Bangor University

DOCTOR OF PHILOSOPHY

Smoking, lung cancer and presentation of symptoms to primary care: accounts of smokers and people with lung cancer.

Hendry, Annie

Award date:
2020

Awarding institution:
Bangor University

Link to publication

Smoking, lung cancer and presentation of symptoms to primary care: accounts of smokers and people with lung cancer.

By Annie Kathleen Hendry

A thesis submitted to
Bangor University
For the degree of
Doctor of Philosophy

PRIFYSGOL
BANGOR
UNIVERSITY

APRIL 1, 2019
PRYFYSGOL BANGOR UNIVERSITY
School of Health Sciences

Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Thesis Abstract

Title

Smoking, lung cancer and presentation of symptoms to primary care: accounts of smokers and people with lung cancer.

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Professor Richard Neal

Institution

Bangor University

Funder

Health and Care Research Wales

Background

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) reports that lung cancer is responsible for the greatest number of cancer deaths in Wales accounting for over two in ten deaths overall (WCISU 2018) and risk factors such as smoking contribute toward the relatively high incidence rate in Wales (Macmillan Cancer Support 2013 www.macmillan.org.uk). The National Survey for Wales lifestyle trends for 2018 reports that 17% of adults reported themselves to be current smokers (National Survey for Wales 2018-2019). It was also reported in 2014 that 20% of adults living within the Betsi Cadwaladr University Health board catchment area identified themselves as current smokers (Welsh Health Survey 2014).

As almost all cases of lung cancer are attributable to smoking smokers are at a significant risk for developing the disease (Parkin 2011). Whilst there are many campaigns encouraging smoking cessation, there is also a need to provide a high standard of care for those who suffer smoking related symptoms and to encourage them to present early by making it clear to patients that they will not be judged or blamed for their condition.

Some evidence has been shown that delays in diagnosis can seriously influence the operability of lung cancer and patients are often inoperable at the time of diagnosis, additionally, smokers with chest symptoms are likely to delay seeing their doctor (Tod et al 2007; Corner et al 2005). The patient interval is defined as the time between the onset of noticeable symptoms and the first presentation in primary care (Weller et al 2012). As survival is compromised by longer patient intervals it is important to seek out the reasons for these delays and to address concerns which may discourage smokers from seeing their GP. It has also been postulated that healthcare providers express a negative attitude toward smokers and especially lung cancer patients who ignore advice and continue to smoke (Lebel et al 2013). It may be of benefit to healthcare providers to have a deeper understanding of patient hesitancy to present in order to minimise feelings of responsibility and blameworthiness often felt by those who suffer 'self-inflicted' cancer (Chapple et al 2004).

This study employed a qualitative methodology to explore this area in-depth and examined the reasons behind delayed presentation in smokers.

Methods

The project is a qualitative study focussing on recently diagnosed lung cancer patients with a history of smoking, and current smokers who do not have cancer, and utilising interview and focus group methods. Interviewees were recruited from secondary care, focus group participants were recruited via primary care, the Health and Care Research Wales workforce assisted both rounds of recruitment. A qualitative methodology provides a depth and richness of data from which conclusions can be drawn. Qualitative methods are ideal for this study as the informal style encourages open dialogue which is the most legitimate way of collecting data comprising people's memories and perceptions. The study included three phases which all provide an evidence base from which to derive implications for policy and practice. The initial phase was a two-part literature review, comprising a systematic review and a broader narrative review, which serve to underpin the rest of the project and provided evidence on which to develop focus group topic guides and interview questions. Phase two involved 29 qualitative interviews with recently diagnosed lung cancer patients. Phase three consisted of three focus groups with current smokers. Phases two and three contained sufficient numbers of participants so that thematic saturation was reached. A qualitative, interpretive thematic analysis was carried out using the Nvivo 11 software package. Full research ethics and R&D approval were granted.

Summary of findings

The findings of this study show that delayed presentation in smokers is a deep and complex issue. Through participant's accounts it was revealed that decisions regarding help seeking are not simple, they were intrinsically bound with perceptions of risk, feelings of stigma and blame, interpretation of symptoms and the blurred lines between health and sickness. Participants described a reluctance to waste doctor's valuable time with symptoms that they felt were minor, or were self-inflicted due to smoking. The current smokers in the study reported feeling stigmatised by society in general and by their health care providers which led them to actively resist seeking primary care.

Implications for policy and practice include a need for complex interventions to encourage people who smoke to seek primary care in a more timely manner.

Acknowledgements

I would like to express my sincere gratitude to Professor Richard Neal and Dr Julia Hiscock for all their invaluable guidance and support throughout the process of this PhD. I would like to thank them both for their academic insight and expertise, which enabled me to develop professionally and academically, and for all the opportunities that undertaking this PhD has granted me. I would also like to thank them for their encouragement and for believing in me from the beginning.

My sincere gratitude goes out to all the participants who gave their time and input to the study, it would not have been possible without them and every one of them made an invaluable contribution.

Special thanks to Bangor University and all the staff at the North Wales Centre for Primary Care Research, especially Ruth Lewis for the systematic reviewing expertise, Stefanie Disbeschl for her proofreading skills, Nic Nikolic for all her financial guidance, Matthew Jones for his bibliographic knowledge and Richard Evans for all the IT support. I would also like to thank all the staff at the Wrexham Maelor library for all their help and support.

To Jess Roberts, Tania Seale and Becki Law for all their PhD help and advice, I would like to say a big thank you.

I would like to express my gratitude to Health and Care Research Wales for the funding and the Health and Care Research Wales workforce for all their recruitment expertise, especially Stella Wright, Jo Lewis, Tori Whitehead and Arwel Lloyd.

I would also like to thank Betsi Cadwaladr University Health Board especially the secondary care recruitment sites, and the primary care practices who kindly took part.

My sincere thanks also goes out to Sian Jones for her Patient and Public Involvement and her invaluable input to the research.

I would like to thank my family, my dad, Ralph, Bekki and baby Finn, and of course my mum for all their kindness, encouragement and support. I would also like to thank Daniel, for always listening.

Finally, I would like to thank all of my wonderful friends. My gratitude goes out to the MLC for always being there when I need them, to the members of the Tuesday night club, and to Cass and Jim and all my friends at Newbattle Abbey College where it all began.

Preface

In qualitative research, it is always important to consider how our own perspectives may influence the work we do and to reflect upon the ways in which we position ourselves as researchers and as human beings. When I began this study, as a very early career researcher in the field of health sciences, I had many options to consider regarding the study development and where I would situate myself in relation to the topic and the participants.

Cancer was a subject with which I had little personal experience, however this changed as the study went on and during the course of this PhD, two people I cared about deeply were diagnosed with, and died from, cancer. I also knew from the beginning that the interviews and focus groups in the study would be sensitive and emotional, however for me they also held a further source of potential personal difficulty, as an ex-smoker myself, I was aware that I may encounter moments during which I would see myself reflected in participants accounts.

When it was time to begin the data collection, I was acutely aware that I needed to ensure that I did not introduce bias to the study through my own opinions, and that the data I recorded and analysed needed to be true to the accounts of the participants as they reported them. I believe that I have done justice to the accounts of participants, however I did see something of myself in many of them and at times their feelings echoed my own. Denise and Earl in particular were resonant with me and will always stand out in my memory. In the focus groups, participants described feelings that I had felt myself for the several years that I smoked, although I had never really realised at the time.

Undertaking this study gave me the opportunity not only to develop as researcher, but also to enter the lifeworld’s of those who took part and by doing so, I learned a lot about myself.

Dedication

For all the participants, and for William and Eliza, for everything they did for us.

‘The place you fight cruelty is where you find it, and the place you give help is where you see it needed’

(Phillip Pullman, 1997)

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CHAPTER

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List of abbreviations

AIDS – acquired immune deficiency syndrome

ASSIA - Applied Social Sciences Indexes and Abstracts

BCUHB – Betsi Cadwaladr University Health Board

BMJ - British Medical Journal

CHD – Coronary heart disease

COPD – Chronic obstructive pulmonary disease

CRD – Centre for reviews and dissemination

CRUK – Cancer Research UK

GCP – Good clinical practice

GP – General practitioner

ICBP – International Cancer Benchmarking Partnership

MMAT – Mixed Methods Appraisal Tool

NHS – National Health Service

NIHR – National Institute for Health Research

NSW – New South Wales

PPI – Patient and public involvement

PRISMA – Preferred reporting items for systematic reviews and meta-analysis

R&D – Research and development

REC – Research Ethics Committee

UK – United Kingdom

USA – United States of America

WCISU – Welsh Cancer Intelligence Surveillance Unit

IRAS – Integrated research application system

Chapter One

Introduction

Introductory statement

This thesis presents a qualitative study into the primary care seeking decisions of recently diagnosed lung cancer patients and of current smokers who do not have cancer, with a particular focus on the influence of the consulting decisions of smokers on the duration of the time period between first symptoms and first consultation in primary care. This study was conducted with two study samples in North Wales. This introductory chapter is intended to guide the reader through the thesis and give an overview of the need for, aims and purpose of the research. This chapter will begin with a background section in order to highlight existing knowledge on the topic and to identify the need for further research. This chapter will then identify the purpose of this study and outline the direction the thesis will take. This introduction will then give provide an overview of the study as a whole following the order of the thesis; this will include the two-part literature review, selection and use of qualitative methodology, findings of primary data collection, discussion of findings in the context of the current literature, and study conclusions.

BACKGROUND

Identifying the area of interest

The design and development of this study began following previous systematic and scoping review work undertaken by the supervisor regarding timely cancer diagnosis (Neal 2009; Neal et al 2015). This previous systematic review was designed to determine whether there exists an association between increased time to diagnosis and cancer outcomes across all cancers (Neal et al 2015). This review determined that it is likely that an expedited diagnosis for symptomatic cancers will facilitate improved outcomes for patients including quality of life and survival (Neal et al 2015). Cancer mortality is higher in the UK than in the rest of Europe (Neal et al 2014; Moller et al 2009; Abdel-Rahman 2009). It has also been suggested in this previous work that reducing symptom duration by facilitating earlier help seeking may be beneficial in leading to earlier diagnosis and potentially improved outcomes (Neal 2009). This opened up an area of interest for this study within the field of early cancer diagnosis and, specifically, the potential significance of early presentation in primary care in facilitating improved future outcomes.

Defining timely help seeking and the 'patient interval'

Previous work in the area of time to cancer diagnosis has defined the patient journey, in symptomatic cancers, in terms of a series of time periods, or intervals, between the patient first noticing the onset of symptoms, to diagnosis and treatment in secondary care (Weller et al 2012). In the model proposed by Oleson et al (2009) the process involves a sequence of intervals between events, beginning with symptom onset, following the pathway to diagnosis including first visit to primary care, referral to secondary care, consultation in secondary care, diagnosis and commencing treatment (Weller et al 2012). The initial interval is that between the onset of symptoms and the first consultation in primary care and is defined as the 'patient interval' (Olesen et al 2009; Weller et al 2012) In more recent work, this model has been revised along with other models to develop the Model of Pathways to Treatment (Scott et al 2013). The Model of Pathways to Treatment was developed to better reflect the complexity of journeys to diagnosis and to show how there may be 'forward and backward' movement between stages, rather than a linear course from symptom onset to diagnosis (Scott et al 2013). These models are illustrated by figures 1 and 2 in the systematic review section (chapter two, part A) of this thesis. As mentioned above, previous research has reported that shorter patient intervals may facilitate earlier diagnosis in some cancers which in turn can affect outcomes including survival (Neal 2009; Neal et al 2015). This study concentrated on the exploration of the patient interval and primary care decision making in the two study populations, recently diagnosed lung cancer patients, and current smokers in North Wales.

Smoking and lung cancer

Smoking is one of the leading causes of health problems in the UK and one of the biggest contributors to chronic and fatal diseases (www.NHS.UK). Smoking increases risk of developing many major diseases including coronary heart disease, stroke and chronic obstructive pulmonary disease (COPD) (www.NHS.UK). Smoking is the cause of many cancers including mouth, throat, oesophagus, bladder, bowel, cervix and liver and it is the leading cause of lung cancer with seven out of ten lung cancer cases being caused by smoking (www.NHS.UK). Lung cancer is also the most common cause of cancer death in the UK (www.cancerresearchuk.org). In the UK, there are around 46,388 new cases of lung cancer each year and 72% of those cases are attributable to smoking (www.cancerresearchuk.org).

Smoking and lung cancer in Wales

As mentioned above, lung cancer is the leading cause for cancer death in the UK and this also applies specifically to Wales. Lung cancer is responsible for the greatest number of cancer deaths in Wales accounting for two in ten deaths overall according to 2018 statistics (WCISU Public Health Wales 2018) and risk factors such as smoking contribute toward the relatively high incidence rate in Wales (Macmillan Cancer Support 2013 www.macmillan.org.uk). In Wales, less than a third of newly diagnosed lung cancer patients will survive one year and approximately half will die within six months (WCISU Public Health Wales 2016; WCISU Public Health Wales 2015). The National Survey for Wales lifestyle trends for 2018 report that in spite of the general decline in the prevalence of smoking, 17% of adults in Wales reported themselves to be current smokers (National Survey for Wales 2018-2019). It was also reported that 20% of adults living within the Betsi Cadwaladr University Health Board (BCUHB) catchment area identified themselves as current smokers in 2014 (Welsh Health Survey 2014). Smoking is the leading cause of lung cancer in Wales with an estimated 1,900 cases per year attributable to smoking (WCISU Public Health Wales 2014).

Lung cancer was chosen as the topic for this study due to its prevalence in Wales and due to the link established by previous research between improved lung cancer outcomes and shorter patient intervals, which is described in more detail below (WCISU Public Health Wales 2014; Tod et al 2007). Smoking was selected as a topic for the research due to it being the primary cause of lung cancers and due to the prevalence of current smoking in Wales (Welsh Health Survey 2014).

Smoking, lung cancer and patient intervals

As the significant majority of cases of lung cancer are attributable to smoking, smokers are at a significant risk for developing the disease (www.NHS.UK). As mentioned above, previous research has indicated that shorter patient intervals may be beneficial in improving cancer outcomes (Neal 2009). It has also been reported in previous research that this may be the case for lung cancer specifically as earlier diagnosis can increase operability and therefore improve survival (Tod et al 2007). However, many cases of lung cancer are diagnosed at late stage, which may lead to worse outcomes such as quality of life and survival (Tod et al 2007). It has been reported in previous work that a contributor towards this late stage diagnosis in lung cancer may be patient hesitancy in presenting symptoms in primary care (Friedemann-Smith et al 2016).

In view of the myriad adverse effects of smoking, and the wide range of morbidities involved, the logical inference would be that people who smoke would suffer more ill health and therefore be likely to engage with health services more often than non-smokers. However, previous research has shown that smokers with chest symptoms are likely to delay seeing their GP (Corner et al, 2005). Work by Friedemann-Smith et al (2016) found that being a smoker was associated with longer patient intervals when potential lung cancer symptoms were experienced.

There may be many reasons behind delayed presentation in smokers who experience potential lung cancer symptoms and previous qualitative work has reported many contributing factors. Previous studies have identified several key themes, which have been reported to be linked to delayed presentation in smokers including perceptions of stigma, concerns regarding who should access primary care and how, symptom recognition and interpretation and the presence of existing comorbidity.

As survival is compromised by longer patient intervals then it is important to further explore the reasons behind delayed presentation in smokers with lung cancer symptoms and to address concerns that may discourage help seeking in primary care.

Identifying the need for research

Following the initial background research, confirming the high prevalence of lung cancer in Wales compared with the rest of the UK, it was clear that potential improvements could be made by facilitating more timely help seeking and earlier diagnosis. Therefore, there is a need for high quality research, which aims at exploring the perspectives of both lung cancer patients and current smokers and at discovering the deeper reasons behind hesitation to present. Identifying this need for research allowed the development of the research aims and objectives which further allowed the development of the research questions to be answered in this thesis.

Research questions

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals:
    a. For any symptoms of ill-health?
    b. For symptoms they perceive to be smoking-related?
    c. For chest or other symptoms they perceive to be indicative of lung cancer?
3. What are the factors associated with smoking that may lead to longer patient intervals (for example stigma, shame, guilt, blame, fear, nihilism, perceived health professionals' negative attitudes towards smokers and smoking, and previous consultation experiences) and how do they impact on smokers' health-related decisions and choices?
4. In what ways do the experiences of people newly diagnosed with lung cancer in Wales reflect delayed presentation in primary care due factors associated with smoking?

Research aims and objectives

- To conduct a systematic literature review to address research questions by:
    - Appraising the evidence relating to differences in primary care service-use between smokers and non-smokers
    - Describing the nature and extent differences and identifying possible reasons for them
- To conduct a narrative literature review to address research questions by further exploring, in more breadth, depth and detail:
    - The factors that may lead to longer patient intervals
    - Possible explanations for smokers' health service-related choices and decisions
    - Perceived barriers to consulting in primary care in people who smoke and have chest symptoms that may be due to serious lung disease, such as lung cancer

    - Factors that deter smokers with chest symptoms from timely presentation in primary care
    - Perceived barriers to primary care in people who smoke but do not suffer chest symptoms
- To conduct a primary qualitative study to address research questions by:
    - Exploring pathways to consultation and/ or diagnosis for people newly diagnosed with lung cancer in Wales, particularly their experiences within primary care
    - Explore attitudes and opinions of current smokers regarding seeking primary care for smoking related symptoms

METHODS

Engaging with the literature

Chapter two of this thesis is a two-part literature review chapter comprising a systematic review followed by a narrative review. This two-part chapter serves to present the existing literature available on the research topics and to provide a reliable bank of evidence on which to build the data collection phases. Furthermore, the reviews provide an insight into where gaps in literature exist and where this research may contribute to the current knowledge. Two separate reviews were conducted as they each serve to fulfil a different purpose.

Systematic review

The systematic literature review was included in order to facilitate an assessment of the existing evidence for delayed symptom-presentation in smokers with and without potential lung cancer symptoms compared with non-smokers. It was designed to examine the nature and extent of differential consulting patterns between smokers and non-smokers, and identify potential reasons for any differences found. The systematic review adopted a traditional design to answer specific research questions, and therefore specific terms were used to create a search strategy, which was then applied across several of the bibliographic platforms that are most widely used in researching questions related to medicine and health. References were screened and studies were selected for inclusion using pre-defined criteria; data were extracted into tables, and findings were presented in a narrative format. The systematic review was registered with PROSPERO and reported in accordance with PRISMA guidelines, these methods are reported in much greater detail in chapter two, part A.

Narrative review

The narrative review was designed to build on the findings of the systematic review by exploring the research topics in a much broader and deeper sense. This was in order to develop a more comprehensive understanding of the context and relevant issues. The narrative review included published literature, covering all aspects of smoking, lung cancer, and delayed presentation. It also focused on reports of qualitative studies in order to explore issues such as healthcare professionals' attitudes towards smokers, and smokers' previous consultation experiences by drawing on the lived experiences of research participants. The review was conducted in stages, with several short search strategies being developed iteratively, drawing on bibliographic databases of both health and social science literature, and following references found in relevant reports. The resulting evidence was mapped out at each stage. Data collection continued until thematic saturation was reached. Findings were synthesised using a meta-ethnographic approach and reported narratively. The methods for the narrative review are reported in greater detail in chapter two, part B.

Informing the study

The literature collected in both reviews was used to inform the subsequent design of recruitment materials and topic guides for the data collection phases of the study. Recruitment materials require a design process in order to make them understandable to and accessible by the lay community. It is also of great importance to ensure that patient facing materials are designed carefully in order to avoid potential misunderstanding or patient distress. The results from the literature reviews revealed that people who smoke may find smoking a sensitive topic and therefore materials were designed accordingly. Lung cancer patients are also a vulnerable population and great care must be taken to avoid potential distress. The literature reviews also highlighted key themes regarding smoking, lung cancer symptoms and primary care use, these key themes provided an evidence base upon which to design the topic guides.

Study development and design

The qualitative approach

Following the development of the research questions, a qualitative approach was selected as most suitable for achieving research objectives. Qualitative methodology is ideal for research that seeks to explore complex issues in-depth such as why and how particular phenomena occur in particular contexts (Marshall and Rossman 2006). Qualitative research aims at achieving depth and richness of data in order to increase understanding of the lived experiences of participants (Mason 2002). In order for this study to be able to fully explore the accounts of participants, a qualitative methodology was ideal. The justification for employing a qualitative methodology is given in more detail in the methods chapter of this thesis.

The interpretivist approach

Following the selection of a qualitative methodology the decision was made to undertake the study using an interpretivist approach. The alternative approach, the positivist approach, is more akin to the natural sciences and quantitative research, which seeks to generalise across study populations (Roth and Mehta 2002; Angus 1986; Marshall 1994). The positivist approach was deemed unsuitable for this study due to the nature of the research aims and objectives. The interpretive approach moves away from the traditional positivist standpoint toward a more flexible approach and research which focusses in gaining access to the lived experiences of participants and the ways in which actors construct their own realities (Roth and Mehta 2002; Willis 2007). The interpretivist approach is one in which the researcher must understand the meanings and motives participants have ascribed to their experiences in order to fully understand the research topic itself (Blaikie 2000). As this study sought to gain a deeper understanding of the perspectives of the participants and allow for exploration of their personal accounts, the interpretivist approach was ideal.

The full rationale for following an interpretivist approach, along with justification of its use in this study and a common critique of the approach, is defined further in the methodology chapter of the thesis.

Ethical considerations and confidentiality

Ethical issues must be taken in to consideration before commencing any research study in order to assess whether any harm may come to participants by being involved (Orb et al

2000). Qualitative healthcare related research can also pose particular ethical issues due to participant’s potential vulnerability and the discussion of sensitive issues (Reid 2009). As lung cancer patients are classed as a vulnerable population and smoking is a sensitive topic, there may be potential for participant distress in research such as this (Reid 2009). Therefore, a full consideration of ethical implications was taken at the beginning of the study and full ethical approvals were obtained. Recruitment materials were designed with Patient and Public Involvement (PPI) to ensure suitability. As interviews were often undertaken in participant’s homes, great care was taken to ensure that the research was carried out in a respectful manner, as is good practice (Reid 2009). All participants in this study were fully informed of what involvement entailed and that they were free to withdraw at any time. All participants gave informed consent to be in the study. All data collection was confidential and all data anonymised in order to protect the identity of the participants. Ethical considerations are explained in full detail in the methods chapter of the thesis.

Ethical approval for this study was sought firstly from the committee for the School of Health Sciences at Bangor University and granted in full in October 2015. The application was then made to the research ethics committee (Wales REC 1) and was granted provisional approval in November 2015 and full approval in March 2016.

Data collection

The collection of primary data in this study comprised two phases utilising appropriate qualitative methods; in-depth, one to one interviews and focus groups. Purposive sampling was used to recruit both study populations via BCUHB and the Health and Care Research Wales workforce. A brief description of data collection and analysis is given below and reported in full in the methodology chapter of the thesis.

Interviews

A total of 29 qualitative interviews were conducted with a purposive sample of recently diagnosed lung cancer patients. The in-depth interviews were designed to build on evidence generated by the literature reviews to provide rich data to enable exploration of the research questions. As mentioned previously, the review evidence along with consultation with a PPI representative was used to create a suitable topic guide (see appendix 4) The literature reviews were able to provide evidence on which to base a set of open-ended questions for use in the interviews.

In qualitative research, a commonly used method is in-depth, semi structured interviews (Mason 2002). This method was deemed the most suitable for the first data collection phase in this study due to their ability to collect rich data and explore the narratives of participants without being restricted by strict or closed questions (Mason 2002). The semi-structured approach ensured that the researcher is able to explore areas of particular salience to participants or relevance to the research topic (Mason 2002). Qualitative interviews are able to produce rich and detailed accounts as described by participants and are ideal for interpretivist studies and therefore were chosen for this research. The interview phase produced data in response to research question four by detailing lung cancer patient's pathways to diagnosis and any patient intervals which may have occurred. Interviews took place either in the participant's homes or in a setting of their choosing and were all approached with every attention paid to ensuring a high ethical standard was maintained.

A full justification for, and account of, the interview phase is presented in the methodology chapter of the thesis.

Focus groups

Three focus groups were conducted with a sample of current smokers aged 50 years and older. The focus group phase was designed to collect data from current smokers to discover their perspectives on the health risks associated with smoking and their experiences and perceptions of accessing primary care both now and in the future. It was anticipated that the focus group participants would give a valuable insight as to how advice from healthcare providers can reach smokers who have misgivings about GP consultation by exploring reasons why they may be reluctant to consult their GP and how they could be encouraged.

Focus group methodology works on the principle that data is generated collectively by the participants (Ritchie and Lewis 2003). Focus groups are designed to provoke discussion around a shared characteristic or interest in order to produce data in response to research questions (Ritchie and Lewis 2003). The focus group participants in this study possessed a shared characteristic in their history of smoking and the topic guide was designed to facilitate discussion around smoking and use of primary care.

The key purpose of the focus group phase was to answer research questions two and three by exploring the reasons for potential patient intervals and the implications for practice in primary care or for further research. The focus groups were designed to build on data generated by the interviews and the literature reviews, both of which provided evidence with which to construct a suitable topic guide (see appendix 4). Each focus group aimed to comprise approximately eight participants and took a semi-structured approach similar to that of the interviews in order to allow for flexibility and exploration of salient topics.

A full account of the focus group phase of this study is given in the methods chapter of the thesis.

Analysis

Thematic analysis

The qualitative data in this study was analysed using a rigorous thematic analysis. Initially all interviews and focus groups were transcribed verbatim and transcripts were then organised using Nvivo 11 software. Thematic analysis can be performed at a basic level or it can be performed at a much higher level which involves an in-depth interpretation of themes (Boyatzis 1998). In this study an in-depth and rigorous thematic analysis was conducted in order to fully explore the data and interpret the themes. Thematic analysis follows a process of predefined phases; immersion within the data, coding of data according to key themes, and interpretation of the themes (Ritchie and Lewis 2003). However, a good thematic analysis is a recursive process rather than a linear one and the researcher will move back and forth between the phases (Braun and Clarke 2006). Thematic analysis was the most suitable for this study as it is not bound by a specific theory and therefore has the ability to be flexible and applied across entire data sets (Nowell et al 2017; Braun and Clarke 2006; King 2004). As this study contained two data sets, which were analysed together, a flexible data analysis approach was ideal. A full description, justification for and defence of thematic analysis is given in the methods chapter of the thesis.

Reporting of study findings

The findings of this study reveal the complexity of the research topics and highlight the need for further understanding. The interview participants in this study described complex accounts of their journeys from first symptoms to diagnosis involving many interweaving factors that affected decisions regarding primary care use. Interview participants also described their symptoms and the ways in which they had recognised and interpreted those symptoms, often as those of minor illness and therefore not of enough concern to seek GP advice. Symptoms were often described as having been accommodated and incorporated into everyday routines rather than prompting help seeking. The presence of a chronic condition or comorbidity was also found to affect help seeking decisions. Participants in both study populations revealed beliefs regarding their health and their perceptions of cancer risk, which may influence their patient intervals. Many participants in both samples expressed concerns about ‘wasting doctor’s time’ which had a major impact on their decisions about help seeking as all were keen to avoid being labelled a ‘time waster’ by healthcare professionals and by society in general. Perceptions of stigma were present in the accounts of many of the focus group participants as they described being potentially stigmatised for their smoking, and for having potentially smoking related illness. Concepts of access to health services, particularly primary care, and use of pharmacies as a first line measure were also pertinent to participants in this study. Finally, the influence of family members and partners may also affect help seeking decisions and patient intervals.

A full account of the study findings, with these themes in detail and illustrated by participant quotes, is given in the findings chapter of the thesis.

Discussion

The evidence from the literature reviews and the new evidence from the study findings are brought together in the discussion chapter of the thesis. In this chapter, the findings can be viewed in the context of the wider literature and of the research area. The discussion chapter is presented thematically with the key findings from this study combined with the relevant literature. The discussion chapter illustrates the ways in which the findings of this study correspond with the existing literature and how they contribute to, and potentially enrich, the current understanding of smoking, lung cancer and patient intervals.

Study conclusions

The final chapter of the thesis will give the conclusions drawn by the researcher following the completion of all other aspects of the study. The chapter will affirm the fulfilment of research objective. The conclusion chapter also summarises the thesis, outlines study strengths and limitations, and gives recommendations for further research.

Chapter two

The two-part literature review

Chapter summary

This chapter presents the two literature reviews carried out for this thesis. A rationale is given for the decision to perform two separate reviews, followed by the independent reporting of each review. Part A of this chapter is the systematic review and comprises an initial background and rationale for use, followed by the methods, findings, discussion and conclusions reached. Part B is the narrative literature review and also comprises background and justification for use, methods, findings, discussion and conclusions. The reviews are reported separately due to the differences in purpose and methods but both reviews were used to build an evidence base on which to construct the rest of the study.

Rationale for conducting two reviews

This thesis contains two literature reviews which were each designed to serve a different but necessary purpose. Prior to designing the specific research objectives and data collection methods for a study, it is vital to fully explore the current literature in order to inform the research design, examine the existing evidence, and identify any gaps within that evidence. Literature reviews bring together the current knowledge surrounding a research topic via the process of evidence synthesis (Sheldon 2005). Evidence synthesis brings together the results of previous research in order to provide a comprehensive map of what is already known (Sheldon 2005). The term 'evidence synthesis' can be applied to the combining of results from studies using qualitative, quantitative and narrative methods (Sutton 1998; Dixon-Woods et al 2005; Rodgers 2009). Reviewing the literature is essential in order to conduct comprehensive and reliable research, however there are several different types of literature review which are suited to reaching different aims. As already mentioned, this thesis contains two separate reviews in order to fully explore all that was relevant.

A conventional systematic review is used to make sense of large amounts of information and to synthesise evidence from all relevant studies in order to answer a specific question (Petticrew and Roberts 2006). The methods for a systematic review are set out in advance and are suited to answering clear and precise research questions (Petticrew and Roberts 2006). However, as they are required to answer a specific question, systematic reviews are tightly bound by narrowly defined search terms in order to answer those particular questions, and to keep the size of the review at a level which is manageable. Therefore, there is potential for the tight search terms of the systematic review to miss evidence which may be relevant to the study as a whole, but does not necessarily answer the specific question asked of the review (Dixon-Woods et al 2006; Greenhalgh and Peacock 2005). In order to identify and review a broader body of literature, narrative reviews are an ideal method as they are not so tightly bound by the research question and take a more flexible approach. The narrative review takes a more iterative approach using not only electronic database searches but also more informal searching techniques and snowballing (Dixon-Woods et al 2006).

In the case of this thesis, there was a need to discover what kind of evidence existed to inform, support or refute the hypothesis that people who smoke are likely to seek healthcare less frequently, and less promptly than non-smokers, and that this delayed consultation phenomenon may be more pronounced when smokers perceive their symptoms to be smoking-related. The best way to determine the answer to that question was to conduct a traditional systematic review with specifically designed search terms to scope this literature. As a very specific question was asked by the systematic review in this study, it was then necessary to investigate the field of interest in a broader and more inclusive manner so that all relevant literature could be assessed. The narrative review was therefore designed to explore the literature more widely to investigate possible explanations of how and why people who smoke may be less likely to seek primary care than those who do not, including factors that influence their decisions, and perceived barriers to consulting.

Due to the rationale given above, this study was designed to incorporate two literature reviews in order to gain the most evidence possible with which to define the research objectives and build the data collection phases. A further advantage of this double approach was that the researcher had the benefit of gaining the skill sets suited to both systematic and narrative reviewing.

Part A: Systematic review of published literature on the primary care consulting decisions of smokers compared with non-smokers

Review Summary

Part A of this chapter presents the systematic literature review conducted for this study. What follows is a detailed background section which highlights the purpose and need for the systematic review, a section describing the methods used in undertaking the review, and the review findings, discussion and conclusions.

As almost all cases of lung cancer are attributable to smoking, smokers are at a significantly greater risk for developing the disease than non-smokers. It is important that lung cancer is diagnosed as early as possible since delays in diagnosis can adversely influence outcomes, including adverse effects of treatment and poorer quality of life as well as shorter survival. However, there is some evidence that smokers may hesitate to use primary care (Corner et al 2006). This systematic review aimed to explore the characteristics of primary care consulting among smokers including: whether the patient interval, the time between first experiencing symptoms and consulting a healthcare professional as described by Weller et al (2012) in the Aarhus Statement, varied between smokers and non-smokers and, if so, to what extent, and whether there was evidence to suggest possible reasons for differential use of primary healthcare services.

Traditional systematic review methods were used and the review was conducted following PRISMA guidelines, where they could be applied to reviews of observational studies (Moher et al 2009). Electronic databases were searched using thesaurus terms and text-word synonyms relating to smoking, primary care, and consultation. References were screened by two reviewers and studies were selected according to specific inclusion criteria. Data were extracted into pre-defined forms and results were summarised in a tabular format and described in a narrative synthesis.

The findings showed that smokers are less likely to use primary care services than non-smokers. Among those who do use primary care, presentation is less frequent in smokers and ex-smokers than never smokers. Due to the relationship between smoking and lung cancer and the potential benefits of earlier diagnosis, further research is needed in order to discover reasons for less frequent use of primary care in order to encourage timely presentation of symptoms and improve clinical outcomes, this is further investigated in the narrative review presented in the second part of this chapter.

Introduction

Background

As previously explained in the introduction chapter to the thesis, cancer mortality overall is higher in the UK than in much of the rest of Europe (Neal et al 2014; Moller et al 2009; Abdel-Rahman et al 2009). Lung cancer is one of the four most common cancers in Wales and is the highest cause of cancer death, more so than breast and bowel cancers combined (WCISU Public Health Wales 2016). Less than a third of patients diagnosed with lung cancer in Wales will survive one year and around half will die within six months (WCISU Public Health Wales 2016; WCISU Public Health Wales 2015). Only cancer of the liver and the pancreas have poorer survival outcomes (WCISU Public Health Wales 2016). The principle risk factor for lung cancer is smoking, and smoking related cancers in Wales have poorer survival rates compared to the rest of Europe (WCISU Public Health Wales 2016). It has been reported by the Welsh Cancer Intelligence and Surveillance Unit (WCISU) that smoking is responsible for approximately 36 cases of lung cancer per week (WCISU Public Health Wales 2016), and that other causes of lung cancer, such as exposure to asbestos, are exacerbated by smoking (WCISU Public Health Wales 2015). The risk of a person developing lung cancer by the time they reach the age of 75 is around one in 200; for a smoker, that rises to one in seven (WCISU Public Health Wales 2015).

Neal et al (2015) suggested that a longer time to diagnosis may contribute to poorer outcomes including stage, survival, morbidity relating to treatment, and quality of life. Curability of lung cancer is low without surgery; late diagnosis can seriously influence the operability of lung cancer and patients are often inoperable at the time of diagnosis (Tod et al 2007). Conversely, earlier stage symptom presentation is a ‘predictor of improved survival’, and timely access to treatment, especially curative treatment, also has a positive effect on survival rates (WCISU Public Health Wales 2015). Delays may happen at any time during the cancer diagnosis pathway, however the time between the symptom onset and the first presentation is important as, if done in timely manner, it may lead to earlier diagnosis and improved outcomes (Neal et al 2015; Neal 2009; Torring et al 2011). The period of time between the symptom onset and the first presentation is sometimes referred to as the ‘patient interval’, first described by Olesen et al in 2009 and further developed by Scott et al in 2013 demonstrated in figures 1 and 2 below.

Figure 1: Milestones and time intervals from first symptom until start of treatment (Olesen et al, 2009)

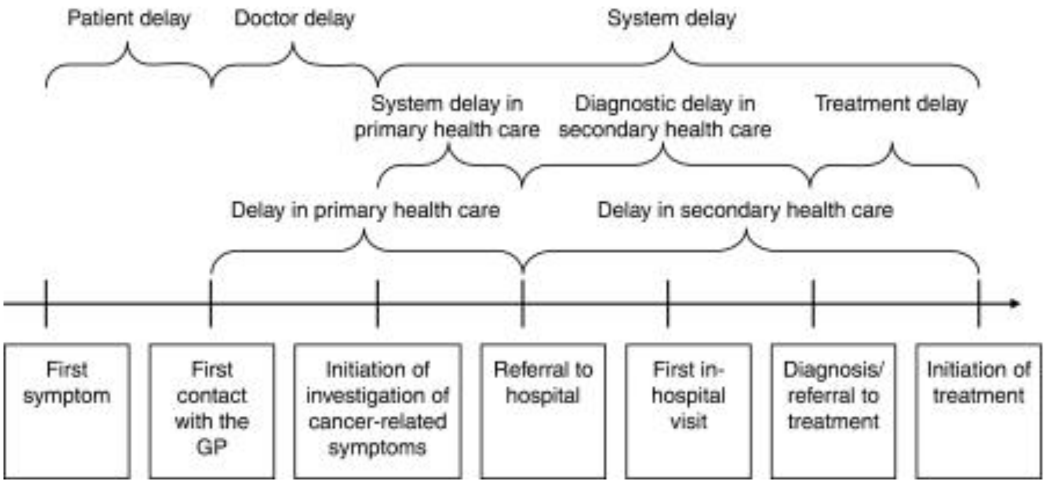
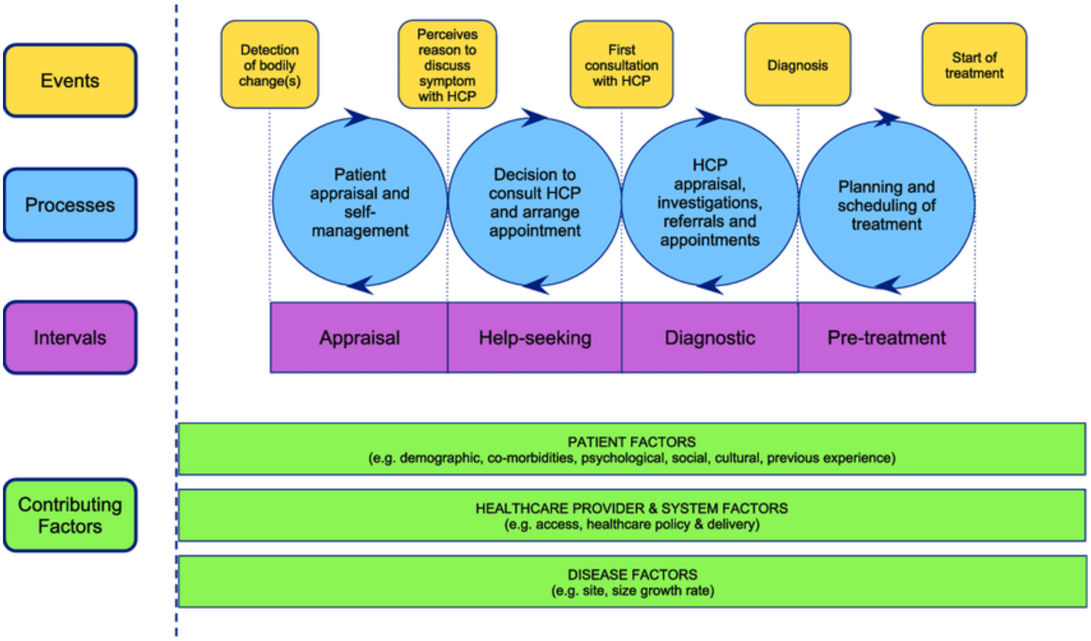


Figure 2: The Model of Pathways to Treatment (Scott et al 2013)



According to research by Neal (2009) there is a consensus that there may be delay during the period between a person first noticing a potential cancer symptom and their first reporting it to a healthcare professional. The Model of Pathways to Treatment defines this stage as the appraisal phase, during which the person will appraise their own symptom and make a decision as to whether or not they require the advice of a healthcare professional (Scott et al 2013). Identifying and recognising the importance of potential symptoms of cancer can be difficult for the patient during the appraisal period as some are more obvious, such as lumps or bleeding, and others are more general such as fatigue and weight loss (Scott et al 2013; Neal et al 2014). Vague or seemingly minor symptoms may not be considered serious enough to warrant medical attention or may be attributed to benign causes such as the ageing process or minor conditions that have been experienced before (Scott et al 2013). According to the Model for Pathways to Treatment, the appraisal phase also accounts for psychological, social and comorbid factors which may also influence presentation decisions (Scott et al 2013). Patients may normalise symptoms such as persistent ('smoker's') cough. Furthermore, noticeable symptoms may not be present; WCISU (2015) reported that symptoms 'tend to be absent, non-specific or have little relationship to stage'. The point of access to the NHS is also cited as a factor which may affect lung cancer outcomes as many late stage diagnoses are made in emergency care, therefore outcomes may be improved by earlier diagnosis via the primary care route (WCISU Public Health Wales 2015).

As survival is compromised by longer patient intervals, or delays in presentation, it is important to seek out the reasons for those delays and to address concerns which may discourage smokers from seeing their GP. For example, it has been postulated that healthcare professionals may express a negative attitude toward smokers, and especially lung cancer patients, who ignore advice and continue to smoke (Lebel 2013). Patients who have experienced this may be reluctant to engage with healthcare. A 2009 systematic review found that UK National Health Service smoking cessation services provide effective support for smokers who want to quit. However, uncertainty remains regarding the efficacy of these interventions with different subpopulations of smokers (Bauld et al 2009). Many older smokers, for example, believe that the damage is already done and therefore do not see the point in stopping smoking (Kerr et al 2006). People who do not wish to give up smoking, or who have tried to give up and failed, may be less willing to engage with services that are very much focused on smoking cessation. Feelings of responsibility and blameworthiness are often felt by smokers, who perceive lung cancer to be 'self-inflicted' (Chapple et al 2004). People who feel their ill-health is deserved may feel less deserving of care and this may lead to delayed presentation. Finally, the International Cancer Benchmarking Partnership (ICBP), an international, multi-disciplinary partnership aiming to quantify international differences in cancer survival and to identify factors that might influence observed variations, has reported findings which indicate that negative beliefs regarding cancer and cancer outcomes are prevalent in Wales and this may also contribute towards later presentations (WCISU Public Health Wales 2015; Forbes et al 2013).

Rationale

Understanding delays in presentation is key to developing this research as a whole and so initially the existing literature must be examined in order to discover whether or not smokers are indeed less likely to seek primary care than those who not smoke and, if so, explore the extent of the delay and the reasons for it.

This systematic literature review was conducted to explore previous research relating to smoking and presentation in primary care. The systematic review facilitated an assessment of the existing evidence for delays or hesitancy to seek primary care in smokers. This addressed the research questions described earlier by describing the current evidence documenting smoking behaviour and its effect on primary care service-use which could then be further explored in the narrative review presented in part B of this chapter. The evidence from both reviews could then be used to fully inform the study as a whole. Findings from the review were also used to inform the process of preparing recruitment materials and data collection instruments, as described in the methods chapter of this thesis.

As previously described in the introduction to the review chapter, this systematic review followed a traditional approach using structured searches of the appropriate electronic databases. A traditional systematic review is a way for researchers to discover what others have already found, which makes it a solid starting point for a new study (Gough et al 2012). Systematic reviews traditionally stick to a predefined and strict methodology which aims to eliminate bias and to ‘identify, appraise and synthesise all relevant studies’ in order to answer a specific research question (Petticrew and Roberts 2006). A systematic review can be described as a ‘fit for purpose’ method of reviewing which aims to answer a particular question, in the case of this thesis, regarding primary care use in smokers (Petticrew and Roberts 2006). Systematic reviewing can be criticised for being tightly bound by its research question and therefore potentially missing works that are relevant but do not include the specific search terms (Gough et al 2012). This thesis attempts to avoid this potential pitfall by following the systematic review with a wider narrative review, as discussed in the chapter summary.

The systematic review in this study was conducted in order to answer the specific research question below and was intended to provide the initial basis for informing a subsequent narrative review and the study as a whole. Traditional systematic reviewing methods were chosen as the best way in which to conduct the review and are given in further detail below.

Research questions

The research questions to be addressed by this systematic review were:

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals:
    a. For any symptoms of ill-health?
    b. For symptoms they perceive to be smoking-related?
    c. For chest or other symptoms they perceive to be indicative of lung cancer?

Aim and objectives

The overall aim was to conduct a systematic literature review to address research questions 1 and 2 above. Specific objectives were to appraise the evidence relating to differences in primary care service-use between smokers and non-smokers, to describe the nature and extent of such differences, and to identify possible reasons for them that could be further explored in the narrative review.

The systematic review was intended to consider the existing evidence around primary care usage among smokers, especially with regard to chest symptoms that could be related to lung cancer. All relevant studies, which could potentially shed light on this were eligible for inclusion.

Methods

The review was conducted using methodology reported in the National Health Service (NHS) Centre for Reviews and Dissemination (CRD) Report four (NHS Centre for Reviews and dissemination 2001). It is registered with PROSPERO (reference no. CRD42015028038) (www.crd.york.ac.uk/PROSPERO) and reported in line with the guidance on methods for the conducting and reporting of systematic reviews according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Liberati et al 2009). The PRISMA guidelines for systematic reviews focus on transparent and complete reporting of review methods and results however it was adhered to where possible in reporting this review of observational studies.

Study selection

In order to avoid missing any relevant studies, inclusion criteria were kept relatively broad; inclusion and exclusion criteria are reported in table 1. Any type of study design, qualitative or quantitative was considered. Participants had to include current or ex-smokers; in comparison studies non-smokers could also be included. Primary care clinicians could be included in studies that considered their interactions with patients who were current or ex-smokers.

To be eligible for inclusion in the review, papers had to present findings specifically related to smokers' use of primary healthcare services. Studies could compare the consultation patterns of smokers and non-smokers, measure smokers alone, or report smoking as a factor within a study containing multiple measures as long as findings for smokers were separately reported. Studies could include several aims or components but must show an interest in timely presentation, frequency of presentation or use of services within a primary care setting. Any outcomes relating to primary care interactions with patients who were current or ex-smokers were considered including attitudes and beliefs of either patients or healthcare professionals. Studies reporting only smoking cessation were excluded. Studies could be of any design as long as they were reported in full. Studies reported in languages other than English were considered eligible for inclusion but, in the event, none were found.

Table 1: Inclusion and exclusion criteria

Inclusion	Exclusion
Participants could be current or ex-smokers	Studies including a mixed population where findings for smokers were not reported separately
The phenomenon of interest was smokers' use of primary healthcare services.	Studies reporting only secondary or emergency care, or health service use as a whole
Non-smokers could be included as part of a comparative studies, but studies did not need to have a comparison group	
Outcomes of interest included frequency or timeliness of consulting, attitudes, views, beliefs or experiences regarding primary care consultation	Studies reporting only outcomes relating to smoking cessation
Studies could be of any design, quantitative or qualitative	Studies not reported in full, such as conference abstracts

Search strategy and database search

A study-specific search strategy was developed for the review. The strategy included thesaurus terms and text word synonyms relevant to the review objectives and was developed for MEDLINE initially. The search terms used covered the subject areas relating to smoking, presentation or consultation, primary care or general practice and patient acceptance of healthcare. A range of bibliographic databases were searched using the strategy which was revised and adapted for each source. Databases used were;

- Via the OVID platform: MEDLINE, EMBASE, CINAHL, and PsychINFO
- Via the Wiley Interscience platform: Cochrane Database of Systematic Reviews

The searches were carried out on the CINAHL and Cochrane databases on 6/11/2015 and on the Embase, Medline, and Psychinfo databases on 9/11/2015. Databases were searched without date or language restrictions applied. All included papers were published in the English language, however it was intended that any non-English language papers which met the inclusion criteria would be translated using Google translate. The reference lists of all included papers were hand searched to identify any further relevant studies.

Search strategy created for Medline and adapted for other databases

1. smoking/
2. (smoker$ or smoking).ti,ab.
3. tobacco.ti,ab.
4. 1 or 2 or 3
5. patient acceptance of healthcare/
6. (consult$ or present$).ti,ab.
7. (care adj3 seek$).ti,ab.
8. 5 or 6 or 7
9. primary healthcare/
10. family practice/
11. physicians, family/
12. general practice/
13. patient centered care/
14. (primary care or primary healthcare or general practi$ or family practi$).ti,ab.
15. 9 or 10 or 11 or 12 or 13 or 14
16. 4 and 8 and 15

Citations were managed using Endnote bibliographic software. All titles and abstracts were screened for relevance against the study inclusion criteria by two independent reviewers, the author and a Bangor University colleague. Full text articles were then retrieved and further assessed for inclusion. Any disagreements were resolved by discussion, a third reviewer was available to resolve any disagreements where a mutual conclusion could not be reached, however this was not necessary.

Data extraction

The purpose of data extraction is to capture details that will help to describe the studies, support quality appraisal, and support the evidence synthesis. In a larger and more complex review there may be a mapping stage where study variables are coded to facilitate a more detailed description of the literature (Gough et al 2012). However, this was not considered necessary for this small systematic review. The following data were extracted from each study using pre-defined forms: characteristics of each study including author, date, location, setting, objectives, details of population and sample, methods of data collection and analysis; results including a summary of relevant measures and results. Reported interpretations of findings, and authors conclusions were also extracted from the studies.

Critical appraisal/ quality assessment

Critical appraisal of the evidence is carried out in order to assess the methodological quality and reporting quality of each included review, and thereby to determine the reliability of the evidence. Many tools and checklists now exist to appraise the quality of studies with different methodological designs and addressing questions such as whether the study is adequate for answering its research question, whether it may be affected by significant bias due to systematic error or other problem, whether the findings are representative of the wider population, or simply whether the numbers add up. The Mixed Methods Appraisal Tool (MMAT) allows for quality appraisal of the most common research methodologies including qualitative, quantitative, and mixed methods studies and so was initially selected as the most appropriate for this systematic review (Pluye 2014). However, once the searches were conducted and references screened for inclusion, all studies that met the inclusion criteria were of the same design, surveys, so the MMAT no longer appeared suitable. Instead, this review used the five-item framework for appraising a survey adapted from Crombie (1996) by Petticrew and Roberts (2006). Quality appraisal tools require the researcher to apply their own judgements about aspects of the conduct or methodology of the study. The chosen framework appeared to be comparatively straightforward to apply and was based on a well-known and well-tested tool. Quality appraisal tools can be somewhat subjective and are often presented as a checklist with options being ‘yes’ ‘no’ and ‘can’t tell’. Due to the restrictive word limits for journal articles it is quite common, particularly in the case of qualitative research, that the methods sections are very briefly reported often resulting in studies appearing to be lower quality than they are. In this study, quality appraisal tools were chosen to allow the most accurate and consistent interpretation of study quality.

A table detailing characteristics, strengths and weaknesses of critical appraisal tools considered are provided in appendix 3.

Analysis

As the studies in this review were too heterogeneous to permit a statistical summary, meta-analysis was deemed inappropriate and was not undertaken (Petticrew and Roberts 2006).

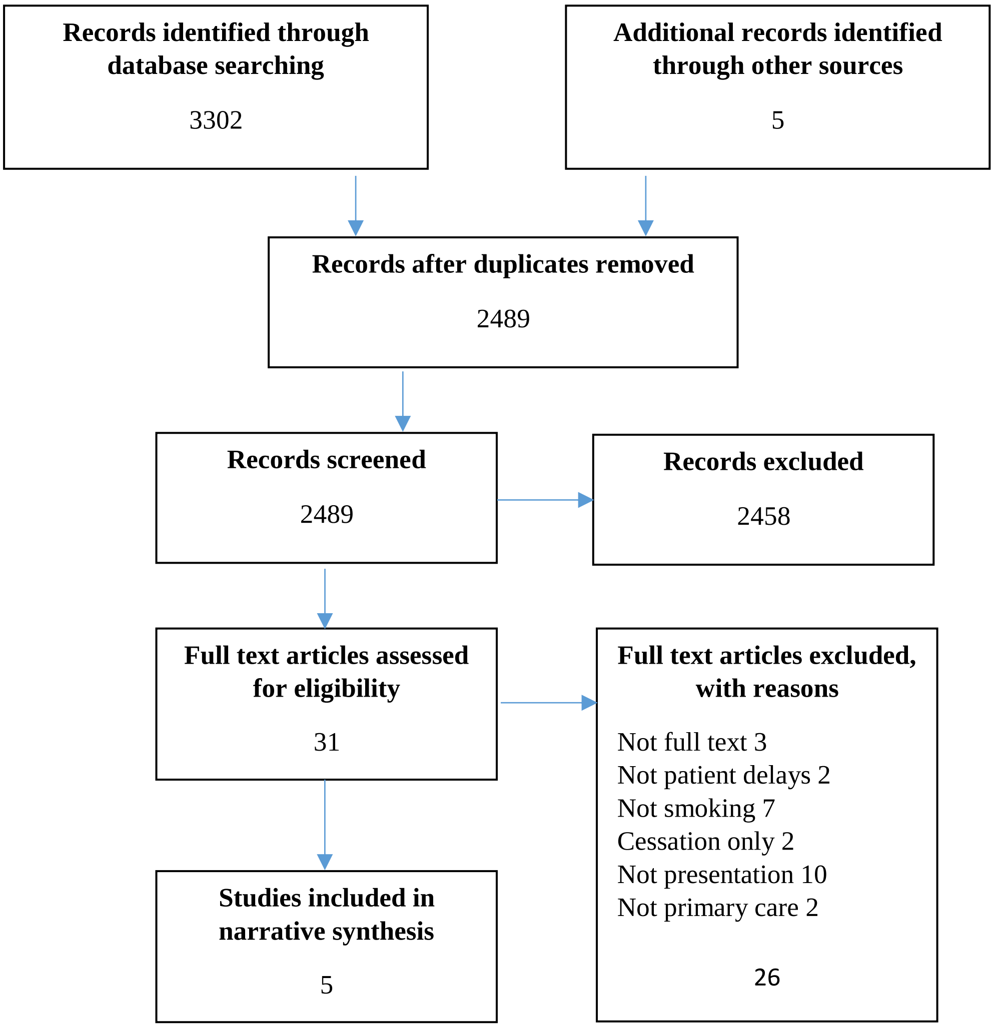
Instead, a narrative synthesis was carried out. Following data extraction, a narrative account of the evidence was written, including detailed description of study objectives, participants, measures, and outcomes (Petticrew and Roberts 2006).

Findings

Study selection

After de-duplication, 2,489 studies were identified by searching the electronic databases. The titles and abstracts of these were screened for relevance, and 31 studies were identified as potentially eligible for inclusion. Full texts of these were retrieved and five of them met the inclusion criteria. Reasons for the exclusion of the remaining 26 were recorded. A further five studies were identified as potentially relevant from the reference lists of included studies, but none of them met the inclusion criteria. The study identification and selection process is illustrated in figure 3, the PRISMA flowchart.

Figure 3: PRISMA Flowchart



Summary of included studies

Following data extraction, five studies were included in the narrative synthesis. The study characteristics are summarised in table 2, below. The publication dates ranged between 2002 and 2014. The studies took place in the UK (Elliott et al 2012 and Smith et al 2009), Australia (Jorm et al 2012; Feng et al 2014) and Canada (Kaplan et al 2002). Three of the studies, those conducted in Australia and Canada, comprised secondary analyses of data collected in large, population-based surveys (Jorm et al 2012; Feng et al 2014; Kaplan et al 2002). Of the UK studies, one was a postal survey of participants randomly selected from 20 General Practices nation-wide (Elliott et al 2012), and the other was a face to face quantitative interview survey of patients recruited from three Scottish hospitals. In this last study (Elliott et al 2012), the participants were patients newly diagnosed with a primary lung cancer, whereas in the remaining studies, the participants were members of the general public. In the Australian studies (Jorm et al 2012; Feng et al 2014), participants were aged 45 and over, in the Canadian study they were over 65, in one of the UK studies they were adults aged between 18 and 60 years (Elliott et al 2012), and in the other, the lung cancer patients could be of any age, although the majority were aged between 60 and 79 years.

All studies included both male and female participants. All five papers reported smoking and use of primary care services, although specific study aims differed. Both of the studies that took place in Australia (Jorm et al 2012; Feng et al 2014) were secondary analyses of data obtained in a large prospective cohort study in New South Wales, the 45 and Up Study. Although these two studies use the same data source, they were unconnected; that is, they were conducted by different teams, and had slightly different aims; Feng et al (2014) looked at multiple unhealthy lifestyle factors (including smoking, alcohol consumption, physical inactivity and poor diet) and their impact specifically on GP attendance, whereas Jorm et al (2012) focused only on smoking status and looked at its impact on use of a number of primary care services including preventive services such as immunisations, Pap smears, PSA tests, health assessments and chronic disease management. The Canadian study (Kaplan et al 2002) also used a sub-section of data from Canadian National Population Health Survey, focusing on the responses from people over the age of 65 who had answered a health section of the questionnaire, to examine the relationship between smoking status and contact with healthcare providers among the elderly population. In the UK, Elliott et al (2012) conducted a postal survey targeting an age and sex-stratified random sample of adults aged 18 to 60 years identified from twenty general practices across the UK to look at patient factors, including smoking status, associated with ‘incongruous consultations’, i.e. frequent consultation for minor symptoms, or failure to consult with potentially serious symptoms. In the second UK study (Smith et al 2009), face-to-face interviews were conducted with patients newly diagnosed with a primary lung cancer, collecting quantitative data in order to explore patient factors associated with the time taken from first noticing symptoms to consulting a healthcare professional.

Sample sizes were substantial for the studies that conducted secondary analyses of population survey data (Feng et al, 2014; Jorm et al 2012; Kaplan et al 2002), ranging from 13,363 in the sub-set of over-65s analysed by Kaplan et al (2002), to 254,382 in the study by Jorm et al (2012). The response rates for the original surveys were 18% for the 45 and Up study, using a postal questionnaire (Feng et al, 2014; Jorm et al 2012); the Canadian National Population Health Survey used a telephone survey approach to achieve an 83% response rate. In the UK, Elliott et al (2012) recruited 2,464 participants using a postal survey mailed out from general practices, with a response rate of 31%, though only 1,681 (21%) of these responses were sufficiently complete to be entered into the analysis. Smith et al (2009) identified 658 eligible patients and interviewed 361 (55%) of them.

All studies collected only quantitative data and used statistical analysis, including backwards stepwise logistic regression modelling (Elliott et al 2012), logistic regression models (Feng et al 2014), separate hurdle regression models (Jorm et al 2012), multiple logistic regression (Kaplan et al 2002), and univariate analysis (Smith et al 2009).

Table 2: Study characteristics

Author and location	Study Design and population	Study Aim	Setting and data collection method	Sample size and response rate	Method of Analysis
Elliott et al A (2012) UK, Nation-wide	A postal survey of an age and sex-stratified random sample of adults aged 18-60 years identified from 20 general practices across the UK	To investigate 'incongruous consultation behaviour', i.e. consulting a GP for very minor symptoms or failing to consult a GP for potentially serious symptoms	Postal questionnaire mailed out from general practices	8,000 individuals were identified; 2,464 (31%) responded and 1,681 (21%) had complete symptom data and were analysed	Descriptive statistics; multivariate logistic regression, odds ratios and 95% confidence intervals
Feng et al X (2014) Australia, New South Wales (NSW)	Secondary analysis of data from the 45 and Up study, a cohort study of men and women aged 45 an over in New South Wales	To investigate the General Practice consultation patterns of patients with multiple unhealthy lifestyle factors, including smoking	Population based, NSW Postal questionnaire linked to Medicare Australia for data on use of services	267,153* in original dataset, 18% response rate, of which 217,377 appeared to be included in the analysis (no explanation for exclusions)	Logistic regression models; Odds Ratios with 95% confidence intervals rate ratios with 95% confidence intervals
Jorm et al R (2012) Australia, New South Wales	Secondary analysis of data from the 45 and Up study, a cohort study of men and women aged 45 and over in New South Wales	To quantify the relationship between smoking status and use of primary care services, including preventive services such as immunisation, screening and chronic disease management	Population based, NSW Postal questionnaire linked to Medicare Australia for data on use of services	266,848* in original dataset, 18% response rate, of which 254,382 with complete data relevant to this study were analysed	Multivariate rate ratios with 95% confidence intervals estimated using modelling techniques
Kaplan et al M (2002) Canada, Nation-wide	Secondary analysis of data from the Canadian National Population Health Survey using data from respondents aged 65 and over	To determine the extent to which contact with healthcare providers correlates with smoking behaviour in the elderly population	Population based telephone survey	83% (73,402) households responded; 13,363 (97%) of those aged 65+ with complete data for the health component analysed	Multivariate logistic regression Odds ratios with 95% confidence intervals
Smith et al SM (2009) UK, Scotland	A cross sectional, quantitative interview survey of patients newly diagnosed with primary lung cancer	To explore the process of presentation of lung cancer symptoms and to determine what patient factors are associated with the time taken to consult a medical practitioner	Face-to-face interview surveys in three Scottish hospitals treating patients across the spectrum of rurality and deprivation	Of 658 eligible patients, 620 (94%) were approached and 361 (55%) were interviewed	Univariate analyses and multivariate linear regression analyses

*The reason for different numbers reported as the total population recruited to the 45 and Up study is unclear, but the two studies reported here reference different sources for their figures.

Study quality

In a systematic review that is designed to inform policy and/or practice, quality appraisal of the included studies is important; studies judged to be of poor quality may be excluded from the review on the grounds that their findings may not be trustworthy. This review, however, was only intended to be a scoping review of the literature to inform the direction of a more detailed, in-depth narrative review, and the design of the study as a whole. The objective of quality appraisal was therefore to establish whether the findings of the included studies were likely to be reasonably reliable, and whether the evidence overall appeared to be credible. It was not necessary to produce quality scores for each individual study. The framework for appraising a survey presented by Petticrew and Roberts (2006) comprises five areas for consideration: general orientation questions, selection of the sample, measurement issues, survey methods, and data and statistical methods. Petticrew and Roberts (2006) provide a number of questions to be addressed in each area and these were considered.

In general terms, all of the included studies clearly reported their aims, and survey designs were appropriate for answering the study questions. The study populations and methods used to carry the surveys out were clearly described. In the case of the three studies that were secondary analyses of data collected in large, population-based surveys, the relevant information from the previous studies were described in detail.

Overall, the survey sample sizes were substantial, especially for the secondary analyses (Feng et al, 2014; Jorm et al 2012; Kaplan et al 2002), which ranged from 13, 363 to 254,382. Elliott et al (2012) recruited 2,464 participants via general practices across the UK. Smith et al recruited 361 patients with lung cancer in secondary care. This was a relatively small number because the participants were recruited from a smaller pool of people, who were likely to have been harder to recruit because they were very ill (several died before they could take part), and the survey was conducted by face-to-face interview which is more time-consuming.

Response rates ranged from 18% to 83%. According to SurveyAnyplace blogger, Andrew Lindemann, the average response rate for surveys varies according to the survey methods and ranges from 57% for an in-person survey to 13% for an in-app survey (Lindemann 2018). The lowest response rate, 18%, was for a postal questionnaire used in the 45 and Up study (Feng et al, 2014; Jorm et al 2012). A lower response rate is less important if the sample size is larger; this study recruited well over 250,000 participants, comprising approximately 10%

of all persons aged 45 and over living in New South Wales. All the studies described the characteristics of the sample and the population from which it was drawn, but there was not always an explicit indication of the representativeness of the sample.

The measures used in all the studies were well described and appeared to be reasonably objective and reliable. In the Australian studies (Feng et al 2014; Jorm et al 2012), individual survey responses were linked to Medicare Australia data to ensure accurate GP consultation data. Elliott et al (2012) examined a two-week time period so as to ensure good recall of symptoms experienced and actions taken. Smith et al supplemented questionnaire data with data from GP and hospital case notes.

The survey methods were well described in all studies, and there did not appear to be any indication of bias. The statistical methods were described in detail and appeared to be appropriate. There was no evidence of other sources of bias.

Study findings

Study findings are summarised in table 3. Although studies had different aims and addressed their questions to different populations, there was high level of similarity in their findings. All five studies reported that patient hesitancy or non-consulting were more common in smokers than non-smokers. Individuals without a regular doctor and with infrequent physical and dental check-ups were more likely to be current smokers (Kaplan et al 2002). Current smokers in Australian studies (Feng et al 2014; Jorm et al 2012) were less likely to have made healthcare benefit claims for primary care services than never smokers. It was also reported that individuals who smoked were more likely to spend 12 months without seeing their GP and, among those who did seek primary healthcare, those who smoked consulted on fewer occasions (Feng et al 2014). In one study 8.8% of smokers reported not having seen a GP within the last 12 months compared with 7.8% of non-smokers (Feng et al 2014). Current and ex-smokers were also less likely to consult their GP for potentially serious symptoms such as chest pain and haemoptysis (Elliott et al 2012). Increasing pack years of smoking were independently associated with increased time to presentation (Smith et al 2009).

Elliott et al (2012) sought to determine the frequency of ‘incongruous’ consultation behaviour in UK general practice for ‘low impact’ and ‘high impact’ symptoms; the results of the study showed that most of the ‘incongruous consultation’ behaviour related to ‘high impact symptoms’ (i.e. symptoms that were potentially serious). Elliott et al (2012) reported that out of all 2,474 respondents with complete data, 623 (25%) reported at least one high impact symptom within the previous two weeks for which they had not sought the advice of their GP. Current and ex-smokers in this study were significantly more likely to report not consulting a doctor when they experienced a ‘high impact’ (i.e. potentially serious) symptom. Reported odds ratios and 95% confidence intervals were 1.7 (1.33-2.17) and 2.00 (1.53-2.60) for current and ex-smokers respectively, $p<0.001$ in both cases (Elliott et al 2012). The authors concluded that around a fifth of all symptoms occurring in the community resulted in ‘incongruous’ consultation based on the respondents’ own interpretation of their symptom impact.

The 2014 study by Feng et al found that participants with multiple unhealthy lifestyles, as defined by the authors, were less likely to use primary healthcare services. Feng et al (2014) reported that those with unhealthy lifestyles were more likely to have not seen a GP within the previous 12 months. Among those who did seek primary care, participants with unhealthy lifestyles saw their GP on fewer occasions. It was found that 8.8% of smokers had not seen their GP in the last 12 months, compared with 7.8% of non-smokers. The level of statistical significance was reported to be $p<0.001$, but it was unclear what statistical test had been performed. Feng et al (2014) concluded that interventions to prevent serious or chronic diseases need to be accessible to all people who will benefit from them and therefore must be available across a wider range of settings to attract individuals who do not consult in the traditional way.

Jorm et al (2012) found that current smokers were less likely than others to use primary care services that incurred out of pocket costs, or specific preventive services, they also reported that these findings were independent of a wide range of predisposing and access-related factors, suggesting that smokers generally have a lower propensity to seek primary healthcare services. Both male and female current smokers in Australia were less likely to have made medical insurance claims for primary care services than never smokers, but the effect size was small. Current smokers were 15-20% less likely to use a range of preventive services such as immunisation and screening independent of access to services and other health and socio-economic factors. The authors conclude that smokers who would benefit from primary care services are potentially missing out on them.

Kaplan et al (2002) reported that contact with GPs and with dentists is strongly negatively associated with smoking among older adults. Current smokers made up 15% of the sample. Among current smokers, 84% of these were daily smokers. In the multiple logistic regression it was reported that there was an association between contact with a healthcare professional and smoking status. Participants who smoked were less likely to have a regular doctor (adjusted odds ratios and 95% confidence intervals: 1.33 (1.11-1.59), $p<0.01$) and to have very infrequent physical check-ups (AOR 1.27 (1.07-1.40) $p<0.01$). The majority of smokers had not visited a dentist in over five years. The model used was adjusted for factors including age, gender, marital status, alcohol consumption, education levels, frequency of physical activity, body mass index and presence of chronic conditions. The reported conclusion from Kaplan et al (2002) is that the findings from the study could be used in order to guide future practice and facilitate discussion about smoking between patients and doctors to encourage consultation.

Smith et al (2009) reported that smoking was associated with increased time to consultation. It was also found that people who smoked did not perceive themselves to be at particular risk of lung cancer, and may have a higher tolerance for symptom, regarding them as ‘normal’ for smokers. Smith et al (2009) found that the median time from the participants’ definition of the onset of symptoms first visit to the doctor was 21 days, and increasing pack years of smoking were independently associated with increased time to consultation, correlation coefficient 0.199, $p<0.001$. The authors’ conclusion is that general practitioners should be aware of the potential for them to diagnose lung cancer symptoms at earlier stages by improving symptom recognition, particularly in high risk groups such as smokers.

Table 3: Summary of findings

Author	Relevant questions/ measures	Main results	Authors' interpretation of findings
Elliott et al 2012	The questionnaire enquired about 25 physical and psychological symptoms experienced in the last two weeks. Symptoms ranged in seriousness from minor (sore throat, diarrhoea, tiredness) to symptoms which could be indicative of potentially serious conditions (coughing up blood, chest pain). Data was also collected regarding sex, age, employment and smoking status.	Out of 2,474 respondents with complete data, 623 reported at least one high impact symptom within the previous two weeks for which they had not consulted their GP. Current and ex-smokers were significantly more likely to be a high impact non consulter.	Most of the incongruous consultation behaviours related to high impact non-consultation. Findings support the suggestion that some people do sometimes feel undeserving of treatment. Feeling of being undeserving of healthcare were independently associated with being a high impact non consulter. There was also evidence to support a perceived lack of effectiveness of healthcare services and medicines.
Feng et al 2014	GP attendance was defined by claims for Medicare benefit for GP attendances and for other medical practitioners. The yearly count of GP attendances was measured. Smoking status was defined as having smoked within the past year.	Those with more unhealthy lifestyles were more likely to spend 12 months without seeing a GP. Among those who did seek primary healthcare, participants with more unhealthy lifestyles consulted GPs on fewer occasions. 8.8% of tobacco smokers did not see at least one GP within the 12 month study period compared with 7.8% of non-smokers.	Participants with multiple unhealthy lifestyles were less likely to engage with primary healthcare. Interventions to prevent chronic diseases need to be located across a range of settings to ensure they reach all people who stand to benefit from them.
Jorm et al 2012	Participants were asked whether they had ever been a regular smoker and if so how old they were when they started smoking. If no longer smoking, they were asked the age at which they stopped. Five measures of primary care use were utilised, including whether participants had claimed Medicare benefit for un-referred services such as visits to GPs and practice nurses.	Both male and female current smokers were slightly less likely to have claimed Medicare benefit for un-referred services than never smokers.	Findings on primary care use were independent of a wide range of predisposing, access and health-related- factors, suggesting that smokers have a lower propensity to seek healthcare. Smokers may be missing out on preventive services from which they would differentially benefit.
Kaplan et al 2002	The dependant variable was 'current smoking' and the independent variables of interest were three variables measuring contact with a physician and a dentist: Do you have a regular medical doctor? When was the last time you had a physical check-up? When did you last visit a dentist?	Current smokers made up 15% of the sample. 84% of them were daily smokers. The majority (50.7%) of older smokers had not visited a dentist in more than five years. The multiple logistic regression revealed an association between contact with a health practitioner and smoking status after adjusting for other variables. Individuals without a regular physician and with infrequent physical and dental check-ups were more likely to be current smokers.	The results suggest that contacts with physicians and dentists are strongly negatively associated with smoking among older adults. These findings may guide future research and practice involving dentists and physicians discussing smoking with older patients.
Smith et al 2009	Participants were asked about their initial symptoms and dates they were first noticed. Questions regarding	The median time from participants defining first symptoms to consultation was 21 days. Increasing pack	Smokers did not perceive themselves to be at risk, nor was it found that high perceived risk was associated with

Author	Relevant questions/ measures	Main results	Authors’ interpretation of findings
	smoking status, symptom awareness, and use of primary care were also asked.	years of smoking were independently associated with increased time to consultation	consulting sooner. It could be that smokers were more tolerant of the symptoms, regarding them as ‘normal’ for smokers. GPs should be aware of the potential to diagnoses lung cancer earlier. This included recognising and acting on chest symptoms, particularly in high risk groups.

Discussion

Summary of main findings

This review aimed to find evidence from the literature regarding the primary care usage of people who smoke. The evidence shows that there is a difference in the consulting behaviour of people who smoke compared to people who do not. The evidence from the five included studies indicated that smokers are less likely to use primary care preventive services, patient intervals are likely to be longer in smokers and, when they do use primary care services, they do so less frequently than non-smokers. It has been shown through these studies that people who smoke are less likely to have a regular doctor and to use their services even when they suffer serious symptoms. It also has been shown that symptom interpretation in smokers is a concern as potentially serious symptoms may be overlooked or assumed to be normal.

Strengths and limitations of review

This review was rigorously conducted and reported in accordance with PRISMA guidelines. There was a lack of primary studies focussing on smoking and primary care. Only five studies could be included, and the majority of included studies were derived from the health aspects of much larger scale surveys. The studies were well conducted and largely well reported, and no significant sources of bias were identified, however one study (Smith et al 2009) failed to report which statistical test was used. Although the response rates were low in some cases, taken in the context of very large sample sizes, the findings appeared to be trustworthy and reliable. It must also be noted that, while results may have been of statistical significance, they were too slight to necessarily be of clinical significance. Notably, none of the included studies explored potential reasons for longer patient intervals or for the lack of presentation altogether. No qualitative studies were found that might have shed light on these issues. Only two of the included papers were UK based; Feng et al (2014); Jorm et al (2012) and Kaplan et al (2002) were conducted in Australia and Canada respectively. It must be taken into account that differing healthcare systems may be an influential factor in primary care usage which makes it difficult to generalise the results to the UK. However, both Canada and Australia have publicly funded healthcare systems which are relatively similar to the UK NHS. Despite the dearth of primary studies focusing on smoking and primary care service use, this review was able to address the review objectives.

Implications for further research and the thesis

Further research is needed to build on the evidence generated by this review, in particular there is a need further explore the literature in a more iterative way to discover potential reasons why smokers are less likely to use primary care. This is done in the narrative review, reported in the second part of this chapter. This review was able to broadly answer the two main research questions posed:

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals?

However, only one of the included studies investigated consulting patterns of smokers specifically in relation to lung cancer symptoms. The sub-questions around failure to consult (For any symptoms of ill-health? For symptoms they perceive to be smoking-related? For chest or other symptoms they perceive to be indicative of lung cancer?) could not be answered. Also, all the included studies were surveys, which are designed to answer questions about who, what, where and when, but not to explore how or why. The need for high quality qualitative research highlighted by this review will be addressed by the research and presented in the succeeding chapters of this thesis.

Conclusion

These findings highlight the inconsistency in consulting behaviour between smokers and non-smokers and the need for constructive measures to encourage GP attendance in general among the smoking population, but in particular when potentially serious symptoms are experienced. This review has also confirmed that patient intervals are likely to be longer in patients that smoke. These longer intervals and lack of access to primary care has potential for a wider, and possibly very serious, impact on lung cancer incidence and outcomes. Following the findings of this review, there is clear need for this study to explore the literature further in order to find evidence as to why smokers may hesitate to consult in primary care, this addressed in part B of this chapter, the narrative literature review.

Systematic review update

Rationale for update

Prior to completion of the thesis, it was recognised that the searches for this systematic review were somewhat out of date and the review would benefit from the inclusion of any more recent studies which met the inclusion criteria.

Methods

It was not deemed necessary to re-run all of the searches, therefore the search strategy was re-run on Medline only as Medline yielded the most relevant studies in the initial searches. The strategy was re-run to cover the most recent five year period.

Search results

This search returned 128 results which were then screened on title and abstract. Of these 128, 21 were potential includes and full texts were retrieved. On full text, four papers met the inclusion criteria for the original review. Other studies which did not meet the inclusion criteria were considered for inclusion in the narrative review.

It was not deemed necessary to carry out a full data extraction of the papers, however brief study characteristics and study findings are presented in table 4 and this data was then used to produce a narrative synthesis and consideration of implications for the review and the wider thesis.

Narrative synthesis of study findings

The four new studies report a mixture of findings regarding the primary care usage of smokers. In two of the studies it was reported that smoking was associated with more frequent consulting in primary care (Jorgensen et al 2016; Muhktar et al 2018) and in the other two studies it was reported that smoking was associated with lower consultation rates (Schlichthorst et al 2016; Walabayeki et al 2017). Two of these differing studies were conducted in primary care in the UK but it may be that differences in findings are due to differences in study aims and methods. Muhktar et al (2018) aimed to examine factors associated with consultation in general practice including smoking, whilst the study by Walabayeki et al (2017) aimed to explore the consultation rates of smokers vs non-smokers for potential cancer symptoms which could be smoking related. The Danish study by Jorgensen et al (2016) reports similar findings to those of Muhktar et al (2018) in that smoking was found to be associated with more frequent consulting, however they also report that other lifestyle factors were associated with more frequent consulting, in particular pre-exiting chronic conditions which may account for frequent consulting in smokers who are at higher risk of some chronic conditions. The study by Schlichthorst et al (2016) examined registry data from a longitudinal study on men's health in Australia and reports that older men and those who smoke are less frequent consulters than younger men and non-smokers.

The findings of these studies show that smoking is likely to be a factor associated with help seeking in primary care, in some cases it may lead to more frequent consulting and in others it may reduce primary care use, however it may be that other lifestyle and clinical factors are also contributors to decision making.

Findings in the context of the review

The findings of Walabayeki et al (2017) show that smokers were less likely to see their GP if they experienced cough, this may fit with the findings of Smith et al (2009) which report that smokers may be more tolerant of cough like symptoms, perceiving them to be 'normal to smokers'. Jorm et al (2012) found that use of primary care was related to a multitude of factors, both access and health related, and this may also fit with the findings reported by Muhktar et al (2018) and Jorgensen et al (2016) who described several lifestyle and clinical factors which may affect consultation rates. Feng et al (2014) reported that those with multiple unhealthy lifestyle behaviours were less likely to consult which may increase risk of developing chronic disease and recommended that interventions should target those who less likely to present which correlates with conclusions drawn by Walabayeki et al (2017). Schlichthorst et al (2016) reported that older men and smokers were less likely to consult than younger men and non-smokers which may invite comparison with the study findings of Kaplan et al (2002) who report that consultation rates were lower in smokers and older adults.

Implications for the review and the wider thesis

The findings from these studies have implications for the review and for the thesis as a whole, whilst two studies (Schlichthorst et al 2016; Walabayeki et al 2017) report findings in accordance with the findings of the previous included studies, the other two studies report findings in opposition to the previous included studies (Jorgensen et al 2016; Muhktar et al 2018) and this must be taken in to consideration regarding the thesis. However, despite this difference in findings, there are also many other factors which may be contributing to the findings of these studies and therefore there is still a clear need for further, qualitative, research in order to explore the reasons behind decision making and consultation in primary care for smokers.

Table 4: summary of recent studies

Author and location	Study design, sample and population	Study aims	Methods	Key Findings	Conclusions
Jorgensen et al (2016) JT. Denmark.	Cross-sectional cohort study of 54,849 50-65 year old participants of the Danish Diet, Cancer and Health cohort from the Danish National Health Service register.	To describe determinants of frequent attendance in general practice in Danish adults by examining medical, gender, and sociodemographic factors.	Secondary analysis of registry data. Logistic regression models were used to identify determinants.	Smoking was associated with frequent attendance in general practice. Current and previous smokers had higher odds of being frequent attenders that never smokers.	Lifestyle factors such as obesity, exercise, alcohol consumption and smoking, are an independent determinate of frequent attendance.
Mukhtar et al (2018) TK. UK	Cross-sectional study of 304,937 patients registered at 316 general practices in England drawn from Clinical Practice Research Datalink.	To examine factors associated with consultation rates in general practice.	Age, gender, ethnicity smoking status and deprivation measures were linked with practice data on rurality, staffing, training practice status and QOF performance. Multilevel analyses of patient consultation rates were conducted.	Smokers were shown to consult more often than non-smokers. Non-smokers had a 12% lower (RR = 0.88 95% CI =0.87-0.89) and ex-smokers a 2% lower (RR = 0.98, 95%CI = 0.97 to 0.99) consultation rate to current smokers.	These findings show consistent trends in consultation rates and can be used to inform the development of staffing models and resource allocation.
Schlichthorst et al (2016) M. Australia.	Cross-sectional study of 13,763 male participants aged between 18 and 55 years. Data drawn from Ten to Men, the Australian Longitudinal Study on Male Health.	To investigate associations between two measures of healthcare utilisation (past visit to GP and regular check-ups) and a number of sociodemographic and lifestyle related factors.	Associations between measures were examined using logistic regression analysis.	The odds for visiting a GP were reduced for smokers (OR = 0.7, 95% CI: 0.6-0.8)	Lower consultation rates may result in missed opportunities to detect problems earlier and which may mean men are missing out compared to women.
Walabayeki et al (2017) J. UK.	Cross sectional study comprising a postal questionnaire to sample of smokers (25.8%) ex-smokers (18.3%) and never-smokers (53.6%) from GP lists in Yorkshire	To investigate symptom experience, awareness of, and consultation rates for symptoms of lung and head and neck cancer.	Postal questionnaire asking about symptoms, awareness and consulting. Data were analysed using STATA 14.	Smokers were less likely to consult for cough but there was no association between smoking and consulting for breathlessness, tiredness, or shoulder pain.	There is a need to promote consulting among smokers and develop interventions to improve symptom recognition and empower smokers to seek help.

Part B: Narrative review of literature on the topics of smoking, primary care use, and lung cancer symptoms

Review summary

Part B of this chapter builds on the previous systematic review (part A) and presents a wider narrative review of the relevant literature. The review methods are outlined in detail in order to give the reader a full picture of how and why the review was conducted. The findings of the review are then presented thematically concluding with a summary of how those findings are relevant to this study and how the thesis will move forward.

Introduction

In order to build further upon the bank of evidence generated by the systematic review, it is necessary to understand the broader issues surrounding patient intervals in those who smoke and experience symptoms of, or are diagnosed with, lung cancer. The findings of the systematic review showed that there is inconsistency in the consulting decisions between smokers and non-smokers and in light of those findings it is important to explore reasons for why that may be. This narrative literature review was designed to give a broader perspective on the existing literature and relevant previous research. This narrative literature review differs from the systematic review in that the search terms and inclusion criteria are of a much broader nature and aim to include a wider range of topics. While the systematic review asked a focussed and specific question, the purpose of the wider, narrative literature review is to allow a deeper exploration of the relevant themes surrounding the research objectives and therefore includes more qualitative work. This narrative literature review is a full account of the available literature which spans varying disciplines, paradigms and perspectives and also takes a critical and analytical approach to that literature in order to refine research objectives for the next phases of the study (Jesson and Lacey 2006). The narrative literature review is designed to put evidence into the context of the study as a whole and explore the meaning of the research topic as it has been lived by research participants (Aveyard 2014). Narrative literature reviews have been criticised for their potential subjectivity and lack of rigour, however these issues were addressed in this review by employing thorough methodology (Green et al 2006). This review, whilst not a systematic review, was carried out using a rigorous and comprehensive approach with clearly defined search methods in order to identify all the key literature available (Aveyard 2014). This narrative review has a defined methodology and consists of clear research objectives, methods and results all of which are reported in this chapter (Jesson and Lacey 2006). A well-defined and clear search strategy was used in order to minimise the possibility of selection bias and increase clarity (Ferrari 2015). The research topic in this review was already defined by the aims of the wider thesis and the systematic review provided a clear field for this second review to explore in order to develop understanding further. The systematic review showed some evidence that people who smoke consult less frequently and have longer patient intervals than those who do not. This review set out to explore primarily qualitative work in order to seek reasons for why these phenomena occur.

Methods

The SPIDER tool was used for creating a web of likely study types to be included and to help facilitate the formulation of the search strategy (Cooke et al 2012). The SPIDER tool was developed as an alternative to PICO for searching for qualitative studies and serves as a structure for synthesising the evidence of studies based on the experiences of individuals and societies (Cooke et al 2012). The SPIDER tool was therefore particularly suitable for use in this narrative review as qualitative studies were of particular interest.

SPIDER

Sample

The samples in the included studies include current and ex-smokers, people with lung cancer, people with cancer symptoms, people with other cancers, healthcare professionals, family caregivers, and relatives of cancer or lung cancer patients.

Phenomena of interest

The phenomena of interest were generated from initial reading, evidence from the systematic review, and generation of key themes. They include smoking, patient intervals, cancer, lung cancer, primary care, symptom recognition, risk, help seeking, stigma and blame.

Design

This review includes studies that employ both qualitative and quantitative methods, theoretical approaches, and policy and practice documents.

Evaluation

The outcome measures include attitudes, beliefs and views about smoking, cancer, and primary care.

Research type

Research types are qualitative or mixed methods with qualitative elements and theory, policy and practice papers.

Literature searching

Initial scoping searches

A comprehensive search strategy beginning with initial scoping searches was employed (Aveyard 2014). The review began with reading through the initial background literature used for designing the study as a whole, and then with screening of all the excluded papers from the previous systematic review and excluding anything irrelevant. The papers which were relevant to this review were kept and citation searched for further references which were then retrieved and screened for applicability.

Initial literature mapping exercise

Following the initial scoping searches, a preliminary map of the literature was created. The mapping exercise was designed to give an overview of what is available on the research topic and what key themes may be apparent (Hart 1998). The mapping exercise consisted of reading all papers and grouping them together according to their principle themes (Aveyard 2014) which allows the researcher to build a visual representation of the literature and how much is available on each theme (Creswell 2014). The literature mapping was first drawn out diagrammatically (see appendix 3). The mapping exercise generated a set of key themes which in turn produced the key terms for the subsequent electronic searches (Aveyard 2014). Two further mapping exercises were conducted following the electronic searches so that all the retrieved papers were mapped diagrammatically and finally a combined thematic map was produced, however it is important to note that not all mapped studies feature in the review as some were later excluded on full text.

Searches

Several short search strategies were created using thesaurus terms relevant to the main research topic and the keywords generated by the mapping exercise. These searches were run on Applied Social Sciences Indexes and Abstracts (ASSIA) as this database covers health related literature and includes journals which publish both quantitative and qualitative work The search strategies were then adapted for, and run on, Medline as this database covers a broad range of biomedical literature. ASSIA was searched on 23/05/2016 and Medline searches were run on 22/06/2016. All studies were assessed for inclusion on title and abstract. Relevant literature was retrieved and assessed on full text. All included papers were citation searched and key authors and journals were also hand searched. Searching stopped when the same studies were being turned up repeatedly (Aveyard 2014).

Search results

The database searches produced 3,170 results from the strategies which were electronically stored using Endnote library software. Following de duplication of the library there were 1,923 results to be screened for relevancy. On title and abstract screening 155 papers were identified as being potentially suitable for inclusion in the review and full texts were retrieved and assessed. A further fifty-seven papers had been identified by initial scoping searches and later hand searching and reference checking. Further literature was identified throughout the study and included in the review when relevant. A total of 102 publications were included in the final review.

Strategies

The comprehensive search strategies used for the narrative review are presented in appendix 3.

Inclusion criteria

While this review was designed to be broader than the systematic review, inclusion criteria were still necessary to provide parameters which prevent the review from becoming too large and unmanageable and keep to literature relating to the research topic (Aveyard 2014). Studies were included if they were relevant to the primary research topic, related to key themes, and addressed the review question. Studies were not limited to cancer only and were eligible for inclusion if they reported findings related to smokers accessing healthcare for other conditions. The inclusion and exclusion criteria for this review were somewhat flexible according to relevancy but studies were excluded if they reported only never-smokers.

Critical appraisal

Critical appraisal was used to assess the main strengths and weaknesses of the included literature and to determine how much weight should be given to each piece of literature in the review (Aveyard 2014). Whilst there are several critical appraisal tools available for use, this review used the RATS tool for critically appraising qualitative health studies (Clark 2003). Other tools considered include the MMAT (2011) tools for assessing mixed methods studies and CASP (2013) checklist for qualitative studies, however it was decided that the RATS tool was most suitable for this narrative review as it is specific to qualitative work and is cited in the British Medical Journal (Clark 2003). The use of the RATS tool in this review involved examining each study and assessing whether or not it met set criteria in order to evaluate its strength (Clark 2003). These criteria were grouped under the following broad headings; Relevance of study question, Appropriateness of qualitative method, Transparency of procedures and Soundness of interpretive approach (RATS) (Clark 2003). Each of these broad headings encompasses the key questions the researcher should ask of the manuscript in order to assess the quality of the research and the reporting and is specific to qualitative work, making it particularly appropriate for use in this narrative review. Whilst assessing the relevance of the research questions, the researcher must also decide whether the question is interesting and relevant to health policy, practice or public health (Clark 2003). The 'appropriateness of qualitative methods' section asks the reviewer to evaluate whether or not the authors have chosen the most appropriate data collection method for answering their research questions, methods most likely used include interviews, focus groups and ethnography (Clark 2003). Under the heading of 'transparency of procedures', the reader is looking for clear reporting of the sampling strategy, recruitment process, data collection and the role of the researchers and ethical considerations (Clark 2003). The final step was assessing the soundness of the interpretive approach by examining the reported analysis and the discussion and presentation of the data (Clark 2003). The RATS tool was applied to each study included in this review. As mentioned in the previous review, quality appraisal tools for this study were selected to allow the most accurate appraisal of study quality possible. A table detailing characteristics, strengths and limitations of critical appraisal tools considered for this thesis is provided in appendix 3.

Narrative synthesis

This narrative review used a meta-ethnographic approach to synthesise data from the included literature. As the included studies were all qualitative, the data were brought together thematically and the evidence within them presented in a running narrative. A meta-ethnographical approach was adopted to combine the data from the included studies to develop the themes, create a strong evidence base and deepen understanding of the existing literature (Aveyard 2014). Meta-ethnography provides a method for bringing together, and deriving meaning from, multiple accounts, narratives, or studies (Noblit and Hare 1988). The meta-ethnography was the most appropriate method of analysis to use in this review as it is intended to enable a critical examination of multiple accounts of a phenomenon and to allow for cross case comparisons (Noblit and Hare 1988). This approach was appropriate for this study as the review, and the thesis as a whole, aims to understand the broader context and complex issues surrounding the research topics and therefore many included studies presented rich qualitative data derived from interviews and focus groups which is ideal for meta-ethnography (Noblit and Hare 1988). The studies had already been grouped according to their overarching themes by the literature mapping process, however following in-depth examination, many of them contained evidence relating to many of the themes of interest. The evidence was extracted from each study according to each theme and therefore the synthesis of data is multi-layered and complex, this further defined the aims of the thesis in that this complexity was kept in mind during later phases of the study.

Findings

Overview of emergent themes

This review is key to the overall thesis as it presents an in-depth look at the factors which can influence decision-making and primary care use in the context of cancer symptoms and the thoughts and feelings of smokers. From the literature emerged a set of key themes that interconnect to inform the decision-making of smokers and of those with lung cancer symptoms. Each of these key themes is complex and encompasses a variety of related sub-themes. It was revealed that concerns about legitimate help seeking and wasting GP time are prevalent within the literature and can be further influenced by perceived stigma and blame within both the clinical and lay community. These concerns surrounding legitimacy of seeking care is of utmost importance to this thesis as it can have a potentially strong influence on a person’s timeliness of presentation. The literature also showed that some people have a tendency to misinterpret their symptoms as being a minor complaint or normalise and accommodate them rather than seek help which again has a potential effect on help seeking decisions. The existence of a link between comorbidity and timely diagnosis also emerged from the literature. Studies also showed a lack of understanding regarding treatment, care, and prognosis for lung cancer, as well as a fear of illness or a sense of fatalism in some people who smoke and/ or experience potential cancer symptoms. Another key theme to emerge was that of low levels of risk perception in smokers which may lead them to not suspect lung cancer in themselves. Finally, relationships with family and friends have also been shown to be contributing factors in healthcare decision making. As all of these overarching themes have a potential effect on patient intervals in smokers and those with lung cancer, they are all of particular relevance and interest in the context of this study. This chapter includes all the evidence generated by the review and each key theme and sub-theme which are presented within the forthcoming narrative synthesis.

Thematic narrative synthesis

Help seeking

A prominent theme in the narrative review is why and how smokers and people with lung cancer symptoms choose to seek help or not. From the available literature, it would seem that help seeking is a complex process and is intrinsically bound with other issues that either facilitate or deter help seeking.

Access to healthcare and negotiating the system

In order to investigate factors which influence presentation it is necessary to consider the ways in which individuals perceive their own ability to access healthcare in the first place. The concept of ‘access to healthcare’ as described in a framework by Aday and Andersen (1974) refers to the resources available in the area in which a person lives, or the availability of health services as and when the patient needs them. Whilst the framework developed by Aday and Andersen (1974) is based upon an American health system model, the ideas can also be applied to a UK context. Aday and Andersen (1974) cite potential barriers to accessing healthcare such as waiting times, availability of appointments and decline of primary care services such as house calls which may also have an influence on help seeking in the UK. An interpretive synthesis of literature by Dixon-Woods et al (2006) reports that navigating the healthcare system in the UK can prove to require considerable effort on the part of the patient who will need to negotiate the route in to ‘permeable sources’ such as primary care and will also need to assert their ‘candidacy’ for, or legitimate use of, healthcare. The Candidacy Framework model can be used to understand the ways in which people access health services and also refers to the ‘permeability of sources’ (Dixon-Woods et al 2016). A further adaptation of the framework by Tookey et al (2018) describes the navigation of and permeability of services as key stages in decision making regarding consultation. Concerns regarding availability of appointments, ability to contact services and levels of perceived gatekeeping have all been identified as potential barriers to help seeking (Tookey et al 2018). The study by Tookey et al (2018) applied the adapted Candidacy Framework to interview data regarding help seeking for cancer symptoms and found that alongside concerns about availability, participants also anticipated time limits in their appointments and therefore restricted time for communication with their GP which may lead to not all symptoms being reported. In the UK a gatekeeping healthcare system is in practice; this may mean several presentations in primary care with the same symptoms (Macdonald et al 2016). The Candidacy Framework refers to ‘professional adjudication’ which can account for concerns about visiting the GP for the same symptoms repeatedly, participants have shown concern about being ‘undeserving’ of care if they were to seek help for a symptom which had already been assessed as minor by their GP (Tookey et al 2018). Professional adjudication may also account for reported negative experiences and lack of confidence in healthcare professionals, previous work has shown that participants described doctors as having insufficient knowledge and being unable to make correct diagnoses (Renzi et al 2016).

Whilst these studies do not focus specifically on lung cancer or smoking, they are still of some relevance to this study as all patients will have to find a way to negotiate their way through the system. The prospect of having to negotiate through gatekeepers, potential repeat presentation, or a lack of appointment availability may mean that those who experience cancer symptoms may delay presentation.

The concepts of the ‘time waster’ vs the ‘legitimate’ help seeker

In the study by Corner et al (2006) formal healthcare providers such as doctors, nurses and hospitals, did not feature much in participants’ lives before diagnosis and most patients were not in regular contact with a GP, which is perhaps understandable in mostly healthy patients who do not suffer chronic conditions or regular health problems. A recurring theme in the literature is that of legitimate help seeking, that is, not wanting to see a GP if they felt it was not absolutely necessary. A common reason given for delaying help seeking is that of not wanting to ‘waste the doctor’s time’ (Whitaker et al 2015). Participants in a study by Tod et al (2007) reported not wanting to be seen as a ‘time waster’ and Whitaker et al (2015) cited ‘worry about wasting the doctor’s time’ as one of the five main reasons for delay. In a study by Hvidberg et al (2015) it was reported that 15% of participants cited concern about wasting time as a barrier to timely help seeking. Part of this concern about legitimate help seeking seems to be due to worry about being seen as a hypochondriac if patients saw their symptoms as being minor and likely to just get better by themselves over time (Smith et al 2005). Respondents in the study by Corner et al (2006) also reported not wanting to waste the doctor’s time and worried that they may be criticised, by peers or by healthcare professionals, for making an appointment about something trivial. Llanwarne et al (2017) also cite worries about wasting time when using primary care services as a theme in their study which also led to participants feeling like they needed to ensure they were a ‘good patient’ or legitimate help seeker. Participants compared themselves to other people who they believed were less careful about their use of primary care, participants wished to avoid being labelled a ‘time waster’ whilst describing other people they knew who would fit the ‘time waster’ profile (Llanwarne et al 2017). Public campaigns designed to encourage careful use of services and the knowledge that services are in high demand also contributed to the need of patients to make sure help seeking was legitimate before making appointments (Llanwarne et al 2017).

It has been shown in previous work that the visibility of time constraints in primary care is a factor contributing to concerns about time wasting (Cromme et al 2016). Participants in the study by Cromme et al (2016) were patients who had experienced a potential cancer symptom and consulted in primary care, the interview study was designed to explore perceptions of time wasting and potential psychological barriers to consulting. Participants in this study explained that they knew how busy doctors were and that they had extra responsibilities such as budgeting and paperwork as well as seeing patients (Cromme et al 2016). Participants seemed reluctant to add to the workload of primary care staff until they were absolutely certain it was necessary (Cromme et al 2016).

The apparent need to wait until help seeking was legitimate means that in some cases patients wait until symptoms are severe before they see a healthcare professional (Smith et al 2005). By waiting, the patient legitimises their help seeking behaviour by having put up with the symptoms for as long as they could manage, and when activities of daily life are seriously impaired by the symptoms they can allow themselves to seek help without being vulnerable to criticism. Smith et al (2005) has reported symptoms going unreported until ‘they reach crisis point' which can legitimise skipping their GP and presenting in secondary care, most likely in accident and emergency departments. An extreme example of this waiting until crisis point is shown by Smith et al (2005) as one study participant stated 'I was lucky I didn't have to go to my GP because I collapsed at church'. This participant saw themselves as being lucky even though their health was potentially at serious risk and so there was no chance they could be viewed as a 'time waster' (Smith et al 2005). The physical point of collapse can only be seen as a serious issue and having done so at church, a public space, may have also decreased the potential for being considered a 'time waster' as it has been witnessed and help was called for by another person, therefore taking the decision out of the patient's hands. Crane et al (2016) states that the majority of their study participants said they would seek help within a week if they had symptoms of lung cancer, however this perhaps shows the connection between legitimate help seeking and symptom recognition, presented in more detail later in this chapter, as they also stated they would not report symptoms they viewed as too mild to warrant seeing a doctor and so the timeliness of help seeking would depend upon the recognition of the symptoms as a potential cancer. Participants in the study by Cromme et al (2017) had experienced potential cancer symptoms but also felt the need to avoid being thought of as a hypochondriac who was wasting GP time and resources. In a study by Neal et al (2000) a population of patients who were frequent attenders in primary care were interviewed regarding their patterns of help seeking. Whilst the participants in the study tended to agree that they were frequent consulters, they too seemed to display the need to legitimise their help seeking by explaining they still only went because they needed to and were keen to avoid being labelled hypochondriac (Neal et al 2000). The study quotes a respondent who explains that even though they are a frequent consulter they know that there are other people who consult even more than they do; this is another form of legitimising or justifying their own visit to the GP (Neal et al 2000). A need for prescription medication was also shown to be a form of legitimate consulting as the only way to obtain it is by seeing the GP (Neal et al 2000). This fear of being considered a time waster, hypochondriac or otherwise illegitimate help seeker may be pertinent to the rest of the review and to the thesis as there appear to be many ways in which a person may be able to legitimise, or not, their need to see their GP.

Age, gender and help seeking

Age and gender norms also have a role to play in help seeking behaviour, with older, male participants being less likely to visit the doctor due to a perception that 'men don't go to the doctor' (Tod et al 2007). The participants of the Scanlon et al (2006) study of an Irish population living in the UK reported that men do not talk about health due to 'an Irish macho or hard man culture where illness was considered a weakness'. The Irish men also reported that they would rather wait and see if the symptoms got better on their own as they had other priorities that came before their own health (Scanlon et al 2006). Tod (2007) reported that stoicism was higher in older, male participants, especially if they had worked in industrial occupations. This could also be due to perceptions of male culture which are perhaps stronger in particular nationalities or religious populations. The Scanlon et al (2007) study findings are reported in the context of Irish men living in the UK, which may either serve to dilute their male culture or indeed to strengthen it due to a desire to preserve traditional values. This thesis features a study population largely from North Wales which potentially may reveal their own perceptions of gender norms and help seeking.

Help seeking as a smoker

The issue of smoking and how it affects help seeking decisions is paramount to this thesis and it is important to note that whilst it is mentioned here, it is detailed further throughout this chapter. Smoking was so deeply intertwined with almost all of the key themes in this review, it was not appropriate to attempt to report the impact of smoking separately as this would detract from the its depth and complexity, therefore it is presented as a key part of each recurring theme. Smoking is an issue which affects people's help seeking choices and how they navigate legitimate help seeking in the context of being a smoker. A study by Smith et al (2005) has shown that some patients who smoke are afraid that their healthcare provider will not take their symptoms seriously due to them being smoking-related, which may increase the likelihood of them waiting until the symptoms can be deemed legitimate. This concern regarding legitimate help seeking has also been shown to affect communication between GPs and patients as previous research reports that smokers are reluctant to raise the issue of smoking when they do choose to see their GP (Farley et al 2016). The study by Farley et al (2016) reported a complex relationship between the desire to discuss smoking with the GP but also a deep sense of discomfort that may arise from conversations. Many current smokers felt that it was important for healthcare providers to discuss smoking with them, however they had not been asked about it by their GP, and some also reported that whilst it was important, it also made them uncomfortable and so they would not bring it up themselves (Farley et al 2016). Some people also stated that smoking cessation should be offered even if they did not think it would help them personally (Farley et al 2016). It was also reported that some smokers did not disclose their smoking status to their GP (Farley et al 2016). This is shown further in work by Stuber and Galea (2009) who found that eight percent of respondents in their study kept their smoking status secret from their healthcare provider and that a respondent's perceived level of smoking acceptability was associated with whether or not a person chose to reveal their smoking status. This difficulty in raising the topic of smoking during help seeking opportunities is just one of the ways in which smoking status may affect patient intervals in that patients who feel uncomfortable discussing smoking may delay, and that GPs may believe a person to be a low risk for lung cancer if they are unaware that the patient is a smoker.

Smoker's perceptions of healthcare professional attitudes to smoking

The perceived attitude of the healthcare provider also seems to be a feature of help seeking decision making and occurs throughout the literature in varying contexts. Some people have been shown to feel negatively about seeking help and therefore adopt their own strategies such as self-treatment or 'learning to live with it' (Whitaker et al 2015). Some patients also perceive that GPs have a 'nihilistic attitude to lung cancer' which may deter them from seeking help early, particularly if they are smokers (Walton et al 2013). Whilst it was previously mentioned that some patients avoid conversations about smoking, some research has found the same to be true of some healthcare professionals. In the work by Tomlinson (2014) some healthcare practitioners reported reluctance to discuss smoking with their patients. In a qualitative study of complimentary therapists in the oncology setting, therapists gave different ethical reasons for not wishing to discuss smoking with patients. In particular, timing was cited by the participants as a reason for not discussing smoking; healthcare practitioners did not want to pressure patients and felt that raising issues about smoking at the time of their illness was potentially intrusive (Tomlinson 2014). Therapists also liked to empathise with their patients and expressed that when they imagined themselves in the patient's position they thought they would not want to discuss smoking as it may bring about feelings of blame (Tomlinson 2014). Therapists were concerned about shaming patients who may already be feeling that they were to blame because of their smoking (Tomlinson 2014). Finally, therapists also cited the fact that many of their patients might enjoy smoking and use it to relieve stress, and did not want to further stress the patient by telling them to stop smoking (Tomlinson et al 2014). This is perhaps contributed to further by several of the therapists in the study reporting that they were smokers themselves and that they felt stigmatised by colleagues who did not smoke (Tomlinson 2014). However, the therapists did think that it would be beneficial if cancer patients could stop smoking but were still reluctant to discuss it (Tomlinson 2014). The work cited above gives a powerful insight into the complexity of the decisions regarding timely consultation, smoking and cancer. The concept of help seeking is revisited throughout the rest of this chapter as it is intrinsically bound with each of the following key themes.

Symptom recognition, normalisation and accommodation

The ways in which people recognise and interpret their health may have an effect on the rapidity in which they choose to seek medical advice. As this thesis has timeliness of presentation at its core, it is important to fully explore the literature regarding the relationship between patients and their own knowledge and interpretation of their symptoms.

Symptom occurrence and recognition

Whilst approximately 90% of cancer presentations will be symptomatic, it appears from the literature that a lack of symptom recognition is prevalent among those experiencing them (Neal 2009). Patient delays are likely to occur, even in symptomatic cases, if the patient does not recognise or act upon those symptoms (Neal 2009). The Model of Total Patient Delay (Scott and Walter 2010) and The Model of Pathways to Treatment (Scott et al 2013) both begin with a person noticing a bodily change or symptom but they also then rely on the person appraising that symptom and interpreting it as something to be concerned about. In a qualitative study in New Zealand it was found that symptom interpretation and health experiences had a role to play in influencing early help seeking and the literature also suggests that knowledge of lung cancer symptoms is poor (Walton et al 2013; Tod et al 2007). In a 2013 study by Walton et al (2013) many people had delayed help seeking and cited misinterpretation of their symptoms as the reason why. Recent evidence showed that many newly diagnosed lung cancer patients were unable to recognise all of their cancer symptoms (Brindle et al 2012). This all indicates that presentation is dependent upon the patient's recognition and interpretation of a symptom as something which warrants a visit to the GP.

Symptom experience and normalisation

Research by Corner et al (2006) showed that patients with lung cancer did not recognise that symptoms such as changes in breathing, persistent cough and fatigue were potentially indicative of lung cancer and, while participants did not intentionally delay help seeking, they did so because they had poor symptom knowledge and had a tendency to normalise their bodily changes. The tendency to normalise symptoms is common among participants within lung cancer research, with patients often experiencing systemic symptoms such as fatigue, weight loss and changes in appetite and assuming they are everyday bodily changes or part of the ageing process (Shim et al 2013). Brindle et al (2012) reported that fifteen participants had experienced potential lung cancer symptoms but had not considered them to be a reason for concern and so had not seen their GP. Symptoms such as breathlessness were believed to be due to ageing, being physically unfit or seasonal changes and therefore just a normal part of life and not a reason to seek medical attention (Brindle et al 2012). Participants in the Brindle et al (2012) study reported health changes were left uninvestigated and instead patients produced normalised accounts of these symptoms. This normalisation process was found in participants irrespective of patient demographics, route to diagnosis, or smoking status (Brindle et al 2012). Andersen et al (2010) used thirty semi-structured interviews with adult Danish cancer patients to explore the phenomenon of ‘containment’ and its role in patient intervals. It was identified that there were three ways in which ‘social and cultural circumstances allowed bodily sensations to be managed within a specific social and cultural context as part of a normal process and not as potential symptoms requiring care’ (Andersen et al 2010). Andersen et al (2010) refers to these processes as types of ‘containment’. Firstly, sensations such as fatigue, pain, and even bleeding were normalised by attributing them to ongoing parts of everyday life such as sports, gardening, or other physical activities and thus not perceived as being significant or a cause for concern (Andersen et al 2010). Participants also framed symptoms such as stomach ache, tiredness, and constipation in psychological terms by citing stress at work, problems at home, and family issues as being responsible (Andersen et al 2010). The second mode of what Andersen et al (2010) refers to as ‘containment’ describes how different biographies can frame symptom interpretation. Participants expressed that they had their own internalised set of health issues that they perceived themselves to be at risk of and therefore they evaluated any bodily sensations according to those perceptions (Andersen et al 2010). When a participant experienced something which did not fit within these perceived health risks, they did not view it as likely to warrant medical attention (Andersen et al 2010). Thirdly, participants also avoided defining their bodily changes as symptoms of illness in order to preserve social relations and self-image (Andersen et al 2010). One particular patient had suffered severe cough and haemoptysis for months before seeking help; following the diagnosis he refrained from informing family members or friends of his condition (Andersen et al 2010). Another patient experienced haemoptysis for five months before telling his wife, instead he had trivialised and attempted to ignore his symptoms (Andersen et al 2010). Whilst it is perhaps natural for a person experiencing mild symptoms to not immediately suspect cancer and therefore not seek help, here we can see evidence of symptoms becoming severe and patients still hesitating to see their GP. This is potentially impactful in this study as participants may have gone through similar processes of normalisation and learning to accommodate symptoms rather than seek advice.

It has been shown by Kummer et al (2019) that during symptom appraisal people may draw upon cognitive heuristics, or ‘rules of thumb’ to help them interpret those symptoms. Kummer et al (2019) identify nine heuristics or rules that participants used to interpret symptoms indicative of cancer. The first heuristic identified is the ‘rate of change rule’ used by those who noticed that symptoms were either worsening or changing rapidly, however some participants also reported having waited for symptoms to worsen (Kummer et al 2019). The ‘chronology rule’ is used by those who contextualise their symptom in relation to life events such as holidays or changes in circumstances, this can then be translated in to symptoms occurring due to eating different food or having a stressful time at work (Kummer et al 2019). For those experiencing repeating symptoms occurring every time they did a certain activity, the ‘pattern rule’ was used to interpret the symptoms, participants used phrases starting with ‘every time I….’ to illustrate the use of this heuristic (Kummer et al 2019). The ‘severity rule’ is used when symptoms are severe and potentially indicative of something serious, the level of severity was assessed by how much the symptom interfered with everyday activities, when the participants could manage their everyday activities despite the symptom, normalisation occurred (Kummer et al 2019). When symptoms were experienced that were new and had never been experienced before, participants in this study were found to have used the ‘novelty rule’ to justify help seeking, whilst those who had experienced symptoms before tended to delay presenting, this links with findings from Renzi et al (2015; 2016) regarding false reassurance which are discussed in the ‘risk’ section of this review (Kummer et al 2019). Some cancers were found to be interpreted as natural signs of ageing using the ‘age-illness rule’ whereby participants assumed that bodily changes were due to the ageing process and not a cause for concern (Kummer et al 2019). The ‘location rule’, which was not seen to be relied upon very often, occurs when a person is worried about a symptom due to its location within the body (Kummer et al 2019). People have been shown to interpret their symptoms in the context of what they believe themselves to be susceptible to, this heuristic is also called the ‘similarity rule’ and may also related to theories of containment (Kummer et al 2019; Andersen et al 2010). The final cognitive heuristic reported by Kummer et al (2019) is the ‘optimistic bias rule’ by which participants believe themselves to be healthy and therefore not at risk of cancer, this also links with other work regarding risk beliefs and optimism (Renzi et al 2015; 2016).

Normalisation of minor symptoms

Further evidence of cancer sufferers normalising their symptoms can be found in work by Corner et al (2006) who found that many participants had not seen their symptoms as being serious enough to warrant seeing a doctor. The study, which interviewed twenty two patients with recently diagnosed lung cancer, reported that all the participants had delayed help seeking for four or more months due to believing that symptoms were minor and not worth reporting (Corner et al 2006). It would seem that assuming symptoms are minor and therefore not worth reporting is common in lung cancer patients with the narrative of the ‘cold that wouldn’t go away’ running through the literature (Levealahti et al 2007). People who reported very mild symptoms did not suspect cancer and it is possible that they were more likely to self-medicate with over the counter remedies rather than see a GP (Tod et al 2007). It has also been reported that people expect cancer symptoms to be severe and therefore the mild changes they experienced would not warrant suspicion or investigation (Tod et al 2007). It is important to note that often the patients who reported experiencing mild symptoms had long delays. The delayed reporting of a mild symptom is understandable, however those who believed that they had a minor complaint such as a cold still did not suspect anything more serious even though their symptoms lasted far longer than a cold usually would. It should also be mentioned that some studies reported participants who did not experience any symptoms and either had an incidental diagnosis made when having other health issues investigated or reported not having experienced any symptoms prior to being admitted to and diagnosed in emergency care (Brindle et al 2012; Walton et al 2013). However, it is also possible that some patients who report themselves to be asymptomatic may actually just not have interpreted their symptoms correctly or, as some evidence has shown, may report the same symptom in different ways (Westerman et al 2007). In a 2007 study, participants showed signs of inconsistent reporting, such as one participant who, during an interview, reported she was tired but had also answered consistently ‘not at all’ to the tiredness item on the questionnaire (Westerman et al 2007). These differing accounts may reflect the ways in which different methodologies produce different accounts and highlights the importance of qualitative research which allows for an exploration of the participants experiences.

Normalising symptoms as a way to legitimate help seeking

Like in other studies, patients in the study by Corner et al (2006) attributed symptoms such as shortness of breath, tiredness, and pain to ageing or ‘over doing it’. It has also been shown that some people normalise their symptoms to such an extent that they are actually minimising the amount of impact the symptom is having on their everyday life (Corner et al 2006). The study by Corner et al (2006) reports that patients minimised their symptoms and described them as minor or ‘nothing serious’ even when accounts suggests that they were actually severe and had ‘a major impact on everyday functioning’. Many patients in the study persevered with symptoms until they became so severe that they could no longer be tolerated, one male participant with extreme tiredness had waited eighteen months before he consulted his doctor (Corner et al 2006). There is a potential link between the reluctance to report minor symptoms and the aforementioned desire for ‘legitimate’ help seeking. If a person has waited until the symptom is actually unbearable then become a legitimate help seeker and not a ‘time waster’ or ‘hypochondriac’.

It is possible that the general public have limited knowledge of lung cancer symptoms and therefore do no not always realise when they experience them. Some research has shown a lack of symptom knowledge among participants, with one Australian study showing that participants could identify some general symptoms but there was doubt about whether they were symptoms of lung cancer (Crane et al 2016). In a study of delay in lung cancer diagnosis it was found that the participants had poor knowledge and awareness of the symptoms of lung cancer (Tod et al 2007). Among participants in a study of Irish people living in Britain knowledge of cancer was ‘general in nature’ and discussion of cancer tended to be focussed on prognosis and treatment rather than the early signs and symptoms (Scanlon et al 2006). Among the Irish population, women tended to have slightly better cancer knowledge than men, although overall it was still poor, and older people had the lowest levels of knowledge; this could be attributed to lower levels of education (Scanlon et al 2006). It may be that people believe that they have a good knowledge of cancer symptoms but in reality their knowledge is more limited. A limited knowledge of what actually constitutes a lung cancer symptom may have an impact on patient intervals as cancer is not suspected.

Recognising ‘alarm’ symptoms

Whilst many cancer symptoms are general in nature, there are some which can be categorised as ‘alarm symptoms’ which people recognise to be serious enough to warrant medical attention, such as an obvious lump or coughing up blood (haemoptysis) (Levealahti et al 2007). The most well-known alarm symptom of lung cancer is haemoptysis and it has been suggested that some patients who experience haemoptysis are unable to normalise their symptoms due to it being a clear sign that something is wrong (Levealahti et al 2007). In work by Crane et al (2016) haemoptysis and chest pain were highlighted by the respondents as being symptoms which would ‘create a sense of urgency’ but it was also noted that respondents, whilst finding these symptoms a cause for concern, would not necessarily see them as indicative of lung cancer. Despite these ‘classic’ signs being more likely to arouse cancer suspicion, it has still been reported that rates of cancer suspicion are low, even in those experiencing alarm symptoms (Whitaker et al 2015). Interview data from Corner et al (2006) shows that while the onset of haemoptysis prompted help seeking in two patients, they had not connected the symptoms with lung cancer. This is again indicative of poor symptom awareness among the public and whilst experiencing an alarm symptom may then prompt the patient to seek help, even if they do not necessarily suspect cancer, they may have still suffered mild or more general symptoms for some time prior to the alarm symptom. This would again mean longer patient intervals and potentially worse outcomes.

Symptoms as ‘normal for smokers’

The majority of lung cancer patients have a history of smoking and therefore many participants in lung cancer research also have been smokers at some point. Corner et al (2006) found that although the majority of participants in their study had a history of smoking, none of them seemed to have connected their symptoms with potential lung cancer. Some research has shown that lung cancer patients do not always have a clear understanding of the link between smoking and cancer. A patient in the study by Hamann et al (2014) reported the belief that cancer cells are present in everybody and would flare up when a person’s immune system was low and this was how their cancer had begun. Smokers were also found to normalise their symptoms and to believe that cough and general ill health were just normal for smokers (Walton et al 2013). This demonstrates a lack of knowledge regarding health risks and the causal link between smoking and lung cancer. Whilst it could be said that the link between smoking and cancer has been in the public domain for many years, it would seem that people are unaware of how exactly smoking causes cancer, believing it to be something that develops by chance. The perception that a cough is ‘normal’ for smokers is also likely to have an impact on patient intervals as they are less likely to notice a change in their cough and are accustomed to it always being there.

Comorbidity

A key issue to emerge from the literature regarding symptom recognition and interpretation was that of people suffering multiple symptoms or health problems. The presence of comorbidities has been shown to make the process of symptom recognition more difficult as they make new symptoms harder to notice and changes in symptoms can be interpreted as a worsening of an existing condition or as normal for a person who has a chronic condition (Shim et al 2013). Systematic review evidence has shown that patients often attribute symptoms to existing chronic conditions (Shim et al 2013). This is echoed in work by Crane et al (2016), who found respondents thought that lung cancer symptoms were the progression of their emphysema, and Corner et al (2006), who stated that comorbidities such as asthma, cardiac conditions, and diabetes were blamed for symptoms such as breathlessness and chest pain, particularly in those who smoked. The study by Andersen et al (2010) also found that participants tended to see their symptoms as being due to comorbidity. One participant who had been a heavy smoker had assumed her symptoms were due to her COPD and had been surprised to hear that she had a diagnosis of lung cancer (Andersen et al 2010). Suffering a chronic condition which has similar physical symptoms to lung cancer make it harder for people to recognise bodily change or worsening symptoms as part of a separate condition (Corner et al 2006). Lung cancer patients may also suffer psychological comorbidities, meaning they are at higher risk of distress than those with other cancers (Millbury 2012). Perhaps conversely to this, a study by Mor et al (1990) found that the presence of a comorbidity had no association with delayed presentation in lung cancer patients. Whilst the presence of comorbidity can affect the ability of the patient to recognise the new symptoms, there is a complex argument surrounding the issue of whether or not it can also affect the point at which the clinician recognises the new symptoms and whether or not it helps or hinders the diagnosis time. The work of Feinstein (1970) explains that a comorbidity may affect the stage at which a cancer is diagnosed when the manifestations of the comorbid condition can ‘simulate those of the index disease’ and so a cancer may be detected at a late stage if the patient suffers a ‘diagnostic comorbidity’ (Feinstein 1970). In the case of lung cancer this could be due to conditions such as COPD. The stage of disease at diagnosis is important when understanding comorbidity and interactions with healthcare professionals as it may give insight in to why and how comorbidity can delay or facilitate earlier diagnosis (Newschaffer et al 1998). There are several hypotheses that may account for comorbidity both delaying and facilitating earlier diagnosis (Fleming et al 2005). Fleming et al (2005) has suggested that there are at least four existing hypotheses that may explain the links between stage of disease at diagnosis and the presence of a comorbidity. The first is the surveillance hypothesis, in which the patients with coexisting disease experience a faster diagnosis due to more frequent contact with healthcare services (Fleming et al 2005). The surveillance hypothesis also can mean that patients with comorbid conditions are more body conscious and therefore more likely to notice new symptoms arising (Fleming et al 2005). Further support for the surveillance hypothesis comes from Jaen et al (1994), who state that a patient may be the focus of prevention measures during follow up appointments for chronic conditions and Feinstein (1970), who explains how a cancer with no symptoms will not give a patient any reason to seek help, whilst a comorbid disease may cause them to see a doctor and during that visit, the cancer may be detected. Feinstein (1970) also suggests that the comorbid patient may have established a ‘medical relationship’ with their GP through their previous visits and so may be more likely to seek help than a person who does not have a regular doctor. In work by Salika et al (2017) it was shown that patients with comorbidities such as hypertension and hypercholesterolemia was consistent with increased help-seeking for persistent cough and hoarseness which may be indicative of lung cancer. The surveillance hypothesis may apply to these patients as they me more aware of bodily changes (Feinstein 1970; Salika et al 2017). The surveillance hypothesis (Feinstein 1970) may also be viewed in terms of ‘body vigilance’ and it may be that those who have comorbidities are more body vigilant than those without (Winstanley et al 2016).

Fleming et al’s (2005) second suggested hypothesis is the pathological hypothesis, in which the comorbidities interact with the cancer pathogenesis and increase the aggressiveness of the cancer causing the stage to advance. The third hypothesis is the ‘competing demand’ hypothesis, in which comorbid conditions actually distract both patients and clinicians from the new symptoms (Fleming et al 2005). Mounce et al (2017) and Lyratzopolous (2015) give further credence for the competing demand hypothesis by stating that a symptom which could be a risk marker for a cancer are often also symptomatic of other diseases. These existing comorbidities may present rational explanations for cancer symptoms and therefore cause the patient and the clinician to misattribute those symptoms (Mounce et al 2017). The competing demand hypothesis may be exacerbated by the presence of more than one comorbidity and multi morbidity may further obscure the new cancer symptoms and increase the length of time to diagnosis (Fleming et al 2005; Mounce et al 2017). The fourth hypothesis given by Fleming et al (2005) is the death from other causes hypothesis, whereby a person who is likely to die from their comorbidity is treated less intensely than a patient without a comorbid condition. The literature surrounding comorbidity and lung cancer is of great importance to this thesis as smokers are perhaps more likely to suffer comorbidities such as COPD, asthma and other respiratory conditions which can impact on their consulting decisions and in turn on their patient intervals. The hypotheses proposed by Fleming et al (2005) may be at work in the study population featured in this thesis, particularly the surveillance hypothesis and the competing demand hypothesis. However, it is unlikely that the remaining two hypotheses will be evident in this study due to the qualitative methodology and the study sample.

Changes in health and biographical disruption

Perhaps conversely to those suffering comorbidities, it has been shown in previous research that some people may not correctly interpret their cancer symptoms due to their belief that they were in good health (Brindle et al 2012). One study of 20 lung cancer sufferers found that the majority described themselves as having been in good health and therefore not concerned about cancer (Brindle et al 2012). The perception of having led a ‘healthy lifestyle’ was also used as a point of emphasis for why a person would not be a likely cancer candidate in that it was thought that healthy behaviours such as good diet and exercise could compensate for other, unhealthy behaviours such as smoking (Andersen et al 2010).

Patients in the study by Andersen et al (2010) expressed that being ill did not fit with their self-image and they wished to avoid the life changes or biographical disruption that can occur following a cancer diagnosis. Biographical disruption refers to unexpected changes in a person’s life trajectory such as loss of employment, relationship breakdowns or sudden and unanticipated health concerns. Biographical disruption has been reported as being of concern to people facing a cancer diagnosis (Maguire et al 2014). The symptoms of cancer have been described as interfering with the activities of everyday life such as gardening, housework, employment, and family responsibilities (Maguire et al 2014). Normalisation of symptoms, as previously mentioned, seems to be borne through a need for ‘carrying on’ in the face of ill health in order to maintain social roles and responsibilities (Corner et al, 2006). The process of normalising symptoms is a method of avoiding biographical disruption (Maguire et al

2014). In a study of patients' accounts as narrative poems, participants and carers tended to give narrative accounts which positioned their illness as an isolated incident in their wider life story, thus resisting the potential biographical disruption that may come with redefining oneself as a cancer patient (Kendall and Murray 2005). The normalisation and misinterpretation of symptoms is perhaps possible in many cases due to the gradual onset of symptoms, which the patient can rationalise as just starting to be part of everyday life rather than the sudden onset of an illness (Levealahti et al 2007). However, for some people, the onset of an alarm symptom, such as haemoptysis, can signify the start of biographical disruption and an abrupt move from 'the world of health to the world of sickness' (Levealahti et al 2007). This desire to avoid the biographical disruption that can occur following a diagnosis of cancer may also be linked with patient intervals in that those keen to avoid the disruption may also avoid their doctor. Once a person has received their diagnosis there is no going back and this may contribute to patients delaying for as long as possible before consulting as this also delays the inevitable changes to one's life. It is unlikely that most people factor in potential cancer when making life plans and therefore it is possible that they delay help seeking until after a significant event, such as a birthday or wedding, so that they can enjoy it before they take on the change of identity that a cancer diagnosis can bring about. It is also possible that some people are afraid of the biographical disruption that their ill health may bring to those close to them such as family and friends and therefore attempt to resist the potential for life changes for as long as they can.

Risk perception and health beliefs

Given the aims of this study it is important to discover whether people who are at risk of lung cancer are aware of their risk status and how that awareness may affect their decisions regarding presentation. The concept of risk and risk perception is ever present in the literature surrounding lung cancer, smokers, and their own diagnosis. It has been shown that some people have inaccurate knowledge about lung cancer risks and believed themselves to be at higher risk for cancers other than lung (Tod et al 2007). Participants have also been described as having a low level of perceived personal risk even if they smoke and are aware of the link between smoking and cancer (Grant et al 2010). This is perhaps indicative of smokers feeling as though, even though smoking can cause lung cancer, it will not happen to them. It is also possible that many smokers choose to keep themselves in a state of denial regarding the risks of smoking as thinking about it may be distressing. Whilst there are also health warnings on cigarette packaging, it is likely that those who still smoke have found ways in which to ignore them or to assume that they do not apply to them. In a study of oral cancer sufferers, most participants knew that smoking was a major risk factor in developing the disease, however smoking did not feature prominently in their own accounts of how they got their cancer (Grant et al 2010). Risk perception may potentially decrease once a person has stopped smoking, with former smokers being described as much less likely to see themselves at risk of cancer than they would be if they had not stopped (Park et al 2013). Some former smokers have been shown to not necessarily believe that their past smoking was related to their cancer diagnosis (Grant et al 2010). A study of surgical lung cancer patients measured risk perceptions associated with smoking and developing another cancer, the study found that those who felt at higher risk of further cancer developing were more likely to abstain from smoking (Hay et al 2007). In a study of adolescents, Romer and Jamieson (2001) found that whilst participants overestimated lung cancer mortality and incidence, they also underestimated their personal risk of lung cancer despite being smokers. It can be argued that the less people believe themselves to be at risk of cancer, the less likely they are to suspect cancer when they have early symptoms and so may not seek advice immediately.

Risk perception and optimism

A study by Weinstein et al (2005) examined optimism in smokers and found that their respondents showed what the authors term ‘unrealistic optimism’ regarding their risk of developing lung cancer. Unrealistic optimism was also found in the (2006) study by Dillard et al, which found that participants did not see themselves to be at risk of smoking related disease . In the Weinstein et al study (2005) both current and former smokers were found to judge themselves as being at lower risk of cancer than the average smoker. In order to understand the implications of this, it would be interesting to see what the participants would define as the ‘average’ smoker. It is understandable that former smokers may believe themselves to be at lower risk than those who continue to smoke, but it would be interesting to see how current smokers define themselves as distinct from the ‘average’ smoker. In work by Park et al (2013) it was again shown that former smokers were optimistic about their risk levels and felt that if they had not developed cancer already, they were now ‘in the clear’ which demonstrates a lack of understanding of the ways in which former smokers are still at an elevated risk. One current smoker in this study felt that he would not be at risk but also was not sure why, saying ‘personally, I don’t think I’ll ever get cancer. Why, I don’t know’ (Park et al 2013). In light of the findings of these studies, it may be that smokers do tend to have an optimistic view of their own risk of cancer; this could be a potential reason for why they smoke in the first place, as they do not believe the health risks will affect them. The lowered sense of risk perception may also be due to choosing to ignore or play down the risks in order to minimise feelings of guilt about smoking. Age can also be associated with unrealistic optimism due to older people having smoked for a long time without symptoms which makes them feel ‘safe’ from smoking related disease (Dillard et al 2006). This lower sense of risk perception could have an effect on early diagnosis, as those who do not believe they are at risk will perhaps take longer to report their symptoms.

Over half of the smokers in the study by Weinstein et al (2005) judged themselves to be at only twice the risk of lung cancer compared to a non-smoker, although they did rate themselves as being at a slightly more elevated risk of lung cancer than other cancers. Optimism has also been found in some lung cancer patients regarding their survival, particularly if they had been diagnosed in the early stages or if they had been told that the tumour was shrinking (Westerman et al 2007). Those described as ‘unrealistic optimists’ thought that lung cancer depends mostly on genes, that if a person smokes only for a few years then the risks are diminished, and that curability is high (Dillard et al 2006). This sense of optimism has also been reported in the findings of work by The et al (2000) and Yardley et al (2001), who both report that there is a lack of clear understanding regarding the treatment and curability of lung cancer. This gave participants a sense of optimism in that if one does develop lung cancer, it can be treated and cured. This level of unrealistic optimism about the severity and occurrence of lung cancer may make it easier to continue with smoking behaviour (Dillard et al 2006). According to Ayanian and Cleary (1999), optimism bias occurs when smokers discount their own personal health risks. Hard core smokers have been shown to be much more likely to ‘reject the notion that smoking was currently harming their health or would do so in the future’ (Jarvis et al 2003).

Risk perception and smoking cessation

As previously mentioned, when comparing their potential risk, it has been reported that some former smokers believe that by stopping smoking they had significantly lowered their risk status (Park et al 2013). One participant in the study by Park et al (2013) reported that having stopped smoking for four years meant that they were no longer at any risk and another felt that having stopped, even though they had smoked for a long time, would mean they had ‘really lowered my odds of having lung cancer’ compared to someone who still smoked . Again, it would be of interest to see how these participants would define an ‘average’ smoker in comparison to themselves. Two respondents in the Tod study (2007) felt that, having stopped smoking, they were no longer at risk of lung cancer. Whilst many participants tended to overestimate the prevalence of lung cancer, this was found to be less to do with smoking status and more to do with personal experience. Those who knew other people who had experienced lung cancer seemed to find the concept more tangible (Park et al 2013). There could potentially be some interesting findings if participants' views in the Park et al study were compared with those in the study by Dillard et al (2006). A subsequent explanation of whether those with personal experiences of lung cancer believed their cancer to be caused by smoking or if they held the same beliefs as those who thought it was due to genetics or other causes would be insightful (Park et al 2013; Dillard et al 2006) . In the study of Irish people living the UK, it was found that many participants did not perceive themselves as being at risk of cancer unless they knew of someone else who had been affected (Scanlon et al 2006). However, it has also been reported by Robinson et al (2010) that participants in their study who had family members with lung cancer, were able to distance themselves from the disease and did not translate their family members' diagnosis as a risk to themselves; often they continued to smoke. Perhaps due to the perception that stopping smoking eradicates risk, some former smokers have been found to report that it is unfair if they do develop the disease (Levealahti et al 2007).

Risk perceptions and being a 'healthy' smoker

It has been shown that some smokers believe that protective behaviours such as exercising and eating a healthy diet can offset the potential health risk that smoking poses (Walton et al 2013). This was seen to not only offset risks, but also to justify smoking (Crane et al 2016). Patients in the Levealahti et al study (2007) on biographical disruption and cancer reported that a healthy diet and exercise would offset the risks of smoking. The most common reasons cited for some smokers being at less risk than others were good diet, regular exercise, and having good genes (Weinstein et al 2005). Participants in the studies by Andersen et al (2010) and Robinson et al (2010) were both reported as believing that it is possible to be a smoker and have a healthy lifestyle. The notion of having good genes, found in the Weinstein et al (2005) study, echoes the findings of Dillard et al (2006) who found that participants believed that cancer occurrence was caused by their genes. If the belief that good health practices can offset the risks of harmful behaviours like smoking is widespread, it may account for longer patient intervals and a sense of optimism in those who smoke, as those who engage in healthy practices are less likely to suspect cancer. It would also be of interest to see whether those who hold this belief regard those who smoke but also engage in other harmful practices, such as poor diet and lack of exercise, as the 'average' smoker whom participants compared themselves to in the study by Weinstein et al (2005).

Risk perception, optimism and false reassurance

There is evidence in the literature that 'false reassurance' may lower a person's risk perception and potentially lead to later presentation (Renzi et al 2015). If a person experiences a potential cancer symptom which they then receive the 'all clear' or a non-cancer diagnosis, this may influence future presentations for similar symptoms due to the person being over reassured that they do not have cancer and they would receive the same, non-cancer, diagnosis as in the previous presentation (Renzi et al 2015). A 2015 systematic review reports that qualitative evidence shows over-reassurance leading to normalisation of symptoms and delays in help seeking (Renzi et al 2015). This review also found that patients who had been given an all-clear may feel that their symptoms were dismissed as being minor, this can impact on their feelings of help-seeking legitimately and therefore less likely to seek help again if symptoms reoccur (Renzi et al 2015). Evidence also shows that when patients are not advised to return if symptoms reoccur then they are more likely to delay help seeking (Renzi et al 2015).

Lowered risk perception due to false reassurance is also evidenced with primary data from qualitative studies which have shown over reassurance to be a key factor behind later presentation (Renzi et al 2016). Participants in an interview study by Renzi et al (2016) explained that they had been reassured by previous non-cancer diagnoses, even those who suspected cancer a second time reported having disregarded their suspicions due to reassuring themselves by trusting previous results. If new symptoms occur affecting the same area of the body, such as new moles appearing, participants reported that they felt there was no need in seeking medical advice as they had experienced the symptoms before and knew that they were nothing to worry about (Renzi et al 2016).

Risk perception, smoking, and the causes of cancer

It has been shown in the literature that many participants in lung cancer research do not see smoking as being the sole factor responsible for their cancer and, in some studies, they have reported that smoking was not responsible at all because 'cancer doesn't discriminate' (Crane et al 2016). In a study by Salander (2007) researchers asked lung cancer patients if they had an explanation for why they had developed the disease, to which the most frequent response was ‘I don’t know’. Respondents also tried to distance themselves from the term ‘smoker’ even if they had a lengthy smoking history (Salander 2007). This effort to distance themselves from the label ‘smoker’ may also contribute to their lower risk perception and not making the connection between their smoking and their cancer. Across the literature, respondents have reported that they believe other factors are implicit in their cancer diagnosis; Crane et al (2016) reported that respondents felt that things such as stress, pollution, or manufactured cigarettes (rather than hand rolled) were also to blame for their cancer. In the Salander (2007) study, only two patients attributed their cancer to smoking while others believed that factors such as air pollution, working with chemicals, and psychological disposition were potentially the cause. In a study by Faller et al (1995), whilst smoking was the most frequently named causal factor for lung cancer, it received less blame than would match up with smoking behaviour, other frequently blamed causes were exposure to toxins in food or at work and air pollution . Participants also stated that smoking could not be the sole cause of their cancer and that they either did not know why they developed the disease or that there must be an additional cause (Faller et al 1995). Patients in the study by Chapple et al (2004) also tended to blame other potential causes such as pollution and stress, with one participant being upset that she was deemed responsible for her disease because she had been a smoker, when she believed it was caused by her going through a stressful time at work. Some participants said they had stopped smoking or did not smoke enough to get cancer, and twelve percent explicitly stated that they did not believe smoking caused lung cancer (Faller et al 1995). The idea of not having smoked enough to get cancer is also present in the work of Dillard et al (2006) as some participants believed that a shorter smoking history meant there was much less risk. In the Lehto (2014) study, environmental factors were again blamed for lung cancer by respondents who did not think smoking could be the sole cause. Patients’ family members in the study by Robinson et al (2010) did state that smoking ‘probably’ caused lung cancer but also blamed other factors such as genetics, toxins in the environment, food or water, and a generally unhealthy lifestyle. Fate was also cited as being the primary cause of lung cancer, another example of the feeling that cancer does not discriminate, rather, a person gets cancer or they do not (Robinson et al 2010; Crane et al 2016). This separation of lung cancer and smoking and attributing the disease to factors more outside of a person’s control, such as genes or environment, may have been used to justify continued smoking in patients or in their family members.

Whilst there is evidence that smokers minimise the link between smoking and lung cancer, it may be a more complex process than just denial. An American study (Finney-Rutten et al 2011) found that while current smokers did see themselves as having higher levels of risk for lung cancer than former or non-smokers, they were also the most reluctant to be tested and agreed less that lung cancer was caused by lifestyle factors. It has been stated in a German study (Kneer et al 2012) that smokers do not seek to purposely harm their own health or to assume a negative self-image. Rather, it has been found that smokers are aware and involved with their behaviour and with its consequences for their health (Kneer et al 2012). The Kneer et al (2012) study reports that rather than being unaware of the consequences of smoking, smokers are actually constantly reminded of it through the media, health campaigns and warnings, and by other people, so the way to cope is to create an emotional distance from it. This emotional distance between themselves and their smoking may account for some level of decreased risk perception. According to Kneer et al (2012) smokers do not seek to damage their own health on purpose; they smoke because they find it pleasurable, to reduce stress or because it seems appropriate in some social situations. The key message for this thesis from the Kneer et al (2012) study is that smokers create a cognitive dissonance by thinking less about the risks involved. Faller et al (1995) also suggests that smokers go through a process of dissonance through which they find other causal attributions for smoking related disease, they do not deny the role of smoking entirely, but also find other factors to be blamed.

Perceptions of risk and cancer candidacy

Whilst discussing risk perception, it may be prudent to also bear in mind theories on the concept of ‘candidacy’ in health beliefs. The concept of disease candidacy was originally developed by Davison et al (1991) when studying patients with coronary heart disease (CHD). Davison et al (1991) developed a profile of who lay people saw as the most likely candidate for CHD. Davison et al (1991) reported that many studies have found that lay participants fail to acknowledge their own risk for CHD due to their not fitting this typical profile (Frich et al 2007; Weiner 2009). More recently, Macdonald et al (2013) further developed this idea of illness candidacy and applied it to the lay epidemiology of cancer. Macdonald et al (2016) explains that the concept of candidacy may provide a ‘bridge between the description of health beliefs and the response to symptoms and signs of illness’. The Macdonald et al (2013) study reports the findings of in-depth qualitative interviews regarding lay beliefs about cancer. The candidacy model may be of particular relevance in this study as it can be applied to the risk factor in smoking and the health beliefs that participants hold.

Macdonald et al (2013) found that participants in the study viewed a smoker as a candidate for all cancers, not just cancer of the lung. Macdonald et al's (2013) work on cancer candidacy also reports similar ideas to those of Walton et al (2013) and Levealahti et al (2007) in that participants believed that engaging in healthy, protective behaviours could outweigh the risk of cancer. Beliefs about cancer candidacy in the work by Macdonald et al (2013) can also be related to the findings of Robinson et al (2010) as participants in both studies expressed a belief that cancer was caused by genetics. These theories of cancer candidacy are relevant to several of the themes that emerged in this narrative review, although the term 'candidacy' was not among the original search terms or research objectives. The theory of candidacy however appears to be of importance and may potentially be applied to the findings of this study; these themes will be further explored in the discussion chapter of this thesis.

Examination of the literature surrounding smokers' perceptions of cancer risk shows that the findings have particular relevance to this thesis as these perceptions may strongly impact patient intervals. Those who do not believe themselves to be at risk, for any of the potential reasons cited above, are perhaps less likely to suspect any serious health problems and consequently may be less likely to see their GP when they experience symptoms.

Stigma

Erving Goffman and the theory of stigma

During the very early stages of this study, it was envisaged that smokers may suffer societal stigma and potentially perceived stigma from healthcare professionals and that this would be a key area of the literature to explore in more detail. Throughout the search phases, the concept of stigma was widespread within the literature on smoking and lung cancer. Arguably, the most well-known work in this area is Erving Goffman's (1963) theory of stigma and the spoiled identity. It is important to note here that, whilst the work of Goffman (1963) can still be of much use today, it is a product of its time and often uses language and terms of reference which are no longer in use in research today. Where such terms occur within this review, they are the words of the original text and not the views of this thesis. The stigma to which Goffman refers comes from the original Greek and traditionally referred to physical marks which were applied deliberately to a person in order to brand them a slave, a criminal or otherwise 'undesirable' (Goffman 1963). Goffman (1963) explains that in modern society the concept of stigma tends to refer to marks upon a person's character rather than physical marks upon the body. Goffman (1963) defines three types of stigma; ‘abominations of the body’, ‘blemishes of character’ and ‘tribal stigma’. For Goffman (1963), an abomination of the body refers to a physical ‘deformity’, which can mean any physical disability that can be seen by others. The ‘blemishes of character’ Goffman refers to include characteristics which may be perceived as due to weak will. The examples given by Goffman (1963) include dishonesty, addiction, homosexuality and mental health conditions. Again it is important to note that whilst these things may still be stigmatised in society, it is not acceptable to do so (Goffman 1963). Goffman’s (1963) ‘tribal’ stigma refers to stigma based upon race or nationality. Whilst the work of Goffman (1963) is often no longer politically correct, the underlying principles of his theory may still be applied in a more up to date fashion. There is much contemporary research concerning stigma and often authors draw on the theory of Goffman (1963). In the context of this thesis, this review is concerned with literature regarding stigma and health, in particular lung cancer and smoking. Lebel and Devins (2008) have applied the theory of the three types of stigma to cancer and have suggested that the ‘abomination of the body’ or physical signs of the cancer may be the tumour itself or other visible signs such as hair loss. The blemishes of character may refer to stigmatised personal behaviours which could include smoking, and the tribal stigma is the perceived belonging to a deviant group such as smokers (Lebel and Devins 2008; Goffman 1963). Rush (1998) also draws on Goffman in relation to health, stating that in order to be stigmatised, a person must bear a mark, whether physical or behavioural, or due to a group membership. According to Rush (2008), stigma arises when other people take notice of the mark. The behavioural mark could be applied to smoking, which is also a physical act that can be seen by others; it seems that the smoker would only begin to feel stigmatised when the smoking is taken notice of by other people (Rush 2008). It is unlikely that a person smoking in their own home or in the company of other smokers feel stigmatised, but when noticed by wider society they may feel that their behaviour marks them as different. The work of Goffman (1963) cannot be ignored when talking about stigma and it may be interesting to see whether or not evidence of the three types of stigma is found within this study.

Smoking, stigma and changing society

It can be argued that there has been a shift in the acceptability of smoking over time. A change in moral discourse surrounding smoking can be seen in the differences in smoking legislation and cigarette marketing and this change may bring about stigmatisation of those who continue to smoke. One study interviewed a number of people who had begun smoking during the time when it was ‘fashionable and desirable’ (Street and Gordon 2004). This study reported that there has been a ‘discursive shift or rupture in the positioning of smoking portrayed as a glamorous and healthy recreation, to that of a morally reprehensible habit that harms all parts of the body’ (Street and Gordon 2004). From this study we can see that smoking was once regarded as a harmless and pleasurable activity which was associated with glamour and wealth but over time the societal perception has changed and now it is viewed as a risk to health, a habit, and an addiction (Street and Gordon 2004). Chapple et al (2004) found that some lung cancer patients referred to having started smoking when it was fashionable and that older smokers are less likely to be stigmatised due to having started at a time when it was socially acceptable and even encouraged with, for example, free tobacco being given out during national service. Therefore, according to the findings of Chapple et al (2004) and Street and Gordon (2004), the societal perception of smoking has changed completely, assigning smokers to membership of a deviant group and thus potentially creating stigma. All participants in a study by Jensen and Hounsgaard (2013) reported smoking less at work, usually citing being more occupied as the reason, although they also all reported having been stigmatised by co-workers, with one person even saying she had been bullied. This may be another example of the stigma occurring when the behaviour is noticed by other people and specifically, in the case of the Jensen and Hounsgaard (2013) study, work colleagues. It is also possible that a person wishes to be taken seriously and respected by work colleagues more so than they do by strangers and so may make more effort to conceal practices or habits which they feel they may be stigmatised for, such as smoking. In a study by Stuber et al (2008) results reveal a substantial level of stigma surrounding smokers with 81 percent of respondents agreeing with the statement that ‘most people would not allow a smoker to take care of their children’. In the same study 21% also agreed with statements saying that most non-smokers would not date a smoker, and that most non-smokers view smoking as ‘a sign of personal failure’ and 39 % of respondents agreed with the statement that ‘most people think less of a person who smokes’ (Stuber et al 2008). Stuber et al (2008) categorises smoking as an emergent stigmatised social status, which further illustrates the shift in acceptability of smoking. Smoking can also be viewed as a personal weakness by non-smokers, who may think that the smoker’s inability to manage their own stress levels and the need to depend on smoking are a sign of weakness (Stuber et al 2008). This categorisation of smoking as a sign of failure or weakness can also perhaps relate to Goffman’s (1963) ‘blemishes of character’ or signs that a person is of weak will. Seeing that this is evident in such a far more contemporary study further emphasises the need to look for potential evidence of the three types of stigma within the context of this study.

Stigma and 'lifestyle' related health conditions

It has been suggested that people who perceive stigma relating to their health experience feelings of rejection, blame, exclusion, and devaluation, these feelings are in turn associated with depression, poor health and poorer outcomes including survival (Cataldo et al 2012). Several studies have sought to explore stigma in lung cancer patients. A study developing a scale to measure stigma in lung cancer patients reports that both smokers and non-smokers had a level of perceived stigma that led to negative outcomes such as depression and reduced quality of life (Cataldo et al 2012). In a study of the role of perceived stigma in depression in lung cancer patients, it was found that higher levels of perceived stigma related to higher levels of depression, avoidant coping, dysfunctional attitudes and poorer social support (Gonzalez and Jacobsen 2012). Similarly, another study reported that those who felt higher perceived stigma had greater levels of distress and lower quality of life (Chambers 2015). Lung cancer was the first disease to be attributed to smoking and the causal relationship is well known. It is possible that this contributes to perceived stigma from others as smoking is seen as choosing to engage in an unhealthy practice (Cataldo et al 2012). The review by Chambers et al (2012) suggests that 'health related stigma is part of the lung cancer experience and that it contributes to psychological distress for patients and impairs quality of life'. Findings by Tod (2007) 'revealed a prevailing expectation that people with lung cancer would experience blame and stigma'. This perception of stigma is explored further below as the review moves into the themes of stigma in relation to personal responsibility, shame and blame.

Chapple et al (2004) has asserted that the level of associated stigma a disease has is dependent on whether or not it is possible for the patient to be held responsible for their disease. In the case of lung cancer, a person who smokes may be perceived to be responsible for their illness while in the case of other cancers, they may not. Participants in the Chapple et al (2004) study reported feelings of stigma related to their lung cancer and to cancer in general. One participant stated that all lung cancer patients are stigmatised for their condition, but especially so if they are smokers (Chapple et al 2004). It has been argued that the term 'lifestyle diseases' in reference to heart disease and lung cancer should be avoided as it attributes responsibility to the patient and increases stigma (Vallgarda 2011). Smokers may also feel stigmatised due to knowledge of the health risks of smoking and having feelings of guilt about not being able to stop; in this way smokers may in fact stigmatise themselves (Jensen and Hounsgaard 2013). Work by Nagelhout et al (2012) reported that feelings of stigmatisation when smoking outside bars and restaurants were higher in those who felt negatively judged, which further suggests that some stigma may be internalised. Participants in one study reported societal stigma in that lung cancer is underrepresented in the cancer community and overlooked in favour of other cancers. One participant cited the pink ribbon for breast cancer and asked 'where's my pretty ribbon?' (Hamann et al 2014). In a focus group study of smoking, lung cancer and stigma, participants felt that lung cancer is a stigmatised disease and that, whilst it is the biggest cause of cancer death, it does not receive major media support like other cancers do (Lehto 2014). One respondent said that following her diagnosis she felt stigmatised, as the first thing people would ask her was whether she had smoked. Another female in the study said that while she did not feel stigmatised, she did feel a need to tell others straight away that she had not smoked (Hamann et al 2014). This suggests a knowledge or awareness of the potential stigma and a desire to avoid it. In a study by Lehto (2014), focus group participants reported having felt stigmatised for their smoking behaviour, including those who had not smoked as they felt that other people automatically assumed they had. Findings from a study by Tod (2007) revealed that among their participants, non and ex-smokers reported concerns of being stigmatised in the same way as current smokers, perhaps due to believing others would operate on the assumption that they had, or still did, smoke. Some former smokers may experience distress at being stigmatised for a habit they had given up a long time ago (Chapple et al 2004). People in the study by Criswell et al (2015) regarded any questions about smoking as a form of stigmatisation. Smokers may also perceive stigma from others due to the harmful effects of passive smoking on other people (Bayer 2008). The role of passive smoking in lung cancer may increase stigma for smokers if they are perceived to not only be responsible for their own disease, but potentially for that of others as well (Bresnahan et al 2013).

Stigma and the barriers to help seeking

Stigma can also contribute towards patient intervals and decisions about help seeking. A USA study of lung cancer stigma showed that whilst smoking status did not predict help seeking delay, perceived stigma did (Carter-Harris 2015). The analysis revealed 'that lung cancer stigma was a significant predictor of increased time from symptom onset to medical help' (Carter-Harris 2015). Patients in the study by Crane et al (2016) reported that perceived stigma due to smoking was a potential barrier to help seeking. They described the disease as being ‘self-inflicted’ and worried that the doctor would not take them seriously as a patient whilst they were still smoking (Crane et al 2016). It has been shown in a study by Gonzalez and Jacobsen (2012) that people who experience health related stigma have poorer social support, a finding further supported by Bresnahan et al (2013) who explains that those who have a stigmatised condition have lower quality communication with people who are in a position to help them. This could also add weight to the evidence that people who perceive smoking related stigma are likely to have longer patient intervals. It has been argued that it is essential to reduce perceived stigma relating to addiction in order to encourage people to access healthcare and therefore improve health outcomes (Bell et al 2010). However, Bayer (2008) questions whether it may actually be acceptable to stigmatise smokers if the effect is that more people give up. This is a utilitarian standpoint however and it is arguably not acceptable to stigmatise individuals for ‘the greater good’. It has also been argued by some that people who smoke should not be offered certain types of medical treatment on the grounds that they have poorer outcomes and it is not a justifiable use of resources (Underwood and Bailey 1993). However this argument has been met with rebuttal by those who believe that refusing to treat is unethical and that smoking is addictive and ‘human frailty should not be penalised’ (Shiu 1993; Higgs 1993).

The findings of previous studies regarding stigma make this study and further research of this nature even more important as it seems that the sense of stigma perceived by lung cancer patients has a direct effect on their quality of life and potentially their disease outcomes. It may be that those who feel stigmatised feel less inclined to engage with clinicians, support groups or social support in general. It may be hard for a person to feel engaged within a society they feel stigmatises them. It is also possible that those who feel stigmatised engage less with primary care, have later presentations, longer patient intervals, and therefore poorer outcomes.

Blame

A natural progression from perceptions of stigma are those of blame and shame. If lung cancer patients and smokers feel a sense of stigma, it is highly likely that they are also affected by feelings of blame and shame. There is evidence in the literature of a sense of blame surrounding some lung cancer patients, particularly those who do or have smoked. Lifestyle factors such as smoking, obesity, and alcohol consumption have been shown to contribute to cases of cancer and therefore, the role of the individual in preventing disease has been recognised (Westbrook and Nordholm 1986). The possibility that individual health behaviours may cause cancer can perhaps increase the perception that the patient is responsible for his or her own disease and therefore induce potential self and societal blame.

Blame and 'lifestyle' related conditions

Lung cancer patients who have smoked may experience feelings of self-blame more so than those with other cancers due to the causal relationship between lung cancer and smoking (Else-Quest et al 2009). In a study designed to measure blame in patients with lung, breast, and prostate cancer, lung cancer patients were significantly more likely to agree with the statement 'my behaviour contributed to my cancer' (Else-Quest et al 2014). Several participants in the Hamann et al (2014) study reported feelings of being to blame for their condition because of their smoking. Findings in a study by Criswell et al (2015) show that lung cancer survivors demonstrate feelings of personal responsibility and regret, especially if they have smoked. Some lung cancer patients who experience feelings of self-blame report feeling as though they were unworthy of treatment due to their 'self-inflicted' disease (Corner et al 2005). Feelings of being to blame for one's own condition may contribute to patient intervals if those patients feel that they are less worthy of help due to having a symptom of a disease they feel their behaviour may have caused.

Blame from others has been shown to increase for those who have engaged in risky health behaviours. In one study participants read fictional case studies of patients with either acquired immune deficiency syndrome (AIDS) or lung cancer, with examples where the patient had engaged in risk behaviours such as smoking or intravenous drug use (Mantler et al 2003). Respondents recorded higher levels of perceived responsibility for cases where patients had engaged in risky health practices (Mantler et al 2003).

For most cancer patients, a good support network is beneficial in coping with the diagnosis and the treatment (Millbury 2012). However, perceptions of blame can affect the relationships between the patient and the family or primary caregiver (Lobchuk et al 2008). In a study of lung cancer patients and their primary caregivers there was evidence of blame for the condition; both self-blame from the patients themselves and outside blame from the caregivers (Lobchuk et al 2008). When asked to rank what they most thought was to blame for the patients lung cancer, both patients and caregivers cited the patient, heredity and genetics and finally chance and environment, suggesting that both caregivers and patients thought that the patient themselves were most responsible for their cancer (Lobchuk et al 2008). If this sense of blame between patients and their caregivers is felt by the patient, then it is perhaps more likely that they will experience lower quality of life as described earlier in the study by Chambers et al (2012). In another study it was found that caregivers who blamed the patient for their condition were likely to experience depression themselves (Siminoff et al 2010). It may be that those caregivers who harbour feelings of blame toward those they care for experience guilt themselves for having those thoughts. Informal or family caregivers may be more likely to blame the patient for their cancer if they have smoked (Lobchuk et al 2008). A family caregiver is more likely to have witnessed the patient's history of smoking which could potentially increase feelings of frustration, especially if they have tried to encourage them to stop. In a study of adult children who had lost a parent to lung cancer, many stated that they harboured feelings of blame due to the parent having smoked (Stone et al 2012). If the patient does not stop smoking following diagnosis, the caregiver may interpret this as an unwillingness to help themselves and could lead to feelings of anger or resentment and even a reduction in help (Lobchuk et al 2008). It may be that if the patient cannot or will not stop smoking, caregiver blame will increase but it is also possible that if the patient succeeds in stopping smoking, feelings of blame may reduce (Lobchuk et al 2008). The caregiver may perceive lack of smoking cessation as irresponsible and as a sign that the patient does not care for their own health or the feelings of family and caregivers (Lobchuk et al 2008). In this study caregivers were found to have feelings of annoyance, anger and aggravation towards patients regarding the potential to control disease progression by stopping smoking (Lobchuk et al 2008). They felt that since cessation could improve their outcomes, patients ought to quit and caregivers described feelings of anger when patients would not (Lobchuk et al 2008). The relationship between patient and caregiver may feel more reciprocal when the patient has stopped smoking as they are seen to be making an effort to manage their own disease (Lobchuk et al 2008). Partners of patients who had stopped smoking following diagnosis expressed feelings of blame toward the patient and felt that smoking behaviour was the cause of the cancer. One participant reported having asked her husband to stop smoking years before and was annoyed that he had not (Badr and Taylor 2006). Anticipation of caregiver blame may influence patient intervals in that smokers may have ignored previous advice from family and friends to quit and, when symptoms arise, worry that they will be blamed for not having taken the advice (Lobchuk et al 2008). Feelings of blame are reported by Lobchuk et al (2008) to negatively impact both patient and caregiver and even the quality of the care the patient receives. It may be that these feelings of blame only arise following diagnosis, however it is worth further investigation as if these feelings are anticipated by patients when they first experience symptoms, they may have an affect on the decision of when to seek help.

Perception of blame from healthcare professionals

In the context of this study, it is also important to discover whether these perceptions of blame are experienced by patients during their contact with healthcare professionals. It has been shown that some patients feel blamed by their doctor for their symptoms or their cancer (Morse et al 2008). In a study of lung cancer patient and doctor interactions it was found that in eight out of 20 interactions, doctors used blaming words when talking to the patient about smoking such as ‘your smoking’s done a number on your lungs’ (Morse et al 2008). Respondents in the study by Lehto (2014) also said that they had felt uncomfortable during health interactions due to their smoking history. They felt that healthcare providers blamed them for their condition even if they did not explicitly say so, and feared their care would be affected due to having been a smoker (Lehto 2014). One participant in the Hamann et al (2014) study reported a very negative reaction from a hospital healthcare provider who had told him ‘that’s what you get for smoking’. It was also shown in the Morse et al (2008) study that when patients talked about their cancer being caused by smoking, doctors were not necessarily empathetic; instead they were more likely to use blaming language and to cite current smoking as a reason for the presence of the cancer or the inability to provide treatment. The interviews in the study by Morse et al (2008) showed that healthcare providers did provide enough emotional support or clarification when the patient was confused, but when empathy was shown patients would attempt to create more opportunities to have their needs addressed. This suggests a need for blame reduction in consultations and increased empathy from doctors (Morse et al 2008). It is possible that previous experience or anticipation of blame from healthcare professionals may cause people to avoid their GP and create longer patient intervals. For this study it will be important to explore the accounts of participants for perceptions of blame.

Guilt and shame

Smokers and those with lung cancer have also reported feelings of guilt and shame related to their condition when they suffer smoking related symptoms (LoConte et al 2008). In a survey to examine feelings of guilt and shame among those with cancer, results show that levels of guilt and shame were associated with smoking and current and former smokers had ‘higher levels of both emotions' (LoConte et al 2008). Patients with lung cancer were also more likely to express feelings of guilt and shame that those with breast or prostate cancers, this is likely to be due to the perceived 'self-inflicted' nature of lung cancer whilst breast and prostate cancers are more likely to be seen as blameless (LoConte et al 2008). Guilt at burdening others is also present in the lung cancer literature, with respondents in one study describing feelings of guilt in relation to having burdened their family by getting a disease they felt they had personally contributed to (Lehto 2014). Participants in the Hamann et al (2014) study stated that they felt guilty at having burdened their family and for continuing to smoke. In a study of smoking behaviour in Greenland, three out of four participants reported feelings of guilt and shame relating to smoking (Jensen and Hounsgaard 2013). Participants in the Greenland study were concerned about smelling of smoke and others being aware of their habit, and talked of doing things like brushing their teeth at work and chewing gum to disguise the smell from colleagues (Jensen and Hounsgaard 2013). In a case study of one lung cancer patient it is suggested that the patient's experiences are framed through guilt and remorse, and the author refers to the 'four windows of guilt and remorse space in lung cancer' (De Guzman et al 2010). The four windows are reminiscence, revolution, reconciliation and renaissance (De Guzman et al 2010). Reminiscence follows the pattern of a retrospective look at the self and one's past behaviour which may have caused the disease. Revolution is the height of emotions where the patient realises his or her own mortality. Reconciliation is when the person makes peace with their diagnosis and draws on the good things in life and the fourth window is the acceptance of the illness and of death (De Guzman et al 2010).

Feelings of guilt and shame can be detrimental to communication channels for people with lung cancer. Some patients in one study reported that they avoided discussion of their disease with family and friends due to feelings of guilt about smoking (Zhang and Siminoff 2003). Patients also were reluctant to discuss their cancer as they did not want others to feel sorry for them (Zhang and Siminoff 2003).

Perceptions of stigma, blame and shame are all factors which may have an influence over a person's willingness to consult their doctor when they suffer smoking related symptoms. The literature shows that patients have described feelings of blame coming from themselves, their families and friends, and indeed their healthcare professionals. This thesis aims to explore these themes in order to see if they are evident in the study population.

Fear and fatalism

In lung cancer research, fear has been cited as a barrier to early presentation as fear of a cancer diagnosis and a fear of death have been reported to delay patients from reporting symptoms (Tod et al 2007; Murray et al 2017). A fear of ‘what the doctor might find’ has been reported as a barrier to presentation in people who smoke (Quaife et al 2015). Crane et al (2016) also found that both current and former smokers reported a fear of bad news was a barrier to their presentation. In the study of Irish people living in the UK, participants who experienced cancer symptoms cited fear of cancer as a main reason for not consulting a doctor (Scanlon et al 2006). Cancer was seen as a death sentence among this population and the fear and pessimism they felt was closely linked to previous experiences of family and friends having cancer and dying from the disease (Scanlon et al 2006). Even the word ‘cancer’ was shown to have associations with fear and the Irish study population used terms such as ‘the big C’ and described it as a ‘demon’ and a ‘terrible curse’ (Scanlon et al 2006). This scary imagery used to describe cancer illustrates the fear that cancer can inspire. Fear of illness and death has also been noted in lung cancer patients, some participants in a study by Westerman et al (2014) reported pessimistic feelings such as not being able to plan for the future and not having much time left.

It has also been shown that fatalistic beliefs about cancer contributed to people’s sense of fear (Tod et al 2007). In a study that used data from the Health Information National Trends Survey in the USA, respondents were asked to report how much they agreed with the following three statements: ‘it seems like almost everything causes cancer’; ‘there’s not much people can do to lower their chances of getting cancer’; and ‘there’s so many recommendations about preventing cancer, it’s hard to know which ones to follow’ (Niederdeppe and Levy 2007). This study revealed that ‘fatalistic beliefs about cancer are prevalent in the US adult population’ (Niederdeppe and Levy 2007). Fatalistic beliefs about cancer are associated with less engagement with prevention behaviours such as smoking cessation, regular exercise and good diet, this is likely due to participants feeling that cancer is due to fate and therefore is out of a person’s control (Nierderdeppe 2007). People with fatalistic beliefs are potentially at greater risk of cancer through the lack of prevention behaviour (Niederdeppe and Levy 2007). In a similar fashion, fatalistic beliefs may also discourage people from participating in screening programmes, particularly if they feel that cancer is always a fatal disease (Niederdeppe and Levy 2007).

Currently there is no UK screening programme for lung cancer. Some previous research in to screening acceptability has reported a reluctance among smokers to take up screening when offered (Prout et al 2018). It may be of interest to this study to consider this reported reluctance, as an aversion to screening may also be linked to an aversion to primary care in general. Quaife et al (2015) also found that 'knowing one's diagnosis might appear to be of little value if the outcome is assumed to be invariably negative' which again may deter screening attendance and primary care usage. A history of cancer in the family was linked to agreeing with the statement 'everything causes cancer', suggesting that a personal experience with cancer suffering might raise perceptions of cancer risk, although there may still be a barrier to prevention behaviours due to the belief that cancer is unavoidable (Niederdeppe and Levy 2007). It may be that a person who smokes but has fatalistic beliefs regarding cancer may see little point in consulting their GP as there is nothing to be gained from knowing that they have cancer.

Park et al (2013) found that some participants were fatalistic in their beliefs about smoking and cancer, with some thinking it was inevitable already and so saw no point in quitting, and others feeling that if they didn't get lung cancer they would 'die of something else' so there was again, no point in quitting. Li et al (2014) also reported that smokers in their study felt that following diagnosis there was no point in stopping smoking as it was already 'too late'. In a study by Quaife et al (2015) respondents were asked to what extent they agreed with six statements about cancer; current smokers were found to be more pessimistic than former or non-smokers and were more likely to agree with statements such as 'I would not want to know if I have cancer' and 'cancer is a death sentence'.

Fear of seeking healthcare and fatalism regarding cancer and health in general may contribute to longer patient intervals as patients do not see the point or are too afraid to see the doctor. This could potentially mean that symptoms are left for an extended period of time and perhaps account for some instances of first presentation in secondary or emergency care.

Family and relationships

A person's health, whilst often a personal or private issue, may also be influenced by their family and social relationships. For the purposes of this thesis, it is important to include literature regarding the role of family and friends in a person's symptom experiences and whether or not they have a part to play in the decision to seek help. In research by Tod (2007) it was reported that early presentation could be positively facilitated by family members as they were key in noticing symptoms and changes that may have been otherwise ignored or normalised by the patient. Neal et al (2000) reported participants being encouraged to see their GP by their family members who helped reassure them that they were not wasting time or going unnecessarily. Participants in another study reported having gone to their doctor following prompts from family and friends (Corner et al 2006). It has been suggested that the conditions of the family environment can impact on the ability of the patient to adapt positively to their diagnosis (Siminoff et al 2010).

It has also been found that the presence and support of family members and friends can be very beneficial following a cancer diagnosis (Street and Gordon 2008). Some patients have reported that it is helpful for them to have a family member present during their appointments with healthcare providers and positive correlations have been found between the presence of a companion in consultations and patient satisfaction (Yardley et al 2001; Street and Gordon 2008). If the presence of a family member is beneficial during appointments prior to diagnosis, perhaps family members can also be a source of support during first presentation.

However, not all patients choose to disclose their disease to family and friends, commonly citing reasons such as ‘it’s none of their business’ and ‘not wanting them to worry’ (Yardley et al 2001). Members of the Irish population in the Scanlon et al (2006) study reported that it was commonplace to conceal a cancer diagnosis so as not to burden their family. In a quantitative study of lung cancer patients it was revealed that some of them had chosen to conceal their diagnosis from their family due to a desire not to burden their loved ones (Gonzalez et al 2015). Although these studies report findings involving patients post diagnosis, it may be important to this study to bear in mind the idea of a reluctance to disclose health status. It may be that prior to diagnosis people choose to conceal their symptoms or feelings of ill health from loved ones due to concerns about burden. It may also be that symptoms are concealed from family members to avoid being pressured in to seeking healthcare when they do not wish to.

It has also been found that couples facing a diagnosis of lung cancer may be at higher risk of relationship distress (Badr and Taylor 2006). The study by Badr and Taylor (2006) found that patients and their partners experienced social constraints such as denial, avoidance, and conflict within their relationships following diagnosis. It seems that patients can find it difficult to communicate with their partner about their disease and reported purposefully avoiding the issue and trying to focus on the positives instead (Badr and Taylor 2006). This tendency to focus on the positive and avoid discussion of the disease was actually found to be frustrating for the partners as they felt the patient was in denial of their condition (Badr and Taylor 2006). Partners wishing to avoid conflict may also avoid raising 'hot button topics' such as smoking for fear of provoking an argument (Badr and Taylor 2006). Patients who are unmarried or without a partner were more likely to continue to smoke after their cancer diagnosis (Berg et al 2013). These study findings are post diagnosis but may also have some implications for this study as relationship dynamics could be affected by worsening health, disagreements regarding seeking help, and one partner wishing to avoid discussion whilst the other wants to talk.

Taking into account the previous work on social relationships and early presentation, this study will further investigate the ways in which a person's social relationships may influence their help seeking decisions.

Conclusion

This narrative review has shown that the relationships between smoking, lung cancer, and patient intervals are multi layered and complex. The need to legitimate one's help seeking by waiting until symptoms become unbearable seems to feature readily among lung cancer patients, particularly in those who do, or have, smoked. This is further exacerbated by confusion over what should be interpreted as a potential cancer symptom and what level of severity a symptom should be at to warrant medical attention. Symptoms that are vague in nature tend to be attributed to minor conditions or ageing and as they worsen, the patient gradually normalises them and does not seek help until they become 'alarm symptoms'. The presence of a pre-existing comorbidity can also affect the time to diagnosis in terms of both the patient and the clinician interpreting the new symptoms and recognising a potential cancer. A distorted perception of personal risk is another factor that affects people who smoke and a lack of risk perception means that a person may be less likely to suspect cancer when they experience symptoms. Those who believe that all people get cancer eventually may have a fatalistic attitude and therefore see no point in seeking help. Feeling unworthy of care due to a sense of shame or blame for one's own condition is also a point of difficulty for lung cancer patients and may discourage them from a timely presentation. Lung cancer patients and smokers have also reported that they experience fear, fear of cancer, fear of treatment and fear of death. Each of these are not separate issues and they all bound within the person's own biography and their personal and social relationships. This review has further shown that there is a need for more, in-depth, qualitative research, in order to make sense of these matters and to learn how they affect the population in this study. Therefore, in light of the evidence generated by this narrative review and the previous systematic review, this study will further explore these themes in the context of the lived experiences of current smokers and lung cancer patients in North Wales. The literature reviews will inform the development of the data collection instruments, the design of which is given in full detail in the forthcoming methods chapter of the thesis. The evidence from the two literature reviews will then be brought together with the analysed data collected in the discussion chapter of the thesis which will collate all of the primary and secondary evidence gathered in this study.

Chapter 3: Methods

Chapter summary

This chapter will give a full and detailed account of the study design and methods used in the data collection phases of this thesis. The chapter begins with an explanation of the interpretive approach used for the thesis and why it was deemed the most appropriate for this study in defining the objectives and designing the research questions. This chapter will then provide a justification for the use of a wholly qualitative approach to the study outline, the use of patient and public involvement in the study design and the ethical considerations and approvals. The next section will explain the use of purposive sampling and the design of the recruitment materials, followed by the actual recruitment process. Finally, this chapter will give a detailed account of the data collection, interviews, focus groups, and data analysis.

The interpretivist approach

Why interpretivism?

This study was designed to gain an in-depth understanding of the ways in which smokers and lung cancer patients present in primary care. The research sought to understand the thoughts and actions of the participants through their personal views of their own health and of the social world and therefore it was believed that the ideal approach to the research would be an interpretivist one. Therefore, the study was undertaken with the principles of interpretivism at its core and those principles were applied to the data collection and analysis.

The approach taken to a study depends on the nature of the research and the standpoint of the researcher (Lin 1998). The two main approaches, positivism and interpretivism, are distinguished by their ‘analytical approach and the goals of the researcher’ rather than the methodology (Roth and Mehta 2002). The positivist approach originates with the natural sciences and seeks to answer questions within an objective reality (Roth and Mehta 2002; Angus 1986; Marshall 1994). The reasons why the positivist approach was not appropriate for this study are given in more detail further on.

The interpretive approach intends to move human enquiry away from the traditional positivist approach towards a more interpretive approach in search of meaning rather than objective fact (Roth and Mehta 2002; Geertz 1973). It has been argued by interpretivists that the objective reality of positivism does not exist and that what is thought of as fact can never be truly objective as everything is constructed by actors and then reconstructed by the researcher according to their own viewpoint (Geertz 1973).

Whilst positivist research is concerned with the existence of an ‘objective reality’, interpretive research views realities as socially constructed by actors within them and values subjectivity (Roth and Mehta 2002; Willis 2007). In this study, the realities to be explored are therefore those of the participants, of current smokers and lung cancer patients, and the life worlds that they construct. The interpretive approach argues that in order to understand a phenomena, it is essential to also understand what meanings the actors involved ascribe to their actions. In other words, it is not enough to have statistical patterns alone, a person’s motives must also be understood (Blaikie 2000). Interpretivists look to the meanings and interpretations of the actors themselves and see the social world as being ‘the world interpreted and experienced by its members from the inside’ (Blaikie 2000). It is widely agreed that in interpretivist research the reality of the participants is discovered through their own views and experiences (Thanh and Thanh 2015; Creswell 2014; Yanow and Schwartz-Shea 2011). The role of the researcher in collecting and analysing data according to the interpretive paradigm is to give an account which is coherent and makes sense of respondents perceptions and beliefs, even those which may be ‘ambivalent, changing or even contradictory’ (Roth and Mehta 2002). Therefore, the researcher takes a flexible and interpretive approach and does not seek to clarify contradictory accounts in order to get one truth; instead, they seek the meaning ascribed to situations by the participants and look for reasons why a contradiction may occur. In this study there may be potential for contradictory accounts, however the things of importance to this thesis are the meanings that participants ascribe to their experiences of primary care and not strict timelines.

For interpretivists, knowledge is created by social actors, background knowledge is constantly recreated and redefined by people as they interact with each other, therefore the social researcher must understand the meanings given to actions in order to gain a deeper understanding of why a phenomena may occur or why those actors do as they do (Blaikie 2000). It is not enough for the researcher to merely describe these actions. In order to understand the reality constructed by social actors, the researcher must also interpret them (Schwandt 1998). The researcher must read the meanings of participants and the interpretation becomes ‘the inquirer’s construction of the constructions of the actors one studies’ (Schwandt 1998).

Interpretivists, therefore are principally concerned which how the social world is constructed by its inhabitants and how they work together to do so (Blaikie 2000). The interpretivist seeks out the meanings ascribed by the actors themselves and ‘it is these meanings, embedded in language, that constitute their social reality’ (Blaikie 2000). Ontologically, the interpretivist approach is regarded as being ‘relativist’ as it assumed there is no single social reality; rather there are multiple realities and they are always subject to change (Blaikie 2000). Within interpretivism, social reality depends on the social actors involved, and each may be ‘real’ to them (Blaikie 2000). From an epistemological point of view, within interpretivist traditions, knowledge is created via the meaning ascribed by actors involved and through ‘socially constructed mutual knowledge’ (Blaikie 2000).

When qualitative research follows an interpretive approach, it seeks to understand the actions of a certain population in certain circumstances (Lin 1998). Interpretivism does not seek to generalise in the same way that positivism or the natural sciences do, rather the interpretivist is interested in the unique aspects of particular contexts (Chowdhury 2014; Myers 1997). This study is interested in the perspectives of current smokers and those with lung cancer within the particular context of their experiences regarding primary care. The interpretive approach allows for exploration of participants’ accounts of the ways that they give meaning to their actions.

Designing the research questions

Following some initial background research and reading of the literature surrounding patient intervals, smoking and lung cancer, it was necessary to focus the research by formulating research questions to be answered. The areas of interest present a causal puzzle that can be addressed via the research (Mason 2002). Mason (2002) gives the example of a causal puzzle as ‘what influence does x have on y?’ The causal puzzle in this case is ‘what influence does smoking, or factors associated with smoking, have on timely presentation?’ In order to solve this causal puzzle, the research questions were required to do several things, namely: to be understood by those other than the researcher, to be consistent and linked to one another, to be open enough that the subject can be fully explored, generate interesting arguments, and, perhaps most importantly, they should be questions worth asking (Mason 2002).

Through preliminary reading, it was evident that there was a need for high quality qualitative research to investigate the complex relationships between smokers, lung cancer patients, and primary care. Early ideas were gradually redrafted and shaped into three specific questions, the first of which would be answered by the literature reviews, and the second two, which would be addressed with the collection and analysis of primary data.

Research questions

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals:
    a. For any symptoms of ill-health?
    b. For symptoms they perceive to be smoking-related?
    c. For chest or other symptoms they perceive to be indicative of lung cancer?
3. What are the factors associated with smoking that may lead to longer patient intervals (for example stigma, shame, guilt, blame, fear, nihilism, perceived health professionals' negative attitudes towards smokers and smoking, and previous consultation experiences) and how do they impact on smokers' health-related decisions and choices?
4. In what ways do the experiences of people newly diagnosed with cancer in Wales reflect delayed presentation in primary care due to factors associated with smoking?

Suitability of interpretivism for answering the research questions

Interpretivism is appropriate for answering the research questions as it seeks to understand the meanings behind the actions of the participants, not just to establish whether or not patient intervals exist, but also why and how they exist and what they mean to participants. The interpretive approach is most appropriate for the methods used in this study.

The first research question in this study was addressed via the two literature reviews, which included literature obtained from any approach as long as it was relevant to the study.

As the research questions seek to understand the reasons behind participants' presentation, or lack of presentation, in-depth interviews were chosen. The interpretive approach complements the interview methods due to its ability to pursue areas that appear to be of particular salience to participants and thoroughly explores how they ascribe meanings to their actions.

To understand the views of smokers in general, meaning those without lung cancer, regarding primary care and presenting symptoms, a focus group method was used as it was desirable to facilitate discussion and interactions between participants. The interpretive approach argues that meanings ascribed to actions are not entirely private, and that groups which share similarities, may share common meanings (Blaikie 2000). Therefore, the interpretive approach and the focus group method were an ideal combination for answering this research question.

Why not positivism

In opposition to the interpretivist approach is the positivist approach. The positivist approach was considered unsuitable for this study, as positivism does not seek the meanings behind actions in the same way that interpretivism does. The positivist approach is based on the principles of the natural sciences; it seeks to test and confirm or refute hypotheses and to create social laws in the same way that the natural sciences create natural laws (Roth and Mehta 2002; Angus 1986; Marshall 1994). Positivism views the social world as ‘an ordered universe made up of discrete and observable events’ (Blaikie 2000). The positivist approach argues that only things which can actually be observed can be regarded as real, and therefore worthy of scientific attention; it relies on the existence of an objective reality that can be known and understood (Blaikie 2000; Roth and Mehta 2002). The positivist tradition examines causal relationships between phenomena based on what is observed by the researcher (Blaikie 2000). This study is more suited to an interpretive approach as it does not seek to generalise across populations but rather to study a particular population in-depth and to go beyond the observable to understand the interpretations of the participants themselves.

The critique of interpretivism

The interpretive approach has come under criticism for being subjective and unscientific. Williams (2000) argues that social research requires the making of generalisations from the data and states that an interpretivist approach denies the importance of generalising, whilst simultaneously making generalisations that are largely unsubstantiated. The interpretive approach has been criticised for being biased via the perspective of the researcher because the positivist approach argues that the researcher should be completely objective and separate their own feelings from the work. However, the interpretivist would argue that there is no objective reality and that the researcher is never truly objective (Blaikie 2000; Geertz 1975). It is important to be aware that neither approach is right or wrong; they come from differing theoretical backgrounds and aim to achieve different objectives. The job of the researcher is to approach their own research in the best way possible for achieving their own research objectives.

Another criticism of interpretivism lies in the perceived lack of testable reliability and validity (Chowdhury 2014; Perry 1998; Eisenhardt 1989). The concepts of reliability and validity in research, in the same way as the positivist approach itself, are rooted in the natural sciences. It is argued from the interpretivist viewpoint that as interpretivism seeks meaning and motives, the methods of the natural sciences are not applicable (Eliason 2002; McIntosh 1997). Further, it is argued that in qualitative interpretive research, rigour is ensured through transparency of methods and depth of analysis, rather than traditional positivist measures of reliability and validity. The question of rigour in interpretivist work is addressed in the analysis section of this chapter.

Justification for qualitative approach and methods

The research methods in this study were chosen according to the research questions and the ability to best fulfil the research objectives (Silverman 2005). It is important to present the rationale behind the employment of a qualitative approach and to demonstrate the logic behind the choice of data collection methods (Marshall and Rossman 2006).

Qualitative research is ideal for this project as it seeks to investigate complex issues in-depth (Marshall and Rossman 2006). This study looks for emergent data on why a phenomenon, in this case presenting in primary care, occurs within a certain context and the complexities surrounding the issues of smoking, lung cancer journeys, and primary care usage (Marshall and Rossman 2006). Whilst a common criticism of qualitative research is that it is based on anecdotal evidence, it can also be argued that qualitative research is not designed to be tightly prefigured and instead it is interactive, humanistic, takes place in the natural world and focuses on context (Mason 2002; Marshall and Rossman 2006). However it can also be argued that in the past research has been dominated by quantitative methods, and that it must be acknowledged that there are areas which reach beyond the scope of quantitative research (Black 1994). The strengths of qualitative research have been highlighted in the work of several authors who seek to bring qualitative methods in to health services research as the best way of investigating topics which quantitative methods are unable to reach (Pope and Mays 1995). Through qualitative research it is possible to understand why some clinical interventions, though promising in theory, do not work in reality (Greenhalgh 2016). An example of this may be in seeking to understand why education messages about smoking cessation are available and understood by some populations, and yet are still not recognised as relevant to everyday life by those same populations (Pope and Mays 1995). Health research is a complex arena, comprising relations between patients, healthcare professionals, the healthcare system and the contexts in which care is delivered, and qualitative methods can be the ideal way to address the variety of research questions raised by this complexity (Pope and Mays 1995; Greenhalgh 2016). Qualitative research celebrates depth and richness and is able to create ‘compelling arguments about how things work in particular contexts’, in this case smokers, lung cancer patients and primary care in North Wales (Mason 2002). This project focuses on the lived experience of individual participants who all have their own personal narrative of events. In order to fully explore these accounts and to discover the deeper meaning ascribed by participants to their own experiences, a qualitative approach is ideal.

Patient and public involvement

Patient and public involvement (PPI) in health research involves the inclusion of lay perspectives in the study design or the undertaking of the research (Entwistle et al 1998). The term ‘lay’ refers to members of the public who are not clinicians or health researchers but who have an interest in research, may have personal experience of the phenomena under study and be active within the research community (Entwistle et al 1998).

PPI in research can be beneficial in ensuring that research is transparent and ethical and can improve quality by including lay views and priorities that may be different to that of researchers and healthcare providers (Entwistle et al 1998). PPI can also improve the credibility of results and make them more directly applicable to clinical practice and real life patients (Domecq et al 2014). There is also some evidence to show that PPI can improve dissemination as results are potentially more accessible and understandable to patients and the general public (Domecq et al 2014; Swartz et al 2004). In the past the most common areas for lay contribution were in the preparation of patient facing materials, appraising study protocols and interpretation of study findings (Entwistle et al 1998). More recently, as the value of PPI has become more appreciated, they may also be involved in protocol writing, serving on study boards and panels, and advising on recruitment procedures (Domecq et al 2014; Swartz et al 2004). The views of lay contributors can be particularly helpful in these areas as they may have valuable insight into how the research materials and protocols may impact upon the members of the public being recruited (Griffiths et al 2004).

When recruiting the lay contributor for this study, the first organisation contacted was the North Wales Cancer Patient forum as it was felt that a person with experience of lung cancer would be an ideal candidate for the role. However, there were no available members with lung cancer and so another approach was taken. An advert was circulated through the members of the Health and Care Research Wales PPI group, the Involving People Network. One reply was received from a PPI member who had an interest in the topic and experience of a family member with a smoking-related illness and she was recruited to the research team.

As this study involved the preparation of participant-facing materials it was beneficial to have the input of a lay contributor in order to ensure that the materials were in lay language and suitable for purpose. The lay contributor gave comments on draft recruitment materials and topic guides for interviews and focus groups. A lay summary of the study is also required for the application to the Research Ethics Committee (REC) and the lay contributor gave advice on the content. Several discussions took place regarding the emotional and sensitive nature of the topic; it was in this capacity that the personal experiences of the lay contributor were particularly useful.

Lay contributors are members of the research team and it is considered good practice to pay them for their contribution. In accordance with Health and Care Research Wales and Involving People guidelines, the lay contributor was paid an honorarium for time spent working on the project and any expenses incurred were covered by the research team.

Research ethics

Ethical considerations

The issue of ethics is present in all research studies (Orb et al 2000). When we discuss ethics in research we do so in terms of potential harm to participants (Orb et al 2000). In qualitative health research the researchers must be aware of any ethical issues that may arise from accessing the environments of their participants and take care to remember that, whilst research practices are common to them, they will not be so familiar to the participants (Orb et al 2000). Observation of ethics in health research should occur through the entire process, during the design, methodology, and the reporting of the data (Orb et al 2000). Whilst ethical review boards scrutinise research proposals the researcher is ‘ultimately responsible for protecting the participants’ (Orb et al 2000).

Research with vulnerable participants presents ethical challenges for the researcher (Reid 2009). This study was concerned with participant vulnerability in the interview stage as cancer patients are classed as a vulnerable population (Reid 2009). Focus group participants were not recruited due to a specific condition which would class them as vulnerable, however many of them did have physical and mental health issues and two of them (Barry and Dean) disclosed that they had suffered addiction problems in the past which could potentially make them vulnerable. As this study was concerned with cancer and smoking there was potential for participants to feel a sense of blame for their condition or to feel unworthy of care and so extra care was taken to ensure that the research could not be construed as judgemental in any way. It was also important to be aware that participants may disclose issues that are concerns for them but are not necessarily related to the research objectives, for example, one participant (Sue) was upset about a dispute with a neighbour. These kind of moments must be handled carefully, whilst they are not the focus of the research, they are clearly important to the participant and dismissing them too readily may be distressing.

In qualitative health research such as this study, the main ethical issue is often the potential for participants to become emotional or distressed due to the discussion of sensitive and emotive topics (Dyregrov 2004). It is likely in health research such as this that sensitive topics will be discussed and are often the focus of the research; therefore, it was anticipated that participants might become emotional during interviews and focus groups (Dyregrov 2004). In order to conduct this study ethically, it was imperative to be able to be empathetic during emotional moments and give the participant the opportunity to take a break or stop the interview or leave the group if they wished to do so (Reid 2009). It is important to remember that emotion does not always equal distress and as long as the researcher manages the situation carefully, the participant is likely to be happy to continue (Dyregrov 2004). It has been suggested that participants are happy to talk about sensitive topics if they believe the study to be worthwhile and so the researcher should take the time to ensure that the participant is aware of the potential benefits of the study (Allmark 2009). In this study it was stated in the participant information that whilst participants may not directly benefit from the research themselves, their contribution may go towards helping others in the future. Interview participants often said that they were glad to take part if it would benefit others in similar situations.

Emotional distress is not the only issue however, and the researcher must consider the ethical implications of loss of personal time due to lengthy interviews and loss of privacy due to the presence of researchers in participants' homes (Reid 2009). Qualitative research involves the researcher entering the participant's private domain and this should be respected at all times (Reid 2009).

The issue of informed consent is a major ethical consideration in healthcare research. Informed consent means that the participants know exactly what they are consenting to and that no coercion has been used (Miller and Bell 2002). Participants should only sign the consent form once they have been presented with all the study information and have agreed that they understand what participation will entail and how the data will be used (Hewitt 2007). Consent can also be seen as an ongoing process and participants must understand that the consent form is not a binding contract and that they are free to withdraw at any point (Reid 2009). In this study, all participants were fully informed and those who lacked capacity to give informed consent were excluded at the recruitment stage. All participants were given a full set of printed information and the study was explained to them during recruitment. All participants were informed that they could withdraw if they wished to do so. In circumstances where participants raised any clinical concerns they were signposted back to their GP or care team.

Complete confidentiality is not possible when face-to-face data collection is used as the researcher will always know the identities of participants, however steps must be taken to ensure anonymity in qualitative research (McIlfatrick et al 2006). Anonymity was ensured in this study by keeping all patient identifiable information in locked filing cabinets and password protected electronic files and by anonymising all transcripts (Reid 2009). All the interviews in this study were recorded and transcribed verbatim by a professional transcriber outside of the research team. The transcriber anonymised the transcripts by removing all identifiable data including all names, locations of homes and healthcare sites. The transcriber was required to sign a Bangor University confidentiality agreement (see appendix 5). All recordings were deleted as soon as transcription was complete. In this thesis, and in most qualitative research, direct quotes are used in the findings chapter in order to show that interpretations of findings are truly grounded within the data. Great care was taken in order to make sure that quotes do not contain identifiable information and are presented in their anonymised format.

In qualitative research, the protection of participant identity is of utmost importance and can be achieved in several ways including through the use of participant ID numbers, codes or the use of pseudonyms. In this study, pseudonyms were assigned to each participant in order to protect their identity and maintain confidentiality. Pseudonyms were chosen using the ‘random name generator’ tool, which generates a random name according to gender and country of origin, in this case, English or Welsh. It has been argued that pseudonyms allow the researcher to impose certain attributes to participants and are influenced by age and social class (Grinyer 2009). However, it was felt that since the random generator chose the names that was not an issue. In addition, the use of names gives a more humanising quality to the research rather than referring to participants by number or code.

Whilst there are ethical concerns in conducting studies with cancer patients and smokers, it is still important to offer them the opportunity to take part in research to allow their voices to be heard and to potentially expand knowledge and improve future outcomes (Reid 2009). Ethical considerations were taken into account throughout all phases of this study in order to provide justice to participants, minimise the potential for distress, and achieve outcomes in an ethical manner.

Ethical approvals

The Bangor University Ethics Committee gave the study full approval in October 2015 (see appendix 1).

An initial application to the Research Ethics Committee (Wales REC 1) was made in November 2015 and a provisional favourable opinion was returned in December 2015, although the committee required a response to several concerns and requested a few changes to protocol and study documents. One concern was that lung cancer patients are vulnerable and that recounting events leading to diagnosis could potentially cause distress. As there is potential for distress in this study population, the REC were reassured that the interviews would be undertaken in a sensitive manner and that participants would be free to pause or stop the interview at any time. The REC also initially suggested changing the population to patients with COPD instead, however this was not feasible as Health and Care Research Wales had provided funding on the original proposal for a lung cancer study.

The REC were also concerned about how a person’s cognitive capacity to take part would be judged. However, a GP or a research nurse would initially screen all participants and those deemed to lack capacity would be excluded at this point. Good Clinical Practice (GCP) guidelines require that participants are able to give informed consent, therefore anybody who was unable to understand the study information would be excluded on the grounds that they were unable to give informed consent (NIHR 2016). In response to concerns about confidentiality, the REC were assured that the recordings would be transferred electronically to a professional transcriber and transcribed verbatim. The transcriber would have access to the anonymised material contained within the recording but not be given any other information about participants such as address or contact details. The recordings would be labelled anonymously and the transcriber asked to sign a Bangor University approved confidentiality agreement.

Committee members questioned the availability of the study in the medium of Welsh and were assured that Bangor University has a committed Welsh language policy and all materials would be offered bilingually. In the event of a participant wishing to be interviewed in Welsh, a Welsh-speaking researcher would have been appointed. Bangor University also has facilities for simultaneous translation that could be used in focus groups. These options were not required as no participant requested a Welsh language interview or focus group.

It was also suggested that details of a smoking cessation service be included in the focus group patient information. This was not included because the explicit signposting toward smoking cessation on the information sheet may give the impression that the purpose of the focus group is to implement smoking cessation which has the potential to misinform some participants and may deter others from taking part.

The ethics committee were also unsure about conducting interviews in participants' homes due to the researcher's lack of clinical experience. However, they were assured that the participant would have a choice of venues, that the visit was entirely non-clinical in nature, and that there is much evidence, such as the study by Sivell et al (2015) and work by Birt et al (2015) that qualitative research benefits from being conducted in the home setting,.

Finally, some minor changes to the wording and structure of recruitment materials were requested and these were fulfilled.

Full ethical approval from Wales REC 1 was granted in January 2016. Full Research and Development (R&D) approval was Grant in March 2016 (see appendix 1).

REC reference number – 15/WA/0423
IRAS reference – 182467

Sampling

Sampling in qualitative research

It is not possible for research to address all people, events, or circumstances in-depth, and therefore sampling strategies are employed to select those that will be studied (Marshall and Rossman 2006). Sampling is the process of choosing whom the participants of the research will be (Mason 2002). When choosing the sampling strategy, in any study, it is important to consider what basis, other than ‘convenience or accessibility to guide us in this selection’ (Silverman 2005). In other words, we must justify our sampling through a clear rationale and not simply pick the easiest option or the first people who come along (Mason 2002). It is essential in qualitative research that the sample be selected with ‘sound judgement’ as this will be the source of the data (Eitkan et al 2016). For this study, a purposive sampling strategy was chosen as the best way to obtain a good sample and relevant data.

Purposive sampling

Purposive sampling, as opposed to random sampling, allows the researcher a degree of control over who is selected as a participant (Barbour 2001). Purposive sampling is often used in qualitative research (Mason 2002). Purposive sampling refers to the deliberate selection of participants due to the possession of a characteristic relevant to the research (Eitkan et al 2016). In the case of this study, those characteristics were people aged over 50 years with either a recent diagnosis of lung cancer (for the interview phase) or a recent history of smoking (for the focus group stage). In purposive sampling, the researcher seeks participants who can provide the data due to experience or knowledge of a particular topic (Eitkan et al 2016). In this study it was decided that in order to answer the research questions, people with direct experience, either of a lung cancer diagnosis, or of smoking and primary care consultation would be required. Those who did not fulfil these criteria would not be able to provide data to address the research objectives. Purposive sampling is used in qualitative research for identifying and choosing the most information rich sources, in this case lung cancer patients and those with a history of smoking who had first-hand experience of the topic (Eitkan et al 2016). Purposive sampling should be carried out with some degree of flexibility (Silverman 2005). It is important to keep this notion of flexibility in mind whilst monitoring the recruitment of the sample. In this study this was particularly important when it came to the gender of the interview participants. It was hoped that an approximately equal number of male and female participants would be recruited, however, if for example there were only female participants responding, the recruitment strategy would have been altered to target more males. Recruitment rates were consistently monitored and there was no need to alter the strategy, as there was always a similar number of males and females, however the ratios for interviews do not necessarily reflect this as not all people recruited were interviewed, some withdrew from the study or were unable to be contacted or interviewed. Participant characteristics can be found in tables 5 and 6. In purposive sampling, the researcher must employ critical thinking about the parameters of the study population and carefully select the sample based upon those parameters (Silverman 2005). In this study, all participants were aged over 50 years, living in north Wales with either a lung cancer diagnosis or a recent history of smoking.

Purposive sampling and the point of saturation

It is often said that purposive sampling in qualitative research is not about achieving numbers but about reaching the point of thematic saturation within the data collected (Bowen 2008). Saturation is the point at which no new themes emerge and ‘no new substantive information is acquired’ and the researcher will continue to sample until this point is reached (Bowen 2008; Eitkan et al 2016). This concept of thematic saturation is common in qualitative research, however it is often far too simplistic and there is very little in the way of published guidelines on how to judge the point of saturation, and thus this posed a challenge for this study as thematic saturation is the goal to be reached (Guest et al 2006; Morse et al 1995; Francis et al 2010; Hennink et al 2017). It can be stated that the pitfalls of poor sampling and unmet saturation points are also ethical challenges as samples which are too big are wasteful and burden participants unnecessarily, whilst those that are too small are unable to adequately capture the phenomena under study (Francis et al 2010; Hennink et al 2017).

Two recent studies have attempted to measure the point at which thematic saturation is reached in order to answer the question ‘how many interviews are enough?’ (Guest et al 2006; Hennink et al 2017). The study by Guest et al (2006) focusses on assessing saturation by the generation of codes and the point at which no new codes emerge from the data. Hennink et al (2017) argue that there are in fact two points of saturation, code saturation and meaning saturation and that these would take differing sample sizes to reach. In both studies, authors were able to give the number of interviews at which they achieved code saturation, twelve in the study by Guest et al (2006) and nine in the study by Hennink et al (2017). Meaning saturation appears to be much harder to assess than code saturation but the study by

Hennink et al (2017) indicates that they needed more than nine interviews. Achieving meaning saturation requires more than monitoring the prevalence of codes and themes; rather it comes via the iterative process of analysis (Hennink et al 2017).

The purposive sampling in this study was designed to continue until saturation was achieved but also with an awareness that there is no ideal number of interviews or focus groups which will guarantee saturation (Hennink et al 2017). Therefore, recruitment continued until no new themes occurred and thematic saturation was achieved after twenty-nine interviews were completed. Recruitment rates for the focus groups were lower than expected (see recruitment section below) but the depth of the data gained meant that saturation was still achieved at three groups. If saturation was not reached then it would have been necessary to continue recruitment. This thesis argues that thematic saturation was achieved in the data collection phases and will be illustrated in the level of interpretation evidenced in the findings chapter of this thesis.

Designing the recruitment materials

All recruitment materials were designed carefully, with PPI input from the lay contributor and given full ethical approval. All recruitment materials were issued in both English and Welsh, according to Welsh law, and bearing the logos for Bangor University, the North Wales Centre for Primary Care Research, Health and Care Research Wales, and Betsi Cadwaladr University Health Board. All recruitment materials are presented in the appendices to the thesis (see appendix 4).

Interviews

Potential interview participants were given a specially designed recruitment pack comprising an invitation letter, a patient information sheet, a reply slip and a consent form. The invitation letter consisted of one page giving a basic description of the study, why the invitation was given, and who the research team were. The letter also directed the participant to the patient information sheet for further details. The patient information sheet gives a detailed description of the study and of what taking part would entail, including possible risks and benefits to the patient, an explanation of confidentiality and consent, organisation and funding of the research, the process of withdrawing from the study or declining to take part, and who to contact for further information. The reply slip for the interviews was designed to be straightforward and simple, with a choice of two tick boxes, either agreeing or disagreeing to be contacted, and space to fill out contact details. A consent form was also included and the research nurses showed the participants which items to initial and where to sign and date at the bottom.

Focus groups

Eligible focus group participants were also issued an invitation pack, which comprised an invitation letter from the research team, a letter from their GP, a patient information sheet, a reply slip, and a freepost envelope. The letter from the GP, on practice headed paper, informed patients that they were invited to take part via their GP and gave a very brief description of the study. The invitation letter from the research team then gave a slightly more detailed invitation and directed the patient to the information sheet for further information. The patient information sheets were similar to those use for the interview invitations but also included information on where the groups would take place and directions to return the reply slip in the freepost envelope provided. Reply slips were of the same design as for the interviews. A consent form was not included in the focus group invitation packs as participants were consented on site when they arrived for the group.

Recruitment

Interviews

Using purposive sampling the study aimed to recruit recently diagnosed lung cancer patients from two hospital sites in North Wales. The inclusion criteria were a diagnosis of a primary lung cancer received within the past three months, in sufficient health to be able to take part in the interview, and with the capacity to give informed consent. There were no gender or age restrictions.

Invitation packs, as described above, were originally planned to be given to eligible patients via their clinical nurse specialists. Those who wished to take part would return the reply slip via a free post envelope. However, recruitment via this method proved to be unsuccessful due to the busy clinical role of the nurses. An amendment to the protocol was sought in order to enable the research nurses and officers at Health and Care Research Wales to recruit patients at their weekly lung clinics and to consent them on site. The research nurses and officers then returned the completed consent forms and reply slips to the researcher, who then contacted them via their preferred method to arrange an interview. This method was far more successful, possibly due to the nature of the role of the research nurses and their ability to explain the study to the participants in more depth. Consent and contact details being taken on site also removed the need for the free post envelope and took the responsibility for first contact away from the patient and on to the researcher.

Across the two sites, 18 men and 11 women were recruited and completed the interview. It was then decided to close recruitment due to having reached data saturation.

Focus Groups

The study set out to recruit approximately 50 participants, to take part in one of a series of four to six focus groups, each containing between six and eight people from two GP sites in North Wales. Inclusion criteria were having a recent history of smoking, being over 50 years of age, in sufficient health to be able to take part in the focus group, and with the capacity to give informed consent. There were no gender restrictions.

Two general practices were approached by the lead for primary care from Health and Care Research Wales and asked if they would act as recruitment sites. Practices were chosen due to their location in different areas to broaden the range of participants' socioeconomic status. Each practice was paid £150 for their participation in recruitment.

The research nurse worked with the practice managers to generate a list of potential participants. The GP checked these lists to ensure that no ineligible patients were included. Bilingual invitation packs were sent via post to all those who were eligible to take part. The packs comprised a letter from the GP, an invitation letter from the research team, a participant information sheet, a reply slip, and a freepost envelope. Those who wished to take part returned the reply slip and were then contacted via their preferred method by the researcher. Informed consent was taken when they arrived for the focus group.

Recruitment for the focus groups was lower than anticipated. A total of 600 invitation packs were sent out, 300 from each practice, and only 25 replies came back. Of those that replied, more were lost due to withdrawing from the study, being uncontactable, and failing to attend on the day. Due to the response rate, it was not possible to carry out the planned four to six focus groups or to sample the individual groups according to age, gender, or general practice area. Recruitment for the focus groups also included an unanticipated event, due to the method of recruitment which was via GP records. More than one eligible participant lived at the same address as another and both received invitations. Therefore, in some cases, both parties returned responses, which led to the recruitment of three pairs of partners. When contacted, those approached for recruitment at the same time as their partner often requested that they take part in the same focus group. This led to the organisation of three focus groups: one for men, one for women, and one for couples.

Conducting the interviews

Rationale for use

In-depth, semi structured interviews are the most commonly used qualitative research method (Mason 2002). It was decided that interviews would be the most suitable method for the first phase of data collection for several reasons. In a study such as this, the participants themselves are the source of data and so it is desirable for the researcher to be as closely connected to them as possible during the process (Mason 2002). This study takes on the ontological perspective that ‘people’s knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties of social reality’ which the research questions in this study are designed to explore (Mason 2002). The interview method is ideal for this study, as it comes from the angle that knowledge is situational and contextual and therefore a ‘one size fits all’ approach, such as a survey, is not suitable. Rather, the one-to-one interview provides the opportunity to talk interactively and for the researcher to ask questions as they arise (Mason 2002). Whilst a quantitative method has the ability to collect a large amount of surface data, this study seeks depth and complexity from fewer people and so the interview can provide a more nuanced, rounded data set (Mason 2002). In the interview setting the researcher is ‘active and reflexive in the process of data generation’ and the interview also allows for different questions to be asked of different participants; this is important in that individual accounts are being collected and different things will be salient to different people (Mason 2002). The participants in this kind of research are likely to have differing accounts of their journeys and the semi-structured design allows the researcher to probe further into areas of interest. In simpler terms, it can also be argued that the interview method is the best way to generate the data as this kind of data is not available in other forms. For example, a survey method will not collect in-depth data regarding patient experiences (Mason 2002). It can also be argued that the interview approach gives the participants more control over the situation and that this will provide a ‘fairer and fuller representation’ of their perspectives (Mason 2002). It has also been suggested that this interactional approach to data collection can make the research more enjoyable for the participant as they have a more active role (Mason 2002).

Designing the topic guide

A qualitative interview can be described as a ‘conversation with a purpose’ meaning that, while the interaction is informal, it must still have some structure in order for it to generate meaningful data and not just simply be a social interaction (Ritchie and Lewis 2003). A well-prepared topic guide is essential in conducting an interview. The initial background reading and the two literature reviews generated a prior sense of themes to be explored during the interview and using these themes, a topic guide for the interviews in this study was created. The topic guide comprised open questions regarding the key themes and lists of probes to be used in case of closed answers. The topic guide was designed to be a flexible document, used to guide the interview but not necessarily be rigidly adhered to, if a participant had a particular area of interest that they wished to discuss then it was possible to deviate from the topic guide to some extent in order to explore those areas. However, if the participant had a tendency to veer off topic too much then the guide was used to bring the conversation back to the research topic, otherwise there may be potential to collect large amounts of data that are not useable. The topic guide evolved as the interviews progressed and participants brought up new themes that were important to explore with other participants. The topic guide in this study was created in a very simple form initially, with PPI input, and gradually evolved following the literature review stages and the early interviews. Topic guides for the interviews are presented in the appendices to the thesis (see appendix 4).

Setting

Interview participants were given a choice of location for their interview, at their own home, or in the hospital where they were being treated. All interviews were carried out at a time of the participant’s choosing. Participants were not specifically invited to have other people present during the interview but those who expressed a wish to do so were allowed; this is discussed in more detail further on in this chapter.

In the participant’s home

The option to be interviewed at home can be beneficial for the participants as it not only minimises their inconvenience in terms of travel and timing, but may also be helpful in this instance as some people may wish to participate but be unable to travel due to ill health (Sivell et al 2015). Previous work has found that people with poor health often request to be interviewed at home (Sivell et al 2015). In a recent qualitative study of lung cancer patients, the majority chose to be interviewed at home (Birt et al 2015). Qualitative research is reliant on the building of rapport between researcher and participant and interview location can facilitate this process (Sivell et al 2015). The nature of the research permits dialogue to be patient-led and a home environment can facilitate this by allowing the participant to feel more at ease and in control of the situation than they perhaps would in a more unfamiliar setting (Sivell et al 2015). The home setting can also help the researcher feel a connection with the participant, which is important for quality data collection (Sivell et al 2015). It was also felt that the home setting would be beneficial in that a person may be more likely to recant a more descriptive account of their journey including the social elements whereas, in a clinical setting, they may be more likely to focus on the medical aspects such as treatment.

The majority of participants in this study, 21 in total, chose to be interviewed at home. In general, it was preferable to interview people at home, as they tended to appear more at ease and in control of the situation. Home visits were also easier to arrange as people tended to know what times they would be in, rather than having to rely on timings of clinical appointments. There were only two occasions on which a participant was unavailable when the researcher arrived at their home; one patient’s husband answered the door and said she was too unwell to take part, an attempt to contact her was made a few days later but was unsuccessful. On the second occasion the participant (Ivor) was not at home when the researcher arrived, however he was contacted on his mobile phone and came home for the interview. The quality of the recordings was also better in the home settings, which were generally quiet and free of distractions and interruptions although there were some exceptions.

In the hospital

Eight of the study participants requested to be interviewed in the hospital. This was generally due to wanting to coordinate the interview with their hospital appointments so that they could do both in one day. It was also common among these participants to want to do the interview whilst they were having their chemotherapy, reporting that they were bored during the treatment and it would give them ‘something to do’. One participant (Denise) said that she would prefer for her interview to take place in the hospital, as she was shy about having people she did not know come to her home.

Approaching the interview

On arrival, the researcher would introduce themselves to the participant. In the home setting this would generally happen at the door or inside; in the hospital the nurse would introduce the patient. This led in to a rapport-building phase, which tended to involve some general discussion about how the participant was feeling that day, the weather, travel and various other topics. Often in a participant’s home, the researcher would be offered a cup of tea which was always accepted if offered in order to be polite. While it may seem rather simple, rapport building is crucial in qualitative research as it fosters a good relationship between participant and researcher and can lead to more in-depth data collection. In order to begin the interview there was an initial discussion following the topic guide, outlining what the interview would involve, confidentiality was explained, consent was taken and the participants were reminded that if they wished to stop at any point they were free to do so.

Each interview was opened in the same way; the participant was asked to say a little bit about themselves such as what they do/did for work and about their family or who they live with. This worked well in most instances, participants were happy to talk about their family life, particularly those with children or grandchildren, and most gave details about their current or former occupation. Following this, the participant was asked about the nature and duration of their symptoms and when they were first noticed. Participants were asked about their experiences with healthcare, particularly primary care, and other influences on their health decision-making such as family and friends.

The interviews tended to come to a natural conclusion as all the relevant areas were covered, although a final question regarding advice for others in the same situation gave a nice, rounded ending. Often, the interview would turn into a conversation about research in general or what would be done with the findings, at which point the recording would be stopped. The majority of the interviews lasted between 30 minutes and an hour, although some were much longer and others considerably shorter, depending on the participant and the setting. Actual length of interviews is reported in table 6 (participant characteristics).

Challenges

There were several challenges to be overcome during the interviews. One of the main challenges was the difficulty in bringing up the topic of smoking if the participant did not bring it up themselves. Having lung cancer, the participants were likely to have a history of smoking although this was not known at first and was not one of the inclusion criteria for taking part. The mention of smoking had been deliberately excluded from recruitment materials due to ethical reasons, as it may inspire feelings of blame and also mislead the participant into thinking the interview was solely about smoking. This led to the difficulty of broaching the subject of smoking. Generally the participants brought it up themselves which made it possible to discuss and ask further questions. However, when they did not, it was up to the researcher to find an appropriate moment to mention smoking. At the appropriate moment, the researcher would raise the topic of smoking by explaining that in other interviews, other participants had had concerns or received advice regarding smoking, this provided a good way of raising the topic without directly asking the participant if they smoked.

A further challenge was keeping the interview on topic whilst also maintaining the semi-structured design. Some participants tended to have issues which they wished to discuss which were not necessarily relevant to the research questions. One participant (Sue) had many problems unrelated to her lung cancer diagnosis, such as a dispute with a neighbour, which she was keen to discuss but which were not pertinent to the research. Another participant (Mariel) consistently changed the subject during the interview, asking questions about the researcher, and discussing social events, which again were not pertinent to the research. The challenge here lay in allowing the person to discuss the issues that they felt to be important, but also bring the conversation back to topic to fulfil research objectives.

As mentioned before, home interviews were generally quiet and free from distraction, however there were exceptions. During one interview, the participant (Mariel) stopped to take a phone call that was followed soon after by a visit from a family member. Interviews that took place in the hospital setting were far more challenging as they were often interrupted. On three occasions the hospital staff were able to provide a private room for the interview to be conducted in which was easier due to the relative quiet, although on two occasions the interviews were interrupted by staff checking to see who was using the room and how long it would take. The other five hospital-based interviews took place on the wards whilst the patients were having chemotherapy. This was the most methodologically challenging as interruptions were frequent, often from nursing staff checking on patients and adjusting medication; on one occasion a consultant arrived to talk to the participant (Denise) and so the interview was paused. Pausing the interviews in this way was not ideal, as it tended to disrupt the flow and make it difficult to resume.

Interviews in the hospital setting, particularly on the wards, were heavily affected by noise. The sound of other people talking, the machines, and on one occasion the television, were a factor in recording and transcribing the interviews. It was also an ethical concern that other people were present on the ward and efforts had to be made to keep the discussion quiet enough so that the interview could not be overheard due to confidentiality and so as not to disturb other patients.

The presence of partners during interviews was occasionally a challenge but also could be beneficial in some cases. Often, in the home setting, a partner was in the house but did not stay in the room during the interview. In some cases a partner was present in the room but did not contribute or contributed very little, for example during the interview with one male participant (Christopher). His wife was in the room but only spoke to confirm things when he asked her too. In a few interviews, the partner was an active participant in the interview which was helpful in some cases, particularly if the respondent gave closed answers. One participant (Sion) gave very short answers and his wife filled in the further information. However, it is not possible to tell if he would have been more responsive had she not been there.

As mentioned previously, only one interview did not go ahead when the researcher arrived at a participant's home. However, non-attendance was a feature of hospital-based interviews for several reasons. Firstly, as interviews were usually arranged to take place during treatment or following appointments, the patient would often be at the hospital early in the morning making it difficult to call beforehand and confirm the interview was taking place. Secondly, when interviews were scheduled to follow appointments with consultants, they were sometimes seen earlier or later than the original appointment time, meaning they missed the interview or did not want to wait around for a long time. A further challenge came in locating patients who were not in the chemotherapy wards, if a patient was having radiotherapy or a consultation with the doctor, and then it was necessary to meet them in the foyer or waiting room, meaning that there was a higher chance of missing each other.

Conducting the focus groups

Rationale for use

Focus groups were selected as the most suitable method for the second phase of the data collection period. The focus group is designed to facilitate and provoke discussion and interaction amongst people with a similar degree of connection to the research topic, in this case, current smokers registered in primary care (Ritchie and Lewis 2003). The group is 'focussed' in that it revolves around a shared interaction and in this way they differ from interviews which are centred upon the individual (Kitzinger 1995). Focus groups are ‘synergistic’ because the group works together to generate the data (Ritchie and Lewis 2003). Focus groups work on the principle that, in the appropriate situation, the whole is greater than the sum of their parts and group-generated data is valuable to the research in question. As the focus group participants did not have lung cancer, the topic of smoking was likely to be less sensitive and so it was felt that a group discussion would be beneficial in that it would be possible to see if those in similar circumstances would share similar views and experiences. The group ought to be used in a way that encourages all participants to engage with one another (Kitzinger 1995). The focus groups were run by the author with a member of the supervisory team acting as a secondary moderator. This is usual practice during a focus group as the presence of two researchers make it less likely that things will be missed such as when people talk at the same time. The second moderator was also able to deal with any practical issues, such as providing more refreshments, or disruption, such as late comers.

Designing the topic guide

A topic guide was also designed for the focus groups using the same process as for the interviews. The topic guide for the focus groups is presented in the appendices to the thesis (see appendix 4).

Setting

All three focus groups took place in a meeting room at the Bangor University campus in Wrexham.

Whilst the room used is an appropriately neutral setting for the focus groups, it was felt that it was important to ensure that the room felt comfortable and not too business like. Seating is arranged in a circle around one central table and no Power Point slides or other materials were used. It is important to remember that not all participants will have experience of office style environments and so may not feel comfortable. Refreshments were provided and the consent taking did not take place until everyone had arrived and been given a cup of tea, so as to make people feel at ease and not under too much pressure

As the building can be difficult to find, the supervisor waited outside the front door to show people where to go.

Focus group composition

For the focus group method to work in the best way, careful thought was given to the composition of the group in order to facilitate good data collection. Focus group composition was carefully selected, and not random. Whilst some diversity within the group aids discussion, too much can inhibit it (Ritchie and Lewis 2003). When discussing sensitive topics, it leaves less space for diversity as people feel safer among people similar to themselves (Ritchie and Lewis 2003). Whilst it was never expected that a hugely diverse sample would be recruited, the practices recruited from were in different socioeconomic areas (calculated using the Welsh Index of Multiple Deprivation https://statswales.gov.wales) and it was intended to use age, gender, ethnicity and location of practice to determine the composition of the focus groups. Unfortunately, due to low recruitment figures, this was not possible and therefore the principle criteria used for the focus group composition was gender. Due to the likelihood that people will talk more when in peer groups it was decided to split the groups as such. As previously mentioned an unforeseen element of the focus group recruitment was that six of the respondents were living together and wished to take part together. As focus groups aim to group participants with others with whom they have something in common it was decided that the ideal situation would be to keep the three couples together, which is why the focus group participants were split into the three groups of men, women, and couples (Richie and Lewis 2003)

Approaching the focus groups

Each focus group began in the same way. When participants arrived, they were shown to the meeting room, and offered refreshments. When everyone had arrived, written consent was taken and they were asked to fill out a short demographics form. Before beginning the discussion, confidentially was explained and participants were assured that their information would be kept confidential by the researcher. They were also asked to respect the confidentiality of their fellow participants. Permission was sought to record the discussion in the groups and there were no objections.

To begin, the lead researcher asked the group to introduce themselves in turn with their first name and something about themselves, such as what they did for a living or something about their family. The researchers also did the same. This was done for similar purposes as the rapport-building phase of the interviews. It is harder to gain rapport in a group situation and so this initial introduction was used to get the focus group off to a positive start and to create a friendly atmosphere and gain some knowledge useful to the discussion.

The first two focus groups began with the researcher asking about use of primary care in general and how often participants visited their GP. The third focus group, the couples, began slightly differently as a participant asked for clarification on the research topic that then led into the discussion.

The first two groups both lasted approximately an hour and 20 minutes and the third lasted for one hour and 50 minutes. Including time before and after the groups began, participants were at the research centre for approximately two hours.

Challenges

The focus groups were faced with some practical challenges regarding transport and directions to the venue. The research centre is difficult to locate due to all the buildings within the large technology park all having the same post code. Participants were offered transport via taxi to the centre if necessary, however a participant for the first focus group was unable to attend as the taxi driver was unable to find the correct building. Another participant for the second focus group also had difficulty finding the building, and although he did manage to find it eventually, he was half an hour late and he had to join in after discussion had started. All participants were sent, either by post or by email, a map and a set of directions to the building in an effort to make sure no one got lost.

There were some issues with non-attendance. The first focus group had five confirmed participants, however, one called the night before to say she was unable to attend and another did not arrive due to being unable to locate the venue. The second focus group had six confirmed members but on the day one failed to arrive. The third focus group, comprising three married couples, had the best attendance with all confirmed participants attending.

During a focus group, the researcher has the task of managing the discussion as well as listening to the content. It is important to ensure that everyone gets a chance to speak and no one is ignored. The first focus group comprised three female participants and it worked well in that they took turns to speak and the group was easy to manage. The second focus group was far more challenging, there were five male participants, and one in particular (Barry) had a tendency to dominate the discussion and talk over the other members. It was challenging to try to move the focus away from Barry and give more attention to the others, particularly more softly spoken members of the group such as Len. At some points, Barry seemed to actively dislike another participant (Harvey) and was visibly dismissive of his opinions. This gave certain points during the group a somewhat negative atmosphere that the researchers had to try and resolve. Barry had disclosed to the researcher prior to the group starting that he had a personality disorder which may account for his dominant nature and required researchers to manage his dominance in a sensitive manner. At one point when Barry began to monopolise discussion or interrupt other group members, researchers tried to deflect away from him and back to others gently by thanking Barry and explaining that we would come back to his point at a later moment. After moving attention away from Barry, another member of the group would be encouraged to speak instead. Whilst Barry was rather dominant and this did create a challenging atmosphere at times, the data obtained during focus group three was rich and made a significant contribution to the study findings. However, it is also important to consider how and whether the other members of the group may have contributed differently had those challenges not been present. In the third focus group there was one participant (Phyllis) who did not speak very much at all, however she did disclose that she had memory problems after suffering a brain haemorrhage and so her lack of participation was likely due to this and not the other members of the group.

Several of the focus group participants disclosed that they had other health problems for which they saw their GP. Some of these were smoking-related problems such as COPD, however they also included brain injury and mobility problems. Some participants in focus group two also disclosed that they had substance abuse problems and mental health issues. This was challenging in the sense that the disclosure was not strictly necessary and had the potential to cause discomfort for themselves or other members of the group. However, it is possible that in mentioning substance problems, such as Dean talking of his alcohol-related illnesses, discomfort was avoided in that other participants did not make negative comments about people with alcohol-related health issues because they were aware of his situation. In the other two focus groups, nobody disclosed any alcohol-related problems and in both groups ‘people who drink’ were named as being as worthy of perceived stigma as a smoker, and perhaps in this way Dean acted in self-preservation rather than out of a sense of over familiarity.

Another challenge of the focus groups was staying on topic; this was in fact a much bigger challenge during the focus groups than it had been in the interviews. The group discussions had a tendency to move off topic, particularly if one member had an issue they were passionate about and the whole group then began to discuss it. A dissatisfaction with primary care in general was evident in some participants and this would steer the discussion towards issues such as GP waiting times. Whilst interesting, this did not fulfil the research objectives and so the researcher would use the topic guide or refer to a previous point to bring the discussion back on track.

Analysis

Thematic analysis

Introduction

The data collected in this study was analysed using thematic analysis. Thematic analysis is a widely used method in qualitative research, however it is often criticised or under-estimated due to a perception that it is more simplistic and less interpretive than other methods such as phenomenology or grounded theory (Sandelowski 2010). In this thesis, it is argued that thematic analysis, when performed rigorously, is a robust method in qualitative research and the most appropriate choice for this study.

This section of the chapter will define the features of a good thematic analysis, discuss the criticisms, defend the approach and present a justification for employing thematic analysis in this thesis. This section will place particular emphasis on what happens when a thematic analysis is done well and will argue that the strength of a thematic analysis lies in its rigour. Finally, this section will give a detailed account of the thematic analysis process used in this study.

Defining a good thematic analysis

A thematic analysis is a process by which the researcher encodes their qualitative data (Boyatzis 1998). This process is done by looking for themes within the data and coding sections of transcripts according to those themes (Boyatzis 1998). A thematic analysis can be conducted at a basic level whereby the data is organised thematically and the themes are simply described or it can be performed at a much higher level that involves in-depth interpretation of those themes (Boyatzis 1998). In this PhD a good thematic analysis aimed to ‘unearth the themes salient in a text at different levels’ and was carried out rigorously and carefully in order to reach the higher levels of interpretation (Attride-Stirling 2001; Ratcliff 2008). Words were analysed in phrases or sentences and, at times, examined one at a time in order to gain an in-depth understanding (Ratcliff 2008).

A good thematic analysis should also highlight meaning within the data (Joffe 2012). This illustrates its suitability in this study as the interpretive approach is concerned with meaning and making sense of data (Blaikie 2000). In qualitative data themes can be explicit; in this study for example, a participant could explicitly state that they feel stigmatised by their GP, or they can be more implicit, implying feelings of stigma through their accounts of avoiding the GP (Joffe 2012). A properly carried out thematic analysis will highlight both explicit and implicit themes and it is the job of the researcher to operate in-depth in order to discover those themes that are more implicit and reach their meaning. The researcher must also understand the difference between a theme and a topic in order to create findings that are accessible, and statements made must 'represent the researchers' thematic syntheses, or coherent integrations of the disparate pieces of data that constitute the findings' (Sandelowski and Leeman 2012). Thematic analysis takes the pre-existing themes from previous work into account in order to avoid 'reinventing the wheel' but also remains open to the new concepts which come from new data. In this way the researcher can see any findings which do not match and seek to understand why that may be (Joffe 2012). It is important to bear in mind that findings may differ between study populations. In the case of this study, the findings may differ between the population of current smokers and lung cancer patients in North Wales, as well as previously studied groups in other locations, and a good thematic analysis will take this in to account.

A thematic analysis involves systematic searching of the data set, usually interview and focus group transcripts, 'to find repeated patterns on meaning' (Braun and Clarke 2006). Whilst a thematic analysis does follow a process of predefined phases, it is not a straightforward linear process and a well-conducted thematic analysis will not simply move from phase to phase (Braun and Clarke 2006). Rather, as explained by Braun and Clarke (2006) the process is recursive and 'movement is back and forth as needed through the phases'. Finally, it can be argued that the strength of a thematic analysis is defined by the rigour with which it was approached; this is described in further detail in the 'defence of thematic analyses below (Joffe 2012; Silverman 2005). Therefore, a good thematic analysis is a careful, deliberate and interpretive process that produces a rich and detailed account.

Justification for use in this study

Thematic analysis is particularly useful when analysing large and varied data sets, such as in this study which encompassed both interview and focus group data and produced a large volume of transcribed material (Nowell et al 2017). Thematic analysis ‘involves the search for and identification of common threads that extend across an entire interview or sets of interviews’ and can be used to produce a rich account of the entire data set so that codes and themes reflect the entirety of the data (Vaismoradi et al 2013; DeSantis and Noel Ugarriza 2000; Braun and Clarke 2006). The ability to be applied across entire data sets made thematic analysis particularly apt for this study as all of the data, interviews and focus groups were always intended to be analysed as a whole in order to provide a rich account of the views of both study populations and allow for comparisons and exploration of shared or differing themes. It was anticipated that divergence between the interview participants and focus group participants could potentially occur and this was another reason for the thematic analysis to be done with both data sets together. Divergence between data sets was noted during the analysis and potential reasons for it are discussed in the findings chapter.

An advantage of thematic analysis is that it is not bound by a specific theory and so is much more flexible and can be adapted to suit the needs of individual studies whilst giving a rich and detailed interpretation of the data (Nowell et al 2017; Braun and Clarke 2006; King 2004). This study favoured a flexible approach to analysis in order to have the freedom to collect data until the point of saturation and to carry out the analysis in a way best suited to the data generated. This study also employed two data collection phases, interviews and focus groups, and so a flexible approach was even more desirable. Thematic analysis also offers an accessible approach, which can easily be made sense of by readers (Braun and Clarke 2006). Whilst this thesis is intended primarily for an audience interested in qualitative health research, it is important that research findings are accessible to wider audiences from different backgrounds and disciplines.

Thematic analysis is an ideal method for examining the accounts of a varied sample of participants, comparing the differences and similarities within these accounts and generating new knowledge from them (Nowell et al 2017; Braun and Clarke 2006; King 2004). Thematic analysis is also suitable for this study as the inclusion criteria for participants allowed for a variation within the sample of sociodemographic characteristics.

It has been argued that thematic analysis is best used in research that aims to discover the real motives behind the actions of a population being studied (Vaismoradi et al 2013; Ten Have 2004). It has also been stated, as previously discussed, that in a good thematic analysis the researcher also seeks meaning from the data (Joffe 2012). Thematic analysis is ‘best suited to elucidating the specific nature of a given group's conceptualisation of the phenomenon under study' (Joffe 2012). Therefore, a thematic analysis is well-suited for an interpretive study, which seeks to understand the meaning ascribed to a phenomenon by a certain population; in this case the phenomenon of interest is experiences and perceptions regarding primary care and the study population is current smokers and those with lung cancer.

The critique of thematic analysis

As already mentioned, the most common critique of thematic analysis is that, when compared with other methodologies such as phenomenology or grounded theory, it stands out as being more simplistic and less interpretive (Sandelowski 2010). There is potential for a thematic analysis to actually fail to analyse the data at all and to merely produce a descriptive narrative of participant accounts with little or no interpretation (Braun and Clarke 2006). Another potential pitfall of thematic analysis is to use the questions from the topic guide as the themes, meaning that again, no actual analysis has been conducted and the researcher is simply dividing the data and reporting what was said in answer to each question (Braun and Clarke 2006). A thematic analysis has the potential to be weak and unconvincing when themes are inconsistent, not grounded in the source data or present a total mismatch with the research objectives (Braun and Clarke 2006). Finally, it seems as though thematic analysis generally has a poor reputation as it is not as well-defined as a named or 'branded' method such as grounded theory and is often used as an umbrella term for badly carried out and weak analysis in studies with poorly reported methodology (Sandelowski and Leeman 2012; Braun and Clark 2006). However, this thesis argues that there is a strong and clear defence for thematic analysis

In defence of thematic analysis

This section will argue in defence of thematic analysis in response to the critique given above. Firstly, it is important to note that all qualitative analysis is essentially thematic (Sandelowski and Leeman 2012). Therefore, thematic analysis should be seen as a foundational method of analysis in qualitative research (Braun and Clarke 2006). As previously mentioned, to be of a high quality, a thematic analysis depends upon the rigour of the research as a whole and this section will also discuss the ways in which that can be ensured (Joffe 2012; Silverman 2005).

Good quality qualitative research must be conducted in a 'rigorous and methodical manner to yield meaningful and useful results' (Nowell et al 2017; Attride-Stirling 2001). It has been argued there is a lack of material designed to guide researchers through a good thematic analysis and that the emphasis tends to be on other methods such as grounded theory or phenomenology (Nowell et al 2017). This lack of guidance may encourage researchers to choose more well-documented methods but they may also be discouraged from using thematic analysis due to a wish to avoid criticism. This thesis would join the argument that believes that thematic analysis deserves recognition as a method in its own right and that the key is rigour and transparency of method (Nowell at al 2017; Braun and Clarke 2006; Joffe 2012).

Authors in favour of thematic analysis have also argued that many qualitative studies say that they have used the more ‘branded’ methods but have not necessarily carried them out correctly, therefore it is preferable to conduct a thorough thematic analysis and be honest about doing so (Nowell et al 2017; Braun and Clarke 2006). Methods such as grounded theory need to be carried out according to their theoretical principles and often researchers will use such approaches without doing a full grounded theory analysis (Braun and Clarke 2006; Holloway and Todres 2003). Perhaps due to a feeling that these methods hold more weight, researchers may label their work as having used such methods whilst actually not being honest about the rigidity with which they follow the theories.

As discussed previously, a key criticism of thematic analysis is that it may be less interpretive than other more theoretical approaches (Sandelowski 2010). However, it also true that poor research often uses thematic analysis as an umbrella term for basic analysis, which is merely descriptive and does not go much beyond the surface of the data. This thesis argues that if the research as a whole is carried out in a rigorous and thorough fashion and enough time and care goes into the analysis, the interpretation should be in-depth, rich and detailed. A high quality analysis depends on the gathering of high quality data and therefore each phase of the research depends on the other phases being of good quality. A thematic analysis done well is one in which the findings, combined with the literature, construct a story that ‘stands with merit’ (Vaismoradi et al 2013; Aronson 1994). This thesis presents a good quality thematic analysis and argues that, whilst a poor thematic analysis may be insufficient, a good one is a robust way in which to analyse and interpret qualitative data.

In this thesis it is argued that in order to use the aforementioned ‘branded’ methods one must be true to them and be bound by their underlying principles; as this research required a more flexible approach, it was therefore more appropriate to carry out a rigorous thematic analysis and be systematic and transparent about doing so (Joffe 2012).

Rigour in qualitative research

Qualitative research can be ‘vulnerable to charges of irrelevance’ due to what Sandelowski (1997) has described as ‘misconceptions about the generalisability and trustworthiness’ of qualitative research and due to the perception that it is less scientific than quantitative work. Whilst this is certainly debateable, it is true that rigour in qualitative research is the way in which the researcher is able to demonstrate integrity and competency (Tobin and Begley 2004; Aroni et al 1999). As previously discussed, rigour is essential for demonstrating a sound thematic analysis and therefore needed to be a prime focus in this study. If rigour is not demonstrated then there is potential for the research to be seen as unbelievable (Tobin and Begley 2004; Morse et al 2002). In other words, if not rigorously conducted and reported as such, there is potential for qualitative work to be criticised as being unfounded. It can also be said that in qualitative research, the standard for rigour and quality is also the standard for ethics, meaning that it is ethical to conduct proper, rigorous research otherwise it can be argued that the researcher has failed their participants by not conducting a credible study (Lincoln 1995). In qualitative research both the researcher and the participants coproduce the data and it is vital to ensure that the study as a whole recognises this coproduction and does it justice through rigorous methods (Koch 1993).

In social research, rigour is traditionally measured using concepts of reliability, validity, and generalisability (Golafshani 2003). Reliability refers to whether or not the results of the research are truly representative of the population they claim to be, embedded within this are also ideas of replicability and repeatability (Golafshani 2003; Joppe 2000). Essentially research is deemed ‘reliable’ if it yields the same results when it is repeated. Validity refers to the ‘truthfulness’ of research results and whether or not the measures accurately measure what they were intended to (Golafshani 2003; Joppe 2000). Generalisability refers to the results of the study being applicable to different research populations (Blaikie 2000). However, these concepts are rooted in quantitative research and the positivist tradition and therefore it has been argued that they are not wholly suited to qualitative research, and therefore this study, due to it being qualitative and following the interpretivist approach (Davies and Dodd 2002).

Lincoln and Guba (1985) suggest that rigour in qualitative data is better thought of in terms of ‘trustworthiness’ which in qualitative research can be used in place of reliability and validity. Further to this, it has been asserted that trustworthiness is indeed grounded within the traditional concepts of reliability and validity (Cypress 2017; Seale 1999). Lincoln and Guba (1985) have argued that the trustworthiness of qualitative research can be assessed by the following criteria; Credibility refers to the reader being able to understand the views of the respondents and the way that the researcher has represented them and transferability refers to generalisability but not in the same way as in quantitative research, rather it means the ability of other researchers being able to transfer the findings to other sites in order to judge generalisation (Lincoln and Guba 1985). Dependability refers to well-documented methods that could be replicated if required (Lincoln and Guba 1985). Confirmability means that the interpretations reached are truly grounded within the raw data (Lincoln and Guba 1985). Reflexivity and a clear audit trail showing clearly how each decision was made are also essential in ensuring rigour in qualitative research (Lincoln and Guba 1985).

This thesis makes the argument that the idea of trustworthiness, measured via these criteria, is a more suitable method for assessing the rigour with which this study was carried out. This thesis would argue that the research is credible and that readers would be able to understand the views of the respondents and the way they are represented (Lincoln and Guba 1985; Cypress 2017). Qualitative research is not generalisable in the same way that quantitative research is, however, this thesis can be described as transferable as it may be possible to transfer the findings to other sites, such as other hospitals and primary care regions in the UK, in order to assess generalisability (Lincoln and Guba 1985; Blaikie 2000). The methods of this study have been well documented and could be replicated and repeated by another researcher and therefore are dependable (Lincoln and Guba 1985). The interpretations reached in thesis are grounded within the data collected and this can be seen through the use of direct quotations in the results chapter of the thesis (Lincoln and Guba 1985). The use of quotations demonstrates the presence of both credibility and confirmability in this study (Lincoln and Guba 1985). The participants’ reflections are given in their own words, which allows to the reader to understand their views (Fereday and Muir-Cochrane 2006; Patton 2002). Quotations also strengthen interpretive rigour and therefore confirmability and they clearly show the link between the raw data and the interpretation (Fereday and Muir-Cochrane 2006; Rice and Ezzy 1999). During the analysis stage of the study, regular interpretive meetings were held between the members of the research team to discuss the data and the interpretations reached. Finally, a clear and reflexive audit trail is present in the research and takes the form of reflexive memos, post-interview and focus group notes and decision-making notes made during meetings (Lincoln and Guba 1985). Transparency and reflexivity on the part of the researcher also serve to minimise bias in qualitative research (Tong et al 2007).

This study was designed and conducted in such a way that the standards for rigour were met and this is reflected in the transparency of the methods in this chapter and the standard of the results in the subsequent chapter of the thesis.

Format of the data

The data generated came in the format of typed transcripts. These were transcribed verbatim from the recordings of the interviews and focus groups.

Using Nvivo

As qualitative research often generates large quantities of data, it is necessary to have a comprehensive system of storing and managing that data (Bazeley 2007). During this study, large amount amounts of data were collected in the form of interview and focus group transcripts. Data were stored and managed electronically using Nvivo 11, a software package designed specifically for this purpose (QSR international). The software provided support for the researcher when doing the analysis by neatly storing all data in one place and allowing easy access to all parts of it and avoiding the confusion that may result from large volumes of hardcopy analysis (Bazeley 2007; Bassett 2004). It is important to state that the software does not perform the analysis; it simply facilitates the researcher in doing so (Bazeley 2007). As well as storing the data, use of this software also allows for the electronic coding of the transcripts and the management of ideas as it is possible to add annotations and memos to the transcripts during the coding process (Bazeley 2007). Following each interview and focus group, transcripts were uploaded into Nvivo and post-interview thought memos were written and then electronically linked to the transcripts so that they could always be easily referred back to at each stage of analysis. The use of the software makes the sorting, matching and comparing of data far more efficient than non-computerised methods and makes it possible to easily run queries within the data set (Bazeley 2007; Richards 2002). Data queries such as text searches and word frequency searches can be particularly useful when comparing themes between participants (Bazeley 2007). Text searches were often used in this study to look for certain words, which could indicate the presence or prevalence of certain themes or ideas.

The Nvivo 11 software can save the results of the queries and has the ability to make graphic models from the data so that relationships can be displayed in the form of word trees, graphs, and word clouds (Bazeley 2007). This rigorous management of the data assisted the analysis in ensuring an easily accessible data set for the interpretation (Bazeley 2007; St John and Johnson 2000).

The stages of thematic analysis

Familiarisation/ immersion

The first stage of analysis is familiarisation with the data. The researcher must do this by re-reading all the transcripts and re-examining any field notes (May 2001). For this study all interview transcripts were thoroughly read through. Although all interviews were conducted by the same researcher, time had passed between them and therefore a strong familiarisation was needed in order to refresh the memory. As the interviews and focus groups were recorded in this study, field notes were limited. However, there were some brief notes and event maps made during focus groups and post-interview memos made after each interview, all of which were revisited during the familiarisation.

Coding

The secondary stage of the analysis was the coding of the data. During the coding process a set of key themes or categories were generated to form a coding structure and then the data were coded according to that structure (Marshall and Rossman 2006). These themes were drawn from the data during the familiarisation stage as well as various sources such as previous conceptual thinking and from the literature (Blaikie 2000). The themes which made up the coding structure for this study were created from familiarisation with the transcripts which allowed themes to emerge from the data whilst also considering initial background reading used to develop the research questions, and the literature included in the systematic and narrative reviews. Once the categories or themes were assembled into the coding structure, the codes were then applied to the data. It may be important to note that not all themes included in the coding framework appear within the study findings, this is due to such a large volume of data being generated and the need to synthesise findings. The coding framework is available in appendix 5.

In a qualitative study, similar replies from participants are organised under the same themes (May 2001). As qualitative data is in the form of text, the codes were applied directly to the documents; this can be done using colour codes or numbering on hard copy documents or via computer software. This study used the Nvivo 11 software, as previously discussed, to code the data although hard copy transcripts were also used throughout analysis. Colour coding is a useful tool in coding the data and this was available within the software. Marshall and Rossman (2006) also emphasise the importance of writing notes and memos alongside the coding process in order to keep track of changes to the codes and any emergent thoughts or ideas regarding the data. In this study, notes and memos were created within the software and any brief notes made during the interviews were also added to the data within the software in order to keep as much data as possible and to keep it all in one place. It is important to keep in mind that the coding structure is an evolving document. As the data are coded it is likely that changes to the structure will occur as new understandings begin to emerge (Marshall and Rossman 2006). It is also important to make the point that often in qualitative research, literature refers to the themes and codes as having 'emerged' from the data. Whilst this terminology is common and useful, it also has the potential to play down the active role the researcher takes in this process (Rubin and Rubin 1995). Therefore, it is important to stress that themes do not simply appear from the data; rather the researcher plays an active role in discovering them and creating links between them (Rubin and Rubin 1995; Ely et al 1997). Marshall and Rossman (2006) state that the researcher ought to anticipate these coding structure changes and plan how to make alterations to the coding structure. The coding of data under these themes allows the researcher to make comparisons between participants and look for patterns within the data (May 2001). In this study, an initial draft coding structure was created using the themes emerging from the data and drawn out of the literature reviews; this structure was then tested on various sections of transcripts to test its suitability. The structure was then adapted in order to better suit the data and stay true to the views of the participants. In many qualitative studies, the data will be double coded, meaning that a second researcher will also code the transcripts in order to check reliability of themes. Double coding was not used in this study as it was an independent PhD study, however several interpretation meetings were held between the researcher and supervisory team during which sections of transcripts were reviewed independently and then the themes were discussed as a group. Simple coding using broad categories can be used to reduce data if a basic level of analysis is all that is needed (Blaikie 2000). However, in this study, a deep level of analysis was required in order to reach the desired level of understanding and thus, coding was used as part of a deeper analytical process. Coding in this way helped to 'expand, transform, and reconceptualise data, opening up more diverse analytical possibilities' (Blaikie 2000).

Therefore, in this study coding was used to engage with the data in -depth and as an opportunity to begin to consider the themes in more detail. Coding both reduces and complicates, as it breaks down the data into more manageable chunks but also begins the process of expanding on that data and the drawing out of ideas (Blaikie 2000). It is important to always recognise that coding is not a simple practice; it must be undertaken with great care and rigour as it makes up the building blocks for the rest of the analysis (Blaikie 2000). The coding structure is included in the thesis appendices (see appendix 5).

Interpretation

This stage of the analysis makes sense of the data collected through what can be called 'the art of interpretation' (Denzin and Lincoln 1998). To begin this process the first step was to move through the coded data, in this case the transcripts, and make decisions about what would be included in the writing of the thesis and the way in which it would be represented (Denzin and Lincoln 1998). This stage drew upon all the work completed during the coding phase, including all the written memos, annotations and graphics to explore relationships between themes and emergent theories (Denzin and Lincoln 1998). During the interpretation, further notes and observations were made alongside engagement in a level of critical thinking about the data (Denzin and Lincoln 1998). In this study, notes were continually made and added to Nvivo and memos were created that were linked to different areas of the data set. Alongside this, a physical hardcopy 'thought board' was created using a flipchart and post it notes which could be moved around to record thoughts and ideas in another format. The interpretation process refined the data and made sense of the participant's experiences (Denzin and Lincoln 1998). The interpretation stage was much more than a description of the data, and explored beyond the content and into the meaning in order to generate theories (Coffey and Atkinson 1996). The act of 'going beyond' in this study can be described in terms of 'abductive reasoning' (Coffey and Atkinson 1996). Abductive reasoning implies that the researcher begins by identifying a phenomenon and then tries to 'account for that phenomenon by relating it to broader concepts' (Coffey and Atkinson 1996). This is achieved by relating the phenomena in the collected data, for example patient intervals, to existing knowledge and the literature (Coffey and Atkinson 1996). Abductive reasoning is particularly suited to qualitative research as it advocates an open-minded approach (Coffey and Atkinson 1996). This stage of the interpretation was given ample time in order to allow for constant reweaving and refining of themes and ideas, which was key in this study as a rushed interpretation would run the risk of losing rigour and therefore giving a descriptive account rather than an in-depth interpretation.

Denzin and Lincoln (1998) describes interpretation in qualitative research as a form of storytelling; interpreters ‘as storytellers tell narrative tales with beginnings, middles and ends’. The interpretation brings themes, categories, notes and memos together into a storyline, and requires the construction of accounts from the data collected (Marshall and Rossman 2006; Coffey and Atkinson 1996). Whilst engaging in this storytelling process it is important to remain true to the participants and to pay close attention to the language they use (Coffey and Atkinson 1996). This study aimed to use the interpretation phase to tell the story of the participants themselves and to make sense of, and draw meaning from, their experiences. When spoken interaction occurs it is ‘constructed through a variety of rhetorical and semantic devices’ (Coffey and Atkinson 1996). Participants may use language in certain ways, especially when recounting past events; they may use language that justifies past actions, for example. In exploring language interpretively the researcher is able to go further beyond the descriptive (Coffey and Atkinson 1996). When participants give information they may draw upon metaphorical explanations which can be very insightful and useful in the interpretation of meaning (Coffey and Atkinson 1996).

The researcher can choose to read the data literally or interpretively (Mason 2002). In choosing to read the data interpretively, the researchers see themselves as a part of that data (Mason 2002). The position of the researcher will have influence on how the data is interpreted (Fontana and Frey 1998). It is important that researchers acknowledge their own position within the data and are reflexive during the interpretation process (Fontana and Frey 1998). The position of the researcher will inevitably have an effect upon the narrative and a reflexive interpretation will give voice to that (Denzin and Lincoln 1998). In this study, memos were made after each interview and focus group to record personal reflections, which later facilitated the reflexive interpretation.

Conclusion

This chapter has given a detailed account of the design and methods behind this study and has illustrated the process by which the specific approaches were chosen and applied to the research. A qualitative, interpretive methodology was the ideal way in which to conduct this study and fulfil the research objectives. The interviews and focus groups were appropriate for gathering a rich data set, which then allowed for a good quality thematic analysis. The following results chapter of the thesis will allow the reader to see the ways in which the chosen methodology, and the rigour with which it was used, gave way to strong and robust results.

Chapter 4: Study findings

Chapter summary

This chapter presents the findings of the thematic data analysis outlined in the previous methods chapter. The findings chapter begins with a brief reminder of the research questions in order to allow the reader to relate the findings back to the study objectives; this chapter contains the data collected to answer research questions two and three. The characteristics of participants are presented in tables 5 and 6. The findings in this chapter are presented thematically, beginning with a short summary and a table (table 7) of key themes, and are the product of a careful and rigorous process of thematic analysis. Interview and focus group data are presented together in order to fully demonstrate the complexity of the findings and to highlight the accounts of both populations, current smokers without cancer, and people with a new diagnosis of lung cancer. This chapter includes direct quotes from participants in order to show how the interpretation of each theme is grounded in the data. The findings chapter offers an in-depth insight and understanding of the decision-making process in participants who smoke and of the pathways to diagnosis in those with lung cancer, and concludes by summarising the data and leading in to the following discussion chapter.

Research questions

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals:
    a. For any symptoms of ill-health?
    b. For symptoms they perceive to be smoking-related?
    c. For chest or other symptoms they perceive to be indicative of lung cancer?
3. What are the factors associated with smoking that may lead to longer patient intervals (for example stigma, shame, guilt, blame, fear, nihilism, perceived health professionals' negative attitudes towards smokers and smoking, and previous consultation experiences) and how do they impact on smokers' health-related decisions and choices?
4. In what ways do the experiences of people newly diagnosed with cancer in Wales reflect delayed presentation in primary care due factors associated with smoking?

Introduction

This chapter will present the findings from the study in relation to the research objectives and in doing so will go ‘beyond the descriptive’ in order to present a deeper interpretation of those findings. This chapter will offer a more in-depth insight and understanding of the decision-making process in participants who smoke and of the pathways to diagnosis in those with lung cancer. The findings of this study are given here, beginning with the recognition and interpretation of symptoms by participants that were often perceived as minor or due to the presence of comorbidities. The findings then proceed to show how participants gradually accommodated symptoms and how many people changed their usual activities in order to allow for their loss of abilities or worsening health. This accommodation and lifestyle adjustment often continued until an alarm symptom was experienced or a crisis point was reached. There were also several perceived barriers to primary care, a major one being access to services. Many participants felt that it was so difficult to get an appointment with their GP that it was not really worth the effort unless they thought that things were serious. This also fed into a narrative of time, in that many people reported that one should not waste doctors’ valuable time with minor symptoms and that they tended to wait until they felt that an appointment was definitely warranted, often choosing to use over the counter remedies until that time was reached. Another major barrier reported by participants was stigma; they felt that smokers would be stigmatised by society in general and by healthcare professionals, especially if they suffered a smoking-related symptom. The data also showed certain ways in which primary care use was facilitated, principally in interactions with family and friends who encouraged them to consult healthcare professionals. This chapter will present the key findings of the study in relation to their use of primary care and their smoking status and symptom experience.

Participant characteristics

The characteristics of participants are shown in tables 5 and 6. There is some data missing from the tables as it was unavailable or unable to be collected. In the screening logs for interview participants, the date of birth was supposed to be recorded, however this information was often missing. This meant that unless participants stated in the interviews how old they were, their exact age was not recorded. Participants were not asked their age during interviews for methodological reasons as it can damage rapport building and create hostility.

Some participants did not specify smoking status during interviews and therefore this could not be accurately recorded in table 5. In focus groups and interviews those who described themselves as ex or former smokers did not always remember exactly how long they had given up for and therefore this could not accurately be recorded. Focus group participants were largely current smokers therefore data for the ‘time since cessation’ column in table 6 often reads N/A.

The occupation of interview participants was not always recorded due to some never stating what their employment history was. Focus group participants were asked to fill in demographics forms in order to capture some of the data which had been found to be missing in interviews, however many of them listed their occupation as ‘retired’ without specifying what they had previously been employed as. Specific employment details are not included in the sample tables in case they were to compromise anonymity.

During the second focus group one participant, Len, arrived late and so there is data missing for him due to his missing the introductions.

Table 5.

Participant characteristics

Interviews

Name	Age	Gender	Recruitment site	Location and length of interview	Household composition	Smoking status	Time since cessation	Occupation	Co-morbidity
Timothy	68	M	Hospital 2	Home (45 minutes)	Living with partner	Ex-smoker	9 years	Retired	Depression, COPD
Daryl	77	M	Hospital 2	Home (40 minutes)	Married – living with wife	Ex-smoker	25 years	Retired	COPD
Mariel	76	F	Hospital 1	Home (44 minutes)	Married – living with husband	Ex-smoker	30 years	Homemaker	N/A
Christopher	83	M	Hospital 2	Home (47 minutes)	Married – living with wife	Ex-smoker	40 years	Retired	N/A
Gayle	N/A	F	Hospital 1	Hospital 1 (32 minutes)	Married – living with husband	Current smoker	N/A	Retired	COPD
Ray	N/A	M	Hospital 2	Home (42 minutes)	Married – living with wife	Ex-smoker	Stopped on diagnosis	Retired	Sciatica
Alex	N/A	M	Hospital 2	Home (35 minutes)	Widower – living alone	Ex-smoker	20 years	Retired	Asthma
John	N/A	M	Hospital 1	Home (55 minutes)	Living with partner	Ex-smoker	N/A	Retired	Heart failure, Thrombosis
Ivor	83	M	Hospital 2	Home (40 minutes)	Married – living with wife	Ex-smoker	N/A	Retired	COPD
Hugh	80	M	Hospital 1	Home (43 minutes)	Married – living with wife	Current smoker	N/A	Retired	Bowel cancer
Earl	82	M	Hospital 2	Home (42 minutes)	Widower – living alone	Current smoker	N/A	Retired	Prostatitis, rhinitis,

									hiatus hernia, hyper-tension
Owen	65	M	Hospital 2	Hospital 2 (54 minutes)	Married – living with wife	Current smoker	N/A	Retired	N/A
Mark	N/A	M	Hospital 2	Home (39 minutes)	Married – living with wife	Ex-smoker	5 years	Working	Bladder cancer
Janine	N/A	F	Hospital 2	Home (70 minutes)	Living with partner	N/A	N/A	Working	Asthma
Denise	N/A	F	Hospital 2	Hospital 2 (43 minutes)	Living with partner	Ex-smoker	16 years	Working	N/A
Nick	N/A	M	Hospital 2	Home (37 minutes)	Married – living with wife	Current smoker	N/A	Retired due to injury	Spinal injury
Fred	71	M	Hospital 2	Hospital 2 (34 minutes)	Married – living with wife	Ex-smoker	18 months	Retired	Pleurisy
Ken	N/A	M	Hospital 1	Hospital 1 (39 minutes)	Married – living with wife	Ex-smoker	4 years	Working	Previous heart attack
Fiona	N/A	F	Hospital 2	Home (47 minutes)	Married – living with husband	Ex-smoker	10 years	N/A	COPD
Helen	N/A	F	Hospital 2	Home (N/A)	Married – living with husband	N/A	N/A	N/A	N/A
Gwen	70	F	Hospital 2	Home (37 minutes)	N/A	Never smoker	N/A	Working	Breast cancer
Sue	N/A	F	Hospital 1	Home (54 minutes)	Married – living with husband	N/A	N/A	Retired	Breast cancer
Betty	N/A	F	Hospital 1	Hospital 1 (37 minutes)	Married – living with husband	Ex-smoker	20 years	Retired	N/A

Rachel	N/A	F	Hospital 2	Home (41 minutes)	Married - living with husband	Ex-smoker	20 years	Working	N/A
Sion	N/A	M	Hospital 2	Home (28 minutes)	Married – living with wife	Ex-smoker	5 years	Retired	N/A
Jane	N/A	F	Hospital 2	Hospital 2 (39 minutes)	Living with partner	Ex-smoker	28 years	Retired	Bowel cancer
Lloyd	N/A	M	Hospital 2	Home (32 minutes)	Single (living in nursing home)	Ex-smoker	Stopped on diagnosis (5 months)	Not working	Asthma
Sidney	N/A	M	Hospital 2	Home (54 minutes)	Married – living with wife	N/A	N/A	Retired	N/A
Paul	61	M	Hospital 2	Hospital 2 (45 minutes)	Unknown	Ex-smoker	Stopped on diagnosis	Working	Type 2 diabetes

Table 6.

Participant characteristics

Focus groups

Name	Age	Gender	Recruitment site	Group attended	Marital/ living status	Smoking status	Time since cessation	Occupation	Comorbidity
Clare	67	F	GP 2	1	Widowed - Living alone	Current smoker	N/A	Retired	Enlarged heart Breast cancer COPD
Belinda	72	F	GP 2	1	Living alone	Current smoker	N/A	Retired	COPD
Trish	66	F	GP 2	1	Living alone	Current smoker	N/A	Retired	Pernicious anaemia
Len	56	M	GP 1	2	N/A	Ex-smoker	N/A	Not working (disabled)	Brain injury
Dean	67	M	GP 2	2	Living alone but in relationship	Ex-smoker	N/A	Retired due to illness	COPD Blood clots (smoking related) Partial bowel removal
Benjamin	N/A	M	GP 1	2	Married – living with wife	Current smoker	N/A	Retired	N/A
Harvey	71	M	GP 2	2	N/A	Current smoker	N/A	Retired	N/A
Barry	60	M	GP 2	2	N/A	Current smoker	N/A	Not working (disabled)	Heart failure
Liz	66	F	GP 2	3	Married – living with husband	Current smoker	N/A	Retired	N/A
Russell	68	M	GP 2	3	Married – living with wife	Current smoker	N/A	Retired	N/A

Phyllis	59	F	GP 2	3	Married – living with husband	Current smoker	N/A	Retired	Brain haemorrhage High blood pressure
Brian	61	M	GP 2	3	Married – living with wife	Current smoker	N/A	Retired	N/A
Anthony	63	M	GP 1	3	Married – living with wife	Current smoker	N/A	Full time employed	Heart condition
Paula	58	F	GP 1	3	Married – living with husband	Ex-smoker	12 months	Full time employed	COPD Asthma

Table 7

Themes and subthemes

Themes	Subthemes
Symptom recognition, awareness and interpretation	❖ Appraisal/ interpretation of first symptoms ❖ Appraisal of symptoms as mild or minor ❖ Timing of symptom occurrence (changing bodies and life events) ❖ Interpreting alarm symptoms ❖ Symptom awareness and self-application ❖ Symptom appraisal and the ‘smoker’s cough’ ❖ Lack of symptom knowledge and being unaware
Comorbidity	❖ Comorbidity and confounding symptoms ❖ Comorbidity and recurring minor conditions ❖ Comorbidity and heart health ❖ Comorbidity and alcohol issues ❖ Comorbidity; physical symptoms and mental health ❖ Comorbidity and continued smoking
Risk perception, optimism, health beliefs	❖ Risk, smoking, and healthy lifestyle ❖ Risk perception and the causes of cancer ❖ Risk perception and chance ❖ Risk perception, smoking cessation, and previous good news ❖ Risk perception and ‘types’ of smoking ❖ Risk perception and attitudes to screening
Symptom accommodation and normalisation	❖ Symptom accommodation and slowing down ❖ Symptom accommodation and changing routines ❖ Symptom accommodation and sleeping patterns
Symptom occurrence and methods of self-treatment	❖ Self-treating, help seeking, and the pharmacy ❖ Self-treating and access to services
Access to health services	❖ Access to services and navigating the system ❖ Accessing primary care and the gatekeeping culture ❖
Stigma and health	❖ Stigma from healthcare professionals ❖ Stigma and access to services ❖ Stigma and encounters with healthcare professionals ❖ Stigma, healthcare professionals and ‘lifestyle’ related symptoms ❖ Stigma, smoking and societal change
Wasting healthcare professional time	❖ Wasting time and minor symptoms ❖ Time wasting, other people and the ‘hypochondriac’ ❖ Wasting time as a smoker
Social networks and health choices	❖ Family, friends and legitimate help seeking

Summary of key themes

After applying the coding structure to the transcripts, key themes emerged from the data, the findings of the study are presented according to these themes and subthemes. The recognition and interpretation of new symptoms is key in understanding the timing of presentation and is also bound with concepts of symptoms awareness, mild or minor conditions and the interpretation of alarm symptoms.

The presence of comorbid conditions was also found to be an important factor when considering presentation for new symptoms. Comorbidities were often thought to be responsible for symptoms, particularly chest symptoms in participants who had COPD or asthma. Participants sometimes expressed the belief that due to comorbidity they were susceptible to minor infections which also could obscure new symptoms. Comorbidity combined with other factors such as smoking, mental health and alcohol consumption was also found to influence presentation.

Risk perception, optimism and health beliefs are also contributing factors to decision making regarding presentation. Beliefs about the causes of cancer, the effects of different types of smoking and smoking cessation were all present in the data. Participants also reported low levels of perceived risk despite smoking due to other health practices, genetic factors and the idea that cancer is a matter of chance.

The accommodation and normalisation of symptoms is also a key theme in this study as many interview participants described ways in which they had adapted their daily lives and routines to accommodate worsening health. Many people also ascribed symptoms to natural life processes such as ageing and therefore were reassured that what they were experiencing was normal.

Self-diagnosis and self-treatment was also a key element of participant accounts and many expressed strong feelings regarding the legitimacy of seeking help in primary care without having first tried to treat the problem with over the counter medications.

Access to health services was a prominent feature of the accounts of participants in this study with many of them believing that appointments were too difficult to get or were always at inconvenient times. There is a strong perception of a gatekeeping culture within primary care and this was viewed as a barrier to accessing services.

A major theme arising from the data was that of stigma in healthcare. There was a perception that smokers would be stigmatised in primary care, by both healthcare professionals and lay people, for having ‘lifestyle’ related health problems.

Wasting healthcare professional time was also a point of concern for many participants. The perception that primary care is in high demand gave participants concerns regarding what constitutes legitimate help seeking.

Finally social networks, family and friends, were shown to have an influence of the help seeking decisions of participants.

These themes are key in understanding the accounts of participants in this study and are given in detail in the forthcoming narrative.

Thematic presentation of study findings

Symptom recognition, interpretation and awareness

Appraisal and interpretation of first symptoms

In order to understand the participant’s consultation decisions, it was important to find out which symptoms they first noticed and how they had interpreted them. These initial symptoms and their interpretation gave a valuable insight into the participants’ lived experiences and revealed them to be far more complex than anticipated. During the interviews, the participants were asked to describe what their initial symptoms were. They reported a range of symptoms that they had first become aware of, often things had started with what were perceived as minor symptoms which gradually worsened over time, but a few participants reported first becoming aware when they experienced alarm symptoms. It was interesting that many participants experienced similar symptoms that are indicative of lung cancer but did not necessarily realise that cancer was a possibility. This could mean that they were less likely to present as they did not link symptoms to a potential cancer diagnosis. The most common symptoms that interview participants experienced were breathing difficulties including shortness of breath when performing everyday activities, wheezing, a dry throat, and feelings of being unable to breathe. Pain in the chest and/ or the back was another common occurrence. A persistent cough is possibly one of the most well-known signs of potential lung cancer and many of the participants in the interviews had suffered with cough or feelings of having a lump in the throat that caused them to constantly try to clear it. Two of the interview participants reported having found visible lumps on the body too. Janine had found one in her neck and Sion had found two, on his arm and back. Visible lumps on the body, although not necessarily indicative of lung cancer, may arouse cancer suspicion. Unexplained weight loss, loss of appetite and the inability to eat much due to feelings of sickness and nausea were also reported by some participants. Many people reported feeling unusually tired, needing to sleep for longer and more often, and being worn out quickly by everyday activities.

'Yeah, I've lost a stone, well, just over a stone I reckon in, what, six weeks? Five weeks?'

(Ray, interview participant, ex-smoker)

A few participants had experienced haemoptysis, which is classed as an alarm symptom for potential lung cancer, with varying degrees of severity. Some stated that they had coughed up blood and others reported finding a little bit of blood in their saliva or on their pillow. Whilst all participants were able to recall the first symptoms that they had noticed, they also reported that experiencing these symptoms did not necessarily prompt them to seek help straight away; rather they had often waited for symptoms to worsen or to get better without treatment. This waiting or hesitancy to seek help became more apparent throughout the analysis and is a feature of many of the key themes in this chapter.

Appraisal of symptoms as mild or minor

A feature of many interview participants' accounts was the attribution of symptoms experienced due to minor problems and therefore people felt that these particular symptoms did not warrant seeing a doctor. Whilst many of the symptoms that were experienced were indeed indicative of potential lung cancer, they were not presumed to be serious as they felt mild or were not thought to be related to the lungs. Breathlessness was often attributed to a minor condition such as a cold, the flu or a chest infection. Interview participants Alex, Daryl and Denise had all experienced first symptoms which they had attributed to minor complaints that would likely improve without the need for medical attention. Alex had experienced breathlessness initially, though he later also experienced chest pain, but thought that he had developed hay fever and had bought some hay fever medication. Daryl stated in his interview that he got colds and flu regularly so when he found that he was suffering from breathlessness in the night he thought he had contracted one of his usual colds and so he chose not to seek help straight away. Interviewee Denise had also thought her breathing problems were just cold or flu-like symptoms and not a matter of concern. Interpreting symptoms as minor ailments was common amongst accounts, many of the interview participants reported that they had had a ‘bad cold’ that lasted for a long time, in some cases months, but that it was not worth bothering a doctor over, even though it lasted much longer than a cold usually would. Perhaps having made the decision to attribute the symptoms to a cold or flu, participants then stuck to this self-diagnosis, even though a cold would not usually last for more than a few days and over the counter medicines did not relieve symptoms.

‘I was shivery. That was like flu symptoms. Cold symptoms. It wasn’t anything sinister’

(Denise, interview participant, ex-smoker)

Some interview participants reported having experienced pain but again they tended not to have felt it was worth consulting a doctor over unless it was deemed to be serious enough, which meant either pain that was unbearable or pain that was in a particularly worrying place. An example in which pain location was considered a matter for medical advice is described by Alex who as mentioned previously had already ascribed breathlessness to having developed hay fever. Alex had suffered from chest pain which he had consulted his GP over but only because he was worried that it was close to his heart. He said that he was surprised to discover that he had lung cancer as the pain ‘wasn’t bad’ and therefore, had he not been concerned about its location, he probably would not have sought advice. The location of the pain was Alex’s justification for seeking help as he was concerned about his heart. This may be partly due to heart problems being deemed as a reason for ‘legitimate’ help seeking and partly due to fear of suffering a heart attack. In a sense, the possibility of a heart attack could be perceived to be more worrying than a symptom relating to the lungs as a heart attack can be sudden and fatal, and therefore it is important to seek help quickly even if the pain is mild.

‘Started off with an ache more than a pain in my chest, actually. But it was close to the heart, I thought.’

(Alex, interview participant, ex-smoker)

Another participant who reported pain but had not perceived it to be serious enough to need medical advice was Denise. Whilst Alex experienced pain in his chest, Denise had suffered pains in her back but she had thought that they were due to bad posture whilst sitting in her office chair or from working in the garden. This may be further evidence that the location of the pain is related to help seeking decisions as chest pain is considered to be a cause for alarm whilst back pain can be more easily attributed to everyday aches and pains. Like Alex and Denise, interview participant Mark also suffered from pain, this time in both his chest and back but thought that it was due to his changing his running routine, and that he had ‘pulled something’ whilst training. Pain from these perceived ‘minor’ injuries and issues were not described as a cause for major concern among participants and so they did not consider them a reason for medical advice. Mark, as shown in the quote below, also referred to his attribution of the pain to an injury as a ‘diagnosis’. This suggests that he felt no need to seek medical advice as he had already correctly ‘diagnosed’ the issue himself. Once he felt he had correctly diagnosed himself, he need no longer worry about the pain, especially when he felt it had subsided as this reinforced his belief that he had correctly attributed the pain to a minor injury.

> *‘I changed my training routine and I just assumed I’d torn something or pulled something, and-and-and, that was supported by disappearing after two or three days. And I assumed that my diagnosis was right, you know’*
>
> *(Mark, interview participant, ex-smoker)*

Changing bodies and life events

Other more general symptoms, such as persistent fatigue, were often assumed to be due to stress from work or life events, ageing, or having been particularly busy at work or at home recently. As they felt that they were tired due to natural processes or life events, these interview participants had not sought help for their fatigue as they believed there was no need, it would not cross a person’s mind to see a doctor if they experienced feelings of tiredness during a busy period in their life. There was also a perception during the interviews that seeing a doctor because one felt tired was a waste of time, particularly if they believed the doctor would simply have to tell them that they were getting older and it was to be expected. Concerns about wasting time are discussed in more detail further on in this chapter. There may also be a point to raise here, however, that life is always busy for some people. Most participants in this study reported being busy in general either with working or home and family responsibilities. Interview participants did not report becoming any more busy than usual and yet, when their symptoms began, they were able to find something to attribute tiredness or stress to. Those who reported having a loss of appetite or feelings of nausea often equated them with having just recently returned from holidays abroad where they had eaten different food or drank tap water instead of bottled. Interview participant Jane had been abroad and had an upset stomach and the symptoms continued for a long time after she returned home. She did eventually report this to her doctor but not until she had needed to go and see her GP for something else. Jane had a primary lung cancer that had spread to her bowel. Like Jane, Daryl too noticed symptoms after returning from holiday. As mentioned above, Daryl had attributed his night time breathlessness to having a cold, which he believed he had contracted on holiday in Spain due to everyone greeting him by kissing him.

> *'Er and it's nothing that ever put me in bed with an illness, except these blooming colds that I've got. They're terrible. And you try and avoid it, you try and stay away from people. Of course there's the kissy-kissy thing in Spain. When you meet somebody, mwah-mwah, kiss-kiss. So you always go, "Cold!"'*
>
> *(Daryl, interview participant, ex-smoker)*

It emerged that participants believed that feeling unwell after returning from a trip abroad was very common and that it took time for the body to get over exposure to foreign germs or reactions to different food and drink. Some participants believed that they would contract different strains of colds or viruses if they were away from home which may take longer than usual to recover from, however there was a sense of reassurance that the body would recover on its own once they were back at home and therefore there was no need to see a doctor. There is also a tendency for people to structure memories and experiences around significant life events such as holidays. It is possible that participants' symptoms had begun earlier, but as a holiday stood out in their memory, for them, that marked the beginning of their symptom journey. This attribution of new symptoms to minor problems is possibly also indicative of a desire for it not to be something serious, as arguably it is more preferable to believe one has a cold or a sports injury than a potential cancer symptom. This could also explain why symptoms were often allowed to continue for a prolonged period before consultation, a point which will be discussed in further detail later on in this chapter.

Interpreting alarm symptoms

Perhaps surprisingly, this attribution of new symptoms to minor ailments was present in participants who experienced more serious or obvious health problems. Even in participants who experienced bleeding, symptoms were often explained away as minor things. Interview participant John had noticed blood in his saliva but thought that he had brushed his teeth too firmly and when another interviewee, Rob, noticed blood on his pillow in the mornings, he thought it was from his stomach due to the aspirin he took regularly. Owen had also experienced unexpected bleeding, when he saw blood in his vomit, he thought it was the pink cough syrup he had been taking for his persistent cough. Whilst these participants had also experienced other symptoms, such as Owen's cough, they had not made the link between them all. This misattribution of symptoms was common throughout the data but in the case of haemoptysis, an alarm symptom, or other unexplained bleeding it could perhaps be partly due to a sense of fear and the participant wishing to seek a reason for it to not be cancer. Experiencing haemoptysis or bleeding is likely to induce fear in a person and those in this study who did experience it looked for less harmful reasons that it may have happened; finding a more everyday thing such as over-brushing teeth to be responsible instead could be reassuring. It may also be that if a participant has felt otherwise healthy, they are more likely to suspect something minor rather than a potential cancer symptom. It also may be the nature of their bleeding; those who noticed traces of blood rather than a feeling of actually 'coughing up' blood may not immediately make the link between their symptoms, their smoking, and their lungs. However, in some cases it seemed that participants were aware that it could be due to something more serious, as we can see from Rob's statement in which he 'hoped to God' it was due to his taking aspirin. The practice of seeking non cancer-related reasons for the bleeding also had an effect on the help seeking decisions of participants. John delayed seeing his doctor and tried brushing his teeth more gently and Owen waited until he could be sure it was not the cough syrup. Only Rob sought help quickly but he also explained that it was because he was hoping to be reassured that it was due to the aspirin and have his prescription changed.

> *'Hoped to God it was just something to do with the um aspirin I was taking. Thought that maybe caused a bit of blood or something, so I stopped taking that and the blood disappeared – traces of blood disappeared. They were only traces, mind. There wasn't much.'*
>
> *(Rob, interview participant, ex-smoker)*

Only interview participants Timothy and Earl reported having been immediately concerned when they saw blood but this could perhaps be because they had both experienced a more severe haemoptysis which would have been harder to attribute to a minor or everyday reason. As Timothy and Earl had coughed up large amounts of blood, they saw it as a sign that they needed to seek medical help. However, they had also delayed help seeking for more mild symptoms that arose prior to the haemoptysis, similarly to John and Owen, they had not made any links between the minor symptoms and potential cancer. This delay in seeking help until the incidence of an alarm symptom is an example of participants waiting until symptoms reach a 'crisis point', which will be examined in more detail later on in this chapter.

'But then when I did start coughing up blood, the first thing I did, straight to the doctors'

(Timothy, interview participant, ex-smoker)

Symptom awareness and self-application

In some cases, participants had an awareness of potential cancer symptoms but did not always recognise them in themselves. There were reported delays in help seeking in participants who appeared to have a good knowledge of cancer symptoms and it was often reported that, although they knew what some of the potential symptoms were, they did not think that lung cancer would ever happen to them. Interview participant Rachel had a high level of awareness regarding cancer symptoms and a good knowledge of cancer pathology as she worked in a lab at a hospital. However, she had not initially suspected lung cancer in herself, perhaps because she was relatively young and had stopped smoking a long time ago. Having given up smoking was a significant factor in several participants' accounts and is revisited in more depth in the 'risk' section of this chapter.

Interview participant Fred was the only person who said that he knew he would have lung cancer because he had been a heavy smoker and had experienced haemoptysis.

'Yeah, when I first went to – the reason I went to the doctor's in the first place was because I'd coughed up some blood. Um no, no, it was it was confirmation, if you like, of something that I knew. I knew I'd have lung cancer'

(Fred, interview participant, ex-smoker)

Many thought that haemoptysis was the primary symptom of lung cancer and without it, a person would not need to worry. As haemoptysis was reported as the point at which a person would know they needed to see the doctor, it is understandable that those participants who did not experience it had delayed presentation; however, there were also delays in some participants who had experienced it as they looked for other explanations for it.

Whilst a persistent cough is perhaps one of the most commonly recognised symptoms of lung cancer, it was not always immediately recognised by the participants as a cause for concern, either because they felt it was a minor symptom or because they were smokers and were used to having a cough. Public awareness campaigns are designed to raise awareness of cancer symptoms and to prompt help seeking in those who experience them, however this strategy depends on the perceptions of the public and the ways in which individuals interpret the meanings behind the campaign messages. During the men's focus group, the members discussed the 'Be Clear on Cancer' campaign and the television advert, which advised that people who experienced a cough for three weeks or more should see their GP. As those who smoke are at much greater risk of lung cancer then perhaps one would expect them to take most notice of campaigns such as this, however those in this focus group, whilst aware of the campaign, had a different interpretation of the message. Focus group participant Dean said he thought that the campaign was not aimed at smokers because most smokers would have a cough anyway, particularly if they were the same age as the man featured in the advert, and therefore they would not be able to tell if the cough had lasted three weeks as it was always there. Similarly to Dean, interviewee Nick also felt that the campaign was aimed at non-smokers as, if they got a cough that lasted three weeks, then they would have cause to worry whereas a smoker would not as they already had an explanation for the cough. Nick had suffered with a persistent cough prior to his cancer diagnosis and had seen the 'Be Clear on Cancer' campaign but he said he had not associated his own cough with cancer because he was a smoker. Nick was coughing violently when his back pain began and so he thought that the cough had caused him to trap a nerve in his back. Again, he thought it was still just his usual smoker's cough and did not see his doctor. The focus group participants were not asked directly about lung cancer symptom awareness but they did discuss awareness campaigns, and knew that literature was available in their local surgeries. This awareness of the availability of information showed that they knew where to go if they required it, however as already discussed, they did not necessarily view awareness campaigns as being aimed at them in which case they were unlikely to encourage timely presentation.

These interpretations of public awareness campaigns have the potential to contribute to a lack of help seeking when the symptoms were experienced. The belief that these campaigns are aimed at other people may be a way for participants to distance themselves from the possibility of cancer and to separate their own actions from those of the people featured in the awareness campaigns. It is possible that by deeming these campaigns as not applicable to themselves they are able to disregard them and therefore, not worry about cancer.

'That whole thing about having a cough for three weeks, well I smoke so I always get coughs, now, if you don't smoke and you cough for three weeks, then you should be worried'
(Nick, interview participant, current smoker)

Symptom appraisal and the 'smokers cough'

Another reason for current smokers in this study to delay seeing their GP when they experienced cough, was the aforementioned belief that cough was 'normal for smokers' and the GP would simply tell them that they had a normal smoker's cough and not investigate further. Throughout the focus group data, there are accounts to suggest that current smokers believed that GPs would use smoking as the cause for any problem they suffered and therefore would not even try to find other explanations. Focus group participants Russell, Brian and Paula all thought that there was little point in presenting with a cough if you were a smoker because you would be dismissed straight away as having a smoker's cough. There was also a view that a doctor could not do much about coughs and colds anyway so it was better to just let them clear up on their own or take some over the counter cough medicine rather than see the GP. It was interesting to try to discover how much of these beliefs were based on true life experiences and how much were based on perception. Some focus group participants seemed to be describing a perception rather than actual experiences in primary care whilst others were able to report specific incidents in which they had felt dismissed in primary care. For example, during focus group three, there was consensus that a GP would dismiss a smoker with a cough. Brian agreed with this view although he also reported that it had never actually happened to him. Brian wondered if perhaps a GP would use smoking status as a reason for dismissing a patient quickly so that they did not have to waste time investigating their symptoms.

'You see, I mention the point but I've never actually had a doctor say to me, "It's because you smoke." They've never actually – I'm just wondering if any of you were thinking that it may be a way out for them, if you know what I mean'

(Brian, focus group participant, current smoker)

There could be several reasons why Brian had never actually experienced being dismissed by his GP, and a likely explanation is that he avoided going, especially with a cough, due to the perception that he would not be helped. This perception versus reality was also evident when discussing stigma with the focus group participants, which will be discussed further on in this chapter.

Some of the interviewees stated that they had no knowledge of lung cancer symptoms prior to their own investigations and diagnosis. Betty reported that she knew ‘absolutely nothing’ about lung cancer before she became ill. She said that there was no information available to her and that there was no awareness in North Wales. This potentially contributed to her time to consult, as she was unaware that her symptoms could be related to lung cancer. If a person does not know what the symptoms of cancer are, or is unaware of the less well-known symptoms, then they may be unlikely to recognise a potential cancer symptom when it occurs. Betty was particularly upset as she believed that she was still not being given adequate information and had to keep asking her healthcare providers what was going to happen to her in terms of treatment and prognosis. It is interesting to note that Betty also seemed to show a general mistrust of healthcare and described each stage of her journey to diagnosis as a ‘fight’ that she had to endure in order to get the help she needed. A belief that one needs to fight for appointments in primary care and for treatment in secondary care may contribute to time taken to consult, as the patient may be reluctant to go through what they see as a battle. This notion of participants believing primary care being difficult to access will be discussed again later in the chapter.

> *‘No, there’s nothing about anything really is there? Especially in (county) where we live. We’ve got nothing at all’*
>
> *(Betty, interview participant, ex-smoker)*

Like Betty, interview participant Ray also said that he was unaware of what the symptoms of lung cancer were, and said that he thought there was very little publicity surrounding cancer and potential cancer symptoms. These participants reported a lack of knowledge of the symptoms of lung cancer, which could account for some delay in presentation as they did not recognise their symptoms as potentially indicative of cancer. Some interview participants also reported a lack of interest in knowing what the symptoms of cancer were. One such participant, Mariel, said that she did not know what the signs of cancer were and that she had avoided cancer awareness information on purpose because ‘ignorance is bliss’. Mariel also said that she was not ‘medically minded’ and so had never been interested in seeking out information pertaining to health. Interviewees Rob and Nick both said that they had thought they were aware of the symptoms but now conceded that the information they had was incorrect. Nick had thought that chest pain would be the most common symptom and so when he experienced back pain he did not suspect cancer. Rob had been told in the 1980's by a nurse that if a person coughed up blood which was not 'bubbly' then it could not be their lungs; he now realised this information was incorrect as it had happened to him and it was his lungs. This lack of knowledge or lack of correct knowledge contributed towards longer patient intervals in these participants as they were unaware that they were experiencing potential cancer symptoms.

Comorbidity and the symptom experience

Comorbidity and confounding symptoms

Noticing a new symptom or a change to health generally was not always a straightforward process for many of the participants due to them already suffering from other, sometimes smoking-related, health conditions. Many of the participants, both interview and focus group, had already been diagnosed with other chest conditions, especially asthma and COPD. The presence of these comorbidities had a paradoxical effect on the presenting decisions of the participants. On the one hand it caused some later presentations as participants were already used to having chest problems and put their lung cancer symptoms down to having 'a bad day' with their COPD or asthma. Several of the interview participants reported using their inhalers more often as they had believed their asthma was worsening. For these participants, having an episode with a pre-existing comorbidity did not necessarily warrant a new trip to the GP. On the other hand, having a chronic condition such as COPD already diagnosed meant that they were likely to be in regular contact with their GP in order to manage it. Interview participant Fiona, for example, was diagnosed with lung cancer following an appointment with the nurse to check on her COPD. During the discussion, Fiona had mentioned that she thought she had been getting many chest infections lately, and the nurse had decided to refer her for an X-ray where her lung cancer had been found. Fiona was able to have surgery which she may not have been suitable for had her lung cancer been discovered later. Had she not had the appointment for a COPD check already arranged, it may have taken Fiona a long time to decide that her repeated chest infections were a cause for concern or for other symptoms to arise. Likewise, interviewee Janine had found a lump in her neck which had worried her, however she already had an appointment with the nurse for her asthma and it was during this appointment that she decided to mention the lump. Whilst Janine did not think that the lump was linked to her asthma, the existing appointment meant she would have an opportunity to mention it without having to make a new appointment. For participants such as Janine and Fiona, their existing conditions meant that they were provided with appointments already and this gave them the opportunity to discuss their new symptoms without having to make an appointment separately. This may also reassure participants that they are seeking help legitimately and not wasting time, beliefs which are mentioned further in this chapter, as they are not taking up any extra appointments and have a pre-defined long-term condition.

'It's just I've got COPD anyway and I was getting quite a lot of infections and the nurse said, "Well we'll send you for an x-ray. Not had one for 12 months." And that's when it showed up. Other than that, there was no reason for me to, you know, me to be sent for an x-ray because there was no symptoms or anything like that'

(Fiona, interview participant, ex-smoker)

Comorbidity and recurring minor conditions

Repeated chest infections were a feature of many interview and focus group participants' accounts, especially if they already suffered with COPD or asthma. The early signs of lung cancer were often believed to be chest infections and participants reported delaying seeing their GP with these symptoms as they were used to them getting better on their own. Participants reported eventually seeing their GP and subsequently requesting antibiotics for these perceived chest infections at first. Asking for antibiotics was reported as something of a last resort for the participants as they preferred to wait until the infection had cleared of its own accord. This waiting until they had decided that it was not going to get better by itself is another example of the existence of a crisis point at which medical help is needed. The notion of a crisis point occurred throughout the data and is discussed in further detail later in this chapter. In the focus groups, participants often said that they knew that they suffered chest infections and that what they needed was antibiotics. In the women's focus group, both Belinda and Clare disclosed that they had COPD and asthma respectively, and so they went to their GP and asked specifically for the antibiotics, which they knew they needed. Neither of them felt that they would ever suspect cancer when they had chest symptoms. For Belinda and Clare, having COPD or asthma legitimised their help seeking when they consulted with chest-related symptoms. They also both expressed a belief that doctors were reluctant to listen to them even though they knew exactly what they needed; they each expressed a defiance in going to the doctor and telling him or her that they knew what they wanted. This sense of defiance seemed to strengthen during the discussion and could be due to the focus group methodology as opinions may be reinforced when other members agree or share the same idea.

'I mean, I've got um steroids, because when I do get it, I mean, I really, and it's within minutes. I need steroids and antibiotics straightaway. I know'

(Belinda, focus group participant, current smoker)

The existence of these comorbidities could also lead to repeated presentations, such as with interview participant Gayle. Gayle had seen her GP several times and received various courses of antibiotics and new inhalers as the initial feeling was that her COPD was worsening or that she had contracted a chest infection due to her COPD. In Gayle's case, her diagnosis had still taken some time as she was not referred immediately. Instead, her GP prescribed antibiotics for chest infections. This is an example of a comorbidity clouding the issue for the GP as she was a patient with a history of chest problems and so they needed to be ruled out first. Had she not have had COPD then perhaps her cancer could have been recognised earlier.

'I had very severe er chest infection which lasted for, going on for a month. And I had to have, well I had three courses of antibiotics and then when I went for the fourth, the doctor then decided to send me for chest x-ray. And that's when they found this cancer. And we've just gone on from there'

(Gayle, interview participant, current smoker)

Comorbidity and heart health

Several participants from both the interviews and the focus groups stated that they suffered from heart conditions and some of them had experienced heart attacks in the past. The symptoms of heart conditions could again have an effect similar to that of COPD or asthma on the help seeking decisions of the participants. While they may attribute their symptoms to already existing heart problems and not necessarily a new smoking-related illness they might be more likely to see their doctor if they thought it was their heart rather than their lungs causing the symptoms. Similarly to COPD, those with already existing heart problems were likely to experience breathlessness and therefore might assign new and similar symptoms to their heart condition. However, having a heart condition was likely to bring them into regular contact with healthcare providers. Some participants, such as interviewee Alex, had seen a doctor because they had thought their lung cancer symptoms were due to heart problems, even though he had not suffered heart problems before. Alex had had chest pains and had seen his GP because the pain was close to his heart, which worried him. Whilst Alex's chest pain was new to him, interview participant John knew he suffered with a heart condition and he explicitly explained that, as the heart problem made him breathless, he would not notice any additional breathlessness. In fact, he had been to the doctor when he noticed he was bleeding when he brushed his teeth. Alex and John illustrate two different outcomes that can potentially occur when lung cancer symptoms are attributed to heart conditions. Alex, who had not suffered heart problems before, had been alarmed by the new pain and consulted a doctor; John however did suffer a heart condition and therefore was not concerned about his breathlessness as he had experienced it before. It is important to recognise however, that Alex and John experienced different symptoms and perhaps, had John suffered chest pain like Alex, he may have consulted sooner.

> *'Yeah. It's more difficult to detect, because of the heart failure made me short of breath. There's one valve that's only working at twenty*-six *percent, or something. And I get short of breath, so you wouldn't notice if you if you started getting short of breath, you wouldn't notice any difference. You know, if-if you didn't have the heart failure you'd have picked, maybe, picked that up quicker that you were short of breath or, you know, those kinds of things'*
>
> *(John, interview participant, ex-smoker)*

Comorbidity and alcohol issues

In some of the focus group participants, alcohol abuse had also been responsible for their ill health. Dean and Barry in particular had both had a long history of alcoholism and this, along with their smoking, had caused them to suffer serious health problems. Dean had managed to give up smoking and drinking but not until after he had major surgery to remove part of his bowel and had suffered collapsed arteries, COPD, and various other conditions. Barry however was still a heavy smoker despite suffering heart problems and COPD. Dean and Barry's existing health problems had brought them in to contact with healthcare services; Dean in particular had spent a prolonged period of time in hospital. However, they both described having sought help for problems which they primarily attributed to drinking, not smoking, and Dean had presented in emergency care rather than primary care. Whilst they had both sought help for alcohol-related problems, both Dean and Barry reported not wanting to seek help in primary care as a smoker; this can be seen in more detail in the ‘access’ and ‘stigma’ sections of this chapter. There may also be a point to mention here about the focus group methodology, as it was not necessary for Dean or Barry to disclose their alcoholic status and yet they did which could be due to them being in a group situation. Dean made his disclosure very early in the discussion and it may be that he anticipated other members expressing negative opinions about alcohol and wanted to avoid having to hear them. In the other focus groups, members often expressed negative opinions regarding drinking and drug use and perhaps Dean anticipated this and believed that due to his disclosure the topic would be handled more sensitively. Whether or not it was down to Dean’s disclosure, it is true that alcoholics were viewed in a more negative light in the other two focus groups than the one in which he was involved.

Comorbidity; physical symptoms and mental health

Alongside physical comorbidity, mental health also had an effect on the help seeking choices of some participants. Focus group participant Barry reported having a personality disorder that he said made his relationship with his GP very difficult, and he reported feeling victimised due to having mental health issues as well as for being a heavy smoker. In the same focus group, Dean mentioned he had also suffered mental health issues, which had left him feeling unable to ask for help as he thought he was in some way unworthy of care. Interview participant Timothy also had a history of mental health issues and had suffered with depression which left him bed bound for five years. Timothy, like Dean and Barry, also suffered from COPD which had previously meant he was in regular contact with his GP, however as the depression had taken over he had run out of his medication and not seen his doctor to have more prescribed. As he was unable to get out of bed and was only moving each day to go to the bathroom, he found his COPD did not bother him so much. It was only when he began to overcome his depression and move around more that he started to feel breathless again, which he attributed to his un-medicated COPD.

> *‘I’d been going for the COPD but I hadn’t gone in the last five years, because, as I say, I was laid up. I wasn’t struggling with breathing because I was only going from bedroom to the loo. I couldn’t get up and down the stairs because of my COPD so I didn’t bother even coming up and down the stairs, so I left it at that’*

(Timothy, interview participant, lung cancer patient, ex-smoker)

Comorbidity and continued smoking

Whilst some participants reported having stopped smoking when they were diagnosed with smoking-related illness or had a previous cancer, many others had not and had continued to smoke. Interviewee Timothy had severe COPD but had continued to smoke for six years after finding out and later developed lung cancer. In the focus groups, Barry reported having heart problems but he had not given up smoking; Clare had a history of breast cancer and had undergone a partial mastectomy but stated that that had not inspired her to stop smoking. In Clare’s case, her breast cancer was perhaps not associated with smoking and so she had not felt the need to stop smoking following her diagnosis. Interestingly, whilst focus group participant Paula had given up smoking after a diagnosis of COPD, her husband Anthony, also present in the focus group, had not as he felt that he was in good health. Interview participant Gayle also continued to smoke despite having a smoking-related illness. Several participants were still smoking despite their lung cancer diagnosis. Many of them cited stress as a reason to continue but others, such as Earl, stated they already had terminal lung cancer and so there was little point in trying to stop now. Interview participant Earl was one of the few who actually smoked during the interview and explained that he still enjoyed it. He had been told that his chemotherapy was palliative and therefore he saw no reason to stop. Interviewees Nick and Owen were also still smoking despite their lung cancer although they both reported that they were unable to smoke as much as they used to. In these instances, participants continued smoking despite advice to the contrary and diagnosis with smoking-related illness suggests that public health messages are not effective and medical advice is sometimes disregarded.

The presence of comorbidities was found to influence decision-making when it came to seeking primary care for symptoms. They were entangled with the recognition of symptoms as new or as recurring and were responsible for both delaying and prompting presentation. Some participants were likely to delay help seeking, as they did not feel that a bad episode of an existing health problem warranted it, and others were more likely to see their GP as they felt that they knew what the symptoms were and that the doctor would be easily able to help. Participants with existing health problems who did not recognise new symptoms are perhaps less likely to feel afraid of their diagnosis as they believe they already know what it is. The presence of comorbidity can make it harder for doctors and patients to be clear about what a new symptom is and what is not; this can be further complicated by the patient's own health beliefs. Participant perceptions of risks and health beliefs are discussed in the following section of this chapter.

Risk perception, optimism and health beliefs

It emerged during both the interviews and the focus groups that many participants would not or had not sought help for their symptoms, as they did not believe that they were at risk of lung cancer, were optimistic about cancer risks, and held incorrect or misguided health beliefs regarding causes and outcomes of lung cancer.

Risk perception, smoking and having a 'healthy lifestyle'

Many of the interview participants believed that although they smoked, the negative impact of smoking upon their health was effectively 'balanced out' by other healthy practices such as a balanced diet or plenty of exercise. When asked whether or not they ever thought that they would be at risk of lung cancer almost all participants said no due to their perception of having an otherwise healthy lifestyle which they believed would compensate for their smoking. Participants were optimistic about how much an otherwise healthy lifestyle would be able to effectively cancel out any potential risks from smoking. Interviewee Lloyd had smoked heavily up until his lung cancer diagnosis yet he described having always had a healthy diet, and in particular always eating breakfast, as a reason why he did not think he was at risk of cancer. Whilst Lloyd emphasised his healthy diet, Denise and Mark both emphasised regular exercise as keeping them healthy. Denise, who described having always been active and making sure she did lots of exercise and ate healthily, and Mark, having been a runner, thought that they had taken care of themselves and would not be at risk for cancer despite having a smoking history. The perception of what constitutes a healthy lifestyle varied between interview participants, with some emphasising physical exercise or having had active jobs to various aspects of their diets such as not eating dairy or red meat or trying to get their 'five a day'. Even though the perceptions of what a healthy lifestyle encompasses is varied, the belief that these perceived healthy practices would offset the risks of smoking were common. Interestingly, Mark seemed to recognise that he has perhaps been over optimistic and somewhat misguided in his thinking and even referred to 'self-delusion' when discussing his otherwise healthy lifestyle meaning he could still smoke. This idea of balancing out the negative with the positive may be a mechanism for the participants to justify their smoking as they could rationalise it in comparison to those who smoke and do not eat well or exercise. This suggests that interview participants were aware that smoking could have negative implications for health but they were able to tell themselves that they would be protected in some way by their otherwise healthy behaviours. There may also be misguided perceptions of public health messages at work here, as diet and exercise are promoted in order to prevent cancer and awareness campaigns may not distinguish between smoking and non-smoking related cancer. It is perhaps likely that those who believe themselves to be protected by their otherwise healthy practices may take longer to seek help due to the belief that by having a healthy diet or regular exercise they are less at risk of smoking-related cancer.

> *'Um but because I was I suppose I was training. I was fit. I was still running marathons and stuff, you know. Um so I could do all that stuff and smoke. So there's nothing like a bit of self-delusion, is there? You know. I, alright, maybe I smoke and maybe I drink but I've just run twenty six miles, so what's the problem? You know. So maybe ((laughs)) I was still doing myself some harm'*
>
> *(Mark, interview participant, ex-smoker)*

Risk perception and the causes of cancer

A person's perception of their risk for lung cancer was also potentially affected by their beliefs regarding what causes cancer in the first place. The idea of cancer being down to genetic factors or 'running in the family' seemed to lessen the risk perception in some participants, which in turn may affect their help seeking decision-making. Participants who believed they did not have the 'cancer gene' within their family may rely on a sense of false optimism and believe that they are able to smoke without considering the risks. If a person believes that cancer is predominantly caused by genetic factors they may be less likely to suspect cancer, even if they have smoked, if there is no family history. Interview participant Alex said he was surprised to get lung cancer, despite having smoked for many years, as there was no history of cancer in his family and so he had not believed himself to be at risk. Like Alex, interview participant Rob also said he was not previously concerned about being at risk of cancer, despite his smoking, because it was heart conditions that tended to affect his family, not cancer. Interestingly, Denise did have a history of lung cancer in her family and explained that her mother and brother had died from the disease, but did not see herself as being at risk. Denise had believed that as her brother had been affected, the cancer had 'gone down that line' and she herself was safe. Denise also explained that she had a healthy lifestyle and had stopped smoking; perhaps this increased her sense of security and lessened her risk perception. A family history of cancer in general could also potentially hasten diagnosis as interviewee Jane had actually seen her doctor about a change in bowel habit rather than her chest symptoms as there was a history of bowel cancer in her family; Jane in fact did have bowel and lung cancer. In the women's focus group, participant Belinda also expressed a strong belief that cancer was caused by genetics and that there was little that could be done otherwise to either cause or avoid cancer. Belinda gave her reasons for believing that genes caused cancer in that she knew many people who had never smoked and still had cancer, so therefore the smoking could not be the cause and it must be genetic. Further to this, Belinda said that she believed that genes were also responsible for whether or not a person smoked. She explained that her mother and sister never smoked but her and her father both had the gene for smoking.

'I mean, I certainly think cancer is more genes-related than smoking-related, because, as I say, I've known so many people who live such healthy lives they were untrue, and they died terrible deaths with cancer. Yeah, so I really do believe that'

(Belinda, focus group participant, current smoker)

A strong belief that cancer is genetic may be comforting as a person may be able to absolve themselves of responsibility and justify continued smoking by reasoning that if the genes are presented then they will get cancer and if they are not then they will not. In the case of Belinda, the idea that genetics are not only responsible for cancer but also for a person smoking might have also helped her justify smoking as it is not her fault and she is somehow genetically predisposed to be a smoker. Regarding the effect on presentation, it may be that if there is a family history of cancer a person may be more aware of cancer symptoms and seek help earlier. If there is no such history then risk perception may decrease and lead to longer patient intervals.

'But, um, and my father smoked. Mother never did. And I'm the only one with the gene for smoking, like my father. The other – my sisters never smoked'

Researcher: Are you joking when you call it a gene do you think?

'No, I genuinely think er it-it is a gene. Um and some bodies tolerate it and some don't'

(Belinda, focus group participant, current smoker)

Risk perception and chance

A common belief held by many participants in the interviews was that getting cancer is a matter of chance; either a person gets it or does not, and there is no way to predict or prevent it. These participants tended not to make a distinction between cancers as to whether they were lifestyle-related or not. Although interview participant Daryl said he knew that smoking was related to lung cancer, he also referred to getting cancer as a ‘Russian roulette’ and a matter of chance, whether you smoke or not. This fed into other ideas from participants, such as previously mentioned Belinda, who gave examples of people they knew who never smoked and had cancer anyway. There was often mention of never thinking of cancer, because no one thinks it will happen to them personally. It is possible that believing cancer to be a matter of chance also allows people to have a positive outlook as there is no reason to worry about what might happen in the future as it is down to chance and cannot be changed.

> *‘I mean, everybody reads about cancer in the paper and how it effects anyway. But you don’t take it personal do you? Until it happens to you’*
>
> *(Alex, interview participant, ex-smoker)*

Risk perception, smoking cessation and previous good news

Having given up smoking a long time ago also lessened the risk perception of, and increased a sense of optimism in, many of the participants. Even if they had been heavy smokers, they tended to describe thinking that once they had stopped the risk disappeared. Interview participant Timothy, despite having once smoked 100 cigarettes a day and already suffering from COPD, had not thought he was at risk for lung cancer as he had stopped smoking a few years ago. Another interviewee, Christopher, had smoked for a long time but had given up in his 50’s and at the time of the interview was in his 80’s, this prolonged period of having not smoked may have lessened his risk perception and increased the shock of diagnosis with lung cancer. Like Timothy and Christopher, Alex and Betty also reported having given up decades before they were diagnosed with lung cancer and so were not expecting it.

Previous ‘all clear’ or positive results provided reassurance of good health, increased optimism and decreased risk perception among participants. There was a tendency among some people to rely on having had clear chest x-rays in the past, even if they were a long time ago. In her interview, Fiona explained that she knew that she was at risk of lung cancer due to smoking and was frightened of that risk. She had a clear x-ray a long time ago and explained that she had hung on to those findings and avoided going for another one for a very long time. Similarly to Fiona, interview participant Nick had also been relying on findings from an x-ray received a long time ago to reassure him that he did not have lung cancer. Holding on to these positive findings had discouraged them from further presentation as they would rather believe in the old, positive result than risk being given a new, negative one. It may also be that the fear of new, potentially negative findings arising from a new presentation is linked to sense of fatalism and the association with cancer and mortality. Those who believe that a cancer diagnosis is a 'death sentence' may be more likely to avoid that risk and comfort themselves with the knowledge that their last test was clear, even if it was a long time ago. However, it is also interesting to see that in this study, whilst interview participants such as Fiona expressed that they had held a fear of what the doctor might find, they did not express fatalism in the sense that they believed their cancer to be a death sentence whilst focus group participants had a much more negative view of cancer outcomes. It may be that the belief that nobody survives cancer changes radically when a person is faced with the reality of their own cancer diagnosis and the realisation that they do not want it to mean that they will die.

'Because I've always been frightened, with smoking. And this is why this come out with such a shock because I'd had these x rays previous. Um. I've always buried my head in the sand over it. Yeah, that sounds silly that doesn't it?'

(Fiona, interview participant, ex-smoker)

Risk perceptions and 'types' of smoking

The participants had differing opinions regarding the risk factors of smoking and this included whether or not certain types of smoking were more or less harmful than others. Most of the participants smoked cigarettes but some, for example interview participants Ivor and Ray, reported that they only smoked cigars as they believed them to be less harmful than cigarettes. Interviewee Hugh also believed that he had taken a more healthy approach to smoking as he explained that he had smoked heavily but he had always rolled his own which was better as he knew what was in them, unlike ready-made cigarettes. As each of these participants believed that they were engaging in the less harmful forms of smoking, they believed themselves to be at lower risk for smoking-related health problems.

'Then I smoked cigarettes, in seventy-six when I was managing (previous workplace) I became very friendly with a (name) who was a local GP. And he said to me, "Oh give

> *these cigarettes up." He said, "Buy a pipe or cigars. They'll do you far less harm than-than er cigarettes."'*
>
> *(Ivor, interview participant, ex-smoker)*

Similarly, perhaps, to continuing to have faith in test findings from a long time ago, participants also seemed to continue to follow advice given by healthcare professionals a long time ago. As previously mentioned in the section on symptom recognition, interviewee Rob had always remembered advice given to him by a nurse decades previously, which was actually incorrect. Rob had relied on advice regarding symptoms, whilst Ivor and Ray had been reliant on advice about smoking. Ivor and Ray, as shown in the above quote, both said that the beliefs they held about cigars being less harmful had been given to them by various doctors in the past. Relying on the word of one doctor, who had an opinion they liked, seemed to be more reassuring and meant that participants could disregard other advice or information that carried a message they did not like. Like Ivor and Ray, interview participant Hugh also repeated information he had been given by a doctor many years ago regarding smoking and cancer. Hugh reported that a doctor had told him that smoking did not cause cancer and he continued to believe that was true, even though many doctors since had told him that smoking could cause cancer. It seems as though this reliance on old medical advice and out-of-date test findings gave the participants reassurance that they were well and that their smoking was either less harmful than it could be or not harmful at all. It is possible that this reassurance could affect help seeking in primary care, as they believed themselves to be at less risk based upon this advice or on their previously positive test findings. Participants may have felt that they did not need to see a doctor when they experienced new symptoms either because they felt that they had already been or had already received advice, even though it was a long time ago. In the case of some participants, such as Fiona, the desire to hold on to old test results was so strong because they were aware of their lung cancer risk and found it preferable to be comforted by an old result than risk having a new, potentially negative result.

> *'More or less, indirectly, yes. The best one I ever met was a Polish doctor who poo-pooed the idea that that was the creation of cancer. But I still trust in what that Polish doctor said.*
>
> *(Hugh, interview participant, current smoker)*

Other health beliefs were also a feature of participants' risk perception. Some participants believed that stopping smoking would actually cause more harm than good, usually in the form of increased stress and anxiety, such as interview participant Gayle who said she was already under enough stress with having cancer to stop smoking too. However, other participants reported that they had suffered coughs and colds during periods of cessation, which they did not have whilst they were smoking. Belinda told the women in the focus group that a friend of hers had developed asthma as a direct cause of stopping smoking and that she would not have had it if she had carried on. Whilst others reported coughs and colds that they believed were due to cessation, focus group participant Liz described another negative effect of quitting when she reported that when she stopped smoking her taste buds had become more sensitive and she had had to stop eating various foods, which had now become too strong for her. The reasoning that stopping smoking could actually be detrimental to health is interesting in that it may provide the smoker with evidence, however anecdotal, that they are better off continuing to smoke than giving up. It is possible that a belief that stopping smoking will do them more harm than good could potentially influence a smoker to avoid seeing their doctor as the doctor would advise that they do stop.

Only interviewee Fred was very clear in explaining that he knew that smoking caused lung cancer and that he chose to take the risk anyway. Fred said that when he went to the hospital for his test findings he knew that he would have lung cancer and was not taken by surprise at the diagnosis. His perception of risk made him stand out among the other participants.

> *'Er..I'm intelligent enough to know the risk I took. And we got the three little strawberries didn't we?'*
>
> *(Fred, interview participant, ex-smoker)*

Risk perception and attitudes to screening

These beliefs regarding smoking and cancer risk among the participants also hold potential implications for future practice as many participants stated that, as they did not believe themselves to be at risk, if lung cancer screening were to be available they would not take it up. Many of the women in the interviews said that they regularly went for their cervical screenings but that they would not attend a lung screening, as they had never thought that lung cancer would happen to them. Similarly, some of the male interview participants said they attended their appointments for prostate screening but again, they would not have attended a lung screening as they did not consider themselves to be at risk. This is particularly interesting as it could be argued that cervical and prostate screening are more invasive procedures than a chest x-ray and yet, the participants seemed to be more comfortable with attending those appointments. There may be a perception that cervical or prostate screening is something everyone is offered, and that the cancers that they detect are not lifestyle-related in the way that smoking-related lung cancer is. People who smoke may perceive a lung screening appointment as an encounter with a healthcare professional who may judge or blame them for any negative findings. This perception regarding primary care was present in the data and will be explained in more detail in the 'stigma' section of this chapter.

'Um would I have gone? Wow. Very, very good question (sighs) I'm gonna be truthful with you. Probably not'

(Paul, interview participant, ex-smoker)

The risk perception of participants had an effect on their decision-making regarding presenting in primary care. Those who did not believe themselves to be at risk for lung cancer are possibly less likely to be aware of the symptoms or to suspect cancer when symptoms arise. Those with lung cancer who believed that their smoking was effectively balanced out by their otherwise healthy lifestyles reported being shocked at their diagnosis as they had not thought themselves to be at risk. Health beliefs regarding smoking and cancer also affected the risk perceptions of the participants and many thought that they were not at risk despite being a smoker. There was also a tendency in some participants to hold on to findings or advice provided to them a long time ago because it was from a healthcare professional and, perhaps, because it gave them reassurance that they were not at risk of cancer. This notion of risk perception contributing to patient hesitancy to present may also be linked with the gradual accommodation of symptoms that was reported by many people in the study as their belief that they are not at risk may mean that they tolerate mild symptoms for a longer period. A detailed examination of symptom accommodation is given in the section below.

Symptom accommodation and normalisation

Throughout the interview data, there is evidence of the participants accommodating their symptoms into their daily lives rather than reporting them to a doctor. The extent of this symptom accommodation was widespread throughout the participants and ranged from being mild to very serious, resulting in major changes to usual activities. It seemed that as symptoms came on gradually, the loss of ability to perform their usual activities was a slow process and therefore not seen as a cause for alarm but rather a sign of ageing or a result of stress due to life events or work. This gradual accommodation of symptoms into everyday life was very common in the participants' accounts and often continued until symptoms worsened and a 'crisis point' was reached. The crisis points differed in nature but all signified the point at which the participant could no longer accommodate the symptoms or find alternative explanations for them. The crisis point was the point at which the person decided that they would need to see their GP or, in some cases, seek emergency care.

Symptom accommodation and slowing down

The ways in which interview participants were able to accommodate their symptoms varied between accounts but often contained some similarities. Perhaps due to the study being located in North Wales, many participants talked of having experienced difficulty whilst they were out walking in their local area. Often it was mentioned that they lived in rural areas and the walking they would usually do involved hills, which they had begun to find more and more challenging. Interview participants also tended to put some emphasis on the amount of walking they usually did as if to confirm to the researcher that it was not the case that they were inactive but rather that they were previously active but had lost ability. During her interview, Betty explained that she had to walk up a hill to get to her house and that this had become a daily struggle for a long period of time. However, this had not prompted her to go to a doctor. Like Betty, Owen lived in a rural area and he too discussed the prevalence of hills in North Wales and how he had begun to find them more taxing. Owen said that he was all right if he 'walked on a flat surface' but that this was hard to find where he lived so he had cut down on the amount of walking he did.

> *'And er really does take a good five minutes if I've exerted myself. Err, and trying to find a flat, you know a flat piece of ground in North Wales is ridiculous, you know'*
>
> *(Owen, interview participant, current smoker)*

In addition to the walking people did to get around, a common everyday activity for many interview participants was walking with their dogs. Many participants reported that dog walking was part of their daily routine, sometimes multiple times a day. They also explained that when they had become too breathless or too tired to cover their usual routes then they would change to shorter walks or do them less often. Sometimes people reported that they had stopped walking the dog altogether and allowed a partner or other family member to take over this activity from them. Again, this loss of ability to carry out their usual everyday activities was accepted as part of the ageing process or tiredness due to life stress and was not seen as something worth seeing a doctor over.

> *'I've lived here for thirty-five years. And I'm convinced that this hill, up from the top, here, has got steeper every year. I'm not saying that. But er you know… old age'*
>
> *(Ivor, interview participant, ex-smoker)*

Symptom accommodation and changing routines

Some of the interview participants talked about their usual activities with regards to their sports or exercise regimes. Again, they reported a reduction in their ability to take part in those activities and that they had to adapt their routines, which sometimes culminated in reaching crisis point. Denise explained that she had begun an exercise regime with her partner with the goal of getting fit for her son's upcoming wedding. Denise and her partner had decided on running three miles in the morning and again in the evenings but then her cough started to develop and she realised that the running made it worse and she was struggling to continue. Denise had not made the decision to see a doctor when she realised that the cough meant she could no longer go running. Rather, they adapted the routine so that they walked instead; she said that had worked as she did not cough whilst walking. Denise and other participants, Mark and Mariel, had actually experienced a steep decline in their activity levels and had not considered it a reason to seek medical help until it reached the aforementioned crisis point. As well as no longer being able to manage her running routine, Denise also had to give up her beloved five-a-side football and explained that she had gone from being very fit to being unable to climb a few flights of stairs. Like Denise, Mark had been very active and had been a marathon runner in his youth and up until very recently had run several times a week. He described that not only had he become unable to run, he was struggling to walk as far as his car in the mornings. Again, similarly to Mark and Denise, Mariel also enjoyed a regular exercise routine which was then adapted to accommodate worsening symptoms. Mariel had been a regular tennis player and had been finding it harder and harder to get around the court and play at her usual speed; the crisis point for Mariel had been when she could no longer play three games and had to tell her friends to stop at two. Similarly, Owen had discovered that he was no longer able to walk around the golf course. Each of these participants spoke so fondly of their sports which were their hobbies and a part of their identity. They were all deeply disappointed at no longer being able to do them, yet they had all gradually accommodated the changes and given up the activity rather than seek help.

The loss of usual activities and changes to routines was not limited to exercise and outdoor activities, it also included the loss of ability to perform household tasks and sometimes basic self-care activities. When discussing usual household activities, gardening was often mentioned as something that interview participants had noticed that they were struggling with. Ivor in particular had begun to notice that he was losing the ability to take care of his garden. He lived in a house with a big lawn, which he had always taken a lot of pride in maintaining. Ivor explained that during the summer months, he had always cut his lawn every day and it was his usual form of exercise, but he had noticed that he was finding it more and more of a struggle. Ivor had been reluctant to give up his lawn mowing until he 'gave in to nagging' from his children who had also noticed that he was having difficulty. He explained that he had come to the decision to hire someone else to take over the responsibility. This decision had been very difficult for Ivor and he was visibly saddened at having to relinquish the care of his lawn to somebody else; he expressed a genuine sense of loss of something that was a source of enjoyment in his life and a task which gave him a sense of pride and purpose. However, he and his family had not seen this as a cause for alarm, rather they had assumed that it was down to ageing and Ivor having suffered from pleurisy in the past. In a way, this may have been the crisis point for Ivor, albeit a more passive one than some of the other participants', as he had continued with his lawn mowing for as long as he could and clearly, the decision to give it up had been a difficult one to make but eventually it had been necessary. It may have been especially hard for Ivor as he would have had to watch somebody else take over the job he so enjoyed.

> *'And I cut this lawn every day. Or, until I had this until I had the pleurisy in April. Then I gave in to the nagging from my children, either to get a sit-down mower (laughs) or to get somebody to do it. And I thought, well, sit-down mower will be a lot of money just to…'*
>
> *(Ivor, interview participant, ex-smoker)*

Mark, too, talked of losing the ability to mow his lawn and described his 'crisis point' as being when he realised he could no longer manage the entire task. Mark actually referred to his ‘crisis point’ and seemed to recognise that he had tolerated his symptoms for a long time and only decided to seek help when he reached his crisis point.

> *‘It was only when it got to crisis point, I suppose, where I went and I couldn’t mow the lawn or I couldn’t do two strips of the lawn or whatever else. Or I couldn’t walk to the car all of a sudden’*
>
> *(Mark, interview participant, ex-smoker)*

Owen also expressed a sense of sadness in no longer being able to take care of his garden. He explained that he usually kept it tidy as he and his partner liked to sit out there and they had pets, but he had ‘let it go’ lately because he was finding it too strenuous. Owen, like Ivor, had allowed someone else to take over his lawn for him, in this case his daughter’s partner and a family friend. Owen seemed especially saddened by this because the family friend was older than he was and yet he was able to manage the task and Owen was not. As decline in activity was often associated with ageing by the participants, Owen perhaps felt that he ought to be more capable that a person older than him which may have contributed to his feelings of helplessness. The loss of gardening ability, similar to loss of ability to manage DIY shown below, was particular to men in this study and of the three interviewees who specifically discussed it; Owen and Ivor seemed to feel its loss more so than Mark. Mark was still working and ran his own business, which perhaps gave him a sense of purpose, however as Ivor and Owen were both retired, perhaps they placed more value in their ability to take care of their gardens as that had now become their work and they took pride in doing it well.

Several of the male interview participants also talked of no longer being able to manage their usual DIY activities. Owen had been in the process of fitting a kitchen for a family member when he realised that he could not manage using the machinery anymore. The dust was making him cough which had never happened when he used the same equipment a few years previously. Like Owen, Sidney had found that he could not carry out DIY tasks he was used to being able to do. Sidney had been putting up a conservatory, something he had done before, and found that it was taking him much longer than he had anticipated and that he was having to take frequent rest breaks. However, Sidney differed from Owen and many other interview participants in that he had taken this to be a sign that there was something wrong and had sought help from his GP; however, he presented repeatedly and felt he was not taken seriously due to his age. The loss of his DIY ability was Sidney’s crisis point as he felt that it was his responsibility to perform these tasks for his family and was perhaps letting them down by being unable to manage. Sidney had had to give up his driving license following his diagnosis and was hoping to get it back as he had a daughter with health problems and it was usually his job to drive her to her appointments. This, along with no longer being able to do DIY, may have added to Sidney's frustration at his repeated presentation as it meant he was unable to take care of his family as he usually would.

> *'Yeah, no, and then they – it was getting worse and then I kept going around there 'cause it was taking me longer to do this conservatory, which should've been done weeks before it was finished and I couldn't do it half the time. I was having to rest'*
>
> *(Sidney, interview participant, ex-smoker)*

Fred too was frustrated by the fact that he was struggling with his DIY activities. He had recently moved to a new home and had 'lots of little jobs' he wanted to do, and was finding that he was unable to complete them. The frustration at struggling with tasks as reported by Fred occurred throughout the participants' accounts but the small frustrations often were accommodated until they accumulated enough to reach crisis point before the participants sought help.

> *'I'd be coming back from taking the dogs to walk, have a cup of tea, go and sit in the lounge and nod-off. Which is not me. It's not me. We'd just moved, then, to the bungalow we're in now. And I had loads of little jobs I wanted to do'*
>
> *(Fred, interview participant, ex-smoker)*

Some of the interview participants also described changes in ability to do household activities other than gardening or DIY. The ability to climb stairs or do laundry was mentioned several times. Mariel explained that she had always done the family laundry but since her symptoms had worsened, she had been unable to do so. Since having her treatment, she was beginning to feel better and she told me during the interview that she was planning to do some ironing later that morning. She did however concede that she still was not quite back to her usual level of ability; after her interview she pointed out the laundry room to show how her husband had set up the ironing board for her and put the basket of clothes on a stool so that she would not have to bend down. It was not the gradual decline in household tasks that had prompted Mariel to seek help though. It was when she was no longer able to play tennis, and interestingly she was more alarmed at no longer being able to do a far more exerting activity than a relatively simple one such as ironing. Perhaps because she enjoyed one activity more than the other she felt its loss was more serious and therefore that was the moment that prompted her to seek help.

> *'Um I was playing tennis here, and always play three sets. Played tennis all my life. Um and er I played two sets and I came to the net and I said, "Girls, I'm awfully sorry," I said, "I can't play a third set today. I'm not up to it." I said, "I can't, I'm struggling with my breathing."'*
>
> *(Mariel, interview participant, ex-smoker)*

Interview participant Helen had also had difficulty bending down and had begun to notice that every time she did so, she coughed. She also reported feelings of fatigue and difficulty managing her household tasks. She had not thought of this as particularly serious and had not decided to see her GP until she found that she was so tired that she did not have the energy to dry herself after getting out of the bath. Helen had accommodated her tiredness and lack of energy until it reached crisis point, at which point she had decided that that she needed to see her GP. Like Helen, Fiona had noticed that household tasks left her feeling fatigued and breathless. Fiona reported having struggled with getting up and down the stairs, getting out of breath and needing to stop halfway up. As previously mentioned, Fiona suffered with COPD prior to her lung cancer and had thought that she was having 'bad days' which may explain why she did not seek help sooner when she realised that she was struggling to climb the stairs. Instead, she had waited until her COPD check-up and mentioned it to the nurses then. Fiona knew that she had an upcoming COPD appointment and so perhaps she felt that she would rather wait for that than make another appointment in primary care. Helen however, did not have any comorbidities that may have caused her extreme fatigue and yet she also hesitated to seek help until she reached a point where she could no longer tolerate the symptoms. This may be another way of legitimate help seeking and a desire to not waste a doctor's time as this crisis point is a clear sign that help is needed. The concepts of legitimate help seeking and time wasting will be discussed in further detail in the 'help seeking' section of this chapter.

> *'The worst part, I found, was having a bath. I was already puffed out or what-have-you. And I thought, "I've gotta get in the bath," you know. And… I washed myself, and I just… I-I couldn't have any energy to dry myself. You know, I just wrapped in a towel, kind of thing. And um I thought, "Gosh, am I gonna be like this for the rest of my life?"'*
>
> *(Helen, interview participant, ex-smoker)*

There was a noticeable gender divide in the types of usual domestic activities that the participants reported having difficulty with. The men tended to talk in terms of the outside domain, of gardening and DIY, whilst the women discussed inside activities such as laundry and cleaning. Only Timothy talked of ‘taking out the bins’ which, in some way, bridged the gap between indoors and outdoors. Many interview participants talked of the loss of other outside activities such as running and walking but it is interesting to see that domestic activities seemed to be divided in this way although leisure activities were not. The men in this study seemed to feel that their crisis points were very much related to their ability to carry out their usual household duties and this was perhaps due to attaching a sense of masculinity to tasks such as DIY or gardening. The loss of these activities impacted upon their lives and their identity as men and this could perhaps contribute to their longer intervals as they struggled to adjust to their symptoms.

Symptom accommodation and sleeping patterns

Changes in sleeping patterns were mentioned by some of the interview participants in this study. Aside from the tiredness reported by those having chemotherapy, people also reported changes in sleeping patterns prior to diagnosis. Fred explained that he had begun to feel exhausted by his usual routine and had begun needing to have a sleep after certain activities. He stated that this was very unusual for him and was frustrated that he needed to sleep in the afternoons rather than go about his usual daily activities. Rob too had noticed that he was tired, but also said that he had always ‘liked a nap’ but had noticed that his napping had become more frequent. Whilst Fred had found this tiredness a source of frustration and barrier to his daily activities, he still had not thought it a reason to see his GP. It is perhaps understandable that Rob did not see a reason for help seeking as his increased sleeping had not particularly bothered him. Sidney too had felt increasingly fatigued and explained how he had regularly gone out to a local pub with his wife for meals but had started to feel like he needed to go home as soon as they had finished eating to go to sleep. The opposite of this was Nick, who had found that his symptoms were rendering him unable to sleep. Nick was already suffering from pain due to an existing spinal injury, and his new symptoms had included back and chest pains and breathlessness that all made it hard for him to lie down. He felt guilty at disturbing his wife in the night so had taken to staying awake and sitting in a living room chair all night. This was a big change to his usual activities and caused great disruption to Nick’s life. He was sleep deprived and distressed at not being able to share his bed with his wife, yet as he believed his symptoms were due to his existing conditions he had not sought help and did not see this new decline in ability as a new symptom but as an extension of an existing one. It is possible that fatigue is a difficult symptom for people to recognise as they may attribute it to ageing or being tired from stress or life events as mentioned earlier. It may also be that fatigue is a rather vague symptom and therefore participants did not see the need in seeing their GP about it. Whilst fatigue is a symptom of cancer, in participants' minds they may not make a direct correlation between their smoking status, fatigue and potential lung cancer.

'Um so – but I wasn't sleeping, I was only getting two hours sleep the whole day. So I was disturbing my wife, she wasn't getting any sleep. I was just getting up and sitting in the chair, waiting for the sun to come up'

(Nick, interview participant, current smoker)

It is possible that people are able to provide alternative explanations for their symptoms and find ways to accommodate them up until they reach a crisis point. The crisis point seemed to be a significant moment in the help seeking process for these participants as it acted as the point at which they were no longer able to ignore or accommodate their symptoms and had to make the decision to seek medical advice. Up until this crisis point was reached, many of the interview participants had accommodated their symptoms by changing their daily routines and adjusting their activities accordingly. In some cases these routine changes were quite drastic yet participants still seemed to have hesitated until reaching crisis point before seeing their GP or presenting in emergency care. Up until the crisis point, daily life was altered to fit around the symptoms which were often attributed to other, non-cancer related causes and, as the next section will explain, sometimes self-treated in other ways by participants.

Symptom occurrence and methods of self-treating

Self-treating, help seeking and the pharmacy

Currently in the UK, people are often advised that when they experience minor symptoms such as cough, cold or flu that they should first seek help from their pharmacist and not go straight to primary care. This is an attempt by the NHS to avoid inefficient use of GP time in cases which are treatable with over-the-counter medicines available from pharmacies. These measures may influence timeliness of help seeking if patients believe that their symptoms are minor and wish to try over-the-counter medicines first and then wait for a period of time for them to work instead of going straight to the GP. This NHS measure also relies on how the patient perceives their symptoms and as shown in the sections above, perceptions of what constitutes minor symptoms can vary widely.

Participants in this study reported a delay in seeking healthcare if they felt that they could, or should, try to treat symptoms themselves with over-the-counter medication first. The general feeling seemed to be that one would try self-treating with remedies from the pharmacy first, and then if that did not work they could justify seeing the GP. Interview participant Sion described how he suffered with a cough for a while but had treated it himself with over-the-counter cough medicine rather than see his GP. Sion explained that the cough medicine had ‘cured’ the cough for a while but then it had reoccurred, however he still did not see the GP until he discovered a lump on his arm. It may be that, for Sion, seeing his GP for the lump constituted a more ‘legitimate’ form of help seeking as he would be unable to treat a lump himself and there would not be an over-the-counter solution. Focus group member Anthony explained that if he did not feel ‘ill ill’ he would try the chemist first. Seeing a pharmacist is a form of help seeking but is perhaps more legitimate initially as no appointment is necessary. Whilst it is perhaps not unusual for people to try the pharmacy route before going to the GP, Anthony said he would still delay seeing the GP for an extended period of time. He reported that he would try over the counter remedies for up to six weeks before he would consider contacting his doctor.

> *‘No, only went with the lump, wasn’t it? Just buy Benylin. Every time I have a bit of a cough, just buy Benylin, see. Then that cured it for a while, then it come back again. Then I went with the lump on the arm, decided to x-ray the lungs as well didn’t he?’*
>
> *(Sion, interview participant, ex-smoker)*

Other participants also reported that when a person suffered what they perceived to be minor symptoms then they should attempt to treat themselves first in order to save time for both themselves and for their doctors as per current advice. For example, interview participant Alex said he would not go to the doctor with something minor such as a sore throat, instead he would try taking paracetamol for a few weeks and see if that solved the problem. Similarly to Anthony, as previously mentioned, Alex reported what seems like a fairly long period of time self-treating before seeing a doctor. Whilst Anthony was a current smoker who did not have lung cancer, Alex was an ex-smoker who now had a lung cancer diagnosis yet he still believed that he would wait and try over-the-counter medicines before seeing a GP. As described earlier in the chapter, Alex had seen his GP when he suffered chest pain and this may be due to the belief that chest pain is a serious symptom that cannot be treated by a pharmacist whilst something like a sore throat can. Interview participant Daryl felt that he ought to try everything he could before he sought help from healthcare professionals. He said that that he would do anything he could to manage the problem himself with non-prescription medications and would only see the GP once things became genuinely unbearable. This is another example of reaching a crisis point. The point at which a symptom becomes unbearable is subjective and may differ from person to person, however, what matters is that they themselves have reported it as unbearable. Interview participant Mark seemed to see help seeking a sign of weakness and reported that he would rather try and sort things out himself rather than go ‘running for help’. Daryl and Mark both expressed the belief that one should try to treat symptoms at home first before accessing primary care, they both explained that it was wrong to go directly to the GP, however whilst Mark seemed to see help seeking as a sign of weakness, Daryl was more concerned with potentially wasting time, that of the GP and his own, by taking up an appointment with a problem he could have treated himself.

Self-treating and access to services

Access to services was also a factor in decisions to self-treat as many participants felt that it was easier to try over-the-counter medicines than it was to wait for an appointment with their GP. Interviewees Rachel, Lloyd and Sion all said that they would attempt to treat symptoms themselves first by taking paracetamol for pain and over-the-counter cough medicine for any other chest symptoms. Interviewee Jane had attempted to soothe her symptoms with throat sweets. Participants also reported being able to self-diagnose in some instances. Several people in interviews and focus groups said they could tell the difference between their usual smokers cough and symptoms occurring through their comorbidities and anything that could be considered more serious. In some cases, participants explained that they felt that doctors were untrustworthy and therefore they preferred to self-diagnose and to self-treat. Liz in particular was extremely wary of doctors and stated that she never went to see her GP if she could avoid it. She felt that doctors were uninformed and that they actually did not follow correct procedures and therefore she refused to see them. It is interesting here that Liz uses the word ‘diagnose’ when talking about assessing her own symptoms, similarly to Mark when he described believing his ‘diagnosis’ of a training injury to be correct. Interestingly, Liz's views regarding GPs and their lack of knowledge was somewhat echoed through the other members of the focus groups, they conceded that GPs were generalists rather than specialists and therefore could not be relied upon to always make accurate diagnoses. Interview participants however did not express this view, which may be due to having sought help for symptoms and having received an accurate diagnosis of lung cancer. Interview participants descriptions of healthcare professionals was often more positive than those of the focus groups participants.

> *'But back to the inadequacy of diagnosis. That they don't do the correct tests for the symptoms. Which is, as I say, why I stay away from the doctors. I self-diagnose'*
>
> *(Liz, focus group participant, current smoker)*

The idea that minor symptoms should be treated at home first with over-the-counter medicines was raised by both focus group and interview participants in this study. As previously mentioned, current NHS advice suggests that seeing a pharmacist should be the first step in the help seeking journey for minor symptoms, including cough, which may be indicative of lung cancer. However, some of the participants in this study reported trying over-the-counter medicines for what may appear as quite prolonged periods of time before taking the next step and contacting primary care. The accounts of the different populations here are interesting as it was expected that they might differ due to focus group participants discussing more hypothetical symptoms and interview participants giving their accounts of real symptoms leading to a lung cancer diagnosis. However, participants in both groups reported that they believed the first thing one should do for minor symptoms is attempt to self-treat rather than going straight to primary care, a belief that may affect time to presentation and potentially cancer outcomes. These beliefs about use of the pharmacy first were closely linked with participants' beliefs regarding help seeking and access to healthcare.

Access to health services

When symptoms are experienced, the decision of whether or not to seek help in primary care may be affected by perceptions of gaining access to services. In this study, many participants recalled difficulty in gaining access to primary care services due to what they perceived as a strict gatekeeping culture. This applied firstly to being able to get an appointment at all and secondly to being able to access the desired healthcare provider.

Accessing services and navigating the system

Interestingly, many participants in both interviews and focus groups reported that due to the perception that it would be hard to get an appointment there was simply no point in trying. Often participants stated that they knew they would be given appointments that were weeks away and that any symptoms would have got better on their own by then, so there was no point in making the appointment in the first place. This is of particular concern as it means that they were not even attempting to contact their GP until they realised that the symptoms had got much worse or reached crisis point. They may still have had a long wait for an appointment, further increasing their patient intervals and potentially jeopardising their outcomes.

'A lot of people are gonna say there's no point because I can't get an appointment, as you said'

(Russell, focus group participant, current smoker)

Inconvenient timing was also an issue when attempting to make GP appointments as people explained that they were expected to telephone the surgery early in the morning and often it would take them a long time to get through, at which point they often reported being told that there were no appointments available. The need to telephone early in the morning was inconvenient for some as they were working and did not have time to be put on hold; often those people also reported that having to take time off work for the appointment itself was not convenient, especially for participants who were self-employed. A few people also felt that having to get up early especially to make the phone call was inconvenient, as they did not usually get up that early. There was also a perception among participants that if you did manage to get an appointment then you would be left in the waiting room, perhaps for hours, waiting to be seen. The possibility of having to wait several hours for a ten-minute appointment, which was seen as insufficient time to explain the problem, was incredibly off-putting and contributed to the idea that it was easier not to bother.

'Again, I'm not an early-riser and I don't feel like getting up at half-past seven in the morning to go to the surgery, on the chance that I'm gonna get an appointment that day'

(Daryl, interview participant, ex-smoker)

Whilst these concerns about access to primary care were present in both interview and focus group populations, they were much stronger in the latter. In all three focus groups, participants discussed the difficulty of ‘getting through’ to the desired person within their general practices. There was a feeling of primary care as a multi-gated system which needed to be negotiated carefully in order to access the desired services. The first step in this gatekeeping system is actually getting the phone call answered in the first place and speaking to the receptionist. There was a strong sense of feeling that GP receptionists are the first barrier that needs to be overcome, first of all by being persistent enough to keep calling until someone answered the phone. Some participants thought that there was a possibility that receptionists sometimes just chose not to answer calls if they did not feel like it. Then, there was the telephone negotiation to actually land an appointment.

> *‘I-I do redial on my phone, yeah? When I’m phoning for an appointment in the morning ‘cause it’s engaged. [Laughs] And I think, right, it’s right on eight o’clock when I’m redialling. By the time I get through, there’s no appointments. And I’m thinking, well, hang on a minute, here! I’ve been there, on the ball. How many people have they spoken to in ten minutes? So that there’s no appointments left? And you think, “Oh, I’ll just take some paracetamol.”’*
>
> *(Paula, focus group participant, ex-smoker)*

Accessing primary carer and the gatekeeping culture

Several focus group participants explained that they found having to deal with receptionists as irritating, as they did not like giving the receptionists descriptions of symptoms particularly as they felt that it was not their business. Receptionists were seen as barriers between doctor and patient and were certainly not very popular among the focus group participants. Focus group participant Anthony referred to ‘Rottweiler receptionists’ conjuring up the image of the receptionist as a guard dog standing between him and his GP. There was a strong feeling that receptionists would try to prevent them from seeing their GP if they could. Anthony did concede that it was the receptionist’s job to take the phone calls but he and the other participants in the group expressed the belief that the role of the receptionist was to prevent people getting appointments rather than to book appointments. There was a mutual agreement in this focus group that surgeries needed to cut down the amount of appointments they made by eliminating the ones which they deemed unnecessary and, as the GPs do not have time to do this themselves, employ receptionists to do it for them. There was an understanding that the receptionist needed to screen calls in order to stop perceived ‘time wasters' but also a frustration as this system also prevented 'genuine' calls like theirs from getting through. This concept of 'time wasting' is revisited further on in this chapter.

'It must be difficult for GPs, themselves, to sort out the wheat from the chaff. Hence the fact that they employ Rottweiler receptionists at times. Right?'

(Anthony, focus group participant, current smoker)

The second stage in the gatekeeping system would be to 'get past' the practice nurse. Participants also felt that initially the receptionists would try to give them an appointment with a practice nurse rather than with a GP. This was seen as a way of further preventing access to the GP and almost as a waste of time as they believed the nurse would not be able to manage and would need to refer to the GP anyway. Participants were annoyed that this would require further appointments once the nurse realised that they did in fact need to see a doctor.

Due to the general perception that gaining access to primary care would be inconvenient and involve many phone calls and long waiting times, the interview participants who had seen their GP with their symptoms expressed some surprise that they had managed to get appointments and quick referrals. Participants often referred to themselves as 'lucky' if they had gained an appointment in what they saw as a reasonable timeframe. One interview participant in particular, Daryl, repeatedly expressed how lucky he felt as there had been a cancellation at his surgery the day he telephoned and so he had an appointment that day. Interview participants were also comforted by being able to now bypass primary care with all its perceived problems and barriers and go straight to secondary care. Daryl himself referred to this as his 'get out of jail free card', meaning that as he now had a cancer diagnosis he was able to go directly to secondary care and was pleased that he no longer needed to worry about the issue of gaining access to primary care. This is interesting as Daryl seemed not only pleased at being able to avoid the issues surrounding primary care access, but also in some way comforted in knowing that there was help available to him and he had been given permission to access it, another form of legitimate help seeking which will be discussed further later in this chapter.

The concept of gatekeeping came up regularly, with the focus group participants in particular. It seemed that people saw healthcare access as a series of obstacles to overcome before reaching the desired healthcare provider. Perhaps surprisingly, GPs were also seen by some as obstacles, as they were the gatekeepers to secondary care which was, by some, considered the 'best' care. The baton of power over these decisions was then passed between the receptionist, the practice nurses, and finally the GP who has the power to refer, or not, to secondary care. The gatekeeping culture perceived to be at work in primary care also appeared to be linked to the participants' smoking status as many of them reported being stigmatised in primary care due to being a smoker. This perception of stigma from healthcare professionals is presented in the following section of this chapter.

Stigma and health

Stigma from healthcare professionals

During the study, in particular during the focus groups, it was revealed that many of the participants deliberately avoided primary care due to a perceived stigma against them due to be being smokers, especially if they were suffering from potentially smoking-related symptoms. The feelings of stigma were multi-layered and extremely complex, encompassing of many related strands.

Stigma and access to services

Access to primary care, as previously discussed, actually went much deeper than the practical issues around getting an appointment with some participants believing that they were deliberately obstructed by healthcare staff due to feelings of being stigmatised as a smoker with a potentially smoking-related illness. Focus group participant Clare felt that she was stigmatised by the receptionist at her practice due to being a smoker and she believed that the receptionist stigmatised her more so than the doctor did. Clare also felt that when she did manage to get an appointment, she was left in the waiting room longer than other people who had arrived later than she had. Clare perceived that the receptionists deliberately delayed her in the waiting room due to her being a smoker and therefore to somehow punish or blame her for her own condition. Other participants disagreed with Clare but she was not convinced by their arguments.

> *'Yeah, but yes, I do by the receptionists and that. Maybe it's not the smoking. But I do find that they treat people differently to… the…way that the doctors treat you. I do find that. I mean, if it was up to me I would ban receptionists whatsoever'*
>
> *(Clare, focus group participant, current smoker)*

As previously mentioned, appointments with practice nurses were described in participants' accounts as a way for receptionists to prevent people from seeing their GP straightaway.

These appointments were also reported to invoke feelings of stigma in participants in two ways: stigma from receptionists who had decided that a smoker was not allowed to see the doctor, and then further stigma from nurses for being smokers. The gatekeeping system was then further perpetuated by the GPs themselves as they are the ones who hold the power to make diagnoses, prescribe medication, and, if necessary, refer to secondary care. Participants referred to being stigmatised by their GP, who would be reluctant to allow a smoker access to further care. Secondary care however was not seen to stigmatise and was where the real help could be found, perhaps because secondary care is not responsible for advising on smoking cessation whilst primary care is. In one focus group, participant Dean explained that once you were able to 'get past' the GP and into secondary care then you would get the genuine help from people who would not stigmatise you for being a smoker. The focus group participants had particularly strong feelings that primary care was a battlefield to be carefully negotiated in order to get past each stage of gatekeeping and gain access to what they really needed, such as a prescription or a referral.

'But I think once-once you get past your GP, if you get into the hospital system, you get real, genuine help from people who don't stigmatise you, generally speaking, people who don't stigmatise you'

(Dean, focus group participant, ex-smoker)

Following the initial gatekeeping concerns, participants also reported that they found the physical environment of the practice waiting room inspired feelings of stigma against smokers from healthcare services. Participants in the women's and the men's focus groups found that the overwhelming presence of anti-smoking and smoking cessation literature in the GP waiting room was oppressive and stigmatising, implying that all health problems were caused by smoking and that people who smoked were responsible for their own ill health. Several of the participants also reported that the presence of 'no smoking' signs in waiting rooms made them feel as though they were being targeted or singled out as a population deserving of stigma. The 'no smoking signs' also seemed to emphasise the feeling among participants that smokers were targeted more so than others who engage in practices detrimental to health, such as those who misuse drugs or alcohol, as they do not put up signs telling people not to drink or use drugs .

> *‘Well, I suppose… I suppose… um… everywhere you go and doctor’s surgeries included, you’re confronted everywhere. “No smoking, no smoking.” So, they’re reinforcing this stigma, all the time. They’re reinforcing this bad behaviour that people have’*
>
> *(Trish, focus group participant, current smoker)*

In terms of the health literature on display in waiting rooms, it is likely that it includes advice on alcohol and drug use but it may be that there is much less of it, or that the smoking cessation literature is more obvious to those who smoke. It is possible that they already feel stigmatised and therefore are looking for further evidence of that stigma. Whilst ‘no smoking’ signs are ubiquitous in public spaces and participants reported feelings of stigma in society in general, these feelings were magnified within the doctor’s waiting room. Focus group participant Trish in particular reported that the doctor’s waiting room was the worst place for making her feel stigmatised as a smoker. This is perhaps due to anticipation at being stigmatised or even reprimanded by the GP and perhaps to feelings of increased vulnerability and fear due to being unwell. During the focus group, Clare agreed with Trish and said that she thought GPs were able to use smoking as a scapegoat for all kinds of health problems so that they did not have to investigate properly; she again cited various leaflets she had seen in the waiting rooms which detailed smoking related illness.

> *‘Smoking causes this, smoking causes that. Shouldn’t be smoking because it’s causing heart disease, diabetes, everything else.” And I think, “How many people have got diabetes that have never smoked in their lives?”’*
>
> *(Clare, focus group participant, current smoker)*

Stigma and encounters with healthcare professionals

Whilst the majority of participants described feeling stigmatised by their healthcare providers in some way, a few focus group participants reported that they had experienced direct encounters in which they felt that they were stigmatised as smokers. Harvey felt strongly that his GP was prejudiced against him because he smoked, and Belinda and Trish reported having been treated unfairly due to being smokers. Trish explicitly stated that she was so unhappy with the treatment she received from one GP at her practice that it had put her off ever going again and that she would not see that GP again as she would feel victimised by her. Barry also felt that his GP had directly stigmatised him as a smoker, however Barry was also the only participant who felt that he had also been stigmatised in secondary care as well. It is often recognised that an important part of the relationship between a healthcare provider and a patient is trust. This perceived stigma toward smokers can be seen a breach of that trust by the patient in several ways; the patient can no longer trust that they will not be judged, the patient cannot trust that they will receive the help they need, and the patient may no longer feel that they can tell the doctor the truth. This notion of a breach of trust is implied throughout the focus group discussions regarding stigma, however it was Trish again who explicitly stated that she feels that she is unable to trust her GP.

There were concerns about potentially being stigmatised in situations with healthcare professionals with whom they had not met before. Participants seemed to express dissatisfaction when they saw a doctor that they had not seen before such as a locum or a new GP and felt that these doctors did not know them and therefore had no business judging them for their smoking or trying to advise them on cessation. Participants expressed a preference for their ‘own GP’ because they knew them and therefore were less likely to be stigmatised by them. Perhaps if they had not felt stigmatised in previous consultations then they would feel safer seeing the same GP again. Trish described two encounters with primary care which actually sounded very similar, however she was very unhappy about one of the appointments as it was an experience with a doctor she didn’t know. She described the experience with the nurses she had met before in a much gentler way. This is potentially because people are more inclined to take advice or criticism from people that they feel comfortable with whereas they do not want to feel judged by a stranger. Clare too referred to her own GP as being a ‘good doctor’ because he knew not to try to advise her about smoking, rather he understood that she was unable to give up and respected that. She also said that she would not see any other doctor at the practice as they would stigmatise her as a smoker and would not have the same level of understanding as her regular GP. Belinda also reported that she had had more than one encounter with a healthcare practitioner whom she had felt stigmatised by. Belinda and Trish attended the same surgery and discussed which doctor they both suspected was negative toward smokers. Interestingly, it did not seem as though they had seen the same GP due to their different descriptions.

‘I don’t know who she was, really, but she was absolutely horrible. She said, “You smoke?” I said, “Yes.” And she said, “Do you want to give up?” So I said, “No.” So she said, “Right. I’ve advised you on smoking cessation.” I thought, “Ok, tick your box. Get your money”’

(Trish, focus group participant, current smoker)

Dean explained that he had avoided seeing the GP for a long time due to a sense of perceived stigma. In Dean's case, this was due to him knowing somebody who moved in similar social circles to him who happened to be a GP. Dean described this person as being extremely prejudiced against smokers and therefore Dean was worried that he would be seen by this person were he to book an appointment. Dean said that he avoided the surgery altogether until he knew that this particular GP no longer worked there. Participant Len also expressed concern about stigma from healthcare professionals but this was again based on perception rather than an actual experience. He said that when he saw the doctor he often thought that they would stigmatise him even if they did not explicitly express it. Len described 'knowing what the doctor is thinking' when he talked about feeling stigmatised by health professionals.

Len: Second you walk in the surgery you know what the doctor's thinking.

Dean: Exactly.

Researcher: What is the doctor thinking as soon as you walk in?

Dean: The doctor's gonna say, well –

Len: That this guy smokes and it's – whatever he's got is his own fault.

(Len and Dean, focus group participants, ex-smokers)

Stigma, healthcare professionals, and 'lifestyle' related symptoms

Alongside feeling generally stigmatised by healthcare providers for being smokers, the participants in the focus groups seemed to feel an extra sense of stigma if they were seeking help for a symptom that could be smoking-related. Seeing the GP regarding a cough, as well as being seen as a potential waste of the doctor's time, was also revealed to be a possible source of stigma for the patient. The focus group participants explained that doctors would almost certainly tell them, or at least remind them in some way, that it was unsurprising they had a cough because they smoked. The focus groups in particular highlighted this notion that smokers would be dismissed by the GP and asked 'what do you expect?' if they presented with a cough or chest symptoms. There was a general feeling among the focus groups that healthcare providers are actually not interested in helping those who smoke, as they are to blame for their own problems and are less worthy of care than those who have not smoked.

Again, Trish was particularly of the opinion that doctors do not want to help smokers, and she asked why this research was being conducted because she thought it was very unlikely that doctors care about what smokers think. Barry too expressed strong opinions regarding being stigmatised by the GP for smoking; he believed that there would be no point in seeing his doctor for smoking-related symptoms, as they would be unwilling to help. Barry also wondered whether it was worth telling the truth about his smoking status but he also did not seem to have faith that that would work as the GP would be able to tell he was a smoker 'because of the smell'. Some participants who said that they wanted to avoid having conversations with their GP about smoking seemed to take one of two options: either see the doctor but lie about their smoking habits or avoid going altogether. Belinda also said that she lied to the GP about how many she smoked a day but she also said that GPs ought to expect patients to lie so they should automatically double the figure the patient gives. Trish said that she told the truth to her doctor about her smoking; however, she also said that she actively avoids the doctor because she does not want to talk about smoking.

> *It's actually coming to the point of: do we tell the truth about the smoking side of it? Do we ask for help? And when we do ask for help, do we get the help? No, we don't. We get ignored. And this is where the point is: around this table, we've mentioned many times about being stigmatized and labelled. You are a smoker, what do you expect?*
>
> *(Barry, focus group participant, current smoker)*

Whilst the focus group participants explained that the sense of stigma they perceived from their healthcare professionals due to being smokers was a reason for them to avoid the doctor, they also detailed how smokers were heavily stigmatised by society in general, the focus group members also often expressed stigma toward other people with lifestyle related health problems. It was expressed in the focus groups that smokers were unfairly stigmatised for their smoking whilst other service users with different 'self-inflicted' conditions or unhealthy lifestyles were not. Focus group participants expressed feelings of stigma regarding people who abused drugs and alcohol, and obese people. During the women's focus group there was much discussion around people who abused alcohol. Belinda in particular explained that smokers did not cause any harm to anyone but themselves whilst people who drank were volatile in temperament and were potentially violent and dangerous. She did not however mention the dangers of passive smoking. Alcohol was also a focus in the couples group as the participants again described feeling that people who drank were not stigmatised at all and yet they used valuable NHS resources in the same way as smokers did. This sense of being singled out for stigma as smokers seemed to add to their reasons for not wanting to see their GP when they suffered smoking-related symptoms as they felt that they were being treated unfairly, having to endure a consultation which left them feeling stigmatised, whilst other people were given help without question for their drink or drugs-related issues.

> *'I-I get – I get quite angry when I think about it, that smokers are attacked as pariahs because of our cost to the NHS. But I don't see the same concentration on obesity and on alcohol consumption'*
>
> *(Russell, focus group participant, current smoker)*

Obesity was another issue raised in the focus groups and was first brought up in the women's group by Trish when she described her encounter with the new GP she had felt stigmatised by. Trish was not only angry that she had been made to feel stigmatised for her smoking, she was also angry because the doctor who had made her feel this way was obese. Trish explained that she believed it to be extremely hypocritical for a doctor to be obese in the first place and even more so for her to then be able to advise others on their smoking habits. This experience, and the potential of it happening again, had left Trish determined to avoid seeing her GP as much as she possibly could. Belinda agreed with Trish and explained why she thought that obesity was just as harmful as smoking:

> *'Well they reckon each extra stone is equivalent to twenty cigarettes a day in the strain on your body'*
>
> *(Belinda, focus group participant, current smoker)*

The participants in the men's focus group also expressed strong feelings about being stigmatised as smokers whilst other people with unhealthy lifestyles were not, however they focussed on obesity and drug-taking far more than alcohol. As mentioned earlier in the chapter, early on in the focus group both Dean and Barry disclosed that they had suffered with alcohol related problems in the past. Dean disclosed this information first and it seemed as though he wanted to get it out of the way, perhaps in anticipation of the discussion stigmatising people who abuse alcohol and him wishing to avoid it. Barry followed Dean and said that he too had alcohol addiction problems. The men then avoided discussing alcohol abuse, perhaps to avoid offending Dean or Barry, and focussed instead on obesity and drug use as unhealthy practices that received less stigma than smoking. Benjamin also described how he perceived smoking to be stigmatised by society in general while unhealthy eating and drinking alcohol are not. He pointed out that people would ask smokers to stop smoking in public spaces but they would not ask someone why they were drinking wine instead of water or a burger and not a salad. He saw this as an example of the unfair stigma received by smokers. Like Belinda before him, he did not mention passive smoking:

> *'I wouldn't dream of frowning upon somebody that went for a burger and chips as opposed to a tuna salad or something like that, in a restaurant. You know, you wouldn't – I wouldn't dream of saying, "Well, why are you eating that rather than something that's healthy? Why aren't you drinking water instead of alcohol?"'*
>
> *(Benjamin, focus group participant, current smoker)*

This sense of unfairness at being stigmatised by both society and healthcare professionals for their smoking whilst other people, who, in the opinions of some participants, were more deserving, were not stigmatised at all had an effect on help seeking. There was a perception that while healthcare professionals and gatekeepers did their best to thwart smokers in their help seeking by fobbing them off or treating them poorly, people who were obese, alcoholics or drug takers could access services and be treated with respect even though their problems could be lifestyle-related. This enhanced the feelings of stigma among the smokers and exacerbated their desire to avoid the doctor.

Stigma, smoking and societal change

There was a sense of frustration expressed by some focus group and interview participants at being stigmatised for smoking due to changes in societal perceptions. Smoking was described by participants as something that was once glamorous or even encouraged and in recent times had become an undesirable and stigmatised practice. In the first focus group, consisting of three female participants, the women discussed how, when they started smoking, smoking had been glamorous and that they had practiced in the mirror, and recalled buying coloured cigarettes in order to look fashionable. The women in this group seemed to have fond memories of the days when smoking was a desirable and widely acceptable practice. During the interviews, many of the male participants described how, in the past, they had been encouraged to take up smoking by peers and often mentioned that they were provided with free tobacco or cigarettes when they were in the armed forces. There was a sense of unfairness, particularly among focus group members, that they were being stigmatised for something that was once so prevalent and acceptable in society.

Clare: We were encouraged to smoke in those days

Belinda: It was cool

Clare: Oh yes, it was cool, yeah…..

(Clare and Belinda, focus group participants, current smokers)

These strong feelings of stigma from healthcare professionals was largely expressed during the focus groups and not the interviews. This is interesting as there may be several reasons as to why. It may be that the focus group methodology exacerbated feelings of stigma as the members were able to join in together and compare experiences and ideas, which then encouraged them to become more passionate about the subject. It may also be that the interview participants were thinking less about hypothetical situations or experiences that had happened in the past but far more tangible recent experiences. Whilst interview participants did report feelings of stigma from society in general regarding smoking, they did not report the same sense of stigma coming from healthcare professionals. This may be because, as they now had a lung cancer diagnosis, they were thinking of recent encounters in which they felt that they had received good quality care. Whilst interview participants did not seem to have the same concerns regarding stigma and smoking as the focus group participants, both groups shared concerns regarding help seeking and the possibility of wasting doctors' time; this is explained further in the section below.

Wasting healthcare professional time

Wasting time and minor symptoms

There may be a perception in UK society that doctors are busy people and that NHS time is valuable. One prominent theme running throughout the data collected in this study is patient concerns about wasting the time of the doctor. During the interviews, almost all of the participants explained they believed that it was important not to waste the doctor's time with seemingly minor complaints such as colds, sore throats or coughs. As all of these people had since been diagnosed with lung cancer, these were often the first symptoms that they themselves had experienced and often contributed to hesitancy in presentation. Focus group participants also expressed strong feelings about seeing the GP for what they perceived to be minor ailments. However, accounts of wishing to avoid time wasting did differ somewhat between the interview and the focus group participants. The interview participants, now diagnosed with lung cancer, tended to talk in the past tense, reasoning as to why they had delayed seeing the doctor due to not wishing to waste time on insignificant things. The focus group participants were more defiant in their opinions on not wasting doctors' time; they talked in the present tense, giving reasons for why they do not currently see their doctor with symptoms unless they deem them to be serious enough. Examples of symptoms that both focus group and interview participants described as minor and not worth wasting time with included coughs, colds, and sore throats These symptoms were also often reported to be the first symptoms experienced by interview participants who explained that they had delayed help seeking due to not wanting to waste time. Focus group participants also believed that these were minor symptoms and would be a waste of the doctor's time. This may be concerning as it suggests that, should they suffer potential lung cancer symptoms in the future, they would not seek help straightaway for fear of time-wasting. There was also a perception that, since doctors' time is valuable and appointments are scarce, one should not take up appointments unnecessarily as there may be somebody else out there who really needs it. This desire to be absolutely certain that they were not wasting time may have contributed to the participants waiting until symptoms reached higher levels of severity or even until crisis point before they sought GP advice.

> *'Well yeah, you don't wanna waste their time either, you know what I mean? You feel a bit of a fraud, you go to the doctors when you've got a bit of a cold. You know, it'll be gone in two or three days. You're wasting time, valuable time, they could be looking after somebody who's really ill'*
>
> *(Rob, interview participant, ex-smoker)*

Time wasting, other people and the 'hypochondriac'

There seemed to be a feeling among the majority of participants in both study populations that a doctor's time was a valuable and precious thing and people who wasted it were clogging up the system and putting a strain on the NHS. Throughout the data there appeared to be a common idea that 'other people' go to the doctor too often and waste time and resources. There was a tendency to describe such people as 'hypochondriacs' and 'time wasters' and there was a strong sense of aversion to being labelled as such. There seemed to be such concern about being branded a hypochondriac by others, that people had actively avoided going to see their GP in order to avoid the label at all costs. Focus group participants in particular seemed to be keen to inform the others that they were not hypochondriacs or time wasters and that they would not go to the GP unless they had to. This may be due to focus group methodology in that they perhaps felt they needed to not only inform the researchers, but also ensure that the other members knew that they were not a time waster. When participants described occasions that they had seen their GP, they made sure that they explained why the visit was legitimate and not an example of time wasting. In the couples' focus group, Brian had said early on that he would wait for a week before he contacted the GP regarding a cough. Following further discussion around perceptions of time-wasting, Brian clarified that the cough would need to be severe for him to see the GP after one week; this may be due to others in the group describing much longer waiting periods and a desire to avoid being thought of as a time waster by other members of the group.

> *'You mentioned earlier on, people having a cough for five weeks and not going. Say, "Oh, I've had it for about five weeks." I mentioned that within a week I would go. When I say, "Within a week", I don't want to sound like a hypochondriac but the cough would have to be severe for a week for me to go'*
>
> *(Brian, focus group participant, current smoker)*

Participants talked of other people in their communities going to the doctor for 'every little thing'. Interview participant Denise for example mentioned that she was from a small community in which the doctor is well respected and that it would certainly not be acceptable to waste his or her time. For Denise especially, being in a small community would make it more likely that other people would notice frequent GP attendance and therefore apply the label of hypochondriac. Frequent consultation however, is a subjective term and it is unlikely that all participants would have the exact same view of what constitutes 'going too much'. People who are frequent consulters are perhaps unlikely to think of themselves as time wasters as they will believe their concerns to be genuine.

> *'And the doctor lived in our community. Our original doctor lived in our village. Respected. And you… you just… you just didn't waste their time, you know?'*
>
> *(Denise, Interview participant, ex-smoker)*

Some participants mentioned knowing people personally who saw the doctor unnecessarily and prided themselves on not doing the same. Focus group member Clare stated that she knew people who had been to their GP with coughs or colds and been prescribed medication whilst she had had similar complaints and did not seek help and expressed a sense of pride at having overcome the symptoms on her own and not having wasted the doctor's time like the others. Like Clare, Interview participant Mark too said that he had 'spoken to' some people and had the impression that their needs were not genuine and that they were simply trying to keep themselves occupied.

'And those people (laughs) exactly those people get on my nerves. They shouldn't be there. It should be genuine-genuine needs. Not-not people looking for something to do, perhaps, I don't know'

(Mark, interview participant, ex-smoker)

Wasting time as a smoker

There was also a perception among the current smokers in the focus groups that the doctors themselves would think that their time was being wasted if a patient smoked. There was a reluctance to take up time that could be used by a non-smoker who was more 'worthy' of the doctor's time and help. Focus group participant Dean explained that he believed that doctors would be annoyed that their time had been wasted if they gave a person advice on smoking cessation and the person was either unable to stop or stopped and started again. He believed that the doctor would express disappointment in having wasted resources on a person who was not willing to help themselves. This could potentially contribute to delayed presentations as if a person had given up smoking and then started again, had ignored previous cessation advice or thought that they would be seen as having wasted time previously, they may hesitate to seek help again for fear of being deemed a time waster.

'All they wish is that you don't start again because (laughs) otherwise they've wasted all their all their time and resources on basically saving your life and you've not made the effort'

(Dean, focus group participant, ex-smoker)

This chapter has made several mentions of the concept of 'legitimate' help seeking and of what that constitutes for participants. There was much discourse throughout the data about what participants felt constitutes legitimate help seeking. Many participants stated that they would go to their GP if they felt really ill, but this raises the question, how ill is really ill? It can be argued that how ill or well a person feels is completely subjective and therefore each person will judge it differently. Much emphasis was placed on looking unwell. Some of the focus group participants talked about having physical injuries such as losing a finger in a gardening incident or breaking a leg or an arm which can be easily seen by others and therefore validates the need for a visit to the GP. It may be that if a person has a visible injury then other people will not be able to label them a hypochondriac or time waster as their reason for seeking primary care is clearly visible. Other symptoms such as cough are less noticeable by others and therefore perhaps people are more reluctant to see the doctor, as they do not appear outwardly unwell. The appearance of other patients in the GP waiting room was also discussed as a point of contention for the focus group participants, particularly Anthony, who explained that he saw other people in there and none of them ‘looked sick’ which led him to believe that they were there to get a ‘sick note’ because they wanted absence from work or to claim benefits. Again, this raises questions, what does a sick person look like?

> *‘And I appreciate that. But when I do go to the GPs, I know that I am genuinely ill. And I sit there and I look round and I think that these people look fit. They’re only here for, dare I say, a sick note. Yeah?’*
>
> *(Anthony, focus group participant, current smoker)*

This also divided the participants as while the focus group members put emphasis on a person’s need to look ill in order to justify their presence at the GP, the interview participants actively resisted looking ill and were concerned that their physical appearance made them noticeably a cancer patient. It can be argued that the interview participants would have been deemed as ‘genuinely ill’ by the focus group members, particularly if they had visible signs of cancer such as hair loss, but the interviewees were resistant to being marked out as a cancer patient. In contrast to the justification of help seeking via visible injury or sickness, the interview participants described themselves as feeling proud of not looking sick or like a ‘typical’ cancer patient. Male interview participants in particular expressed pride at having been able to put weight back on following diagnosis and treatment whilst female participants often said that they had lost a bit of weight but they thought they looked better for it. One of the most well recognised visible signs of cancer is hair loss and the women in this study in particular worried about losing their hair, partly due to not wanting to look like a cancer sufferer, but also as hair is often an intrinsic part of a woman’s identity and femininity. The contrast in the views of the participants is interesting in that it presents an impossible ideal, that a person should outwardly appear to be ill if they want to be taken seriously and viewed as a legitimate help seeker, but all the while the people who are ill actively resist looking like they are to avoid stigma and loss of identity. It is also possible that those who have already been diagnosed with cancer no longer feel the need to justify their help seeking as they now certainly have a legitimate reason. It may be that they do not want to appear sick, but they know that they are and that is enough to make their help seeking legitimate.

Social networks and health choices

Family, friends and legitimate help seeking

Several of the participants in this study reported that they had sought help in primary care due to the influence or advice of their family members. Some participants who reported that they consulted a doctor due to encouragement from their family were also people who felt that one should not waste doctors' time with minor or 'illegitimate' health issues. The fact that a family member persuaded them to go seemed to give a feeling of legitimacy to help seeking, even if it was just to 'keep them happy' or to stop someone 'nagging'. Focus group participant Anthony had strong feelings about what did and did not constitute a good enough reason to see a doctor, but he also explained that when he had suffered symptoms which later led to the fitting of a pacemaker, he had to be 'nagged' by his wife and son to seek help.

Interview participant Ivor had seen a doctor regarding his chest symptoms and was given a diagnosis of pleurisy and a prescription for antibiotics. When the symptoms continued after the course of medication, Ivor was not planning to return to the GP but still did because his wife 'made' him. Ivor felt that although he was still coughing, as he had taken the prescribed antibiotics there was no need to seek further help and only did so because his wife wanted him to. This may have helped Ivor to feel that his return to the GP was legitimate in that it would make his wife feel better. The encouragement of a family member may also contribute to perceptions of legitimacy, as the patient would already have somebody else, albeit a layperson, who is of the opinion that they need to see their GP. Like Ivor, interview participant Mark had also relied on the encouragement of his wife to legitimise his help seeking. Mark had waited a long time before he had sought help and his health had deteriorated drastically but he still felt that he would have waited longer had his wife not told him that she thought he needed to go to the GP. There may also be a certain level of comfort in knowing that if the symptoms do turn out to be nothing to worry about, the appointment still holds some legitimacy as it reassured the family member who suggested they go. In the unlikely scenario that somebody was accused of wasting doctors' time, the blame could potentially be shifted on to the person who insisted that they go, rather than the patient.

> *'Then I felt really rough in the middle of April. And I went to see (GP Surgery) who've been very good. And they said I had a touch of pleurisy. And gave me some antibiotics. I thought I was fine but my wife made me go back again after the fortnight as he suggested'*
>
> *(Ivor, interview participant, ex-smoker)*

Like Ivor and Mark, interviewee Nick, who already suffered comorbidity, also reported having been pressured by his wife to see the doctor when his health worsened. Nick had been extremely resistant to his wife's suggestions that he see a doctor and said that he had persevered with his cough and pain and whilst his wife wanted to phone the GP on his behalf, he had requested that she did not. Nick had grown annoyed with his wife for trying to contact the doctor, he had told her to 'stop bothering people' because he felt that his symptoms would improve on their own and therefore it was not legitimate to seek help.

Interview participant Timothy had suffered from haemoptysis, which had concerned him far more than other symptoms which he believed were due to COPD. He reported that at first, it was only a small amount of blood, but then it had worsened and he had decided to show his wife. He said that when he showed her the amount of blood he was bringing up she had decided that he must see the doctor.

> *'Yeah. It wasn't just a little tiny bit at the start. It was, I wasn't coughing up any phlegm whatsoever. All it was was clots. Pretty big clots of blood. And I just put them on a tissue and showed (partner) and she said, "Doctors'*
>
> *(Timothy, interview participant, lung cancer patient, ex-smoker)*

The participants who reported that they had seen the GP due to pressure or advice from their family or partner were predominantly men, and they often used words that implied that they had gone in the end to keep their partner happy or to keep a quiet life. Words such as nagging and pushing were a feature of these accounts; however, it also seemed that the concern of a partner supplied the legitimacy needed in order for these men to justify seeing a doctor. From the accounts of these participants, particularly the interviewees, it would seem likely that if their partners or children had not intervened they may have experienced longer patient intervals. The support of family and friends seemingly contributes to feelings of legitimacy around consultation and may be helpful where other factors such as perceptions of stigma or time-wasting may be involved.

Conclusion

The process of seeking help in primary care for current smokers, and those with lung cancer symptoms, is a complex one. Help seeking decisions are influenced by many different factors which work together to encourage or discourage GP consultation, which may in turn result in delayed presentation and affect cancer outcomes.

Participants in this study often reported not having recognised their first symptoms as potential cancer signs. Many interview participants explained that their initial symptoms were minor or rather general, and it seems they were easily attributable to common or minor illnesses such as colds or flu. These minor complaints were not considered serious enough to warrant seeing their GP and so participants delayed in help seeking until they had worsened or reached ‘crisis point’. In the focus groups, participants also described minor illness such as colds and flu to be ‘not worth bothering’ the doctor over and reported that they would tend to wait until these symptoms persisted for a long time until they would seek GP advice. There also seemed to be a general lack of awareness of lung cancer symptoms among interview participants, with some reporting that they were unaware of any of the symptoms and others explaining that they were only aware of the most common symptoms. A persistent cough was understood to be a common sign of lung cancer but perhaps because cough is also easily attributed to minor illness, comorbidity or ‘normal’ for smokers, it was not necessarily of immediate concern to participants and so they did not seek help straight away.

The recognition of symptoms appears to be closely related to the existence of comorbidity in participants, especially in those with lung cancer. Accounts often featured comorbidity which were described as influencing the recognition of new symptoms and the decision to seek help and comorbidity could act as both a barrier to and a facilitator of help seeking. Some participants who suffered comorbidities such as asthma or COPD were brought in to contact with healthcare professionals regularly, and were able to use pre-existing appointments to draw attention to new symptoms which were then followed up by the nurse or GP. The presence of a comorbidity and a pre-existing appointment with a healthcare professional could potentially facilitate earlier help seeking in several ways. Firstly, the appointment was ready-made and there was no need to go through the process of booking another. Secondly, the premade appointment may help to alleviate concerns regarding wasting time, as the help seeking was already legitimate due to the comorbidity. It may also be that perceived stigma is lower in patients with comorbidity as they are already receiving treatment for their current condition. If that condition is smoking-related then they already have passed the stage where they may experience stigma. However, the existence of a comorbidity which produces similar symptoms to lung cancer also have the potential to delay help seeking as the participant may not recognise the new symptom when it occurs. Participants may also wait a long time for their next comorbidity appointment rather than make a separate GP appointment, which may happen sooner. The existence of a comorbidity may also lead to repeated presentation as the GP may not recognise the new symptoms.

The risk perception of the participants in this study was also a potential factor influencing presentation. The accounts of interview participants seemed to show that the participants did not see themselves as being potential candidates for lung cancer and that, even if they smoked, they did not believe themselves to be at risk. The interview participants, who had a diagnosis of lung cancer, often explained that they had led healthy lifestyles aside from their smoking. They described exercise, diet and limited alcohol consumption as keeping them healthy even if they smoked. There seemed to be a suggestion among the participants that these other healthy choices would minimise their risk of cancer. Risk perception was also tied in with other factors such as beliefs regarding the causes of cancer. Both focus group and interview participants reported that they believed cancer to be a matter of chance or genetics. Beliefs such as these may also serve to justify continued smoking and delay presentation due to not believing that they were at risk. Other beliefs regarding the risks of smoking were also present in the data, with participants explaining that they believed stopping smoking would cause them more harm than good or that smoking cigars or hand-rolled cigarettes was less harmful than standard cigarettes. Several interview participants reported having received medical advice regarding smoking and risk a long time ago which they had held onto, despite it being rather outdated, and both interview and focus group participants described previous positive examination findings satisfied them that they were well. It would seem that participants had faith in these findings for a long time and therefore kept them in mind when experiencing new symptoms. It is likely that it is preferable for participants to hold on to previous favourable test findings or advice which told them that they were not at risk and this could potentially influence presentation with new symptoms due to feelings of not needing to see a doctor because they had already been told they were well.

An interesting feature of accounts in this study is the ways in which people were able to accommodate their symptoms into their everyday routines rather than seek help. This accommodation would continue and become more drastic as symptoms worsened and often culminated in the reaching of a ‘crisis point’, which would be the making of the decision to see their GP or even seek emergency care. Interview participants described becoming unable to manage their usual routines such as exercise regimes, dog walking and housework, but also described the ways in which they altered their lives to accommodate this loss of ability by taking shorter walks, giving up exercises or asking other family members to take over certain tasks. Participants made, in some cases rather drastic, changes to their usual routines rather than seeing their doctor about their loss of ability to perform usual tasks. This may affect presentation timeliness due to them waiting for a crisis point, but may also indicate other reasons for not wanting to see a doctor and preferring to make lifestyle changes instead. If participants are concerned about potential stigma, shame or blame then they may delay as long as possible. This may also be compounded by concerns about wasting GP time and patients may make changes to their routine until they feel that they can be seen as a legitimate help seeker as they can no longer manage their necessary tasks. The belief that a person should attempt to self-treat minor symptoms rather than seek primary care straight away was present in both interview and focus group accounts and may be influenced by current NHS guidelines. It is interesting however that some participants, especially in the focus groups, reported that they would self-treat for a rather protracted period of time before seeking primary care. This may have an impact on timeliness of presentation if patients are waiting for a long time for over-the-counter remedies to work. Current NHS guidelines suggest seeking the advice of the pharmacist for minor symptoms before contacting the GP. However, if people do not actually ask for advice and simply buy what they think they need, they may not receive any indication of how long they should wait until they do need to contact the GP if symptoms persist.

The concept of primary care being difficult to access was a topic for discussion during the focus groups with many participants reporting that it was hard to book timely appointments and that, by the time there was availability, symptoms would often have got better on their own. This may lead to delayed help seeking as people may see little point in trying to get an appointment at all. There was also a perception among focus group participants that there was a strict gatekeeping culture within primary care and that a person would need to ‘get past’ each gatekeeper in order to access care. GP’s receptionists were mentioned by several focus group participants as being the first gatekeeper, with some people expressing the idea that receptionists would deliberately not answer calls in order to prevent too many people booking appointments. Receptionists were also seen to be responsible for assigning patients to the practice nurses rather than the GP and some focus group participants described this as being a source of frustration for them as the nurse would not be able to prescribe and they would need a doctor anyway. Whilst some participants saw nurses as a poor substitute for the GP, the GPs themselves were also viewed in a gatekeeping capacity as they were the ones able to refer to secondary care. Interestingly, the focus group participants who described the GPs in this gatekeeping capacity also described secondary care in a positive way, believing it to be where the best care lay. Access seemed to be less of a concern for the interview participants but this may be due to having had potential lung cancer symptoms when they presented and therefore receiving prompt care and quick referrals. Some interview participants however reported that they were pleased that they now no longer needed to try to navigate primary care as they were given permission to call or go straight to secondary care. This concept of strict gatekeeping and difficulties in accessing in primary care may contribute to patient intervals as people who experience symptoms may delay contacting primary care until the symptoms reach ‘crisis point’ and they feel they have no other option. The perception that availability of appointments is poor may also affect the decision to try to see the GP. The preference for secondary care rather than primary was also mentioned during focus group discussions about stigma from healthcare professionals.

The perception of stigma from healthcare professionals was discussed in the focus groups with many participants reporting that they believed that smokers were stigmatised by their healthcare providers. Many focus group participants described feelings of being stigmatised in primary care and the stigma seemed to come from multiple directions. In the women’s focus group, the participants all agreed that they felt a sense of stigma against smokers due to the presence of anti-smoking posters and literature on display within the GP surgery. The participants in the women’s focus group all agreed that they felt that anti-smoking signs targeted them specifically and were there to increase a sense of shame in people who smoked. Whilst some participants reported specific times they had experienced stigma in primary care, others reported it as a more general perception or as something they anticipated which discouraged them from seeing their GP. The anticipation of being stigmatised as a smoker may be exacerbated if the patient is presenting with smoking-related symptoms. In all of the focus groups there was discussion surrounding the perception that smokers were stigmatised by primary care whilst people with other lifestyle-related health problems, such as alcoholism or obesity, were not. These perceptions of smokers being a stigmatised group were also influenced by the concept of legitimate help seeking and who should or should not be taking up NHS time.

The concept of what constitutes ‘legitimate’ help seeking was present throughout the data, in both interviews and focus groups. Many participants explained that people should not seek primary care unless they definitely needed to do so and those who did so unnecessarily were often labelled ‘time wasters’ or ‘hypochondriacs’ and participants were keen to avoid being labelled as such themselves. This concern about being viewed as a ‘time waster’ may contribute to hesitancy to present due to people waiting until they can definitely be sure that they are a legitimate help seeker. It may also contribute toward many of the other factors related to presentation outlined in the study findings such as the need to try pharmacy treatments first, and to wait until a family member or friend advises them to see a doctor.

The encouragement of a family member or friend seemed to facilitate help seeking for several participants in this study. A family member noticing the symptoms may reaffirm that symptoms are genuine and therefore help seeking is legitimate. It is also possible that the encouragement of family members can legitimate help seeking as patients can justify it as being for the sake of a loved one’s peace of mind or to stop them ‘nagging’.

The findings of this study highlight the complexity surrounding the use of primary care by participants in North Wales who smoke and may have symptoms indicative of lung cancer. Decisions regarding whether or not to seek GP advice when symptoms are experienced is intrinsically bound with wider issues regarding society in general and healthcare specifically. From the accounts of participants detailed above it would seem that the two populations in this study both delay help seeking when they experience symptoms which in turn may influence their outcomes should they have lung cancer. It is important that the complexity of presentation is understood in order to discover ways in which primary care use can be encouraged and more timely diagnoses can be made which may then influence cancer outcomes, including survival. The data from this study needs to be understood within the context of the wider literature and the two are brought together in the discussion chapter of this thesis.

Chapter 5: Discussion

Chapter summary

This chapter brings together the findings of this study and the wider literature contained in both reviews. The discussion chapter presents the new findings of this study alongside the existing literature and demonstrates how the findings of this study contribute to the existing body of knowledge surrounding smokers, lung cancer symptoms and presentation in primary care. The chapter begins with an introduction and overview of key themes, the full discussion is then presented thematically in the same manner as the previous chapters. Finally, the chapter concludes with a summary of the discussion leading in to the subsequent study conclusions chapter.

Introduction

The findings of this study have a place among the wider literature and make a valuable contribution to the existing knowledge of the research topics. This chapter will relate the study findings to the existing literature and examine how and where the specific findings of this study fit in with the current literature and previous research.

Issues concerning access to services and the ways in which to navigate those services were raised by both groups of participants in this study. It has been postulated in previous work that navigating and gaining access to primary care can involve considerable effort on behalf of the patient (Aday and Andersen 1974; Dixon-Woods et al 2006). Accounts in this study also described difficulty in accessing services and negotiating with gatekeepers in order to see their GP. These issues may be factors affecting timely presentation and is discussed in the first section of this chapter.

Previous research has reported that lung cancer symptom awareness among the lay community may be poor (Tod et al 2007; Crane et al 2016; Scanlon et al 2006). In this study, it was found that participants who experienced vague symptoms did not suspect cancer, and even those who reported being aware of lung cancer symptoms did not necessarily recognise them in themselves. Many participants in this, and other, studies report that when they experienced their initial cancer symptoms, that they believed them to be those of minor illness that did not warrant presentation (Neal 2009).

Following the initial onset of symptoms, many interview participants in this study described the ways in which they had managed to accommodate their symptoms in to their everyday lives; this is also reported in previous work (Corner et al 2006). Brindle et al (2012) explains that participants may normalise their symptoms, and in this study interview accounts described a process of normalising bodily changes rather than viewing them as symptoms of illness.

Processes of accommodation, normalisation and symptom interpretation may also be further complicated in those who suffer from a comorbid condition. Lung cancer symptoms may be confused for the symptoms of pre-existing comorbidity, especially in those with conditions such as COPD, asthma or other chest conditions (Shim et al 2013; Crane et al 2016; Corner et al 2006; Andersen et al 2010). Fleming et al (2005) has described four hypothesis regarding comorbidity and early cancer diagnosis and these are applied to the data from this study in this discussion chapter.

There is evidence in the existing literature that some participants report the belief that they are able to offset the risks associated with smoking by engaging in other, healthy practices such as having a good diet or regularly exercising (Walton et al 2013; Leveahlati 2007; Brindle et al 2012). This may have an effect on the risk perceptions of the participants and lead to delays in presentation. These misconceptions regarding risks and smoking may also be related to theories of cancer candidacy (Macleod 2012). These ways in which a person may gauge their own potential risk of lung cancer were also present in accounts in this study.

Previous research has reported that there is a perception among smokers that they are stigmatised for their smoking by society and by healthcare professionals. This perception of stigma emerged strongly in the focus group data generated in this study (Chapple et al 2004). The section on stigma in this chapter will relate participants' perceptions to those reported in other studies and apply the theory of the three types of stigma to this study (Goffman 1963).

The majority of these factors which may influence decisions regarding help seeking were also related in some way to participants' concerns about wasting GPs' time. These concerns are also discussed in previous literature (Tod et al 2007; Corner et al 2006). The belief that one should not waste doctors' time is also related to perceptions of stigma held by participants, this may have a strong influence on timely consultation.

The ways in which family and friends can facilitate help seeking are also discussed in this chapter, as it may be that encouragement from family members or partners can have a positive effect on timely help seeking (Tod et al 2007).

Thematic discussion

Access to health services and navigating the system

Access to health services and availability of services

The issue of navigating the healthcare system was raised in both this study and within the existing literature. In this study, many participants, particularly focus group members, described the lengthy process involved when navigating the system of UK primary care and reported a perceived level of difficulty in negotiating access to services. The Candidacy Framework refers to the 'permeability of sources' in terms of navigation and availability of appointments as a potential barrier to help seeking and this can be applied to accounts of participants in this study (Dixon-Woods et al 2016; Tookey et al 2018). Interview participants such as Daryl reported having to get up early in order to start telephoning the surgery and that they experienced difficulty getting through to reception. They also reported that there was little availability regarding appointments and often they were weeks away by which time symptoms would have already improved on their own. This initial hesitancy to attempt to contact the GP was perhaps due to the perceived level of effort it would take even just to get an answer on the telephone. As previously discussed in the narrative review chapter of this thesis, a concept of 'access to healthcare' is described via a framework developed by Aday and Andersen (1974) which refers to access in healthcare as the resources available within a person's area of residency and the availability of services when needed. The framework developed by Aday and Andersen (1974) is based upon the system of healthcare in the USA in 1974; however, it seems that it is still applicable to the North Wales population within this study. The work of Aday and Andersen (1974) cites issues such as waiting times and appointment availability as potential barriers to help seeking and these issues were discussed by participants in this study as reasons to not attempt to seek primary care. Aday and Andersen (1974) also include the decline in primary care services such as GP house calls as a barrier to help seeking. It is also true that house calls by GPs have become much less common in the UK and it may be that patients are reluctant to request them due to concerns about wasting time, bothering the doctor unnecessarily, or even a belief that they will be unavailable and therefore there is no point trying. None of the participants in this study reported having tried to request a house call from their GP when they first experienced symptoms although some of the interview participants had experienced their symptoms during out of hours periods. It may be worth considering whether or not some of those participants, particular those such as Owen who sought emergency care, would have attempted to contact their GP earlier, had they believed that an out of hours service was available. This perception that accessing primary care initially is so difficult may have a significant impact on hesitancy to present as people may avoid help seeking until they reach the ‘crisis point’, a phenomena which will be discussed in more detail in the following sections of this chapter.

Access to services and the gatekeeping culture

As previously mentioned, it may be possible to apply the Candidacy Framework to participants in this study as the model refers to the ‘permeability of sources’ and the navigation of services as integral to timing of presentation (Dixon-Woods et al 2016; Tookey et al 2018). The Candidacy Framework describes gatekeeping in terms of ‘professional adjudication’ and this can be applied to the accounts given in this study as there was a perception among participants that primary care consists of a culture of gatekeeping (Tookey et al 2018). Primary care was described as a system involving a series of gatekeepers which a patient must ‘get past’ in order to access the next one, and finally to get an appointment with the GP. The first gatekeeper to negotiate in this process was the practice receptionist. Participants in this study, again mostly focus group members, expressed negative opinions regarding receptionists and their role within primary care. Reception staff were described as being there to filter calls and to make the decisions regarding who would and would not be eligible for an appointment, some participants also expressed a belief that reception staff would purposely ignore telephone calls in order to minimise their own workload or that of the GP. There was some understanding in the third focus group that there was a need for reception staff to screen calls in order to prevent people who were potential ‘time wasters’ taking up appointments, but there was also a sense of frustration as they believed themselves to be genuine or legitimate help seekers and they were also unable to gain access.

Interestingly, practice nurses were also seen by some focus group participants as gatekeepers in the sense that receptionists would give what they deemed to be the less serious cases to nursing staff rather than GPs. Some focus group members explained that they believed the practice nurse to be less able to meet their needs and therefore a poor substitute for the GP. This is possibly also related to their frustration with receptionist staff and not being recognised as legitimate help seekers. Focus group participants reported that they would not seek primary care unless it was necessary, and therefore, whilst a nurse may be able to treat someone with a minor complaint, they would require the services of the GP. The GP was also described by some focus group participants as another potential gatekeeper as they held the power to refer to secondary care where, some participants explained, the best care lies. This staged gatekeeping and ‘professional adjudication’ may also account for lack of confidence in healthcare professionals as has been reported in previous work (Renzi et al 2016). Similarly, some focus group participants in this study also stated that both nurses and GPs were not specialists and lacked knowledge and skills in many areas whilst reception staff had no medical knowledge whatsoever. This is particularly evident in focus group three when Liz explained that diagnoses made in primary care were often inaccurate and she preferred to self-diagnose. This was not the case for interview participants however as they tended to express confidence in their healthcare practitioners and this may be due to having received accurate diagnoses.

As previously explained, primary care can be described as a ‘permeable source’ which the patient must find a route through in order to gain access to services (Dixon-Woods et al 2006). The work of Dixon-Woods et al (2006) reports that the navigation of the UK healthcare system requires considerable work on the behalf of the patient. The patient must negotiate each stage of the process in order to make an appointment with their GP and, for some patients, it may be that this level of work is perceived to be too difficult or time consuming and therefore they prefer to avoid it wherever possible (Dixon-Woods et al 2006).

The accounts of the focus group participants in this study seem to reflect the amount work that patients’ feel they need to do in order to see their GP. The structure of primary care was described as involving a long process of tasks beginning with contacting the reception by telephone, this was described as a time consuming activity as participants reported having to make repeated calls and stay on hold for long. It is possible that many people abandon their attempts to contact the surgery if they are unable to establish quick telephone contact as they feel they are wasting their own time or are being deliberately ignored by reception staff. For those who continue to try to make an appointment and manage to get through to reception staff there is then further work to be done in order to get an appointment with the desired healthcare professional. Some focus group participants in this study also expressed a concern that they were left waiting in the waiting room for long periods to then be rushed through a ten-minute appointment, which they felt was not long enough. It has also been shown that visible time constraints in primary care, such as noticeably timed appointments, may contribute to concerns regarding access to services and time wasting (Cromme et al 2017). Previous research, the Candidacy Framework and accounts in this study, indicate that further perceived gatekeeping by practice nurses and then by GPs, if referral to secondary care is required, may lead to repeated presentation of the same symptoms, meaning that patients have to negotiate this system multiple times (Macdonald et al 2016; Tookey et al 2018). The prospect of having to go through the process repeatedly may further discourage primary care use and may contribute toward presentation in emergency care following the ‘crisis point’ being reached as was evidenced in the study by Smith et al (2005).

It is interesting that this frustration regarding gatekeeping and access to primary care was largely coming from focus group members in this study. This may be due to the focus group members discussing help seeking in a more general manner rather than relating specific accounts of actual diagnostic journeys that culminated in cancer diagnosis like the interview participants. Levels of reported frustration may also be increased by the focus group methodology, as participants were able to agree with and elaborate on the perceptions of other members. Interview participants did discuss gatekeeping on some occasions but also seemed to be less frustrated, this may be due to their symptoms being indicative of lung cancer and therefore they had passed through the system quickly. Some interview participants described themselves as being ‘lucky’ that they had received prompt referrals to secondary care and had avoided repeated presentation, however this may also be due to having delayed help seeking until symptoms had worsened or reached crisis point. Some interview participants also expressed some sense of reassurance at no longer needing to go via primary care as after diagnosis they were allowed to go directly to secondary care or to contact other healthcare services such as Macmillan cancer support.

The concept of access to healthcare, especially primary care services may have a significant impact on patient decision making regarding presentation of symptoms. The participants in this study expressed a belief that primary care involves many barriers and gatekeepers to be negotiated which creates significant work to be done on the part of the patient such as that described in previous literature (Aday and Andersen 1974; Dixon-Woods et al 2006). The prospect of having to go through what may be perceived as an arduous process may mean that patients avoid primary care for as long as possible and potential cancer symptoms may be tolerated for long periods before presentation. This perceived difficulty in accessing services may also provoke a desire to wait until symptoms are severe or the patient believes help seeking to be ‘legitimate’ a concept that will be revisited throughout this chapter. The time at which to begin the process of accessing primary care may also depend upon the person’s recognition and interpretation of symptoms.

Symptom recognition, awareness and interpretation

Symptom awareness

Interview participants in this study were asked whether or not, prior to diagnosis, they were aware of the symptoms of lung cancer. Whilst some of the participants explained that they did have some knowledge of lung cancer symptoms, such as persistent cough, they had not necessarily experienced those symptoms or had not interpreted them as potential cancer in themselves. Haemoptysis was cited by several interview participants as being the most common sign of lung cancer and this may contribute to delays in presentation for patients that don't experience this, as not all patients do. In this study, only four out of 29 interviewees reported having experienced haemoptysis. Previous studies of cancer awareness have reported poor symptom knowledge in their participants and that lay discussions surrounding cancer tend to focus on prognosis and outcomes rather than potential symptoms (Tod et al 2007; Crane et al 2016; Scanlon et al 2006). In the study by Scanlon et al (2006), older participants were found to have the lowest level of symptom knowledge, which was attributed to lower levels of education. Whilst the population in this study is different from that on the Scanlon et al (2006) study, which focussed on an Irish community in the UK, there may still be some potential similarities. Many of the interview participants in this study were over 60 years of age and any previous experiences of cancer, such as family members with the disease, may have occurred when there was less public knowledge regarding cancer symptoms. A feature of some of the accounts of older interview participants included explanations of how the risks of smoking were less well known when they took it up and that the connection with lung cancer was far less publicised.

Interview accounts in this study also included participants such as Betty who said that they were completely unaware of the symptoms of lung cancer or, like Mariel, that they deliberately avoided gaining knowledge of cancer symptoms as they would rather not know. This may be due to a desire to avoid being afraid of future cancer, especially in those who smoke and are aware that this may put them at risk. Mariel was aware that there was information available in primary care but did not wish to access that information herself, however, Betty explained that she had no symptom awareness because there was no information available in North Wales and that she was still not receiving adequate information from her healthcare professionals.

Symptom appraisal and the 'smokers cough'

Whilst the occurrence of a persistent cough was the most common symptom that participants reported knowing to be indicative of lung cancer, there was also a perception among many of them that cough was ‘normal’ for smokers and therefore if a person smoked then they need not be overly concerned about cough. In the men’s focus group, participants discussed the ‘Be Clear on Cancer’ campaign and there was a general consensus between participants that they did not see the campaign as being applicable to them because they smoked and so they always coughed. Interview participant Nick also said that he was aware of this campaign but that he saw it as being aimed at non-smokers as those who smoke would be accustomed to coughing. Previous work has reported findings which suggest that those with lung cancer do not always have a full understanding of the connection between smoking and lung cancer, and believe that persistent cough and feelings of general ill health were ‘normal’ for smokers (Corner et al 2006; Hamann et al 2014; Walton et al 2013). The perception that symptoms are normal for smokers may also increase the likelihood or delayed presentation as a new cough will be less noticeable or taken less seriously. Participants in this, and other studies have reported delaying help seeking due to their cough being a ‘normal’ smokers cough.

It may be that a general lack of symptom awareness contributes toward longer delays in presentation as people are unable to recognise cancer symptoms when they experience them. The initial symptoms of lung cancer may be missed due to patients being unaware, this means that first symptoms are difficult to identify.

Appraisal and interpretation of first symptoms

The model for Pathways for Treatment begins with the noticing of a bodily change and the interpretation of that change as a symptom of illness or cause for concern (Scott et al 2013). The initial symptoms experienced by interview participants in this study were, in many accounts, not interpreted as overly concerning or potential signs of cancer. Many interview participants described experiences of minor or vague symptoms which they had not attributed to a potential cancer but rather to a range of common illnesses such as colds and flu, ageing or existing comorbidities, which will be discussed in detail further on in this chapter. First symptoms reported by interview participants included shortness of breath, dry throat, wheezing, persistent cough, fatigue and occasionally back or chest pain. Two participants had found visible lumps on their body which they described as their first symptoms but they both also described experiencing other symptoms such as fatigue or cough. In some accounts it may be that ‘first’ symptoms were not always interpreted as such and participants may report their first symptom as being the one that first gave them cause for alarm, rather than the first they actually experienced. The presence of blood was also sometimes interpreted by interview participants as a minor symptom caused by brushing teeth too hard or taking aspirin. Therefore, symptomatic cancer, in this study and elsewhere, may still be subject to delayed presentation if the patient interprets the symptoms as being due to minor illness or the ageing process (Neal 2009). Participants in this study who reported their first symptoms as being minor did not necessarily delay help seeking intentionally at first; it may be that they just did not interpret those early signs as being potential cancer. This is also reported in the literature with participants in other studies attributing symptoms such as cough to colds and flu and fatigue to stress or ageing (Corner et al 2006; Brindle et al 2012; Walton et al 2013). It may also be that first symptoms are not always clear and easy to notice; rather they may be experienced alongside stress or signs of ageing and therefore may be less easy to distinguish as new or separate symptoms. Similarly to findings reported in previous studies, some interview participants in this study reported having had no symptoms prior to diagnosis, however they then often described a range of bodily changes such as fatigue, weight loss and loss of appetite which suggests that they in fact did experience symptoms but did not interpret them as lung cancer symptoms (Brindle et al 2012; Walton et al 2013). It may be that vague or general symptoms such as fatigue are less tangible and it is harder for participants to pinpoint when they began, meaning that they do not always recognise them as the first symptom.

Experiencing minor symptoms may not be deemed serious enough, to warrant seeing a doctor until they worsen or reach crisis point. Interestingly, some interview participants in this study who reported having interpreted their symptoms to be those of colds or flu and so not worth consulting a doctor, had not consulted even if the symptoms lasted much longer than colds or flu usually would. Accounts in this study feature many descriptions of colds that ‘wouldn’t get better’ or protracted periods of flu or chest infections.

Chest and back pain were also a feature of some interviewees’ accounts but these too were interpreted as minor, or not attributable to the lungs. It may be that back pain is a less well-known sign of lung cancer and people may be more likely to attribute it to tiredness or injury. Chest pain was taken more seriously, for example interview participant Alex, but he interpreted the pain as being his heart rather than his lungs. It may be that chest pain constitutes a more ‘legitimate’ reason for help seeking, as it is potentially heart related.

The recognition and interpretation of symptoms as minor complaints may potentially affect presentation time as participants would not seek primary care for a minor complaint and therefore they delay until the symptoms have worsened or persisted to a level that makes presentation justifiable. This delay until symptoms worsen leads to a need to accommodate the symptoms in to everyday life until presentation is legitimate or crisis point is reached.

Symptom accommodation and normalisation

As reported in the findings chapter of this thesis, the accounts of interview participants regularly feature descriptions of how participants managed to accommodate their lung cancer symptoms in to their everyday lives and routines rather than seek medical advice. This accommodation of symptoms differed depending on how participants usually functioned in their everyday activities but they all involved, sometimes drastic, changes to lifestyle in order to manage symptoms. This is perhaps closely linked with the misattribution of symptoms to minor illness, as reported in this study and in previous work, as many people are used to ‘carrying on with life’ when they have a cough or a cold (Levealahti et al 2007).

Slowing down and changing routines

The accommodation of symptoms in this study did not seem as though it was a deliberate act, rather, as symptoms were usually deemed as minor at their onset, they were gradually accommodated in to everyday life, with routines changing more and more as symptoms worsened and, in many cases, reached crisis point. Perhaps due to the study location in North Wales, many interview participants lived in rural locations or by the coast and a regular feature of accounts was a love of walking or of dog walking in the local area. Many interview participants described being no longer able to manage their usual routes due to breathlessness or fatigue but they interpreted these symptoms as signs of tiredness or ageing and, rather than consult a doctor, they changed their routes to make distances shorter or to avoid hills. Some of the interview participants explained that they had given up their walks altogether but had not seen it as a reason to visit the doctor as it was just due to ‘getting old’ and they would use their car or ask other family members to take over shopping or dog walking. It was also evident in the findings of this study that interview participants made alterations in other areas of their usual lives such as cutting down or stopping recreational activities, exercise and household tasks. As previously mentioned, interview participants described changing routines in increasingly drastic ways to accommodate worsening symptoms until help seeking seemed to become more legitimate or crisis points were reached. Crisis points for interview participants included becoming completely unable to manage their activities, being unable to climb stairs, sleep or walk short distances.

In this study interview participants had sometimes gone to quite drastic lengths in order to accommodate symptoms, however it would seem that this is also a finding reported in previous studies in which participants who had experienced cancer symptoms had found ways in which to accommodate those symptoms rather than seek medical attention (Corner et al 2006; Levealahti et al 2007). Some lung cancer patients in other studies were reported as believing symptoms to be signs of minor illness at first and therefore not worth seeking help and so they were assimilated in to day-to-day routines instead (Corner et al 2006). Previous research has found that alongside accommodating symptoms, patients may also have a tendency to normalise them by believing they are a normal part of ageing or being physically unfit and therefore they needed to be accommodated in to everyday life, as they were unavoidable (Brindle et al 2012). A slow progression of symptoms could also lead to symptom accommodation and can be explained by use of cognitive heuristics such as the ‘rate of change rule’ by which symptoms which progress rapidly are more likely to be taken seriously whilst those which progress more gradually are not (Kummer et al 2019). In a study by Brindle et al (2012) it was reported that normalisation of symptoms occurred in participants irrespective of patient demographics, smoking status or route to diagnosis. In this study there were similar findings as interview participants of a range of ages (50 to 80) explained they believed symptoms to be due to ageing and symptom accommodation also occurred in participants who were both current and former smokers. A similar study to this one with a population of Danish cancer patients, explored the possibility of the role of ‘containment’ and its potential influences on presentation of symptoms (Andersen et al 2010). Andersen et al (2010) refers to containment as ways in which bodily changes are able to be normalised and managed within social contexts so that they become normal parts of natural life processes and not symptoms that require medical attention. The first type of containment described by Andersen et al (2010) occurs when participants experience symptoms such as fatigue, pain and bleeding and attribute them to everyday activities such as sports injuries or gardening and, therefore, as normal and not a cause for concern. This first type of containment can be seen in the findings of this study as interview participants explained that they had believed symptoms such as pain or fatigue were due to running injuries, stress at work, or life events such as moving house. The second form of containment as described by Andersen et al (2010) is the way in which different biographies frame symptom interpretation in different ways, that is, people have their own internalised set of health issues that they perceive themselves to be at risk of and therefore any bodily changes will be evaluated according to relevance for those particular issues. This second form of containment is also present in the accounts of interview participants in this study as some believed themselves to be at risk of illness that ‘ran in the family’ such as heart disease, but not of lung cancer, even if they had a history of smoking. This form of containment is also accounted for in work on cognitive heuristics in which the ‘similarity’ rule refers to the interpretation of symptoms in the context of what a person believes themselves to be at risk of (Kummer et al 2019). The final form of containment is avoiding defining symptoms or bodily changes as illness in order to preserve self-image and social relationships (Andersen et al 2010). Two participants in the Danish study were reported as having suffered haemoptysis for several months without disclosing to partners or family members, instead they had attempted to normalise their symptoms and accommodate them in to everyday life (Andersen et al 2010). In this study, some interview participants had avoided disclosing to family friends that they were experiencing symptoms in order to protect them, claiming they did not want family members, particularly children and grandchildren to worry. Some interview participants also avoided disclosing their diagnosis, as they did not want friends and family to see them differently. The three types of containment given by Andersen et al (2010) do feature in the accounts of participants in this study as they try to normalise and accommodate symptoms; this is likely to affect patient delays, as this may be a long process before reaching the point at which they seek help.

It may be that the participants in this study, and potentially those in others, were able to gradually accommodate worsening health and, if symptoms were slow to progress, did not realise how serious they were. It may also be the case that it is easier in some ways for participants to make lifestyle adjustments rather than to go through the process of presenting in primary care, especially if they believe that there will be difficulty in gaining access, as has been reported in previous research (Aday and Andersen 1974; Dixon-Woods et al 2006). It may also be preferable to accommodate symptoms for a range of other reasons that will be discussed further in this chapter, including the presence of a comorbidity, which may make new symptoms difficult to recognise and potentially increase patent intervals.

Comorbidity

Comorbidity and confounding symptoms

In this, and previous studies, the presence of a comorbidity has been reported to be a complex factor in the recognition, interpretation, and presentation of new lung cancer symptoms. In this study, many of the participants in both populations reported having comorbidities or long term chronic conditions such as COPD, asthma and diabetes. The presence of multiple or comorbidity has been described in previous studies as making the interpretation of new symptoms difficult as they make them harder to notice and they are often misinterpreted as being an extension of an existing condition or as ‘normal’ for a person who suffers chronic health problems (Shim et al 2013). Some of the interview participants in this study had interpreted symptoms such as breathlessness or cough to having ‘bad days’ with their comorbidities and this is also reported in several previous studies in which participants interpreted lung cancer symptoms to be due to their comorbidities including emphysema, asthma, heart conditions, COPD, and diabetes (Shim et al 2013; Crane et al 2016; Corner et al 2006; Andersen et al 2010). There is also the possibility that the presence of comorbidities is a form of the third type of containment, whereby a person understands their symptoms in the context of their existing disease but not within the context of a new one (Andersen et al 2010).

There is evidence to show that the presence of a comorbidity can affect the ways in which patients recognise and interpret new symptoms that may be indicative of lung cancer, however, whether or not comorbidities have an influence on presentation time is far more complicated. It has been postulated that a comorbidity can affect the stage at which a cancer is diagnosed due to the comorbidity having similar manifestations to the cancer; therefore, a lung cancer may be diagnosed at a later stage if the patient suffers an existing chest condition such as COPD (Feinstein 1970). The stage of disease at diagnosis can facilitate understanding of the ways in which comorbidity can influence interactions with healthcare systems and symptom presentation (Newschaffer et al 1998).

There are several hypotheses regarding the ways in which multiple or comorbidities may affect time of presentation, this section will examine the four hypotheses as described in work by Fleming et al (2005) and Fleming et al (2006) and the ways in which they may be applicable to the findings of this study. The first hypothesis from Fleming et al (2005) is the ‘surveillance’ hypothesis in which patients with multiple or comorbidity are already in frequent contact with healthcare professionals, which facilitates an earlier diagnosis. The surveillance hypothesis may also mean that those with comorbidity are more accustomed to seeking healthcare, more body conscious and prone to noticing new symptoms, and have regular follow up appointments for existing conditions in which they may have fostered a good relationship with their clinician (Salika et al 2017; Fleming et al 2005; Jaen et al 1994;

Feinstein 1970). In a comorbid patient, there is also the possibility that an asymptomatic cancer may have a better chance of detection due to regular clinician contact (Feinstein 1970). In this study, there are several examples of how the surveillance hypothesis may be applicable to the samples in this study, interview participants Fiona and Janine were both referred for further investigations after mentioning new symptoms in existing appointments for COPD and asthma. They both explained that they had not thought that their new symptoms were worth making new appointments for but since they already had regular check-ups for a comorbidity they would mention it then. If Fiona and Janine had not had these appointments already arranged then they may have delayed much longer before contacting primary care. In the focus groups, Clare, Belinda, Barry and Trish all described a dislike of seeking primary care and a reluctance to present with smoking related symptoms; however, they all also reported that they did go for their regular follow-ups for existing conditions including COPD and heart conditions. This may mean that if any of them were to experience a potential cancer symptom they could bring it up with a healthcare professional during an existing appointment and they would not have to make a new one. Fleming et al's (2005) second hypothesis is the pathological hypothesis in which the comorbidity interacts with the cancer and causes the cancer to become more aggressive and a more advanced stage at diagnosis; however, due to the nature of this study, the pathological hypothesis is not applicable to the findings. The third hypothesis is the 'competing demand' hypothesis, which, somewhat in opposition to the surveillance hypothesis, suggests that the presence of the comorbidity actually delays diagnosis by distracting both patient and doctor from the new symptoms (Fleming et al 2005). In accordance with the competing demand hypothesis, symptoms which are potential signs of lung cancer are missed by both patient and clinician as being symptoms of the existing comorbidity (Fleming et al 2005; Lyratzopolous 2015; Mounce et al 2017). The more comorbidities present, the harder it may be for new symptoms to be recognised (Mounce et al 2017). In this study, many interview participants reported that they believed their new symptoms to be due to their existing conditions and therefore they had not been concerned enough to see a doctor straight away. The final hypothesis, the 'death from other causes' hypothesis, in which the cancer is detected post mortem as the patient dies from their comorbidity prior to its discovery, is also not applicable to this study, as all interview participants were already diagnosed with lung cancer, but it may have relevance in others.

Comorbidity and recurring minor conditions

Whilst not chronic comorbidities, repeated bouts of minor illnesses may also affect presentation for new symptoms. Many participants in this study reported that they suffered from repeated chest infections, possibly due to smoking. The occurrence of chest infections seemed to either facilitate or deter help seeking, some participants reported preferring to wait until they were sure the infection would not clear on its own before seeing the GP. Others however, explained that when they suffered these infections they knew what to do because they had had it before, and so they contacted the doctor and asked for antibiotics. Comorbidity and recurring minor illness was also found to be a reason for repeated presentation in some participants, especially Gayle who is perhaps an example of the 'competing demand' hypothesis as she saw her GP several times with symptoms and was prescribed several courses of antibiotics for chest infection before eventually being referred for an x ray (Fleming et al 2005).

The presence of comorbidity was a feature of participants' accounts in both study populations in this thesis and has the potential to both encourage and delay presentation of symptoms. The presence of a comorbidity may also be of less cause for concern for participants depending on their personal perceptions of cancer risk.

Risk perception, optimism and health beliefs

Risk, smoking, and healthy lifestyles

It may be that a person's presentation with symptoms is not only linked to their symptom knowledge and interpretation, but also to their perceptions of risk in relation to cancer. In this study, during the interviews, there were many descriptions of participant's previously 'healthy' lifestyles which they reported believing would lessen their risk of cancer, even if they did smoke. The perception of what constitutes a 'healthy' lifestyle differed between interview participants but descriptions tended to include having a 'good' diet, such as Denise who explained that she did not eat red meat or dairy products or Lloyd who said he had always eaten breakfast. Exercise was also commonly mentioned in descriptions of healthy lifestyles and range from lots of walking to running or playing sports. Interestingly, there was a perception in many interview participants that engaging in these healthy practices would in some way balance out any negative effects of smoking. It may also be that engaging in these other healthy practices lessened any feelings of self-blame felt by participants as they had tried to live a healthy lifestyle despite smoking.

Previous research has also reported finding some evidence of this notion of ‘balancing out’ the negative effects of smoking with other healthy lifestyle practices such as a good diet and exercise (Walton et al 2013; Levealahti et al 2007; Brindle et al 2012). Healthy lifestyle practices have been said not only to give participants a feeling that they are able to offset the risks of smoking but also to allow participants to justify continued smoking (Crane et al 2016). Participants in this study expressed a belief that it is possible to lead a healthy life and be a smoker at the same time, interview participants Mark and Alex explicitly stated that they knew they had been fit and healthy despite smoking, although Mark now explained that he thought that had been a delusion. In the men’s focus group, there was discussion around the idea that smoking was not that bad for your health and participants focussed more on the risks of being overweight. This perception that it is possible to be a smoker and lead a healthy lifestyle is also reported in previous studies (Robinson et al 2010; Andersen et al 2010). In several previous studies, participants cited regular exercise, a good diet, and having good genes as being ways in which they were at less risk than other smokers who did not have these things (Weinstein et al 2010; Dillard et al 2006).

There may be a link between risk perception and a person’s perception of his or her own cancer candidacy. A person’s sense of cancer candidacy may explain the relationship between personal health beliefs and the response to symptoms of cancer (Macleod 2012). It may be that whilst some participants in this study were aware of the risks of smoking, they did not view themselves as potential candidates due to many of the reasons given in this section (Macleod 2012). It seems that it is quite possible that engaging in other healthy practices, belief in other causes of cancer, and emotional distancing may all be related to theories of candidacy (Macleod 2012; Walton et al et al 2013; Levealahti et al 2007; Robinson et al 2010). In this study many participants did not seem to see themselves as potential lung cancer candidates despite smoking, they were able to find ways in which to distance themselves from the risks.

Risk perception and the causes of cancer

Further to engaging in healthy lifestyle practices such as healthy diets and exercise routines, some participants in this study also stated that getting cancer was down to a person’s genes and that lifestyle factors were less to blame. Interestingly, this seemed mostly to be used to justify smoking but not other lifestyle factors such as obesity, alcohol consumption or drug taking. The belief that cancer is down to genes may delay presentation time even in people who smoke as they may not suspect it if there is no family history of lung cancer, in this study Alex explained he was surprised to receive a lung cancer diagnosis as there was no family history of cancer and Rob too said he was more concerned about heart conditions which ‘ran in his family’. This may be another example of containment as these participants had an idea of which illnesses they would be at risk of due to family history and therefore lung cancer was not seen as being a risk for them, even though both had a long history of smoking. Interview participant Jane reported having been to see her GP following a change in bowel habit because there was a family history of bowel cancer, she was subsequently diagnosed with bowel and lung cancer. In Jane’s case, a family history of bowel cancer had encouraged her to see her GP however, she did not expect to be diagnosed with lung cancer as it was bowel cancer that she suspected. In the women’s focus group Belinda described cancer as being down to a person’s genes as she knew many people who had cancer who had never smoked, therefore the smoking could not be the cause, however she seemed to be referring to various cancers and not specifically lung. Belinda also explained that genes were responsible for whether or not a person smoked. The belief that cancer is purely genetic may have an effect on presentation time as those who are at risk due to smoking may not believe themselves to be due to the lack of family history, which may lead to symptoms going unrecognised as potential cancer.

It may be that risk perception is also influenced by other beliefs about what exactly causes cancer in the first place. It has been reported that some smokers have a low sense of risk perception regarding themselves and lung cancer and sometimes believe themselves to be at higher risk for other cancers even if they are aware of the links between lung cancer and smoking (Smith et al 2009; Tod et al 2007; Grant et al 2010). In this study, each interview participant was asked if they had believed themselves to be at risk of lung cancer and each one reported that they did not. In the focus groups in particular there was discussion of the health warnings on cigarette packaging but almost all the participants said these did not really apply to them, they believed them to be scare tactics and one participant (Anthony) explained that the photographs they feature to show the risks of smoking were not real. There is a possibility that risk perception lowers over time, especially if a person smokes for many years without experiencing any health issues, and that participants had become somewhat desensitised to the images shown on cigarette packets. In previous work, it has been reported that participants who had smoking related cancer did not always believe smoking to be the only cause (Lehto 2014). Family members of lung cancer patients have also been reported as citing other factors alongside smoking to be to blame for lung cancer, such as poor diet, unhealthy lifestyles and toxins present in food, air or water (Robinson et al 2010). It may be that those who believe that lung cancer is not solely caused by smoking are able to lessen their own risk perception, especially if they do not believe themselves to be exposed to any of these other potential causes.

Risk perception, smoking cessation and previous good news

In this study, interview participants who had stopped smoking appeared to believe themselves to be at reduced, or no risk at all, compared to people who still smoked. Some interview participants had a long history of heavy smoking but expressed the belief that as they had stopped some time ago that they were no longer at risk of lung cancer. In previous studies, it has also been reported that former smokers express the belief that since stopping smoking they are no longer at risk for smoking related cancer (Park et al 2013; Grant et al 2010; Tod et al 2007). Some former smokers, later diagnosed with cancer, have been reported as not believing that their previous smoking could be responsible for their new diagnosis (Grant et al 2010). In this study many interview participants who were now former smokers expressed that they no longer believed themselves to be at risk for lung cancer, Timothy, Christopher, Alex and Betty all described having given up smoking many years ago and so did not believe that smoking was the cause of their lung cancer. Similarly, to the findings of previous studies, interview participants believed that there must be other causes for their cancer, Christopher blamed working with asbestos many years ago and Timothy believed that the nine years he had not smoked would have given his lungs time to repair and therefore there must be another cause (Robinson et al 2010; Lehto 2014). Having stopped smoking appears to lessen the risk perception of many participants in this and in other studies, this may influence presentation with participants again not realising that they may have lung cancer symptoms. It has also been shown in previous work that those who have had previous ‘all-clear’ results following investigation of symptoms may increase optimism in those who smoke and also decrease risk perception (Renzi et al 2015). It may be that over reassurance leads to a false optimism and that people may, like Fiona in this study rely on these results, whilst continuing to smoke, for a long time (Renzi et al 2015).

Risk perception and types of smoking

It has been reported in previous work that some participants may have decreased risk perception if they minimise the link between smoking and lung cancer or are able to distance themselves from the potential risks (Finney-Rutten et al 2012). It may be that whilst many smokers are actually aware of the risks of smoking, they find ways in which to minimise their own personal risk by including other lifestyle choices in their risk narratives (Finney-Rutten et al 2012). It has been postulated that smokers are far from unaware of the health risks and are actually constantly reminded of them via public health campaigns, effects of anti-smoking literature and health campaigns will be discussed further in the ‘stigma’ section of this chapter (Kneer et al 2012). As mentioned above, participants in this study found ways in which to ignore health warnings on cigarette packaging and this may be a part of the process of creating a cognitive dissonance between themselves and their smoking, which has also been reported in the findings of Kneer et al (2012). This process of dissonance may also involve finding other causes for cancer or other health issues that are not smoking related (Kneer et al 2012; Faller et al 1995). In this study, some interview participants were aware of the risks of smoking but believed that since they smoked hand rolled cigarettes or cigars they were at less risk than those who smoked ready rolled cigarettes; this may be another way of creating a distance between oneself and the harmful effects of smoking. The study by Kneer et al (2012) also states that smokers do not smoke because they wish to damage their health, rather they do so because they enjoy or it or believe it to reduce stress. Several participants in this study also described the stress relieving properties of cigarettes as why they kept smoking, which may increase the emotional distance from the risks, as participants believe smoking to be doing them some good.

The findings of this study are able to contribute to the existing literature as risk perception among the participants was often bound with other narratives of health and health beliefs. The risk perception of participants may contribute to patient delay in presentation as if they do not believe that they are at risk of lung cancer, they may not recognise their symptoms as being potential lung cancer and therefore continue to attribute them to other causes such as comorbidity or minor illness.

Fear and fatalism

The current literature has shown evidence of a sense of fatalism and a fear of death which may discourage people from consulting their GP (Tod et al 2007; Murray et al 2017). Several studies have reported that fatalism regarding cancer is particularly strong and that many regard a cancer diagnosis as a death sentence (Scanlon et al 2006; Nierdeppe and Levy 2007; Quaife et al 2015). Lung cancer patients in previous studies have shown themselves to hold fatalistic beliefs regarding their cancer and have reported feeling that death is inevitable and there is no point planning for their future (Westerman et al 2014). In this study participant accounts regarding fatalism differ from the literature in that interview participants did not tend to express fatalistic beliefs despite their cancer diagnosis. Interview accounts feature a sense of determination among participants who want to ‘fight’ their cancer and want to live. Interview participants actually talked of their plans for the future, of getting back to work, holiday plans and family occasions, that they were looking forward to and aiming to get better in time for. However, focus group participants did tend to express fatalistic beliefs regarding cancer, their views were similar those of participants in other studies who agreed with statements that said everything caused cancer and that there was nothing anyone could do to lower their risk of getting cancer (Niederdeppe and Levy 2007). Focus group participants were much more fatalistic in their views, explaining that people got cancer whether they smoked or not and that everyone had to die of something so one may as well continue to smoke, this is similar to the findings of Park et al (2013).

Interview and focus group participants in this study differed in outlook regarding cancer and mortality and it may be that once a person has received a diagnosis of cancer they no longer wish to be fatalistic, finding it more beneficial to be optimistic and to find hope in treatment. Focus group participants talked of cancer in a hypothetical sense and it may be that fatalistic beliefs may be a factor in their reluctance to use primary care.

Stigma and health

Stigma from healthcare professionals

The findings of this study, and of many previous studies, have revealed that many current smokers, and those who have lung cancer, hold a perception that they may be stigmatised by their healthcare professionals, especially if they suffer symptoms which may be smoking related. Participants in this study, especially in the focus groups, reported a sense of being stigmatised in primary care. The aforementioned gatekeeping culture in primary care seemed to be an important aspect of the perceptions of stigma, as mentioned above some focus group members stated that they believed reception staff to be there to filter appointments and it was also expressed by some that they would deliberately prevent appointments being given to patients they knew to be smokers. Focus group member Clare also stated that she thought smokers would be left in the waiting room longer than non-smokers. The concept of stigma and gatekeeping in primary care continued as focus group members believed that smokers would be given appointments with the nurse first rather than the GP, and that they would then have to negotiate with the GP to get referred to secondary care which seemed to be the only area in which they did not feel stigmatised. There appeared to be a perception among focus group participants in particular that healthcare professionals would want to punish them in some way and therefore would try and deny them access to the desired healthcare professional for as long as possible. The findings of this study suggest that the focus group participants felt that their perceptions of stigma from healthcare professionals were exacerbated if they were experiencing symptoms such as cough which may be smoking related. They expressed less reluctance to go if they were experiencing something non-smoking related such as a physical injury, it may be that constitutes more ‘legitimate’ help seeking and therefore can not be stigmatised.

Stigma and encounters with healthcare professionals

Interestingly, focus group participants, particularly in the women’s session, described feeling that the GP surgery was a stigmatising environment for them, due to the presence of anti-smoking literature and no smoking signs on the walls. As previously mentioned, smokers may find themselves constantly reminded of health risks and perhaps in the GP waiting room is where they find the reminders to be the most persistent (Kneer et al 2012). It may be that in everyday life, a person may only see smoking awareness campaigns infrequently and, as mentioned above, it may be possible to distance oneself from health warnings, but in the doctors waiting room they may feel that they are being stigmatised from all angles and that smoking is blamed for all health problems (Kneer et al 2012). In this study, many focus group participants reported that they felt stigmatised by their GP, sometimes this was reported as an account of an actual experience and sometimes it was reported more as a feeling, something that they anticipated happening and therefore deterred them from presenting. Focus group participants expressed a preference for healthcare professionals that they had met before, as they knew that certain GPs would not stigmatise them for their smoking.

Stigma, smoking and societal change

There is much discussion in the existing literature around smoking and stigma, some of which focuses on the change in attitudes to smoking in society over time (Street and Gordon 2004; Chapple et al 2004). In the women's focus group especially the participants discussed how they now felt stigmatised for something which had once made them feel glamorous, this parallels with the findings of Street and Gordon (2004) who described smoking as changing from a fashionable act to one which is undesirable and harmful. The women in the focus group described practicing smoking in front of the mirror and believing themselves to be glamorous and it may be that their sense of stigma is heightened due to the dramatic change in societal perception. In this study, men too discussed the change in perception surrounding smoking, several male interview participants reported that they were supplied with free cigarettes in the army and it may be that they now feel stigmatised for having a habit that they were once encouraged to take up (Chapple et al 2004). This feeling of stigma surrounding a practice which was once acceptable and now is not, may encourage some participants to conceal their smoking, not only from society in general but also from their healthcare professional (Jensen and Hounsgaard 2013; Rush 2008). It has also been reported in previous work that those who feel stigmatised for having certain health conditions are likely to have poorer social support and lower quality communication with healthcare professionals (Gonzalez and Jacobsen 2012; Bresnahan et al 2013). Focus group participants in this study reported having concealed their smoking status from family members, work colleagues and healthcare professionals. The desire to conceal smoking status may increase delays in presentation due to not wanting to have to disclose smoking status to the GP.

Stigma, healthcare professionals and 'lifestyle' related symptoms

Previous studies have reported that stigma regarding health conditions is related to how much the patient can be held responsible for their disease (Chapple et al 2004). If this is true then it may be that lung cancer is highly stigmatised if the patient has a history of smoking (Chapple et al 2004). There may also be the potential for further stigma against smokers in recent years as the potential consequences are more well-known (Jensen and Hounsgaard 2013). It has also been suggested in previous work that in some sense smokers may stigmatise themselves with feelings of guilt and perceptions of being judged by society (Jensen and Hounsgaard 2013; Nagelhout et al 2012). In several previous studies, it has been reported that those with lung cancer feel stigmatised and underrepresented in the cancer community due to the perception that they are to blame for their own disease (Lehto 2014; Chapple et al 2004; Bresnahan et al 2013). Perceived stigma due to potential lung cancer symptoms has also been found to have a positive association with delayed presentation (Carter-Harris 2015; Crane et al 2016). Interestingly, in this study, whilst there was much discussion in the focus groups and in the interview accounts of smokers being stigmatised, the interview participants did not describe feeling stigmatised for having lung cancer. It may be that following their cancer diagnosis they preferred to stay positive and to further distance themselves from any sense of stigma or blame for their condition. It may be that in order to cope with their diagnosis, interview participants did not want to dwell on feelings of stigma about their smoking but rather try to focus on their prognosis and treatment. However, it may also be the case that they had each delayed presenting their first symptoms and that was partly due to concern about stigma due to seeking help with chest symptoms.

As previously mentioned, it is possible that certain health conditions are stigmatised according to how much the patient may be perceived to be to blame (Chapple et al 2004). There is also a possibility that lung cancer patients who have smoked experience self-blame for their condition, which may further contribute to feelings of stigma (Westbrook and Nordholm 1986; Else-Quest et al 2009; Hamann et al 2014). Some lung cancer patients have reported feeling less worthy of treatment due to feelings of self-blame at having smoked (Corner et al 2005). Whilst this was not so visible in interview accounts in this study, in the focus groups participants did express the thought that they would be stigmatised for taking up appointments that could be used by non-smokers who, unlike them, did not have ‘self-inflicted’ symptoms. There were also some expressions of frustration at being stigmatised in this way due to smoking while others with ‘lifestyle related’ illness such as complications from obesity or alcohol, were not. Several previous studies have also reported that caregivers for people with lung cancer may blame the patient for their condition, which may lead to difficulty in maintaining relationships (Lobchuk et al 2008; Siminoff et al 2010; Stone et al 2012). It has also been reported that feelings of guilt can affect relationships with family and friends following lung cancer diagnosis (Zhang and Siminoff 2005; De Guzman et al 2010; LoConte et al 2008). In this study, only one participant, Gayle, reported that her diagnosis was affecting her relationship with her husband due to feelings of guilt regarding smoking.

In this study, there may be some evidence of the three types of stigma as first theorised by Goffman (1963) and applied to cancer by Lebel and Devins (2008). The first type of stigma, the ‘abominations of the body’ may refer to the physical signs of cancer, to the tumours or to other physical characteristics such as hair or weight loss (Goffman 1963; Lebel and Devins 2008). Participants in this study did express some concern about the desire to not outwardly appear to be a cancer patient. Several interview participants mentioned not wanting to be treated differently due to their diagnosis but this seemed to be due to awkward conversations with people who did not know what to say, or with unwanted sympathy, rather than the worry that they might be treated negatively. The second type of stigma, the blemishes of character, refers to engaging in stigmatised behaviours, which could include smoking (Goffman 1963; Lebel and Devins 2008). This is perhaps evident in the findings of this study as focus group participants reported feeling personally stigmatised by healthcare professionals and society due to their smoking. Finally, the third type of stigma, the belonging to deviant groups, may include smokers (Goffman 1963; Lebel and Devins 2008). This third type of stigma may be applicable to the feelings of stigma reported by focus groups when they used smoking areas in public spaces as stigma is most acutely felt when it is noticed by others (Rush 2008).

In this, and in previous work, there exist many accounts of smokers experiencing feelings of stigma from society and from healthcare professionals. These feelings of stigma may have an affect on presentation time, particularly if the symptoms are associated with smoking, due to a desire to avoid feelings of blame and stigmatising encounters. The concept of stigma was also bound with further concerns about being perceived as wasting NHS time with ‘self-inflicted’ symptoms.

Wasting healthcare professional time

Occurring throughout the data in this study is the concern of participants not to waste, or be seen to be wasting, NHS time and resources. The concept of wasting healthcare professional’s time is also bound with several of the other prominent themes in this study and reluctance to present for many reasons was often also attributed to a desire to not waste time. The concept of wasting time was also intrinsically bound with ideas about what may constitute ‘legitimate’ help seeking.

Wasting time and minor symptoms

In this study, during the interviews, almost all of the participants explained that they believed it to be important that GP time was used carefully and that it should not be wasted with trivial or minor complaints. As these minor complaints included colds and coughs, many of them included their own first symptoms in the list of things that would be a waste of GP time. Focus group participants also described instances in which seeking help would be wasting GP time and included many of the same reasons as interview participants. The common factor seemed to be that NHS time is valuable and people who are ‘hypochondriac’ should not be seeking primary care for minor complaints, smokers' cough, or things that could be treated over the counter (Smith et al 2005). The key difference in the accounts of the two populations regarding time wasting, was that interviewees tended to recall their actual concerns on their lead up to diagnosis whilst focus group members discussed things more generally, describing what they believed to be time wasting and why they themselves do not do it.

A finding of some previous studies is that patients report having delayed help seeking due to a desire not to waste time (Whitaker et al 2015; Tod et al 2007). In some studies, participants reported not wanting to 'be seen as a time waster' and this was also a finding of this study (Tod et al 2007; Corner et al 2006). It is interesting to discuss who the participants do not want to view them as a time waster, and in this study, it seems to be a combination of themselves, people they know, and primary care staff including the receptionist, practice nurses and GPs. It may be that participants feared that they would be criticised by people in the community or healthcare professionals for taking up valuable time with minor illnesses and this was mentioned in the accounts of participants in this study, such as Denise, who explained that the doctor was respected in the local community and it was expected that people did not waste their time. The concern about being criticised in the community or labelled a hypochondriac is likely to influence people to delay as long as possible, potentially until reaching crisis point, before seeking help.

It is likely that public awareness campaigns designed to encourage people to be sensible regarding their use of services may add to the knowledge that NHS time is in high demand and it is a person's duty to ensure they do not waste it (Llanwarne et al 2017). In the UK, current NHS guidelines advise that patients should first see their pharmacist when they suffer certain symptoms including persistent cough (www.NHS.UK). The NHS guidance states that people should first try home remedies such as hot water with lemon and honey, or waiting a few days to see if symptoms get better on their own, and then visiting the pharmacy if they do not (www.NHS.UK). After the cough persists for three weeks, they recommend seeking primary care advice (www.NHS.UK). Whilst these guidelines are in place to prevent using GP time in cases which may be treatable by a pharmacist, participants in this study discussed pharmacy use in terms of wasting GP time. Many participants, from both interviews and focus group, explained that they would wait and see if the symptoms get better first, then try the pharmacy for over the counter remedies, and then finally the GP. The difference between NHS guidelines and participant accounts is the reported periods participants said they would wait in between each of the services. Participants in this study reported that they would wait for far longer than the recommended time of three weeks before seeking primary care. This seems to be a way of ensuring that symptoms have lasted a long time, or reached crisis point, and therefore they are legitimate help seekers and not time wasters or hypochondriacs. As mentioned previously in the 'access to services' section of this chapter, there was a perception among participants that appointments were scarce and therefore it may be that they wished to be certain that it was necessary before trying to gain access. It may also be that those who expressed the belief that smokers were less worthy of care also believed that they should be more careful not to waste time than non-smokers who were more deserving of appointments.

The concept of time wasting appears to be an important factor in people's decision making when they experience symptoms. The desire to avoid being labelled a time waster by peers and healthcare professionals may encourage patients to wait for longer than necessary before seeking primary care and, in the case of those with cancer symptoms, this may influence outcomes. The concept of time wasting is connected with many of the other factors affecting presentation time such as believing symptoms to be minor and wanting to avoid being stigmatised as a time waster, therefore participants wait a long time until help seeking is definitely legitimate, which may involve reaching the crisis point. One factor that may help facilitate more timely help seeking and assuage concerns about time wasting is the encouragement of family and friends, which can perhaps help to legitimise help seeking.

Social networks and health

The involvement of family and friends in help seeking decisions in this study, and others, was reported to be a facilitator towards timely help seeking for some interview participants. Family members sometimes have the ability to notice symptoms that the participant either had not noticed yet or had perhaps been normalising. This has been reported in previous work and was also present in interview accounts in this study with participants whose partners had noticed they were breathless or had seen physical lumps on their body (Tod et al 2007). Partners in previous studies have also been reported as being able to facilitate help seeking by reassuring participants that their concerns are legitimate and that they are not wasting time, in this study several participants reported having sought help, or gone back for a second appointment because their partner wanted them too and had reassured them that they were not wasting time (Neal et al 2000). Some interview and focus group participants described help seeking in order to reassure their partner or to stop them from ‘nagging’ which is likely to be another form of ensuring that help seeking is legitimate, as it is for the peace of mind of a partner. The encouragement of family and friends can facilitate earlier presentation and the presence of a family member at appointments and at the time of diagnosis can be beneficial (Corner et al 2006; Siminoff et al 2010; Street and Gordon 2008; Yardley et al 2001).

In previous work, it has been reported that some participants may conceal ill health from partners in order to protect them from the burden of worry (Scanlon et al 2006; Gonzalez et al 2015). In this study, some participants had made the decision to conceal their diagnosis from family members such as children or grandchildren in order to preserve them from worry. Several interview participants said that they had waited to tell their grown up children until they could see them in person, as they did not want to give such news over the telephone. Others had avoided disclosing diagnosis to grandchildren because they did not want to frighten them or thought that they were too young to understand. Previous work has also reported that cancer diagnosis can cause strain and conflict within relationships due to uncertainty regarding outcomes and potentially negative feelings about prognosis, however that was not evident in this study and interview participants who had partners reported them to be a source of support (Badr and Taylor 2006).

The encouragement and support of family and friends appeared to have a positive influence on earlier presentation in this study as family members, in particular partners, reassured participants that they were not wasting time and should seek help from their GP when symptoms persisted. This reassurance may take different forms but all seemed to reinforce the idea that help seeking was legitimate and participants need not delay any further.

Conclusion

In this chapter, the findings of this study are presented in the context of the wider literature and are able to contribute to the existing knowledge regarding smoking, lung cancer symptoms, patient intervals and presentation in primary care.

The issues surrounding the concepts of access to primary care and legitimate help seeking were found to be present in the existing the literature and were also pertinent to the findings of this study, particularly regarding the perceptions of the focus groups participants. Symptom experiences are also revealed in this, and in previous studies, to be complex and bound with the ways in which participants recognise and interpret those symptoms. The processes of symptom accommodation and normalisation were also present in participant accounts in this study as they have been in those of other study populations in previous research. The findings of this study also add weight to theories regarding comorbidity and the presentation of new cancer symptoms. Participant's accounts in this study add to those in other studies regarding risk perceptions, awareness, and beliefs surrounding health practices and smoking risks. This study may also contribute to existing knowledge regarding stigma, smoking, and help seeking as the accounts of participants, particularly focus group participants, revealed strong perceptions of stigma within primary care. The findings of this study revealed the ways in which family members and partners may be able to help to facilitate early presentation and adds to the current literature surrounding the influence that family members can have on help seeking choices. The findings of this study may also make a valid contribution to the knowledge surrounding concepts of time wasting as many participant accounts featured strong opinions on how and when healthcare professionals time in primary care should be used. This study has also highlighted two key areas for potential interest, that of the concept of legitimate help seeking, and the existence of the 'crisis point' in participants' accounts of lung cancer presentation.

The findings of this study strengthen the findings reported by previous studies in that they often report similar issues and factors, which may have an effect on time to presentation. The body of existing knowledge may be enriched by the findings of this study in that it will add the perspectives of these particular study populations in this North Wales setting.

Chapter 6: Conclusion

Chapter Summary

In this chapter, the study is brought to a conclusion, beginning with a recapitulation of the initial identification of the need for research, the research aims, objectives and subsequent research questions. There follows a brief summary of the approach and the methods. This is followed by a summary of the key findings of the study and the ways in which they fulfil the aforementioned research aims. Finally, this chapter will outline the strengths and limitations of the study, and detail the implications of this research for future policy, practice and further research.

Study purpose

This research was conducted in response to the issue of potentially delayed presentation of lung cancer symptoms in patients who smoke. This study was intended to explore the presentation journeys and decision making regarding help seeking in primary care within two specific study populations in North Wales, recently diagnosed lung cancer patients, and current smokers without a cancer diagnosis. The formulation of the research aims and objectives led to the design of the questions for the study to answer and in order to allow for a full and rich exploration of the topic, an interpretive approach and qualitative methodology were utilised.

Reminder of aims/ objectives

Research questions

1. Are there differences in the primary care consulting patterns of people who smoke compared with non-smokers, particularly in the duration of the patient interval?
2. To what extent do people who smoke delay or avoid consulting primary care health professionals:
    a. For any symptoms of ill-health?
    b. For symptoms they perceive to be smoking-related?
    c. For chest or other symptoms they perceive to be indicative of lung cancer?
3. What are the factors associated with smoking that may lead to longer patient intervals (for example stigma, shame, guilt, blame, fear, nihilism, perceived health professionals' negative attitudes towards smokers and smoking, and previous consultation experiences) and how do they impact on smokers' health-related decisions and choices?
4. In what ways do the experiences of people newly diagnosed with cancer in Wales reflect delayed presentation in primary care due factors associated with smoking?

Research aims and objectives

- To conduct a systematic literature review to address research questions one and two by:
    - Appraising the evidence relating to differences in primary care service-use between smokers and non-smokers
    - Describing the nature and extent differences and identifying possible reasons for them
- To conduct a narrative literature review to address research question three by further exploring, in more breadth, depth and detail:
    - The factors that may lead to longer patient intervals
    - Possible explanations for smokers' health service-related choices and decisions
    - Perceived barriers to consulting in primary care in people who smoke and have chest symptoms that may be due to serious lung disease, such as lung cancer
    - Factors that deter smokers with chest symptoms from timely presentation in primary care
    - Perceived barriers to primary care in people who smoke but do not suffer chest symptoms
- To conduct a primary qualitative study to address research questions four and five by:
    - Exploring pathways to consultation and/ or diagnosis for people newly diagnosed with lung cancer in Wales, particularly their experiences within primary care
    - Explore attitudes and opinions of current smokers regarding seeking primary care for smoking related symptoms

Summary of methods

Reviewing the literature

This study began with two comprehensive literature reviews, a systematic review and a narrative review, which both served different but necessary purposes. The systematic review was designed to identify evidence that people who smoke are more likely to delay use of primary care when they experience symptoms than non-smokers. The narrative review was intended to take a broader approach in order to capture the existing knowledge regarding the reasons why smokers may delay help seeking.

The knowledge gained from the two literature reviews effectively answered research questions one and two and also highlighted a need for this research to be conducted. The literature reviews provided a strong evidence base upon which to build the subsequent stages of the study and to design data collection materials.

Data collection

Interpretive approach and qualitative methodology

As previously discussed in the methods chapter of the thesis, this study followed an interpretive approach and utilised the most appropriate qualitative methodology in order to best fulfil research aims.

Interviews

The first stage of data collection involved in-depth qualitative interviews with a sample of twenty nine recently diagnosed lung cancer patients, recruited via secondary care sites in North Wales. The interviews employed a semi-structured approach using topic guides designed using evidence from the literature reviews.

The interviews explored the individual accounts of those with a recent diagnosis of lung cancer, with particular emphasis on their route to diagnosis and their use of primary care.

Focus groups

The second stage of the data collection comprised a series of three focus groups with current smokers recruited via two primary care sites in North Wales. The focus groups were designed to build upon evidence already generated in the literature reviews and in the interview phase of the study.

The focus groups explored the views and experiences of current smokers regarding primary care use and smoking related symptoms.

All data collected was analysed as a whole data set using a rigorous thematic analysis as previously described in the methods chapter of the thesis.

Key findings

This section presents a summary of the key findings in this study and the ways in which they answer research questions three and four by exploring the accounts of both study samples, regarding smoking, lung cancer symptoms and primary care.

The findings of this study reveal the complexity surrounding the decision making of smokers and those with lung cancer symptoms regarding primary care and help seeking. The decision of when and how to approach primary care was revealed to be a complex process involving many different factors, all of which can influence time of presentation.

Each interview participant in this study had their own, unique set of circumstances which led to their lung cancer diagnosis, however their accounts often featured similar beliefs regarding the ways in which primary care should be utilised. The focus group participants also shared many of these beliefs, particularly those concerning what constitutes legitimate help seeking. The concept of time wasting was raised often in this study by participants in both samples, as they reported that NHS time was valuable and limited and those who sought help for minor symptoms which did not warrant seeing a doctor, were wasting time and using up appointments that could be taken by someone more deserving. Minor symptoms such as cough were described as something that did not warrant seeing the doctor and therefore was not a legitimate reason to seek help.

Whilst participants believed that coughs and chest infections were minor illnesses that ought not to be worth seeing the doctor over, for many of the interview participants, these were the symptoms they experienced which later led to their lung cancer diagnosis. Symptoms awareness varied between interview participants but it seems that when symptoms are experienced, the decision of whether or not to seek help, depends very much on how those symptoms are recognised and interpreted. Many interview participants in this study described how they had attributed their symptoms to minor illness, ageing, or stress and therefore waited for them to improve on their own rather than see a doctor.

Alongside minor illnesses, interview participants also sometimes reported having attributed their symptoms to an existing comorbidity or chronic condition such as COPD or asthma. The presence of a comorbidity can potentially influence time to presentation in different ways, in some cases it meant help seeking earlier due to already having follow up appointments, or a belief that having a chronic condition makes them a legitimate help seeker. However, comorbidity may also increase time to presentation as the person believes that they are going through a ‘bad spell’ with their asthma or COPD and it will improve soon, or if participant’s wait until they have a follow up appointment rather than arranging an appointment in primary care which may occur sooner.

The availability of appointments was also a common concern for participants in this study. Gaining access to primary care services was described by focus group participants as being an arduous process involving negotiating with many gatekeepers in order to be seen by the GP. The perceived difficulty in gaining access to the system may increase the likelihood of delayed presentation as patients decide to wait and see if symptoms will improve with over the counter medications rather than go through the process of trying to see the doctor.

In this study, many participants in both samples described trying to treat symptoms at home with over the counter medications when they believed themselves to have a minor illness. This is backed up by current UK guidelines which encourage those with potentially minor symptoms to consult their pharmacist first. Self-treating may contribute to delayed presentation however, if participants continue to do so when symptoms persist for a long time rather than seek help. This self-treating may also contribute to concepts of legitimate help seeking as a person may believe help seeking to be legitimate once they have tried other options and symptoms have not improved.

The perception that smokers are stigmatised in society, and specifically during healthcare encounters, was also a perception held by some of the focus group participants in this study. It may be that, as current smokers, they believe that they will be judged by healthcare professionals as being to blame for any smoking related illnesses they experience. Whilst some focus group participants reported actual encounters which they found stigmatising, others reported deliberately avoiding primary care due to the belief that they may be stigmatised. The perception that smokers will be dismissed or stigmatised by healthcare professionals as symptoms are ‘self-inflicted’ may contribute to delayed presentation, especially if the symptoms are smoking related.

In this study, interview participants reported not believing that they had been at risk of lung cancer. A feature of many interview accounts was the belief that one could effectively ‘balance out’ the risks associated with smoking by engaging in other, healthy practices such as exercising or having a good diet. There were also various other health beliefs present in the data from this study, including the belief that cancer in general was genetic or a matter of chance rather than being due to lifestyle factors, although participants did tend to be aware of the link between smoking and lung cancer. It may be that participants are able to distance themselves from the harmful effects of smoking with the belief that they are able to smoke because they are engaged in other healthy behaviours which will minimise the risks. In terms of time to presentation, it may be possible that those who do not believe themselves to be at increased risk for cancer are less likely to consider that symptoms may be potential cancer when they arise, and therefore do not seek help straight away.

A feature of many interview accounts in this study was the process of accommodating and normalising symptoms rather than reporting them to a doctor. Interviewees described the ways in which they altered their day to day routines to accommodate the changes in their health and ability to do everyday tasks, often by cutting down on physical activities such as walking or housework. Interviewees also normalised their symptoms, especially vague symptoms such as fatigue, as being part of the ageing process or due to stress from life events. This accommodation and normalisation may slow the help seeking process as participants may continue to alter their routine for as long as possible before deciding to see their GP. The participants in this study seemed to manage and accommodate their worsening health until a crisis point was reached which would be the point at which they decided to seek help.

The influence of family and friends was also a factor related to presentation for interview participants in this study. Family members or partners may facilitate help seeking by noticing symptoms and advising participants to see the doctor, or to see the doctor for a second time when symptoms did not improve. The encouragement of family members or partners may also make help seeking more legitimate as the participant is able to reason that they are seeing the doctor in order for family members peace of mind.

This study has added to the existing knowledge regarding smoking, lung cancer, and delayed presentation by exploring the accounts of two study samples in North Wales, current smokers without cancer, and recently diagnosed lung cancer patients. This study brought together the two samples for a unique examination of the attitudes to, and ways in which participants use, primary care. The findings of this study reflect the findings of previous research but also enrich the body of knowledge and create new avenues for exploration in further research.

Strengths, limitations and implications for policy and practice

Introduction

This study makes a valuable contribution to the knowledge surrounding patient intervals, smoking and lung cancer symptoms and has implications for policy and practice. This study makes a unique contribution due to the combined data from two study populations, recently diagnosed lung cancer patients and current smokers who do not have cancer, in North Wales. However, the study also has some limitations due to sampling, recruitment challenges and some methodological issues. The full study strengths, limitations and implications are given in detail below. Overall, this study is able to provide more information regarding the complexity of decision making regarding primary care use in the two study populations and utilised two qualitative methodologies in order to obtain rich data and highlight areas for further research.

Strengths

This study explored two populations and in doing so gained a thorough insight in to the views and opinions of smokers and those with lung cancer regarding primary care use in North Wales.

This study took place across four recruitment sites within BCUHB in North Wales and inclusion criteria was broad and inclusive. This allowed for recruitment of participants with varying sociodemographic backgrounds and from both urban and rural locations.

This study was carried out in a transparent and ethical manner and all care was taken to ensure participants were fully informed and supported throughout the study. The data collection took place in a caring and sensitive way and care was taken to ensure participants did not become distressed. There were procedures in place should participants become distress or require further information.

The study included two comprehensive literature reviews involving different review methods. These two reviews allowed for literature to be included across broad spectrum, from different disciplines and employing different methods, to ensure that the study was fully informed and grounded within the current knowledge. The systematic review was updated to include several papers published since the initial searches took place. Papers were also included in the narrative review as they came to light.

At the beginning of the study, care was taken to recruit a member of a PPI forum in order to ensure that the study was inclusive, accessible, and aimed to address issues that would be important to patients and the public. The PPI representative was involved in study design, ethical considerations, and gave input on the design and content of participant facing materials.

This study also employed two different data collection methods, in depth qualitative interviews and focus groups. Using these two different methods meant that each data collection occurred in the most appropriate ways for each sample group. The interviews were designed to collect and compare individual accounts of those with a recent diagnosis of lung cancer. The focus groups were designed to gain insight into the views and opinions of current and former smokers, who do not have cancer, regarding using primary care as a smoker. These two different methods complement each other and allowed for high quality and rich data to be collected.

Due to the careful and rigorous data collection and analysis, the findings of this study are reliable and provide an important insight in to the life worlds and consulting decisions within the two study populations. Whilst not necessarily generalisable, the findings are transferable and this will be discussed in further detail under study implications.

This study has generated novel findings which give a valuable insight in to the consulting choices and journeys to diagnosis of the two study populations. These novel findings can be seen in particular in the participants’ views around fatalism, where the literature reports fatalistic accounts of those with lung cancer, this study showed that those with lung cancer were not fatalistic in their outlook. Lung cancer patients in this study expressed a wish to recover and to carry on with their lives despite their diagnosis. They also expressed faith in their doctors and their treatment. In contrast, the focus group participants expressed more fatalistic beliefs in regards to cancer.

Limitations

The systematic review was updated prior to finalising the thesis and recent publications were included. However not all searches were re-run on all platforms but the search was re run on Medline as this platform yielded the most results in the original search. Whilst theoretical models were taken in to account in the study, it may be useful in future work to apply models to each theme.

No double coding was used during analysis as this was an independent PhD study. This may have implications for rigour. However, interpretation meetings were held throughout the analysis stage during which the researcher and supervisory team discussed transcripts and themes

The study was limited to a sample of lung cancer patients and current/ former smokers. To strengthen the design it may have been helpful to widen the study to include interviews with never smokers and healthcare professionals.

In order to be inclusive, understandable and to ensure informed consent, the recommended reading level for participant facing materials is that of a person 11 to 12 years old (Ennis and Wykes 2016). This was not an explicit consideration when designing recruitment materials for this study, however, due to PPI input at all stages of design, the materials were deemed accessible. In future work reading age of materials will be assessed during design.

Duration of patient intervals was not recorded due as the study was concerned with participant experiences and interpretation of happenings rather than quantifiable interval data. However, this may have been useful for future research had it been collected.

There were methodological challenges presented due to poor response to focus group recruitment. Focus group members were recruited via primary care and, as smokers are a hard to reach population, it was expected that response rates would be low, however they were very low with only 4% approached eventually providing consent and taking part. Focus group one consisted of only three participants which is below the ideal amount. However, whilst recruitment rates were low, only focus group one had such a small number of attendees, focus group two had five participants and focus group three had six. Despite recruitment being lower than expected, focus groups were still insightful and generated rich and useable data.

During focus group two, one participant displayed challenging behaviour which had to be managed and controlled by researchers. The participant in question had previously disclosed a personality disorder which may account for his dominance. He also displayed an apparent dislike to one other member of the group which may have been due to a perceived difference in their sociodemographic characteristics. Whilst the majority of the challenging behaviour was effectively managed by researchers, it is possible that other participants may also have found the situation challenging and this may have had an effect on their contributions. Taking more care to match sociodemographic characteristics of participants may have resulted in a less challenging atmosphere.

Implications for policy

Policy makers may wish to revise content of awareness campaigns in order to highlight issues relevant to smokers and to make it clear that they are the intended audience of certain health messages. Policy makers may include messages to advise that a persistent cough may not be a ‘smoker’s cough’ and that presentation is advised.

Policy makers may also consider awareness campaign strategies which target family members and friends of those who smoke to educate them on cancer symptoms and to encourage presentation if they believe someone is showing those symptoms.

It may be useful to provide better education to the public regarding the lesser known symptoms of lung cancer such as fatigue and back pain and encourage presentation with these symptoms.

Policy makers may also consider ways in which to avoid symptom normalisation and accommodation by creating health messages which explain that if seemingly minor symptoms persist for a long time then they should seek advice rather than change routines.

Implications for practice

Healthcare professionals may consider ways in which they can discuss smoking with their patients without contributing to feeling of stigmatisation. Patients who smoke may benefit from encouragement during appointments and reassurance that they should present if they experience symptoms.

Healthcare professionals may wish to encourage patients with comorbidities to mention changes in symptoms during appointments and to make new appointments should they experience a new symptom or marked change in condition.

Healthcare professionals should also consider ways in which to encourage patients to return if their symptoms do not improve within a reasonable space of time.

Allied health professionals such as pharmacists may also benefit from the findings of this study as they may be able to encourage smokers to seek primary care should over the counter medicines not be effective.

Implications for further research and the future

The findings of this study, whilst related to smoking and lung cancer in this thesis, may also be transferable to other conditions which may be considered lifestyle related. Many of the issues raised by participants in this study were specifically related to smoking being a lifestyle choice and therefore smoking related conditions could be perceived as being ‘self-inflicted’ leading to feelings of stigmatisation and being less worthy of care. These perceptions were key factors in delaying or avoiding presentation.

These findings may then be transferable to other conditions which may be perceived as lifestyle related or self-inflicted. They may include other smoking related conditions such as COPD, conditions such as liver damage or liver cancer caused by alcohol consumption, and obesity related conditions such as heart disease, bowel cancer and type two diabetes.

Further research could include interviews with healthcare professionals to strengthen design and to gain further perspectives on the issues raised in this study.

Future research may benefit from international comparisons which may also be useful to inform future research proposals.

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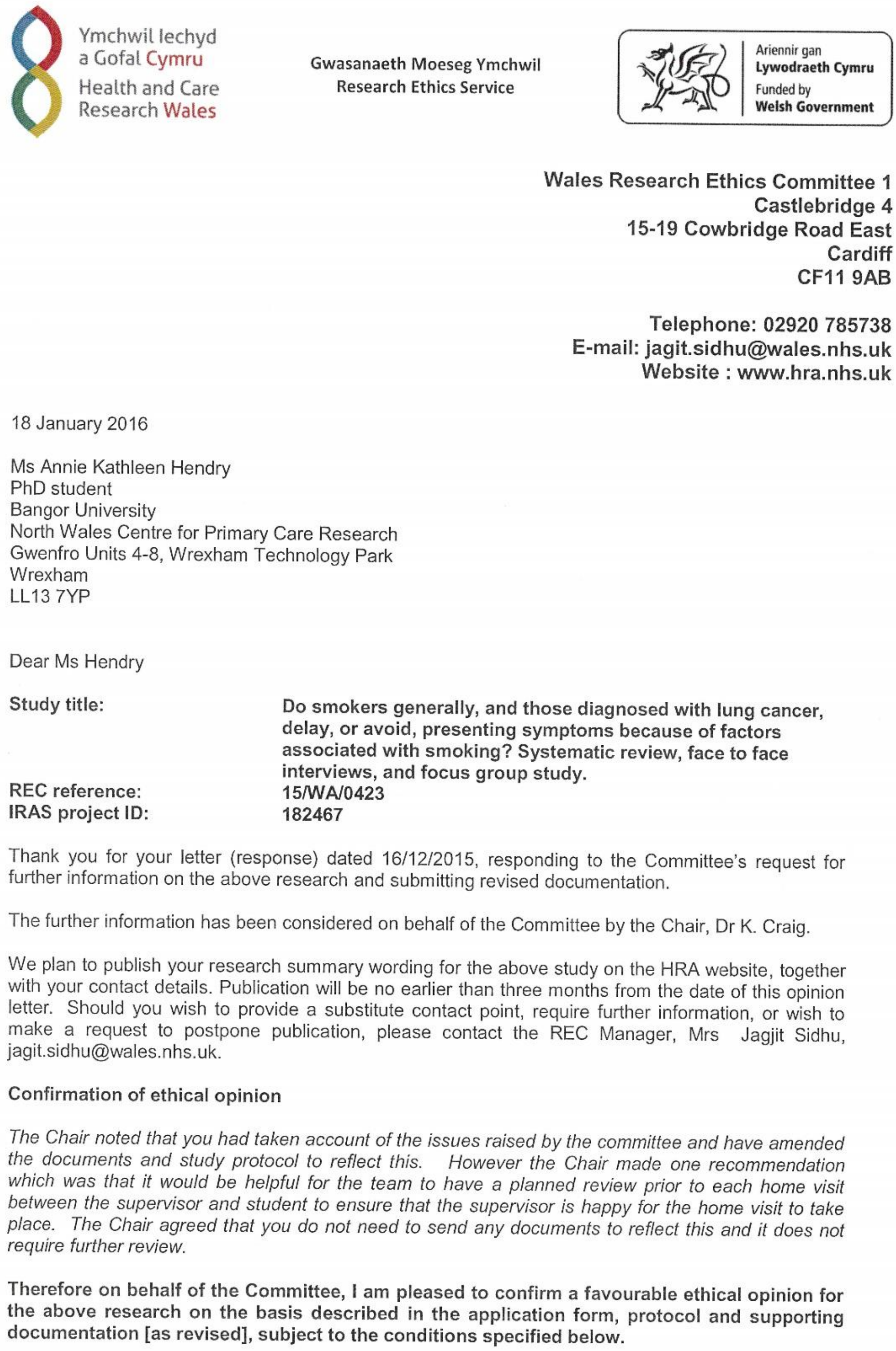
Appendix 1: Proposals and approvals

1) Wales REC 1. Letter of favourable opinion.
2) BCUHB letter of confirmation for R&D governance checks.
3) Bangor University School of Health Sciences ethics committee. Letter of ethical approval.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Wales Research Ethics Committee 1
Castlebridge 4
15-19 Cowbridge Road East
Cardiff
CF11 9AB

Telephone: 02920 785738
E-mail: jagit.sidhu@wales.nhs.uk
Website : www.hra.nhs.uk

18 January 2016

Ms Annie Kathleen Hendry
PhD student
Bangor University
North Wales Centre for Primary Care Research
Gwenfro Units 4-8, Wrexham Technology Park
Wrexham
LL13 7YP

Dear Ms Hendry

Study title:	**Do smokers generally, and those diagnosed with lung cancer, delay, or avoid, presenting symptoms because of factors associated with smoking? Systematic review, face to face interviews, and focus group study.**
REC reference:	**15/WA/0423**
IRAS project ID:	**182467**

Thank you for your letter (response) dated 16/12/2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Dr K. Craig.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Jagjit Sidhu, jagit.sidhu@wales.nhs.uk.

Confirmation of ethical opinion

The Chair noted that you had taken account of the issues raised by the committee and have amended the documents and study protocol to reflect this. However the Chair made one recommendation which was that it would be helpful for the team to have a planned review prior to each home visit between the supervisor and student to ensure that the supervisor is happy for the home visit to take place. The Chair agreed that you do not need to send any documents to reflect this and it does not require further review.

Therefore on behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).
Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UMAL Insurance certificate]	1	20 July 2015
GP/consultant information sheets or letters [Letter to GPs]	2	16 December 2015

Interview schedules or topic guides for participants [Topic Guide Interviews]	1	29 June 2015
Interview schedules or topic guides for participants [Topic Guide Focus Groups]	1	29 June 2015
IRAS Checklist XML [Checklist_06112015]		06 November 2015
IRAS Checklist XML [Checklist_18012016]		18 January 2016
Letters of invitation to participant [Invite Letter Interviews]	2	16 December 2015
Letters of invitation to participant [Invite letter focus groups]	2	16 December 2015
Other [Letter From GP Focus Groups]	1	24 June 2015
Other [CV second supervisor]	1	20 October 2015
Other [Letter of ethical approval Bangor University]	1	27 October 2015
Other [Reply Slip Interviews]	3	16 December 2015
Other [Reply Slip Focus Groups]	2	16 December 2015
Other [Letter From GP Focus Groups]	2	16 December 2015
Other [CV second supervisor]	2	16 December 2015
Other [Response to reviewer comments]	1	16 December 2015
Participant consent form [Participant Consent Form]	2	16 December 2015
Participant information sheet (PIS) [PIS Interviews]	3	16 December 2015
Participant information sheet (PIS) [PIS Focus Group]	3	16 December 2015
REC Application Form [REC_Form_06112015]		06 November 2015
Research protocol or project proposal [Study Protocol]	2	26 October 2015
Summary CV for Chief Investigator (CI) [Student CV]	2	16 December 2015
Summary CV for supervisor (student research) [Supervisor 1 CV]	2	16 December 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WA/0423	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

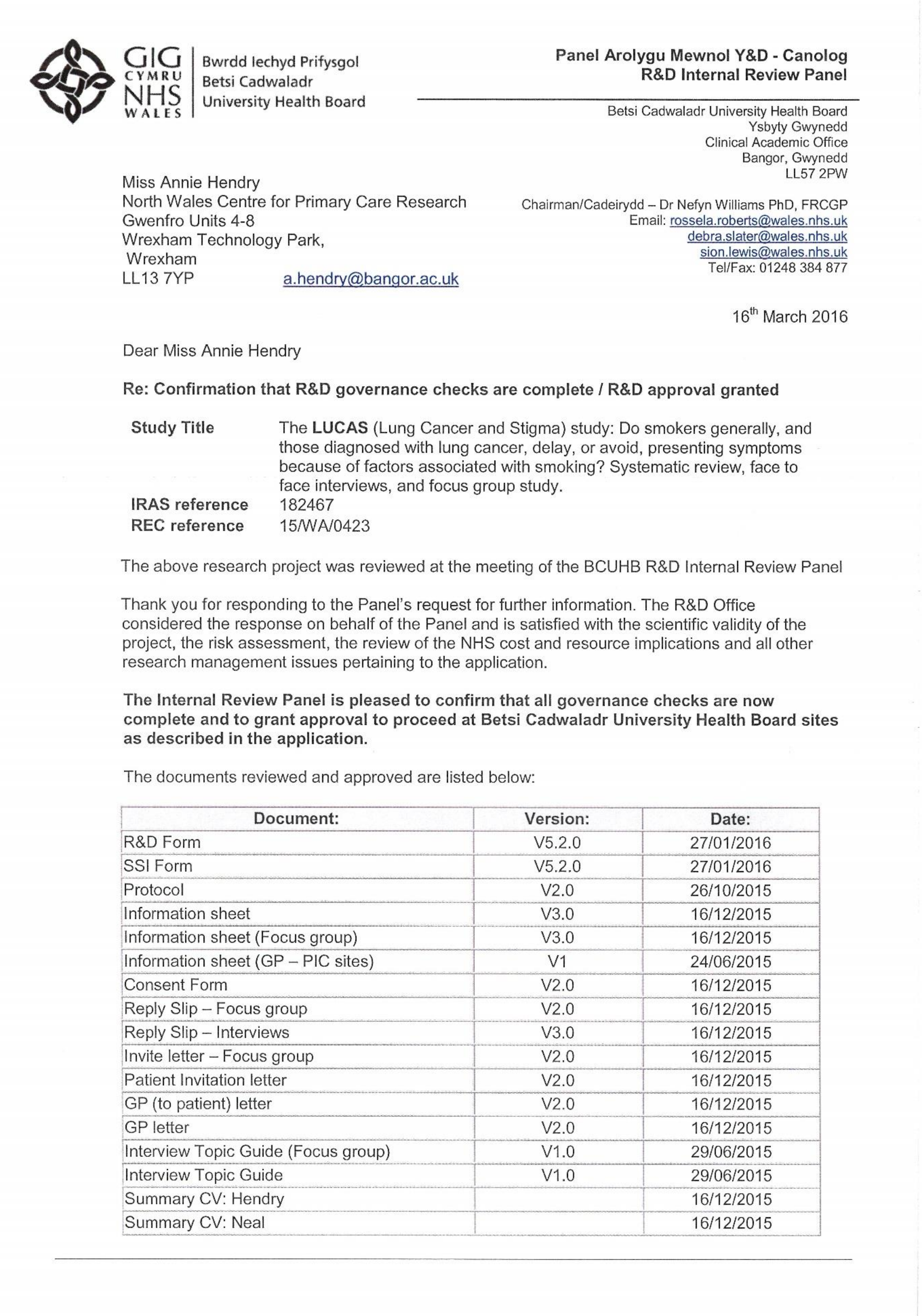
Yours sincerely

p.p.
Dr K J Craig
Chair

Email:jagit.sidhu@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Professor Jo Rycroft-Malone*
Dr Rossela Roberts, Betsi Cadwaladr University Health Board



GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D - Canolog
R&D Internal Review Panel

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Chairman/Cadeirydd – Dr Nefyn Williams PhD, FRCGP
Email: rossela.roberts@wales.nhs.uk
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Miss Annie Hendry
North Wales Centre for Primary Care Research
Gwenfro Units 4-8
Wrexham Technology Park,
Wrexham
LL13 7YP a.hendry@bangor.ac.uk

16th March 2016

Dear Miss Annie Hendry

Re: Confirmation that R&D governance checks are complete / R&D approval granted

Study Title	The **LUCAS** (Lung Cancer and Stigma) study: Do smokers generally, and those diagnosed with lung cancer, delay, or avoid, presenting symptoms because of factors associated with smoking? Systematic review, face to face interviews, and focus group study.
IRAS reference	182467
REC reference	15/WA/0423

The above research project was reviewed at the meeting of the BCUHB R&D Internal Review Panel

Thank you for responding to the Panel's request for further information. The R&D Office considered the response on behalf of the Panel and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the application.

The Internal Review Panel is pleased to confirm that all governance checks are now complete and to grant approval to proceed at Betsi Cadwaladr University Health Board sites as described in the application.

The documents reviewed and approved are listed below:

Document:	Version:	Date:
R&D Form	V5.2.0	27/01/2016
SSI Form	V5.2.0	27/01/2016
Protocol	V2.0	26/10/2015
Information sheet	V3.0	16/12/2015
Information sheet (Focus group)	V3.0	16/12/2015
Information sheet (GP – PIC sites)	V1	24/06/2015
Consent Form	V2.0	16/12/2015
Reply Slip – Focus group	V2.0	16/12/2015
Reply Slip – Interviews	V3.0	16/12/2015
Invite letter – Focus group	V2.0	16/12/2015
Patient Invitation letter	V2.0	16/12/2015
GP (to patient) letter	V2.0	16/12/2015
GP letter	V2.0	16/12/2015
Interview Topic Guide (Focus group)	V1.0	29/06/2015
Interview Topic Guide	V1.0	29/06/2015
Summary CV: Hendry		16/12/2015
Summary CV: Neal		16/12/2015

Document:	Version:	Date:
Summary CV: Hiscock		16/12/2015
Evidence of Insurance (UMAL)		Expires 31/07/2016
REC Favourable Opinion		18/01/2016
University Ethics letter		27/10/2015
Letter of Access (BCU) Hendry		Expires 31/01/2017

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (2009). An electronic link to this document is provided on the BCUHB R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If your study is adopted onto the NISCHR Clinical Research Portfolio (CRP), it will be a condition of this NHS research permission, that the Chief Investigator will be required to regularly upload recruitment data onto the portfolio database. To apply for adoption onto the NISCHR CRP, please go to: http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571 and/or from your NHS R&D office colleagues.

To upload recruitment data, please follow this link:
http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment.
Uploading recruitment data will enable NISCHR to monitor research activity within NHS organizations, leading to NHS R&D allocations which are activity driven. Uploading of recruitment data will be monitored by your colleagues in the R&D office. If you need any support in uploading this data, please contact debra.slater@wales.nhs.uk or sion.lewis@wales.nhs.uk

If you would like further information on any other points covered by this letter please do not hesitate to contact me.

On behalf of the Panel, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr Nefyn Williams PhD, FRCGP
Director of R&D
Chairman Internal Review Panel

Copy to:

Sponsor:
Dr Chris Burton
School of Healthcare Sciences,
Bangor University
c.burton@bangor.ac.uk

Academic Supervisors:
Professor Richard Neal
Professor of primary care and director of the North Wales Centre for Primary Care Research
r.neal@bangor.ac.uk

Dr Julia Hiscock
Research Fellow – Bangor University
j.hiscock@bangor.ac.uk

Appendix 2: University approval

1) Bangor University Health Sciences ethics committee approval.

Our ref: SW/SM

27 October 2015

Annie Hendry
North Wales Centre for Primary Care Research
Bangor University
Gwenfro Units 4-8
Wrexham Technology Park
Wrexham.

Dear Annie

Re: Proposal 2015-08-02 Do smokers generally, and those diagnosed with lung cancer, delay, or avoid, presenting symptoms because of factors associated with smoking? Systematic review, face to face interviews, and focus group study

Thank you for your application to the AEC which was subject to an expedited review as requested. All of the necessary documentation was provided and appropriately completed.

I am therefore able to give approval for your study on behalf of the AEC, and this letter constitutes evidence of that approval should it be necessary for any applications to other RECs.

Please note that approval from this AEC does not convey automatic authority to proceed with your study. You are formally advised that it is essential to confirm with the relevant authorities whether you are required to submit your proposal to any other Ethics Committee(s), such as Local NHS Research Ethics Committee, and NHS Research Governance Departments, <u>prior</u> to commencing your study.

Should you need to make any substantial amendments to your study protocol during the lifetime of the research, you are required to submit notice of these to the AEC for further approval, including major amendments requested by an external REC or R&D Commit

If you have any queries, please do not hesitate to contact me for clarification.

Yours sincerely

S. Williams

Dr Sion Williams
Chair, HCMS AEC

Appendix 3: Literature reviews

1) Critical appraisal tool for surveys. Adapted from Crombie, I. 1996. *The pocket guide to critical appraisal.* London: BMJ Publishing Group. By the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists of the EEPI centre.
2) RATS
3) Table of characteristics, strengths and limitations of critical appraisal tools
4) Narrative literature mapping exercise one
5) Narrative literature mapping exercise two
6) Narrative literature mapping exercise three
7) Narrative literature review combined thematic map
8) Narrative review search strategy

CEBMa
center for
Evidence-Based Management

Critical Appraisal of a Survey

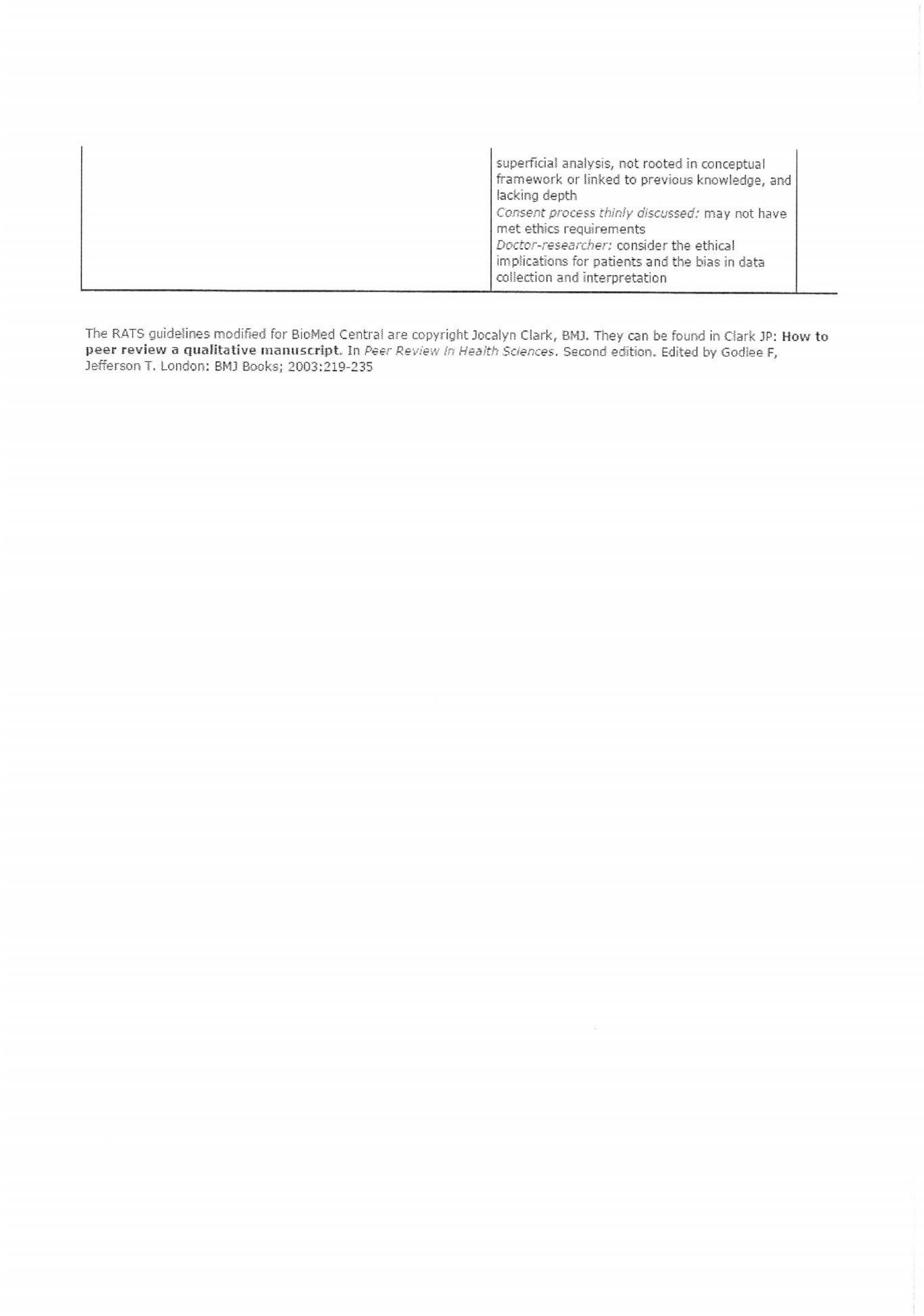
Appraisal questions	Yes	Can't tell	No
1. Did the study address a clearly focused question / issue?			
2. Is the research method (study design) appropriate for answering the research question?			
3. Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?			
4. Could the way the sample was obtained introduce (selection)bias?			
5. Was the sample of subjects representative with regard to the population to which the findings will be referred?			
6. Was the sample size based on pre-study considerations of statistical power?			
7. Was a satisfactory response rate achieved?			
8. Are the measurements (questionnaires) likely to be valid and reliable?			
9. Was the statistical significance assessed?			
10. Are confidence intervals given for the main results?			
11. Could there be confounding factors that haven't been accounted for?			
12. Can the results be applied to your organization?			

Adapted from Crombie, *The Pocket Guide to Critical Appraisal*; the critical appraisal approach used by the Oxford Centre for Evidence Medicine, checklists of the Dutch Cochrane Centre, BMJ editor's checklists and the checklists of the EPPI Centre.

Qualitative research review guidelines – RATS

	ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT	✓
R	**Relevance of study question**		
	Is the research question interesting?	Research question explicitly stated	✖
	Is the research question relevant to clinical practice, public health, or policy?	Research question justified and linked to the existing knowledge base (empirical research, theory, policy)	✖
A	**Appropriateness of qualitative method**		
	Is qualitative methodology the best approach for the study aims? *Interviews:* experience, perceptions, behaviour, practice, process *Focus groups:* group dynamics, convenience, non-sensitive topics *Ethnography:* culture, organizational behaviour, interaction *Textual analysis:* documents, art, representations, conversations	Study design described and justified e.g., why was a particular method (i.e., interviews) chosen?	✖
T	**Transparency of procedures**		
	Sampling		
	Are the participants selected the most appropriate to provide access to type of knowledge sought by the study? Is the sampling strategy appropriate?	Criteria for selecting the study sample justified and explained *theoretical:* based on pre conceived or emergent theory *purposive:* diversity of opinion *volunteer:* feasibility, hard-to-reach groups	✖
	Recruitment		
	Was recruitment conducted using appropriate methods? Is the sampling strategy appropriate?	Details of how recruitment was conducted and by whom	✖
	Could there be selection bias?	Details of who chose not to participate and why	✖
	Data collection		
	Was collection of data systematic and comprehensive?	Method (s) outlined and examples given (e.g., interview questions)	✖
	Are characteristics of the study group and setting clear?	Study group and setting clearly described	✖
	Why and when was data collection stopped, and is this reasonable?	End of data collection justified and described	✖
	Role of researchers		
	Is the researcher (s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Do the researchers occupy dual roles (clinician and researcher)?	✖
		Are the ethics of this discussed?Do the researcher(s) critically examine their own influence on the formulation of the research question, data collection, and interpretation?	✖

	Ethics		
	Was informed consent sought and granted?	Informed consent process explicitly and clearly detailed	✖
	Were participants' anonymity and confidentiality ensured?	Anonymity and confidentiality discussed	✖
	Was approval from an appropriate ethics committee received?	Ethics approval cited	✖
S	**Soundness of interpretive approach**		
	Analysis		
	Is the type of analysis appropriate for the type of study? *thematic:* exploratory, descriptive, hypothesis generating *framework:* e.g., policy *constant comparison/grounded theory:* theory generating, analytical	Analytic approach described in depth and justified	✖
	Are the interpretations clearly presented and adequately supported by the evidence? Are quotes used and are these appropriate and effective?	*Indicators of quality:* Description of how themes were derived from the data (inductive or deductive) Evidence of alternative explanations being sought Analysis and presentation of negative or deviant cases Description of the basis on which quotes were chosen Semi-quantification when appropriate Illumination of context and/or meaning, richly detailed	✖ ✖
	Was trustworthiness/reliability of the data and interpretations checked?	Method of reliability check described and justified e.g., was an audit trail, triangulation, or member checking employed? Did an independent analyst review data and contest themes? How were disagreements resolved?	✖
	Discussion and presentation		
	Are findings sufficiently grounded in a theoretical or conceptual framework? Is adequate account taken of previous knowledge and how the findings add?	Findings presented with reference to existing theoretical and empirical literature, and how they contribute	✖
	Are the limitations thoughtfully considered?	Strengths and limitations explicitly described and discussed	✖
	Is the manuscript well written and accessible?	Evidence of following guidelines (format, word count) Detail of methods or additional quotes contained in appendix Written for a health sciences audience	✖
			?
	Are <u>red flags</u> present? these are common features of ill conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.	*Grounded theory:* not a simple content analysis but a complex, sociological, theory generating approachJargon: descriptions that are trite, pat, or jargon filled should be viewed sceptically *Over interpretation:* interpretation must be grounded in "accounts" and semi-quantified if possible or appropriate *Seems anecdotal, self evident:* may be a	✖



	superficial analysis, not rooted in conceptual framework or linked to previous knowledge, and lacking depth *Consent process thinly discussed:* may not have met ethics requirements *Doctor-researcher:* consider the ethical implications for patients and the bias in data collection and interpretation	

The RATS guidelines modified for BioMed Central are copyright Jocalyn Clark, BMJ. They can be found in Clark JP: **How to peer review a qualitative manuscript.** In *Peer Review in Health Sciences*. Second edition. Edited by Godlee F, Jefferson T. London: BMJ Books; 2003:219-235

Table 8

Critical appraisal table of characteristics for tools considered

Tool considered	Description	Strengths	Limitations	Decisions for use
Mixed Methods Appraisal Tool (MMAT) 2011 (Pluye 2011)	Specifically developed and pilot tested to assess Mixed methods studies, for which there was no previous consensus.	The tool was pilot tested and found to be efficient and reliable. The MMAT tool also provides a comprehensive tutorial with guidance and examples to guide the reviewer in its use. There is also guidance on interpreting the results and describing overall quality.	In regards to appraising mixed methods studies there are no obvious limitations of the MMAT tool.	This tool appeared to be the ideal one for a review including multiple study designs, however neither review in this thesis included multiple designs. Only survey studies met inclusion for the systematic review and only qualitative studies were included in the narrative review.
Critical Appraisal of a Survey tool (adapted from Crombie 1996 by the Centre for Evidence-Based Management)	Designed to assess surveys. Based on the approach used by the Oxford centre for Evidence Medicine, the Dutch Cochrane Centre, BMJ editors' checklists and checklists of the EPPI Centre.	The twelve included questions are stated clearly and concisely.	The final question 'can the results be applied to your organisation' is not relevant to the reviews in this thesis. There is a lack of guidance on how to apply the tool, or interpret the results and describe overall quality.	This tool was used for the systematic review. The clarity of the questions facilitated consistent application.
Critical Appraisal Skills Programme (CASP) checklist for qualitative research (www.casp-uk.net)	Designed to assess qualitative studies. A five point checklist developed by the Critical Appraisal Skills Programme (CASP).	The five included questions are stated clearly and concisely, with 'hints' to guide the reviewer.	The brevity of both the questions and the 'hints' could lead to inconsistent application and a more subjective interpretation.	The CASP tool was found to be adequate but was rejected in favour of the RATS tool.
Qualitative research review guidelines (RATS) checklist (Clark 2003)	Designed to assess qualitative studies. A detailed checklist in four sections developed by JP Clark (2003) for a chapter in 'Peer Review in Health Sciences', and further developed for BioMed Central.	The four sections are broken down in to a number of relevant questions and guidance is given on what corresponding evidence should be shown in the manuscript. The tool includes a section on 'red flags' i.e. common features of ill-conceived or poorly executed qualitative studies.	There are no obvious limitations of the tool.	The RATS tool contained more guidance and examples to ensure consistent application and objective interpretation. The RATS tool was chosen for the narrative review in this thesis.

Literature mapping exercise 1 (from initial scoping searches)

Primary Care

Hamilton 2004

Smoking and Lung cancer

Chen 2012

Jarvis 2003

MacIntosh 2006

Underwood 1993

Late diagnosis/ delays/ intervals

Andersen 1995

Corner 2005 x2

Scanlon 2006

Scott 2006

Tod 2007

Shim 2013

Guilt

De Guzman 2010

LoConte 2008

Help seeking

Birt 2014

Nooijer 2001

Smith 2005

Whitaker 2005

Stigma

Bayer 2008

Bell 2010

Bell 2010

Cataldo 2011 x2

Chambers 2012

Chapple 2004

Else-Quest 2009

Gonzalez 2010

Halkjelsvik 2014

Hamann 2014

Jiang 2013

Lebel 2008

Lebel 2013

Lehto 2014

Mosher 2007

Rush 2009

Stuber 2008

Stuber 2009 x2

Verger 2008

Wilson 2006

Symptoms recognition interpretation

Brindle 2012

Sand-Andersen

Blame

Lobchuck 2012

Lobchuk 2008 x2

Mantler 2003

Milbury 2012

Westbrook 1986

Perceptions of risk

Ayanian 1999

Chatwin 2010

Finney Rutten 2011

Gillespie 2012

Hay 2004

Kneer 2012

Li 2014

Park 2014

Salander 2007

Weinstein 2005

Communication

Morse 2008

Stuber 2009

Literature mapping exercise 2 (from ASSIA keyword searches)

Family/ relationships

Badr 2006

Badr 2008

Robinson 2010

Siminoff 2010

Street 2008

Zhang 2003

Continued smoking

Berg 2013

Chun 2015

Cooley 2008

Hughes 2009

Lynne 2014

Parsons 2010

Regan 2015

Sanderson 2002

Westmaas 2015

Risk

Bepler 2004

Faller 1995

Kanvill 2000

Lin 2015

Moore 2013

Pepper 2015

Roberts 2014

Steenland 1990

Smoking and lung cancer

Becher 1989

Chinthapalli 2014

Cowen 1999

DeMaria 1987

Doll 1991

Lopez 1999

Pearce 2005

Peto 2000

Street 2004

Volk 2014

Woloshin 2002

Diagnosis/ delay

Brewster 2001

Davies 2001

Walton 2013

Alcohol

Dean 2010

DeLeon 2007

Stigma

Burgess 2009

Chambers 2015

Criswell 2016

Nagelhout 2012

Shen 2015

Tan 2013

Vallgarda 2011

Symptoms

Gift 2003

Maguire 2014

Quality of life

Cai 2011

Denial

Sharf 2005

Vos 2008

Gender

Payne 2001

Media

Warner 1991

Weeks 2011

Biographical disruption

Levealanti 2007

Blame

Gonzalez 2015

Communication

The 2000

Care and needs

Li 2006

Lorhan 2014

Siminoff 2006

Siminoff 2008

Stone 2012

Literature mapping exercise 3 (from Medline keyword searches)

Symtpoms

Crane 2016

Grant 2010

Screening

Ali 2015

Lifestyle

Hart 2001

Jensen 2013

Wang 2014

Blame

Christensen 1999

Smoking and LC

Cutler 1954

Stigma

Carter-Harris 2014

Coughlan 2004

Fear

Humphris 2004

Leventhal 1966

Fatalism

Niederdeppe 2007

Quaife 1015

Risk

Bauld 2005

Butterfield 2003

Evangelista 2003

Hahn 2006

Hay 2005

Humphris 2004

Kefahi 2005

Kropp 2004

Li 2013

Li 2015

Lonergan 2014

Lund 2014

Messima 2013

Mheen 1996

O'Neill 2013

Oncken 2005

Park 2009

Park 2013

Peiper 2010

Peretti Waltel 2007

Peretti Watel 2013

Persoskie 2013

Romer 2001

Savoy 2014

Combined thematic map

Theme	References
Introduction	Hamilton 2004 Neal 2009 Neal 2014 Neal 2015 Parkin 2011 Weller 2012
Delay/ intervals/ Diagnosis	Andersen 1995 Brewster 2001 Corner 2005 Corner 2006 Scanlon 2006 Scott 2006 Shim 2013 Tod 2007 Walton 2013
Smoking and lung cancer	Becher 1989 Chen 2012 Chinthapalli 2014 Cutler 1954 DeMaria 1987 Doll 1991 Jarvis 2003 Lopez 1999 MacIntosh 2006 Pearce 2005 Peto 2000 Street 2004 Underwood 1993 Woloshin 2002
Risk	Ayanian 1999 Bauld 2005 Bepler 2004 Butterfield 2003 Chatwin 2014 Dillard 2007 Evangelista 2003 Faller 1995 Faller 1995 Finney Rutten 2011

	Gillespie 2012 Hahn 2006 Hay 2005 Hay 2007 Kanvil 2000 Kneer 2012 Kofahi 2005 Kropp 2004 Li 2014 Li 2014 Li 2015 Lin 2014 Lonergan 2013 Lund 2014 Messina 2013 Moore 2013 O'Neill 2013 Oncken 2005 Park 2009 Park 2013 Park 2014 Peiper 2010 Pepper 2015 Peretti-Watel 2007 Peretti-Watel 2013 Persoskie 2014 Roberts 2014 Romer 2001 Salander 2007 Savoy 2014 Steenland 1990 Van de Mheen 1996 Weinstein 2004
Communication	The 2000
Alcohol	Dean 2010 De Leon 2007
Lifestyle	Hart 2001 Jensen 2013 Wang 2014
Gender	2001
Biographical disruption	Levealahti 2006
Media	Weeks 2011 Warner 1991
Denial	Salander 1999 Sharf 2005 Vos 2008

Quality of life	Cai 2011
Screening	Ali 2015
Fatalism	Quaife 2015 Niederdeppe 2007
Symptoms	Crane 2006 Gift 2003 Grant 2010 Humphris 2004 Maguire 2014 Westerman 2006
Continued smoking	Berg 2013 Cooley 2008 Lynne 2014 Regan 2015 Sanderson 2002 Westmaas 2015
Help seeking	Birt 2014 Nooijer 2001 Smith 2005 Whitaker 2015
Symptom recognition	Brindle 2012 Sand Andersen 2010
Care and needs	Li 2005 Lorhan 2014 Siminoff 2006 Siminoff 2008 Stone 2010
Family and relationships	Badr 2006 Badr 2008 Robinson 2010 Siminoff 2010 Street 2008 Zhang 2003
Fear	Leventhal 1965 Humphris 2004
Guilt	De Guzman 2010 LoConte 2008
Blame	Christensen 1999 Else-Quest 2009 Gonzalez 2015 Lobchuk 2008 Lobchuk 2008 Lobchuk 2012 Mantler 2003

	Milbury 2012 Morse 2008 Westbrook 1986
Stigma	Bayer 2008 Bell 2010 Bell 2010 Bresnahan 2013 Burgess 2009 Cataldo 2011 Cataldo 2011 Chambers 2012 Chambers 2015 Chapple 2004 Chun 2015 Coughlan 2004 Criswell 2015 Gonzalez 2010 Halkjelsvik 2014 Hamann 2014 Lebel 2008 Lebel 2013 Lehto 2014 Mosher 2007 Nagelhout 2012 Rush 1998 Shen 2015 Stuber 2008 Stuber 2009 Stuber 2009 Tan 2013 Vallgarda 2011 Verger 2008 Volk 2014 Wilson 2006
Mixed themes	Carlsen 2004 Farley Brodersen 2010 Kendall 2005 Yardley 2001

Narrative review search strategy

1) SU EXACT smoking
2) SU EXACT symptoms
3) SU EXACT recognition
4) SU EXACT interpretation
5) 1 AND 2 AND 3 OR 4

1) SU EXACT smoking
2) SU EXACT health risks
3) SU EXACT risk behaviour
4) SU EXACT risk perception
5) SU EXACT cancer
6) SU EXACT lung cancer
7) 1 AND 2 OR 3 OR 4 AND 5 OR 6

1) SU EXACT smoking
2) SU EXACT stigmatisation
3) 1 AND 2

1) SU EXACT smoking
2) SU EXACT stigmatisation
3) SU EXACT cancer
4) SU EXACT lung cancer
5) 1 AND 2 AND 3 OR 4

1) SU EXACT smoking
2) SU EXACT blame
3) SU EXACT cancer
4) SU EXACT lung cancer
5) 1 AND 2 AND 3 OR 4

1) SU EXACT smoking
2) SU EXACT fear
3) SU EXACT cancer
4) SU EXACT lung cancer
5) 1 AND 2 AND 3 OR 4

Appendix 4: All recruitment materials and data collection tools

1) Participant information sheet: interviews
2) Invitation letter: interviews
3) Informed consent form: interviews and focus groups
4) Participant information sheet: focus groups
5) Invitation letter: focus groups
6) Letter from GP: focus groups
7) Reply slip: focus groups
8) Topic guide: interviews
9) Topic guide: focus groups

Participant Information Sheet

The LUCAS Study

Invitation and study summary

Lung cancer is one of the four most common cancers in the UK. Patient experiences are important in understanding the ways in which people with lung cancer symptoms are able to seek help from their GP. The purpose of this study is to learn more about the experiences of people with lung cancer.

You have been invited to take part because you have been identified, via your health care provider, as a person with a recent diagnosis of lung cancer and your views are very important to help us to find ways of helping other people in the future.

What will taking part involve?

It is up to you whether you decide to take part in the study. If you agree to take part we will ask you to sign a consent form. You are, of course, free to not take part or to withdraw at any time without giving a reason and it will not affect the care you receive.

You will be invited to take part in a one to one interview with a researcher which will last no more than 90 minutes. The interview will take place either in the research centre, in the hospital, or in your own home, whichever is most convenient for you. If you incur any travel expenses then they will be paid for by the research team.

You will be asked about your experiences regarding your diagnosis in order to explore your thoughts and feelings. The focus will be on the time which you first saw your GP about your symptoms, what your experiences of presenting your symptoms were, and what prompted you to see your doctor when you did.

What are the possible risks of taking part in the study?

We do not foresee any major disadvantages or risks to you taking part in the study. However, some people may find some topics distressing. You are welcome to take a break or to stop the interview at any time if you wish to do so and this is will not affect the care you receive. If you have any concerns the researcher will be happy to discuss these with you.

What are the possible benefits of taking part?

The study will not help you directly but your contribution to the study may help other people in similar situations in the future.

What if I decide not to take part?

If you do not want to take part then please disregard the invitation and you will not be contacted again.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason. If you do withdraw, all data relating to you already collected with your consent will be used in the study but it will all be anonymised and your details will be removed from our records.

What if there is a problem?

Whilst we do not foresee any problems, if you do have a concern about any aspect of the study, you should speak to the research team who will do their best to answer your queries (*contact details are supplied below*). However, if you are still unhappy or dissatisfied about any aspect of your participation, then you can contact the Concerns Team at Betsi Cadwaladr University Health Board (BCUHB, Ysbyty Gwynedd, Penrhosgarnedd, Bangor, LL57 2PW. Tel: 01248 384384, email: ConcernsTeam.bcu@wales.nhs.uk)

How will my information be kept confidential

All information about you will be kept strictly confidential and secure. Comments you give us during the interview will be anonymised and will not be used for anything other than this research. It will not be possible to identify you in any report or publication of the study.

The interview will be tape recorded for the researchers use but all recordings will be kept confidential and deleted once the study is complete. Your GP may be informed that you have taken part but will not be given access to your comments during interview. You may choose to take part in a Welsh speaking interview if you prefer.

What to expect during the consent process

Once you have read all of the information and decided to take part in the study, you will be asked to sign a consent form. There will be three copies of the form, two will be kept by the research team and one will be for you to keep.

How have patients and the public been involved in this study?

This study has been designed with the help of a patient and public representative to make sure the interests of participants are represented.

What will happen to the results of the study?

The results of the study will be used to write academic papers which will be submitted for publication in peer reviewed journals.

Who is organising and funding the research?

The study is funded by Health and Care Research Wales and will be carried out by a PhD student from Bangor University who is based at the North Wales Centre for Primary Care Research in Wrexham.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The NRES

Committees – Wales REC 1 has reviewed the study and it has also been reviewed by the Bangor University School Research Ethics Committee.

Where can I get further information?

For more information or to discuss any concerns about this study, please feel free to contact:

Professor Richard Neal and

Annie Hendry (PhD student)

North Wales Centre for Primary Care Research

Bangor University, Cambrian Two

Wrexham Technology Park

Wrexham, LL13 7YP

Telephone: 01248 383518

E-mail: a.hendry@bangor.ac.uk

What do I do now?

If you have indicated that you would like to take part then the researcher will contact you to arrange a suitable time for interview and answer any questions you may have.

The LUCAS Study

Dear Sir/ Madam,

Thank you for agreeing to receive information about the research study we are conducting in North Wales about the experiences of those with lung cancer.

We are a Bangor University research team based in Wrexham and this study is a PhD project in the school of health care sciences. The study will involve interviews with people who have lung cancer to find out their opinions and experiences

You have been invited as a person with a recent diagnosis of lung cancer and the information within this pack is for you to read so that you can decide whether or not you would like to take part in the study.

The information sheet contained in this pack will outline the reasons for running this research study and what is involved if you wish to participate. It would be much appreciated if you could take the time to consider your participation by reading the information given to you.

If you do not wish to take part in the study then please disregard the invitation and you will not be contacted again.

If you have any queries or would like any further information before you decide whether or not to take part in the study then please contact the researcher using the details below.

Thank you for your time.

Professor Richard Neal and Annie Hendry (PhD student)

Bangor University

North Wales Centre for Primary Care Research

Cambrian Two

Wrexham Technology Park

Wrexham

LL13 7YP

E mail – a.hendry@bangor.ac.uk

Telephone – 01248 383518

Centre Number:

Study Number:

CONSENT FORM

Title of Project: **The LUCAS Study**

Name of Researcher: Annie Hendry

Please
initial box

1. I confirm that I have read the information sheet dated.....16/12/2015...... (version....3.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. (If appropriate) I understand that relevant sections of my medical notes and data collected during
   the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. (If appropriate) I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

5. (If appropriate) I agree to my General Practitioner being informed of my participation in the study. ☐

6. (If appropriate) I understand that the information held and maintained by the Health and Social Care Information Centre (or amend as appropriate) and other central UK NHS bodies may be used to help contact me or provide information about my health status. ☐

7. I agree to take part in the above study. ☐

______________________	______________________	______________________
Name of Participant	Date	Signature

________________________ ________________________ ________________________

Name of Person taking consent Date Signature

Patient Information Sheet

The LUCAS Study

Invitation and study summary

It has been found by previous research that people who smoke may be reluctant to see their GP regarding chest symptoms. Patient experiences are important in understanding the ways in which people who do smoke and have chest symptoms are able to seek help from their GP. The purpose of this study is to learn more about the health seeking choices of people who smoke.

You have been invited to take part because you have been identified, via your health care provider, as a person with a history of smoking and your views are very important to help us to find ways of helping other people in the future.

What will taking part involve?

It is up to you whether you decide to take part in the study. If you agree to take part we will ask you to sign a consent form. You are free to not take part or to withdraw at any time without giving a reason and it will not affect the care you receive.

You will be invited to take part in a focus group (a small, informal, group discussion) of between six and eight people and a researcher which will last no more than 90 minutes. The focus group will take place in the research centre, at your general practice, or in a local community venue. Your travel expenses will be paid and refreshments will be provided.

You will be asked about your experiences and opinions regarding smoking and health care in order to explore your thoughts and feelings. The focus will be on when and why you use your GP and what happens when you do.

What are the possible risks of taking part in the study?

We do not foresee any major disadvantages or risks to you taking part in the study. However, some people may find some topics potentially distressing. You are welcome to take a break or to stop the discussion at any time if you wish to do so and this is will not affect the care you receive. If you have any concerns the researcher will be happy to discuss these with you.

What are the possible benefits of taking part?

The study will not help you directly but your contribution to the study may help other people in similar situations in the future.

What if I decide not to take part?

If you do not want to take part then please disregard the invitation and you will not be contacted again.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason. If you do withdraw, all data relating to you already collected with your consent will be used in the study but it will all be anonymised and your details will be removed from our records.

What if there is a problem?

Whilst we do not foresee any problems, if you do have a concern about any aspect of the study, you should speak to the research team who will do their best to answer your queries (*contact details are supplied below*). However, if you are still unhappy or dissatisfied about any aspect of your participation, then you can contact the Concerns Team at Betsi Cadwaladr University Health Board (BCUHB, Ysbyty Gwynedd, Penrhosgarnedd, Bangor, LL57 2PW. Tel: 01248 384384, email: ConcernsTeam.bcu@wales.nhs.uk)

How will my information be kept confidential?

All information about you will be kept strictly confidential and secure. Comments you give us during the focus group will be anonymised and will not be used for anything other than this research. It will not be possible to identify you in any report or publication of the study.

The discussion will be recorded for the researchers use but all recordings will be kept confidential and deleted once the study is complete. Your GP may be informed that you have taken part but will not be given access to your comments during the focus group. You may choose to take part in a Welsh speaking focus group if you prefer.

What to expect during the consent process

Once you have read all of the information and decided to take part in the study, you will be asked to sign a consent form. There will be three copies of the form, two will be kept by the research team and one will be for you to keep.

How have patients and the public been involved in this study?

This study has been designed with the help of a patient and public representative to make sure the interests of participants are represented.

What will happen to the results of the study?

The results of the study will be used to write several academic papers which will be submitted for publication in peer reviewed journals.

Who is organising and funding the research?

The study is funded by Health and Care Research Wales and will be carried out by a PhD student from Bangor University who is based at the North Wales Centre for Primary Care Research in Wrexham.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The NRES Committees – Wales REC 1 has reviewed the study and it has also been reviewed by the Bangor University School Research Ethics Committee.

Where can I get further information?

For more information or to discuss any concerns about this study, please feel free to contact:

Professor Richard Neal and Annie Hendry (PhD student)

Bangor University

North Wales Centre for Primary Care Research

Cambrian Two

Wrexham Technology Park

Wrexham, LL13 7YP

Telephone: 01248 383518

E-mail: a.hendry@bangor.ac.uk

What do I do now?

Please fill out the enclosed reply slip and return in the freepost envelope. If you have indicated that you would like to take part then the researcher will contact you to arrange a suitable focus group and answer any questions you may have.

The LUCAS Study

Dear Sir/ Madam

We are a Bangor University research team based at the North Wales Centre for Primary Care Research in Wrexham. This study is a PhD project in the school of health care sciences.

We are conducting a study regarding the ways in which people who smoke visit their GP. We are inviting suitable people to attend a focus group to discuss this topic. The focus group will involve a general, group discussion about how people who smoke feel about visiting their GP.

You have been invited as a person with a history of smoking and the information within this pack is for you to read so that you can decide whether or not you would like to take part in the study.

The information sheet contained in this pack will outline the reasons for running this research study and what is involved if you wish to participate. It would be much appreciated if you could take the time to consider your participation by reading the information given to you.

If you are happy to take part please fill in the enclosed reply slip and return it in the prepaid envelope. When the researcher receives your reply slip then you will contacted to arrange a convenient time to attend a focus group.

If you do not wish to take part in the study then please disregard the invitation and you will not be contacted again.

If you have any queries or would like any further information before you decide whether or not to take part in the study then please contact the researcher using the details below.

Thank you for your time.

Professor Richard Neal and Annie Hendry (PhD student)

Bangor University

North Wales Centre for Primary Care Research

Cambrian Two

Wrexham Technology Park

Wrexham

LL13 7YP

E mail – a.hendry@bangor.ac.uk

Telephone – 01248 383518

ON GENERAL PRACTICE HEADED PAPER

The LUCAS Study

Dear XXXXX

We are attaching an invitation and detailed participant information sheet to take part in a research study being undertaken by North Wales Centre for Primary Care Research, which is part of Bangor University in North Wales.

The researchers want to find out how people who smoke or have smoked feel about visiting their GP when they have chest related symptoms. It is important to explore the opinions and experiences of people with a history of smoking in order to provide better care for people in the future. The researchers would like to invite people with a history of smoking to help by joining one focus group for about one to one and a half hours. The research is not about stopping smoking but about listening to smokers views.

Please take your time to read all the enclosed information carefully before making your decision. Your care at this practice will not be affected whether or not you choose to take part.

Yours sincerely

Doctor

Attachment: Study pack comprising invitation letter, reply slip, patient information sheet, Freepost envelope.

Reply Slip: The LUCAS Study

Please tick as appropriate and return in the freepost envelope provided

I would like to take part in the study and am happy to be contacted……………………….……….☐

I would like more information about the study ……………………………………………………………☐

Contact details

Name ………………………………………………………………..

Address………

………..

Postcode………………………………………………………….

Telephone Number……………………………………….

Mobile Number…………………………………………….

E-mail Address ………………………………………………..

Preferred time to be contacted …………………………………………………………………………………………

Preferred method of contact ……………………………………………………………………………………………….

The LUCAS Study

Interview Topic Guide

Objectives

- To explore participants accounts of their presenting history and their diagnosis
- To explore participants experiences regarding why and where they first presented their symptoms
- To explore any barriers and/ or facilitators to presentation

Note: The topic guide is designed to guide the interview. The topics will need to be tailored according to individual participants and the answers they give. The focus of the topics may shift over the course of the study as literature informs and refines the direction of the study.

Introductions

- Explain what will happen
- Explain confidentiality
- Take consent

Topics to discuss

- Explore pathways to diagnosis
- Perceived barriers to presentation
    - Symptoms
    - Selves
    - Societal factors
    - Previous experiences
- Facilitators to presentation
    - Symptoms
    - Selves
    - Societal factors
    - Previous experiences
    - Family, friends, media

Probe any mention of delays

- Are there ways that things could be done differently to encourage presentation in the future

Ending the interview

- Explain what will happen to the data
- Signposting for any concerns
- Reassure confidentiality

The LUCAS Study

Focus Group Topic Guide

Objective

- To explore participants perceptions and experiences of consulting with their GP in general and regarding smoking related symptoms
- To explore what could be done to encourage smokers to see their GP in the future

Note: The topic guide is designed to guide the interview. The topics will need to be tailored according to individual participants and the answers they give. The focus of the topics may shift over the course of the study as literature informs and refines the direction of the study.

Introductions

- Explain what will happen
- Explain confidentiality
- Take consent

Topics to discuss

- Barriers and facilitators to presentation
    - Symptoms
    - Selves
    - Societal factors
    - Previous experiences
    - Family, friends, media

Probe any mention of delays/ avoidance

- In what ways could things be different to encourage smokers to see their doctors

Ending the session

- Is there anything else you would like to add?
- Explain what will happen to the data
- Thanks and explain value of their contribution
- Signposting for any concerns
- Reassure confidentiality
- Any expenses

Thanks again

Appendix 5: analysis

1) Coding structure
2) Transcriber confidentiality agreement

Coding structure – all transcripts

- **Stigma** – from others
    - Stigma about smoking
    - Stigma about lung cancer
    - Embarrassment
- **Shame**
- **Blame**
    - Self blame
    - Blame from others
- **Co-morbidity**
    - Having a comorbidity
    - Believing symptoms to be of co-morbidity
    - Disease progression
- **Previous experiences of cancer**
    - Self
    - Others
- **Knowledge of cancer**
    - Knowledge of lung cancer symptoms
    - Knowledge of causes of cancer
    - Knowledge of treatment of cancer
- **Symptom recognition**
    - First symptoms
    - Symptoms as something else
    - Symptoms as normal for smokers
    - Symptoms only minor – not worth seeing a doctor
    - Minor symptoms – will get better
    - Alarm symptoms
- **Family and friends**
    - Support
    - Disclosure
    - Responsibility
    - Partners
- **Life in general**
    - Change to usual activities
    - Accommodating symptoms
    - Managing usual activities – since diagnosis
    - Getting back to normal

- **Health and lifestyle**
    - Otherwise healthy
    - Diet
    - Weight
    - Exercise
    - Balancing out – smoking vs other healthy behaviours

- **Help seeking**
    - Asking for help
    - Wasting the doctors time
    - Wasting own time
    - Too busy to see the doctor
    - Other people going too much
    - I only go if I need to
    - Just getting on with it
    - Self treating
    - Legitimate help seeking
    - Initial help seeking –primary care
    - Initial help seeking – secondary care
    - Access issues
- **Diagnosis**
    - Point of diagnosis
- **Delay**
    - Despite worsening symptoms
    - Difficult journeys
    - Repeated presentation
    - Patient interval
    - Care interval
- **Care**
    - Good experiences of care
    - Bad experiences of care
    - Relationships with HCPs
    - HCP manner
- **Attitude**
    - Positive attitude
    - Negative attitude
- **Emotional responses**
    - Fear
        - Of death
        - Of disease
        - Of treatment
    - Shock
    - Anger

  - Frustration
- **Smoking**
  - Previous smoking
  - Current smoking
  - Reasons for smoking
  - Quitting smoking
- **Treatment**
  - Type of treatment
  - Experiences of treatment
  - Side effects
  - Good results
- **Risk**
  - Smoking and risk
  - Risk of cancer
  - Aware of risk
  - Unaware of risk
- **Information**

- Demographics
  - Age
  - Gender
  - Relationship status
  - Children
  - Living arrangement
  - Smoking status

PRIFYSGOL
BANGOR
UNIVERSITY

YOUR DEPARTMENT
Bangor University
45 College Road, Bangor,
Gwynedd LL57 2DG
Telephone: (01248) 383719

Transcriber Confidentiality Agreement:

LUCAS Study

As a transcriber of this research, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have responsibility to honour this confidentially agreement.

I agree not to share any information on these recordings, about any party, with anyone except the Researcher of this project, Annie Hendry. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I, Emma Grace Bray agree to:

	Initials
1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. mp3 files, CDs, transcripts) with anyone other than the Researcher of this project.	EB
2. Keep all research information in any form or format (e.g. mp3 files, CDs, transcripts) secure while it is in my possession.	EB
3. Return all research information in any form or format (e.g. mp3 files, CDs, transcripts) to the Researcher when I have completed the transcription tasks.	EB
4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. information stored on my computer hard drive).	EB

Transcriber:

Emma Grace Bray — Bray — 22/08/2016
(Print name) (Signature) (Date)

Researcher:

Annie Hendry — 22/08/2016
(Print name) (Signature) (Date)

Appendix 6: training and dissemination

1) Year one training and dissemination log
2) Year two training and dissemination log
3) Year three training and dissemination log

PhD Training and Dissemination Log

Year One

Date	Training	Provider	Skills/ content
16th January 2014 (pre PhD)	Good Clinical Practice	NISCHR CRC	Value of clinical research GCP standards Study set up process Informed consent Case reports and data entry Safety reporting in clinical trials
25th February 2015	Refworks Software training	Bangor University	Complete beginners guide to using Refworks
25th February 2015	Using library databases	Bangor University	Guide to using e databases
25th March 2015	Qualitative software planning seminar	National Centre for Research Methods (Manchester)	CAQDAS project network information Guidance on choosing appropriate software for projects
2nd June 2015	Improving cancer diagnosis: the impact of the discovery programme	RCGP London	Impact of the discovery programme on cancer diagnosis (conference)
10th – 11th June 2015	Qualitative Interviewing in Health Research	Institute of Health and Society Newcastle University	Interviewing Planning Analysis Sampling Ethics

			Publication
6th – 7th July 2015	NVivo training workshop	CAQDAS networking project, University of Surrey	NVivo software training
9th-11th September 2015	MedSoc 2015	York University BSA	Poster presentation (conference)
22nd September 2015	Writing for publication workshop	Dr Jess Roberts, Bangor University	Writing for publication guidance
27th October 2015	Qualitative research workshop	Dr Julia Hiscock and Dr Becki Law, Bangor University	Qualitative research and reviewing methods guidance
12th November 2015	Health Care Sciences annual conference	Bangor University	Poster presentation
25th November 2015	How to be an effective researcher	Bangor University	Time management, team work, planning
26th November 2015	Making the most of year 2 of your PhD	Bangor University	Thesis planning, time management, effective supervision
11th December 2015	Effective project management	Bangor University	Managing the project as a whole, time management, supervision

PhD Training and Dissemination Log

Year Two

Date	Training/ conference	Provider/ location	Skills/ content/ presentation
03/02/2016	Good Clinical Practice refresher course	Health and Care Research Wales, Glyndwr University	Good Clinical Practice certificate
03/05/2016	LUCAS systematic review presentation	Cardiff University	Presented systematic review and gained feedback
18/05/2016	‘Pushing the boundaries’ PGR day	Bangor University, School of Healthcare Sciences	Profiling self Athena Swan PhD and career development PhD viva preparation Creative approaches Writing and socialising Language awareness
19/05/2016	SAPC early career networking event	Society for Academic Primary Care, University of Manchester	Early careers intro Speed networking and elevator pitches Career trajectories Funding Team work and collaboration Primary dare beyond the UK
05/07/2016 – 08/07/2016	SAPC annual conference	Dublin Castle	The systematic review elevator pitch
13-14/07/2016	Nvivo Training course	University of Surrey	Software training
14/09/2016	Cancer researcher’s introductory course	Health and Care Research Wales, Abergele	Cancer biology Treatments

			Quality of life Survivorship
21/09/2016	Health and Care Research Wales mentorship programme first meeting and matching event	Health and Care Research Wales, Cardiff	Mentor/ mentee training Speed meet and matching event
October 2016	Preparation for teaching	Online course from Bangor University	Pending

PhD Training and Dissemination Log

Year Three

Date	Event	Provider/ location	Skills/ content/ presentation
23-24th February 2017	Cancer Research UK early diagnosis research conference	CRUK London	ECR quick fire presentation and poster presentation – preliminary findings from the LUCAS interviews
24th March	‘Finish up and move on’	Bangor University – Dave Filipovic-Carter	Thesis writing and submission guidance
18th-20th April 2017	Ca-Pri 2017	University of Edinburgh	E-Poster presentation – preliminary findings from the LUCAS interviews