11.3.2.2, having the student conduct the case review and SEA analysis removed the workload from the practice staff, and allowed an independent and consistent assessment of each case. However reflections and insights from the PCP involved in each case were lost as a result of having the student conduct all the cases.

When presenting the findings of the case review in the educational meeting the Cochrane review on EOV states that visits by a GP or peer were most effective, however the review on audit and feedback suggested the feedback should be given by a supervisor (97, 105). As such the student in this case met the suggestions in one of the reviews, but was not a supervisor. It may

have been possible to have the student's supervisor participate in the meetings. This could be considered if the study was to be repeated.

The student did not play any role in the design or development of the action plans. It was felt that the practice staff would have the best understanding of the workings of their individual practices and the potential barriers and facilitators to implementing any plans. In addition to this, the thesis aimed to generate novel interventions with the aim of improving the recognition and referral of cancer symptoms. The generation of 35 action plans across the nine practices suggests this was successful.

Following the development of the action plans the student offered his support in implementing them. It was felt that in order to reduce the workload on the practice, it would be helpful if the student offered this help. Again this had strengths and weaknesses. The student's offer of help was accepted in most of the practices. This ensured that jobs such as the development of computer record templates, leaflets, posters and reminders were set up promptly without any additional work from the busy practice staff. However as discussed in chapter 9.2, the fact that the student conducted this work on behalf of the practice meant that the opportunity for *collective action* as recommended by NPT was lost. This may have contributed to the possible failure of implementation and lack of impact of some of the action plans. This was balanced by the fact that due to the high workload of practice staff, without student help the action plans may not have been implemented at all.

The impact of the student as an active participant in research is well documented in some areas of qualitative research, particularly in observational research (286). However this is subject to some limitations. Chapter 11.2 discusses the quality criteria used to judge research. Once such criteria is confirmability which is an assessment of the accuracy of findings, asking to what extent the findings of the study are due to actions and thoughts of the participants, rather than the biases of the researcher. It is possible, due to the role of the student as an active participant, that the biases of the student have affected the results. However, as discussed above, by using methods of triangulation and being aware and open about the role of the student, these biases can be avoided or taken account of.

11.3.6 The impact of intervening at an individual practice level

A decision was made to focus the audit and feedback intervention at an individual practice level for multiple reasons. Firstly it was felt that by focusing on individual practices, there was more opportunity for the COM-B

model of behaviour change to be implemented. Staff at each general practice would be better able to recognise the opportunity for change and would recognise the barriers and facilitators to change, improving capability. Secondly, this approach was felt to be more feasible within the confines of the PhD, as being able to contact and work with individual practices was simple to organise, with emails and letters sent to practice managers and senior GPs, who were responsible for their own patients and patient records. Similarly organising educational feedback meetings and designing and implementing action plans was easier in an individual practice setting. Thirdly, due to the organisation of general practice, it was felt that if the intervention was successful and could be implemented more widely, it was likely that this would be done at an individual practice level.

It could be argued that intervening at an individual practice level would reduce the generalisability of the findings of the PhD. But as discussed in chapter 5.3 it was hoped that by selecting a mixture of general practices, varying by size, rurality and practice demographics that this limitation would be minimised. An alternative would have been to attempt to undertake the intervention at the level of the CCG which oversees all of the general practices in a given area. However this would likely to have been much more difficult to organise and would have lost much of the benefits of behaviour change discussed in the COM-B model, as there would be less knowledge available on the workings of each practice. In addition to this, the motivation for change driven by discussing each individual practice patients and examples of care would be lost.

It is possible that the opportunity costs of practices developing unique solutions could be high. It could be argued that it would be more effective to intervene at a regional level, developing area wide interventions with more support from CCGs or GP leads to reduce the costs to individual practices. However this method would also reduce the strength of the COM-B model, Region wide interventions would not take in to account each practices capability and opportunity to enact such plans. In addition to this, the motivation gained by demonstrating and discussing the care of individual patients would be lost. It was felt that by having an awareness of their own capability and opportunity, the individual practices would be better able to reduce the opportunity costs of developing individual plans

11.3.7 Working with primary care practitioners and the patient perspective

The overall aim of this thesis was to investigate ways in which the primary care interval in the diagnosis of cancer could be improved by exploring the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer symptoms by PCPs. When researching the literature on the primary care interval in the recognition and referral of cancer it was felt that the vast majority focused on PCPs, rather than patients. This was supported by pathway to diagnosis literature discussed in chapter 1.3.2 which clearly separates the patient interval and the primary care interval. In addition to this, the research method used, including SEAs, audit and feedback and educational meetings, would be targeted at PCPs rather than patients. As discussed in chapter 2.4, SEAs are widely used in general practice as a learning aid, but this very often happens without the knowledge or involvement of patients. Earlier work using SEAs to investigate the patient pathway to diagnosis of lung cancer and in emergency admissions did not involve the patient perspective.

However, patient and public involvement in research is increasingly recognised as a key component in research and in the design of healthcare services. It is felt to improve patient safety and prevent medical errors (287). The NIHR recommends patient and public involvement in every stage of the research process from the prioritisation and design of studies to the dissemination of findings. NIHR highlight the valuable contribution patients can make to research, offering alternative views and aspirations for the design and outcomes of research studies (288). With hindsight, despite the research within the thesis entirely focusing on the role of the PCP, it may have been helpful to have a patient and public involvement group available, with the aim of discussing the aims, design, findings and outcomes of the research and gaining differing perspectives on the thesis outcomes. Future research could usefully explore with patients the findings of this thesis and suggest areas for further development and investigation.

11.4 Implications of findings

11.4.1 Improving the primary care interval in the pathway to cancer diagnosis

Chapter seven reports on the findings of 192 lung and colorectal cancer SEAs which aimed to investigate opportunities to improve the recognition and referral of cancer symptoms in primary care. Whilst the primary aim of these SEAs was to develop an audit and feedback intervention for the nine practices involved in the research, the findings have identified a number of opportunities to improve the recognition and referral of cancer symptoms. The SEAs were completed in nine purposely selected practices in one area of the country. As discussed in chapters 11.2 and 11.3.2, this may limit the potential applicability and transferability of the SEA findings and must be considered when interpreting the results. However, the practices included did vary in terms of size, number of GPs, rurality and deprivation which should improve the generalisability. In addition to this, a similar number of SEAs were obtained compared to other research using SEAs as part of the methodology (69, 95). The SEAs involved only patients diagnosed with lung and colorectal cancer and as such it is possible that the findings could only be considered relevant to patients with suspected lung and colorectal cancer, However, the overall pathway to diagnosis of any cancer is similar, The vast majority of cancers present with symptoms which are also present, and more common in benign disease, most will have a period of investigation or possible treatment in primary care and most will require a referral to secondary care when the diagnosis is suspected. Many of the findings from the SEA work and action plans developed focused on actions within the process from first presentation to referral, such as safety netting, the use of investigations and follow up. These actions are similar and applicable to many more settings than solely the recognition and referral of lung and colorectal cancer. As a result it is possible for the findings of this thesis to be applicable in other settings and with other possible diagnoses.

11.4.1.1 Safety netting

Throughout the results of this thesis and in the comparison with existing literature in chapter 11.1.1 the important role of safety netting in the recognition and referral of cancer symptoms is discussed. The vital role safety netting could play seems only recently to be coming to the fore, with its inclusion for the first time in the NICE recognition and referral of cancer

guidance (25), and CRUK publications and primary care teaching on safety netting (185) being produced in 2015 and 2016 respectively.

This thesis suggests more research is needed on the role of safety netting, in particular on its efficacy. It is hoped that following the scoping review conducted in chapter six, a more detailed systematic review can be undertaken to explore the efficacy of safety netting. Similarly, given SEA research as far back as 2013 showed the importance of safety netting, research considering the barriers of conducting safety netting, perhaps using qualitative methods could be helpful.

Finally this thesis has generated several interventions which could help to improve both the use and documentation of safety netting, as well as the management of investigations and follow up. These interventions were simple to set up and seemed to be feasible, however they require further testing and evaluation with more rigorous methods of assessment.

11.4.1.2 Normal CXRs

The prevalence and management of normal CXRs in the lung cancer diagnostic pathway was noticeable in the SEAs and significantly increased the time to diagnosis. A better awareness of the prevalence of a normal CXR and, as a result, a change in practice to continue to investigate patients if clinical suspicion or red flag symptoms persist may improve the diagnosis and potentially survival from lung cancer.

In this study, guidance was obtained from two local experts, secondary care colleagues from the hospital, who receive referrals from all practices involved in the study. This was a simple way to obtain some local consensus on the management of normal CXRs, but essentially the message was that if the PCP is worried, the patient should be referred, regardless of the CXR finding. This message relies on the PCP's gut instinct and perhaps still leaves the problem of the normal CXR unsolved. Again this issue was highlighted in Mitchell et al's SEA work in 2013 (69) and the "miss-rate" of CXRs for lung cancer in primary care was also highlighted in 2006 by Stapley et al. (270). One may question if CXR is such a poor diagnostic test should a CT scan be arranged for all patients with symptoms? But this would result in much larger doses of radiation to patients, potentially doing harm, would overload secondary care and would result in the finding of nodules of unknown clinical significance possibly creating unnecessary anxiety, the need for repeat scans and sometimes surgery.

The student would argue the implication from this finding is that PCPs need to be aware of the false negative rate of CXRs and not completely rule out a cancer diagnosis in a patient with a normal CXR.

11.4.1.3 Multimorbidity

Another important finding from the SEAs, which was supported by findings from the NCDA (68), was the impact multimorbidity can have on the pathway to diagnosis. The NCDA found that comorbidity was one of the most common reasons given for having three or more consultations prior to referral. In this research comorbidity was frequently found to prolong the primary care interval, mostly as a result of new symptoms being explained due to existing disease. Studies are currently underway looking at the impact of multimorbidity on all aspects of cancer care, and research has shown comorbidities can affect both patient help seeking (289) and clinical management (290). This PhD research suggests that PCPs should be more vigilant when a patient with other comorbidities presents with new symptoms which could be due to cancer and should potentially be investigated as if the patient was otherwise fit and well.

11.4.2 Replication of the method

Despite the limitations discussed above this thesis has met the aims and objectives planned and has found some evidence that audit and feedback using SEAs and action plan development is feasible, accepted by PCPs and could potentially improve the recognition and referral of cancer symptoms. Importantly though, for this finding to be useful the method used within this thesis needs to be replicated and formally evaluated with a control group, ideally within an RCT. One could question how easily this method could be replicated as it relied heavily on the input of the student. Significant time was spent by the student collecting the data in the form of SEAs, collating and analysing the results and presenting the findings. When action plans were developed, the student undertook further work to produce leaflets and consultation reminders. It was clear, when trying to arrange PCP interviews, that the current workload in general practice is high which could make it difficult for PCPs to take time to conduct SEA analysis.

If the findings of this work are to be useful and could be recommended to policy makers, the method used need to be replicated without the input of the student which, as discussed above was significant in this study. Multiple factors may support PCPs in carrying out this method in an individual practice. Currently GP appraisal (a yearly assessment of a GPs work), as

well as the RCGP and the Care Quality Commission encourage the use of SEAs to learn from examples of clinical practice, suggesting that many PCPs may already be conducting SEAs (291, 292). If this is the case, the workload involved in using these SEAs in a feedback and action planning exercise would be significantly reduced. In addition to this, CRUK run a Facilitator programme which offers free support to GP practices and can help carry out local audits which may include SEA work (293). GPs could approach their local facilitator for help when conducting the audit and feedback intervention to aid the replication of this method without significant increases in workload. Similarly the National Cancer Diagnosis Audit (NCDA) is run every two years by CRUK and the RCGP and could act as the audit part of the audit, feedback and action planning method used in this thesis (67). Participation in the NCDA is not mandatory but in 2014, 439 general practices took part. If this work is undertaken for the NCDA, practices receive detailed feedback which could allow for action planning and changes in behaviour similar to the work undertaken in this thesis (68). Finally, as SEAs provide an in-depth review of the process from presentation to diagnosis, individual practices may find useful learning points and a source for behaviour change from just a handful of SEA reports. This would speed up the data collection process and still allow the method and process to be useful to practices with much less work involved in data collection. In addition to this, most practices already run educational meetings for their PCPs. It would be feasible and relatively straightforward to use the template developed in chapter eight to feedback the findings of practice SEAs or NCDA data. In this thesis, the action plans were developed by practice staff, using their knowledge of the facilitators and barriers to the implementation of the plans, but then the plans were implemented by the student. This was done to reduce the workload and burden on individual practices but as was shown in chapter nine, this method may have reduced the opportunity for *cognitive participation* and *collective action*. If the intervention in this thesis is to be recommended to policy makers and used more widely, it should be explained to practices taking part that any plans developed need to be implemented by the existing practice staff. This will ensure that plans are feasible and will provide more opportunity for *cognitive participation* and *collective action*.

It is possible for the method used in this thesis to be replicated and the process could be done on a smaller scale with the same potential for benefit. The Cochrane review on audit and feedback found that the method was significantly more effective when feedback was given by a colleague or supervisor (97), so it could be argued that work done at an individual practice

level maybe more effective than when undertaken by a researcher. If some of the help discussed above through CRUK facilitators or the NCDA can be obtained, the potential increased workload from undertaking this process can be reduced.

Finally in this research, the student completed the SEAs in the capacity of an independent GP. This meant that the student had some clinical knowledge which may help in conducting and assessing the SEAs. In addition being independent meant the student was consistent in the quality of the SEAs produced. As well as being unbiased when selecting cases, selecting the index presentation and considering the 'why did it happen?' section of the SEA analysis. Being independent may be beneficial in conducting SEAs for research purposes. However when conducting SEAs for the purpose of quality improvement or professional development, it is possible that having an independent auditor or researcher conduct the SEAs could be a disadvantage, as the SEA will lack the personal level of detail provided by the patient's own PCP (however with the growth of federations and large general practices, it could be argued that a personal level of detail may not be possible). As such it may not be necessary or desirable for the person conducting the SEAs to be independent.

11.4.3 Lessons learnt from undertaking this PhD thesis intervention

If the intervention in this thesis were to be replicated, it would be helpful to consider what the student would do differently were the process to be repeated or the project extended.

Chapter seven of this thesis highlights the vast amount of useful data produced by undertaking SEAs of actual patient care. The analysis undertaken by the student was able to find opportunities for improvement in patient care and was of interest to practice staff. Through the educational meetings it became clear that PCPs wanted to focus on individual patient cases rather than an overarching assessment of multiple cases from that practice. As a result the student felt that SEAs were an excellent way of gathering data and would support their use in future studies. However, it may be possible to reduce the number of SEAs completed, perhaps focusing on those with a longer primary care interval. It is likely this would still identify opportunities for improvement in care and would enhance PCP motivation for change by using examples of their own care. It is also possible that this

would require much less analysis as individual case reviews could be discussed.

The student felt the educational meetings were generally successful. Chapter three described evidence from Cochrane reviews on audit and feedback and educational outreach visits as well as evidence for action planning by Sniehotta et al. (97, 105, 106). It was possible to operationalise most of this evidence into the action planning and audit and feedback intervention. However, were the study to be replicated, it may be possible to follow the Cochrane advice and allow a supervisor or colleague to present the data. The Cochrane review by Ivers et al. suggested this may increase the effectiveness of feedback but was not possible during this thesis (97). When developing action plans, the when, where and how of the plans discussed by Sneihotta et al. was considered and was able to be operationalised within the planning (106). However if the action planning were to be replicated the student feels it is also vital to consider outcomes of the plans, how are the new plans going to be documented and assessed? This consideration was perhaps missing from the action planning in this thesis and may have led to the difficulties in assessment discussed in chapter nine. If the project was extended perhaps the S.M.A.R.T. technique first documented by Doran would be helpful to consider when action planning. This technique suggests management goals need to be specific, measurable, acceptable, realistic and time-bound. It is the measurable which was possibly missed when designing action plans in this study.

This thesis supports the use of SEAs for research purposes and supports the findings by Mitchell et al. that SEAs can be used to gather detailed data on the recognition and referral of cancer symptoms (69). Similarly this thesis has shown that SEAs can be used as the audit part of an audit and feedback intervention which can be successfully delivered to PCPs. If researchers were to use the methods demonstrated in this thesis, the student would recommend the changes discussed in the paragraph above, ensuring that actions plans have a clear method of assessment and documentation built into them to be able to assess their potential to change behaviour. SEAs may be a suitable way to assess the feasibility and impact of some action plans, but this does rely on documentation in the patient's medical record.

11.4.4 Learning from SEAs and case studies

A significant and important finding from this thesis was the unanimous preference from the PCPs for looking at individual cases during feedback. As a result, the format of the feedback presentation was changed after the first couple of meetings to focus more on important and interesting cases within the audit. The student aimed to use cases which summarised key findings seen throughout the audit. This method of learning from case studies is common in medical education (294), forms much of the basis of problem based learning (PBL) (295) and could be vital to the potential feasibility and success of the methods used in this thesis.

Story telling in medicine is widely documented and discussed with many potential benefits including improving meaning (296), enhancing memory (297), promoting empathy (298) and encouraging reflective practice (299). A qualitative study of the use of stories by medical teachers found that stories were used on a variety of themes and were used to provide relevant context, as a 'hook' to engage the audience and as a memory aid (252).

The use of case studies forms an important part of PBL. PBL has been widely adopted and used in undergraduate medical education and there is some evidence of increased effectiveness. Dolmans and Schmitt argue PBL students are better able to learn and recall information through activation of prior knowledge, elaboration on newly acquired knowledge and contextual learning (300). Bennett et al. suggest that case study learning and PBL are even more suited to postgraduate education and continuing medical education, as was used in this thesis(301). Bennett et al. argues that PBL can not only increase knowledge and skill but can also improve physician competence and performance in practice (301). However, a more recent literature review found only six studies evaluating PBL as a method of education (although five of these were in general practice) and found no consistent benefit of PBL over other methods of education. However they did find that interactive methods were more effective than others in improving doctors performance and patient health (295).

The findings from this thesis supported the use of stories to encourage engagement and interaction from PCPs. Examples of cases highlighted in the feedback were often discussed when developing interventions and action plans and were preferred by staff present at the meeting. This supports other work on story telling in medical education and suggests this technique could be used for SEA feedback. This finding could influence the way in which feedback is given to clinicians in future audit and feedback work.

11.4.5 The use of behaviour change models in audit and feedback interventions

The BCW and NPT were used throughout the design, undertaking and assessment of the audit and feedback intervention in this thesis. The results from this thesis largely support the use of both models. Figure 25 shows how the two models were used in the thesis. The blue sections represent the design and method of the studies used and the red sections show the models of behaviour change and how they influenced each section.
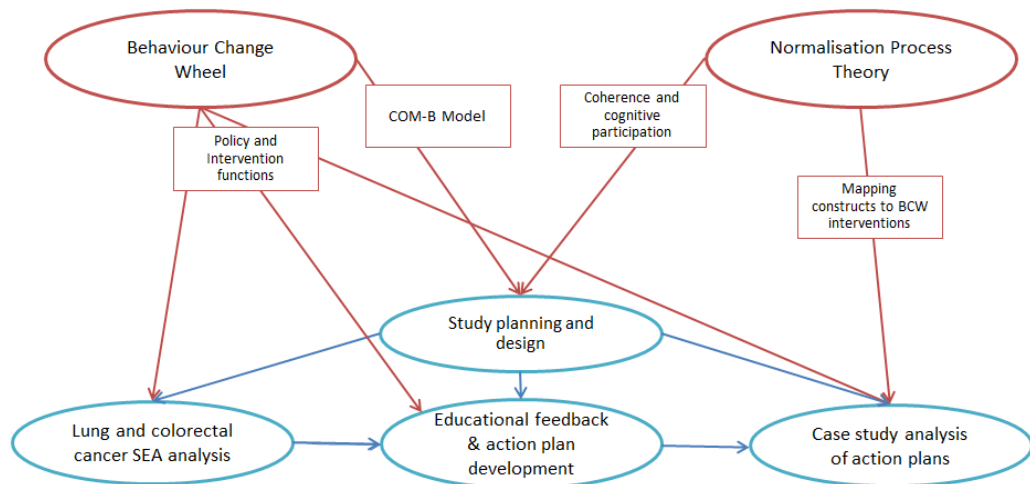
Figure 25: The research methods and the models of behaviour change

As discussed in chapter four the use of theory in interventions is frequently noted to be important (118-121). Foy et al. argue that theoretical models can provide a basis or vocabulary in order to describe key features of the target's behaviours, contexts and interventions (99). Michie and Prestwich showed that theoretically informed interventions lead to better outcomes (122). The methods and findings of this thesis show how two separate models of behaviour change can be used simultaneously throughout the whole process of a research project from design to evaluation. The mapping of BCW policies and interventions to the NPT core constructs and mechanisms undertaken in chapter nine followed a similar technique to that used by Johnson and May (104) but had not been undertaken before using the BCW. The method provided a novel assessment of the potential feasibility of the action plans developed by each practice and could be used on a larger scale if the method were to be replicated.

11.4.6 Summary

The findings of this thesis have a number of implications for the management of suspected cancer symptoms in primary care, the design of future educational packages for PCPs around cancer symptoms and safety netting and further research into this area.

Chapter 11.4.1 has highlighted three potentially important areas which could improve the primary care interval in the pathway to diagnosis. Safety netting, a theme which runs through much of this thesis, is frequently shown to be important in the effective management of patients with potential cancer symptoms. Chapter six has provided conceptual clarity around the term safety netting and chapter seven highlights cases in which safety netting was done well and where there were opportunities for improvement. It is hoped the safety netting lifebuoy developed following the synthesis of the results in chapter 10 can be formally evaluated and used both as an aide memoir for safety netting and in the teaching of consultation skills. The management of normal CXRs and the need to have an awareness of the high false negative rate of CXRs was highlighted as important, as was the management of new symptoms in patients with coexisting medical problems or multimorbidity.

Chapter 11.4.2 address the important issue of whether or not the research conducted in this thesis can be replicated, a vital consideration should the work be useful in real life settings. The large amount of work done by the student in conducting the SEAs, facilitating the educational meetings and aiding with implementation of interventions was highlighted as a potential problem, but solutions to this issue are available, and the process seemed to be feasible and acceptable to PCPs suggesting the process can be replicated in other general practices.

Finally chapters 11.4.3 and 11.4.4 highlight other aspects of the research project which could be relevant for future work in this area. Firstly chapter 11.4.3 highlighted the preference from PCPs to learn from individual case studies or patient stories, rather than overall summaries of practice data. This finding will help to influence the design of future educational work which may consider using individual case studies to shape PCP learning. The use of behaviour change models discussed in chapter 11.4.4 allowed a theory based evaluation of the project and highlighted aspects of both the BCW and NPT when designing interventions aimed at PCPs.

Chapter 12 – Conclusion

The overall aim of this thesis was to investigate ways in which the primary care interval in the diagnosis of cancer could be improved by exploring the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer symptoms by PCPs. The introduction to this thesis showed the potential importance of safety netting in the recognition and referral of cancer symptoms. This finding was particularly clear in previous SEA work looking at cancer diagnosis in primary care. As a result, the first objective of this thesis was to understand the role of safety netting in the recognition and referral of cancer symptoms. Using a scoping review methodology, this thesis has developed an updated definition of safety netting andh has answered the questions of what safety netting is, when it should be used and what information it should contain. The results from this scoping review were then used when conducting the audit and feedback intervention.

The aim of exploring the feasibility of action plans as a mechanism to improve the recognition and referral of possible cancer symptoms, required both a target for the interventions and a method for developing them. As a result the second objective was to investigate opportunities to improve the recognition and referral of cancer symptoms in primary care using the technique of SEA. Multiple opportunities to improve the recognition and referral of cancer symptoms on a variety of themes were identified following the collection of SEAs at nine general practices. The key themes and learning points from the SEAs at each practice included the use of safety netting, the management of CXRs and IDA and the importance of good communication between primary and secondary care.

The third objective of the thesis was to explore the feasibility of developing action plans aiming to improve the recognition and referral of cancer symptoms at each practice. The audit and feedback educational meeting at each practice was well received and generated a discussion between the staff on the findings of the SEAs and how to improve the recognition and referral of cancer symptoms. Between three and five action plans were made for each practice. The findings of chapter eight suggest that this method involving audit and feedback and practice discussion is a feasible way of developing individual practice action plans and is supported by the behaviour change theories of the BCW and NPT.

The next objective of this thesis was to explore the feasibility of implementing and assessing the action plans developed, using repeat SEAs and practice staff interviews. This is explored in chapter nine which reports on the findings of interviews with practice staff and repeat SEAs conducted six months following the educational meeting. The results suggest it is feasible to implement action plans developed by practice staff following an audit and feedback educational meeting, with most of the interventions showing some evidence of being implemented. The method of assessment however, using SEAs and staff interviews to explore the feasibility and outcome of the action plans had mixed success, as it relies on PCPs documenting changes in behaviour in the medical notes and being willing to be interviewed. As a result of this it was not possible to comment on the impact of all interventions planned.

The final objective was to gain insights into the use of audit and feedback and action planning as a technique to improve the recognition and referral of cancer symptoms in primary care. Together, the results from chapters seven, eight and nine helped to provide these insights. Both this thesis and previous work using SEAs have shown the method can be successfully used to gain insights into the primary care interval in the recognition and referral of cancer symptoms. Whereas chapter eight and nine show that SEAs can be used to generate interventions which are feasible, they fit with models of behaviour change and may have the potential to improve the recognition and referral of cancer symptoms. The intervention as a whole seems to have been acceptable to the practices involved.

Key findings

- The existing evidence on the topic of safety netting is limited and mainly focused within educational articles and opinion pieces. This evidence suggests that the definition and content of safety netting may include not only advice or information for patients at the end of the consultation, but also the management and follow up of investigations, referrals and the active follow up of patients.

- The lifebuoy model of safety netting has been developed following the scoping review of safety netting, SEA findings and staff discussions following educational meetings. It suggests safety netting advice may differ depending on the outcome of the consultation, and could help

PCPs better focus safety netting advice and actions around the consultation.

- SEA review of lung and colorectal cancer diagnoses in nine practices around Hull and the East Riding of Yorkshire found that safety netting, improved management of normal CXRs and anaemia, better communication with secondary care colleagues and an awareness of the risks in patients with multimorbidity, could improve the primary care interval in the pathway to lung and colorectal cancer diagnosis.

- Using SEAs as the audit part in an audit and feedback intervention with practice educational meetings and action planning is a feasible and acceptable method to generate interventions to improve the primary care interval in the pathway to lung and colorectal cancer diagnosis.

- Implementing practice action plans developed following the process of audit and feedback is feasible and acceptable to practice staff and PCPs. Assessment of impact was not within the scope of this PhD but would be possible with different study designs.

- Case studies and patient stories seem to be a preferred method of learning for PCPs and practice staff when compared to overviews or summaries of practice findings and may be a more effective way to provide education to PCPs.

Chapter 13 – Future work

Following the completion of this research study, a legitimate question is what should be done next?

13.1 Safety netting

The scoping review has brought together the available literature on safety netting from a wide variety of sources including guidelines, editorials and research. The review has developed a better understanding of the definition of safety netting, when it should be used and what information or actions it should contain. The results of this scoping review can help to guide a more detailed systematic review on important aspects of safety netting which have not currently been addressed, such as potential effectiveness. By providing a detailed definition of safety netting it should be possible to develop a search strategy which will allow for the component parts of safety netting to be searched for and assessed. For example, prior to this scoping review, the management and review of investigations was not widely included in definitions of safety netting. As a result it would now seem prudent to include this in literature reviews for safety netting and attempts could be made to study the effectiveness of including this component of safety netting advice. In addition to this, questions around patient factors and patient responsibility remain unanswered, Even if safety netting is adequate, patients may choose not to have tests or attend follow up or referral appointments, what should PCPs do about this and whose responsibility is it?

Unanswered questions

1. How can safety netting advice, activities and documentation be improved and embedded in primary care?

2. How effective is safety netting?

3. Can improved safety netting advice and documentation improve cancer outcomes?

4. What is the most effective method of following up patients in primary care?

5. What is the role of patient responsibility in safety netting?

6. Can safety netting be taught? If so how?

7. Do different patient groups require different safety netting advice?

8. Is the lifebuoy model of safety netting acceptable / helpful for PCPs?

9. Is the lifebuoy model of safety netting effective?

13.2 The use of SEAs and the opportunities to improve the recognition and referral of cancer symptoms

The results from chapter seven support previous work using SEAs showing the technique is a legitimate, acceptable and effective method of studying the primary care interval of a cancer diagnosis. The continued use of SEAs should be encouraged by all PCPs to learn from events such as new cancer diagnoses. This work also supports the continued use of SEAs in cancer research, both as a tool to learn from diagnoses and to stimulate behaviour change. SEA data have been used to study lung cancer diagnosis and the diagnosis of cancer through emergency presentations. However the diagnosis of other cancers has not been reviewed using this method. The findings of this chapter suggest further study of other cancer types using SEA may be helpful in understanding the process to diagnosis.

Chapter seven highlights a number of important opportunities to improve the recognition and referral of cancer symptoms including the management of investigations, patient factors, multimorbidity and communication between primary and secondary care. These opportunities require further investigation in order to improve the primary care interval.

Unanswered questions

1. Can SEAs be used to investigate other cancer sites including rarer cancers?

2. How should the problem of normal CXRs in patients with suspicious symptoms be managed in primary care?

3. How should anaemia with normal ferritin, low ferritin levels without a low haemoglobin, or consistently low haemoglobin be managed?

4. What constitutes a significant drop in haemoglobin when considering a diagnosis of colorectal cancer?

5. How can communication between primary and secondary care be improved? Can methods be put in place to allow easier discussion between PCPs in primary care and colleagues in secondary care, particularly in patients with vague symptoms or when patients deteriorate or develop new symptoms whilst awaiting secondary care input or investigations?

6. Co-morbidities seemed to have a negative effect on the primary care interval. How can this be further evaluated and what interventions could help prevent these possible delays?

13.3 Audit and feedback, educational meetings and action plan development

The findings from chapter eight suggest that SEAs are a feasible and acceptable method to obtain data for the audit section in an audit and feedback intervention. Chapter eight shows that the SEA data collected in each practice can be successfully used in an audit and feedback discussion. The format was acceptable to the PCPs in each practice and generated discussions which resulted in the formation of action plans which aimed to improve the recognition and referral of cancer symptoms. The technique was informed by two theories of behaviour change, research using SEAs (69, 77, 95) and a large Cochrane review on audit and feedback (97), and generated a number of interventions which aimed to change behaviour and improve care. Given the fact this technique has a strong theoretical underpinning and seems to have been feasible, accepted by the practices and has developed action plans, further research may concentrate on ways to evaluate the interventions or action plans developed. SEA enables practices to look in detail at the primary care interval in the pathway to diagnosis of their own patients and using this as the audit in an audit and feedback intervention does seem to have been feasible, acceptable and successful.

Unanswered questions

1. Can valid and informative SEA data be effectively collected by independent auditors / researchers?

2. What is the burden of PCP collected SEAs or completion of national audits? Is this perceived as a worthwhile exercise for PCPs?

3. How can case studies / stories be effectively used to bring about behaviour change?

4. What is the most effective way of providing feedback to busy PCPs? Are educational meetings the most effective? Could paper based reports be effective? Would face to face or individual feedback be feasible / preferred?

5. Other than using SEAs, how could data for the 'audit' part of the audit and feedback intervention be collected?

13.4 Action plans

Chapter nine reports on an attempt to assess the feasibility and ease of implementation of action plans developed by each practice. This was done by re-visiting practices six months following the educational meeting and repeating the collection of SEA data, as well as interviews with staff at each practice. This had mixed success. Whilst most action plans seemed to be feasible and were at least partially implemented, any measure of potential impact was not within the scope of this thesis, and could not be judged using the methods of analysis chosen. As a result the thesis has developed 35 potential interventions which *could* improve the recognition and referral of cancer in primary care, but with limited evidence of their effectiveness. This leaves many unanswered questions regarding each action plan, but also wider questions on the best way to measure outcomes or change in practice on a smaller scale in primary care.

Unanswered questions

1. Is there a more effective method of assessing the potential impact of the action plans that repeat SEAs?

2. Are certain BCW policy / intervention categories more effective than others in changing PCP behaviour around the recognition and referral of cancer symptoms?

3. What interventions can improve safety netting practice? Examples could include computer templates and reminders, patient mediated methods or PCP incentives.

4. How can follow up be improved in general practice?

5. How should patients who miss appointments and follow up be dealt with by practices and hospitals?

6. What is the most effective method of ensuring results of investigations in primary care are seen and acted upon in a timely and effective manner?

7. Do behaviour change theories have a role in the recognition and referral of cancer symptoms?

8. How can we ensure any change in behaviour is sustained in general practice?

13.5 A future study?

On a larger scale it may be possible to test some of the action plans with more formal research designs. Ideally in order to show a definite effect of the intervention a study would include a control group and would be tested in a RCT. A RCT would allow a detailed assessment of outcomes such as primary care interval times or time to diagnosis. By randomising whole practices using cluster randomisation, it may be possible to develop a complex intervention to evaluate the impact of bespoke action planning using a RCT design. This would be a huge project requiring a strong team of researchers but may be feasible as other studies have used this technique to study complex interventions in the management of multimorbidity (302), musculoskeletal problems (303) and promotion of healthy lifestyle in patients with coronary heart disease (304). A possible intervention would require further development in consultation with PCPs, researchers and the public. The intervention could potentially include further practice specific audit and feedback as undertaken in this PhD, or could use more widely available data such as findings from the NCDA to generate discussion and action plan development following educational meetings. However there are potential pitfalls to this approach, the most important being the need to demonstrate an improvement in the primary care interval in the recognition and referral of cancer. This may be difficult to achieve in primary care based studies at an individual practice level even if an RCT design is used largely due to the small numbers of new cancer diagnoses and therefore perhaps proxy measures may be needed to show an impact. These measures may vary depending on the intervention planned.

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List of Abbreviations

2ww Two week wait referral

BCW Behaviour change wheel

BMJ British medical journal

CAG Confidentially advisory group

CAPER Cancer prediction in Exeter

CCG Clinical commissioning group

CME Continuing medical education

COM-B Capability, opportunity, motivation, behaviour

COPD Chronic obstructive pulmonary disease

CRUK Cancer research UK

CT Computerised tomography

CXR Chest xray

ED Emergency department

EOV Educational outreach visit

EUROCARE European cancer registry

GP General practitioner

HRA Health research authority

ICBP International cancer benchmarking partnership

IDA Iron deficiency anaemia

IMD Index of multiple deprivation

IPA Interpretive phenomenological analysis

MRC Medical research council

NAEDI National awareness and early diagnosis initiative

NCDA National cancer diagnosis audit

NHS National Health Service

NICE National Institute for Health and Care Excellence

NPSA National patient safety agency

NPT Normalisation process theory

NRES National cancer registration service

OOH Out of hours

OR Odds ratio

PBL Problem based learning

PCP Primary care practitioner

R&D Research and development

RAT Risk assessment tool

RCGP Royal College of General Practitioners

RCT Randomised controlled trial

SEA Significant event analysis

TA Thematic analysis

TPB Theory of planned behaviour

UK United Kingdom

WHO World Health Organisation

Appendix A
Health Research Authority Decision Outcome

NHS
Health Research Authority

MRC | Medical Research Council

Is my study research?

ⓘ To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

Using significant event analysis and individual audit and feedback to develop strategies to improve lung and colorectal cancer diagnosis at an individual general

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at HRA.Queries@nhs.net.

For more information please visit the Defining Research leaflet

Appendix B
Hull York Medical School Ethical Approval Letter

H·Y·M·S

THE HULL YORK
MEDICAL SCHOOL

2 November 2015

Dr Dan Jones
SEDA
Hull York Medical School

Dear Dr Jones

15 08 – Using significant event analysis and individual audit and feedback to develop strategies to improve lung and colorectal cancer diagnosis at an individual general practice level

Thank you for your application received on 13 October 2015 which was reviewed via our expedited process. On behalf of the HYMS Ethics Committee, I am pleased to inform you that your project has been given ethical approval. Our reviewers have made some comments on your application in the attached document that we recommend you consider.

Please ensure that the documents used in the study are equivalent to the attached referenced versions which you should retain for your records. If during the course of the project you need to deviate significantly from the above-approved document please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

I wish you success with this study.

Please let me know if I can be of further assistance.

Yours sincerely

R. Gabe

Dr Rhian Gabe
Chair
HYMS Ethics Committee

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Appendix C
CAG pre application checklist

Am I advised to apply to the CAG?

Please go through the questions below which will help you to find out whether or not you are advised to submit an application to the CAG.

1. Do you require *Patient Identifiable Information*?

YES → Q2

NO → No need to submit application

Patient Identifiable Information:

- Confidential patient information is identifiable based on required information and other information that is held* or likely to be held by the applicant;
- Contextually driven consideration. Case by case consideration.
- Need to see entirety of dataset being requested and interaction with other datasets held by you.
- Obvious identifiers are name, address, postcode, date of birth, date of death and NHS Number. The combination of data items can sometimes result in the information becoming identifiable. If you are not sure you can contact the Advice team for advice.

*If you hold other identifiable datasets you will have to explain in your application the legal basis for holding that information.

---

2. Is it within England and Wales?

YES → Q3

NO → Outside remit of CAG

If you intend to use patient identifiable information from Scotland or Northern Ireland then you should contact the relevant privacy advisory committee.

Scotland:
http://www.nhsnss.org/pages/corporate_privacy_advisory_committee.php

Northern Ireland:
r.j.mcclelland@qub.ac.uk

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3. Who is accessing/processing the data – are they outside the *Care Team*?

YES → Q4

NO → Check whether de-identified data only being provided/extracted

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Care Team:

The care team refers to health professionals involved in the diagnosis, treatment or care of a patient. This includes pathology and radiology staff whose activities directly support the care of the patient even though usually they have no contact with the patient. A staff member, who is not involved in the direct delivery of care, who is brought in just to carry out a research activity is not considered a member of the care team and so a recommendation of support under the Health Service (Control of Patient Information) Regulations 2002 would be required for this person to access identifiable information. Members of a care team accessing the records of a patient under the care of another care team, who they are not directly treating, would also require a recommendation of support.

4. Can a different methodology be used to prevent the need for seeking approval

YES → You are advised to pursue different methodology as an application to the CAG should be your last resort

NO → Q5
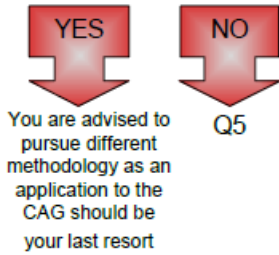
5. Is the activity research, audit, service evaluation, surveillance or screening?

5.1 If research, does it have *REC Approval*?

YES → Q6

NO → If research, you need to apply to a REC; you can apply to the CAG at the same time, however final approval is subject to REC favourable opinion
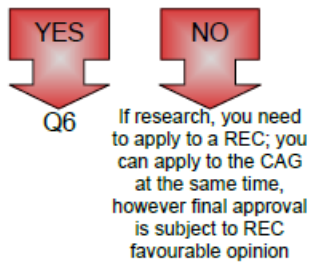
For more information about REC approval please visit the National Research Ethics Service (NRES) website, http://www.nres.nhs.uk/

5.2 If audit, is it national, regional or local?

National or regional → Q6

Local → Does it involve a third party?

YES → Q6

NO → No need to submit an application
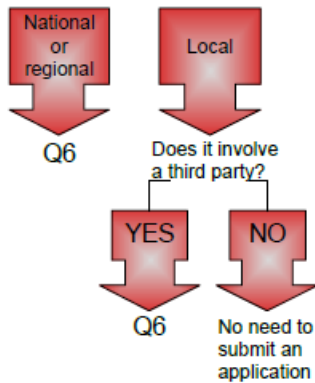
An application to the CAG is not advised for local clinical audit as long as:
•the audit is conducted by one of the organisations that has delivered the patient's care or treatment;
•the audit is carried out in accordance with clinical governance guidelines;
•it has been approved by the NHS Trust's medical director and Caldicott Guardian.
For national and regional clinical audits or where third party organisations are used to conduct a clinical audit the use of de-identified data should be considered. If it is not possible to use de-identified data then patient consent should be sought, or if this is not feasible, an application to the CAG will be advised. The CAG expects to see national audits make reasonable attempts to seek consent and involve patients and service users, where identifiable data is needed.

If your responses to questions above indicate that you should apply to the CAG, you will have to satisfy the legal requirements established under section 251 of the NHS Act 2006. Questions 6 to 11 reflect the minimum legal criteria set out in legislation

6. Is it for a medical purpose?

YES → Q7

NO → Outside remit of s.251

- Must be a medical purpose as stated within s.251(1)
- Specified categories s.251(12)(a)): Preventative medicine, medical diagnosis, medical research, the provision of care and treatment, management of health and social care services.

7. Can consent be reasonably sought? Is it possible and practicable in resource terms to seek consent/re-consent?

YES → You are advised to seek consent

NO → Q8

Applicant must demonstrate that it is not possible to carry out the activity another way, taking into account cost and available technologies (s.251(4)).

The CAG will have to be satisfied, based on evidence, that seeking consent is not possible and practical.

8. Is the purpose to improve patient care or in the *public interest*?

YES → Q9

NO → Outside remit of s.251

Public Interest

Overarching purpose of the activity has to focus on improving patient care, or to be in the public interest (s251(1)(a-b))

9. Can *pseudonymised/ anonymised data* be used?

YES → You are advised to use pseudo/ anonymised data

NO → Q10

Applicant must demonstrate that it is not possible to carry out the activity another way, taking into account cost and available technologies (s251(4)).

The CAG will have to be satisfied, based on evidence, that the use of de-identified data (anonymised or pseudonymised data) cannot satisfy the purpose of the activity.

10. What is the purpose of the activity – is it other than direct patient care?

Primary purpose of application cannot be for care and treatment in relation to specific individuals (s.251(6))

YES → Q11

NO → No need to submit application

11. Is the activity *compliant with the Data Protection Act 1998*?

- Regulations under section 251 cannot make provisions for or in connection with the processing of patient identifiable information in a manner inconsistent with any provision under the *Data Protection Act 1998*.
- Minimum threshold to be met in s.251(7) of the NHS Act 2006.
- If you are planning to process deceased patient identifiable information please note that it is generally accepted that the duty of confidentiality extends after death (Bluck v Information Commissioner and Epsom and St Helier University NHS Trust). Whilst the DPA only applies to personal information of living individuals, the CAG would expect that the DPA principles are applied and respected, where relevant, when processing patient identifiable information related to the deceased.

YES → Q12

NO → Advised to address this before submit an application

If your activity satisfies the legal requirements above, please consider questions 12 to 14

12. Is applicant linking to non-NHS data?

The CAG cannot advise support if the legal basis for onward linkages is unknown.

YES → Applicant to establish legal basis for accessing non-NHS data before making application to CAG

NO → Q13

13. Is there evidence of proportionate *patient and public involvement* in the development of the study?

YES → Q14

NO → You are advised to address this before submit an application

Patient and Public Involvement:

Whatever the purpose of your application, you must be able to demonstrate that you have specifically tested the views of patients or public on the use of their health information without consent, where this is feasible. You are required to include as part of this participation: the justification of each data item, the impracticality of seeking consent and how the public interest is served. Please then summarise in your application what patients' views were on not seeking this consent.

The CAG will be unable to provide a favourable recommendation of support without this.

14. Approval is a temporary measure to access patient identifiable information without consent. Have you considered an *exit strategy* when you will no longer need support?

YES → Q15

NO → You are advised to consider exit strategy before submitting an application

Exit Strategy:

You will have to consider measures which will allow you to carry out your activity not using patient identifiable information without consent. For example, seeking consent from patients or using de-identified data. You will need to explain in your application how you have considered an exit strategy.

If you are now eligible to proceed, you need to consider which route your application should take, either to a full CAG meeting or proportionate review. The route the application will take will be determined by the Advice team during validation 1 (see high level process). Question 15 is designed to make you familiar with the criteria.

Appendix D
Search Strategy for Scoping Review

Database: Ovid MEDLINE(R) <1996 to April Week 1 2018>

Search Strategy:

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1   safety net*.mp. (3359)

2   safety netting.mp. (30)

3   (safe* adj3 net*).mp. (3643)

4   ("safety net" adj2 clin*).mp. (229)

5   ("safety net" adj2 hosp*).mp. (531)

6   ("safety net" adj2 prac*).mp. (40)

7   ("safety net" adj2 sett*).mp. (112)

8   1 or 2 or 3 (3643)

9   4 or 5 or 6 or 7 (852)

10   8 not 9 (2791)

Appendix E
Table of included studies for scoping review

Study ID	Country	Study design	Setting	Participants
Ablett-Spence 2013	UK	Multiple initiatives	Primary care	GPs and patients
Almond 2009	UK	Editorial	Primary care	GPs
Balla 2012	UK	Interview	Primary care	PCPs
Bankhead 2011	UK	Systematic review; Delphi	Primary care	Adults
Bertheloot 2016	Belgium	Interview	Primary care	GPs
Buntinx 2011	UK	Editorial	Primary care	GPs
Cabral 2014	UK	Interview	Primary care	Children with respiratory tract infections
Chafer 2003	UK	Educational	Primary care	GP trainees
Campion-Smith 2014	UK	Educational	Primary care	GPs
CRUK 2016	UK	Educational	Primary care	PCPs
Clarke 2014	UK	Interview	Tertiary referral centre	Children with acute leukaemia
de Vos-Kerkhof 2015	The Netherlands	Systematic review	ED	Children and adults attending ED
Eden 2010	UK	Audit	Primary care	GPs
Hirst 2018	UK	Focus group; interview	Primary care	GPs
Jacob 2016	UK	Questionnaire; records review	Children's ED	Doctors
Jones 2013	UK	Focus group; interview	Primary care and ED	Doctors
Jones 2014	UK	Focus group; interview	Primary care and ED	Doctors, nurses and parents
Kaufmann 2008	UK	Educational	Primary care	Nurses
Kurtz 1998	UK	Educational	Primary care	PCPs
Maguire 2011	UK	Questionnaire	Urgent care services	Children under 5 with a fever
McKelvey 2010	UK	Educational	Primary care	GPs
MDDUS 2016	UK	Educational	Primary care	GPs
MDU 2018	UK	Educational	Primary care	GPs
Mitchell 2012	UK	Educational	Primary care	GPs
Mitchell 2013	UK	Case review	Primary care	Patients diagnosed with lung cancer
Mitchell 2015	UK	Case review	Primary care	Patients diagnosed with cancer via emergency admission
Morgan 2014	Australia	Educational	Primary care	GP trainees

Study ID	Country	Study design	Setting	Participants
NPSA 2010	UK	Audit	Primary care	GPs
Neighbour 1987	UK	Book	Primary care	GPs
Neill 2015	UK	Systematic review	All	Acutely unwell children
NHS healthy London Partnership 2016	UK	Educational	Primary care	PCPs
NICE 2013	UK	Educational	Primary care	PCPs
NICE 2015	UK	Educational	Primary care	PCPs
Nicholson 2016	UK	Systematic review	Primary care	PCPs
Pearson 2007	UK	Educational	Primary care	GP trainees
Rees 2017	UK	Case review	Primary care	Acutely unwell children
Roland 2014	UK	Commentary	Primary care	GPs
RCGP 2011	UK	Educational	Primary care	GPs
Royal College of Paediatrics and Child Health 2010	UK	Questionnaire	Urgent and emergency care services	Children under 5 with fever
Schiff 2012	USA	Commentary	All	Doctors
Seneviratne 2010	Sri Lanka	Letter	Primary care	GPs
Singh 2010	UK	Educational	Primary care	GP trainees
van Dorp 2008	UK	Educational	Primary care	GP trainees
Van Galan 2018	The Netherlands	Educational	Primary care	PCPs
Walter 2014	UK	Interview	Primary care	Patients diagnosed with melanoma
Young 2010	UK	Educational	Primary care	Nurses

Appendix F
Read Codes used for SEA patient search

Colorectal cancer
B13
B14
B713
B714
B1z
B803
B804
Byu12
Byu13
x78g0
x78Np
x78Nq
x78Ny
x78OA
xa34H
xa84v
XE1x2

Lung cancer
B22
B2z
B23
B26
B72
B81
R131
Byu2
B2221
B224
B2241
B570
B812
x78QE
x78QF
x78QJ
x78QN
x78QP
x78QS
Xa0KF
Xa0KG
XaBtz
XE1vb
XE1vc

Appendix G
SEA template for data collection

SIGNIFICANT EVENT AUDIT OF CANCER DIAGNOSIS
Cancer SEA Report Template

Diagnosis:	
Date of diagnosis:	
Age of patient at diagnosis:	
Sex of patient:	
Is the patient currently alive (Y/N):	
If deceased, please give date of death:	
Date of meeting when SEA discussed:	

N.B.: Please DO NOT include the patient's name in any narrative. Please anonymise the individual involved at each stage by referring to them as GP1, GP2, Nurse1, Nurse2, GP Reg1 etc.

1. WHAT HAPPENED?

Describe the process to diagnosis for this patient in detail, including dates of consultations, referral and diagnosis and the clinicians involved in that process. Consider for instance:

■ The initial presentation and presenting symptoms (including where if outwith primary care). ■ The key consultation at which the diagnosis was made. ■ Consultations in the year prior to diagnosis and referral (how often the patient had been seen by the practice; for what reasons; the type of consultation held: telephone, in clinic etc; and who - GP1, GP2, Nurse 1 - saw them). ■ Whether s/he had been seen by the Out of Hours service, at A&E, or in secondary care clinics. ■ If there appears to be delay on the part of the patient in presenting with their symptoms. ■ What the impact or potential impact of the event was.

2. WHY DID IT HAPPEN?

Reflect on the process of diagnosis for the patient. Consider for instance:

■ If this was as good as it could have been (and if so, the factors that contributed to speedy and/or appropriate diagnosis in primary care). ■ How often / over what time period the patient was seen before a referral was made (and the urgency of referral). ■ Whether safety-netting / follow-up was used (and if so, whether this was appropriate). ■ Whether there was any delay in diagnosis (and if so, the underlying factors that contributed to this). ■ Whether appropriate diagnostic services were used (and whether there was adequate access to or availability of these, and whether the reason for any delay was acceptable or appropriate).

3. WHAT HAS BEEN LEARNED?

Demonstrate that reflection and learning have taken place, and that team members have been involved in

considering the process of cancer diagnosis. Consider, for instance:

■ Education and training needs around cancer diagnosis and/or referral. ■ The need for protocols and/or specified procedures within the practice for cancer diagnosis and/or referral. ■ The robustness of follow-up systems within in the practice. ■ The importance and effectiveness of team working and communication (internally and with secondary care). ■ The role of the NICE referral guidelines for suspected cancer, and their usefulness to primary care teams. ■ Reference the literature, guidance and protocols that support your learning points ■ Is the learning the same for all staff members or who does it apply to

Learning point 1:

Learning point 2:

Learning point 3:

Learning point 4:

4. WHAT HAS BEEN CHANGED?

Outline here the action(s) agreed and/or implemented and who will/has undertaken them.

Detail, for instance:

■ If a protocol is to be/has been introduced, updated or amended: how this will be/was done; which staff members or groups will be/were responsible (GPs, Nurses; GP Reg 1, GP2 etc); and how the related changes will be/have been monitored. ■ If there are things that individuals or the practice as a whole will do differently (detail the level at which changes are being/have been made and how are they being monitored). ■ What improvements will result/have resulted from the changes: will/have the improvements benefit(ed) diagnosis of a specific cancer group, or will/has their impact been broader. ■ Consider both clinical, administrative and cross-team working issues.

5. WHAT WAS THE IMPACT/POTENTIAL IMPACT ON THOSE INVOLVED?

Outline here the impact or potential impact on the patient, carer / family, GP and practice.

Consider, for instance:

■ How did the pathway to diagnosis impact on the patient and/or their family. Has the pathway to diagnosis affected the patient–GP (or practice) relationship, and in what way (positive or negative). ■ Has the pathway to diagnosis for

this patient impacted on how individual GPs or the practice as a whole deal with other patients ■ What is the potential impact of any changes on the systems within the practice.

WHAT WAS EFFECTIVE ABOUT THIS SEA?

Consider how carrying out this SEA has been valuable to individuals, to the practice team and/or to patients.
Detail for instance:

■ Who attended and whether the relevant people were involved ■ What format the meeting followed ■ How long the meeting lasted ■ What was effective about the SEA discussion and process ■ What could have made the SEA more effective in terms of encouraging reflection, learning and action.

SOME INFORMATION ABOUT YOUR PRACTICE *

How many registered patients are there?							
How many F.T.E. GPs are there (inc. principals, salaried GPs, trainees etc.)?							
Is your practice a training practice?				Yes		No	
Does your practice teach medical students				Yes		No	
What were your QOF points last year?	Clinical		Quality and productivity		Total		
OUT OF:		610		100			900

* This information is useful when collating results across practices and/or localities

Appendix H
Read code poster for action plan

NHS

Does a patient have suspicious symptoms but does not
meet the two week wait criteria? Do you want to make
sure a patient is followed up?

Use read code **"patient awaiting investigation – 9R56"**
in the consultation

This read code will be regularly searched, ensuring tests
are done and patients followed up as needed

Appendix I
Patient self-booking leaflet for action plan

NHS

Patient information for urgent referrals

This information sheet explains why your GP has referred you to hospital, what it means and what you need to do

Why have I been referred urgently to hospital?

You've been referred urgently because your GP feels your symptoms need further investigation and has referred you to a specialist. There are many common conditions that these symptoms could be linked to, including the possibility of cancer.

Because this referral is urgent, it means that you will be offered an appointment at hospital within two weeks.

Does this mean I have cancer?

Having an urgent referral does not necessarily mean you have cancer. Most people who have an urgent referral don't have cancer. However, you have been referred because you need to see a specialist or have some investigations quickly to help find out what is wrong with you.

In the event that cancer is diagnosed, then ensuring that the diagnosis is made early means treatment is likely to be more effective and this is why it is important that you are seen within 2 weeks of the referral being made.

What happens next?

Your GP will write a letter to the hospital to tell the hospital doctors about you and your symptoms.

You should phone the hospital 24 hours after seeing the GP to book an urgent appointment. They will also help you book transport and an interpreter if needed. You can write your appointment date, time, location and doctor below

The urgent appointment phone number is 01482 604308

Appointment date: _____ Time: _____

Where: _____ Doctor: _____

Appendix J
Advice from respiratory consultants on normal CXRs

Consultant 1

My initial thoughts are;
I think the info is on that paper. http://www.gp-update.co.uk/files/docs/Lung_cancer.pdf
"Looking at X-rays taken in the 3m before diagnosis; 90.5% of the CXRs were reported as abnormal with suspicions of malignancy"
For those whose CXR was older (taken in the last year), 23% of cancers were missed (10% were reported as completely normal,13% were reported as abnormal but no suspicions of malignancy).
I want GP colleagues to have done a CXR within a month before referral (not even within 3 as above). Older than 3 months is absurdly out of date for ongoing symptoms or newly presenting ones.
I was thinking through the East Riding PTL. I 've pulled some genuinely normal CXRs...
I think the question is at what interval should they be repeated if they were normal a few months back and the patient comes back to see you. I will think on that. But, the answer would appear to be if its greater than 3 months…..
All the best,

Consultant 2

I think the issue of how to manage patients with possible symptoms of lung cancer but a normal CXR is the big unanswered question in this area and I don't know the answer.

For haemoptysis it's easy as I think most patients need a CT. Our local audit data suggests that the yield from allcomers with haemoptysis/normal CXR referred to our service (accepting there will be a lot of selection bias with the latter consideration) is 6% from CT (and 0% from bronchoscopy if CT normal).

My personal prejudice is that for breathlessness, chest wall pain, weight loss, if these symptoms are due to a lung cancer then the chance of not picking this up on CXR is very low. Breathlessness is almost always due to large airway occlusion or effusion, and by the time something is invading the chest wall it's usually large. I can't remember the last patients with lung cancer causing weight loss with a normal CXR - it's almost always metastatic disease. Cough is more difficult as arguably may be triggered by smaller cancer. However, I think a lot of our patients with cancer diagnosed following investigation of cough, the cough is incidental and not related to the lung cancer.

Clearly if you do CT scans in patients with normal CXR and breathlessness/chest pain/weight loss/cough then you will pick up cancers, but I suspect the majority of these cancers won't be causing the symptoms, and that effectively you are screening for lung cancer albeit using symptoms of COPD as a risk selection tool.

The yield from any such scans needs to be considered alongside the yield from CT screening a high risk asymptomatic population (1% in NLST, 2% in UKLS). Richard Hubbard's primary care data paper in Thorax (using the THIN dataset) showed that the predictive value of cough for lung cancer (i.e. patients with cough in GP records who went on to be diagnosed with lung cancer within next 12 months) was about 0.25%.

My personal recommendation is
1. Any haemoptysis (>40yrs) gets a CT scan
2. Any persistent respiratory symptoms gets a CXR
3. I agree with Gavin regarding repeating this at 3/12 but I don't know of any specific evidence guiding this time interval
4. We have always said locally to our GPs that if any concern about lung cancer despite normal CXR then to send to us. They do, we CT them, but we rarely find anything.

The latter is definitely in need of a large definitive study. There is a grant in to Roy Castle for this (albeit on quite a small stage). Hopefully this will get funded and will provide some answers.
Best wishes,

Appendix K
Protocol and leaflet for safety netting for phlebotomy team

Phlebotomist follow up protocol

```
┌─────────────────────────────────┐
│ Check the reason for the bloods │
│   and which tests are being done│
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│  Check if bloods are urgent or  │
│             routine             │
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│ See if the GP requesting the    │
│ bloods has suggested follow up  │
│ in the patients notes           │
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│  Check that the patient         │
│  understands the reason for the │
│  test                           │
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│ Take blood ensuring the         │
│ clinical details are documented │
│ on the request form and both    │
│ the bottle and form have at     │
│ least three patient identifiers │
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│ Ensure the patient knows any    │
│ follow up plan in the notes or  │
│ ask the patient to phone for    │
│ the results after 2pm if there  │
│ is no follow up plan documented │
└─────────────────────────────────┘
              │
              ▼
┌─────────────────────────────────┐
│  Fill in and give the patient   │
│  the blood test information     │
│  sheet                          │
└─────────────────────────────────┘
```

NHS

What to expect after blood tests

We have taken blood today for:

When should I expect the results?

Blood test results usually take 2-3 days to come back, they need to be checked by the GP who will put a comment on the blood test result.

How will I get the results?

If there is anything abnormal we will try to ring you with the results

If we do not contact you

☐   The GP has asked to review you in _____ days/weeks

☐   You should ring the surgery to get the results after 2pm