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Understanding Lung Cancer Screening Participation

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Abstract

Background: Lung cancer is the leading cause of cancer death worldwide. There are evident health inequalities in lung cancer mortality, with those from more deprived groups more likely to be diagnosed with lung cancer and die of the disease. Understanding the factors associated with cancer screening uptake is vital to implementing an effective and efficient UK lung cancer screening programme in the future. This thesis aimed to explore the socioeconomic and psychosocial factors associated with lung cancer screening participation.

Methodology: This thesis used a mixed methods approach. A systematic review, of the public perceptions and awareness of lung cancer and lung cancer screening, used an integrative methodology, exploring both quantitative and qualitative literatures. Two secondary analyses of data from an early detection of lung cancer trial were conducted (n = 11,164). The first of the two quantitative studies examined the demographic and psychosocial differences across socioeconomic groups among trial participants, while the second study looked to explore any demographic or psychosocial differences of those who were recruited to participate in the trial by their GP and those recruited via the community. Data from both studies were analysed using univariate and multivariate analyses. Finally, a qualitative study (n = 8) used semi-structured interviews to examine the barriers to attendance among people who initially arranged a lung cancer screening appointment but did not attend. Two analytic approaches were applied to the data. First, data were analysed using a thematic framework approach to generate themes, this was then followed by a theoretical framework approach using two different behavioural models (the Health Action Process Approach and the Common-Sense Model of Self-Regulation) in order to identify overlap and gaps in the models.

Main Findings: The findings of these studies suggest that beliefs about lung cancer and lung cancer screening vary by socioeconomic status, with those from more deprived backgrounds more likely to report barriers to screening, less likely to perceive that their actions can impact the development of lung cancer and more likely to feel upset when they think about lung cancer. The secondary analyses highlight the need to consider how best to measure deprivation if it is to be used as a criterion in targeted cancer screening, and further consider how we optimise the way we invite high risk people to participate in lung cancer screening. Results of the secondary analyses of recruitment type in the ECLS trial indicate that community and opportunistic screening invitations encourage uptake in people from less deprived backgrounds, and therefore might not be the best method to reach those at high risk of lung cancer and living in more deprived areas. Results of the qualitative study indicate that people experience both practical and emotional barriers to attending lung cancer screening. Those who agreed to participate, but did not attend their appointment, were more likely to first cite practical barriers, such as competing priorities or ill-health. However, the reasons for not making another appointment were often more emotive, with lung cancer fear and fatalism high among non-attenders. The study also identified significant overlap between the HAPA model and CSM, particularly with regard to the role coping strategies play in a group of people who already have positive intentions. Coping planning and coping appraisal seem to be significant problem areas for non-attenders, with the time between invitation and appointment vital to whether or not they attend their appointment.

Conclusions: There are sociodemographic and psychosocial factors associated with participation in lung cancer screening. It is important to identify the barriers to lung cancer screening and provide solutions if a lung cancer screening programme is to be implemented in the UK. Further work is required in order to explore the development of targeted interventions to support those at high risk of lung cancer, particularly those from more deprived groups.

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Author's declaration

I declare that, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Abbreviations

AAB	Autoantibody
ABC	Awareness and Beliefs about Cancer measure
CAM	Cancer Awareness Measure
CHI	Community Health Index
COPD	Chronic Obstructive Pulmonary Disease
CRUK	Cancer Research UK
CSM	Common-Sense Model of Self-Regulation
CT	Computed Tomography
CXR	Chest X-ray
DANTE	Detection and Screening of Early Lung Cancer with Novel Imaging Technology trial
DNA	Did Not Attend
ECLS	Early detection of Cancer of the Lung Scotland trial
FIT	Faecal Immunochemical Test
FOBT	Faecal Occult Blood Test
GP	General Practitioner
HAPA	Health Action Process Approach
HBM	Health Belief Model
HINTS	Health Information Trends Survey
IMD	Index of Multiple Deprivation
ISD Scotland	Information Services Division Scotland
ITALUNG	Italian Lung Cancer Screening trial
LDCT	Low-dose Computed Tomography
LLP	Liverpool Lung Project
MILD	Multicentric Italian Lung Detection trial
NCI	National Cancer Institute
NELSON	Dutch-Belgian Lung Cancer Screening trial

NLST	National Lung Screening Trial
NSCLC	Non-small Cell Lung Cancer
PAPM	Precaution Adoption Process Model
PLCO	Prostate, Lung, Colorectal and Ovarian Screening trial
RCT	Randomised Controlled Trial
RIPQ-LC	Revised Illness Perception Questionnaire – Lung Cancer
SCLC	Small Cell Lung Cancer
SCT	Social Cognitive Theory
SEP	Socioeconomic Position
SES	Socioeconomic Status
SIMD	Scottish Index of Multiple Deprivation
TB	Tuberculosis
TCTU	Tayside Clinical Trials Unit
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TTM	Transtheoretical Model
UK NSC	UK National Screening Committee
UKLS	UK Lung Screening trial
USPSTF	US Preventative Services Task Force
VIF	Variance Inflation Factor
WHO	World Health Organisation

Chapter 1 : Lung cancer epidemiology and lung cancer screening

The aim of this chapter is to set lung cancer and lung cancer screening in context and provide a clear rationale for the studies described in this thesis. This will be achieved by describing the epidemiology of lung cancer and the current position of lung cancer screening, including reported barriers to uptake. The chapter will also highlight the body of literature that explores cancer inequalities and discusses the mechanisms surrounding the variation in uptake in lung cancer screening.

1.1 The problem: a cancer of substantial unmet need

Lung cancer is the leading cause of cancer death worldwide (World Health Organisation (WHO), 2020). It is a disease of high symptom burden, psychological distress and is associated with poor quality of life (Mazières et al., 2015; Yang et al., 2012). Despite the burden lung cancer places on individuals, and the association with very poor outcomes, lung cancer research is severely underfunded (Carter & Nguyen, 2012). Lung cancer has been described as a cancer of substantial unmet need by Cancer Research UK (CRUK), and there have been calls for prioritisation of lung cancer to ensure that progress in research is akin to other types of cancer (CRUK, 2015). While overall cancer survival has doubled since the 1970's, the survival rate of lung cancer has only shifted marginally, with 5-year survival being around 9% in the UK (CRUK, 2015).

Health inequalities exist in lung cancer incidence and mortality. Lung cancer disproportionately impacts those from deprived groups. Those from more deprived groups are not only more likely to be diagnosed with lung cancer, but they are also more likely to die from it when compared to their less deprived counterparts (Powell, 2019). The mechanisms behind this health inequality are also under-researched, which is evident by the dearth of literature when compared to other types of cancer (Powell, 2019).

It is clear that there is much work to be done to improve lung cancer outcomes and our understanding of the drivers of the health inequalities that exist in relation to incidence and mortality.

1.2 Lung cancer epidemiology

1.2.1 Lung cancer presentation

Lung cancer develops from the abnormal growth of cells within the lungs, bronchi or trachea. Lung cancer can be categorised into two main types: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). The distinction between these types of lung cancer is important for management, prognosis, and screening efficacy (Nanavaty, Alvarez & Alberts, 2014).

SCLC accounts for 15-20% of all lung cancers diagnosed. Although a smaller proportion of the total lung cancers diagnosed, it is described as aggressive and characterised by rapid doubling time and early metastasis, making it more challenging to detect during the early stages (CRUK, 2020; Nanavaty, Alvarez & Alberts, 2014). NSCLC is the most common form of lung cancer, accounting for 80-85% of all lung cancers (CRUK, 2020). There are three main types of NSCLC, including adenocarcinoma, squamous cell carcinoma and large cell carcinoma. These types of lung cancer behave and respond to treatment in a similar way. Significantly, in contrast to SCLC, NSCLC are easier to detect at an earlier stage using screening.

1.2.2 Incidence and mortality of lung cancer

Lung cancer is both the most commonly diagnosed type of cancer, and the leading cause of cancer death worldwide. In 2018, lung cancer accounted for over two million diagnoses of cancer. Lung cancer accounts for 18.4% of all cancer deaths, which is double that of bowel cancer (9.4%), the second highest cause of cancer death (WHO, 2020). In the UK, lung cancer accounts for 13% of all new cancer cases and 21% of all cancer deaths. Lung cancer mortality rates are significantly higher in Scotland when compared to the UK average (CRUK, 2020).

Lung cancer is the most common type of cancer in Scotland, with 15.8% of all cancers diagnosed attributed to lung cancer (Public Health Scotland, 2020a). A quarter of all deaths from cancer in Scotland are attributed to lung cancer. The number of deaths owing to lung cancer are more than double that of colorectal cancer, which is the next most common cause of death from cancer (Information Services Division (ISD) Scotland, 2019).

Lung cancer mortality is higher than other forms of cancer, often because of late stage diagnosis. Almost half of those with lung cancer (46%) are diagnosed when the cancer has already metastasised to other areas of the body, making it more difficult to treat (Public Health Scotland, 2020). Late stage lung cancer diagnosis (Stage IV) can, in some cases, be attributed to an absence of any recognisable symptoms (such as a persistent cough or unexplained weight loss) until the later stages of the disease (Public Health Scotland, 2020a).

Lung cancer mortality in Scotland reduced by 18.5% between 2008 and 2018 (Public Health Scotland, 2020a). However, mortality rates are predicted to increase as a response to restrictions to some healthcare services throughout the COVID-19 pandemic. This is the result of a reduction in the number of people seeking help for lung cancer symptoms and the reduced availability of diagnostic services. It is estimated that there will be a 4.8% increase in 5-year lung cancer death in the UK, compared to pre-COVID (Maringe, Spicer, Morris, Purushotham, Nolte, Sullivan, Rachet & Aggarwal, 2020).

1.2.3 Demographic characteristics associated with lung cancer incidence and mortality

1.2.3.1 Sex

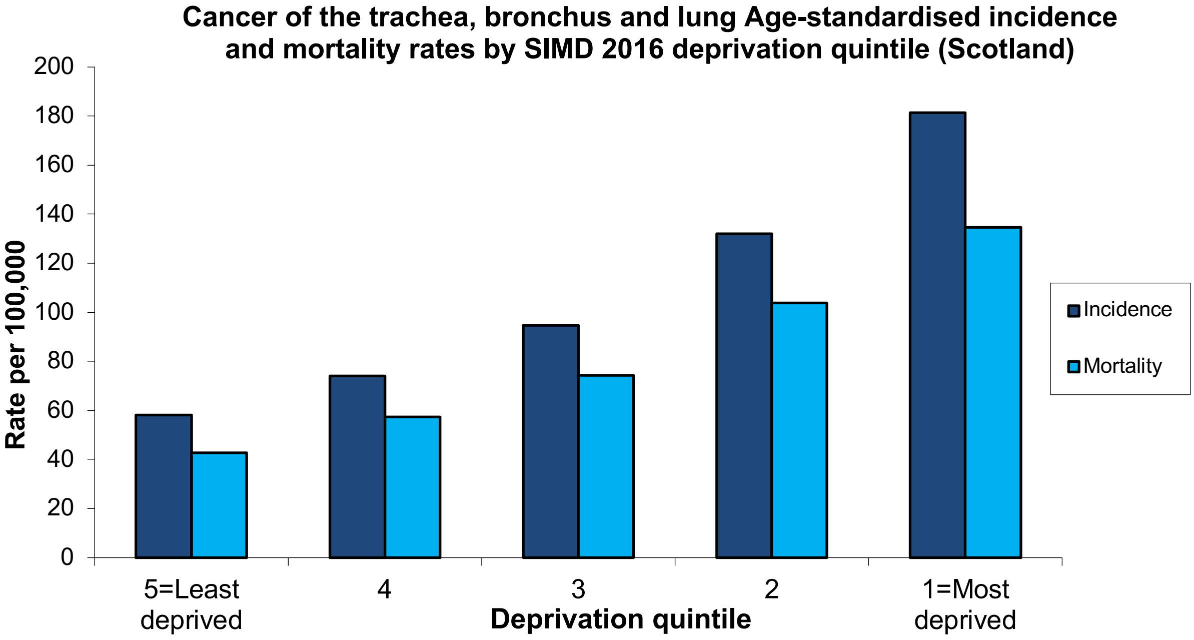
In contrast to other UK nations, the incidence of lung cancer in Scotland is slightly higher among women than men (Public Health Scotland, 2020b). This reflects a change in both incidence and mortality rates between men and women over the past 10 years. Lung cancer mortality rates in men have decreased by 25% in the past decade when compared to women, whose mortality rate has decreased by 10%. The difference in the rates of reduction, between men and women, is a result of historic trends in smoking behaviour prevalence (Public Health Scotland, 2020b).

1.2.3.2 Socioeconomic status

There is a clear association between lung cancer incidence and deprivation (Fig. 1-1). In Scotland, the incidence rate is three times higher in the most deprived areas (Scottish Index of Multiple Deprivation (SIMD) 1) when compared to those in the least deprived areas (SIMD 5) (Public Health Scotland, 2020c). This social gradient can also be seen in lung cancer mortality rates, which indicate that those from the most deprived areas of Scotland are also three times more likely to die of the disease when compared to those from the least deprived areas of Scotland (Public Health Scotland, 2020c). This association, between incidence and mortality and deprivation level, is not unique to Scotland; it is also evident in other countries of the UK (National Cancer Intelligence Network, 2014) and internationally (Mihor, Tomsic, Zagar, Lokar & Zadnik, 2020).

Higher incidence of lung cancer among those from the most deprived groups is correlated with the increased prevalence of smoking in these groups (Hiscock, Bauld, Amos, Fidler & Munafo, 2012). Smoking is more common in deprived areas of Scotland (32% prevalence) when compared to the least deprived areas (9% prevalence) (Public Health Scotland, 2020a). Further, those from more deprived groups are less likely to successfully quit smoking compared to more affluent groups, despite being just as likely to attempt to stop (Hiscock et al., 2012).

Figure 1-1: Incidence and Mortality Rates by SIMD (2016) Deprivation Quintile (Public Health Scotland, 2020)



1.2.4 Risk factors

1.2.4.1 Smoking

Tobacco smoking is the most significant contributor to lung cancer incidence, responsible for 72.2% of all lung cancers diagnosed in the UK (Brown et al., 2018). Risk of lung cancer death is around 15 times higher in current smokers compared with never-smokers (Doll, Petro, Boreham and Sutherland, 2005). This risk increases with higher daily consumption of cigarettes, longer duration and starting smoking at a younger age (Doll et al., 2005; Lubin & Caporaso, 2006; Kenfield et al., 2010). Around 1% of all lung cancers in the UK are the result of environmental tobacco smoke, and account for 15% of lung cancer diagnosis that occur in never-smokers (Brown et al., 2018). Smoking cessation is the most effective way to decrease risk of lung cancer and improve life expectancy (Pirie, Peto, Reeves, Green and Beral, 2013).

Smoking prevalence in Scotland has declined significantly since 2003, with adult smoking rates declining from 28% to 19% in 2018 (Scottish Government, 2020c). Changes in policy may have had significant implications on the reduction in smoking rates in Scotland. For example, the Smoking, Health and Social Care (Scotland) Act 2005 prohibited smoking in most enclosed public places, and more recently, the Scottish Governments five-year action plan set out interventions and policies to help reduce the use of and associated harms from using tobacco in Scotland (Scottish Government, 2018a). However, despite the proactive approach to reduce smoking related harm, smoking prevalence in Scotland is still higher than England and Wales (Office of National Statistics, 2020).

1.2.4.2 Age

There are a number of risk factors associated with the development of lung cancer. Age is associated with the development of lung cancer, with higher incidence of lung cancer being found in people over the age of 60 (Public Health Scotland, 2020b).

1.2.4.3 Pre-existing lung disease or lung condition

A person’s medical history may also play a role in the risk of developing lung cancer. Risk of lung cancer increases significantly with a history of lung disease (such as COPD). Lung cancer risk is 104-144% higher in smokers with a history of emphysema, and 47-52% higher in smokers with a history of chronic bronchitis (Brenner et al., 2012).

Pre-existing lung conditions have been found to be correlated with socioeconomic status, with those from more deprived groups disproportionately affected by COPD (Pleasants, Riley & Mannino, 2016). This is the result of higher rates of tobacco use and also occupational exposures to inhalant toxins in low socioeconomic groups.

1.2.4.4 Environmental exposure

There are significant associations between environmental and occupational exposure and the development of lung cancer. Around 8% of all lung cancer cases are caused by air pollution and 13% are caused by occupational exposure, such as asbestos exposure (Brown et al., 2018).

Those from lower socioeconomic groups are historically more likely to have been exposed to harmful environmental and occupational carcinogenic toxins (Hovanec et al., 2018). This is the result of traditional occupation types carried out by those from lower socioeconomic groups, such as metal production and processing, construction, mining, the chemical production and occupations working with asbestos, have significantly higher carcinogenic risk (Hovanec et al., 2018).

1.2.4.5 Family history

A family history of lung cancer significantly increases risk of developing lung cancer. Lung cancer risk is 50% higher in people who have a family history of lung cancer. There is a significant association between having a sibling who has had lung cancer and developing lung cancer. This association is stronger in siblings compared to risk based on lung cancer history of parents (Coté et al., 2012).

A family history of lung cancer does not appear to be related to SES. Evidence suggests that this type of risk is associated with genetic factors that contribute to susceptibility to lung cancer (Cassidy, Myles, Duffy, Liloglou & Field, 2006).

1.3 Screening for lung cancer

1.3.1 Definition of screening and screening criteria

The UK National Screening Committee (UK NSC) defines screening as “the process of identifying healthy people who may have an increased chance of a disease or condition. The screening provider then offers information, further tests and treatment. This is to reduce associated problems or complications. Screening should always be a personal choice” (UK NSC, 2017). National screening programmes target large population groups to identify the early signs of cancer or disease. The aim of national screening programmes is to lower incidence and improve early diagnosis and health outcomes for patients (NHS England, 2019).

The WHO published a set of criteria to determine whether a condition or disease should be considered a population screening programme (Wilson & Jugner, 1968). The initial criteria were first developed in 1968 and argued that national screening programmes should only be considered for implementation if the condition is an important public health problem, with an identifiable early stage at which treatment is demonstrably more effective. The screening test itself must be acceptable, with adequate infrastructure for follow-up, and any risk of harm from the test must be outweighed by the likelihood of benefit (Wardle, Robb, Vernon & Waller, 2015). The UK NSC last updated their screening criteria in 2015 (NHS England, 2019). In the UK, screening for cervical, breast and bowel cancer are considered to meet the criteria for national cancer screening programmes (UK NSC, 2017).

1.3.2 Existing national cancer screening programmes in the UK

The UK currently has three organised cancer screening programmes for breast, cervical and bowel cancer. Breast screening is offered to women aged 50-70 in all UK nations. The screening uses a test called mammography which involves taking x-rays of the breasts. Mammography is offered every three years.

Cervical screening is offered to women aged 25-64 in the UK. It is offered every three years for women aged 25-49, and every five years for women 50-64. The test aims to pick up cell changes that could develop into cancer if left untreated and involves taking a sample of cells from the cervix.

Bowel screening is offered to men and women aged 60-74 in England, Wales and Northern Ireland. In Scotland, men and women aged 50-74 are offered screening. The screening programme sends a bowel cancer testing kit every 2 years to people eligible to take part. The kits sent out in the UK vary depending on country as each has its own bowel screening programme – those in England, Wales and Scotland are offered faecal immunochemical test (FIT), while those in Northern Ireland are offered faecal occult blood (FOB) tests. Both types of test involve collecting a sample of bowel movement at home and returning it by post to a screening centre for analysis.

In order to be invited to be screened for breast, cervical or bowel cancer in the UK, you must be registered with a GP. At present all invitations for breast and bowel screening are sent centrally, whereas invitations for cervical screening are sent via primary care.

1.3.3 Cancer screening uptake in Scotland

Uptake of the screening programmes vary. In Scotland, 71.2% of women invited to take part in breast screening attended their screening appointment (ISD Scotland, 2019a), 73.1% attended cervical screening (ISD Scotland, 2019b), and among men and women eligible for bowel screening 63.9% completed screening (ISD Scotland, 2019c). Analysis of Scottish uptake of cancer screening indicates that screening participation is lower for those in lower socioeconomic status groups across all of the cancer screening programmes offered. Of those eligible to take part, those who fall into the lowest SIMD group (SIMD 1) uptake for bowel screening is 46.5%, compared to those in the least deprived group (SIMD 5) who have an uptake rate of 68.9% (ISD Scotland, 2019c). Similarly, in Scotland's cervical screening programme, women from the most deprived areas are also less likely to take part in the screening programme (67% of those living in the most deprived areas attend, compared to 78% from the least deprived areas; ISD Scotland, 2019b). Breast screening uptake was 58.5% in the most deprived group, compared to 79.1% in the least deprived group (ISD Scotland, 2019a).

The difference in screening uptake contributes to widening health inequality in Scotland, with the cancer mortality rates between Income-Employment Index[1] group one and Income-Employment Index group ten being significantly different (Scottish Government, 2018). Of people in the 45-74-year age group, those in Scotland's most deprived areas are more than twice as likely to die of cancer than those in the least deprived (567.1 deaths per 100,000 population compared to 257.1 per 100,000 population, in 2017; Scottish Government, 2018).

There are a number of barriers to screening for deprived groups (Lo et al., 2013; Smith et al., 2016) and the way in which people are invited to screen may impact whether they choose to take part.

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[1] Income-Employment Index is a 'sub-measure' of SIMD, which includes the income and employment domains of the index only. The reasoning behind this was that income / poverty / employment are felt to be the best indicators of deprivation for health inequalities analysis

1.3.4 Screening tests for lung cancer

Early diagnosis of lung cancer is challenging because it can often be asymptomatic in early stages (Blandin Knight, Crosbie, Balata, Chudziak, Hussell and Dive, 2017). Most patients (75%) are therefore diagnosed when the disease is in advanced stages (stage III/IV) (Walters et al., 2012) and the window for successful treatment reduces as the disease advances (Blandin Knight et al., 2017). This highlights the significant need for the implementation of strategies for detecting lung cancer at an early stage.

The development of early detection screening for lung cancer has progressed rapidly in the last decade, with promising advances in low-dose computed tomography (LDCT) and alternative forms of screening such as lung cancer antibody detection (Blandin Knight et al., 2017).

1.3.4.1 Chest x-ray

Chest X-Ray (CXR) was the first form of lung cancer screening, with a number of trials evaluating the effectiveness of x-ray as a tool for early diagnosis in the 1970s, and the first large-scale randomised controlled trials (RCT) being carried out in the 1980s. Early trials all produced null findings, with CXR not making any significant difference in mortality (Frost et al., 1984; Kubik & Polak, 1986; Melamed et al., 1984). More recently the Prostate, Lung, Colorectal and Ovarian Cancer Screening trial (PLCO) found that there was no mortality benefit to annual screening with CXR compared to usual care (Oken et al., 2011). The results of these studies indicate the limited effectiveness of CXR as an early diagnosis screening test.

1.3.4.2 Low-dose computed tomography

Computed tomography (CT) produces more detailed images of the chest compared to CXR alone by combining x-ray equipment with advanced computer technology in order to generate multiple cross-sectional images of the inside of the body. The 3D scan images are interpreted by radiologists in order to identify potential pulmonary nodules that could be cancer.

The radiation dose of CT scanning is about 100 times higher than CXR (Blandin Knight et al., 2017). This is too high for the benefits of early diagnosis to outweigh the risks of radiation exposure. However, the development of CT scanning capabilities with lower radiation doses has made LDCT scanning a promising technique for the early diagnosis of lung cancer. LDCT has 22% of the effective radiation dose of a standard CT, making it more viable as a screening tool (Larke et al., 2011).

There have been a number of trials that have explored the effectiveness of LDCT in the detection of lung cancer, with a significant proportion of these studies carried out in Europe. So far, all of these trials have focused on at-risk populations, with eligibility commonly defined by age and smoking history (i.e. 20-30 pack years) (Blandin Knight et al., 2017). Unfortunately, a number of the studies did not have adequate statistical power to detect an effect on lung cancer mortality. Three Italian studies (Multicentric Italian Lung Detection Trial (MILD; n = 4099); Italian Lung Cancer Screening Trial (ITALUNG; n = 3206); and the Detection and Screening of Early Lung Cancer with Novel Imaging Technology trial (DANTE; n = 2472) all reported no mortality benefit to LDCT when compared to control groups (Infante et al., 2008; Lopes Pegna et al., 2013; Pastorino et al., 2012). Similar trials have been carried out in France (DEPISCAN; n = 765), Denmark (DLCST; n = 4104) and the UK (UKLS; n = 4055) but did not report on mortality as the focus was on the number of cancers detected at an early stage (Blanchon et al., 2007; Field et al., 2015; Saghir et al., 2012).The UKLS trial did, however, report that LDCT screening can be used to detect lung cancer at an early stage in over 80% of cases (Field et al., 2015).

There have also been some successes in reducing lung cancer mortality with the use of LDCT. At 10-year follow up of the Dutch-Belgian trial (NELSON; n =15,822) results indicated that lung cancer related mortality was 24% lower among current and former smokers who underwent LDCT, compared to those who underwent no screening (de Koning et al., 2020). The National Lung Screening Trial (NLST), carried out in the United States, conducted the largest LDCT RCT to date (n =53,454; The National Lung Screening Trial Research Team, 2011). Participants at high risk of lung cancer (aged 55-74; 30-pack year history; smoked within the past 15-years) were randomised to annual LDCT or CXR over three years. After follow-up, there was found to be a significant reduction in lung cancer mortality (20%), as well as a reduction in late-stage diagnosis in the LDCT group compared to the CXR group.

Despite the apparent success of the NLST, there has been some criticism, including overdiagnosis (Infante et al., 2012). Overdiagnosis is the term used when a condition is diagnosed that would otherwise not go on to cause symptoms or death (Welch & Black, 2010). Overdiagnosis is estimated to account for 18% of cancers in the NLST and could be an explanation for the higher detection rates in the LDCT group. The NLST also reported a high number of false positives in the LDCT arm (96%) compared to CXR (94%) (National Lung Screening Trial Research Team, 2011). This was thought to be the result of the trial criteria to refer any nodule more than 4mm in diameter for further investigation (Blandin Kinght et al., 2017).

However, as a direct result of the NLST, the US Preventative Services Task Force (USPSTF) have been supportive of the findings and made recommendations that annual screening for lung cancer with LDCT in asymptomatic people at high risk of lung cancer is beneficial. They further advised that the upper age limit be extended to 80 years (USPSTF, 2013). However, population screening using LDCT is yet to be recommended in the UK by the UK NSC. The UK NSC do not consider there to be enough evidence that a screening programme would be effective at improving lung cancer outcomes or that there is a suitable test for the use in a screening programme (UK NSC, 2007). This recommendation is currently under review in light of the recently published findings of the NELSON trial. Since the original recommendation in 2007, there have been a number of LDCT screening trials in the UK (e.g. UKLS) and the landscape is changing rapidly. Some of the focus is on understanding how we can minimise the risk of LDCT by improving our understanding of individual risk in a minimally invasive way. For example, in Scotland, the Early detection of Cancer of the Lung Scotland (ECLS) trial explored the use of biomarker detection to refine the criteria for LDCT screening.

1.3.4.3 Biomarker detection

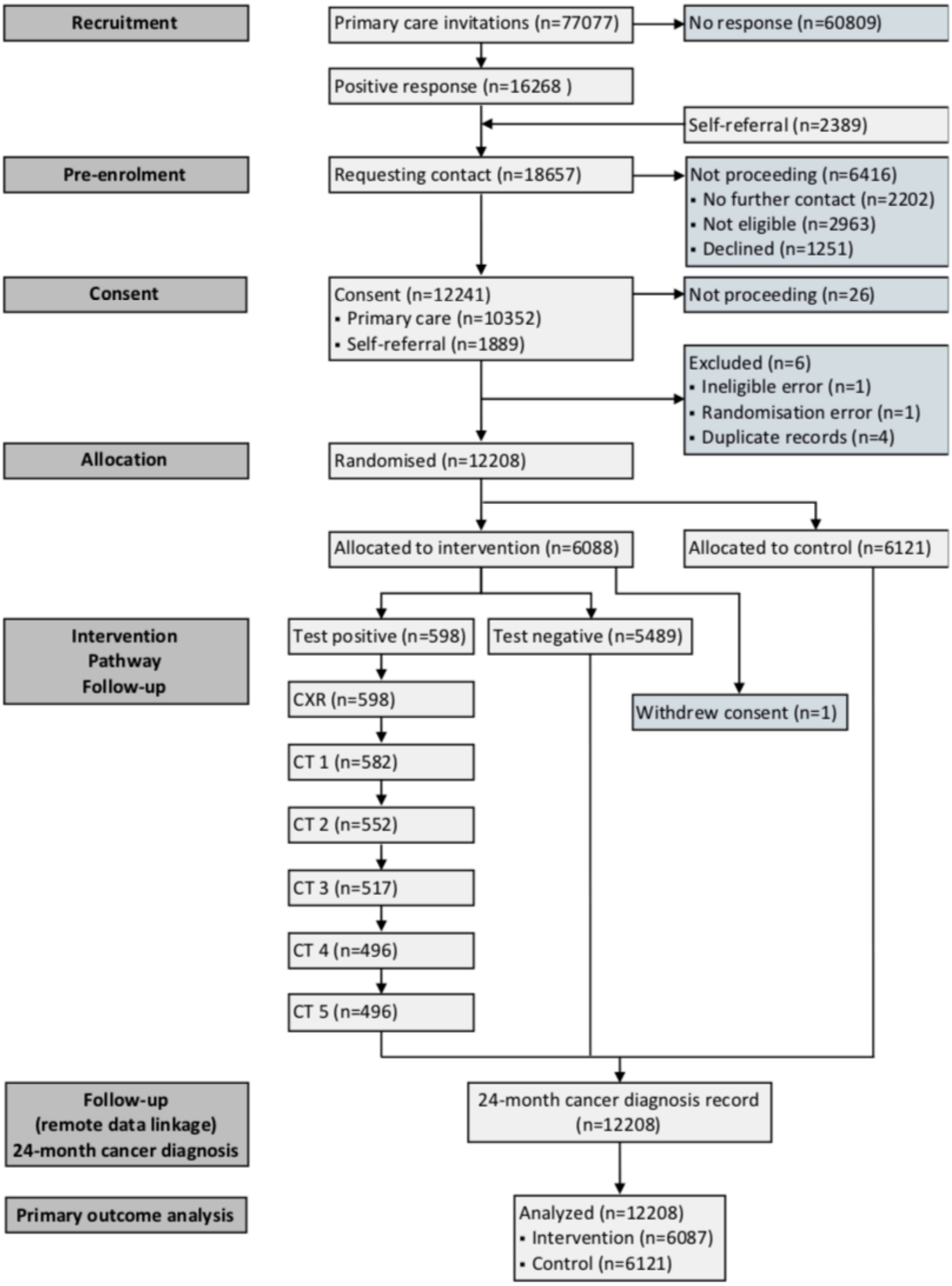
Biomarker testing has been posited as a promising development in the early detection of lung cancer, providing a form of screening that is not invasive and is cost effective (Brambilla et al., 2003). Biomarker detection can be carried out using a number of biological sources, including sputum, exhaled breath, urine, saliva and blood. A blood test is often the first choice as it is efficient and a minimally invasive way to obtain biomarkers (Seijo et al., 2018).

One such biomarker are the autoantibodies (AABs) that develop in response to an abnormal tumour antigen that presents in some patients with lung cancer. This AAB response often occurs before symptoms present or before image-based detection is possible (Seijo et al., 2018). It is estimated that AABs can be detected in peripheral blood in patients with solid tumours up to 3-4 years before symptomatic presentation (Yongliang et al., 2005). However, the sensitivity of AAB tests is only around 40%, making test accuracy a significant issue (Blandin Knight et al., 2017). It has been suggested that biomarker testing could be used to optimise image-based screening, such as LDCT, by providing further refinement of screening selection criteria. The use of biomarker testing in this way would help with risk management of LDCT and reduce the overall costs of lung cancer screening (Seijo et al., 2018).

The ECLS trial (n = 12,208) was a randomised controlled trial that aimed to use an enzyme-linked immunosorbent assay (EarlyCDT-Lung) that measures seven different AABs to identify those at high risk of lung cancer (Sullivan et al., 2020). Participants of the trial provided a blood sample before being randomised to the intervention arm or control arm (figure 1.2). Participants allocated to the intervention arm were tested with the EarlyCDT-Lung test. If this was positive, they received a baseline CXR (in order to prioritise access to CT for patients with positive findings on CXR) and chest LDCT-scan followed by 6-monthly LDCT scans up to 24 months post randomisation. Participants allocated to the control arm, and those who tested negative, received standard clinical care in the NHS in Scotland following national guidelines for identification and management of symptoms suggestive of lung cancer with no further study investigations. After a two-year follow-up, a total of 127 lung cancers were detected in the study population across both control and intervention arms. Those in the intervention arm were detected at an earlier stage, compared to those in the control arm. Participants in the intervention arm were diagnosed with lung cancer, on average, 87.3 days earlier compared to the control arm. However, there were no significant differences in lung cancer mortality between the intervention and control groups.

The ECLS trial has indicated that biomarker detection can be effective in detecting lung cancer at an earlier stage. Further investigation is required to determine the long-term impact of the EarlyCDT-Lung test on mortality, with additional follow-up analysis planned after five and 10 years.

Figure 1-2: ECLS Trial Consort Flowchart (Sullivan et al., 2020)



1.3.4.4 Sputum analysis

There is an association between abnormal sputum cytology and lung cancer (Prindiville et al., 2003). Sputum cytology is a non-invasive and non-radiological test that could be used for the early detection of lung cancer. The test does not require any specialist equipment, making sample collection simple and it can be carried out at home.

However, early studies have failed to reduce lung cancer mortality (Blandin Knight et al., 2017; Fontana et al., 1975). More recently, a randomised controlled trial in the UK aimed to use a sequential screening approach to target those with COPD by using a combination of sputum cytology, LDCT and autofluorescence bronchoscopy to detect lung cancer. LungSEARCH (n = 1568) randomised participants into either a control arm (usual care) or surveillance arm. The surveillance arm included five annual sputum screenings, with further investigation with LDCT and autofluorescence bronchoscopy if sputum cytology indicated abnormalities. After five-year follow-up there were 42 lung cancers among 785 screened individuals and 36 lung cancers among 783 controls. There was found to be no significant difference in the detection of early stage lung cancers or lung cancer mortality (Spiro et al., 2019).

1.3.5 Potential harms of lung cancer screening

The benefits of cancer screening are clear, with screening enabling the early detection of cancers, as well as supporting earlier treatment and decreasing cancer mortality. However, there are a number of risks associated with cancer screening that must be considered to ensure that participants of cancer screening are able to make an informed decision about taking part.

Informed decision-making is fundamental to the ethical implementation of organised cancer screening programmes. Informed decision-making involves providing participants with adequate information about screening in order to weigh up and use the information to make decisions consistent with their values (Marteau, Dormandy & Michie, 2001). In practical terms, this includes providing screening candidates with standardised information material, ensuring both benefits and risks of screening are presented in a balanced way.

As indicated by previous RCTs, lung cancer screening can miss cancers and can produce false negative results, with cancers often developing during screening intervals (Pinsky, 2014; The National Lung Screening Trial Research Team, 2011). In addition to the harm caused by false negatives, false positives can also cause significant challenges. In LDCT, there has been found to be a high rate of false positives, where screening detected nodules that are harmless or benign. A systematic review of lung cancer LDCT trials found that nodules were detected in 20% of screening participants, with 90% of these being benign (Bach et al., 2012). The associated diagnostic procedures, that are the result of false positives, can cause further harm, as well as psychological distress. A matched cohort study of the Dutch Lung Cancer Screening Trial participants found that receiving a false positive result in lung cancer screening was more likely to lead to higher rates of negative short-term psychosocial consequences, compared to those in the control group and the true-negative group (Rasmussen, Siersma, Malmqvist & Brodersen, 2020).

Overdiagnosis has been highlighted as a potential risk of lung cancer screening, with cancers detected that would not have become symptomatic or caused death. Overdiagnosis can lead to unnecessary and harmful treatments causing negative physical and psychological adverse effects (Welch & Black, 2010).

The screening test can also cause potential harm, although most are non-invasive. LDCT and CXR have risks associated with radiation exposure, with exposure increasing with the repeated scans that are often required to monitor abnormal screening results (Bach et al., 2012). All radiation poses the risk of causing cancer, including the radiation produced by cancer screening. Modelling, using the NLST data, predicts approximately one cancer death is caused per 2500 people screened (Bach et al., 2012). The risk of radiation caused by lung cancer screening typically presents 10-20 years later, therefore the benefit of preventing lung cancer deaths is greater than the risk of radiation for those over the age of 55 (Bach et al., 2012). The risk posed by radiation highlights the need for ‘triage’ before using LDCT as a tool for screening, with the developments in biomarker and sputum analysis providing potential benefits to lessen the risk of unnecessary radiation exposure.

Chapter 2: Achieving equitable uptake - psychosocial predictors of cancer screening uptake

2.1 Challenges for lung cancer screening

2.1.1 Selecting a target population

Optimal delivery of lung cancer screening requires the targeting of those individuals most at risk. Screening programmes in the UK, such as bowel, cervical and breast screening, set eligibility for screening by age. However, it is unclear if those not in high risk categories for lung cancer screening would benefit from lung cancer screening. For example, there is limited evidence of the benefit of lung screening for never-smokers (Blandin Knight, 2017). Further analysis of the NLST data, stratified by lung cancer risk, indicated that screening with LDCT prevented the greatest number of deaths among participants who were at highest risk and prevented very few deaths in those at lowest risk. Further, the study also found that there was a significant decrease in the number of false positives as participant risk level increased, decreasing the need for unnecessary diagnostic and invasive test procedures (Kovalchik et al., 2013). As a result, it might be more appropriate to have a more refined, risk-based eligibility criteria if a screening programme was to be implemented.

Currently, there is only one widely implemented lung cancer screening programme. The US screening programme is based upon the eligibility criteria of the NLST with an increased upper age limit (see section 1.3.4.2), however this has been criticised for not having a more risk-based approach by only including age and pack-year history (Marcus, Raji & Field, 2015). Other lung cancer screening trials have had variable criteria for eligibility, with some taking an individual risk-based approach. The UK based Liverpool Lung Project (LLP), in addition to the standard age and smoking history criteria, developed a risk prediction model that incorporated family history of lung cancer, previous cancer diagnoses, history of respiratory conditions (such as COPD, bronchitis, emphysema and pneumonia) and work place exposure to asbestos (Cassidy et al., 2008). It is suggested that this more advanced individual risk-based model could predict approximately two-thirds of lung cancers within 5-years, screening only 30% of the population. This more restricted screening criteria could reduce the cost of a screening programme while also screening those most at risk (Cassidy et al., 2008). However, there are ethical considerations that must also be addressed if this approach was implemented. There is a substantial risk of missing a proportion of lung cancers in individuals who do not meet the strict eligibility criteria.

Regardless of eligibility criteria of implemented screening programmes or screening trials, evidence suggests that there are observable inequalities in the uptake of cancer screening. It is unclear how an individual risk-based approach to eligibility criteria would impact screening uptake in those who are eligible.

2.1.2 Sociodemographic predictors of uptake

The sociodemographic characteristics of people who do and do not attend cancer screening are important to the understanding of possible health inequalities that may exist. Failing to acknowledge the possible inequalities in cancer screening, and addressing the potential causes, further exacerbates and widens the health inequality gap that exists between some groups. The identification of health inequalities allows for positive action to be taken to reduce disadvantage and improve health outcomes. Like many health behaviours, distinct inequalities exist in screening participation.

Age, sex, ethnicity and socioeconomic status are all predictors of uptake of cancer screening (Sarma, Silver, Kobrin, Marcus & Ferrer, 2019). Understanding and monitoring uptake across different demographic groups helps us to understand the variation in uptake and target interventions towards certain groups where uptake is low.

There is only one functioning lung cancer screening programme worldwide, so there is limited opportunity to explore the sociodemographic predictors of this type of screening. As a result, we can draw on evidence from other, more developed, cancer screening programmes and screening trials to help us further understand what could be expected with regard to uptake if lung cancer screening was widely implemented.

2.1.3 Sex

There is an underlying assumption that men are less willing to engage with healthcare services, and subsequently, are less likely to also participate in cancer screening. However, research examining the sex differences in the participation of bowel cancer screening has been varied. In a study assessing the demographic and psychological mediators of sex differences in uptake of flexible sigmoidoscopy screening for bowel cancer concluded that attendance rates are significantly higher in men, compared to women (Wardle, Miles & Atkin, 2005). This result is contrary to the expectation that men are considerably less likely to utilise health services or be convinced of the value of preventative behaviours (Wardle et al., 2005). However, further bowel cancer screening literature also indicates that women are more likely to take part in home-based faecal occult blood testing (von Wagner et al., 2011).

The limited literature available on the uptake of lung cancer screening indicates that men are more likely to participate. In the UKLS trial, women who were at high risk of lung cancer, were less likely to participate compared to high risk men (Ali et al., 2015). Similarly, a systematic review of participation in lung cancer screening programmes also indicated that men are more likely than women to participate, with the mean participation rate for men being approximately 56% (Schütte et al., 2018). However, research from the US indicates that there is no sex difference in uptake of lung cancer screening. A cross-sectional study of the sociodemographic variables associated with lung screening behaviour in Indiana found that there was no significant difference in sex between screeners and non-screeners (n =438) (Carter-Harris et al., 2018). This is further supported by analysis of the LDCT screening programme in the US, which also indicates that there is no difference in uptake between males and females (Yong et al., 2020). Overall, the uptake of lung screening in the US is low (<6%) and this analysis of the lung screening programme is limited to only three states (Florida, Nevada and Georgia). Further extensive analysis is required to ensure generalisability of these findings.

2.1.4 Age

Across existing cancer screening programmes, the evidence of difference in uptake by age is varied. There is no apparent difference in uptake by age in breast screening, but younger women are less likely to participate in cervical screening (Wardle et al., 2015). Uptake of bowel cancer screening is lowest among adults aged 60 to 64 years (Sarma et al., 2019) with uptake increasing with age (von Wagner et al., 2011).

Within the current lung cancer screening literature, the UKLS trial found that older age is associated with non-uptake of lung screening (Ali et al., 2015). However, uptake of lung screening in the US does not appear to differ by age (Yong et al., 2020).

2.1.5 Ethnicity

There are differences in uptake of cancer screening by ethnicity. In the UK, participation is higher in those who are White in breast, cervical and bowel screening (Wardle et al., 2015). A recent study of bowel cancer screening uptake in Scotland reported complex patterns of variation in screening by ethnic groups. Those from South Asian groups had significantly lower uptake in screening compared with the White Scottish population, but there was higher uptake among Chinese and other White British populations (Campbell et al., 2020). In the US, African Americans have lower bowel cancer screening rates but similar rates of breast and cervical screening to non-Hispanic white Americans, with Hispanics reporting lower rates of breast, cervical and bowel cancer screening compared to non-Hispanics (Sarma et al., 2019).

Low uptake among non-white groups is also evident in lung cancer screening. A study (n = 675) exploring the racial differences in lung cancer screening uptake and follow-up adherence in the US indicate disparities between white and African American study participants (Lake et al., 2020). Black patients were significantly less likely to undertake LDCT screening and have longer follow-up time intervals compared to white participants. The authors were unable to identify reasons for this disparity but highlight potential biases in the healthcare system that could account for issues in uptake and follow-up. This study did not undertake analysis of other ethnic group uptake beyond participants who were white or African American. This is a clear limitation given the ethnic diversity of the US population and does not provide insight into other underserved groups, such as Hispanic Americans.

It is markedly clear that the picture with regard to variation in lung cancer screening by ethnicity is not complete and is an area that requires further research.

2.1.6 Socioeconomic status

Socioeconomic status (SES) has been found to be a significant predictor of cancer screening uptake. In general terms, low SES leads to low uptake of screening behaviour and increased health inequalities (Weller & Campbell, 2009). SES acts as a measure of a person’s access to social and economic resources and is usually determined by markers such as education level, income or occupation (Adler and Newman, 2002).

SES can also be described as socioeconomic position or socioeconomic group, and these three terms are often used interchangeably (Conway, McMahon, Brown & Leyland, 2019). SES is commonly used as an indicator of socioeconomic deprivation level, with lower SES equating to higher levels of deprivation (Galobardes, Lynch & Smith, 2007).

There are a number of ways to measure SES, but it is frequently measured with individual measures of SES (such as, income, education level, occupation and household indicators), or composite measures of SES (a combination of individual measures) (Galobardes, Lynch & Smith, 2007). Composite measures can be used to determine the SES of individuals or groups and capture multiple dimensions of SES. Composite measures are commonly used to measure area-level SES, such as SIMD (Scottish Government, 2020b).

Moser, Patnick & Beral (2009) studied the relationship between women's reported use of breast and cervical screening in the UK and their sociodemographic characteristics and concluded that indicators of wealth were important for predicting uptake of breast screening, but not cervical screening. Those who had a higher economic position based on markers of wealth (vehicle ownership and house ownership) were more likely to attend breast screening, with this group also significantly more likely to be inclined to be screened for breast cancer before, or at the onset, of symptoms. Similarly, cervical screening uptake in England was found to be lower in those from more deprived areas (Bang, Yadegarfar, Solijak & Majeed, 2012). In the US, the proportion of women who attended breast and cervical screening increased with increasing education and income level, with uptake lowest in those who did not have healthcare insurance (White et al., 2017). A similar pattern is evident in bowel cancer screening, with uptake lowest in the most deprived groups in the UK (Joseph et al., 2012; von Wagner et al., 2011).

Other contributing factors might also play a role in why those from lower SES groups are less likely to participate in cancer screening. For example, health literacy could act as a mediating factor that helps to explain the relationship between SES and inequalities in screening uptake (Stormacq, Van den Broucke & Wosinski, 2019; Kobayashi, Wardle & von Wagner, 2014). Those from lower SES groups are more likely to have lower levels of health literacy, and therefore knowledge about cancer and cancer screening (Peterson et al., 2007).

Similarly, variation in other individual beliefs may also act as mediators between SES and screening uptake. Fatalism is believed to partly explain some variation in cancer screening uptake, with those from lower SES groups being more fatalistic and less positive about early detection (Beeken, Simon, von Wagner, Whitaker & Wardle, 2011). Dispositional optimism has also been found to play a mediating role in health, with those with from lower SES groups more likely to view the future as containing more negative events (e.g. more pessimistic) (Robb, Simon & Wardle, 2009). However, it is unclear whether optimism plays specific a role in cancer screening uptake.

Overall, those with higher SES appear to be overrepresented in lung cancer screening programmes, with those from more deprived backgrounds less likely to participate (Schütte et al., 2018). This is problematic for the development of a national screening programme. Lower SES is associated with smoking status and lung cancer risk. Without sufficient uptake from those from deprived groups, a national lung cancer screening programme could further widen lung cancer mortality inequalities.

2.2 Barriers to lung cancer screening

With cancer screening rates being less than optimal, exploring the motivational and volitional factors associated with uptake of screening is becoming increasingly relevant in public health (Eiser & Cole, 2002). Practical, cognitive and emotional barriers can impede uptake and understanding the variation in barriers experienced by different groups helps us to identify modifiable variables as targets for intervention. Significant variation in uptake by demographic characteristic indicates that there is much to be done to support high-risk groups overcome the barriers they experience when invited to participate in cancer screening.

Research exploring the barriers to lung cancer screening is sparse, but insight gained from our existing knowledge of barriers to other types of cancer screening, and work exploring the uptake of lung cancer screening trials, have assisted in building a better understanding of the common barriers experienced.

2.2.1 Practical barriers

Practical barriers play a significant role in the uptake of cancer screening and have been found to be predictive of screening uptake in other forms of cancer screening (Waller, Bartoszek, Marlow & Wardle, 2009).

2.2.1.1 Financial barriers

Financial constraints are a barrier to screening in countries where healthcare is not covered by the state. The LDCT screening for lung cancer in the US is covered by the Government insurers, Center for Medicare and Medicaid Services, as preventative service for eligible beneficiaries. However, this form of insurance coverage only covers the cost of the screening and does not cover the costs associated with the monitoring of detected nodules. In short, eligibility ceases when a person receives an abnormal screening result and therefore it is no longer deemed to be a preventative service (Li et al., 2018). Despite the ‘universal’ insurance coverage of lung cancer screening, uptake is lowest among those who have no insurance coverage, or those with government-based health insurance (Yong et al., 2020). In a cross-sectional study that aimed to understand lung cancer screening behaviour there was a significant difference between screeners and non-screeners by insurance status. Participants in receipt of government-based insurance were less likely to be screened and were more likely to be unaware of lung cancer screening (Carter-Harris et al., 2018). The association between insurance coverage and income in the US are well known, with government-based health insurance predominantly providing coverage for low income populations (Pezzi et al., 2020). As a result, those who do not have a higher level (i.e. private insurance) of coverage might find the constraints of their insurance plan to be a barrier to screening causing further exacerbation of health inequalities between high and low SES groups.

2.2.1.2 Geographic barriers

The geographic location of screening test facilities can be a barrier to uptake of cancer screening, with those required to travel further from home less likely to attend a screening appointment (Onitilo et al., 2014). As a consequence, distance from healthcare services can have an adverse impact on cancer outcomes, with increased travel requirements being associated with later stage cancer diagnosis and increased cancer mortality (Ambroggi, Biasinim Giovane, Fornari & Cavanna, 2015). The effect that geography has on cancer outcomes is even more evident in countries with a high proportion of rural and remote communities, such as Australia (Tracey, McCaughan, Badgery-Parker, Young & Armstrong, 2015). Screening appointments can be difficult to get to geographically as they are often held in hospitals, and require significant travel (Carter-Harris, Brandzel, Wernli, Roth & Buist, 2017).

The inaccessibility of some screening services means that those from rural or remote areas are required to travel long distances to be screened (Bobridge et al., 2017). However, it is not a barrier that is unique to those from rural or remote areas, it is also a barrier reported to those living in urban areas (das Nair, Orr, Vedhara & Kendrick, 2014). Lung cancer screening using LDCT usually require people to travel to larger hospitals, which can be located in central urban locations or sometimes on the outskirts of cities. For those living in larger towns and cities, without access to a vehicle, this can be problematic and requires some to rely upon public transport. A study exploring the impact of car ownership, and public transport usage, in cancer screening coverage in England, indicates that car ownership is significantly associated with improved breast and cervical cancer screening uptake. Public transport use was associated with reduced breast screening uptake, but not cervical screening uptake because this type of screening is usually performed in primary care settings (Wang, 2016).

Mobile screening units, such as those used in breast screening in the UK, have been proposed as a way to increase uptake in areas where uptake is low. Mobile screening units for breast cancer screening appear to increase access to services for under-screened groups (Greenwald, El-Zein, Bouten, Ensha, Vazquez & Franco, 2017). However, it is uncertain if offering this type of service for lung cancer screening will reflect the success of mobile mammography units. A pilot study that aimed to explore the difference in lung health check uptake between mobile and hospital-based (fixed) CT units in London found that there were similar levels of participant uptake at both mobile and hospital-based screening facilities (Bartlett et al., 2020). Similar pilot studies in Manchester have indicated that providing lung health checks in the proximity of local shopping centres is effective and engages high-risk populations in deprived areas (Balata et al., 2019; Crosbie et al., 2019).

2.2.1.3 Competing priorities

Competing priorities are often cited as a barrier to screening. This includes work commitments, caring responsibilities and co-morbidities (Ali et al., 2015). Often scheduling and attending a cancer screening appointment is not convenient or perceived to be a priority compared to other aspects of individuals' lives (NHS England, 2019). For example, screening appointments for breast and cervical cancer are offered to those who are of working age in the UK, as is the LDCT screening offered in the US. As screening appointments are predominately offered during daytime working hours, those wishing to attend their appointment might be required to take time off work, which sometimes has knock-on financial consequences (Travis, Ashley, Pownall & O'Connor, 2020). In response to this, a recent review of adult screening programmes in England, conducted by Professor Sir Mike Richards, recommended financial incentives for screening providers to promote out of hours and weekend appointments (NHS England, 2019).

Those with caring responsibilities also often find it difficult to find time to attend their screening appointment. Rearranging appointments to a more convenient time can also be problematic as there can be a lack of flexibility built into healthcare booking systems (Travis et al., 2020).

Living with two or more health conditions could also be perceived to be a barrier to cancer screening. Comorbidity negatively impacts cancer screening uptake, and in some cases is associated with more advanced stage cancer at time of diagnosis (Renzi et al., 2019). A European cross-section study of the impact of comorbid conditions on participation in an organised bowel cancer screening programme reports that having three or more chronic diseases was associated with lower uptake of screening (Guiriguet et al., 2017). Having to manage multiple conditions can be challenging, with some individuals having to prioritise their existing conditions over attending early detection screening appointments (Ali et al., 2015).

2.2.2 Psychological barriers

Cognitive barriers, such as knowledge, perceived risk and attitudes, are significant determinants of cancer screening uptake (Sarma et al., 2019). The cognitive constructs are commonly described within health behaviour theories, some of which have been used to explain cancer screening participation, namely: Health Belief Model (HBM), Theory of Planned Behaviour (TPB), Precaution Adoption Process Model (PAPM), and the Transtheoretical Model (TTM) (Wardle et al., 2015). It is believed that these cognitive determinants of screening uptake are modifiable and, therefore, could be the focus of future interventions.

2.2.2.1 Knowledge and awareness

Knowledge and awareness of cancer and cancer screening are important factors in the uptake of early detection screening. An understanding of cancer risk, risk factors, cancer symptoms and the benefits of cancer screening are necessary for people to make an informed decision about their participation. The more knowledge or awareness a person has about cancer and cancer screening increases the likelihood that they will be screened (Berkowitz et al., 2008; Rakowski et al., 2006). This has been well exemplified in the case of bowel cancer screening, with lack of knowledge about bowel cancer and bowel cancer screening commonly reported as a barrier to screening adherence (Garcia, Buvlla, Nicolas-Perez & Quintero, 2014). Health literacy is associated with level of knowledge, with those with lower levels of health literacy having less knowledge about cancer and cancer screening (Peterson et al., 2007) and being less likely to attend cancer screening (Sarma et al., 2019; Kim & Han, 2015). This may also help us to understand the contribution that level of knowledge makes to socioeconomic differences in uptake. For example, an analysis of the Health Information National Trends Survey (HINTS) in the US indicates that those from higher SES groups are more likely to have better knowledge about prevention of lung cancer and lung cancer screening (Rutten, Hesse, Moser, McCaul & Rothman, 2009). Education level is often used as an indicator of SES, with those from more deprived groups more likely to have lower educational attainment (Conway et al., 2019).

Level of knowledge is a modifiable behaviour, making health education a target for intervention development. Patient education has been found to be somewhat successful in increasing knowledge of cancer and cancer screening. A meta-analysis of the effect cervical cancer education has on screening rates indicates that women who received educational interventions were significantly more likely to screen for cervical cancer, compared with women in control groups (Musa et al., 2017).

2.2.2.2 Attitudes

Public perceptions of cancer screening are generally very positive (Wardle et al., 2015). A study exploring enthusiasm for cancer screening in the UK (n = 2024) indicates that attitudes towards cancer screening are overwhelmingly positive, with almost 90% of survey respondents believing that cancer screening is ‘almost always a good idea’ (Waller et al., 2015). This belief is not unique to people from the UK, with similar results reported from the US (Schwartz, Woloshin, Fowler & Welch, 2004). A stronger belief about the effectiveness of cancer screening is associated with increased participation (Berkowitz et al., 2008). Conversely, negative beliefs about cancer screening, such as fatalism and fear, are negatively associated with cancer screening uptake (Lo et al., 2013).

Despite the overall positivity towards cancer screening, there are concerns that individuals might overemphasise the benefits of screening and underestimate the potential limitations and harms of screening (Schwartz et al., 2004; Waller et al., 2015). A systematic review exploring the expectations of the benefits and harms of treatments, tests or screening indicates that over 50% of participants overestimate the benefits of cancer screening, and only between 9-20% of participants could correctly identify the potential harms of cancer screening (Hoffman & Del Mar, 2015).

2.2.2.3 Perceived risk

Perceived risk is a construct that features in many theoretical models that have been used to explain screening behaviour (Wardle et al., 2015). Perceived risk is often divided into three distinct dimensions: perceived likelihood of developing the disease; perceived susceptibility/vulnerability to the disease, and perceived severity of the disease (Brewer et al., 2007). These dimensions collectively contribute to the formation of a person's overall view of their perceived risk. However, perceived risk is often not an accurate reflection of true risk (Ferrer & Klein, 2015). For example, those who incorrectly consider themselves to be at low risk of developing cancer can be said to have 'unrealistic optimism' (Weinstein, 1980). This form of bias is common across different health protective behaviours, including cancer screening, with individuals underestimating their risk, particularly when they compare their own risk to other peoples' (Ferrer & Klein, 2015). It is, therefore, evident that the formation on accurate risk perceptions has important consequences for health outcomes. However, the association between risk perception and screening participation is unclear (Wardle et al., 2015).

For some forms of cancer screening, such as breast screening, higher perceived risk is positively associated with increased participation. A meta-analysis exploring the predictors of perceived breast cancer risk, and the relation between perceived risk and breast cancer screening, found a consistent association between mammography participation and perceived risk, although the study did report a small effect size (Katapodi, Lee, Facione, & Dodd, 2004). However, there is no clear consensus about the association between risk perception and participation in other forms of screening (Vernon, 1999).

More recent work on lung cancer screening suggests that worry and perceived seriousness of a lung cancer diagnosis are strongly associated with the desire to participate in lung cancer screening (See et al., 2020). Furthermore, unrealistic optimism does not appear to occur among high risk participants (such as current smokers) of lung cancer screening trials who report either accurate or overly pessimistic perceived risk (Park et al., 2009; van den Bergh et al., 2009). Although, in contradiction, non-participants in the UKLS trial who perceived themselves to be at high risk of lung cancer, indicated lower intention to be screened (Ali et al., 2015). The picture of the impact perceived risk has on participation in screening is unclear; it can act as both a barrier and a motivator that is dependent on how the individual responds emotionally to their risk.

2.2.3 Emotional barriers

Cancer is an emotive topic, and quite rightly individuals often have an emotional response to cancer and cancer screening, which might influence their participation in screening. Negative responses such as fear, fatalism and perceived stigma can adversely impact the decision people make about cancer screening and can lead to some maladaptive coping mechanisms such as avoidance and denial (Sarma et al., 2019).

It is recognised that the beliefs about lung cancer and beliefs about lung cancer screening can be different (see section 2.2.2.2). Lung cancer as a disease may evoke negative psychological responses, while lung cancer screening, as an early detection medical procedure, may not. For this reason, a distinction between lung cancer and lung cancer screening is made and are identified as distinct beliefs. Despite being distinct concepts, it is understood that beliefs about one (e.g. lung cancer) might significantly impact beliefs about the other (e.g. lung cancer screening) and therefore act as a determinant of screening uptake.

2.2.3.1 Fear

Like perceived risk, the association between cancer fear and cancer screening uptake has been mixed. Fear of cancer can be both a barrier and a facilitator of cancer screening (Consedine, Magai, Krivoshekova, Ryzewicz & Neugut, 2004). Despite improvements in prognosis and treatment, cancer worry remains consistently high, enduring for decades (Wardle et al., 2015). In the 1960’s 31% of adults in the US considered cancer to be a significant worry in their lives (Kirscht, Haefner, Kegeles, & Rosenstock, 1966). More recently, a large community-based study in the UK (n = 7, 971) found that more than half (59%) of this older adult sample reported cancer as their greatest health fear (Vrinten et al., 2014). Cancer fear in this sample was found to be higher in women, those with lower education levels and those from ethnic minority backgrounds (Vrinten et al., 2014).

Further, those with cancer fear are more likely to be fatalistic about cancer and avoid cancer information (Miles, Voorwinden, Chapman & Wardle, 2008). This association between fear and avoidance of cancer information could perpetuate negative beliefs about cancer.

Studies exploring the relationship between fear and cancer screening participation have been contrasting (Hay, Buckley & Ostroff, 2005). Some studies indicate that fear increases participation in breast and bowel cancer screening (Moser et al., 2007; Hay et al., 2006), while others indicate that fear is a barrier to screening in some ethnic groups (Good, Niziolek, Yoshida & Rowlands., 2010; Vrinten et al., 2016). Variation in results about the association between fear and cancer screening participation might be because of the way in which studies measure cancer fear or worry (Consedine et al., 2004). It is hypothesised that variation is the result of the relationship between cancer worry and screening participation appear to be an 'inverted U-shape' (Hay et al., 2005; Consedine et al., 2004). This means that moderate levels of worry facilitate screening participation, while both high and low levels of fear inhibit cancer screening participation.

Cancer fear research, exploring the association with lung cancer and lung cancer screening, is not as well developed, but early research into what individuals fear about lung cancer offers some insight into whether fear is a barrier or motivator to this form of screening. Commonly reported fears include fear of a cancer diagnosis (Delmerico, Hyland, Celestino, Reid & Cummings, 2014) and concerns about having a CT scan as part of screening (Cataldo, 2016; Jonnalagadda et al., 2012) with both of these reported fears being associated with lower intention to screen for lung cancer. Non-participation in lung cancer screening is associated with fatalistic beliefs, and avoidance, leading us to speculate whether fear will also play a similar role in lung cancer screening (Patel et al., 2012). Lung cancer screening is unique from other forms of cancer screening because it is only used in those who are high risk, meaning that fear among this group towards this form of screening, may vary considerably from other types of cancer.

2.2.3.2 Fatalism

Cancer fatalism, or the belief that a cancer diagnosis is out of individual control or that cancer always leads to death, can be an emotional barrier to cancer screening. Fatalism has been associated with lower cancer screening uptake in a number of cancer screening programmes, including cervical, breast and bowel cancer (Chavez, Hubbell, Mishra &

Valdez, 1997; Powe & Finnie, 2003; Vernon, 1997). A cross-sectional study that compared the barriers to bowel cancer screening with the barriers of breast and cervical screening results indicates that cancer fatalism is a significant barrier associated with general non-participation in screening to cancer screening (Lo et al., 2013). Avoidance, a maladaptive coping mechanism, was often cited by people who did not attend any form of cancer screening indicating a general negative perception to all cancer screening (Lo et al., 2013). Fatalistic beliefs are associated with delayed presentation and diagnosis and are more common in those from more deprived groups, those with lower education levels and health literacy levels (Agustina et al., 2018; Kobayashi & Smith, 2016; Niederdeppe & Levy, 2007).

Cancer fatalism has also been found to be a barrier to lung cancer screening. A qualitative study (n = 60) embedded within the Lung-SEARCH trial, explored the attitudes towards participation of lung cancer screening. Themes of fatalism, worry, and avoidance in those who declined to be screened were reported (Patel et al., 2012). Those who held fatalistic beliefs about lung cancer were all current smokers that considered that lung cancer was either inevitable or predetermined (e.g. outside their control) and, therefore, taking part in screening was pointless. Fatalism, as a barrier to lung cancer screening, is supported by similar studies from the US (Jonnalagadda et al., 2012).

Often, as a response to fatalistic beliefs, people put coping mechanisms in place to help deal with these feelings. However, not all coping mechanisms are applied effectively and often individuals will adopt maladaptive coping mechanisms, such as avoidance or denial (Patel et al., 2012). Stoicism and other forms of avoidance are a possible explanation for non-attendance of cancer screening. A stoic attitude – a belief that controlling emotions leads to less suffering and a view that death is inconsequential – is often considered to be a deliberate life choice (Moore, Grime, Campbell, & Richardson, 2013; Pathak, Wieten, & Wheldon, 2017). In the context of cancer, choosing not to worry and avoiding information about cancer is a way to cope with what they feel they have no control over. Stoicism is associated with an indifference to, and tolerance of, adversity – having a "stiff upper lip". It is most commonly associated with older men and it is hypothesised that stoicism is a coping strategy that they adopt because they find it more difficult to identify and express their emotions (Cairncross, Magee, & Askham, 2007; Calderón et al., 2017). Asking for help can be perceived as a weakness, therefore, stoicism has been linked with reduced help-seeking behaviour (Pathak et al., 2017). Coping strategies of this type have been reliably associated with heightened levels of distress and a reduction in quality of life in cancer patients (Aguirre-Camacho, González-Márquez, & García-Borreguero, 2017; Gillanders, Sinclair, MacLean, & Jardine, 2015). Stoicism has been identified in research as a coping strategy used by men in their response to prostate cancer (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014; Gannon, Guerro-Blanco, Patel, & Abel, 2010). However, there is limited literature exploring how stoicism impacts other forms of cancer and cancer screening. One study, exploring the uptake of breast cancer preventative therapy in the UK, indicates that stoicism within the family influenced women's beliefs towards taking regular medication and reduced the likelihood of discussing tamoxifen[2] with family members (Hackett et al., 2018). Similarly, stoicism has been found to influence the uptake of bowel cancer screening in men with those with more stoic attitudes less likely to attend (Oster, McGuniness & Turnbull, 2015).

2.2.3.3 Cancer stigma

Lung cancer, unlike some other types of cancer, often carries a stigma that can be detrimental to those who are diagnosed with the disease and can slow the diagnosis (Chapple, Ziebland & McPherson, 2004). A fundamental definition of stigma is an 'attribute that is deeply discrediting' which can reduce an individual from a 'whole and usual person to a tainted, discounted one' (Goffman, 1963). Those attributes considered to be negative within a society are those that contradict the 'social norms' of that society. Individuals who do not conform to societal norms are likely to be discriminated against (Turner, 1991). A diagnosis of lung cancer can be associated with attributes perceived to be negative - for example, smoking. As a result, individuals with lung cancer may be stigmatised or blamed for their own illness (Weiss, Stephenson, Edwards, Rigney & Copeland, 2014). There are two distinguishable types of stigma: public/social stigma and self-stigma (Corrigan, 2004). Public, or social, stigma can be defined as the stigmatising ideas of one group about another group - for example, society's general belief about lung cancer. When asked, participants in a number of studies believed that individuals with lung cancer are partially or fully to blame for their illness (Weiss et al., 2014; Gulyn & Youssef, 2010; Chapple, Ziebland & McPherson, 2004). Johnson, Brodsky & Cataldo (2014) consider this stigma and blame to be felt equally by smokers, past-smokers and never-

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[2] Tamoxifen – a hormone therapy for breast cancer, sometimes used in women who have a high risk of breast cancer, to prevent breast cancer from developing.

smokers. This follows the common misconception that those with lung cancer are all current smokers (Carter-Harris, 2014).

‘Self-stigma’ occurs when a member of the stigmatised group internalises the beliefs held by wider society (Barney, Griffiths, Jorm & Christensen, 2006; Corrigan, 2004). Vogel, Wade & Hackler (2007) considers there to be a direct relationship between public and self-stigma, concluding that one’s perceptions of public stigma may play a role in the development of self-stigma. Moreover, self-stigma and attitudes towards help-seeking have a mediating effect between perceived public stigma and actual help-seeking behaviour (Vogel et al., 2007). Those with higher stigma scores are significantly more likely to delay medical help-seeking for lung cancer symptoms, compared to those with illnesses with less stigma attached (Carter-Harris et al., 2014; Chapple, Ziebland & McPherson, 2004). A delay in medical help-seeking was found to be as a result of the anticipation of stigma as a result of a lung cancer diagnosis (Scot, Crane, Lafontaine, Seale & Currow, 2015).

When lung cancer is compared to other types of cancer, it appears that the stigma experienced by those with lung cancer is unique because of the clear causal relationship with smoking. Conversely, other forms of cancer (e.g. bowel, breast, cervical and prostate) often do not have a clear cause and have less stigma attached to diagnosis. Patients with lung cancer have higher levels of perceived cancer related stigma than patients with prostate or breast cancer (LoConte et al., 2008) and head and neck cancer (Lebel et al., 2013). A randomised survey study (n = 1,205), which aimed to explore stigma between lung cancer and four other cancer types, found that lung cancer attracted higher stigma scores than breast cancer, cervical cancer and bowel cancer. Lung cancer was deemed similar to skin cancer on personal responsibility measures but attracted higher stigma than skin cancer (Marlow, Waller & Wardle, 2010).

The implications of lung cancer stigma are far reaching. In addition to delayed help-seeking behaviour, individuals who experience stigma associated with lung cancer also have reduced quality of life scores (Johnson et al., 2014; Chambers et al., 2012), increased psychological distress (LoConte et al., 2008; Chambers et al., 2012) and social isolation (Carter-Harris, 2014).

2.3 Interpersonal determinants of screening participation: GP endorsement

Given that certain types of people are more likely to attend cancer screening, a concerted effort must be made to assess the best way to reach ‘hard-to-reach’ groups. Evidence indicates that individuals are more likely to attend screening appointments if it has been recommended by their doctor (Brawarsky, Brookes, Mucci & Wood, 2004). A meta-analysis exploring the impact cervical cancer education and provider recommendation has on screening rates indicates that endorsement by health care provider improves uptake (Musa et al., 2017). Similarly, GP-endorsed invitations were also found to consistently improve participation in screening among those from more deprived groups (Duffy, Myles, Maroni & Mohammad, 2017).

Previous research in lung cancer screening trials indicates that there are significant differences between participants who are invited to take part, and those who self-select. Participants in the US NLST, who were recruited by the media, appeared to be younger, higher educated and less likely to be current smokers (The National Lung Screening Trial Research Team, 2011). Similarly, in the NELSON trial, respondents to the initial invitation that self-selected were somewhat younger, and less likely to be a current smoker. In addition, those responding to the national screening invitation were more likely to be categorised as ‘healthy volunteers’, and more likely to be ineligible for participation in the trial (van der Aalst et al., 2012). Similar results can also be found outside lung cancer screening trials. In the Oslo Health Study, respondents to community and media advertisement were associated with older age, higher education levels, being married, and also not in receipt of benefits (Søgaard, Selmer, Bjertness & Thelle, 2004). When comparing the respondents of community invitations and personal invitations, Manjer, Elmstahl, Janzon & Berglund (2002) found that community respondents were older, and more often females, than participants recruited using personal invitations. Furthermore, participants recruited through community advertisement had a comparably more favourable situation with regard to sociodemographic and lifestyle factors. They also had a lower frequency of prevalent disease, lower incidence of cancer and lower mortality (Manjer et al., 2002).

2.4 Theories of health behaviour and cancer screening participation

Identifying how people make choices is important to understanding why they might make risky health decisions. Psychological theories and their application to cancer screening have helped us to further understand the behavioural mechanisms that contribute to non-participation. Theory-driven approaches to the design and evaluation of interventions can increase our ability to identify strategies that change behaviour and have the potential to be implemented successfully (Bartholomew & Mullen, 2011).

2.4.1 Health behaviour theories and construct overlap

A large number of theories have been used to try and explain cancer screening participation. In a review of the use of health behaviour theory in National Cancer Institute (NCI) grant applications between 1998 and 2009, the authors report that all but one grant that met the criteria included a conceptual model in their research (Kobrin et al, 2015). A total of six theories were used in the 38 grant proposals that met the criteria of the review: Transtheortical model (TTM); Health belief model (HBM); Social cognitive theory (SCT); Precaution adoption process model (PAPM); Theory of reasoned action (TRA); and Theory of planned behaviour (TPB). Beyond the grant proposals reviewed by Kobrin et al, (2015), these theories also commonly feature in public health intervention literature (Glanz & Bishop, 2010). However, there are some criticisms of the use of theory in behavioural science and the challenges of how theory is applied. It is argued that the constructs within a given theory are often not applied consistently and sometimes omitted without rationale or, conversely, add constructs that are not part of the conceptual model in question. The addition of extra constructs was found in all the NCI grant applications, with an average of nearly three non-related constructs for each proposal (Kobrin et al., 2015).

There is significant overlap between the theories frequently used to describe cancer screening participation. For example, the HBM (Rosenstock et al., 1988) and PAPM (Weinstein & Sandman, 1992) both discuss perceived barriers, perceived severity, perceived susceptibility and self-efficacy as constructs of the behavioural models. As a result of the lack of distinct theories and constructs it is a challenge to find the best model to describe cancer screening participation and apply them in meaningful ways (Glanz & Bishop, 2010).

Behavioural models applied less frequently to cancer screening but, commonly used to explain other health behaviours, such as the Common-Sense Model of Self-Regulation (CSM) (Leventhal, 2003) and the Health Action Process Approach (HAPA) (Schwarzer, 1992; Schwarzer, 2008) could be used to explain screening behaviour and provide insight that other models cannot. The CSM and HAPA have been previously used to understand individuals' response to illness and explore both cognitive and emotional representations of illness. The CSM and HAPA models provide a unique perspective on screening behaviour not yet considered, particularly when exploring the screening behaviour of those with positive intentions to screen (see section 2.4.2 and section 6.1.1). The models both account for how emotional and cognitive representations form and change after intention and allow for individuals to reassess their decision to participate in a given health behaviour. This is of particular benefit if we wish to explore the reasons why people might change their mind after they agree to participate in cancer screening.

There is some overlap between the CSM and HAPA, but each model has components that makes them significant to developing our understanding of screening behaviour. For example, the CSM describes a parallel process that accounts for the development of both cognitive and emotional representations occurring simultaneously, while also considering the interaction between cognitive and emotional representations. Critically, the CSM model includes a 'feedback' loop that allows for individuals to reappraise their decisions (e.g. change their mind).

The HAPA, in contrast, is a staged model of behaviour, with individuals progressing through each stage in order to encourage long term behaviour change. The model includes both motivational and volitional phases, and also describes the formation of action and coping planning. These components are of particular importance to understanding any potential intention-behaviour gap that might be evident in cancer screening.

2.4.2 Intention-behaviour gap

Cancer screening is often unique to other health behaviours as the majority of people think it is a good idea and attitudes towards screening are overwhelmingly positive (Waller et al., 2015). However, we still witness obvious intention-behaviour gaps in cancer screening participation, with positive attitudes and intent not always converting into action. While some behavioural theories address this gap (TPB) (Ajzen, 1991) and TTM (Prochaska & Diclemente, 1983), most theoretical models and, interventions developed focus on the motivational mechanisms that play a role in cancer screening participation. It can be argued that future theory-driven research should look to address the intention-behaviour gap by exploring the volitional factors that play a role in cancer screening decision-making.

Orbell and Sheeran (1998) state that the intention-behaviour gap is caused by individuals not being consistent with their intentions, either positive or negative. In particular, Sheeran (2002) considers there to be two groups of people that explain the intention-behaviour gap: inclined abstainers and disinclined actors. In the area of risky decision-making, inclined abstainers are of significant interest. This group of people have positive intentions to carry out a given health behaviour, but fail to act, unlike disinclined actors who initially have negative intentions but carry out the behaviour anyway (Orbell & Sheeran, 1998). Participants who change their minds pose a considerable issue for public health programmes. This is supported by research conducted in the area of cancer screening. In a study exploring unscreened women in a campaign that aimed to increase participation in cervical cancer screening, it was found that 57% percent of women who said that they intended to attend cervical screening within a year failed to do so (n =166) (Orbell & Sheeran, 1998). Similar results were found with intention to use condoms (57%; n =447) (Gallois, Kishima, Terry, McCamish, Timmins & Chauvin, 1992) and intention to exercise (54%; n =163) (Sheeran & Orbell, 2000).

2.4.3 Dual process models

The way in which inclined abstainers make decisions can partly be explained by the 2-system model of decision-making. There has been a growing interest in Dual Process Models in recent years, and their potential to have practical application in increasing the uptake of cancer screening (Wardle et al., 2015). The model states that there are two distinct systems of information processing: System 1 is an impulsive, fast and effortless process of decision-making, based on an individual’s perceptions, schema and emotions. In contrast, System 2 is a slower decision-making process, based on logic, and reasoning (Kahneman, 2003; Strack & Deutsch, 2004). For example, those who positively intended to take part in screening, but did not attend, may use System 1 to make their initial positive decision to take part in the programme. However, after engaging System 2, more complex decisions are made and reflected upon, and as a result, the participant may change their mind.

This insight into the decision-making processes we engage in helps us develop interventions that may improve participation. In some cases, it might be more appropriate to target System 1, capitalising on people making a fast, intuitive decision because of their positive attitude towards cancer screening (Wardle, 2015). Some interventions that target System 1 decision-making, such as physician endorsement, have been found to efficiently encourage people to make default decisions to attend, removing the need for them to evaluate the risks and benefits themselves (Brawarsky et al., 2004). Interventions that focus on engaging System 2 include providing information to improve informed decision-making, particularly when trying to explore the risks and benefits of cancer screening (Wardle et al., 2015).

To date, there has been no theoretical exploration of the mechanisms behind participation in lung cancer screening. Understanding the mechanisms to decision-making in lung cancer screening will help us to engage with and target intervention development to high risk groups, ensuring optimal uptake and reducing cancer inequalities.

2.5 Thesis aims and research questions

2.5.1 Aim of thesis

The aim of this thesis is to use an integrative mixed methods approach to holistically explore the factors associated with the uptake of lung cancer screening. In order to achieve this objective, the thesis includes four studies, each with individual research questions that help create an overall picture of lung cancer screening participation.

A description of the studies included in this thesis, alongside corresponding research questions, are described in Table 2-1.

Table 2-1: Thesis Research Questions

Study	Research Questions	Sub-Research Questions	Chapter
Integrative systematic review	Do public perceptions of lung cancer and lung cancer screening differ between socioeconomic groups?	I. Do public perceptions and awareness level of lung cancer differ between socioeconomic groups? II. Do public perceptions and awareness level of lung cancer screening differ between socioeconomic groups?	3

Table 2-1: Thesis Research Questions			
Study	Research Questions	Sub-Research Questions	Chapter
Quantitative analysis of lung cancer screening uptake by socioeconomic status in the ECLS trial	Do the demographic and psychosocial characteristics of lung screening trial participants vary by socioeconomic status?	I. Do the demographic characteristics of ECLS trial participants vary by area-based SIMD or individual SES? II. Do the psychosocial characteristics of ECLS trial participants vary by SIMD or SES?	4
Quantitative study of lung cancer screening uptake by invitation type in the ECLS trial	Do socioeconomic status, beliefs and attitudes towards lung cancer and lung cancer screening differ by invitation type?	I. Are socioeconomic status and demographic characteristics different between self-referrers or GP invited ECLS trial participants? II. Do the beliefs and attitudes towards lung cancer and lung cancer screening differ between self-referrers and GP invited ECLS trial participants?	5
Qualitative study of non-attenders beliefs about lung cancer and perceived barriers to lung cancer screening	What are the perceived barriers and beliefs about lung cancer and lung cancer screening held by screening non-attenders?	I. What are the perceived barriers to participating in a lung cancer screening trial? II. What beliefs do non-attenders hold about lung cancer and lung cancer screening? III. Do the Common-Sense Model of Self- Regulation and the Health Action Process Approach help to explain the processes behind those who intend to participate in screening but do not attend?	6

2.5.2 Overview of thesis

In this section I present an overview of the thesis.

Chapters 1 and 2 introduce the thesis and the rationale for the studies. This includes setting out the current picture of lung cancer rates in the UK and Scotland and explores the uptake of lung cancer screening programmes. These chapters highlight the existing inequalities in cancer screening uptake and cancer mortality. The chapters also set out the body of literature that explores the mechanisms surrounding the variation in uptake including the common barriers to cancer screening, highlighting the variation across socioeconomic groups.

Chapter 3 reviews the current literature that exists surrounding the difference in lung cancer beliefs across SES. The systematic review looks at both quantitative and qualitative literature to synthesise the evidence that variation in lung cancer beliefs exist across different socioeconomic groups and describes what these differences are. The review discusses how these differences in beliefs might impact uptake of lung cancer screening and, therefore, mortality. The review concludes that cancer fear and fatalism are significant emotive barriers to cancer screening, particularly among those with lower SES.

Chapter 4 displays the methodology and results of a secondary quantitative analysis that looks to explore the demographic and psychosocial differences of participants in the ECLS trial and compares the differences across SES. A secondary aim of this study was to investigate how best to measure SES. To do so, two distinct measures were used; area-level and individual-level SES. The use of two measures helps us to ascertain whether either method of measuring SES is more appropriate when SES is used as a criterion for cancer screening trials. The study concluded that those from more deprived groups are less likely to be aware of their risk of lung cancer or understand that their own health behaviours might impact their chance of getting lung cancer. This was found to be the case for both measures of SES.

Chapter 5 describes the results of a further secondary quantitative analysis that looks to explore the demographic and psychosocial differences of ECLS trial participants who were invited to participate in two distinct ways; via their GP or via the community. It is hypothesised that those who self-selected for community recruitment have more positive beliefs about lung cancer and have more awareness of the risk factors associated with lung cancer. Results indicate that this is the case, and that those recruited via the community are less deprived than those recruited via their GP.

Chapter 6 qualitatively investigates the lung cancer beliefs and barriers to attending a lung cancer screening trial among people who initially accepted their invitation to screening but did not attend (non-attenders) their appointment to participate in the ELCS trial. Semi-structured interviews elicited the views of people at high risk of lung cancer. A framework analysis was used to map data onto two theoretical models: Health Action Process Approach and the Common-Sense Model of Self-Regulation. The results of the study indicate that participants cited two distinct types of barrier to attending their cancer screening appointment – practical and emotional. Practical barriers, such as competing priorities, were often cited first, before emotional barriers, such as cancer fear were introduced. The results mapped onto the concepts of the HAPA and CSM models, but neither fully captured the reasons for non-attendance of a lung cancer screening appointment in isolation, highlighting the argument for the use of multiple models to explain cancer screening behaviour.

Chapter 7 brings together and discusses the results of all four included studies and compares the results with the existing body of literature and describes the extent to which the studies have addressed the aims of the thesis. Overall, the findings of the studies are supportive of the broader cancer screening literature. However, as there are few studies on barriers to lung cancer screening, this thesis contributes novel findings. The chapter also outlines the strengths and limitations of the studies, proposes areas for future study and discusses implications for policy and practice.

Chapter 7 also draws conclusions of the thesis and highlights the novel contribution the study has made to the field of behavioural medicine, in particular our understanding of perceptions of lung cancer and how they may influence the uptake of any future lung cancer screening programme implemented nationally.

2.6 Chapter summary

This chapter presented an overview of the epidemiology of lung cancer, and the development of lung cancer screening. This chapter also described the sociodemographic predictors of cancer screening and explored the common practical, cognitive and emotional barriers involved in non-participation.

The next chapter will present an integrative systematic review that further explores the public perceptions and awareness of lung cancer and lung cancer screening across different socioeconomic groups.

Chapter 3 : Public perceptions and awareness of lung cancer and lung cancer screening in different socioeconomic groups: an integrative systematic review

3.1 Introduction

The previous chapter described the literature surrounding public perceptions of lung cancer and lung cancer screening. The variability in lung cancer mortality across socioeconomic groups emphasises existing health inequalities. Differences in beliefs about lung cancer and lung cancer screening could go some way to explain this variability.

In order to understand the role deprivation level plays in awareness of, and beliefs about, lung cancer and lung cancer screening, it is important to examine what has already been explored and identified in the literature. This chapter presents a systematic review of both quantitative and qualitative literature that explores beliefs about lung cancer and lung cancer screening and investigates if those beliefs vary by SES. The systematic review approach was chosen to explore the subject holistically and draw conclusions that provide a more comprehensive understanding of public perceptions of lung cancer and lung cancer screening. Integrative systematic review is a form of mixed-methods approach to synthesising literature (Pearson, White, Bath-Hextall, Salmond, Apostolo & Kilpatrick, 2015) which allows for the inclusion of diverse methodologies in order to draw conclusions that provide a more comprehensive understanding of a given phenomenon (Sutton, Clowes, Preston & Booth, 2019).

3.2 Aim of review and research questions

The aim of this systematic review is to explore and synthesise the current literature surrounding the public perceptions of lung cancer and lung cancer screening in different socioeconomic groups.

The review will answer the following questions:

I. Do public perceptions and awareness level of lung cancer differ between socioeconomic groups?

II. Do public perceptions and awareness level of lung cancer screening differ between socioeconomic groups?

3.3 Methodology

This section details the methodology of the systematic review.

3.3.1 Protocol and registration

A protocol was created, and the review registered on PROSPERO, the International Prospective Register of Systematic Reviews (CRD42015025259) (Appendix 1).

3.3.2 Eligibility criteria and scope of review

Studies exploring beliefs and awareness of lung cancer and lung cancer screening were searched for. An exhaustive search strategy was deemed suitable, as the aim was to summarise all the relevant literature on this topic. Limitations of English language and year of publication 1990 and onwards were set. There were no geographical restrictions. Study types included in the review were mixed methods, qualitative, descriptive and RCTs.

As lung cancer literature is diverse, and often clinical in nature, it was agreed that as well as literature related to public views, studies that include primary care practitioner beliefs and/or awareness would also be included in the review. Studies that included the views of lung cancer patients were also deemed appropriate, however were only included if beliefs were about lung cancer and lung cancer screening in general and excluded if the focus of the study was about the diagnostic process or treatment of lung cancer.

Studies that do not have lung cancer or lung cancer screening as the sole focus, such as those that compare different types of cancer were considered to be eligible for inclusion if there was sufficient lung cancer content and results reported related to lung cancer or lung cancer screening. Only the results relating to lung cancer or lung cancer screening are presented in the review unless cancer comparison is directly relevant to the review.

As the review focuses on the beliefs and awareness of different socioeconomic groups, included studies were required to report an individual or composite measure of SES but SES did not have to be the primary focus of the study. Eligibility criteria for paper inclusion are displayed in Table 3-1.

Table 3-1: Eligibility Criteria		
	Studies Included	Studies Excluded
Language	English language	Non-English language
Geography	No geographical restrictions	N/A
Timescale	1990-2020	Papers published before 1990
Study type	Mixed method studies; qualitative studies; descriptive studies; randomised controlled trials	Reviews (including systematic reviews); economic analyses
Paper topic	Comparisons of cancer type; public awareness of lung cancer / screening; general beliefs about lung cancer / screening	Palliative care in lung cancer patients; views on the diagnostic process of lung cancer; views on the treatment of lung cancer; quality of life in lung cancer patients
Participant type	Public; primary care practitioners; patients of lung cancer; patients at high risk of lung cancer	Childhood cancer
Measures	Socioeconomic status – individual (such as income, or employment) or composite (such as an area-based deprivation measure or a composite measure composed of individual measures)	No measure of socioeconomic status

3.3.3 Information sources

The electronic databases of Medline, Pubmed, Cinahl, EMBASE, IBSS, PsychINFO and Web of Science Core Collection were searched to provide published literature.

3.3.4 Search strategy

Scoping searches were carried out to identify key literature and to familiarise reviewers with key terms. A formal database search strategy was subsequently developed by the reviewers with the assistance of a subject librarian (Appendix 2). Individual key words were combined to narrow the search and identify the most relevant references.

The keywords used as part of the search strategy produced 14,326 references. A total of 2,691 duplicates were removed before title and abstract screening using *EndNote* reference management system (2013) leaving 11,635 studies. A further 11,194 were excluded at this stage as a result of title and abstract review. A total of 441 went to full paper review, with 30 of these included in the final review. Fig. 3-1 displays the PRISMA chart to describe the inclusion and exclusion process for the review. Reasons for exclusion are included in Table 3-2.

Figure 3-1: PRISMA Chart

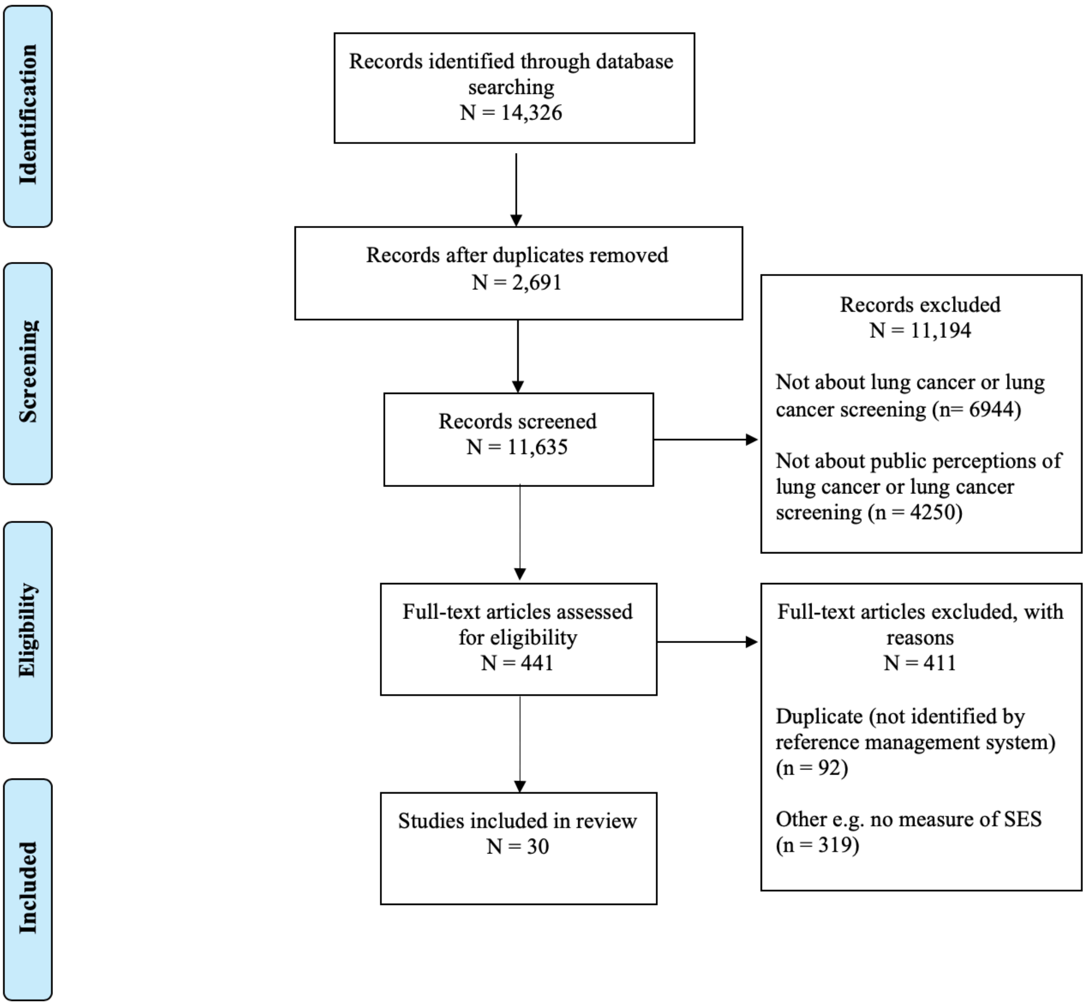


Table 3-2: Reason for Exclusion from Systematic Review	
Reason for exclusion	**Number excluded**
Not about lung cancer or lung cancer screening	6944
Not about public perceptions or awareness of lung cancer or lung cancer screening	4250
Duplicate	92
Other	319
TOTAL Exclusions	**11605**

3.3.5 Data management

The review was conducted by utilising two computer-based aids. *EndNote* (EndNote Team, 2013) was used to extract references from electronic databases and to identify and exclude duplicate references. DistillerSR (Evidence Partners, Ottawa, Canada) was used to manage the remaining references after duplicates were removed.

3.3.6 Article selection and quality assessment process

The search of all databases was carried out in December 2015 and updated in June 2020. A three-step process in article selection was adopted: title, abstract and full paper screening. The relevance of the study to the review question was assessed at each stage using the questions displayed in Table 3-3. If the relevance was uncertain, studies moved on to the next stage of the review in order to ensure that it was not incorrectly excluded.

One reviewer (HS) carried out the title, abstract and full paper screening with a percentage (20%) of these second reviewed by the other review team members (KR/SM). Data were extracted from the papers included in the full paper review (n = 30) using data extraction (Appendix 3) and quality assurance tools. A number of quality assurance tools were used for the different methodologies that were used across the 30 papers in the final review. Quantitative studies were assessed using an adapted version of the NIH study quality assessment tool (NIH, 2014); mixed methods studies were assessed using an adapted version of O'Caithan, Murphy & Nicholl (2008); and qualitative studies were assessed using the Critical Appraisal Skills Programme (CASP) Qualitative checklist (2018).

All tools used considered a number of aspects of quality such as rigour, validity and transparency. Each paper was given a rating of 'Good' (2), 'Fair' (1), or 'Poor' quality (0). A paper was awarded a 'Good' if they received no 'Poor' scores (a zero) on any aspect of the assessment tool. A 'Fair' was awarded if they received one 'Poor' score on any aspect of the assessment tools. A paper is deemed 'Poor' if it was awarded two or more 'Poor' scores on any aspect of the assessment tool.

Studies were not excluded based on quality and data was extracted regardless of rating. The rating of studies was only used to inform the discussion and analysis.

Table 3-3: Article Selection Questions

Stage of Review	Assessment Question	Possible Answers
Title Review	Could this paper be relevant to lung cancer or lung cancer screening? Could this paper be relevant to perceptions or awareness of lung cancer or lung cancer screening?	Yes (include) No (exclude) Unsure (include)
Abstract Review	Is this paper relevant to perception or awareness of lung cancer or lung cancer screening? Is this paper relevant to perceptions or awareness of lung cancer or lung cancer screening?	Yes (include) No (exclude) Unsure (include)
Full Paper Review	Should this paper be included?	Yes (include) No (exclude)

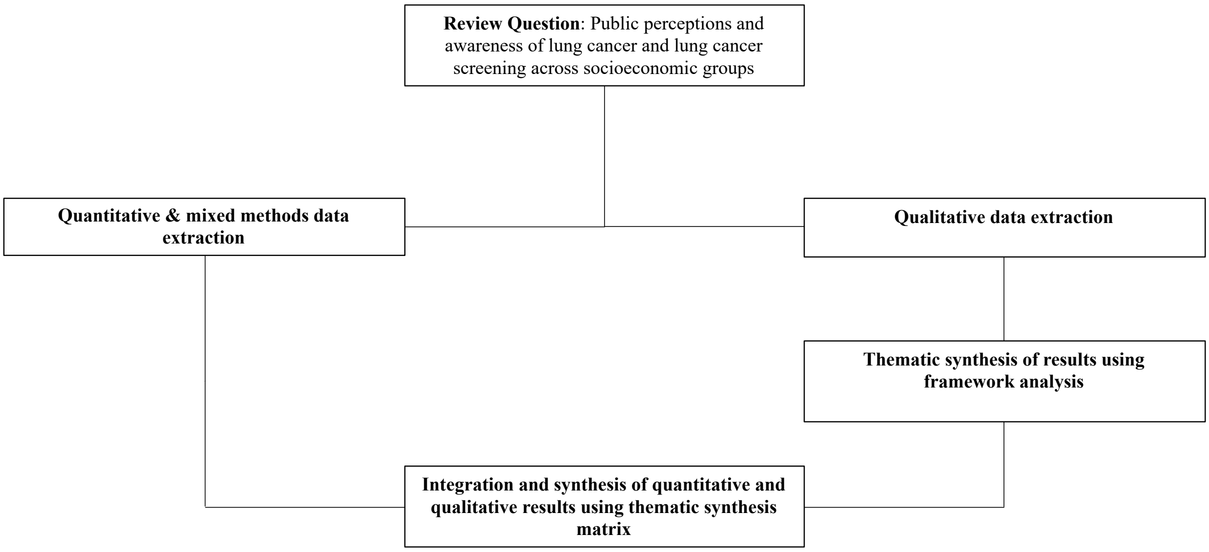
3.3.7 Data synthesis

The review includes papers on both beliefs and awareness of lung cancer and lung cancer screening. It was decided that, although the beliefs about lung cancer and lung cancer screening are often distinct from one another, it was appropriate to integrate them in the review in order to provide a comprehensive understanding of the awareness and beliefs across both lung cancer as a disease, and lung cancer screening as an early detection procedure. In order to highlight the differences and overlap between the beliefs about the disease, and beliefs about the screening test, they are synthesised and presented separately within the results.

An outline of the synthesis method is presented in Fig. 3-2. A convergent design was used to synthesise findings. In a convergent design, qualitative and quantitative evidence is collated and analysed in a parallel, as opposed to sequential synthesis design, where the collation and analysis of quantitative and qualitative evidence takes place in a sequence with one synthesis informing the other (Noyes, Booth, Moore, Flemming, Tunçalp and Shakibazadeh, 2019).

The first step in the synthesis process was to extract data. The data from quantitative and mixed methods studies (n = 22) were extracted separately from qualitative studies.

Figure 3-2: Outline of Data Synthesis Method



The data were extracted, summarised and displayed in tables. Tables 3-5, 3-6, 3-7 and 3-8 present study characteristics including study population, study design, aims, main findings, and assessed quality rating. Studies relating to lung cancer and lung cancer screening are presented separately. Quantitative and qualitative papers were presented separately for each.

The systematic review identified eight papers that used qualitative methodologies. These papers were used to carry out an additional analysis. A thematic synthesis was used to synthesise qualitative research (Thomas & Harden, 2008). In order to thematically synthesise the findings of all qualitative papers, a three-step procedure was adopted in line with that of Thomas & Harden (2008). The first step was to code text of the studies, followed by developing descriptive themes, and finally generating analytical themes in order to draw out the cross-cutting analytical themes contained in all qualitative studies included. The text was coded, and initial descriptive themes were developed by HS. The analytical themes were developed by HS and discussed with KR and SM to ensure agreement of themes.

A thematic synthesis matrix was created to integrate the quantitative and qualitative syntheses. This allowed all studies to be plotted against the themes generated in the qualitative thematic synthesis. The matrix displays areas of crossover in the findings of all papers, and also helps identify gaps in literature. The matrix, which displays the included studies in rows and generated themes in columns, was created by HS.

3.4 Results

This section presents the results of the systematic review.

3.4.1 Description of included studies

The review included a total of 30 papers. This included quantitative (n = 19), mixed methods (n = 3) and qualitative research (n = 8). The focus of the research was broken down into two categories, those about lung cancer (n = 21) and those about lung cancer screening (n = 9). Of all the papers included in the review, eight included only low SES groups, and 22 included both low and high socioeconomic groups. Included papers came from six countries including: Australia (n = 3), Denmark (n = 1), France (n = 1), Nigeria (n = 1), UK (n = 13) and USA (n = 11). Publication dates spanned from 1994 to 2019, with a clear publication cluster between 2014 and 2016 (n = 18). The majority of papers were considered to be of good quality (n = 28).

A summary of included studies is displayed in Table 3-4.

Table 3-4: Summary of Included Studies

Area of focus	Socioeconomic Status	Study Design	Country of Origin	Year of publication	Quality Appraisal
Lung cancer (n=21) Lung cancer screening (n=9)	Low (n=8) Low and high (n=22)	Quantitative (n=19) Mixed Methods (n=3) Qualitative (n=8)	Australia (n=3) Denmark (n=1) France (n=1) Nigeria (n=1) UK (n=13) USA (n=11)	1994 (n=1) 2003 (n=1) 2006 (n=1) 2008 (n=1) 2009 (n=1) 2010 (n=1) 2012 (n=3) 2013 (n=1) 2014 (n=5) 2015 (n=8) 2016 (n=5) 2018 (n=1) 2019 (n=1)	Good (n=28) Fair (n=2) Poor (n= 0)

3.4.2 Quantitative and mixed method study results

The following tables describe the quantitative and mixed methods studies exploring the perceptions and awareness of lung cancer and lung cancer screening respectively.

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)

Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
Crane, Aranda, Stacey, Lafontaine, Scott, O'Hara & Currow (2016)	Australia	Qualitative study (n=126; n=16 focus groups); Quantitative study (n=1,000). Participants were aged over 40 years.	Mixed Methods	Comprehensively investigate current knowledge of risk factors and symptoms suggestive of lung cancer in New South Wales and explore attitudes and beliefs which might impact help-seeking behaviour.	Lung-CAM[3]; Composite measure of SES; Area based SES.	***Focus groups*** – Smoking status was associated with low SES. Perceived risk was low amongst those at risk with current smokers preferring to deny their risk while former smokers were generally unaware of any ongoing risk. Current smokers perceived there to be stigma associated with smoking. ***Survey –*** The majority of participants were able to identify smoking as a risk	Good

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[3] Lung-CAM - The Cancer Awareness Measure (CAM) is a validated questionnaire designed to measure the public's awareness of the symptoms and risk factors of cancer as well as the barriers to seeking help.

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
						factor for lung cancer (90.6 %). Age (<65 years), sex (female), and high SES contributed to a higher recognition of symptoms.	
Desalu, Fawibe, Sanya, Ojuawo, Aladesanmi & Salami (2016)	Nigeria	Participants (n=1125) were taken from a random sample of households in the Ilorin West and East Local Government Area of Kwara State, Nigeria. The mean age of the respondents was 33 years.	Cross-sectional	To determine the awareness about the warning signs of and risk factors for lung cancer and its association with the anticipated delay before seeking medical help in a sample of the general population of Ilorin, Nigeria.	Lung- CAM; composite measure of SES.	The demographic correlates of a good awareness score and recognition of risk factors were higher educational level and higher income. Males and those with lower education level and income were more likely to wait 2 weeks or more before seeking help for symptoms.	Good
Hvidberg, Pedersen, Wulff & Vedsted (2014)	Denmark	A total of 3,000 participants were recruited to the study. n =1,000 respondents aged 30–49 years and n = 2,000 respondents aged	Cross-sectional	Assess awareness of cancer symptoms, risk factors and perceived 5-year survival from bowel, breast, ovarian, and lung	Awareness and Beliefs about Cancer (ABC); individual measures of SEP (education, occupation and	Overall, across all cancers, there was a strong socioeconomic gradient in cancer awareness. People with a low educational level and a low household income were more likely to have	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)

Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
		50 years and older. Respondents were identified using the Danish Civil Registration System.		cancer in a Danish population sample and to analyse the association between these factors and socio-economic position indicators.	household income).	a lower awareness of cancer symptoms, cancer risk factors and the growing risk of cancer with age. There was no clear association between knowledge of 5-year survival and SEP.	
Marlow, Waller & Wardle (2010)	UK	A population-representative sample of women (n=1620) from randomly selected addressed postcodes in the UK. Mean age of the sample was 50 years old.	Cross-sectional	Assess attributions of blame for five common cancers and two conditions widely seen as a matter of individual responsibility (obesity and chlamydia).	Blame attribution measure; individual measure of SES (education level).	Attributions of blame were higher for lung cancer than any other cancer type. Higher education level was associated with greater blame for lung cancer.	Good
Mazières, Pujol, Kalampalikis, Bouvry, Quoix, Filleron, Targowla, Jodelet, Milia	France	A representative sample of n=1469 respondents from a permanent polling database.	Cross-sectional	To evaluate the perception of lung cancer in the general population to identify obstacles in patient–doctor communications.	Knowledge of symptoms, treatment, prognosis, screening for lung cancer, and how they evaluated their own level of	Lung cancer was identified as a severe disease (82%) with a worse prognosis than other cancers but overall survival of patients with lung cancer (32%) was overestimated. When compared to breast	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)

Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
& Milleron (2015)					knowledge about lung cancer; composite measure of SES (education level and work status); verbal association with words 'lung cancer'.	cancer, lung cancer was associated with a loss of autonomy or seen as a punishment. The most common words participants associated with lung cancer include: Death, Cure, Black, Fatigue and Pollution. Negative word associations (such as death or black) were associated with high education level and those in employment. Positive words (such as cure) were associated with those outside of employment and low education level.	
Moffat, Bentley, Ironmonger, Boughey, Radford & Duffy (2015)	England, UK	Men and women over the age of 50 years, from lower socioeconomic groups were recruited to evaluate a lung cancer campaign	Cross-sectional	Investigate the impact on public awareness and the number of patients presenting to general practitioner (GP) practices with symptoms	Lung-CAM; SES Measure; GP attendance.	Awareness of hoarseness/coughing as a symptom of lung cancer increased after the campaign (41% - 50%). There was a pre to post campaign increase in awareness on both men	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
		(n=1412/1246 pre-/post-lung campaign). Data was also obtained from GP practices to cross-check GP attendance (n=486).		highlighted in the campaigns on samples of the population sub-grouped by sex, age and a measure of SES.		and women and a greater increase in GP attendances for practices in less-deprived areas.	
Moran, Glazier & Armstrong (2003)	USA	A total of n=1184 women were recruited from 225 primary care physician practices in Pennsylvania and New Jersey. The mean age of the sample was 54.6 years.	Cross-sectional	Explore perceptions of the health-related risks of smoking among women smokers.	Lifetime risk of lung cancer; individual measures of SES (income and education level).	The rating of perceived lifetime risk for developing lung cancer differed significantly among never smokers, former smokers, and current smokers. There was no difference in perceived risk across education levels.	Good
Niksic, Rachet, Duffy, Quaresma, Moller & Forbes (2016)	England, UK	A population-based survey that sampled n=35,308 from 25 primary care trusts across England.	Cross-sectional	This study aimed to identify how cancer symptom awareness and barriers to help seeking vary by small geographical region (PCT) in	CRUK Cancer Awareness measure; SES based on the income domain of the English indices of Deprivation.	Cancer symptom awareness and barriers scores varied greatly between geographical regions in England, with the lower cancer symptom awareness and more barriers observed in	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
				England, and whether average levels of awareness and barriers are associated with cancer survival at the PCT level.		socioeconomically deprived parts of East London. Low cancer awareness score was associated with poor cancer survival at trust level. There were no statistically significant associations between survival from lung cancer, and the awareness score or recognition of each cancer symptom. There was no association between the barriers score or individual barriers and lung cancer survival.	
Power & Wardle (2015)	England, UK	The sample were randomly selected via the Office for National Statistics Opinions and Lifestyle survey over a two-month period in 2010 (n= 2090) and 2012 (n=2001).	Cross-sectional	Test the prediction that there would be greater awareness of the symptoms highlighted in national campaigns than non-targeted symptoms, following the national	Amended CAM consisting of awareness of warning signs and symptoms, perceived barriers to seeking help and cancer experience;	Participants from 2012 were significantly more likely to be able to recall 'cough' or 'hoarseness' as a symptom of lung cancer compared to those asked in 2010. Recognition of lung cancer symptoms was much higher in 2012. There were no significant	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
				advertising campaigns.	individual measures of SES (education and occupation).	interactions between survey year and sex, age, ethnicity, occupation or cancer experience in the changes in lung symptom recall or lung symptom recognition.	
Price & Everett (1994)	USA	A random sample of Ohio residents (n=500) with an income <$18,000 were identified via telephone company registration and census data. Mean age of the sample was 58 years.	Cross-sectional	Assess socioeconomically disadvantaged adults' perceptions of lung cancer and smoking by utilizing the HBM.	Lung cancer belief survey including subscales of knowledge, perceived susceptibility, perceived severity, perceived barriers and perceived benefits; individual measures of SES (education level).	Those with the highest level of education knew more about lung cancer than either the middle level or lowest level of educated respondents. The least educated respondents perceived themselves as more susceptible to developing lung cancer than those with higher education levels, considered lung cancer to be more severe, and perceived fewer benefits to quitting smoking. No significant difference was found across education levels with regard to perceived	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
						barriers to quitting smoking.	
Quaife, McEwan, Janes & Wardle (2015)	UK	As part of the International Cancer Benchmarking Partnership, Random, probability sampling methods were used to select households from electronic listings of telephone numbers (n=6965).	Cross-sectional	Use data from a large population-based survey to compare beliefs about cancer, early diagnosis, and help-seeking for symptoms in current- smokers compared with former-smokers and never-smokers.	Awareness and Beliefs about Cancer (ABC); individual measure of SES (education level).	Current smokers are more pessimistic, fatalistic and avoidant of cancer and its outcomes Current smokers were significantly more pessimistic about cancer outcomes and early detection than former- or never smokers. More negative perceptions of cancer outcomes are independent of demographic characteristics (including SES), self-rated health and cancer experience.	Good
Rawl, Dickinson, Lee, Roberts, Teal, Baker, Kianersi & Haggstrom (2019)	USA	A random, stratified sample of who had been seen at least once in the past year at one of 178 Indiana University Health system	Cross-sectional	Examine differences in cancer-related knowledge, beliefs, and behaviours (cancer screening, physical activity, tobacco use)	Cancer knowledge and beliefs; health promotion/cancer prevention behaviours; individual measures of SES	Individuals most likely to perceive that they were unlikely to get cancer were more often black, with low incomes or less than a high school degree. Those with lower incomes were less likely to have	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
		facilities. Participants (n=970), were aged between 18 and 75 years old, either white/ Caucasian (n=743) or black/African American (n=192) and lived in counties with higher than average cancer mortality rate.		between racial and socioeconomic groups among Indiana residents in counties with high cancer mortality rates.	(education level, income, financial security, home ownership, occupational status).	had a lung scan in the last year. Those with some college education were also less likely to have had a lung scan. Knowledge about appropriate ages to start lung screening did not differ by race or SES.	
Simon, Juszczyk, Smyth, Power, Hiom, Peake & Wardle (2012)	UK	A total of n=1484 participants were recruited as part of the British Market Research Bureau's (BMRB) Omnibus survey.	Cross-sectional	Describe the development of the Lung Cancer Awareness Measure (Lung CAM) and presents results from a population survey using the Lung CAM.	Lung-CAM; Individual measure of SES (occupation or 'social grade').	People in the highest social grade had higher symptom awareness than those in the lower grades. Familiarity with cancer was associated with higher recognition of risk factors. People with the highest social grade had greater risk factor recognition ($p<.001$) and	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)

Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
						recall (p<.05) than those in the lowest social grade.	
Weiss, Stephenson, Edwards, Rigney & Copeland (2014)	USA	Telephone surveys were conducted among a random cross-section of American adults selected using a random digit dial sample (n=1071). Participants were aged over 21 years old.	Cross-sectional	To better understand public attitudes regarding lung cancer.	Awareness of lung cancer; attitudes of cause; individual measures of SES (education, employment, household income).	Most participants felt that lung cancer was principally caused by external factors (78%), that it could be cured if caught early (73%), and that lung cancer patients were at least partly to blame for their illness (59%). 'Supporters' of the efforts against lung cancer were have higher income. Stigmatization of lung cancer might have negatively influenced support.	Good
Whitaker, Simon, Beeken & Wardle (2012)	UK	Data were collected from n=2018 adults using a random location, quota-sampling technique to ensure that the distribution of	Cross-sectional	Use data from a British population sample to compare estimated survival for three common cancers distributed across the survival spectrum (breast,	Quantitative survival estimates; perceived curability; individual measure of SES (occupation).	There was a tendency to overestimate lung cancer survival. Respondents correctly recognised that 5-year survival for breast cancer was higher than for colorectal cancer, which in turn was recognised to be higher than for lung	Good

Table 3-5: Data Extraction - Lung Cancer Quantitative & Mixed Methods Studies (n = 15)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
		respondents (aged ⩾15 years) across area types matched census data.		colorectal and lung).		cancer. Similarly, curability was perceived to be higher for breast cancer than colorectal cancer, and both were perceived to be more curable than lung cancer. Awareness of survival differences did not vary by sex, age or socioeconomic status.	

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
Ali, Lifford, Carter, McRonald, Yadegarfar, Baldwin, Weller, Hansell, Duffy, Field & Brain (2015)	UK	A total of n=748 UKLS participation decliners completed the Non-Participant Questionnaire and of these n=434 provided comments in the optional free-text field. Participants were high-risk individuals aged 50–75years residing in six primary care trusts in the Cambridge and Liverpool areas.	Mixed Methods	Use a mixed methods approach to identify the barriers to uptake among high-risk individuals invited to participate in UKLS trial.	Revised cancer worry scale; composite measure of SES (Index of Multiple Deprivation); reason for non-participation (free text).	Socioeconomic group was significantly associated with lung cancer screening uptake. Individuals in the lowest quintile were almost twice as likely to decline screening compared with those in the highest quintile. Reasons for non-participation include: Practical Barriers (e.g. travel, comorbidities, caring responsibilities); Emotional Barriers (e.g. avoidance of lung cancer information, fear); Trial acceptability, Age (e.g. too old); Dislikes (e.g. hospitals or healthcare) and Low Perceived Risk.	Good
Cataldo (2016)	USA	Smokers, over the age of 55 (n=338) were recruited as part of the larger	Cross-sectional	To describe older smokers' health risk beliefs	Attitudes and beliefs about lung cancer and lung	Over 82% of the sample believed that a person who continues to smoke	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
		Tobacco Attitudes and Beliefs Study. Mean age of respondents was 61.5 years.		related to cigarette smoking and lung cancer; identify demographic, smoking history, health risk perceptions, knowledge, and attitude factors related to whether a smoker would agree to a LDCT scan.	cancer screening; individual measures of SES (income, education, employment).	after the age of 40 has at least a 25% chance of developing lung cancer and 77.3% would "agree to a LDCT today". None of the demographic variables were significantly associated with the decision to have a LDCT, including SES. No other SES differences reported.	
Crothers, Kross, Reisch, Shahrir, Slatore, Zeliadt, Triplette, Meza & Elmore (2016)	USA	A total of n=6 focus groups were carried out, and n=45 patients participated (mean age of 61 years). Participants were recruited from an urban county hospital setting, that serves low-income individuals.	Mixed Methods	To determine, in a low-income, racially diverse population, participants' experience, preferences, and reactions to web-based and paper decision aids, and their understanding of	Attitudes and knowledge of lung cancer screening; individual measures of SES (income and education level).	Participants, from a low-incomes sample demonstrated improved knowledge about lung cancer screening after reviewing two decision aids and spending 1.5 hours in a discussion group. There was no significant change in subjects' perception of their own lung cancer	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
				harms and benefits of lung cancer screening.		risk or the feelings of worry that would result from an abnormal LDCT scan. Few participants agreed that if they had a normal LDCT scan they could "continue to smoke without worrying'. The focus groups highlighted that participants were not aware of the purpose of lung cancer screening. Participants expressed surprise that the magnitude of their lung cancer risk and benefits of screening were lower than anticipated. No SES comparisons presented as all participants were from low SES groups.	
Jonnalagadda, Bergamo, Lin, Lurslurchachai,	USA	Patients (n=108) were recruited from the primary care outpatient clinic of a	Cross-sectional	Use the Self-Regulation Model (SRM) to assess	Survey based on SRM domains (identity, cause,	Beliefs reflecting main components were not significantly associated	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
Diefenbach, Smith, Nelson & Wisnivesky (2012)		large urban academic medical centre. The study cohort consisted of asymptomatic individuals with a ≥10 pack-year cigarette smoking history, with a mean age of 62.3 years.		the influence of health beliefs on lung cancer screening among asymptomatic smokers.	timeline, emotional representations); individual measures of SES (ethnicity, income and education level).	with intention to screen. Beliefs reflecting fatalism and spirituality were endorsed more often by minority and low-income groups in addition to fear and anxiety. Cost of screening, fatalism and fear of radiation exposure from screening were perceived barriers for minority groups and those with low incomes.	
Quaife, Vrinten, Ruparel, Janes, Beeken, Waller & McEwan (2018)	UK	A total of n=1445 participants from a number of geographical areas England were recruited to participate in the Attitudes, Behaviour and Cancer UK Survey (ABACUS). Mean age of respondents was 60 years old.	Cross-sectional	Examine how screening intentions and perceptions of early detection of lung cancer might differ by smoking status, and measure interest in, and acceptability of, an NHS lung	Lung cancer screening intentions; adapted ABC; worry about lung cancer risk; individual measure of SES (education level).	Current smokers had a lower level of education. 48% of participants considered a lung cancer diagnosis to be a death sentence. Worry about lung cancer risk was most common among smokers (48%). The large majority of current and former smokers intended to be screened	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
				cancer screening programme offered in different invitation scenarios.		for lung cancer. The proportion of intenders was highest if recommended by a GP. Sex, age, ethnicity, level of education, marital status and cancer experience were not associated with screening intentions. No SES differences were reported.	
Rutten, Hesse, Moser, McCaul & Rothman (2009)	USA	The data analysed was obtained the HINTS 2005. A representative sample (n=5586) was achieved by using random digit dial of all tele- phone exchanges in the United States.	Cross-sectional	Evaluate what the current public understanding of colon, lung, and skin cancer in terms of prevention, detection, and survival/cure; public understanding of prevention, detection, and survival/cure	Public understanding of cancer prevention, detection, and survival/cure; individual measures of SES (income, education level and employment status).	18.1% of respondents believed that there was not much that can be done to lower chances of getting lung cancer. Prevention knowledge was associated with higher education level. 87.4% of respondents agreed that screening increases chances of finding lung cancer early. No significant association between	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)

Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
				compare with state-of-science evidence; differences in perceptions of cancer by sociodemographic subgroups; and the consistency of perceptions of cancer prevention, screening, and survival with state-of-science evidence.		screening beliefs and demographic characteristics. Only 17.3% of respondents accurately reported that 25% or fewer people would survive at least 5 years. No significant association between survival beliefs and demographic characteristics.	
Tanner, Egede, Shamblin, Gebregziabher & Silverstri (2013)	USA	US veterans (n=209) were recruited in a healthcare setting where they were being treated as outpatients. Adults over the age 18 were approached to participant, with participant mean age being 56.2 years. 87.1% of participants were male.	Cross-sectional	Assess the role of beliefs and attitudes toward LC screening in US veterans.	Knowledge about and willingness to be screened for lung cancer; individual measures of SES (education, household income, and employment).	Smokers were significantly (p<.05) more likely than never smokers to be less educated, have a lower income, and report poorer health. 80% of current smokers believe that they were at increased risk of lung	Good

Table 3-6: Data Extraction - Lung Cancer Screening Quantitative & Mixed Methods Studies (n = 7)							
Author / Year	Location	Participants (n, age, sampling)	Study type	Study aims	Measures	Findings	Assessed quality score
						cancer. 50% believed that early detection of lung cancer results in a good chance of survival. No SES differences reported, but smoking status is associated with low SES background.	

3.4.3 Qualitative study results

The following tables describe qualitative studies exploring the perceptions and awareness of lung cancer and lung cancer screening respectively.

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)

Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
Chatwin, Povey, Kennedy, Frank, Firth, Booton, Barber & Sanders (2014)	North West England, UK	Adults with lung cancer diagnosis (n=11) and adults' high risk of lung cancer (n=14) recruited from healthcare settings were situated in an area of high economic deprivation on the outskirts of a major (UK) Northern industrial city.	Semi-structured interview	Investigate the social factors which influence symptom recognition and help seeking behaviour.	***Fatalism*** **-** Both patients and high-risk individuals had fatalistic views of lung cancer. Participants in both groups reported that acknowledging and looking for symptoms was something they chose not to think about ***Awareness of smoking risk*** **-** Those in the diagnosed group who continued to smoke believed that 'the damage was done'. Smokers in both groups would actively avoid lung cancer media campaigns. Participants could identify smoking as a risk but were ambivalent about the effects of smoking. ***Social Network and help seeking*** - All male participants in the study said they tended to avoid going to the doctors for	Good

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)

Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
					any reason and were usually pressurised into it by a spouse or family member. Many reported that they would have to be in acute pain before making contact themselves.	
Corner, Hopkinson & Roffe (2006)	North and South England, UK	Adults with lung cancer diagnosis (n=22), aged between 42-82 years. Participants were recruited from two cancer centres in the South and North of England. For participants where occupational status was relevant, 13 described themselves as having or having had manual occupations, five had professional occupations.	Semi-structured interviews	Examine whether any or all types of delay were factors in the timing of diagnosis among patients with lung cancer, and to understand more fully how processes of delay occur.	***Disconnected interpretations of bodily changes*** - Delay in help seeking occurred because symptoms were not important enough to warrant making a GP appointment. Most were not in regular contact with primary care services and did not consider the GP as someone to go to about their health or any bodily changes. Bodily changes put down to age, or incorrectly attributed to co-morbid illness. ***Unworthy of treatment*** – Delay to help seeking occurred as a result of stigma attached to smoking.	Good

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)

Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
Lathan, Waldman, Browning, Gagne & Emmons (2015)	Boston, USA	Two-part study which recruited people with no cancer history (n=32) and current lung cancer patients (n=10). Participants were aged 35+, and self-identified as African American. Participants were recruited from a subsidised housing community in an underserved community in Boston.	Focus Groups (n=32) and semi-structured interviews (n=10)	Identify potentially salient but under-recognised factors that may account for differences in care and medical outcomes of African Americans with lung cancer.	***Smoking as a risk factor*** **–** Both lung cancer patients and those who had no cancer history were aware of the link between smoking and lung cancer, common symptoms and possible poor prognosis. However, the majority of participants from the patient group did not think smoking was the cause of their current cancer diagnosis. ***Race or SES as a risk factor*** Most participants considered insurance status and other socioeconomic factors were more likely to impact diagnosis and treatment of lung cancer than racial discrimination.	Good
Page, Bowman, Yang & Fong (2015)	Australia	Aboriginal and Torres Strait Islander peoples (n=67) including community members and Indigenous health workers. Participants were from communities of lower socioeconomic status.	Structured interviews	Survey the level of lung cancer awareness in rural and remote Aboriginal and Torres Strait Islander communities and discover perceived barriers to timely	***Lung cancer knowledge*** - Around half of participants had a low level of awareness/ knowledge of lung cancer but had some awareness of smoking as a cause. Participants were able to identify some symptoms of lung cancer.	Fair

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)						
Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
				diagnosis and treatment of lung cancer.	***Accessibility* -** The main barrier to early diagnosis was thought to be accessibility – travel to specialist doctors located in urban areas was difficult and costly. Many would not even attempt to attend a specialist appointment.	
Scott, Donato-Hunt, Crane, Lafontaine, Varlow, Seale & Currow (2014)	Australia	Culturally and Linguistically Diverse communities (n=51) - Mandarin (n=7); Cantonese (n=13); Vietnamese (n=16); Arabic (n=15). Aged between 44 and 65 years old. Participants were recruited from underserved communities that have low socioeconomic status.	Focus groups	Explore knowledge, attitudes and beliefs about lung cancer in three CALD communities in NSW.	***Perceived susceptibility*** - Smokers' idea of susceptibility varied across the different CALD groups. This was clear in the Arabic-smokers group, who did not believe the risk was any different to non-smokers and that healthy behaviours outweigh smoking behaviour. ***Perceived severity*** – There was some awareness that early diagnosis of lung cancer is beneficial, but all groups thought survival rates were poor. There was limited knowledge of lung cancer and groups believed that diagnosis would happen at a late	Fair

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)						
Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
					stage. All groups reported fatalistic views of lung cancer. ***Awareness of symptoms -*** Responses across the CALD groups were mixed. Levels of trust in participants GP appears to influence help-seeking behaviour.	
Tod, Craven & Allmark (2008)	UK	Adults with lung cancer diagnosis (n=18) and adults previously diagnosed and survived lung cancer (n=2), aged between 47 and 81 years old. Participants were recruited from a health board in the North of England described as 'deprived'.	Semi-structured interviews	Explore and explain delay, particular pre-diagnostic delay, in lung cancer and to consider the implications for public education and nursing.	***Symptom experience*** **–** Many participants believed their symptoms to be minor or unspecific leading them to delay diagnosis. A recurring belief that non-smokers and ex-smokers would not get lung cancer. As a result, there was a lack of symptom vigilance and belief that any symptoms were not attributed to lung cancer but another illness. ***Fear*** **–** Fear was fostered by a lack of knowledge of treatments and strong fatalistic beliefs. Fear of death and a cancer diagnosis delayed reporting of symptoms.	Good

Table 3-7: Data Extraction - Lung Cancer Qualitative Studies (n = 6)						
Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
					Blame and Stigma **–** The findings revealed a prevailing expectation that people with lung cancer would experience blame and stigma. Non- or ex-smokers delayed in reporting symptoms because of an expectation, based on previous experience, that they would be stigmatized as a smoker and blamed for their illness. ***Culture -*** Cultural factors such as stoicism in older males and non-standard patterns of health care utilization. Often, participants would not use GP's at all having previously used 'pit' doctors and fear that they will be wasting time.	

Table 3-8: Data Extraction - Lung Cancer Screening Qualitative Studies (n = 2)

Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
das Nair, Orr, Vedhara & Kendrick (2014)	Glasgow and Dundee, Scotland	Adults high risk of lung cancer (n=32), aged between 50 and 75 years old. Participants recruited from the most disadvantaged areas of Glasgow and Dundee.	Focus groups	Explore the recruitment barriers and facilitators in early lung cancer detection trials.	***Invitation to participate -*** Participants from Glasgow considered GP invitations a good idea for recruitment; however, some were sceptical that the GP would be willing to give the time. Participants suggested that word of mouth might be the best way to recruit to the lung cancer screening trial. ***Understanding randomisation and issues related to the control group*** - Participants all struggled with the concepts of randomisation and control groups. When explained, participants understood that they were a good idea, but would still want to be in the 'treatment' arm ***Perceived barriers and facilitators to participation -*** Many participants identified the need for flexible	Good

Table 3-8: Data Extraction - Lung Cancer Screening Qualitative Studies (n = 2)						
Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
					appointments. Participants felt stigmatized because of their smoking status and the targeted nature of the screening trial. They considered that smokers should not be singled out as non-smokers can also get lung cancer.	
Zeliadt, Heffner, Sayre, Klein, Simons, Williams, Reinke & Au (2015)	USA	US Veterans high risk of lung cancer (n=37), aged between 55 and 72 years old.	Semi-structured interviews	Aim to learn from patients who were offered screening how the availability of screening influenced their motivations regarding smoking cessation.	***Misperceptions About Screening and Smoking -*** current smokers exaggerated the personal benefits of lung cancer screening. Participants were very positive about screening – it was considered very easy to do, compared to stopping smoking which was seen as much more difficult. Many believed that screening meant that there was less urgency to stop smoking. Participants felt ‘protected’ from lung cancer because they had been screened / that	Good

Table 3-8: Data Extraction - Lung Cancer Screening Qualitative Studies (n = 2)						
Author / Year	Location	Participants (n, SES, sampling)	Study type	Study aims	Findings / Reported Themes	Assessed quality score
					a screening programme was available. ***Screening and Self-reflection About Smoking*** - Lung cancer screening stimulates a period of self-reflection and induced 'emotional arousal'. Many would consider quitting as a result.	

3.4.4 Qualitative thematic analysis

A framework approach was used to generate analytical themes for qualitative lung cancer and lung cancer screening studies. The frameworks of identified themes, including extracts from the included studies, are displayed in Tables 3-9 and 3-10.

3.4.4.1 Qualitative thematic framework – lung cancer

The table below displays a thematic framework based on the findings of the qualitative lung cancer studies. The table includes extracts from the included studies.

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies

	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
Chatwin, Povey, Kennedy, Frank, Firth, Booton, Barber & Sanders (2014)	A strong thread with our diagnosed participants was a kind of fatalistic attitude towards post diagnosis processes Elements of fatalism, where they were apparent, were more akin to resignation about having to go through a potentially painful and ultimately tenuous (in terms of possible outcomes) treatment process	This gave us the opportunity to explore the issue of smoking related stigma […] In our data, however, negative issues such as these were not strongly evident, even among those who had non-smoking related lung cancer. Work by De Nooijer et al. has suggested that shame and embarrassment about symptoms actively hinders early presentation and diagnosis, but again, this was not the case in the people we interviewed.	There was often the admission that looking out for, or acknowledging the appearance of worrying symptoms was something that people chose not to think about in any formalised way its [symptom] appearance might be attributed to any number of other lung problems apart from cancer Most participants said they'd go to their doctor if they started	They regarded the damage as having already being done [with regard to smoking]. On the one hand, participants would readily admit that there was a real risk of lung cancer (or other health implications) if they continued to smoke. But on the other, the reasons they cited for not giving up outweighed this.

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			noticing persistent symptoms such as coughing, or 'a different kind of coughing'. However, as outlined already, these wouldn't necessarily be attributed to cancer, or the possibility that these could be early symptoms.	
Corner, Hopkinson & Roffe (2006)	Participants did not appear to have consciously 'delayed' seeking help for symptoms through fear, neither did we find obvious evidence of 'denial' among participants who were smokers or former smokers that the symptoms they were experiencing might be due to lung cancer, although this warrants further study.	There was evidence in the account of one woman that she felt because she smoked she may not have the right to professional care The woman's account accords with recent work […] which reveals the stigma experienced by people with lung cancer because the disease is so strongly associated with smoking and led some to conceal their illness, while others worried that diagnosis, access to care and research into lung cancer might be adversely affected by the stigma attached to the disease and to those who smoke.	For many, symptoms were not perceived as important enough to warrant making an appointment. They were uncertain as to what should be considered normal, or they felt what they were experiencing was probably a minor problem. For example, a man who had been very active describes how he had experienced profound tiredness for 18 months prior to his diagnosis, yet it took him over 1 year to go to his doctor about it Knowing what was 'normal' and knowing what was reasonable, or bad enough to warrant making an appointment	Most of the participants were smokers or former smokers, a number had even given up smoking as a result of the health changes they were experiencing, but none seemed to have considered the possibility of lung cancer or they had suppressed the possibility of a connection. There is no evidence in the interviews that individuals had considered that they may have lung cancer until after they had been referred by their doctor for investigation of their symptom

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			was an issue for some and worrying that they might be wasting their doctor's time or that they might be criticised for this, seemed to be a common preoccupation. 'Carrying on' in the face of growing ill-health was common place and was driven by the need to hold down a job, or to keep up familiar roles and responsibilities Since the symptoms participants experienced were not considered to be matters relating to health, or for that matter ill-health, but were bound up in their experience of everyday life, it had not occurred to them that they might seek help from anyone and this is possibly the most important factor underlying the health-related behaviours revealed in this study	

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			Symptoms were attributed to bodily functions or changes and therefore were experienced as part of the everyday fluctuations one experiences of one's body and its functioning They were uncertain as to what should be considered normal, or they felt what they were experiencing was probably a minor problem	
Lathan, Waldman, Browning, Gagne & Emmons (2015)	Participants seemed well aware of treatment options for lung cancer, including surgery, radiation, and chemotherapy. Several spoke specifically about chemotherapy, focusing on its side effects. Although some participants believed it was effective, others believed it could be fatal. Participants overwhelmingly reported that they did not fear	All participants believed that others assume lung cancer patients are smokers and that many use it to judge their character. Focus group and lung cancer participants alike discussed the stigma associated with a lung cancer diagnosis and the lack of attention lung cancer gets in relation to other diseases in African American communities.	Most participants were aware that cigarette smoking was the main environmental exposure. Several also mentioned that some patients are diagnosed with lung cancer without a smoking history and that other environmental agents can also cause lung cancer. Asbestos, second-hand smoke, and air pollution were all mentioned as possible causes.	Most participants were aware that cigarette smoking was the main environmental exposure. Several also mentioned that some patients are diagnosed with lung cancer without a smoking history and that other environmental agents can also cause lung cancer. Asbestos, second-hand smoke, and air pollution were all mentioned as possible causes.

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	the treatments but had different reasons. Some expressed confidence in the environment, whereas other noted their age and life experience. The lethality of lung cancer was also discussed, but a majority of participants maintained a positive outlook on their personal circumstances.		When asked what they would do if diagnosed with lung cancer, participants most commonly responded that they would seek information about treatment options from their doctor. Only one participant reported that he would not seek treatment because of his father's experience. Most did not suspect that they had lung cancer prior to diagnosis. A few reported that the initial shock they experienced made it difficult to interact with their care team or to recall their initial conversations. All but one participant felt that lung cancer was not viewed a prevalent issue among African Americans and that there was more emphasis on other illnesses and cancers.	Most focus group participants worried about getting lung cancer as a result of their smoking history. Most participants felt that African Americans were at high risk for lung cancer because they smoked more cigarettes. The targeting of African Americans in tobacco advertising was a key theme that emerged. Although 9 of the 10 participants had a smoking history, only 2 identified smoking as the sole or primary cause of their lung cancer. Four male participants believed occupational exposure to hazardous chemicals may have also been a contributing factor, and two female participants noted that they had quit smoking decades earlier. Three participants further mentioned

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
				that non-smokers can also develop lung cancer, and one suggested that heredity was an additional factor because not everyone who smokes develops lung cancer. Nevertheless, most reported wishing they had quit sooner or never smoked at all.
Page, Bowman, Yang & Fong (2015)	In reply to the question: 'what do you know about lung cancer?' 18% (n=9) of community members and 28% (n=4) Indigenous health workers mentioned lung cancer mortality. Responses included words such as 'death' or 'kills'.		The following question was 'What do you think causes lung cancer?' Forty-six of 51 (46%) community members and 14/14 Indigenous health workers cited smoking. Four of 51 (8%) community members, and four of 14 (28%) Indigenous health workers also cited toxic fumes, including gas, petrol, paints and pesticides as a cause of lung cancer. All participants identified at least one warning symptom of lung cancer from the list in Table 3. Thirty-five of 51 (69%) community participants and nine of 14 (64%)	

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			Indigenous health workers said they would seek health- care promptly if they developed one of these warning symptoms. Traditional medicine was used (but not regularly or exclusively) by 17 community members (33%) and six Indigenous health workers (43%). All participants reported seeking conventional treatment when ill. We found a low level of lung cancer awareness in this survey and identified contributing factors.	
Scott, Donato-Hunt, Crane, Lafontaine, Varlow, Seale & Currow (2014)	All groups thought survival rates would be very poor for people with lung cancer. Arabic-speaking smokers generally believed that a person would die six months after diagnosis, and the groups could not recall any cases where lung	Arabic-speaking groups also expressed a cultural perception and stigma towards cancer, whereby the more one talks and thinks about cancer the higher the risk.	As well as smoking, other perceived risk factors for lung cancer were suggested, including stress, lifestyle, environmental factors and genetics. Environmental risk factors and agricultural food production	Participants accurately reported that a person diagnosed with lung cancer was more likely to be male than female, over 40 years of age and be a regular long-term or heavy smoker. While smoking was the most discussed risk factor, the

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	cancer treatment was successful. There was limited knowledge of lung cancer, however generally it was felt diagnosis would occur in a late stage. Further, fatalistic views towards cancer in general were apparent across all three CALD groups. Compared with other illnesses Arabic-speaking smokers felt that cancer was of greater concern as participants believed other diseases could be managed and some cured, whereas cancer could not be. Overall, a greater sense of fear was articulated in the Arabic-speaking groups in relation to help-seeking for health concerns. Participants discussed reluctance to go to the doctor for fear of bad news, particularly if one is referred to		were discussed in the Cantonese and Mandarin-speaking smoker groups. Arabic-speaking smokers were less knowledgeable about symptoms than non-smokers and advised they would not be concerned by a cough that changes/new cough or persistent cough as they were not seen to be symptoms of lung cancer. In the Arabic-speaking smoker group there was a sense of denial towards the risk of developing lung cancer, and cancer more generally, as well as the link between smoking and lung cancer. There was some awareness of the importance of early diagnosis of lung cancer (primarily amongst Cantonese-speaking smokers), however all	general concept of risk factors was not clearly understood. As well as smoking, other perceived risk factors for lung cancer were suggested, including stress, lifestyle, environmental factors and genetics. Environmental risk factors and agricultural food production were discussed in the Cantonese and Mandarin-speaking smoker groups. Further, smokers in all three CALD groups were mixed in their views of whether smoking increased their risk of lung cancer; some felt they had no greater risk of lung cancer than ex-smokers or non- smokers. Some of those in the Arabic-speaking smoking group felt they were not at increased risk compared with non-smokers due to their healthy lifestyle choices being more influential

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	a specialist, with associated stress and anxiety when waiting for a diagnosis.		groups thought survival rates would be very poor for people with lung cancer. Opinion on early diagnosis was also not consistent, as some in the Cantonese non-smoking group thought diagnosis was not possible in the early stages of lung cancer. There was a mixed response between the groups regarding awareness of symptoms consistent with lung cancer	than their smoking or that their bodies were immune. Arabic-speaking groups also expressed a cultural perception and stigma towards cancer, whereby the more one talks and thinks about cancer the higher the risk.
Tod, Craven & Allmark (2008)	Fear was fostered by a lack of knowledge of treatments and strong fatalistic beliefs. Fear of death and a cancer diagnosis delayed reporting of symptoms. Current information campaigns were seen to contribute to fatalistic views as they focused on death rather than treatment.	The findings revealed a prevailing expectation that people with lung cancer would experience blame and stigma. Non- or ex-smokers delayed in reporting symptoms because of an expectation, based on previous experience, that they would be stigmatized as a smoker and blamed for their illness.	There was wide variation in symptoms and therefore no clear symptom profile emerged. Symptoms were often minor and unspecific Some participants thought that lung cancer was different from other cancers which had clear symptoms detectable through physical self-examination	Participants did not have accurate knowledge of lung cancer risk and saw themselves as more at risk of other cancers. Two participants believed that after they gave up smoking their risk of lung cancer would be nil. This belief prompted them to ignore symptoms.

Table 3-9: Thematic Framework Analysis of Qualitative Lung Cancer Studies				
	Fatalism and Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	Great value was placed on stoicism, not complaining and ‘‘putting on a brave face’’. Fear of a medical consultation and being seen as a time- waster further prompted delay, especially where people had previous bad experiences. Stoicism was present in older, male participants and those who had worked in traditional industries such as coal mining and steel, and at the railway plant.		There was a tendency to attribute symptoms to other acute and chronic conditions […] This tendency was exaggerated in those who did not smoke. Knowledge and awareness of lung cancer symptoms and treatments was poor, and available information focused on other cancers. Any lung cancer information was smoking- related.	

3.4.4.2 Qualitative thematic framework – lung cancer screening

The table below displays a thematic framework based on the findings of the included qualitative lung cancer screening studies. The table includes extracts from the included studies.

Table 3-10: Thematic Framework Analysis of Qualitative Lung Cancer Screening Studies

	Barriers to screening	Smoking status and cessation	Lung cancer (screening) awareness and beliefs
Das Nair, Orr, Vedhara & Kendrick (2014)	We class the perceived barriers as practical barriers and psychosocial barriers. Of the former, the main obstacle to participation appeared to be the need for flexible appointments that were local to participants While most of the respondents were retired, work commitments among some of the younger participants were seen as a potential barrier and so the need for flexible appointments was perceived to be greatest for this demographic (under 60s) With regard to perceived psychosocial barriers, participants felt stigmatized (because of their smoking status) by some of the language used in the PILs (such as targeting smokers, because of their higher risk of developing lung cancer). Some strong views were expressed that cancer	Indeed, some participants believed that by taking part in the trial and finding out that they had lung cancer may force people to stop smoking, even though they did not want to […]Such views were, however, contrasted with equal numbers of participants who said that they would continue to smoke, regardless of what the test found With regard to perceived psychosocial barriers, participants felt stigmatized (because of their smoking status) by some of the language used in the PILs (such as targeting smokers, because of their higher risk of developing lung cancer). Some strong views were expressed that cancer could affect anyone and smokers should not be made to feel singled out or challenged:	With regard to perceived psychosocial barriers, participants felt stigmatized (because of their smoking status) by some of the language used in the PILs (patient information leaflet) (such as targeting smokers, because of their higher risk of developing lung cancer). Some strong views were expressed that cancer could affect anyone and smokers should not be made to feel singled out or challenged

Table 3-10: Thematic Framework Analysis of Qualitative Lung Cancer Screening Studies			
	Barriers to screening	Smoking status and cessation	Lung cancer (screening) awareness and beliefs
	could affect anyone and smokers should not be made to feel singled out or challenged One possible barrier to recruitment was the perception held by some participants that the trial is designed to encourage people to stop smoking Altruism was perceived to be a motivator for participants, particularly for those in the control group who saw their role in participating in the research, even to the extent that they viewed the blood they were giving (which was not going to be tested for the lung cancer) as helping others		
Zeliadt, Heffner, Sayre, Klein, Simons, Williams, Reinke & Au (2015)	They described lung cancer screening as much simpler than other cancer screening tests. One participant described the test as "no fuss, no muss." Many study participants expressed that offering screening was a highly valuable service because everyone who undergoes screening will receive a benefit from it Many participants wanted to undergo screening to	The emotional arousal induced by screening was strongly influential to some participants. Notably, 3 participants reported having quit smoking for at least 30 days because of screening One participant indicated that he quit after being offered screening because the conversation caused him to think differently about his health and smoking. One participant who reported quitting described	Participants described the offer of lung cancer screening as stimulating a period of self-reflection. Most participants described the availability of screening very positively; however, some participants described being anxious for many days thinking about smoking and lung cancer during the entire screening process, from the time of being offered the test, scheduling it, and waiting for the results.

Table 3-10: Thematic Framework Analysis of Qualitative Lung Cancer Screening Studies			
	Barriers to screening	Smoking status and cessation	Lung cancer (screening) awareness and beliefs
	see “how much damage” they had done to their lungs Most participants described the availability of screening very positively; however, some participants described being anxious for many days thinking about smoking and lung cancer during the entire screening process, from the time of being offered the test, scheduling it, and waiting for the results.	how suspicious findings provided motivation for quitting Other participants described being motivated to consider quitting by results of their tests, although most ultimately commented that now was not a good time to try quitting, said they could wait to see if the findings on their LDCT scan progressed, or provided other reasons why they were not likely to take immediate action to quit. The exasperated and hopeless tone about quitting contrasted strongly with the language used to describe the ease and effortlessness of screening They described lung cancer screening as much simpler than other cancer screening tests. One participant described the test as “no fuss, no muss.” Although no participants directly stated that they saw screening as a substitute for cessation, most were extremely enthusiastic about how simple the screening process was while earlier in the interview they had spent a	They described lung cancer screening as much simpler than other cancer screening tests. One participant described the test as “no fuss, no muss.” Although no participants directly stated that they saw screening as a substitute for cessation, most were extremely enthusiastic about how simple the screening process was while earlier in the interview they had spent a significant amount of time recounting the futility of trying to quit smoking. Many study participants expressed that offering screening was a highly valuable service because everyone who undergoes screening will receive a benefit from it. Although patients were provided with education about the limited absolute benefit of screening, nearly all participants mentioned the belief that everyone who is screened will benefit in some way. Several patients used future-looking phrases to describe how they felt protected from lung cancer just knowing that a screening program is available.

Table 3-10: Thematic Framework Analysis of Qualitative Lung Cancer Screening Studies			
	Barriers to screening	Smoking status and cessation	Lung cancer (screening) awareness and beliefs
		significant amount of time recounting the futility of trying to quit smoking. In interviews conducted after patients had received the results of their scan, some participants reported feeling they should be more motivated to quit. However, when asked in more depth to describe those feelings, several patients described a lack of urgency for quitting linked with plans to follow their findings with additional imaging.	Many participants wanted to undergo screening to see "how much damage" they had done to their lungs, a theme that arose both in interviews prior to knowing the LDCT results as well as interviews after results were known. Several participants indicated that they were expecting bad news; so, when they were told the findings were not urgent and did not require immediate action, they expressed relief Interestingly, even participants who were identified with nodule findings described feeling that their smoking had not yet harmed them because they were not told they have a cancer diagnosis.

3.4.5 Synthesis matrix – lung cancer

The following table displays a thematic synthesis matrix of quantitative and qualitative lung cancer studies, in order to identify overlap and gaps in the identified literature.

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies

	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
Chatwin et al. (2014) (Low SES)	Both patients and high-risk individuals (from low SES areas) had fatalistic views of lung cancer.		Poor awareness among participants of the symptoms of lung cancer.	Participants could identify smoking as a risk but were ambivalent about the effects of smoking.
Corner et al. (2006) (Low and High SES)	Participants did not appear to have consciously 'delayed' seeking help for symptoms through fear.	Delay to seek help occurred as a result of stigma attached to smoking in both low and high SES areas.	Delay in help seeking occurred because symptoms where not important enough to warrant making a GP appointment across SES.	
Crane et al. (2016) (Low and High SES)	A sense of fatalism amongst both current and former smokers about their current and future health was also evident.	Current smokers would not go to their doctor about symptoms because of feelings of stigma associated with smoking.	The majority of participants were able to identify smoking as a risk factor for lung cancer. Higher socioeconomic status contributed to a higher recognition of symptoms.	Perceived risk was low amongst those at most risk.
Desalu et al. (2016) (Low and High SES)			Those with lower education level and income were more likely to wait 2 weeks	Good awareness and recognition of risk factors

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies

	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			or more before seeking help for symptoms	were higher educational level and higher income.
Hvidberg et al. (2014) (Low and High SES)			People with a low educational level and a low household income were more likely to have a lower awareness of cancer symptoms.	People with a low educational level and a low household income were more likely to have a lower awareness of cancer risk factors.
Lathan et al. (2015) (Low SES)		Stigma associated with a lung cancer diagnosis. Participants believed that others assume lung cancer patients are smokers and that many use it to judge their character.	Both lung cancer patients and those who had no cancer history were aware of common symptoms and possible poor prognosis of lung cancer.	Both lung cancer patients and those who had no cancer history were aware of the link between smoking. The majority of participants from the patient group did not think smoking was the cause of their current cancer diagnosis.
Marlow et al. (2010) (Low and High SES)		Higher education level was associated with greater blame attribution for lung cancer.		
Mazieres et al. (2015) (Low and High SES)	Lung cancer was identified as a severe disease with a worse prognosis than other cancers but overall survival	Lung cancer was associated with a loss of autonomy or seen as a punishment.	Negative word associations were associated with high education level and those in employment. Positive words were associated with	

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies

	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	of patients with lung cancer was overestimated.		those outside of employment and low education level.	
Moffat et al. (2015) (Low and High SES)			Awareness of hoarseness/coughing as a symptom of lung cancer increased after the campaign – there was no significant difference across deprivation groups. There was a greater increase in GP attendances for practices in less-deprived areas.	
Moran et al. (2003) (Low and High SES)				Current smokers rated their lifetime risk for developing as average or below average. There was no difference in perceived risk across education levels.
Niksic et al. (2016) (Low and High SES)			Cancer symptom awareness and barriers scores varied greatly between geographical regions in England, with the worst scores observed	

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies

	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
			in socioeconomically deprived areas.	
Page, et al. (2015) (Low SES)	Participant responses to lung cancer were often negative and included words such as 'death' or 'kills'.		Around half of participants had a low level of awareness/ knowledge of lung cancer but had some awareness of smoking as a cause. Participants were able to identify some symptoms of lung cancer.	
Power & Wardle (2015) (Low and High SES)	Being too scared and being worried about what the doctor might find were cited as barriers to help seeking but reduced significantly between the two campaigns. SES differences not reported.		There were no significant interactions between survey year and sex, age, ethnicity, occupation or cancer experience in the changes in symptom recall or symptom recognition.	
Price & Everett (1994) (Low and High SES)	The least educated respondents considered lung cancer to be more severe.		Those with the highest level of education knew more about lung cancer than either the middle level or lowest level of educated respondents.	The least educated respondents perceived themselves as more susceptible to developing lung cancer than those with higher education levels.
Quaife et al. (2015) (Low and High SES)	Current smokers are more pessimistic, fatalistic and avoidant of cancer and its			

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies				
	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	outcomes. Negative perceptions of cancer outcomes were not associated with demographic characteristics.			
Rawl et al. (2019) (Low and High SES)			Those with lower incomes were less likely to have had a lung scan in the last year.	Individuals most likely to perceive that they were unlikely to get cancer were more often black, with low incomes or less than a high school degree.
Scott et al. (2014) (Low SES)	All groups reported fatalistic views of lung cancer.	Only Arabic-speaking groups expressed a perceived stigma towards cancer.	There was limited knowledge of lung cancer There was some awareness that early diagnosis of lung cancer is beneficial, but all groups thought survival rates were poor.	Perceived susceptibility varied across the different cultural groups.
Simon et al. (2012) (Low and High SES)			People in the highest social grade had higher symptom awareness than those in the lower grades.	People with the highest social grade had greater risk factor recognition and recall than those in the lowest social grade
Tod et al. (2008) (Low SES)	Fear was fostered by a lack of knowledge of treatments and strong fatalistic beliefs.	An expectation that people with lung cancer would experience blame and	Symptom awareness was poor, and symptoms experienced were seen as	Knowledge of lung cancer risk was poor, with participants believing they

Table 3-11: Thematic Synthesis Matrix for Lung Cancer Studies

	Fatalism & Fear	Stigma	Lung cancer and symptom awareness	Risk Perception
	Fear of death and a cancer diagnosis delayed reporting of symptoms.	stigma. Non- or ex-smokers delayed in reporting symptoms because of an expectation, based on previous experience, that they would be stigmatized as a smoker and blamed for their illness.	minor and not attributed to lung cancer.	would be more at risk of other types of cancer.
Weiss et al. (2014) (Low and High SES)		Stigmatization of lung cancer negatively influenced support for lung cancer initiatives. Participants believed that lung cancer patients were at least partly to blame for their illness.	Participants perceived that lung cancer was caused by external factors, and that it could be cured if caught early. ‘Supporters’ of lung cancer initiatives were more likely to be employed and have higher income.	
Whitaker et al. (2012) (Low and High SES)	Lung cancer perceived to be more fatal when compared to other cancers.		There was a tendency to overestimate lung cancer survival, however awareness of survival differences did not vary by sex, age or socioeconomic status.	

3.4.6 Synthesis matrix – lung cancer screening

The following table displays a thematic synthesis matrix of quantitative and qualitative lung cancer screening studies, in order to identify overlap and gaps in the identified literature.

Table 3-12: Thematic Synthesis Matrix for Lung Cancer Screening Studies

	Barriers to screening	Smoking Status and Smoking Cessation	Lung cancer (screening) awareness and beliefs
Ali et al. (2015) (Low and High SES)	A number of perceived barriers to the lung cancer screening trial were cited including practical barriers, emotional barriers, trial acceptability, and low perceived risk. Practical barriers are more likely to be perceived by those with lower SES. Smokers were more likely to report emotional barriers to participation.	Smokers were less likely to participate in the lung cancer screening trial.	Older age, female gender, smoking status, low SES, and higher perceived risk were significantly associated with non-uptake of lung cancer screening.
Cataldo (2016) (Low and High SES)		Older smokers are aware of the risks of smoking and were interested in smoking cessation.	Older smokers are interested in and positive about lung cancer screening. Demographic variables were not significantly associated with the decision to have lung cancer screening.
Crothers et al. (2016) (Low SES)		Current smokers wanted to learn about lung cancer but believed that other risk factors deserved more emphasis. Smokers felt a sense of	Participants were not aware of the purpose of lung cancer screening, wanted to know about the benefits and harms and believed physicians need to communicate more

Table 3-12: Thematic Synthesis Matrix for Lung Cancer Screening Studies

	Barriers to screening	Smoking Status and Smoking Cessation	Lung cancer (screening) awareness and beliefs
		stigmatisation because of their smoking status.	effectively. Participants expressed surprise that the magnitude of their lung cancer risk and benefits of screening were lower than anticipated.
Das Nair et al. (2014) (Low SES)	Cited potential barriers include lack of flexibility for appointments and smoking related stigma.	Participants felt stigmatized because of their smoking status and the targeted nature of the screening trial. They considered that smokers should not be singled out as non-smokers can also get lung cancer. Participants were concerned that they would be forced to stop smoking.	
Jonnalagadda et al. (2012) (High and Low SES)	Cost of screening, fatalism and fear of radiation exposure from screening were perceived barriers for minority groups and those with low incomes.		Minority groups were more likely to report difficulty understanding lung cancer and to hold misconceptions about lung cancer cause. Beliefs reflecting fatalism and spirituality, fear and anxiety were endorsed more often by minority groups compared to non-minority subjects.
Quaife et al. (2018) (High and Low SES)		Current smokers were found to have lower level of education. Worry about lung cancer risk was most common among smokers. The	Participants had fatalistic beliefs about lung cancer. Sex, age, ethnicity, level of education, marital status and cancer experience were

Table 3-12: Thematic Synthesis Matrix for Lung Cancer Screening Studies

	Barriers to screening	Smoking Status and Smoking Cessation	Lung cancer (screening) awareness and beliefs
		majority of current and former smokers intended to be screened for lung cancer.	not associated with screening intentions.
Rutten et al. (2009) (High and Low SES)			Lung cancer prevention knowledge was associated with higher education level. There were no significant associations between screening beliefs and survival beliefs and demographic characteristics.
Tanner et al. (2013) (Low and High SES)		Smokers were significantly more likely to be less educated, have a lower income, and report poorer health.	Current smokers believe that they were at increased risk of lung cancer. Half of participants believed that early detection of lung cancer results in a good chance of survival. Nearly all surveyed would have a CT scan for lung cancer screening.
Zeliadt et al. (2015) (Low SES)		Current smokers exaggerated the personal benefits of lung cancer screening. Many believed that screening meant that there was less urgency to stop smoking. Lung cancer screening stimulates a period of self-reflection and induced ‘emotional arousal’.	

3.4.7 Further synthesis: reflecting on research question

The following section describes the evidence from the included studies using the identified themes with the aim to answer the research questions.

3.4.7.1 Do public perceptions and awareness level of lung cancer differ between socioeconomic groups?

3.4.7.1.1 Fatalism & fear

Eleven studies contained elements of fear and fatalism (Chatwin et al., 2014; Corner et al., 2006; Crane et al., 2016; Mazieres et al., 2015; Page, et al., 2015; Power & Wardle, 2015; Price & Everett, 1994; Quaife et al., 2015; Scott et al., 2014; Tod et al., 2008; Whitaker et al., 2012).

Fear of lung cancer and its consequences was assessed in three studies (Power & Wardle, 2015; Quaife et al., 2015 & Tod et al., 2008). In studies where lung cancer fear was reported, it was not found to vary by SES.

Lung cancer fatalism was discussed in nine studies (Chatwin et al., 2014; Crane et al., 2016; Mazieres et al., 2015; Page, et al., 2015; Price & Everett, 1994; Quaife et al., 2015; Scott et al., 2014; Tod et al., 2008; Whitaker et al., 2012). Cancer fatalism was reported in all but one of these studies, which concluded that the survival of lung cancer was significantly overestimated by participants (Page et al., 2015). A fatalistic view of lung cancer was also found to delay help-seeking for lung cancer symptoms (Tod et al., 2008). The association of fatalism and SES was mixed. Low SES was associated with fatalistic beliefs of lung cancer in four studies (Chatwin et al., 2014; Page et al., 2015; Price & Everett, 1994; Tod et al., 2008). However, fatalism was not associated with SES in the remaining four studies fatalism was identified in (Crane et al., 2016; Quaife et al., 2015; Scott et al., 2014; Whitaker et al., 2012). Smoking status was also associated with fatalistic views of lung cancer, with current smokers more likely to hold fatalistic beliefs (Crane et al., 2016; Quaife et al., 2015).

The studies reviewed reveal that fear and fatalism are commonly held beliefs about lung cancer, but the association with SES is unclear.

3.4.7.1.2 Stigma

Perceived stigma was discussed in eight studies (Corner et al.,2006; Crane et al., 2016; Lathan et al., 2015; Marlow et al., 2010; Mazieres et al., 2015; Scott et al., 2014; Tod et al., 2008; Weiss et al., 2014).

Stigma was directly associated with smoking status in all studies; current smokers were more likely to believe that there is a stigma associated with lung cancer. A level of blame is also attributed to a diagnosis of lung cancer (Lathan et al., 2015; Marlow et al., 2010; Mazieres et al., 2015; Scott et al., 2014; Tod et al., 2008; Weiss et al., 2014). Blame was described as personal (i.e. the individual would blame themselves for a lung cancer diagnosis) and also attributed by others (i.e. other people would blame them for a lung cancer diagnosis). The result of perceived lung cancer stigma was a delay in help-seeking for symptoms of lung cancer (Corner et al., 2006; Crane et al., 2016; Tod et al., 2008).

The association of lung cancer stigma and SES was mixed. No differences in perceived stigma and SES were reported in four studies (Corner et al., 2006; Crane et al., 2016; Lathan et al., 2015; Scott et al., 2014). Perceived stigma was found to be higher in low SES groups (Tod et al., 2008; Weiss et al., 2014), while those in higher SES groups were more likely to attribute blame to smokers (Marlow et al., 2010; Mazieres et al., 2015).

The studies reveal that smokers perceive a high level of stigma attached to lung cancer but the association between stigma and SES varies.

3.4.7.1.3 Lung cancer and symptom awareness

Lung cancer and symptom awareness was discussed in eighteen studies (Chatwin et al.,2014; Corner et al., 2006; Crane et al., 2016; Desalu et al., 2016; Hvidberg et al., 2014; Lathan et al., 2015; Mazieres et al., 2015; Moffat et al., 2015; Niksic et al., 2016; Page, et al., 2015; Power & Wardle, 2015; Price & Everett, 1994; Rawl et al., 2019; Scott et al., 2014; Simon et al., 2012; Tod et al., 2008; Weiss et al., 2014; Whitaker et al., 2012).

Lung cancer knowledge, including perceived severity and cause, was discussed in nine studies (Lathan et al., 2015; Mazieres et al., 2015; Page, et al., 2015; Price & Everett, 1994; Rawl et al., 2019; Scott et al., 2014; Weiss et al., 2014; Whitaker et al., 2012). Lung cancer knowledge was associated with SES in all but two studies (Lathan et al., 2015; Whitaker et al., 2012). Lung cancer knowledge was lower in lower SES groups.

Lung cancer symptom awareness and recognition was discussed in eleven studies (Chatwin et al., 2014; Corner et al., 2006; Crane et al., 2016; Desalu et al., 2016; Hvidberg et al., 2014; Lathan et al., 2015; Moffat et al., 2015; Niksic et al., 2016; Power & Wardle, 2015; Simon et al., 2012; Tod et al., 2008).

Symptom awareness was found to be associated with delay in help-seeking, with those with lower lung cancer recognition scores more likely to wait longer to seek medical help for symptoms (Corner et al., 2006; Desalu et al., 2016). Symptom awareness varied by SES in the majority of studies, with those with low SES having poorer lung cancer symptom recognition (Chatwin et al, 2014; Crane et al., 2006; Desalu et al., 2016; Hvidberg et al., 2014; Niksic et al., 2016; Simon et al., 2012; Tod et al., 2008). However, four studies indicated that that there was no difference in symptom awareness across SES groups.

The studies reveal a clear association between SES and lung cancer knowledge, and a suggestion that symptom recognition is related to SES. Results indicate that those from lower SES groups have poorer knowledge and recognition.

3.4.7.1.4 Risk perception

Risk perception was discussed in eleven studies (Chatwin et al., 2014; Crane et al., 2016; Desalu et al., 2016; Hvidberg et al., 2014; Lathan et al., 2015; Moran et al., 2003; Price & Everett, 1994; Rawl et al., 2019; Scott et al., 2014; Simon et al., 2012; Tod et al., 2008).

Lung cancer risk factor recognition varied across studies. Smoking was a well-recognised risk factor (Chatwin et al., 2014; Lathan et al., 2015), although, patients with lung cancer who smoked were unlikely to attribute their diagnosis to their smoking status (Lathan et al., 2015). Risk factor awareness and recognition was better in higher SES groups (Desalu et al., 2016; Hvidberg et al., 2014; Simon et al, 2012).

Perceived risk of lung cancer varied by smoking status; smokers perceived their risk as average or below average (Moran et al., 2003). Perceived risk also varied by cultural group in one study (Scott et al., 2014). In some studies, perceived risk was associated with SES (Crane et al., 2014; Price & Everett, 1994; Rawl et al., 2019; Tod et al., 2008). Three studies reported that those from lower SES groups perceived themselves to be at lower risk of lung cancer (Crane et al., 2016; Rawl et al., 2019; Tod et al, 2008). Conversely, one study reported that those from low SES groups were more likely to perceive themselves at higher risk of lung cancer (Price & Everett, 1994), and one found that there was no difference in risk perception across SES groups (Moran et al., 2003).

The studies reveal a mixed picture of lung cancer risk perception. Risk factor recognition was higher in high SES groups. However, the studies indicate the link between perceived risk and SES is not as transparent. General trends indicate that those from lower SES groups perceive themselves at lower risk of lung cancer.

3.4.7.2 Do the public perceptions and awareness level of lung cancer screening differ between socioeconomic groups?

3.4.7.2.1 Barriers to screening

Barriers and motivators to attending lung cancer screening were discussed in three studies (Ali et al., 2015; das Nair et al., 2014; Jonnalagadda et al., 2012). All studies cited both practical and emotional barriers. Practical barriers include travel to, and flexibility of appointments (Ali et al., 2015; das Nair et al., 2014), the presence of comorbidities and caring responsibilities (Ali et al., 2015), and cost of lung cancer screening in health care systems that require private insurance (Jonnalagadda et al., 2012). Emotional barriers cited include lung cancer fear (Ali et al., 2015), lung cancer and smoking stigma (das Nair et al., 2014), and lung cancer fatalism (Jonnalagadda et al., 2012).

Low SES groups reported more barriers to screening (Jonnalagadda et al., 2012). Those from low SES groups were more likely to report practical barriers to screening, compared to those in higher SES groups (Ali et al., 2015; Jonnalagadda et al., 2012). Smokers were more likely to report emotional barriers like fear, fatalism and stigma (Ali et al., 2015).

The studies indicate that both practical and emotional barriers play a role in non-uptake of lung cancer screening. Those from lower SES groups are more likely to report more barriers to screening.

3.4.7.2.2 Smoking status and smoking cessation

Seven studies discussed smoking status and smoking cessation in relation to lung cancer screening (Ali et al., 2015; Cataldo, 2016; Crothers et al., 2016; das Nair et al., 2014; Quaife et al., 2018; Tanner et al., 2013; Zeliadt et al., 2015).

The perceptions of lung cancer screening varied by smoking status. Smoking status was associated with intention to attend lung cancer screening, with smokers less likely to participate in lung cancer screening, or lung cancer screening trials despite positive intentions (Ali et al., 2015; Quaife et al., 2018). Lung cancer worry was highest among smokers (Quaife et al., 2018). Smokers were also likely to report perceived stigma because of their smoking status (Crothers et al., 2016; das Nair et al., 2014).

Smoking cessation was discussed in three studies (Cataldo et al., 2016; das Nair et al., 2014; Zeliadt et al., 2015). Results across the studies were mixed. Older smokers reported being interested in smoking cessation as a result of lung cancer screening (Cataldo et al., 2016). However, another indicated that smokers would be concerned that they would be forced to stop smoking if they attended lung cancer screening (das Nair et al., 2014). The remaining study indicated that smokers were less likely to stop smoking as a result of lung cancer screening because participants overestimated the protective benefits of screening (Zeliadt et al., 2015).

Smokers were found to be more likely from lower SES groups (Quaife et al., 2018; Tanner et al., 2013). SES differences went unreported in all but two studies that indicate that there were no differences in beliefs across SES groups (Cataldo et al., 2016; Quaife et al., 2018).

The studies indicate that smokers are more likely to be from lower SES groups, less likely to attend screening, are more worried and perceive greater stigma because of their smoking status. However, the gaps in SES comparison mean potential difference in beliefs across SES are inconclusive.

3.4.7.2.3 Lung cancer (screening) awareness and beliefs

Lung cancer and lung cancer screening beliefs were discussed in seven studies (Ali et al., 2015; Cataldo, 2016; Crothers et al., 2016; Jonnalagadda et al., 2012; Quaife et al., 2018; Rutten et al., 2009; Tanner et al., 2013).

There were a number of misconceptions about lung cancer screening, including the purpose of lung cancer screening and overestimating the benefits of lung cancer screening (Crothers et al., 2016). Fear, anxiety and fatalism were also reported (Jonnalagadda et al., 2012).

Those from lower SES groups were less likely to attend lung cancer screening (Ali et al., 2015), despite positive intentions (Tanner et al., 2013). Fear, anxiety and fatalism were commonly reported by those from lower SES groups (Jonnalagadda et al., 2012) and those from lower SES groups were more likely to overestimate the benefits of screening and underestimate their own risk (Crothers et al., 2016). Those from high SES groups were more likely to have better knowledge about lung cancer and lung cancer screening (Rutten et al., 2009). Three studies indicated that there was no difference in lung cancer screening beliefs across SES groups (Cataldo, 2016; Quaife et al., 2018) or beliefs about lung cancer survival (Rutten et al., 2009).

The studies indicate that the evidence about differing beliefs about lung cancer screening across SES groups is mixed. Those from lower SES groups appear to hold greater misconceptions about lung cancer screening and have more emotional barriers. However, results about the association between SES and lung cancer screening beliefs are inconclusive, with a number of studies reporting no difference across SES groups.

3.5 Discussion

3.5.1 Overview of findings

This systematic review identified evidence that indicates that there is some variation in the public perception and awareness of lung cancer and lung cancer screening across different socioeconomic groups. The evidence explored suggests that those from lower SES groups have poorer knowledge of lung cancer and its symptoms, are more likely to perceive themselves at lower risk of lung cancer and report more barriers to lung cancer screening. However, we cannot conclude that there are stark differences in fear and fatalism, stigma, smoking status and cessation and lung cancer screening awareness and beliefs. The results of these aspects were mixed and therefore do not offer a clear picture about potential socioeconomic differences. An overview of the review findings can be found in Table 3-13.

Table 3-13: Summary of Review Findings

Area of focus	Identified Theme	Conclusion
Lung Cancer	Fear and fatalism	Differences not clear – results are mixed
Lung Cancer	Stigma	Differences not clear – results are mixed
Lung Cancer	Lung cancer and symptom awareness	Those from lower SES groups have poorer knowledge and symptom recognition.
Lung Cancer	Risk perception	General trends indicate that those from lower SES groups perceive themselves at lower risk of lung cancer.
Lung Cancer Screening	Barriers to screening	Those from lower SES groups are more likely to report more barriers to screening.
Lung Cancer Screening	Smoking status and cessation	Differences not clear – results are mixed
Lung Cancer Screening	Lung cancer (screening) awareness and beliefs	Differences not clear – results are mixed

3.5.2 Comparison with other literature

There are currently no other systematic reviews that explore the variation in lung cancer and lung cancer beliefs or awareness across SES. There are a significant number of reviews that explore the treatment of lung cancer, and mortality rates across socioeconomic groups, but these do not illuminate the differences in beliefs, knowledge and awareness of lung cancer and lung cancer screening. However, these reviews provide important detail on the potential outcomes of differences in beliefs and awareness. For example, a systematic review exploring the sex and socioeconomic differences in participation in lung cancer screening programmes concluded that men and those with high SES are over-represented in screening programmes (Schütte, Dietrich, Montet & Flahault, 2018).

Overall, excepting the studies included in the review, studies that explore the differences in beliefs by SES are limited. Within the studies included in the review, only four studies mentioned socioeconomic differences as a primary aim of the study (Hvidberg et al., 2014; Moffat et al., 2015; Price & Everett, 1994; Rawl et al., 2019), despite the clear and well discussed health inequalities in cancer mortality rates across socioeconomic groups.

3.5.3 Methodological strengths and limitations

The studies included in the review were broadly assessed to be of good quality, with only two assessed to be of 'fair' quality (Page et al., 2015; Scott et al., 2014).

There was a great amount of variability in outcome variables in the included studies. This might account for the inconclusive nature of the review results. As mentioned, very few studies had differences in SES as the primary aim of the study. As a result, the reporting of differences by SES was often lacking in detail.

There was a lack of consistency in the measurement of beliefs, knowledge and awareness, with a number of different measures used across the included studies. As a result, drawing conclusions about the differences in beliefs and awareness was challenging and did not allow for further in-depth quantitative analysis.

Similarly, there was also a lack of standardisation in the measurement of SES. SES was measured using a number of different components that reflect socioeconomic position, for example, income, education level or occupation. Often, it was measured only using one individual measure. This was most frequently education level. Individual measures of SES can be indicative of current SES level but cannot account for other aspects of SES that might be associated with screening behaviour. The use of composite measures or area-based measures can create a more reliable measure of SES (Galobardes, Lynch & Smith, 2007).

It is evident that there is limited literature about the beliefs and awareness of lung cancer screening as a result of the lack of national lung cancer screening programmes internationally. As a result, this review included studies using lung cancer screening trials. It is acknowledged that these are not ‘true’ cancer screening programmes, but they reflect the conditions of screening programmes.

3.5.4 Gaps in literature

The integrated synthesis of quantitative and qualitative evidence allowed for the identification of gaps in the current literature. It is evident that there is a difference in studies that explore the beliefs about the physical aspects of lung cancer, and those exploring the emotional beliefs surrounding lung cancer. There appears to be more concentrated study of symptom awareness in quantitative studies, but these detailed very little about emotional representations of lung cancer or lung cancer screening. Conversely, qualitative studies were more likely to discuss emotional representations of lung cancer in a more in-depth manner.

Very few studies explored the barriers to lung cancer screening. This might be the result of lung cancer screening not being widely implemented. However, this gap in knowledge has practical implications if a lung cancer screening is to be implemented in the UK; optimal uptake is fundamental to the successful introduction of a screening programme.

Overall, the included studies did not sufficiently articulate the differences in beliefs and awareness of lung cancer and lung cancer screening across socioeconomic groups. Emotional representations, such as fear, fatalism and stigma, are areas of particular interest.

3.5.5 Review strengths and limitations

The review had a broad research question and inclusion criteria. This resulted in the inclusion of studies with diverse methodologies, aims and outcomes. The inclusion of both qualitative and quantitative methodologies allowed for a comprehensive exploration of the perceptions and awareness of lung cancer and lung cancer screening, not limited by methodology.

To overcome the challenges of synthesising a diverse body of literature an integrative approach was adopted. The integrative review method has been criticised (Whittemore & Knafl, 2005) as incorporating diverse methodologies may to contribute to lack of rigour, inaccuracy, and bias (Whittemore & Knafl, 2005). This review aimed to overcome these criticisms by carrying out the review using a systematic methodology throughout, including study criteria, data extraction and method of synthesis and the inclusion of a strong review team. This helped to ensure that the review had limited bias and improved the accuracy of the conclusions.

The review included studies from different countries, and therefore, different health care systems and relative levels of SES. As a result, the findings of the review are difficult to truly compare. For example, the barriers to lung cancer screening might vary by health system when comparing insurance-based health systems, and those that have national health care, such as the NHS. However, where appropriate, the review distinguishes between the barriers of different health systems within the presentation of the results.

As SES is often relative to the geographical context, there is also a challenge when comparing SES across different countries. The review included papers from six different countries. While some are directly comparable, others may not be. For example, measures of income and education might not be as relevant in some contexts as it is on others. There is an underlying assumption that SES is the same across different international contexts, and as a result, it is important to highlight that this is not always the case.

3.6 Chapter summary

This chapter presented an integrative systematic review exploring the perceptions and awareness of lung cancer and lung cancer screening across different socioeconomic groups. This systematic review provides a novel integrative synthesis of lung cancer literature.

The review synthesised 30 studies, including both qualitative and quantitative methodologies. The integrative synthesis concluded that the literature in this area is mixed, with only clear socioeconomic differences in symptom knowledge and recognition, perceived risk and barriers to lung cancer screening. There is a considerable gap in knowledge with regard to emotional representations of lung cancer and lung cancer screening across socioeconomic groups, with this review finding mixed results.

The next chapter will present a quantitative study that comprehensively explores the differences in lung cancer beliefs across socioeconomic groups and attempts to address some of the gaps identified in this review.

Chapter 4: Socioeconomic status and lung cancer beliefs among participants of a lung cancer screening trial

4.1 Introduction

4.1.1 Socioeconomic status and health inequalities

Health inequalities are the unfair and avoidable differences in health between people of different social groups and can be linked to forms of disadvantage such as poverty, discrimination and lack of access to services or goods (WHO, 2013). There are a number of social determinants of health inequalities including a person's socioeconomic position within society.

Socioeconomic status (SES) is a term used to describe a person's social and economic position in society (Galobardes et al., 2006). The determinants of this position in society are debated (Economic Commission for Europe, 2019) but usually it is understood in terms of access to social and economic resources (Adler and Newman, 2002).

Low SES is a predictor of mortality for many diseases (Kivimäki et al., 2020). Mortality and negative health outcomes are significantly higher for those in more deprived groups – this trend persists globally (Mackenbach, Stirbu, Roskam et al, 2008). Kivimäki et al. (2020) carried out a multi-cohort study exploring associations between SES and the development of mental and physical health conditions in adulthood, using data from two Finnish prospective cohort studies: The Health and Social Support study and the Finnish Public Sector study. Results of the study indicated that low SES is a risk factor for a wide range of disorders including both physical and mental health issues. The authors also reported that the health inequalities that result from variation in SES create a 'lifelong cascade of physical diseases', suggesting the persistence of health inequalities across the lifespan.

4.1.2 Health inequalities in Scotland

In Scotland, the premature mortality rate in the most deprived groups is four times higher than the mortality rate in the least deprived groups (Scottish Government, 2020a). It is evident that deprivation impacts life expectancy and healthy life expectancy in Scotland. National records indicate that there is a significant gap in life expectancy between the most and least deprived areas of Scotland. The difference in life expectancy between those in SIMD decile one and ten has grown from 12.2 to 13.1 years for men and 8.6 to 9.8 years for women since 2016 (National Records of Scotland, 2019). For Healthy Life Expectancy (the number of years they might live in a 'healthy' state), the difference between the most and least deprived areas is even greater. For men, there is a difference of 23.0 years between SIMD decile one and SIMD decile ten and for women, there was a difference of 23.9 years (National Records for Scotland, 2019).

In line with this trend, cancer incidence and mortality are highest in the most deprived areas of Scotland. Of people aged between 45 and 75 years old, those in the most deprived groups are more than twice as likely to die of cancer than those in the least deprived groups. The biggest gap in incidence and mortality between the most and least deprived areas is largest for cancer of the trachea, bronchus and lung (Scottish Government, 2020a). The overall SES differences in cancer mortality are fundamentally driven by variations in screening uptake in the existing cancer screening programmes (e.g. breast, cervical and bowel). This leads to socially patterned rises in cancer incidence and, in turn, cancer survival for some types of cancer in the least deprived areas (Scottish Government, 2020a). Although cancers of the trachea, bronchus and lung do not currently have national screening programmes in the UK, we should anticipate these challenges if a screening programme is implemented.

4.1.3 Socioeconomic status and cancer screening uptake

There is variation in participation that exists both within and between national screening programmes. It has been recognised that people at higher risk of cancer are significantly less likely to participate in cancer screening (NHS England, 2019). Level of deprivation has been identified as an important determinant of cancer screening uptake, with uptake of cancer screening in the UK being significantly lower in more deprived groups (Weller & Capmbell, 2009).

In Scotland, the uptake of the three national screening programmes varies significantly by deprivation level. Women from the most deprived areas are less likely to attend breast screening, with 59.9% of women from deprived areas attending screening, compared to 79.7% of women from the least deprived areas of Scotland (Public Health Scotland, 2020). Similarly, women from the most deprived areas of Scotland are less likely to attend cervical screening (67%) compared to women from the least deprived areas (78%). This trend is also reflected in Scotland's national bowel screening programme with uptake being 21.2% lower among people from the most deprived groups of Scotland (51.8%) compared to those from the least deprived areas (72.9%) (Public Health Scotland, 2020b).

Although the variation in uptake of cancer screening among different socioeconomic groups are multilevel, differences in cancer beliefs may offer a potential malleable target for future interventions

4.1.4 Socioeconomic status and cancer beliefs

Certain beliefs and attitudes about cancer can impact cancer screening uptake. Lower uptake is often associated with beliefs such as cancer fatalism (Powe & Finnie, 2003; Schueler et al., 2008; Jonnalagadda et al., 2012), low perceived risk (Katapodi et al., 2004) and cancer worry (Good et al., 2010; Vrinten et al., 2014).). Overall, those from more deprived groups are likely to report more barriers to cancer screening (Ali et al., 2015)

As discussed in Chapter 3, there is some variation in beliefs across SES that partially explain difference in uptake of cancer screening across SES. The findings of the systematic review indicate that those from lower SES groups having lower knowledge, perceived risk and are more likely to report more barriers to lung cancer screening.

Existing literature exploring the variation of attitudes towards cancer and cancer screening, fatalism, fear and perceived risk across different SES groups, is summarised in the following section.

4.1.4.1 Positive and negative attitudes

Robb, Simon, Miles & Wardle (2014) indicate that people are in ‘two minds’ about cancer, with positive and negative beliefs coexisting. Participants of the qualitative study would often respond in a negative way when discussing cancer (for example, articulate fear of cancer) but would also describe the great improvements in treatments in a positive way. As a result of this duality, whether positive or negative beliefs about cancer impact the uptake of cancer screening is debated. Positive beliefs about cancer might increase uptake by viewing screening as an opportunity to undertake preventative behaviour (Quaife et al., 2017; Sarma et al., 2019). Negative beliefs about cancer might create barriers to cancer screening or encourage people to take part. This duality of beliefs exists across SES (Quaife et al., 2017).

A population-based study that aimed to assess SES differences in positive and negative attitudes towards cancer in the UK found that those with lower SES were significantly more likely to hold negative beliefs about cancer compared to those from higher SES groups (Quaife et al., 2015). Similarly, a study exploring inequalities in bowel cancer screening participation also indicates that negative attitudes towards bowel cancer are strongly associated with education level (Smith et al., 2016). Those with lower education levels were likely to perceive more emotional and practical barriers, and have lower levels of perceived benefit of screening.

4.1.4.2 Fatalism and cancer fear

Cancer fatalism - the negative belief that cancer has fatal consequences - is cited as both a barrier and an encouraging factor in cancer screening uptake (Wardle et al., 2015; Vrinten et al., 2015). A systematic review and meta-synthesis exploring cancer fears in the general population found that cancer fear is founded on the view that cancer is severe, unpredictable and indestructable. It is often described as an ‘enemy’ and this negative belief is believed to impact cancer screening uptake, acceptance of cancer early detection and the effectiveness of prevention messages (Vrintern et al., 2016).

Exitising literture on the variation of cancer fear and fatalism across SES groups is fragmented, as indicated in the review of literature in Chapter 3. In some cases, levels of cancer fear and fatalism have been found to be higher in those from more deprived groups. In a mixed method study, which explored the beliefs about lung cancer of smokers and ex-smokers from socioeconomically deprived communities in England, respondents perceived lung cancer to be an uncontrollable disease that is self-inflicted and untreatable indicating a high level of fatalism (Quaife et al., 2017). On the other hand, studies also indicate that there is no differences in fatalism across SES groups (Chatwin et al., 2014; Quaife et al., 2015).

4.1.4.3 Perceived risk

Perceived risk is a complex construct that can be divided into three distinct dimensions: perceived likelihood of developing the disease; perceived susceptibility/vulnerability to the disease; and perceived severity of the disease (Brewer et al., 2007). The combination of these distinct forms of risk perception leads to the development of overall perceived risk of cancer. The development of perceived risk of cancer can be based on a number of factors including family history (Robb, Miles, & Wardle, 2007), and awareness of cancer risk factors and symptoms of cancer (Wardle et al., 2015).

The association between perceived risk and screening uptake is unclear. Like cancer fear, it can be seen as both a barrier and a motivator to cancer screening (Warlde et al., 2015). A meta-analysis exploring whether bowel cancer risk perceptions are associated with screening behaviour indicates that greater perceived risk positively predicts bowel cancer screening uptake (Atkinson et al., 2015). Similarly, another meta-analysis exploring the predictors of perceived breast cancer risk also found a positive assocation between perceived risk and breast screening participation (Katapodi et al., 2004). However, other studies point to there being no clear association between risk perception and screening participation (Vernon, 1999).

Perceived risk of cancer has been shown to vary by socioeconomic deprivation level. A quantitative study that investigated participants' lay beliefs of cancer risk factors in a French population (n = 3359) found that those with higher SES scores were more likely to emphasise behavioural factors in the development of cancer and were more aware of risk factors in general (Peretti-Watel, Fressard, Bocquier & Verger, 2016). Those with higher SES, particularly those with a higher education level, were more aware of behavioural risk factors for cancer (Pretti-Watel et al., 2016). This was also found to be the case in some of the studies reviewed in Chapter 3, with more deprived groups more likely to have lower perceived risk of lung cancer (Crane et al., 2016) and lower awareness of cancer risk factors and symptoms (Desalu et al., 2016; Hyidberg et al., 2014). Further studies indicate that income (as a measure of SES) can also predict perceived risk (Hawkins, Berkowitz & Peipins, 2010).

4.1.5 Measurement of socioeconomic status

There are a number of ways to measure SES, with each providing benefits and limitations. SES is a multifaceted construct that means that there is not one standardised measure.

4.1.5.1 Individual-level measures

Individual determinants of SES are often used to measure the level of deprivation experienced by individuals or groups (Conway et al., 2019). Measures such as income, education level, occupation and household indicators can act as individual measures but are often highly correlated (Darin-Mattsson, Fors & Kåreholt, 2017).

Income, used as a measure of SES, often refers to access to material resources and services. Income is also a reliable measure of SES (Conway et al., 2019). In order to predict SES, income is usually measured as household gross income per number of persons dependant on the income (Galobardes et al., 2007). A related measure of SES is wealth, which includes income and all accumulated material resources such as land, property and car ownership (Galobardes et al., 2007; Conway et al., 2019).

Education level has successfully been used as an indicator of SES. An individual's highest attained level of education, or the age at which they left school, reflects early-life SES and usually remains stable across the life course (Conway et al., 2019; Darin-Mattsson, Fors & Kåreholt, 2017). It is a strong determinant of employment and income.

Similarly, occupation can also act as a measure of SES and is a strong determinant of income and can be predicted by educational attainment. Occupation can be measured in a number of ways such as employment or job history (e.g. blue or white collar; manual or non-manual worker) or type of work contract and job security (Conway at al., 2019).

Certain aspects of a person's living condition can also indicate level of deprivation. Housing quality, overcrowding and house ownership all relate to individual material circumstances (Conway et al, 2019).

Another less commonly used measure of SES is subjective SES. This relates to an individual's perception of his or her socioeconomic standing (Conway et al., 2019). Subjective measures of SES relate to objective indicators (Nobles, Weintraub, & Adler, 2013), and can uniquely reflect the social norms of a given society (Oakes & Rossi, 2003).

Overall, individual measures of SES are a straightforward way to indicate a person's level of deprivation. However, on their own, might not be as useful in providing a holistic view of deprivation level. For example, using just one measure, such as income, might limit our understanding of individual experience of deprivation. Deprivation is multifaceted, and the absence of one indicator of deprivation does not mean that another does not exist.

4.1.5.2 Composite measures

Composite measures are used to capture multiple dimensions of SES that can be used at an individual or an area-level (Galobardes et al., 2007).

Composite measures are typically made up of multiple individual measures (such as income, education and occupation) and a composite score is created by the presence or absence of the given individual measures. However, composite measures can mask certain relationships and mechanisms which individual SES measurements provide (Conway et al., 2019). The selection and weighting of the individual measures used to create composite measures of SES are not standardised and can be misinterpreted if poorly constructed (Organisation for Economic Co-Operation and Development, 2008).

A composite, standardised measure of deprivation often used in Scotland is the Scottish Index of Multiple Deprivation (SIMD). SIMD is used as a tool for identifying area-level deprivation across 6,505 areas of Scotland, broken up by postcode. It is a relative measure of deprivation which indicates whether one area of Scotland is more deprived than another (Scottish Government, 2013).

SIMD combines seven different aspects of deprivation: employment; income; health; education, skills and training; geographic access to services; crime; and housing. These seven 'domains' are measured using a number of indicators which are combined to form overall SIMD. This overall SIMD allows us to rank all areas of Scotland, ranging from 1 to 6,505. As there is no natural cut-off between 'more deprived' and 'less deprived' the ranked areas are often split into five or ten distinct groups, creating SIMD quintiles or deciles.

By measuring area-level deprivation, it can help improve our understanding of the outcomes and circumstances of people who live in the most deprived areas of Scotland, allowing for local and national governments to target policies and funding toward areas of high multiple deprivation (Scottish Government, 2020b).

There are a number of limitations to using SIMD as a measure of deprivation; the measure ranks groups from most to least deprived, it does not indicate how deprived one area is compared to another.

Of even more significance, SIMD identifies deprived areas, not people. Around two thirds of people on low income do not live in the 20% most deprived areas in Scotland. Conversely, not all of those living in deprived areas experience deprivation, with only around one third of people living in deprived areas being on a low income (Scottish Government, 2020b). A further issue with SIMD is how areas of Scotland are divided into 'data zones' using postcodes. Postcode areas in rural and remote parts of Scotland cover large areas of land that might not reflect an accurate picture of the level of deprivation some people face (Scottish Government, 2020b).

Given the social gradient that exists in cancer screening uptake and cancer mortality, it is evident that the way in which SES is measured is important to understanding the scale of the issue. This is particularly significant to the use of individualised risk scores that have been proposed for use in the development of lung cancer screening (see section 2.1.1). Understanding SES as a construct and the most effective way to measure it will provide insight into how we should move forward to reduce screening inequalities.

4.2 Aim and research questions

The systematic review presented in Chapter 3 highlighted that there are still significant gaps in our knowledge when looking at the differences in beliefs about lung cancer and lung cancer screening across SES groups, with a number of the findings being inconclusive. In an attempt to create a clearer, more robust picture of variation of beliefs across SES groups further investigation is essential. It is hoped that the use of a large, deprived sample, as well as the use of two distinct measures of SES will provide insight that the studies in Chapter 3 could not provide.

The aim of this chapter is to explore the differences in demographic and psychosocial characteristics of ECLS trial participants across socioeconomic groups using two different measures of SES; area-level SES (SIMD) and individual-level SES.

To meet this aim, this chapter will answer the following research questions:

I. Do the demographic characteristics of ECLS trial participants vary by area-based SIMD or individual SES?
II. Do the psychosocial characteristics of ECLS trial participants vary by area-based SIMD or SES?

The next section describes the methodology of the secondary analysis of the ECLS trial data. This is followed by the presentation of results of the analysis and the discussion of the results.

4.3 Methodology

This section describes the methodology of the ECLS Trial and the secondary analysis of the trial data.

4.3.1 Study design

4.3.1.1 ECLS trial design and participants

The Early Detection Lung Cancer Screening Trial aimed to develop a new form of lung screening that uses a blood test to identify antibodies that indicate lung cancer. The EarlyCDT-Lung Test is a novel autoantibody diagnostic test for the early detection of lung cancer that helps identify those most at risk of lung cancer. The test leads to a targeted approach to CT scanning for early lung cancer detection which may be a more cost-effective and potentially less harmful approach to population lung screening. The primary research question for the ECLS trial was: 'Does using the EarlyCDT-Lung Test, followed by X-ray and CT scanning, to identify those at high risk of lung cancer reduce the incidence of patients with late-stage lung cancer or unclassified presentation at diagnosis, compared to standard clinical practice?'.

This thesis will not describe the randomisation of the RCT as the focus of this chapter is the recruitment of participants to the trial and the pre-randomisation baseline questionnaire. More detail of the ECLS trial can be found in section 1.3.4.3.

The trial aimed to recruit 12,000 high-risk participants from deprived areas of Scotland. Participants had to be adults aged 50 to 75, and at risk of developing lung cancer to be eligible for trial participation. High risk was defined as those who were current or former cigarette smokers with at least 20 pack-years[4], or have a history of cigarette smoking less than 20 pack-years plus a family history (mother, father, brother, sister) of lung cancer which gives an individual a personal risk similar to a smoking history of 20 pack years. The inclusion criteria for the ECLS trial is displayed in Figure 4-1.

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[4] One pack-year is equivalent to smoking 20 cigarettes a day for one year.

Figure 4-1: Inclusion Criteria of the ECLS Trial

Figure 4-1: Inclusion Criteria of ECLS Trial	
1	Participant is willing and able to give informed consent for participation in the study
2	Male or female aged 50 years to 75 years
3	Current or ex-smoker with at least 20-year pack history
4	or Less than 20-year pack history but with family history of lung cancer in a 1st degree relative (mother, father, sister, brother, child)
5	ECOG Status: 0, 1 and 2 (Eastern Co-operative Oncology Group)[5]
6	Geographical postal sectors of: **Tayside** – DD1 – DD11, PH1–PH3, PH6-PH8, PH10, PH11, PH13, PH15 & PH16, KY13 **Greater Glasgow & Clyde** – G1-G5, G11 –G15, G20-G22, G31-34, G40 –G46, G51- G53, G60-G62 &G64, G66 & G69, G72 & G73, G76-G78, G81-G83, PA1–PA8 (except PA6), PA11-PA16 & PA19 **Lanarkshire** – G33, G65, G67, G69, G71-75, ML1-12

4.3.1.2 GP recruitment

In order to recruit participants for the trial, GP practices within the lowest quintile of deprivation (measured using the SIMD) in NHS Tayside, NHS Greater Glasgow & Clyde and NHS Lanarkshire were engaged. A total of 170 GP practices within these areas agreed to partner with the trial. GP practices were used to help identify eligible patients, and subsequently send out invitations to those identified as eligible.

4.3.1.3 Community recruitment

The trial also used a significant amount of community-based advertisement and media campaigns to recruit participants to the trial. These alternative recruitment methods such as adverts on TV and radio, posters, flyers, beer mats and other community-based interactions (such as stalls in local hospitals) aimed to increase the awareness of the trial and encouraged people to make contact if they believed they met the trial inclusion criteria.

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[5] ECOG is a measure used to describes a patient's level of functioning in terms of their ability to care for themself, daily activity, and physical ability (walking, working, etc.).

All interested individuals not recruited via GP practices were assessed in relation to inclusion/exclusion criteria including residing within the selected geographical post codes.

4.3.1.4 ECLS procedure – baseline questionnaire

On receipt of an invitation to take part in the trial, potential participants made an appointment with a research nurse for an initial consultation. These appointments took place in local hospitals and health centres across Greater Glasgow & Clyde, Tayside and Lanarkshire.

The aim of the consultation was to ensure that the participant was eligible and met the inclusion criteria. If they were eligible, consent was taken followed by providing a blood sample and subsequently randomised into a treatment arm. Before randomisation took place, participants were asked to provide some information on their medical history and complete the baseline questionnaire. The research nurse provided active support to complete the questionnaire ensuring that questions were understood. When required, the research nurse would scribe on behalf on the participant.

The medical data collected, such as smoking history (pack year) and current medications were manually entered into the patient management system by the research nurse. Participants were also asked where they had heard about the trial in order to collect recruitment method. The baseline questionnaire data was initially handwritten and then uploaded onto a patient management system manually. Participant records and baseline questionnaire data were aligned using a unique cohort ID assigned to them, as well as Community Health Index (CHI).

4.3.2 The present study: data access

The secondary analysis reported in this thesis included analysis of the baseline questionnaire that ECLS trial participants completed prior to being randomised. Data were obtained via the Tayside Clinical Trials Unit (TCTU). In order to transfer data, an access agreement was developed and agreed upon. Training on good practice in clinical trial procedures was a prerequisite of the data being transferred.

Data was accessed via an NHS Safe Haven hosted by NHS Tayside. A Safe Haven is a secure environment whereby health data can be processed and linked with other health data. It is a safeguard for confidential information which is being used for research purposes. The Safe Haven was accessed remotely via the internet.

The data uploaded to the Safe Haven included all baseline questionnaire data. Supplementary to this, demographic data including date of birth, SIMD and CHI were provided. Data were merged using the participants' cohort ID and CHI.

4.3.2.1 Ethical approvals

The secondary analysis used ECLS trial data, which was carried out in conjunction with the NHS. As a result, ethical permission was sought from NHS Scotland East of Scotland Research Ethics Service. Ethical approval was sought based on an amendment to the original ECLS trial ethical approval. Ethical approval for the amendment was granted by the committee in December 2015 (Appendix 4).

4.3.2.2 Participants

In order to be included within the statistical analyses for this study, participants were required to have taken part in the ECLS trial and completed the baseline study questionnaire. Of the 12,243 ECLS trial participants, 11,164 completed the baseline questionnaire. As a result, 1079 ECLS trial participants were excluded from this analysis (Table 4-1).

Table 4-1: ECLS Participants Eligible for this Analysis

	ECLS (All Cases)	**ECLS (Completed baseline questionnaire)**	**Difference in no. cases**
Community advertisement recruitment	2039	1943	96 (95.3%)
GP letter recruitment	10204	9220	984 (90.4%)
Total	12243	11164	1079

4.3.2.3 Measures

The measures used in this analysis are described in the Table 4-2 below.

Table 4-2: Measures

Measure	Description	Questions	Scale
Recruitment Method	An indicator of how participants were recruited to the ECLS trial. This was established by trial records which indicated if a postal invitation was sent by a GP or not. In the absence of a postal invitation being sent, recruitment was assumed to be via the community methods employed. This was cross-checked with the participants self-report of recruitment method. In cases (n=30) where there was a disparity between trial records and self-report, trial record of recruitment method was used.	N/A	1– No GP letter sent 0 - GP Letter Sent
Sex	An indicator of the sex. This was not included in the baseline questionnaire. A person's sex was established by their CHI linked to NHS records.	N/A	1-Male 2-Female
Age	A measure of chronological age. This was calculated by date of birth, and then grouped into age groups.	Date of Birth	1 - 50-60 2 - 61-70 3 - 71-75
Marital Status	An indicator of current marital status.	Marital Status	1 - Married 0 – Not married

Table 4-2: Measures

Measure	Description	Questions	Scale
Ethnicity	An indicator of the ethnicity identified with. These were then grouped into three categories.	I would describe my ethnic origin as …	1 - White 2 - Other Ethnic Group 0 - Prefer Not to Say
Geographic Region	An indicator of the geographic location that they live. This was not included in the baseline questionnaire but was established by their CHI linked with NHS records.	N/A	1 - Greater Glasgow 2 - Tayside 3 - Lanarkshire
Scottish Index of Multiple Deprivation (SIMD) (2012)	A standard measure of deprivation in a given geographical area. A persons SIMD score is determined by their postcode. The most current record of SIMD was used at the time the trial was initiated in 2013. SIMD was calculated based on participants NHS record. The data used was split into quintiles and analysed as five distinct groups.	N/A	1 (Most Deprived) 2 3 4 5 (Least Deprived)

Table 4-2: Measures

Measure	**Description**	**Questions**	**Scale**
Individual measure of socioeconomic deprivation (SES)	A measure of socioeconomic status. This is calculated based on three indicators of socioeconomic status: educational qualifications (left school after 16 years of age); car ownership; and home ownership. The presence of any one of these indicators provided respondents with a score of one. The score for each indicator was summed to create an overall socioeconomic status score. Scores can range from zero to three. Composite measures such as this have been used successfully in previous studies (Robb, Simon, & Wardle, 2009).	Age at which you left full-time education How many cars or vans are available for use by one or more members of your household? Do you own or rent your home?	0 – Most Deprived 1 2 3- Least Deprived
EQ-5D-3L – Visual Analogue Health Scale (Rabin & de Charro, 2001)	Measure of perceived current health status that asks participants to rate their health out of 100.	To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.	0-100

Table 4-2: Measures

Measure	Description	Questions	Scale
Revised Illness Perception Questionnaire – Lung Cancer (IPQ-LC) Moss-Morris et al. (2002)	A measure of illness perception adapted for lung cancer. The Illness Perception Questionnaire was developed to provide a quantitative assessment of the five components of the illness representation – identity, consequences, timeline, control/cure and cause in Leventhal's Self-Regulatory Model. This iteration of the IPQ, adapted for the ECLS trial, consists of seven items. Each component is given a score of 1– 5. Items were recoded to dichotomise into 'agree' and 'disagree'. Those who answered, 'Strongly Disagree', 'Disagree' or 'Neutral' were recoded as 'Disagree', while those who answered, 'Strongly Agree' or 'Agree' were recoded as 'Agree'.	What I do can affect my risk of getting lung cancer (personal control) When I think about my risk of getting lung cancer, I get upset (emotional response) I do not know how likely it is that I might get lung cancer (illness coherence) Finding lung cancer early can improve my chances of survival (treatment control) Lung cancer would have a big impact on my life (consequences) Lung cancer lasts for a long time (timeline) A blood screening test can accurately detect lung cancer (treatment control)	Original 1 -Strongly Disagree 2 - Disagree 3 - Neutral 4 - Agree 5 - Strongly Agree Recoded 0 – Disagree 1 – Agree
Smoking Behaviour	A measure of smoking status.	Have you smoked any cigarettes or tobacco in the last seven days / week?	1- Yes 0- No

4.3.2.4 Analysis

The secondary quantitative analysis included descriptive analysis of all ECLS Trial participants who completed the baseline questionnaire data. This descriptive analysis including frequencies and means examined the differences between demographic and psychosocial measures across both area-level SES (SIMD) and individual- level SES groups. Univariate statistical tests conducted included chi-square for categorical variables and one-way ANOVA for continuous variables. Univariable and multivariable multinomial logistic regression analyses were conducted to examine the associations between demographic and psychosocial factors and SIMD and SES groups. Only those variables found to be significant in the univariate analysis were entered into the multinomial logistic regression analyses. Data analysis was carried out using IBM SPSS V.23 (IBM, 2015).

4.4 Results

4.4.1 Demographic characteristics of the sample

A total of 11,164 trial participants completed the baseline questionnaire. As displayed in Table 5-3, of those who completed the questionnaire, 50.6% were male (n = 5645) and 49.4% female (n = 5510). Over half of the participants were aged between 50 – 60 (53.6%) and were married or in a civil partnership (52.9%). The majority of participants identified as white (99.1%), with only 0.6% identifying with another ethnic group. Participants were primarily from Greater Glasgow (67.4%), followed by Tayside (22.8%) and Lanarkshire (9.8%).

The majority of participants were from the most deprived SIMD groups, groups 1 and 2 (40.7% and 20.0% respectively). Those from group 5 (least deprived) accounted for 10.5% of participants. However, when using the individual measure of socioeconomic deprivation just under one third were considered least deprived (SES group 3) (32.8%) and those in the most deprived group (SES group 0) accounted for 10.5% of trial participants. A spearman's rho analysis indicated that there was a significant positive correlation between SIMD and the individual measure of SES (r_s= .420, p<.001).

4.4.2 Univariate analysis of the demographic characteristics of the ECLS trial participants by the Scottish Index of Multiple Deprivation (Table 4-3)

4.4.2.1 Sex

There was a significant difference between the number of men and women across SIMD quintiles (Table 4-3). There was little variation in SIMD groups one to four but there were significantly more men in the most affluent quintile (SIMD 5) (55.8%) relative to the most deprived quintile (50.6%; $\chi^2(1) = 6.48$, p = .011). Conversely, there were significantly fewer women in the most affluent quintile (SIMD 5) (44.2%) compared to the most deprived quintile (SIMD 1) (49.4%)

4.4.2.2 Age

The number of participants aged 50-60 decreased as deprivation level increased (Table 4-3). There were more participants aged 50-60 in the most deprived quintile (SIMD 1) (56.2%) compared to the most affluent quintile (SIMD 5) (48.4%; $\chi^2(1) = 42.30$, p<.001).

4.4.2.3 Marital status

The number of people who were married or in a civil partnership increased as deprivation level decreased ($\chi^2(1) = 588.91$, p <.001). There were fewer participants who were married or in a civil partnership in the most deprived quintile (SIMD 1) (41.6%) compared to those from the most affluent quintile (SIMD 5) (74.2%).

4.4.2.4 Ethnicity

There was no significant association between ethnicity and SIMD ($\chi^2(1) = .796$, p = .372).

4.4.2.5 Region

Participants from Greater Glasgow were significantly more likely to be in the most deprived quintile SIMD 1 (78.1%) compared to those from Tayside or Lanarkshire (Table 4-3). The number of participants from Tayside or Lanarkshire generally increased as deprivation level decreased ($\chi^2(1) = 218.30$, p <.001).

4.4.3 Univariate Analysis of the psychosocial measures of the ECLS trial participants by the Scottish Index of Multiple Deprivation

4.4.3.1 Health state (Table 4-4)

There was a significant difference in health state across SIMD groups. Health state improved as deprivation levels decreased (F (1) = 347.15, p <.001).

4.4.3.2 Revised Illness Perception Questionnaire (Table 4-5)

“What I do can affect my risk of lung cancer” (Personal Control)
There were significantly more participants who agreed that their actions could control their risk of lung cancer among those in the least deprived SIMD 5 (91.8%) compared to the most deprived SIMD 1 (88.6%; $\chi^2(1) = 18.59$, p<.001).

“When I think about lung cancer, I get upset” (Emotional Response)
Participants in the most deprived quintile SIMD 1 were significantly more likely to agree that they get upset when they think about lung cancer (46.2%) compared to those in the least deprived quintile SIMD 5 (38.4%; $\chi^2(1) = 51.75$, p <.001).

“I don’t know how likely it is that I might get lung cancer” (Illness Coherence)
There were no significant differences across SIMD groups for illness coherence ($\chi^2(1) = 6.47, p = .11$).

“Finding lung cancer early can improve my chances of survival” (Treatment Control)
There were no significant differences across SIMD groups for treatment control ($\chi^2(1) = 2.39, p = .122$).

“Lung cancer would have a big impact on my life” (Consequences)
Significantly more participants in the least deprived quintile SIMD 5 agreed that lung cancer would have a big impact on their lives (97.3%) compared to the most deprived quintile SIMD 1 (95.4%; $\chi^2(1) = 10.46, p =.001$).

“Lung cancer lasts for a long time” (Timeline)
Significantly more participants in the most deprived quintile SIMD 1 agreed that lung cancer lasts a long time (65.5%) compared to the least deprived quintile SIMD 5 (59.8%; $\chi^2(1) = 10.78, p<.001$).

“A blood test can accurately detect lung cancer “(Treatment Control)
Participants in the most deprived quintile SIMD 1 were significantly more likely to agree that a blood test can accurately detect lung cancer (67%) compared to the least deprived quintile SIMD 5 (53.2%; $\chi^2(1) = 101.19, p <.001$).

4.4.3.3 Smoking status (Table 4.5)

“Have you smoked any cigarettes or tobacco in the last 7-days?”
Participants in the most deprived quintile SIMD 1 were significantly more likely to say that they had smoked cigarettes or tobacco in the last seven days (64%) compared to people in the least deprived quintile SIMD 5 (42.5%; $\chi^2(1) = 265.55, p <.001$).

Table 4-3: Demographic Characteristics by SIMD 5

	All (n = 11,130)	SIMD 1 *Most Deprived* (n = 4534)	SIMD 2 (n = 2231)	SIMD 3 (n = 1578)	SIMD 4 (n = 1614)	SIMD 5 *Least Deprived* (n = 1173)	Sig.
Sex							
Male %	50.6 (5634)	50.6 (2292)	48.1 (1073)	50.3 (794)	50.8 (820)	55.8 (655)	$\chi^2(1, 11130) = 6.48$, p = .011
Female %	49.4 (5496)	49.4 (2242)	51.9 (1158)	49.7 (784)	49.2 (794)	44.2 (518)	
Age (years)							
50-60 %	53.6 (5961)	56.2 (2550)	54.2 (1209)	53.5 (844)	48.6 (785)	48.8 (573)	$\chi^2(1, 11130) = 42.30$, p<.001
61-70 %	38.7 (4310)	37.1 (1682)	38.2 (852)	38.5 (608)	41.9 (677)	41.9 (491)	
71-75 %	7.7 (859)	6.7 (302)	7.6 (170)	8 (126)	9.4 (152)	9.3 (109)	
Marital Status							
Married/Civil Partnership %	52.9 (5807)	41.6 (1853)	50.4 (1112)	59.0(916)	66.5 (1062)	74.2 (864)	$\chi^2(1, 10977) = 588.91$, p <.001
Not Married %	47.1 (5170)	58.4 (2605)	49.6 (1093)	41.0 (637)	33.5 (534)	25.8 (301)	
Ethnicity							
White %	99.1 (10895)	99.3 (4435)	99 (2184)	99.2 (1547)	99.1 (1586)	98.3 (1143)	$\chi^2(1, 10997) = .796$, p = .372
Other Ethnic Group %	0.6 (69)	0.5 (23)	0.6 (13)	0.6 (10)	0.6 (9)	1.2 (14)	
Prefer not to say %	0.3(33)	0.2 (9)	0.5 (10)	0.2 (3)	0.3 (5)	0.5 (6)	
Region							
Greater Glasgow %	67.4 (7503)	78.1 (3541)	64.5 (1438)	59.9 (945)	52.8 (852)	62 (727)	$\chi^2(1, 11130) = 218.30$, p <.001
Tayside %	22.8 (2540)	15.1 (683)	21.7 (485)	27.6 (435)	37.9 (612)	27.7 (325)	
Lanarkshire %	9.8 (1087)	6.8 (310)	13.8 (308)	12.5 (198)	9.3 (150)	10.3 (121)	

Table 4-4: Mean Health State Score by SIMD 5 (One-way ANOVA)

	All (n = 11164)	SIMD1 *Most Deprived* (n = 4534)	SIMD2 (n = 2231)	SIMD 3 (n =1587)	SIMD 4 (n = 1614)	SIMD5 *Least Deprived* (n = 1173)	Sig.
Health State Mean (SD)	78.73 (17.97)	75.35 (19.39)	78.68 (18.10)	80.74 (16.99)	82.17 (15.13)	84.28 (13.84)	F(1,10881)= 347.15, p <.001

Table 4-5: Psychosocial Measures by SIMD 5

	All (n=11,164)	SIMD 1 *Most deprived* (n = 4534)	SIMD 2 (n = 2231)	SIMD 3 (n = 1587)	SIMD 4 (n = 1614)	SIMD 5 *Least Deprived* (n = 1173)	Sig.
Revised Illness Perception Questionnaire							
What I do can affect my risk of lung cancer							
Agree %	89.5 (9845)	88.6 (3957)	88.0 (1936)	90.8 (1419)	91.3 (1462)	91.8 (1071)	$\chi^2(1, 10996) = 18.59, p<.001$
Disagree %	10.5 (1151)	11.4(508)	12.0 (263)	8.7 (144)	8.7 (140)	8.2 (96)	
When I think about lung cancer, I get upset							
Agree %	42.4 (4646)	46.2 (2054)	42.2 (923)	41.0 (637)	36.5 (584)	38.4 (448)	$\chi^2(1, 10959) = 51.75, p <.001$
Disagree %	57.6 (6313)	53.8 (2392)	57.8 (1266)	59.0 (918	63.5 (1017)	61.6 (720)	
I don't know how likely it is that I might get lung cancer							$\chi^2(1, 10896) = 6.47, p = .11$
Agree %	64.4 (7019)	65.5 (2889)	65.5 (1428)	62.8 (970)	62.7 (998)	63.0 (734)	
Disagree %	35.6 (3877)	34.5 (1523)	34.5 (753)	37.2 (575)	37.3 (594)	37.0 (432)	
Finding lung cancer early can improve my chances of survival							$\chi^2(1, 10975) = 2.39, p = .122$
Agree %	97.1(10657	96.9 (4319)	96.7 (2120)	97.6 (1524)	97.6 (1559)	97.3 (1135)	
Disagree %	2.9 (318)	3.1 (138)	3.3 (72)	2.4 (38)	2.4 (38)	2.7 (32)	
Lung cancer would have a big impact on my life							
Agree %	96.1(10557	95.4 (4258)	96.1 (2113)	96.4 (1507)	96.5 (1543)	97.3 (1136)	$\chi^2(1, 10989) = 10.46, p =.001$
Disagree %	3.9 (432)	4.6 (204)	3.9 (85)	3.6 (56)	3.5 (56)	2.7 (31)	
Lung cancer lasts for a long time							
Agree %	64.0 (6960)	65.5 (2886)	64.2 (1393)	63.4 (980)	63.7 (1009)	59.8 (692)	$\chi^2(1, 10867) = 10.78, p = .001$
Disagree %	36.0 (3907)	34.5 (1523)	35.8 (778)	36.6 (566)	36.3 (575)	40.2 (465)	

Table 4-5: Psychosocial Measures by SIMD 5

	All (n=11,164)	SIMD 1 *Most deprived* (n = 4534)	SIMD 2 (n = 2231)	SIMD 3 (n = 1587)	SIMD 4 (n = 1614)	SIMD 5 *Least Deprived* (n = 1173)	Sig.
A blood test can accurately detect lung cancer							
Agree %	62.6 (6876)	67.0 (2992)	63.9 (1404)	59.9 (934)	58.0 (928)	53.2 (618)	$\chi^2(1, 10981) = 101.19$, p <.001
Disagree %	37.4 (4105)	33.0 (1472)	36.1 (792)	40.1 (626)	42.0 (671)	46.8 (544)	
Smoking Status							
Have you smoked any cigarettes or tobacco in the last 7 days?							
Yes %	55.6 (5617)	64.0(2637)	56.7 (1146)	49.9 (712)	45.6 (672)	42.5 (450)	$\chi^2(1, 10097) = 265.55$, p <.001
No %	44.4 (4480)	36.0 (1481)	43.3 (874)	50.1 (716)	54.4 (801)	57.5 (608)	

4.4.4 Multivariate analysis of the demographic and psychosocial measures of the ECLS trial participants by the Scottish Index of Multiple Deprivation

Ordinal logistic regression was planned to ascertain the independent effects of demographic and psychosocial characteristics of the ECLS trial participants by the SIMD. A full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters suggested that the assumption of proportional odds was violated: χ^2 (36) = 192.68, $p < 0.001$.

If the assumptions of ordinal logistic regression are violated, a multinomial logistic regression can be conducted (Laerd, 2020). A multinomial logistic regression was therefore used to ascertain the independent effects of demographic and psychosocial characteristics of the ECLS trial participants by the SIMD.

Prior to carrying out the multinomial logistic regression analysis, a test for multicollinearity was conducted. This was done by running a linear regression using SIMD as the predictor variable in order to obtain tolerance and Variance Inflation Factor (VIF) statistics. Tolerance values less than 0.1 (Menard, 1995) and VIF values greater than 10 (Myers, 1990) indicate a problem with multicollinearity. The table below displays the tolerance and VIF statistics for each of the variables. These indicate that the assumptions of the regression analysis were not violated.

Only those variables found to be significant in univariate analyses were included in the multivariate analyses. It was decided to conduct the analysis in two stages in order to understand the contribution of each distinct factor in relation to SIMD. The first model included demographic variables only and the second model included both demographic variables and psychosocial variables. The model explained 16.1% (Nagelkerke R^2) of variance in SIMD and correctly classified 42.6% of cases.

Table 4-6: Test for Multicollinearity

Variable	Tolerance	VIF
Marital Status	.951	1.052
Age (Dummy variable)		
61-70	.927	1.079
71-75	.931	1.075
Region (Dummy variable)		
Tayside	.947	1.056
Lanarkshire	.948	1.055
Health State	.926	1.039
What I do can affect my risk of getting lung cancer	.964	1.038
When I think about my risk of lung cancer, I get upset	.936	1.069
Lung cancer would have a big impact on my life	.956	1.046
Lung cancer lasts a long time	.901	1.110
A blood screening test can accurately detect lung cancer	.907	1.103
Have you smoked any cigarettes or tobacco in the last seven days/ week?	.931	1.074

4.4.4.1 Model 1 - demographic characteristics of ECLS participants by SIMD (Table 4-7)

4.4.4.1.1 Sex

The model indicated that there was no significant difference in sex between those in the most deprived quintile (SIMD 1) compared to those in SIMD 5 (OR =.90, 95% CI 0.79 – 1.03). The likelihood of a participant being male increased in SIMD 2 (OR = .79, 95% CI 0.69 – 0.92), SIMD 3 (OR = .86, 95% CI 0.74 – 1.00) and SIMD 4 (OR= .86, 95% 0.74 – 0.99).

4.4.4.1.2 Marital status

It was more likely that a participant in the most deprived quintile (SIMD 1) was not married compared to those in the least deprived quintile (SIMD 5) (OR = 3.87, 95% CI = 3.35 – 4.48). The likelihood of being not married decreased as deprivation increased.

4.4.4.1.3 Region

The likelihood of a participant being from Greater Glasgow was significantly higher if they were in the most deprived quintile (SIMD 1) compared to least deprived quintile (SIMD 5) (OR = 1.76, 95% CI = 1.39 – 2.21). A participant from Tayside was less likely to be in SIMD 1 compared to SIMD 5 (OR = .76, 95% CI .59 – .97).

4.4.4.1.4 Age

Participants aged between 50 – 60 were significantly more likely to be in the most deprived quintile (SIMD 1) compared to the least deprived quintile (SIMD 5) (OR = 1.46, 95% CI = 1.14 – 1.87). There was no significant difference in SIMD in the age group 61 – 70.

4.4.4.2 Model 2 - demographics and psychosocial characteristics of ECLS participants by SIMD (Table 4-8)

4.4.4.2.1 Health state (Table 4-8)

There was marginal variation in health state across SIMD groups. Those with lower health state scores were more likely to from the most deprived quintile (SIMD 1) compared to the least deprived quintile (SIMD 5) (OR = 0.98, 95% CI = .97 - .98).

4.4.4.2.2 Revised Illness Perception Questionnaire (Table 4-8)

"What I do can affect my risk of lung cancer" (Personal Control)
The likelihood of disagreeing with the statement was significantly higher in those from the most deprived quintile (SIMD 1) compared to the least deprived quintile (SIMD 5) (OR = 1.69, 95% CI 1.29 – 2.19). Similarly, the odds of disagreeing with the statement was significantly higher in those from SIMD 2 compared to SIMD 5 (least deprived quintile) (OR = 1.72, 95% CI 1.31 – 2.28). There was no significant difference SIMD 3 and SIMD 4 compared to SIMD 5.

"When I think about my risk of lung cancer, I get upset" (Emotional Response)
A participant was significantly less likely to disagree with the statement if they were in the most deprived quintile (SIMD 1) compared to the least deprived quintile (SIMD 5) (OR = .83, 95% CI .71 - .96). There was no significant difference across SIMD 2, SIMD 3 and SIMD 4 compared to SIMD 5.

"Lung cancer would have a big impact on my life" (Consequences)

A participant was significantly more likely to disagree with the statement if they were in the most deprived quintile (SIMD 1) compared to the least deprived quintile (SIMD 5) (OR = 1.69, 95% CI 1.11 – 2.59). There was no significant difference across SIMD 2, SIMD 3 and SIMD 4 compared to SIMD 5.

"Lung cancer lasts for a long time" (Timeline)

There was no significant difference across SIMD groups in perceptions of how long lung cancer lasts.

"A blood test can accurately detect lung cancer" (Treatment Control)

Most participants agreed with this statement. However, they were significantly less likely to be in the most deprived quintile (SIMD 1) than in the least deprived quintile (SIMD 5) if they disagreed with the statement (OR = .56, 95% CI .48 - .66).

4.4.4.2.3 Smoking status (Table 4-8)

"Have you smoked any cigarettes or tobacco in the last 7-days?"

A participant was more likely to respond 'no' to the question '*Have you smoked any cigarettes or tobacco in the last 7 days?*' if they were in the most deprived quintile (SIMD 1) than in the least deprived quintile (SIMD 5) (OR = 1.93, 95% CI 1.67 – 2.25). As SIMD increased the odds of having smoked a cigarette in the past seven days increased. However, there was no significant difference between those in SIMD 4 and SIMD 5.

Table 4-7: Multinomial Logistic Regression of SIMD 5 (Model 1: Demographics)

	SIMD 1 *(Most Deprived)* vs. SIMD 5 *(Least Deprived)*		SIMD2 vs. SIMD 5		SIMD3 vs. SIMD 5		SIMD4 vs. SIMD 5	
	OR	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Sex								
Male	.90	.79 – 1.03	.79	.69 - .92	.86	.74 – 1.00	.86	.74 - .99
Female	1		1		1		1	
Marital Status								
Married	1		1		1		1	
Not Married	3.87	3.35 – 4.48	2.74	2.34 – 3.21	1.96	1.66 – 2.31	1.44	1.22 – 1.70
Region								
Greater Glasgow	1.76	1.39 – 2.21	.73	.57 - .92	.75	.59 - .97	.90	.69 – 1.17
Tayside	.76	.59 – .97	.55	.42 - .71	.78	.59 – 1.02	1.45	1.09 – 1.91
Lanarkshire	1		1		1		1	
Age								
50-60	1.46	1.14 – 1.87	1.23	.95 – 1.61	1.19	.89 – 1.57	.89	.68 – 1.18
61-70	1.25	.98 – 1.61	1.11	.85 – 1.46	1.07	.80 – 1.42	.95	.72 – 1.26
71-75	1		1		1		1	
Nagelkerke R^2		.105			Sig.		p<.001	

Table 4-8: Multinomial Logistic Regression of SIMD 5 (Model 2: Demographic & Psychosocial Measures)

	SIMD 1 vs. SIMD 5		SIMD2 vs. SIMD5		SIMD3 vs. SIMD 5		SIMD4 vs. SIMD5	
	OR	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Sex								
Male	.88	.76 – 1.02	.78	.66 - .91	.84	.71 - .99	.84	.71-.99
Female	1		1		1		1	
Marital Status								
Married	1		1		1		1	
Not Married	3.39	2.89 – 3.98	2.51	2.12 – 2.98	1.87	1.56 – 2.24	1.41	1.17 – 1.
Region								
Greater Glasgow	1.61	1.26 – 2.05	.65	.51 - .84	.72	.56 - .94	.87	.66 – 1.14
Tayside	.64	.49 - .84	.49	.38 - .64	.72	.55 - .95	1.39	1.05 – 1.85
Lanarkshire	1		1		1		1	
Age								
50-60	1.54	1.16 – 2.04	1.29	.95 – 1.74	1.26	.92 – 1.73	.68	.72 – 1.31
61-70	1.31	.99 – 1.74	1.13	.83 – 1.53	1.12	.81 – 1.54	.99	.74 – 1.36
71-75	1		1		1		1	
Health State	.98	.97 - .98	.98	.98 - .99	.99	.98 - .99	.99	.99 - 1
Revised Illness Perception Questionnaire								
What I do can affect my risk of lung cancer								
Agree	1	1.29 – 2.19	1	1.31 – 2.28	1	.91 – 1.65	1	.77 – 1.41
Disagree	1.69		1.73		1.22		1.04	

Table 4-8: Multinomial Logistic Regression of SIMD 5 (Model 2: Demographic & Psychosocial Measures)

	SIMD 1 vs. SIMD 5		SIMD2 vs. SIMD5		SIMD3 vs. SIMD 5		SIMD4 vs. SIMD5	
When I think about my risk of lung cancer, I get upset								
Agree	1	.71 - .96	1	.79 – 1.09	1	.80 – 1.14	1	.93 – 1.32
Disagree	.83		.93		.96		1.11	
Lung cancer would have a big impact on my life								
Agree	1	1.11 – 2.59	1	.90 – 2.23	1	.79 – 2.10	1	.78 – 2.05
Disagree	1.69		1.42		1.29		1.27	
Lung cancer lasts for a long time								
Agree	1	.74 – 1.01	1	.77 – 1.07	1	.75 – 1.06	1	.74 – 1.05
Disagree	.87		.91		.89		.88	
A blood test can accurately detect lung cancer								
Agree	1	.48 - .66	1	.53 - .74	1	.62 - .88	1	.71 – .99
Disagree	.56		.63		.74		.84	
Smoking Status								
Have you smoked any cigarettes or tobacco in the last 7 days?								
Yes	1	1.67 – 2.25	1	1.32 – 1.82	1	1.02 – 1.43	1	.88 – 1.24
No	1.93		1.55		1.20		1.05	
Nagelkerke R^2	.161				Sig.	p<.001		

4.4.5 Univariate analysis of the demographic characteristics of the ECLS trial participants by individual socioeconomic status measure (Table 4-9)

4.4.5.1 Sex

There was no significant association between sex and individual SES ($\chi^2(1) = .914$, p = .339).

4.4.5.2 Age

There was a significant association between age and SES ($\chi^2(1) = 243.06$, p <.001). The number of participants aged between 50 – 60 increased as SES increased; 39% of participants in the most deprived group (SES 0) were aged between 50 – 60, this increased to 66.4% in SES 3. There were fewer participants aged between 61 – 70 as SES increased; 61 – 70-year olds accounted for 50.7% of those in SES 0 (most deprived), and 28.5% of those in SES 3 (least deprived).

4.4.5.3 Marital status

There was a significant association between marital status and SES ($\chi^2(1) = 1367.74$, p <.001). The number of participants who were married or in a civil partnership increased with SES. Those in SES 3 (least deprived) were more than three times as likely to be married (69.2%) compared to those in SES 0 (most deprived) (21.4%).

4.4.5.4 Ethnicity

There was a significant association between ethnicity and SES ($\chi^2(1) = 5.78$, p =.016). As SES increased so too did the number of participants in an ‘Other Ethnic Group’. In SES 0 (most deprived) 0.3% of participants said they were part of an ‘Other Ethnic Group’, this increased to 1.2% of participants in SES 3 (least deprived). However, it must be noted that in two categories there were fewer than five participants which violates the assumptions of a chi-square test.

4.4.5.5 Region

There was a significant difference between the number of participants from Greater Glasgow in SES 0 (most deprived) (75%) and SES 3 (least deprived) (62.1%; $\chi^2(1) =$

98.48, p<.001). Conversely, the proportion of participants from Tayside and Lanarkshire increased as SES increased.

4.4.6 Univariate Analysis of the Psychosocial Measures of the ECLS trial participants by Individual Socioeconomic Status Measure

4.4.6.1 Health state (Table 4-10)

The mean score of perceived health state significantly increased with SES (F(1) =761.08, p <.001).

4.4.6.2 Revised Illness Perception Questionnaire (Table 4-11)

"What I do can affect my risk of lung cancer" (Personal Control)
There were significantly more participants in the least deprived group (SES 3) (92%) that agreed that their actions could control their risk of lung cancer compared to those in SES 2 (88.3%), SES 1 (88.2%) and SES 0 (most deprived) (88.6%; $\chi^2(1) = 21.53$, p<.001).

"When I think about lung cancer, I get upset" (Emotional Response)
Participants in the most deprived group (SES 0) (52%) were significantly more likely to agree with this statement than those in least deprived group (SES 3) (36.8%; χ^2 (1) = 104.76, p <.001).

"I don't know how likely it is that I might get lung cancer" (Illness Coherence)
Those in most deprived group (SES 0) (69.2%) were significantly more likely to not know their risk of getting lung cancer compared to those in the least deprived group (SES 3) (63.6%; $\chi^2(1) = 8.93$, p = .003).

"Finding lung cancer early can improve my chances of survival" (Treatment Control)
There was no significant association between SES and participants' tendency to agree with the statement ($\chi^2(1) = 0.66$, p = .42).

"Lung cancer would have a big impact on my life" (Consequences)
Those in the least deprived group (SES 3) (97.2%) were significantly more likely to agree that lung cancer would have a big impact on their life compared to those in most deprived group (SES 0) (94.8%; $\chi^2(1) = 19.17$, p < .001).

“Lung cancer lasts for a long time” (Timeline)

Those in the most deprived group (SES 0) (71.1%) were significantly more likely to agree that lung cancer lasts a long time compared to those in least deprived group (SES 3) (60.7%; $\chi^2(1) = 44.44$, p <.001).

“A blood test can accurately detect lung cancer” (Treatment Control)

Those in the most deprived group (SES 0 (76.3%) were significantly more likely to agree that a blood test could accurately detect lung cancer compared to those in the least deprived group (SES 3) (51.3%; $\chi^2(1) = 265.78$, p <.001).

4.4.6.3 Smoking status (Table 4-11)

“Have you smoked any cigarettes or tobacco in the last 7-days?”

Those in the most deprived group (SES) 0 (70.7%) were significantly more likely to have smoked cigarettes or tobacco in the last seven days than those in the least deprived group (SES 3) (46.3%; $\chi^2(1) = 317.65$, p <.001).

Table 4-9: Demographic Characteristics by Individual SES Score

	All (n = 11,164)	SES 0 *Most Deprived* (n = 1166)	SES 1 (n = 2551)	SES 2 (n =3761)	SES 3 *Least Deprived* (n = 3647)	Sig.
Sex						
Male %	50.7 (5639)	50.8 (529)	48.7 (1242)	52.0 (1956)	50.7 (1849)	$\chi^2(1, 11125) = .914, p = .339$
Female %	49.3 (5468)	49.2 (574)	51.3 (1309)	48.0 (1805)	49.3 (1768)	
Age (years)						
50-60 %	53.7 (5969)	39.0 (455)	52.0 (1327)	46.9 (1765)	66.4 (2422)	$\chi^2(1, 11125) = 243.06, p <.001$
61-70 %	38.7 (4303)	50.7 (591)	39.6 (1010)	44.2 (1661)	28.5 (1041)	
71-75 %	7.7 (853)	10.3 (120)	8.4 (214)	8.9 (335)	5.0 (184)	
Marital Status						
Married/Civil Partnership %	52.9 (5819)	21.4 (243)	31.7 (785)	60.4 (2270)	69.2 (2521)	$\chi^2(1, 11008) = 1367.74, p <.001$
Not Married %	47.1 (5189)	78.6 (890)	68.3 (1689)	39.6 (1487)	30.8 (1123)	
Ethnicity						
White %	99.1 (10925)	99.2 (1134)	99.4 (2499)	99.5 (3716)	98.3 (3576)	$\chi^2(1, 11027) = 5.78, p =.016$
Other Ethnic Group %	0.6 (69)	0.3 (4)*	0.4 (11)	0.3 (11)	1.2 (43)	
Prefer not to say %	0.3 (33)	0.4 (5)	0.2 (4)*	0.2 (6)	0.5 (18)	
Region						
Greater Glasgow %	67.4 (7502)	75.0 (875)	72.8 (1856)	66.6 (2505)	62.1 (2266)	$\chi^2(1, 11124) = 98.48, p<.001$
Tayside %	22.8 (2539)	17.9 (209)	19.3 (492)	23.4 (878)	26.3 (960)	
Lanarkshire %	9.7 (1083)	7.0 (82)	8.0 (203)	10.0 (377)	11.5 (421)	

Table 4-10: Mean Health State Score by Individual SES Score (One-way ANOVA)

	All (n = 11,164)	SES 0 *Most Deprived* (n = 1166)	SES 1 (n = 2551)	SES 2 (n = 3761)	SES 3 *Least Deprived* (n = 3647)	Sig.
Health State Mean (SD)	78.75 (17.96)	70.79 (20.07)	73.50 (19.81)	79.76 (18.13)	83.77 (17.96)	F(1,10886)=761.08, p <.001

Table 4-11: Psychosocial Measures by Individual SES Score

	All (n = 11,164)	SES 0 *Most deprived* (n = 1166)	SES 1 (n = 2551)	SES 2 (n = 3761)	SES 3 *Least deprived* (n = 3647)	Sig.
Revised Illness Perception Questionnaire						
What I do can affect my risk of lung cancer						
Agree %	89.5 (9858)	88.6 (1011)	88.2 (2213)	88.3 (3295)	92.0 (3339)	χ^2(1, 11011) = 21.53, p<.001
Disagree %	10.5 (1153)	11.4(130)	11.8 (297)	11.7 (437)	8.0 (289)	
When I think about lung cancer, I get upset						
Agree %	42.4 (4650)	52.0 (587)	46.3 (1159)	42.2 (2148)	36.8(1334)	χ^2(1, 10974) = 104.76, p <.001
Disagree %	57.6 (6324)	48.0 (542)	53.7 (1342)	57.8 (2148)	63.2 (2292)	
I don't know how likely it is that I might get lung cancer						
Agree %	64.4 (7028)	69.2 (770)	64.8 (1609)	63.5 (2354)	63.6 (263)	χ^2(1, 10911) = 8.93, p = .003
Disagree %	35.6 (3883)	30.8 (342)	35.2 (875)	36.5 (1352)	36.4 (1314)	
Finding lung cancer early can improve my chances of survival						
Agree %	97.1 (10672)	96.9 (1096)	97.0 (2432)	97.1 (3616)	97.3 (3528)	χ^2(1, 10990) = 0.66, p = .42
Disagree %	2.9 (318)	3.1 (35)	3.0 (76)	2.9 (108)	2.7 (99)	
Lung cancer would have a big impact on my life						
Agree %	96.0 (10569)	94.8 (1075)	95.4 (2394)	95.7 (3600)	97.2 (3530)	χ^2(1, 11004) = 19.17, p < .001
Disagree %	4.0 (435)	5.2 (59)	4.6 (115)	4.3 (161)	2.8 (100)	
Lung cancer lasts for a long time						
Agree %	64.1 (6975)	71.1(793)	66.1 (1634)	63.9 (2359)	60.7 (2189)	χ^2(1, 10882) = 44.44, p <.001
Disagree %	35.9 (3907)	28.9 (323)	33.9 (837)	36.1 (1332)	39.3 (1415)	

Table 4-11: Psychosocial Measures by Individual SES Score

	All (n = 11,164)	SES 0 *Most deprived* (n = 1166)	SES 1 (n = 2551)	SES 2 (n = 3761)	SES 3 *Least deprived* (n = 3647)	Sig.
A blood test can accurately detect lung cancer						
Agree %	62.6 (6880)	76.3 (870)	68.7 (1724)	63.4 (2362)	53.1 (1924)	$\chi^2(1, 10998) = 265.78, p < .001$
Disagree %	37.4 (4118)	23.7 (270)	31.3 (785)	36.6 (1363)	46.9 (1700)	
Smoking Status						
Have you smoked any cigarettes or tobacco in the last 7 days?						
Yes %	55.6 (5633)	70.7 (772)	66.0 (1556)	52.6 (1784)	46.3 (1521)	$\chi^2(1, 10123) = 317.65, p < .001$
No %	44.4 (4490)	29.3 (320)	34.0 (802)	47.4 (1605)	53.7 (1763)	

4.4.7 Multivariate analysis of individual-level socioeconomic status

Ordinal logistic regression was used to ascertain the independent effects of demographic and psychosocial measures on SES. A full likelihood ratio test comparing the fit of the proportional odds model to a model with varying location parameters suggested that the assumption of proportional odds was violated: χ^2 (30) = 214.39, $p < 0.001$.

If the assumptions of ordinal logistic regression are violated, a multinomial logistic regression can be conducted (Laerd, 2020). A multinomial logistic regression was therefore used to ascertain the independent effects of demographic and psychosocial measures have on SES.

Prior to carrying out the multiple logistic regression analysis, a test for multicollinearity was conducted. This was done by running a linear regression using SIMD as the predictor variable in order to obtain tolerance and Variance Inflation Factor (VIF) statistics. Tolerance values less than 0.1 (Menard, 1995) and VIF values greater than 10 (Myers, 1990) indicate a problem with multicollinearity. The table below displays the tolerance and VIF statistics for each of the variables. These indicate that the assumptions of the regression analysis were not violated.

Only those variables found to be significant in univariate analyses were included in the multivariate analyses. It was decided to conduct the analysis in two stages in order to understand the contribution of each distinct factor in relation to SES. The first model included demographic variables only and the second model includes both demographic variables and psychosocial variables. The model explained 27.7% (Nagelkerke R^2) of variance in SES and correctly classified 45.6% of cases.

Table 4-12: Test for Multicollinearity

Variable	Tolerance	VIF
Marital Status	.950	1.052
Age (Dummy variable)		
61-70	.927	1.079
71-75	.933	1.072
Region (Dummy variable)		
Tayside	.946	1.057
Lanarkshire	.946	1.057
Ethnicity (Dummy variable)		
Not white	.996	1.004
Prefer not to say	.998	1.002
Health State	.962	1.040
What I do can affect my risk of getting lung cancer	.962	1.040
When I think about my risk of lung cancer, I get upset	.898	1.113
I do not know how likely it is that I might get lung cancer	.931	1.074
Lung cancer would have a big impact on my life	.954	1.048
Lung cancer lasts a long time	.899	1.113
A blood screening test can accurately detect lung cancer	.902	1.109
Have you smoked any cigarettes or tobacco in the last seven days/ week?	.928	1.078

4.4.7.1 Model 1- demographic characteristics of ECLS participants by Individual-level SES (Table 4-13)

4.4.7.1.1 Marital status

The likelihood of being not married decreased as SES increased. It was more likely that a participant in SES 0 (most deprived) was not married compared to those in SES 3 (least deprived) (OR = 10.32, 95% CI = 8 .74– 12.17).

4.4.7.1.2 Region

The likelihood of a participant being from Greater Glasgow was significantly higher if they were from the most deprived group (SES 0) (1.86, 95% CI 1.43 – 2.42) compared to the least deprived group (SES 3).

4.4.7.1.3 Age

Participants aged between 50 – 60 were significantly less likely to be in the most deprived group (SES 0) compared to the least deprived group (SES 3) (OR = .21, 95% CI = .16 – .27). There was found to be no significant difference in SES in the age group 61 – 70.

4.4.7.1.4 Ethnicity

The likelihood of a participant being white and in SES 1 was significantly higher compared to SES 3 (least deprived) (OR = 3.12, 95% CI = 1.08 – 9.06).

4.4.7.2 Model 2 - psychosocial measures of ECLS trial participants by individual-level SES (Table 4-14)

4.4.7.2.1 Health state

The general trend indicated that as SES increased so too did perceived health state; SES 0 (most deprived) (OR= .96, 95% CI .96 – .97)), SES 1 (.97, 95% CI = .96 - .97), SES 2 (OR = .98, 95% CI .98 - .99).

4.4.7.2.2 Revised Illness Perception Questionnaire

"What I do can affect my risk of lung cancer" (Personal Control)
Participants in SES 0, SES 1 and SES 2 were significantly more likely to disagree that their actions could affect their risk of lung cancer. The likelihood of disagreeing with the statement was significantly higher in those from SES 1 compared to SES 3 (OR = 1.87, 95% CI 1.51 – 2.31).

"When I think about my risk of lung cancer, I get upset" (Emotional Representations)
A participant was significantly less likely to disagree with the statement if they were in SES 0 (most deprived) compared to SES 3 (least deprived) (OR = .62, 95% CI .52 - .74).

"I don't know how likely it is that I might get lung cancer" (Illness Coherence)
There was no significant difference across SES groups.

“Lung cancer would have a big impact on my life” (Consequences)

The belief that lung cancer would have a big impact on life increased with SES. A participant was significantly more likely to disagree with the statement if they were in SES 0 (most deprived) compared to SES 3 (least deprived) (OR = 1.98, 95% CI 1.31 – 3.02).

“Lung cancer lasts for a long time” (Timeline)

There was no significant difference across SES groups for the perception that lung cancer lasts for a long time.

“A blood test can accurately detect lung cancer” (Treatment Control)

The likelihood of participants disagreeing with this statement decreased as SES increased. A participant was significantly more likely to disagree with the statement if they were in SES 0 (most deprived) than if they were in SES 3 (least deprived) (OR = .40, 95% CI .33 - .48).

4.4.7.2.3 Smoking status

“Have you smoked any cigarettes or tobacco in the last 7-days?”

As SES increased the odds of having not smoked a cigarette in the past seven days decreased. A participant was more likely to have responded ‘no’ to the question *‘Have you smoked any cigarettes or tobacco in the last 7 days?’* if they were in SES 0 (most deprived) than in SES 3 (least deprived) (OR = 2.82, 95% CI 2.36 – 3.37).

Table 4-13: Multinomial Logistic Regression of Individual SES (Model 1: Demographic Variables)

	SES 0 *(Most Deprived)* vs. SES 3 *(Least Deprived)*		SES 1 vs. SES 3		SES 2 vs. SES 3	
Variable	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Marital Status						
Married	1		1		1	
Not Married	10.32	8.74 – 12.17	5.56	4.96 – 6.23	1.69	1.53 – 1.87
Region						
Greater Glasgow	1.86	1.43 – 2.42	1.60	1.33 – 1.93	1.24	1.07 – 1.45
Tayside	1.15	.86 – 1.55	1.08	.871 – 1.33	1.05	.88 – 1.24
Lanarkshire	1		1		1	
Age						
50-60	.21	.16 - .27	.36	.29 - .45	.37	.31 - .45
61-70	.89	.68 – 1.17	.81	.65 – 1.02	.88	.72 – 1.07
71-75	1		1		1	
Ethnicity						
Prefer not to say	1.85	.41 – 8.29	.76	.18 – 2.89	1.16	.37 – 3.68
White	3.12	1.08 – 9.06	3.29	1.56 – 6.94	4.16	2.12 – 8.14
Not White	1		1		1	
Nagelkerke R^2	.187		Sig.	p<.001		

Table 4-14: Multinomial Logistic Regression of Individual SES (Model 2: Demographic and Psychosocial Variables)

	SES 0 *(Most Deprived)* vs. SES 3 *(Least Deprived)*		SES 1 vs. SES 3		SES 2 vs. SES 3	
Variable	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Marital Status						
Married	1		1		1	
Not Married	9.94	8.23 – 12.02	5.24	4.61 – 5.97	1.66	1.49 – 1.85
Region						
Greater Glasgow	1.62	1.22 – 2.15	1.51	1.22 – 1.83	1.21	1.03 – 1.42
Tayside	.93	.68 – 1.28	.97	.77 – 1.22	1.01	.85 – 1.21
Lanarkshire	1		1		1	
Age						
50-60	.16	.12 - .23	.34	.26 - .44	.39	.31 - .48
61-70	.84	.61 – 1.15	.85	.65 – 1.11	.96	.77 – 1.19
71-75	1		1		1	
Ethnicity						
Prefer not to say	2.25	.42 – 12.09	.68	.14 – 3.25	.95	.28 – 3.29
White	3.81	1.11 – 13.14	4.27	1.81 – 10.07	4.08	2.04 – 8.18
Not White	1		1		1	
Health State	.96	.96 - .97	.97	.96 - .97	.98	.98 - .99
Revised Illness Perception Questionnaire						
What I do can affect my risk of lung cancer						
Agree	1	1.39 – 2.44	1	1.51 – 2.31	1	1.41 – 2.02
Disagree	1.84		1.87		1.69	

Table 4-14: Multinomial Logistic Regression of Individual SES (Model 2: Demographic and Psychosocial Variables)

	SES 0 *(Most Deprived)* vs. SES 3 *(Least Deprived)*		SES 1 vs. SES 3		SES 2 vs. SES 3	
Variable	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
When I think about my risk of lung cancer, I get upset						
Agree	1	.52 - .74	1	.65 - .85	1	.71 - .88
Disagree	.62		.74		.79	
I don't know how likely it is that I might get lung cancer						
Agree	1	.76 – 1.08	1	.88 – 1.15	1	.97 – 1.21
Disagree	.90		1.01		1.08	
Lung cancer would have a big impact on my life						
Agree	1	1.31 – 3.02	1	1.31 – 2.52	1	1.23 – 2.19
Disagree	1.98		1.82		1.65	
Lung cancer lasts for a long time						
Agree	1	.71 – 1.03	1	.79 – 1.04	1	.89 – 1.12
Disagree	.86		.91		.99	
A blood test can accurately detect lung cancer						
Agree	1	.33 - .48	1	.47 - .61	1	.62 - .77
Disagree	.40		.53		.69	

Table 4-14: Multinomial Logistic Regression of Individual SES (Model 2: Demographic and Psychosocial Variables)

	SES 0 *(Most Deprived)* vs. SES 3 *(Least Deprived)*		SES 1 vs. SES 3		SES 2 vs. SES 3	
Variable	*OR*	*95% CI*	*OR*	*95% CI*	*OR*	*95% CI*
Smoking Status						
Have you smoked any cigarettes or tobacco in the last 7 days?						
Yes	1	2.36 – 3.37	1	1.86 – 2.41	1	1.27 – 1.57
No	2.82		2.12		1.42	
Nagelkerke R^2	.277		Sig.	p<.001		

4.5 Discussion

4.5.1 Summary of main findings

The primary aim of this study was to explore the differences in beliefs about lung cancer across different SES groups. However, it also looked to discuss the different ways in which we can measure SES. This opens up some considerations on how we should measure level of deprivation, particularly if it is used as a criterion in cancer screening trials, such as the ECLS trial.

The aim of this chapter was to explore the differences in demographic and psychosocial characteristics of ECLS trial participants across socioeconomic groups using two different measures of SES.

To meet this objective, this chapter aimed to answer the following research questions:

I. Do the demographic characteristics of ECLS trial participants vary by SIMD or SES?

II. Do the psychosocial characteristics of ECLS trial participants vary by SIMD or SES?

An overview of the findings for area-level (SIMD) and individual-level SES are displayed in Tables 4-15 and 4-16.

Table 4-15: Area-level SES (SIMD) Findings

	Conclusion
Demographics	Those from the most deprived group (SIMD 1) were more likely to be women, unmarried and from Glasgow compared to those from the least deprived group (SIMD 5). There was no difference in ethnicity across SIMD.
Health State	Health state appeared to increase as SIMD increased, but the differences between the most and least deprived groups were marginal.
Illness Perception	Those from the most deprived group (SIMD1) had lower perceived control over lung cancer risk, were more likely to have an emotional response to their risk and less likely to believe that lung cancer would have a big impact on their life. The perceived efficacy of the ECLS trial screening test was high across the board but those from the least deprived group were marginally less likely to believe lung cancer can be detected by a blood test.
Smoking Status	Smoking status increased by SIMD, with those from the least deprived group (SIMD5) more likely to have smoked in the last seven days.

Table 4-16: Individual-level SES Findings

	Conclusion
Demographics	Those from lower SES groups were more likely to be unmarried, and from Glasgow compared to those in higher SES groups. There was found to be no difference in sex across different SES groups.
Health State	Health state appeared to increase as SES increased, but the differences between the most and least deprived groups were marginal.
Illness Perception	Those from more deprived groups (SES 0) were more likely to have lower perceived control over their risk of lung cancer, have a greater emotional response to their risk of lung cancer and less likely to believe that lung cancer would have a big impact on their life compared to those in less deprived groups (SES 3). The perceived efficacy of the ECLS trial screening test was high across the board but those from the least deprived group were marginally less likely to believe lung cancer can be detected by a blood test. There was no difference in perceived risk or the timeline of lung cancer across SES groups.
Smoking Status	Smoking status increased as SES increased, with those from the least deprived group (SES 3) more likely to have smoked in the last seven days.

Using two measures of SES also highlighted some differences in the ECLS trial participant sample. The SIMD measure used in the ECLS trial indicated that the majority of participants were from the most deprived groups, with 60% of participants being from group one or two. However, when using a composite measure of individual SES, the sample did not appear to be as deprived as first indicated – over 65% of participants were from the least deprived groups - groups two and three. The inconsistency is a result of how we measure SES. SIMD is an area based, composite measure and cannot indicate individual level of deprivation. This means that a person can be from an area that is deprived, but on an individual level they are relatively affluent, as can be seen from participant sample in this study. This discrepancy opens up some considerations on how we should measure level of deprivation, particularly if it is used as a criterion in cancer screening trials, such as the ECLS trial.

There was some variation in demographic characteristics at both area- and individual-level SES. Of particular note, marital status appears to be a predictor of SES, at both area- and individual-levels. Those who were married or in a civil partnership were significantly more likely to be from more affluent groups (SIMD 5 or SES 3), compared to those who were not married or in a civil partnership.

Sex of a participant was found to be a predictor of area-level SES (SIMD), but not of individual-level SES. When SES is measured using SIMD, women were significantly more likely to be from the most deprived group (SIMD 1) compared to men. Significantly more men were found to be in the least deprived quintile (SIMD 5) compared to women.

Those recruited from Glasgow were significantly more likely to be from the most deprived groups of both area-level SES (SIMD 1) and individual-level SES (SES 0). This was not particularly surprising as it is a result of the ECLS trial's successful recruitment strategy, that looked to recruit those from the most deprived groups. Recruitment predominantly focused on Greater Glasgow and Clyde in the first instance and recruitment numbers were highest in this location compared to Tayside and Lanarkshire. The high level of low SES participants in Glasgow does however indicate that the recruitment strategy put in place was relatively successful.

Univariate analysis indicated that SES was positively associated with perceived health state, with perceived health increasing as deprivation level decreased. This was found to be the case at both area-level and individual-level SES. However, when controlling for other variables, there was very little variation in perceived health state across both area and individual-level SES in multivariate analysis. Although, there does appear to be a more obvious gradient when looking at individual-level SES.

There was some variation in lung cancer illness perception across both area- and individual-level SES. Those from more deprived groups (SIMD 1 and SES 0) were more likely to have low perceived control over the risk factors of lung cancer, as well as a more emotional response to their risk of lung cancer compared to those in the least deprived groups (SIMD 5 and SES 3). This might indicate a level of fatalism about lung cancer (e.g. it is not something they can control or that it is inevitable) and a high level of fear that evokes an emotional response. Those from more deprived groups were also less likely to understand the long-term consequences of having lung cancer, at both area and individual-level SES. This might be indicative of having lower level of knowledge about lung cancer and lung cancer symptoms.

Univariate analysis indicated that those from affluent groups were significantly less likely to have smoked in the past week. However, when controlling for other variables, the results indicated that those recruited from affluent groups were actually more likely to have smoked in the past week. This was the case at both area- and individual-level SES. There could be a number of explanations for this unexpected result, including bias in self-report. Another possible explanation is that those from more affluent groups might be more likely to see screening as an opportunity to stop smoking or as an opportunity to reassure themselves that they do not have cancer despite their smoking status.

As we can see, there was only a small variation between the measures of SES. This would indicate that both area-level and individual-level measures of SES in the ECLS trial were successful in measuring the SES of the trial participants. It can be argued that individual measures of SES can be more sensitive to different types of deprivation not measured at area-level, for example, health state. When considering the use of SES to calculate individual cancer risk or as a criterion of cancer screening trials, it might be more appropriate to use individual measures of SES. Area-based measures of SES (such as SIMD), despite being more convenient, have some drawbacks. For example, area-based measures cannot account for individual wealth or access to services.

Our understanding of the socially graded nature of lung cancer beliefs is important to ensuring optimal uptake of any lung cancer screening programme in the UK. As a result of our understanding of lung cancer beliefs in the most deprived groups, it would be appropriate to target areas such as personal control over risk and the emotional response to lung cancer, when developing interventions to improve screening uptake in deprived groups. For example, the use of mass media campaigns, or the development of appropriate screening information materials that address lung cancer risk and the control individuals have over their own risk might go some way to reduce screening inequalities.

4.5.2 Comparison with other literature

This study indicates that being married or in a civil partnership was associated with higher level of SES. Existing research would suggest that being in a long-term relationship is also an indicator of cancer screening participation (van Jaarsveld, Miles, Edwards & Wardle, 2006; Hanske et al., 2016; Saghari et al., 2015). The mechanisms behind this variation might be the result of having a more ‘stable’ lifestyle (including housing and income) (Petrelli et al., 2018) and also the social support provided by a spouse when married or in a civil partnership (Hanske et al., 2016).

Participants’ beliefs about lung cancer reflect the findings of existing literature. Perceived lack of control of risk factors and emotional response to perceived risk in those from deprived groups has been found in other forms of cancer screening (Peretti-Watel et al., 2016). These negative responses to lung cancer suggest a level of lung cancer fatalism among those from low SES groups (Quaife et al., 2017). The emotional response to perceived lung cancer risk, as well as less understanding of the consequences of lung cancer could be as a result of lower levels of knowledge about lung cancer and lung cancer symptoms. Those from more deprived groups have been found to have lower level of knowledge about lung cancer (Rutten et al., 2009). However, these findings do, to some extent, contradict the findings of the review presented in Chapter 3 which concluded that there was no evident variation on fatalism or fear across different SES groups. Conversely, the review does support the conclusion that level of knowledge about cancer is socially graded. The corresponding construct in the Revised Illness Perception Questionnaire (*Illness Coherence*) does not appear to differ by SES.

Findings surrounding smoking status were unexpected, and contradictory to our knowledge of smoking uptake across SES - that smoking rates are commonly higher in those from more deprived groups (Hiscock, Bauld, Amos, Fidler & Munafò, 2012). In this study, those from the least deprived groups were more likely to have smoked in the past seven days. It is unclear why ECLS trial participants would go against this trend but there is some evidence to suggest that lung cancer screening and lung cancer screening trials can be used as an intervention to promote smoking cessation (Taylor et al., 2007; Pistelli et al., 2020). Although, these interventions are usually as a result of participating in screening, and not before screening has actually taken place.

4.5.3 Strengths and limitations

The study used data from both the ECLS trial and NHS patient data in order to explore the demographic and psychosocial characteristics of the ECLS trial participants. As a result of this robust analysis, the study has provided a holistic exploration of SES and lung cancer beliefs. The use of a large sample in this study, from predominately deprived groups, has provided insight into lung cancer beliefs that previous studies have not. Further, this is the first study exploring lung cancer beliefs in a Scottish population. The ECLS trial screening test is a novel form of screening, and this study also provides insight into the perceived efficacy and acceptability of this form of cancer screening.

To my knowledge, there have been no previous studies that have explored the predictors of uptake of a lung cancer screening trial by two different measures of SES. This study therefore makes a novel contribution to cancer screening literature. This study, alongside the systematic review presented in Chapter 3, contribute to our knowledge of socioeconomic variation in lung cancer beliefs and provides insight into how we might effectively reduce the social gradient of screening uptake that might occur if lung cancer screening is implemented in the UK.

There are some limitations to the study. Firstly, the study was a secondary data analysis which means that there was a lack of control over the variables used in the analysis. This somewhat limited the development of the individual-level measure of SES. In order to create the composite measure three individual indicators of SES were combined (age at which they left education, house ownership and car ownership) and an overall SES score created. However, given more control over the data collected, a more comprehensive measure could have been developed. For example, the inclusion of income or job type might be a better indicator of wealth.

A second limitation of the study is the use of self-report, particularly for smoking status and health state. There are clear limitations to self-report questionnaires that could reduce reliability. An example of this might be social desirability bias, where respondents answer questions in a way that they believe to be socially desirable. A way to circumvent issues such as this is to triangulate self-report with health records.

The ECLS trial baseline questionnaire used in this analysis adapted a version of the revised illness perception questionnaire. The IPQ has successfully been adapted for other forms of cancer (Lee et al., 2019; Hagger & Orbell, 2005). However, there is no standardised measure for lung cancer and the ECLS trial adapted the original revised questionnaire to meet the needs of the trial. As a result, the adapted IPQ used in the analysis has some limitations. For example, the questions developed for the trial do not directly map to those previously used, which created some challenges when attempting to understand which question related to each of the IPQ concepts. Remaining cognisant of the limitations of the measure used in the analysis, and a potential ceiling effect is important when attempting to interpret the results of the study. Similarly, it is important to recognise that a small effect size, as result of the trials large sample size, might produce statistically significant results.

4.6 Chapter summary

This chapter has presented the results of the secondary quantitative analysis of the ECLS trial data that explored the demographic and psychosocial differences across different socioeconomic groups using two distinct measures of SES.

The findings of this analysis indicate that lung cancer beliefs do vary by SES, with those from lower SES groups having lower perceived control of risk, higher emotional response to risk and less likely to perceive lung cancer as having long term consequences than those in less deprived groups.

This chapter also opened up methodological discussion on what the most effective way to measure SES and compared the findings of area-level and individual-level SES measures. The findings indicate that there is little variation in the differences in lung cancer beliefs between the two different measures. There is no clear conclusion on which is the most effective measurement, but it is thought that perhaps individual SES measures can be used to explore more complex indicators of SES, such as health state, and therefore might be more helpful when using SES as a measure of individual cancer risk, or as a criterion for cancer screening trials. On the other hand, the study also indicates that the differences in results between individual- and area-level SES are slight, providing some reassurance of the effectiveness of both forms of SES measurement. With area-level SES, such as SIMD, being more readily available it is evident that they are also an efficient way to measure SES.

This study has clear implications for any future cancer screening programme implemented in the UK. Understanding the socially graded nature of lung cancer beliefs is important to ensuring that appropriate interventions and mitigating actions can be put in place in advance of any programme implementation.

The next chapter describes and presents the results of another secondary analysis of the ECLS trial that explores the differences in demographic characteristics and beliefs about lung cancer in two distinct recruitment groups.

Chapter 5: Do recruitment methods to cancer screening impact uptake across socioeconomic groups? A comparison of GP and community recruitment

5.1 Introduction

5.1.1 Alternative invitation methods to increase uptake of screening

Previous research has explored how different invitation types encourage participation in screening. Traditionally, in the UK, screening invitation letters are sent to those eligible by post. These invitations are sent on behalf of an NHS board by a centralised administration function. In Scotland, letters are automatically generated based on the population register Community Health Index (CHI). CHI Index contains details of all Scottish residents and exists to ensure that patients can be correctly identified, and that relevant information pertaining to a patient's health is available to providers of care. The CHI number is a unique 10-character numeric identifier, allocated to each patient on first registration with the system. For screening purposes, this is how eligible screeners are identified by age and sex. This is a simple way to identify and invite eligible persons but given the inequalities in uptake this approach does not appear to effectively engage the most deprived compared to the most affluent. Consideration of alternative methods of invitation to improve access to screening among those at highest risk (the most deprived groups) is vital if inequalities are to be addressed.

Alternative types of invitation have been explored in order to ascertain if they support increased uptake in health behaviours in underserved groups.

5.1.2 Phone and text-based invitations

Phone or text-based invitations are suggested to be an effective means of increasing participation in screening. A systematic review conducted by Rat et al. (2018) indicated that telephone contacts and the involvement of 'navigators' led to higher uptake of bowel screening tests compared to standard postal invitation, but concluded that this type of invitation is more resource-intensive and may be difficult to implement in the usual screening setting.

A study exploring the uptake of cervical screening in Portugal developed an intervention that invited women to undertake the screening through automated, customised text messages and phone calls, followed by text message reminders before the arranged appointment (Firmino-Machado et al., 2018). This intervention was compared to standard care – a written letter received in the post. The study found that automated and customised text messages, phone calls and reminders increased adherence to cervical screening by 13.3%, when compared to standard care. However, the RCT did not address the socioeconomic barriers to access screening services this way, with those in deprived groups less likely to have access to a mobile phone. Kerrison et al. (2015) discussed this in relation to text reminders for routine breast screening in the UK and concluded that lack of access to mobile phones is a significant barrier to this type of invitation. However, for those in the most deprived groups who do have access to a mobile, this type of intervention is effective in increasing uptake. The study by Kerrison et al. (2015) further concluded that text message reminders increased uptake in women living in the most deprived quintile area by 13.6% despite poor mobile records within this group when compared to usual care (a letter with no reminder text).

5.1.3 GP endorsement

Research indicates that GP-endorsed invitations are particularly successful in increasing uptake across the board, including those from more deprived groups. A review and evaluation of interventions that improve participation in cancer screening services carried out by Duffy et al. (2017), concluded that GP endorsement was found to consistently improve participation in cancer screening, including in underserved populations. GP endorsement includes recommending screening, and in the case of the UK, having a GP’s name on a screening invitation or recall letter. Such a technique has been found to increase participation in bowel cancer screening. Hewitson et al. (2011) explored whether a general GP’s letter encouraging participation and an enhanced procedural leaflet explaining how to complete faecal occult blood test (FOBT) included with the English Bowel Cancer Screening Programme invitation materials would improve uptake. GP endorsement and an explicit leaflet were both found to increase uptake of bowel screening by 5.8% and 6% respectively. This was further supported by Raine et al. (2016) who reported that the addition of a simple statement of endorsement from GPs to the standard English bowel cancer screening invitation letter increased the likelihood of participation in FOBT screening programme by 7%. GP-endorsed reminder letters for people who did not respond to their original bowel screening invitation also significantly increased uptake of screening by 1.7%. However, GP endorsement did not have a significantly stronger effect in lower versus higher socioeconomic groups (Raine et al., 2016). In a study carried out in England, GP-endorsed reminders, sent three months after the original invitation, increased uptake by 3% when compared to those in a standard reminder letter control group (Benton et al., 2017). Studies exploring the uptake of breast and cervical screening in Italy and the Netherlands also found that receiving a GP-endorsed screening invitation increased uptake, when compared to non-GP endorsed invitations (Giorgi et al., 2000; de Nooijer et al., 2005; Hermens et al., 2000)

5.1.4 Opportunistic invitations

There is limited research exploring the effectiveness of increasing uptake of screening by using opportunistic or community-based invitations. This is a result of it not being a frequently employed invitation strategy. In the UK, opportunistic screening refers to tests that are recommended for certain groups but do not involve actively inviting people for a test. Chlamydia screening is the most common form of opportunistic screening (NHS England, 2019). This type of screening in the NHS is embedded into other health services (primary, secondary and local authority funded) and is offered when attending services for other healthcare needs.

Similarly, in the United States, health care providers are directly involved in recommending screening to patients. This type of opportunistic screening, with endorsement from a trusted healthcare professional has been found to be an effective way to increase cervical screening uptake in the United States (Balas et al., 2000). Although, opportunistic screening methods in the US differ slightly from the UK. The majority of cancer screening in the US is opportunistic. It is reliant on a physician recommendation or the individual’s request to be screened. As a result, it is often more appropriate to target behavioural interventions at healthcare providers, ensuring that they prompt patients to consider cancer screening (Wardle et al., 2015).

Studies indicate that the use of opportunistic screening creates a widening of screening inequality with those from more deprived groups less likely to screen when invited in this way. Differences in screening participation were observed in opportunistic screening of breast and cervical cancer in a study exploring screening programmes in EU-15 countries (Walsh, Silles & O’Neill, 2011). The study indicated that opportunistic cervical screening programme participation was determined by both SES and education level, but population-based screening programmes did not result in significant differences in screening participation across SES (Walsh et al., 2011). A similar study by Palència and colleagues (2010) also found that socioeconomic inequalities in the uptake of cancer screening were exacerbated in countries that did not have population-based breast and cervical screening programmes.

5.1.5 Community-based invitations

Community-based screening invitations are even less frequently used than opportunistic screening. Community-based invitations refer to passive advertisement of screening in local communities where the expectation is that those eligible for screening will make contact with the relevant healthcare professional (e.g. ‘self-select’). Advertisement of the screening test might include posters, leaflets or stalls.

One Swedish study concluded that community-based invitations to an RCT more successfully encouraged participation in a cohort study in those from the least deprived groups (Manjer et al., 2002). Manjer et al. (2002) described how those who responded to community directed invitations (for example, posters or pamphlets) in the Malmo Diet and Cancer Study were more likely to be older, female, have higher SES and were overall, healthier when compared to those who were recruited using personal invitations (i.e. letter). Other studies have found that community advertisement for cancer screening is more likely to attract those who are not high-risk candidates for cancer (das Nair et al., 2014).

This type of community-based recruitment or invitation has not been employed by cancer screening programmes in the UK to date. However, it has been used to recruit participants to cancer screening trials. The ECLS trial used a mix of both GP-endorsed invitation letters and community-based recruitment to recruit over 12,000 participants to a RCT. Pre-trial focus groups, with people at high-risk of lung cancer, highlighted the desire for an alternative invitation type other than a letter from their GP, including word of mouth within the community (das Nair, 2014). Different forms of media, especially local papers and the radio, were also seen as a valid form of raising awareness about the study and increasing participation. There was a view among focus group participants that they would not respond to an invitation to the lung screening trial from their GP. This was related to their trust in their GP practice as well as viewing letters from their GP as junk mail because of frequent correspondence:

> *‘Not through the GP. I wouldn’t bother contacting them and asking them to do it, ‘cause they’re hopeless.’*
>
> *‘Well, the first thing you would do with that [GP letter and reply slip] is bin it.’*

The insight gained from the focus groups significantly influenced the recruitment method of the lung cancer screening trial. As a result of the feedback, a particular focus was given to community advertisement as a method of recruitment.

5.1.6 Demographic and psychosocial differences impacting uptake

In order to understand what the most effective invitation strategy to encourage participation in screening we must also explore the individual determinants of cancer screening participation. As presented in Chapters 3 and 4, beliefs about lung cancer and lung cancer screening vary by SES. The efficiency of the invitation may vary depending on a person’s beliefs and attitudes towards cancer screening. Investigating the population subgroups most likely to engage with different types of recruitment (e.g. GP or community-based recruitment) could support the development of interventions that encourage participation in those least likely to participate.

We know that participation in screening not only varies by SES, but also other demographic characteristics. Sex, age and ethnicity are all predictors of cancer screening uptake. Uptake by sex varies for different types of screening (Wardle et al., 2015). Preliminary studies on the uptake of lung cancer screening in men and women is mixed, with some indicating men are more likely to participate than women (Ali et al., 2015), and others indicating that there is no difference in participation in lung cancer screening (Carter-Harris et al., 2018; Yong et al., 2020). Similarly, variation in uptake by age also varied from screening to screening (Sarma et al., 2019). Conversely, literature exploring variation in screening uptake by ethnicity is much clearer, with participation higher in those who identify as white, compared to other ethnic groups (Wardle et al., 2015).

As previously discussed, variation in beliefs can lead to differences in uptake of cancer screening. For example, existing literature indicates that a person’s knowledge about cancer, cancer symptoms or cancer screening impacts their participation in screening programmes (Wardle et al., 2015). The more knowledge a person has about cancer and cancer screening increases the likelihood that they will be screened (Berkowitz et al., 2008). This is supported by the findings of the systematic review presented in Chapter 3, with those with greater knowledge of lung cancer and lung cancer screening more likely to be from higher SES groups and more likely to participate in lung cancer screening. Other beliefs that predict screening uptake are positive attitude (Power, Miles, von Wagner, Robb & Wardle, 2009) and perceived risk (Walsh, 2006; Sarma et al., 2019). Other individual determinants of cancer screening include current health state or the presence of comorbidity. Poor health is also barrier to screening (Constantinou, Dray-Spira & Menvielle, 2016).

Understanding the variation in demographic characteristics and beliefs between those who engage with different forms of screening invitation, such as GP recruitment and community recruitment, will provide insight into how to best optimise screening uptake in high risk groups.

5.2 Aim and research questions

Overall, the aim is to understand how GP and community-based recruitment might attract different types of people and to quantitatively explore the demographic and psychosocial differences between people who respond to screening invitations in different ways. It is hypothesised that those who respond to GP-endorsed screening invitations may differ significantly from those who 'self-select' via community-based recruitment in a number of ways, including SES, sex, age and health status, and health beliefs.
To meet this objective this chapter aims to answer the following research questions:

I. Are socioeconomic status and demographic characteristics different between self-referrers or GP invited ECLS Trial participants?
II. Do the beliefs and attitudes towards lung cancer and lung cancer screening differ between self-referrers and GP invited ECLS Trial participants?

5.3 Methodology

This section describes the methodology of the ECLS Trial and the secondary analysis of the trial data. It should be noted that the study design and measures presented in this section replicate the methodology set out in Chapter 4 but has been included in Chapter 5 to ensure consistency and to allow the individual chapters to stand alone.

5.3.1 Study design

5.3.1.1 ECLS trial design and participants

The Early Detection Lung Cancer Screening Trial aimed to develop a new form of lung screening that uses a blood test to identify antibodies that indicate lung cancer. The EarlyCDT-Lung Test is a novel Autoantibody diagnostic test for the early detection of lung cancer that helps identify those most at risk of lung cancer. The test leads to a targeted approach to CT scanning for early lung cancer detection which may be a more cost-effective and potentially less harmful approach to population lung screening. The primary research question for the ECLS trial was: ‘Does using the EarlyCDT-Lung Test, followed by X-ray and CT scanning, to identify those at high risk of lung cancer reduce the incidence of patients with late-stage lung cancer or unclassified presentation at diagnosis, compared to standard clinical practice?’.

This thesis will not describe the randomisation of the RCT as the focus of this chapter is the recruitment of participants to the trial and the pre-randomisation baseline questionnaire. More detail of the ECLS trial can be found in section 1.3.4.3.

The trial aimed to recruit 12,000 high-risk participants from deprived areas of Scotland. In order to be eligible for the trial, participants had to be adults aged 50 to 75 who were at risk of lung cancer. These were defined as those who were current or former cigarette smokers with at least 20 pack-years, or have a history of cigarette smoking less than 20 pack-years plus a family history (mother, father, brother, sister) of lung cancer which gives an individual a personal risk similar to a smoking history of 20 pack years. The inclusion criteria for the ECLS trial is displayed in Figure 5-1.

Figure 5-1: Inclusion Criteria of the ECLS Trial

Figure 5-1: Inclusion Criteria of ECLS Trial	
1	Participant is willing and able to give informed consent for participation in the study
2	Male or female aged 50 years to 75 years
3	Current or Ex-smoker with at least 20-year pack history
4	or Less than 20-year pack history but with family history of lung cancer in a 1st degree relative (mother, father, sister, brother, child)
5	ECOG Status: 0, 1 and 2 (Eastern Co-operative Oncology Group)[6]
6	Geographical postal sectors of: **Tayside** - DD1 - DD11, PH1–PH3, PH6-PH8, PH10, PH11, PH13, PH15 & PH16, KY13 **Greater Glasgow & Clyde** - G1-G5, G11 –G15, G20-G22, G31-34, G40 –G46, G51- G53, G60-G62 &G64, G66 & G69, G72 & G73, G76-G78, G81-G83, PA1–PA8 (except PA6), PA11-PA16 & PA19 **Lanarkshire** - G33, G65, G67, G69, G71-75, ML1-12

5.3.1.2 GP recruitment

In order to recruit participants for the trial, GP practices within the lowest quintile of deprivation measured using the SIMD in NHS Tayside, NHS Greater Glasgow & Clyde and NHS Lanarkshire were engaged. A total of 170 GP practices within these areas agreed to partner with the trial. GP practices were used to help identify eligible patients, and subsequently send out invitations to those identified as eligible.

5.3.1.3 Community recruitment

The trial also used a significant amount of advertisement to recruit participants to the trial, this included community-based advertisement and media campaigns. These alternative recruitment methods including adverts on TV and radio, posters, flyers, beer mats and

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[6] ECOG is a measure used to describes a patient's level of functioning in terms of their ability to care for themself, daily activity, and physical ability (walking, working, etc.).

other community-based interactions aimed to increase the awareness of the trial and encouraged people to make contact if they believed they met the trial inclusion criteria.

All interested individuals outwith the GP recruitment strategy were assessed in relation to inclusion/exclusion criteria including residing within the selected geographical post codes.

5.3.1.4 ECLS Procedure – baseline questionnaire

On receipt of an invitation to take part in the trial, potential participants made an appointment with a research nurse for an initial consultation. These appointments took place in local hospitals and health centres across Greater Glasgow & Clyde, Tayside and Lanarkshire.

The aim of the consultation was to ensure that the participant was eligible and met the inclusion criteria. If they were eligible, consent was taken followed by providing a blood sample and subsequently randomised into a treatment arm. Before randomisation took place, participants were asked to provide some information on their medical history and complete the baseline questionnaire. The research nurse provided active support to complete the questionnaire ensuring that questions were understood. When required, the research nurse would scribe on behalf on the participant.

The medical data collected, such as smoking history (pack year) and current medications were manually entered into the patient management system by the research nurse. Participants were also asked where they had heard about the trial in order to collect recruitment method. The baseline questionnaire data was initially handwritten and then uploaded onto a patient management system manually. Participant records and baseline questionnaire data were aligned using a unique cohort ID assigned to them, as well as CHI.

5.3.2 The present study: data access

The secondary analysis reported in this thesis included analysis of the baseline questionnaire that ECLS trial participants completed prior to being randomised. Data were obtained via the Tayside Clinical Trials Unit (TCTU). In order to transfer data an access agreement was developed and agreed upon. Training on good practice in clinical trial procedures was a prerequisite of the data being transferred.

Data was accessed via an NHS Safe Haven hosted by NHS Tayside. A Safe Haven is a secure environment whereby health data can be processed and linked with other health data. It is a safeguard for confidential information which is being used for research purposes. The Safe Haven was accessed remotely via the internet.

The data uploaded to the Safe Haven included all baseline questionnaire data. Supplementary to this, demographic data including date of birth, SIMD and CHI were provided. Data were merged using the participants' cohort ID and CHI.

5.3.2.1 Ethical approvals

The secondary analysis used ECLS trial data, which was carried out in conjunction with the National Health Service. As a result, ethical permission was sought from NHS Scotland East of Scotland Research Ethics Service. Ethical approval was sought based on an amendment to the original ECLS trial ethical approval. Ethical approval for the amendment was granted by the committee in December 2015 (Appendix 4).

5.3.2.2 Participants

In order to be included within the statistical analyses for this study, participants were required to have taken part in the ECLS trial and completed the baseline study questionnaire. Of the 12,243 ECLS trial participants, 11,164 completed the baseline questionnaire. As a result, 1079 ECLS trial participants were excluded from this analysis (Table 5-1).

Table 5-1: ECLS Participants Eligible for this Analysis

	ECLS (All Cases)	**ECLS (Completed baseline questionnaire)**	**Difference in no. cases**
Community advertisement recruitment	2039	1943	96 (95.3%)
GP letter recruitment	10204	9220	984 (90.4%)
Total	12243	11164	1079

5.3.2.3 Measures

The measures used in this analysis are described in the Table 5-2 below.

Table 5-2: Measures

Measure	Description	Questions	Scale
Recruitment Method	An indicator of how participants were recruited to the ECLS trial. This was established by trial records which indicated if a postal invitation was sent by a GP or not. In the absence of a postal invitation being sent, recruitment was assumed to be via the community methods employed. This was cross-checked with the participants self-report of recruitment method. In cases (n=30) where there was a disparity between trial records and self-report, trial record of recruitment method was used.	N/A	1– No GP letter sent 0 - GP Letter Sent
Sex	An indicator of the sex. This was not included in the baseline questionnaire. A person’s sex was established by their CHI linked to NHS records.	N/A	1-Male 2-Female
Age	A measure of chronological age. This was calculated by date of birth, and then grouped into age groups.	Date of Birth	1 - 50-60 2 - 61-70 3 - 71-75
Marital Status	An indicator of current marital status.	Marital Status	1 - Married 0 - Not Married

Table 5-2: Measures

Measure	Description	Questions	Scale
Ethnicity	An indicator of the ethnicity identified with. These were then grouped into three categories.	I would describe my ethnic origin as …	1 - White 2 - Other Ethnic Group 0 - Prefer Not to Say
Geographic Region	An indicator of the geographic location that they live. This was not included in the baseline questionnaire but was established by their CHI linked with NHS records.	N/A	1 - Greater Glasgow 2 - Tayside 3 - Lanarkshire

Table 5-2: Measures

Measure	Description	Questions	Scale
Scottish Index of Multiple Deprivation (SIMD) (2012)	A standard measure of deprivation in a given geographical area. A persons SIMD score is determined by their postcode. The most current record of SIMD was used at the time the trial was initiated in 2013. SIMD was calculated based on participants NHS record. The data used was split into quintiles and analysed as five distinct groups.	N/A	1 - Most Deprived 2 3 4 5 - Least Deprived
Individual measure of socioeconomic deprivation (SES)	A measure of socioeconomic status. This is calculated based on three indicators of socioeconomic status: educational qualifications (left school after 16 years of age); car ownership; and home ownership. The presence of any one of these indicators provided respondents with a score of one. The score for each indicator was summed to create an overall socioeconomic status score. Scores can range from zero to three. Composite measures such as this have been used successfully in previous studies (Robb, Simon, & Wardle, 2009).	Age at which you left full-time education How many cars or vans are available for use by one or more members of your household? Do you own or rent your home?	0 – Most Deprived 1 2 3- Least Deprived
EQ-5D-3L – Visual Analogue Health Scale (Rabin & de Charro, 2001)	Measure of perceived current health status that asks participants to rate their health out of 100.	To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from	0-100

Table 5-2: Measures

Measure	Description	Questions	Scale
		the box below to whichever point on the scale indicates how good or bad your health state is today.	
Revised Illness Perception Questionnaire – Lung Cancer (IPQ-LC) Moss-Morris et al. (2002)	A measure of illness perception adapted for lung cancer. The Illness Perception Questionnaire was developed to provide a quantitative assessment of the five components of the illness representation – identity, consequences, timeline, control/cure and cause in Leventhal's Self-Regulatory Model. This iteration of the IPQ, adapted for the ECLS trial, consists of seven items. Each component is given a score of 1– 5. Items were recoded to dichotomise into 'agree' and 'disagree'. Those who answered, 'Strongly Disagree', 'Disagree' or 'Neutral' were recoded as 'Disagree', while those who answered, 'Strongly Agree' or 'Agree' were recoded as 'Agree'.	What I do can affect my risk of getting lung cancer (personal control) When I think about my risk of getting lung cancer, I get upset (emotional response) I do not know how likely it is that I might get lung cancer (illness coherence) Finding lung cancer early can improve my chances of survival (treatment control) Lung cancer would have a big impact on my life (consequences) Lung cancer lasts for a long time (timeline) A blood screening test can accurately detect lung cancer (treatment control)	Original 1 -Strongly Disagree 2 - Disagree 3 - Neutral 4 - Agree 5 - Strongly Agree Recoded 0 – Disagree 1 – Agree
Smoking Behaviour	A measure of smoking status.	Have you smoked any cigarettes or tobacco in the last seven days / week?	2- Yes 1- No

5.3.2.4 Analysis

The secondary quantitative analysis included descriptive analysis of all ECLS Trial participants who completed the baseline questionnaire data. This descriptive analysis included frequencies and means examined the differences between demographic and psychosocial measures of those who responded to GP invitations and those who were recruited via community advertisement recruitment. Univariate statistical tests conducted included chi-square for categorical variables and independent sample t-tests for continuous variables. Univariable and multivariable logistic regression analyses were conducted to examine the associations between demographic and psychosocial factors and cancer screening invitation type. Data analysis was carried out using IBM SPSS V.23 (IBM, 2015).

5.4 Results

5.4.1 Demographic characteristics of the sample

A total of 11,164 trial participants completed the baseline questionnaire. As displayed in Table 5-3, of those who completed the questionnaire, 50.6% were male (n = 5645) and 49.4% female (n = 5510). Over half of the participants were aged between 50 – 60 (53.6%) and were married or in a civil partnership (52.9%). The majority of participants identified as white (99.1%), with only 0.6% identifying with another ethnic group. Participants were primarily from Greater Glasgow (67.4%), followed by Tayside (22.8%) and Lanarkshire (9.8%).

The majority of participants were from the most deprived SIMD groups, groups 1 and 2 (40.7% and 20.0% respectively). Those from group 5 (least deprived) accounted for 10.5% of participants. However, when using the individual measure of socioeconomic deprivation just under one third were considered least deprived (group 3) (32.8%) and those in the most deprived group (group 0) accounted for 10.5% of trial participants.

5.4.2 Univariate analysis

5.4.2.1 Demographic characteristics of GP recruited vs. community recruited participants (Table 5-3)

5.4.2.1.1 Sex

Uptake was significantly higher among women invited by community recruitment (55.2%) than by GP letter (48.1%; χ^2 (1) = 32.37, p <.001).

5.4.2.1.2 Age

Over half of participants were in the age range 50-60 years for both recruitment sources. However, a chi-square test of association between age and recruitment source revealed no significant difference: $\chi^2(2) = 3.78$, p =.151.

5.4.2.1.3 Marital status

People recruited via the community were significantly more likely to be married (56.2%) compared to those recruited via GP letters (52.2%; $\chi^2(5) = 19.19$, p =.002).

5.4.2.1.4 Ethnicity

There was no significant association between ethnicity and recruitment source (χ^2(2, 11030) = 2.31, p =.314).

5.4.2.1.5 Region

People from Greater Glasgow were more likely to be recruited via their GP (72.7%), compared to community recruitment (42.5%). Conversely, in Tayside 17.2% of the sample were recruited by GP letter compared with 49.7% recruited via community advertisement (χ^2(2, 11163) = 968.3, p <.001).

5.4.2.1.6 SIMD

Significantly more people from SIMD group 1 (most deprived) were recruited via GP letter (43.4%) than community advertisement (28%; χ^2(1, 11130) = 282.41, p <.001). Those recruited from the least deprived group (group 5) were more likely to be recruited via the community (18.1%) compared to GP recruited (9.0%).

5.4.2.1.7 Individual SES

Among those in the most deprived group (group 0), twice as many people were recruited by GP letter (11.5%) compared to community advertisement (5.8%) (χ^2(1) = 196.99, p <0.001.

Table 5-3: Demographic Characteristics by Recruitment Source

	All (n = 11,164)	GP Recruitment (n = 9,920)	Community Recruitment (n = 1943)	Sig.
Sex				
Male %	50.6 (5645)	51.9 (4783)	44.8 (870)	$\chi^2(1, 11163) = 32.37, p < 0.001$
Female %	49.4 (5510)	48.1 (4437)	55.2 (1073)	
Age (years)				
50-60 %	53.6 (5982)	53.2 (4906)	55.4 (1076)	$\chi^2(2, 11163) = 3.78, p =.151$
61-70 %	38.7 (4322)	38.9 (3590)	37.7 (732)	
71-75 %	7.7 (859)	7.9 (724)	6.9 (135)	
Marital Status				
Married / Civil Partnership %	52.9 (5820)	52.2 (4738)	56.2 (1082)	$\chi^2(1, 11010) = 10.49, p =.001$
Not Married / Civil Partnership %	47.1 (5190)	47.8 (4347)	43.8 (843)	
Ethnicity				
White %	99.1 (10928)	99.1 (9021)	99.0 (1907)	$\chi^2(2, 11030) = 2.31, p =.314$
Other Ethnic Group %	0.6 (69)	0.6 (58)	0.6 (11)	
Prefer not to say %	0.3 (33)	0.3 (24)	0.5 (9)	
Region				
Greater Glasgow %	67.4 (7525)	72.7 (6700)	42.5 (825)	$\chi^2(2, 11163) = 968.3, p <0.001$
Tayside %	22.8 (2548)	17.2 (1583)	49.7 (965)	
Lanarkshire %	9.8 (1090)	10.2 (937)	7.9 (153)	

Table 5-3: Demographic Characteristics by Recruitment Source

	All (n = 11,164)	GP Recruitment (n = 9,920)	Community Recruitment (n = 1943)	Sig.
SIMD				
1 (most deprived) %	40.7 (4534)	43.4 (3994)	28.0 (540)	$\chi^2(1, 11130) = 282.41$, p <0.001
2 %	20.0 (2231)	20.5 (1884)	18.0 (347)	
3 %	14.2 (1578)	13.9 (1282)	15.3 (296)	
4 %	14.5 (1614)	13.2 (1217)	20.6 (397)	
5 (least deprived) %	10.5 (1173)	9.0 (824)	18.1 (349)	
SES				
0 (most deprived) %	10.5 (1166)	11.5 (1054)	5.8 (112)	$\chi^2(1, 11124) = 196.99$, p <0.001
1 %	22.9 (2551)	24.4(2243)	15.9 (308)	
2 %	33.8 (3760)	33.81 (3108)	33.6 (652)	
3 (least deprived) %	32.8 (3647)	30.3 (2779)	44.7 (868)	

5.4.2.2 Psychosocial measures by recruitment source

5.4.2.2.1 Health state (Table 5-4)

Those that were recruited via the community were more likely to have higher health state scores (M = 80.31, SD = 17.16) indicating that they perceived themselves to be healthier, compared to those recruited via their GP (M = 78.38, SD = 18.3; t (10917) = -4.27, p<.001 ; Table 5-4).

5.4.2.2.2 Revised Illness Perception Questionnaire (Table 5-4)

"What I do can affect my risk of lung cancer" (personal control)
There were significantly more people who agreed that their actions could control their risk of lung cancer among those recruited via the community (92.2%) compared to those recruited via their GP (89.0%): $\chi^2(1) = 18.15$, p <.001).

"When I think about my risk of lung cancer, I get upset" (emotional response)
Those recruited via their GP were more likely to agree that they would get upset when they thought about their risk of lung cancer (43.0%) compared to those recruited via the community (39.6%: $\chi^2(1) = 7.61$, p =.006).

"*I don't know how likely it is that I might get lung cancer" (illness coherence)*
Those recruited via their GP were more likely to not know how likely it is that they might get lung cancer (65.2%) compared to those recruited via the community (61.1%). A chi-square test of association between level of agreement with their understanding of their risk of lung cancer and recruitment source revealed a significant association: $\chi^2(1) = 11.69$, p =.001.

"Finding lung cancer early can improve my chances of survival" (treatment control)
There was a high level of agreement that finding cancer early would improve outcomes among those recruited by their GP (97.1%) and those recruited via the community (97.2%) and a chi-square test did not reveal a significant association: $\chi^2(1) = .02$, p = .883.

"*Lung cancer would have a big impact on my life" (consequences)*

There was a high level of agreement that lung cancer would have a big impact on participants' lives: GP Recruitment (95.9%); Community Recruitment (96.8%; χ^2(1, 11022) = 3.36, p =.067).

"Lung cancer lasts for a long time" (timeline)

Those recruited via their GP were more likely to think that cancer lasts a long time (64.7%) compared to those recruited via the community (61.3%; χ^2(1) = 7.83, p = .005).

"A blood test can accurately detect lung cancer" (treatment control)

Those recruited via their GP were more likely to believe that lung cancer can be detected by a blood test (64.1%) compared to those recruited via the community (55.4%; χ^2(1) = 50.99, p <.001).

5.4.2.2.3 Smoking status (Table 5-5)

"Have you smoked any cigarettes or tobacco in the last 7-days?"

Those recruited via their GP were more likely to have smoked tobacco products in the last seven days (58.3%) compared to those recruited via the community (43.7%; χ^2(1) = 130.55 p <.001).

Table 5-4: Mean Health State Score by Recruitment Source

	GP Recruitment (n = 9,920)		Community Recruitment (n = 1943)		Sig.
	Mean	SD	Mean	SD	
Health State	78.38	18.13	80.31	17.16	t (10917) = -4.27, p<.001

Table 5-5: Psychosocial Measures by Recruitment Source

	All (n = 11,164)	GP Recruitment (n = 9,920)	Community Recruitment (n = 1943)	Sig.
Revised Illness Perception Questionnaire				
What I do can affect my risk of lung cancer				
Agree %	89.5 (9875)	89.0 (8094)	92.2 (1781)	$\chi^2(1, 11029) = 18.15$, p <.001
Disagree %	10.5 (1154)	11.0 (1004)	7.8 (150)	
When I think about my risk of lung cancer, I get upset				
Agree %	42.4 (4662)	43.0 (3897)	39.6 (765)	$\chi^2(1, 10992) = 7.61$, p =.006
Disagree %	57.6 (6330)	57.0 (5163)	60.4 (1167)	
I don't know how likely it is that I might get lung cancer				
Agree %	64.5 (7044)	65.2 (5871)	61.1 (1173)	$\chi^2(1, 10929) = 11.69$, p =.001
Disagree	35.5 (3885)	34.8 (3137)	38.9 (748)	
Finding lung cancer early can improve my chances of survival				
Agree %	97.1 (10689)	97.1 (8812)	97.2 (1877)	$\chi^2(1, 11008) = .02$, p = .883
Disagree %	2.9 (319)	2.9 (264)	2.8 (55)	
Lung cancer would have a big impact on my life				
Agree %	96.1 (10587)	95.9 (8717)	96.8 (1870)	$\chi^2(1, 11022) = 3.36$, p = .067
Disagree	3.9 (435)	4.1 (373)	3.2 (62)	
Lung cancer lasts for a long time				
Agree %	64.1 (6987)	64.7 (5821)	61.3(1166)	$\chi^2(1, 10900) = 7.83$, p = .005
Disagree	35.9 (3914)	35.3 (3177)	38.7 (736)	

Table 5-5: Psychosocial Measures by Recruitment Source

	All (n = 11,164)	GP Recruitment (n = 9,920)	Community Recruitment (n = 1943)	Sig.
A blood test can accurately detect lung cancer				
Agree %	62.6 (6894)	64.1 (5828)	55.4 (1066)	$\chi^2(1, 11014) = 50.99$, p <.001
Disagree %	37.4 (4120)	35.9 (3263)	44.6 (857)	
Smoking Status				
Have you smoked any cigarettes or tobacco in the last 7 days?				
Yes %	55.7 (5639)	58.3 (4835)	43.7 (804)	$\chi^2(1, 10130) = 130.55$ p <.001
No %	44.3 (4491)	41.7 (3455)	56.3 (1036)	

5.4.3 Multivariate analysis

Multiple logistic regression analysis was conducted in order to examine how each variable was associated with recruitment source (GP Recruitment = 0; Community Advertisement = 1). Only those variables found to be significant in univariate analyses were included in the multivariate analyses.

Prior to carrying out the multiple logistic regression analysis a test for multicollinearity was conducted. This was done by running a linear regression using recruitment source as the predictor variable in order to obtain tolerance and Variance Inflation Factor (VIF) statistics. Tolerance values less than 0.1 (Menard, 1995) and VIF values greater than 10 (Myers, 1990) indicate a problem with multicollinearity. The table below displays the tolerance and VIF statistics for each of the variables. These indicate that the assumptions of the regression analysis were not violated (Table 5-6).

Table 5-6: Test for Multicollinearity

Variable	Tolerance	VIF
Sex	.946	1.057
Marital Status	.967	1.034
Region	.967	1.034
SES	.744	1.344
SIMD	.795	1.257
Health State	.595	1.682
What I do can affect my risk of getting lung cancer	.966	1.036
When I think about my risk of lung cancer I get upset	.782	1.279
I do not know how likely it is that I might get lung cancer	.933	1.072
Lung cancer lasts a long time	.911	1.098
A blood screening test can accurately detect lung cancer	.890	1.124
Have you smoked any cigarettes or tobacco in the last seven days/ week?	.917	1.091

It was decided to conduct the analysis in two stages in order to understand the contribution each of the distinct factors made in relation to recruitment source. The first model included demographic variables only and the second model includes both demographic variables and psychosocial variables (Table 5-7). The final model explained 19.5% (Nagelkerke R^2) of the variance in recruitment source and correctly classified 83.3% of cases.

5.4.3.1 Demographic characteristics

5.4.3.1.1 Sex

The multivariate model indicated that women had lower odds of being recruited via the community than men (OR 0.75, 95% CI 0.67 – 0.85).

5.4.3.1.2 Region

Those recruited from Lanarkshire had significantly higher odds of being recruited via the community (OR 3.90, 95% CI 3.20 - 4.75) when other demographic factors were controlled.

5.4.3.1.3 Marital status

Those who were married or in a civil partnership were significantly more likely to be recruited via the community (OR 1.17 95% CI 1.04 - 1.32) in the multivariate analysis.

5.4.3.1.4 SIMD & individual SES

Both SIMD and individual SES significantly predicted recruitment groups. The odds of being recruited via the community increased as deprivation level decreased in SIMD (OR 0.67, 95% CI 0.55 - 0.81 for those from the least deprived group compared to the most deprived) and individual SES (OR 0.83, 95% CI 0.73 - 0.95 for those from the least deprived groups compared to the most deprived).

5.4.3.2 Psychosocial measures

The model indicated that understanding how behaviour affects risks of lung cancer significantly predicted recruitment source. Those who agreed that what they did impacted their risk had lower odds of being recruited via the community (OR 0.68, 95% CI 0.55 - 0.84).

Participants had higher odds of being recruited via the community if they did not know how likely it was that they will get lung cancer (OR 1.18, 95% CI 1.04 - 1.33) and if they considered a blood test to be an effective way to screen for lung cancer (OR 1.41, 95% CI 1.25 - 1.59).

Those who had not smoked in the last week had lower odds of being recruited via the community (OR 0.52, 95% CI 0.46 - 0.59).

Table 5-7: Multiple Logistic Regression (0 = GP recruitment; 1 = community recruitment)

	Model 1 (Demographic Characteristics)		Model 2 (Demographic Characteristics and Psychosocial Measures)	
Variable	*OR [95% CI]*	*Sig.*	*OR [95% CI]*	*Sig.*
Sex				
Male	1		1	
Female	.77[.69,.86]	p <.001	.77 [.69, .87]	p<.001
Marital Status				
Not Married	1		1	
Married	1.15 [1.02, 1.30]	p = .022	1.17 [1.04, 1.32]	p = .011
Region				
Greater Glasgow	1		1	
Tayside	.81 [.67, .98]	p = .030	.826 [.68, 1.00]	p = .054
Lanarkshire	3.54 [2.92, 4.30]	p<.001	3.90 [3.20, 4.75]	p <.001
SIMD				
1(Most Deprived)	1		1	
2	.46[.38, .55]	p <.001	.51 [.42, .62]	p<.001
3	.52 [.43, .63]	p <.001	.56 [.46, .68]	p<.001
4	.54 [.44, .66]	p <.001	.56 [.46, .69]	p<.001
5 (Least Deprived)	.66 [.55, .80]	p <.001	.67 [.55, .81]	p<.001
SES				
0 (Most Deprived)	1		1	
1	.41 [.32, .53]	p = <.001	.49 [.38, .64]	p < .001
2	.54 [.46, .64]	p = <.001	.60 [.50, .72]	p < .001
3 (Least Deprived)	.76 [.67, .87]	p = <.001	.81 [.71, .92]	p = .002
Health State			.99 [.99, 1.00]	p = .521

Table 5-7: Multiple Logistic Regression (0 = GP recruitment; 1 = community recruitment)

	Model 1 (Demographic Characteristics)		Model 2 (Demographic Characteristics and Psychosocial Measures)	
Variable	*OR [95% CI]*	*Sig.*	*OR [95% CI]*	*Sig.*
Revised Illness Perception Questionnaire				
What I do can affect my risk of lung cancer				
Agree			.64 [.52, .79]	p<.001
Disagree			1	
When I think about my risk of lung cancer, I get upset				
Agree			.99 [.88, 1.11]	p = .811
Disagree			1	
I don't know how likely it is that I might get lung cancer				
Agree				
Disagree			1.18 [1.04, 1.33]	p = .009
			1	
Lung cancer lasts for a long time				
Agree			1.07 [.95, 1.21]	p = .253
Disagree			1	
A blood test can accurately detect lung cancer				
Agree			1.45 [1.28, 1.63]	p < .001
Disagree			1	
Smoking Status				
Have you smoked any cigarettes or tobacco in the last 7 days?				
Yes			1	p< .001
No			.57 [.50, .64]	
Nagelkerke R^2	.161		.184	

5.5 Discussion

5.5.1 Summary of main findings

This study offered a valuable opportunity to explore the effectiveness of recruitment methods in Scotland's first lung cancer screening trial to engage high risk groups. Although a lung cancer screening trial and not a cancer screening programme, the uptake rate and the way in which those from high risk groups engaged with recruitment methods could have significant implications on any future lung cancer screening programme if implemented. Making sure that the right method of recruitment is employed by a national screening programme to reach high risk groups could help to ensure the future sustainability of a programme, lower mortality rates in high risk groups, and potentially address the stark inequalities in uptake observed in existing cancer screening programmes.

The current analysis explored the differing demographic and psychosocial characteristics of people who were recruited to the ECLS trial by their GP compared to those who were recruited via the community. The study aimed to address the following questions:

I. Are SES and demographic characteristics different between self-referrers (community-based) or GP invited ECLS Trial participants?
II. Do the beliefs and attitudes towards lung cancer and lung cancer screening differ between self-referrers and GP invited ECLS Trial participants?

A summary of the findings is presented in Table 5-8.

Table 5-8: Summary of Findings	
	Conclusion
Demographics	Those from more affluent groups were more likely to be recruited via the community, compared to those from more deprived groups. Men and those who were married or in a civil partnership were also more likely to be recruited via the community.
Health State	Those recruited from the community were more likely to report higher perceived health state, compared to those recruited via their GP. However, when controlling for other variables there was found to be no difference in health state between the two recruitment groups.
Illness Perception	Those who were recruited via their GP were more likely to understand their own risk of developing lung cancer, compared to those recruited via community advertisement. Those recruited via the community were more likely to believe in the efficacy of a blood test to screen for lung cancer.
Smoking Status	Those recruited from the community were more likely to have smoked in the past seven days.

The SES of participants did significantly differ between GP recruited and community recruited participants. An observable trend in both SIMD and individual SES indicated that as deprivation level decreased, the likelihood of community-based recruitment increased. Those from more affluent groups were more likely to self-refer via community-based recruitment. The availability of two measures of SES provides greater robustness to this finding. It suggests that community-based recruitment does not assist in engaging people from more deprived backgrounds in cancer screening as suggested by the pre-trial qualitative work (das Nair et al., 2014). However, the pre-trial work was a proactive attempt at co-design, and it was important for the ECLS trial to respond to the feedback received in the focus groups that indicated that participants would be less likely to respond to an invitation from their GP.

There were some demographic differences seen between the two recruitment types. Of significance, the sex of the participant was a predictor of recruitment type. Univariate analysis indicated that women were more likely to be recruited via the community, however, multivariate analysis indicated that men had higher odds of being recruited via the community, when controlling for other variables.

Univariate analysis indicated that those recruited via community advertisement were significantly less likely to have smoked in the past week. However, when controlling for other variables, the results indicated that those recruited from the community were actually more likely to have smoked in the past week. This might be as a result of being more motivated to screen for lung cancer because of their smoking status, as indicated by their more proactive approach to signing up to join the screening trial as opposed to being passively recruited via their GP.

With regard to the perceptions and beliefs about lung cancer, those who were recruited via their GP were more likely to understand their own risk of developing lung cancer, compared to those recruited via community advertisement. However, they were less likely to believe that a blood test can accurately detect lung cancer. Those recruited via the community were more likely to believe in the efficacy of a blood test to screen for lung cancer. This is not unexpected as they are unlikely to proactively engage with a screening trial if they did not believe the test was accurate.

5.5.2 Comparison with other literature

To my knowledge, there has been no previous research that has directly compared community and GP recruitment methods. In light of this, the findings will be discussed and compared to previous literature exploring the predictors of uptake in other cancer screening programmes and trials.

This study found that being male, married, and affluent were significantly associated with community recruitment. With regard to sex, this is not entirely in keeping with previous research, that indicate that women are more likely to engage with cancer screening in general (von Wagner et al., 2011; Davis, Buchanan, Katz & Green, 2012). However, as discussed by Wardle et al. (2005), contrary to common expectation, men are more likely to take part in some forms of screening than women. Higher male uptake via community methods might be explained by being more affluent or being more likely to be married.

Those recruited from the community were more likely to be married than those recruited via their GP. This result is supported by previous literature that indicate that married adults are more likely to participate in screening than the non-married (van Jaarsveld et al., 2006). This might be a result of increased social support, but also the ‘healthy marriage’ effect, where spouses monitor their partner’s health behaviours and encourage them to undertake positive health behaviours. The consequence of this is that married people lead healthier lives because the wellbeing of the family is partly dependent on all members’ good health (van Jaarsveld et al., 2006). Participants who were recruited via community engagement might be more proactive with their health because of their increased likelihood of being married.

Participants’ beliefs about lung cancer and lung cancer screening also reflect the current literature. Those recruited via the community were less likely to understand the control they might have over their own risk of developing lung cancer but still self-referred to participate in the screening trial. Although this group were more affluent and healthier, they were also, overall, more worried about lung cancer compared to those recruited via their GP. This might be reflective of the ‘worried well’ phenomenon who undertake screening to confirm their belief that they are either not at risk of lung cancer or for reassurance that they do not currently have cancer (Brodersen, Siersma & Ryle, 2011). Conversely, those who were recruited via their GP, who indicate an understanding of their own risk of developing lung cancer, might believe so because they have been prompted by a GP-endorsed letter that tells them that they are in a high-risk group. Their eligibility to participate and the active invitation to the trial confirms their at-risk status.

5.5.3 Strengths and limitations

There were no previous studies identified that explore the predictors of uptake of a cancer screening trial by recruitment. This study, therefore, makes a unique contribution to the literature. This study used both ECLS trial and NHS data to explore the demographic and psychosocial characteristics of the ECLS trial participants.

A strength of this study is that participants were recruited from multiple regions of Scotland, with participation targeted at those who are most at risk of lung cancer. The three study sites used in the trial were selected because of their high incidence of lung cancer and high levels of deprivation. The representativeness of the study participants (with the exception of ethnicity) means that the findings are on the whole generalisable to the people who are high risk of lung cancer in Scotland. Further study is required to understand the best way to recruit BME groups to cancer screening trials and improve our understanding of the processes leading to inequalities in cancer screening uptake.

This was a secondary data analysis. As a result, there were limitations relating to the control of the design of the questionnaire (previously discussed in Chapter 4). This includes a lack of control over measures used within the baseline questionnaire and understanding of the rationale to use unstandardised measures. However, the data used were appropriate to answer the research questions of the study, and consistency of data was assured as a result of strict RCT protocol guidelines.

The ECLS trial was an RCT to test the effectiveness of a lung cancer screening test. As a result, the trial was not a 'true' screening test akin to those that have national screening programmes in the UK. While it is noted that participating in a cancer screening trial is not the same as participating in a screening programme, given that there is no current national lung screening programme, it is useful to draw on the findings of this study to understand the screening behaviour of high risk groups, with the aim to help shape future screening programmes.

There could be 'study contamination' across recruitment groups, with people receiving GP letters also potentially being exposed to community-based advertisement. Those from the GP recruitment group could have been influenced by receiving the letter and seeing posters in their community that might further influence participation, compared to those who received only a GP letter or community advertisement. In order to understand the true effectiveness of different recruitment methods, an alternative study design could be implemented. By only using one method of recruitment per area, for example, differences in uptake and demographics of those engaging with each method would be clearer.

5.6 Chapter summary

This chapter has presented the results of the secondary quantitative analysis of ECLS trial data that explored the demographic and psychosocial differences between the people recruited via a letter from their GP and those recruited via the community.

The findings of this analysis are indicative that community recruitment to screening trials attract higher uptake from more affluent groups, when compared to those who receive an invitation to screening via GP-endorsed letters, such as those used in current national cancer screening programmes in the UK. It is hypothesised that community-based recruitment methods and other opportunistic screening attract those from more affluent communities. As a result, this method of recruitment may further widen cancer screening inequality.

Chapter 6 : What barriers and beliefs lead to non-attendance in the ECLS trial?

6.1 Introduction

Non-attendance in healthcare is common and can be problematic in a number of ways. Repeated missed appointments in primary care settings are associated with poorer health outcomes (McQueenie, Ellis, McConnachie, Wilson & Williamson, 2019). Further, non-attendance at screening appointments has been found to be socially graded, with the likelihood of missing an appointment increasing with level of deprivation (Ellis, McQueenie, McConnachie, Wilson & Williamson, 2017). There is increased risk that more deprived groups miss preventative activities, such as screening, and as a result, existing health inequalities are exacerbated by non-attendance.

There are also significant financial implications of non-attendance at health care services. It is estimated that each missed hospital outpatient appointment costs the NHS in Scotland £120 (Williamson, Ellis, Wilson, McQueenie & McConnachie, 2017). In order to ensure the viability of a potential lung cancer screening programme in the UK, we must look to minimise non-attendance by developing appropriate evidence-based interventions.
As discussed in Chapters 3 and 4, beliefs about lung cancer vary by SES. These beliefs could provide insight into why people might not to attend their screening appointment. While the previous chapters focused on motivational factors associated with cancer screening attendance, it is also important to explore the volitional factors. Key to understanding non-attendance in deprived groups is exploring how people make decisions and why they might change their minds.

6.1.1 Decision-making about cancer screening

The way in which people make decisions may influence whether or not they attend an appointment for cancer screening. Our beliefs about an illness can determine how we choose to behave in relation to our health. Previous literature on cancer screening decision-making has highlighted both cognitive and practical barriers as reasons for non-attendance.

6.1.1.1 Inclined abstainers

In order to engage in a behaviour such as cancer screening, you must have the motivation to do so in the first instance. McBroom and Reid (1992) set out four distinct groups that describe the patterns of motivation and behaviour (Table 6-1). When individuals make an appointment for cancer screening, it suggests they are motivated and intend to go to the screening appointment. However, this intention to attend does not always translate into action (i.e. attending the appointment) and 'did not attend' (DNA) status and appointment cancellations are frequent outcomes at screening clinics (Sheeran, 2002; Webb & Sheeran, 2006). The term inclined abstainer is used to describe people with positive intentions who fail to act (McBroom & Reid, 1992; Orbell & Sheeran, 1998).

Table 6-1: Patterns of Intention - Behaviour (adapted from Orbell & Sheeran, 1998)

Screening behaviour	**Inclined to be screened**	**Disinclined to be screened**
Screened	Inclined Actor	Disinclined Actor
Not Screened	Inclined Abstainer	Disinclined Abstainer

Inclined abstainers are a particularly interesting group and, because of their already positive intentions, are important in reaching optimal uptake of cancer screening. A meta-analysis of meta-analyses concluded that intention to carry out a behaviour accounts for 28% of variance in future behaviour (Sheeran, 2002). Despite this, there are inconsistencies in patterns of motivation that result in positive intentions not translating into action (McBroom & Reid, 1992). Inclined abstainers differ from other patterns of intention because barriers to carry out a given behaviour are volitional, unlike disinclined abstainers, who are more likely to have motivational barriers (Orbell & Sheeran, 1998). This knowledge allows for interventions to be tailored to both of these groups; interventions based upon volitional processes concerning the translation of intention into action may be effective for inclined abstainers (Orbell & Sheeran, 1998).

6.1.1.2 Cognitive and practical barriers to screening

In order to bridge the intention-behaviour gap, we must first understand the individual determinants of cancer screening participation, including the cognitive and practical barriers experienced by those invited to cancer screening. As shown in section 2.2, there are a number of cognitive (e.g. fear and low perceived risk) and practical barriers (e.g. proximity to screening appointment and competing priorities).

6.1.1.3 Theoretical models for cancer screening

Currently, there is no one model that can explain the variation in cancer screening, with researchers drawing from a range of different models e.g. HBM; TRA /TPB; PMT; PAPM; and TTM (Kobrin et al., 2015) (see section 2.4). It is important to consider the theoretical underpinnings of behaviour change, allowing us to gain insight into the motivational and volitional mechanisms that play a role in participation in cancer screening. A number of behavioural models help to explain the process in which inclined abstainers make decisions about cancer screening.

The HBM (Rosenstock et al, 1994) is among the most widely used model to explain screening behaviour (e.g. Yarbrough & Braden., 2001; Orbell et al., 1996; Savage and Clarke, 2003). HBM was originally used to understand the uptake of tuberculosis (TB) screening in the early fifties. The theory evolved over time to include a number of key components: perceived susceptibility; perceived severity; perceived benefits; perceived barriers; cues to action, sociodemographic factors; and self-efficacy. The components of the model lend itself well to explorations of other types of screening behaviour, such as lung cancer screening. However, limitations of the model mean that the efficacy of the model in explaining behaviour has been questioned, with previous studies concluding that its predictive capacity is limited when compared to that of other social cognition models (Taylor et al., 2007). Overall, the model considers people to be ‘rational actors’ and does not account for individuals’ emotional responses to carrying out a health behaviour, such as cancer screening. Previous literature has indicated that emotional representations of cancer play a significant role in the uptake of cancer screening (Sarma et al., 2019; Kotzur et al., 2019; Wardle et al., 2015)

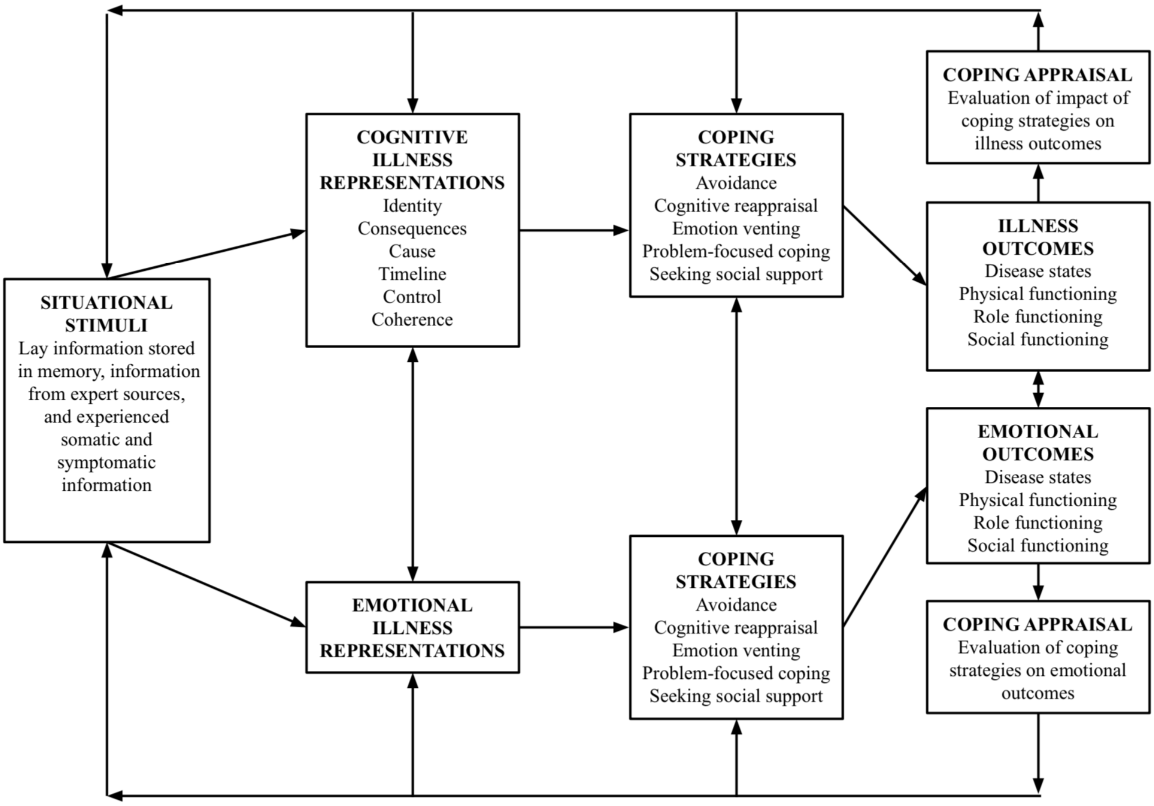
Models such as the HBM, despite being widely used, do not account for either intention or emotional representations of cancer screening. However, there are models that do consider both of these aspects, and therefore might be useful to explore when considering non-attenders. The Common-Sense Model of Self-Regulation (CSM) (Leventhal, 2003) and the Health Action Process Approach (HAPA) (Schwarzer, 1992; Schwarzer, 2008) have been used to understand individuals’ response to illness. When applied to cancer screening, these models both include emotional processes and coping response that can determine whether a person will participate in cancer screening. The CSM and HAPA have rarely been used to explore cancer screening participation (Kobrin et al., 2015). Although their use in cancer screening is novel, they could provide us with insight into non-attendance that other models, such as the HBM, might be unable to provide.

6.1.1.4 Common-Sense Model of Self-Regulation

The CSM states that individuals develop representations of illness from information that is easily accessible to them. An example of this ‘pool’ of information is social communication with others (e.g. friends, family or health professionals) or first-hand experience of illness. A change in somatic activity (a new symptom or the introduction of a stimulus e.g. an invitation to screening) begins a self-regulation process where individuals integrate their existing perceptions about an illness with their current experience of the illness. The perception of the illness directly influences coping strategies. Leventhal’s model posits that there are two parallel processing pathways – one involves the development of illness representations, the other involves the creation of emotional representations in relation to a health threat. The two pathways are proposed to interact, as the threat develops, via feedback loops and appraisal of coping strategies.

The CSM can provide us with an understanding of the role of emotional representations associated with cancer screening and helps to elaborate our existing knowledge of lung cancer illness representations which is important when exploring new forms of cancer screening.

Figure 6-1: Common-Sense Model of Self-Regulation (Leventhal, 2003)

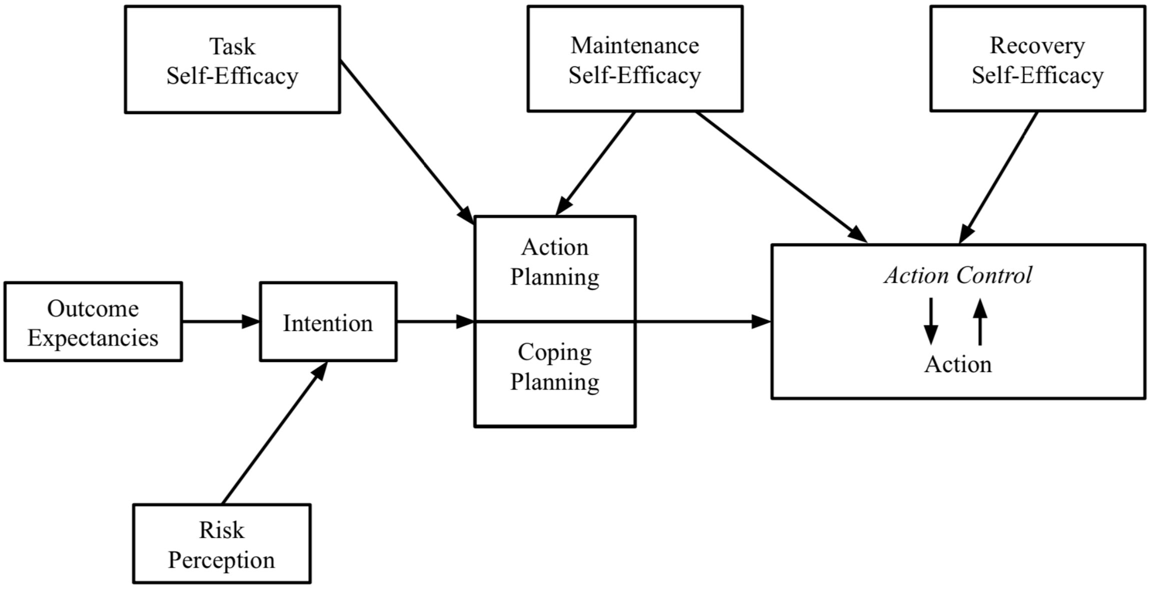


6.1.1.5 Health Action Process Approach

The HAPA model (Schwarzer, 1992; Schwarzer, 2008) theorises that the process of participating in health behaviours occurs in two stages – motivational phase and volitional phase. The motivational phase includes the forming of an intention. This intention is formed by individuals’ awareness of risk, outcome expectancies and task self-efficacy. The volitional phase is a stage in which individuals plan to act and carry out the action. This phase of the model comprises of action planning, coping planning, coping self-efficacy and recovery self-efficacy.

The HAPA model is particularly helpful to understanding the intention-behaviour gap, which is key to understanding non-attendance. The inclusion of both motivational and volitional in phases in the HAPA model will help create a clearer picture of the mechanisms that might cause the intention-behaviour gap to occur in those who were initially motivated to attend their screening appointment but ultimately did not.

Figure 6-2: Health Action Process Approach (Schwarzer, 1992; Schwarzer, 2008)



6.1.1.6 Using two models to explain cancer screening participation

There is significant overlap between behavioural models, including the CSM and HAPA model. The aim of this study was to explore the beliefs and perceptions about lung cancer and lung screening among people who initially expressed an interest in screening, were appointed to be screened, but who later cancelled or did not attend their appointment, and in some cases did not attend a reappointment. This study used the CSM and HAPA models to provide a comprehensive conceptual understanding of the motivational and volitional factors involved in being invited to lung cancer screening and attempt to identify any gaps that do not fit either model.

6.2 Aim and research question

The aim of this study was to explore the beliefs and perceptions about lung cancer and lung screening among people who initially expressed an interest in screening but who later declined to participate.

To meet this objective this chapter aims to answer the following research questions:

I. What are the perceived barriers to participating in a lung cancer screening trial?
II. What beliefs do non-attenders hold about lung cancer and lung cancer screening?
III. Do the CSM and HAPA model help to explain the processes behind those who intend to participate in screening but do not attend?

6.3 Methodology

6.3.1 Context

This study, like the secondary analyses described in Chapters 4 and 5, was a sub-study of the ECLS trial. A detailed description of the ECLS trial design and recruitment methods can be found in sections 4.3 and 5.3.

The trial looked to develop a lung cancer screening test to detect lung cancer at an early stage, in order to decrease mortality rates (Sullivan et al., 2020). The test (EarlyCDT-Lung Test) involved participants at high risk for lung cancer providing a blood sample to be screened for higher levels of autoantibodies, which can be indicative of an immune response to antigens produced by solid-tumour cells. Those found to have a positive blood test were invited for a chest x-ray and follow-up computed tomography (CT) scan if necessary. Thus, like the existing UK cancer screening programmes of breast, bowel and cervical, lung screening aims to detect cancers at an earlier, more treatable stage among a supposedly asymptomatic population.

6.3.2 Design and sample of present study

All participants (n = 123) who were eligible to take part in the ECLS trial, initially accepted an appointment but subsequently did not attend or cancelled their screening appointment, were invited to participate in the non-attender interviews. Participants were contacted by post after they have been identified as a suitable candidate using the ECLS Trial patient management system. Participants were identified within the patient management system by searching for key phrases, such as ‘did not attend’, ‘DNA’ and ‘cancelled’. Of those contacted, n = 15 indicated that they would be interested in participating and a total of n = 8 agreed to participate.

6.3.3 Procedure

Interviews were conducted over the telephone (n = 7), with the exception of one which was conducted face-to-face - this was most convenient to the participant. Telephone interviews were used in order to maximise participation. The use of telephone interviews was thought to be an appropriate method in which to conduct interviews with this particular sample. As previous non-attenders, the participants were deemed to be a hard-to-recruit group and it was a concern that uptake for the interviews would be low. As a result, both face-to-face and telephone interviews were offered to all participants. There are methodological implications for utilising telephone interviews. The lack of visual cues during telephone interviews is one potential drawback. This might lead to a loss of non-verbal data and rapport with the participant as well as loss of contextual data. This, in turn, might lead to reduced richness of data (Novick, 2008). However, there are also clear benefits of conducting qualitative interviews over the telephone. For example, the convenience of telephone interviews is particularly beneficial when conducting research with working age adults who might have competing priorities. In addition, participants are more likely to feel relaxed in their own environment, experience fewer social pressures and it provides more anonymity to answer questions honestly (Novick, 2008). In this study, one participant chose to take part in a face-to-face interview. This interview was found to be longer in duration but did not produce richer data than that of the telephone interviews.

Participants received the Participant Information Leaflet (Appendix 5) and Informed Consent Form (Appendix 6) with their letter of invitation by post before the interview was conducted. In the case of telephone interviews, participants were invited to send their reply and completed consent form in a prepaid envelope. Prior to the telephone interview, participants were asked to confirm their verbal consent. Interviews lasted between 30 minutes and 1 hour. Interviews were conducted based on a topic guide (Appendix 7) developed from the existing screening literature with a particular focus on barriers to lung cancer screening. To avoid post-hoc rationalisations of their screening behaviour, participants were asked to discuss their general views on screening first before moving on to their personal experience.

The interview began with the opening question ‘what do you think about cancer screening?’, followed by ‘how do you think people make a decision about whether they will take part in screening or not?’. Participants were then asked about their own screening behaviour (‘have you ever participated in any other type of cancer screening?’) and their family and close friends’ participation in cancer screening (‘do you know anyone else who has taken part in any cancer screening?’). Elicitation of cancer and lung cancer beliefs followed (‘what comes to mind when you think about cancer?’; ‘what comes to mind when you think about lung cancer?’). Subsequent to this, perceptions of lung cancer screening (‘what comes to mind when you think about lung cancer screening?’) and their experience of being invited to participate in the lung screening trial (‘do you remember receiving an invitation for the screening test?’) were explored. Finally, participants were asked about their perceived risk of lung cancer (‘how likely do you think it is that you will get lung cancer?’).

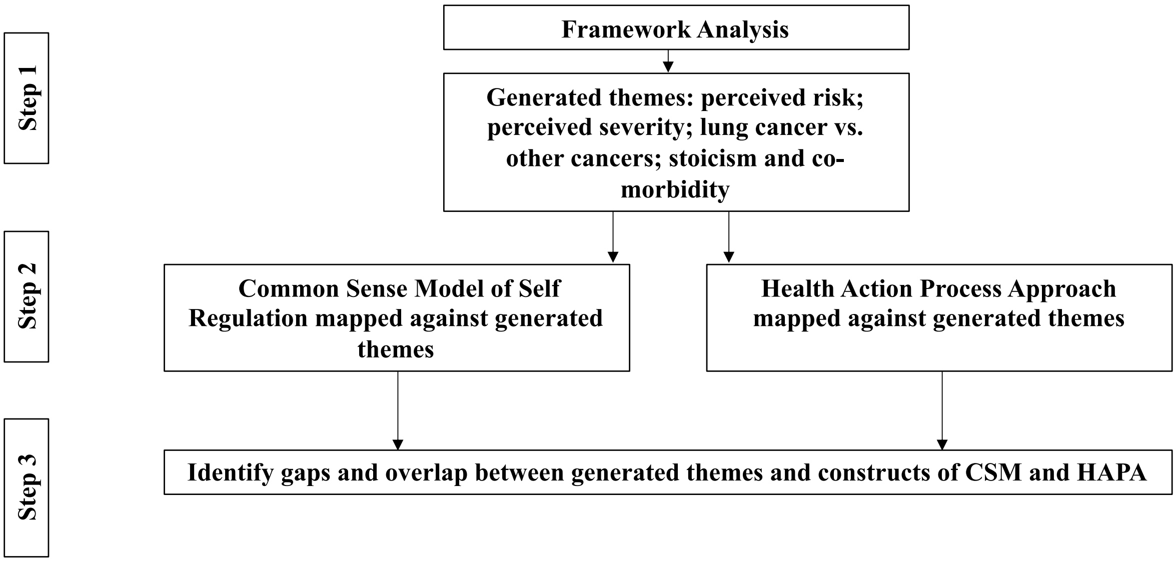
Interviews were audio-recorded with participants’ permission. Those who participated in the interviews were offered a £20 voucher as a token of appreciation for their participation.

6.3.4 Data analysis

The interviews were transcribed verbatim and checked for accuracy. The data were analysed using the `framework approach´, a type of thematic analysis (Ritchie & Spencer, 1994). Thematic analysis is a method for identifying, analysing, and reporting recurring patterns within data, which can then be reported in a detailed way (Braun & Clark, 2006). A two-step analytic method was used. The data were initially analysed with the aim to identify recurring themes, and then subsequently analysed using a theoretical framework. This ‘bottom up’ approach allowed for greater initial exploration of the data, free from the constrains of a theoretical model. This methodology was considered to be appropriate in order to truly recognise themes that the models might not account for.

First, the interview transcripts were read multiple times in order to become familiar with the data. The data were coded and then placed into a framework where the data were collated and organised. The initial thematic analysis of data developed five common themes: perceived risk; perceived severity; lung cancer vs. other cancers; stoicism and co-morbidity. The data were then coded and analysed using the CSM (Leventhal, 2003) and the HAPA (Schwarzer, 1992; Schwarzer, 2008). To do so, the conceptual constructs of each of the theories were placed within separate frameworks and relevant data were extracted and collated within each of the frameworks (Figure. 6-3).

Figure 6-3: Analysis Process



The use of two theoretical models was appropriate for this study as it provided a comprehensive conceptual understanding of the motivational and volitional factors involved in being invited to lung cancer screening. Utilising more than one theory allows for complex data to be explored from different aspects and creates a holistic picture of the issue being discussed. The initial thematic analysis was considered to be appropriate in order to identify and understand the gaps and overlap in that data with the two theoretical models.

In addition to the theoretical analysis, participants reported barriers for attending their lung screening trial appointment and demographic characteristics of the participants (including age, sex and smoking status) were also described.

6.3.5 Ethical considerations and approvals

Participants were recruited from the ECLS trial, which was carried out in conjunction with the National Health Service. As a result, ethical permission was sought from NHS Scotland East of Scotland Research Ethics Service. Ethical Approval was granted by the committee in December 2015 (Appendix 4). A complete study protocol submitted as part of the ethics application can be found in Appendix 8.

There were a number of ethical considerations discussed before commencing the study. Participants were invited to participate in the study by writing to them up to a year after they had originally engaged with the ECLS Trial. It was possible that individual circumstances may have changed between not attending their appointment for the ECLS Trial and being invited to participate in the sub-study. In some circumstances it is possible that potential participants may have passed away or become unwell. This potential issue was mitigated by using the Health Informatics service at the University of Dundee to check if participants were still alive using CHI numbers through NHS health records. In addition, invitation letters sent to participants included the sentence: ‘We apologise if this letter arrives at a particularly difficult time for you.’

The topic of the study - lung cancer - and the discussion of it can often be a sensitive area. It was recognised that the discussion of cancer might cause distress to some participants. Although no participants were openly distressed throughout the course of the interviews, a few disclosed that cancer was not a comfortable area of discussion for them. Others felt that taking part in an interview gave them a chance to talk about something that was significant to them and provided an opportunity to talk about their personal experiences. Regardless of whether participants believed discussing cancer had a positive or negative impact, the researcher was able to react in an empathetic manner. If required, participants were signposted to relevant professional organisations and charities that could provide advice and support.

Those who participated in the interviews were offered a £20 voucher, however, if the participant wished to withdraw from the interview at any point during the interview, the participant would still receive the voucher.

6.4 Results

6.4.1 Demographics

A total of eight participants took part in the interviews (n = 5 female and n = 3 male; mean age = 57.5). Among the respondents, four considered themselves past smokers, three current smokers and one non-smoker. Three participants reported living with chronic health conditions, and three had a family history of lung cancer. Participant characteristics are described in Table 6-3.

6.4.2 Reasons for non-attendance

Participants discussed both practical and psychological reasons for not attending their lung cancer screening appointment. Often, the practical barrier faced was initially described as the reason for non-attendance but underlying negative perceptions of lung cancer were difficult to overcome. Reasons for non-attendance or reappointing are presented in Table 6-3.

6.4.3 Related themes and CSM & HAPA constructs

The original five themes identified are presented in Table 6-4. This table shows the recurring themes with illustrative quotes. In addition to the original themes, I mapped my themes to the corresponding CSM & HAPA constructs. There was significant overlap between the themes developed from the data and the theoretical constructs of the CSM and HAPA models. This section will discuss the way in which the themes and constructs overlapped.

Table 6-2: Participant Characteristics & Reasons for Non-attendance

Participant no.	**Sex**	**Age**	**Smoking Status**	**Employment**	**Location**	**SIMD**	**Family History of Lung Cancer**	**Reason for not attending ECLS Trial appointment**	**Reason for not rescheduling ECLS Trial appointment**
1	F	51	Past Smoker	Nurse	Glasgow	3	No	Ill-health (minor ailment)	Had no symptoms; scared
2	F	55	Past Smoker	Nurse	Glasgow	2	No	Competing priorities (work)	No family history
3	M	56	Current Smoker	Unemployed	Glasgow	1	No	Ill-health (co-morbidity)	Did not want to know; fatalism
4	M	52	Current Smoker	Support Worker	Glasgow	1	Yes	Ill-health (co-morbidity)	Did not want to waste doctor’s time
5	F	60	Past Smoker	Accountant	Lanarkshire	3	No	Could not get appointment at convenient time	Attempted to make appointment but found it too difficult
6	M	64	Current Smoker	Labourer	Glasgow	1	No	Competing priorities (work)	Could not decide if they wanted to participate; did not want to worry
7	F	55	Non-smoker	Carer	Glasgow	1	Yes	Could not remember being invited	Could not remember being invited
8	F	67	Past Smoker	Retired	Lanarkshire	1	Yes	Ill-health (co-morbidity)	Attempted to remake appointment but could not participate because of ill-health

Table 6-3: Quotes Illustrating Developed Themes and Related CSM & HAPA Constructs

Identified theme	Quote	CSM Construct	HAPA Construct
Perceived Risk	*But I think every one of us is a toss of a coin whether we're going to get, and I don't care what kind of... money can't... see money? You can be the richest guy in the world, you could be Bill Gates and get cancer and you're snookered. (Participant 3)*	Cause	Risk Perception
Perceived Severity	*Well, to me, I always thought lung cancer was really a killer. I didn't think there was anything could ever be done about that. I thought that was the one that would automatically kill you (Participant 7)*	Consequences	Outcome Expectancy
Lung Cancer Vs. Other Cancers	*If I had a - it's a bit of a... - if I had a choice between lung cancer and being diagnosed with breast cancer, I'd rather be diagnosed with breast cancer, I think. (Participant 1)*	Identity	X
Stoicism	*I think it's their mind-set. This sense of either not even wanting to face up to illness, or, you know, scared of it. Pretending it didn't exist. Particularly West of Scotland. (Participant 2)*	Coping Strategies & Appraisal	Coping Planning
Co-morbidity	*[…] it turns out I've got a couple of gastric ulcers, although I didn't know that at the time. So, and it's a kind of, the, kind of, that, the sort of symptoms of that have sort of dragged on over that - you know, from then until pretty much now. So, you know, my lung health, as it were, really, I never really thought about it at all. I was so busy with the gastric systems that I haven't really - I haven't had any chest symptoms, and I never really gave it a second thought. (Participant 1)*	X	X

6.4.4 Identified themes mapped against the constructs of CSM and HAPA

The following section describes the themes generated, and the overlap between the themes and the constructs of the CSM and HAPA.

6.4.4.1 Perceived risk / Cause (CSM)/ Risk perception (HAPA)

Participants discussed their own perceived risk of lung cancer, other peoples' risk of lung cancer and potential risk factors of lung cancer.

A number of risk factors were identified by participants. All participants identified smoking as a risk factor of lung cancer. However, the importance of smoking was often minimised. The impact was minimised in a number of ways, including overemphasising the risk of workplace environmental hazards and genetic causes of cancer. This is illustrated by participant 7, who considered that exposure to asbestos and an industrial work environment are the primary cause of lung cancer:

> *[...] was it not years ago, I would think, it's the type of job more so that caused a lot of problems, wasn't it, with people working with asbestos and in the docks and the type of work they done that caused a lot of their lung problems and things. (Participant 7, Female)*

A number of participants believed genes played a key role in the development of lung cancer.

> *I tend to look sort of at family history and things like that, and I've never - I suppose although I was a smoker - I've never really thought that that's what was going to get me. (Participant 1, Female)*

The concept of lung cancer being hereditary was often tied up with the 'predetermined' nature of cancer. This was related to the concept that everyone is born with cancer, but something can 'trigger' it. 'Triggers' were considered to be both risk factor-related and luck.

> *You know, on one hand, I think… You know, they say that everybody's born with a cancer in them. [...] And it's just something that triggers it. So, basically, I just hope that mine doesn't get triggered. That's all. (Participant 6, Male)*

When asked how they perceived their own risk of developing lung cancer, most participants underestimated their own risk. This was prevalent in some participants categorised as ‘current smokers’, who, when comparing themselves to non-smokers, believed they were no more at risk of lung cancer. The existence of lung cancer in non-smokers was used as evidence to justify minimising the risk smoking posed to their health.

> *Well, you know, you hear about - I mean, I'm a heavy smoker - and you hear about people with lung cancer that never smoked a cigarette in their day, you know, which is quite, you know, I don't understand that one (Participant 3, Male).*

Participants would also attach considerable weight to their own family history, in particular, a lack of lung cancer in their immediate family made them feel less vulnerable to lung cancer. Often, participants would identify diseases that were common within their family and consider that they are more likely to develop that.

> *Because all the females in my family older than me, you know, parent, mother, aunt, you know, that kind of thing, all of them are smokers, or have been smokers, and lung cancer has never - none of them have developed lung cancer. They've developed other things, plenty of other things, but never the lung cancer, and I think I probably thought 'I'll probably get away with lung cancer. I'll probably get a different type of cancer, but I'll probably get away with the lung one.' (Participant 1, Female)*

Participants had clear views on who they considered to be a candidate for lung cancer. Four participants considered men to be the most at risk of lung cancer. Three participants did not consider sex to be a risk factor.

> *You know, any time you hear of guys having cancer, it’s usually lung cancer…It seems to be the norm for males. […] You know, you can't... I just – I just know that a lot, lots and lots of females in the past, that I’ve known or heard about, it’s always been breast cancer. And I’ve never heard of a guy having it. So… But I’ve heard of a lot guys having lung cancer. […] And not a great deal of females. (Participant 6, Male)*

> *And it wouldn't really have to matter if it was male or female, it would be an older… to me, it's an older person who's smoked all their days that would have it, and that's one of the reasons I think my mum doesn't like to go to the doctor's, because she probably thinks she's got it. (Participant 7, Female)*

One participant could not identify who they believed to be a candidate of lung cancer. Participant five had a strong belief that all cancers were the same, and that luck played a significant role in the development of lung cancer. This might contribute to their opinion that there is not a ‘profile’ for someone at risk of lung cancer.

> *I don't think they look like anything.*
>
> ***They're just like anybody**?*
>
> *If you lined up twenty cancer patients, they would all look absolutely different. You know, you could pick anybody, you know, pretty much any age, I would imagine. (Participant 5, Female)*

Overall, they perceived someone at risk of lung cancer to be severely unwell. The descriptions given were usually highly visual.

> *I tend to see thin, wrinkled, grey, men and women. They all tend to be around about, but not exclusively, around about ten years older than I am now, ten to fifteen years older than I am now, so you're probably talking... I tend to see someone in their 60s as being thin, they probably smoke more than they eat, and they all, and you can see they almost look you know, like, a sort of... as if their face has been, you know, it's very leathery and wrinkly and often that's the kind of person. Yeah. People who, I tend to, I suppose, the people I visualise are people who are heavy smokers. (Participant 1, Female).*
>
> *I should imagine someone with having to get oxygen and stuff, you know, the tents you get in the house and that, and… (Participant 4, Male)*

This view of someone at risk of lung cancer was influenced by common lay beliefs and the generalised knowledge that all lung cancer is severe, with significant physical consequences. These participants believed that the symptoms of lung cancer are so significant that oxygen is required to assist breathing. It is unclear whether any less 'severe' breathlessness or wheezing is seen as a symptom.

6.4.4.2 Perceived Severity / Consequences (CSM) / Outcome expectancies (HAPA)

The participants discussed how they felt about lung cancer. All participants perceived lung cancer to be severe and survivability to be low. This belief made the interviewees fearful of lung cancer.

> *Because it can very quickly, you know, be serious, or more serious than others. So, yeah, I do think that people, if they were worrying about it at all, that would probably be the number one. But I do think it's a bit demonised. Yeah, so I think that's the one that – if people are told that, you know, that they've got it, that they're immediately fearful and they think that they're not going to survive. (Participant 5, Female)*

This fear of lung cancer made participants view lung cancer with a level of fatalism. The fatalism that the participants experience exhibits itself as both the inevitability of death when lung cancer is present, a sense of hopelessness and lack of control over the development of cancer.

The inevitability of death when lung cancer is present was a frequent view of participants – they considered there to be fewer treatment options and less chance of recovery.

> *If you did have a diagnosis, initially, I'd imagine 99% of the population think 'This means I'm going to die' (Participant 1, Female)*
>
> *Well, to me, I always thought lung cancer was really a killer. I didn't think there was anything could ever be done about that. I thought that was the one that would automatically kill you (Participant 7, Female)*

The inevitability of death appears to lead to a sense of hopelessness and belief that there is nothing that can be done to stop cancer progressing. As discussed previously, many participants believed in the idea that cancer is predetermined which adds to the sense of hopelessness they experience.

> *Well, I've always had – I've always just had the opinion, you're damned if you do, and you're damned if you don't, so what's the point? (Participant 6, Male)*
>
> *I think we're all stamped when we're born, when we're going to go. (Participant 3, Male)*

There is a passive belief that we should only concern ourselves with what is in our control – this leads to the 'what's the point worrying' attitude. This attitude might be a coping mechanism for feeling a lack of control. This coping strategy also extends to the avoidance of talking and reading about lung cancer.

> *I tend, I try not to worry. What's the point? It's not going to go anywhere, even if you worry about it. You know the old expression, people will worry themselves sick. (Participant 6, Male)*
>
> *You know, certain articles I read, and I buy the papers all the time, but certain things I just think 'No, I'm not going to look at that'. I think it'd be dwelling on it too much, and at my age you don't want to start dwelling on things too much. (Participant 8, Female)*

Some participants did recognise advancements in medicine meant that some lung cancers can be treated, however the sense of hopelessness persevered. Treatment was not seen as the end, but part of a life altering event. This is clear from discussion from participant 3, who considered that even if treatment was successful cancer would continue to reoccur until they died.

> *Once you've got - whether these drugs... I mean, I've never heard of anybody that's got cancer and then totally lived a valued life after it (Participant 3, Male)*

6.4.4.3 Lung cancer vs. other cancers / Identity (CSM)

The criteria to join the ECLS trial required participants to be asymptomatic, and therefore participants did not discuss changes in physical functions or any other visible signs and symptoms that might be indicative of lung cancer. Participants were stimulated to develop cognitive representations by being invited to take part in the lung cancer screening trial. Often participants discussed lung cancer in an abstract manner. Lung cancer was frequently compared to other cancers. This comparison of types of cancer appeared to assist participants to understand, label and define lung cancer. Two clear views of cancer emerged – all cancers are the same or some are more severe than others.

Those who did not distinguish between types of cancer had strong views and were more likely to be fatalistic about cancer. It is seen as one disease, one type as aggressive as another.

> *I just think cancer is cancer. I just think it's the dirtiest disease on the planet, and I don't care what part of cancer it is (Participant 3, Male)*
>
> *Well, I don't know because, to me, the word 'cancer' just is the whole thing itself. You know, it's just the whole thing is just cancer. I don't kind of go 'Oh, it's lung cancer.' 'Oh, it's bowel cancer.' 'Oh, it's thingmy cancer.' (Participant 7, Female)*

However, this view was often contradictory of their view of survivability of lung cancer, where they considered some cancers more treatable than others. This is illustrated by Participant 4, who believed all cancers are the same but, some are more treatable.

> *And I think, I know there is cancers that are more treatable than others. As I say, I know a bit about cancer, and I know there is ones that's – you get ones that's just not curable, if you know what I mean (Participant 4, Male)*

This contradiction in some interviewees might connote a feeling of uncertainty about cancer in general and may display itself as an ambivalent attitude towards cancer or their health in general.

Participants that viewed cancers differently often discussed them as if on a scale of severity, with lung cancer being seen as the most severe and breast cancer as the least.

> *I think people are more aware now that people can maybe be diagnosed with the likes of breast cancer and they know people who've survived that diagnosis. Lung cancer, I don't know that most people know someone who's survived lung cancer. (Participant 1, Female)*

One participant went as far as to describe what type of cancer they would prefer to have:

> *If I had a - it's a bit of a... - if I had a choice between lung cancer and being diagnosed with breast cancer, I'd rather be diagnosed with breast cancer, I think (Participant 1, Female)*

This hypothetical preference for one type of cancer over another displays that the participants had a different attitude towards different types of cancer. It might also be indicative of having no close experience of breast or lung cancer but gaining knowledge of cancer from an easily accessible general pool of knowledge of cancer from social interactions and popular media.

6.4.4.4 Stoicism / Coping strategies (CSM) / Coping planning (HAPA)

Stoicism was often discussed with regard to lung cancer, and the screening of lung cancer. This was used as an avoidant coping response. The possibility of enduring symptoms without seeking help and without complaint was seen as a male characteristic, particularly seen in those from the West of Scotland.

> *I think it's their mind-set. This sense of either not even wanting to face up to illness, or, you know, scared of it. Pretending it didn't exist. Particularly West of Scotland. (Participant 2, Female)*
>
> *Well, I don't know if it's just him personally, but I think men don't… I think they're… how do you say it? They're a lot different to women. Women, I think, have got to do these things. Whereas men, they just get up, get ready, go to work and go 'Ach, don't bother me'. ''Don't - I can't be bothered' (Participant 7, Female)*

Stoic attitudes often manifest in the feeling of not wanting to make a fuss or bother the doctor with their worry.

> *You tend to not want to waste a doctor's time, you know what I mean? (Participant 4, Male)*

This attitude is often seen as a deliberate choice – choosing not to worry about cancer and just getting on with life. The stoic attitude might also be seen as a mechanism to cope with what they feel they have no control over.

> *I mean, you know, whatever happens, then it's going to happen anyway. And then what happens when they find out something and they've worried all that time and for nothing. [...] So, I tend not to do it anymore. Just get on with it. (Participant 6, Male)*

6.4.4.5 Co-morbidity

A number of participants had ongoing health conditions that were discussed during the interviews in relation to recognising symptoms of lung cancer and also competing health priorities when it comes to attending lung cancer screening. Participants tended to concentrate on any ongoing health conditions they had rather than worry about the possibility of having lung cancer.

> *[...] it turns out I've got a couple of gastric ulcers, although I didn't know that at the time. So, and it's a kind of, the, kind of, that, the sort of symptoms of that have sort of dragged on over that - you know, from then until pretty much now. So, you know, my lung health, as it were, really, I never really thought about it at all. I was so busy with the gastric systems that I haven't really - I haven't had any chest symptoms, and I never really gave it a second thought. (Participant 1, Female)*

6.4.5 CSM & HAPA constructs not identified in initial identification of themes

6.4.5.1 CSM constructs

6.4.5.1.1 Timeline

The 'timeline' of lung cancer was discussed by few participants. This might be the result of having little direct experience of lung cancer. When discussed, it was described as fast, quick and painful or as slow and painful.

> *So, I just see that there's less options there, and you're more likely to die from it, and it'd be quite a quick cancer. (Participant 2, Female)*

> *But I don't know [...] how long it would, your lungs take to deteriorate, do you know what I mean? [...] You know whether it, maybe you do that every three fours or four years, just depends how long your lungs take, you know, what timescale it would be. (Participant 4, Male)*

Other participants did not indicate what they perceived the timeline of lung cancer to be, but it was unclear whether this was because they did not know or just that it was not considered for discussion.

6.4.5.1.2 Cure/control

As previously discussed, a number of participants did not believe that they had any control over the development of lung cancer. This is tied with the idea that cancer is predetermined, and the development of cancer cannot be impacted by changing risk factors (i.e. stopping smoking) or by attending cancer screening. There was a passive belief that we should only concern ourselves with what is in our control – this leads to the ‘what’s the point worrying’ attitude. This attitude might be a coping mechanism for feeling a lack of control over their health. This coping strategy also extends to the avoidance of talking and reading about lung cancer.

> *It’s definitely, it’s a word I don’t like to discuss, it’s a subject that I’m not happy discussing, because it strikes fear into me. So it’s just... To me, it’s one of those taboo things. […]] It strikes fear into people. Human beings. (Participant 6, Male)*

6.4.5.1.3 Coherence

Overall, participants’ knowledge of lung cancer varied greatly. Some participants could describe lung cancer, its risk factors and quantify their own risk coherently. Those with some knowledge of lung cancer, its causes and treatments were more likely to recognise that cancer is not one disease, but cancer comes in many distinguishable forms. However, some had little or no knowledge of lung cancer. In general, these participants considered cancer to be one indistinguishable disease.

Lack of knowledge was sometimes attributed to lung cancer information not being as widely available to the general public, compared to other types of cancer.

> *And I think, again, that’s back to information. You get bombarded with information about breast cancer and these types, but you… Well, most people I know, know very little about lung cancer. You know, it doesn’t seem to get the same high profile that other ones do. (Participant 5, Female)*

With regard to the lung cancer screening trial they were invited to participate in, no participants were able to describe the lung cancer screening test they were invited to despite receiving all the trial information on multiple occasions. Some had some ideas of what might be involved in lung cancer screening in general, but overall knowledge was poor.

> *I think it would be - I get a lung function test every year due to another condition, and I think it would be the lung function test. Also probably - I don't know if it'd be x-ray or a type of scanning, I don't know if that would be maybe certainly part of it, or if it would be based on history and... I imagine it would be history and a lung function test. (Participant 2, Female)*

The poor knowledge of the lung cancer screening test might be attributed to the trial information they received. Only one participant understood that they had been invited to take part in a RCT and could comprehend what randomisation meant. The trial targeted areas of high deprivation, and participants had a varied education level as a result, the information they received might not have been accessible to all.

6.4.5.1.4 Emotional representations

The participants discussed how they felt about lung cancer. All participants perceived lung cancer to be severe and survivability to be low. This belief made the interviewees fearful of lung cancer.

> *I'd be scared, I think, of the lung cancer more than anything. (Participant 8, Female).*

Fear was perceived to be either a motivator or a barrier to lung cancer screening.

> *There are some people that fear pushes them to investigate, and some people their fear is they just don't want, they'd rather not know. (Participant 1, Female)*
>
> *Well, I think people would act… I think if you had an immediate fear, you maybe… (Participant 4, Male)*
>
> *Other people shy away because they're scared in case it'll happen to them. (Participant 8, Female)*

6.4.5.1.5 Coping (not including stoicism)

Leventhal's model proposes that people put coping strategies in place in order to protect themselves when their health is under threat. Coping strategies guide actions in response to a threat for both cognitive and emotional responses.

6.4.5.1.6 Active coping

Participants did not often use problem-focused (or active) coping in response to being invited to participate in the lung cancer screening trial. All participants indicated that they participate in all other cancer screening programmes and their participation would be automatic. However, this did not seem to be the case with lung cancer screening. Although they stated that their participation would be automatic, their behaviour (i.e. not attending) indicates that they did not implement problem focussed coping in this situation. This was common amongst most participants. For example, Participant 2 believes strongly that they are an active coper:

> *Generally, I would probably tend to just act immediately and do something about it, because I'm a nurse as well, a mental health nurse, so, I tend to be that way, that's how my brain functions. I'll tend to - I'm not somebody who'll mull over things for a long time. I have an idea about the process of something and I'll just get on board with it, get it over and done with, really. (Participant 2, Female)*

Participant 2 believes that most other people do not implement active coping in response to health issues. The participant distances themselves from this behaviour. However, it is clear that having not made an attempt to reappoint they are not problem focused but avoidant. This is a result of their cognitive representation of their risk of lung cancer.

> *I think most people will maybe mull it over and then forget about it. [...] Some people, I've got people in my family who are of the mind-set that, 'Oh, I'd rather not know.' [...] And that's how some people think. (Participant 2, Female)*
>
> *[...]Probably if I had a lot of knowledge and a strong connection to lung cancer, then I would have contacted and rearranged, and the fact that I didn't makes me think it was more 'Och, I'll just leave it', because maybe what I've got to contribute will not really be much. (Participant 2, Female)*

Only two out of eight participants attempted to actively remake their missed lung cancer screening test.

6.4.5.1.7 Denial and avoidance

Denial was implemented as a strategy by some participants to cope with the cognitive and emotional response to being invited to the lung cancer screening test. All participants of the trial were categorised as high risk of lung cancer. However, this status was often rejected by participants.

> *I don’t think I’m any higher, lower, or anything. I think it’s just your luck. (Participant 6, Male)*

Participants also implemented avoidance and believed that most others would most likely use this strategy. It was often discussed in relation to older age and being male.

> *No. It was… Again, just going back to what we said earlier, it was just the fact… Oh, God, you know, I hope I don’t have anything and do I want to find out? (Participant 6, Male)*
>
> *I think it's their mind-set. This sense of either not even wanting to face up to illness, or, you know, scared of it. […] I think, again, it comes back to a generation thing as well, as to how probably men at that age that aren't perceiving... you know, the things that they have, have grown up with things that didn't get talked about. (Participant 2, Female)*

6.4.5.1.8 Illness outcome

Leventhal’s CSM culminates in a given illness outcome based on the emotional and cognitive representations made and how an individual chooses to cope with these representations. The model is dynamic and proposes that people reassess their representations and coping strategies based on the information they have available to them at that time. For this reason, participants in this study may make an initial decision about lung cancer screening and subsequently change their mind at a later date.

All participants stated that they did not have to think about their initial decision to take part in the lung cancer screening trial and automatically wished to participate. The perception of cancer screening in general was positive and all agreed a programme should be in place.

> *I've got quite a positive view about cancer screening. I believe that it's something that should be picked up a lot more by the public. Because of our opportunities to identify risk, we've got an opportunity to reduce that risk, to do something about it rather than wait until someone's got a diagnosis and then they go down that long road of recovery, if recovery is possible. […] I feel quite strongly about screening. (Participant 2, Female)*
>
> *But, no, it’s never a question of I wouldn’t do it. (Participant 5, Female)*

Participants often cited practical or situational barriers as reasons for their non-attendance to their lung cancer screening test (Table 6-2). Half of the participants cited ill-health as the reason for their non-attendance (n = 4). Two of the four participants with ill-health had chronic health conditions. The remaining two participants were unwell for a short period of time.

> *I'd totally forgotten. I was feeling so ill so I'd completely forgotten I was supposed to go to it [...] and I got in the taxi to go to the lung cancer screening thing and I just felt so nauseated that I actually just said to the guy half way along, I said, "Look, please take me home", because I just felt so sick, and that was the reason I didn't go.* (Participant 1, Female)
>
> *Right, everything was set and I really took… it wasn't really… in a way, it was a COP episode but not bad, all my nose and my throat, you know? And I thought 'I can't go for that like this.' That's the only reason I cancelled. (Participant 8, Female)*

A number of participants with ongoing health conditions that were discussed during the interviews in relation to recognising symptoms of lung cancer and also competing health priorities when it comes to attending lung cancer screening. Participants tended to concentrate on any ongoing health conditions they had rather than worry about the possibility of having lung cancer.

> *[...] it turns out I've got a couple of gastric ulcers, although I didn't know that at the time. So, and it's a kind of, the, kind of, that, the sort of symptoms of that have sort of dragged on over that - you know, from then until pretty much now. So, you know, my lung health, as it were, really, I never really thought about it at all. I was so busy with the gastric systems that I haven't really - I haven't had any chest symptoms, and I never really gave it a second thought. (Participant 1, Female)*

Two participants could not attend their appointment because of work commitments. These participants prioritised work commitments over being screened for lung cancer. Prioritising the screening appointment was not seen as an option and doing so would make their everyday lives more difficult. In this sense, it was more practical for them not to attend their appointment.

> *Aye, yeah, I was thinking, 'I have to go out and earn some money,' that's what I was thinking. (Participant 6, Male)*
>
> *I was actually caught up - we do a crisis duty - and I got caught up in a crisis duty that day, it just, I never got up to it. And then I forgot all about it. (Participant 2, Female)*

One participant also found the practicalities of attending their screening appointment difficult. The time and location of the screening appointments were seen as problematic, particularly among those with work and caring commitments.

> *But the original date they gave me, I honestly can't remember what it was I was doing but I had somewhere I had to be […] But they didn't make it easy, put it that way. And that's why I ended up not going […] (Participant 5, Female)*

One participant could not recall being invited to take part in the trial, however, it was unclear whether this was because of the length of time between being invited to take part in the trial and the sub-study interview, or whether this was the reason they did not attend.

Participants had the option to remake the appointment that they did not attend. Two participants attempted to reschedule an appointment, six did not. The reasons for not remaking their appointment are described in in Table 6-2.

In addition to the practical and situational barriers to their attendance, participants discussed in depth their beliefs around lung cancer. These beliefs also impacted participants' attendance to their appointment and the likelihood that they would attempt to reappoint. Four participants did not try to rearrange their appointment because they did not feel at risk of lung cancer. This is a result of their cognitive representations of lung cancer. For example, Participant 2 did not feel the need to reappoint because of a lack of family history with lung cancer.

> *No, I think it's probably a lack of a connection to lung cancer. Maybe about the strength of the connection to lung cancer (Participant 2, Female)*

Participants were more likely to give an emotive reason for not reappointing compared to the reason they originally gave for their non-attendance. This might indicate that the participants might have reassessed their representations between their original invite and remaking their missed appointment. This was potentially a more deliberative decision compared to the automatic decision made when responding to the original invite. Participants were more likely to cite fear, worry or not wanting to know as the reason for non-attendance at this point.

> *No, I think I felt a little bit more scared, actually (Participant 1, Female)*
>
> *But the… at some point, it was one of those ones, again, it was always in the back of my head, but I wasn't sure whether I wanted to… I hadn't made my mind up entirely. […] So, it was lying there, it was just, it was pending in my head. (Participant 6, Male)*

6.4.5.2 HAPA constructs

6.4.5.2.1 Intention

All participants had intention to attend their lung cancer screening trial appointment. The appointments were not automatically allocated, as a result, participants were required to make contact with the study team to arrange an appointment. This indicates a positive intention to attend and a level of motivation.

> *I think I must have got it... a few weeks before... It was a few weeks, I think. I'm trying to think. I'd went on holiday somewhere, I think it was my brother's down in Manchester, so, I must have got it a few weeks before that, and I did contact them and I was planning to go. (Participant 1, Female)*
>
> *I was actually going to do it, and I phoned up. (Participant 4, Male)*

One participant could not remember making the appointment, but records obtained from the ECLS Trial indicated that an appointment was made. Given the significant time between being initially invited to participate in the screening trial and being interviewed for the sub-study, it is possible that the participant had forgotten making the appointment.

Overall, participants were very positive about lung cancer screening and screening programmes in general. They believed them to be a good idea and necessary.

> *Well, I'm very supportive of cancer screening. (Participant 1, Female)*

The positive support for lung cancer screening was highlighted by participants' descriptions of automatically making an appointment in response to the invitation letter

> *No, no. No, I'd soon as… if I get anything through saying 'We'd like you to do this' then if it's anything to do with cancer, I do it. 'Cause my sister-in-law died with cancer when she was only thirty-seven. (Participant 7, Female)*

6.4.5.2.2 Task self-efficacy

Participants all believed that they would be able to attend their appointment when they initially made it. As a result, we can consider them to have high levels of Task Self-Efficacy. However, the nature of the screening trial meant that this action self-efficacy was not often required. For example, participants' belief that they had the required resources to attend their appointment was heightened because of the proactive recruitment strategies of the ECLS trial. The study team covered expenses and travel for participants to attend their prearranged appointment making planning, financial implications and geographical limitations negligible. Only one person discussed how they had planned to travel to their appointment.

> *Yeah, and I was all set to go, they told me to get a taxi and everything. I said "No, I've got my bus pass." (Participant 8, Female)*

6.4.5.2.3 Maintenance self-efficacy

Participants did not cope effectively with the barriers that arose before their screening appointment, as a result, they can be considered to have low maintenance self-efficacy. Strategies were not employed to overcome barriers and participants were not persistent in their efforts to overcome barriers.

> *I did. I was actually caught up - we do a crisis duty - and I got caught up in a crisis duty that day, it just, I never got up to it. And then I forgot all about it. (Participant 2, Female)*
>
> *But the… at some point, it was one of those ones, again, it was always in the back of my head, but I wasn't sure whether I wanted to… I hadn't made my mind up entirely. So, it was lying there, it was just, it was pending in my head. It was just a matter of making my mind up, and at that particular time... again, you know, I hadn't made – I hadn't made my mind up, and then all of a sudden I got busy at work, so it kind of went to the back burner. That's what happened with that. (Participant 6, Male)*

6.4.5.2.4 Recovery self-efficacy

As a result of lack of attendance, it is evident that participants had low levels of recovery self-efficacy. Participants were unable to 'recover' from barriers to their attendance and did not attempt to rearrange their missed appointment. Participants had the option to remake the appointment that they did not attend. Two participants attempted to reschedule an appointment, four did not.

> *You know, so, and then I just never rescheduled it. And I think I probably never rescheduled it because I thought 'I feel okay, and my lungs, I don't have any symptoms. I feel okay', so, you know, I wasn't that worried. (Participant 1, Female)*
>
> *...on that particular day. And when I had phoned to try and rearrange a time, it was really difficult, actually. To – to get them to pick another time. And I do appreciate, obviously hundreds of people are getting called. And they can't possibly re-jig everybody's appointment just to suit one person. But I just felt there wasn't any effort made to get another appointment. And it did kind of put me off. (Participant 5, Female)*

6.4.5.2.5 Action planning

Often, participants did not have to put in place any sort of action planning. This might be a result of the nature of the screening trial. The trial team provided travel and expenses when required to maximise participant attendance. The result of this additional support meant that participants were not required to put into place any sort of preparatory strategies.

6.4.5.2.6 Coping planning (not including stoicism)

Coping planning was not effectively implemented by participants, in contrast, participants were more likely to implement maladaptive coping strategies. As with the CSM, participants did not often use effective coping in response to being invited to participate in the lung cancer screening trial. This is highlighted by the lack of reappointing amongst participants - only two out of eight participants attempted to actively remake their missed lung cancer screening test. When posed with a barrier (practical or cognitive) they were unable to overcome due to ineffective coping planning. If they had put in place plans on how to cope if a barrier emerged, they might have successfully attended another appointment.

Denial was implemented as a strategy by some participants to cope with the cognitive and emotional response to being invited to the lung cancer screening test. All participants of the trial were categorised as high risk of lung cancer. However, this status was often rejected by participants.

> *I don't think I'm any higher, lower, or anything. I think it's just your luck. (Participant 6, Male)*

Participants also implemented avoidance and believed that most others would most likely use this strategy. It was often discussed in relation to older age and being male.

> *No. It was… Again, just going back to what we said earlier, it was just the fact… Oh, God, you know, I hope I don't have anything and do I want to find out? (Participant 6, Male)*

> *I think it's their mind-set. This sense of either not even wanting to face up to illness, or, you know, scared of it. […] I think, again, it comes back to a generation thing as well, as to how probably men at that age that aren't perceiving... you know, the things that they have, have grown up with things that didn't get talked about. (Participant 2, Female)*

6.4.5.2.7 Self-monitoring

Self-monitoring was not required in this screening trial – this was a one-off appointment that did not require them to monitor their future behaviour.

6.5 Discussion

6.5.1 Summary of main findings

This study offered the unique opportunity to explore the perceived barriers to lung cancer screening and beliefs about lung cancer and lung cancer screening in a group of ECLS trial non-attenders. This particular group are of significant interest because of their positive intentions to attend their screening appointment. Understanding the barriers and beliefs of non-attenders can offer insight into what we must do to encourage attendance in this already motivated group. The development of a national cancer screening programme, such as lung cancer screening, requires it to be both clinically effective and sustainable. Optimising screening attendance among those most at risk of lung cancer is fundamental to the success of any potential screening programme.

The qualitative analysis explored the perceived barriers to attending a lung cancer screening appointment and the beliefs about lung cancer in a group of non-attenders in the ECLS trial. The study aimed to address the following questions:

I. What are the perceived barriers to participating in a lung cancer screening trial?
II. What beliefs do non-attenders hold about lung cancer and lung cancer screening?
III. Do the CSM and HAPA model help to explain the processes behind those who intend to participate in screening but do not attend?

Participants were likely to initially state practical reasons for non-attendance at their lung cancer screening appointment, such as ill-health, competing priorities or being unable to secure a suitable appointment time. However, all participants also provided psychological reasons for not attending. This pattern of discussing practical barriers followed by psychological barriers suggests that their underlying beliefs about lung cancer might impact the way in which they tackle the practical barriers they face when attending an appointment. This idea is supported by participants choosing not to reappoint after missing their initial appointment. When the practical barrier they perceived was removed, the underlying perceptions of lung cancer were difficult to overcome and resulted in participants not remaking an appointment.

The thematic framework analysis generated five distinct themes: perceived risk; perceived severity; lung cancer vs. other cancers; stoicism; and co-morbidity. A summary of the findings is displayed in Table 6-4. The beliefs about lung cancer that participants held influenced their non-attendance at their screening appointment.

Participants' perceived risk and understanding of risk factors played a role in their non-attendance. Although participants could identify smoking as a risk factor, they underestimated their own risk of getting lung cancer, placing significant weight on external factors such as family history. Some participants considered lung cancer to be predetermined and seen as something that they had no control over. A low perceived risk, or the view that lung cancer is predetermined, meant that non-attenders did not consider it necessary to attend their lung cancer screening appointment.

Lung cancer was perceived to be a severe condition with participants holding fatalistic beliefs. As a result, participants were often fearful about lung cancer and a feeling of hopelessness about the lack of control they have over the development and treatment of lung cancer. The emotional response to how serious lung cancer is meant that participants were fearful of attending lung cancer screening and of the results of the screening test. The fear they feel about lung cancer could perhaps have also lead them to underestimate their own risk in order to distance themselves from lung cancer, and lessen their emotional response that might occur if they felt at risk.

Lung cancer was often compared to other types of cancer. There were two distinct views which emerged; some participants believed all cancers to be the same and others believed that some cancers were more severe than others. Those who did not distinguish between types of cancer had strong views and were more likely to be fatalistic about cancer. It was seen as one disease, one type as aggressive as another. Participants that viewed cancers differently often discussed them as if on a scale of severity, with lung cancer being seen as the most severe and breast cancer as the least. Both the uncontrollability of cancer and the severity of lung cancer induced emotional responses that acted as a barrier to attending or remaking a lung cancer screening appointment.

A stoic attitude made some feel they did not want to make a fuss, bother their doctor or worry about lung cancer and its symptoms. Those who displayed a stoic attitude often considered it to be a deliberate life choice. Choosing not to worry and avoiding information about lung cancer made it easier for them and can be seen as a coping mechanism to cope with what they feel they have no control over. This avoidant behaviour is a possible explanation for non-attendance of their lung cancer screening appointment. This might also indicate that fatalism, often believed to be an irrational response, can be employed as a coping mechanism.

A number of participants lived with other health conditions. The existence of an underlying condition left participants with competing health priorities. The lung cancer screening appointment was not seen as a priority at the time they were invited, with any potential symptoms of lung cancer overlooked. Participants tended to concentrate on any ongoing health conditions they had rather than worry about the possibility of having lung cancer.

Table 6-4: Summary of Findings - How do Different Beliefs Influence Non-attendance or Reappointing to a Cancer Screening Trial?

Theme	Conclusion
Perceived risk	Participants underestimated their own risk of getting lung cancer
Perceived severity	Participants perceived lung cancer to be severe and survivability to be low
Lung cancer vs other cancers	Two clear views of cancer emerged – all cancers are the same or some cancers are more severe than others. When compared to other cancers, lung cancer was perceived to be the most severe
Stoicism	The stoic attitude towards lung cancer displayed by some is seen as mechanism to cope with what they feel they have no control over
Co-morbidity	Participants with co-morbidities concentrated on any ongoing health conditions they had rather than worry about the possibility of having lung cancer

The use of two theoretical frameworks provided greater insight into non-attendance and helped to identify themes that had not been identified in the initial thematic analysis. When comparing the generated themes with the constructs of the HAPA and CSM there was found to be significant overlap. The only theme that did not map directly to the CSM or HAPA was ‘co-morbidity’. This was identified as a significant barrier to a number of participants of the study. The HAPA also did not account for how frequently participants compared lung cancer to other types of cancer. However, this mapped directly to the CSM construct ‘identity’.

The secondary aim of the study was to explore to what extent HAPA and CSM explained non-attenders behaviour. A summary of the findings can be found in Tables 6-5 and 6-6.

Table 6-5: Summary of Findings - HAPA Constructs

Construct	Conclusion
Intention	All participants had intention to attend their lung cancer screening trial appointment.
Task self-efficacy	Participants all had a belief that they would be able to attend their appointment when they initially made it. As a result, we can consider them to have high levels of task self-efficacy.
Outcome expectancies	All participants perceived lung cancer to be severe and survivability to be low. This belief made the interviewees fearful of lung cancer.
Risk perception	Participants underestimated their own risk of getting lung cancer
Maintenance self-efficacy	Participants did not cope effectively with the barriers that arose before their screening appointment, as a result, they can be considered to have low maintenance self-efficacy
Recovery self-efficacy	The lack of attendance indicates that participants had low levels of recovery self-efficacy
Action planning	Participants did not have to put in place any sort of action planning because of the nature of the lung screening trial procedures
Coping planning	Coping planning was not effectively implemented by participants. Participants often implemented maladaptive coping mechanisms, such as denial or avoidance

Table 6-6: Summary of Findings - CSM Constructs	
Construct	Conclusion
Identity	Participants were stimulated to develop cognitive representations by being invited to take part in the lung cancer screening trial. Often participants discussed lung cancer in an abstract manner and frequently compared to other cancers
Cause	The importance of smoking was often minimised. Participants overemphasised the risk of workplace environmental hazards, genetic causes of cancer and often discussed the predetermined and uncontrollable nature of cancer
Timeline	Very few discussed the timeline of lung cancer. When discussed, lung cancer was described as quick and painful or as slow and painful
Consequences	All participants perceived lung cancer to be severe and survivability to be low. This belief made the participants fearful of lung cancer
Coherence	Participants’ knowledge of lung cancer varied greatly. However, no participants were able to describe the lung cancer screening test they were invited to
Emotional representations	Participants were fearful of lung cancer and held fatalistic beliefs. Fear was perceived to be either a motivator or a barrier to lung cancer screening
Coping strategies	Participants did not employ active coping, but instead used maladaptive coping strategies such as denial and avoidance
Coping appraisal	Participants were unable to appraise the coping strategies they employed. This is evidenced by the lack of reappointing among participants
Illness outcomes	Participants were likely to cite practical barriers as the reason for not attending their screening appointment but would cite emotional barriers for the reason not to make another appointment. This indicates that the participants might have reassessed their representations between their original invite and remaking their missed appointment

There was not one theoretical model that fully explained non-attendance of the lung cancer screening trial. However, each model has important components that go some way to explain the behaviour of non-attenders in this context. There was significant overlap between CSM and HAPA with regard to the role coping strategies play in a group of people who already have positive intentions. Participants were unable to employ action focused coping strategies that would help them overcome the initial practical and emotional barriers they faced when the time came to attend their appointment. Further, they were unable to appraise their maladaptive coping strategies and recover in order to make another appointment. Despite there being similarities in the lung cancer beliefs of ECLS trial attenders (Chapters 4 and 5) such as perceived lack of control over risk and negative emotional responses to lung cancer, coping response might be a key difference between attenders and non-attenders. Coping planning and coping appraisal seem to be significant problem areas for non-attenders with the time between invitation and appointment vital to whether or not they attend their appointment.

6.5.2 Comparison with other literature

The reported barriers to the cancer screening trial are comparable to those of other cancer screening programmes. Both practical and emotional barriers have been previously cited as reasons for not taking part in lung cancer screening (Ali et al., 2015). Practical barriers, such as competing priorities with regard to work and family commitments, as well as ongoing health condition were cited by the participants of this study. A study exploring non-participation in the UKLS trial found that alongside emotional barriers, participants most commonly cited travel, co-morbidities, caring responsibilities and work commitments as the reason they did not participate. This study did not find travel to be a barrier because of the proactive recruitment procedures of the ECLS trial, with participants often being provided with door-to-door transport. However, outwith a trial setting we could expect this to be the case if a national lung cancer screening programme was implemented.

The practical barriers experienced by the participants are legitimate reasons for not attending an arranged appointment. Barriers are more likely to be perceived by those of lower SES (Ali et al., 2015) and go some way to exacerbate health inequalities. These barriers could have been resolved by attempting to make another appointment at a more convenient time to them. This would require participants to apply effective coping mechanisms and planning. The design of our national screening services could also be adapted to help optimise participation; making them accessible by design and ensuring flexibility to meet the needs of all communities.

Among the participants, emotional barriers played a significant role in why they chose not to make another lung cancer screening appointment. Participants displayed a high level of fear and fatalism. This is also frequently reported in previous studies (Jonnalagadda et al., 2012; Quaife et al, 2018). This negative association with lung cancer is prevalent, as well as the adoption of maladaptive coping mechanisms such as avoidance or denial (Patel et al., 2012; Walton et al., 2013). The fear and fatalism experienced by participants also left them with a feeling of hopelessness that could have contributed to their non-attendance of their appointment.

An important finding of this study is the exploration of what happens between invitation, appointment and reappointment. The study found that participants made their choice to take part in the screening trial automatically, based on their previous reported screening behaviour. However, given time, participants became more reflective in their decision-making, making their final decision to not attend or reappoint based on their knowledge and emotional representations of lung cancer. Dual process models of decision-making posit that there are two distinct systems of processing (Kahneman, 2003). System 1 is described as intuitive, fast, and emotion-focused, while System 2 is deliberative, slow, reflective (Kahneman, 2011). These systems of processing are reflective of how non-attenders made their decision to participate. Participants engaged System 1 when first invited to take part in the trial - a decision to attend was made quickly and based on their existing knowledge. Within the period of time between invitation and attending their appointment, they engaged the more reflective System 2. Making a deliberative decision not to attend their appointment or make another for a later date might be the result of having time to ruminate on their emotional representations of lung cancer. When faced with practical barriers, there is less inclination to put in place effective coping responses to overcome them and a deliberate decision was made not to make another appointment. This insight would lead us to believe that interventions for non-attenders could focus on reducing the time between engaging System 1 and the appointment date in order to encourage more intuitive decision-making.

Exploring non-attenders’ barriers and beliefs has developed the wider understanding of the decision-making processes inclined abstainers implement when invited to participate in screening. The two-system approach to decision-making adopted by this group will help us to identify appropriate interventions to increase screening uptake in not only lung cancer screening, but other forms of cancer screening. For example, the use of patient navigators to provide emotional and practical support could improve uptake in screening non-attenders (McGregor et al., 2016). The setting of implementation intention (Gollwitzer &

Sheeran, 2006) or the combination of action and coping planning interventions for non-attenders (Kwasnicka, Presseau, White & Sniehotta, 2013) could also support non-attenders to overcome some of the barriers they might face when invited to participate in cancer screening.

6.5.3 Strengths and limitations

There were no previous studies that looked at non-attenders of lung cancer screening using qualitative methodology. A major strength of the current study is therefore that this unique sample provides us with important insight into the cancer screening decision-making processes, enabling us to develop interventions to support non-attenders and optimise cancer screening.

A further strength of the study is the holistic approach to analysis by exploring two theoretical models, allowed for greater understanding of the overlap and gaps in the HAPA and CSM. The use of both models highlights the need to move away from the view that only one theoretical model can or should be used to describe behaviour. Decision making is complex, and by using just one theoretical model we limit our understanding of individual experience. Individually, both models provided insight that helps to develop our understanding of screening behaviour, but when used in tandem they expand our understanding and highlight areas not previously considered, such as the impact underlying health conditions have on screening behaviour. It is recognised that each of the models also have some limitations in relation to the study. The HAPA did not map directly onto two of the identified themes of the initial thematic analysis and as a process model, did not account for reappraisal of decisions without starting the decision process again. Conversely, the CSM mapped to all identified themes apart from co-morbidity, and also includes a feedback loop that accounts for people changing their minds at various stages of the process (see table 6-3). As a result, we could conclude that the CSM better explained the decision making of non-attenders. However, without examining the qualitative data with both models, the gaps in the data would not have been recognised.

A limitation of the study is that the ECLS trial was not a true lung cancer screening programme but an RCT. However, as previously discussed, it is useful to draw on the findings of this trial to understand the screening behaviour of high-risk groups, with the aim to help shape future screening programmes. The majority of participants did not discuss any aspect of the trial research question or methodology but discussed their experience like they would any other screening programme such as bowel or breast screening. Only one participant discussed issues around randomisation, and why this might have impacted their decision to participate.

The nature of the sample meant that the recruitment was challenging, and final uptake of the study was low. As a result, only eight non-attenders participated in interviews. Although a relatively low number, in some ways it can be regarded as a strength that as many as eight agreed to be interviewed given they may have been reluctant to speak about their non-attendance. Furthermore, the data that resulted from the interviews were rich and allowed for in-depth and holistic analysis. It is evident that non-attenders require extra support to encourage actual participation. Future study of this group should aim to reflect this in their recruitment strategy.

6.6 Chapter summary

This chapter has presented the results of a qualitative study exploring the barriers to a lung cancer screening trial in a group who initially agreed to participate, but ultimately did not attend their arranged appointment. The study also looked to explore to what extent the HAPA and CSM help explain the processes behind non-attenders decision-making.

The findings of the study indicate that non-attenders made their initial decision to participate instinctively and are motivated to participate. However, they do not effectively implement coping mechanisms to overcome practical barriers, such as competing priorities or ill-health. When faced with remaking their appointment, participants engaged a more reflective and emotive decision-making process, often citing fear and fatalistic beliefs as the reason for not reappointing.

There was significant overlap between HAPA and CSM, particularly with regard to the role coping strategies play in a group of people who already have positive intentions. Coping planning and coping appraisal seem to be significant problem areas for non-attenders with the time between invitation and appointment vital to whether or not they attend their appointment. This insight will help us develop interventions that will minimise non-attendance at lung cancer screening.

The next chapter will present the overall discussion of the findings of the thesis and provides a conclusion.

Chapter 7: Discussion and conclusions

7.1 Introduction

Lung cancer is the most commonly diagnosed form of cancer, and the leading cause of cancer death worldwide. Lung cancer disproportionately impacts those from certain groups, including those from more deprived groups. Failing to acknowledge the possible inequalities in cancer screening, and addressing the potential causes, can further exacerbate existing health inequalities that exists between some groups. By not addressing the variation in cancer screening participation there is potential risk that any future lung cancer screening programme might not be efficient or sustainable.

This thesis has comprehensively explored lung cancer screening participation. In particular, I sought to understand the determinants of lung cancer screening participation, including the perceptions and beliefs of lung cancer, and what the implications of these perceptions and beliefs might have on screening participation. To address the research questions set out, I used a mixed methods approach that allowed me to extensively understand the factors associated with lung cancer screening participation.

This chapter aims to integrate the results of the thesis by outlining the main findings, discussing the limitations of the thesis and reflecting on future research needs and, policy and practice implications.

7.2 Overview of main findings

This section will provide an overview of the main findings of the thesis and discuss how these findings compare to existing literature.

7.2.1 Do public perceptions of lung cancer and lung cancer screening differ between socioeconomic groups?

There is some variation in the public's perception, and awareness, of lung cancer and lung cancer screening across different socioeconomic groups. However, this was not the case for all aspects discussed in the literature reviewed in Chapter 3. In general, the evidence explored suggests that those from lower SES groups have poorer knowledge of lung cancer and its symptoms, are more likely to perceive themselves at lower risk of lung cancer and are more likely to report more barriers to participating in lung cancer screening.

The findings, in relation to poorer knowledge and increased perception of barriers to screening among those from lower SES, were not unexpected and are generally reflective of the literature exploring other forms of cancer screening (McCutchan et al., 2015; James et al., 2008; von Wagner et al., 2011). However, this is not the case with risk perception. Existing literature on perceived risk of cancer across SES indicates a confounded picture (Wardle et al., 2004; Wardle 2015). Perceived risk of cancer has been found to be both higher and lower in more deprived groups. It is surprising that there is an indication that lower perceived risk of lung cancer is recurrent in lower SES groups, particularly when criteria for participation in lung cancer screening is usually based on risk. This might be an example of unrealistic optimism (Weinstein, 1980) among high risk groups, such as smokers. A particular bias might be present in the existing literature, including those reviewed, that often uses smokers as a sample in lung cancer screening research. This is undoubtedly the correct approach, but we must remain mindful of the relationship between SES and smoking status when drawing conclusions about perceived risk in different SES groups.

No clear conclusions could be made about the SES differences in fear, fatalism, stigma, smoking status/cessation, and lung cancer screening awareness. The lack of social gradient in the studies, exploring differences in smoking status and smoking cessation, were not completely unforeseen given the over representation of smokers in lung cancer screening research. Although rates of smoking among those from lower SES groups are higher compared to high SES groups, greater variation in beliefs about lung cancer screening can be seen by smoking status rather than SES. Similarly, it is not unsurprising that there was no variation in lung cancer screening awareness by SES group given the lack of organised screening programmes in most countries. Where screening programmes do exist (e.g. United States) a lack of awareness of lung cancer screening was made evident by the number of misconceptions about lung cancer screening, including believing that the purpose of screening is prevention and to act to provide reassurance. A significant number of people also overestimate the benefits of lung cancer screening regardless of SES (Hoffman & Del Mar, 2015).

Conclusions surrounding the lack of variation in fear, fatalism and stigma were not as anticipated. It would be expected that those from lower SES groups would experience greater fear, fatalism and perceived stigma with regard to lung cancer. The belief that fear and fatalism would be greater in more deprived groups was founded from the idea that greater fear and fatalism would be the result of having less knowledge of lung cancer and lung cancer screening. Similarly, the increased uptake of smoking in more deprived groups would be expected to be associated with higher levels of perceived stigma. Existing literature also supports the hypothesis, with fatalistic beliefs and fear about cancer being more common in low SES groups (Beeken et al., 2011; von Wagner et al., 2011; Niederdeppe & Levy, 2007; Wardle et al., 2004; McCutchen et al., 2015). Low SES has also previously been associated with increased higher lung cancer stigma (Assari et al., 2019; Chambers et al., 2012).

The inconclusive nature of the findings in Chapter 3 might be explained in a number of ways. For example, fear and fatalism might not be as high as anticipated in those from lower SES groups, as argued by Blaxter (1997), because they have greater experience of having or knowing someone with chronic ill-health. Consequently, they might also have greater experience of knowing of someone who has survived despite being high risk, and of people who die prematurely despite apparent healthy lifestyles. As a result of these lay beliefs, those from lower SES backgrounds might consider ill-health, such as developing cancer, to be luck or chance and, therefore, there is nothing within their control that can be done to prevent it. This lack of control might come as a relief to some, and potentially reduce levels of fear.

Another possible explanation for there being no variation in fear and fatalism across socioeconomic groups is that levels of fatalism and fear remain consistent across all groups. Cancer fear is generally high across all forms of cancer and is commonly viewed as the enemy (Vrinten et al., 2014; Vrinten et al., 2016). However, lung cancer is considered to be the most severe form of cancer, and more fatal compared to others (Mazières et al., 2015). This persisted in the participants' views described in Chapter 6, who also considered lung cancer to be the deadliest form of cancer and the one they feared most. The enduring belief that lung cancer is fatal is perhaps a reflection of the consistently high mortality rate of lung cancer, a lack of knowledge about lung cancer, and its treatments.

There are evident differences in public perceptions and awareness of lung cancer and lung cancer screening between socioeconomic groups and, as a result, this could cause the uptake of lung cancer screening to be socially graded.

7.2.2 Do the demographic and psychosocial characteristics of ECLS trial participants vary by socioeconomic status?

There were demographic and psychosocial differences at both area (SIMD) and individual-level SES among ECLS trial participants. Results were generally supportive of existing literature.

There were few demographic differences across socioeconomic groups, but the differences that were reported highlight some areas of interest. For example, those from more affluent groups were more likely to be married than those from more deprived groups at both area and individual-level SES. Marital status has been previously associated with breast, cervical and bowel cancer screening uptake, with those who are married or in civil partnerships more likely to attend (Hanske et al., 2016; Saghari et al., 2015). The relationship between SES and marital status, reported in the results of Chapter 4, could indicate an area for further research. The social support provided by close relationships, such as marriage or civil partnership, has previously found to be beneficial to screening behaviour (Hanske et al., 2016). The mechanisms that underlie this relationship between social support and screening uptake could provide insight that would be helpful in the development of interventions that encourage screening uptake in those less likely to participate (e.g. those from deprived groups and those without social support). For example, exploring how social norms and relationship interdependencies influence lung cancer screening uptake could perhaps be an important direction for future research.

In multivariate analysis (Chapter 4), when controlling for demographics, participants in the ECLS trial were more likely to say they are a current smoker if they were from a more affluent group at both area and individual-level SES. This was very surprising, as existing literature would suggest that smoking rates are higher in those from more deprived groups (Hiscock et al., 2012). There could be a number of explanations for this anomaly. First, we should consider whether being invited to participate in the trial acted as a ‘teachable moment’ for more deprived smokers (Taylor et al., 2007). Participating in lung cancer screening has been found to promote smoking cessation (Pistelli et al., 2020). However, this is usually as a result of planned intervention and not merely being invited to participate. It is unclear whether being invited to participate is enough to encourage people to reassess their risk behaviours.

The question asked to participants in the ECLS trial baseline questionnaire (*‘Have you smoked any cigarettes or tobacco products in the last seven days?’*) might not have captured any recent changes in smoking status. The question also does not identify the number of cigarettes smoked or the number of years of active smoking, both of which are key risk factors in lung cancer. Those from more deprived groups have been found to smoke more cigarettes and to have started from a much younger age compared to those from more affluent groups (Doll et al., 2005; Lubin & Caporaso, 2006; Kenfield et al., 2010). The self-report approach to the ECLS trial baseline questionnaire might have also contributed to under reporting of smoking, perhaps because of smoking-related stigma. Another possible explanation for higher smoking rates in more affluent groups could be a result of these groups using the opportunity to screen for lung cancer as a reassurance that, despite their smoking status, they are ‘safe’ from lung cancer. Results from Chapter 5 indicate that more affluent participants were more likely to self-select to participate in the trial, as well as being healthier. Using screening as a tool to provide reassurance ties in with the idea that some of the more affluent participants of the trial could be considered to be the ‘worried well’.

There was some variation in illness perception across SES in both area- and individual-level SES. Perceived control of individual risk was found to be lower in those from more deprived groups at both area- and individual-level SES. Having low perceived control of risk factors might indicate a level of fatalism towards lung cancer. Contrary to the results of the systematic review presented in Chapter 3, ECLS trial participants from more deprived groups may have held more distinct fatalistic beliefs. More deprived participants may have tried to minimise the control they have over their own risk as a coping mechanism (Lo et al., 2013), or as a response to anticipated smoking-related stigma (Johnson et al., 2014). A lack of perceived control over the development of lung cancer was an area discussed by non-attenders of the ECLS trial (Chapter 6) who were also from high risk, deprived groups. Interview participants underestimated the risk smoking posed to them, and also believed they had no control over the development of lung cancer. Among these participants, a number considered that lung cancer was predetermined. It appears that this view of lack of perceived control is not unique to non-attenders, but it might be the case that attenders of the ECLS trial are less avoidant than non-attenders.

The emotional response to lung cancer was also found to be higher in those from deprived groups at both area and individual-level SES. This result contradicts the findings of the systematic review reported in Chapter 3, where there was not found to be any clear variation in fear across SES groups. Therefore, the ECLS results need to be interpreted with caution. ECLS trial participants from more deprived groups (SIMD 1 / SES 0) were more likely to feel emotional about their risk to lung cancer. The emotional response to lung cancer risk could perhaps be as a consequence of lower levels of lung cancer knowledge and higher fatalistic beliefs among those from more deprived groups. Those from more affluent groups were more likely to recognise that lung cancer would have a big impact on their life across both area- and individual-level SES. This could be a reflection of having an increased level of knowledge of lung cancer among more affluent groups. Those from more deprived groups have been found to have less knowledge of lung cancer and lung cancer screening compared to those from less deprived groups (Rutten et al., 2009). Understanding the consequences of lung cancer, such as treatment types and high mortality rates, are inevitably associated with a person's knowledge of cancer, and their overall health literacy level. The results of both Chapter 3 and 4 indicate that illness coherence (knowledge) of lung cancer is socially graded. Addressing lung cancer knowledge variation to increase screening participation could be a simple and potentially effective intervention for future development.

Notably, univariate analysis reported in Chapter 4 indicated that there was no difference in belief that early detection of lung cancer can improve chances of survival in both area- and individual-level SES. There was a high level of agreement, which is in line with existing literature about attitudes towards cancer screening (Waller et al., 2015). This positive attitude towards lung cancer screening is also reflected among non-attenders (Chapter 6). This indicates that there is an overall positive attitude toward lung cancer screening across all groups, but that positive attitude is not enough to encourage participation in all cases.

Trial participants from Glasgow were more likely to be from the most deprived groups (SIMD 1 / SES 0) compared to those recruited from Tayside and Lanarkshire. This is unsurprising and is a result of the trial recruitment strategy. However, it does indicate that, despite the shortcomings of area-based SES measures, the recruitment strategy predominately used in Glasgow was effective in reaching more deprived groups. As discussed in Chapter 5, those from Glasgow were more likely to be invited to participate via their GP and very few were recruited via the community. Conversely, a larger proportion of those from Tayside were more likely to have been recruited by community-based methods and were more affluent. The use of GP invitations to take part in screening appear to reach high-risk deprived groups more successfully than community-based approaches regardless of how SES is measured.

Chapter 3 highlighted the need for better, more consistent measures of SES that would allow for a more reliable comparison of results. The use of two measures of SES opened up further discussion about the most appropriate way to measure SES. This is also reflected upon in Chapter 4 and 5. Results indicated that the use of area-based measures of SES, such as SIMD, might not be the most effective measure of SES. When used as a recruitment tool to reach people who are at the highest risk of lung cancer, the use of SIMD in the ECLS trial appears to recruit predominately (60%) from the most deprived groups (SIMD 1 and SIMD 2). However, when individual measures of SES are applied, those who participated in the ECLS trial were not as deprived as initially believed, with more participants falling into the least deprived group (65% falling into SES 2 and SES 3). This indicates that they have greater access to wealth and services than their postcode suggests that they should. Area-based SES measures assume similar levels of deprivation across a geographical area but individuals within the area may be relatively affluent in terms of individual wealth and access to services. This can be seen in the ECLS trial sample. This discrepancy makes us consider how we should measure level of deprivation, particularly if it is used as a criterion in cancer screening. The use of area-based SES measures are more convenient, but do not correspond with the developing argument for individual-risk criteria for lung cancer screening. To ensure risk levels are accurate, it might be more prudent to use individual and individual composite measures of SES.

The results of Chapters 3 and 4 indicate that variation in beliefs about lung cancer and lung cancer screening does exist across different SES groups. This provides us with insight into how to effectively reduce the social gradient of screening uptake that might occur if lung cancer screening is implemented in the UK.

7.2.3 Do socioeconomic status, beliefs and attitudes towards lung cancer and lung cancer screening differ by invitation type?

Those who respond to different types of invitation to lung cancer screening vary by SES, as well as beliefs and attitudes towards lung cancer and lung cancer screening.

The results reported in Chapter 5 indicate that those who self-referred to the ECLS trial via the community-based recruitment were more likely to be from more affluent groups. This was the case for both area-level SES (SIMD) and individual-level SES, indicating a strong relationship between SES and recruitment methods. This somewhat contradicts the findings of pre-trial focus groups, which concluded that those who are high risk and from deprived groups might better engage with screening if recruited via alternative community methods such as local TV advertisement and posters placed in high footfall areas (such as GP practices and community centres) (das Nair et al., 2014). It was important that the ECLS trial acted upon the feedback from the pre-trial focus groups and proactively work with potential participants to optimise engagement with the trial. This was a positive approach to co-design, although, it was recognised at the time that community-based recruitment had not been systematically evaluated (das Nair et al., 2014). It does appear that GP-endorsed letters, such as those used in current UK national screening programmes, are the most effective means to invite deprived groups to participate in lung cancer screening (Brawarsky et al., 2004; Duffy et al., 2017). Existing literature indicates that interventions using GP-endorsed letters to increase screening uptake are based on the idea that people trust their healthcare provider to give recommendations and a letter from them provides a level of personalisation that encourages participation as well as informed choice (Duffy et al., 2017). Although the ECLS trial successfully recruited those living in deprived areas via their GP, more can be done to optimise this type of invitation. For example, GP endorsement letters should ideally be electronically signed by the GP, and on practice-headed paper, as letters sent on behalf of the practice are generally less effective (Hewitson et al., 2011). GP-endorsed invitations are a simple and effective way to encourage screening uptake which should be encouraged if a future lung cancer screening programmed is to be implemented in the UK. The use of community-based methods to invite people to participate in cancer screening may further exacerbate cancer screening inequality.

There were some demographic differences between those who engaged in community-based recruitment and those who were invited to participate via their GP. The sex of participants was found to be associated with recruitment type. Results indicated that men were more likely to be recruited via the community, when controlling for other variables. This is somewhat surprising as it would suggest that men were more proactive in their approach to screening which contradicts the general view that men are less likely to engage with health care. Nevertheless, it does fit with the existing literature about some forms of cancer screening such as bowel cancer screening, where men are more likely to screen than women (Wardle et al., 2005). Chapter 4 highlighted that there were no significant differences in sex across different SES groups when controlled for in the multivariable analysis and, as a result, we can infer that SES does not explain why the sex difference in recruitment type engagement exists. The variation is feasibly related to marital status, with those who are married or in a civil partnership being more likely to engage with community-based recruitment. It is possible that being in close relationships, such as marriage or civil partnerships, allow for spouses or partners to monitor each other's health behaviours. Within heterosexual relationships, women have often been deemed 'family health gatekeepers' and are more likely to attempt to change their spouse's behaviour, more so than men (van Jaarsveld et al., 2006). It is perhaps this relationship dynamic that led to more men engaging with community-based recruitment and being encouraged to attend by their spouse.

Some components of illness perception varied by recruitment type. Unexpectedly, those recruited via the community were more likely to consider that they had no control over the development of lung cancer. This is surprising because this group were more proactive in their approach to lung cancer screening and, based on existing literature, would consider them to have greater perceived control over their risk. Having lower perceived personal control has previously been found to be incompatible with undertaking protective health behaviours (Martinez & Lewis, 2016). Those recruited via the community were also more likely to have smoked in the previous seven days. It is possible that they might not have perceived themselves to have the self-efficacy to stop smoking, or that they were more passive about their risk in general, believing their risk or the development of cancer was down to factors out with their control. Similar to the results discussed in Chapter 4, smokers recruited via the community might also appear more proactive because they considered screening as an opportunity to get reassurance that they do not have lung cancer and persist with the belief that they do not need to stop smoking (Tonge et al., 2018; van der Aalst et al., 2011; Young et al., 2018).

People recruited via the community were also less likely to know what their risk of developing lung cancer is. This might be because, unlike the GP recruited participants, community recruited participants were never actively told that they are high risk of lung cancer. By being invited to participate by their GP, GP-recruited participants were actively informed of their risk of lung cancer. Unlike other forms of screening, only those who are at high risk of lung cancer receive invitations to attend. This is an explicit signal to them that they fall into an at-risk group. It could be posited that those recruited via the community might not be making a fully informed choice about taking part in the lung cancer screening trial when they make their initial decision to make contact. Future research could perhaps explore the drop-out rate between the initial contact after seeing community-based advertisement and undertaking the screening test. Chapter 6 highlighted that decision-making occurs in two stages; first, a quick intuitive decision based on existing knowledge, followed by a more reflective, informed decision.

It is evident that the way in which we invite people to participate in cancer screening is of great importance when targeting high-risk groups. Optimising cancer screening invitations, by further exploring the level of personalisation required in GP-endorsed invitations will provide cost-effective and efficient means to improve uptake in at-risk groups, as well as improving informed decision-making. The use of community-based recruitment may exacerbate cancer screening inequality, with those from more deprived groups less likely to engage with this form of recruitment. As a result, this community-based recruitment should be avoided when attempting to target this population.

7.2.4 What are the perceived barriers and beliefs about lung cancer and lung cancer screening held by screening non-attenders?

Non-attenders of the ECLS trial cited a number of different barriers that led them to cancel or not attend their initial appointment. Initially, all participants perceived there to be practical barriers to attending their appointments. Reasons such as ill-health, competing priorities or being unable to secure a suitable appointment resulted in non-attendance. These are commonly reported barriers to cancer screening, including lung cancer screening (Ali et al., 2015). The pre-trial qualitative work identified some practical barriers that might occur (e.g. travel and inconvenient appointment times) and as a result attempted to mitigate these barriers during the trial duration (das Nair et al., 2014). Mitigating actions included providing transport to the screening appointment and allowing participants to rearrange their appointment up to three times. However, pre-trial work did not account for other practical barriers such as ill-health, or the financial implications of having to take time off work to attend. Further, the mitigating actions put in place were not always sufficient enough to overcome barriers, which is made evident by the lack of attempts to reappoint at a more convenient time.

Unlike the barriers to attending their initial appointment, participants were more likely to provide psychological barriers for not making or attending another appointment. Participants at this stage gave reasons such as low perceived risk of lung cancer, fear, worry and fatalism. There was also a high level of overt avoidance of lung cancer screening, with some not wishing to know if they had lung cancer. These are also commonly cited barriers to lung cancer screening in existing literature (Patel et al., 2012; Jonnalagadda et al., 2012). The recurring pattern of citing practical barriers, followed by psychological barriers, is of particular interest. It suggests that the underlying psychological beliefs about lung cancer might impact the way in which they approach the practical barriers they face when attending a scheduled appointment. When the practical barrier is removed (i.e. offered another appointment) the underlying beliefs still persist and are more difficult to overcome. This results in participants not remaking an appointment.

The recurring pattern also provides us with key insights into the decision-making processes. It appears that non-attenders make an automatic decision to participate in lung cancer screening when they receive their invitation letter. This is an almost reflexive decision, based upon their previous screening behaviour. However, owing to the time between initial invitation and the eventual screening appointment, participants became more reflective in their decision-making, resulting in them not attending or remaking their appointment. This final decision not to attend or remake their appointment is based on their existing knowledge of lung cancer and lung cancer screening, as well as their emotional representations of lung cancer. This decision-making process corresponds to Dual Process Models of decision-making (Kahneman, 2003). It is hypothesised that participants engaged System 1 when first invited to take part in the trial; a decision to attend made quickly and based on their existing knowledge. Within the period of time between invitation and attending their appointment, they engaged the more reflective System 2. Making a deliberative decision not to attend their appointment, or make another for a later date, might be the result of having time to ruminate on their emotional representations of lung cancer. When faced with practical barriers, there is less inclination to put in place effective coping responses to overcome them and a deliberate decision was made not to make another appointment.

Understanding how non-attenders make decisions to not attend a lung cancer screening appointment has important applications to not only any future lung cancer screening programme implemented in the UK, but to existing cancer screening programmes. The insight gained will help to optimise interventions to increase uptake in cancer screening by targeting either System 1 or System 2 decision-making processes. In the case of screening non-attenders, it would be more helpful to capitalise on System 1, when people make fast decisions and are more positive towards screening. A key recommendation for this group would be to reduce the time between initial invitation and attending a screening appointment. This ensures that participants can still make an informed decision, but do not have time to engage with emotional representations of cancer.

Alongside the emotional representations non-attenders hold about lung cancer, their beliefs also contribute to their non-attendance of lung cancer screening. Non-attenders tended to underestimate their own risk of getting lung cancer. Further, some also considered that they had little or no control over their risk of lung cancer. This is similar to the findings of the ECLS trial attenders discussed in Chapters 4 and 5, where those from more affluent groups and those recruited via the community where found to have lower perceived control over their own risk. It is unclear of the mechanisms behind the low perceived control of risk in attenders of the ECLS trial, however non-attenders considered lung cancer to be predetermined and outwith their control. In this group, it led them to believe that attending lung cancer screening was unnecessary. This is in line with existing literature on the barriers of lung cancer screening in the UK (Patel et al., 2012), as well as breast, cervical and bowel cancer screening (Lo et al., 2013). This belief appeared to be stronger in smokers in ECLS trial non-attenders, but also persisted in some past smokers. Smokers were more likely to minimise the risk of smoking and all non-attenders appear to underestimate their own personal risk. This was particularly evident when smokers compared their risk to that of non-smokers and considered there to be no difference in risk. This indicates that there might be a level of unrealistic optimism among non-attenders who smoke. Although, this risk perception bias might be a coping mechanism (denial and avoidance) adopted in order to deal with the emotional response they might feel if they confirmed their own risk.

The perceived severity of lung cancer led non-attenders to hold fatalistic beliefs. They considered that lung cancer was severe, more so than other cancers. As a result, non-attenders believed the survivability of lung cancer to be low. Both the uncontrollability of cancer risk and the severity of lung cancer induced emotional responses that acted as a barrier to attending or remaking a lung cancer screening appointment. Fatalism and fear among this group was common, alongside adopting a generally stoic attitude towards life and health. Fatalistic beliefs about lung cancer appear to be a common theme and persists across SES and ECLS trial attenders and non-attenders (Chapters 3, 4, 5 and 6). The difference between ECLS trial attenders and non-attenders could lie in how each group applies appropriate coping mechanisms. Non-attenders were more likely to employ maladaptive coping mechanisms, such as avoidance. Perhaps attenders were more successful at adopting coping mechanisms despite their feeling of risk or lack of control.

Non-attenders beliefs were successfully mapped onto the CSM and HAPA model in an attempt to explain the processes behind non-participation in lung cancer screening, with the exception of the impact of comorbidity. There was found to be significant overlap between the constructs of the CSM, HAPA model and the themes developed in thematic analysis. Neither the CSM nor the HAPA model could fully explain non-attendance of lung cancer screening but each model included important components. The use of two models has highlighted areas of overlap and helped to identify gaps that should be the focus of future research.

There was significant overlap between CSM and HAPA with regard to the role coping strategies play in a group of people who already have positive intentions. Non-attenders were unable to employ action-focused coping strategies that would help them overcome the initial practical and emotional barriers they faced when the time came to attend their appointment. They were also unable to appraise the maladaptive coping strategies adopted and realign in order to make another appointment. Coping planning and coping appraisal seem to be significant problem areas for non-attenders, with the time between invitation and appointment vital to whether or not they attend their appointment - this supports the knowledge that non-attenders use a two-system approach to decision-making (Kahneman, 2003).

Of interest, current health state significantly contributed to participants non-attendance. Often, those with comorbidities considered their current health conditions not only as a barrier to physically attending their appointment, but also as a cognitive barrier to screening. Participants with poor health were often more focused on their current health conditions, and did not have the capacity to worry about, or deal with having lung cancer. However, neither behavioural model could adequately explain the role ill-health plays in non-attendance. This is a clear gap in our theoretical knowledge, which could perhaps have practical implications to the implementation of cancer screening programmes in the UK.

The use of theoretical frameworks in analysis has highlighted that in order for individuals' experience of cancer screening to make sense we should not stick rigidly to one model to explain behaviour. It has been useful to explore more than one model in the context of non-attendance of lung cancer screening and it has helped to identify themes in analysis that would otherwise not have been considered.

Overall, exploring non-attenders' barriers and beliefs have aided in developing our understanding of the decision-making processes inclined abstainers implement when invited to participate in screening. The two-system approach to decision-making adopted by this group will help us to identify appropriate interventions to increase screening uptake in not only lung cancer screening, but other forms of cancer screening.

7.3 Strengths and limitations

The research conducted for this thesis contained both a number of strengths and limitations, which will be outlined briefly in this section.

7.3.1 Exploration of an unmet research need

Lung cancer has been described as a cancer of substantial unmet need and is under researched compared to other forms of cancer. The novelty of the topic and the application of psychological methods and theories to the topic are a strength of the thesis. The research described in this thesis provides insight that has practical implications on existing cancer screening programmes, and future lung cancer screening programmes.

7.3.2 Mixed methods approach

An important strength of this thesis is the mixed methods approach taken to explore the factors associated with the participation in lung cancer screening. The thesis includes an integrative systematic review exploring both qualitative and quantitative literature (Chapter 3), two quantitative analyses using a large trial dataset (Chapters 4 and 5) and qualitative interviews (Chapter 6). Each study has contributed to providing a holistic picture of lung cancer screening participation and the demographic and psychosocial predictors of screening uptake.

Mixed methodologies are valuable to health research in a number of ways, including helping to address complex and multifaceted research questions, such as those explored in this thesis. The use of qualitative and quantitative methodologies has provided both deep and broad insights in answering the thesis research questions more so than if either methodology had been used in isolation. The use of both methodologies is considered to highlight the strengths of each, while counterbalancing the limitations of the individual approaches. For example, qualitative approaches help us to understand, in more detail, the mechanisms behind decision-making, while quantitative approaches are effective in producing generalisable findings.

The approach to analysis in this thesis can be considered to be novel, particularly so with the integrative systematic review (Chapter 3) and qualitative analysis (Chapter 6). The systematic review presented in this thesis explored both quantitative and qualitative literature separately, at first, and then integrated them in an innovative way using thematic analysis and integrative matrices, in order to draw conclusions in a cohesive manner. Similarly, qualitative analysis used in Chapter 6 provided a unique approach by comparing themes - generated using framework analysis - to the constructs of two theoretical models of behaviour. This ‘bottom up’ methodology meant that the data was explored in a way that was comprehensive, providing helpful insight into the overlapping constructs and gaps that are not accounted for by the theoretical models.

All of the studies in the thesis have been integrated in such a way that the findings have allowed for comprehensive discussion, conclusions to be drawn, and recommendations to be made. The use of novel approaches to analysis have provided interesting perspectives of the factors associated with lung cancer screening participation and have positively contributed to methodological discussion.

7.3.3 Generalisability of screening trial

The ECLS trial is central to this thesis. Data from the ECLS trial was used within Chapters 4 and 5, and ECLS trial non-attenders were interviewed to explore barriers to lung cancer screening in Chapter 6. The UK does not routinely provide lung cancer screening via a national screening programme. Consequently, there is no opportunity to explore the uptake of true screening programmes. Lung cancer screening trials offer a unique opportunity to explore potential issues around uptake before widespread implementation.

However, it is noted that participating in a screening trial is not the same as participating in a screening programme, which must be taken into account when considering generalisability of findings. For example, this might explain some of the variation in findings of the systematic review (Chapter 3), and the findings of the analysis in Chapter 4, both of which explored the differences in beliefs across different SES groups. Individuals participating in the lung cancer screening trial should be aware that the primary aim of the trial was to evaluate the effectiveness of a blood test to detect biomarkers that indicate the presence of lung cancer, which obviously varies from the true aim of real-world screening services, where the primary aim is to detect cancers.

Despite this, there was significant overlap between the findings of the thesis with existing screening literature. Further, there was a high level of support for lung cancer screening among ECLS attenders, and the perceived effectiveness of the blood screening test. In the qualitative work presented in Chapter 6, only one participant discussed issues of the ECLS trial being an RCT and not a ‘real screening programme’, leading them to reconsider their participation.

The trial has also successfully recruited high-risk people from deprived groups. This might be the result of more robust recruitment strategies but must not be overlooked. The recruitment strategies discussed in Chapter 5 have real-world applications and should not be reserved for the purposes of reaching optimal numbers required for screening trials.

7.3.4 Secondary data set

The thesis used a secondary data set to explore the beliefs of ECLS trial participants. There are some challenges when it comes to the use of secondary data. As the baseline questionnaire was not developed in order to answer the research questions of this thesis, it might be the case that more appropriate variables could have been used to explore the beliefs about lung cancer and lung cancer screening. The baseline questionnaire also used a number of single item measures and psychosocial variables. This was done in order to minimise the length of the questionnaire and therefore the burden on trial participants. The use of single item measures might not be as effective in exploring complex beliefs and attitudes associated with lung cancer, such as worry or fear. Single-item measures can also be less reliable than multiple item scales because measurement error can be reduced when the scores of multiple items are summed.

Having no control over the development of the baseline questionnaire required a flexible approach to analysis and meant maximising the available data to gain as much insight as possible and adequately answer the research questions. This required extensive exploration of the ECLS data; how the data was collected by the ECLS team, and any potential gaps in the data. This was labour intensive but resulted in having a considerable understanding of the ECLS trial and the baseline questionnaire data.

7.3.5 Recruitment challenges

The qualitative work presented in the thesis (Chapter 6) involved recruiting non-attenders of the ECLS trial. This was a challenging process, with uptake in the study generally quite low. The initial pool available to draw from was determined by ECLS trial records. All of those identified as non-attenders were contacted and invited to participate in the interviews, however, only 15 indicated they would be interested in participating and a total of eight took part in the study. This was not entirely unexpected given that those targeted for the study had previously indicated their willingness to participate in the ECLS trial but ultimately did not. Time restraints of the study also meant that we could not recontact those who did not respond to the initial study invitation. As a consequence, the sample size was relatively small.

There is much debate about appropriate sample size for qualitative research (Braun & Clark, 2019), for example if one should continue to sample until data saturation (Gentles et al., 2015) or use fewer participants with richer data collected (Morse, 2000). The small sample size allowed me to get to know each participant in greater detail than might have been the case if more participants had been recruited. This greatly assisted with the data that resulted from the interviews, which was rich, detailed and contributed to our understanding of cancer screening decision-making processes.

7.4 Implications for future research, policy and practice

The findings of this thesis have implications on future research, policy and practice. These implications are presented in the following section.

7.4.1 Future research

The findings of this thesis point toward several different avenues for further research. First, an important direction for future research would be to explore the beliefs of lung cancer screening attenders, decliners and non-attenders. To my knowledge, a comparison of the lung cancer beliefs held by these distinct groups has not been investigated. Predominantly, research has focused on the views of lung cancer screening attenders. Both decliners and non-attenders are important groups to engage with and are key to optimising the uptake of lung cancer screening. In order to compare the views of these groups, we must use validated and comprehensive measures of the potential psychosocial and attitudinal barriers to lung cancer screening. The findings of this thesis indicate that the views of attenders and non-attenders are similar, but as indicated in Chapter 6, non-attenders do not adopt effective coping mechanisms. Previous research has concluded that these groups cannot be distinguished in terms of motivation to attend cancer screening (Orbell & Sheeran, 1998). However, in order to successfully compare the groups beyond motivation and intention, it would be prudent to compare them both quantitatively and qualitatively. On this basis, it might be possible to understand the nuances between attenders and non-attenders in order to improve engagement with lung cancer screening in those with positive intentions.

A second future direction for research could be to assess the differences observed between recruitment types in the ECLS trial by conducting an RCT. The results reported in the thesis (Chapter 5) indicate that GP-based invitations are more effective in the recruitment of high-risk deprived groups, compared to community-based recruitment. However, it has been noted that there was potential for ‘study contamination’ across the different recruitment groups, with those receiving GP invitations potentially exposed to community-based advertisement. Those from the GP recruitment group could have been further influenced by seeing study advertisements in the community, on top of receiving their GP letter. In order to assess the true effectiveness of different recruitment methods on different SES groups, I propose an alternative study design. By using one recruitment method in different geographic areas we can explore the differences in uptake and the demographics of those engaging with each method. For example, if we take the geographical locations used in the ECLS trial - Glasgow, Tayside and Lanarkshire - it would be of particular interest to assign each a single recruitment method (GP-endorsed letter, community advertisement or standard screening invitation) and observe the differences in uptake. There is existing literature of the effectiveness of GP-based invitations on the uptake of bowel cancer screening in underserved groups (Duffy et al., 2017). However, because of the infancy of lung cancer screening programmes, little work has been done in this area, but would be beneficial for any future screening programme.

The work reported in Chapter 6 of this thesis indicates that non-attenders of lung cancer screening make their decision not to participate by implementing a two-system approach. First, making a fast and intuitive decision leading them to agree to participation (System 1), followed by engaging a more reflective decision-making process (System 2), and with time not participating in screening despite their positive intentions. There are a number of potential interventions that can be developed in order to address non-attendance at screening trials, but given the insight gained from this thesis it would be appropriate to explore interventions that aim to optimise System 1 decision-making. This might include reducing the time between initial invitation and screening appointment, or by employing GP endorsement of screening that might result in people sticking with their default decision and removing the need for them to evaluate the risks and benefits themselves (Brawarsky et al., 2004). However, these interventions alone do not actively encourage informed decision-making. Another way to support uptake in non-attenders might be to provide them with further support to help them overcome the barriers they perceive. This could involve providing a patient navigation service that can give one-to-one tailored support by providing clear information and practical guidance, in an emotionally supportive context (McGregor et al., 2016). Patient navigators have been found to effectively increase uptake in other forms of screening, and it is hypothesised that it would be beneficial for non-attenders of lung cancer screening. Developing and testing of an intervention package that involved a combination of GP endorsement, patient navigation services, and reduced time between invitation and appointment might provide greater insight into which is most effective for increasing uptake of non-attenders.

7.4.2 Implications on policy and practice

The findings of this thesis point to several recommendations about increasing the uptake of lung cancer screening. First, it should be noted that there was a high level of positive attitude towards lung cancer screening across the ECLS trial studies conducted (Chapters 4, 5 and 6). This highlights that there is an appetite for this type of screening among those who are at high risk of lung cancer, which has positive implications for any lung cancer screening programme implemented in the UK. Positive attitude towards lung cancer screening, as well as the perceived effectiveness of the screening test (in the case of the ECLS trial, a blood test), has been shown to be positively associated with greater cancer screening participation (Berkowitz et al., 2008). Even among non-attenders, there was a strong indication that lung cancer screening in the UK was necessary, and there was surprise among participants that one did not already exist.

The thesis sets out that lung cancer rates are higher among those from more deprived groups and it is with this knowledge that lung cancer screening trials often aim to explore SES as a predictor of uptake, or as with the ECLS trial, use SES as a criterion for participation. However, as discussed in Chapters 3 and 4, there is no standardised measure of SES and this presents us with a number of challenges. First, if we are to use SES as a criterion for participation in lung cancer screening or screening trial, or as a contributing factor to individualised risk assessment, we must ensure we are truly identifying a person's SES. Second, the use of a variety of measures of SES in screening research presents a challenge when trying to make comparisons across research. Both area-based, and individual measures of SES have their merits and shortfalls, with both measuring different aspects of SES. This thesis indicates that in the case of lung cancer screening, although the ECLS trial were successful in the recruitment of deprived groups using the area-based SIMD measure, the participants were not as deprived as first thought, with participants having greater access to wealth and resources than expected. As a result, it would be recommended that individual measures of SES are used to create a standardised composite measure in order to calculate individual SES. This individual risk score could contribute to the calculation of a person's overall risk of developing lung cancer and, therefore, eligibility for lung cancer screening. Further work should be done to understand what components of a composite measure would create an effective measure of SES.

The results of the thesis have also provided insight into how different types of screening influence screening uptake in different SES groups. Those from more deprived groups engage better with invitation via their GP, compared to community-based recruitment. Conversely, community-based recruitment was much more effective in engaging those from more affluent groups. This has clear implications on the invitation strategies we might want to employ in a future lung cancer screening programme, but there are also practical implications for other forms of cancer screening currently in existence. The results of the thesis indicate that the use of GP-endorsed invitation letters should be routinely employed by UK screening programmes in order to optimise screening uptake in under-screened deprived groups. The results also indicate that community-based invitations should be used sparingly, and not in isolation. Community-based invitations have the potential to widen screening inequalities among different SES groups as it would appear that those from low SES groups are less likely to engage with them. This group are already less likely to participate in cancer screening and the invitation strategies we employ should not inadvertently exacerbate that.

The exploration of perceived barriers to lung cancer screening among non-attenders has provided us with some foresight into the potential barriers that might hinder a future lung cancer screening programme from reaching optimal uptake. Of note, the practical barriers faced by the non-attenders of the ECLS trial are also commonly cited by non-participants of other forms of screening programmes. These practical barriers are potentially easier to overcome with the right organisational changes, compared to the emotional barriers non-attenders might face. If the non-attenders of the ECLS trial did not come up against practical barriers, it can be posited that they might have attended their appointment. The ECLS trial attempted to address some of the anticipated barriers to participation (e.g. transport), which was somewhat successful. However, providing paid transport to attend cancer screening might not be as practical in a ‘real-life’ context. The practical barriers cited in this thesis were primarily competing priorities (e.g. work) and comorbidities. Both of these barriers could be addressed by implementing simple changes to the organisation of screening programmes. For example, as recommended by Mike Richards in the recent review of screening programmes in England (NHS England, 2019), it would be possible to ensure that screening programmes that require physical attendance operate outside of traditional working hours. This would lessen the burden screening appointments might have on some working age people who either find it difficult to be absent from work, or there are financial implications to attending screening appointments within working hours. There are fundamental issues with the flexibility of appointments in cancer screening that, if addressed adequately, could help to reduce inequalities in screening uptake. Competing priorities are a valid barrier to cancer screening, particularly among deprived groups and those with other health conditions. Embedding accessibility into cancer screening, including location and flexibility of appointment times, would go some way to increase participation in those with positive intentions to attend.

7.5 Conclusions

This thesis set out to grow our understanding of lung cancer screening participation. In doing so I have explored the demographic and psychosocial factors associated with lung cancer screening.

Lung cancer screening participation is lowest among those from more deprived groups, with these groups also more likely to be at high risk of lung cancer. This thesis identified variation in beliefs and awareness of lung cancer and lung cancer screening across SES groups that might help somewhat explain the differences in screening uptake. Compared to those from more affluent groups, those from deprived groups are more likely to have a lower level of knowledge of lung cancer, lower perceived control of lung cancer risk and more pronounced emotional response to the thought of their own risk of lung cancer. It is considered that this might be evidence of greater fatalistic beliefs about lung cancer and, in the case of non-attenders, might result in the adoption of maladaptive coping strategies, such as avoidance.

The thesis also looked to examine how different cancer screening invitation types might influence uptake of lung cancer screening. In doing so, it was found that there was variation in engagement across SES groups, with those from more deprived groups more likely to engage with GP-endorsed invitations, compared to community-based invitations. This insight not only has implications on lung cancer screening participation, but also existing cancer screening programmes.

The thesis also provided opportunity to explore factors that contribute to non-participation in lung cancer screening. Non-attenders of lung cancer screening are likely to cite both practical and emotional barriers to lung cancer screening. It is believed that they employ a two-system approach to decision-making. This has provided a greater understanding of non-attendance in those with positive intentions, and the possible interventions that could be developed to encourage participation.

This thesis has made a novel contribution to the literature by advancing understanding of the factors that might explain variation in lung cancer screening participation and has provided practical recommendations that could reduce screening inequalities among high-risk deprived groups. The development of interventions to address the identified screening inequalities, and improve overall engagement with lung cancer screening, should remain a priority in future screening research.

Appendix 1: PROSPERO systematic review registration

Public perceptions and awareness of lung cancer in different socioeconomic groups

Hannah Scobie, Katie Robb, Sara Macdonald

Citation

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Review question

What are the public perceptions and awareness of lung cancer, and do they vary by socioeconomic status?

Searches

The search strategy will include publishes literature.
Databases: MEDLINE/PubMed; EMBASE; CINAHL; PsycINFO; Web of Science Core Collection; and IBSS
Period: 1990 - 2015
English language only

Types of study to be included

No restrictions on study design type eligible for inclusion.

Condition or domain being studied

The review will study beliefs and awareness of lung cancer among lung cancer patients and the lay public.

Participants/population

Inclusion:
Studies from any geographical location
Adults
Patients with lung cancer
Lay public
Exclusion:
Children (aged under 16 years)

Intervention(s), exposure(s)

We will identify all papers investigating perceptions and awareness of lung cancer.

Comparator(s)/control

Not applicable.

Main outcome(s)

An integrated synthesis of qualitative and quantitate studies that aim to describe the beliefs and awareness of lung cancer amongst different socioeconomic groups.

Additional outcome(s)

The results from the review will inform the development of future interventions for improving early detection of lung cancer.

Data extraction (selection and coding)

Title, abstract, and full paper screening will be carried out by the review team, aided by Distiller software. Data analysis will be carried out using a formal data extraction instrument. Discrepancies will be reviewed by a member of the research team.

Risk of bias (quality) assessment

The researchers will assess included studies for quality using Popay’s (2006) seven point scale. Studies will not be excluded on the grounds of quality.

Strategy for data synthesis

Intervention studies will, if appropriate, be synthesised to provide a meta-analysis. However, if aggregation is not possible, a narrative review will be presented. Both qualitative and quantitative observational studies will be presented as a narrative analysis. For qualitative studies in particular, findings will be first subject to initial coding, classification into broad themes and then finally an addition 'line of argument' will be presented.

Analysis of subgroups or subsets

None planned

Contact details for further information

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Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Awareness; Humans; Lung Neoplasms; Perception

Date of registration in PROSPERO

26 August 2015

Date of first submission

Stage of review at time of this submission

The review has not started

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

26 August 2015

Appendix 2: Systematic review search strategy

Databases: Medline / Pubmed ; Embase ; Cinahl ; PsychInfo ; Web of Science Core Collection ; IBSS

Period: 1990 - 2015

Keywords
1. Cancer
2. tumour
3. neoplasm
4. lung

-

5. patient*
6. lay
7. public

-

8. detect*
9. aware*
10. recognise*

-

11. knowledge
12. education*
13. information*
14. lay concept*

-

15. health belief*
16. attitude*
17. expectation*
18. behav*
19. perception*

-

20. difference*
21. variation*

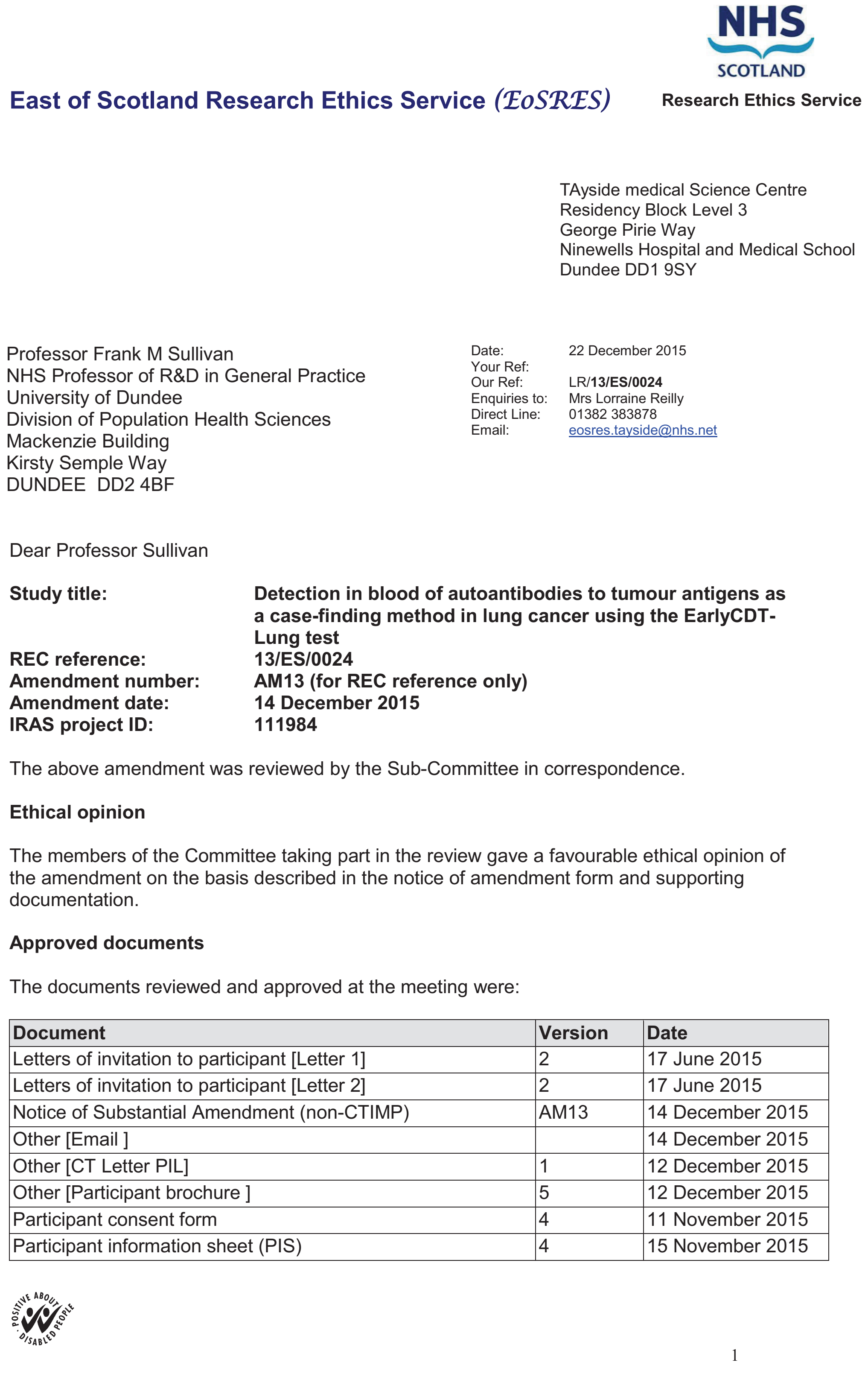
-

22. #1 OR #2 OR #3
23. #1 OR #2 OR #3 AND #4
24. #5 OR #6 OR #7
25. #5 OR #6 OR #7 AND (#4 AND #1 OR #2 OR #3)
26. #8 OR #9 OR #10
27. #25 AND #26
28. #11 OR #12 OR #13 OR #14
29. #25 AND #28
30. #15 OR #16 OR #17 OR #18 OR #19
31. #25 AND 30
32. #20 OR #21
33. #25 AND #26 AND 28 AND #30 AND #32

Appendix 3: Systematic review data extraction form

Ref ID (from Distiller)	_ _ _ _ _		
Authors			
Title			
Source (Journal Name)			
Year	Volume	Part	Page no.
Study Design			
Methodology Score (from quality assurance form)			
Study Location (city; country)			
Study Topic	Belief	Awareness	Both
	Lung cancer	Lung cancer screening	Both
Duration of Study (if applicable)			
Participant Characteristics (including numbers)			
Intervention/ Control used (if applicable)			
Main Findings			
Other Relevant Comments			

Appendix 4: NHS ethics application approval correspondence



NHS SCOTLAND
Research Ethics Service

East of Scotland Research Ethics Service (EoSRES)

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Professor Frank M Sullivan
NHS Professor of R&D in General Practice
University of Dundee
Division of Population Health Sciences
Mackenzie Building
Kirsty Semple Way
DUNDEE DD2 4BF

Date:	22 December 2015
Your Ref:	
Our Ref:	LR/**13/ES/0024**
Enquiries to:	Mrs Lorraine Reilly
Direct Line:	01382 383878
Email:	eosres.tayside@nhs.net

Dear Professor Sullivan

Study title:	**Detection in blood of autoantibodies to tumour antigens as a case-finding method in lung cancer using the EarlyCDT-Lung test**
REC reference:	**13/ES/0024**
Amendment number:	**AM13 (for REC reference only)**
Amendment date:	**14 December 2015**
IRAS project ID:	**111984**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letters of invitation to participant [Letter 1]	2	17 June 2015
Letters of invitation to participant [Letter 2]	2	17 June 2015
Notice of Substantial Amendment (non-CTIMP)	AM13	14 December 2015
Other [Email]		14 December 2015
Other [CT Letter PIL]	1	12 December 2015
Other [Participant brochure]	5	12 December 2015
Participant consent form	4	11 November 2015
Participant information sheet (PIS)	4	15 November 2015

Research protocol or project proposal [Tracked Changes]	6	12 December 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

13/ES/0024: **Please quote this number on all correspondence**

Yours sincerely

pp
Dr Carol Macmillan
Chair

E-mail: eosres.tayside@nhs.net

Enclosures:	List of names and professions of members who took part in the review
Copy to:	NHS Tayside R&D office TASC

East of Scotland Research Ethics Service REC 1

Attendance at Sub-Committee of the REC meeting on 21 December 2015

Committee Members:

Name	Profession	Present	Notes
Dr Carol Macmillan	Consultant Anaesthetist	Yes	Chair
Dr Gary Lyon	Retired	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs Lorraine Reilly	Senior Co-ordinator

Written comments received from:

Name	Position
Dr Carol Macmillan	Consultant Anaesthetist, Chair
Dr Gary Lyon	Retired

Appendix 5: Participant information sheet

Participant Information Sheet

Title: Exploring public perceptions of lung cancer screening.

Introduction

We would like to invite you to take part in a research study. Before you decide we would like to tell you why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being carried out by a research team from the Institute of Health and Wellbeing at the University of Glasgow working in partnership with the Early Cancer detection test – Lung cancer Scotland (ECLS) research team. The research is part of a PhD project.

What is the purpose of this study?

We want to know what people think about lung cancer screening and find out why people decide not to take part. This will help us improve the information we give to people about tests for lung cancer in the future.

Why have I been invited?

We are contacting men and women who were invited to take part in the ECLS study in Glasgow and Lanarkshire. We would like to talk to people who decided NOT to take part in the study.

What will this study involve?

This study will involve meeting one of our researchers either at your home or at our office at the University of Glasgow, or speaking with them on the telephone, whichever suits you best. If you choose for the researcher to come to your home to conduct the interview, the safety of the participant and researcher will be ensured by following the procedure in the University of Glasgow's Lone Working policy. If you choose to come to our office at the University of Glasgow your travel expenses will be reimbursed.

The researcher will ask you some questions about why you decided not to take part in the early cancer detection test study. You will have an opportunity to add any extra comments you would like to make. With your permission, this discussion will be audio recorded so that the researcher does not have to make notes during the session and can concentrate fully on listening to what you say. This will take up to 1 hour.

After your meeting with the researcher you will not be required to do anything further but we will send you the results of the study if you wish. If you would like a summary of the results, your name and address will be taken after the interview is completed.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you may receive now or in the future.

What do I do if I want to take part?

If you are interested in taking part in this study, or have any questions about the study, please call or text Hannah Scobie on XXX XXXXXXX or email.

Alternatively, please return the reply slip in the FREEPOST envelope. Once you have returned your reply slip, a member of the research team will call you to discuss the study with you and, if you are willing to take part, to arrange a convenient date and time for your interview.

Confidentiality

All the information you give us is strictly confidential. All audio-recordings will be stored securely and your name will not be held with the recording. Notes will be taken from the recording and the recordings will then be destroyed. Your name will not be held with the notes. Only the research team will have access to the information.

What happens to the information that is collected?

It is intended that the results of the research will be used within a PhD thesis and published in an academic journal.

Data from interviews will be digitally recorded and recordings will be uploaded to password protected university computers. The recordings will be assigned a unique ID number rather than the participant name. Thereafter paper copies of transcripts will also be stored in locked filing cabinets at the University of Glasgow. Any direct quotations that may be used with publications or reports will use the unique identifier. As such individual participants will not be identified. Data will be retained for 10 years after the study is completed.

The information collected should help to improve the information we give people about cancer screening in the future and help them make decisions about taking part in the screening programmes. It is important to point out that no volunteers included in the research will be able to be identified from any report or publication.

What will happen if I don't want to carry on with the study?

At any time during the study, if you do not wish to carry on you may withdraw, without giving any reason. With your permission we will retain any data collected up until that point. However, if you do not wish for the data to be used in any way it will be destroyed and not included in the study.

What are the possible benefits of taking part?

We cannot promise the study will help you directly, although in previous studies participants have commented that they have enjoyed the opportunity to think about their health and express their views. We are able to offer you a £20 shop voucher as a token of our appreciation for your participation.

What are the possible disadvantages of taking part?

The study will take about an hour of your time. There are no right or wrong answers to the questions and you can talk about anything that you feel is relevant. It is possible that during the interview you may find a topic sensitive or upsetting and you are free to ask the interviewer to move on to another subject or stop the session altogether. If you wish to stop the interview, the information you have given up to that point will be retained with your permission. However, if you do not wish for the information to be used it will be destroyed.

It is important for you to understand that you are not required to discuss anything that you do not want to and you should discuss only the things which you feel are relevant. If you have concerns you can discuss them fully with the research team.

Who has reviewed this study?

The East of Scotland Research Ethics Committee, REC 1, which has the authority to scrutinize proposals for medical research on humans, has examined this study and has raised no objections from the point of view of medical ethics.

If you have a complaint about any aspect of the study

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanism is also available to you. Please contact:

Feedback & Complaints Officer
NHS Greater Glasgow and Clyde,
J B Russell House,
Corporate Headquarters,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow, G12 0XH
Telephone: 0141 201 4550

Further information and contact details

If you wish to obtain further information about this research, please do not hesitate to call or text Hannah Scobie on XXX XXXXXXX. If you would like to speak to someone outwith the research team please contact (person to be appointed).

Thank you very much for considering taking part in our research. Please discuss this information with your friends, family or doctor if you wish.

Hannah Scobie

MRC PhD Student
General Practice and Primary Care
Institute of Health and Wellbeing
University of Glasgow
1 Horselethill Rd
Glasgow G12 9LX
Tel: +44(0)141 330 8214
Email: h.scobie.1@research.gla.ac.uk
http://www.gla.ac.uk/departments/generalpracticeprimarycare/
www.eclsstudy.org

MRC Medical Research Council

Appendix 6: Participant consent form

Participant Consent Form

Title of Study: Exploring public perceptions of lung cancer screening.

Name of Researcher: Hannah Scobie

Please initial each box to the right of each statement

I confirm that I have read and understood the participant information sheet (V4, 15th November 2015) and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time without having to give a reason.	
I understand that if I choose to withdraw from the study all data collected up to that point will be retained with my permission. If permission is not given, the data will be destroyed.	
I agree to my interview being audio recorded.	
I understand that information or quotes from the studies may be used in publications / reports, but that this will be completely anonymous so that I cannot be identified.	
I understand that data collected during the study will be used by researchers involved in the study and the data will be retained for 10 years after the study is completed.	
I understand that I can have a summary of the results if I provide the researcher with my name and address.	
I understand that the interview may be conducted either in my home, over the telephone, or at the University of Glasgow.	
I agree to take part in the study.	

Participant's Name:

……………………………………………………………………………………………………

Signature: ……………………………………………………………………… **Date:**

Researcher Signature: ………………………………………………… **Date:**

Appendix 7: Non-attender interview schedule

Study Title: Understanding why people who are initially interested in lung screening fail to participate.

1) **General views about cancer screening**

What do they think about it, what do they feel about it

How do they think people make decisions about whether to do screening – 'know' as soon as invited/think it over/don't know

2) **Beliefs about cancer in general and lung cancer**

Are they aware of spouse/family/friends taking part in screening?

What comes to mind when you think about:

i. Cancer?

ii. Lung cancer?

Following elicitation of participants' beliefs about, ask how fearful participants are of cancer in general and lung cancer and whether they believe they (lung or other types) can be successfully treated (if these have not come up in response to the first questions).

3) **Understanding of the lung screening test**

What comes to mind when you think about lung cancer screening?

Following the elicitation of image, ask them to explain how they would explain this image and why they had it.

What is their understanding of what the test involves?

What is their understanding of the purpose of the test – detection/prevention?

4) **Personal decision about lung cancer screening participation (show example invitation letters and leaflets to prompt memory)**

Do they remember receiving an invitation for the screening test?

As best they can remember, when invitation letter arrived in the post how did they think, how did they feel?

How did they decide what to do next? (e.g. Knew right away what they'd do/thought it over/don't know/remember)

What did they do next? (e.g. Acted immediately, acted after a reminder, forgot, changed mind, didn't get round to it...)

Did other things happen in life at the time influence decision?

What did they think when decided not to attend the lung screening appointment? How did they feel about it? Were other things happening in their life that influenced their decision?

5) Feelings of risk lung cancer

What do they feel about their chances of getting lung cancer? Do they feel equally at risk/not at risk/higher risk for lung cancer compared to other types of cancer? Do they feel their chances of getting lung cancer is the same or different for other types of cancer? Why?

Who do they think would be at high risk of getting lung cancer and why?

Conclusion

Thank participant for time

Is there anything else you would like to add that we might have missed out?

Appendix 8: ECLS sub-study protocol submitted for NHS ethics

Exploring public perceptions of lung cancer screening

Researcher: Hannah Scobie

Supervisors: Dr Katie Robb, Dr Sara MacDonald, Professor Sally Wyke, Dr Stephen Harrow. University of Glasgow

Funder: Medical Research Council

1. Introduction

1.1 Rationale

Lung cancer kills more people than any other cancer, with approximately 5,000 people dying from lung cancer every year in Scotland. This is often because there are few symptoms until the cancer is at an advanced stage when the chance of cure is low. Lung screening offers the potential to detect lung cancers at an earlier stage when they are easier to treat. A recent trial in the US found that lung cancer mortality decreased by 20% among those receiving low dose computed tomography screening (Aberle, Adams, Berg, Black, Clapp & Fagerstrom, 2011). However, the benefits of cancer screening are only realised if people are willing to participate. Cancer screening participation rates remain suboptimal (Audit Scotland, 2012), and may be particularly challenging in the case of lung screening. Smokers are disproportionately represented among people living in more deprived areas who also have lower uptake of other cancer screening programmes (Scottish Household Survey, 2013). This means that the potential lung screening target population could be particularly hard-to-reach.

1.2 Proposed research

The proposed research consists of two further sub-studies within the Early Cancer detection test – Lung cancer Scotland (ECLS) Trial. The first sub-study will qualitatively investigate why individuals decided not to take part in the ECLS Trial, after showing initial interest. This study (Study 1) will involve interviewing ECLS Trial ‘non-attenders’ – those who initially expressed an interest in having the test, were appointed to be screened, but later decided not to participate. It is intended that up to a total of 20 men and women non-attenders in the ECLS trial will be interviewed. The sample will be drawn from the NHS Greater Glasgow and Clyde and NHS Lanarkshire Health Boards.

The second proposed sub-study (Study 2) will be a quantitative analysis of ECLS Trial attenders examining potential demographic and psychosocial differences by recruitment type. Participants in the ECLS Trial were recruited by two strategies: i) those who were invited to take part via their General Practice (GP) or; ii) those who ‘self-selected’ after seeing community advertisement/media releases or responded as a result of word of mouth. This study will examine potential differences in the demographic characteristics, beliefs about lung cancer and lung cancer screening, subjective health and risk perceptions among these two groups.

The proposed studies will complement the embedded psychological sub-studies currently being conducted by researchers at the University of Nottingham including emotional and behavioural responses following screening; exploring why people declined to participate; understanding of screening results; and smoking cessation in participants of the lung screening Trial. The proposed work therefore adds two new aspects to the ECLS Trial research by considering; i) why people change their mind about participating in the Trial; and ii) exploring any potential differences between participants recruited through GPs and ‘self-selectors’.

2. STUDY 1

2.1 Background & Literature Review

While it is noted that participating in a screening Trial is not the same as participating in a screening programme, it is useful to draw from the literature on cancer screening programme participation in helping to understand screening behavior. When participants make an appointment for cancer screening, it suggests they are motivated and intend to go to the screening appointment. However, this intention to attend does not always translate into action (i.e. attending the appointment) and ‘did not attend’ (DNA) and cancellations are frequent outcomes at screening clinics (Sheeran, 2002). Within the psychological literature. Orbell & Sheeran (1998) used the term inclined abstainers. To describe people with positive intentions who fail to act.

In the context of the present study, participants who initially make an appointment (positive intention) but go on to cancel or do not attend their appointment would be considered to be inclined abstainers. It is this group who are the primary interest of Study 1.

Among the small number of studies on psychosocial barriers to lung cancer screening, cancer fatalism appears to play a significant role in uptake. A qualitative study in England exploring attitudes towards participation in lung cancer screening found themes of fatalism, worry, and avoidance in those who declined to be screened (Patel, Akporobora, Chinyanganya, Hackshaw, Seale, Spiro, & Griffiths, 2012). This conclusion was also supported by a quantitative study in the US, where participants who had fatalistic beliefs about lung cancer were less likely to undergo screening (Jonnalagadda, Bergamo, Lin, Lurslurchachai, Diefenbach, Smith, Nelson & Wisnivesky, 2012). Other barriers to lung cancer screening included: denial of risk, shame about smoking, fears about screening and embarrassment (Walton, McNeil, Stevens, Murray, Lewis, Aitken & Garrett, 2013).

Understanding the socio-demographic characteristics of attenders and non-attenders of cancer screening is crucial to ensure the introduction of a screening programme does not exacerbate health inequalities. For example, those from more deprived groups may be less likely to attend cancer screening (Weller & Campbell, 2009; Moser, Patnick & Beral (2009), but have a higher risk of cancer due to e.g. smoking, unhealthy diet, sedentary lifestyle. Other socio-demographic characteristics that may play a role in cancer screening attendance include age and gender.

2.2 Potential Risks & Benefits

Risks - This study is low risk, however there are a few areas to consider as potentially problematic. Study 1 (invitation Strategy 2) will involve writing to potential participants in some cases 6 months or more after they did not attend their appointment. It is possible that individual circumstances may have changed within this time. In some circumstances it is possible participants may have passed away or become unwell. As a result, Health Informatics (HIC) University of Dundee will check against the patients CHI number through NHS health records to see if participants are still alive. In addition, the Study 1, Strategy 2 invitation letter will include the sentence: ‘We apologise if this letter arrives at a particularly difficult time for you.’

Another potential area of risk could be the topic of the study. We are discussing a health issue and cancer in particular, which might upset some participants. This will be avoided by reminding the participant that they are under no obligation to answer all of the questions and may stop the discussion at any point. Moreover, the interview will be flexible enough to allow participants to introduce information that they feel comfortable with. If the participant appears hesitant or in doubt about responding, the interviewer will give them some time to proceed, alter the question or move on. Finally, we will provide the telephone number and email address of the researcher at the end of the interview in case participants wish to talk about any of the issues raised in the interview. If necessary, the researcher will refer participants to one of the project supervisors to provided further information or support. If required, the supervisor will provide details for professional organisations for people who feel they need to discuss issues further.

Benefits –There are few potential benefits to research participants although in the past some participants in similar studies have reported enjoying the opportunity to take part in research. Those who participate in the interviews will be offered a £20 voucher as a token of appreciation for their participation (Appendix A). Participants will be required to sign for the voucher received at the end of the interview. If the participant wishes to withdraw from the interview at any point during the interview, the participant will still receive the voucher.

2.3 Aim

The aim of Study 1 is to explore the beliefs and perceptions about lung cancer and lung screening among people who initially expressed an interest in screening, were appointed to be screened, but who later cancelled or did not attend their appointment, and in some cases did not attend a reappointment.

Methodology

2.4 Inclusion Criteria

Participants are required to have been invited and subsequently been eligible to participate in the ECLS Trial. Further, participants will have shown initial interest in the study, but at a later time, declined to participate. See Table 1 for further details.

2.5 Exclusion Criteria

Participants who were invited to take part in the ECLS trial and completed the study. Also, inability to speak, read or write English. The study involves understanding a Participant Information Sheet, completing a consent form and taking part in an interview in English. People who are unable to speak, read or write English will therefore be excluded most likely because they will not have responded to the initial invite to take part in the Trial. See Table 1 for further details.

Table 1: Study 1 Inclusion / Exclusion Criteria

Inclusion	Exclusion
Invited to take part in the ECLS trial	Inability to speak, read or write English
Eligible to take part in ECLS trial on reassessment	Individuals who contacted the team for information, but did not make an appointment
Participants who made an appointment, but subsequently cancelled or DNA	Individuals whose eligibility to take part in the ECLS trial was not established
	Participants who cancelled or DNA but rescheduled another appointment for a later date and attended.

2.6 Study Design

Interviews will be conducted face-to-face in the participants' own homes or at the University of Glasgow, or over the telephone, whichever is most convenient to the participant. Participants' travel expenses will be reimbursed if they choose to come to the University of Glasgow. It is recognised that the researcher will be working alone. As a result, the University of Glasgow's policy on lone working will be followed to ensure the safety of the researcher and participant.

Participants will receive the Participant Information Leaflet and informed consent form with their letter of invitation by post before the interview is conducted. Contact numbers are given to contact the study team to answer any questions they may have. In the case of telephone interviews being the preferred interview format, participants are invited to send their reply and completed consent form in the prepaid envelope. Prior to the telephone interview they will be asked to confirm their verbal consent. Participants will be offered the opportunity to ask any questions about the study before informed consent is taken by the researcher. The researcher will seek consent in the first instance. Interviews will last approximately 1 hour and will be based on a topic guide (Appendix B) developed from the existing screening literature with a particular focus on barriers to cancer screening. To avoid post-hoc rationalisations of their screening behaviour we will ask participants to discuss their general views on screening first before moving on to their personal experience. With the permission of the interviewee, interviews will be audio-recorded and transcribed verbatim. If the participant does not consent to be recorded, the participant can continue with the interview with the researcher taking detailed notes instead. Data from interviews will be anonymised during the transcription process. Thereafter paper copies of the transcripts will be stored in locked filing cabinets at General Practice & Primary Care, University of Glasgow. Interview transcripts will be assigned unique identifiers and any quotations that may be used with publications or reports will use the unique identifier. As such individual participants will not be identified.

2.7 Researcher Effects

Researcher effects will be kept to a minimum by using a topic guide to ensure participants are asked the same questions. However, due to the nature of qualitative research, supplementary questions may vary depending on the responses of the participants.

2.8 Duration of Participation

Participants will be asked to take part in one qualitative interview lasting approximately one hour. The research team will not contact the participant again, although study results will be disseminated to the individual following completion of the study if requested. If participant request the study results, their name and address will be noted. Participants requesting the results will be mailed a summary of the main findings. The study results will also be disseminated through the normal academic channels, including, publications and conference presentations.

2.9 Criteria for Discontinuation

Study 1 involves a one-off interview, and this will be the only contact with the research team. If informed consent is taken at the time of interview and the participant completes the interview, the research team will have no further contact with the research participant. If a participant decides part way through the interview to withdraw from this study the data collected would be retained if permission is given. If no permission is given, the data will be withdrawn.

If participants make an appointment with the researcher and cancel or DNA the researcher will attempt to make contact again. Appointments will be rearranged up to three times. If a participant is unable to make the interview after the third attempt of rearranging an appointment, they will be removed from the invitation list.

2.10 Procedure for collecting data

This will be a difficult group to engage, as a result, three recruitment strategies will be used:

1a. It is normal practice that the ECLS study team call participants the day before their appointment as a reminder in an attempt to reduce the number of DNAs. If during this call a potential participant states they wish to withdraw from the Trial the study team will ask the participant if they would be interested in taking part in a research project for people who decide not to attend their appointment. If participants express an interest, they will be asked if they agree for a member of the research team to contact them directly to provide more information about the research. The participant will be reassured if they wish to decline and no further contact will be made by the research team.

1b. Within the ECLS Trial protocol, if a participant DNA, the study team will call the participant to offer a new appointment time. If during this call the participant states they wish to withdraw from the Trial, the study team will ask the participant if they would be interested in taking part in a research project and the procedure would be as described in 1a.

2) We will retrospectively identify and contact people who booked an appointment, accepted an appointment, but cancelled or DNA initially within the previous 12 months (i.e. 1 year from the commencement of the sub-study). If insufficient participants respond, we will contact people from the beginning of the Trial in Glasgow. Participants will be identified from the Patient Management System used by the ECLS Trial. Eligible participants will be identified by the researcher, searching the additional text related to each case for key words such as, ‘cancelled’, ‘did not attend’ or ‘DNA’. Once participants have been identified, the Health Informatics Centre (HIC at Dundee University) will extract the names and addresses of those eligible.

Participants will be contacted by post after they have been identified as a suitable candidate via HIC. Invitation letters will be sent out via a mail merge at HIC and those identified by HIC as having died will be excluded. Participants will be given a reply slip to return if they would like the researcher to contact them. Alternatively, they can contact the researcher by telephone or email. The researcher will not know the identity of the participant until the reply slip stating that they wish to participate is returned.

2.11 Data Protection

When potential participants express an interest, contact details will be stored in a locked filing cabinet at the University of Glasgow. Consent forms will similarly be stored in locked filing cabinets. Data from interviews will be digitally recorded and recordings will be uploaded to password protected university computers. The recordings will be assigned a unique ID number rather than the participant name. Thereafter paper copies of transcripts will also be stored in locked filing cabinets at the University of Glasgow. Any direct quotations that may be used with publications or reports will use the unique identifier. As such individual participants will not be identified. Data will be retained for 10 years after the study is completed.

Statistical Considerations

2.12 Sample Size

We will undertake interviews with a sample of approximately 20 ECLS Trial non-attenders. Based on previous literature, this is the likely number required to reach 'saturation' in terms of identification of new themes/ideas/issues. Based on previous experience, in order to obtain a sample of 20 participants, around 400 people may need to be contacted although this may be less depending on the success of Strategies 1a and b. The study aims to interview a mix of males and females. If possible, a sampling frame will be used so the balance of gender reflects the ratio of men to women among the DNA group overall. However, we anticipate that it will be challenging to obtain 20 participants so this may not be possible.

2.13 Method of Analysis

The data will be analysed using the `framework approach´, a type of thematic analysis. Thematic analysis is a method for identifying, analysing, and reporting recurring patterns within data, which can then be reported in a detailed way. The demographic characteristics of the participants including age, gender and Scottish Index of Multiple Deprivation score will also be described.

3. STUDY 2

3.1 Background & literature review

The ECLS trial recruits participants in two distinct ways: i) invitation via GP or; ii) through community advertisement/ media releases/word of mouth and website review. As a result, it may be possible that there are sociodemographic and psychosocial differences between the participants who were invited by their GP and those who self-selected to participate.

Previous research in lung cancer screening indicates that there are significant differences between participants who are invited to take part, and those who self-select. Participants in the US National Lung Screening Trial, who were recruited by the media, appeared to be younger, higher educated and less likely to be current smokers (NLST, 2010). Similarly, in the Dutch–Belgian Lung Cancer Screening Trial (NELSON trial), respondents to the initial invitation were somewhat younger, and less likely to be current smokers (van der Aalst et al., 2012).

Similar results can also be found outside lung cancer screening trials. In the Oslo Health Study, respondents to community and media advertisement were associated with older age, higher education levels, being married, and also not in receipt of benefits (Sogaard, Selmer, Bjertness & Thelle, 2004). A secondary analysis of the Malmo Diet and Cancer Study concurs with the results of Sogaard et al. (2004). When comparing the respondents of community invitations and personal invitations, Manjer et al. (2002) found that community respondents were older, and more often females, than participants recruited using personal invitations. Furthermore, participants recruited through community advertisement had a comparably more favourable situation with regard to sociodemographic and lifestyle factors. They also had a lower frequency of prevalent disease, lower incidence of cancer and lower mortality (Manjer, Elmsta, Janzon&Berglund, 2002).

The present ECLS study will examine potential differences between the two invitation groups of the ECLS trial. This will assist with the future development of more efficient invitation strategies that will target the most high-risk groups.

3.2 Aim

The primary aim of Study 2 is to explore if there are any sociodemographic or psychosocial differences as assessed by a baseline questionnaire between participants of the ECLS study who were invited by GP or self-selected through community advertising.

Methodology

3.3 Inclusion Criteria

In order to be included within the statistical analyses, participants are required to have taken part in the ECLS trial and completed the baseline study questionnaire.

3.4 Exclusion Criteria

Participants who took part in the ECLS trial but did not complete the study questionnaire will be excluded from the analysis.

3.5 Procedure for identifying participants

Participants will be identified from the patient management system (PMS) used by the ECLS trial. Eligible participants for the analyses will be identified by their invitation type group (GP or self-select). Once cases have been identified, the anonymised data required including demographic characteristics (age, gender, Scottish Index of Multiple Deprivation) and the responses to the psychosocial questionnaire will be extracted from OpenClinica. Data will be extracted using participants' cohort ID.

3.6 Study Design

The required anonymized data will be extracted from study data base; Open Clinica in order to complete the analysis. Data will be analysed at the University of Glasgow. The data will be transferred and stored as per the Data Sharing Agreement. The data will be analysed using Microsoft Excel 2010 and IBM SPSS version 21, provided by the University of Glasgow.

Statistical Considerations

3.7 Sample Size

This sub study will analyse the data from all attenders of the ECLS Trial.

3.8 Method of Analysis

Statistical analysis will be conducted using IBM SPSS. Participants’ base-line data will be compared for the two groups of interest – GP invitation and self-selected. This will include demographic characteristics, beliefs about lung cancer and lung cancer screening, perception of general health and risk perception obtained from the baseline questionnaire.

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