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**Help-Seeking among People with  
Symptoms of Lung or Colorectal Cancer:  
Experience and social context**

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**Thesis submitted for the degree of Doctor of Philosophy**

**School of Medicine, Pharmacy and Health**

**Durham University**

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## Abstract

The UK has some of the poorest cancer outcomes in Europe, commonly attributed to diagnostic delays. The patient interval appears to be a substantial contributor to these, with awareness raising campaigns a key strategy for encouraging earlier presentation. However, research has identified a number of barriers to help-seeking beyond a lack of awareness of cancer symptoms, such as fear, concerns about wasting the doctor's time, personal commitments and access.

This research sought to explore social context and help-seeking for people with symptoms of lung or colorectal cancer, comparing the experiences of prompt consulters with those who prolonged presentation. 164 people with symptoms of lung or colorectal cancer completed a questionnaire on symptom experience and social context and 26 of these took part in follow-up semi-structured interviews.

People with symptoms of bleeding or pain had shorter patient intervals than those experiencing other symptoms. Those with symptoms which were perceived of as severe body state deviations decided to seek help much quicker than those with general or systemic symptoms, who instead reappraised symptoms over time. Symptom appraisal and help-seeking processes were informed by numerous contributory elements, which were drawn from four contextual domains of a person's life; individual experience, interpersonal relationships, health-care system interactions and social and temporal context. They included micro-level elements, such as exposure to carcinogens as well as macro-level factors, like social discourses on morality, calling into question the centrality of awareness-raising campaigns to encourage earlier presentation among the symptomatic population. A novel model *The Contextual Model of the Patient Interval*, is presented to illustrate this part of the diagnostic pathway.

The concept of risk is used to explain how people assess the necessity of help-seeking and the threshold of tolerability is introduced as a means of explaining the timing of help-seeking decision making, based on contextual contributory elements and symptom burden. The assessment of cancer risk is one contributory element which is explored in detail and its incorporation into calculations of the threshold of tolerability is considered. The idea of 'critical incidents' is used to explain the assessment of cancer risk among people who

consulted quickly about symptoms, with 'cancer candidacy' being used to explain the cancer risk assessments undertaken by those with prolonged patient intervals.

In line with a societal focus on risk generally, public health developments have now resulted in a shift away from contagion and treatment, towards prediction and prevention, under the 'new public health' approach. The focus on risk and prevention has created an environment in which discourses of 'early presentation' and the 'good patient' have emerged. These discourses place moral obligations on people in relation to acceptable responses to symptoms and the need to present oneself as a 'good patient', which are explored through the examples of 'time wasting', the Be Clear on Cancer campaign, and discrepant reports of patient interval length from this study.

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## List of Acronyms

UK	United Kingdom
CRS	Cancer Reform Strategy
2ww	Two Week Wait
GP	General Practitioner
NAEDI	National Awareness and Early Diagnosis Initiative
HCP	Health Care Practitioner
NICE	National Institute for Health and Clinical Excellence
SES	Socio Economic Status
CAM	Cancer Awareness Measure
CGT	Constructivist Grounded Theory
IPA	Interpretative Phenomenological Analysis
UHNT	University Hospital of North Tees
RSQ	Reaction to Symptoms Questionnaire
GI	Gastrointestinal
NAD	No Abnormalities Detected
COPD	Chronic Obstructive Pulmonary Disorder
NRES	National Research Ethics Service
BCOC	Be Clear on Cancer
CCG	Clinical Commissioning Group
SCLC	Small Cell Lung Cancer
NSCLC	Non Small Cell Lung Cancer
IMD	Index of Multiple Deprivation
FOBT	Faecal Occult Blood Test
NHS	National Health Service
CXR	Chest X-Ray

## Statement of Copyright

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## Publications from this Thesis

### Journal Papers

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### Peer-Reviewed Conference Abstracts

**Dobson, C.M.**, Brown, S.R., Russell, A.J. & Rubin, G.P. (2015) The help-seeking experiences of patients with symptoms of lung or colorectal cancer. *The Cancer and Primary Care Research International Network (Ca-PRi)* Aarhus, Denmark. [abstract published in *European Journal of Cancer Care* (2015) 24: 52-3]

**Dobson, C.M.**, Brown, S.R., Russell, A.J. & Rubin, G.P. (2015) Explaining discrepant results from questionnaires and interviews concerning help-seeking: are 'public' and 'private' accounts the key? *UCL Qualitative Health Research Symposium: Enriching Qualitative Enquiry in Health* London, UK. [abstract published in *BMJ Open* (2015) 5: 4]

**Dobson, C.M.**, Brown, S.R., Russell, A.J. & Rubin, G.P. (2014) The impact of social support and symptom disclosure on time to presentation for patients with symptoms of lung and colorectal cancer. *BSA Medical Sociology Group Annual Conference* Birmingham, UK.



# Chapter One: Introduction

This chapter outlines UK policy and subsequent national activity intended to address the comparatively poor outcomes for British cancer patients. It then introduces the concept of the diagnostic pathway and the consequences of delays within the context of cancer and cancer services in the UK. Three models of the diagnostic pathway are discussed, along with examples of delays that commonly occur within the patient interval, primary care, and secondary care. Finally, this chapter provides a brief introduction to the scope of the study and outlines the content of this thesis.

## 1.1 Diagnostic Delay and Cancer

Cancer is the leading cause of death worldwide, accounting for 13% of annual global mortality (World Health Organisation 2013). Therefore reducing cancer incidence and improving outcomes is a key global priority. A major line of enquiry focuses on the length of time it takes an individual to be diagnosed, predicated on the association between time to diagnosis and survival (Tørring et al. 2011; Tørring et al. 2012; Richards et al. 1999; Tørring et al. 2013). The reason for this association is that as diagnostic intervals increase, so does the likelihood that cancer is diagnosed at a more advanced stage, meaning less treatment options are available, and so survival is less likely (Sant et al. 2003).

## 1.2 Cancer in the UK

The burden of cancer in the United Kingdom (UK) is significant, accounting for over 160,000 deaths per annum (Cancer Research UK 2016b), with lung and colorectal cancer being the most prevalent cancers for both men and women (Office for National Statistics 2014a). The UK has significantly poorer cancer survival rates than comparable countries (Coleman et al. 2011; Thomson & Forman 2009) and these international disparities in survival are believed to equate to thousands of avoidable UK deaths each year. The National Clinical Director for Cancer in England (2000-2012) notably said that:

*'The size of the prize is large – potentially 5,000 to 10,000 deaths that occur within five years of diagnosis could be avoided every year.'* (Richards 2009b)

The 2007 Cancer Reform Strategy (CRS) aimed to reduce the gap in cancer outcomes between the UK and comparable countries. It took a multi-pronged approach, comprising exploration of cancer genetics, vaccination, extension of screening programmes, awareness raising, reductions to waiting times, employment of clinical audit and improvements to treatment options (Department of Health 2007).

As part of the CRS, the National Awareness and Early Diagnosis Initiative (NAEDI) was established with the scope of co-ordinating activities and research promoting the earlier diagnosis of cancer. NAEDI has four key areas of activity; achieving early presentation, optimising clinical practice and systems, improving General Practitioner (GP) access to diagnostics, and research, evaluation and monitoring (Cancer Research UK 2016c).

One of the major pieces of work which NAEDI spearheaded was the national 'Be Clear on Cancer' (BCOC) awareness raising campaign (Cancer Research UK). The BCOC campaign was launched by the Department of Health in 2011 to raise awareness of cancer signs and symptoms and to encourage earlier presentation by symptomatic individuals. There have been local, regional and national campaigns, with bowel, lung, breast, bladder and kidney, and 'general cancer symptoms' (blood, a lump, weight loss and pain) campaigns all receiving national coverage. The campaigns heavily utilised the media, with adverts appearing on television, in newspapers, and in magazines, as well as being delivered at a community level, through local events and advertisements in bus shelters (National Cancer Action Team (NCAT) 2012). The first national bowel campaign ran from January to March 2012, with a reminder campaign taking place between August and September 2012. The national lung cancer campaign was initially launched in 2012 and then re-ran from March to April 2014, during the time of this fieldwork.

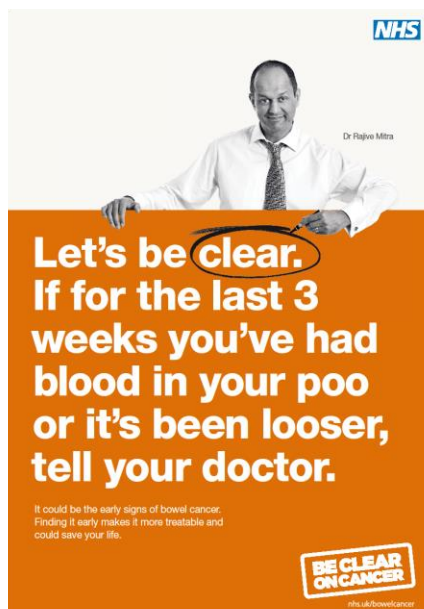


Figure 1: BCOC bowel cancer campaign poster

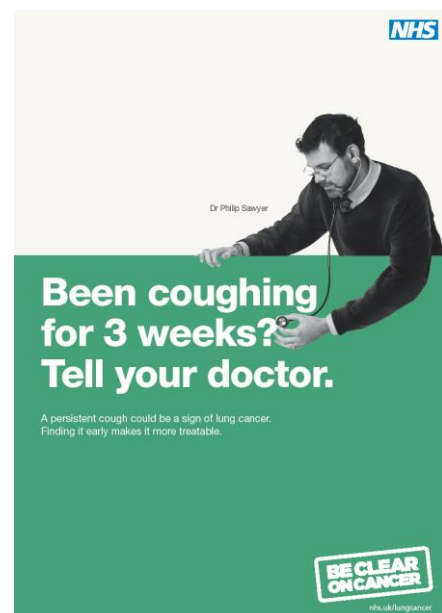


Figure 2: BCOC lung cancer campaign poster

Early evaluations of the BCOC campaigns have found that they have had a positive impact on stage at diagnosis, implying an improved likelihood of survival (Ironmonger et al. 2014).

It was found that there was a significant increase in spontaneous awareness of symptoms (Ironmonger et al. 2014; Power & Wardle 2015), as well as increased consultations with targeted symptoms in the weeks surrounding the campaigns (Moffat et al. 2015; Ironmonger et al. 2014).

There has been disagreement about the value of such awareness raising campaigns. A review of interventions to promote cancer awareness and early diagnosis found that interventions aimed at individuals may only have short-term effects, whilst those aimed at a community level appear to have no effect at all on early presentation (Austoker et al. 2009). Interestingly, it has been found that UK awareness of cancer signs and symptoms is no poorer than in comparable countries, reinforcing the fact that there is likely to be other factors contributing to delayed presentation in the UK (Forbes et al. 2013).

In 1999 the two week wait (2ww), or urgent referral, pathway was introduced which aimed to ensure that patients with symptoms suspicious of cancer were seen and investigated quickly (Department of Health 1997). It appears that the introduction of this pathway has contributed to a reduction in diagnostic intervals (Neal et al. 2014). High usage of the pathway by practices is associated with cancers being diagnosed at an earlier stage (Maclean et al. 2015) and patients from practices with the lowest usage of the pathway had a 7% greater hazard of death (Møller et al. 2015).

A national audit of cancer diagnosis in primary care explored the nature and extent of diagnostic delays in the UK (Rubin et al. 2011). The audit found that poor access to diagnostic tests in primary care and greater frequency of multiple consultations prior to referral were both central to diagnostic delays across cancer sites. As a result of the audit GPs now have improved access to both diagnostic testing and clinical decision support tools, which are increasingly being incorporated into practice to assist GPs in their appraisal of patient's symptoms. Specifically, work undertaken to assess positive predictive values for individual, and combinations of, cancer symptoms, has been used to assist GPs in their appraisal of patients' cancer risk (Hamilton et al., 2013)

As a result of recent research into GP appraisal and the development of positive predictive values for symptoms, the NICE referral guidelines were updated in June 2015. The revised guidelines shift the focus of appraisal away from disease sites, towards symptoms, more closely mirroring the manner in which patients present to primary care (National Institute for Health and Care Excellence (NICE) 2015). They also have lower thresholds of risk

meaning that more patients are eligible to be referred urgently, potentially reducing the length of the primary care interval, and time to diagnosis overall.

Although such efforts do appear to be contributing to an improvement in survival rates, the survival gap between the UK and its comparators still remains (Walters et al. 2015). Therefore, there are further questions to be asked about the underlying factors which are perpetuating poorer survival rates in this country.

### 1.3 The Diagnostic Pathway

The diagnostic pathway is the term used to describe a specific time period in a patient's journey, detailing the time from initial symptom onset to the point of diagnosis and, in some versions, commencement of treatment. There are a number of models of the diagnostic pathway, with three notable models being *The Model of Total Patient Delay*, *The Categorisation of Delay*, and *The Model of Pathways to Treatment*. Here I will briefly outline these models, which are frequently used in cancer diagnosis research, and outline the merits and drawbacks of the different approaches.

*The Model of Total Patient Delay (Figure 3)* (Andersen et al. 1995) details key events along the diagnostic pathway and categorises the types of delay which can occur at each point. This model highlights the cyclical nature of diagnostic journeys, with patients able to return to previous stages within the model, as so often occurs within real-life patient experiences. *The Model of Total Patient Delay* explains in detail the stages which occur prior to the first presentation to a health care practitioner (HCP) but provides little elaboration of what occurs between the first contact with a HCP and treatment commencing. It also places significant emphasis on the role of the patient, with the framework not accounting for the influence which practitioners and the health care system have on the diagnostic process. *The Model of Total Patient Delay* has faced criticism because of its adherence to a constructed normative pathway in which the 'ideal' patient is vigilant and reacts promptly and correctly to health changes (Granek & Fergus, 2012). This conceptualisation is somewhat different to the reality of symptom appraisal and help-seeking, as it fails to account for the fact that these stages are rarely discrete and frequently overlap (de Nooijer et al, 2001).

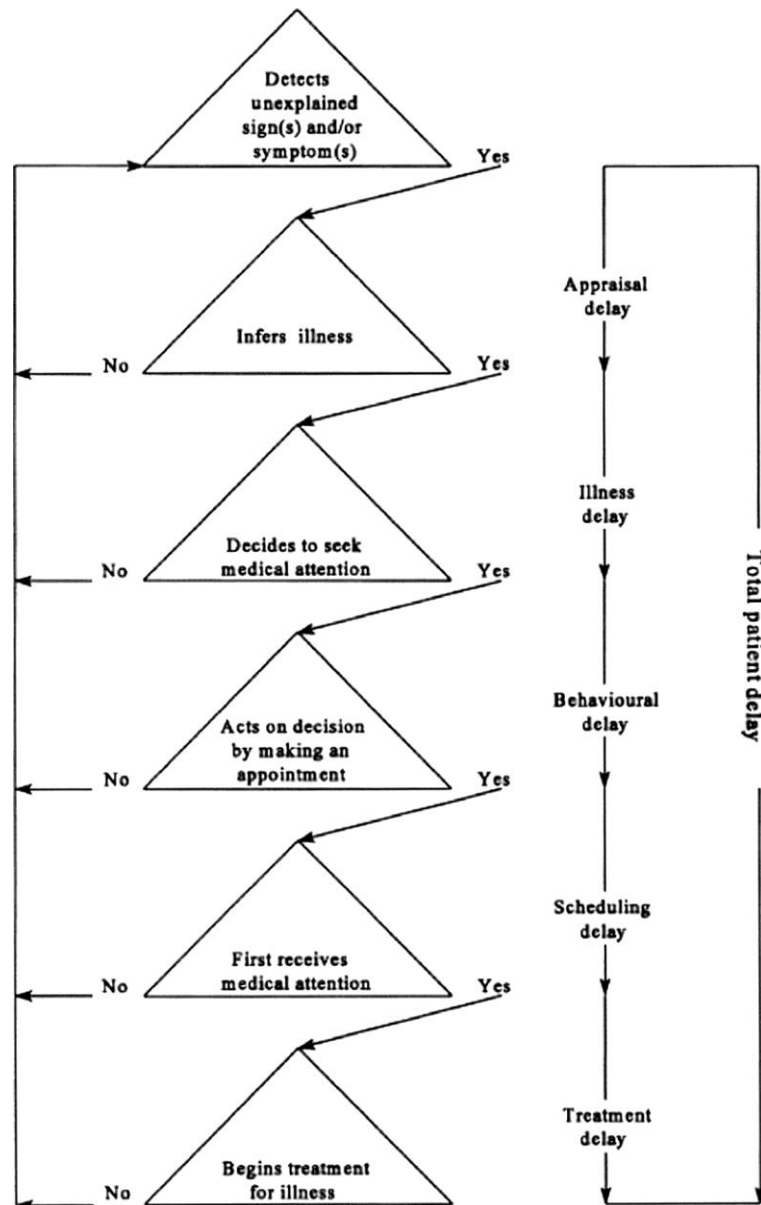


Fig 3: Model of Total Patient Delay (Andersen et al. 1995)

*The Categorisation of Delay (Figure 4)* (Olesen et al. 2009) seeks to consider the impact of wider factors on the patient's diagnostic journey, by introducing additional layers of information, including location and cause of delay. In this model much more focus is placed on the period after first consultation, explaining in detail the processes which take place once an individual has engaged with the health care system, something absent from *The Model of Total Patient Delay*. However, it has lost the nuance and details of the events occurring prior to the first consultation, which are described by Andersen et al (1995). Although this model enables us to consider the different structures and stakeholders within the diagnostic pathway, it implies a universally logical and linear progression through stages

and so fails to account for the fluid nature of events. It also fails to acknowledge the influence of different individuals (i.e. patient, doctor and system) throughout the pathway. According to this model patients can only cause delays in the pre-consultation period and all delays occurring in secondary care are attributable to the system, despite the fact that there can be patient, practitioner or system induced delays throughout the diagnostic pathway.

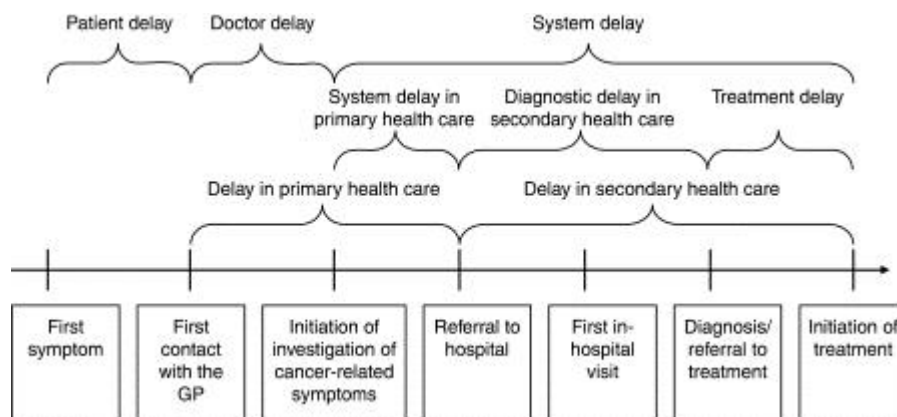


Fig 4: Categorisation of Delay (Olesen et al. 2009)

*The Model of Pathways to Treatment (Figure 5)* addresses some of the failings of the two previously discussed models, in that the non-linear nature of the pathway is represented and the pathway is also broken down into intervals, within which key events occur (Walter et al. 2012). By introducing the patient, system, practitioner, and disease, as contributing factors it considers how a range of actors can facilitate or hinder progression through the diagnostic journey. One of the drawbacks of this model is the proportionate value it places on the different intervals, with the appraisal, help-seeking and diagnostic intervals being equally weighted. Contrary to this depiction of a pathway with equally weighted intervals, recent research has shown that actual diagnostic interval lengths are not equally distributed (Lyratzopoulos et al. 2015).

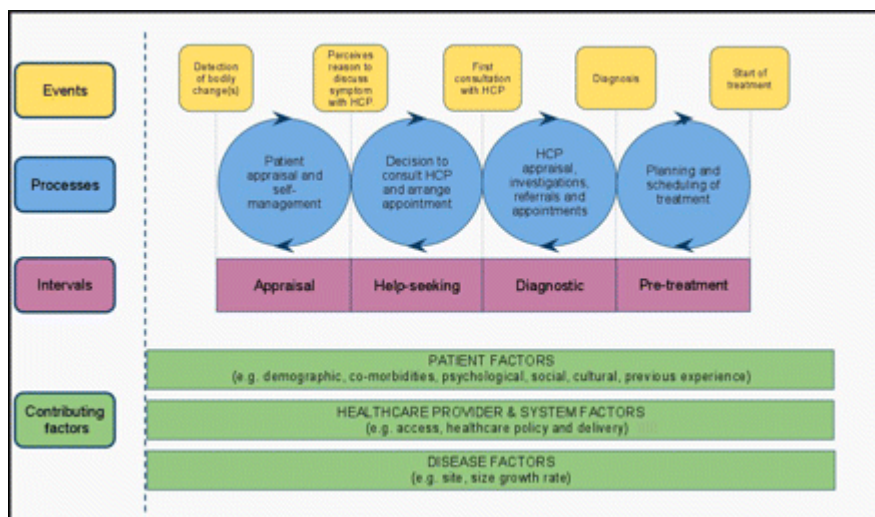


Fig 5: The Model of Pathways to Treatment (Walter et al. 2012)

Research utilising GP reports of avoidable delay has found that the majority of reported delays occurred within the diagnostic interval and so the limited emphasis placed upon the component processes may not be entirely accurate (Dobson & Rubin 2013). Another drawback of this model is that it does not explicitly address the setting of delay i.e. pre-consultation, primary care or secondary care, which is of importance. For instance, appraisal delays may occur in any of these three settings, either on the part of the patient, GP or specialist.

Despite their differences there are clear similarities between the three models which we can integrate to inform our vision of the diagnostic pathway. There is consensus on the presence of a pre-consultation period, in which the individual experiences and acts upon symptoms, as well as a post-consultation period, in which the patient undergoes investigations which ultimately lead to diagnosis and commencement of treatment. There is an emerging acceptance that a number of actors can influence the length of the diagnostic pathway and its component intervals, which comprise an amalgam of the patient, the practitioner, the system, and the nature of the disease. These will be briefly presented here.

### 1.4 Diagnostic Delay

By understanding the nature of the diagnostic pathway we are able to examine how and why situations may arise which prolong the time it takes to receive a diagnosis. One approach is to examine delays in relation to where they occur along the diagnostic pathway, be it pre-consultation, in primary care or secondary care. At each of these points

delays can occur which are attributable to the patient, the practitioner, or the health care system with the most commonly reported issues outlined below.

### **Pre-Consultation**

Delays in help-seeking are thought to be an important contributor to overall diagnostic delay, with around one fifth of all cancers being diagnosed via an emergency route (Barrett et al. 2006; National Cancer Intelligence Network 2015). Although awareness of cancer symptoms and risk factors is argued to be a key factor in delayed presentation (Power et al. 2011; Redeker et al. 2009; Simon et al. 2010a) there are also many other factors which influence help-seeking behaviour. It has been found that in the UK people report many more perceived barriers to help-seeking than in other countries (Forbes et al. 2013).

Fear (Dubayova et al. 2010; Robb et al. 2009), fatalistic beliefs about cancer (Beeken et al. 2011), concerns about wasting the doctor's time (Forbes et al. 2011; Robb et al. 2009), and failure to recognise symptom severity (Macleod et al. 2009; Molassiotis et al. 2010) are all factors which influence people's help-seeking decisions. Beyond individual factors, access to healthcare, particularly among people in rural locations (Robb et al. 2009; Thompson & Van Der Molen 2009), as well as social support and symptom disclosure (Pedersen et al. 2011) have also been identified as important in shaping time to presentation. All of these factors will be looked at in greater detail in the following chapter.

### **Primary Care**

Once a patient has presented to a HCP, there are a number of issues which may result in avoidable delays, with one of the greatest being the impact of inaccurate GP appraisal (Dobson & Rubin 2013). Every year GPs see hundreds of patients with symptoms that could be cancer yet only 8 of these patients will ultimately be diagnosed with cancer (Richards 2009a). Patients are sometimes treated symptomatically, or not investigated when appropriate due to inaccurate GP appraisal of presenting symptoms and previous medical histories (Macleod et al. 2009; Molassiotis et al. 2010). There appears to be a relationship between readiness of the GP to investigate and both stage (Maclean et al. 2015) and survival (Rose et al. 2015) for cancer patients. However, the relationship between primary care investigations and outcomes is complex, as investigations inevitably result in lengthier primary care intervals. Some practitioners investigate patients whose symptomatology already makes them suitable candidates for an urgent referral and therefore unnecessarily prolong the primary care intervals of these patients (Rubin et al. 2015).



Misappraisal of patient's symptoms, and failure to examine a patient, both result in an increased time to referral (Macdonald et al. 2006; Mitchell et al. 2008). Patients with lung or colon cancer are significantly more likely to consult a primary care practitioner three or more times before being referred, than patients with rectal cancer (Lyrtzopoulos et al. 2012).

### **Secondary Care**

Investigations of delays in secondary care have mainly focused on system related delays, particularly in relation to the follow up of investigations (Wahls & Peleg 2009). False negative results from investigations which take place in secondary care can result in an increased time to referral from primary to secondary care (Mitchell et al. 2008). The scheduling of appointments and investigations, as well as correct processing of referrals appears to be another potential cause of delay in secondary care (Dobson & Rubin 2013). Although help-seeking delays are the most commonly reported delays which are attributable to the patient, it is important to remember that patients can also influence progression in diagnosis throughout the diagnostic pathway, for instance by declining investigations or by failing to attend specialist appointments.

## **1.5 The Study**

The study that forms the basis of this thesis is an exploration of help-seeking among people with symptoms that could be caused by lung or colorectal cancer, the two most prevalent cancer sites across both sexes. In this study I examine how people navigate their symptom appraisal and help-seeking journeys, focusing on the social context in which symptom appraisal and help-seeking take place. I compare the accounts of people who have short, medium and long patient intervals, to consider whether there are differences in their help-seeking journeys. Theoretically informed studies of patient delay are still sparse within the field and one of the key aims of this thesis is to provide further insight into the social context of help-seeking by situating my findings within anthropological and sociological theories of health and illness.

### **The Structure of this Thesis**

In the next chapter I will review the literature about help-seeking among people with symptoms of cancer. Findings from epidemiological and qualitative studies will be presented in order to consider the possible associations between time to presentation and particular characteristics, along with a discussion of the individual, health care system, and contextual barriers which people face when making help-seeking decisions. Chapter Three presents the methodology for this research, outlining the epistemological and

methodological approaches adopted, as well as detailing the reasons behind, and operationalising of, the mixed-methods study design.

The results from a questionnaire study of time to presentation for people with symptoms of lung or colorectal cancer are presented in Chapter Four. Descriptive analyses of the data and tests of association between particular characteristics and time to presentation are reported and discussed. The discussion of the quantitative results compares my findings to those of similar studies to examine whether this research aligns with existing knowledge in the field.

Chapter Five goes on to present the findings from one-to-one semi-structured interviews with people with symptoms of lung or colorectal cancer. The findings are presented independently of other literature, to give the data the opportunity to stand alone, allowing the reader to form their own impressions before imposing my analytical voice on the narratives. Chapter Six presents a selection of vignettes, the purpose of which is to illustrate typical stories which are necessarily fragmented and decontextualized in the preceding chapters. By including a number of examples of help-seeking stories I seek to highlight the complexity and nuances of symptom appraisal and help-seeking processes, in order to evidence the many elements which contribute to help-seeking decisions and behaviour.

In Chapter Seven I present *The Contextual Model of the Patient Interval*, which illustrates the pathway to consultation, and introduce the concept of the threshold of tolerability as a means of explaining timing of help-seeking. I go on to explore the concept of risk and morality, using a number of examples of data from this research, suggesting that discourses of 'early presentation' and the 'good patient' place moral obligations on symptomatic individuals to respond to deviant bodily states in socially acceptable and proscribed ways. Finally, Chapter Eight presents my reflections on the research process, a summary of the research findings and suggestions for future research directions.

## 1.6 Summary

The UK has some of the worst outcomes for lung and colorectal cancer in Europe and these have been attributed to delays in diagnosis. Various models have been proposed to describe the diagnostic pathway, its stages and actors, most notably the *Model of Total Patient Delay*, *The Categorisation of Delay* and *The Model of Pathways to Treatment* (Olesen et al. 2009; Andersen et al. 1995; Walter et al. 2012). Delays can occur throughout the diagnostic pathway and can be attributed to the patient, the practitioner or the health care system. It is not uncommon for delays to occur at more than one point in a person's

diagnostic journey and so the cumulative effect has the potential to substantially impact time to presentation, staging and survival.

It is important to understand the pathway to diagnosis in greater detail in order to identify factors which could be addressed to aid in tackling and reducing delays at each stage. This study seeks to illuminate the patient interval, identifying facilitators and barriers to presentation, and examining whether people who report longer help-seeking intervals face specific challenges to consulting.

## Chapter Two: Literature Review

In the preceding chapter I described how delays can occur at any stage in the diagnostic process. Delays are generally attributed to one of three intervals; the patient interval (symptom onset to first presentation to a health professional); the primary care interval (period from first consultation to referral); or the secondary care interval (period from referral receipt to treatment initiation) (Burgess et al. 1998; Weller et al. 2012). As this research examines the help-seeking experiences of people with symptoms of cancer this review focuses on the factors which influence the patient interval.

This chapter provides a comprehensive overview of the existing help-seeking literature within the field of cancer research. It has been argued that factors associated with patient delay are very similar across cancer sites, cultures and countries (Facione & Facione 2006) and therefore, this review has not been restricted by cancer site or geographical location, in order to provide a more holistic account of current knowledge.

There have been two main approaches to studying the patient interval. One has been to explore associations between demography and time to presentation, the other has been to explore barriers to presentation, both of which will be discussed here. Although these two methodological approaches are presented separately in this chapter they are intrinsically linked, with one illuminating, and providing an explanation, for the other. This chapter addresses some of the factors which contribute to experiences of liminality during symptom appraisal and help-seeking, arguing that the patient interval is a complex period, wherein the individual is not the only actor affecting decision making.

### 2.1 'The Patient Interval' in Cancer Research

The patient interval appears to be a period of substantial delay within the diagnostic pathway (Andersen et al. 1995; Hansen et al. 2011). A recent analysis found that the mean patient interval for a number of cancers ranged from 22 to 78 days, lung cancer patients had a mean patient interval of 33 days and colorectal cancer patients had a mean patient interval of 50 days (Lyrtzopoulos et al. 2015). The patient interval is particularly salient to early diagnosis efforts because there is evidence to suggest that it is associated with stage at diagnosis (Thornhill et al. 1987) and survival (Afzelius et al. 1994).

The patient interval is the period within which the processes of symptom appraisal and help-seeking are situated. The process of symptom appraisal entails recognising and acknowledging that a bodily sensation is something to be concerned about, or out of the ordinary, and therefore a symptom. The help-seeking process is the period from when the individual decides they need to consult a HCP about their symptom(s) and the point of

attending the consultation. It is important to remember that not everyone with symptoms will consult and seek help about them, a phenomenon referred to as 'The Symptom Iceberg' (Hannay 2011). Recent studies in Denmark and the UK have both found that over a third of people who reported experiencing a cancer symptom in the preceding month never sought help about their symptoms (Whitaker et al. 2016; Elnegaard et al. 2015).

Neither symptom appraisal nor help-seeking should be viewed as straight forward processes. Individuals rarely follow linear interpretation and decision making processes, a period which Granek & Fergus (2012) refer to as the two states of 'pre-diagnosis liminality':

*'The first state involves the liminality between knowing and not knowing about their cancer symptom. Here women may go back and forth between awareness of a change in their breast (often worrying that they have cancer), to dismissing their symptom as normal, benign, or there, but not significant. In other words oscillating between interpreting the symptom as "something" or as "nothing" ...The second state involves liminality around action and inaction where a woman may be caught between acting or not acting on the symptom while knowing that the former is the 'correct' choice'.*

(Granek & Fergus 2012, pp.1758–1759)

We need to be mindful of this oscillation and liminality when considering how people appraise and respond to their symptoms and the rest of this chapter will go on to discuss the main factors which have been identified as influential for time to presentation.

## 2.2 Demography and Delay

Epidemiological research has largely focused on identifying particular groups of people who are more likely to delay presentation. Particular demographic characteristics have been examined to explore their relationship with the length of the patient interval for patients with symptoms of cancer and the main ones are discussed below.

### Age

Age is often thought to be influential upon time to presentation and there is evidence that older age is related to delay among breast cancer patients (Burgess et al. 2006; Innos et al. 2013; Ramirez et al. 1999). Contradictorily, older age is associated with shorter symptom appraisal intervals for patients with lymphoma (Howell et al. 2008) but no such association has been confirmed for any other cancer sites (Macleod et al. 2009; Esteva et al. 2014; Forbes et al. 2014). There are varying findings about the significance of age on time to presentation and the effect appears to differ depending upon the cancer site in question.

## Sex

A systematic review of risk factors for patient delay found no association between sex and the length of patient interval, except for bladder and other urological cancers, where men were shown to take longer to present (Macleod et al. 2009). Marshall et al (1982) also found that sex was not significantly associated with help-seeking behaviour (Marshall et al. 1982), whereas Korsgaard et al (2008) found that women with colorectal cancer tended to take longer to present than men. They suggest that this is possibly because the women presented with much vaguer symptoms than their male counterparts (Korsgaard et al. 2008).

Considering help-seeking in relation to gender, as opposed to sex, presents a different perspective on how men and women seek help about cancer symptoms. Men's perceived need to appear 'strong' and women's caring responsibilities can shape help-seeking decisions, both of which are discussed later in this chapter.

## Ethnicity

There have been differing and inconsistent findings on an association between ethnicity and time to presentation. A study of individuals from ethnic minority groups in London found that there were significant differences in anticipated help-seeking, with over half of Chinese participants saying they would wait longer than two weeks before consulting about a lump, compared to only 7% of African participants (Waller et al. 2009). However, a second UK study found there to be no significant differences in anticipated time to presentation for breast cancer symptoms, between Black, White and Asian women (Forbes et al. 2011). An inherent flaw in both of these studies, however, is that they were carried out with members of the general public, who were asymptomatic. Participants were asked how long they would wait before seeing the doctor *if* they had particular symptoms and so made judgements based on hypothetical situations. Such an approach is problematic, as it has been shown that we cannot assume that reports of anticipated behaviour, in response to hypothetical situations, will mirror actual behaviour (Sheeran 2002).

In their review of studies looking at *actual* patient intervals it was found that the relationship between delay and ethnicity varied by cancer site (Macleod et al. 2009). Non-white participants showed increased delays for breast and urological cancers, yet decreased delays for stomach cancer compared to white participants. Hispanic patients tended to take longer to present than Non-Hispanic patients and, among women diagnosed with symptomatic breast cancer in the UK, Black African women have the longest self-reported times to presentation, compared to Black Caribbean and White British women (Jones et al. 2015; Samet et al. 1988). Coates et al (1992) found small differences in time to

presentation between Black and White women, which they conclude was a result of awareness and differential access to health care (Coates et al. 1992).

It appears that the association between ethnicity and time to presentation is not fixed, with differing effects apparent for different cancer sites. The link also seems to be more complex than simple 'ethnicity', with additional factors, such as awareness and access to health care, also influencing help-seeking decisions. Another consideration is that each cancer site has its own distinct symptomatology and we know from anthropological studies that symptom interpretation is culturally bound (Helman 2007). Therefore, differences in cultural understanding and meaning of symptoms could also be a confounding factor when analysing the relationship between ethnicity and time to presentation.

### **Socio-Economic Status**

There are conflicting findings as to the relationship between socio-economic status (SES) and patient delay. Lower SES appears to be associated with a higher risk of patient delay for those with symptoms of oral cancer (Llewellyn et al. 2004) and for upper GI and prostate cancer (Macleod et al. 2009). Burgess et al (1998) found no association between SES and delay among breast cancer patients (Burgess et al. 1998), whilst Low et al (2013) found that higher SES was a significant predictor of longer anticipated time to help-seeking in relation to ovarian cancer symptoms (Low et al. 2013).

Interestingly, it has been found that people from lower SES groups reported more emotional barriers to help-seeking (worry about their symptoms, embarrassment of presentation, lack of confidence to talk to the doctor), whereas people of higher SES reported more practical barriers to presentation (too busy, other priorities) (Robb et al. 2009). Among people from lower SES groups being fearful and fatalistic about cancer led to later presentation (McCutchan et al. 2015). Therefore, in a similar vein to the complex findings for sex, it may be that individuals of different SES groups may have categorically unique barriers to presentation, as opposed to one group being intrinsically more at risk than another.

### **Education**

No association between education and delay was found among Dutch oral/pharyngeal cancer patients (Brouha et al. 2005). However, Macleod et al (2009) found associations between education and patient delay evident for both breast and colorectal cancer. Education has been shown to be predictive of patient delay among people with symptoms of oral cancer (Llewellyn et al. 2004), cutaneous squamous cell carcinoma (Kakagia et al. 2013), and for those experiencing a range of common cancer symptoms (van Osch et al.

2007). In an assessment of beliefs about cancer it was found that people with lower education levels were much more likely to hold negative beliefs about cancer, perceiving it to be a death sentence (Quaife et al. 2015)

### **Marital Status**

Although it has been hypothesised that being married would positively impact time to presentation, studies of breast (Burgess et al. 1998; Ramirez et al. 1999), oral, pharyngeal (Brouha et al. 2005), gynaecological, lung, upper gastrointestinal and urological cancer (Macleod et al. 2009) have shown no association between marital status and patient delay. These studies were largely conducted in 'Western' countries and research in other countries suggest that marital status may affect time to presentation more explicitly in other cultures. A study of Thai women found that being unmarried was predictive of patient delay (Thongsuksai et al. 2000) and marriage has been found to be negatively associated with time to presentation for Iranian women (Harirchi et al. 2005). Harirchi et al (2005) argue that this was because of the time constraints Iranian women face in light of the demands of running a household and raising children. Again, these findings imply that there are deeper social and cultural factors which could be influencing time to presentation in relation to marital status.

### **Living Alone**

Living alone does not appear to be significantly associated with time to presentation for breast cancer patients (Meechan et al. 2003), however, it is so for lung cancer patients (Smith et al. 2009). There is conflicting evidence as to the effect of living alone on time to presentation for patients with oral and pharyngeal cancers, as one study found no association (Brouha et al. 2005) whilst another found a significant association (Rozniatowski et al. 2005). The impact of living alone on time to presentation could possibly be associated with symptom disclosure and identification, issues which will be discussed later in this chapter.

The lack of definitive association between demographic characteristics, such as sex, age, ethnicity, SES, education, marriage or cohabitation status implies that patient delay is more complex than mere demography. This prompts us to question the role of such epidemiological data in framing efforts to encourage earlier presentation. We have seen from the brief discussion of certain characteristics that the possible meanings of causal associations are multi-faceted and entangled within individuals' wider social contexts. Therefore, it could be that although demographic characteristics may not independently be



predictors of patient delay, there are factors and influences within each category which affect the patient interval and shape the journey to the doctor. Arguably, studies which aim to find demographic groups who take significantly longer to present may be much less beneficial than exploring the causes for delay within different sub-categories, in order to understand how and why each individual may face obstacles to early presentation.

These inconsistencies mean that it is unhelpful to either draw conclusions on patient delay from demographic analyses, or, view demographic categories as sufficient when seeking to understand and explain the patient interval, as they provide no explanatory context. Although an epidemiological approach may be useful for identifying particular sub-groups who have longer patient intervals than others, it does not allow us to understand *why* these individuals take longer to present. Additionally, just because there is not a statistically significant association between a particular group and time to presentation this does not mean that individuals within these groups are not facing any categorically induced barriers to presentation. As Facione (1993) argues:

*'reported correlations between delay in help-seeking and particular demographic variables...are not adequate...What is needed is a better understanding of why, for instance, age or race is correlated with delay in a particular study'*

(Facione 1993, p.1529)

## 2.3 Barriers to Presentation

The following sections review the key barriers to presentation for patients with symptoms indicative of cancer. The literature has been grouped into three broad themes, reflecting the main foci and approaches to help-seeking research to date: 'the individual', 'the health-care system', and 'the social context'. These themes are by no means mutually exclusive and barriers to presentation could be attributable to, and influenced by, all three. Nor are the individual, the health-care system and social context conceived of as static categories but instead are fluid constructs which differ for each patient and are rooted in culture. These categories are merely constructs to enable a clear overview of the emerging themes in existing research, as categories are actually intertwined and co-productive.

It is important to remember how rare it is for participants to report only one barrier to help-seeking, as, in reality, people cite a number of barriers which affect their decision to seek help for their symptoms. For instance, a patient with testicular cancer:

*'delayed seeking help for 4 months partly because he did not consider the symptoms to be serious, partly because he hated making a fuss, partly because of*

*embarrassment, partly because he was due to go on holiday, and partly because he did not want to be seen as a hypochondriac.'*

(Chapple et al. 2004, p.28)

The symptomatic individual must navigate multiple competing obstacles, re-appraising and re-prioritising their symptoms throughout the patient interval, before the decision to consult is reached.

## **'The Individual'**

There are a range of influences on help-seeking which can be attributed to the individual, namely awareness of cancer signs and symptoms, misinterpretation of symptoms and their severity, the reinterpretation of changing symptoms, and the impact of fear. This section discusses how these influences manifest within people's help-seeking journeys.

### ***Awareness***

A substantial focus of the drive for earlier diagnosis of cancer has been on increasing public awareness of cancer signs and symptoms. Such awareness raising efforts are based on the premise that the reason people do not consult about their symptoms is because they do not know that they could be a sign of cancer. Therefore, it is expected that by educating the public about the signs and symptoms of cancer, they will present sooner and hopefully be diagnosed at an earlier stage.

Women who received a leaflet intervention on symptoms of gynaecological cancer reported an increased range of symptoms for which they would seek help promptly, compared to pre-intervention (Morris et al. 2016). A UK survey of recognition of warning signs and anticipated delay also found that respondents consistently reported longer anticipated time to presentation if they did not recognise the symptom as a sign of cancer (Quaife et al. 2014)

Assessments of public knowledge of symptoms, using the Cancer Awareness Measure (CAM), and anticipated time to presentation found that although CAM score was associated with reports of 'having experienced a symptom' there was no association between CAM score and anticipated help-seeking (Simon et al. 2010b). There was also no association found between knowing a symptom was a warning sign of cancer and anticipated time to presentation for symptoms of ovarian cancer (Low et al. 2013) or for 'alarm' symptoms (Whitaker et al. 2016).

There appears to be a gap between symptom recognition and symptom recall (Jones & Johnson 2012), and Quaife et al (2014) acknowledge that the trends in their data may be exaggerated because recognition, as opposed to recall, was used as a measure of

awareness. This is of importance when considering help-seeking behaviours, as patients will need to independently link their symptoms with prior knowledge of cancer signs in order to consider cancer as a possible cause (Jones & Johnson 2012). This implies that increased knowledge of cancer symptoms makes an individual more likely to recognise that their symptoms could be indicative of cancer, however, this increased knowledge may not necessarily translate into action.

A number of studies have looked at the relationship between knowledge of melanoma and time to presentation and have found that there appears to be an inverse relationship between knowledge and patient delay (Temoshok et al. 1984; Oliviera et al. 1999). An inverse relationship between awareness and tumour thickness was found among patients with cutaneous melanoma in Germany (Schmid-Wendtner et al. 2002), as well as patients in North America (Oliviera et al. 1999).

Interviews with testicular cancer patients found that many men reported seeking help for their symptoms as a result of information in the media about the disease. Prior to receiving the information they had assumed that their symptoms were not serious, implying that low knowledge was a barrier to presentation for this group (Chapple et al. 2004). In a study of Swedish prostate cancer patients, it was found that men who had looked for information about prostate cancer online were more likely to present sooner, arguing that:

*'access to health information may enable the patients to be alerted and to become health conscious when they perceive symptoms of disease.'*

(Sunny et al. 2008, p.738)

However, it may be inappropriate to draw such a conclusion, as to search for information on prostate cancer suggests that these men already had a suspicion of cancer. Therefore, they had already attributed their symptoms to potential cancer causality and were possibly looking for further information to support or reject their suspicions, in order to make a more informed decision. It may be that they wished to present a 'stronger case' to the doctor when they consulted, and online material supporting their suspicion acts as 'evidence' to justify their consultation, an issue which will be discussed further in relation to concerns about wasting the GP's time. Thomson et al (2012) found that a quarter of colorectal cancer patients had consulted the internet during their symptom appraisal period and that although there was a significant association between internet use and appraisal delay (defined as time from first symptom to first consultation, as opposed to decision to seek help as is often otherwise used), consulting the internet was not predictive of patient delay (Thomson et al. 2012). Therefore, it may be that taking longer to consult

means patients take time to research their symptoms online, as opposed to the internet prompting people to consciously delay seeking health care.

It has been argued that the idealised view of a linear process whereby a knowledgeable person notices a bodily change, immediately recognises it as a potential indicator of cancer and presents to their doctor, is far too simplistic, because:

*'symptoms are accordingly contained in a dynamic interplay of factors related to specific social situations, life biographies and life expectations and their accordance with cultural values and explanations. Interpreting bodily signs and sensations as potential symptoms of cancer is therefore not a linear process in the sense that it is only a matter of recognizing these symptoms.'*

(Andersen et al. 2010, p.383)

It appears that the impact of awareness on help-seeking is varied and questionable. This may be because knowledge is only element which contributes to symptom appraisal and help-seeking decisions.

### ***Symptom 'Misinterpretation'***

When a new sensation is identified there is a period in which that sensation must be assessed to decide whether it is a 'normal' feeling or something unusual. If a bodily sensation is felt to be out of the ordinary it then transforms in status into a 'symptom' and the individual attempts to interpret that symptom to determine its causality (Andersen et al. 2010).

A frequently cited source of patient delay is the misinterpretation of symptoms, whereby people believe their symptoms to be the result of some cause other than the actual underlying pathology, a process also referred to as symptom normalisation. For instance, patients with symptoms of oral, head and neck cancers often think that their symptoms are due to minor illnesses, such as a cold, and expect their symptoms to improve relatively swiftly, sometimes with the assistance of self-medication (Brouha et al. 2005; Brouha et al. 2005b; Scott et al. 2007; Ramos et al. 2010). In other studies, patients who believed their rectal bleeding was insignificant, or the result of haemorrhoids, took longer to present than those who didn't (Cockburn et al. 2003; Dent et al. 1990). To a certain extent initial attribution of relatively common symptoms to minor illness is sensible, as, if everyone with a cough immediately presented at the doctors practice, instead of engaging in a period of watchful waiting, then GP practices would be overrun with the 'worried well'.

Attribution of symptoms to every day causes, such as pulled muscles, overwork and strain (Gascoigne et al. 1999; Howell et al. 2008; Molassiotis et al. 2010), physical trauma

(Chapple et al. 2004), or psychological stresses, such as bereavement (Andersen et al. 2010), has been documented across a range of cancer sites. People interpret their symptoms in relation to recent changes in their daily activities and behaviour. For instance, smokers may think that new chest symptoms are a result of smoking too much and so stop smoking as a perceived solution to the problem (Corner et al. 2006), or change in bowel habit may be attributed to poor eating habits (Oberoi et al. 2015) and therefore the symptoms are assessed as insignificant. People interpret their symptoms within the context of their jobs and occupations, for instance, recent changes in working environment have been believed to be the cause of chest symptoms by some (Corner et al. 2006). By concluding that symptoms are the result of everyday activities, the individual is able to rule out the need to consult, as the symptoms are no longer contained within the biomedical model of 'illness', meaning that there is no underlying pathology for a doctor to treat.

The symptom interpretation process is grounded in the context of daily life, hence the focus on everyday explanations for initial bodily changes, but it is also based on individuals' life biographies and life expectations (Andersen et al. 2010). Some people may believe they have particular bodily 'weaknesses' and so accept certain changes because of their expectations of their own body. They do not think that their symptoms are unusual for themselves, therefore they perceive their risk to be smaller and take longer to present (Scott et al. 2007). Corner et al (2006) found that lung cancer patients with asthma believed that their symptoms were part of their pre-existing condition and so took longer to present, with the GP also taking longer to interpret their symptoms (Corner et al. 2006). People have evolving and changing expectations of how their bodies should behave, particularly as they get older, and so new symptoms are interpreted as a part of the natural ageing process. Mouth ulcers, dental problems (Scott et al. 2007), skin changes (Walter et al. 2014) and fatigue (Howell et al. 2008) have all been found to be symptoms which are normalised in relation to ageing and altered bodily expectations. Some women may think that breast and gynaecological symptoms are natural and expected bodily changes, based on ideas about the menopause, expected fluctuations in reproductive hormones, or other benign causes, such as milk lumps (Granek et al. 2012; Bottorff et al. 2007; Brandner et al. 2014).

#### **Symptom Misinterpretation: Perceived Symptom Severity**

The interpretation of symptoms is also related to an individual's perception of the severity of the symptom and their expectations of cancer. People are more likely to recognise bodily changes as 'abnormal' when they are severe, or have a sudden onset (Hall et al. 2015) and people with alarming or severe symptoms also consult about them much sooner than

patients who experience mild, or systemic symptoms (Smith et al. 2005; Emery et al. 2013). Forbes et al (2014) found that both change in bowel habit and systemic symptoms were significantly associated with delay (Forbes et al. 2014) and patients with malignant glioma were accepting of minor symptoms, such as headaches, attributing them to normal causes and taking longer to present than those who experienced an acute symptom, such as a seizure or a fall (Salander et al. 1999). Among patients with colorectal cancer in Australia, perceiving a rectal bleed, or change in bowel habit lasting more than 2 weeks, as a 'serious' symptom was also associated with earlier help-seeking (Courtney et al. 2012). Appraisal of symptom severity is not based solely on the type of symptom, but also on the nature of the symptom. The intermittent nature of symptoms often results in individuals ignoring them and believing them to be trivial, with decisions to consult only occurring after the symptoms become more persistent or severe (Evans et al. 2014; Whitaker et al. 2015)

One of the reasons why oral cancer patients initially attributed symptoms to minor illness was that there was a mismatch between their symptoms and their expectations of how cancer presents (Scott et al. 2006), as for many people pain and a lump are central expectations of cancer. Among breast cancer patients the absence of pain or a lump often discouraged help-seeking, as individuals believed these to be universal symptoms of breast cancer, therefore thought their own, painless or lump-less symptoms, must be benign (Burgess et al. 2001; Jones et al. 2015). Among Kenyan women with breast cancer, a lack of pain associated with breast symptoms was the cause of delayed presentation for 23.5% of the participants (Otieno et al. 2010), however, amongst women diagnosed with breast cancer in Ireland breast pain was associated with delayed help-seeking (O'Mahony et al. 2013). Many patients with suspicious pigmented lesions were not initially concerned about vague, cosmetic changes in their moles, however, the arrival of a lump or pain added gravity to the evaluation of their symptom (Walter et al. 2010). The existing literature suggests that pain and, or, a lump are central to people's conceptions of cancer and the absence of these symptoms makes people appraise the symptoms as non-severe.

### *Symptom Re-Interpretation*

Among those patients who initially believe their symptoms to be insignificant, there comes a point when they will likely question their initial interpretation, should symptoms persist. Patients with vague symptoms often re-evaluate their decision to consult when a new 'trigger symptom', which is perceived to be more serious, emerges (Corner et al. 2005; de Nooijer et al. 2001a).

*'If the first symptom detected is not a specific cancer signal, this seems to increase appraisal delay. As soon as the non-specific symptom changed into a specific cancer symptom, most patients inferred illness.'*

(de Nooijer et al. 2001a, p.155)

Work examining the development of lung cancer symptoms found that patients experienced a median of 12 months from symptom onset to diagnosis, however, upon the development of a 'trigger symptom', patients consulted within an average of two months (Corner et al. 2005).

Not all patients will experience 'trigger symptoms' prior to presentation but may instead undergo a re-appraisal process when their symptoms change or do not behave in the way they expect them to (Smith et al. 2005). Scott et al (2007) argue that there are three reasons why patients may re-appraise their symptoms:

1. Symptom persistence
2. Symptom development
3. Receipt of new information

When people experience a symptom, many have expectations of how long it should last, assuming it is benign, therefore the persistence of a symptom past the conceivably acceptable time period can instigate re-appraisal (ibid). People also have expectations of how symptoms should and should not develop, often self-medicating based on these expectations and beliefs. However, if after self-medication the symptom goes on to develop and change, it will likely arouse concern and prompt re-appraisal (ibid). Walter et al (2010) found that people whose moles underwent rapid or multiple changes sought help sooner than patients whose moles developed steadily and changes in blood colour have also been found to prompt individuals with rectal bleeding to re-appraise their symptoms (Ramos et al. 2010).

The receipt of new information, either from friends or family, or through the media, has been shown to encourage patients to reconsider the potential cause of their symptoms (Chapple et al. 2004; Scott et al. 2007). As was discussed earlier, however, Simon et al's (2010b) work demonstrated that knowledge of cancer symptoms does not always translate into help-seeking behaviour and so it is important to be conscious of the limitations of increased knowledge on reducing patient intervals. It may be that persuasion, or sanctioning, by family, friends, or the media, may influence help-seeking, above and beyond basic knowledge acquisition.

Other research shows that the re-interpretation of symptoms is less about the bodily experience of that symptom and more about the effect of that symptom on daily

functioning and the individual's wider world (Gascoigne et al. 1999; Molassiotis et al. 2010). While people may be aware of bodily changes, unless these changes impact upon daily routine and functioning, they may feel that their symptoms are tolerable and not significant enough to consult a doctor about (Corner et al. 2006). For example, one eighty year old woman with oral cancer went to extreme lengths to accommodate her symptoms, whereby she liquidised all food in order to be able to eat and it was only when this disruption to daily life became intolerable that the lady made the decision to consult (Scott et al. 2006).

People rarely consider only one explanation for their bodily changes, as a number of scenarios will be contemplated before a final conclusion is drawn. Therefore, people can hold multiple concurrent interpretations of their symptoms and periods of re-appraisal may make them reconsider an explanation they had previously rejected. Scott et al (2007) found that some patients were aware that their symptoms were indicative of a serious condition, in particular cancer, however, they did not believe that this could be the cause of *their* symptoms (Scott et al. 2007).

The symptom appraisal period is multifaceted and there are a number of factors which can influence an individual's evaluation of their bodily changes. People often rationalise their symptoms in relation to their daily lives and bodily expectations, monitor and manage symptoms through self-medication and 'deadlines', and re-appraise when symptoms change, worsen or become intolerable. Once an individual has appraised their symptoms, and decided that they may be of potential concern, there are other 'individual' factors which can still influence their help-seeking decisions.

### ***Fear***

Fear has been shown to have differing effects upon help-seeking behaviour, depending upon the person, and can act as both a prompt and barrier to help-seeking. Fear prompts particular behaviours, depending upon how the individual reacts to it and has been said that fear invokes either a fight or flight response (Dubayova et al. 2010).

Pedersen et al (2013) frame their examination of the effect of fear on help-seeking in relation to coping strategies, using the concepts of 'approaching' and 'avoidance'. Approach coping strategies refer to '*the feeling of sensitization evoked by the threat-related aspects of information*', whereas, avoidance coping strategies refer to '*cognitive distraction techniques used to avoid threatening health information*' (Pedersen et al. 2013, p.205). They found that approach coping was associated with short appraisal intervals and avoidance coping with long appraisal intervals. However, there was a positive association



between these two styles, implying that individuals may oscillate between the two coping styles during the process of symptom appraisal.

De Nooijer et al (2001) similarly suggest that individuals harness fear as a coping strategy, but that those who *delay* help-seeking because of fear, use it as 'fear control'. Whereas, those who *consult promptly* because of fear, utilise fear as 'danger control' (de Nooijer et al. 2001b).

'Being anxious' about symptoms has been shown to be associated with shorter time to presentation (Dubayova et al. 2010), as has emotional response to symptoms (Meechan et al. 2003) and experiencing worry or anxiety about symptoms appears to be a trigger to consultation for some (Scott et al. 2009). Among people who display such responses to their symptoms, the decision to consult readily is a means of addressing and hopefully alleviating their anxiety, thereby utilising their anxiety as 'danger control'. However, 'having fear' about a symptom was associated with longer times to presentation (Dubayova et al. 2010; Scott et al. 2009).

Granek & Fergus (2012) discuss how people's coping styles have an effect on others' perceptions of them, in relation to societal expectations of acceptable behaviour.

*'Women for whom their anxiety motivates presentation are fortunate in this regard, because their coping style is in keeping with the dominant, accepted help-seeking discourse. Women who cope with anxiety through avoidance, however, must work around this natural tendency in order to seek out medical evaluation.'*

(Granek & Fergus 2012, p.1759)

The literature has identified two key manifestations of fear which impact help-seeking behaviour: fear of cancer and fear of embarrassment (Smith et al. 2005).

### Fear of Cancer

There are conflicting findings as to the impact of fear of cancer on time to presentation (Balasooriya-smeeckens et al. 2015). Fear can be a prompt to help-seeking, with fear of disease (Jassem et al. 2013), or fear that a symptom may be due to cancer (Whitaker et al. 2015), motivating some individuals to consult about their symptoms.

The word cancer invokes an emotional response for many people, with the word still remaining taboo amongst some people, as the disease is still perceived to be a 'death sentence' (Gould et al. 2010; Scanlon et al. 2006). People experience fear about the necessary investigations and perceivably ineffective and painful treatments associated with

cancer, which can discourage presentation (Chapple et al. 2004; Smith et al. 2005; Mitchell et al. 2008; Facione & Facione 2006).

### Fear of Embarrassment

Embarrassment about symptoms has been shown to be associated with longer time to presentation (Balasooriya-smeeckens et al. 2015). This is particularly so when symptoms relate to 'private' parts of the body, as people may feel reluctant to allow a HCP to examine them in a 'private' area for fear of embarrassment:

*'To have somebody explore, examine and hold that part of the body, was potentially threatening. I think it's almost an invasion of privacy, an invasion of the self.'*  
(Gascoigne et al. 1999, p.148)

Interviews with people with symptoms of colorectal cancer found that for a small number of people, embarrassment about a potential rectal examination was a significant barrier to help-seeking (Hall et al. 2015).

A significant number of South Asian women reported that embarrassment, or lack of confidence to talk about their symptoms, would prevent them from going to the doctors (Forbes et al. 2011). Embarrassment about the body and 'private' parts of the body not only prevents people from consulting, but can also prevent some from self-examining, thereby never discovering their symptoms (Granek et al. 2012).

Research looking at the impact of gender on time to presentation has found that men are often reluctant to go to their GP about their symptoms because of fear of looking 'weak' (Chapple et al. 2004) and that they feel a sense of obligation to maintain a 'strong' and 'macho' reputation (Smith et al. 2005), which notably encompasses continuing with work commitments (Williams et al. 2003).

Some people may avoid presentation because they feel embarrassed about their lifestyle choices and are concerned about the potential stigmatisation they may face. This is the case for diseases for which the patient holds a degree of culpability, whereby others may feel that it is the individuals' lack of behavioural control that is the cause of their disease development (Chapple et al. 2004b). Interviews with lung cancer patients found that they experienced a lot of stigmatisation as a result of their disease and felt that others blamed them for allowing themselves to get ill through their 'dirty habit' of smoking (Chapple et al. 2004b). Therefore, smokers with lung symptoms may feel reluctant to present because they are embarrassed about their behaviour and are wary of the stigmatisation they may face. A number of lung cancer patients who were smokers thought that they would not be treated, or have any right to medical care because of their lifestyle choices (Chapple et al.

2004b; Corner et al. 2006). Stigma is not only a barrier for those whose illness is associated with lifestyle choices. Granek et al (2012) found that a fear that people would abandon you, as a result of the stigma associated with having cancer, deterred one woman from consulting about her breast symptoms (Granek et al. 2012).

We can see that individuals' beliefs about, and understandings of, different symptoms are central to help-seeking, and manifestations of fear, and the individual response to fear, seem to play a role in the help-seeking process for many. It has been argued that *'delays are predominantly caused by psychological factors, rather than medical, social or demographic ones'* (Chojnacka-Szawlowska et al. 2013, p.155). However, the literature reviewed in the rest of this chapter challenges and, arguably, dispels this assertion, as it demonstrates that time to presentation is influenced by an array of factors related to the health care system and social context of an individual's life.

### **'The Health Care System'**

The structures and processes of the health care system can shape and influence people's decisions to seek help about their symptoms. Medical knowledge, language, procedures, equipment and even buildings can all be intimidating for patients (Broom & Doron 2011). This is particularly true for people who are not used to engaging with the health care system, for instance in countries where the biomedical health care system is not the dominant system. When experiencing symptoms of cancer many Chinese American women use traditional Chinese medicine before consulting a doctor (Facione et al. 2000) and many Nigerian women seek treatment from alternative practitioners and prayer houses initially (Ezeome 2010). Whilst the use of complementary and alternative medicine may be referred to as a cause of delayed presentation, it is important to be wary of ethnocentricity in our definition of presentation as these individuals did seek help for their symptoms, just not in the world of Western biomedicine. The main barriers to presentation attributable to the health care system, concerns about wasting the GP's time, the doctor-patient relationship and access to health care services, are discussed.

### ***Time Wasting***

A frequently reported barrier to presentation is concern about 'wasting the doctor's time'. People may feel that they should be stoical about symptoms, so as not to appear to be the type of person who 'goes running to the doctor' (Whitaker et al. 2015). Other people may feel reluctant to seek help because they are concerned that their doctor will think that the symptoms are trivial or minor and will be frustrated at the patient for having wasted their time. Therefore, they avoid seeking help, so as not to appear neurotic, foolish or a

hypochondriac (Andersen et al. 2011; Burgess et al. 2001; Smith et al. 2005; Hvidberg et al. 2015).

Apprehension to consult in case you are 'wasting the doctor's time' has been found to be particularly prevalent among patients with less alarming symptoms, such as tiredness, excessive sweating, problems with eating or subtle changes to moles (Howell et al. 2008; Walter et al. 2010). People with small pigmented lesions felt they may not be 'taken seriously' by the doctor and so monitored changes in their lesions in order to accumulate evidence which would justify their decision to consult (Walter et al. 2010). Similarly, interviews with people with colorectal symptoms showed that individuals waited for symptoms to recur, persist or worsen, in order to justify use of health care resources (Hall et al. 2015).

The presence of co-morbidities does appear to be related to presentation of cancer symptoms, as symptoms are often disclosed during consultations for other conditions (Courtney et al. 2012; Ramos et al. 2010). For gastrointestinal, breast and colorectal patients the presence of co-morbidities, or other chronic conditions, was associated with reduced patient delay, however no such association was found for lung patients (Macleod et al. 2009; Mitchell et al. 2008; Mor et al. 1990). The variation in effect of co-morbidities on presentation is possibly because, depending upon the pre-existing condition, the patient's current state of health and bodily experience may mask the emerging symptoms. Among patients with symptoms of lung cancer, having co-morbidities such as COPD made it difficult for individuals to recognise changes in their symptoms (Birt et al. 2014) or they may mistakenly believe that new symptoms are a different manifestation of their existing illness (Molassiotis et al. 2010) and so never report them.

Some patients choose to mention their symptoms during consultations for other conditions because they feel that their symptoms do not warrant a specific consult, or wish to avoid taking up too much of the doctor's time (Gould et al. 2010; Howell et al. 2008; Hall et al. 2015). Ethnographic research in Danish clinics found that patients are aware of the need for efficiency in the clinical encounter and so negotiate what information to divulge, and when, in order to make most appropriate use of time with the doctor (Andersen & Vedsted 2015). Disclosing symptoms during consultations for other illnesses could be detrimental to patients because raising these symptoms as a secondary issue within a consultation may cause the GP to believe that these symptoms are not of significant concern to the patient. It is also a risky strategy because patients are increasingly limited to presenting only one complaint per consultation and so doctors may not be willing, or able, to address additional concerns (Andersen et al. 2014).

Anxiety about 'wasting the doctor's time' is bound in an individual's perception of appropriate use of the health care system and appropriate ways of interacting with health care professionals. Whilst for many 'appropriate' use of the health care system focuses on minimising the amount of resources they use, for others 'appropriate' use is about timely consultation and proactive and efficient responses to developing symptoms. It has been shown that those who regularly consulted their GP were significantly less likely to delay help-seeking when experiencing a new symptom (van Hout et al. 2011; Smith et al. 2005; Smith et al. 2009) and the regularity with which people attend the doctor's appears to influence the likelihood of early presentation with cancer symptoms. It has been found that patients who delay help-seeking rarely go to see their doctor on a regular basis (Rozniatowski et al. 2005) and that there is a significant relationship between having regular check-ups and decreased patient intervals (Samet et al. 1988). Being proactive about one's own health could also be a motivating factor in presentation as Caplan et al (1995) found that women who regularly self-examined their breasts and took part in mammography screening were less likely to delay help-seeking (Caplan 1995), however, this relationship could also be the result of knowledge and, or, access to health services.

### *Doctor-Patient Interactions*

People who believe that the GP would not be able to do anything about their symptoms have been shown to delay help-seeking (de Nooijer et al. 2001a) and GPs themselves have also reported that they feel that some undue patient delay is because of a lack of trust in the GP on the patient's part (de Nooijer et al. 2001b).

Mistrust can be the result of previous negative experiences wherein a patient's concerns were dismissed, causing them to feel reluctant to re-consult and so more likely to delay presentation (Granek et al. 2012; Smith et al. 2005; Renzi et al. 2015). After having been dismissed, some people demonstrate 'passive resistance', by accommodating their symptoms until they are so severe that the benefits of medical attention outweigh the costs. For one woman, previous humiliation caused by a GP's dismissal of her symptoms, and implication that only 'dirty' women get mastitis, prevented her from consulting with new breast symptoms, until they were seriously advanced and required immediate surgery (Granek & Fergus 2012).

Previous reassurance that the presenting symptom is benign can also act as a deterrent to re-consult when symptoms remain concerning for individuals. Women who had previously been reassured about breast symptoms, such as lumps, have been shown to postpone

help-seeking (Bottorff et al. 2007; Otieno et al. 2010), as have people who had previously been reassured about skin lesions (Walter et al. 2014).

Previous negative investigations and non-cancer diagnoses provided reassurance for persisting and new symptoms, which were then appraised as benign (Renzi et al. 2015; Renzi et al. 2016). Even when people remain concerned about their symptoms, many individuals project negative expectations on to future consultations (Facione & Facione 2006) and are reluctant to re-consult because of fear of appearing hypochondriacal (Renzi et al. 2016). A study of Dutch head and neck cancer patients found that 10% of those who were not referred or scheduled for follow up at their first consultation waited over four months to re-consult (Tromp et al. 2005).

The relationship between the GP and the patient is inherently asymmetrical because of the GP's role as a gatekeeper to knowledge, investigations and treatment (Vedsted & Olesen 2011). As a result of this power imbalance, patients tend to accept the GP's judgement without challenge, even if they may disagree with a diagnosis (Andersen et al. 2011).

### *Access*

For people who live in countries with health care systems that are largely private and insurance based, the costs of accessing health care, both in relation to obtaining a diagnosis and undergoing treatment, can play a role in their consultation decisions. Cost of care is a barrier to help-seeking for the uninsured, with those concerned about the financial implications of consulting taking longer to present (Facione et al. 2000; Friedman et al. 2006). Concerns about the cost of care do not just exist for the uninsured but have also been reported amongst the growing group of 'underinsured' (Thomson & Siminoff 2015). There was found to be a significant association between financial barriers, such as low income and lack of health insurance, and appraisal delay among colorectal cancer patients in the United States (Siminoff et al. 2014).

Direct costs of medical consultation theoretically should not be a significant barrier to presentation in countries with taxation based health care systems, such as the UK. However, we do see cost of consultation become a potential barrier to presentation when we look at oral cancer symptoms, for which a number of patients may decide to go to their dentist and the cost of dental appointments has been shown to be a barrier to presentation for oral and oropharyngeal patients in the UK (Rogers et al. 2011).

Studies which look at the impact of geographical access to primary care on time to presentation have shown varied results with some finding rurality to be associated with a

longer time to presentation, whilst others found no evidence to support this (Hall et al. 2008; Mitchell et al. 2008; Smith et al. 2009).

It is evident from the literature that the health care system can adversely affect time to presentation, even in countries with health care systems which are free at the point of access. Concerns about (in)appropriate use of the GP's time, GP efficacy, previous (mis)diagnoses, and access, both financial and geographical, all appear to play a role in people's decisions as to whether or not to consult about their symptoms.

### **'The Social Context'**

The term 'social context' is used to describe the range of influences upon individuals' beliefs and behaviour that are situated within social relationships, social obligations and cultural systems. The two key contextual influences on help-seeking are the competing priorities in an individual's life, most notably employment, and the influences of others on help-seeking decisions, such as caring responsibilities, concerns about the impact of symptoms on others, and the sanctioning of help-seeking by others.

### ***Competing Priorities***

There is a substantial body of evidence which shows that competing life priorities can prolong help-seeking, even when symptoms are acknowledged as serious, and individuals are faced with no emotional or systemic barriers to presentation (Andersen et al. 2010; de Nooijer et al. 2001a; Scott et al. 2006; Burgess et al. 2001).

Women often prioritise the care and health of other family members over their own need to seek medical attention (Scott et al. 2006; Smith et al. 2005; Low et al. 2015), as a result of their role as health guardians, or custodians, for the family. In a study of Iranian women who had been diagnosed with breast cancer, a number said that the demands of family and work commitments caused them to delay presentation because they felt that they did not have the time to consult, be investigated and potentially undergo treatment (Rastad et al. 2012).

For many women it is only when the care of others is no longer their priority that they feel able to consult about their own symptoms (Smith et al. 2005). Structural inequalities, both in terms of gender roles and women's access to finances, have been reported as a barrier to presentation for women, by researchers in India (Broom & Doron 2011), adding a cultural dimension to the constraints on help-seeking which are imposed by gender.

Granek & Fergus (2012) talk about 'deliberate ignorance' of symptoms, whereby individuals are aware of their symptoms, yet choose to ignore them. They found 'deliberate ignorance' to be very prevalent among women who had competing priorities at the time of symptom

discovery, such as pending divorce, spousal unemployment and wayward teenage children (Granek & Fergus 2012).

People have been shown to delay help-seeking when they have upcoming events, such as a holiday, Christmas or work commitments, that they feel they cannot change, and so instead decide to wait until after that event to consult (Burgess et al. 2001; Gould et al. 2010; Emery et al. 2013; Walter et al. 2014). Issues which are perceived to be more pressing also prevent people from deciding to consult, such as depression, relationship problems, or redundancy (Jones et al. 2015). For some people, the associated change in social status which might result from receiving a diagnosis prevents them from seeking help for their symptoms, as they wish to avoid the potential marginalisation which comes with the role of the sick person (Andersen et al. 2010). Therefore, people may choose not to acknowledge particular symptoms, or engage in 'deliberate ignorance', so as to avoid being unable to carry out their normal responsibilities and facing altered relationships with family and friends.

### *Faith*

Some studies have touched upon the impact which faith and religion have upon help-seeking behaviour. Spirituality was found to be negatively associated with delay among American women (Friedman et al. 2006) and some Irish women reported that prayer gave them strength to access health care for worrying breast symptoms (O'Mahony et al. 2011). However, faith can deter or discourage presentation, with prayer being reported as an initial management strategy for new symptoms by Black British women (Marlow et al. 2014) and a belief that illness was inevitable, bound in fate, and linked to religious devotion, also deterred help-seeking (Bottorff et al. 2007). A recent systematic review found limited evidence that 'religiosity' affected time to presentation, but there was some evidence that beliefs about the efficacy of religious intervention may affect choices around medical treatment (Jones et al. 2014).

### *The Influence of Others*

It has been shown that people with strong social relationships have a greatly increased likelihood of survival when compared to individuals with weak social relationships (Holt-Lunstad et al. 2010) and so it is of value to examine the ways in which social relationships may affect help-seeking behaviour among patients with symptoms of cancer.

### *Family History*

It appears that a family history of cancer prompts people to consider cancer as a possible explanation for their symptoms (Hall et al. 2015), although there is disagreement about the



extent to which it affects time to presentation. Some studies have found it to be positively associated with time to presentation (Molassiotis et al. 2010), others have found no such association (Macleod et al. 2009), whilst another found it to be detrimental to help-seeking (Ramos et al. 2010). As is the case with fear, it may be that whilst a family history of cancer is likely to shape the symptom appraisal process, its relationship with help-seeking is less clear, possibly because it is a lesser element in people's consultation decision making.

### Symptom Disclosure and the Sanctioning of Help-Seeking

Social support has been shown to be associated with patient delay for various cancer sites. Social networks have been found to be an important factor in reducing delay for colorectal cancer patients although no such association has been found for lung cancer patients (Macleod et al. 2009; Pedersen et al. 2011; Reifstein 2007). Among breast cancer patients those who delayed presentation were much less likely to have immediately disclosed their symptoms to someone else ( $p = <0.0001$ ) (Burgess et al. 1998) and among female cancer patients, disclosing a symptom to someone else was more important in reducing patient delay than being in a relationship (Pedersen et al. 2011). Previous studies show that the majority of patients discuss their symptoms with someone else prior to presentation (de Nooijer et al. 2001a) and this is more likely among patients who live with someone else (Burgess et al. 1998), as the majority of people initially disclose their symptoms to a spouse or partner (Bränström et al. 2003; Rogers et al. 2011).

For many people, decisions about whether to consult are influenced by other people in their lives, most commonly family and friends. Sanctioning of help-seeking behaviour requires the symptomatic individual to disclose information about their symptoms to significant others and this disclosure generally has a positive effect upon an individual's time to presentation (Howell et al. 2008; Scott et al. 2006; Oberoi et al. 2015). For over a fifth of oral and oropharyngeal cancer patients the trigger to consultation was the advice of someone else to seek help (Rogers et al. 2011).

The discussion of symptoms and the sanctioning of help-seeking behaviour by others serves a number of purposes for the symptomatic individual. It legitimises thoughts and concerns about symptoms, provides additional information about potential causes and appropriate courses of action, provides justification to consult and alleviates fears about 'wasting the doctor's time' (Burgess et al. 2001; Smith et al. 2005; Mwaka et al. 2015). Discussing symptoms with others is often a 'cue to action', as friends or family members encourage, and sometimes insist, that the individual goes to the doctor (de Nooijer et al. 2001a). Studies of people with colorectal and prostate cancer have both found that wives and

daughters prompted help-seeking in men, however, the female participants often did not disclose their symptoms to family members until after an initial consultation (Ramos et al. 2010; Forbat et al. 2014). Ramos et al (2010) argue that this is a manifestation of gendered roles within Mediterranean culture, whereby men are passive in relation to their health care and women are caretakers of the family. Forbat et al (2014) extend this observation to discuss how health behaviours are a means of enacting masculinities, as many men allow women to mediate risk interpretation and help-seeking decisions to uphold accepted masculine and feminine roles within the family (Forbat et al. 2014).

In a small number of cases, significant others can be detrimental to help-seeking as they may dismiss the symptomatic individual's concerns, and so discourage presentation (Howell et al. 2008; Scott et al. 2006). Women with breast symptoms have been shown to take longer to consult after receiving reassurance from family members and friends, who said that they need to be concerned about their particular symptoms (Bottorff et al. 2007; Khakbazan et al. 2014).

Part of the role of 'others' in facilitating help-seeking is the identification of symptoms, a factor which has been shown to be associated with shorter patient intervals (Molassiotis et al. 2010). Among patients with malignant gliomas, spouses were often central in the identification of health changes and acknowledgement of their potential severity, as the patients were not always aware of their symptoms because of impaired cognitive functioning (Salander et al. 1999). For people who had suspicious pigmented lesions on parts of their body which they could not readily see, others often identified them (Walter et al. 2010) and rural Australian women who asked a partner or friend to examine a suspected lump and confirm its presence were found to have shorter intervals (Emery et al. 2013). Interestingly, in a Belgian study of delay among patients with cutaneous melanoma, it was shown that lesions on men were most frequently detected by family members, whereas, lesions on women were most frequently discovered by physicians (Brochez et al. 2001), which relates to the gendered constructions of self-care and individual health.

### Familial Obligations

A desire to protect others, particularly partners, children and parents, can be a barrier to disclosing symptoms for some people. A number of studies have found that some patients, particularly older people, wish to avoid making their family anxious and so choose to keep their symptoms a secret, so as not to burden their loved ones (Leydon et al. 2003; O'Mahony et al. 2011; Scanlon et al. 2006). Concern about loved ones' reactions to symptoms, or a diagnosis, prevented some women from presenting with their breast

symptoms, as they believed that a diagnosis of breast cancer and the physical ramifications of undergoing a mastectomy would ruin their relationships and cause their partners to leave them. These women believed that it was better to take a risk in relation to their symptoms, than it was to risk losing their spouse (Facione & Facione 2006).

A perceived duty to protect loved ones can also manifest positively, with some people seeking help because of the impact of their symptoms on those around them, or the implications of their symptoms on future caring roles. A sense of moral obligation to yourself and your family was associated with appropriately timed help-seeking (de Nooijer et al. 2003) and being conscious of significant others' views about 'the right behaviour' prompted people to seek help, so that their family saw them to be doing 'the right thing' (Granek & Fergus 2012). Among Maori men, a desire to watch their family, particularly their grandchildren, grow up was a motivating factor in seeking help about prostate symptoms (Williams et al. 2003).

The desire to protect one's family from 'shame' is also evident, particularly in studies conducted in non-Western cultures. Women with cervical cancer in Ethiopia often do not present until the disease is advanced, and the pain intolerable, because of the shame a cervical cancer diagnosis would bring on themselves and their family, as symptoms are believed to be the result of improper behaviour (Birhanu et al. 2012). Maori men with prostate symptoms often had reservations about being examined in *tapu* (sacred) areas of the body and were also anxious about the implications of a diagnosis, as illness was thought to be *whakama* (shameful) (Williams et al. 2003). Shame was also a theme in Canadian women's accounts of their help-seeking for breast symptoms. Women felt shame and guilt for having not behaved in the 'right' manner in relation to their symptoms (i.e. consulting a practitioner), as within the dominant medical discourse their failure to consult made them a 'bad' medical subject or a 'bad woman' (Granek & Fergus 2012).

We can see that the influence which significant others have on help-seeking is complex, yet also very powerful. Others can actively encourage, or discourage, presentation and identify symptoms, and a symptomatic individual's decisions about help-seeking can also be based on the implications of consultation, and diagnosis, for loved ones.

## 2.4 Summary

The review of existing research presented in this chapter highlights the complexity of factors influencing time to presentation, with individual, systemic and contextual factors all acting as potential barriers. There are inconsistencies in relation to the influence of particular demographic characteristics upon help-seeking. Research which has gone beyond

demographic correlates shows that there are multiple interwoven influences acting upon symptomatic individuals, which are complex and, at times, competing. Increasing awareness of cancer signs and symptoms could improve patient attribution of symptoms, however, this may not always translate into prompt help-seeking. This could be because, although people may know that their symptoms are indicative of cancer, the symptoms are rationalised in relation to everyday life, personal experience and bodily expectations, and are therefore often believed not to be sinister. Even when people feel that their symptoms may be significant there are barriers which prevent them from consulting including fear, embarrassment, concerns about time-wasting, competing priorities, or lack of social support.

The majority of help-seeking research to date has focused on individuals and their behaviour in relation to their symptoms. There has been criticism of this psychologically based approach, as it does not account for the wider social and contextual influences upon patients' behaviour. There is a lack of work which views the patient interval holistically, meaning that much evidence fails to account for the influence of social context and social support on help-seeking, an issue which has been highlighted:

*'a new research agenda is required which sets out to study in detail the processes by which individuals come to recognise and act on health changes as a prelude to a cancer diagnosis and how recognition occurs within, rather than independently of, or in interaction with, a social context.'*

(Corner & Brindle 2011, p.480)

My own research, then, seeks to address this call and to contribute to the emerging knowledge which examines the help-seeking of people with symptoms of cancer in a situated, nuanced, and contextualised manner. How I set out to achieve this goal is the subject of the next chapter.

## Chapter Three: Methodology

In this chapter I outline the epistemological foundations from which this research has been approached, along with the methodological choices which this led to. I then discuss the methods used during the fieldwork along with the practicalities of design, implementation and analysis. Finally, I consider some of the ethical issues which arose from the study design.

### 3.1 Research Aims and Questions

This research aimed to understand the help-seeking experiences of patients with symptoms of lung or colorectal cancer. In particular, it sought to understand whether, and how, social context and social support influence help-seeking, including an examination of the help-seeking journeys of people who consult about their symptoms quickly and those who have prolonged patient intervals.

The following questions were used to explore the research aims:

- What do the help-seeking journeys of people with symptoms of lung or colorectal cancer look like?
- Does social context play a role in people's help-seeking experiences? If so, how?
- Are there any key differences in the social contexts of people who present quickly and people who prolong presentation?
- Is there any association between time to presentation and particular social contexts?

As we saw in Chapter Two, of the many studies looking at the help-seeking experiences of cancer patients few have specifically focused on social context in relation to time to presentation. This research aims to extend the current knowledge base around social context and help-seeking, by examining the wider context in which help-seeking occurs. This research aimed to move beyond simplistic examinations of demographic characteristics associated with time to presentation and to explore how and why certain factors affect help-seeking. Although a number of studies examine barriers to presentation, or factors which may cause delay in help-seeking, my research also aimed to explore differences in help-seeking journeys generally, and social context specifically, between those who presented quickly and those who took a long time to present.

There were a number of epistemological and methodological choices to be made in order to explore these questions. It was felt that these questions required data which were detailed

and rich, represented a number of perspectives, while not seeking to identify a superior perspective, and enabled a comparison of experiences. These choices, which moulded the design of this study, are outlined in the rest of this chapter.

## 3.2 Epistemological Approach

### Constructionism

Constructionism marked a move away from the historically prevailing models of positivism and objectivism, perspectives that believe that reality exists, irrespective of consciousness, and that this extant reality represents a measureable and singular 'truth'. Constructionism acknowledges that 'things' do exist but that it is the meanings which humans place on these things that give them their values and properties. These meanings are not uniquely composed but are constructed using individual's prior knowledge, the knowledge of others and the objects' own inherent characteristics.

Constructionism marries the oppositional models of objectivism and subjectivism, by acknowledging the existence of 'things' and their inherent properties, whilst also acknowledging that meaning, and therefore knowledge, is made by humans. In the construction of meaning:

*'There is a call for creativity. Yet we are not talking about imagination running wild or untrammelled creativity. There is an 'exactness' involved, for we are talking about imagination being exercised and creativity involved in a precise interplay with **something**.'* (Crotty 1998, p.98)

It is from this perspective which this research(er) approached meaning and knowledge. This research was interested in how people experienced symptoms and made decisions on appropriate courses of action based on their engagements with the world. Constructionism allows us to explore the nuances of subjective experiences, whilst still acknowledging the importance of objective events in the patient interval.

### Social Constructionism

Social constructionism, a derivation of constructionism, also asserts that knowledge or 'truths' are interpretations of an extant reality. Although the reality of everyday life presents itself as the 'paramount reality' (Berger & Luckmann 1967, p.35), people's version or representations of reality are heterogeneous and multiple and can never be claimed to represent objective facts.

*'reality is socially defined but this reality refers to the subjective experience of everyday life, how the world is understood rather than to the objective reality of the natural world'*  
(Andrews 2012, p.40)

For social constructionists, knowledge is believed to be created, as opposed to discovered, and this creation of knowledge occurs socially, through interactions with others (Burr 2003). As well as being socially created, knowledge is socially and historically situated, whereby understandings and interpretations are produced within a particular context, meaning that knowledge must be interpreted in light of its historical and cultural framing (Burr 2003). People's cultural references, or symbols, with which they interpret the world are already extant in the world they are born into and will remain largely the same throughout their life, and even after death (Crotty 1998).

Social constructionism is a useful lens through which to view this research question, as it helps us to consider patients' experiences within the wider social and cultural context in which they occur, acknowledging that experiences will be rooted in a historical and cultural context and will be socially created. It has been argued that one of the great strengths of social constructionism is that it:

*'can effectively marry the 'micro' attention to interaction...and more 'macro' elements...in which data is being generated and with regard to which it should be analysed'*  
(Barbour 2014, p.43)

Like knowledge, research data are a constructed version of reality. Data are not objects waiting to be collected, but are actively generated and constructed through the enactment of the discussion by both researcher and participant, and through the unspoken meanings attributed to the event (Mason 1996). Through the exchanges and dynamics between researcher and participant narratives, or 'truths' are generated. Truths are not static, but are made and re-made in the performance of the interaction, and the evolving nature of the relationship between the two parties.

*'we invent concepts, models, and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experiences...We do not construct our interpretations in isolation but against a backdrop of shared understandings, practices, language, and so forth'*

(Schwandt 2003, p.305)

It has been argued that social constructionism is agnostic, in that it doesn't adopt a specific ontological position as to what exists and what does not (Schwandt 2003). For some studies this may be problematic, as an objectivist approach would require the individual to establish what elements are 'real'. However, as this research is interested in people's experiences and journeys to consultation, it does not matter which elements are 'real, as it is the participant's version of 'reality' which we are seeking to explore. In light of this, the researcher must acknowledge that within their analyses they are presenting their interpretations of others' presentations of their own realities, as what is, and what is not, 'real' will be different for every person.

Constructionism and social constructionism therefore provide helpful and informative frameworks from which to approach this study. They view knowledge and meaning as created, through a number of mediating channels of information, yet do not reject the inherent nature of things themselves. Social constructionism acknowledges that meaning and knowledge are culturally created and are uniquely positioned historically and socially, factors which are of key interest in this project. Although constructionism is historically aligned with qualitative research, it does not force us to solely conduct research of this type, so long as quantitative data are treated with the same scrutiny and appreciation for the means in which they were produced, as we would treat qualitative data. This epistemological viewpoint can therefore aid in exploring how peoples' experiences of, and reactions to, symptoms are concurrently borne out of 'factual' knowledge and culturally, socially and historically situated sets of meanings.

### **Pragmatism**

As with social constructionism, pragmatism views knowledge as simultaneously based in a 'real world' and socially constructed. Knowledge can consist of single and multiple realities, and is ever changing and tentative (Feilzer 2010; Johnson & Onwuegbuzie 2004). It has been argued that pragmatism is a '*commitment to uncertainty*' whereby the knowledge produced through research is not absolute and that any causal relationships identified are ultimately transitory (Teddlie & Tashakkori 2009).

*'This commitment to uncertainty is different from philosophical skepticism saying that we cannot know anything but an appreciation that relationships, structures, and events that follow stable patterns are open to shift and changes dependent on precarious and unpredictable occurrences.'*

(Feilzer 2010, p.14)



Pragmatism rejects the traditional dualisms of research paradigms and instead recommends a more pluralistic approach, whereby researchers choose the combination of approaches most suitable for addressing the research question, as opposed to methods which conform to a particular philosophical tradition (Johnson & Onwuegbuzie 2004). Pragmatists believe that research cannot be representative and, as such, we should stop striving for representativeness within our work. Instead we should aim for utility and usefulness in our research endeavours, which comes from engaging in reflexive research practice (Feilzer 2010).

Pragmatism is therefore a good fit with the aims and philosophy of this research, as it acknowledges that data are one representation of an ever-shifting reality, and does not seek to produce statements of representativeness. It allows the researcher to use the methods that best support the research endeavours, meaning that we are empowered to explore questions from a number of angles and approaches, seeking different perspectives on the same concept.

With its roots in constructionism, pragmatism values the way meaning is constructed out of historical and cultural knowledge, interaction with others, and the inherent qualities of objects themselves. The coupling of social constructionism and pragmatism in this research creates an approach that acknowledges the social construction of meaning from objective and subjective realities, whilst aiming to explore the research questions using the most appropriate methods, rather than bounding research by the methods traditionally associated with particular traditions. By striving to produce a more holistic picture of the relationship between social context and help-seeking this research aims to produce research findings which are of use when translated into real world contexts, or used to enact change.

### **3.3 Methodological Approach**

#### **Mixed Methods**

There has been debate as to the validity of mixed methods designs, because of the supposedly conflicting underpinning epistemological and ontological assumptions that qualitative and quantitative research have (Spicer 2004). In particular, qualitative-quantitative mixed methods designs have been critiqued because of the perceived incompatibility between constructionist and positivist paradigms, calling into question the meaningfulness of such studies.

Quantitative and qualitative approaches have traditionally been viewed as dichotomous entities, with very differing cultures, evident in the continuing debates around the 'paradigm wars' (Feilzer 2010; Goertz & Mahoney 2012). Oakley (2000) has argued that that such oppositional descriptions are essentially an extension of the dichotomisation of gender, whereby quantitative equates to 'masculinity' and 'hard science' and qualitative equates to 'femininity' and 'soft science' (Oakley 2000).

It has been argued that the purported distinction between the two approaches '*overly caricatures research in practice*' (Spicer 2004, p.295). For instance, quantitative research is often viewed as a completely deductive process, with qualitative research perceived to be solely inductive. However, the reality is that quantitative research can also be exploratory and less linear than generally expected, whilst most qualitative research is based upon some pre-conceived question, or 'hunch', as the driver for the research in the first place (Spicer 2004). The lines between qualitative/quantitative and inductive/deductive are less clear than they may initially appear and, in fact, most research is iterative, moving backwards and forwards between ideas and data. Therefore, a dualistic view of the two research paradigms is inherently flawed and ultimately unhelpful.

As this study is rooted in social constructionism and pragmatism the perceived conflict between paradigms is of lesser importance, as we acknowledge that there are multiple realities, from which an interpretation is drawn when presenting research, and we aim to answer research questions using the most appropriate methods. This epistemological stance fits with a mixed methods methodology and Oakley (2000) encourages us to move beyond dichotomised views and instead begin to use methods that most effectively answer the research question.

There is an emerging body of scholars who are conducting mixed methods research, to the extent that 'mixed methods' has recently been referred to as a 'third wave' or 'third methodological movement' (Johnson & Onwuegbuzie 2004; Teddlie & Tashakkori 2009). The strength of mixed methods research is its ability to offer parallel insights into a single phenomenon, whereby different types of data are used concurrently to produce a 'bigger picture' of the topic of study (Barbour 2014; Gray 2014).

It has been argued that between methods approaches (i.e. qualitative *and* quantitative, as opposed to two qualitative or two quantitative approaches) are particularly valuable because they enable triangulation, whereby the biases of one paradigm are counterbalanced by the other (Denzin 1978). Triangulation generally takes place during the

interpretation phase, whereby findings are simultaneously examined to look for convergence, complementarity and dissonance (O’Cathain et al. 2010). However, the concept of triangulation has more than one definition, and it is important to clarify how triangulation is conceived of in this study.

The ‘increased validity model of triangulation’ states that by employing and integrating more than one source of data the validity of the research is strengthened; if similar findings are produced then the research is accurate, if there are discrepancies then the research is inherently flawed (Moran-Ellis et al. 2006). However, this view of triangulation implies that the introduction of an opposite, or additional, method will unequivocally increase the validity of research, should the findings concur. It is positivistic in that it assumes that there is a single ‘truth’ to be discovered and that multiple methods are a means of confirming that the research has successfully identified the ‘truth’. The increased validity model of triangulation has been critiqued for being naively realist, in that it assumes that there is a single, fixed truth that can be ‘outed’ with multiple methods, also referred to as the ethno-methodological critique of triangulation (Spicer 2004).

This study is grounded in the premise that the world consists of multiple truths, which are socially constructed interpretations of an intangible and transient reality. Based upon these assumptions, it follows that the triangulation of methods cannot bring us closer to ‘the truth’, as there is no singular truth for us to arrive at. Critiques of the ‘increased validity model of triangulation’ have been raised which argue that triangulation in cross-paradigmatic mixed methods research should not aim to prove validity, but aim to reveal different dimensions of a phenomenon, highlighting complexity and enriching understandings of the multi-faceted nature of the world (Moran-Ellis et al. 2006). Quantitative methods can be employed to provide a picture of what has happened and qualitative methods can illuminate why it has happened (Helman 1996).

It is this view of triangulation and mixed methods research that was in the design of this study, with the belief that this approach would illuminate different elements of the help-seeking journey. Quantitative analysis of questionnaire data allowed an investigation of factors within the social context which may have been associated with time to presentation, whilst qualitative interview data enabled an exploration of patient’s experiences to understand if, why, and how, certain contexts influenced help-seeking (Byrne 2004). Both qualitative and quantitative data were used to explore factors related to

help-seeking, with quantitative data assisting in pattern identification and qualitative data used to understand and compare help-seeking journeys.

Use of two methods made parallel insights into the same phenomenon possible. It shone light on areas which one method alone would have missed, producing a more holistic account of how social context affected help-seeking. In this study, the two methods were conducted concurrently, as it was not the intention that one aspect informed another, but that multiple data sources would be used to create a 'bigger picture' (Gray 2014). The quantitative data also supported the qualitative research, in that it enabled me to purposively sample interviewees for both time to presentation and particular social context characteristics (Barbour 1999).

### **Constructionism and Grounded Theory**

One of the main aims of this research was to produce a rich and detailed account of patients' experiences of help-seeking, based upon their own narratives and priorities, embracing difference and ambiguity in alignment with a social constructionist approach. Grounded Theory is well suited to assist in the generation of such data as it provides the structure within which an inductive and nuanced analysis can be undertaken.

#### ***Grounded Theory and its Development***

Grounded theory was developed by Barney Glaser and Anselm Strauss in an attempt to legitimise qualitative research in a time when deductive, quantitative research and ways of knowing dominated. The grounded theory approach, based on 'constant comparison' of data, was outlined in their 1967 publication '*The Discovery of Grounded Theory*'. There are some key features of a grounded theory approach which are universal to grounded theory studies; constant comparison, memo-writing, and theoretical sampling. Here, I will discuss each of these concepts, however, it is important to note that they are also discussed in the methods sections, detailing how I engaged with these processes in reality.

Glaser and Strauss' constant comparison approach was created to combine systematic coding of data and an environment in which theoretical concepts could still be generated throughout the analysis (Glaser & Strauss 1967). Constant comparison encourages researchers to engage with and compare their data from the outset of research, comparing data within, and between, categories, comparing categories with theories, and comparing one's own categories and theories, with those of different analysts. The purpose of this degree of comparison is to harness the inductive process of analysis to generate concepts

and theories, with the level of abstraction being raised throughout analysis until the researcher is finally able to compare their theory with the theories and research of others.

Memo-writing should take place when the analyst is considering a theoretical notion arising from the analysis of their data, often whilst engaging in constant comparison. Glaser and Strauss (1967) stated that when such musings occur, the researcher should pause their activities and note down their thoughts in the form of a memo. These memos are used to build categories and theories within the data, with many memos being developed during the course of analysis.

Theoretical sampling does not select participants based on particular characteristics, but samples to elaborate categories in an existing theory. Theoretical sampling is the process whereby the analyst simultaneously collects and codes data to develop emerging theory and then re-enters the field to sample participants whose data will aid in testing and saturating the emerging theories. This means that the identification of people the researcher may wish to speak to next is driven by emerging theories and does not seek representativeness. It is through theoretical sampling that the saturation of emerging theoretical categories is generated and systematic checks are built into the analysis process (Charmaz 2014).

Constant comparison, memo-writing and theoretical sampling are inherently interlinked as it is the discoveries and insight from constant comparison, which are elaborated in memo-writing to form the foundation of emerging theory, which in turn prompts theoretical sampling.

Since the conception of grounded theory, and Glaser and Strauss' seminal publication, there have been numerous developments and derivations of the method, most notably the infamous divergence between the primary scholars themselves.

Glaser's version of grounded theory centres on the concept of emergence, wherein codes and theories organically emerge from the data, in a highly inductive view of analysis. Glaser believes that 'all is data', meaning that grounded theory is not simply a qualitative analytical method, but that quantitative data can also be incorporated into a grounded theory analysis. He encourages isolation from the literature until latter stages of analysis in order to prevent the researcher being biased and influenced by *a priori* knowledge. Glaser argues that '*the dictum in grounded theory research is: There is a need not to review any of the literature in the substantive area under study*' (Glaser 1992, p.31) and that grounded

theorists need to be free from the findings, assumptions and claims of the literature, in order to be free to discover in every possible way.

In opposition, Strauss's interpretation of grounded theory focuses on a methodical and structured process of data analysis, with *Basics of Qualitative Research* providing detailed procedures for the analysis of data (Strauss & Corbin 1998). Most significantly, Strauss and Corbin advocate the use of a coding paradigm whereby researchers are encouraged to identify phenomenon, conditions, action/interaction, and consequences within the data. The formulaic nature of the Straussian interpretation has faced criticism, with Melia (1997) fearing that in this approach *'the technical tail is beginning to wag the theoretical dog'* (Melia 1997, p.32). It has been argued, particularly by Glaser, that Strauss' method results in the forcing of data into pre-conceived categories, as opposed to allowing the 'real' story to emerge (Melia 1997).

Although this brief summary of grounded theory only focuses on the originators and their subsequent interpretations, it is also important to note that there are other adaptations of the grounded theory approach, such as feminist grounded theory and postmodernist grounded theory. Because of the multiplicity of versions, it has been suggested that grounded theory can today be viewed as a spiral of methodological development, from which there are numerous departure points depending upon one's ontological and epistemological assumptions (Mills et al. 2006b).

### ***Constructivist Grounded Theory***

One of the most well-known variants of grounded theory is Constructivist Grounded Theory (CGT), developed by Kathy Charmaz. CGT was selected for this research because of its position on three key areas; the role of pre-existing knowledge in research; the ontological approach to knowledge and truth; and the centrality of a dogmatic methodological process.

One of the key elements of Glaser & Strauss's original grounded theory, and particularly the later Glaserian version, was the belief that reviews of the literature should be conducted after analysis had been developed (Glaser & Strauss 1967). Traditional, and Glaserian, grounded theory encourage the researcher to not review the literature until the emerging theory is substantially developed so as *'not to contaminate, be constrained by, inhibit, stifle, or otherwise impede the researcher's effort'* (Glaser 1992, p.31). However, complete detachment from the field is problematic as researchers are often required to undertake a literature review in advance of fieldwork in order to write research questions which are valid and original, and to design proposals which are robust. Even if a researcher was able

to avoid reviewing literature until theory emerged, they would still inevitably bring with them ideas, concepts and constructs from previous research projects and, on the most basic level, simply from life experience.

Total isolation from the literature has been criticised, as ignorance can cause duplication of ideas, repetition of mistakes and triviality in research (Thornberg 2012). Charmaz (2006) states that having a detailed knowledge of the topic being studied is not as detrimental as Glaser and Strauss argued, but that the knowledge, or 'sensitizing concepts', which we bring to our studies should be viewed as vantage points (Charmaz 2006). Although we approach research from particular vantage points we should remain open to the data, being responsive to what we see and sense, particularly in early stages of analysis.

Charmaz's approach to topic knowledge is helpful in relation to this piece of research as I not only had to review existing literature in order to identify a suitable research question but my research experience in the early diagnosis of cancer field also meant that I brought pre-existing knowledge to the study with me. Using a CGT approach I was able to acknowledge my background and be reflexive about how these 'sensitizing concepts' shaped my vantage point in this study. The implications of my 'vantage points' and the issue of positionality are discussed in Chapter Eight. The actual process of data analysis will be discussed in further detail later, however, it is of importance to note that I tried to give equal weight to all emerging codes and concepts, irrespective of whether they were novel, and was particularly critical about my development of codes which aligned with the previous findings of other scholars.

A literature review was undertaken to position this study within the existing field, identify a suitable question, and therefore avoid acting unethically by duplicating existing research. A literature review on help-seeking among cancer patients was conducted to achieve this, however, review of the theoretical literature on patient behaviour and help-seeking more generally was left until the end. Once I was clear of the arguments and findings of this research, I then went back to relate these to other literature on help-seeking behaviours, trying to draw on broader and more theoretical work, as well as research specific to cancer and help-seeking.

Constructivist Grounded Theory moves away from positivist views of the world still present in early grounded theory and assumes instead that reality is multiple, complex and constructed. Not only does it view the 'knowledge' we are about to unearth as subjective, but it also acknowledges the fact that the research process itself is constructed (Charmaz

2014). This view of knowledge being fluid and multiple, and there being no entity out there to be recorded, fits with the epistemological approach of social constructionism.

Constructivist Grounded Theory is a lot less mechanical than the Straussian version of grounded theory, allowing the analyst scope to explore emerging data without being constrained by a pre-ordained coding paradigm (Strauss & Corbin 1998). Charmaz presents CGT as '*flexible guidelines*' from which '*you direct your study but let your imagination flow*' (Charmaz 2006, p.15). For this research I sought a methodological approach which provided sufficient guidance to support me in my research endeavours whilst allowing enough flexibility to acknowledge the fact that research is messy, complicated and non-linear, whereby necessary adaptations to your analytical trajectory are not detrimental. I did not want to be constrained by a coding paradigm, which is arguably imbued with a positivistic view of reality and truth.

Whilst CGT allows a degree of flexibility in the research process it also facilitates novelty in inquiry by enabling unexpected areas of importance to be identified and investigated.

*'grounded theory quickens the speed of gaining a clear focus on what is happening in your data without sacrificing the detail of enacted scenes. Like a camera with many lenses, first you view a broad sweep of the landscape. Subsequently, you change your lens several times to bring scenes closer and closer into view.'*

(Charmaz 2006, p.14)

As discussed earlier there are certain processes which are intrinsic to grounded theory research (constant comparison, memo-writing and theoretical sampling) and these processes are also a fundamental part of CGT. Jane Mills (2006a) argues that the three main characteristics which differentiate a CGT study from any other piece of grounded theory are:

*' 1. The creation of a sense of reciprocity between participants and the researcher in the coconstruction of meaning and, ultimately, a theory that is grounded in the participants' and researchers' experiences.*

*2. The establishment of relationships with participants that explicate power imbalances and attempts to modify these imbalances.*

*3. Clarification of the position the author takes in the text, the relevance of biography and how one renders participants' stories into theory through writing'*

(Mills et al. 2006a, p.9)



These key features of CGT fit with the epistemological approach to this research, whereby data are viewed as being co-constructed and emerging theory should be grounded not only in the researchers' interpretations and experiences but also the participants. From the outset of this study, ensuring that participants voices were at the fore in the presentation of this data was important in order to ensure that it was participants' realities which I was representing and not simply constructs of my own. The approaches used to achieve this are discussed in further detail later in the chapter, but it is of worth to note that they included the use of *gerunds* to most accurately represent participants' voices, verbatim quotes in the presentation of the analysis, patient involvement in analysis, and participant feedback on the developing theory.

Addressing the power imbalances inherent in research was an ongoing concern in this study and from the outset it was the intention that this would not be a 'top down' piece of research but one which emerged from participants. I tried to facilitate this through the inclusion of patient representatives, by offering participants control over where and when the interview took place (including the option of evenings and weekends), through reflection upon power within the research encounters themselves, and finally through reflection on the implications of myself as a research instrument, which is discussed in further detail in Chapter Eight.

### **Alternative Methodological Approaches**

One possible alternative methodological approach to this research would have been Interpretative Phenomenological Analysis (IPA), which focuses on experience and people's reflections on their experiences, being based in phenomenology and hermeneutics (Smith et al. 2009). This focus on individual experience would have fitted with the aims of this research, in that there was value placed on subjective experience. However Smith et al (2009) argue that IPA is not an appropriate method for comparing data, and one of the major goals of this research was to compare and explore differences in journeys between people who took a long time to present and people who presented early.

Another option would have been to undertake a Framework Analysis, a benefit of which is that it is functional, focused and structured, enabling a speedy analysis of data, something which would be beneficial within a time-constrained research project (Ritchie et al. 2014). However, this form of analysis can be too rigid and prescriptive, as the coding framework is largely decided upon in advance of fieldwork and analysis, resulting in a deductive analysis process which leaves little scope for unanticipated findings to emerge.

In light of this it was felt that a CGT approach was most appropriate and suited to addressing the research questions in a manner which was coherent with the epistemological foundations of this research.

### **3.4 Methods**

This study aimed to gain an understanding of the factors which affect help-seeking, as well as to undertake a detailed exploration of why and how such factors impact help-seeking. In order to answer these questions two methods were utilised; a postal questionnaire and semi-structured interviews.

#### **The Research Site**

Although it seems most logical to identify patients in primary care, therefore reducing the time elapsed since symptom appraisal and help-seeking occurred, this approach would have been logistically problematic. It would have entailed recruiting a large number of GP practices and liaising with them to recruit patients who had presented with lung or colorectal symptoms (irrespective of whether they were referred) which would have required a significant amount of time and resources, two things which are limited in a doctoral study. Therefore, it was more feasible to identify patients in secondary care, as this route provided a large pool of potential participants. However, it is important to note that recruiting from secondary care meant that only symptomatic patients who had been referred were identified and approached. This meant that the experiences of people who were symptomatic and had presented to their GP but were not referred, or who had never consulted at all, were absent from this study.

This research was conducted in Teesside, in the North East of England, an area which faces some of the poorest health outcomes in the country, with low life expectancy, high deprivation (Department of Health 2010) and one of the highest cancer incidences in England (Office for National Statistics 2014a). In 2011 the North East had some of the highest rates of self-reported 'not good health' for both men and women in the UK (Office for National Statistics 2013)

Potential participants were identified through referrals sent to the University Hospital of North Tees (UHNT), which is located within NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group (CCG). The UHNT serves people residing in Stockton-on-Tees, Hartlepool, Sedgefield and East Durham, with the approximate catchment area illustrated in figure 6.

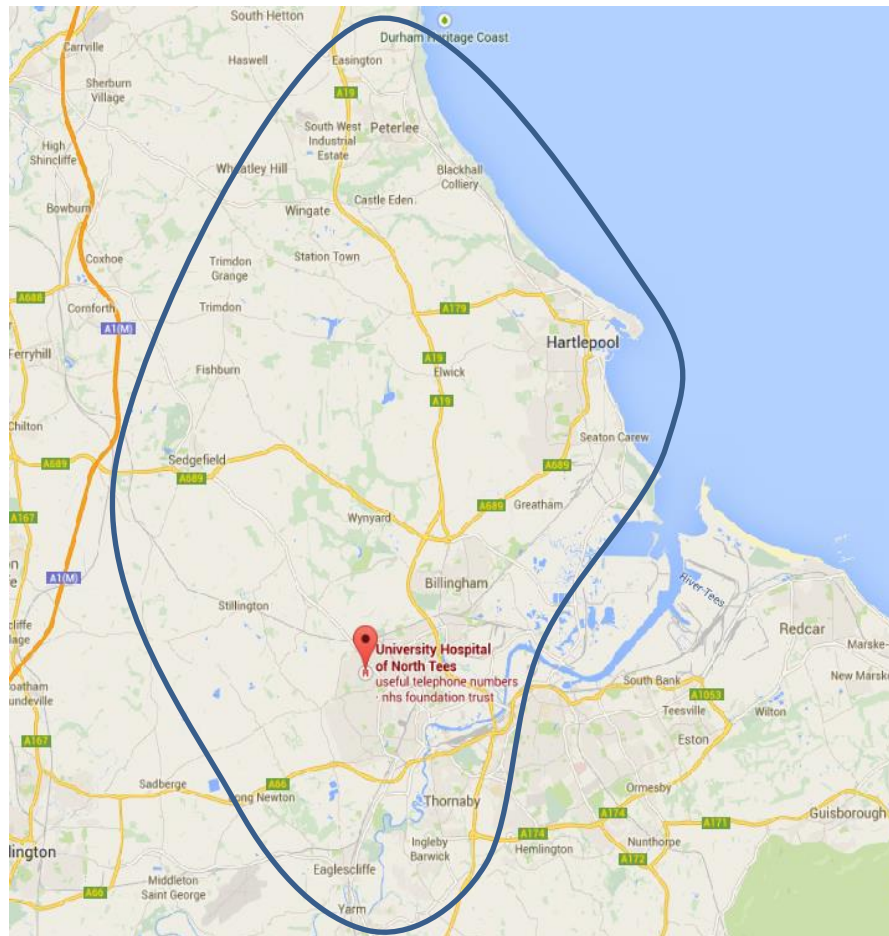


Figure 6: UHNT catchment area

The region has a significant industrial history with the coal industry being a major employer historically and British Steel and ICI being prominent employers more recently. The fact that many people in the region worked within such industries is of importance as such occupational histories are linked with the development of work-related diseases, such as asbestosis, and the impact of work upon participants' health featured in a number of interviews, particularly amongst men. The area is predominantly White British (97% Stockton-on-Tees and 98% Co. Durham) and the relatively small ethnic minority population within the area is reflected in the demographic spread of people recruited to this study (Office for National Statistics 2011b).

The University Hospital of North Tees (UHNT), located in Stockton-on-Tees, was selected as the recruitment site for two key reasons. The hospital serves a large population, which ranges from areas of high deprivation to affluence, meaning that a range of people could be approached about participation. There were also existing relationships between the researcher, clinicians and research nurses at UHNT, as a result of collaboration on previous studies. These existing relationships facilitated engagement with the study on the part of

the hospital staff, which was particularly important as there was no funding to support their involvement. These teams also had a track record of effectively supporting studies and so we could be reassured of the feasibility of this site.

Patients with symptoms of lung or colorectal cancer were identified as the populations of interest for this study as lung and colorectal cancer are the second and third most common cancers, for men and women, after prostate and breast cancer (Office for National Statistics 2014a). To include sex-specific cancers in the study (breast and prostate are both the most common cancers in women and men, respectively) would have made it more difficult to compare patient journeys across cancer sites, as we would expect sex-specific issues to arise, which would likely be imbued with concepts and theories about gender and the body, beyond those relating to more general symptom experience. Focusing on two cancer sites was also deemed to be more feasible within the scope of a PhD study.

Lung cancer accounts for 14% and 12% of all newly diagnosed cancers in men and women respectively (Office for National Statistics 2014a) with the average one year survival rate being 29% and the average five year survival rate being 8% (Office for National Statistics 2014b). Almost 90% of all lung cancers are attributable to lifestyle choices, with 86% of lung cancers being caused by smoking. However, occupational exposure to asbestos and radon is also associated with lung cancer (Parkin et al. 2011).

Common symptoms of lung cancer, such as coughing and breathlessness, pose a diagnostic challenge for primary care physicians, as it is difficult to distinguish between the respiratory symptoms caused by a lung malignancy and those which are the result of a benign condition (Hamilton et al. 2005). Moreover, respiratory symptoms are prevalent in the general population and the symptoms experienced by patients leading up to their diagnosis are often non-specific (Weller & Campbell 2006), with more specific symptoms often only becoming evident once a tumour has grown relatively large and the cancer has metastasised (Birring & Peake 2005). The classic 'red flag' symptom of haemoptysis has one of the highest positive predictive values for lung cancer as a single symptom (2.4%), it is also relatively uncommon, being reported by only 40% of lung cancer patients (Hamilton et al. 2005).

The process of diagnosing lung cancer usually entails a chest x-ray, which is generally scheduled whilst the patient is still under the care of the GP, and subsequently a CT scan, bronchoscopy and lung biopsy once under the care of a specialist respiratory consultant. Lung cancer has a particularly long diagnostic interval, with an average of 113 days from

symptomatic presentation to diagnosis (Din et al. 2015). Depending upon the type of lung cancer (i.e. small cell lung cancer (SCLC) or non-small cell lung cancer (NSCLC)) and the stage at which the cancer is diagnosed, patients would either be treated with surgery and, or, radiotherapy or chemotherapy.

Colorectal cancer accounts for 13% and 11% of all newly diagnosed cancers for men and women respectively (Office for National Statistics 2014a) with an average one year survival rate of 70% and average five year survival rate of 52% (Office for National Statistics 2014b). Over half (54%) of all colorectal cancers are associated with lifestyle and environmental factors, with the biggest lifestyle and environmental risk factors being meat consumption (21%), obesity (13%), fibre consumption (12%) and alcohol consumption (12%) (Parkin et al. 2011).

Abdominal pain, constipation and diarrhoea are common symptoms of colorectal cancer, however, all have low positive predictive values (Hamilton et al. 2009) and are often misdiagnosed in primary care as irritable bowel syndrome (Hamilton et al. 2013). Although rectal bleeding is considered to be the classic 'red flag' symptom for colorectal cancer, and has a much higher positive predictive value than other symptoms (Hamilton et al. 2009), in actuality only a small proportion of patients who experience rectal bleeding will have a colorectal cancer (Jones et al. 2007; Heintze et al. 2005)

Diagnosis of colorectal cancer usually entails a digital rectal examination and blood tests in primary care followed by a colonoscopy in secondary care, with biopsies also being taken to determine a histological diagnosis. Colorectal cancer also has a long diagnostic interval, with an average of 80 days from symptomatic presentation to diagnosis (Din et al. 2015). If tumours are contained within the colon most patients will be eligible for surgery, however, should there be any lymph node spread, and therefore possible metastases, patients will additionally be treated with a course of chemotherapy or radiotherapy.

Although here I talk about two 'cancer sites' of interest, it is very important to remember that most people in this study did not have cancer and that most people who are referred urgently also do not have cancer. Within Hartlepool and Stockton-on-Tees CCG 8% of all 2ww referrals (for any cancer type) result in a cancer diagnosis, a non-significantly smaller proportion than the national average (National Cancer Intelligence Network 2014). Although only a small proportion of patients referred as a 2ww will be diagnosed with cancer, it is important to explore the entire referral group, as symptom appraisal and help-seeking take place in light of symptom experiences, not eventual diagnoses. People with

symptoms of colorectal cancer have been shown to face similar challenges, barriers and facilitators in their help-seeking decisions, irrespective of whether they are ultimately diagnosed with cancer or another benign condition (Hall et al. 2015).

This study therefore examines the help-seeking experiences of people with symptoms of, and a clinical suspicion of, cancer. This approach is of value and relevance to the field of cancer research because the majority of cancer patients begin their diagnostic journey in exactly the same way as people whose symptoms turn out to be benign, passing through stages of symptom experience, appraisal and help-seeking decisions. Participants in this study had a range of eventual diagnoses, both benign and malignant and, for some, no diagnosis or explanation for the symptoms was reached.

## **Methods: Questionnaire**

### *The Questionnaire*

The purpose of the questionnaire was to gather information from a range of participants about patient interval length and social context. This data was then used to examine whether any demographic or contextual factors were associated with time to presentation, as well as being used to inform sampling for the qualitative interviews.

A self-administered questionnaire was felt to be the most appropriate method for gathering this type of information as it allows the researcher to achieve a large number of responses at relatively low cost. Participants are believed to be more likely to report socially less acceptable behaviour (such as prolonged time to presentation) in a self-administered questionnaire than in face to face interviews, because the anonymity of this method provides a sense of security (Bernard 1995).

The Aarhus statement lays out guidelines for 'best practice' in early diagnosis research, and was drawn up in response to the disparity in methodological approaches in the field, which are often atheoretical (Weller et al. 2012). The Aarhus statement provides a checklist of considerations for those undertaking research which measures time points and intervals in the diagnostic pathway and these recommendations have been integrated into the design of this study, including the use of a validated questionnaire. As is outlined in the survey of the field undertaken by Weller et al (2012), there are a range of questionnaire approaches which have been used to collect data on patient intervals, many of which do not make their questionnaire design and definitions transparent.

One approach to address the lack of questionnaires which make their design and terminology explicit would have been to design a novel questionnaire which would specifically address all of the research questions. However, designing questionnaires requires piloting and validation phases which would have taken a considerable amount of time in the research process. As this study was time limited it was decided that it was most appropriate to identify and utilise a pre-existing, pre-validated questionnaire in order to allow maximum time to be devoted to recruitment proper.

A good example of transparent and precise questionnaire design is the C-SIM questionnaire, which gathers data on the length of the patient interval, and is explicit about its time point definitions and validation processes (Neal et al. 2014). C-SIM measures the length of the patient interval by eliciting dates of symptom onset and consultation for both cancer site specific and general cancer symptoms, as well as for 'any other symptoms' experienced (Neal et al. 2014; Neal et al. 2008). Participants can provide exact or estimated dates and, where estimates are provided, there is a protocol for calculating pseudo-exact dates (Neal et al. 2014). C-SIM also asks participants for demographic information; employment status, highest level of qualification, ethnicity, co-habitation status, co-morbidities, smoking status and perceived risk of cancer. However, C-SIM was designed for use with patients with a cancer diagnosis, and so frequently makes reference to cancer throughout.

The C-SIM was later developed by the investigators in The SYMPTOM study, to make it suitable for patients who had symptoms of cancer, as opposed to a cancer diagnosis (Walter et al. 2015). The questionnaire wording was changed to remove references to a cancer diagnosis, and to phrase questions in a manner which related to symptomatic experience. The SYMPTOM study questionnaire has been successfully used to measure patient interval amongst people presenting with symptoms indicative of lung and colorectal cancer and so was believed to be the most appropriate validated tool to use in this study, along with the protocol for calculating 'pseudo-exact' dates from the C-SIM, when necessary (Neal et al. 2014).

Along with data on time to presentation and demography this study was also interested in wider social context and so it was thought to be of value to gather data on social support and other social contextual factors. The Reaction to Symptoms (RSQ) questionnaire measures perceived social support during symptomatic episodes, and was developed to explore the impact of social support on 'delay' (Pedersen et al. 2011). The RSQ asks

participants if they disclosed their symptoms to their partner or anyone else in their social network. We expanded this question, instead asking whether participants had discussed their symptoms with anyone before consulting (yes or no) and going on to ask who they discussed their symptoms with (partner, parents, children, friend, sibling, colleague or other), thus providing a more detailed picture of who people talked to about their symptoms. The RSQ asks participants to rate perceived social support on a 4 point likert scale, in reference to their partner, where applicable, and also in reference to 'others' (defined as 'children, other family members, friends colleagues and so on'). From these ratings mean scores for 'partner support', 'partner avoidance', 'other support' and 'other avoidance' are calculated (Hansen 2008; Pedersen et al. 2011).

The RSQ was also designed for patients who had received a cancer diagnosis and so explicitly referred to cancer, however, as was discussed earlier, the participants in this study had simply got symptoms of cancer. The questionnaire was also developed in Denmark and so some of the statements were culturally specific, with language such as 'physician' not highly used in the UK, particularly the North East. Therefore, the wording of the RSQ statements were modified to more accurately mirror British language and to make the statements relevant to all symptomatic patients, not just those with a cancer diagnosis.

The statements were discussed between myself, my supervisors and the patient representatives, whose involvement overall is discussed later in this chapter, and consensus was reached as to the phrasing. Out of ten statements, seven were rephrased, with the same phrasing used for both the 'partner' and the 'others' statements:

RSQ Statement	Statement used in this Study
My partner asked about my symptoms	My partner asked about my symptoms
My partner took the initiative to talk about my concerns	My partner asked how I felt about my symptoms
My partner advised me to talk to my physician	My partner suggested I go to see the doctor
My partner tried to calm me	My partner tried to reassure me
My partner talked directly about cancer	My partner discussed what they thought my symptoms may be
My partner minimised my concerns	My partner brushed off my worries about my symptoms
My partner pretended nothing had happened	My partner pretended nothing was wrong
My partner avoided talking about cancer	My partner avoided talking about my symptoms
My partner hid his/her concerns	My partner hid his/her worries
My partner was not worried	My partner was not worried

Figure 7: Questionnaire Statement Development



As this study was interested in social context and help-seeking two further questions about religion and caring responsibilities were added to the questionnaire. These questions were replicated from the Office for National Statistics census (Office for National Statistics 2011a) and this information was used to support purposive sampling of interviewees.

### *Recruitment Process*

Urgent referrals (2ww's) were used as a proxy measure for identifying patients who had experienced symptoms indicative of lung or colorectal cancer. According to the NICE referral guidelines for suspected cancer, patients must fulfil the following criteria to be referred urgently (National Institute for Health and Clinical Excellence 2005).

Lung	Lower Gastrointestinal
<p>1.3.2 - Haemoptysis or</p> <ul style="list-style-type: none"> <li>- Any of the following symptom lasting longer than 3 weeks               <ul style="list-style-type: none"> <li>- Chest and/or shoulder pain</li> <li>- Dyspnoea</li> <li>- Weight loss</li> <li>- Chest signs</li> <li>- Hoarseness</li> <li>- Finger clubbing</li> <li>- Cervical and/or supraclavicular lymphadenopathy</li> <li>- Cough with or without any of the above</li> <li>- Features suggestive of metastasis from a lung cancer</li> </ul> </li> </ul> <p>Lung 1.3.3 - Persistent haemoptysis in smokers or ex-smokers who are aged 40 and older</p> <ul style="list-style-type: none"> <li>- A chest x-ray suggestive of lung cancer</li> </ul>	<p>1.5.4 - Patients aged 40 and older reporting rectal bleeding with a change in bowel habit (looser stools and/or increased stool frequency) lasting 6 weeks or more</p> <p>1.5.5 - Patients aged 60 and older with rectal bleeding lasting longer than 6 weeks</p> <p>1.5.6 - Patients aged 60 and older with a change in bowel habit to looser stools and/or more frequent stools lasting 6 weeks or more without rectal bleeding</p> <p>1.5.7 - Patients presenting with a right lower abdominal mass, irrespective of age</p> <p>1.5.8 - Patient presenting with a palpable rectal mass, irrespective of age</p>

Figure 8: NICE referral guidelines for suspected lung and lower gastrointestinal cancer

Referral guidelines 1.5.9 and 1.5.10 for lower gastrointestinal (GI) symptoms state that men and non-menstruating women presenting with unexplained iron deficiency anaemia and a haemoglobin of 11g/100ml and 10g/100ml, respectively, should also be referred urgently (National Institute for Health and Clinical Excellence 2005). However, these patients were excluded from this study as many will be asymptomatic and therefore would not have a symptom appraisal and help-seeking interval. Patients with a previous colorectal or lung cancer diagnosis, respectively, and patients under review of a pre-existing diagnosis were also excluded. Patients deemed to lack the mental capacity to participate were not eligible to take part in this study, however, we cannot assume all such patients were identified as

such exclusions were simply based on the presence of a condition being noted on the referral. Copies of the inclusion and exclusion criteria are available in appendix 1.

Urgent referrals for lung and lower GI specialities were collected by UHNT research nurses and screened by myself for eligibility on a weekly basis. Eligible patients were sent an invitation pack, via second class post, which contained an invitation letter tailored to either lung or colorectal referrals (see appendices 2 & 3), a participant information sheet (see appendix 4), a lung or colorectal questionnaire (which also contained a consent form) (see appendices 5&6 ) and a postage paid reply envelope. Patients were asked in the questionnaire whether they wished us to inform their GP of their participation in the study and for those who did, a standardised letter was sent to their GP (see appendix 7).

Packs were sent a minimum of a day after the patient's first secondary care appointment and, after having being posted, was likely to arrive at least two days later. The referrals which the nurses were able to obtain were not always consecutive, i.e. appointments were made for different clinics, by different secretaries at different times, and so I was not always able to send packs out immediately after the patient's first appointment. It was agreed that the longest acceptable interval between seeing the consultant and patients being approached to take part in the study was a fortnight. Nobody whose interval from consultation was greater than this was invited to participate.

It was important to be mindful of the point at which patients were being contacted: I had to balance the need to minimise the length of time elapsed since help-seeking, in order to reduce recall bias, with the need to avoid contacting patients at an inappropriate time. I decided that it was best to contact patients after their first secondary care appointment, so that they would have already seen the consultant, in the hope that this would reduce confusion and potential distress on the patient's part (i.e. by receiving a letter associated with the hospital prior to having attended). However, the majority of patients would not have received a diagnosis by this point and so this could have been a difficult time for patients, which may have potentially affected the response rate.

Patients who wished to take part in the study completed the consent form and questionnaire and returned it to myself in the freepost envelope. Patients were reassured in the information sheet that they did not have to take part and that it would not affect their health care should they choose not to participate.

### *Response Rate*

It was anticipated that this study would achieve a response rate of 30%, based upon previous recruitment experiences for a similar study with the same population. The SYMPTOM study achieved a 17% response rate in this region, using the same questionnaire, (Walter et al. 2015) and it was felt that recruitment to this study would be higher for two main reasons. Permission to access primary care records was not being sought in this study and secondly it was thought that the study documents were more accessible and user friendly than those used in The SYMPTOM Study, as a result of patient involvement in the document design.

The Trust research nurses anticipated 35 lung and 35 lower GI 2ww referrals being received each week. Based on the anticipated number of eligible referrals, we projected recruiting 200 patients, per cancer site in approximately five months. This time frame was agreed with the collaborating clinicians to keep the recruitment period as short as possible, so as not to affect other studies in the departments.

However, from the outset recruitment was around 12%, with a final response rate of 12.3% for colorectal (93 participants) and 11.2% for lung (71 participants), giving an overall response rate of 11.8%. The number of patients eligible to be invited was not as high as anticipated, both because of fewer referrals and greater numbers of patients needing to be excluded from invitation. Of those eligible, a smaller than anticipated proportion agreed to take part. Because of the unexpectedly low response rate we had to extend the period of recruitment. Recruitment began in January 2014 and ended in December 2014, with the final completed questionnaire being received in January 2015. The response rate will be discussed further in Chapter Eight.

### *Analysis*

Demographic data were collected in relation to age, sex, education, occupation, deprivation and co-habitation. Descriptive analysis was undertaken to illustrate the questionnaire responses in relation to a number of symptoms, type of symptoms, patient interval characteristics and symptom disclosure. Mean interval length was explored in relation to sex, age, employment status, educational attainment, deprivation, living alone, symptom site, type of symptom, symptom disclosure and social support.

For some analyses it was decided to look at characteristics in relation to interval length as a categorical variable, to assess whether there were key differences between those who consulted quickly, those who had an 'average' patient interval length, and those who had

prolonged patient intervals. There is great variability in the definition of long patient intervals, ranging from one month (Courtney, Paul, Sanson-Fisher, F. Macrae, et al. 2012) to three months (Pack & Gallo 1938), an issue which is discussed further in Chapter Seven. For the purposes of this research a consensus on the categorisation of intervals was reached between myself and my supervisors, based on consideration of previous research and the biological course of cancers. Two months was agreed to be a clinically relevant time period which represented a prolonged patient interval. Therefore, a short interval was categorised as less than or equal to 1 week, a medium interval as between 1 week and 2 months, and a long interval as equal to or greater than 2 months.

Tests of association were performed for time to presentation in relation to type of symptom, symptom disclosure and social support score. These variables most directly related to the social context of help-seeking and, or, descriptive analysis of the data seemed to imply a possible association. T-tests were used to compare the mean time to presentation for symptom disclosure to ascertain whether symptom disclosure was significantly associated with time to presentation. Linear regression analyses (ANOVA) were carried out to test whether there was an association between time to presentation and type of symptom, and social support scores (Field 2009). Descriptive analysis was completed using Microsoft Excel and the statistical analyses, of t-tests and regressions, were completed using IBM SPSS Statistics 20.

As per the protocol developed by Pedersen et al (2011) for their analysis of the social support score questionnaire data, a mean item score was calculated for each of the four subscales; partner support, partner avoidance, other support, other avoidance. Each of these subscales consisted of five items, and each item was scored on a four-point likert scale, ranging from 1 'completely disagree' to 4 'completely agree'. A mean value was then calculated for each of the subscales, for participants who had a maximum of one item missing per subscale. Therefore, a high mean score related to high partner support, or avoidance, or other support, or avoidance, as reported by the participants. Social support scores were then looked at in relation to mean interval length, to ascertain whether any trends were evident in the data for social support and time to presentation.

### **Methods: Interviews**

One of the key aims of this research was to produce detailed data on individual experiences of help-seeking and to explore how time to presentation may be affected by the social context of participants' lives.

A semi-structured interview method was chosen because it allowed participants the freedom to discuss issues of importance to them yet, the use of a topic guide meant it was possible to ensure that the topics of interest to this research were still addressed. Semi-structured interviews allow the researcher to steer the interview around themes of interest, whilst still enabling a degree of flexibility for the participant's to explore avenues that are of importance to them. A semi-structured approach is believed to be particularly suitable for studies in which participants will only be interviewed once as:

*'It has much of the freewheeling quality of unstructured interviewing, and requires all the same skills, but semistructured interviewing is based on the use of an interview guide'*  
(Bernard 1995, p.209)

Prior to the research commencing a topic guide was produced by myself and the patient representatives that broadly covered the areas of interest to this research (see appendix 8). Throughout the interview process this guide evolved with topics seemingly of less importance (for instance previous health experiences) being touched on less frequently in interviews, and topics emerging from previous interviews (for instance media coverage of cancer information) being introduced.

Other approaches to interviewing would have been less well suited to this study. Unstructured interviews do not always cover all of the topics of interest to the researcher, as it is the participant who controls the direction of the conversation. When follow up interviews are not conducted, this can mean losing out on vital information relating to your research questions. On the other hand, structured interviews can be overly formal, making it difficult to build rapport and follow new threads of enquiry, and so can result in a loss of narrative.

Within the questionnaire consent form participants were asked if they were happy to be contacted about taking part in an interview. From the pool of those who consented a sample of participants were identified for interview. The purpose of the interviews was to explore patients' help-seeking experiences and, in particular, symptom disclosure, personal context at the time of symptom emergence and consultation, and the role of others in the decision to consult.

### ***Interview Sampling***

The diagnoses of all participants agreeing to be interviewed were obtained from medical records and endoscopy reports prior to making contact with participants. This meant that I

was aware of each participants' diagnosis prior to conducting the interviews, as per ethical approval requirements, and also meant that I was able to purposively sample interviewees to include individuals with a range of eventual diagnoses.

Interview participants were purposively sampled from the wider pool of participants for time to presentation and diagnosis to engage with a wide range of experiences. Patients with a cancer diagnosis were purposively sampled and the number of cancer patients interviewed (3) attempted to mirror the proportion of patients who would be diagnosed with cancer after having being referred urgently, in this region (approximately 8%) (National Cancer Intelligence Network 2014). Participants were categorised as having taken either a short, medium, or long time to presentation for sampling purposes, the categorisation of which has previously been discussed. This method of sampling was employed to ensure a spread of participants, and to avoid clusters in one particular area of experience.

Theoretical sampling was also undertaken to explore developments and questions in the analysis, as per a CGT approach. It had been intended to theoretically sample for Asian ethnicity, because of the themes which emerged in one participant's interview, about the cultural shame and stigma of illness. However, it was not possible to follow this avenue of inquiry as there were no other participants from an Asian background who consented to interview.

In accordance with the constant comparison approach, interviews continued until emerging theories were repeatedly supported by new data, with subsequent interviews no longer challenging or altering analysis, as is the case at the beginning of fieldwork when concepts and theories are still developing (Glaser & Strauss 1967). This approach is slightly different to the concept of 'saturation', an idea which is frequently used in qualitative research to guide and explain how and when interviewing should cease. Saturation is said to be reached when nothing new emerges from the data and therefore codes and themes have become 'saturated'. The concept of saturation has been critiqued as pretentious, as in reality it is very rare that no new data is present in an interview. What more often occurs is that the researcher can no longer see new data, or decides that the new data is not relevant to the themes and theories under development (Barbour 2014). The concept of saturation is contested, with critiques being raised that many qualitative researchers employ this term to legitimise the termination of data collection, the decision for which is

often based more in resource availability (time, money, participants), than true saturation of themes.

In this study interviewing ceased when a point of 'accuracy', as opposed to 'saturation', was believed to be reached. Charmaz (2004) describes the point of accuracy as '*collecting sufficient data that we have as full a range of observations of the phenomenon as possible*', as opposed to '*rely[ing] on the rhetoric of saturation to dismiss doing thorough fieldwork*' (Charmaz 2004, p.986). In total, 26 interviews were conducted, 14 with people with symptoms of colorectal cancer and 12 with people with symptoms of lung cancer, with the key characteristics of these participants being presented in figure 9.

Participant	Gender	Age	Occupation	Discussed Sx's?	First Symptom (q'airre)	Interval Category	Interval (q'airre)	Interval (interview)	Diagnosis
<b>Abdul</b> (R001)	M	41	Job Centre Key Worker	Y	<i>I began to cough up blood and chest/breathing became tight</i>	Long	3 months	3-4 years	Inflammation
<b>Pamela</b> (R003)	F	71	Retired Teacher	Y	<i>Blood in phlegm</i>	Medium	Same month	'a few weeks' ?3 weeks?	Bronchiectasis
<b>Audrey</b> (R011)	F	73	Retired	N	<i>Coughed up some blood in phlegm</i>	Short	1 day	2 days	Resolving Infection
<b>Richard</b> (R013)	M	69	Retired	Y	<i>Cough/Irritation in chest</i>	Long	4 months	5 months	Reflux Disease
<b>John</b> (R027)	M	70	Retired	Y	<i>Cough and breathlessness</i>	Long	6 months	9 months	NAD
<b>Tom</b> (R029)	M	74	Retired	Y	<i>My daughter mentioned that I was wheezing when I was walking with her</i>	Long	1 year	2 years	Chronic Bronchitis
<b>Sandra</b> (R031)	F	55	Nurse	Y	<i>Tight chest, coughing up green sputum, cough, little breathless</i>	Short	Same day	2 days	Inflammation
<b>Pauline</b> (R047)	F	66	Shop Owner-> Retired	Y	<i>Coughing</i>	Long	2.5 years	4-5 years	COPD
<b>Melanie</b> (R058)	F	48	Working Full Time	Y	<i>Pain in right side of back going through body</i>	Short	Same day	Same day	Small Cell Lung Cancer
<b>Maggie</b> (R055)	F	70	Retired	Y	<i>fainting, diarrhoea/sickness, tiredness, lack of appetite, cough</i>	Short	6 days	9 days	Pneumonia
<b>Des</b> (R061)	M	64	Retired	N	<i>Coughed up small amount of blood</i>	Short	Same day	1 week	Non-small cell lung cancer
<b>Joseph</b> (R068)	M	65	Full time Carpenter	N	<i>Coughing up blood</i>	Short	7 days	11 days	NAD



Participant	Gender	Age	Occupation	Discussed Sx's?	First Symptom (q'airre)	Interval Category	Interval (q'airre)	Interval (interview)	Diagnosis
<b>Arthur</b> (C001)	M	80	Retired	Y	<i>Very loose bowel movements</i>	Medium	4 weeks	2 weeks	Diverticulosis
<b>Steve</b> (C004)	M	50	Night Shift Worker	Y	<i>Bleeding when going to the toilet for a poo</i>	Short	2 days	3 days	NAD
<b>Mary</b> (C006)	F	78	Retired	Y	<i>Bleeding from back passage</i>	Short	4 days	5/6 days	Diverticulosis
<b>Julie</b> (C013)	F	59	Unemployed	Y	<i>Pains in my stomach, feeling sick, dizzy and diarrhoea</i>	Medium	2 weeks	4/5 days	NAD
<b>Fred</b> (C014)	M	78	Retired	Y	<i>More toilet visits. Stools very loose</i>	Medium	2.5 weeks	6 weeks	NAD
<b>Roy</b> (C015)	M	65	Cleaner -> Retired	Y	<i>Constant diarrhoea</i>	Long	5.5 months	18 months	Spirochetosis
<b>James</b> (C016)	M	74	Retired Clinician	N	<i>Belly ache</i>	Medium	1 month	6 weeks	Diverticulosis
<b>Elaine</b> (C017)	F	65	Customer Services	Y	<i>Very loose bowel movement</i>	Long	4 months	4 months	Diverticulosis
<b>Mark</b> (C057)	M	63	Mental Health Nurse	N	<i>Slight, but not consistent, change in bowel function</i>	Long	6 months	6 months	Rectal Carcinoma
<b>Christine</b> (C067)	F	50	Shop Manager	Y	<i>Stomach cramps and bleeding from bowel</i>	Short	Same day	4 days	NAD
<b>Harry</b> (C068)	M	79	Retired	N	<i>Loose bowel motions</i>	Long	3 months	4 months	Microscopic Colitis
<b>Jack</b> (C071)	M	84	Retired	N	<i>Bleeding from back passage</i>	Short	3 days	3 days	Diverticulosis
<b>Angela</b> (C079)	F	67	Retired Teacher	Y	<i>Blood on the toilet paper when I passed a motion</i>	Long	3 months	3 months	Haemorrhoids
<b>Eleanor</b> (C085)	F	67	Retired Care Home Manager	N	<i>Bleeding from back passage</i>	Medium	2 months	6 months	Diverticulosis

Figure 9: Interview Participants

### *Pre Interview and The Interview Setting*

Potential interviewees were contacted by myself, by phone, to ask if they were still interested in taking part in an interview. A suitable time and date was agreed with those still interested and the interview participant information sheet was then posted out (see appendix 9), for them to read and consider prior to the interview. This also contained my contact details should they decide to re-schedule or cancel. We agreed a suitable location for the interview, with participants having the choice of being interviewed in their own homes, or at the University, in which case we would reimburse transportation costs. By offering the participants choices about the timing and location of the interview I hoped to minimise some of the inherent power bias between researcher and researched, by giving participants greater control over the experience (Mills et al. 2006a). It has been argued that conducting interviews in a congenial environment helps to put participants at ease and can aid recall (Hindley 1979). Generally, participants chose to be interviewed in their homes, either during the day or early evening. However, five participants did choose to be interviewed at the University.

From the moment I met the interviewees, I tried hard to establish and build rapport with them, in order to put them at ease and make them feel more comfortable with the interview experience. I tried to be warm and friendly, in an effort to endear myself to them, and I always made small talk at the beginning of the interview in order to show interest in their lives. This also gave participants an opportunity to get a sense of who I was and I hoped that this helped to reduce my position as an outsider.

After initial chat I asked the interviewees if they had any questions about the participant information sheet that they had been sent and also briefly described the purpose of the study, outlining the topics I was going to raise during the interview. I then asked them to sign a consent form (see appendix 10), which sought their consent to be interviewed, for the recording of the interview, and for the use of anonymised quotes.

### *The Interview Proper*

A topic guide was used to direct the interviews. I rarely had to ask all of the questions, as people often touched upon relevant topics un-prompted, and I rarely followed the listed order, as people's stories meandered through topics at different paces and points. The topic guide evolved throughout the course of the research, as I identified the need to explore new topics as a result of emerging themes. Interviews ranged in length from 30 minutes to 2 hours, but the majority lasted just under an hour. I made sure that I thanked participants, both before and after the interview, for sharing their time and stories with me.

Some participants became upset when sharing their story. In such instances I tried to give the participants the space they needed, whether that be to remain quiet for a while or to allow them to discuss the issue upsetting them. I tried to make a conscious effort not to offer advice, however, in a couple of situations I did share with the interviewee some of my own experiences. For instance, one participant was discussing his mother's terminal illness and death, and I decided to disclose to him my step-father's terminal illness. Whether or not such personal disclosures are appropriate could be debated *ad infinitum*, however, I believe that the participants had placed me in a position of privilege, through their willingness to share their time and experiences with me, and so sharing pieces of information about oneself, as opposed to remaining an 'objective scientist', is the appropriate response in some situations. As researchers, we ask interviewees to be incredibly open with us and it is unrealistic and unfair to expect them to give so openly if we ourselves are closed and impersonal (Rubin & Rubin 1995). Self-disclosure in interviews can act as a form of reciprocity and helps to break down some of the power imbalance of the situation (Edwards 1993). By disclosing my personal experience the interview actually took a different shape than it may have otherwise done, as the participant went on to discuss the impact of his mother's illness and death on his own health behaviours.

I always tried to answer any questions participants asked me and, a recurring interest among participants was about my professional life, seeking clarification around who I was (a student, a clinician, a researcher?), what I did day-to-day in my role, and what my future career may look like. Jane Mills (2006) supports personal disclosures in research encounters, saying that:

*'the researcher needing to invest his or her own personality in the research process so as to establish a more non-hierarchical relationship'*

(Mills et al. 2006a, p.10)

I put a lot of thought into how I would present myself professionally to participants; calling yourself a researcher is thought to be unhelpful, as 'researcher' is not a meaningful category to many people and so I chose to present myself as a student, as 'student' is generally an acceptable role to interviewees (Rubin & Rubin 1995). Again, I was happy to share such information with participants and I hope that it helped to make me to seem less alien and build trust between us (Mills et al. 2006a).

Reciprocity was an issue which I grappled with throughout the study. Here were individuals who had been, or were, ill, who were giving of their time and stories to me, with no obvious benefit to them. I felt acutely aware of the fact that I did not give anything back to participants in return for their involvement, such as a voucher, as is common practice in research. This made it of even greater importance to me that I share a little information about myself, if asked.

As these were single interviews, I also felt a sense of guilt when leaving participants, as I had taken something from them, given nothing back, and was now leaving them. This internal struggle reflected what Oakley refers to as 'the rape of empirical research' (Oakley 2000). I felt particularly culpable among participants whom I believed to be more vulnerable and isolated. For instance, in one interview I was at a lady's home for over three hours and only forty minutes of my time there was spent conducting the interview. The rest of the time she talked about her husband's terminal cancer and death, as well as showing me around her home and showing me pictures of her children and grandchildren. She cried a lot during my time there and I found it difficult to leave as I felt that I had possibly brought these painful emotions to the surface for her. However, I think that she wanted company and was aware of the fact that I had tried to give her my time as, as I left she said *'it was very good of you to stay for so long'*. Although I felt guilt about the lack of tangible benefit for participants, what I may have given back to some individuals was the opportunity to share their stories with a non-invested stranger.

As the research progressed I felt that my skills as an interviewer improved. I think this was a combination of increased confidence, decreasing anxiety around not mentioning cancer, and a greater trust in my own abilities as an interviewer. It has been suggested that an interview is a performance, wherein the data produced are highly conditional on the interaction, and the broader social norms referred to in this interaction (Rapley 2001). I was performing the role of the interested, attentive and knowledgeable interviewer and the interviewees were also performing, through the re-telling of their experiences in a way they thought was interesting and relevant. This notion of an interview as a performance parallels constructionist ideas of the co-creation of knowledge, as a result of the pre-conceptions and biases that both parties bring to the interview encounter.

### ***The Presence of Family Members in Interviews***

It had initially been planned that family and friends, with whom the participant had discussed their symptoms, would be approached about taking part in a separate interview,

to explore others' role in, and perceptions of, the individuals' help-seeking journey. Despite trying on many occasions to recruit family members and friends to an interview, only one was forthcoming, the daughter of Tom. What did occur though, was that spouses were present in a large number of interviews. In some cases they popped in and out of the room during the interview, in others they were a silent presence throughout, and in others they actively contributed to the interview and helped to shape its direction and content. In interviews where spouses did contribute to the dialogue, something which was unpredictable in advance, I asked them at the end of the interview if they would consider also taking part in the study. I informed them that they could think about their participation and post the completed consent form back to me, if they chose to take part, and if they didn't return it I would take this as notification that they did not consent to their responses being used. Everyone consented to their data being used and the majority of people completed and returned the form to me there and then.

The presence of spouses in interviews was beneficial in most cases, with spouses reinforcing or contradicting narratives, or reminding participants of details which prompted further discussion around certain topics. It has been argued that fuller accounts and richer data are produced when couples are interviewed together (Allan 1980) because of the cueing phenomenon, where one individual helps another divulge information (Bjornholt & Farstad 2012). This was certainly what I found with my participants, where one often prompted another to mention an additional piece of information or to provide further contextualisation of an already divulged piece of information.

It could be argued that the presence of a spouse during an interview could be detrimental as it may alter the participant's narrative, deterring them from discussing certain topics, or sharing certain pieces of information. However, as this study is based in social constructionism, it does not seek to find a singular truth, but instead acknowledges that participants' narratives will be (co)constructed in relation to a number of contextual factors, the presence of a spouse being just one of these.

*'Taking a fully relational self as a starting point, one could argue that when co-production takes place between an interviewer and an interviewee in a real-life context, which involves significant others from the informant's lifeworld, the stories presented are just as 'true' as the ones produced between interviewer and interviewee in an individual research interview context. While accepting that all research interviews involve producing knowledge together, going beyond the*

*one-on-one researcher-informant relationship can be seen as a way of opening up new and interesting knowledge, rather than as a limitation.'*

(Bjornholt & Farstad 2012, pp.4–5)

Spousal quotations have been included in the analysis of the data, in so much as sections of dialogue between participants and their spouse have been analysed and considered in their entirety, however, there has not been a separate analysis of the spousal data. This is because their contributions to interviews tended to be in conversation with their partner, and rarely did spouses present substantial narrative by themselves. Therefore, analysing this separately would lose much context and detail, particularly when the focus is on participants' help-seeking journeys.

### ***Recording and Transcription***

All of the interviews were recorded using a digital dictaphone as it was felt that this was the most effective way of capturing dialogue whilst allowing myself to make notes and remain attentive to participants (Rubin & Rubin 1995). One alternative to audio recording the interviews would have been to solely make notes but I felt that this would have affected rapport in the interview and would have relied too heavily on my immediate memory. It would have been difficult to record quotes verbatim, something which I was specifically wanting to obtain, so that I could ensure that participants' voices were present in the analysis and discussion.

The interviews were all transcribed verbatim, however, I chose not to transcribe language patterns and conversation fillers (such as 'uh-hum's') because the research focus was on meanings and content. There would have been minimal benefit in transcribing every utterance for this CGT study, as would have been appropriate had I been undertaking conversation analysis with the data, for instance (MacLean et al. 2004; Oliver et al. 2005).

The first eight interviews were transcribed by myself and subsequent interviews were outsourced to an approved transcription service because of time constraints. The main benefit of transcribing the interviews myself was that I was able to begin preliminary analysis during the act of transcribing, making notes which would go on to inform codes and memos. In fact, it has been argued that transcription is analysis in itself, as you are selecting which elements to transcribe and which to leave out (Branley 2004). Listening to the audio recordings and hearing participants' voices helped me to 'return' to the interview setting and contextualise the narratives in my memory. In order to not lose this valuable step with the interviews which were professionally transcribed, I listened to each audio

recording whilst reading the prepared transcript, simultaneously beginning early analysis and checking for errors.

The dilemma of transcription in relation to regional dialects was something I was conscious of from the beginning of this research. I wanted to ensure that transcripts and quotations were not devoid of the participant's identity, however, I also had to consider whether transcribing dialect may portray participants as uneducated, unrefined or unintelligent, which may offend participants (Oliver et al. 2005). I decided to transcribe regional dialect, which were words that contained meaning, however, chose not to transcribe 'accent'. Instead I transcribed the word using the correct spelling, as opposed to the way it was pronounced. I hoped in doing this I would still retain some of the participants' regional identities, whilst avoiding portraying them as uneducated because of mispronunciation. It has been argued that regional and class differences can lead to misinterpretation of words or phrases during transcription (MacLean et al. 2004) and a number of errors were identified in the outsourced transcripts during spot-checking. These errors generally related to misunderstandings because of dialect or local geographical references, and were corrected.

### *Analysis*

In line with a CGT approach, analysis occurred concurrently with fieldwork, with coding and memoing being done throughout the research process. However, there were also particular points at which detailed analysis took place, such as the development of a coding theme matrix after the first eight interviews and at a number of other points along the analytical journey, deep, concentrated analysis took place.

*'grounded theorizing involves collecting data in episodes punctuated by periods of data analysis; it cannot occur if data collection takes place at a single point in the research process.'*

(Seale 2004)

### *Coding*

*'Through coding, you define what is happening in the data and begin to grapple with what it means. The codes take form together as elements of a nascent theory that explains these data and directs further data-gathering. By careful attending to coding, you begin weaving two major threads in the fabric of grounded theory: generalizable theoretical statements that transcend specific times and places and contextual analyses of actions and events'*

(Charmaz 2006, p.46)

Coding took the form of two main stages: initial line-by-line coding and more focused, thematically relevant coding.

With the first eight transcripts I undertook line-by-line coding, however, I did allow a degree of flexibility in this process. Some lines had multiple codes whilst in other lines, particularly during 'off topic' sections, there may not have been a code used. In this initial phase I wanted to pay close attention to the data and tried to use *in vivo* codes, or gerunds, where possible, to most accurately mirror participant's narratives and build action into the codes (Charmaz 2012). The use of gerunds helps to maintain authenticity in the coding, avoiding the voice of the researcher becoming dominant and ensuring that the fluidity of participant experiences is preserved (Barbour 2014; Charmaz 2006). The decision to stop line-by-line coding after the first eight transcripts was made because at this point similar codes were being used and Charmaz argues that line by line coding should only continue until there are sufficient codes of interest with which to work (Charmaz 2012).

Some of the codes which I identified in this phase did relate to the pre-existing literature but there were also new codes and themes which emerged from the data. Although I tried to follow the data and not allow *a priori* assumptions to colour my analysis, the presence of codes which mirrored existing literature may have reflected subconscious bias on my part. However, I would argue that if the codes are evident in the data, and not forced, it does not make their presence in the analysis any less valid.

As a result of the line-by-line coding I compiled a matrix of broader and recurrent codes (see appendix 11) which were then grouped into loose themes. I revisited the original eight transcripts and re-coded them using the code matrix to assess the adequacy of these codes and also to see if there were additional emergent themes, as an iterative process.

All subsequent transcripts were coded using the code matrix which enabled me to begin to draw together data from the different interviews. Charmaz describes this second coding phase as a:

*'Focused, selective phase that uses the most significant or frequent initial codes to sort, synthesize, integrate and organize large amounts of data'*

(Charmaz 2014, p.113)

Although I describe two distinct coding phases here, in reality the phases were not entirely separate. Codes and themes emerging later on in the analysis process were incorporated



into the code matrix and I revisited previous transcripts to see whether these codes were also present in those accounts. Charmaz describes coding as not only iterative, but also interactive, in that the researcher interacts with their data, by returning to it and using new insight to inform future lines of enquiry (Charmaz 2014). The revisiting of the code matrix during the focused coding phase also helped to test and confirm the validity of the codes.

I tried to engage in a constant comparison approach throughout the analysis, comparing one persons' data to itself, comparing data with other participants' data, comparing data with codes and comparing codes with other codes. At the end of the fieldwork a large table was produced which cross referenced participants against themes, with a summary of each participants responses in each of the theme boxes. This table was very beneficial in the later stages of analysis, as it aided in the comparison of data within and between participants, and across the entire dataset. This level of comparison helped to sharpen analysis and allowed me to gain insight into the data, which then fuelled memo-writing.

#### Memo-Writing

Memos were written from an early stage of the research proper, as is encouraged in CGT, in order to embed analysis and capture early analytical insights. Memos generally related to a code or topic and were documents where I fleshed out my thinking on specific issues, using both raw data and my own musings and interpretations to populate them. They were dynamic documents which I frequently revised and added to. Charmaz describes memos as *'an interactive space and place for exploration and discovery'* (Charmaz 2014, p.170). This approach fits with my personal writing and analysis style, wherein writing is a process of discovery, providing opportunity to focus on and draw together what are sometimes disparate ideas.

#### Theory Building

I did not come to the research with an idea of a theory I was hoping to use, as it has been argued that such an approach will result in a synthetic analysis (Charmaz, 2006). Instead, I analysed the data independently, tried to build theory from the data and only after I was confident that the theory I had produced adequately described my data, did I explore existing theory which may illuminate the issues, patterns and theories which I had identified.

Formulation of theory from the data in this study took the form of exploring all codes and themes and considering how these elements related and interacted with one another. This

process involved me identifying overarching concepts which explained a group of data and then considering how these overarching concepts linked with one another. The building of theory also involved revisiting and integrating the memos which had been written throughout the analysis process.

### **3.5 Ethical and Governance Issues**

#### **Ethical Approvals**

Before the research started ethical approval was sought and obtained from Durham University School of Medicine, Pharmacy & Health Ethics Committee (see appendix 12), University Hospital of North Tees Research & Development Peer Review Committee (see appendix 13), and the NHS National Research Ethics Service (NRES) North East Committee (see appendix 14). One minor amendment was submitted after the study began, an alteration to the GP letter, which was approved (see appendices 15 & 16).

#### **Ethical Issues**

All data was stored confidentially and used anonymously. Questionnaire participants were assigned an anonymous code, and interviewees, as well as any individuals named in interviews, were given a pseudonym to protect anonymity (Rubin & Rubin 1995). All physical documents were stored securely in locked filing cabinets and all data stored electronically (transcripts, audio recordings and questionnaire responses ) were anonymised before being put onto a password protected computer, within the University secure server.

Some of the main ethical issues which were identified and addressed for this project were the identification of eligible participants, the time at which patients were being approached, the potential for distress as a result of invitation to participate, and the potential for distress in interviews.

It was originally intended that the research nurses would screen referrals and send packs to eligible patients, so that I was not privy to any patient details prior to their consent. However, the lack of funding to support the nurse activities meant that the Research and Development department requested that I undertook this part of the process instead. In order to allow me to view urgent referrals without patients' consent I applied to, and was granted, Caldicott approval (see appendix 13). In order to minimise the extent to which data was accessed and used without patient consent, no record was kept of patients who had been invited to the study.

The time at which we approached patients to take part in this study was a concern, as most patients would be awaiting results of investigations and diagnoses and we did not want to cause any confusion or distress to patients. It was decided that packs would be sent to patients within the two weeks after their first appointment, as leaving it much later than this would also mean that their help-seeking was more distant and participants may struggle to recollect their experiences.

As the majority of patients would not have a diagnosis at this point it was decided that the word 'cancer' should not be introduced, as it would possibly cause distress to patients if they assumed that the invitation to participate was because they had an as yet undisclosed cancer diagnosis. Therefore, the word 'cancer' was never used on any of the study documentation.

There was the potential for interviewees to become distressed as a result of talking about their help-seeking experiences, social context, or diagnosis, and procedures were in place to deal with such situations, should they have occurred. In instances where a participant was distressed I was to stop the interview, allow them to decide whether or not they wished to continue, and, if appropriate, signpost them to specific organisations (such as Macmillan or The Patient Experience Team at UHNT) who would have been able to support and address their concerns. No participants became distressed during the interviews, however, some did become upset. For these people I offered to stop the interview, an option which was never chosen, and allowed them the time to address their feelings before continuing with the interview. I think it is important to be clear that someone being upset is not necessarily a bad thing, nor does it inevitably equate to 'distress' or 'harm'. For some, participating in an interview, and the opportunity to tell their story to a stranger, can be cathartic (Richards & Emslie 2000). It is not the interview itself which is upsetting, it is the topic being discussed, and as researchers sometimes we need to allow this, responding as humans, as opposed to researchers (Barbour 2014).

A final ethical consideration was the risk posed to myself by undertaking this research. By interviewing strangers within their own homes there was the possibility that I may have entered a dangerous situation, in which I was alone, vulnerable and exposed to harm. In order to protect myself I left the details of the interview in a sealed envelope with a colleague, along with an expected completion time, and once the interview was over I called them to confirm I was safe, following my research team's lone working policy.

The other issue was that of the emotional impact of the interviews on myself. I had a support network available to me, in the form of my supervisors, as well as my husband and mother, whom I could talk to about my reactions and feelings to the interview, whilst ensuring that the interviewee remained anonymous in my discussions.

### **Patient and Public Involvement**

The study was supported by two patient representatives, Margaret Johnson and John Shepherd. They were involved from the beginning of the PhD, and offered comments and advice about the research design and study documentation, including the study summary sheet, which was sent to all participants who indicated that they wished to be informed of the study findings (see appendix 17).

### **3.6 Methodological Reflections on 'Delay'**

Many authors use the term 'patient delay' in relation to help-seeking, however, recently this language has been critiqued, as it is felt to be judgemental and pejorative (Scott, E. Grunfeld, et al. 2006). Critics of the word delay have suggested that we instead refer to the appraisal interval, help-seeking interval or time to presentation (Walter et al. 2010; Weller et al. 2012) of patients. Examination of the literature and design of this study meant that the concept of delay, and current approaches to it, had to be grappled with. I suggest that the current conception of 'patient delay' is problematic both semantically and methodologically.

A comprehensive reflection of 'patient delay' is presented in appendix 18, however, it is important to specifically detail the stance on terminology in order to frame this piece of research. The suggested linguistic alternatives to 'patient delay' (i.e. appraisal interval, help-seeking interval and time to presentation) remain problematic as they actually refer to discrete time periods within the patient interval, which exist for every individual who consults. They are therefore conceptually different to the notion of 'patient delay', which separates those who present quickly and those who take a long time to present. The conflation of language used to describe conceptually different phenomenon can only serve to hinder clarity when discussing help-seeking. However, it is still inappropriate to use language which places judgement and blame on the patient, who is often bound in their behavioural choices by wider contextual constraints. We propose that the term 'prolonged' can be used as a prefix to more effectively describe the length of discrete time periods whilst avoiding attributing blame to the individual.

### **3.7 Summary**

This research explores experiences of help-seeking among patients with symptoms of lung or colorectal cancer, from a perspective of constructionism and pragmatism. A mixed methods approach was taken, with questionnaires and semi-structured interviews utilised to investigate the range of factors which influence how, and when, people decide to consult about their symptoms. Questionnaire data were explored statistically to identify any associations between time to presentation and participant characteristics, and interview data were analysed using a constructivist grounded theory approach, which entailed thematic coding, constant comparison of data and theory building.

## Chapter Four: Questionnaire Results

This chapter presents the results of the questionnaire data analysis. Descriptive analysis of the data was undertaken to provide a picture of people's help-seeking experiences, by considering questions such as how many symptoms people experienced, and how long it took people to present after symptoms began. Tests of association were undertaken to see if any of the participants' characteristics, such as their age, type of symptom, or level of social support, were related to the length of their patient interval.

### 4.1 Participant Characteristics

A total of 164 completed questionnaires were received from 1390 invited participants, resulting in an overall response rate of 11.8%. These responses consisted of 71 lung participants (11.2% response rate) and 93 colorectal participants (12.3% response rate). 56% of lung participants and 47% of colorectal participants being male, meaning 51% of participants overall were male.

Participants ranged from age 40 to 88, with most aged between 60 and 79 (see figure 10).

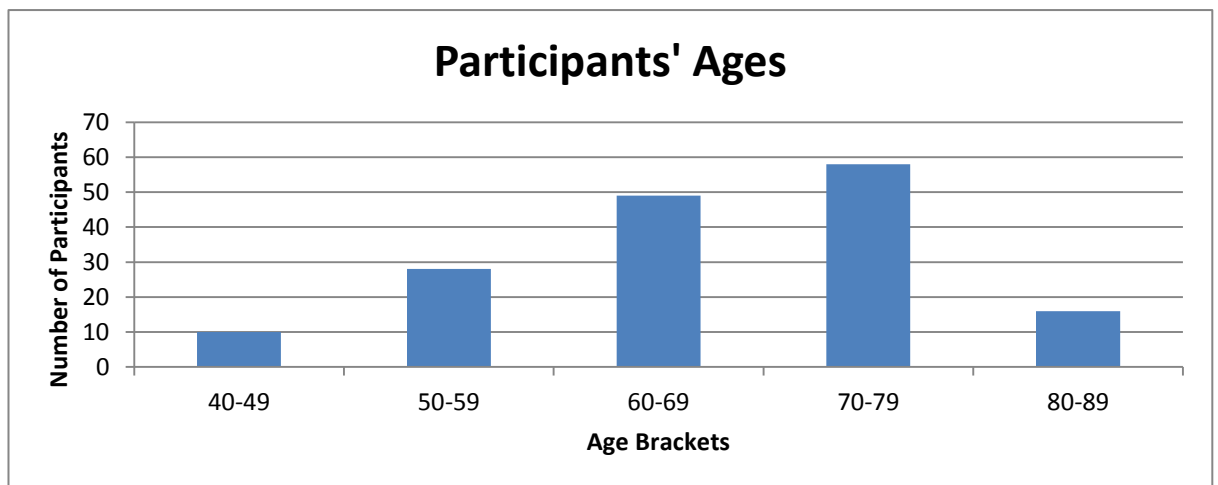


Figure 10: Participants' Ages

The majority of participants (69%) were retired, however, a number of participants still worked, either full time (19%) or part time (5%), with the remaining participants identifying as either unemployed or sick/disabled.

Educational attainment varied across the sample and although the majority of participants reported no formal qualifications, or education to GCSE level, there was also a notable number of participants educated above A level (see figure 11).

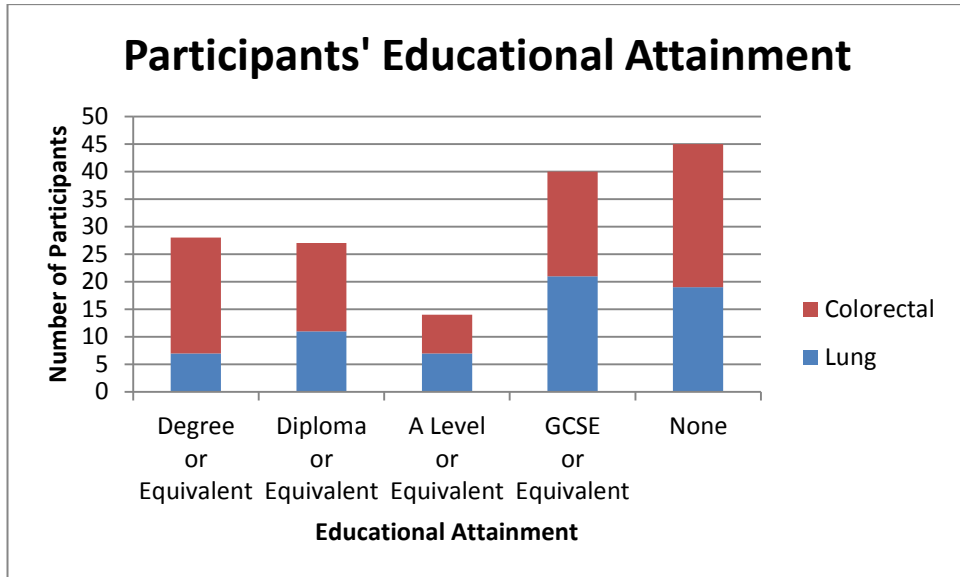


Figure 11: Participants' Educational Attainment

Of the entire dataset, 24% lived alone, with a slightly higher percentage of colorectal participants (28%) living alone than lung participants (18%).

The majority of lung participants were in the 4<sup>th</sup> or 5<sup>th</sup> quintiles of Index of Multiple Deprivation (IMD) (see figure 12), whereas the majority of colorectal participants were in the 1<sup>st</sup> or 2<sup>nd</sup> quintiles (see figure 13).

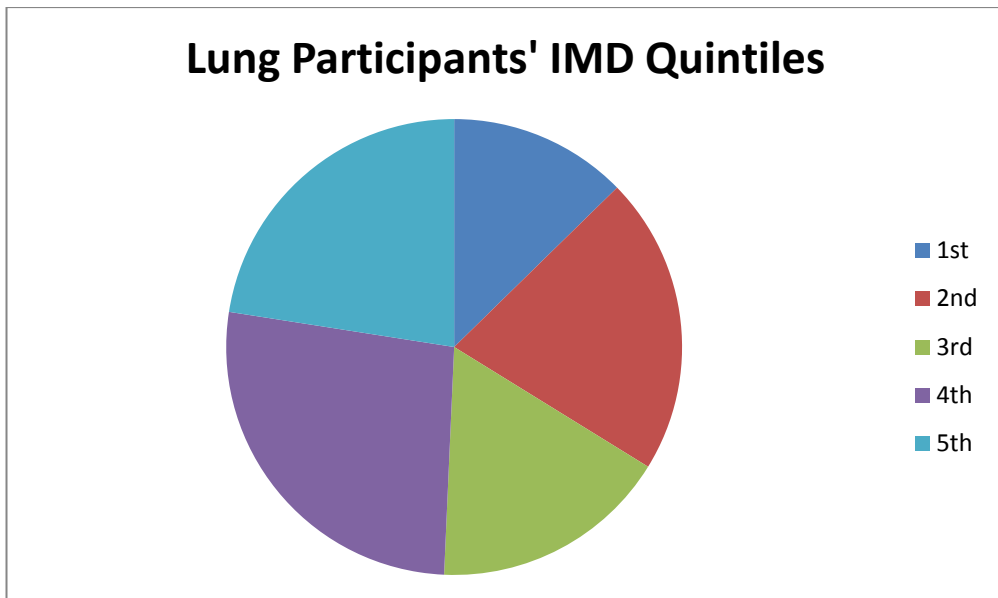


Figure 12: Lung Participants' IMD Quintiles

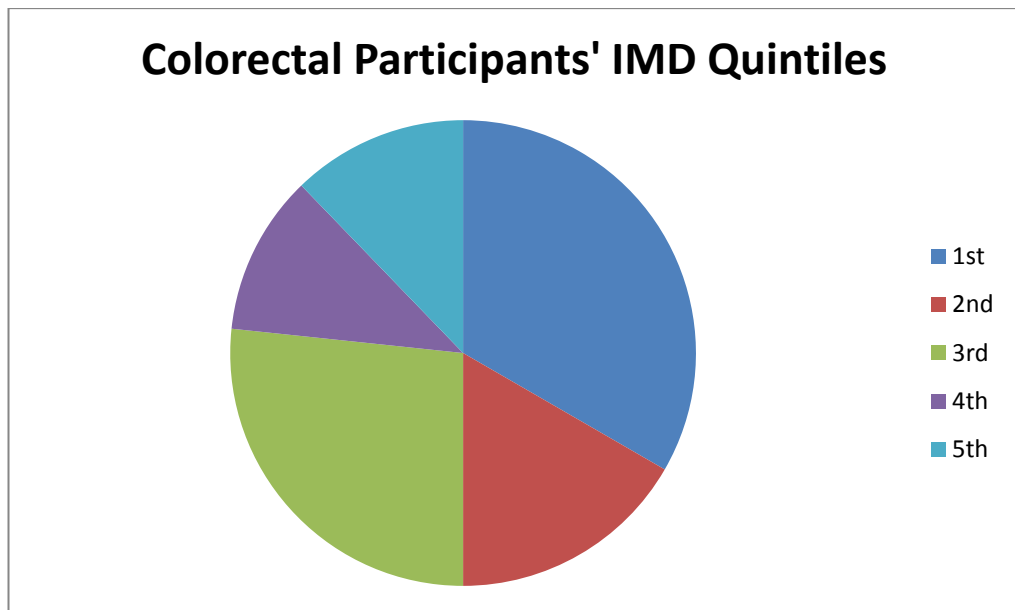


Figure 13: Colorectal Participants' IMD Quintiles

There could be a number of explanations for these differences in levels of deprivation between the two symptom sites. It may be that those most deprived are more likely to experience respiratory symptoms as a result of smoking, work related exposure and environmental exposure in the form of air pollution, whereas those in the least deprived quintiles may be more likely to experience bowel symptoms, may be more aware of the significance of bowel symptoms and, or, more likely to seek help for them. Another explanation could be that those from the least deprived areas felt more comfortable taking part in research about bowel symptoms, an often sensitive and embarrassing subject, whereas such embarrassment is rarely reported by people discussing respiratory symptoms.

## 4.2 Descriptive Analysis

### Symptom Experience

The first question asked participants '*What was the first thing or symptom you noticed that made you think something might be wrong?*'. Participants varied in the number of symptoms they reported in response to this question, with up to five symptoms being noted (see figure 14).



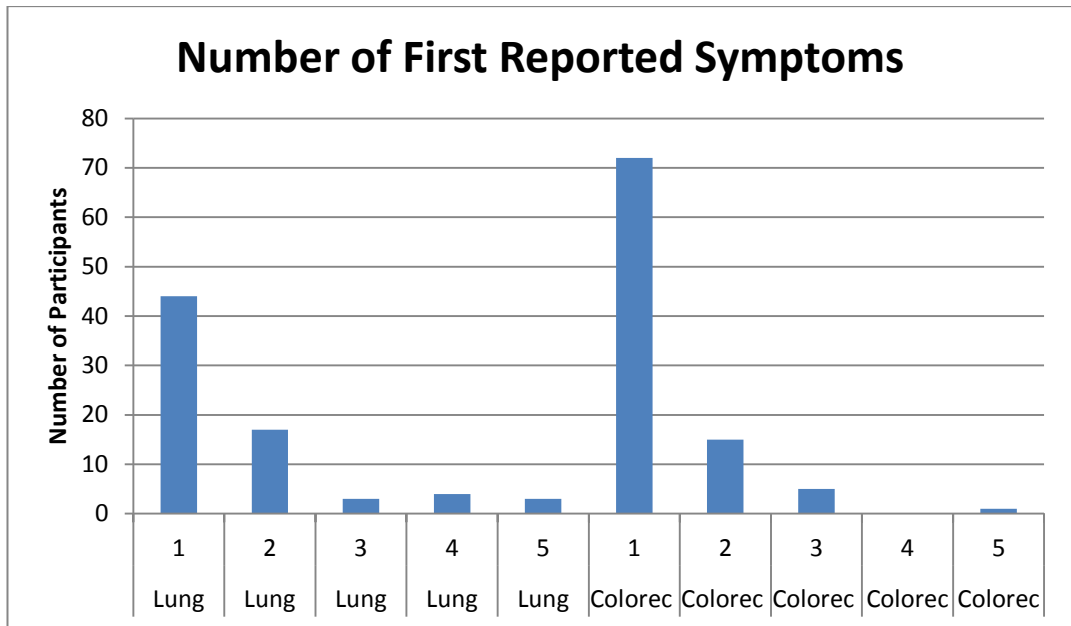


Figure 14: Number of First Reported Symptoms

Among lung participants the most commonly reported symptom was a cough, followed by breathlessness and then more general, systemic symptoms (fatigue, feeling unwell, decrease in appetite, headaches, high temperature, weakness and weight loss) (see figure 15). Pain was reported by a number of participants, which was either located in the chest, back or neck, and haemoptysis (coughing up blood) was reported 11 times. Hoarseness/loss of voice/wheezing was reported by six people, ‘an infection’ (‘bronchitis’, ‘chest infection’ or a ‘cold’) by four people and there were five instances of ‘other’ symptoms being reported (acid reflux, diarrhoea/sickness, fainting, sore throat, urine infection).

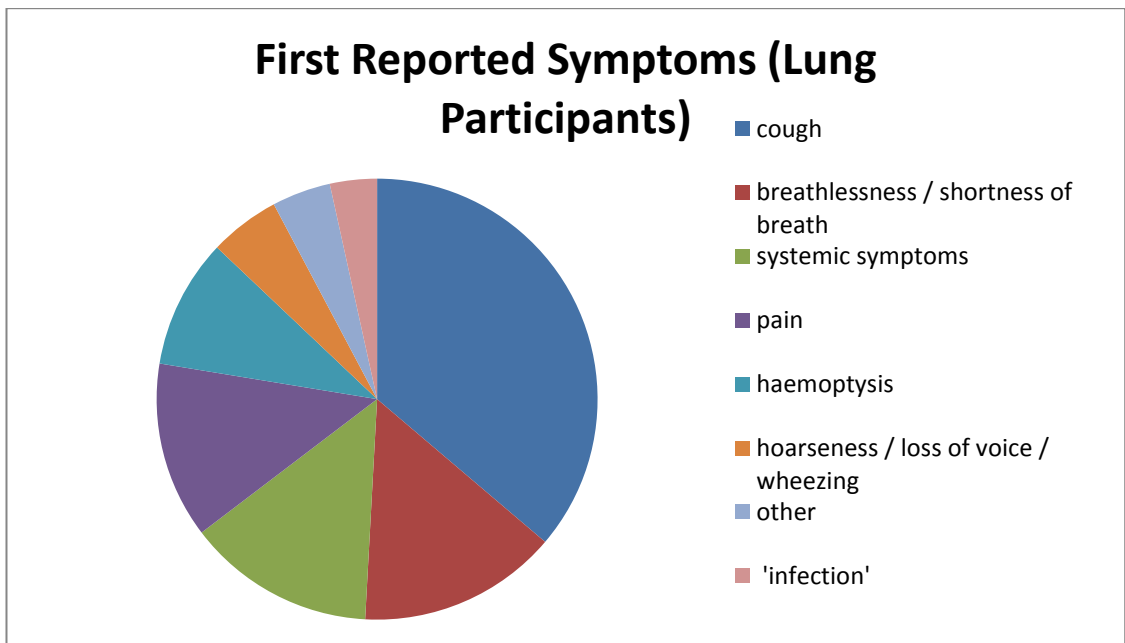


Figure 15: First Reported Symptoms (Lung Participants)

The majority of colorectal respondents (40%) reported a change in bowel habit (diarrhoea, constipation or loose bowel movements), followed by episodes of rectal bleeding, or pain (in the stomach, rectum, bowel or back) (see figure 16). Eight participants reported an increased frequency or urgency of their bowel motions and there were also eight reports of systemic symptoms (feeling unwell, decreased appetite, dizziness, light-headedness, tiredness or weight loss). Five participants reported flatulence, itching, bloating or the passing of mucus, with a smaller number reporting sickness/nausea and only two reports of 'other' symptoms (cold/flu like symptoms and coughing up phlegm).

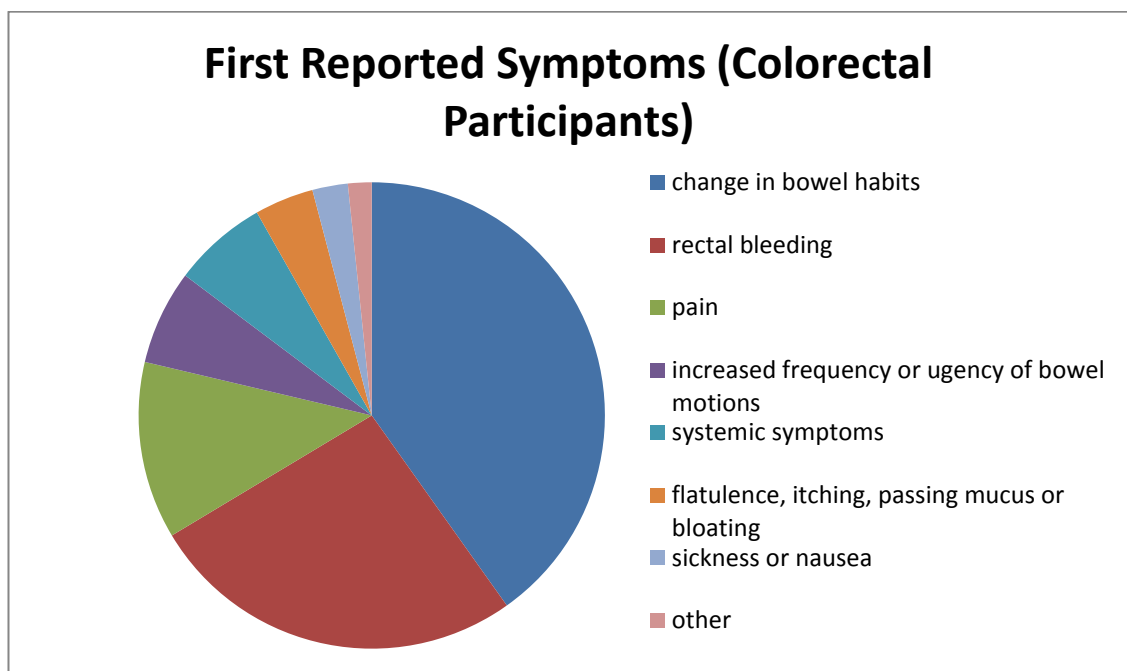


Figure 16: First Reported Symptoms (Colorectal Participants)

### Patient Intervals

The length of the patient interval for the first reported symptom was calculated for 163 respondents, as one lung participant did not provide usable information. Participants with colorectal symptoms took longer to consult, on average, than participants with respiratory symptoms. There was also a greater range of times to presentation among colorectal participants (see figure 17).

	Lung Participants	Colorectal Participants	All Participants
range	0-1082 days	0-1973 days	0-1973 days
mean	50 days	74 days	64 days
median	16 days	31 days	23 days
mode	0 days	0 days	0 days
standard deviation	136 days	211 days	183 days
inter quartile range	45 days	61 days	58 days

Figure 17: Patient Interval Lengths

### Symptom Disclosure

Data on symptom disclosure was provided by 70 of the 71 lung participants, but only 70 of the 93 colorectal participants.

The majority of participants discussed their symptoms with someone else, with only 17% of lung participants and 21% of colorectal participants not discussing their symptoms with anyone. Lung participants who discussed their symptoms with someone else talked to two people on average (median), and colorectal participants who discussed their symptoms with someone talked to one person on average (median). It was most common for participants to discuss their symptoms with one or two people, although discussion of symptoms with a large number of other people appeared to be more prevalent among lung participants (see figure 18).

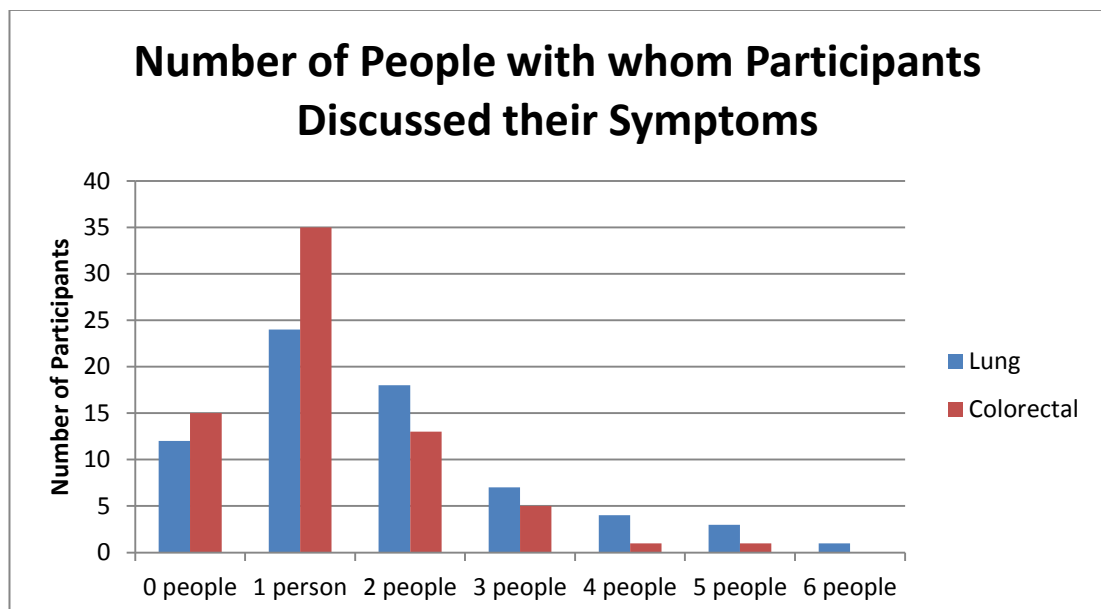


Figure 18: Number of People with Whom Participants Discussed their Symptoms

Lung participants talked to a wide range of people, with twelve different types of individuals identified (see figure 19). Participants most commonly discussed their symptoms with partners, children and friends, but also with other family members and colleagues. Interestingly, lung participants also discussed their symptoms with a range of HCPs, including the urgent care centre, a pharmacist and a GP, before deciding whether or not to consult.

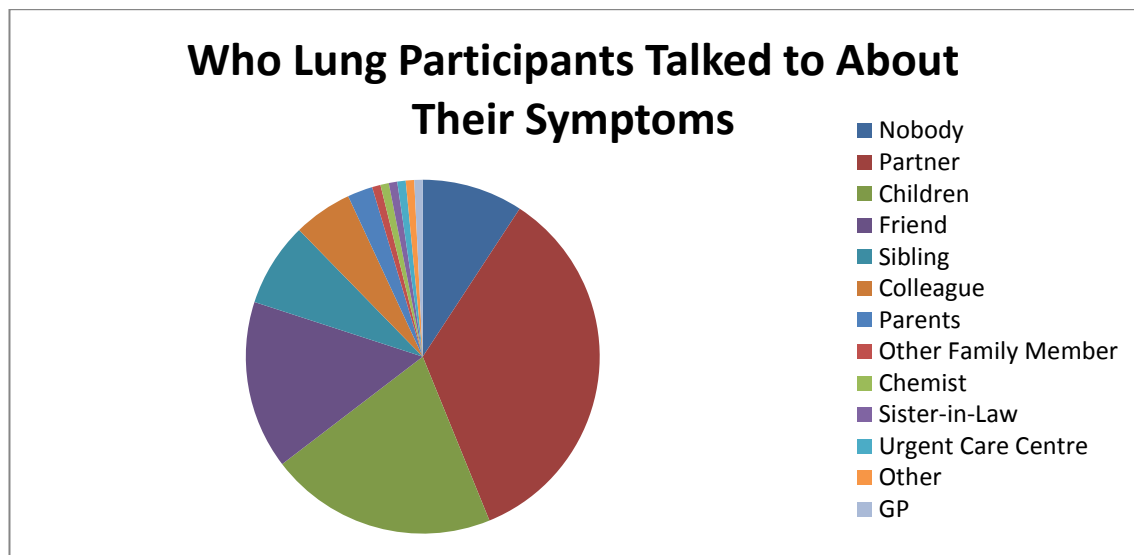


Figure 19: Who Lung Participants Talked to About Their Symptoms

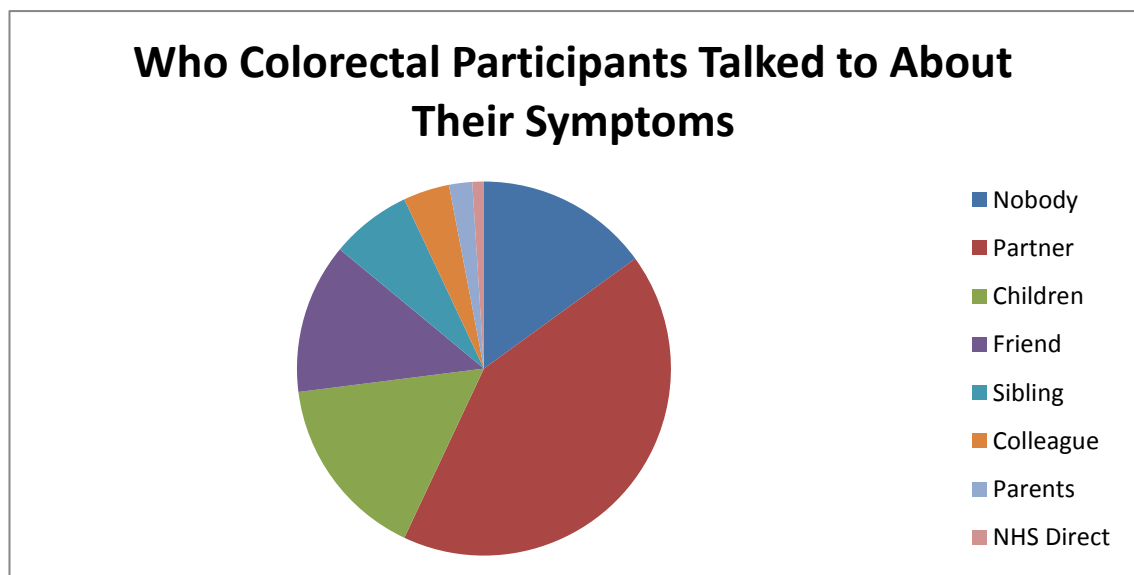


Figure 20: Who Colorectal Participants Talked to About Their Symptoms

Colorectal participants (see figure 20) talked to a smaller range of people than lung participants did, with seven types of individuals identified. As with lung participants, partners, children and friends were the people with whom colorectal participants most commonly discussed their symptoms. Other types of individuals with whom colorectal

participants discussed their symptoms were siblings, parents and colleagues, with one individual talking to a HCP at NHS Direct about their symptoms.

### **4.3 Patient Interval Length and Participant Characteristics**

Two participants were excluded from all analyses of the patient interval (R048 and C081) as the onset of the symptoms reported in the questionnaire was many years ago and was not plausibly related to the symptoms presented to their GP, and which triggered a referral into secondary care.

Mean patient interval length was explored in relation to a number of participant characteristics; sex, age, employment status, educational attainment, deprivation, living alone, symptom site, type of symptom, symptom disclosure and social support. Tests of association were undertaken for time to presentation in relation to type of symptom, symptom disclosure and social support score. These variables were investigated for statistical association because they most directly related to the social context of help-seeking and either the descriptive analysis of this data seemed to imply the possibility of an association (type of symptom, symptom disclosure), or because this was a novel question, rarely addressed in the existing literature (social support score).

For the remaining characteristics (sex, age, employment status, educational attainment, deprivation, living alone and symptom site) other researchers have extensively examined their relationship with time to presentation using much larger data sets. Therefore, I decided that an examination of these characteristics using this dataset would not add anything to the existing body of knowledge because of the small sample size of this study.

#### **The Patient Interval and Sex**

It was not possible to ascertain sex for three colorectal participants but all lung participants were included in this analysis. Female lung participants had greater mean patient intervals (55 days) than male lung participants (43 days). However, among colorectal participants it was men who had greater mean interval lengths (56 days) than women (51 days) (see figure 21).

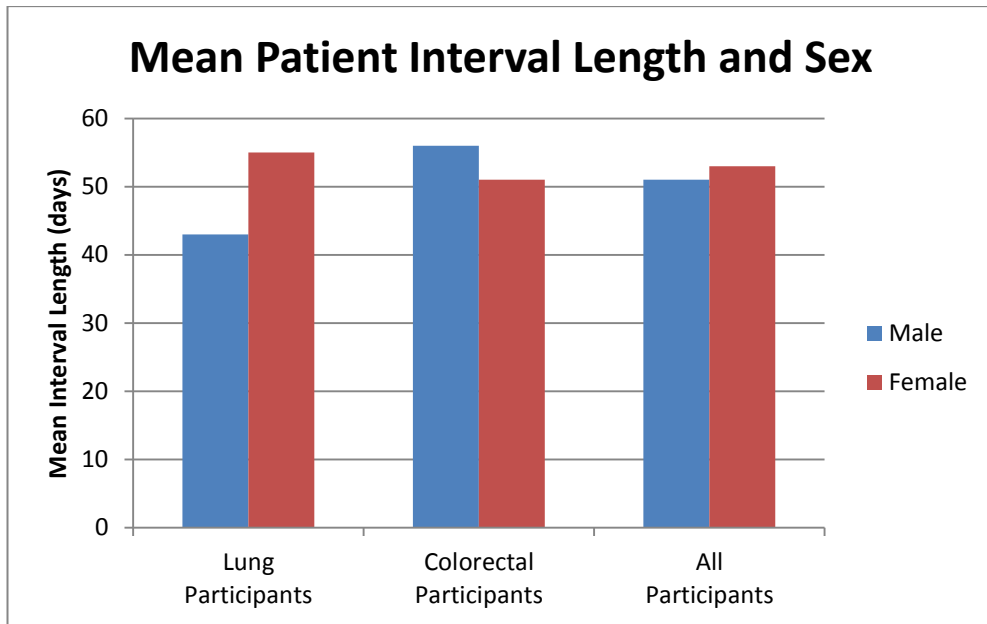


Figure 21: Mean Patient Interval Length and Sex

### The Patient Interval and Age

Three colorectal participants did not provide data on their age but data on participants' age and time to presentation is presented in figure 22 for all other participants.

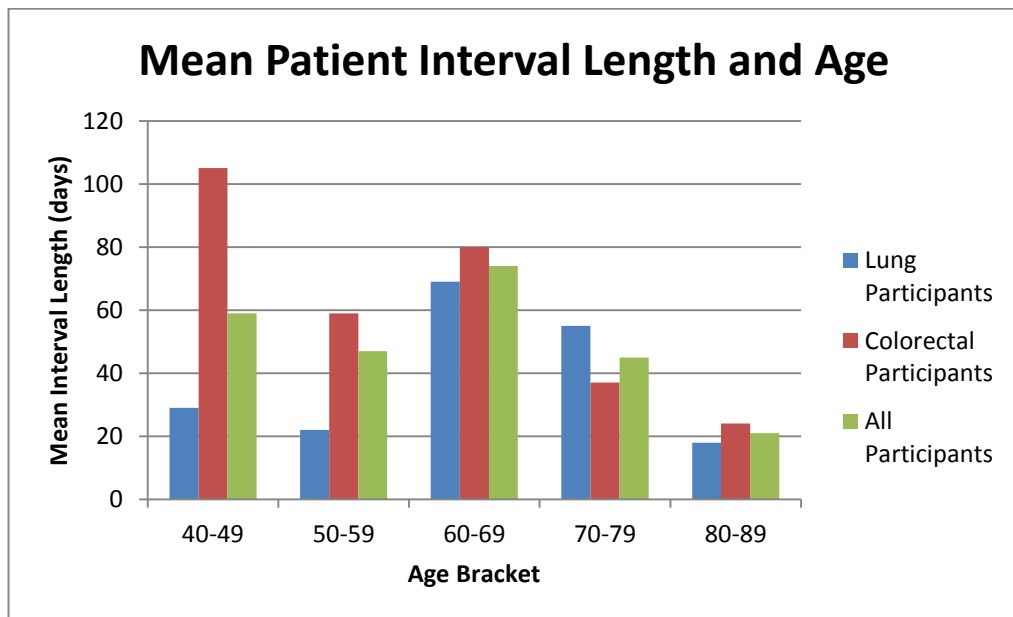


Figure 22: Mean Patient Interval Length and Age

With the exception of colorectal participants aged 40-49, the greatest mean intervals across both cancer sites were amongst participants aged 60-69. There were only four colorectal participants aged 40-49, and it is possible that the data of one participant within this group, whose interval was 245 days, compared to the other three whose intervals were 21, 62 and

92, has skewed this category. If we are to remove that participant, the distribution of mean interval length appears to be more as expected (see figure 23).

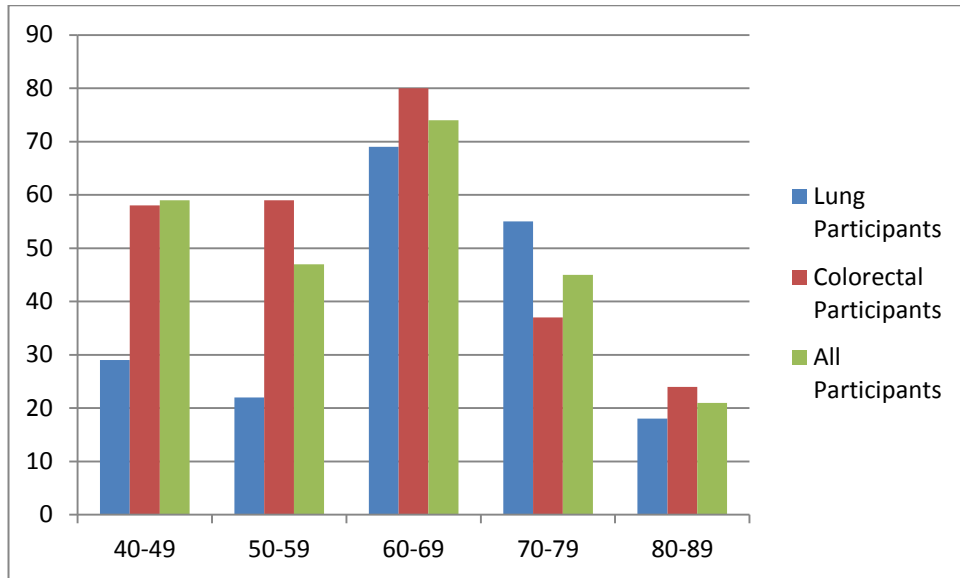


Figure 23: Mean Patient Interval Length and Age (v2)

### The Patient Interval and Employment Status

Data on employment status was available for all colorectal participants and 69 of the 71 lung participants. Mean time to presentation in relation to employment status is presented in figure 24.

	Lung Participants	Colorectal Participants	All Participants
Employed full time	23 days n=13	84 days n=18	58 days n=31
Employed part time	33 days n=2	80 days n=6	68 days n=8
Unemployed	0 days n = 1	75 days n=5	62 days n=6
Retired	60 days n=49	42 days n=61	50 days n=110
Sick/disabled	51 days n=3	18 days n=2	38 days n=5

Figure 24: Mean Patient Interval Length and Employment Status

Among lung participants, those who were unemployed had the shortest mean patient intervals, followed by those who were working full time, with retired participants taking the longest to present. Conversely, among colorectal participants those working full and part time took the longest to present, with sick/disabled participants having the shortest mean patient intervals. The data on mean patient intervals across different employment

categories appears to show no real trends, which is most probably the result of the small number of cases within some categories.

### The Patient Interval and Educational Attainment

Educational attainment information was provided by 65 lung participants and 89 colorectal participants.

	Lung Participants	Colorectal Participants	All Participants
Degree or Equivalent	17 days	46 days	39 days
Diploma or Equivalent	36 days	49 days	44 days
A Level or Equivalent	34 days	38 days	36 days
GCSE or Equivalent	37 days	88 days	62 days
None	103 days	123 days	114 days

Figure 25: Mean Patient Interval Length and Educational Attainment

Those with no qualifications reported notably longer intervals than those with at least GCSE or equivalent qualifications and higher. It appears that the higher the educational attainment, the shorter the mean patient interval, for individual cancer sites and for both sites combined.

### The Patient Interval and Deprivation

Index of multiple deprivation (IMD) quintiles were identified for all lung participants, however, three colorectal participants did not provide their postcodes and so were excluded from this analysis.

	Lung Participants	Colorectal Participants	All Participants
1st Quintile	29 days n=9	55 days n=30	49 days n=39
2nd Quintile	61 days n=15	46 days n=15	53 days n=30
3rd Quintile	16 days n=12	68 days n=24	50 days n=36
4th Quintile	94 days n=18	39 days n=10	74 days n=28
5th Quintile	29 days n=16	48 days n=10	37 days n=26

Figure 26: IMD Score by Cancer Site



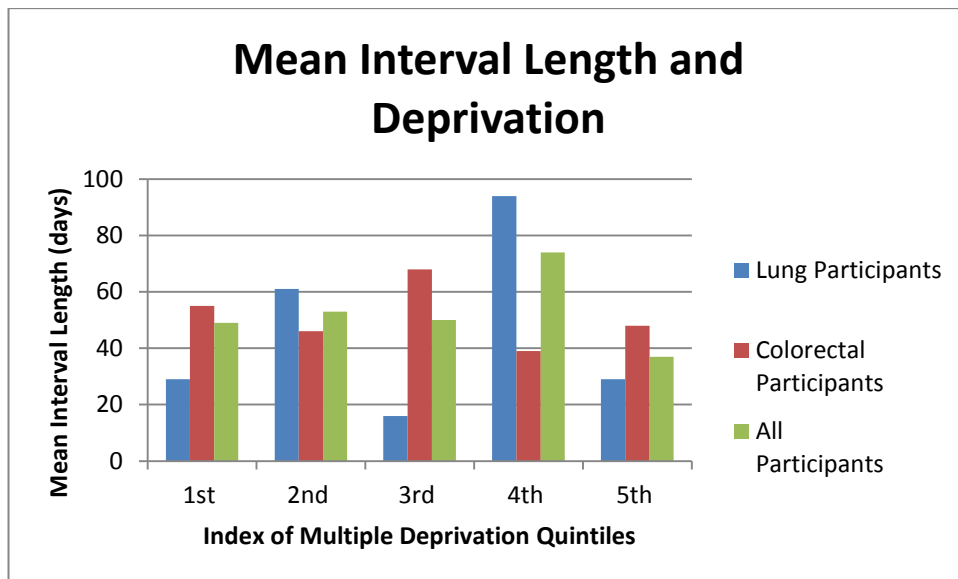


Figure 27: Mean Patient Interval Length and Deprivation

Among lung participants, those in the 4<sup>th</sup> or 2<sup>nd</sup> quintile of deprivation had longer mean patient intervals, whereas those in the 3<sup>rd</sup> quintile had the shortest mean patient intervals. Conversely, for colorectal participants those in the 3<sup>rd</sup> quintile of deprivation had the longest mean patient intervals, while participants in the 4<sup>th</sup> quintile of deprivation had the shortest mean patient intervals. We can see from figures 26 and 27 that there does not appear to be a discernible trend in relation to quintile of deprivation and mean time to presentation, which may be because of the small sample size.

### The Patient Interval and Living Alone

Fourteen lung participants and 25 colorectal participants lived alone, compared to 56 lung and 67 colorectal participants who cohabited.

	Lung Participants	Colorectal Participants	All Participants
Mean Patient Interval for Participants who Live Alone	43 days	67 days	58 days
Mean Patient Interval for Participants who Cohabit	52 days	49 days	50 days

Figure 28: Mean Patient Interval Length and Cohabitation

The data in figure 28 shows that lung participants had shorter mean intervals when living alone, whereas colorectal participants, and all participants combined, had shorter mean intervals when cohabiting.

## The Patient Interval and Symptom Site

Lung participants reported shorter patient intervals than colorectal participants, with lung participants having a mean patient interval of 50 days and colorectal participants a mean patient interval of 54 days (see figure 29).

Patient Interval Length	N	Mean	Std. Deviation	Std. Error Mean
Lung Participants	70	49.94	136.535	16.319
Colorectal Participants	92	53.71	73.605	7.674

Figure 29: Mean Patient Interval Length and Symptom Site

Figure 30 depicts a breakdown of mean patient interval for participants with short, long and medium intervals by symptom site. As was discussed in Chapter Three, a short interval was categorised as less than or equal to 1 week, a medium interval as between 1 week and 2 months, and a long interval as equal to or greater than 2 months.

	Lung Participants	Colorectal Participants	All Participants
short interval	2 days n=28	2 days n=26	2 days n=54
medium interval	29 days n=29	33 days n=42	32 days n=71
long interval	200 days n=13	145 days n=24	165 days n=37

Figure 30: Mean Patient Interval Length, Symptom Site and Interval Category

A greater proportion of colorectal participants (26%) reported a long patient interval than lung participants (19%), whilst a larger proportion of lung participants (40%) reported short patient intervals when compared to colorectal participants (28%).

## The Patient Interval and Symptom Type

From analysis of the interviews, which will be discussed later, acuteness of symptoms seemed to be linked with time to presentation. Amongst those interviewees who presented most quickly it appeared that they experienced much more acute, alarming and severe symptoms, when compared to those who took longer to present. Therefore, it is valuable to consider type of symptom, or symptom severity, in relation to time to presentation.

For the purposes of this analysis symptoms were categorised as either blood, pain, general 'chest' symptoms (cough, breathlessness, shortness of breath, hoarseness, wheezing, loss of voice, 'bronchitis' 'chest infection' or 'cold), general 'bowel' symptoms (diarrhoea, constipation, loose bowel movements, increased frequency or urgency of bowel motions,

flatulence, itching, or bloating), or systemic symptoms (dizziness, decreased appetite, 'feeling unwell', fatigue, weight loss, light-headedness, headaches, high temperature or 'weakness'). When participants reported multiple first symptoms, the more 'alarming' symptoms of blood and pain 'outranked' more general symptoms, which in turn 'outranked' systemic symptoms. Two participants were excluded from this analysis as their first reported symptom did not relate clinically to their referral for investigation; one lung participant reported a urine infection and one colorectal participant reported general symptoms of a chest infection as their first symptoms.

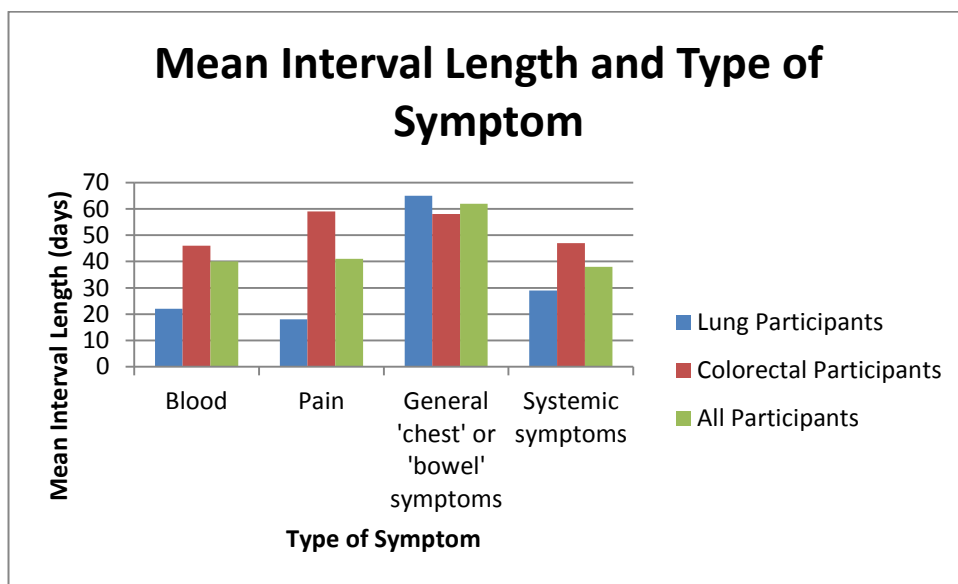


Figure 31: Mean Patient Interval Length and Symptom type

We can see from figure 31 that lung participants who experienced pain or bleeding (i.e. haemoptysis) had shorter mean interval lengths, whereas those with more general respiratory symptoms had longer mean interval lengths, even when compared to systemic symptoms.

Colorectal participants who experienced bleeding (i.e. rectal bleeding) reported the shortest interval lengths, however, pain was associated with the longest mean interval lengths. As with lung participants, people who experienced general bowel symptoms took longer to present than those who experienced more systemic symptoms.

Overall, blood and pain appear to be associated with the shortest mean patient intervals, followed by systemic symptoms and then, finally, the more localised yet general symptoms resulted in the longest mean patient intervals. However, regression analysis (ANOVA), with patient interval length as the dependent variable, showed that these trends were not statistically significant ( $p=0.282$ ).

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	12855.817	1	12855.817	1.164	.282
Residual	1767016.140	160	11043.851		
Total	1779871.957	161			

Figure 32: Regression Analysis of Mean Patient Interval Length and Symptom Type

### The Patient Interval and Symptom Disclosure

One lung participant and 23 colorectal participants did not provide information on symptom disclosure and so have been excluded from this analysis. Twelve lung participants and 15 colorectal participants did not discuss their symptoms with anybody, compared to 57 lung participants and 54 colorectal participants who did discuss their symptoms. Participants who discussed their symptoms had shorter mean patient intervals than patients who did not discuss their symptoms, both in relation to specific symptom sites and across participants generally (see figure 33). A t-test to explore these differences in mean time to presentation found there to be no statistical significance ( $p=0.632$ ) (see figure 34).

	Lung Participants	Colorectal Participants	All Participants
Mean interval length: Participants who <b>did not discuss</b> their symptoms with somebody else	52 days	51 days	51 days
Mean interval length: Participants who <b>did discuss</b> their symptoms with somebody else	49 days	45 days	47 days

Figure 33: Mean Patient Interval Length and Symptom Disclosure

				95% Confidence Interval	
	T	Df	2 tailed sig	Lower	Upper
Equal Variances Assumed	-.170	136	.865	-48.377	40.701

Figure 34: Association between Mean Patient Interval Length and Symptom Disclosure

The distribution of participants across different interval lengths, in relation to symptom disclosure, for lung and colorectal participants combined, is presented in figure 35. Again, for the purposes of a descriptive analysis, a short interval was categorised as less than or equal to 1 week, a medium interval as between 1 week and 2 months, and a long interval as equal to or greater than 2 months.

	Short Interval	Medium Interval	Long Interval
Participants who <b>did not discuss</b> their symptoms with somebody else	n=7 (26%)	n=12 (44%)	n=8 (30%)
Participants who <b>did discuss</b> their symptoms with somebody else	n=42 (38%)	n=48 (43%)	n=21 (19%)

Figure 35: Symptom Disclosure across Interval Category

It appears that among participants who discussed their symptom(s) with somebody else, a greater proportion had short patient intervals and a much smaller proportion had a long patient interval, when compared to participants who did not discuss their symptoms with anybody else.

### The Patient Interval and Social Support Score

Participant reported social support score was calculated for each respondent, using the four subscales of the social support questionnaire; ‘partner support’, ‘partner avoidance’, ‘other support’, and ‘other avoidance’. A large number of participants did not complete the question on social support, 20 lung participants (28%) and 48 colorectal participants (52%) in total. Of the remaining participants, a number were excluded because of incomplete data, whereby 3 or fewer points on the subscale had been answered, as per Pedersen et al’s (2011) approach. The table below (figure 36) shows completeness of data by symptom site and subscale, incorporating those who never answered the question at all, and those whose data was incomplete.

	‘Partner Support’	‘Partner Avoidance’	‘Other Support’	‘Other Avoidance’
Lung	n=45 (63%)	n=43 (61%)	n=51 (72%)	n=44 (62%)
Colorectal	n=43 (46%)	n=40 (43%)	n=40 (43%)	n=37 (40%)

Figure 36: Completeness of data for Social Support Scores

Therefore, the number of cases within the following analyses is small, and so this must be considered in relation to the findings of these tests.

### The Patient Interval and ‘Partner Support’

Figure 37 illustrates the mean patient interval length in relation to ‘partner support’. We would expect to see an inverse relationship between ‘partner support’ and interval length, based on the hypothesis that the greater the levels of social support from one’s partner, the sooner someone is likely to present. However, the data appears to show no discernible

patterns and regression analysis also showed there to be no significant relationship between time to presentation and 'partner support' ( $p=0.274$ ) (see figure 38).

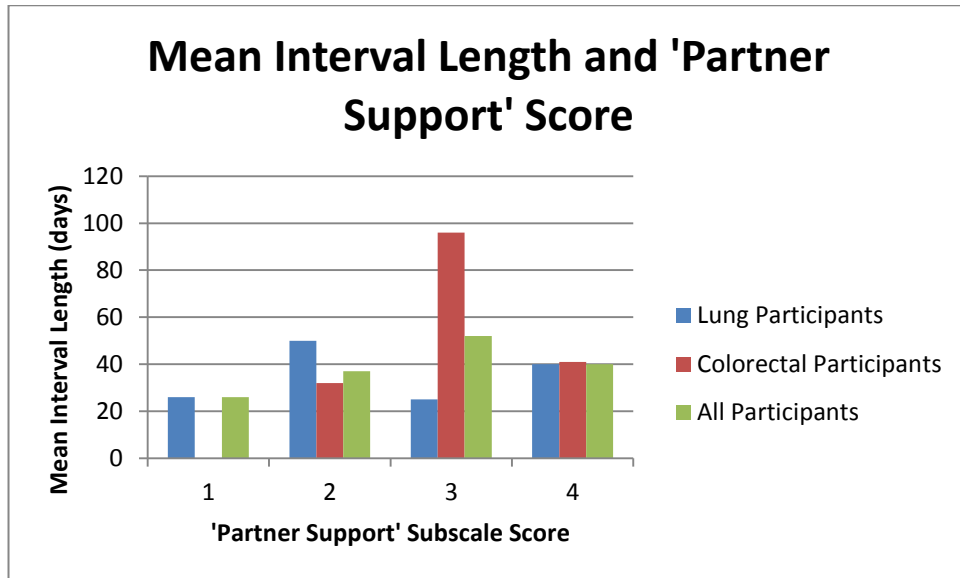


Figure 37: Mean Patient Interval Length and 'Partner Support' Score

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	13314.321	1	13314.321	1.206	.274
Residual	1766557.636	160	11040.985		
Total	1779871.957	161			

Figure 38: Regression Analysis of Mean Patient Interval Length and 'Partner Support'

### *The Patient Interval and 'Partner Avoidance'*

Conversely, we would expect that as 'partner avoidance' increased, so would mean interval length, however, we can see from figure 39 that again there appear to be no clear trends. Regression analysis, using mean patient interval length as the dependent variable, also found the relationship between interval length and 'partner avoidance' not to be significant ( $p=0.104$ ) (see figure 40).

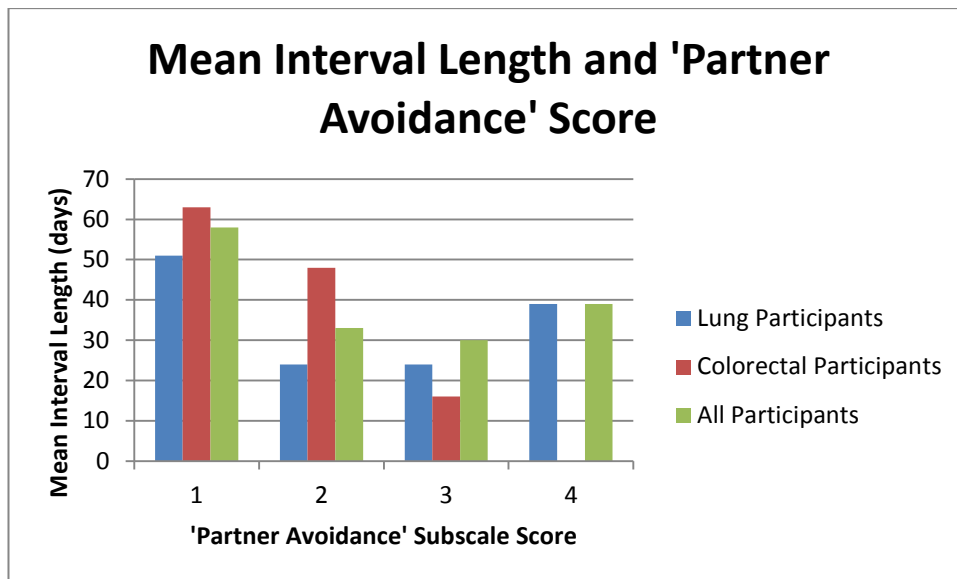


Figure 39: Mean Patient Interval Length and 'Partner Avoidance' Score

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	29320.636	1	29320.636	2.680	.104
Residual	1750551.321	160	10940.946		
Total	1779871.957	161			

Figure 40: Regression Analysis of Mean Patient Interval Length and 'Partner Avoidance'

### *The Patient Interval and 'Other Support'*

As with 'partner support', we would expect to see shorter mean intervals as 'other support' increased and we can see from figure 41 that this was true for colorectal participants, for whom mean interval length decreased with increasing social support. For lung participants we see the opposite trend, with interval length increasing with increasing 'other support'. Overall there appears to be a trend for shorter patient intervals with increasing level of 'other support' and regression analysis of patient interval length and 'other support' showed this to be a statistically significant relationship ( $p=0.020$ ) (see figure 42).

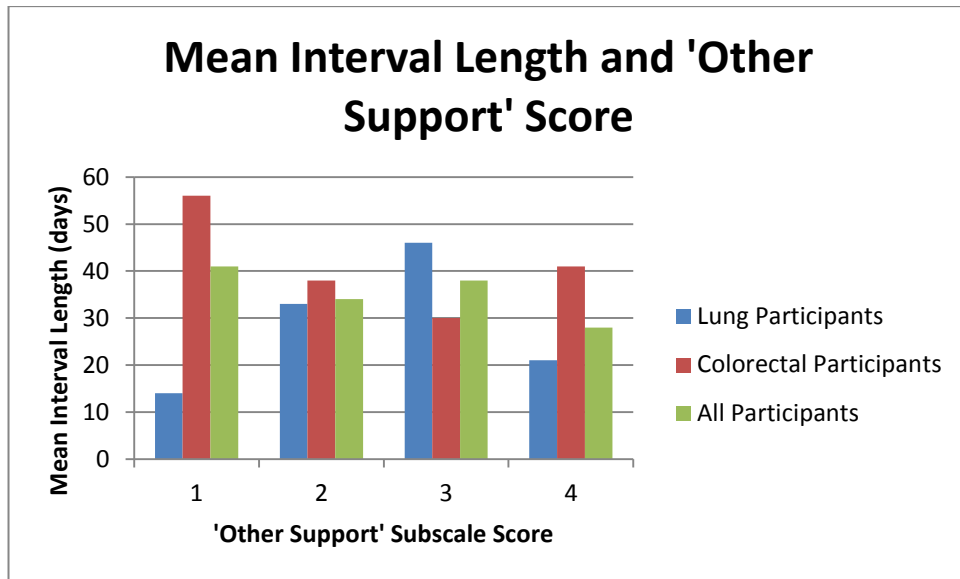


Figure 41: Mean Patient Interval Length and 'Other Support' Score

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	59319.235	1	59319.235	5.516	.020
Residual	1720552.721	160	10753.455		
Total	1779871.957	161			

Figure 42: Regression Analysis of Mean Patient Interval Length and 'Other Support'

### *The Patient Interval and 'Other Avoidance'*

Figure 43 illustrates mean intervals lengths in relation to 'other avoidance'. We would expect to see a positive relationship, with mean interval length increasing with increasing 'other avoidance' score. Overall, participants who reported the lowest levels of avoidance by others had the greatest mean patient intervals. However, at avoidance scores of 2 and greater there does appear to be a trend for greater intervals to be associated with greater scores of others' avoidance. Regression analysis of time to presentation and 'other avoidance' did not find a significant relationship ( $p=0.278$ ) (see figure 44).



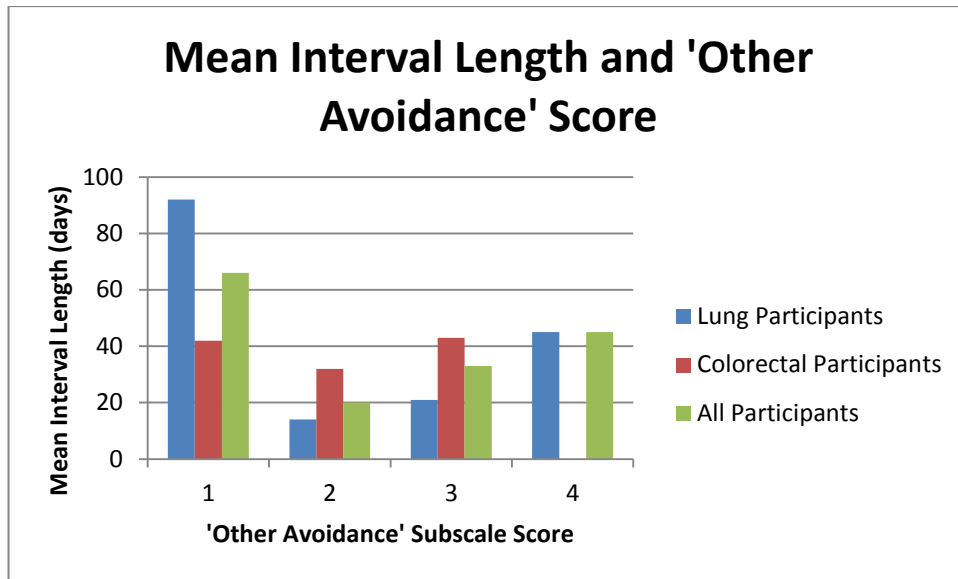


Figure 43: Mean Patient Interval Length and 'Other Avoidance' Score

Model	Sum of Squares	df	Mean Square	F	Sig.
Regression	13100.227	1	13100.227	1.186	.278
Residual	1766771.729	160	11042.323		
Total	1779871.957	161			

Figure 44: Regression Analysis of Mean Patient Interval Length and 'Other Avoidance'

#### 4.4 Discussion of Results

These data show that colorectal participants had longer mean patient intervals than lung participants, which concurs with the work of Lyratzopoulos et al (2015) on patient intervals. This may be because people tolerate and consider bowel symptoms for longer than they would respiratory symptoms.

There did not appear to be any association between time to presentation and age, employment status, or deprivation within this sample. This finding is in line with other research which also found no association between these characteristics and time to presentation (Macleod et al. 2009). There was little evidence of an association between the length of the patient interval and sex, which also concurs with previous research (Macleod et al. 2009).

Participants with no educational qualifications had longer mean patient intervals, compared to those educated to GCSE level or above. An association between education and time to presentation has previously been shown for colorectal cancer patients (Macleod et al. 2009) and the same appears to be true for lung participants in this sample also.

Cohabitation was associated with shorter patient intervals for colorectal participants and all participants combined. Lung participants who lived alone actually had shorter mean patient intervals than lung participants who cohabited. The finding for colorectal, and 'all', participants would fit with the hypothesis that co-habiting increases social contact and support, leading to shorter patient intervals. However, the lung data contradicts both this hypothesis, and other research which has shown that living alone is strongly associated with patient delay for lung cancer patients (Smith et al. 2009).

The type of symptom people experience could be associated with time to presentation. Bleeding was associated with short patient intervals for both colorectal and lung participants in this study, however, other studies have found rectal bleeding and unexplained bleeding to be associated with longer help-seeking intervals (Pedersen et al. 2013), and lower levels of help-seeking (Whitaker et al. 2016), respectively. Pain was only associated with shorter intervals for lung participants and it may be that people respond differently to experiences of pain in the chest or back (lung participants) than they do to experiences of pain in the abdomen or rectum (colorectal participants). It may be that pain in the stomach and rectum is more normalised, because pain in these areas is a more common occurrence, whereas pain in the chest and back is of greater alarm for individuals as it is more unusual or 'out of the blue' for most people. An examination of symptom type and diagnostic intervals for lung cancer found that chest or shoulder pain was associated with a shorter total diagnostic interval, however, this work does not differentiate between the length of the patient interval in relation to the two locations of pain (Walter et al. 2015). Across all participants, 'systemic' symptoms were associated with shorter intervals than symptom site specific 'general' symptoms, which is an interesting finding.

Although my results are not statistically significant, the trend for shorter patient intervals amongst those who discussed their symptoms concurs with other studies which have found that symptom disclosure is associated with shorter patient intervals (Burgess et al. 1998; Pedersen et al. 2011). Among participants who discussed their symptom(s) with somebody else, a greater proportion had short patient intervals and a much smaller proportion had a long patient interval, when compared to participants who did not discuss their symptoms with anybody else. This correlates with the findings of Pedersen et al (2011), from their work on social support and time to presentation, who found that disclosure of symptoms significantly reduced the likelihood of women having 'long patient delay' (Pedersen et al. 2011).

No associations between the length of the patient interval and 'partner support', 'partner avoidance' or 'other avoidance' were found in this sample. However, there was a significant relationship between the length of the patient interval and 'other support.' Pedersen et al (2011), in their analysis of data using these subscales, found that increasing levels of partner and other support significantly reduced the likelihood of having 'long patient delay', whereas increasing levels of other avoidance significantly increased the risk of having 'long patient delay' among females. Although data from this study has not shown there to be a significant relationship between 'partner support' and time to presentation, there was a statistically significant relationship between 'other support' and time to presentation.

Interestingly Pedersen et al (2011) found that for women the length of the patient interval was influenced by the levels of support from both partners and others, whereas for men, being in a relationship and partner support were the most important factors for reducing time to presentation. Therefore, we would have expected it to be more likely that we would see an association with 'partner support' and time to presentation than we would see an association between 'other support' and time to presentation. It may be that for participants within this sample the support of wider social networks was most influential on their time to presentation. Because of the small sample size for this data, it would not be viable to explore time to presentation, social support and sex together, as the numbers of participants within categories would be very small, with a number of categories containing no data.

The lack of statistical significance found in some analyses, and unexpected findings in others, is very probably the result of the small sample size of this study, particularly in analyses of social support score. If there were more participants, trends in the data would likely be clearer and any anomalous, or outlying, results would have less of an impact on the dataset overall. The results from this questionnaire analysis do provide some interesting departure points from which it would be of value to examine a larger sample, particularly the association between social support, symptom disclosure and symptom type on time to presentation.

#### **4.5 Summary**

The quantitative findings presented in this chapter have thrown up a number of interesting observations, particularly the fact that colorectal participants had longer patient intervals than lung participants and that blood and pain were associated with shorter patient intervals than general, or systemic, symptoms.

Qualitative research is often used to help explain the bare bones of quantitative data and it is to the qualitative aspects of this research that we will turn in the next two chapters. The second of these (Chapter Six) looks at patient's narratives in their entirety: the first (Chapter Five) analyses the results of the interviews with a view to identifying certain patterns across and between the groups.

## **Chapter Five: Interview Findings**

The findings from the qualitative interviews are broken down into three sections. The first section explores patient pathways to consultation, looking at experiences of symptom onset, appraisal and help-seeking decisions. The wider contextual factors which influenced how participants appraised and responded to their symptoms are then considered, focusing on four key areas; individual experience, interpersonal relationships, health care system interactions and social and temporal context. Finally, I compare the help-seeking journeys of patients who presented quickly, those who took slightly longer to present, and those who reported prolonged patient intervals, in order to consider factors salient to each of these groups of people.

### **5.1 The Help-Seeking Journey**

Journeys to the doctor are unique, multi-faceted and rarely linear. Despite the differences in individual journeys to presentation, there are three main processes which all individuals go through: symptom onset/experience, symptom appraisal, and help-seeking. This chapter will explore the help-seeking journeys of the interview participants through the lens of these processes.

Although this chapter is structured in a way that presents symptom onset, appraisal and help-seeking as sequential, this is merely a writing construct as, in reality, people move backwards and forwards between processes and repeatedly revisit and revise their thoughts throughout the help-seeking journey. This chapter will demonstrate that although there are elements of help-seeking which are integral to all help-seeking journeys, the realities of people's appraisal and decision making experiences are often messy and complex.

#### **Symptom Onset and Symptom Experience**

The first bodily experience which goes on to be conceived of as a symptom is the natural departure point for people's help-seeking journeys and is also where this discussion will start. Interestingly, first symptomatic experience is rarely the departure point for an individual's narrative, with people tending to start their stories with the 'conclusion' to their journey, by describing their investigations, diagnosis and treatment, instead visiting and revisiting their first symptomatic experience throughout the course of their narrative.

#### **Nature of Symptoms**

When people talked about how their symptoms first began, and what was noticeably different about their bodily state, there was a range of experiences both across, and within, the lung and colorectal interviews. Symptoms ranged from the systemic and vague, to the

acute and severe. Even amongst those who reported the same initial symptom, symptoms often manifested, and were described, in different ways.

For some people their symptomatic experience started with relatively vague symptoms, which were not easy to categorise:

*I basically felt unwell for about three or four days...a bit lethargic, I didn't have a lot of energy. It's like I got up one morning and somebody had pulled the plug. I found it difficult to just get up and do things that I'd normally do...it was like everything was in slow motion and I just couldn't get out of first gear.*

**(Christine: fatigue then rectal bleeding, NAD)**

For other people, their initial experience was a change to their normal bodily functioning, however, this was not something which they believed to be of any significance:

*Well, I just like developed this cough, you know. And I never thought nothing about it, you know, it was just like a cough.*

**(John: cough & breathlessness, NAD)**

Symptoms which presented unexpectedly and acutely were common and included urgency of bowel movements, pain, or the presentation of blood. Arthur's first symptomatic experience was of diarrhoea, which presented itself with an intense urgency:

*It started off with, sat at the table in August having my evening meal, and rushed off upstairs, and I didn't even make it to the bathroom, and that was the first indication that there was something wrong.*

**(Arthur: very loose bowel movements, diverticulosis)**

It seems that for Arthur, not only was the diarrhoea itself of concern, but the urgency with which it presented was also alarming. The fact that it caused him to soil himself was a specific alert to him that something was 'not right' in his body.

Pain was another symptom which manifested acutely and therefore was an immediate signal to people that something was 'not right':

*There was a pain...I'd come in from work half past nine, I was sat where you are, looking at my post and this pain just come on right through my back and through my body and out the front. Oh it was killing us.*

**(Melanie: pain in right side of body & back, small cell lung cancer)**

However, an absence of pain was something which was noted by some individuals and this absent symptom was used in the appraisal of the presenting symptoms. As pain was

associated with symptom severity, the absence of pain acted as a reassurance for some, causing them to be less concerned about their symptoms:

*Even though it's loose (bowel movements) I think 'well, I'm in no pain, it's not bothering me, just a nuisance, that's all'.*

**(Roy: persistent diarrhoea, spirochetosis)**

'Bleeding' was another symptom which appeared in an acute and alarming manner:

*What first concerned me was I had blood on the toilet paper when I passed a motion.*

**(Angela: rectal bleeding, haemorrhoids)**

*I went to the toilet and there was blood, red blood on the toilet paper.*

**(Jack: rectal bleeding, diverticulosis)**

Blood was a symptom which acted as a very clear signal to people that something was 'not right'.

### **Changing Symptoms**

For many participants symptoms were not static, but instead changed, and often escalated, over time. The change may have been the addition of a new symptom:

*I retired in January, sold the business, retired. I thought 'right, enjoy my life now' and this coughing and coughing. Then the breathing started when I retired...I only had to go into town and I was out of breath and that wasn't me.*

**(Pauline: cough & breathlessness, COPD)**

a change in the nature of the symptoms:

*And then it was November time or October I started, I thought 'ey up' and it [the blood] was getting a darker colour...It was a light blood colour as I call it. But the October was a deeper red, and I thought 'oh'.*

**(Joseph: coughing up blood, NAD)**

or a change in the frequency of the symptoms:

*It wasn't as much the last few years, it was specks here and there and I thought 'oh, I'll be alright, it's been a sore throat or a cold', which would accompany the symptoms. But the last year or so it got a bit more noticeable, marked and I was like 'oooh God I don't like the look of this' and then in the last Autumn and Winter onwards I noticed it was more regular.*

**(Abdul: coughing up blood, inflammation of the lungs)**

New and evolved symptoms generally manifested later in the patient interval, whilst an individual was in the appraisal phase. The changed and new symptoms catapulted the

individual back into a symptom experience phase before having to re-enter and re-negotiate appraisal.

### **Symptom Appraisal**

The symptom appraisal period is the longest and most complex process within peoples' help-seeking journeys. It includes the initial, and subsequent, responses to symptoms and encompasses emotional and practical responses to embodied experiences.

### **Feelings about Symptoms**

Most participants were able to articulate how they felt about their symptoms. Some participants were not particularly concerned about their symptoms, viewing them as insignificant or bothersome:

*It wasn't bothering me at all, just a nuisance more than anything.*

**(Roy: persistent diarrhoea, spirochetosis)**

*I had this cough which I tend to think nothing of, of course if you've got anything very insignificant.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

However, others showed notable concern and anxiety about their symptoms, a response which was particularly prevalent among people who experienced bleeding:

*I looked in the [toilet] bowl and the bowl was completely red, so that kind of threw me a bit.*

**(Steve: rectal bleeding, NAD)**

*The colour of the blood, and I'm thinking 'hmmm, that doesn't look right'. Because about a year and a half before the wife had a vein go in her [neck], and that was horrendous. And I thought, panicking, I thought 'oh Christ, the same' and that's what panicked me.*

**(Joseph: coughing up blood, NAD)**

Just as people's symptoms changed, their feelings and thoughts about their symptoms also changed:

*To begin with I wasn't bothered at all, I just thought it was a bug you know, and a couple of weeks or so and it'll go. And I think because I didn't feel ill, that I didn't really worry too much about it. It was only when it went on and on and on and it did get to the point where 'well this is ridiculous' and it's stopping me doing what I want to do.*

**(Elaine: loose bowel movements, diverticulosis)**



### *Responding to Symptoms*

There were a variety of responses to the onset of symptoms, ranging from proactive, practical actions, to attempts to ignore the symptoms. The practical responses to symptom onset included self-medication, researching symptoms and monitoring diet.

Some people chose to self-medicate, either by purchasing over-the-counter medication specifically for the purpose of treating their symptoms:

*I took cough medicine, I tried that but that was just a waste of money...I tried throat tablets, Throaties or whatever they call them to try and, but nothing stopped it.*  
**(Pauline: cough & breathlessness, COPD)**

using tailored complementary medicine:

*My daughter [who is a herbalist] always sends me a tincture. I've got a bottle...it's very good, but it's mainly Echinacea and all the other bits and pieces that she puts in, devil's claw.*

**(Tom: wheezing & breathlessness, chronic bronchitis)**

or taking someone else's prescription medication which was used to treat similar symptoms to the ones that they were experiencing:

[Roy] *I tried the odd tablet. My wife had a major operation about 12 years ago on her bowel, part of her bowel took away.*

[Roy's Wife] *Had part of my colon took away, so I've had diverticulitis and I'm loose all the time, but they give me a tablet that I can take to thicken it up if needed.*

[Roy] *So a few weeks ago*

[Roy's Wife] *Tried that.*

[Roy] *I started and it helped in the sense that you weren't going maybe on the Wednesday, then the Thursday you would start to go again. So it helped in the sense that you weren't going every day if you like.*

**(Roy: persistent diarrhoea, spirochetosis)**

For a small number of people, one of their first responses was to try to find out more information about their symptoms in order to try to understand them, and their possible cause, more fully:

*I thought 'well is it all that, is it irritable bowel?' I've even got, you know, I know what irritable bowel syndrome is and I know people who suffer from it, but got on the net, looked at irritable bowel, unbeknown to my family or anybody, basically I've looked at things.*

**(Mark: change in bowel habit, rectal carcinoma)**

*I've looked it up on the internet, and it started off with cancer and what have you, and it had bronchio-something and I thought 'I wonder if it could be that'.*

**(Pamela: blood in phlegm, bronchiectasis)**

Participants experiencing bowel symptoms often monitored and adapted their diet in an attempt to manage their symptoms, as over-indulgence during the festive period for example, was something a number of participants thought may be to blame for the change in bowel habit:

*I used to take vitamin C tablet and cod liver oil capsule each morning. I've stopped that 'cause I thought the cod liver oil may be lubricating the whole system and making it easier but since stopping that it hasn't made any difference.*

**(Arthur: very loose bowel movements, diverticulosis)**

*I thought 'well over Christmas and New year I might have been over indulgent, eaten things that I don't normally eat and stuffing myself so I gave the, a wait, but the symptoms didn't improve.*

**(Fred: change in bowel habit, NAD)**

Other people took a less proactive response to their symptoms, engaging in a period of monitoring. This monitoring was often based on a belief that if the symptoms were 'nothing' they would 'clear up' and sometimes was accompanied by a timeframe within which the individual expected their symptoms to improve:

*I thought 'well, I'll see what it's like tomorrow and if it's still happening, well then I'll phone the doctors'. So the next morning it still happened, about three times.*

**(Audrey: coughing up blood, infection)**

For some people, their response to their symptoms was to try to tolerate them. People did this by making small adjustments, or shifting their expectations of themselves and their bodies:

*I was taking like spare undies, I was taking pantyliners, like more pantyliners. Normally I would have a spare one with me, but having a fair number with me. And even, I mean they were just permanently in a carrier bag in the bottom of my big handbag so that wherever I went, whether I was at work or not, I had them with me as a bit of a back up. But when you get to the stage where you're stripping off in the toilet at work and rinsing them out in the sink and drying them with the hand dryer, 'cause you don't know what. The thing is, if you have an accident, it doesn't stop stuff getting marks, or I couldn't just put them in me carrier bag stinking.*

**(Elaine: loose bowel movements, diverticulosis)**

*It [the cough] was something that was there that I was just taking for granted.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

There were also those who tried to ignore their symptoms, and tried to 'sweep it under the mat' (**Abdul**: coughing up blood, inflammation of the lungs) either because of the responsibilities in their lives at that time, or because the symptoms didn't cause them any degree of concern. Other people did not pay much attention to their symptoms and initially dismissed them as of no real significance:

*I thought nothing about it at the time, or I didn't give it a great deal of thought, and that happened once or twice in the morning, then the feeling went off and it was just like sort of normal.* (**Mark**: change in bowel habit, rectal carcinoma)

Although the reactions of those who chose to wilfully ignore their symptoms and those who dismissed them appear similar, in that they are choosing not to respond to their symptoms, these groups of people are actually very different in their approach. Those who 'swept it under the mat' did feel that there may be something to be concerned about, but chose to not address it, whereas those who dismissed their symptoms did so because they felt that there was nothing which needed to be addressed.

### *Considering a Cause*

Both during and after people's initial responses to their symptoms they began to consider possible explanations for them. For many, this explanation seeking was the catalyst for their response as they attempted to narrow down the possible causes of their symptoms, i.e. monitoring diet and researching symptoms. Or, their initial response may have been based upon a potential explanation which they already had in mind, i.e. self-medicating or imposing time limits.

People generally considered potential causes for their symptoms very shortly after symptom onset. By seeking an explanation for the bodily anomaly which they were experiencing, people tried to rationalise their symptoms and find logical and plausible explanations which fitted within their lived experiences. People sought explanations for their symptoms from different realms of their lives, including previous symptomatic experiences, lifestyle, work history and the health of others.

People tended to initially seek unthreatening or 'everyday' explanations for their symptoms, which helped them to normalise their experiences. By ascribing an 'everyday' explanation to their symptoms, people reassured themselves that there was nothing to be concerned about:

*My wife came home and said 'Oh, that dog we had in on Monday had campylobacter', I said 'really', she said 'I wonder if that's what's wrong with you?'.* (**Arthur**: very loose bowel movements, diverticulosis)

*I think I must have been coughing that much that I've probably burst a little vessel or something. (Abdul: coughing up blood, inflammation of the lungs)*

People's explanations for their symptoms tended to change with time, as their symptoms remained, changed, or did not respond in the way that they initially expected them to. People tended to start with smaller, less concerning explanations for their symptoms and then progress to increasingly serious explanations, when their previous hypothesis no longer held:

*My initial thought was that it was a bug, so, I mean I did, after when it started to continue, I did wonder whether it was any of the medication I was taking that might've caused it. But then I thought, 'well really, I've been on thyroxin for twenty odd, thirty years, the fluoxetine I only got given by the doctor when I went to see him with depression in the September, so could it be that that was causing it?' But I couldn't really, I couldn't really pin it down. I kept a food diary for a while and I couldn't pin it down to anything specific. I did stop eating oranges 'cause I used to eat about 6 satsumas a day and I've stopped eating them completely and I did think maybe that was it 'cause it did seem to ease up but then I have the odd bouts and I'm not eating oranges so I think 'oh blow it, it obviously isn't'. (Elaine: loose bowel movements, diverticulosis)*

Cancer was often one of the final hypotheses that people held prior to consultation, and was generally a prompt to consultation:

*At first I thought 'oh God, what is it?' and then when you think about it you actually think 'well it's probably nothing but it needs to be checked out.' But then your mind starts working overtime and you think 'what if it's the worst case scenario and not just haemorrhoids or polyps or whatever?' You know. So that's what made me go. (Steve: rectal bleeding, NAD)*

*It was in my mind 'I wonder if there was a major problem.' And I thought, 'well, if there is, the sooner I get there', that day came. When before that I didn't think it was [cancer], I just wondered. I thought I'd eaten something, but then that day came and I thought 'well, I've got to do something, I've got to see somebody that would do something if there was something that could be done, if there was a problem, a major problem'. (Harry: loose bowel movements, microscopic colitis)*

Although people tended to consider cancer as a viable explanation for their symptoms as they neared a help-seeking decision, it was rarely the first time someone had ever considered cancer as a possibility. In fact, throughout the symptom appraisal process many people considered cancer as a possible explanation for their symptoms, however, went on to quickly dismiss this possibility.

The dismissal of cancer as an explanation for symptoms was mainly because people's experiences did not fit with their concepts of how cancer manifests. These conceptions of the manifestation of cancer focused on bodily experiences which included 'feeling ill' and losing weight:

*It wasn't bothering me in a sense because I knew, if it had gone on that long and it was cancer I would've lost weight and my appetite would have gone, I'd have felt different in myself. But I didn't, I just still felt as normal.*

**(Roy: persistent diarrhoea, spirochetosis)**

*I don't feel ill, I'm not losing weight, I can't see that it's anything too bad.*

**(Elaine: loose bowel movements, diverticulosis)**

However, some participants talked about a wilful choice to try to dismiss cancer as a possibility and think up other, more 'plausible' explanations:

*I think maybe when the blood periodically started to appear, maybe late January, February, and there wasn't a great deal, and I thought 'well, I'm bound to have a bit, I'm going to the toilet so many times now, it's bound to be a bit irritable down there, isn't it? But you want to think of anything but the obvious aren't you really, and so I like semi closed that door thinking 'well, if I'm going to the toilet, it may well be just because I'm wiping my bum more regularly, you know and all the rest of it, and there might be some irritation down there. You're looking for reasons and rationales as to why that might be there, but you're looking to reasons and rationales just to sort of, as a defence mechanism to say that 'no, there can't be sinister.*

**(Mark: change in bowel habit, rectal carcinoma)**

This concept of someone rejecting cancer as a possible explanation for their symptoms because their experiences do not fit with their expectations of cancer is something which will be discussed further in subsequent chapters.

Although what has been described here is a process in which people move from less severe to more severe explanations for their symptoms, this does not mean that people do not consider the more serious explanations at earlier points in their appraisal periods. What appears to happen is frequent re-appraisal, in which a multitude of explanations are considered and a 'best-fit' explanation is selected as a working hypothesis at that time. As the individual's experience changes and evolves the hypothesis may no longer hold and so is rejected. During symptom reappraisal the remaining pool of explanations, along with new ones, are revisited and another hypothesis is selected, which best explains their situation at that point. This process continues until the individual decides on the need to consult, at which point they may be on their fourth, fifth, or further revision of their working hypothesis or explanation. This complex appraisal period takes place in light of changing

embodied experiences and circumstances. However, it does not occur in isolation, but is influenced by a range of wider contextual factors and influences, which will be discussed later in this chapter.

The number of explanations considered also related to the length of the symptom appraisal process. Those who had longer appraisal periods considered more potential explanations and those who had shorter appraisal periods tended to consider fewer. This also relates to the length of the patient interval overall and at the end of this chapter the help-seeking journeys of those who took a short, medium and long time to present, are compared, drawing together a range of factors which appear to be at play in relation to their time to presentation.

### **Help-Seeking**

The final process in the patient interval is the help-seeking phase, the period between an individual deciding to consult about their symptoms and making and attending the appointment with a HCP.

### ***Coming to a decision***

The beginning of the help-seeking period is marked by the point at which the individual makes the decision to consult a HCP about their symptoms. The decision to consult was prompted by a need for answers, an urge to seek treatment, or a desire to regain control over one's body.

Some immediately thought of their symptoms as serious and something which needed to be consulted about:

*As soon as I started the bleeding that's when I thought 'I need to see somebody'.  
(Christine: fatigue then rectal bleeding, NAD)*

whilst others had expectations of how long their symptoms should remain to be classified as serious:

*cause it happened on the Friday night and it kept happening over the weekend  
and on the Monday I decided to ring the doctors...I think if it had stopped I  
wouldn't have done. (Steve: rectal bleeding, NAD)*

Some people decided on the need to consult when they felt unable to adequately explain what was happening to their bodies:

*Well I can't tolerate it anymore because I had no idea what was causing it,  
whether it was some horrible thing developing in my gut...you need to find out  
what's going wrong. (Arthur: very loose bowel movements, diverticulosis)*

*I thought 'I need to get to the bottom of this. This I've never had before.'  
...Because, I thought like, 'if it is [cancer] I need to know'.*

**(Julie: stomach pains and diarrhoea, NAD)**

People often talked about reaching a point where they simply 'needed to know' and this was the biggest motivator for consultation. This need to know relates to how people appraise their symptoms, moving backwards and forwards between possible explanations until their inability to produce a viable explanation causes them to seek assistance from someone who can explain their symptomatic experience.

'Needing to know' was frequently a need to know whether symptoms were the result of a cancer. For these participants, consulting provided the opportunity to rule out cancer as a possibility and therefore alleviate that concern:

*Obviously with the [previous] prostate cancer, I don't understand how or where it can spread to, but that was at the back of my mind and that's what influenced me to go to the doctor.*

**(Fred: change in bowel habit, NAD)**

*Well the reason they want you to go and check it out is because they want to check it out to make sure it isn't [cancer], you know. You're doing it with elimination. So that's what moves you to the GP isn't it, from just dealing with it yourself to going to the GP is 'this could be more serious, I have to go and get this checked out'.*

**(Eleanor: rectal bleeding, diverticulosis)**

For others the decision to consult was based on a possible diagnosis which they had in mind. Consulting, and engaging with the health care system, was a means of pursuing the validity of their ideas of causation, by being investigated for a definitive answer, by getting a diagnosis, or by obtaining a prescription:

*Well that's when I thought, 'I need an inhaler', it might be asthma or that and when I got, I thought, 'oh he might give me inhaler and then I'll be able to go shopping and go to places with my daughter without being out of breath'*

**(Pauline: cough & breathlessness, COPD)**

*You know it's [cough] not going to go away, so you think, 'right, I'll go and have a word with somebody' and my first thoughts I had in my mind I thought, 'I'll give somebody a ring, I'll go and get an x-ray, we'll see what it's all about' and that's the frame of mind I was in at that time.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

This approach of 'consulting with a purpose' is linked to people's expectations of consultation specifically and the wider health care system more generally, with them approaching the consultation as a consumer, accessing resources, including prescription medication:

*That was when I decided that I really should go and see, get it sorted out, because if I go any longer it's not going to go away. I couldn't see then that it was going to go away without treatment.*

*(Harry: loose bowel movements, microscopic colitis)*

Similarly to those who went with a specific action in mind there were those who felt that, should their symptoms be being caused by cancer, there was a need to act quickly:

*What actually prompted this was my husband. He had urinary bleeding and he went immediately and he had bladder cancer. So that triggered me, you know, how important it was to go straight away because he's clear now...so immediate treatment resolved his and I thought 'you can't wait.' You can't really with bleeding.*

*(Mary: rectal bleeding, diverticulosis)*

The decision to consult was not always based upon a need for a diagnosis, or the intention to deal with a particular diagnosis. For some people the decision to seek help was prompted by feeling unable to cope with their symptoms any longer:

*I tried to put it to the back of my mind until I couldn't put it to the back of my mind anymore because it was coming so frequently. And I was doing some work in the garage, I would come in, I'd have to go to the loo, went outside for 10, 15, 20 minutes, half an hour sometimes, had to come back in, and I had to rush...there comes a point where it drains you, where you're that drained because of it and things, that you think to yourself 'I just can't go on like this anymore'. I think it comes to a point, I think it was, I think it had actually come to that point 'I can't go on living like this anymore, this is too much of a burden to put up with'.*

*(Mark: change in bowel habit, rectal carcinoma)*

*I mean I had some accidents, lets put it like that. So, of course it became 'this really is now sort of disturbing my life' as opposed to 'I feel ill.' It was just disturbing my life.*

*(Elaine: loose bowel movements, diverticulosis)*

For these people, consulting was a step towards regaining some control over their lives. They hoped that the practitioners' input would assist in returning them to the bodily state they had known before these symptoms began, or to a bodily state less plagued by symptoms.

Although I have so far described isolated motivations for consultation, it was often a combination of a number of factors which culminated to prompt the individual to decide to seek help:

*I think I was getting to the stage where it was becoming more, interrupting my life more, and I had that niggly thing at the back of my mind that said 'your dad died of bowel cancer.' And also the family and friends that you talk to, they were 'really, it's not normal, you ought to go get it checked out, there's something not right.' So people start to put things in your head, as well as the ones you've*



*already got there yourself, you know, and by then I'd had enough of it, because I had a particularly bad week at work with it where I'd just get sat down at me desk and I'm back up. And I had to go home one day and, you know, I thought 'this is getting worse and it's affecting everything now'. So that's why I went really.*

**(Elaine: loose bowel movements, diverticulosis)**

*I put the package in my mind together, 'well how do I relate that [someone else's bowel cancer diagnosis] with my own, what I'm thinking about here, and what I'm experiencing at the minute...[The Macmillan TV advert] where the bloke's coming out and various other people coming out, and the look on people's faces. And you wanted to push that to one side, you wanted to not believe that, because of the way you've been and things. 'No, that's not me.' And then the closer it gets and the worse symptoms you get, that was part of it as well I think. And I think you're right, I was putting everything together. You don't want to go and burden people, you won't go bother people about things that no...but as time was going by there was too many things. And having the knowledge that you have and things [Mark is a nurse], there was too many things that were stacking up.*

**(Mark: change in bowel habit, rectal carcinoma)**

These excerpts from Elaine and Mark's interviews show how there were many factors which influenced their appraisal and decision making around their symptoms, from the individual factors, such as expectations of one's symptoms and concerns about possible diagnoses, to the wider contextual factors, such as the sanctioning of help-seeking by others, including the media. These examples highlight the complexity of decision making for help-seeking and the wider contextual factors which have briefly been touched upon here will be explored in greater detail in the proceeding section.

### ***Making an Appointment***

Most people made an appointment relatively quickly after deciding upon the need to consult:

*There was no sort of dawdling. Being motivated I did it. It might have been the same day.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

However, for a few there was still a period of time which elapsed between taking the decision to consult and making the appointment:

*I was very worried about these shows of blood but I thought 'well I don't want to cancel the holiday'. I know it's stupid, but...I thought of going while we were in the States but that would have been horrendously expensive and might not have been covered by the insurance and then that would have just ruined the holiday, so I just thought, 'no, wait until I get home'.*

**(Angela: rectal bleeding, haemorrhoids)**

*Even when I knew about it I delayed. There was a delay from early January to, a month, until early February before I did go to the doctors...I suppose really a month might've been, had there been something seriously wrong, a month might've been too long 'cause in most cancers they say the earlier you go and have it investigated the better, so perhaps I waited a month when I should have been earlier to the doctors' but I was almost getting used to the symptoms.*

*(Fred: change in bowel habit, NAD)*

When it came to actually making the appointment, this appeared to be a straight-forward process for all of the interviewees, who found the process easy. None of the participants reported problems in attending their appointment or having to reschedule their initial appointment either. Although there were some complaints voiced about difficulties in getting an appointment more generally, all of the participants were able to see a GP within a week of requesting an appointment and everyone seemed satisfied with the time period within which they were seen.

### **Summary**

Participants had a variety of initial symptom experiences, ranging from systemic symptoms (i.e. lethargy), or 'everyday' symptoms (i.e. cough), to 'acute' (i.e. pain) or 'unacceptable' (i.e. blood) symptoms. Symptoms often changed and evolved during the patient interval, as did people's feelings about their symptoms, which included, and moved between, apathy and anxiety. People responded differently to the onset of symptoms, from the proactive (eg. self-medication), to intentional ignorance.

Potential causes of symptoms were contemplated early in the symptomatic period and it appears that people considered a range of explanations before selecting the one that they felt most suited their experience. As time and symptom experience progressed, people revisited and revised their explanatory models. Earlier explanations, which appeared no longer viable, were rejected and replaced with new explanations which more adequately explained their experiences at that point. Cancer was often a final hypothesis in this explanation seeking process.

It was generally after considering a number of explanations that people finally decided to consult about their symptoms, except for those who experienced acute and alarming symptoms. The point at which someone decides to consult appears to be influenced by a range of factors. It seems that people either reach a point of intolerable uncertainty, whereby they need to know what is going on in their bodies, or they reach a point where they are no longer able to manage or tolerate their symptoms and so seek the input of a HCP to improve their situation.

Once a decision had been made to consult, making an appointment was a straight-forward and quick process for most people, although a small number did report barriers to consultation after deciding upon the need to consult.

This section demonstrates that although there are stages in the help-seeking process which appear to be sequential, these periods are actually characterised by fluctuation and oscillation. People's appraisal of their symptoms, and subsequent responses to them, are complex. Despite the complexity of responses, there is generally a substantial degree of logic and method in people's approaches. It is naïve to think of the help-seeking journey occurring in an isolated fashion and some examples of contextual influences have been touched upon in this sub-chapter. The following section will go on to locate these individual journeys within a wider social context, illustrating the range of external forces which can influence an individual in their journey to the doctor.

## **5.2 Beyond 'The Individual': Situating Help-Seeking in Lived Realities**

The previous section outlined the journey which interviewees took to get to the doctor's, moving from, and between, symptom experience, symptom appraisal and help-seeking. The manner in which the data was presented implies that the help-seeking journey was isolated and limited to the individual. However, there were hints of external forces, which impacted the symptom appraisal and help-seeking processes in some of the accounts presented. The reality is that help-seeking decisions occur in light of, and in reference to, a myriad of other forces, all of which influence and mould the patient journey. These influencing factors can be categorised into four contextual domains; individual experience, interpersonal relationships, health care system interactions, and social and temporal context.

### **Individual Experience**

People's thoughts about their symptoms, including if, when, and how, to act upon them were influenced by their personal experiences. Their experiences of illness, previous exposures to 'risk factors' and conceptions of themselves all influenced how they perceived, and responded to, symptomatic episodes.

### ***Experiences of Illness***

Previous experiences of illness influenced how people perceived and evaluated emerging symptoms, with details of previous conditions used in the assessment of new experiences:

*It's just an accepted thing really. You know, it's sort of if you get, I used to get what, two or three chest infections a year.*

*(Des: coughed up blood, non-small cell lung cancer)*

First-hand experiences of similar symptoms aided people in their symptom appraisal, as they were able to conceive of a plausible diagnosis, and monitor symptom progression, appraising it against their expectations of that particular condition.

Among participants who had previously had cancer, many reflected upon this symptomatic episode in relation to their previous cancer diagnosis, irrespective of whether the symptoms related to the original cancer site or not. Among participants who had a previous cancer diagnosis, the possibility of a recurrence of their cancer, or the arrival of a new cancer, was their foremost concern during their symptom appraisal:

*In 2003 I was diagnosed with prostate cancer and I had the radiotherapy and then after that I had six monthly checks which happen every year in August and February and the PSA count was round between 0.6 and 0.8 for a long time. Round from then, 2003, right up to 2012 and then all of a sudden it jumped to 2 and then 2.17...That was a concern, a big concern, because at the time I thought 'well, the fact that me PSA has risen, does that mean that, has it spread? Does it go into the colon? I don't know, could that be a reason [for the change in bowel habit]?' and that was one of the, perhaps the biggest concern I had.*

**(Fred: change in bowel habit, NAD)**

*I have bladder cancer and the symptom of that is blood in the urine. So on three occasions I had blood in my urine and it was a real symptom, I did have cancer. I still do have it for that matter, but when there's blood in the urine it means it's getting worse. So I thought 'blood in the rectum, tell the doctor'.*

**(Jack: rectal bleeding, diverticulosis)**

In the same way that people used information about their own previous illnesses to appraise their symptoms, information about family illness was also used in the symptom appraisal process. People looked for recurrent complaints, or patterns of susceptibility, within their family to try to explain their symptomatic experiences:

*My grandmother passed away at the age of 55 after an asthma related incident and then my dad's lost two sisters to asthma, through asthma related incidents, where they've initially just started with an asthma attack which has then led to a heart attack, or something along those lines. And that's quite, the two sisters he's lost, that's quite recent. So asthma's quite prevalent in my family.*

**(Abdul: coughing up blood, inflammation of the lungs)**

Participants also evaluated their symptoms in light of a family history of cancer and considered their symptoms in relation to their perceived hereditary susceptibility to specific cancers:

*I thought like 'I know my mum died of it [stomach cancer] and obviously all this going on, yeah, it's time for me to go'. (Julie: stomach pains and diarrhoea, NAD)*

*What actually prompted this was my husband. He had urinary bleeding and he went immediately and he had bladder cancer. So that triggered me that, you know, how important it was to go straight away 'cause he's clear now.*

**(Mary: rectal bleeding, diverticulosis)**

As we can see from Mary's quote, people also reflected on their symptoms in relation to the cancer experiences of non-blood relatives and friends, by comparing symptoms and considering eventual diagnoses and outcomes.

### **Exposure to Risk Factors**

Biographical information about exposures to potential risk factors was a key consideration in people's symptom appraisal. Participants' narratives focused on two key risk factors; smoking and occupational exposure to carcinogens.

Amongst the participants who were smokers, and were experiencing respiratory symptoms, their smoking history was often prevalent in their narratives:

*I smoke, that's why I've got a cough! Everybody who smokes has a cough.*

**(Pauline: cough & breathlessness, COPD)**

*Twenty five years ago I smoked and I think if you had the symptoms that I had then you might start thinking to yourself 'well, yeah, I'll go and have a word'.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

These quotes illustrate how people used their smoking history to either dismiss their symptoms or, conversely, to consider that their symptoms may be indicative of cancer, as caused by their smoking.

Exposure to toxic chemicals in the course of people's working lives, particularly asbestos, was a recurring consideration for men who were experiencing respiratory symptoms:

*I've been in the motor trade and the chemical. That's all I've done. And I don't know whether I've breathed in anything there.*

**(John: cough & breathlessness, NAD)**

*I was worried about my lungs because I'd worked with asbestos, and I'd worked in very dusty atmospheres for a lot of years, all my life almost, and I was worried about the asbestos.*

**(Tom: wheezing & breathlessness, chronic bronchitis)**

People used biographical information about exposure to dangerous substances to aid them in their appraisal of their symptoms. Exposure to chemicals, be it through smoking or industry, caused people to be concerned about a possible link with their symptoms, however, symptoms could also be seen as a benign side effect of the exposure, for instance 'the smoker's cough'.

### *Perceptions of the Self*

People's perceptions of themselves influenced their appraisal and help-seeking decisions, as concepts of who they were, who they were not, and how who they were had changed, all shaped what they felt were plausible explanations for their symptoms.

#### *'Who I am'*

A number of participants perceived of themselves as 'healthy' individuals, referring to their levels of fitness, healthy lifestyle choices, absence of disease, or infrequent consultations with a HCP, to support this claim:

*I've always sort of looked after myself and things, and I've always played sport and, you know....I was playing five-a-side football every Friday night, you know young lads that, 19, 20, and up to maybe 40s that were a hell of a lot younger than me and I've always took pride in myself with my fitness that I keep up.*

*(Mark: change in bowel habit, rectal carcinoma)*

*[They] didn't know me at the doctor's*      *(John: cough & breathlessness, NAD)*

The conception of oneself as a 'healthy' individual made some participants feel that they were unlikely to get a serious disease, cancer in particular, as this did not fit with their image and perceived susceptibility to illness.

#### *'Who I am not'*

In the same way in which people wanted to present themselves as 'healthy', people also rejected, or resisted an 'ill' identity, as this was not part of how they wanted to perceive themselves, or be perceived by others:

*It's accepting that you are vulnerable...I don't want to be seen as being ill because there's been enough illness in the house already.*

*(Abdul: coughing up blood, inflammation of the lungs)*

*You see the adverts of the TV with like the blokes and the women coming out and they've just been told by the consultant they've got cancer, and you're probably seeing them where they walk down the corridor, this bloke almost collapsed and that sort of thing, and when you sit and watch those, you think that must be terrible for people with that. But, you know, you never associate*

*that with yourself, because, and because of my sort of philosophy on life and things, you think, 'no, that's not, that can't happen to me and things', but it does.*  
(**Mark:** change in bowel habit, rectal carcinoma)

The rejection of illness as a valid characteristic of oneself also entailed a rejection of cancer as a viable condition, as a cancer diagnosis is not something which fits within one's projected life narrative. This perception that cancer is something which happens to others is apparent in people's accounts of their symptom appraisal processes, with many people considering cancer as a possibility, but rejecting it as a potential diagnosis, as their lived experiences did not fit with their perceptions of what 'someone with cancer' would be like. This rejection of cancer as a possibility is something which will be explored in greater detail in Chapter Seven, in relation to the concept of 'cancer candidacy'.

#### **'Who I am is changing'**

For some people their perceptions of themselves were in a state of transition, or were fluctuating, and these changing identities were used in people's evaluation of their symptoms:

*I'm the youngest of four and I've gone from being the last in line in my family to almost being, I know my dad's on show the head of the household, but the power behind the throne, and I'm thinking to myself 'how have I ended up like this' and I think ever since my mum went there was a massive psychological and emotional change and it affected my health as well.*

(**Abdul:** coughing up blood, inflammation of the lungs)

*When I was younger it was like 'oh, it's nothing', but now I've got that bit older, I'm 55, you suddenly start thinking 'hang on, this isn't just going to go away now.' I take far more, I listen to my body more and I think I'm more conscious of my age and my health.*

(**Sandra:** cough, chest pain & breathlessness, inflammation)

In particular, ageing was something which a number of participants mentioned as changing the way they perceived of themselves and their body, and this changing image caused them to change the way in which they responded to symptomatic experiences.

#### **Interpersonal Relationships**

People's relationships and interactions with others influenced how they appraised and acted upon their symptoms. This influence came through the discussion of symptoms with others and through others' encouragement of help-seeking.

### *Discussing Symptoms*

The majority of interview participants discussed their symptoms with someone else. This mirrors the questionnaire results presented in Chapter Four, which showed that 4/5<sup>ths</sup> of participants discussed their symptoms with someone else.

Most people initially mentioned their symptoms to their spouse but children and friends were also people with whom symptoms were discussed. Disclosure of symptoms tended to be relatively low-key, often in the form of an off-hand comment:

*Initially I told her, you know, over the last few years when I had spates of when it would happen, I mentioned it in passing.*

**(Abdul: coughing up blood, inflammation of the lungs)**

*I possibly might have said one day, 'oh I'm getting a bit sick of this, going every day'.*

**(Roy: persistent diarrhoea, spirochetosis)**

One exception to this was Melanie, for whom the main purpose of the interaction with her husband was to discuss the symptoms, because of their unexpected and intense nature:

*He [Melanie's husband] was at work. I phoned him and said 'eee God, I've got this pain. I think if it was on the other side I'm having a heart attack'.*

**(Melanie: pain in right side of body & back, small cell lung cancer)**

Some people felt forced to mention their symptoms to others because of how evident the disruption was to their daily functioning or routine:

*Obviously my husband knew. He couldn't not know if he didn't have a strong sense of smell.*

**(Elaine: loose bowel movements, diverticulosis)**

Although most people instigated discussions about their symptoms themselves, in some cases other people brought up the issue of their symptoms:

*They brought it up with me. 'Time you got rid of that cough', 'time you went to the doctors', 'nag, nag, nag, nag'.*

**(Pauline: cough & breathlessness, COPD)**

Most participants felt comfortable discussing their symptoms, with many citing an openness in their relationships, particularly with spouses, as a reason for the ease with which they discussed their symptomatic experiences:

*She knew what was going on because we talk...there's nothing held between us, there's no barriers.*

**(Arthur: very loose bowel movements, diverticulosis)**



Although most people were comfortable talking about their symptoms with others, discussion of bowel symptoms outside of immediate family relationships, was sometimes difficult for people:

*It's not a word you spread about like. I think you asked me earlier, obviously family know, but I wouldn't go out in the pub and say 'I've been five times this morning'. It's not a thing you talk about.*

**(Roy: persistent diarrhoea, spirochetosis)**

*It's not something you go broadcasting around. I mean, I didn't go knocking on doors saying 'here, I've got the craps.*

**(Arthur: very loose bowel movements, diverticulosis)**

The 'private' nature of bowel symptoms made them something which people tended not to readily share with others because of potential embarrassment, and instead kept this information within private spheres of close family and friends.

### ***Motivations for Interactions***

There were clear motivations underlying decisions of whether or not to discuss symptoms, which included avoiding worrying others, informing others of a potentially role changing element, seeking reassurance and justifying help-seeking.

Among people who chose not to discuss their symptoms the reason given for withholding this information was always to avoid worrying others:

*It was a very conscious decision not to [discuss his symptoms]. I think you'll have gleaned already from what I've said to you and things that I was being the strong one, the go to person and things, and I didn't want to worry anybody. I had my own worries obviously, but I didn't want to worry my wife and certainly my son.*

**(Mark: change in bowel habit, rectal carcinoma)**

*I didn't talk to anybody. There's no point. I have two daughters and they phone me once a week. I do go out for a meal with my eldest daughter, elder daughter, every Wednesday, and I hadn't told them that I had this bleeding, that I'd been to the doctor, because why worry them, you know, let them enjoy life.*

**(Jack: rectal bleeding, diverticulosis)**

The levels of stress or demands on other peoples' time was often cited as a barrier to disclosing symptoms, as people felt that this would simply add to their burden by providing another cause for concern. Instead, people waited to gather more information about the situation, through consultation with a HCP, before informing others of the situation. Even

then people often only discussed the symptoms and, or diagnosis, if they believed it to be serious enough for the other person to *have to* know about it:

*I think 'I don't have to alert people if there's nothing to be alerted about' and I only get to know that when I go to the hospital and then they tell me what the score is and **then** I can tell them. I don't want them worrying about it before.*

**(Fred: change in bowel habit, NAD)**

Amongst people who did disclose their symptoms to other people, some did so in a bid to seek reassurance from the other person about their symptoms:

*Rob is always 'go to the doctors' because I discuss it with Rob and he'll say 'look, I'm not a doctor', but I'm wanting him to say something reassuring like 'oh you're alright, it's nothing, that's fine'.*

**(Pamela: blood in phlegm, bronchiectasis)**

*I think sometimes you just want somebody to say 'well it isn't anything to worry about', or, 'yes, really you ought to'. I think all of us are of the same opinion that you like a little bit of back up to what's going on.*

**(Elaine: loose bowel movements, diverticulosis)**

The reassurance which people sought was either reassurance that the symptoms were insignificant or reassurance that the symptom was in fact something significant and that help-seeking was the appropriate response. Therefore, those who sought reassurance from others when discussing their symptoms used this input to assist in their symptom appraisal and subsequent decision making.

Another motivation for disclosure of symptoms was to inform others about their situation. Those who disclosed symptoms in order to inform others tended to do so after the decision to consult the GP had been made, and so were not involving that person in their symptom appraisal process. However, this does not mean that they didn't discuss their symptoms with someone else, earlier in the appraisal period, whose input had been used to inform decisions:

*It was more informing her [his sister], yeah, and letting her know what was going on and what was happening and stuff like that. **(Steve: rectal bleeding, NAD)***

*[So did you speak to anyone else about it before you went to the doctors?] Let me cast my mind back. My dad. I just kind of acknowledged and he just kind of acknowledged me sort of thing, you know dads and lads, ships that pass in the night, and he said 'yeah, okay, go and see the doctor... I kind of OK'd it with him and checked it with him. Even though I say I'm an independent man, you know,*

*but I kind of checked in with him. And even afterwards I found myself saying to him 'oh, the doctor's, a bit worried' you know, letting him know that the doctors concerned you know. And it was just really making him aware that I am really poorly, well not really poorly but that I could be really poorly.*

*(Abdul: coughing up blood, inflammation of the lungs)*

Disclosure of symptoms as a means of informing people, served to notify others of the fact that their symptoms existed. As is evident in Abdul's narrative, disclosure of symptoms, and a potential diagnosis, was often for the purpose of making others aware that their illness may affect their ability to function and therefore require some shift in the roles and expectations placed upon them.

Irrespective of whether the individual started the discussion of symptoms, or if someone else did, a number of people used the advice of others to justify their help-seeking. This is different to seeking advice about what to do, as these individuals specifically cited other people, generally spouses, as the reason why they consulted:

*[What made you think 'now is the time that I'm going to go and see the doctor'?] I was persuaded...but you're approaching the time when you're thinking that you might want to do something about it, so I didn't take any persuading really.*

*(Richard: cough & chest irritation, gastro-oesophageal reflux disease)*

*She [his wife] nagged me for a few 'why don't you go to the doctor's?' Then two or three days later she's nagging me again...and he [his son] would nag me all the time to go...In a sense I suppose it was me [who made the decision to consult], but having said that it was because our Tony was nagging on, and you [his wife] were nagging on a couple of days.*

*(Roy: persistent diarrhoea, spirochetosis)*

*She was going on and on about going the doctors and, apart from it getting a bit worse, I did it to shut her up.*

*(John: cough & breathlessness, NAD)*

Justifying help-seeking based upon the insistence of others helps an individual to place the decision making in the hands of another. By stating that the sole reason for consultation was 'because the wife told me to' people were shifting the decision onto another, despite the fact that it is evident from the narratives above that these men actually wanted to consult the doctor themselves. They are therefore shifting the potential culpability and loss of face onto the other person, should the decision to consult the doctor have been an inappropriate decision. This relates to the idea of what it is to be a 'good patient',

appropriate use of the health care system, and the presentation of oneself as a responsible and moral human being, which will be explored in Chapter Seven.

### *Others' Influence on Help-Seeking*

As discussed above, some people justified their help-seeking, by framing others as the instigator or decision maker. However, this was not true for all interactions where others were encouraging of help-seeking. Many participants were encouraged, or discouraged, to consult by other people but this advice was not always central in people's decision making, sometimes being only a small element in an evaluation which comprised many factors.

Family members, particularly spouses, were the people who most frequently influenced people's thoughts and decisions about help-seeking. Once they were aware of the person's symptoms, family members were generally encouraging of help-seeking, with many participants talking about how family members 'nagged' them to consult about their symptoms:

*Oh I didn't decide, it was decided for me, 'enough is enough, get an appointment!'* (Arthur: very loose bowel movements, diverticulosis)

*She [his wife] said 'oh, it'll be nowt, don't worry about it', along them lines, but she said 'you need to go and obviously see a doctor about it'.*  
(Steve: rectal bleeding, NAD)

As we can see from Steve's quote, although his wife did soothe his anxiety by reassuring him that it was probably nothing, she still encouraged him to go and see the doctor about his bleeding.

For a couple of participants, Julie and Maggie, family members (in both cases daughters) did not simply encourage help-seeking, but acted to create a situation whereby their mothers had to consult a HCP about her symptoms:

*My daughter, I phone my daughter, and I said 'oh I can't stand this pain any longer' and she said 'what's the matter' and what have you. I said 'Do you know when you feel as if you stand up and like the cramps and what have you?' I said 'and I just feel as if I'm going to burst' and she went 'well, what have you ate?' and I went 'well, apples and pears' and she says 'oh mum, like how bad do you feel?' I said 'Anna, really bad' I said 'I just want to lay down and go to sleep' and she said 'Oh no, I'm not happy with that.' So she phoned the paramedics.*  
(Julie: stomach pains and diarrhoea, NAD)

Sometimes the encouragement of help-seeking by others did not have the desired effect, and instead made people less willing to consult about their symptoms:

*In the end, I don't know, sometimes you don't go 'cause you're stubborn and you think 'I'm not going to do what everybody wants me to do'.*

*(Elaine: loose bowel movements, diverticulosis)*

However, for most people encouragement of help-seeking by others was received favourably, and their encouragement often helped people to finalise their decision. It appears that although encouragement of help-seeking from a family member was often a facilitator in the decision to consult the doctor, it was rarely the sole prompter, with people often encouraging help-seeking for long periods of time before the person finally consulted. The nuanced role of family members' encouragement of help-seeking upon the final decision making is articulated by both Elaine and Richard:

*People start to put thoughts in your head, as well as the ones you've already got there yourself.*

*(Elaine: loose bowel movements, diverticulosis)*

*Eventually, your thoughts and the thoughts of others meet, and then you say 'okay, I'm going to do something about that'.*

*(Richard: cough & chest irritation, gastro-oesophageal reflux disease)*

What seems to happen is that people incorporate the opinions of others with the thoughts that they already have themselves in order to come to a decision. A few participants talked about how people other than family members, mainly friends and colleagues, influenced help-seeking:

*If I got a cold the cough got worse and the lasses would say 'you've seen that advert on telly about cancer and coughing?' I said 'I've got a cold, you cough when you've got a cold'.*

*(Pauline: cough & breathlessness, COPD)*

People outside of the family would always be encouraging of help-seeking, telling people to go to the doctor's as it was *'the right thing to do'* and although most family members also encouraged help-seeking, there was more of a nuanced and tailored discussion with family members than with 'others'. This may be because family members understood the person's health and health behaviour better, but it may also be that people outside of the family felt more compelled to provide a socially acceptable response than family members did.

## Health Care System Interactions

How people viewed and interacted with the health care system shaped how they responded whilst symptomatic. The influence of the health care system upon help-seeking behaviour can be considered in relation to three key areas; previous encounters, anticipation of this encounter, and concepts of 'patienthood'.

### *Previous Encounters with the Health Care System*

People's previous experiences and encounters with the health care system shaped how they appraised and responded to their symptoms, as well as how they felt about consulting a HCP. People who had positive previous interactions with the GP felt comfortable to discuss their symptoms and seek help from their doctor:

*I have a good relationship with the doctors. Over the last number of years I've attended regularly with different things. And it's not as though I had any fear of the doctor's or that nature.* (Joseph: coughing up blood, NAD)

However, for people who had previously had negative interactions with their doctor, these encounters could influence their decision making, as some felt reluctant to consult their doctor, or have lacked confidence in the doctor's ability to deal with their condition:

*Her eyes glazed over when I said 'a change of bowel habit.' She ticked a box...It takes time to listen to patients, especially patients who are not well educated or inarticulate, or trying to persuade the doctor that they've come about something else.* (James: 'belly ache', diverticulosis)

*I've seen two different sides to the doctor. I've seen the side where the doctor was quite interested and forthcoming and wanting to, but then I've seen another side of the doctor. The same GP, where I've kind of, really tried to say 'I want to thank you for all the interest you're taking'. That's what I was trying to say to him and he said 'thank you but I really can't speak to you right now 'cause I squeezed you in'...it makes me think twice about what I'm going to say. I must concentrate when I'm going to see the doctor to make sure that I say the right things to him at the right time and not waffle on.*

(Abdul: coughing up blood, inflammation of the lungs)

People talked about their typical pattern of consulting behaviour. Some people liked to get symptoms checked out by the doctor when they were unsure as to their cause as they felt that this was 'the right thing to do', even if the experience wasn't pleasurable:

*I'm always anxious when I go, I just, I know it's the right thing to do, it's the right people to see, but I'm always glad when I'm coming out.*

(Pamela: blood in phlegm, bronchiectasis)

*I never shirk that, we've always kept, I'm not conscious of ever ever not turning up for a doctor's appointment or hospital appointment.*

**(Fred: change in bowel habit, NAD)**

Whereas other people stressed the infrequency with which they saw the doctor, implying that managing symptoms themselves, where possible, was *'the right thing to do'*:

*I will tend to go to the doctor's if I think it's necessary, but I tend to, if there's something, if there's an issue and I don't think it's important then I wouldn't go. I'd just bide my time until things appeared to be worse or I feel that it's necessary. (Richard: cough & chest irritation, gastro-oesophageal reflux disease)*

*Well just on, not on principle, just because I don't like going to the doctor's, I don't feel that I need to go to the doctors....So I don't go to the doctor's unless I absolutely have to. (Tom: wheezing & breathlessness, chronic bronchitis)*

Both types of narrative, those who consult because it is the *'right thing to do'*, and those who put off consultation because it is the *'right thing to do'*, are bound up in notions of morality and the presentation of oneself.

Some people discussed the strategies which they incorporated into their consulting behaviours, which either enabled the decision to consult, or facilitated the consultation itself. Some people talked about seeking advice from a 'legitimate' outside source, such as the pharmacist or NHS direct in order to guide their decision making:

*When I phoned 111 they just said 'ooh chest pains and that we need', I said 'well it's not so much my chest it's starting in my back and coming through my body and that.' She said 'oh no, we'll get you an urgent appointment' and that's when my son took us through.*

**(Melanie: pain in right side of body & back, small cell lung cancer)**

Others talked about strategies which they employed to make the consultation experience easier, such as taking their partner to the appointment with them:

*Another thing we always do, we always go together, so if one doesn't take in what's been said, well the other one can confirm it later.*

**(Mary: rectal bleeding, diverticulosis)**

A different type of encounter with the health care system which influenced peoples' help-seeking decisions, was having taken part in the national bowel cancer screening programme. A number of participants had taken part in the Faecal Occult Blood Testing

(FOBT) bowel cancer screening programme in the preceding year and had received a negative, or 'clear' result, which influenced how they appraised their symptoms:

*That was another reason because that, I think it was last year, earlier on in the year, that it's been my time to do one of the bowel tests and that'd come back as clear.*

**(Elaine: loose bowel movements, diverticulosis)**

*In between all this the poo test thing came through, so I thought 'oh right, good, I'll do this.' And then that came back negative. 'Oh right, so it must be all right.' So then you go along a bit further then*

**(Eleanor: rectal bleeding, diverticulosis)**

### ***Anticipation of the Encounter with the Health Care System***

Expectations of what would occur in a consultation often influenced people's decision making processes. Some participants who experienced rectal bleeding said that they had expected to be examined rectally. Although anticipation of a rectal examination often made people feel uncomfortable, it did not appear to be a deterrent for help-seeking:

*I expected to be examined so I just prepared myself for it, even though it was a little bit embarrassing.*

**(Steve: rectal bleeding, NAD)**

Others had expectations for the consultation, with the consultation being seen as a way of accessing particular resources. For some people consultation was a means of gaining access to investigations, which they believed would give them definitive answers as to the cause of their symptoms:

*What I wanted really was some reassurance and perhaps an x-ray and sure enough the doctor said 'okay' he said 'let's start the ball rolling. The first thing we'll do, we'll get an x-ray'.*

**(Richard: cough & chest irritation, gastro-oesophageal reflux disease)**

*That was the whole point of going to the doctors, I just wanted it cleared up and I wanted the scan. I knew that the scan would tell me one way or the other, and I got it done.*

**(Tom: wheezing & breathlessness, chronic bronchitis)**

Others also based their help-seeking decisions on the belief that the consultation would lead to a prescription, which would ultimately alleviate their symptoms:

*I thought 'well, I'll go to the doctor. If it's haemorrhoids he'll give me some cream or something'.*

**(Jack: rectal bleeding, diverticulosis)**



*That's when I thought 'I need an inhaler, it might be asthma or that.' And when I got, I thought 'oh he might give me an inhaler and then I'll be able to go shopping and go to places with my daughter without being out of breath'.*

**(Pauline: cough & breathlessness, COPD)**

### **Concepts of the 'Good Patient'**

Many participants touched upon their concepts of what it was to be a 'good patient' and their desire to present themselves, both to myself and to their GP, as a 'good patient' was evident. The previous discussion of people's views of consultation or non-consultation being the 'right thing' reflected people's ideas of what being a 'good patient' entailed. In interviews people presented themselves as a 'good patient' by contrasting their behaviour with the 'unacceptable' behaviour of others. In doing this they sought to affirm their position as someone who only acted in an acceptable manner:

*On the television there seems to be a lot of concern about people going to the doctor's for very little reason...Somebody gets a splk in their finger and they rush to the hospital, or you think you've got a cold coming on so they run to the doctor...I would have to feel the need to want to go to the doctors, not just for the sake of going.*

**(Fred: change in bowel habit, NAD)**

People were mindful that the doctor's resources were finite and so being a 'good patient' also meant appropriately using the doctor's time or, more specifically, not wasting it:

*I wanted to know that when I got there I wasn't wasting their time. Because that's my biggest fear, going in and wasting people's time. I don't want to, if somebody else is in more need than me, let them go in front of me, you know. I wanted to know that I was that person that should be there at the front of the queue.*

**(Christine: fatigue then rectal bleeding, NAD)**

*I don't want to waste my doctor's appointment. I would feel a waste of time if I went across and nothing was going on.*

**(Sandra: cough, chest pain & breathlessness, inflammation)**

The quotes above highlight how reluctance to waste the doctor's time is based upon both an awareness of finite resources (i.e. the doctor's time and the number of sick people) and a desire for the GP to evaluate their presenting complaint as legitimate, and therefore a valid use of the doctor's time.

Related to the need to legitimately use the GP's time is the desire to avoid looking foolish in front of the GP, since part of being a 'good patient' is being informed and making rational, responsible decisions around one's health:

*I don't want to go to the GP for something which he considered insignificant. You don't like to pester as it were.*

*(Richard: cough & chest irritation, gastro-oesophageal reflux disease)*

*When I went to the doctors I said 'six months'. I'd actually had it well over a year, so I was telling him lies...[Why did you tell him you'd had the symptoms for six months and not a year?]...Well embarrassment I think more than anything else I would say. If I'd have probably said well over a year he would have probably 'oh', but I just told him it was six months. Even then he went 'six months', because mainly I think it didn't bother me. I thought well if I said over a year he might say 'why didn't you come to see me before now?' Yeah, that's a long time, and I just said 'I'll shorten it, six months'. But I'd had it well over a year.*

*(Roy: persistent diarrhoea, spirochetosis)*

People wanted to present themselves as 'good patients' who only made use of limited resources when absolutely necessary, and who acted upon information (i.e. symptoms) in a timely, logical and informed manner. The need to present oneself as a 'good patient' is influenced by discourses of socially acceptable responses to symptoms and morality, and will be discussed in detail in Chapter Seven.

### **Social and Temporal Context**

People's wider social and temporal contexts played a large role in their response to their symptoms. This section is titled both 'social' and 'temporal' because it encompasses people's social commitments and obligations, which are often bounded and constrained within a specific time, whereby commitments are rooted in discrete periods in their lives. The main factors which influenced help-seeking within the realm of people's social and temporal context were responsibilities and commitments, culture, and the media.

### **Social Responsibilities and Commitments**

Work was the biggest commitment that people discussed during their interviews. It was central to their accounts of symptom experience, as symptoms often occurred during work hours, and formed part of their appraisal and help-seeking decisions.

People's symptoms affected their ability to function and perform within the work environment, as well as being a source of distraction, stress and embarrassment:

*It was work that was the worst, because you're in a situation where you're at your desk, there's only one toilet and you think 'God, if I get to that toilet and there's somebody on it, then I'm afraid I'm going in the gents regardless', which is only a single toilet again, it's not like I'm going to be...But if someone's in both of them I would be up the creek without a paddle. Literally! And then of course you were always embarrassed because the smell was horrendous, really was*

*horrendous. It wasn't normal, you know what I mean, so I used to carry round spray aerosols with me, or perfume, and the toilets smelt permanently of Alien.*

*(Elaine: loose bowel movements, diverticulosis)*

*The coughing was affecting me at work and I couldn't do my job properly because I was coughing that much...and it stops your functioning. It gets to the point where, you know, it's getting a bit mad when you can't string a sentence of words together. My job is to speak to people and you're forever coughing.*

*(Abdul: coughing up blood, inflammation of the lungs)*

Symptoms affected people's abilities to work and became a source of stress and frustration for them when they manifested within the work place. People also considered their job when appraising their symptoms, contemplating whether a workplace exposure or incident could be the cause for their symptom manifestations:

*I worked at, I was a cleaner up there, [GP surgery]...I'm just guessing but I think I may have contracted some kind of bacteria from there...I mean I used to wear gloves but half the time you took the gloves off to do something and you probably thought 'oh'. But if you're doing something then, yeah, I don't know, I'm just guessing it come from there. (Roy: persistent diarrhoea, spirochetosis)*

*I just thought I'd been working a lot, doing overtime and that you know. When they were short they had nobody at work hardly, so I was doing extra shifts and I thought. (Melanie: pain in right side of body & back, small cell lung cancer)*

Just as people incorporated work-related factors into their symptom appraisal, it also informed the help-seeking decision making process. People's concerns about the impact which consultation would have upon work influenced some people's decisions about if, and when, to consult:

*I haven't got time to go to the bloody doctors...Always at that time of the year the work's absolutely crackers because people want stuff doing for Christmas. And I thought 'look, I'll hang on until after the busy time's over'.*

*(Joseph: coughing up blood, NAD)*

After work, the other realm of people's lives which influenced their thoughts about, and responses to, their symptoms was family. Symptoms seemed to be less disruptive to people's family responsibilities than they were to work responsibilities, and they generally found it easier to manage and accommodate their symptoms in the context of their family commitments. Commitments, such as childcare, largely took place in the home, and so people were able to manage their symptoms within the privacy and comfort of their own homes:

*Usually see the grandchildren on a weekend. They come over probably only for two or three hours on the Saturday lunchtime and spend the afternoon with us...[So thinking about the symptoms, in terms of the frequency and the urgency with which you were needing to go to the toilet. I was just thinking if that impacted on your time with your family?...]...Not really, because usually with the grandbairns, they came here on a Saturday anyway. I mean, yes, sometimes we'd have dinner and then go out, but usually, I'm in my own house, if I needed the toilet I was fine, I didn't have to really think about it.*

*(Elaine: loose bowel movements, diverticulosis)*

*[Just so I can get a bit of an idea about what was going on in your life at that time, maybe like responsibilities of other stuff and work and hobbies.] It was just work. And like I was having time off to go backwards and forwards to [local hospital] and that was like half a day here and half a day there, which was putting me a bit further behind. So that's why I would have preferred waiting until afterwards [to consult].*

*(Joseph: coughing up blood, NAD)*

What is interesting about Joseph's quote is that his responsibility to take his wife to the hospital was not seen as a barrier by him, despite the fact that this was having a big impact upon the pressures on his time. For Joseph, the additional 'workload' involved in his wife's cancer treatment was something which was acceptable and which he incorporated into his life, prioritised, and worked around unquestioningly. However, he did not feel to be in a position in which he could prioritise his own health concerns over the demands of work and his wife's treatment.

There were numerous other examples of people prioritising family-related commitments over their own health. For instance, for Elaine, preparing for Christmas was the most pressing concern to her whilst she was symptomatic and so she 'coped' with her symptoms in the run up to Christmas. Mark's mother died whilst he was symptomatic and his focus was on dealing with the funeral arrangements and grief around her loss. Eleanor's husband was undergoing chemotherapy treatment for bowel cancer at the time when she was experiencing rectal bleeding and her priority was caring for him, and taking care of other aspects of their life which he had had to temporarily withdraw from, as opposed to attending to her own health.

Participants also talked about how symptoms impacted upon their commitments and responsibilities in other aspects of their lives, such as hobbies, socialising with friends, church commitments and holidays. Symptoms often impacted upon people's abilities to

partake in their hobbies, however, they seemed accepting of having to withdraw from any such roles initially for, what was anticipated to be, a short period of time:

*[Did your symptoms affect your lifestyle in terms of responsibilities at church?]  
Slightly, but I've got an assistant there, well another warden, and she's a lady and she would say to me, because I was coughing, 'I'll go', because we've got to hand out the bread and the wine, 'I'll go down to the altar today' because I was coughing. So probably for three weeks she did it because I was tending to, I wouldn't know when a cough was coming on, and when it did come on it came on viciously, it was a really rough cough. And I wouldn't like to be doing that over the sacrament. (Tom: wheezing & breathlessness, chronic bronchitis)*

*I'm clerk to [town] Parish Council, which makes me the finance officer as well...and it's affected that in so much that I've lacked energy, in fact I've only just this week really forced myself to do the year end for the church. The auditor likes to have it before the end of February and I'm having to force myself to do it because I lack energy, which is unusual.*

*(Arthur: very loose bowel movements, diverticulosis)*

A few people talked about how holidays impacted their symptom appraisal and help-seeking processes, with pre-booked holidays sometimes acting as a motivator to seek help, in order to rid oneself of the symptoms before the holiday, or as a deterrent to seeking help, because of the lack of available time to consult before departing for holiday:

*I had blood on the toilet paper when I passed a motion and the first time was on August the, when was it? August the 3<sup>rd</sup>, but we were going on a holiday of a lifetime on the 5<sup>th</sup>, and I thought 'I don't want to cancel this two months because of this'. (Angela: rectal bleeding, haemorrhoids)*

*Well, I can't tolerate it anymore because I had no idea what was causing it, whether it was something horrible developing in my gut. You don't like to think about that but I feel quite confident that I should be able to go on holiday and enjoy it [without experiencing the diarrhoea]. So, you know, that's basically it, you need to find out what's going wrong.*

*(Arthur: very loose bowel movements, diverticulosis)*

### **Culture**

People's cultural beliefs affected the way in which they conceived of their symptoms and concerns around other people's responses also impacted help-seeking decision. Lay beliefs about symptoms, health and illness were presented in a number of accounts, and influenced how people appraised and responded to their symptomatic experiences:

*I've never taken anything like that [anti-diarrhoeal medication] because initially my thoughts were that it was a bug and they always say that you shouldn't stop the bug getting out, you're better off just letting it work its way out.*

**(Elaine: loose bowel movements, diverticulosis)**

*It was the cough, you know, but somehow I managed to shove the cough down...And I'd move it down so it wasn't hurting my chest so much...But with pushing the cough down, I must have cracked my ribs.*

**(Maggie: cough, fainting, tiredness, pneumonia)**

Concerns about the stigma associated with illness and having 'a condition' was a significant part of Abdul's narrative:

*It's this culture, this bubble that's preserved here, especially if there's an ailment or if someone's child is maybe of a different orientation, you know...Already a lot of the eyes were turned towards us when my mum passed away...for me personally I feel this pressure, and I really don't want to be seen as, I feel as though I'm letting everybody down, and myself...[Do you think there's a thought that once you start, from watching your mum, that once you start getting ill]...It'll do that and also be tarred with the same brush by the family, by the wider family. Really, I've always tried to think to myself that 'I don't care what anyone, I'm a young second, third generation Asian, I don't live with their old society rules', and then suddenly without realising, subconsciously you're being bound by them...The fact that, you know, you're permanently being labelled with asthma. I don't want to be labelled as one of, the next one in line, you know, and so it's, I suppose, culturally I just don't want to accept it.*

**(Abdul: coughing up blood, inflammation of the lungs)**

We can see how for Abdul, he felt that carrying the label of a particular diagnosis would single him out as someone who would be stigmatised and 'othered', as having a disease or illness would be viewed with the same type of stigmatisation as homosexuality within his community. Unfortunately, no other Asian participants offered to be interviewed as part of this study, however, the concept of stigma around illness within South East Asian communities in Britain is a theme which it would have been valuable to explore further.

Even amongst the White British participants in this study, concepts of stigma are detectable in accounts where people try to present themselves as moral and appropriate users of the health care system, as within this cultural framework, what is important is not abusing a limited and valuable resource, the NHS. There is stigma around people who inappropriately and repeatedly consult their GP and many people offered narratives in which they presented themselves as someone who was healthy, hard working and reluctant to use up

resources. Underlying the stigma which Abdul felt was present within his community in relation to illness are cultural notions of acceptable behaviour and morality, something which is discussed in Chapter Seven.

### *Public Health Campaigns and the Media*

Around the time when the interviews took place, a number of BCOC campaigns ran throughout the region and news coverage of stories on 'early diagnosis of cancer' was prevalent, with both of these media influences being present in the narratives of participants.

Many people directly referred to the BCOC campaigns and discussed how the messages in these campaigns were integrated into their symptom appraisal and help-seeking processes:

*It was when I heard, saw, all the adverts about bowel cancer, that's what sort of pushed me into going to the doctors. (Fred: change in bowel habit, NAD)*

*I did see the campaign in the newspaper where they were saying 'if you've had a cough for more than three weeks go and see someone about it'. I think that's the one that had the most impact on me, perhaps after the event I was more aware of that then, and I might have been motivated by that at some stage.*

*(Richard: cough & chest irritation, gastro-oesophageal reflux disease)*

A few people also talked about how others used the BCOC campaigns as a means of initiating a conversation about that person's symptoms, and citing it as a source of evidence that the person should seek help about their symptoms.

Many people who mentioned seeing the BCOC campaigns reported that their exposure to these had positively affected their symptom appraisal and help-seeking, such as in the examples of Fred and Richard above. However, for others, exposure to the campaigns had a negative effect on their symptom appraisal and help-seeking decisions:

*I think the campaign, because I looked at that, you know, I've seen that, it's been on for a while now, hasn't it, or various campaigns, but the most recent one and things, and you think 'no, it's' and other people will be like mainly 'no, that's not me, that can't happen to me'. (Mark: change in bowel habit, rectal carcinoma)*

*['Did you see any of them [the BCOC adverts?]] Yeah, bowel cancers and if you pass blood and all this, yeah...[And did they make you think?...] Well, no, because I wasn't passing blood, so as far as I was concerned, that wasn't it. Had I been passing blood I would've gone immediately.*

*(Elaine: loose bowel movements, diverticulosis)*

The specific nature of the BCOC campaigns, whereby they focus on ‘alarm’ symptoms, could be potentially damaging for some people, as absence of that symptom may provide false reassurance that their symptoms are not being caused by cancer. The campaigns depict a ‘typical cancer patient’ and when that scenario does not fit with someone’s own experiences, it can reinforce the possibility that cancer is not a plausible explanation for their symptoms, linking to the concept of ‘cancer candidacy’, which will be discussed later in this thesis.

Some participants did not explicitly refer to the BCOC campaigns, but did refer to items that they had seen in the news, or early diagnosis public health promotion which they had seen:

*I got a letter through the, it’s fate, a letter came through from the NHS or whatever it was, ‘do you have coughing or breathing problems? Go to’ I don’t know whether it was ‘go to see your doctor or some clinic’ something. I think it was ‘go to see the doctor. (Pauline: cough & breathlessness, COPD)*

[Harry] *Well, we watch the news on a night*

[Harry’s Wife] *If you have symptoms go straight to the doctors, don’t delay*

[Harry] *But then I had the screening and it was fine so we thought differently from that.*

[Harry’s Wife] *But then it didn’t go away and we knew you have to go early if it is that [cancer]. (Harry: loose bowel movements, microscopic colitis)*

In both of these cases, coverage of early diagnosis, either in the news or through public health materials, acted as a prompt to help-seeking. Although Harry initially dismissed the possibility of cancer, because of his negative bowel screening result, as his symptoms persisted he used the information he had gained from the news story in his re-appraisal of his symptoms and his ultimate decision to consult the doctor.

It seems that media coverage of early diagnosis stories and cancer awareness raising campaigns does play a role in people’s symptom appraisal and help-seeking processes. However, for some people it can inadvertently reinforce the belief that cancer is not a possibility.

### **Balancing Multiple Contributory Elements**

This chapter has presented data on the wider contributory elements which influence how people respond to symptoms of lung or colorectal cancer. These factors have been categorised into four domains; individual experience, healthcare system interactions, interpersonal relationships, and social and temporal context. The themes in each of these sections have been presented in isolation, however, the reality is that multiple factors and



influences are present within people's help-seeking accounts and that these influences are interlinked and entangled within people's experiences and narratives.

One way in which people deal with the multiple demands and influences which they face is by prioritising some issues over others:

*Because I was so busy I didn't really pay much, give it much thought or attendance basically. And because I was so busy and there was so much to do, you know, and I had some specialist work was coming in and things, it was organising all that, and I wanted to get this house cracked out because I had somebody coming to rent it...So there was all that sort of stuff going on as well, which I can now look back on and things and, you know, I shouldn't have used it as an excuse about not going to the doctor's, but I probably did probably at that time and things, about getting all that sorted out. The way things, my mum's funeral and all the emotion and trauma that goes with it as well.*

**(Mark: change in bowel habit, rectal carcinoma)**

*You think 'right, okay, this is happening. Right, I've done that, I'll deal with that later, because I'm doing this now' you know, that kind of thing. That was the only way I could cope with it.*

**(Eleanor: rectal bleeding, diverticulosis)**

People made judgements as to what issues were the most important, or pressing, at that time, and ranked their symptoms and health in amongst all of these other issues. For people who prioritised some demands over others, addressing their symptoms was generally not a priority to begin with. As other competing demands were removed from the situation, or as symptoms took a greater toll on that person's functioning, attending to their health rose up the list of priorities:

*Well what it was, I did have a cough, but I run my own business, and I was like, my husband, I spent a lot of time there. So, I had this cough and it was annoying but it wasn't, well, life threatening...and I had it for, I don't know, about four or five years. It was a long time. Then I retired in January, sold the business, retired. I thought 'right, enjoy my life now' and this coughing and coughing. Then the breathing started when I retired...Then I got a letter through the, it's fate, a letter came through from the NHS...Well, I had time on my hands, nothing to do, I thought 'oh yeah', so I went to the doctors.*

**(Pauline: cough & breathlessness, COPD)**

We can see from the excerpt above that whilst Pauline was working, her cough was not a key priority for her, as her time was focused on running the business. However, when she retired she had more time on her hands, with which she could deal with her symptoms and,

at the same time her symptoms began to change, with the introduction of breathlessness, and so consulting became a priority for her when it previously had not been.

For other people, as time progressed, the resonance of certain influential factors diminished or grew, prompting them to review previously rejected considerations or act in a way which they had not felt possible to do before. This is particularly the case for participants who integrated different information into the appraisal of their symptoms over time, considering numerous contributory elements.

In Elaine's interview, she talked about how her friends and family were encouraging her to consult about her symptoms, and that her family history of bowel cancer was something that was in the back of her mind throughout the symptomatic period. The symptoms sometimes interrupted her socialising and also affected her workday, as she was having to rush to the toilet without much warning. She also took precautions to ensure that the toilets didn't smell and she began carrying changes of clothing in anticipation of soiling herself. She talked about reaching the decision to seek help after having a particularly bad week at work, as a result of the diarrhoea and soiling, and how all of these factors came together in her thoughts about her symptoms leading her to decide that it was time to consult as *'this is getting worse and it's affecting everything now'* (**Elaine**: loose bowel movements, diverticulosis).

Among people who considered a number of contributory elements in their appraisal of symptoms, all of the elements were assessed in at a point where the symptoms became something which they now believed to be an issue that had to be addressed:

*It was putting everything together. You don't want to go and burden people, you don't go bother people about things that no. But as time was going by there was too many things. And having the knowledge that you have and things, there was too many things that were stacking up, that you think, and the way you described, there were things, stacking up processes and then basically there was too many things that were hand in hand.*

**(Mark**: change in bowel habit, rectal carcinoma)

## Summary

Symptom appraisal and help-seeking decisions take place against a backdrop of many influences which extend beyond the individual and can be categorised as occurring within one of four contextual domains; individual experience, interpersonal relationships, health care system interactions and social and temporal context. People's previous experiences of illness, exposure to carcinogens and perceptions of their identity all influences the

evaluation of symptoms and the discussion of symptoms with others assisted symptom appraisal and help-seeking decision making, through the sanctioning of help-seeking and the use of others insistence as a justification for consultation. Notions of appropriate 'patienthood' shaped help-seeking decisions with some people believing consulting early was 'the right thing to do', whereas others believed that 'not wasting the doctor's time' was 'the right thing to do'. These beliefs about appropriate use of health care system resources were informed by wider social discourse context, including people's social roles, culture and the media.

This section sought to illustrate that help-seeking is multi-faceted and complex and that people's symptom experience, appraisal and help-seeking are influenced by many factors, some on an individual level and some on a wider societal level. I will shortly present in full the stories of a small number of participants to illustrate this, re-contextualising what have, up until this point, being presented as fractured and disparate stories. The ways in which multiple influences on help-seeking behaviour, both positive and negative, combine to enable the individual to reach the final decision to seek help will be explored Chapter Seven, using theories of patient behaviour and concepts of health and illness to consider how these relate to the influences on help-seeking presented by participants in this study.

### **5.3 Help-Seeking Journeys of Early and Prolonged Presenters**

One of the aims of this research was to compare the social contexts of people who presented quickly about their symptoms and those who took longer to present. This section explores the differences in the help-seeking journeys and social contexts of those who had short (less than one week), medium (between one week and two months) and long (greater than two months) patient intervals.

#### **Short Intervals**

There were many similarities in the narratives of patients who went to the doctors quickly about their symptoms. Most notably, all had acute, dramatic and sudden onset symptoms. This was mostly episodes of bleeding (either rectal bleeding or haemoptysis) but there was also one woman with reflux who aspirated and another who experienced an acute incident of excruciating pain through her chest. Participants were immediately concerned about their symptoms, as they were experiencing something that they felt to be very 'out of the norm':

*I basically felt unwell for about three or four days, and then I got up on the morning and I went to the toilet and I was just passing large, and I mean large*

*like that, lumps of jellied blood, and it was just sitting in the bottom of the basin, toilet, and I was like quite - I'd never seen anything like it so I was a bit worried.*

**(Christine: fatigue then rectal bleeding, NAD, patient interval of 4 days)**

Although there was immediate concern, this didn't necessarily translate into immediate action, but always resulted in immediate appraisal of the situation. Everyone considered what the possible cause of their symptoms may be, even if they couldn't conclusively explain it. Symptoms were generally attributed to 'something serious', often cancer, but also possible heart attack or aspiration:

*But then when the pain comes and you're being sick blood and you're losing blood from your back passage and, then you think this isn't irritable bowel syndrome, this is something else, yeah go and get it sorted...[How did you feel about them [the symptoms] a bit?]...Sick really, thinking oh my goodness, I've got it [cancer], I think I've got it, you know what I mean?*

**(Julie: stomach pains and diarrhoea, NAD, patient interval of 5 days)**

After first experiencing their symptoms most people waited a couple of days before seeking help. This was sometimes due to the timing of symptoms, where they occurred just before the weekend, and sometimes because participants chose to monitor their symptoms to see if they persisted or developed, then incorporating this information into their symptom appraisal:

*Recently I went back again on to the colonic irrigation and the first time I used it again I had bleeding, which bothered me a little bit and then I thought 'maybe it isn't anything' and I tried it several days later and bleeding again so I thought 'well for safety's sake I'd better go and check that out'.*

**(Mary: rectal bleeding, diverticulosis, patient interval of 5 days)**

Although people may have waited a few days before arranging an appointment, this didn't necessarily mean that it took them that long to decide on the need to consult. Some participants may have decided on the need to consult almost immediately but waited a short period of time before making an appointment. Generally, this was because participants waited until Monday to seek help via their own GP, as opposed to attending an out of hours appointment, which was felt to be inappropriate:

*Yes, [the bleeding happened] just the once. I went to the doctor. It bled on the Friday and I phoned the doctor on the Monday. I suppose I had the weekend to think about it. But I didn't rush to the telephone on the Friday, but I thought over the weekend, well, get some help on this, so on the Monday I rang the doctor. I didn't panic...[So you just mulled it over for a few days]...Well, Saturday and Sunday you can't...[You couldn't have gone anyway, no, but Friday]...Oh I didn't*

*panic. I just thought oh that's serious; it could be serious and is it? On the Monday I phoned, it's easy to ask for help and I got help.*

*(Jack: rectal bleeding, diverticulosis, patient interval of 3 days)*

Most people mentioned their symptoms to others, with the exceptions being participants who lived alone. Although people mentioned their symptoms it was often a matter of disclosing, or sharing the information, as opposed to seeking out a dialogue and discussion about the symptoms, their causality, or the appropriate course of action. Participants had largely decided on their intended course of action prior to mentioning their symptoms to, usually, their significant other, and were resolute in their intended behaviour, irrespective of the advice which was offered to them:

*[Did you mention it to him [her husband]?]...I told him. He said 'what were you doing' and I told him, and he just like, 'get to the doctors straightaway', that's his answer to everything...[And what did you; how did you?...]Well I knew something wasn't right because I didn't feel right. I felt my chest wasn't quite right and my first thoughts were, 'I'm back at work on Monday, I'll ask one of the girls to listen.' I always had that in my mind anyway. If I hadn't have been able to I would have just made an appointment to see the GP..[So you'd already decided before you spoke to your husband.]...Yes, that I was going to get it sorted out anyway.*

*(Sandra: cough, chest pain & breathlessness, inflammation, patient interval of 2 days)*

None of the participants who presented to their GP quickly had any pressing social responsibilities, with most people describing life as pretty normal at the time. Although people may have had commitments at the time their symptoms began, such as work or parenting, none of these commitments were out of the ordinary or overwhelming:

*[I was just wondering if you could tell me just a little bit about, to put things into context, what was your life like at the time? So you were working?]*...

*Working as normal, nothing else going on in my life, everything was really normal wasn't it? No, nothing out of the ordinary...[Nothing, you had no stresses or emergencies or anything?]*...No I had no stresses. Life was just normal.

*(Steve: rectal bleeding, NAD, patient interval of 3 days)*

### **Medium Intervals**

Among participants who took a few weeks to consult about their symptoms there were also some commonalities. The symptoms experienced by these individuals were a lot less alarming than the symptoms experienced by people who presented very quickly. Common

complaints were a change in bowel habit, including diarrhoea, a cough, which was sometimes productive, or a general feeling of being unwell.

People often engaged in periods of observation to monitor their symptoms and see if there was any improvement. For instance, among participants reporting a change in bowel habit it was common for them to amend their diet, to see if their symptoms improved, as many related their change in bowel habit to over-indulgence:

*I didn't go and see the doctor until February, but it didn't improve you know. And we eat healthily, lots of salad and greens and so I thought well it may be something that I've done wrong over Christmas and New Year, over-feeding or whatever but it continued so that's when I decided to go to the doctors.*

*(Fred: change in bowel habit, NAD, patient interval of 6 weeks)*

These people monitored their symptoms to see if they would improve, as many believed that symptoms would clear up quickly, (i.e. a cough) or would return to normal (i.e. bowel habits). In this sense, people initially considered basic, everyday explanations for the symptoms they were experiencing, however, for most people there came a point at which the symptoms were deemed to have been present for 'too long':

*Well I think it went on for about six weeks and I realised it wasn't improving so I thought 'I'd better seek some advice.'*

*(James: 'belly ache', diverticulosis, patient interval of 6 weeks, patient interval of 6 weeks)*

When people felt that their symptoms had been present for 'too long' they began moving toward explanations which were more disease based, than based in everyday life. For instance, Arthur initially thought his wife had given him a 'bug', however, as it was present for an increasingly long time he began to consider other explanations, implying that cancer was an underlying concern for him:

*On Wednesday my wife came home and said 'Oh, that dog we had in on Monday had campylobacter', I said 'really', she said 'I wonder if that's what's wrong with you?', I said 'well what happens with it?' she said 'well we give it antibiotics' I said 'well I can imagine getting antibiotics at the doctors, no chance' and I said 'it'll pass off' and I struggled for a fortnight...[So what was it that made you think, 'right this is it I can't?']...Well, I can't tolerate it anymore because I had no idea what was causing it, whether it was some horrible thing developing in my gut, you don't like to think about that but I feel quite confident that I should be able to go on holiday [laughs] and enjoy it. So, you know that's basically it.*

*(Arthur: very loose bowel movements, diverticulosis, patient interval of 2 weeks)*

Amongst people who took a few weeks to present there were different approaches to the sharing and discussion of their symptoms. Some people didn't discuss their symptoms with other people. One man, a retired clinician, didn't feel the need to seek input from his family as he was in control, and most knowledgeable, about his symptoms. Another didn't discuss his cough with anyone because of the frequency with which he got chest infections, meaning that a cough was a regular and normal experience for him. Others discussed their symptoms and potential causality with their partners, although not all actively sought advice during these discussions. One woman, who had been 'bringing up fatty globules which were dark red/brown' talked to her husband in the hope that he would reassure her and dismiss her anxiety, however, she was disappointed by his response:

*[Did you talk to your husband about your symptoms?]. Oh yes, and his, Ray is always 'go to the doctors' because I discuss it with Ray and he'll say 'look, I'm not a doctor', but I'm wanting him to say something reassuring like 'oh you're alright, it's nothing, that's fine', but he always says 'go to the doctors, they have the answers'. So, he's the opposite of me.*

*(Pamela: blood in phlegm, bronchiectasis, patient interval of 3 weeks)*

We can see that amongst participants who took a few weeks to present to their GP there were a lot of similarities, including perceived (non)severity, or normalcy, of symptoms, engagement in periods of monitoring, and changing explanations of causality. One exception to this was Joseph. Joseph had been 'spitting up blood', which he had tried to hide from his wife. What was different for this participant compared with the other people who consulted within a few weeks, was the acute and serious nature of his symptom and the chaotic nature of his personal life at that point.

While he was symptomatic his wife was being treated for cancer, which was obviously a central concern in their lives at the time. Not only did he not want to worry his wife, hence trying to hide the blood from her, but, being self-employed, he also couldn't really afford to take any more time off work, in light of the time he had already taken off to attend his wife's appointments. When his wife 'discovered' the fact that he had been spitting up blood she encouraged him to go to the doctor's. He had also felt a need to consult because of his concern over the severity of the symptoms, however, he was hoping to wait a bit longer before doing so, leaving it until work was quieter:

*Well I tried to hide it but of course her indoors, it was her who said 'get it'. 'Oh don't, I haven't got time to go to the bloody doctors'. 'You're going'. And about seven days after that...[And do you remember when she, I know it restarted in*

*October but do you remember how long after it restarted that she told you to go?]*...About four or five days I think, because I was, she came in and caught me. 'What are you doing?' 'Nothing.' And then all hell broke loose...[So you say she came in and caught me, were you trying to hide it from her?] ...Yes...[Because?]... Well it was because always that time of the year the work's absolutely crackers because people want stuff doing for Christmas. And I thought 'look I'll hang on until after the busy time's over', but she wouldn't have it.

**(Joseph: coughing up blood, NAD, patient interval of 2 weeks)**

In contrast to Joseph's situation the other people who consulted within a few weeks of symptom onset all had relatively stable and unpressured lives at the time. Participants who took a few weeks to present experienced less alarming symptoms than those who went within a couple of days and their social context was not producing additional pressures which had to be juggled alongside decisions around appropriate self-care. It may be that for Joseph it was the social barriers which he faced which made him behave differently to how we might expect someone with an alarming symptom to behave (i.e. consult very quickly).

### **Long Intervals**

Among the participants who took the longest to present there was a range of symptoms, from a wheeze or a more frequent need to defecate to haemoptysis and rectal bleeding. For many people, their symptoms seemed to change, or progressively worsen, generally commencing with a more minor symptom and progressing to include more serious symptoms:

*I was walking with her [daughter] down in Bradford on Avon where she lives, near Bath. And she said 'you're wheezing dad.' And that was a couple of years ago, and the wheezing got worse and it got worse when I was in bed with my wife, and she would say 'you're wheezing, you wheezed all night I couldn't get to sleep for your wheezing'. But that was about a year later.*

**(Tom: wheezing & breathlessness, chronic bronchitis, patient interval of 2 years)**

Everyone considered possible causes for their symptoms and, in much the same way as the symptoms progressed and changed over time, so too did people's explanations for their symptoms. There was a very linear and logical progression to people's attribution of cause, moving from the mundane to the serious:

*I thought 'right okay so maybe it's just, if it is anything', I am a nurse, 'maybe it's the lower part of the bowel and it won't be anything serious. I know the symptoms, other than I get constipated but I've been like that for years, so it wasn't anything suddenly different'.....*



*'I thought 'well we'll not panic, it could be just haemorrhoids or something like that. I'll just go over to the doctors first and see what she says'....  
'You work your way through from the simplest things up to the 'well it's whatever'. You don't go in at the 'well it's definitely cancer or something like that'. Do you know what I mean? I wasn't at that stage.*

*(Eleanor: rectal bleeding, diverticulosis, patient interval of 6 months)*

Although cancer was frequently the final attribution of potential causality before people decided to consult their GP, this was rarely the first time that people considered cancer throughout their symptom experience. Cancer was frequently considered by people, however, it was repeatedly rejected as a possibility. People's consideration then dismissal of cancer was based on judgements that they made concerning the nature of their symptoms (i.e. if they were symptoms of cancer) alongside other considerations of indicators of risk (eg. the absence of other perceived signs of cancer and reassurance from negative FOBT bowel screening tests):

*I wasn't passing blood. So as far as I was concerned, that wasn't it. Had I been passing blood, I would've gone immediately, 'cause to me that's one of the main symptoms. Because I didn't have that and because I wasn't losing weight, then it was obviously some type of bug.*

*(Elaine: loose bowel movements, diverticulosis, patient interval of 4 months)*

[Harry's Wife] *We'd just done, both of us had just done a cancer screening by post. And you took that down to the doctors to show him that it said it was clear.*

[Harry] *And that was while I had, I hadn't visibly saw any blood, but that was when I was on, the stools has been loose.*

*[Was when you did the screening?]*

[Harry] *I sent this away, and it came back all right.*

*[So did having the letter back saying that the screening was clear, did that influence your decision on going to the doctors then?]*

[Harry] *Well yeah, because I thought at the time 'if I'm clear', obviously you wait for the post and it took about a fortnight to come. And then when it come it was clear, so.*

[Harry's Wife] *It says normal.*

[Harry] *Normal, it satisfied me for a while. But then it was still happening, so I thought 'well there is something wrong.'*

*(Harry: loose bowel movements, microscopic colitis, patient interval of 4 months)*

These people were not ignorant of the possibility that their symptoms may be caused by cancer but they considered this possibility in light of a number of other mediating factors. They perceived their potential risk of having cancer as being low, and so dismissed cancer as a possible explanation.

As symptoms progressed, or didn't improve, people revisited the previously rejected possibility of cancer and reconsidered it in light of their current situation. It was when people could no longer dismiss cancer as a possible cause that they decided to consult their GP, as this was the only remaining means of definitively ruling out cancer as a possibility:

*I had it in my own mind that what I wanted really was some reassurance and perhaps an x-ray, and sure enough the doctor said, 'okay', he said, 'let's start the ball rolling, the first thing we'll do we'll get an x-ray and then we'll see what the results are next week and then we'll decide what we're going to do after that...[And then as the time progressed and you decided to go, did you have any thoughts then about what it might be or as to what, when time progressed and you thought, I should go to the doctor's now, did you have any thoughts?]...Oh yeah, I thought, 'oh it might be cancer', and that's why the idea of having an x-ray would give you that reassurance if it was clear and that's the way it went. (Richard: cough & chest irritation, gastro-oesophageal reflux disease, patient interval of 5 months)*

The other key motivation for help-seeking was the impact that symptoms were having on people's lives. Many people consulted after experiencing a particularly pronounced episode of symptoms, with people talking about having had 'a really bad week' just as they decided to go to the GP:

*I must have had a really bad week that week where I was going four or five times, and by the Wednesday it was a bit sore. And I suppose in a sense, I don't know why after a year, I must have got myself down on that day because it must have been bad.*

*(Roy: persistent diarrhoea, spirochetosis, patient interval of 18 months)*

People who took the longest to consult about their symptoms often had many responsibilities and commitments in their lives. Symptoms had an impact on people's abilities to perform in these roles, yet roles also acted as barriers to help-seeking. These roles and commitments were different for each individual, and were often numerous. They included responsibilities towards the family, work, leisure activities, and infrequent commitments and problems, such as a previously booked holiday or a bereavement.

As people's symptoms came to a head the impact which they had on their lives was increasing. For many the effect of symptoms on their ability to perform 'as normal' in one area of their life was one of the key factors which prompted help-seeking.

*Although it'd been at that stage 5, 6, 7, 8 times a day, it was that one particular week in January and I thought 'oh I can't'. I mean I had some accidents, lets put it like that, so of course it became, 'this really is now sort of disturbing my life', as opposed to 'I feel ill'. It was just disturbing my life.....I was taking like spare undies, I was taking pantyliners, like more pantyliners. Normally I would have a*

*spare one with me, but having a fair number with me. And even, I mean they were just permanently in a carrier bag in the bottom of my big handbag so that, wherever I went, whether I was at work or not, I had them with me as a bit of a back up. But when you get to the stage where you're stripping off in the toilet at work and rinsing them out in the sink and drying them with the hand dryer, 'cause you don't know what. The thing is if you have an accident it doesn't stop stuff getting marks or, I couldn't just put them in me carrier bag stinking. So that was when, that week was just the final straw that broke the camel's back.'*

*(Elaine: loose bowel movements, diverticulosis, patient interval of 4 months)*

*[But they [the symptoms] did have an impact on what you could do at the gym?]. Oh yeah, I mean one of the reasons I went, because I've said to you haven't I, I can't do what I used to. I know I'm getting older and I know you're not going to be able to do, but just tailed, well it didn't tail off, it just stopped. Just say for argument I used to, just say I ran half an hour on the treadmill, well that's come down gradually. Well not really gradually, pretty swiftly really, where now I still do my half hour but it takes a hell of a lot more out of me. I know I'm getting older and it should do, but I just don't feel right.*

*(John: cough & breathlessness, NAD, patient interval of 9 months)*

Eleanor's story, below, illustrates how people are often not able to contemplate seeking help about their symptoms, because of the numerous roles which they must fulfil:

*So all the architects and the meetings with builders and all that kind of stuff was all going on. In between we're still looking after the grand bairn, going to hospital for this that and the other, so it's all very busy and very stressful I suppose. But I'm a doer as a person, so doing helps, do you know what I mean? If I have things to do, if I'm sat here worrying oh it would be worse, I like to get up and do...[So by being busy it's almost you don't have to, not don't think about it but it's not]...It's a therapy itself in some ways yeah, by having that to do. But you were talking over the building work in the morning with the builders and that kind of stuff. Then we might take Tim [husband] off to hospital or we'd go and collect the grand bairn. And that time with the grandkids was lovely because you couldn't think about anything else, you just had to be on their level and with them and it's just lovely. And if you come home a bit exhausted well that's all the better. And you have your meal and a bit of telly and go to bed.*

*(Eleanor: rectal bleeding, diverticulosis, patient interval of 6 months)*

Another example of the complex relationship between inability to perform within a role, and how roles constrained one's ability to act upon symptoms, was Abdul's experience. Abdul is a married father of two, who lives with, and cares for, his elderly father, whilst also working full time and taking on additional responsibilities, such as the chair of governors at a local school. For Abdul his response to his symptoms was bound up in concerns of work, familial responsibilities and the cultural stigma of illness:

*I don't want to now be seen after my mum's gone to be falling ill. Already a lot of the eyes were turned towards us when my mum passed away, they thought, a lot of our family relatives thought our house would come to a standstill, and life goes on and we do move on. But for me personally I feel this pressure and I really don't want to be seen as, I feel as though I'm letting everybody down, and myself...[Do you think it's 'cause you might be frightened that, not frightened but, there's a thought in you that once you start, from watching your mum, that once you start getting ill]...It'll do that. And also be tarred with the same brush by the family, by the wider family. Really I've always tried to think to myself that I don't care what anyone, I'm a young second, third generation Asian, I don't live with their old society rules and everything and then suddenly without realising, subconsciously you're being bound by them and you think 'hang on, where did that come from?'...I don't want to be seen as being ill because there's been enough illness in the house already and my dad is no, God bless him, he's getting old, but I suppose I'm being a bit intolerant because, he could make himself better but, you know...Yeah and you know siblings come round and they say 'oh, he's lovely dad', all this that and the other but they don't live with it. They don't see that when he can't make it to the toilet who's going to clean it up and all that, food, washing, you know?...['Was The coughing affecting work?'] Yeah and to the point where I was dreading it. And even now I'm a bit apprehensive when it comes to that time of year, I'm thinking 'oh Jesus, oh, it's going to happen again'. And it stops your functioning, it gets to the point where, you know, it's getting a bit mad when you can't string a sentence of words together. My job is to speak to people and you're forever coughing and then I was speaking, oh yes it came to four o'clock and I'd be going for my break at four o'clock and I'd be sitting in the tea room and I'd be exasperated because I'd coughed that much.'*  
*(Abdul: coughing up blood, inflammation of the lungs, patient interval of 3-4 years)*

Many people talked to others, including spouses, children and friends, about their symptoms and these conversations often occurred throughout the symptomatic period. Although many people discussed their symptoms with others, and listened to others' advice, these conversations were rarely prompts to help-seeking, and instead others' opinions were supplementary factors which people used in the appraisal of their symptoms. Some people initially used others' 'nagging' as justification for help-seeking, however, as the interviews progressed it frequently transpired that the turning point which actually prompted help-seeking was a change in their own thoughts or concerns:

*This year I went to the doctor's when my wife told me to, as you do...I began to worry about it being asbestosis yeah, that was the major reason why I went to the doctors; otherwise my wife would never have forced me to go. Well she'd have tried but...*

*(Tom: wheezing & breathlessness, chronic bronchitis, patient interval of 2 years)*

While some people actively sought out these conversations, for others these conversations were imposed on them and, in those instances, the advice and suggestions of others were considered to a much lesser extent than it was by people who actively brought about conversations with others:

*Yeah and it didn't bother me at all. It bothered other people more than it bothered me, because they worked with me...[Yeah, so did they mention it to you, your cough, a lot?]. Yeah...[Or did you talk about it to them or did they bring it up with you?]. No, they brought it up with me. Time you got rid of that cough! Time you went to the doctors! Nag, nag, nag, nag! Have you seen that advert on the telly? You could have cancer, or whatever the advert was at the time. I said I've got a cough. I smoke, that's why I've got a cough! Everybody who smokes has a cough, and that's how I put it across, but as I say I thought it was.*

**(Pauline: cough & breathlessness, COPD, patient interval of 4-5 years)**

However, there were two others who chose not to discuss their symptoms with others. These two were both nurses who also happened to be taking care of spouses with serious health conditions at the time. They felt that they did not want to trouble or worry their partners with information about their symptoms and instead considered and appraised their symptoms on their own:

*[You've touched on it already that you hadn't mentioned to your wife about your symptoms. I'm just wondering if you could tell me a little bit more about why you chose not to. Was it a conscious decision not to, or?]. It was a very conscious decision not to. I think you'll have gleaned already from what I've said to you and things that I was being the strong one, the go to person and things, and I didn't want to worry anybody. I had my own worries obviously but I didn't want to worry certainly my wife and certainly my son. Jenny has got a condition. It's a genetic condition called multiple endocrine neoplastic syndrome, which is MEN1, which basically it's transmitted itself to my son....So they've got issues as well that I didn't want to worry her about, and certainly didn't want to worry Christopher about. I didn't tell Christopher about it. I told you I told Jenny on the Sunday night before the doctor's.*

**(Mark: change in bowel habit, rectal carcinoma, patient interval of 6 months)**

## Summary

There are a range of issues which people face when experiencing symptoms, some of which are common to all those who have sought help. By using categories of time to presentation to facilitate analysis it was possible to compare whether, and how, the help-seeking journeys of people who present quickly, and those who take longer to present, differ. There are four key areas where we can consider differences in time to presentation: symptom onset and appraisal, the impact of symptoms, disclosure and discussion of symptoms, and social context and responsibilities.

### *Symptom Onset and Appraisal*

Patients who consulted within short periods of time tended to have alarming symptoms which came on very quickly whereas, people who took longer to consult had symptoms which tended to be vaguer and more insidious. However, for those who took the longest times to present there was a range of symptoms, from the systemic (i.e. a change in bowel habit) to the acute (i.e. haemoptysis), and these people's symptoms tended to change or progress over time.

People who presented quickly immediately considered the potential cause of their symptoms and often attributed the symptoms to a serious condition, whereas those who took slightly longer to present generally monitored their symptoms for a short time to rule out 'normal' explanations (change in diet or a common cough), before going on to consider more disease-based explanations. Those who took the longest to present also had changing explanations for their symptoms, working through a number of possible causes throughout the appraisal period. Whereas those who presented within a few weeks generally only considered a maximum of two explanations for their symptoms. People taking a long time to present took a logical approach to the attribution of potential causality, moving from the mundane to the serious, and although people's final attribution was often cancer, this was never the first time people considered cancer, as they had previously considered and rejected it as a possibility.

### *Impact of Symptoms*

For those who presented very quickly their symptoms didn't have much opportunity to impact on their daily lives, however, their symptoms were perceived of as drastic body state deviations and caused the person concern. The same was true for patients who presented within a few weeks, with symptoms not really encroaching on their daily functioning, however, unlike those who presented very quickly these people's symptoms did not induce a significant amount of concern or anxiety. For those who took the longest times to seek help, symptoms increasingly impacted their daily functioning the longer they were present. Symptoms often affected people's ability to perform and function in the work place, or in their recreational activities and personal commitments. People also said that their roles and responsibilities hindered help-seeking, as these other responsibilities were more pressing or important.

### *Disclosure/Discussion of Symptoms*

People who presented quickly generally mentioned their symptoms to other people, however, these conversations were more about disclosing information than discussing it.

People had largely already decided upon their course of action and were informing others, mainly spouses, about the situation, with the exception being those who lived alone. For people who took longer to present there was an array of approaches to the discussion of symptoms; some chose not to discuss their symptoms at all, others chose to discuss their symptoms and potential causality but were not necessarily seeking advice or input as to appropriate future actions. Of those who took the longest time to present many spoke to a number of other people during their symptomatic period and treated the advice they were given as a factor in their overall consideration of information. Those who chose not to discuss their symptoms with others felt no need to divulge this information. They were concerned that it would cause additional worry to their spouses, who had their own health concerns, and so saw themselves as protecting their spouses from the information and potentially unnecessary additional anxiety.

### *Social Context and Responsibilities*

The lives of those who presented very quickly after symptom onset tended to be very 'normal', facing no additional concerns or responsibilities at that time. The lives of those who took a few weeks to consult about their symptoms were also typically normal, with the exception to this being Joseph, who was both working and caring for his sick wife at the time. Yet, Joseph experienced a markedly different symptom than those who presented within a few weeks, in that he had an acute and alarming symptom, and also from those who took the longest time to present who, although sometimes experiencing bleeding, tended to experience this within a trajectory of symptom progression and which, initially, wasn't as substantial or significant.

Those who took the longest time to present were often experiencing a complex period in their lives, which entailed performing numerous roles. Life was generally 'not normal' at the time, with the symptomatic period being punctuated by bereavements, family illness, or pre-organised commitments, alongside longstanding commitments and roles within the workplace, the family and the church. For some it was only when symptoms significantly impacted on their functioning in these roles that the decision to consult was made, whereas for others, the pressure to perform within these roles discouraged them from acting on their symptoms.

## Chapter Six: Participant Vignettes

This chapter contains an overview of the stories of six interview participants. These particular participants were selected because they represent a range of different experiences, both individual and contextual, and also represent a range of lengths of time to presentation. The purpose of including vignettes at this point is to try to re-contextualise the help-seeking journey, which has been fragmented in the preceding chapters into themes. By outlining the patient journey in its entirety the intention is not only to give the voices of participants greater spotlight within this work, but also to illustrate the multiplicity of factors, both micro and macro, which influence how people respond to, and act upon, symptoms of cancer.

### 6.1 Melanie

Melanie is 48 years old and has small cell lung cancer which *'had not been caught early'*. At the time of the interview she had undergone two rounds of chemotherapy and was about to start a third and felt hopeful that the treatment would halt the tumour for a substantial period of time.

The first symptom she had which indicated that something was wrong was a sharp pain which travelled through her chest, from her back to her breast. The pain was on the right hand side of her body and she described it as a pain that, had it been on her left hand side, she would have thought it was a heart attack. The pain came on suddenly when she got home from work one evening. It was a debilitating pain and she struggled to walk, bend or sit. She rang her husband and he told her to ring 111, which she did, who advised her to go to the urgent care centre. She got her son to drive her there that evening and she was given three possible diagnoses (pleurisy, a blood clot, or costochondritis), prescribed antibiotics and painkillers and told to consult her doctor within a week, which she did. Melanie didn't really have any thoughts as to what may be causing the chest pain, however, when the GP investigated her and the CXR showed an opacity Melanie thought that this must be scarring left from having swine flu five years previously and never even considered cancer to be a possibility.

In retrospect she did identify two other symptoms which she had been experiencing for roughly four months prior to the pain, which were breathlessness and fatigue. She never really paid either of these symptoms much attention, thinking the breathlessness was a result of weight gain after her hysterectomy and the fatigue was a result of doing overtime at work. She didn't really consider herself to have been symptomatic, particularly not in



relation to any of the typical lung cancer symptoms, as the first symptom of significance for her was the pain.

## 6.2 Steve

Steve is a 50 year old married man who lives with his wife and teenage son. He is a shift worker and takes care of his mother, who has COPD and is housebound, every Monday so his father can go to work. He says that at the time he was experiencing his symptoms life was *'normal'* with no *'stresses or emergencies'* going on. Overall, his health had been good, however, a few years ago he began experiencing blackouts, which the consultants haven't been able to provide an explanation for.

He was on a night shift one Friday evening, went to the toilet in the early hours of Saturday morning and noticed that there was blood in the toilet bowl. At first he thought it may be a one-off and caused by a pile, however, he noticed more rectal bleeding over the weekend, which concerned him and made him start to worry that it may be a sign of cancer.

He mentioned the bleeding to his wife on the Saturday, after it had happened for a second time, and she reassured him that it was *'probably nothing'* but that he needed to go to the doctor's to get checked out. His wife said that she *'nagged'* him to make an appointment, but knew that he would make one himself anyway. Steve said that although he talked to his wife about his symptoms and they discussed what to do, he had already made the decision to consult the GP before his conversation with his wife.

Because the symptoms persisted over the weekend, Steve felt that he needed to consult and get the bleeding checked out, to make sure it wasn't anything *'serious'*. He rang up the doctor's on the Monday morning, stressing the urgency with which he needed to see a doctor, and was able to get an appointment that morning.

He was a bit embarrassed about being examined rectally by the GP but felt that it was something which *'had to be done'*. He didn't mind talking to his family about the rectal bleeding, however, he never told anyone at work about his symptoms as he found it embarrassing

## 6.3 Joseph

Joseph is a 65 year old married man who works full time as a joiner. Work is a really big part of his identity and he has no intention of retiring any time soon as he believes that working is what keeps him fit and stops him from *'seizing up'*. His wife had been diagnosed with

cancer two years previously and had had a lot of treatment resulting from the cancer ever since.

In October Joseph started to notice that he was coughing up blood. He had previously had a brief period of coughing up blood in January of the same year, which only lasted for a couple of days. He did consult in February, after his wife prompted him to, and the doctor told him he wasn't that concerned by it but that he should come back if it happened again. However, this time the symptoms were somewhat different to how they had been in the January as the blood was a darker colour, a deep red, whereas previously it had been pink. This change in colour was something that concerned Joseph, along with the greater volume of blood this time.

Eighteen months prior to this symptomatic episode, Joseph's wife experienced a rupture in a vein in her neck, and so Joseph related his symptoms back to his wife's experience and became concerned that the same thing may be happening to him.

He tried to hide the blood from his wife to begin with, because he felt that she had enough to worry about with her own health, but she '*caught*' him about five days after the symptoms started. She told him he needed to go to the doctors, and Joseph booked an appointment almost straight away, which was for a weeks' time, which he was happy to wait for, as he wanted to see his own GP. He later says that although his wife '*made*' him go, he himself wanted to consult, in order to address his own concerns, but would have waited a bit longer to consult if it hadn't been for her input.

He was reluctant to go straight to the doctors because work was incredibly busy with it being the run up to Christmas, and Joseph felt that he couldn't justify consulting during such a busy period, and so was intending to wait until after the Christmas rush to address it. Amidst the increased workload he was also having to take time off to take his wife to her hospital appointments, which was putting him further behind with his work, however, her health was a priority to him.

## **6.4 Elaine**

Elaine is a 65 year old woman who lives with her husband and works part time in the customer services department of a car dealership. She has three adult children and a number of grandchildren who she sees regularly. She had been absent from work since the beginning of September due to stress and depression, and had just gone back to work at the end of November on reduced hours, as she had previously worked full time.

Elaine started experiencing diarrhoea after she returned from a holiday to Madeira in October and initially thought that she had *'picked up a bug'*, a theory which appeared to be confirmed when her husband also experienced diarrhoea a couple of days later. Her husband's diarrhoea went away, however, Elaine's continued over the following month, to the point where she was going up to eight times a day, with less and less control over her bowel movements. As it was the run up to Christmas Elaine put the symptoms to the back of her mind as she felt that they weren't a priority given how busy she was preparing for Christmas. As time was progressing she began to wonder whether her symptoms were the result of Irritable Bowel Syndrome. By January the diarrhoea had got worse to the point where she was going up to nine times a day, with little to no control. By this point she describes her symptoms as being griping pains followed by an incredibly swift need to go to the toilet and, although she felt better after going, it could be only fifteen minutes before she needed to go again. In February she experienced a particularly bad week where she was *'backwards and forwards'* to the toilet all day long and also soiled her clothes on a couple of occasions.

She found the diarrhoea restrictive for her social life, as she didn't go anywhere without a toilet. It also had a massive impact upon work, as she was constantly having to go to the toilet and experienced faecal incontinence. She was now carrying a large amount of panyliners, clean underwear and carrier bags in her handbag, in anticipation of having to clean and change her soiled clothing. There were only two toilets at work and Elaine would get anxious that there wouldn't be one available when she needed to use it. She was also embarrassed by the smell in the toilet after she had used it, so she took perfume in with her to try to mask it.

She talked to her husband about her symptoms, as he *'couldn't have not known'* given her change in behaviour, and she also mentioned them to her children. She chatted about it with a close friend, who had lost her husband to bowel cancer, as they *'discuss everything together'*, and was hoping that her friend would reassure her and tell her it was nothing to worry about. Her husband and two of her children left her to decide what to do about her symptoms, however, her friend and one daughter encouraged her to consult, because of their concerns that it may be bowel cancer.

Elaine said that a lot of people *'nagged'* her about the diarrhoea, reminding her that it could be bowel cancer and that she should go to the doctor's to get it checked out, particularly as her father had died of bowel cancer. However, Elaine didn't consider cancer

to be a possibility, as she felt that the fact she didn't feel ill and wasn't losing weight meant that she couldn't possibly have cancer. She had seen the Be Clear on Cancer campaigns, which talked about rectal bleeding and, as she didn't have any blood in her stool, she was reassured that she couldn't have cancer. She had also done the FOBT bowel screening earlier in the year in which the symptoms started, which was clear, which also reassured her that she couldn't have cancer.

Elaine talked about a range of factors eventually all coming together to influence her to make the decision to go to the GP; her dad's bowel cancer, the prompting of help-seeking from family and friends, the particularly bad week of symptoms, the impact the symptoms were having on her daily functioning, and her own underlying doubts about the possibility of cancer. When she made her decision to go to the doctors, she rang the surgery the same day and was able to book an appointment for the following day.

### 6.5 Mark

Mark is a part-time senior nurse in a challenging behaviours unit, who had also bought a house to lease just before his symptoms began, which needed a lot of work doing to it. He had always eaten healthily and been a very active person, playing five-a-side football regularly. Because of his 'healthy identity' he felt that he was someone who could never get cancer. Mark was diagnosed with rectal carcinoma and at the time of the interview he had undergone surgery to remove the tumour and was about to start chemotherapy the following week.

In late November Mark noticed that he had to go to the toilet more often than he usually did and that there was a feeling of urgency with which he needed to pass a motion. However, this only happened about twice a day and wasn't happening every day, so he *'thought nothing of it'* at the time. His symptoms continued and by February he was feeling a lot more tired and noticed that there was a small amount of blood when he went to the toilet. He thought that the bleeding was possibly because his skin was irritated because of how often he was having to go to the toilet and wipe his bottom, or possibly down to the amount of work he was doing, which would also explain his tiredness. He thought that his tiredness was probably to do with the combination of his long work days, the extra responsibility of the rental property, and the fact that he was getting older. He also considered, and researched, IBS as a possible explanation for his change in bowel habit. The fact that he had some days where his bowel functioning was *'normal'* also provided reassurance that it could be IBS that was causing his symptoms. As time went on he tried to

put his symptoms to the back of his mind, until the increasing presence of his symptoms, and the constant feeling of pressure in his bowel, meant he could no longer do so, as by May he was having to defecate up to twelve times a day. In May he began to consider the possibility that it could be *'the worst case scenario'*, cancer, an explanation which he had considered and rejected numerous times up until this point. He had initially avoided seeking help because he was afraid that it could be cancer, but by this point he was beginning to feel afraid that if it was cancer, and he didn't deal with it early enough, then it would get progressively worse and be untreatable.

During his symptomatic period Mark was very busy renovating his rental property, which he would go and do on an evening and his days off, and he had completed it by the end of March. His diet changed while working on the property, as it fell more in line with what the other builders ate, starting to regularly eat pies and crisps, and take sugar in his tea, something he hadn't done before, and so he thought his change in bowel habit may be because of all the *'rubbish'* he was eating. He also found that his symptoms weren't as bad when he was at work and so he wondered if this was because he had less time to eat and therefore may be the amount and type of food he was eating at home and when working on the rental house that was causing the bowel changes. He went through a period of trying to cut down his food consumption to see if that would help, but it didn't. Mark's elderly mother also died at the end of March and he talks about using the preparations for the funeral and feelings of grief as an excuse for not attending to his bowel symptoms. He went back to playing five-a-side football in April, which he had put on hold for a few months because of all of his other responsibilities, and when he returned he noticed that he was getting significantly more tired from playing than he ever used to.

At the beginning of May he found out that the wife of one of his patients had bowel cancer. When this woman next came in to visit her husband, towards the end of May, Mark asked her how she was doing post-surgery and also asked her how she knew something was wrong, to which she told him that it was an incidental finding through the bowel screening campaign. The fact that she was asymptomatic and yet had bowel cancer started to make Mark seriously consider the possibility of cancer. He says that although this wasn't what made him go to the doctors, it was a major part of his decision making process. This lady told him more about her treatment and told him that her son had said to her that her choices were basically *'a bag or a box'*. Hearing this phrase jolted Mark and made him weigh up his fears about a cancer diagnosis, and a possible colostomy, with the possibility of death, should he not attend to his symptoms in time.

He chose not to discuss his symptoms with anyone, as he felt that his wife and son had enough concerns in relation to their own health conditions (both have multiple endocrine neoplastic syndrome) and he felt that it was his responsibility to shelter and protect his family from worry and difficulty.

He decided to consult the GP about his symptoms at the end of May as his symptoms were now very frequent and difficult to manage, and he also felt that he now had time to address them, having got the house finished and having dealt with his mother's funeral and estate. He made the decision to make an appointment one morning when he was at the rental property doing some maintenance for the tenant. Whilst he was at the property he had to go to the toilet three times in half an hour and he talked about how although the alarm bells had already started ringing, this incident was when the '*big bell rang*'. He reached a point, that morning, where his symptoms had become too much of a burden and he felt that he couldn't continue enduring the major impact they were having on his life. He was seriously considering cancer now and also beginning to consider what the impact would be on his family if he did have cancer but left it too late for any treatment.

On his way home from the property he took a de-tour and went into the surgery to book an appointment, which was in one weeks' time. He remembers thinking that he should have asked if there were any earlier appointments, and stressed that he really needed to see a doctor, but he actually felt relieved that he wouldn't have to deal with it for another seven days.

## **6.6 Abdul**

Abdul is a father of two who lives with his wife, children and elderly father, whom he and his wife care for. Abdul is struggling to come to terms with how quickly his identity has changed from that of a bachelor, to a married man and father, then a carer for his terminally ill mother, and finally a carer for his father, all whilst being the sole provider for the family.

He works full time and work is a significant part of his identity, with Abdul taking a lot of pride in his performance and attendance. His symptoms have had a big impact on his ability to function at work over the past few years and he feels that they prevented him from getting a promotion because of his inability to speak during an interview. He also has many other roles in his life; equality officer at work, governor at the school and charity work, for which he received an MBE for his services to the community a couple of years ago. His

mother, who he cared for, passed away a couple of years ago and he is still very much grieving for her.

He is asthmatic and describes himself as *'reactive'* about using his inhalers, as he doesn't want to accept that he has asthma. He has suffered with coughs and wheezing for about five years and three to four years ago he began coughing up blood, which he thought was the result of having burst a blood vessel from coughing so much. He initially dismissed the blood as it wasn't that regular and seemed to coincide with when he was coughing badly however, this year it was more noticeable and regular, occurring most days, which made him feel more anxious and concerned about what may be causing it.

Initially, he tried to ignore his symptoms as he felt that he didn't have time to be ill because of the responsibility he felt in relation to running the household. He did talk to his wife about his symptoms and she encouraged him to go and see the doctor, but he was frightened that if he went that he would be diagnosed with a serious condition and that would mean that he, and his family, would be labelled with *'another illness'*, and face the judgement and stigma which came with that.

After he kept dismissing his symptoms, Abdul's wife asked their sister-in-law (a health care assistant) to come round and talk to him about them. He discussed his symptoms with her and she encouraged him to consult about them and also suggested tuberculosis as a possible cause. A couple of weeks after the discussion with his sister-in-law he coughed up a significant amount of blood and decided it was time to seek help in relation to his symptoms, in case they got worse. Prior to calling to make the appointment he told his dad about his symptoms and his intention to go to the doctor's and his dad agreed he should go. He didn't necessarily discuss his symptoms and help-seeking with his dad, it was more a case of informing him, as the head of the family.

Abdul has a good relationship with his asthma nurse but has struggled with his GP, as he sometimes feels dismissed by him though this did not deter him from consulting. Instead it makes him think about what he will say and almost prepare a *'script'* in advance of the consultation so as not to forget any important information.

His family history and ethnicity were some of the main factors which framed his views of himself and his health. One of the reasons he was concerned the bleeding may be a result of tuberculosis was because his family were from Africa and India and so he thought that his ethnicity may make him more vulnerable, even though he knew it was not a hereditary

condition. The fear of being labelled with illness, and the potential stigma that could bring to himself and his family was arguably the key barrier to presentation for Abdul. He said himself that although he viewed himself as a modern man, free from cultural boundaries, he was still constrained by them, because of fear of how others would judge him and his family.



## Chapter Seven: Discussion

The preceding chapters have demonstrated how people come to understand and act upon their symptoms. They illustrate how help-seeking decisions are complex, involving many considerations from multiple domains of an individual's life, as is evident in the participant vignettes. In order to understand the implications and meanings of the study, they need to be considered in the light of existing knowledge on help-seeking behaviours.

In this chapter I provide an overview of the patient interval, presenting a model to illustrate this period. The model details the 'individual' processes of symptom experience, appraisal and help-seeking, and the wider contextual domains which mediate and influence them, using examples from the interviews to explicate these categories. I then go on to focus on two key issues which arise in this study and provide interesting and novel insights into the help-seeking experiences of symptomatic individuals.

With a public health focus on prevention and prediction, and the current 'risk society' within which we live, risk appraisal has now become an everyday part of people's lives. The point at which people decide to consult about a symptom is a key moment in the diagnostic journey and in this chapter I use the notion of risk to introduce the idea of a 'threshold of tolerability'. This threshold is calculated using a range of contributory elements and their perceived implications for 'risk'. The decision to consult is made once symptom burden breaches this tailored threshold. Whilst numerous factors contribute to the calculation of risk and tolerability, the example of people's calculation of their risk of cancer is used to highlight how contributory elements are incorporated into the production of the threshold of tolerability.

The second topic to be discussed is the concept of the 'good patient'. As is established in the preceding section, the 'risk society' expects individuals to calculate and manage risk daily and independently. Alongside this, there is a 'new public health' approach which places emphasis on the individual to be motivated and proactive about their health after the absorption of governmental messages about appropriate behaviour. These discourses go on to place obligations and duties on an individual, in relation to how they should behave, and it is these obligations which moralise behaviour. A discourse of early presentation lays tenets for appropriate responses to symptomatic experiences and these obligations result in the moralisation of illness and help-seeking behaviour. Social discourses about the 'good patient' will be explored through three examples from the data:

beliefs about 'wasting the doctor's time', responses to the BCOC campaign, and discrepancies in the reporting of patient interval length.

## 7.1 Describing and Modelling the Patient Interval

The interview findings presented in Chapter Five describe the patient intervals of participants in this study, progressing through the 'individual' processes of symptom experience, appraisal and help-seeking decision making, to the wider contextual domains which influenced these journeys. Despite the findings being presented in a linear manner the realities of help-seeking experiences are rarely linear, in actuality being iterative, complex and personal. The complexity of the patient interval means that it can be difficult to conceive of this period holistically and in its entirety and, therefore, models can be useful tools for considering how the different elements of the patient interval combine and relate to one another.

### Models of Help-Seeking

Within the field of cancer diagnosis there are a number of models of the diagnostic pathway, which illustrate the processes and intervals of the diagnostic journey. Three of these models were presented in Chapter One. The *Categorisation of Delay*, developed by Olesen and colleagues, places the greatest emphasis on processes, and potential delays, occurring within primary and secondary care, and so does not provide a useful framework for helping to explain the complexity of help-seeking (Olesen et al. 2009). Andersen et al's (1995) *Model of Total Patient Delay* places a much greater focus on the help-seeking journey, outlining the stages an individual must pass through before seeking help and highlighting the iterative nature of these processes (Andersen et al. 1995). This model is useful in breaking down the help-seeking journey into four key stages ('detects symptom', 'infers illness', 'decides to consult', 'makes an appointment'). This helps us to visualise the detailed nature of help-seeking, but fails to consider how factors outside of the individual influence the help-seeking process. *The Model of Pathways to Treatment* takes into account some of the wider elements which shape patient pathways, incorporating patient, HCP and system, and disease as contributory factors in the model (Walter et al. 2012). This model has been used by a number of researchers to explain people's help-seeking behaviours in relation to both cancerous and benign conditions (Whitaker et al. 2015; Birt et al. 2014; Usher-Smith et al. 2013; Hall et al. 2015; Walter et al. 2014). It presents patient pathways as iterative, in the same way as Andersen's model does, and also breaks down the patient interval into appraisal and help-seeking intervals, helping to provide further clarity about these two different processes (Walter et al. 2012). Despite these strengths it fails to

illustrate how the contributory factors relate to one another, and to the help-seeking journey overall.

None of these models are completely effective in helping us to understand how and why people seek help when experiencing symptoms. This may in part be due to the fact that they all illustrate the diagnostic pathway in its entirety, meaning they are too overarching to adequately explain the detail of help-seeking. There is another theoretically grounded model of help-seeking behaviour based on interviews exploring the diagnostic trajectories of Mexican women experiencing breast symptoms (Unger-Saldaña & Infante-Castañeda 2011). This study found that social context and health care system factors interacted with the individual's thoughts and feelings about their symptoms, to impact how and when they were responded to. From their findings they produced the *Grounded Model of Help-Seeking for Breast Symptoms* (see figure 45).

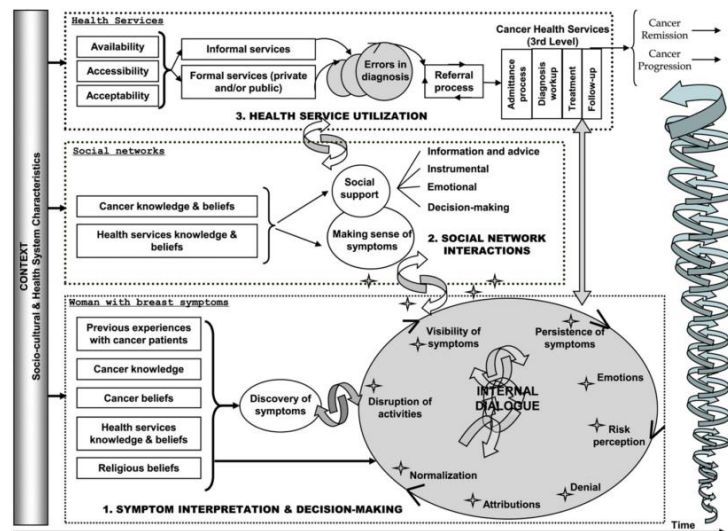


Figure 45: The Grounded Model of Help-Seeking for Breast Symptoms

The *Grounded Model of Help-Seeking for Breast Symptoms* depicts the non-linear nature of the diagnostic journey, its multi layered context and the range of people who may be involved in the journey, from the individual to social networks and the health services, while accounting for the influence of social context on the entire process. This model much more clearly illustrates the detail of participants' help-seeking, highlighting the complexity and multi-factorial nature of this journey. It depicts three levels of influence (the individual, others and the health care system) and breaks these down into smaller elements which contribute to decision making.

This model could be used to explain the data from this study, as many of the elements it contains are evident within participants' narratives. However, the flaw of this model, when

applied to the data from this study, is that it assumes that thoughts about 'cancer' are evident for all symptomatic individuals. Whilst this may have been the case for the patients in their study, for a number of participants in this research cancer was something which was never contemplated. This may in part be due to the typical symptoms of breast cancer (lump or nipple discharge) being very commonly present but may also be related to greater discourse and awareness of breast cancer, compared to lung and colorectal cancer. In this research a number of interviewees never considered cancer as a possible explanation for their symptoms, despite their symptoms being typical of cancer, and even despite an eventual cancer diagnosis.

The other drawback of this model is that it positions context at the beginning of the help-seeking journey, with the authors arguing that it occurs prior to the other dimensions, while potentially affecting all of them. Not only does it not explain what contextual factors may be influential, it also assumes that context is static. Yet, we know from this and other research, that context fluctuates and changes constantly, with contextual influences on the individual's perception of, and response to, symptoms potentially arising at any point on the help-seeking pathway.

### **Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer**

Because existing models fail to satisfactorily capture the complexities observed in this study, a novel model of help-seeking behaviour, which considers how both individual, social and systemic factors influenced symptom appraisal and help-seeking for participants, has been produced (see figure 46 overleaf). This model depicts the patient interval in its entirety and complexity. The categories presented are directly derived from the codes used in the analysis of the data and are grounded in the accounts presented by participants.

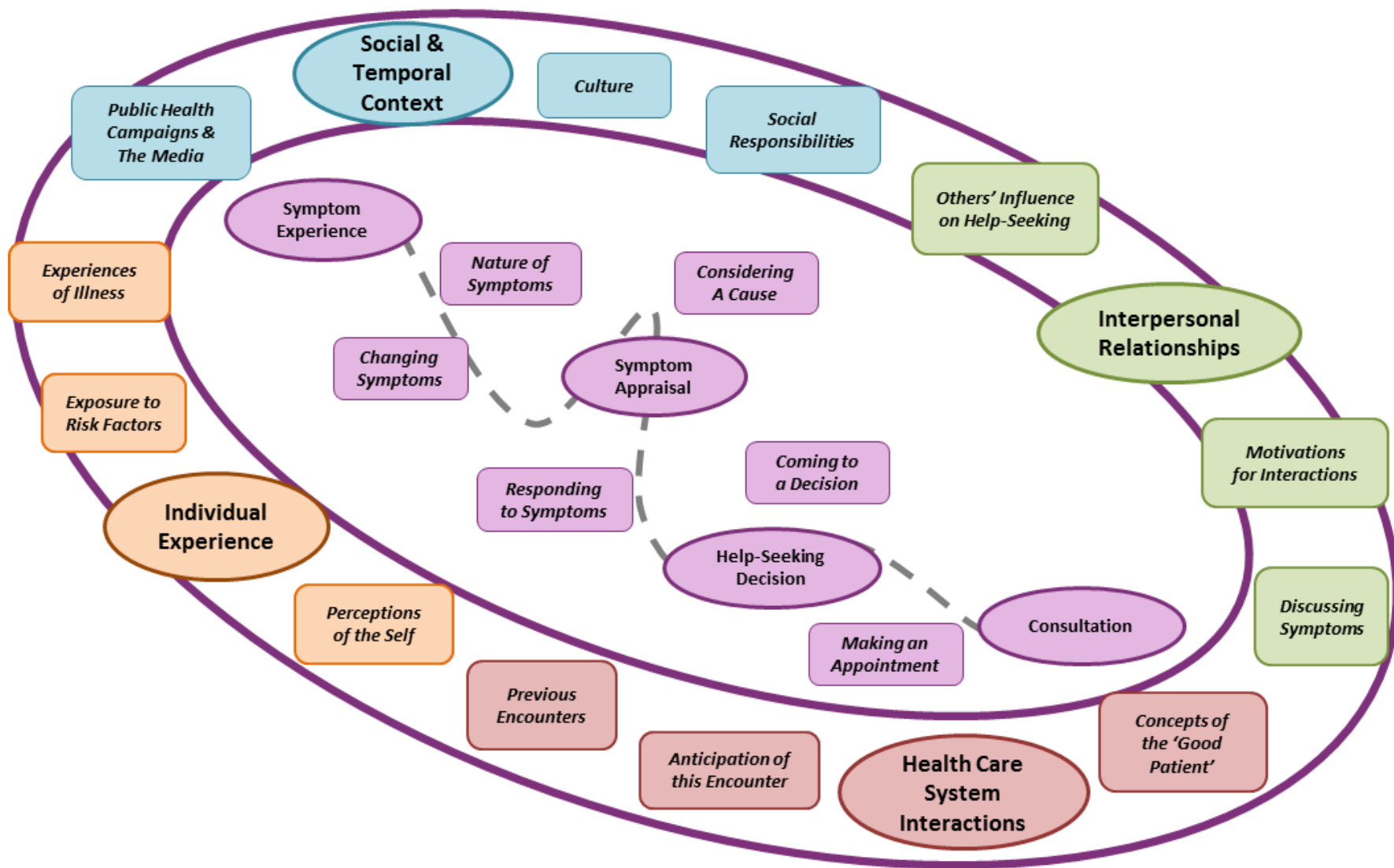


Figure 46: Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer

*The Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer* (figure 46) illustrates the individual's journey, separating symptom onset, symptom appraisal, help-seeking and consultation processes, and includes the immediate contributory elements which participants reported as influential, such as the nature of symptoms and consideration of causality, as outlined in Chapter Five. The help-seeking journey is encased by four broader contextual domains, which are broken down into smaller contributory elements, as reported by participants and presented in the preceding chapter. The contextual domains which influenced how those in this study responded to their symptoms are identified as individual experience, interpersonal relationships, health care system interactions and social and temporal context. Within each of these domains there are contributory elements which participants identified as salient, such as culture, the influence of others, previous experiences with the health care system, and exposure to risk factors. I will now go on to clarify the processes and domains depicted in this model, situating these categories, and some of the most salient sub-categories, in the data from this study.

As already mentioned, the model is a holistic depiction of the influences within the patient interval, as reported by participants, and, as such, contains some factors which have previously been identified as pertinent to help-seeking by other researchers, such as the monitoring of changing symptoms, the sanctioning of help-seeking by others, and the influence of previous encounters with the health care system. The presence of these findings could be argued to be the result of an imposition of *a priori* knowledge upon the data, whereby such categories were, intentionally or unintentionally, sought out within the data. Whilst it is naïve to state that the analysis was unequivocally devoid of any influences of *a priori* knowledge, the analytical process undertaken in this study was highly grounded, iterative and open. As outlined in Chapter Three, codes were derived from the transcripts, with multiple stages of coding and comparison taking place, including the comparison of raw data, codes and broader analytical categories. I strongly believe that the codes which are presented in this thesis are an honest reflection of the accounts presented to me by participants. The presence of similar categories within my analysis and the analyses of others can be seen to represent a confirmation of the importance of particular experiences, such as the monitoring of changing symptoms, and highlights their centrality to the experiences of symptom appraisal and the patient interval overall.

The following explanation of the model is intentionally brief, seeking to clarify the categories identified and situate them within the data from this study, although there is a

greater focus on 'symptom experience' in order to clarify the position which this research takes in relation to the concept of 'the symptom'. In doing so, I will forego discussion of aspects of the patient interval which have already been well documented by other researchers, in favour of a detailed analysis of two key, and arguably novel, insights from this study, the notions of thresholds and morality, which are the key focus of the remainder of this chapter.

### *The Processes of the Patient Interval*

#### Symptom Experience

Within *The Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer* symptom experience is presented as the first process in the help-seeking journey, being informed by the initial nature of, and subsequent changes in, symptoms. This is, in fact, an over-simplification, for illustrative purposes, of what is actually a transitory period, from the experience of an embodied sensation, to the creation of a 'symptom'.

A sensation can be described as a sensorial embodied experience. People experience many sensations on a daily basis but the majority of these never transition from the status of a sensation to a symptom. The 'symptom' is often perceived of as the starting point of illness, help-seeking, and disease, however, before an individual has 'symptoms' they first experience embodied, felt, sensations (Eriksen & Risør 2014, p.97). Sensations are routinely experienced and, neurologically, the brain continually scans lived bodily experience to bring attention to any anomalies. People engage in '*cognitive grappling*' (Hay 2008, p.202) with sensation experience in order to interpret whether the sensation is normal or not. This cognitive grappling can sometimes result in the individual identifying '*a bodily phenomenon [which] transcends the habitual balance, breaks through the absence of experience and becomes a subject of attention*' (Malterud et al. 2015, p.415). The detection of an abnormal sensation causes the individual to attribute meaning to the sensation and a desire to understand this deviant embodied episode.

Perception of a sensation as a symptom, as opposed to an acceptable bodily experience, '*occurs when any kind of altered balance brings forward a bodily attention towards phenomena which previously were taken for granted, independent of a potential association with disease...People will sense the deviations, without a conscious bodily awareness until a departure from their customary state occurs.*' (Malterud et al. 2015, p.415). Therefore, whilst people may experience sensations frequently, it is only once a

sensation challenges the individual's parameters of usual functioning or bodily state, that it comes to be perceived of as a symptom.

For a number of participants in this study attribution of a sensation as a symptom occurred when the experienced sensation fell outside of usual, or expected, bodily functioning. These sensations were either marginally outside of bodily expectations, for instance when Harry's stools became a bit looser and therefore no longer conformed to the usual pattern which they had followed for many years, or they were drastic deviations from bodily expectations, such as when Pamela coughed up blood. The speed with which a sensation was conceived of as a symptom was much faster among those who experienced sensations which were acute or drastic deviations from normal bodily functioning, than it was amongst those whose symptoms were minor bodily deviations. Among those who experienced symptoms which were only slight deviations from usual functioning, these changes were often described as a 'nuisance' or 'annoying', with the individual only constructing these sensation as symptoms after a longer period of time. Severe deviations in bodily functioning, by contrast, were almost always conceived of as a symptom immediately.

Participants in this study did not discuss the experience of sensations and transformative emergence of symptoms in great detail. Instead, they presented the symptom as an objective fact, which was not constructed. This may be because I did not probe the issue sufficiently but, more probably, because symptom-making processes are challenging to articulate and describe. Meaning is lost at every stage because *'thought lags behind feeling and words lag behind thought'* (Heath 2008, p.52). For instance, on reflections on the symptom of 'pain' Eriksen & Risor (2014) discuss the *unsharability* of pain as a symptom because, by its nature, it resists language. Therefore, the symptom is a construction which indexes a sensation and this construction is constrained by the inadequacies of both interpretation and language.

This means that the transition from sensation to symptom is inherently difficult to capture, as there is a dilution of meaning in both sensation acknowledgement and articulation. As a result, researching the symptom creation process is challenging and may account for the lack of focus on this in cancer research to date. Although participants did not explicitly verbalise the transition from sensation to symptom, we can use the work of others to consider explanations for why sensations are reconstituted as symptoms, in addition to deviation from usual embodied experience.



Through her fieldwork with the Sasaks of Lombok, Indonesia, Cameron Hay (2008) identifies three scenarios in which a sensation has the potential to become a symptom; vulnerability, duration and disability. When an individual experienced a sensation which closely matched their perceived vulnerabilities, they were likely to interpret this sensation as a symptom. Within this study we can consider how Fred saw himself as vulnerable to 'cancer', as a result of his previous prostate cancer and recent raised PSA levels, and therefore interpreted his change in bowel habit as a symptom quickly, as he viewed it as a signal of cancer, to which he felt vulnerable. Secondly, when a sensation lasted longer than was expected, even if that sensation was not considered unduly intense, individuals interpreted it to be a symptom. James monitored his stomach ache for six weeks as initially he had expected it to dissipate and be a transient, benign bodily deviation. When the sensation remained for longer than he felt was acceptable he then conceived of it as a symptom and something which he needed to seek advice about. Finally, sensations which were seriously disruptive to daily activities were also constructed as symptoms, an assertion also echoed by Cecil Helman (Helman 2007). There are many examples from participants in this study of sensations being constructed as symptoms once they impacted daily functioning. Roy had diarrhoea for many months which, at first, didn't bother him, despite going to the toilet up to five times a day. It was when the diarrhoea affected his ability to go for his morning walk that he began to conceive of it as something 'deviant' and a symptom.

Symptoms are also created through social interaction, as individuals seek advice and interpretation of their sensation from others, which either legitimises them as symptoms, or not (Cameron Hay 2008). For instance, Pamela talked about how she mentioned the blood in her phlegm to her husband and was seeking reassurance that it was 'nothing', thereby hoping he would **not** legitimate this sensation, or experience, as a symptom. However, in legitimising the blood as a symptom he also encouraged her to consult a HCP about it. Symptoms must be legitimated for an individual to be able to enter the '*village of the sick*' (Hay 2008, p.224) and this legitimisation also draws upon cultural knowledge, whereby phenomenological experience is interpreted in context.

This context refers not only to the contextual knowledge (i.e. of sensations, symptoms and illness) of a community, but also relates to the environment. Lock & Kaufert (2001) introduce the concept of 'local biologies', which refers to the manner in which people experience and respond to symptoms, rooted within their locality and based on factors such as knowledge and lifestyle. In their comparison of reports of menopausal symptoms among women in Japan, Canada and the United States they found that women's experience and

identification of menopausal symptoms was heavily related to these 'local biologies'. For instance, Japanese women rarely reported hot flushes as a symptom, whereas Western women did. They identified Japanese women's consumption of a healthier diet, heavy in natural oestrogens, as one explanation for why they may be less likely to experience such symptoms, along with Japanese concepts of menopause being based within the autonomic nervous systems, which correlates with the type of symptoms reported (Lock & Kaufert 2001). Interestingly, the authors point to the change in familial structure as one possible explanation for why middle class 'professional housewives' reported many more menopausal symptoms than their rural counterparts, and more closely mirrored the experiences of North American women. As it was commonplace for three generations of a family to live together, once a woman no longer needed to care for her children her role changed to that of carer for parents. As middle class Japanese families are increasingly living in nuclear family set ups, the point at which the caring responsibilities of a woman are removed fall at the same point at which menopause is thought to begin, meaning that symptoms could be related to the sudden and dramatic role changes.

In his fieldwork exploring the field of Ayurvedic medicine in Southern India Nichter (2008) transformed his understandings of sensations, their meanings, and their cultural significance, through the adoption of a 'local' diet. By undergoing these dietary changes his sensorial experiences became grounded in his temporal lifestyle and environment and as such, the embodied experiences constituted a local biology. We can also consider how symptoms are temporally created within Western societies. For instance, in a society which places significant value on physical fitness, an active 55 year old may perceive of a musculoskeletal ailment as a symptom, because it prevents them engaging in valued activities, whereas such discomfort may have been perceived of as a natural and expected part of ageing in 'earlier times' (Malterud et al. 2015). Similarly, the focus on 'risk' in modern day Western society means that people *'are adopting risk roles as one feature of biomedicalization and in the course of doing so are giving new meaning to bodily sensations they now associate with the warning signs of diseases.'* (Nichter 2008, p.186). This idea of risk and the interpretation of bodily sensations, and symptoms, in relation to risk, is something which will be examined further later in this chapter.

Within this study a number of men talked about how the onset of coughs, wheezing, or breathlessness alarmed them because of their occupational history working in the local chemical industry and their exposure to asbestos. Their occupational history shaped the way they monitored their body, paying specific attention to sensations which were signs of

illnesses which they believed themselves to be vulnerable to, as a result of their working life. In this sense, respiratory sensations were responded to in light of local biologies, through the lived experience of working in industry and the cultural impression which that industry left on the community and their expectations of the body . The response to symptoms is therefore temporally located as it specifically refers to a discrete period in which men's health , and lungs in particular, are seen as having been exposed to potential damage by the systems of production within which they were employed. It would be interesting to compare how respiratory sensations are experienced and valued in populations for whom there are no such industrial exposures and for whom the potential appearance of 'chest diseases', does not loom heavily.

While these scenarios show us how sensations can be perceived of as symptoms, another consideration is how sensations arise in the first place. For some people, the presence of some symptoms has no biomedical explanation. It has been argued that symptoms can act as vessels for channelling distress, with the body serving as a symbolic arena (Sobo 1993), a process referred to as somatisation. In relation to diet-related symptoms Ogden (2007) argues that tensions arising from notions of conflict and control are communicated through symptoms, which are then mediated by social meaning, cognition and emotions, to enable the individual to deal with tension in a manner which is both socially meaningful and acceptable (Ogden 2007). For people suffering with Medically Unexplained Physical Symptoms (MUPS) pain has also been shown to communicate meaning, particularly in relation to loss and loneliness, with the sensation of pain being the embodiment of social isolation and struggle (Eriksen & Risør 2014).

Whilst somatisation was not overtly apparent for the majority of participants within this study, we can consider, through the example of Julie, how the experience of symptomatic suffering may have been a bodily representation of her social suffering. Julie reported having experienced a range of symptoms, including pain, nausea, dizziness, diarrhoea, rectal bleeding and haemoptysis over a number of years, however, the episode which prompted the referral to secondary care was diarrhoea and bloating followed by acute, excruciating stomach pain. She lived in a relatively deprived area, had recently lost her mother from stomach cancer and suffered with spondylitis of the spine. The pain in her back caused her to give up work three years previously and significantly affected her daily functioning, most notably for her, impacting her ability to play with her grandchildren. She had a close relationship with her daughter, who suffered from mental health issues and so Julie tried to support her in the care of her six children. Julie had been claiming Disability Living

Allowance and shortly before the symptomatic period she had been re-assessed and deemed to be fit for work and subsequently only eligible to receive Jobseeker's Allowance. This equated to a significant drop in income which meant that she was unable to meet her basic bills, including rent and council tax. Julie felt a vast amount of pressure to make the required number of job applications to be able to receive Jobseeker's Allowance, despite not feeling capable of working due to her health.

We can see how, in Julie's case, her symptom experience may have been a means of channelling the stress and tension she felt in relation to the reassessment of her suitability to work and the subsequent change in financial circumstances. On top of the inability to meet bills, Julie faced pressure to seek out employment, despite feeling physically unable to perform in a work environment, so that she did not lose the small income she had in the form of Jobseeker's Allowance. She was anxious about the impact of a potential return to employment on the lives of her daughter and grandchildren, as she would no longer be able to provide her daughter with the informal care and support which she regularly provided. We can see how Julie could be considered to be disenfranchised within her environment, with external forces shaping her world in a negative manner which was beyond her control. It is possible to think of Julie's symptoms as a means of channelling the turmoil she was feeling about her precarious situation and embodying this distress in a manner which was socially acceptable to herself, her family, and the wider society.

In summary, research into symptom manifestation shows that people experience sensations on a regular basis but that it is the sensations which contravene expected bodily functioning that are identified as deviant and potential symptoms. Symptoms may come into being because the sensation correlates with perceived vulnerabilities, remains 'too long' or impacts the individual's functioning. They are grounded in locality and time and can be the embodiment of social suffering.

The symptom creation process is a topic which would benefit from further examination and application in relation to early diagnosis of cancer research in order to more fully appreciate the patient interval. However, it was not within the scope of the study to undertake this. This brief discussion of the transition from embodied sensation to 'symptom' has sought to emphasise the subjectivity of 'the symptom' and highlight its perceptive and social construction.

For the purposes of the model and the resulting discussion the term 'symptom experience' is used to represent both the embodied experience of sensation(s), the process of

transformation of this experience from sensation to symptom, and the end product of 'the symptom', which is the conception of the sensation, by the individual, as a deviation from usual bodily functioning. Whilst it is accepted that this is an over simplification or 'umbrella-ing' of a complex moment, this discussion has sought to position this research in relation to the idea of the symptom and provide a framework from which discussion can progress. I will now go on to outline the processes and contextual domains of the patient interval, as depicted in *The Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer*.

### Symptom Appraisal

The symptom appraisal process refers to the period between a symptom being established and the decision to seek help being made. Symptom appraisal entails people considering and responding to their symptoms, in a way which seeks to impart meaning and potential resolution.

In appraising their experiences people considered the severity of their symptoms in relation to the level of deviation from usual functioning and impact on daily activities. This assessment of severity fed into consideration of causality and, as discussed in Chapter Five, people considered, rejected and revised their explanations for symptoms numerous times, incorporating novel pieces of information into this appraisal as time progressed. During this period of symptom attentiveness and reflection, people engaged in particular activities in response to their symptom(s), which were related to the explanatory hypothesis which they held at that time. For instance, people used over-the-counter medication to treat a cough or altered their diet in response to a change in bowel habit which was perceived to have been the result of over-indulgence.

Symptom appraisal was the longest process within the help-seeking journey for participants in this study, with the monitoring of, response to, and explanation seeking for, symptoms being an iterative process.

### Help-Seeking Decision and Consultation

Whilst help-seeking is the next process in the patient interval it is important to remember that the majority of people who experience a symptom (it is estimated to be around 80%) will never consult about it, instead choosing not to respond to it or to manage it independently, or in the context of the family or social network (Kleinman 1980). This study presents the experiences of those who **did** consult a HCP about their symptoms, a population who have been referred to as representing the 'symptom iceberg' (Hannay

2011). We must be mindful therefore that the analysis presented here is the experiences of those individuals who sought help about their symptoms. Although many individuals never 'progress' to the process of help-seeking and consultation, the model is still useful to consider how these individuals' experiences and appraisal of symptoms are bound by wider contextual domains.

The help-seeking decision is the point at which the individual chooses to consult a HCP about their symptoms. For participants in this study the decision to seek help was often the result of an inability to explain one's own symptoms, an inability to restore 'normality' through personal efforts, and a desire to access the resources of the health care system, either in terms of investigations or treatments.

The final process within the model is consultation, the event when the individual and the HCP first meet. The help-seeking and consultation processes are discussed together in this section as, for participants in this study, there were no reported barriers in moving from the decision to seek help to the consultation. Whilst for these participants, accessing HCP input was uncomplicated it is conceivable that this transition may not be as easy to negotiate for other individuals. For instance, poor access to a HCP, be it geographically or in relation to waiting times, could hinder someone in their intention to seek help. It is also possible that an individual may decide to seek help but then reverse this decision and return to the symptom appraisal process, either never reaching consultation, or requiring a further decision to seek help to occur in order to arrange a consultation.

The category of consultation is not explained in detail here as the ultimate consultation with the GP was not something which was a key focus of this piece of research or, more importantly, the narratives presented by participants. Work by other scholars has highlighted the negotiation of the clinical encounter, whereby patients must present symptoms in a manner which is accessible to the clinician, and from which they can transform the reported symptoms into signs of pathology, moving from 'subjective experience' to 'objective fact' (Malterud et al. 2015; Risor 2011; Andersen & Vedsted 2015).

### *The Contextual Domains of the Patient Interval*

The processes of symptom experience, appraisal, help-seeking decision making and consultation all exist within a wider context. This context is broken down into four domains which are described below. The contributory elements in these domains are themes which arose from this research, and are examples of factors from these domains which influenced the patient interval for people in this study, but are not exclusive. The contextual domains

are presented as concurrent, whilst acknowledging that each domain relates to and affects others. However, another way to conceive of these is from the micro domain of the individual, to the macro domain of society, moving from individual experience, to interpersonal relationships, then health care system interactions and finally social and temporal context.

### Individual Experience

The first of the four domains entails how an individual's past experiences and conceptions of themselves influence their patient interval. Whilst the processes depicted in the centre of the model are the experiences of the individual within the moment, the domain of Individual Experience encompasses the individual as conceived of as existing in other times, be it the past or the future. This will differ for everyone, depending upon their life history and life expectations.

Interviewees identified previous illnesses and considered these in relation to current symptomatic experiences, comparing and contrasting the two episodes. People also considered previous exposures which would increase their risks of particular illnesses, most notably smoking and asbestos exposure in relation to lung cancer, but also more generalised consideration of risk exposure such as alcohol consumption and diet.

People also incorporated projections of themselves in their assessment of symptoms, aligning themselves with health and rejecting illness, and cancer specifically, as viable parts of themselves. People considered changes and transience in themselves in relation to their embodied experiences, most notably the transition of age shaped the patient interval for some participants.

### Interpersonal Relationships

The domain of interpersonal relationships refers to the ways in which 'others' influenced the help-seeking journey. These 'others' refer to people who interact and engage with the symptomatic individual in their everyday life, such as family, friends and colleagues. Whilst the individual does indeed interact with wider social structures, this domain specifically refers to the one-to-one, personalised relationships which individuals hold within their community.

These relationships are the location of interactions about embodied experience and appropriate behaviour. Within this research individuals discussed sensations with other people which served to legitimate the sensation as a symptom. Once the symptom was established discussions with others helped people to appraise their symptoms, considering

causality and appropriate courses of action. For some people the motivation for discussing symptoms with others was to gain information and guidance, which could be incorporated into their appraisal and decision making. For others, discussions were a means of seeking sanctioning of symptoms and help-seeking, so that any actions taken to address deviant bodily states were seen to be socially approved. Interpersonal relationships were also considered by individuals in the construction of their decisions around appropriate behaviour in response to symptoms. For instance, not discussing symptoms to avoid causing undue worry to others.

### Health Care System Interactions

The domain of health care system interactions refers to people's previous, current, and projected engagement with health care. Participants in this study conceived of the health care systems solely in relation to the NHS, as the contributory elements which they discussed specifically referred to the British NHS system. However, we can also consider Tom's consultation with a herbalist and treatment with a tincture to be an interaction with a health care system, simply an alternate one to the dominant system in our society. There may be multiple health care systems which may, and may not, interact and overlap and people's encounters with one practitioner and system will also influence how they engage with another.

People's previous encounters with the health care system shaped how they conceived of their symptoms and responded to them. This entailed previous consultations about similar symptoms, previous negative experiences with a clinician for unrelated symptoms, or engagement with screening programmes. People's anticipations of the consultation also influenced their help-seeking, for instance ideas about what the consultation would entail, such as an examination. A desire to 'not waste the doctor's time' and to appear to be a 'good patient' also influenced how people interacted with the health care system and this is an idea which will be explored further later in this chapter.

### Social and Temporal Context

The final domain refers to the social and temporal context which the individual is located in during the patient interval. This social context speaks to the wider societal, structural and political contexts of the person's world.

People considered their symptoms and the possibility of help-seeking in relation to their social responsibilities, weighing up the necessity of consultation in light of the impact this would have on social obligations at work, in the family, or in a valued community role, such



as within the church. Awareness of public health campaigns, primarily the BCOC campaign, was often reported by participants as influential in their symptom appraisal, as well as exposure to news stories on early presentation and early diagnosis more generally. Whilst these can be considered to also be part of the health care system, this is located more broadly in the social context as it incorporates elements outwith the health system, i.e. the mass media, and also is somewhat conceptually separate from the health care system, through its routes of dissemination.

Culture mediated how people responded to symptoms, with 'culture' being conceived of as both ways of life, including ideas, beliefs, language, institutions and structures of power, and as cultural practise, evident in art, architecture, everyday activities and eating habits (Lupton, 1994). Abdul talked frequently about how within his 'culture' there was stigma attached to illness, and there were cultural expectations on men to be healthy, which influenced his willingness to consult. However, the culture of the Stockton-on-Tees area, and the North East region more broadly, can also be seen to shape people's experiences. As has been alluded to in Chapter Three, the North East, and Stockton-on-Tees in particular, has faced rapid, and sometimes catastrophic deindustrialisation and despite the closure of much industry, the ways of life and attitudes which this heritage created still persist, in what has been referred to as 'industrial structures of feeling' (Garthwaite 2016; Williams 1973). We can consider how this industrial heritage affects how people perceive of their body and episodes of illness, as expectations of bodily functioning directly relate to the ability to work and earn a wage.

The 'time' at which symptoms are experienced and acted upon affects how, why and when, certain sensations or actions are given precedence. I discussed in relation to symptom creation processes how, in a society which places worth on physical activity, certain sensations may be conceived of as symptoms, whilst in another society (be it geographically or temporally separate) this sensations may be conceived of as accepted parts of ageing.

*The Model of the Patient Interval for Participants with Symptoms of Lung or Colorectal Cancer* (figure 46) is a graphical depiction of the factors which influenced help-seeking for participants in this study. This model does not profess to include every potential element which may influence patient journeys, only those which emerged in this research. In other studies, particularly those undertaken in different localities and cultures, it is conceivable that additional and alternative factors may emerge, such as the financial implications of consultation for individuals living in countries with private health care systems, or barriers

to accessing health care because of environmental factors, such as destruction of infrastructure as a result of flooding, for example. Although different influences on help-seeking would likely be identified in different localities and populations, these could conceivably be accommodated in the processes and domains identified here.

Furthermore, whilst the contextual domains are presented as separate realms, they are actually interlinked and co-productive, with elements within one domain being influenced by factors from another. For instance, drawing on examples which will be discussed in the rest of this chapter, a desire to appear to be a good patient affects the individual's interactions with the health care system yet is influenced by discourses located within the social and temporal context. A person may assess their symptoms and potential cancer risk in light of their individual experience, including conceptions of the 'cancer candidate', which are in turn shaped through discussions with others, and the reporting of risk factors through public health campaigns and media coverage. Therefore, these contextual domains bleed into one another, with contributory elements from different domains influencing contributory elements in others. The fluid nature of the contextual domains reinforces the complexity of influences on the patient interval, with facilitators and barriers to presentation being shaped through numerous aspects of an individual's life.

*The Contextual Model of the Patient Interval* (figure 47), is presented below, which illustrates the overarching domains identified as influential in the help-seeking process. This broader incarnation of the model, which is grounded in the data from this study, could be used to explain the plethora of factors that influence the patient interval. For instance, the examples of financial constraints and environmental pressures cited earlier would both be encapsulated within this model, under the domains of health care system interactions and social and temporal context, respectively.

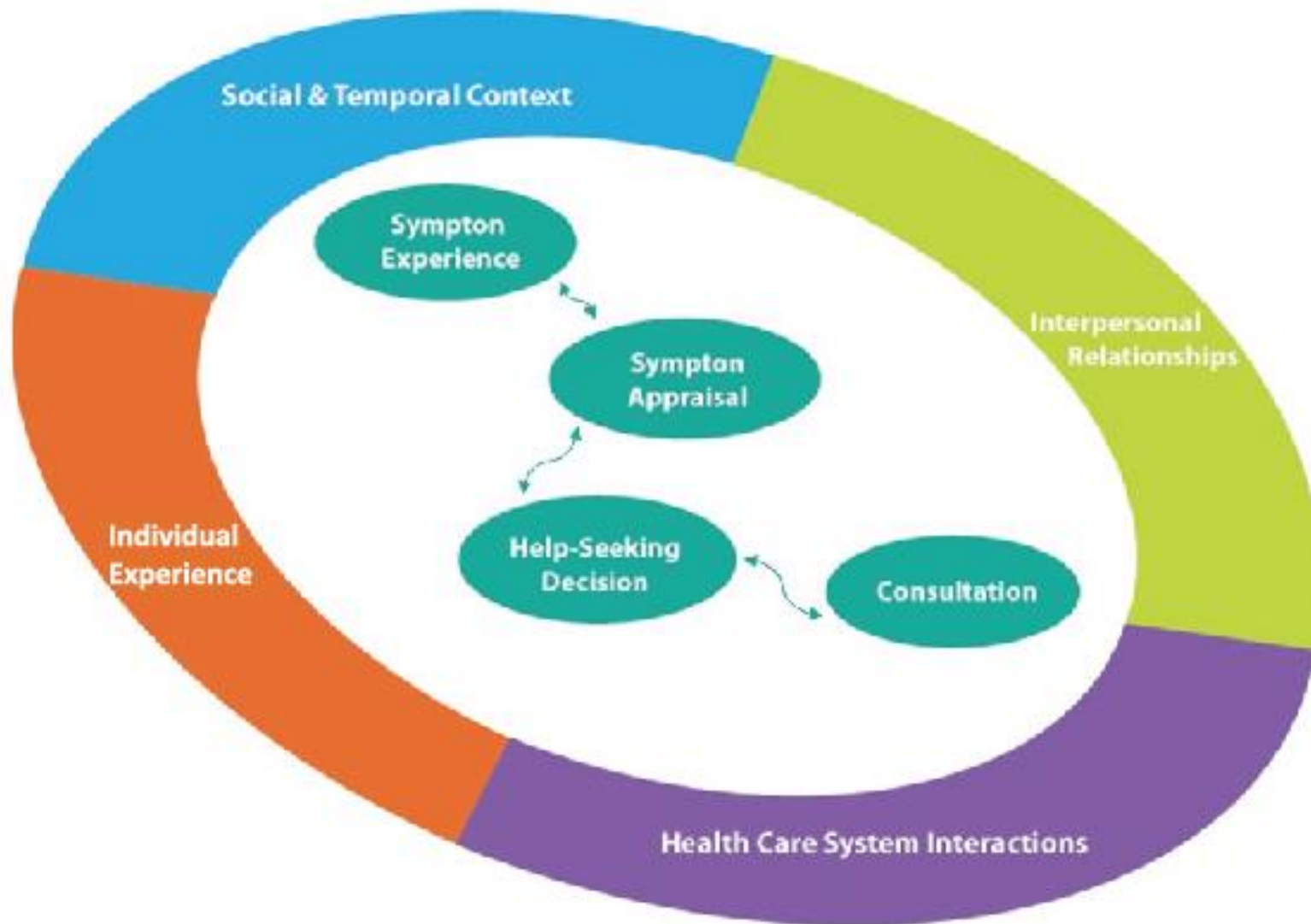


Figure 47: The Contextual Model of the Patient Interval

This model of help-seeking could be useful in future research to examine how the multi-factorial nature of the patient interval influences patients' journeys to presentation, for both a range of symptoms and conditions. The application of the model is felt to be most efficacious for those working within health research, as opposed to being a model which has direct clinical utility. *The Contextual Model of the Patient Interval* could be effectively used as a tool for guiding enquiry in future research examining help-seeking of symptomatic individuals, either with cancer or other conditions. It provides a framework through which the experiences of an individual can be approached in order to assess the wider context within which symptomatic episodes are acted upon. It could be used to help compose a topic guide for interviews, to ensure that the different contextual domains which may influence the processes within the patient interval are raised within the research encounter, giving participants opportunities to reflect on the 'bigger picture' of the experiences. It could also be used in analysis, to explore transcripts for factors which relate to different domains and to consider how contributory elements relate to and affect one another, particularly how the wider social structure influences symptom experience, appraisal and help-seeking. More directly, it could also be presented to research participants as a means of both prompting discussion around the constraints and facilitators to presentation, as well as being an object of critique. By introducing the model in a protagonistic manner, the participant can suggest and revise this representation of the patient interval, enabling them to depict a scenario which mirrors their lived experiences.

## **7.2 The Threshold of Tolerability and the Timing of Help-Seeking**

The *Contextual Model of the Patient Interval* depicts the processes involved in the journey to the doctor's consulting room, as well as the contextual domains that exert influence on the individual and their actions. In this section I will consider how someone comes to the decision to seek help about their symptoms, referring to previous research relevant to the findings from this study. I propose a new explanation of the timing of help-seeking, the idea of a threshold of tolerability. The concept of a threshold of tolerability is grounded in a discussion on a societal focus on risk and the implications of living in a risk averse society for people's responses to symptomatic experiences. A number of contributory elements are integrated into calculations of risk which collectively define the boundary for a threshold of tolerability. The assessment of cancer risk is one contributory element which is incorporated into the calculation of thresholds and will be used as an example for exploration.

### **The Construction of Help-Seeking Decisions**

The findings from this study show that help-seeking decision making is complex, incorporating many influences from the four contextual domains of an individual's life. Contributory elements can influence any of the processes within the patient interval and may occur simultaneously or in isolation. Individuals negotiate these contributory elements when making decisions about their symptoms, with different elements often suggesting different courses of action.

The elements which contributed to decision making were wide-ranging, covering all of the domains illustrated in figure 47, and evident to varying degrees. Those who consulted quickly tended to report fewer contributory elements in their help-seeking decisions and experienced alarming bodily sensations which were severe deviations from usual bodily functioning and were conceived of as symptoms quickly. The questionnaire data also showed that people who experienced bleeding or pain tended to have shorter patient intervals than those who experienced more generalised or systemic symptoms.

Those who took a long time to consult reported a wider range of elements which contributed to symptom appraisal and help-seeking decisions, both positively and negatively. These individuals were not initially alarmed by their deviant bodily state and often accepted the sensations as minor deviations to normal functioning initially. Once conceived of as a symptom, people often managed these unusual embodied experiences within their everyday life for a period of time. As time progressed these individuals went through multiple periods of symptom reappraisal, which incorporated novel contributory elements, particularly the changing effect which their symptoms were having on their different social roles. The consideration of information from the four domains, in relation to symptoms, was often reflexive and cumulative in nature. As symptoms persisted or evolved people pieced together contributory elements from different parts of their lives to decide upon the necessity of consultation.

There are two formative approaches to explaining the timing of a help-seeking decision; the concept of accommodation, as presented by Irving Zola, and Angelo Alonzo's use of the concept of containment.

Zola's (1973) seminal work examining '*pathways to the doctor*' showed that people did not seek help for their symptoms at the point when they were at their 'sickest', but at a point when there was a break in the accommodation of symptoms. He argued that '*there is an accommodation both physical, personal and social to the symptoms and it is when this*

*accommodation breaks down that the person seeks, or is forced to seek medical aid'* (Zola 1973, p.679). He identified five triggers to a breakdown in symptom accommodation:

- 1: An interpersonal crisis (which may or may not be related to the symptoms)
- 2: Perceived interference with personal relationships
- 3: Sanctioning of help-seeking by others
- 4: Perceived interference with work or physical functioning
- 5: The setting of external time criteria

Although these five triggers are evident in the narratives of a number of participants in this study, experience of one did not always provoke help-seeking. They were not necessarily discrete triggers to consultation for participants but constituted one of a number of elements which cumulatively led to a decision to consult. For instance, Tom experienced three of Zola's triggers throughout his two year patient interval, the interference with a relationship (his wife's unhappiness about his snoring), the sanctioning of help-seeking (by his wife) and the interference in work and social roles (his inability to process with the offertory during mass). However, none of these factors were a discrete trigger to consultation. It was later in his symptomatic period when Tom considered all of these factors, alongside his growing concern that his symptoms could be related to earlier asbestos exposure when working in local industry, that he decided to seek medical attention.

In this study, participants with longer patient intervals did accommodate their symptoms for a period of time, until a tipping point was reached, whereby consideration of a number of contributory elements, as opposed to an isolated trigger, resulted in the breakdown of symptom accommodation, prompting the decision to seek help. However, for those in this study who consulted quickly, physiological experience was at the forefront of decision making, with wider contextual factors, or triggers, holding lesser importance than the impact of the deviant bodily state. Zola's theory that symptoms are accommodated until one of the five triggers to consultation occurs is problematic in relation to the data from this study as symptoms were never accommodated by individuals who sought help very quickly, and for those who took longer to consult, isolated triggers were unlikely to prompt the breakdown of symptom accommodation.

Angelo Alonzo uses the concept of 'containment' to explain how and why people act upon their symptoms. He argues that symptom interpretation occurs within a particular social context and that individuals must negotiate bodily sensations within that context. People

side-line their symptoms and integrate them into the situation until they feel that it is necessary to acknowledge them, a decision which is based on the responsibilities and nuances of their particular social context (Alonzo, 1984). Containment is *'the interaction between body state deviation and the social situation...everyday, typical signs and symptoms of illness and injury will not reach medical attention if individuals can contain them in their daily situational setting'* (Alonzo 1979, p.397). Containment depends on the individual's engrossment in other social situations, others' assessment of role enactment, the degree of power the individual has over situational settings, the implications of symptom containment on others, and the resources the individual has to aid the containment of symptoms. Containment is not always viable when a symptom represents a 'biological intrusion' beyond what we would expect from our bodies.

Interview participants in this study often 'contained' their symptoms in a manner which negated the need to consult. People related their bodily changes to everyday explanations, such as colds, and also talked about how their health and expectations of their own bodies allowed them to contain their symptoms. For instance, Pauline saw the presence of a cough as an expected side effect of being a smoker. The containment of symptoms in order to continue social obligations and roles was also evident in participants' narratives. For example, Angela did not want to consult about her rectal bleeding because she felt that the repercussions of a consultation would prevent her going on an imminent cruise with her husband and from taking care of her grandchildren which had already been agreed. Therefore, she decided to wait to consult about her rectal bleeding until these two social obligations had been fulfilled.

The concept of containment has previously been applied to other accounts of help-seeking among patients with symptoms of cancer. Andersen et al (2010) found that people contained their symptoms in relation to their personal situations, with physical explanations for bodily changes being sought through reference to everyday activities (i.e. gardening), as well as psychological explanations for bodily changes (i.e. emotionally stressful periods). People contained their symptoms in light of their life biographies (i.e. perceived hereditary susceptibility to cancer) and life expectations, side-lining bodily changes which affected their ability to perform in social roles.

Alonzo acknowledges that some people will consult very quickly and suggests that these people seek help quickly because they experience drastic symptoms, which represent 'biological intrusions' to bodily expectations and therefore cannot be contained. This

correlates with the findings from this study, whereby those with the shortest patient intervals experienced acute and drastic symptoms. Other research has shown that cervical cancer patients with alarming symptoms, i.e. pain, consulted in a shorter time than those presenting with non-alarming symptoms (Mwaka et al. 2015) and among people living in rural Western Australia those with severe symptoms presented much sooner than those who had mild or intermittent symptoms (Emery et al. 2013).

For those who 'contain' their symptoms Alonzo (1984) proposes that the decision to seek help will be made when symptoms are no longer controlled by self care, are beyond lay competence, are disrupting valued situational participation or are beyond the individual's previous adaptive experience (Alonzo 1984, p.504). When symptoms can no longer be contained the individual moves into a state of 'coping' whereby they will seek help about their symptoms.

We can find examples of each of these prompts to coping within the narratives of participants in this study. John tried a range of over-the-counter medicines to deal with his symptoms yet his decision to consult was not made until a substantial period of time after he decided that these medicines were inefficacious. The decision was based on an amalgamation of inability to deal with his symptoms through self-medication, his wife's concerns, his inability to perform at the gym, and concerns around industrial exposures throughout his lifetime. Richard talked about '*needing to know*' the cause of his symptoms, after his initial hypothesis of temporary dryness of the throat was appearing to be decreasingly plausible. His explanatory models were no longer viable in explaining the continued presence of his cough, and so he needed the expert input, and resources, of the medical practitioner. Again, this was not a prompt in isolation, as he also identified his concerns about his smoking history, his son and wife's sanctioning of help-seeking, and awareness of media coverage of early diagnosis stories, including the Be Clear on Cancer campaigns, as thoughts which all '*met*' and prompted him to '*do something about it*'.

For Pauline, a valued part of her existence were her outings with her daughter, either shopping in town or walking the dog. However, her breathlessness prevented her from going and so was jeopardising a valued role in her life. Again, this was only one of the contributory elements which Pauline reported as influential in her decision to consult. Her additional free time and reduced commitments she had as a result of retiring and the letter she received from the GP encouraging consultation in the case of a cough both were considered alongside her inability to go out with her daughter within the help-seeking



decision making process. Part of Fred's decision to consult was based around the fact that his bowel symptoms, of very loose stools, were different to the bowel symptoms he had experienced in the past, of constipation, but this consideration was combined with his concerns that his prostate cancer may have metastasised, knowledge of a friend who had recently been diagnosed with bowel cancer, and a heightened awareness of the importance of early presentation as a result of the BCOC campaign.

Alonzo acknowledges that factors which interrupt containment of symptoms can occur simultaneously, and be multiple. We can see from the examples above that multiple prompts to 'coping' were common and encompassed those factors identified by Alonzo. Additional to the factors identified by Alonzo as marking a break of containment it is apparent from the interviews in this research that social sanctioning is influential in people's decision making, both in terms of sanctioning of help-seeking by others and the sanctioning of help-seeking through public awareness campaigns. The fluid and changing appraisal of symptoms in relation to particular conditions is also neglected within this approach, yet is frequently reported as a key element which is incorporated into the decision to consult about symptoms by participants here.

In summary, participants in this study with short patient intervals tended to recognise and act upon symptoms quickly, meaning that symptoms were never accommodated or contained. These people tended to experience acute symptoms which drastically fell outside of the person's parameters of acceptable bodily functioning, and could be referred to as 'biological intrusions'. The majority of participants waited a period of time before seeking help about their symptoms and tolerated the symptoms within their daily lives whilst considering a number of pieces of information from the wider contextual domains of their worlds in relation to the symptoms.

The end of the symptom appraisal period is marked by the decision to consult about symptoms and Irving Zola and Angelo Alonzo propose situations which prompt the individual to make this decision. Many participants experienced one of Zola's triggers during their symptom appraisal period yet it did not prompt to help-seeking. The experience of a trigger instead became one of the contributory elements of their appraisal of the situation, a process which often took place over an extended period of time. Alonzo's prompts to 'coping', or consultation, were evident in participants' narratives and there were often multiple prompts within the appraisal period. However, the factors reported by participants were wider ranging than the four prompts identified by Alonzo (Alonzo 1984).

Zola and Alonzo's explanations imply that symptom burden is static and that it is a change in context, including an individual's inability to cope, that is the mechanism that instigates consultation. However, the other circumstance which prompted help-seeking for participants in this study was a change in symptom burden. This research suggests that people's symptom burden can alter throughout the patient interval, with individual symptoms intermittently improving, increasing in severity, or additional symptoms emerging. It appears that changes in symptom severity are also relevant triggers to consultation, this could either be because the symptoms themselves have worsened, or something has changed in the individual's appraisal of their symptoms which has made them re-evaluate symptom severity. The narratives of participants highlight how both symptoms and contributory elements within a person's wider world fluctuate and it is a combination of these factors which are incorporated into symptom appraisal and decision making.

Whilst Alonzo and Zola's presentations of help-seeking decision making provide useful components for considering this process, they do not thoroughly explain the triggers to help-seeking for participants in this study. To revisit the findings of this research, it was found that those individuals who experienced symptoms which were severe deviations from expected and accepted bodily functioning sought help quickly after symptom onset however, amongst those who took longer to consult a number of different contributory elements were considered, over time, to assess the necessity of help-seeking. Contributory elements from the individual's wider context were incorporated into decision making alongside information about the symptoms until a threshold of tolerability was reached. Once the symptom burden crossed this threshold the individual could no longer tolerate their symptoms within their everyday life and so consulted.

### **The Threshold of Tolerability**

In this section I will explore this notion of a threshold of tolerability, considering how the point at which the decision to seek help is reached, dependent upon both the contextual contributory elements and symptom burden. As outlined above it appears that participants in this study used information from each of the contextual domains to create a boundary within which symptoms were acceptable and manageable. Once the symptoms crossed this boundary or threshold they were no longer tolerable and so an expert, in the form of a HCP, needed to be involved.

A threshold of tolerability is produced using multiple pieces of information, which are considered concurrently to reach a scenario wherein symptoms are tolerable within the

individual's life and do not require the expert input of a HCP. All of the contributory elements reported by participants, which come from the contextual domains illustrated in the model, are used to appraise symptom experience and the need to consult. This consideration of elements is intuitive, not taking up great priority or time in the individual's consideration, but happening in the day to day way in which people commonly reflect upon information and make decisions. The threshold is dynamic since, as information changes or new pieces of information arrive, they are incorporated into the construction of the boundaries within which symptoms are tolerable, meaning that the threshold may shift. This dynamic threshold of tolerability is the product of a constant, fluid assessment and reassessment of symptoms in relation to the contributory elements from an individual's life.

For instance, someone experiencing diarrhoea may think about how long previous experiences of diarrhoea lasted for, the likelihood that a 'stomach bug' is the cause, the comments of others about the nature of the diarrhoea and the necessity of consultation and any adaptations to daily life required to tolerate the symptoms. All of this information is concurrently considered to produce boundaries within which the diarrhoea is tolerable within one's daily life. However, if the diarrhoea stays for 'too long', does not fit the working 'diagnosis', requires unacceptable adaptations to life in order to perform as usual, and, or, help-seeking is encouraged by others then the diarrhoea may no longer be tolerable and may cross the threshold created by the individual.

The threshold of tolerability is therefore a boundary which is placed on symptom experience, using many pieces of information which relate to that symptom experience in the individual's mind. If we accept that people produce thresholds of tolerability we can consider how people move from symptom toleration to a decision to seek help, once the threshold is breached.

For some people, the arrival of new symptoms is so acute and deviant, that the symptoms immediately cross the individual's threshold of tolerability and so the decision to consult is immediate (see figure 48). For other people symptoms are initially below that threshold and so there is no perceived need to consult (see figure 49).

--- Threshold of Tolerability  
— Symptom(s)

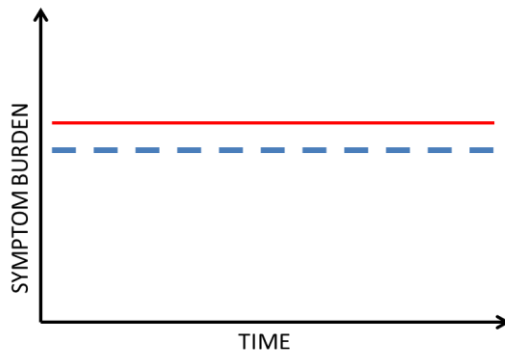


Figure 48: Symptom Burden Beyond Threshold of Tolerability

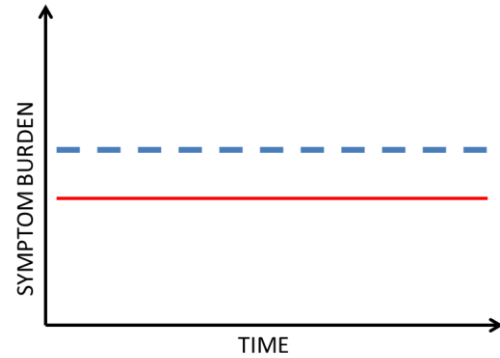


Figure 49: Threshold of Tolerability Beyond Symptom Burden

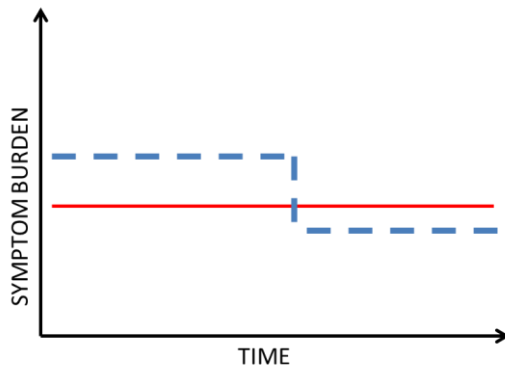


Figure 50: Lowered Threshold of Tolerability, Constant Symptom Burden

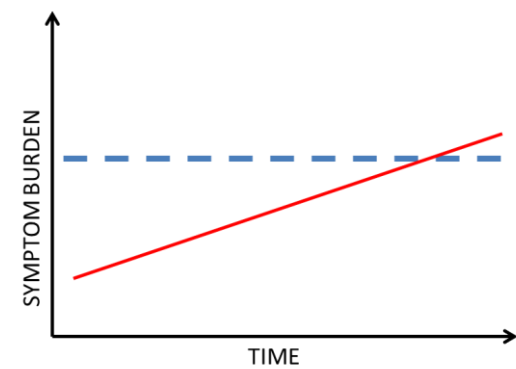


Figure 51: Increasing Symptom Burden, Constant Threshold of Tolerability

Amongst people whose symptoms remain below the threshold of tolerability one of two scenarios must occur in order for that individual to seek help about their symptoms. The first is that the threshold of tolerability changes as a result of a reappraisal of relevant, and potentially novel, elements. This revision of tolerability results in the threshold moving. Should the threshold be raised (i.e. perceived risk in relation to help-seeking barriers is judged to be minor) then the individual will continue to manage their symptoms in their everyday life. However, if the reappraisal of tolerability results in the threshold of tolerability being lowered (i.e. perceived risk in relation to help-seeking barriers is judged to be significant), then the individual seeks help for their symptoms (see figure 50). The second scenario in which the decision to seek help for previously tolerated symptoms occurs is when symptom burden changes over time. Whilst the threshold of tolerability

remains static the increasing symptom burden will eventually break through the threshold in time (see figure 51).

Whilst what is presented here are two simplistic explanations for the point at which a decision to consult is made among people who were not immediate consulters (either threshold of tolerability shifts or symptom burden increases) the reality for most people who do not seek help immediately, will likely incorporate a degree of both (see figure 52). For instance, Abdul's threshold of tolerability shifted over time in relation to concerns about tuberculosis and the sanctioning of help-seeking by his wife and sister-in-law, alongside an increase in the quantity and frequency with which he was coughing up blood.

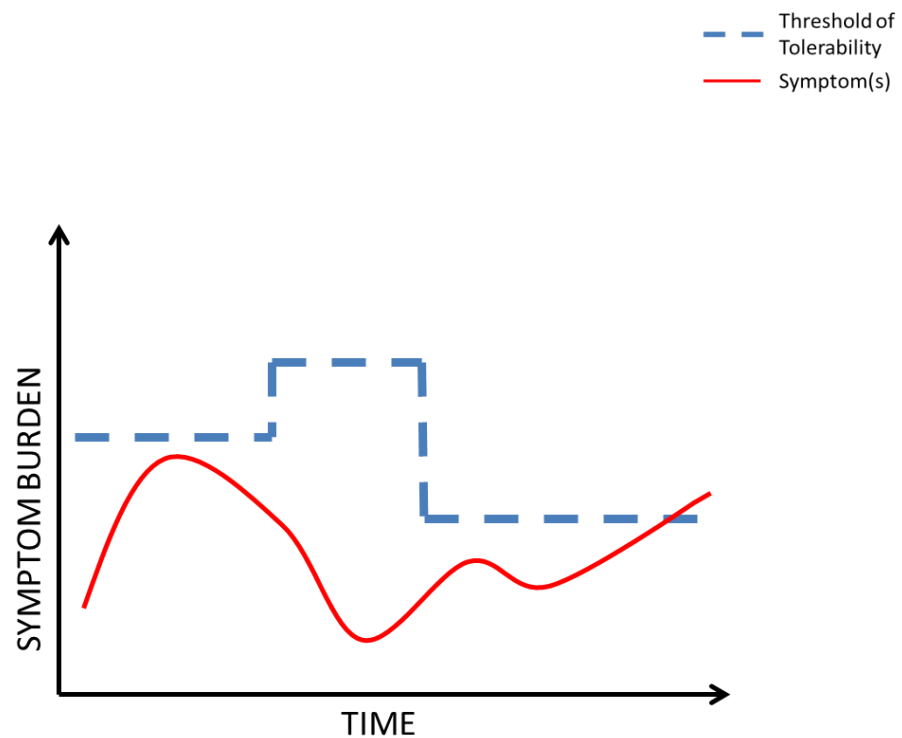


Figure 52: Changing Symptom Burden, Changing Threshold of Tolerability

The notion of thresholds of tolerability is useful for considering how people reach a decision to seek help for symptoms which they had initially decided to tolerate. It seems that contributory elements which endorse help-seeking accumulate within an individual's assessment of tolerability, producing a threshold beneath which people will tolerate symptoms. Once symptoms cross this threshold there is overwhelming evidence which indicates that the person should seek help and so they are no longer able to dismiss the mounting evidence as insufficient to act upon. This threshold of tolerability is calculated

using a range of contributory elements from the four domains of an individual's life; individual experience, interpersonal relationships, health care system interactions, and social and temporal context.

Exploring the idea of the threshold of tolerability further we can reflect on how the language used to describe this boundary is relevant. The word tolerability, as opposed to accommodation or containment, for instance, was used to describe this boundary, as containment and accommodation are both words that imply that the 'problem' is managed successfully and completely. For someone to accommodate their symptoms implies that the symptom is successfully integrated into a revised everyday existence and, similarly, for a symptom to be contained, there is an implication that it is isolated and controlled, affecting only a small and acceptable portion of an individual's life. From the narratives presented by participants in this research who had long patient intervals we know that symptoms can be problematic and uncontrollable, even when they are not deemed to require HCP input. For instance, whilst Elaine attempted to accommodate her faecal incontinence, by carrying changes of clothing and sanitary products, there were a number of occasions where she was unable to accommodate her symptoms effectively. When she had '*accidents*' she arguably wasn't containing her symptoms as they were spilling into her daily life in a manner which was problematic for her functioning in the work place. Not only did she have to return home to get changed but she also had to deal with the embarrassment which the incontinence caused. Whilst she attempted to accommodate and contain the symptoms by carrying spare underwear and sanitary pads, this adjustment to her life, along with the occasions where she had '*no control at all*' were causing her distress. Therefore, it would be more accurate to say that Elaine tolerated her diarrhoea, adjusting her parameters of acceptability and incorporating objects which helped her to deal with situations in which the symptoms were not contained, despite feeling unhappy about the situation.

Architecturally, a threshold is an object which sits in the bottom of a doorway and must be stepped over in order to enter a room or building. The threshold is therefore a divisive object, clearly defining and separating two spaces. Just as a threshold in a building is a boundary between two physical spaces, we can think of a threshold of tolerability as a boundary between two spaces. Beneath the threshold is the individual's everyday life, consisting of certain activities and obligations. Beyond the threshold is a different space, the world of the 'patient'. By deciding to seek help about symptoms the individual moves themselves into a new place, where their role and status change from being a person, to

being a patient. People may therefore tolerate their symptoms for a period of time so as to remain within the world of 'the person', so that they can enact their usual social roles, as once they cross the threshold into the world of 'the patient' their position, relationships and activities change in light of their changing role (Frank 1997).

If we further the threshold analogy we can consider how a threshold in the entrance door of a building separates the outside from the inside. The dirt floor is tolerated outside, as it is situationally appropriate however, were the dirt to cross the threshold and enter into the building the mud would not be tolerable, as it does not belong inside. Once the dirt crosses the threshold and is present on the floor of the building it would need to be cleaned up. This is because it is now in a space in which it should not exist, and therefore needs to be addressed for order to be restored. The threshold therefore is a division between two spaces which contain matter in an existentially different manner.

We can consider symptoms which represent intolerably deviant bodily states to be 'dirt'. Whilst the symptoms are beneath the threshold they are situated within an appropriate space, however, once they breach the threshold they enter a space in which they should not exist without being acted upon. In this sense, we can liken symptoms to dirt as, what they now become is '*matter out of place*' (Douglas 1966, p.66). As matter out of place the symptoms are therefore anomalous in the new space beyond the threshold and so must be dealt with for order to be restored. If we apply this thinking to the notion of the symptom and the threshold of tolerability, once symptom burden breaches the threshold it enters into a new conceptual space, the space of the patient. The symptom can no longer be ignored as it should not exist within this space without being acted upon and so the consultation needs to occur. The threshold is therefore a conceptual, transitioning border, which defines a moment of movement from 'personhood' into 'patienthood'.

As has been said before, the threshold is a dynamic boundary, shifting as additional pieces of information are incorporated into its assessment. If we were to think about a threshold of a doorway shifting we can see how if a threshold was lowered then the dirt would burst into the building and need to be dealt with, however, if the threshold was raised, then further mud could accumulate. Unlike before it is now tolerable for dirt to be on that piece of floor as it is within the threshold. Similarly, should a threshold of tolerability be lowered, for instance through reappraisal incorporating reflections on previous asbestos exposure, a cough which had previously been tolerated may now breach the revised threshold, and so warrant help-seeking. However, if the threshold of tolerability was raised, for instance through reassurance from others that cough is a normal side effect of smoking, a cough

which an individual may have been on the cusp of seeking help for may now be perceived of as tolerable.

A threshold of tolerability is therefore a conceptual boundary within which symptoms are accepted and incorporated into an individual's everyday life. Once symptoms breach that threshold, either because the threshold is lowered or symptom burden increases, they enter a new space, that of 'the patient'. The individual must consult about their symptoms as they are in a space in which the person must now exist as a patient as they require the involvement of the expert clinician to restore order. We can consider the threshold of tolerability to be the product of a risk assessment. All of the contributory elements are considered to produce a boundary over which the symptoms present a potential risk which require expert input and are not appropriate to tolerate within everyday life. People's appraisal of symptoms in light of contextual information and their subsequent assessment of risk is importantly underpinned by societal attitudes towards risk, which shape how we respond to anomalous situations.

*'Just as Douglas called attention to the incipient dangers lurking within the spaces lying outside of and between the main categories of the extant classification system, public health was beginning to embark on the great crusade to promote an ecologically conscious hygiene which recognised the existence of danger everywhere.'* (Armstrong 1993, p.408)

### **'Risk Society' and its implications for responses to symptoms**

Changes in the structure of society have resulted in an environment in which risks must be identified and managed as part of everyday life, a situation which has been referred to as the 'risk society' (Beck 1992). Transformations in the relationships between the individual, the community and society, as a result of the industrial revolution and the later demand for educated, expert workforces, have meant that people now conceive of themselves as isolated, active agents who must navigate life, and risk, independently. In other words, there has been a shift away from the *we* and towards the *I* as the primary agent (Beck 1992). A 'risk society' is preoccupied with the future and the notion of risk is employed to manage the uncertainty and hazards inherent in modern society, such as the impact of unemployment as the individual is no longer part of a community which adopts collective responsibility for workload and resource allocation. Alongside the ecological hazards which man has always faced, such as the risk of natural disaster, there are now new, potentially global, hazards, which are the product of social and economic development, with the threat of nuclear accidents for instance posing risk to all (Gabe 2013). Within the increasingly risk



laden, and focused, society people must identify, calculate and reflect upon risk frequently, simultaneously trusting expert authority on risk and being reflexive of the *'indeterminate status of knowledge about risk'* (Gabe 2013, p.89).

As the notion of social and environmental risk embeds itself there is a move towards greater surveillance and prevention of risk. In relation to health this takes the form of the promotion of preventative medicine. Castel (1991) uses the example of the psychiatric patient to highlight how public health focus has shifted. Whereas the dangerousness of the patient used to be the subject of attention, considering what the patient had done that made them an inherent danger to society, the attention has now moved to the potential risk of the patient. This assessment of risk within the psychiatric patient, essentially a consideration of the abstract factors which govern the probability that the undesirable will occur, is the result of policy shift away from management (dangerousness) to prevention (risk). *'What the new preventive policies primarily address is no longer individuals but factors, statistical correlations of heterogeneous elements. They deconstruct the concrete subject of intervention, and reconstruct a combination of factors liable to produce risk.'* (Castel 1991, p.288). People are now conceived of as active agents in the endeavour of health, who should manage the risk factors associated with illness, maintain and monitor psychological vigilance and be responsible for self-management (Armstrong 2014).

Alongside an emphasis on the risk inherent in the individual, the public health gaze has also turned to the identification of 'at risk' and 'risky' groups. This is particularly evident in responses to the HIV/AIDS epidemic, whereby public health approaches created 'risk groups', namely gay men, intravenous drug users and prostitutes (Lupton 1994). These risky groups contained deviant people, as they engaged in behaviours that were, during the 1980's at least, seen of as socially unacceptable. This meant that initially, HIV/AIDS was often perceived of as a risk to 'others' and was even seen, by some, as a punishment for living an unhealthy life (Lupton 1994). By identifying 'risky' groups in relation to diseases it is possible for public health bodies to take targeted approaches to the reduction and prevention of the disease, however, it can also affect the way the lay person perceives of their vulnerability to disease, based on whether or not they belong to a particular group. For instance, whilst condom use was promoted as a universal strategy for the reduction of HIV/AIDS, individuals who did not identify themselves as part of a 'risky group' may have believed that this message did not apply to them. This is despite the fact that they may still have been at risk because of, for instance, previous exposures of their sexual partner.

Whilst the 'at risk' and 'risky' groups in relation to cancer are not as clearly defined as they are for AIDS, it is easy to conceive of the smoker, the excessive drinker and the 'unhealthy person', who does not take care of their body through appropriate diet and physical activity, as groups of people who are conceived of as 'at risk' or 'risky' in relation to cancer. People consider beliefs about who is 'at risk' in relation to themselves and then use this information as one of the contributory elements in the calculation of the threshold of tolerability. The idea of the person 'at risk' of cancer will be explored shortly, using the idea of the 'cancer candidate'.

In the same way that we can identify a focus on risk in modern public health, so too is this underpinning concern evident in clinical practice. Biomedicine is becoming increasingly scientific, with an emphasis on rational and quantitatively grounded decision making. The focus on logic and reason in the clinical decision means that the practitioner's intuition is now replaced by calculation (Lupton 2003). Within cancer diagnostics we can see how this shift towards calculation of risk is taking increasing precedence within the clinical consultation, through the estimation of positive predictive values for symptoms suspicious of cancer (Hamilton 2009) and the integration of these values into risk assessment tools that interface with the GP's computer (W Hamilton et al. 2013; Rubin et al. 2014).

With the biomedical focus on risk and illness prevention, and the societal focus on management of risk, it is unsurprising that the lay public are increasingly conscious of the relationship between risk and health. People are more attuned to the endeavour of identifying and responding to health risks in their daily life, for instance through what has now become a widely accepted risk reduction strategy, the application of sunscreen to reduce the risk of skin cancer. It has been suggested that the introduction of screening programmes has specifically reinforced a risk mind set in relation to health. As a result of the introduction of screening for tuberculosis, individuals were forced to consider the possibility of pre-symptomatic disease, requiring what could be described as a paradigmatic shift for people, where they had to acknowledge the potential presence of disease despite feeling healthy. Public health practitioners therefore had to heighten alertness among the public to the risk of diseases that were hidden from lived, embodied experience (Armstrong 2014). The introduction of screening programmes promotes a viewpoint in which disease is always a possibility, fostering a need for hyper-vigilance whereby the individual is continually reflexive about the body and illness. Interviews with women who had been invited for cervical cancer screening highlighted how women made decisions about the necessity of participation in relation to a number of risk factors. The risk factors which

women used to decide upon the appropriateness of screening came from information provided by public health bodies (number of partners, smoking, age at first penetrative sex), as well as risk factors from their own lay understandings of cervical cancer (frequency of sexual intercourse, trauma to the cervix as a result of certain sexual positions and childbirth and the menopause) (Armstrong & Murphy 2008). Whilst both biomedical and lay risk factors were incorporated into the assessment of appropriateness of screening, expert-defined risk factors were often transformed as they were considered alongside women's own experiences and social contexts, with women weaving the factors into a tailored and coherent whole (Armstrong & Murphy 2008).

We can use this example to reflect upon how participants in this research incorporated a range of information about symptoms and context to decide on the necessity of consultation. The assimilation of information to produce a threshold of tolerability can also be considered to be an assessment of a threshold of tolerable risk, with symptom burden constituting the risk. Although symptoms are always potential risks, a view which is instilled through the modern focus on disease prevention, it is not appropriate to act upon every symptom. Within the confinements of the threshold the symptom, as a risk, is tolerable, as it falls below the parameters which the individual has defined. However, once the threshold is breached, the risk leaves the realm of lay management and enters the realm of biomedical intervention, moving from the realm of the person to the realm of the patient. Through obtaining the status of the patient, the risk can be dealt with and the individual returned to the world of the person, returning bodily experience beneath that threshold.

Just as people incorporate numerous pieces of information into their assessment of symptom risk and the calculation of a threshold of tolerability, people also produce assessments of people 'at risk' of cancer. This assessment of the 'at risk' person falls within the 'individual experience' domain of a person's wider context, as the creation of the 'at risk' archetype is compared against personal experience to assess how the individual correlates with this image, based on their personal attributes. However, it is influenced by interactions with others, in the form of things they may say which shape an individual's definition of the person at risk of cancer, as well as by social discourses on cancer which belong to the domain of social and temporal context. I will consider how assessment of 'cancer risk' is one example of a contributory element which feeds into calculation of the threshold of tolerability and therefore influences symptom appraisal and help-seeking decision making. The responses to 'cancer risk' amongst those who presented swiftly and

those who took longer to present are considered in relation to the concepts of the 'critical incident' and the 'cancer candidate'.

### **Considering Cancer Risk**

During the symptom appraisal process people considered a range of possible explanations based on their symptomatology and other factors which were relevant to each possible diagnosis. Most people were not ignorant of the possibility of cancer as an explanation for their symptoms and did consider it as a possible cause. However, they considered this diagnosis in light of a range of other pieces of information, such as lifestyle factors, age, presence/absence of other symptoms and family history. This information assessment was not directly articulated but appeared to be a subconscious, or intuitive, evaluation of their experience in relation to perceived cancer risks. People calculated a perceived risk that their symptoms were being caused by a malignancy using a range of factors and based their decisions about future actions on this analysis of risk.

The evaluation of one's probable risk of symptoms being cancerous is something that was not overtly articulated by participants, but is evident in their narratives of appraisal and re-appraisal. For instance, upon noting his cough Richard was aware that it was a symptom of cancer but initially dismissed it as insignificant. As his symptoms remained for a longer time than he expected he revisited cancer as a possible explanation, but rejected cancer as an explanation, as he had no other notable symptoms which he felt would have corroborated cancer as a plausible hypothesis. When his cough persisted he began to think about his symptoms in relation to his previous smoking status and subsequently reassessed the likelihood of cancer using this additional element, yet again dismissed cancer as a likely explanation. As time progressed and his symptoms did not act in the way in which he expected them to (i.e. by resolving) he began to incorporate additional pieces of information into his appraisal of his symptoms. It was only towards the end of his patient interval, after considering the initial symptom, the absence of other symptoms, the longevity of the symptom, and his smoking history, that he then perceived of the risk of cancer to be great enough for it to be considered as a plausible explanation. Harry's symptom appraisal process is another example of an ongoing internal assessment of cancer risk. Harry experienced loose bowel motions which he initially thought were related to his diet. His symptoms waxed and waned for a number of months and each time they reappeared he reconsidered his explanations for them. Throughout the course of his patient interval Harry incorporated multiple pieces of information into his assessment of cancer risk. He reflected on the fact that he had always eaten a healthy diet, he had never

smoked or drank alcohol, the symptoms were not constant and intermittently improved, he had not experienced any bleeding and he had had a negative FOBT screening result during the symptomatic period. However, he was also felt that cancer was indiscriminate and had the potential to strike anyone at any time. All of these pieces of information were analysed independently and simultaneously to calculate a perceived risk of his symptoms being caused by cancer, an assessment of possible risk which changed during the appraisal process.

It seems that participants intuitively undertook risk assessments of the possibility that their symptoms may be the result of cancer throughout the symptom appraisal period. Other research has similarly found that people consider and reject multiple explanations for symptoms before deciding upon the most plausible explanation (Locker 1981). Perceptions of symptom severity are based on assessment of symptom duration, comparison with others' symptoms, the impact of the symptoms on daily functioning (Locker 1981), knowledge of cancer, family history of cancer (Khakbazan et al. 2014), the absence of symptoms (Low et al. 2015) and recent negative cancer screening (Mwaka et al. 2015).

If we consider how participants in this study responded to symptoms we know that those who consulted quickly had more severe symptoms and few potential explanations in mind, whereas, those who took longer to consult engaged in numerous episodes of symptom appraisal, with cancer repeatedly considered and rejected as a hypothesis. People with longer patient intervals often considered cancer as a possibility from very early on in the symptom appraisal process but rejected this explanation because of the lack of other factors which corroborated this as a plausible hypothesis. The possibility of cancer was revisited as new pieces of information became available and people undertook risk assessments to assimilate this information. The fact that people consider and reject multiple explanations for their symptoms, particularly cancer, from early on in the symptom appraisal process challenges current public health approaches to improving time to presentation, as an awareness of cancer as a possibility appears not to be sufficient to make everyone seek help, since cancer is often rejected as a hypothesis for plausible reasons.

One lens through which to view the assessment of risk of cancer for those who presented quickly is the concept of 'critical incidents'. In an examination of patients who had experienced a first heart attack, the point at which chest pain both persisted and increased in severity has conceived of as a 'critical incident' (Cowie 1976). Whilst everyone

experienced this critical incident, those who were unable to formulate an alternative explanation for the pain considered a heart attack immediately. However, those who had other factors which influenced how they felt about chest pain, for instance a history of indigestion, considered a less serious diagnosis more plausible and so tolerated their symptoms for longer, seeking help when the symptoms became unbearably acute. This is consistent with the findings of this study, whereby those who responded quickly to the 'critical incident' (i.e. by consulting) experienced bodily sensations which were drastic deviations from usual bodily functioning and few possible explanations were considered for the symptoms. Possible explanations were always a 'serious' condition and cancer was the primary explanation people considered. People experiencing blood or pain, when compared to other symptoms, have been reported to feel that these symptoms are more legitimate to consult about (Hall et al. 2015), which is supported by the findings from both the questionnaire and interview data in this study, whereby those experiencing these initial symptoms consulted soonest. It may be that these symptoms represent more drastic deviations from expected bodily functioning and so are more clearly symptoms for which it is appropriate to seek HCP input. The belief that certain symptoms legitimate consultation more than others relates to beliefs about appropriate use of the health care system and the concept of the 'good patient', which will be explored later in this chapter.

For those who took longer to present the initial bodily sensations were often minor deviations from usual functioning and were not conceived of as 'critical incidents' from the outset. As symptoms progressed over time 'critical incidents' did take place for some participants, such as Maggie for whom chest pain prompted her to seek emergency medical attention, after having experienced a cough for over a week. However, for most participants the symptom appraisal was based on an accumulation of multiple pieces of contextual information and rarely solely on physiological experience. The concept of critical incidents is useful for explaining the response to symptoms by those who experience acute symptoms which immediately cross thresholds of tolerability because of the severity of deviation from typical bodily experience. However, it fails to explain the complexities of the symptom appraisal process for people whose symptoms were not particularly alarming and for whom action was motivated by contextual factors which prompted repeated revision of the threshold of tolerability more so than bodily experiences.

The calculation of probable risk of cancer is complex and assimilates lots of different elements, such as experiences of symptoms, absent symptoms, lifestyle factors, previous encounters with cancer, and recently completed cancer screening. Related to this

assessment of the relevance of cancer to the presenting symptoms was people's perceptions of how likely it was that they, personally, would get cancer. This perception of one's potential to have cancer was not solely based on an assessment of specific risk factors, but also entailed consideration of whether they envisaged cancer as a condition which was applicable to them as an individual. Roy dismissed cancer as a relevant diagnosis because he had been experiencing his symptoms for *'too long'*. Had he actually had cancer he felt that it would have produced other visible signs, such as weight loss and decrease in appetite. For other people, such as Mark, his perception of himself as a 'healthy' individual meant that he didn't conceive of himself as someone who would ever get cancer: *'you never associate that with yourself... you think 'no, that's not, that can't happen to me''*.

The rejection of cancer as a possibility appears to be informed by the individual's ideas about who belongs to the 'at risk' group for cancer, thinking about how their own characteristics aligned with the characteristics of 'at risk' people. When the individual did not identify themselves as belonging to this group they rejected cancer as a possible explanation for their symptoms. One framework for considering this rejection of cancer as something which is likely to happen to 'me', is the notion of cancer candidacy.

Davison et al (1991) introduced the idea of the 'coronary candidate' to explain how people perceived of the archetypal person who would suffer 'heart problems'. Candidacy provides a means of retrospectively explaining one's own, or someone else's, illness, as well as prospectively predicting risk of illness (Davison et al. 1991). Definitions of candidacy are reached collectively, based on an assimilation of information from many social contexts, including observations of individual cases, aetiological theories, mass media, and information from family, friends and colleagues. The 'coronary candidate' was found to be the stereotypical overweight, middle aged man. The characteristics of the 'coronary candidate' meant that those who didn't fit this profile, notably women, would often underestimate their own risk and put off help-seeking (Emslie et al. 2001). Macdonald et al (2013) sought to ascertain whether this notion of candidacy was relevant for cancer, and undertook interviews with *'ordinary people'* (non-cancer patients from a community sample) to explore their conceptions of the cancer candidate (Macdonald et al. 2013).

They found that there were three elements to people's discussions of the 'cancer candidate'; risk factors, family susceptibility and environmental factors. Risk factors were strongest in people's narratives, with smoking and a 'healthy lifestyle' being the main considerations in people's construction of the 'cancer candidate'. Family susceptibility and

environmental factors, mainly in the form of workplace exposure, provided less consistent feelings and were of lesser significance in people's notions of candidacy. The authors concluded that candidacy for cancer was narrow. The 'cancer candidate' was found to be a challenging concept for most people, thought to be the result of poor awareness of cancer risk profiles, as well as the level of fear which still surrounds cancer within our culture (Macdonald et al. 2013).

Within this research all three of these elements were present in people's calculations of their own risk of cancer, with assessment of protective and damaging behaviours, family history and exposure to asbestos all frequently reported. From the findings of this research, however, we can see that symptoms also play a substantial part in people's assessment of potential cancer candidacy, be it the presence or absence of particular symptoms. Numerous participants talked about how they, at some points at least, didn't believe cancer to be a possible explanation for their symptoms, as they did not display the 'typical' cancer signs, of weight loss, lethargy and loss of appetite. In relation to his diarrhoea Roy said *'I knew, if it had gone on that long and it was cancer I would have lost weight and my appetite would have gone, I'd have felt different in myself. But I didn't, I just still felt as normal'*. By considering the symptoms which should have manifested if the diarrhoea was being caused by cancer Roy used characteristics of his archetype of the 'cancer candidate' to compare his own experiences to and appraise his risk of cancer based on this. Previous results from cancer screening programmes were also integrated into people's assessment of potential candidacy. *'The poo test thing came through and I thought 'Oh right, good, I'll do this'. And then it came back negative. 'Oh right so it must be all right'. So then you go along a bit further then before you...'* Here Eleanor explains how a negative screening result provided reassurance that she did not fulfil the criteria of the cancer candidate, so she disassociated herself from this 'risky group' and sought other plausible explanations for her symptoms, including constipation and haemorrhoids. As time progressed and she rejected her initial hypotheses as implausible, she revisited cancer as a possible explanation, reconsidering her symptoms against her image of the 'cancer candidate'.

One explanation for why these additional elements were present in my participants' constructions of cancer candidacy, yet were not evident in Macdonald et al's (2013) analysis, could be that they explored *'ordinary people's'* concepts of cancer candidacy. The 'cancer candidate' may have been an abstract concept at the time of their interview, relatively removed from their daily existence and experience. Whereas, for participants in this study, constructions of the 'cancer candidate' were tangible and salient to them at the



point of the interview, as they had used these concepts of candidacy in their recent appraisal of, and response to, their own symptoms. The notion of the 'cancer candidate' may not exist in people's minds prospectively, but can be drawn upon during symptomatic periods, or retrospectively, in relation to recent bodily deviations and circumstances.

The concept of 'the cancer candidate' appears to be a useful means of examining data on patient's perceptions of their own risk of cancer, and helps to explain why people either act upon, or ignore their symptoms, based on perceived alignment with the 'cancer candidate'. It has previously been found that people with symptoms of oral cancer were aware that their symptoms were indicative of cancer but did not believe that cancer could be the cause of *their* symptoms (Scott et al. 2007). Other studies also show people assessing symptoms and rejecting cancer as a possible explanation because their experiences do not match their expectations of cancer. For instance, when skin changes did not match people's mental image of melanoma people normalised their symptoms and took longer to present (Walter et al. 2014). Women with cervical cancer did not attribute their symptoms to cancer because they believed they were not at risk of cervical cancer (Mwaka et al. 2015) and there may be a perception that there is a certain 'type' of woman who is more at risk (Armstrong & Murphy 2008). As touched upon earlier, perceptions of oneself as 'healthy' also jar with the image of the typical 'cancer candidate', as the cancer candidate is someone who engages in 'risky' behaviours. Lupton (2003) discusses how people associate cancer with previous indulgence in risky behaviours and quotes a magazine article about the actress Olivia Newton-John's experience of a breast cancer diagnosis, wherein she says: *'I was puzzled that this had happened to me, because I eat sensibly, exercise regularly, don't smoke and hardly ever drink.'* (Lupton 2003, p.100). The 'cancer candidate' is therefore made up of previous risks which may now be coming into play, as well as symptomatic risks and this is evident when people talk about the protective (i.e. healthy diet and exercise) and the damaging, or risky, behaviours (i.e. smoking) behaviours they have engaged in.

This research implies that people use an accumulation of information on risk factors, family susceptibility, environmental exposure, previous cancer screening results and symptomatic experiences to compare themselves with their concepts of the 'cancer candidate'. Through the analysis of potential risk people produce a model of the 'cancer candidate' which they assess themselves against. Notions of candidacy were used to assess the likelihood of cancer as an explanation for deviant bodily states, irrespective of whether or not the individual ultimately aligned themselves with the 'cancer candidate'.

Although the notion of a 'cancer candidate' was not particularly robust among Macdonald et al's (2013) participants, from a community sample, it appears that the 'cancer candidate' is a concept which can be defined and invoked when appraising one's own symptoms. This tailored construct influences people's perceptions of their own need to consult based on an assessment of how well they fit the 'cancer candidate' model. This highlights the fact that people are rarely ignorant of their symptoms' association with cancer but that they undertake complex assessments of risk, incorporating concepts of candidacy, to produce a perceived risk of cancer which is tailored to themselves.

Calculating one's risk of cancer does not, in and of itself, result in a decision to seek help. This section has sought to explore further how initial assessment of symptom risk feeds into calculation of thresholds of tolerability, and therefore contributes to the transition of the individual from the realm of the person into the realm of the patient. For individuals whose symptoms were drastic deviations from usual bodily expectations we can compare their experiences to the idea of the 'critical incident' which immediately breached the threshold of tolerability and prompted the individual to seek help to attempt to restore order to their bodily functioning. For participants who did not perceive of symptom onset as a 'critical incident' people considered a range of possible explanations for their symptoms, including cancer. People's assessment of the risk of cancer in relation to themselves was based upon a consideration of the characteristics of the 'cancer candidate'. This perceived risk of cancer is assimilated into decision making processes, along with information about a number of other contributory elements to compute a threshold of tolerability. The archetypal 'cancer candidate' is an example of how tailored assessment of risk, using multiple pieces of contextual information, feeds into a wider appraisal of risk and is used to assess the boundary within which the symptom should be tolerated and subsequently the point at which this symptom poses an intolerable risk which must be addressed.

### **Summary: Help- Seeking Decision Making in a 'Risk Society'**

Participants in this study either consulted quickly about their symptoms, considering few explanations for what were generally 'severe' symptoms, or, they took longer to consult, considering multiple contributory elements in relation to their symptomatic experiences. People calculated a threshold of tolerability, based on a range of contextual information, beneath which symptoms were tolerated within everyday life. Symptom burden could breach the threshold immediately, as was the case for people who consulted quickly, or could be tolerated for a long time should symptom burden fall below the threshold. However, once the threshold was breached the individual entered into the space of the

patient. The assessment of tolerability was based on an assessment of risk and this was influenced by the public health focus on prevention and risk, which is, in turn, a product of the 'risk society' within which participants live. A threshold of tolerability is an assessment of symptoms as 'risky' and a boundary imposition which indicates when someone should seek out expert clinical input to redress bodily balance.

An assessment of the risk of cancer is one contributory element which is incorporated into the production of a threshold of tolerability. People who experienced symptoms which were drastic deviations from usual bodily functioning perceived of their bodily experiences as 'critical incidents', considering cancer as a possibility promptly. Whereas, those whose symptoms did not represent such drastic deviations to expected functioning compared and contrasted their experiences with their conceptions of the 'cancer candidate', which incorporated information on both bodily experiences and risk factors. Assessment of cancer risk was one element which fed into the calculation of an individual's threshold of tolerability. Belief that symptoms may be the result of cancer was not sufficient in and of itself to act as a catalyst for help-seeking. For instance, we know that Mark considered cancer as a plausible explanation yet did not seek help about his symptoms until the incorporation of other contributory elements into his calculation of tolerability (work responsibilities and the conversation with a patient's wife who had bowel cancer) resulted in the revision and lowering of the threshold, meaning that symptom burden breached it.

The factors which people incorporate into their threshold of tolerability are all pieces of information which provide an indication of when it is appropriate to manage symptoms independently and when it is appropriate to seek expert input. As I shall discuss in the following, and final, section of this chapter, people are reluctant to enter the space of 'the patient' because of the implications that this role has on the representation of the individual as 'good' and 'moral'.

### **7.3 The 'Good Patient'**

One of the issues found to be central to participant's beliefs about appropriateness of entering the patient role was the desire to be perceived of as a good patient. Here I will explore how beliefs about what it means to be a 'good' or 'moral' patient are created and subsequently influence response to symptoms. I will establish the existence of an 'early presentation' discourse, considering how it is underpinned by the 'new public health' approach. Through the existence of a discourse on appropriate symptom responses it is possible for judgements to be made about an individual's behaviour, which subsequently

produces dichotomous images of the 'good' and the 'bad' patient, grounded in notions of morality.

### **'New Public Health' and the Early Presentation Discourse**

As has been established earlier society requires an individual to calculate and manage risk independently on a daily basis. Alongside this, the 'new public health' approach places emphasis on the individual to be motivated and proactive about their health after the absorption of governmental messages about appropriate behaviour. Discourses of early diagnosis and early presentation lay tenets for appropriate responses to symptomatic experiences and these obligations result in the moralisation of illness and help-seeking behaviour. These messages place obligations and duty on the individual, in relation to how they should behave.

Current public health approaches hold prevention and risk as the objects of their attention. The 'old' system of public health focused on dirt and contagion as the means of reducing illness; however, contagious diseases are no longer such a pressing public health priority due to improvements in living standards and vaccination programmes. Whereas, under the 'old public health' approach, attention was given to the threats which existed externally to the individual and were conceived of as dangerous at a population level (i.e. air borne disease), 'new public health' now focuses on the risks as relevant to the individual (i.e. smoking), meaning that the object of attention has become the body. 'New public health' conceives of the 'population' and the 'environment' in a much broader sense, encompassing psychological, social and physical elements. In particular, the emphasis is now on the social, or lifestyle, factors influencing the aetiology of disease (Petersen & Lupton 1996). Through the focus on lifestyle risk factors, people's personal and social lives have become the objects of scrutiny and regulation.

'New public health' is neoliberal, in that it emphasises the devolution of responsibility for health to communities and, more specifically, the individual. This is achieved through the creation of 'capable', self-regulated citizens, amongst whom the state, through its institutions and agencies, encourages ideal behaviours. *'The emphasis of the new public health is upon persuading people to conform voluntarily to the goals of the state and other agencies.'* (Petersen & Lupton 1996, p.12). The disciplinary power of public health is maintained through health education campaigns, fitness testing, health risk appraisal and mass screening, yet its rhetorical nature means that the public is unaware of it as disciplinary, perceiving instead of such initiatives as benevolent (Lupton 2003).

This means that, as opposed to introducing legislation to enforce ideal behaviours and therefore eliminate risk, 'new public health' seeks to inform the individual about the risks inherent in particular lifestyle choices and encourage ideal behaviours through less direct strategies, such as 'nudging' (Thaler & Sunstein 2008). For instance, as opposed to making tobacco consumption illegal recent public health approaches to reducing smoking related risk and disease have been to educate the population about the risks of smoking, through the 'smokefree' campaign, and to introduce plain packaging of cigarettes and remove tobacco products from view within shops (Department of Health n.d.; DoH 2011).

Public health, as a body of knowledge and practice, is based on binary classifications: clean/dirty; inside/outside; healthy/diseased; self/other. The epidemiological research which underpins most public health is also based on the binary categorisation of epidemiological groups into the 'normal' and 'abnormal' (Petersen & Lupton, 1996). It provides standards that the individual is, on a superficial level, encouraged to attain and, more fundamentally, judged against. This therefore introduces another binary classification in relation to conformance to the doctrines of appropriate behaviours, the conformer and the dissenter. It contends that the conformer is conceived of as the good citizen, behaving in the approved manner, whereas, the dissenter is a bad citizen, contravening expert guidance. Within a modern, biomedical, risk focused society there has emerged a discourse around the 'good' or 'moral' patient which dictates appropriate 'patient' behaviour in response to symptoms, exemplifying the knowledgeable, proactive citizen who is self-motivated in relation to their health (Granek & Fergus 2012). For instance, using the example of smoking as a public health risk moral judgements are placed on those who continue to smoke, aligning the individual with the archetypal 'bad citizen' as they have failed to conform to the public health advice given.

We can reflect on how a discourse of 'early presentation' exists within this context. A discourse provides a means of describing and categorising our worlds, both social and physical (Parker 1992) and discourses gather around a 'thing' (be it an object, person, social group, concept, action or event) to enable people to make sense of it (Lupton 1994). Parker (1992) presents seven criteria for distinguishing discourses. Discourses are realised in texts; they are about objects; they contain subjects; they are coherent systems of meanings; they refer to other discourses; they reflect on their own way of speaking; they are historically located. A discourse has the power to define what it is possible for people to say and do, and subsequently what it is not possible for them to say or do. The ability of a discourse to define behaviour is reinforced through the symbiotic relationship between

discourse and practice, as the adoption of the behaviours promoted contributes to and reinforces the discourse's validity (Lupton 1994).

If we return to Parker's characteristics of a discourse we can consider how there is a discourse around early presentation in response to experience of symptoms indicative of cancer. When Parker refers to discourses existing in texts, he does not solely mean the written word, but all '*tissues of meaning*' (Parker 1992, p.5), which means all modes of conveying a message, be it an advertisement, non-verbal behaviour, architecture, tarot cards or even a bus ticket. We can easily identify public health campaigns on the importance of early presentation and news media stories on the links between early presentation, diagnosis and survival as the *texts* through which the discourse of early presentation is realised. This discourse creates both the symptom and the cancer as the *object*, and the individual is the *subject* who reads and hears the texts which the discourse inhabits. Considering the 'early presentation' discourse as a *coherent set of meanings* we can readily identify how the statements within this discourse are interrelated and coherent (certain symptoms are a risk of cancer, you should present early when experiencing these symptoms, early presentation increases the likelihood of early diagnosis, early diagnosis increases your likelihood of survival).

The 'early presentation' discourse clearly *refers to other discourses*, both the discourse of 'risk' and the discourse of the 'good patient'. Public health frames the symptomatic experience as a risk, which needs to be managed, and presents the individual who acts upon risky symptoms by consulting as a 'good patient'. Texts and individual subjects are not all expected to *reflect on their own way of speaking* but instances of reflection can be found in discourses as a whole. From the interviewees in this study we can identify instances where people talked about an awareness of the need to present early yet acknowledged that this in itself was problematic, as we can see in Richard's comment: '*I think it's all very well having these advertisements on the television, but I think that might encourage everybody to go!*'. Finally, as is evident in the discussions above, the 'early presentation' discourse is *historically located*, being grounded in a 'new public health' approach to prevention and risk, yet is simultaneously evolving in line with scientific innovations.

As individuals are expected to effectively navigate risk within modern society, through the provision of information as to the appropriate course of action in response to such a risk, there are expectations of how the individual should respond to symptomatic episodes. People want to be seen to be successfully managing their risk, as to do so demonstrates to

the wider society that they are 'good' or 'moral' agents, capable of acting appropriately. *'Managing their own relationship to risk has become an important means by which individuals can express their ethical selves and fulfil their responsibilities and obligations as 'good citizens'.*' (Petersen & Lupton 1996, p.65). However, discourses are essentially ideological, in that they seek to persuade audiences to accept a particular version of reality (Lupton, 1994). The focus on the individual, their knowledge and behaviour as the means of ensuring appropriate response to risk has been critiqued as it assumes that the individual has the control and agency to enact appropriate behaviours. This assumed level of freedom and agency to enact ideal behaviours is not possible for most people within their everyday life (Shoveller & Johnson 2006) and so the individual is often unable to act in the 'correct' manner.

In the rest of this chapter I will go on to explore how a discourse of 'moral patienthood' was evident in participants' narratives and how this discourse influenced the patient interval. I will use the examples of concerns about 'wasting the doctor's time', exposure to the Be Clear on Cancer campaign, and the reporting of discrepant patient interval lengths to consider how obligations of early presentation and the subsequent framing of behaviour as good/bad and moral/immoral in relation to help-seeking impacted the responses of participants in this study.

### **Appropriateness of Consultation and Conceptions of the 'Good Patient'**

The early presentation discourse frames prompt help-seeking upon discovery of a symptom as the appropriate response of the 'good patient'. However, in this research, whilst some people saw going to the doctor's as 'the right thing to do', others talked about self management of symptoms and judicious consultation as 'the right thing to do'. It appears that there are two related yet competing expectations and discourses which influence people's views about appropriate responses to symptoms. The first is the early presentation discourse, wherein the 'good patient' seeks expert input promptly for emergent health conditions. However, the second construction of the 'good patient' requires the individual to be a responsible consumer of medical resources, who distances themselves from the frequent attender, the 'hypochondriac' or the 'malingerer'. We can see how, from different perspectives, the good/bad patient dichotomy can be identified in both response. For some people, consulting early is believed to be the behaviour of a 'good patient' as symptoms are presented to the clinician at a time when disease is less likely to be clinically advanced. However, other people believe that not consulting too early typifies

the behaviour of the 'good patient' and that initial self-management is more appropriate in the first instance, since it conserves finite GP resources for those most in need.

In this research, a number of people discussed how self-care was the responsible approach when minor illness arose: *'Somebody gets a splk in their finger and they rush to the hospital, or you think you've got a cold coming on so they run to the doctor you know...I would have to feel the need to want to go to the doctors, not just for the sake of going to the doctors.'* (**Fred:** change in bowel habit, NAD). Many people also highlighted the importance of not *'wasting the doctor's time'*. *'I don't want to waste my doctor's appointment. I would feel a waste of time if I went across and there was nothing going on'* (**Sandra:** cough, chest pain & breathlessness, inflammation). This derision of those people who wasted the doctor's time was evident in people's narratives and participants tried to present themselves as 'good patients' by emphasising their responsible and appropriate use of GP appointments, contrasting their behaviour with that of 'bad patients', who consulted unnecessarily.

A concern about 'not wasting the doctor's time' was more complex than it appears on the surface. Although, this statement refers to a desire not to waste a finite and valued resource, it also reveals a desire, on the patient's part, for the GP to perceive of the complaint as legitimate and worthy of consultation. Therefore, the desire to be a 'good patient' was categorised by both a need to conform to socially acceptable ways of managing symptoms and minor illness, as well as a need to avoid looking foolish to the GP, by presenting with a complaint which turned out to be clinically insignificant.

Patients with symptoms of colorectal cancer have, elsewhere, reported being concerned about 'wasting the doctor's time' and reluctance to take up publicly funded healthcare resources was reported as a barrier to help-seeking (Hall et al. 2015). In a community study of responses to alarm symptoms *'not wanting to waste the doctor's time'* was the dominant reason for not seeking help. This appears to be less about rationing access, and more about ensuring that individuals are not categorised as someone who goes to the doctor's for trivial things (Whitaker et al. 2015). These findings are echoed in this research by Richard, who said that *'I don't want to go to the GP for something which he considered insignificant. You don't like to pester as it were.'*

Whilst the early presentation discourse is influential in people's constructions of 'good patients', in relation to their assessment of their symptoms, it is overshadowed by cultural constructions of socially acceptable versions of being both ill and a patient. *'Illness behaviour is a normative experience governed by cultural rules: we learn "approved" ways*



*of being ill'* (Kleinman et al. 2006, p.141) . Individuals are expected to act promptly upon identification of any symptoms, as this is the rational thing to do. This message is reiterated by both practitioners and public health messages which seek to impart knowledge in order to catalyse 'correct' behaviour (Hunt 1998; Seale 2002). However, becoming a patient marks a change in role for people, and this role change impacts social relationships and activities. The implications of taking on a 'patient' or 'illness' role are profound as they shape how people are able to act, as the individual now sits within the realm of the patient. The obligations placed on an individual from the competing, yet interrelated, discourses of the 'good patient' mean that people must seek the morally right behaviour, despite there being no single right behaviour available, something which has been referred to as the morality of illness (Frank 1997). People are caught between consulting a HCP about a condition which is insignificant, or monitoring symptom development, a risky strategy which may result in someone leaving it 'too late'. Navigating the appropriate course of action is problematic as *'in both cases charges of incompetence or irresponsibility may result'* (Locker 1981, p.141).

Wanting to present oneself as a responsible, rational citizen and a 'good patient' is influenced by societal expectations of morality. People wish to present themselves as only seeking out the 'sick role' when it is absolutely necessary as adopting this role undeservedly would align the individual with the 'malingerer', an immoral or 'bad' individual who undeservingly seeks out the role of patient in order to absolve themselves of responsibility (Locker 1981). When people describe their decisions to consult they are providing justifications for the use of the doctor's time, in order to *'identify what they did as situationally appropriate and themselves as responsible patients'* (Locker 1981, p.138).

In an ethnographic study of help-seeking it was found that patients feel obliged to present with 'legitimate' complaints, despite their key concerns often being mentioned as an aside in the consultation, because they fear that these concerns might appear trivial (Andersen et al. 2014). The patient wants to appear to be a 'good patient', someone who is intelligent enough to make sensible decisions about what is appropriate to consult about, and so frames the consultation around this issue. By introducing other, sometimes more pressing, yet ambiguous, concerns as afterthoughts patients are presenting themselves as someone who uses the doctor's time responsibly, for the 'concrete' complaint, as opposed to a foolish person who takes up the resource for something inconsequential.

In this study people used the insistence of others to justify their consultation, as a means of avoiding looking foolish should the decision to consult have actually been inappropriate. A number of interview participants, mainly men, repeatedly cited the insistence of others as their main motivator for seeking help, using phrases such as *'she was going on and on'* (**John**: cough & breathlessness, NAD), or *'I went to the doctors when my wife told me to, as you do'* (**Tom**: wheezing & breathlessness, chronic bronchitis). However, during the course of the interviews it transpired that there were other motivations for consultation, alongside the insistence of a significant other. Often these other concerns were actually a greater factor in people's help-seeking decisions than the sanctioning of others. For instance, despite claiming that his wife was the key reason for consultation four times during his interview, Tom also said *'I began to worry about it being asbestosis, yeah, that was the major reason why I went to the doctors; otherwise my wife would have never have forced me to go.'* A quotation from Roy also illustrates how people used the insistence of others as a means of justifying help-seeking, despite a personal desire to consult: *'She nagged me for a few [days]. 'Why don't you go to the doctors?' Then two or three days later she's nagging me again...I said to her 'I'll go but just to satisfy you, and curiosity for myself'*. This implies that although people like to cite others as their main reason for consulting, they also have a desire to seek help, and so the insistence of another was used as a means of justifying what was ultimately their decision.

The fact that it was mainly men who talked about 'only going because the wife told me to' is important as we know that there are gendered aspects to illness behaviour. It is believed that men's tendency to use women's insistence as a means of justifying help-seeking is because frequent attendance in primary care is seen as a feminine responsibility. This means that male frequent attendance can be seen to be emasculating. Therefore, men choose to characterise their attendance as following a female lead, so as to avoid this potential emasculation (Branney et al. 2012).

The construction of the 'good patient' as an informed, rational being is not only created within discourses of early diagnosis, and appropriate illness and, or, patient behaviour, but is subsumed within wider cultural notions of morality. It has been argued that medicine has now become a system of morality (Helman 2007) and that illness is essentially a moral category:

*'It involves ideas about what is desirable and undesirable and about what is appropriate conduct for a given social status. Further, it is a moral category because it involves judgements about responsibility...only where an individual is*

*seen to manipulate a definition of illness in pursuance of personal ends can a charge of deviance be made.'* (Locker 1981, p.130)

When people employ dichotomous notions of the 'good patient' and the 'bad patient' they are projecting the notions of 'goodness' and 'badness'. The desire to present oneself as a 'good patient' is based in culturally defined notions of morality and deviance. Standardised cultural values determine how one must present oneself and people will strive to perform as 'good' and conforming individuals in order to align themselves with socially accepted behaviours (Goffman 1959). Therefore, for people not to conform to socially accepted patterns of behaviour, i.e. being a responsible user of the GP resource, they are placing themselves in a position in which they could be perceived of as deviant and a 'bad' person. One of the reasons people with alarm symptoms give for not seeking help is that they want to distance themselves from the stereotype of the person who is a hypochondriac and over-consulter (Whitaker et al. 2015). People who have had previous negative experiences around consulting feel that consulting about new symptoms may make them appear to be 'crying wolf' and wasting their GP's time, thus making help-seeking humiliating (Cromme et al. 2016). Although participants in this study did not highlight reluctance to re-consult as a key issue, other research has found that people are reluctant to re-consult about a symptom, even when they believe the GP may have misappraised it and made an incorrect diagnosis (Bottorff et al. 2007; Otieno et al. 2010; Facione & Facione 2006). This is likely a result of the power which the GP holds, as part of being a 'good patient' entails not questioning the knowledgeable and powerful individual, and so one must accept the initial diagnosis provided.

It has been argued that medicine now '*polices social deviance through the creation of a sick role in the doctor-patient relationship*' (Turner 1992, p.18) and that, in functional terms, the GP has now replaced the confessor and priest. Help-seeking decisions are imbued with judgements of morality. The fact that these people were dealing with symptoms of cancer placed an additional element of judgement and morality on their decision making, as cancer is a disease riddled with intonations of morality, which are then transformed into behavioural expectations (Sontag 2002; Hunt 1998). The data from this study implies that people are compelled to present themselves as 'good patients', either by acting on symptoms in a timely manner, or by avoiding 'wasting the doctor's time'. Not wanting to 'waste the doctor's time' is both about conserving valued, finite resources, and wanting to not appear 'foolish'. There is an inherent tension between the two ways in which people choose to present themselves as 'good patients', as one approach is to consult, whereas

the other is not to. The need to be perceived of as a 'good patient' is informed by social discourses around early presentation and diagnosis, and acceptable conditions for illness and therefore entry into 'patienthood'. These discourses dichotomise individuals who are proactive about their health, yet only consult when absolutely necessary, as the 'good patients', whilst stereotyping 'bad patients' as those who consult unnecessarily, often in order to exempt themselves from particular social responsibilities (Locker 1981).

It would be valuable to explore how people construct 'good' and 'bad' patients further, insights from which could help to explain the broader context in which individuals must negotiate help-seeking. This includes incorporating and responding to awareness raising campaigns, which arguably perpetuate these stereotypes and this social discourse. Robbins (2011) has recently called for anthropology to shift focus, moving away from an examination of the suffering subject and towards 'an anthropology of the good' (Robbins 2011). He proposes that such endeavours would examine the ways in which people organise their personal and collective lives to foster what they perceive of as good, based within the realm of morality. In the health arena the concept of 'the good patient' could be a valuable concept for further examination, both theoretically and in relation to the early diagnosis agenda specifically.

#### *The Be Clear on Cancer Campaign and its implications for 'Moral Patienthood'*

For many people in this study, seeing the BCOC campaigns served to encourage help-seeking, with exposure to campaigns serving as a contributory element which was incorporated into the threshold of tolerability. For most people in this study the campaigns did not impart new knowledge about cancer signs and symptoms, but highlighted the importance of seeking help early. The campaigns also served as a tool for others to encourage help-seeking, as they provided a means of initiating a conversation and evidencing what was the appropriate response, as was the case for the wives of Richard and Harry. It was not just the BCOC campaign which served to reinforce the importance of early consultation but stories of early presentation and diagnosis within the news which also acted as a prompt to help-seeking.

Unexpectedly, some participants talked about how the BCOC campaigns provided reassurance that their symptoms could not be the result of cancer, because they had not experienced the alarm symptoms targeted in the campaigns. For instance, Elaine was reassured that her change in bowel habit could not be the result of cancer because she wasn't experiencing rectal bleeding, the symptom highlighted in the campaign she had

seen. When asked how she felt about seeing the BCOC bowel campaign she said *'I wasn't passing blood so as far as I was concerned, that wasn't it. Had I been passing blood I would've gone immediately'*. The BCOC campaigns could be potentially detrimental to help-seeking for a small portion of the population as they may inadvertently convey the message that *only* the symptom highlighted in the campaign is indicative of that cancer. This is particularly concerning when we know that many of the alarm symptoms targeted in the campaigns actually have a low predictive value for cancer, when experienced as single symptoms (Hamilton 2009). The focus on single symptoms could be detrimental, in that it could discourage people from considering cancer as a possibility should they not display the targeted symptom as, being a 'good patient' also entails knowing when *not* to consult a HCP. Therefore, people may be discouraged from presenting with symptoms that are not highlighted in awareness raising campaigns as, such campaigns place clear expectations as to who is justified in help-seeking. Individuals outside of this symptomatic group may be concerned that help-seeking will portray themselves as 'time-wasters' who are irresponsible and contravene what is expected of a 'good patient'.

Other research has shown that when people believe pain or a lump to be universal to breast cancer occurrences, the absence of either symptom discourages help-seeking, as people are reassured that the explanation for their own symptoms must be a benign condition (Burgess et al. 2001; Jones et al. 2015). A recent study has found that women who experienced 'non-lump' breast symptoms had substantially longer patient intervals than women whose had the symptom of a breast lump (Koo et al. 2016). An evaluation of the BCOC lung campaign, which focused on the symptom of a cough, found that there was a small decrease in the number of people who spontaneously reported 'coughing up blood' as a symptom of cancer (Ironmonger et al. 2014). This highlights the potential which these campaigns have to negatively impact people's appraisal processes, should 'red flag symptoms' not be included in campaigns.

The early presentation discourse does not stand in isolation but also relates to wider societal discourses on cancer more broadly. Cancer as a disease has long been a focus of media attention, with endless coverage of innocuous factors, often dietary or environmental, which are hailed as the new 'cause' or 'prevention' of cancer (Seale 2002). The propensity for the media to repeatedly report cancer stories using war metaphors has been well documented and heavily critiqued because of the moral undertones and judgements it places on those who choose not to 'fight', as well as the passivity with which the patient's body is presented as a battle ground without agency (Sontag 2002; Lupton

1994). Our exposure to media shapes our view of the world (Gerbner et al. 1994) but the media is not an independent body spewing forth wholly unique views. It is politically, historically and socially situated and accounts are cultural products which *'do not merely reflect societal norms, values and ideologies but also serve to constitute them, as part of a complex and constantly reflexive relationship'* (Lupton 1994, p.26).

The dominant discourse, which is socially endorsed, is that one should consult as soon as possible when experiencing symptoms which are a sign of cancer (Granek & Fergus 2012). 'New public health' approaches to early diagnosis, through awareness raising, are based on the premise that if people are educated they will act appropriately (i.e. consult) because knowledge will result in action. However, the findings from this research show that most people are already aware that their symptoms are associated with cancer, but that they calculate their perceived risk of cancer in relation to a number of factors. They often rationally dismiss cancer as a viable hypothesis based on their assessment of cancer risk, and, even when suspicious of cancer, perceived cancer risk is only one element which is incorporated into a threshold of tolerability, which dictates when help-seeking occurs.

The *'hypodermic needle'* approach to behaviour change has been criticised because of its conception of 'the audience' as passive receivers of information, which fails to account for the external constraints which people have to contend with in order to make the 'right', lifestyle choice (Seale 2002). Davison et al (1991) have argued that British health education is based on two 'dishonest' principles:

*'that individual citizens cannot or will not take part in behavioural change unless they are encouraged to anticipate individual benefit. Second, that the broadcasting of propaganda based on half truth, simplification and distortion is a legitimate use of public funds, so long as the goal of the enterprise is the good of the community'* (Davison et al. 1991, pp.16–17)

These 'top-down' information imparting interventions reinforce a discourse of early presentation which says that 'good' people will go to the doctors promptly upon emergence of symptoms. A long history of such interventions within our culture creates a context in which we expect that *'a rational individual, after an appropriate amount of caution, would seek aid. When he does not or delays over-long, we begin to question his rationality'*. This research has shown that most patient intervals, irrespective of their length, are often highly rational, despite not always conforming to the expectation of prompt presentation. Harry for instance made very rational assessments of his symptoms

and the need to consult about them throughout his help-seeking journey. He knew his symptoms could be indicative of cancer, however, he considered the likelihood of cancer in light of a number of other relevant factors, such as his diet, recent negative FOBT screening result and lack of other symptoms. Although his response to his symptoms was very rational, weighing up the risk of his symptoms being cancer against logical external factors, he would traditionally fall into the category of the 'irrational' patient because of his failure to consult promptly.

When an individual experiences a symptom and is unsure of its significance, they are placed in a compromising situation in terms of the appropriateness of any response, as at that moment they are unaware of the probability that their symptoms is being caused by a cancer. On one hand, they could go to the doctor with a complaint that proves to be insignificant or they could wait and monitor symptom development, risking leaving their consultation too late, in both cases potentially appearing incompetent (Locker 1981).

Some participants in this study mentioned that they had seen the BCOC campaigns but that they were already aware of the relevance of the targeted symptoms. This fits with Moffat et al's (2015) survey which found that only half of respondents felt that the campaigns had told them something new. Although awareness raising campaigns may be questionable in their approach to early presentation one of their less obvious functions is to sanction help-seeking. Being able to cite the campaign as a reason for consultation could help to address the concerns which some people report in relation to 'wasting the doctor's time'. This is particularly true if the individual receives a tailored approach, alongside the population-wide intervention. We know from Pauline's experience that she was aware of the lung cancer campaign through colleagues', and her own, media exposure, but it was the personalised letter from her GP that acted as the prompt to presentation. Personalised approaches have been found to be effective, with primary care endorsement of the bowel cancer screening campaign having a positive impact on uptake (Hewitson et al. 2011). A message which endorses help-seeking, either general or personalised, provides justification for consulting, as the individual is following instructions and 'doing the right thing'. It conveys authority in the sanctioning of a particular behaviour, meaning that those who consult during the time of the campaign may feel that their behaviour is in line with social expectations and they are being 'good patients'. In the same way that sanctioning of help-seeking by others can encourage presentation, as the individual can justify their use of resources by citing the insistence of another, these campaigns can also serve as justification that one's course of action is not foolish and is socially acceptable.

People's responses to their symptoms are influenced by the social and cultural discourse which exists around early presentation and early diagnosis of cancer. This discourse makes people aware that they should consult early with symptoms of cancer, however, 'top down' behaviour change approaches, wherein knowledge is assumed to result in action, are problematic. They assume that with knowledge people will always act in the desired manner, but do not consider how the nature of the information imparted could negatively impact behaviour, for instance, by providing false reassurance that non-targeted symptoms are not manifestations of cancer. The biggest problem with such approaches to behaviour change is that they are based on the flawed assumption that knowledge is all that is required to produce desired responses. This research has shown that many people are aware that their symptoms are indicative of cancer, however, they do not act promptly, as is expected of the 'rational being', because of a myriad of other factors which influence their help-seeking journeys. Early presentation and diagnosis discourses, reinforced by the media and public health campaigns, serve to caricature the individual who does not act promptly upon discovery of a symptom as an irrational being. This dichotomy between the 'good patient' who consults promptly and the 'bad patient' who does not act quickly is destructive in that it can serve to vilify those who do not conform to the socially accepted pattern of behaviour and calls into question the morality of the individual.

#### *Discrepant Reports of Patient Interval Length*

The final example from this study of how people's behaviour is bound by expectations of 'good patient' is a reflection on the discrepant reports of patient interval length, depending upon the research method employed. As this study used two methods to explore the patient intervals of people with symptoms of lung or colorectal cancer, a questionnaire and a semi-structured interview, two reports of patient interval length were obtained for each of the 26 participants who took part in an interview. The table below (figure 53) details reported time to presentation for these participants.

What is notable about these data is that, for the majority of participants, patient interval length differs depending on the method used to generate the data. Discrepancies in time to presentation range from one day to three and a half years. For all except one of these participants (Arthur), the time to presentation reported in the interview is longer than the time to presentation reported in the questionnaire.



	Age	First Symptom (as reported in the questionnaire)	Interval (questionnaire)	Interval (interview)	Difference
Arthur	80	Very loose bowel movements	4 weeks	2 weeks	- 2 weeks
Steve	50	Bleeding when going to the toilet for a poo	2 days	3 days	+ 1 day
Mary	78	Bleeding from bowel	4 days	1 week	+ 3 days
Julie	59	Pains in my stomach which were unbearable and feeling sick, dizzy and diarrhoea, unable to keep food down or in stomach	2 weeks	1-2 weeks	/
Fred	78	More toilet visits. Stools very loose	2.5 weeks	6 weeks	+ 3.5 weeks
Roy	65	Constant diarrhoea	5.5 months	18 months	+12.5 months
James	74	Belly ache	1 month	6 weeks	+ 2 weeks
Elaine	65	Very loose bowel movement	4 months	4 months	/
Mark	63	Slight, but not consistent change in bowel function	6 months	6 months	/
Christine	50	Stomach cramps and bleeding from the bowel	Same day	4 days	+ 3 days
Harry	79	Loose bowel motions	3 months	4 months	+ 1 month
Jack	84	Bleeding from back passage	3 days	3 days	/
Angela	67	Blood on the toilet paper when I passed a motion	3 months	3 months	/
Eleanor	67	Bleeding from back passage	2 months	6 months	+ 4 months
Abdul	41	I began to cough up blood and chest/breathing became tight	3 months	3-4 years	+ 3.5 years
Pamela	71	Blood in phlegm	Same month	'a few weeks'	/
Audrey	73	Coughed up some blood in phlegm	1 day	2 days	+ 1 day
Richard	69	Cough/Irritation in chest	4 months	5 months	+ 1 month
John	70	Cough and breathlessness	6 months	9 months	+ 3 months
Tom	74	My daughter mentioned that I was wheezing when I was walking with her	1 year	2 years	+ 1 year
Sandra	55	Tight chest, coughing up green sputum, cough, little breathless	Same day	2 days	+1 day
Pauline	66	Coughing	2.5 years	4-5 years	+ 2 years
Melanie	48	Pain in right side of back going through body	Same day	Same day	/
Maggie	70	fainting, diarrhoea/sickness, tiredness, lack of appetite, cough	6 days	9 days	+ 3 days
Des	64	Coughed up small amount of blood	Same day	1 week	+ 6 days
Joseph	65	Coughing up blood	7 days	11 days	+ 4 days

Figure 53: Reported Patient Intervals

As this research is based within a social constructionist perspective, it is appropriate to view each account as a valid representation of patient interval length, differing because they were produced within a specific context. 'Illness narratives' are used by people to give voice to their illness, not only in a biomedical sense, but to the subjective experience of that illness experience (Kleinman 1988). These narratives are constructed using situational factors and are continually reproduced in new contexts, meaning that there are numerous possible narratives, determined by the situation and the interaction between individuals (Hyden 1997).

Yet, acknowledging that these discrepant reports of time to presentation are situated, co-produced accounts, still does not explain why there are systematic discrepancies between

the accounts presented in the questionnaires and the interviews. We must therefore consider whether the methods used made participants present particular narratives because of the manner by which they were being asked about their experiences and behaviour.

Although this study does not examine topics as overtly sensitive as illicit drug use or sexual violence, it would be fair to argue that people's experiences of symptoms and help-seeking could be considered sensitive topics. A sensitive topic, in research terms, is said to be research which involves some degree of cost to the participant, beyond that of time and inconvenience, which includes the emotional and psychological costs of guilt, shame or embarrassment (Lee & Renzetti 1993). In this study people shared personal, embodied experiences, which often relate to areas of the body which can be perceived of as 'private', or embarrassing to discuss. Being asked how long it took them to consult about their symptoms is also sensitive, as the early presentation discourse places moral expectations on help-seeking behaviour and so the individual may have felt as though their responses to the question would be judged.

Questionnaires have traditionally been advocated as an ideal method when researching sensitive topics as the anonymity provided means that people are more willing to report socially undesirable behaviours (Bloch 2004). Questionnaires are believed to reduce social desirability bias, as participants do not feel a compulsion to 'impress' the interviewer (Bernard 1995; Nederhof 1985). Face to face interviews on the other hand, are believed to introduce bias because participants wish to provide socially desirable responses (Bloch 2004). Based on these traditional beliefs about methods, we would expect that the accounts provided in the interview would be more socially deferent and influenced by a need to appear to be a 'good patient'. However, this does not fit with the data from this study, as people reported longer times to presentation in the interview setting, a behaviour which is constructed as that of a 'bad patient'.

During an interview with Roy, a retired cleaner who had been experiencing severe diarrhoea, he talked about his consultation with the GP and how he presented his symptomatic experience:

*I've had diarrhoea for a year and half, but when I went to the doctors six weeks ago I only told him it was six months...[why did you tell him you'd had the symptoms for six months and not over a year?]. Well embarrassment I think more than anything else I would say. If I'd have probably said 'well over a year' he would have probably 'oh', but I just told him it was six months. Even then he*

*went 'six months!' because mainly I think it didn't bother me. I thought well if I said over a year he might say 'why didn't you come to see me before now?' Yeah, that's a long time, and I just said 'I'll shorten it, six months'. But I'd had it well over a year.* (Roy: persistent diarrhoea, spirochetosis)

Roy felt a need to reduce the length of time he had been symptomatic in his account to the GP, so that he was not perceived of as foolish or incompetent. Roy was presenting what he believed to be a more socially acceptable account of six months to the doctor, rather than the actual length of his symptomatic experience, which he knew to have been over 18 months. In other words, Roy is presenting a version of his patient interval in which he aligns himself with the 'good patient'. What is most notable about this is that in the questionnaire Roy also reported his time to presentation as six months, meaning that the accounts Roy provided to the GP and in the questionnaire align. The possibility that participants in this study presented socially deferent accounts in the questionnaire, as opposed to the interview, will now be considered.

Mary Douglas (1966) explores the concepts of purity and pollution to consider how people respond to anomalies within their classificatory systems. She argues that culture provides standardisation of communal values, meaning that ideas and values are tidily ordered through the provision of basic categories and concepts. This system of communal values has authority, as individuals are required to assent to it because others within the community also assent. The public nature of this classificatory system makes its components rigid, as definitions of the components are a public matter. However, definitions and boundaries can be revised within one's personal life, so long as the individual maintains assent to the cultural classificatory system publically (Douglas, 1966). It is taken for granted that the rules of public situations are not enforceable in private situations, and that the boundaries of the private exclude and render irrelevant society and its social meanings, therefore no longer being obstructive to how one wishes to behave (Douglas, 1971). Jocelyn Cornwell, during her fieldwork in the East End of London found participants would provide different accounts during different encounters. She believed that the substantially different accounts which people provided at different times were the result of changes in the relationship between herself and the participant, and the different interviewing techniques which she employed (Cornwell 1984). Cornwell drew on Douglas' concept of public and private realms to argue that, depending on the circumstances of the encounter, participants provided either their 'public account' or their 'private account', of a particular event or experience.

Cornwell found that 'public accounts' were most common when people were uncertain of their position in relation to others and so coped with this by putting on their 'best face'. These *'public accounts are sets of meanings in common social currency that reproduce and legitimate the assumptions people take for granted about the nature of social reality'* (Cornwell 1984, p.15). This 'best face' is not necessarily deceptive but is simply the reproduction of a culturally normative pattern, whereby people are able to stick with the relative security of a 'public account', knowing that what they say will be socially acceptable to whoever they are talking to. 'Private accounts' on the other hand *'spring directly from personal experience and from the thoughts and feeling accompanying it'* (Cornwell 1984, p.16). They represent how people would think and react if not considering the reactions or perceptions of wider society.

Taken together, these concepts of the 'public' and the 'private' present a world in which a cultural classificatory system exists and must be assented to publically, however, one is able to revise and challenge these classifications privately. People tend to present socially acceptable 'public accounts' when they are less clear of their position in relation to others, whereas 'private accounts' are more likely to emerge when an individual is in a position of relative privacy and therefore, less concerned about adhering to wider social classifications and perceptions.

This notion of the 'public account' and the 'private account' also relates to the work of Erving Goffman, who presented the concept of 'frontstage' and 'backstage' arenas (Goffman 1959). He argues that when people present themselves before others they will exemplify socially accredited values within their performances, mirroring and affirming the moral values of the community. However, the backstage is a separate arena and so different information and values can remain, as one does not need to perform to socially acceptable values (Goffman 1959). Therefore, we can liken the 'public' to the 'frontstage', as people must ensure that their performances appeal to socially normative values and belief systems, whereas in 'private', or 'backstage', people are not compelled to adhere to such socially imposed standards and ideologies.

As a result of the 'early presentation' discourse, going to the doctor's early has become 'the right thing', the socially and morally acceptable course of action. Therefore, it follows that publicly individuals must conform to the notion of early presentation, and present themselves as a 'good patient' whereas privately individuals are able to revise this framework and anomalous behaviours (i.e. prolonged intervals) can exist. If the public

account must conform to socially acceptable notions of early presentation we can consider whether participants in this study were reporting shorter times to presentation in the questionnaire because of a perceived need to present a 'public account' whereas, participants were able to report longer times to presentation, therefore more deviant behaviours, in the interview setting as here they were in a position in which they could present a 'private account'.

We can use the notion of the 'public' and 'private' accounts to consider the discrepant reports of interval length by participants in this study, reflecting on why 'public accounts' may have been presented in the questionnaire and 'private accounts' presented in the interview. When participants were invited to take part in this study they received, through the post, a pack which contained an invitation letter, an information sheet and a questionnaire. The invitation letter was signed by the clinician, a common approach in health services research, in order to show that the research is endorsed by the treatment and care provider. All of the documents had the logos of the NHS Trust and the University printed on them, in order to formalise and validate them, by demonstrating approval from these respected bodies. However, both of these facts could serve to overly formalise the documents, emphasising their official nature. Although the information sheet provided full details of the research team and their roles, the fact that the covering letter was from the clinician could foster a belief that the clinician is heavily involved in the study and, as we have established, people seek to present themselves as competent, 'good' patients (Andersen et al. 2014; Dougall et al. 2000). If participants believed that their clinician was heavily involved in the research it may cause them to report shorter times to presentation, in order to conform to more socially acceptable behaviours, and present a 'best face' version of themselves. Goffman says that in 'frontstage' performances a person will *'incorporate and exemplify the officially accredited values of the society, more so, in fact than does his behaviour as a whole'* (Goffman 1959, p.45).

The closed nature of the questionnaire could serve to reinforce its formality, as participants are expected to produce precise answers, with no opportunity for explanation or commentary around a question. The impact of closed styles of questioning on the types of response provided was also evident in Cornwell's (1984) research, as she found that when she asked people direct questions they tended to respond with their 'public account', whereas when she invited them to tell a story they were more likely to give a 'private account' (Cornwell 1984).

The interviews in this study were discursive and open, with participants being given the opportunity to tell a story. The opportunity to tell a story not only allowed participants to present their narrative in a format of their choosing but, most importantly, allowed them to provide explanations. Within the interview environment it was possible for people to rationalise, justify and explain their behaviour, in a way which wasn't possible within the questionnaire. The importance of the opportunity to justify one's behaviour was evident in Harry's narrative. In the questionnaire Harry said it had taken him three months to present about his change in bowel habit, whereas in the interview he said that he took four to five months to present. In the interview he was able to discuss his reasoning around the timing of his consultation and outline factors used in his assessment of cancer risk and therefore the urgency with which he felt he should present. He talked about how he was a very active man, who ate a healthy diet and had never smoked or drank, all of which made him feel like he was an unlikely 'cancer candidate'. Most importantly, during his symptomatic period he was invited to take part in the national FOBT bowel screening campaign:

*And that was while I had, I hadn't visibly saw any blood, but that was when I was on, the stools has been loose...[When you did the screening?...]I sent this away, and it came back all right. But I mean having said that they do say that, well they did say in the letter or the reading that it doesn't have to be bleeding or blood in the stools, but that test was for blood. And it didn't mean that it was cancer if there was blood so...[Yeah that's right]...But it would start things going...[So having done the screening at the time you were having your symptoms, when you got that back that must have reassured you]...Well it settled me for a little bit, yes.....because I thought at the time if I'm clear, obviously you wait for the post and it took about a fortnight to come. And then when it come it was clear, so.*

*(Harry: loose bowel movements, microscopic colitis)*

Having a negative FOBT screening result provided reassurance to Harry that his symptoms were not the result of a cancer and instead he thought that his symptoms were most likely the result of his diet, particularly as they kept intermittently improving. His response to his symptoms, although discordant with the socially acceptable narrative of 'early presentation', was based in logic and reason. It is understandable why he did not feel the need to consult the doctor quickly about his symptoms as he had plausible explanations for them, for which cancer had initially been rejected. When he did consult, it was a news item that he had seen on television about people putting off going to the doctors that prompted him to consult, as he felt that what he had actually been doing was 'delaying'.

Another element of the interview encounter which could have helped to increase participants' willingness to respond with 'private accounts' was that the interview participants were talking to an individual, and not a faceless organisation, as they were in the questionnaire. It was not the first time that participants had spoken to me, as I called each interviewee at least once prior to the interview, and so a degree of trust and rapport had been established between participants and myself, as well as familiarity with the study. Cornwell (1984) found that her first interviews with participants were often *'taken up with public accounts, and was usually only in later interviews and often when a subject had already been broached once, that people gave private accounts'*(Cornwell 1984, p.16). Therefore, given the opportunity to provide explanations for behaviour which contravened societal expectations, people were more likely to present accounts which contradicted the 'early presentation' discourse.

The concept of 'public and private accounts' appears to be a useful lens for understanding the discrepant accounts provided by participants in this study and offers an explanation as to why people reported interval length differently, based upon research method. This finding has implications for some of the assumptions and beliefs currently held about the strengths and limitations of particular research methods for dealing with sensitive topics. This piece of research challenges long held beliefs about the effectiveness of self-administered questionnaires for eliciting 'truthful' accounts of sensitive topics along with assumptions that interviewees alter their accounts in order to produce narratives which they believe will be more pleasing to the interviewer.

Acknowledging that people present 'public accounts' and 'private accounts' of their behaviour depending upon research method prompts us to reflect upon the research methods traditionally employed within the field of help-seeking research. The majority of studies which explore the patient interval use validated questionnaires to elicit time to presentation, as this is believed to be the most accurate and rigorous approach (Weller et al. 2012). The findings from this study suggest that such data may systematically underestimate time to presentation, as people may feel compelled to produce a 'public account' in questionnaires. In reality, data on interval lengths are subjective representations of a phenomenon which will be experienced, rationalised and reported differently, depending on context. It is naïve to consider interval length as an objective unit which can be accurately and repeatedly measured empirically. It is not, and should not be viewed as, an absolute measurement, in the same way we would conceive of the weight of a droplet of water, for instance. Repeated attempts to measure the length of the patient

interval would inevitably result in inconsistent results, as has been found here, because of the subjective nature in which this phenomenon is experienced and relayed, and the multiplicity of illness narratives. What this research does highlight though is that the discrepancies in reported interval length appear to be consistently shorter in questionnaire reports than those presented in interview encounters. It appears that the reporting of time to presentation in both questionnaire accounts and within GP consultations is shaped by social discourses, which oblige the individual to present themselves as a 'good patient'.

### *Summary: The 'Good Patient'*

'New public health' approaches have placed the focus for disease prevention on the individual, identifying him or her as an agent who engages in risky behaviour and who is also responsible for identifying and managing risk. Public health is based on binary classifications, one of which is the dichotomisation of the good and the bad patient, based on health knowledge, behaviours and intentions. An 'early presentation' discourse is also evident within our society, which encourages people with symptoms of cancer to present as soon as possible, notably through the BCOC awareness raising campaigns. The discourse of 'early presentation' combines with the discourse of the 'good patient' to place expectations on individuals to consult promptly upon identification of any symptoms of cancer.

These discourses of prompt help-seeking being the moral action are problematic as they jar with a competing discourse which derides those '*wasting the doctor's time*', an issue which was frequently reported by participants in this study. People wanted to ensure they did not take up GP appointments unnecessarily, however, it appears that wanting to not 'waste the doctor's time' was more importantly related to a desire to appear to be a competent manager of risk, only consulting when appropriate. Some participants used the insistence of help-seeking by others as a means of justifying consultation, so as to not appear incompetent should the GP actually perceive of their presenting complaint as illegitimate. The discourse of early presentation is reinforced through the BCOC campaigns, through their endorsement of help-seeking in relation to specific symptoms. However, this approach may be problematic in that it may isolate those experiencing non-targeted symptoms, making them feel that consultation is no longer justifiable, and it also fails to account for the wider contextual constraints which people face in relation to help-seeking decisions, instead assuming that 'top-down' health education strategies will result in ideal behaviour. Discourses on seeking help within a reasonable time from symptom onset may make individuals feel obliged to not only present more socially acceptable accounts to



clinicians, but also to others, as was discovered in the discrepant reporting of patient interval length in this research. It appears that discourses which proscribe socially acceptable behaviour result in the presentation of 'public' or 'private' accounts of patient interval length, depending upon the research method employed, which has implications for the assumptions made about the comparability of data collected by different means.

### Chapter Summary

This chapter has considered the key findings from this research of the help-seeking experiences of people with symptoms of lung or colorectal cancer. I have presented a novel model of the patient interval, which outlines the key processes of symptom onset, symptom appraisal, help-seeking decision making and consultation, as well as outlining the position of this research on the transformation of a sensation into a symptom. The four contextual domains which exert influence over the patient interval are presented in the model, namely individual experience, interpersonal relationships, health care system interactions and social and temporal context.

Explanations for the timing of help-seeking are considered and the concept of a threshold of tolerability is proposed as a means of explaining this. Thresholds of tolerability are produced through the accumulation and assessment of a range of contributory elements which relate to the individual's symptoms. If symptom burden remains beneath the threshold, symptoms are tolerated within everyday life. If, however, symptom burden breaches the threshold then the individual is moved into the space of the patient and must consult in order to redress bodily equilibrium. Symptom burden may breach the threshold of tolerability either when symptom burden increases, or, when the threshold of tolerability is revised as a result of the incorporation of additional contributory elements. People's assessments of tolerable risk is unsurprising, given that people must calculate and navigate risk as part of their everyday life, and are increasingly aware of risk because of living in a 'risk society'.

One example of a contributory element which people use in their calculation of the threshold of tolerability is the assessment of cancer risk. Among people whose symptoms were perceived of as severe body state deviations we can consider these experiences as 'critical incidents' which prompted the individual to consult quickly. Amongst those whose symptoms were not perceived to be drastic deviations from usual functioning, bodily experience, personal and familial history were all considered in relation to the image of the 'cancer candidate' in order to assess the personal risk of cancer.

Alongside the increasing focus on risk within society there has been a shift from 'old public health' to 'new public health', with attention now located on the risks inherent in the individual and their behaviour towards, and the prevention of, such risks. Appropriate responses to health risks are communicated through public health messages, which frame compliant, knowledgeable citizens, and 'early presenters' as 'good' and 'moral' patients. This places an obligation on the individual to conform to societal expectations of proactive behaviours around health and illness. However, it also contradicts a widely held belief that one should avoid 'wasting the doctor's time'. This is not only about preserving GP resources, but reflects a desire to appear to the GP to be a 'good patient', to avoid appearing foolish should consultation have in fact been inappropriate. The 'good patient' message is reiterated in the BCOC campaigns, but this may be problematic for individuals who do not experience the targeted symptoms, as it can serve to discourage presentation as individuals do not want to appear to be a 'time waster'. Images of the 'good patient' appear to influence how people report time to presentation, since, should they perceive that time to have been 'too long' they may report a reduced patient interval length in order to provide a more socially acceptable account. Participants consistently presented 'public' accounts of shorter patient intervals in their questionnaire responses when compared to interview, where they tended to present 'private' accounts of help-seeking, possibly because they were able to provide explanations and justifications for their behaviour.

Discourses around early presentation and the subsequent framing of the timely presenter as a 'good' or 'moral' patient place unrealistic expectations on symptomatic individuals because they over simplify the patient interval, failing to account for the constraints which the individuals face within their wider worlds which may inhibit 'ideal' behaviour.

## Chapter Eight: Reflections and Conclusions

In this final chapter I reflect upon this study and consider how I, as the researcher, may have affected the process and interpretation of the research through some of my inherent biases. I consider the key strengths and limitations of this thesis and outline the original contribution which I believe it makes to the field. Finally, I look at the implications of the research findings in terms of policy and the early diagnosis agenda, as well as considering future directions which this research could take.

### 8.1 Reflexivity and Positionality

Reflexivity about the researcher's role in the creation of data is a key consideration in qualitative research practice (Byrne 2004; Oakley 2000). This study has been shaped by various biases which I brought and, in line with a social constructionist perspective, it is important to reflect on these. Reflexivity is a strategy for situating knowledge and avoiding the *'false neutrality and universality of so much academic knowledge'* (Rose 1997, p.306). By examining my position in relation to the research I hope to make explicit some of the underlying factors which will have undoubtedly shaped some of the perspectives within this thesis.

Researchers are not simply receptacles for the views of others, they are themselves a variable in the interview (Edwards 1993), because *'who she is, what she is like, and the relationship she has with the interviewee affects the content of the interviews'* (Cornwell 1984, p.17). There has been an expectation that matching key characteristics, such as class, sex, and race, between researcher and researched, will result in improved empathy on the part of the researcher and greater openness on the part of the participant (Mellor et al. 2014). Possession of an "insider status", particularly in relation to cultural identity, has also been considered a 'holy-grail' for researchers (Ganga & Scott 2006). The matching of researcher and participant for particular characteristics has, however, been challenged, as every individual possesses so many variant characteristics that it would be unmanageable to undertake such matching (Mellor et al. 2014). Instead, it has been argued that researchers need to be reflexive about how both similarities and differences influence the research process (Byrne 2004), as well as how *a priori* knowledge, or 'sensitizing concepts' (Charmaz 2006), shape the research process and findings.

What follows is some reflection on the characteristics and experiences which I brought to this study, in an attempt to lay clear my position in relation to this research and consider how I may have shaped it.

Prior to commencing this PhD I worked as a researcher in the field of cancer diagnosis for two years, in particular, working on an NIHR funded study about help-seeking and the patient interval, The SYMPTOM Study, the questionnaire from which was used in this study. My experience as a research assistant and my BA and MSc in medical anthropology combined to influence my research interests and a desire to explore why some people present later than others, and how social context may influence this. My background knowledge of the field of cancer diagnosis and specifically research on help-seeking among symptomatic people, may have influenced both the research question and the way in which I viewed data. This *a priori* knowledge may have caused me to see patterns based upon pre-conceived ideas, rather than truly emergent, grounded findings. When analysing my data I made great efforts to remain true to the data during the coding and interpretation periods, not comparing my data to existing research until I was certain of my findings. Some themes already identified in the literature, such as the sanctioning of help-seeking and the importance of familial history of cancer, were believed to have also 'emerged' in this analysis. Although it could be argued that the identification of these themes was based upon *a priori* knowledge it does not necessarily follow that these themes do not exist within the data. I would argue that the presence of these issues in both this study and other studies confirms that these are key issues in the help-seeking journey of individuals with symptoms of cancer.

Personally, I have an innate set of unchangeable characteristics which will have affected the way participants viewed, and responded to me, also known as *response effects* (Bernard 1995). I am a white, married woman, in her late twenties, who is a postgraduate student. Each of these aspects of my identity carry particular connotations and, although we can suppose general responses to these characteristics, associations with these traits will differ for each individual, based upon their own characteristics and experiences. Reflecting on the research process, there were three key parts of my identity which I believe may have been important in this study; my non-clinical status, my regional dialect and my class

A lot of participants often assumed I was a clinician and numerous conversations were had during interviews about my education and 'credentials'. I tried to make it explicit that I was not a health professional and I felt that this was important for two main reasons: primarily, I did not want them to think I could give medical advice and, by disassociating myself from the medical profession, I hoped that they would be more descriptive about their symptoms and health, as they would not automatically assume that I knew about the things which they were referring to (Richards & Emslie 2000). I believe that not being a clinician enabled

me to probe topics further, in that I could ask participants to elaborate on issues, whereas with a clinician there may have been an assumed level of knowledge, which would hinder fuller descriptions.

I am from the North East and speak with a regional dialect and it could be argued that this would have helped to give me “insider” status, as most of the participants were also from the local area. Throughout the fieldwork my dialect was something which I subconsciously used in different circumstances: when I was with participants who had broader dialects my dialect also became broader and I also used local terminology with participants who also spoke in this way. This mirroring of dialect was not a conscious decision but something which I naturally fell into and, upon reflection, I believe that it helped to build rapport with participants. In particular I think it helped to diffuse the power differentials between myself and participants, something which I strove to achieve during all of the interviews (Oakley 2000).

Participants ranged in SES and so it is important to reflect on how I perceive of my own class, and how others might have perceived my class, because of the range of SES groups which interview participants belonged to. I identify as working class, or more specifically upper working class, as I was educated in a state school and come from a family which has historically been employed in typically working class professions, (cleaning, factory work, and manual occupations), and lived in council owned accommodation. My parents, my husband and I have arguably moved away from a ‘working class’ identity having moved into more ‘skilled’ professions and becoming private homeowners. Despite my personal identification as ‘upper working class’ the initial impression which I projected to participants may have been of someone who was middle class, on account of my profession and my association with the University. The idea of a ‘working class academic’ has been problematised and it is suggested that academics from working class backgrounds straddle the realms of the working and middle classes, without ever fitting entirely into either (Mellor et al. 2014). Although the ‘working class academic’ is a problematic notion, the ambiguity in my class as perceived by participants may have been beneficial, as there were elements of my class identity which most participants may have felt able to relate to, or find affinity with, making it easier for both working and middle class participants to engage with me.

My life experiences also alter the way I view the world, and in particular it is important to mention the fact that my step-father, to whom I was incredibly close, died from lung cancer

six months before I commenced this PhD. The idea for the research had already been conceived prior to his illness so this did not affect the research design. However, it could have affected the way in which I interpreted some of the data and viewed people's stories.

My step-father's symptoms started in September 2011, when he experienced pain in his chest and believed he must have cracked a rib whilst working in his plumbing business. He presented to his GP and went for a Chest X-Ray (CXR) which was clear. In October it became apparent that he had lost weight, because his clothes were not fitting him properly, and we all thought the weight loss was due to the stress of the preceding four months, whereby a large client went bankrupt, owing him a substantial amount of money, only two months after my brother-in-law suddenly passed away with brain cancer, aged 28. In November David began experiencing a nagging cough and increased tiredness and the GP attributed the symptoms to asthma. His symptoms worsened and despite encouragement from family members to return to the GP he tolerated his symptoms. He eventually agreed to go to the doctor's after my mum slept in the spare room because David's coughing was so bad, and she told him that he *had* to go back to the doctor's or there would be 'hell on'. He re-consulted mid-November and was sent for investigations, whereby he had a positive CXR, and went on to have a bronchoscopy and CT scan in December. In January he was diagnosed with non-small cell lung cancer (which he frequently joked would have been much less obtuse if it was called big cell lung cancer) and he underwent two courses of palliative chemotherapy before passing away on the 26<sup>th</sup> July 2012.

In describing the experience of my step father's help-seeking and diagnostic journey it is evident that there are many similarities and themes in his experience which could be identified in the stories of the participants in this study, such as reassurance provided by previous health care encounters, social sanctioning of help-seeking and rationalisation of symptoms in relation to other contextual factors. As there are so many elements of his story which mirror the stories and findings of this research it is important that I acknowledge this experience and reflect upon how it may have shaped the way I approached and responded to this research. For instance, some may argue that my experiences would make me biased towards narratives in which spousal prompting of help-seeking and symptom rationalisation are prominent. It could also be argued that it may have affected how I interviewed people, as I view the world from a different perspective now and have greater insight into experiences of cancer, as well as losing a parent from it, both of which enabled me to empathise with certain participants. I acknowledge that my outlook and motivations for my research have been shaped by the illness of my step-father,

as this experience has given me added drive to undertake high quality research which will hopefully contribute to improving earlier diagnosis of cancer, even if in a minor way. Despite my motivation for my work being influenced by my step father's illness, I was not aware that my personal experiences shaped the interviews and subsequent analysis as throughout I strove to remain true to the accounts which participants presented to me and to prioritise their voices over my own throughout this work.

To summarise, my professional and personal background have ultimately shaped who I am, what I am interested in, and how I perceive the world, which in turn will have influenced how I approached this research. However, by being reflective about these elements of my identity I am able to consider where they may creep in and acknowledge that this piece of work, like all qualitative research at some level, is ultimately a co-construction between myself and my participants. This product is situated in a specific time and place and is the result of the stories which participants *chose* to present to me, with my personal interests and insights influencing how I ultimately conceived of their stories and the overarching issues for symptomatic people in their decisions about help-seeking.

I am in no doubt that a single, black, male clinician, from an upper class family in Cambridgeshire, who had no familial experience of cancer, would produce very different data and findings to the ones I present here. However, this does not make his or my thesis any less valid than the other, they are simply different versions of the same truth.

## 8.2 Study Strengths

### Contextual Approach to Help-Seeking

This research is one of a small number of studies which takes a holistic view of help-seeking, situating individual behaviour within wider social contexts (Unger-Saldaña & Infante-Castañeda 2011; Pedersen et al. 2011; Andersen et al. 2010). Many of the studies in the field, exploring help-seeking behaviour among people with cancer, focus solely on factors which influence presentation at the individual level, concentrating on factors such as the role of knowledge or the role of emotions in decisions around help-seeking. This approach fails to acknowledge that appraisal and help-seeking decisions are rarely made in isolation and that there are many micro and macro level factors which influence how people respond to symptoms, from the sanctioning of help-seeking by others, to the behavioural constraints imposed by social discourses of 'early presentation' and the 'good patient'. . This research has highlighted that help-seeking is influenced by factors from four domains of people's lives; individual experience, interpersonal relationships, health care

system interactions and social and temporal context. By identifying contributory elements from within broader domains of people's lives this research has helped to evidence the importance of these factors in the patient interval, challenging analyses which focus solely on individualistic factors. The findings of this research add weight to the growing body of evidence which highlights the importance of wider context in help-seeking and strengthens the argument that help-seeking, and efforts to reduce help-seeking intervals, should be viewed in a more holistic manner, considering social, political, economic and environmental factors which influence symptom appraisal and presentation.

### **Symptomatic Participants**

Another strength of this work is that it looked at experiences of people with symptoms of cancer, as opposed to a cancer diagnosis. The majority of studies of help-seeking in the field of cancer recruit participants who have already received a cancer diagnosis, with only a few working with patients pre-diagnosis (Birt et al. 2014; Hall et al. 2015; Andersen & Vedsted 2015). This approach could be problematic as people will reconsider their behaviours and reconfigure their narratives in light of their eventual diagnosis, thus giving a version of their help-seeking behaviour which is coloured by their cancer diagnosis. By recruiting people who had been referred with a suspicion of cancer, because of their presentation to a GP with symptoms of lung or colorectal cancer, a much greater range of eventual diagnoses were included in the sample, ranging from no abnormalities detected, or diverticular disease or infection, to lung or colorectal cancers. Most of the participants would not have received a diagnosis at the point of completing their questionnaire and a number of interviewees also had not had a diagnosis communicated to them at the point of being interviewed. This means that people's narratives were less likely to have been shaped by their diagnosis and so their responses would have been based upon their symptoms as opposed to a particular disease. When people first experience and respond to symptoms they are ultimately responding to a specific change in bodily function and even though they may have possible diagnoses in mind for these symptoms, their experience is ultimately of a symptom, as opposed to a disease. By recruiting people who were symptomatic it was possible to explore a range of accounts of the patient interval, whereby commonality was in symptom experience. This aligns findings with actual symptom appraisal and help-seeking experiences among the symptomatic population, which is important as it is this group of people who are ultimately targeted in public health efforts to encourage early presentation.



### Use of Theory

A final strength of this study is that the findings have been considered and related to wider theoretical approaches to help-seeking. Much of the existing work in the field of early diagnosis is atheoretical, in that findings are not considered in relation to theories about health and illness, and so analyses can remain superficial. For instance, much research identifies concerns about 'wasting the doctor's time' as a barrier to help-seeking but does not explore what this actually means. Superficially it may appear that an awareness of constraints on GP's time makes people reluctant to overburden this resource. However, as I have argued in Chapter Seven, concerns about 'wasting the doctor's time' appear to be grounded in perceptions of acceptable and unacceptable patient behaviour, which are themselves underpinned by discourses of 'early presentation' and a desire to be perceived as a 'good patient' or a moral citizen. By considering findings in relation to theory we are able to begin to unearth some of the underlying explanations for particular phenomena and see how these things may be related to greater societal constructs. This enables comparison between patient groups, to consider the wider explanations for, and implications of, particular behaviours. By understanding behaviour in a broader sense we can begin to incorporate this knowledge into attempts to modify it.

## 8.3 Study Limitations

### Prospective versus Retrospective Approaches

This study took a retrospective approach to investigating help-seeking, approaching patients after they had consulted often weeks, if not months, after the periods in question. This approach has been critiqued because of the potential for recall error on the part of participants, as a consequence of the nature of symptoms, traumatic treatment, the impact of a cancer diagnosis on patient's identities, and the passage of time (Andersen & Risør 2014; Scott & Walter 2010). Presenting participants' retrospective accounts of help-seeking as 'accurate' fails to consider the fact that patients construct their narratives, based upon the particular social, cultural and political context, as well as a need to justify and legitimate their behaviour (Andersen & Risør 2014).

*'Retrospective analyses...will always be biased by a need among informants to confer meaning and intelligibility to their illness experience, and the information obtained is potentially predisposed toward a normative presentation of what ought to happen because the retelling of the story encourages informants to justify their behaviour'*

(Andersen et al. 2010, p.383)

To address this, a prospective approach has been called for, in which we move away from research design based on biomedically constructed diagnostic categories and instead focus on everyday symptom interpretation as the object of enquiry (Andersen et al. 2010). It has been argued that a prospective approach would increase the validity of data, as symptom experience can be studied as it occurs, and help-seeking decisions explored as they are made (Andersen et al. 2009; Scott & Walter 2010). Andersen (2010) also advocates the importance of a consideration of the macro-social context in patient delay research and others have also suggested that we should be undertaking ethnography to gain a more contextualised understanding of help-seeking (Corner & Brindle 2011).

One of the biggest challenges to a prospective approach is that of funding and resources. To undertake truly prospective research we would need to recruit a large number of participants and wait for a number of them to become symptomatic. We would need to be there at the exact moment when they experienced their symptoms, which would require hundreds of ethnographers to essentially shadow participants at all times, a necessity which is neither practical for the researcher, nor appealing to the patient.

Although a prospective approach may manage to address issues such as recall bias and changing patient identities, this approach isn't entirely unproblematic either. I would argue that assuming that a prospective approach to research will entirely eliminate issues of recall bias and re-presentation of stories and identities is problematic. Whenever, and however, we ask patients about their symptoms their responses will always be retrospective, as we are asking them to reflect on how they experienced the sensation, even if it was only experienced moments previously. Although the sensation will be more recent in their memory, and not linked to a diagnosis as of yet, they still must reflect upon and rationalise their response. We are also limited in our presentations of experience by language; not only do participants have to rationalise bodily sensations in their minds, they have to then communicate them using our limited vocabulary (Heath 2008).

In asking participants to verbalise their experiences we will still be faced with the inherent need for individuals to construct their narratives in a way that portrays themselves in a particular light, one which conforms to the image of the 'good patient'. The act of participating in research will influence symptom appraisal and subsequent behaviour, as participants will be more likely to pay attention to bodily sensations and consider such sensations in greater depth (Scott & Walter 2010). Had they not been asked to reflect on and discuss sensations and decisions, they may have given no weight to the experience. By

placing value on the experience it prompts participants to also do so, and thus will affect behaviour, a phenomenon in research also referred to as reactivity (Spicer 2004).

Instead of changing our methodological approach to such research, it may be of more value for researchers to be reflexive about the time at which they ask participants about their experience and the implications of the timing, and make this clear in the presentation of their findings. As participants in this study were all referred into secondary care for their symptoms, they may have reconsidered the severity of their symptoms in light of this referral, and have begun to reconstruct their narrative accordingly. Many had received a diagnosis by the time I interviewed them and this could have also prompted a reconstruction of their narratives, as well as the fact that I was asking them to describe and explain their behaviour. Acknowledging that these influences may have affected the accounts given helps us to remember that patients may re-frame their behaviour in a more positive light. However, I would argue that this reframing of narratives to present oneself as a 'good patient' will occur whether you undertake research 5 minutes, or 5 months, after first symptom experience. Therefore, we need to be mindful of the possibility that reframing has occurred and consider how this may have influenced the results.

### **Poor Response Rate**

As discussed in Chapter Three, the response rate to the questionnaire was poor, with only 11.2% of invited lung participants and 12.3% of invited colorectal participants returning completed questionnaires. This response rate is poorer than that of a comparable study (The SYMPTOM study) which used the same questionnaire and recruited from the same hospital, yet had a response rate of 17% in this region (Walter et al. 2015). The reasons for this poorer than anticipated response rate to the questionnaire study could be numerous.

One explanation could be that the lack of a follow-up reminder letter may have contributed to poor overall response rate (Bloch 2004). Neal et al (2008) found that 42% of their responses were achieved after sending a first or second reminder letter (Neal et al. 2008). An unsolicited postal questionnaire to Norwegian and Danish women about cervical screening had a poor response rate after initial contact (0.6%) and although reminder letters were not effective in improving the number of respondents, follow up via phone call with non-respondents was very successful (Azerkan et al. 2015). The reason that reminder letters were not sent in this study was because, for confidentiality and ethical reasons, no record of invited participants was kept. Had follow up of non-respondents taken place the

response rate to the study may have been better, particularly if this follow up had been by phone call.

One disadvantage of the approach taken was that patients were isolated from the researchers and were expected to complete the questionnaire alone. This isolation from the researcher may have meant that people were less willing to participate in the study. A randomised controlled trial of the C-SIM found that a researcher-completed method of delivery resulted in lower levels of anxiety among participants and greater data completeness (Neal et al. 2014). However, it would have been difficult to undertake researcher administered questionnaires in this study because of the lack of time and resources. Another explanation may be that the time we were approaching people was far from ideal as patients could be in a state of anxiety as to the outcome of their investigations, or they were having to come to terms with their diagnosis.

A final consideration in relation to the poor response rate to the questionnaire is the fact that the questionnaire was not piloted. It may be that the structure or layout of the questionnaire was not suitable, or that some of the questions were not comprehensible. It may be that the re-phrasing of the RSQ was not effective and that people did not understand what was being asked of them. This is supported by the fact that 39.6% of respondents failed to complete this section. Had I undertaken a pilot of the questionnaire, this would also have enabled me to identify any issues with the wording or format and to undertake a sample size power calculation. This would have indicated exactly how many responses were needed to obtain a sufficiently powered sample, and would have given us a more definitive time period in which recruitment must run.

It was felt to be unnecessary to pilot the questionnaire as the changes made to the phrasing of the RSQ and the inclusion of the two questions on religion and caring, were agreed to be minor. However, in hindsight both the response rate and the data obtained would likely have been improved had the questionnaire been piloted.

## **8.4 Original Contributions and Implications**

### **What Does this Study Contribute?**

This PhD adds to the growing body of evidence which stresses the centrality of contextual influences on the patient interval, situating the individual and their help-seeking decision making within the wider social context. It highlights the importance of social context in help-seeking decisions and points to a role for social discourses in shaping what people believe to be appropriate behaviours. The main contributions of this study to the field are:

1. It highlights the differences in the help-seeking journeys of people who present quickly and those who have prolonged intervals, which appear to relate to perceived symptom severity and social responsibilities.
2. It proposes a new model, *The Contextual Model of the Patient Interval*, which is grounded in data and incorporates both individual and contextual factors.
3. It proposes the concept of the 'threshold of tolerability' as a means of explaining the point at which people decide to seek help, based on contributory contextual elements and symptom burden.
4. It highlights how people appraise their symptoms in light of the possibility of cancer, with the concepts of the 'critical incident' and the 'cancer candidate' used to explain the assessment of cancer risk by those who have short and prolonged patient intervals, respectively.
5. It relates the assessment of cancer risk and the calculation of the threshold of tolerability to the notion of risk and considers how this is influenced by the modern societal approaches to risk.
6. It identifies 'early presentation' and the 'good patient' as discourses which place moral obligations on individuals, producing socially sanctioned ways of responding to symptoms, which are reinforced by the 'new public health' approach.
7. It presents a novel finding about how different methodological approaches to help-seeking may elicit different narratives, and links this to the concept of 'public' and 'private' accounts.

### **Implications of this Research**

This thesis has placed biomedically framed phenomena, symptom appraisal and help-seeking, within the wider context within which lived experience is situated. This research shows that help-seeking decisions are complex, with the individual having to negotiate mediating factors from four key domains of their wider world: individual experience, interpersonal relationships, health-care-system interactions, and social and temporal context.

The findings imply that media campaigns that aim to raise cancer symptom awareness among the population may be insufficient for achieving early presentation. Knowledge of cancer is simply one contributory element in people's symptom appraisal and help-seeking decision making processes. A focus on knowledge provision is naïve in that it follows traditional health behaviour change models in which imparting knowledge results in correct behaviour. In reality we know this is not the case. Many participants in this study were

already aware of the link between their symptom(s) and cancer, yet undertook complex assessments of the likelihood that *their* symptoms were a manifestation of cancer, considering the severity of symptoms and the alignment between oneself and the 'cancer candidate'.

Lock & Scheper-Hughes (1996) have argued that the exemption of cultural analysis in medicine causes a dichotomisation of nature and culture, resulting in the assumption that the body can be mastered and understood through the application of science and technology. They go on to say that '*With respect to health and illness, this objectivist perspective assumes that the entire range of human explanations and practices regarding health, illness, disease and death...can be rendered superfluous through universal education in public health and human biology and through the availability of affordable Western medical care.*' (Lock & Scheper-Hughes 1996, p.43). This analysis of help-seeking behaviour has aimed to highlight the centrality of society and culture in the help-seeking process, repositioning the individual as no longer the isolated, purposeful agent, but as an agent whose thoughts and actions are constrained by a wider context which imposes pressures upon behaviour. Awareness raising campaigns will always be limited in their ability to change behaviour, as they fail to account for the wider pressures which individuals face when making decisions about their symptoms, which reach far beyond simple knowledge of a correlation between symptoms and cancer.

This is not to say that awareness raising campaigns have no role in improving early presentation as, even amongst those who do not need to be educated on the significance of particular symptoms, campaigns can serve to sanction help-seeking behaviour, by legitimising someone's use of the health care service. However, efforts to encourage early presentation must begin to consider the constraints which people face in relation to help-seeking, which are of a much more macro nature. Although well established discourses of 'early presentation' and the 'good patient' cannot be changed overnight, interventions can be mindful of how culture influences behaviour. People must navigate a fine line between the obligation to present early whilst simultaneously being insightful enough to manage symptoms independently and not 'waste the doctor's' time. Public health efforts could seek to break down some of the barriers which have been identified, considering notions of 'a cancer candidate', challenging social discourses around 'the good patient' and morality, and considering how help-seeking is constrained by people's social realities.

The finding that people consistently reported different times to presentation in the questionnaire and interview scenarios prompts us to reconsider the assumed 'accuracy' of the accounts elicited in questionnaires. Much research into help-seeking uses questionnaires to gather data on interval length and it appears that participants may systematically under-report time to presentation, possibly in order to conform to social discourses around early presentation. When undertaking analyses of such data we need to be transparent and reflexive about the fact that reported intervals may be conservative estimates and consider what the implications of this are for the conclusions drawn from such datasets.

## 8.5 Future Research Directions

This research suggests a number of areas which would benefit from further examination, through which the findings of this study could be applied and developed. The four questions which I believe are most potent for examination are:

- **How do notions of stigma and shame influence help-seeking among the Asian community?**

This is a question which I had hoped to explore further within this research, however, there was a paucity of Asian participants who offered to be interviewed. This question could be explored in a similar way to how this research project was conducted, using questionnaires to elicit experiences of symptoms and interviews to explore symptom appraisal and help-seeking, but participants would be recruited through and from the community. This should lead to both a larger sample, as well as inclusion of people who did, and did not, consult about their symptoms, helping to explore in further detail how shame and stigma may affect help-seeking decisions.

- **Is the *The Contextual Model of the Patient Interval* applicable to other types of cancer and other conditions?**

Further research into the patient interval would enable the validity of *The Contextual Model of the Patient Interval* to be tested and refined. Examinations using this model would add to the growing body of literature which situates help-seeking among people with symptoms of cancer in the wider social context. It would be of value to use the model with other cancer sites and with a wide range of symptoms, to see how the model translates to other diseases and symptom experience more broadly.

- **How are social discourses of ‘early presentation’ and ‘the good patient’ created and perpetuated?**

Such an examination would take into account how the media, social history and interpersonal relationships influence how people construct appropriate behaviour in relation to symptoms. It would unpick the notion of ‘wasting the doctor’s time’ and examine how social constructions of the ‘good patient’ are formed. This would include an examination of the role that the creation of a free NHS played in shaping views of appropriate ‘patienthood’ and how a desire and pressure to be a ‘good patient’ can influence how people choose to respond to episodes of illness.

- **How can public health campaigns for early diagnosis of cancer be best configured to account for the individual, social and cultural influences within the patient interval?**

One of the key messages from this research is that awareness raising campaigns are limited in their facilitation of early presentation because they fail to acknowledge the wider constraints which individuals face when experiencing new symptoms. A focus on single ‘alarm symptoms’ could be detrimental when they do not fit with an individual’s symptom experience. It would be of value to explore how public health campaigns could be redesigned to acknowledge and respond to these issues and a comparative study of public health campaign design, content and implementation methods would provide evidence for the most appropriate means of encouraging early presentation among the general public.

## **8.6 Conclusion**

The research presented in this thesis has explored the help-seeking experiences of people with symptoms of lung or colorectal cancer. A mixed-methods approach was adopted, which used questionnaires and semi-structured interviews to examine help-seeking behaviour from a number of perspectives.

Questionnaire data showed that participants with symptoms of colorectal cancer had longer patient intervals than participants with symptoms of lung cancer, and that blood and pain appear to be associated with shorter patient intervals than other types of symptom. This study showed that symptom appraisal and help-seeking decisions are influenced by a myriad of factors, many of which extend beyond the individual and their remit of control. It



identified four contextual domains which influence the patient pathway: individual experience, interpersonal relationships, health care system interactions and social and temporal context. Within each of these domains a number of contributory elements were also identified, including previous experiences of illness, conceptions of identity, exposure to risk factors, motivations for interactions, discussion of symptoms, sanctioning of help-seeking, concepts of 'patienthood', previous encounters, and anticipations of encounters, with the health care system, social responsibilities, the media and culture. This list of contributory elements is not exhaustive but is a representation of the factors which participants in this study presented as influential within their narratives. Other contributory elements will undoubtedly arise in studies with other populations, however, *The Contextual Model of the Patient Interval* could provide a means of examining and incorporating such factors within its four domains.

The respondents who consulted quickly tended to have symptoms which were perceived of as severe and drastic deviations from usual bodily functioning. Those who took longer to consult experienced symptoms which did not represent severe body state deviations initially. In time these symptoms often evolved, as did people's responses to, and explanations for, them. Symptom appraisal and help-seeking decision making were influenced by a number of contributory elements, which could serve to either encourage or deter presentation. People used information about numerous contributory elements to compute a threshold of tolerability within which they tolerated their symptoms in their everyday life. When the threshold was breached, either because reappraisal of contributory elements resulted in a revision of the threshold, or because symptom burden increased, the individual sought help for their symptoms, as they moved from the place of the 'person' to the place of the 'patient'. In the same way that people calculated a threshold of tolerability, beyond which symptoms were perceived of as a potential risk which required expert input, they also assessed their risk of cancer, which fed into the threshold of tolerability. People who experienced drastic body state deviations considered cancer as a possible explanation quickly and symptoms can be seen to represent 'critical incidents' for these people. Amongst people who took longer to consult symptoms tended to be less severe deviations from usual functioning, and the image of the 'cancer candidate' was drawn upon to consider the likelihood of cancer both in relation to symptom experience and risk factors.

The societal emphasis on risk and the development of the 'new public health' focus on prediction and prevention has created an obligation on individuals to be vigilant about their health. Should any 'risky' health states emerge the individual is expected to seek help

promptly. This response is reinforced in discourses of 'early presentation' and the 'good patient'. The moralisation of patient behaviour is evident in participants' concerns about wasting the doctor's time, as they sought to present themselves as responsible, knowledgeable individuals who only consulted when appropriate, yet simultaneously were proactive and timely in relation to health matters. The desire to be seen as a 'good patient' is evident in the discrepant reports of patient interval length, which can be seen to represent 'public' and 'private' accounts of help-seeking. The 'good patient' discourse is utilised in the Be Clear on Cancer media campaigns to encourage help-seeking, however, this approach may be problematic for individuals experiencing symptoms different to those highlighted in the campaign, as they may imply that these 'other' symptoms are not worthy of a HCP's involvement.

The overriding message from this thesis is that symptom appraisal and help-seeking are not confined to the realm of the individual, but are influenced by wider societal factors, often outwith the individuals control. Current approaches to improving time to presentation among the general public are based on a top-down dissemination of knowledge, which is intended to act as a 'magic bullet' that results in help-seeking. This approach fails to consider the plethora of contributory elements which influence the help-seeking process beyond knowledge and the public sanctioning of help-seeking which these campaigns provide. Not only are people influenced by factors from a number of domains when responding to bodily changes, they are also bound by discourses of acceptable and unacceptable patient behaviour, which moralise and place judgement on individuals.

Symptomatic individuals need to be viewed as agents within a wider sphere of constraints and enablers, as opposed to autonomous actors in complete control of their behaviour, as is often the case. The lack of acknowledgement of the wider context in which help-seeking occurs means that awareness raising campaigns remain limited in their effectiveness. Although it is not suggested that it is within the scope of public health bodies to re-write social discourses, what it does point to is a requirement that social context, and social constructions of the 'good patient', are acknowledged and incorporated into the design of interventions aimed at encouraging early presentation. In order to adequately address this issue within public health campaigns further work needs to be undertaken which examines the social discourses surrounding early presentation, early diagnosis and the expectations of the 'good patient'. By unpacking these discourses to examine their details, parameters and foundations, it will be possible to consider how to most appropriately frame public health approaches so that they address more holistically the constraints which individuals

experience and thereby resonate with the general public, in a manner which supports and legitimises early presentation among the symptomatic population.

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## **Appendices**

## **1. Inclusion / Exclusion Criteria**

## A Study About What Makes People Decide To Go To Their Doctor

### Respiratory Patient Identification

#### Eligibility Criteria:

All patients referred as a two week wait

All patients sent for direct access chest x-ray with:

- Persistent or changed cough
- Breathlessness
- Haemoptysis (coughing up blood)
- Chest pain which worsens on breathing or coughing
- An indicated suspicion of lung cancer

#### Excluding criteria:

- Patients under 40 years old
- Previous GI cancer
- Patients under review of established diagnosis
- Patients considered to lack the mental capacity to take part in the study because of learning difficulties, mental health problems, severe illness or frailty

#### Contact Details:

Christina Dobson

Tel: 0191 334 0806

Email: [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

## A Study About What Makes People Decide To Go To Their Doctor

### Colorectal Patient Identification

#### Eligibility Criteria:

All patients referred as a **two week wait**

#### Excluding criteria:

- Patients under 40 years old
- Previous GI cancer
- Patients under review of established diagnosis
- Patients considered to lack the mental capacity to take part in the study because of learning difficulties, mental health problems, severe illness or frailty

#### Contact Details:

Christina Dobson

Tel: 0191 334 0806

Email: [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

## 2. Lung Invitation Letter

### A Study About What Makes People Decide To Go To Their Doctor

Date as postmark

Dear

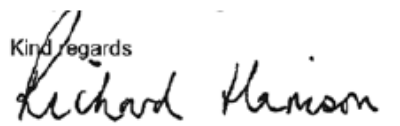
The hospitals which make up North Tees and Hartlepool NHS Foundation Trust are working with researchers at Durham University on a research study. The project looks at what makes people decide to go to the GP about their symptoms.

You are being invited to take part in the study because your doctor has referred you to hospital because of your symptoms. Taking part in the study involves completing a questionnaire and possibly taking part in an interview.

In this pack is an information sheet, which explains the study in more detail, for you to read before deciding if you want to take part. If you have been invited to take part in this study before, then please ignore this invitation.

If you have any questions or concerns about the study please contact the researcher, Christina Dobson, on 0191 334 0806 or by email: [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

Many thanks for taking the time to read this letter.

Kind regards  


Dr R N Harrison  
Consultant – Respiratory Medicine  
North Tees and Hartlepool NHS Foundation Trust

### 3. Colorectal Invitation Letter

### A Study About What Makes People Decide To Go To Their Doctor

Date as postmark

Dear

The hospitals which make up North Tees and Hartlepool NHS Foundation Trust are working with researchers at Durham University on a research study. The project looks at what makes people decide to go to the GP about their symptoms.

You are being invited to take part in the study because your doctor has referred you to hospital because of your symptoms. Taking part in the study involves completing a questionnaire and possibly taking part in an interview.

In this pack is an information sheet, which explains the study in more detail, for you to read before deciding if you want to take part. If you have been invited to take part in this study before, then please ignore this invitation.

If you have any questions or concerns about the study please contact the researcher, Christina Dobson, on 0191 334 0806 or by email: [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

Many thanks for taking the time to read this letter.

Kind Regards,



Dr M. D. Rutter  
Consultant Gastroenterologist  
North Tees and Hartlepool NHS Foundation Trust

## 4. Participant Information Sheet

## A Study About What Makes People Decide To Go To Their Doctor

*We would like to invite you to take part in our research study. Please read this information, and discuss it with others or the researcher if you wish, before you decide to take part.*

### What is the purpose of the study?

People often spend some time deciding whether their symptoms are important and whether they should see their GP about them. We are hoping this study will help us to understand some of the reasons why people may decide to go to the doctors quite quickly or may decide to wait longer before going.



### Why have I been invited?

You are being invited to take part because you have recently been referred to the hospital with symptoms we are interested in. We are hoping to recruit around 500 patients, aged 40 and over, who have been referred to North Tees University Hospital with particular symptoms.

### Do I have to take part?

No. It is up to you if you would like to join the study. If you agree to take part but then feel you no longer want to, you are free to withdraw at any point. This will not affect your healthcare in any way.

### Who is doing this study?

The research is being organised by the School of Medicine, Pharmacy and Health at Durham University. Christina Dobson is leading the research as part of her PhD. The study is also being supervised by Prof. Greg Rubin and Dr. Andrew Russell, from Durham University.



Mrs Christina Dobson  
Questionnaire Participant Information Sheet



Prof. Greg Rubin



Dr. Andrew Russell  
Version 3 – 03/10/13



**What will I have to do?**

If, after you have read this information, you would like to take part you should:



- complete the questionnaire and consent form
- return it to us in the freepost envelope in this pack.

If you are chosen for an interview, the researcher will check the relevant parts of your medical notes before contacting you. This is to see what the consultant thought was causing your symptoms.

If you are chosen for an interview the researcher will contact you to check you are still happy to be interviewed and to arrange a suitable time. This is often within your home but, if you would prefer to be interviewed at the University (Queen's Campus, Stockton), we will cover your travel costs. Interviews will take place within roughly 8 weeks of us receiving your questionnaire.

In the interview we will ask about when you first noticed your symptoms, if you talked to anybody about them and also what made you decide to go to the doctor.

*If you do not want to be interviewed please leave box 6 on the consent form blank.*

*If you prefer for us not to look at the relevant parts of your medical records please leave box 3 on the consent form blank.*

**Will my taking part in this study be kept confidential?**

Yes. All information about you will be handled in confidence and will only be used for the purpose of this research. It will be stored securely at Durham University, with your personal details being kept separately to your study answers, so you cannot be identified. Twelve months after the end of the study your personal contact details will be securely destroyed. We will keep the answers you provide for 3 years after the end of the study but this is anonymised and so will not identify you.

**What will happen to the results of the research study?**

The results will form part of Christina Dobson's PhD thesis and will be presented at conferences and published in journals, but you will not be identified.

If you would like to receive a summary of the study's findings at the end of the project then please tick box 6 on your consent form.

### Some Frequently Asked Questions (FAQ's)

**What are the disadvantages of taking part?**

Taking part means giving up some of your time to complete the questionnaire and to be interviewed, if selected.

**What are the benefits of taking part?**

This study will not directly help you but the information we get from the study could help patients with similar symptoms in the future.

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

If you wish to withdraw from the study your data will be destroyed and the researchers will not contact you again. If you wish to withdraw you can do so by contacting the researcher, Christina Dobson (0191 334 0806). You will not be expected to explain your reasons for withdrawing.

**What if there is a problem?**

If you have any concerns about the study please contact Christina Dobson (0191 334 0806) who will do her best to address your concerns. If you are still unhappy or wish to make a formal complaint you can contact the Patient Experience Team on 01642 624719 or by email at [patientexperience@nth.nhs.uk](mailto:patientexperience@nth.nhs.uk)

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the York Research Ethics Committee (REC).

**Who is paying for this study?**

The research is funded by the Evaluation, Research and Development Unit (ERDU) at Durham University, as part of a PhD studentship.

#### Additional Information

For further information of public involvement in research and the NHS you can contact INVOLVE on 023 8065 1088 or visit their website at [www.invo.org.uk](http://www.invo.org.uk)

If you have any questions about this study please contact Christina Dobson on 0191 334 0806 or [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

*Thank you so much for taking the time to read this information sheet and for considering taking part in the study.*



*Wolfson Research Institute, Durham University, Queens Campus*

## 5. Lung Questionnaire

## **A Study About What Makes People Decide To Go To Their Doctor**

## Consent Form

Title of Project: A study about what makes people decide to go to their doctor

Name of Researchers: Christina Dobson

Please initial each box

1. I confirm that I have read and understand the information sheet dated 3rd October 2013 for the above study. I have had the opportunity to consider the information and ask questions.
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. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the study team, 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. I agree to take part in this study.

\_\_\_\_\_  
Title                      Your Name                      Date                      Signature

Date of Birth         /    /    - -                                            
                    day / month / year                      Postcode

5. I am happy to be contacted by a researcher regarding a face-to-face interview.  
*Please leave this box empty if you do not wish to be contacted.*
6. I would like to receive a summary of the results by post at the end of the study.  
*Please leave this box empty if you do not wish to receive a summary*

*If you are happy to be contacted about possibly taking part in an interview and/or would like to receive a summary of the results at the end of the study, please provide your contact details below:*

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Tel Number: \_\_\_\_\_

Email: \_\_\_\_\_

## Section 1-About your symptoms

We are interested in symptoms which you think are related to your recent referral to hospital.

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Here is an EXAMPLE question:

Sore Toe

Did you have this symptom?

Yes

Please complete A then B or C below

No

Please go to next question

**A** When did you first notice this?

Exact Date  
dd/mm/yyyy

OR

Estimate  
"3 months ago" or  
"June"

**B** When did you first tell your GP or nurse?

Exact Date  
dd/mm/yyyy  
23/12/2010

OR

Estimate

OR

**C** Tick here if you didn't tell your GP or nurse

**1.** What was the first thing or symptom you noticed that made you think something might be wrong?

**A** When did you first notice this?

Exact Date  
dd/mm/yyyy

OR

Estimate

**B** When did you first tell your GP or nurse?

Exact Date  
dd/mm/yyyy

OR

Estimate

OR

**C** Tick here if you didn't tell your GP or nurse

## 2. Coughing up blood

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 3. A cough, or worsening of a long-standing cough, for more than 3 weeks

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 4. Breathlessness or worsening of long-standing breathlessness for more than 3 weeks

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

### 5. Chest or shoulder pain for more than 3 weeks

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

### 6. Hoarseness for more than 3 weeks

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

### 7. Decrease in appetite

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse



## 8. Unexplained weight loss

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 9. Fatigue or tiredness that is unusual for you

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 10. Feeling different "in yourself" from usual

Did you have this symptom?

Yes  Please complete A then B or C

No  Please go to next question

**A** When did you first notice this?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

**B** When did you first tell your GP or nurse?

*Exact Date  
dd/mm/yyyy*

OR

*Estimate*

OR

Please describe the feeling below

**C** Tick here if you didn't tell your GP or nurse

Please try to describe what the feeling was

.....  
.....

**11. If you had any further symptoms which you feel are relevant to your present condition, please list them below. Please describe the symptom and complete A, then B or C below. If not, please tick here  and go to Question 12.**

11.1.....  
.....

<b>A</b>	When did you <u>first notice</u> this?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
<b>B</b>	When did you <u>first tell</u> your GP or nurse?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
OR				
<b>C</b>	Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

11.2.....  
.....

<b>A</b>	When did you <u>first notice</u> this?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
<b>B</b>	When did you <u>first tell</u> your GP or nurse?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
OR				
<b>C</b>	Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

11.3.....  
.....

<b>A</b>	When did you <u>first notice</u> this?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
<b>B</b>	When did you <u>first tell</u> your GP or nurse?	<input type="text" value="Exact Date&lt;br/&gt;dd/mm/yyyy"/>	OR	<input type="text" value="Estimate"/>
OR				
<b>C</b>	Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

## Section 2-People you talked to about your symptoms

The next questions are about whether you talked to other people about your symptoms.

### 12. Did you talk to anyone about your symptoms, before you went to your GP?

Yes  No

Please go to next question    Please go to question 13

### 12a. If so, who did you talk to? (please tick all that apply)

Partner	<input type="checkbox"/>	Parents	<input type="checkbox"/>
Children	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Brother/Sister	<input type="checkbox"/>	Colleague	<input type="checkbox"/>
		Other, please state...	<input type="checkbox"/>
		<input type="text"/>	

### 13. Please read all of the statements and decide how much you agree with each (1 being completely disagree and 4 being completely agree) If you do not have a partner please go to question 14

	Completely Disagree		Completely Agree
	X	x	✓
My partner asked about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner asked how I felt about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner suggested I go to see the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner tried to reassure me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner discussed what they thought my symptoms may be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner brushed off my worries about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner pretended nothing was wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner avoided talking about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner hid his/her worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner was not worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**14. Please read all of the statements and decide how much you agree with each:  
 (1 being completely disagree and 4 being completely agree)  
 When we say 'others' we mean children, other family members, friends, colleagues and so on**

	Completely Disagree	→		Completely Agree
	X	x	✓	✓
Others asked about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others asked how I felt about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others suggested I go to see the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others tried to reassure me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others discussed what they thought my symptoms may be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others brushed off my worries about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others pretended nothing was wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others avoided talking about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others hid their concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others were not worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please turn over to section 3**

## Section 2-About you

The next questions relate to general information about you. This will help us to understand more about you and your answers to the questions so far.

### 15. Which best describes your employment status? Please tick one box only

Employed full-time	<input type="checkbox"/>	Retired	<input type="checkbox"/>
Employed part-time	<input type="checkbox"/>	Student	<input type="checkbox"/>
Self-employed full-time	<input type="checkbox"/>	Permanently sick/disabled	<input type="checkbox"/>
Self-employed part-time	<input type="checkbox"/>	Temporarily sick/disabled	<input type="checkbox"/>
Unemployed (seeking work)	<input type="checkbox"/>	Looking after family/home	<input type="checkbox"/>
Unemployed (not seeking work)	<input type="checkbox"/>	Other, please describe	<input type="checkbox"/>

↳

### 16. What is your highest level of qualification? Please tick one box only

Degree (or equivalent)	<input type="checkbox"/>	GCSE/ O' Level	<input type="checkbox"/>
Diploma (or equivalent)	<input type="checkbox"/>	None	<input type="checkbox"/>
A' Level	<input type="checkbox"/>	Other, please specify	<input type="checkbox"/>

↳

### 17. How would you describe your ethnicity? Please tick one box only

White

British	<input type="checkbox"/>
Irish	<input type="checkbox"/>
Any other white background	<input type="checkbox"/>

↳ Please write in

Mixed

White and Black Caribbean	<input type="checkbox"/>
White and Black African	<input type="checkbox"/>
White and Asian	<input type="checkbox"/>
Any other Mixed background	<input type="checkbox"/>

↳ Please write in

Chinese or other ethnic group

Chinese	<input type="checkbox"/>
Any other ethnic group	<input type="checkbox"/>

↳ Please write in

Asian or Asian British

Indian	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>

Any other Asian background

↳ Please write in

Black or Black British

Caribbean	<input type="checkbox"/>
African	<input type="checkbox"/>
Any other Black background	<input type="checkbox"/>

↳ Please write in

## 18. What is your religion?

No Religion	<input type="checkbox"/>
Christian (including Church of England, Catholic, Protestant and all other Christian denominations).	<input type="checkbox"/>
Buddhist	<input type="checkbox"/>
Hindu	<input type="checkbox"/>
Jewish	<input type="checkbox"/>
Muslim	<input type="checkbox"/>
Sikh	<input type="checkbox"/>
Any other religion	

Please write:

\_\_\_\_\_

## 19. Do you live alone?

Yes  No

Please go to next question

Please say who you live with

Who do you live with?...  
(e.g. Wife, husband, partner, family member)



## 20. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- Long-terms physical or mental ill-health/disability?
  - Problems related to old age?
- (Do not count anything you do as part of paid employment)

No	<input type="checkbox"/>
Yes, 1-19 hours a week	<input type="checkbox"/>
Yes, 20-40 hours a week	<input type="checkbox"/>
Yes, 50 or more hours a week	<input type="checkbox"/>

**21. Are you suffering from, or have you suffered from, any of the following in the past 2 years? Please tick any that are applicable to you**

Asthma	<input type="checkbox"/>
Chronic Obstructive Pulmonary Disease (COPD)	<input type="checkbox"/>
Other lung disease (e.g. fibrosis, bronchiectasis etc)	<input type="checkbox"/>
Heart disease	<input type="checkbox"/>
Anxiety or depression	<input type="checkbox"/>
Inflammatory bowel disease	<input type="checkbox"/>
Irritable bowel syndrome	<input type="checkbox"/>
Peptic Ulcer	<input type="checkbox"/>
Cancer	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>
Arthritis	<input type="checkbox"/>

**22. About smoking, Please tick one box only**

Are you a current smoker?	<input type="checkbox"/>
Are you an ex-smoker?	<input type="checkbox"/>
Are you a non-smoker (never smoked)?	<input type="checkbox"/>

**23. Do you think you are more at risk of one of the conditions listed below because of your family history? Please tick a box for each.**

	Yes	No	Don't know
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>		

If you would like us to write to your GP, to let them know that you have taken part in this study, please could you provide your GP's contact details below.

If you do not wish us to inform your GP that you have taken part, that is not a problem, simply leave the contact details blank.

Doctors Name: \_\_\_\_\_

GP Practice and Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Thank you for taking the time to complete this questionnaire.**

**We are very grateful for your help.**

## 6. Colorectal Questionnaire



## **A Study About What Makes People Decide To Go To Their Doctor**

## Consent Form

Title of Project: **A study about what makes people decide to go to their doctor**

Name of Researchers: **Christina Dobson**

Please initial each box

1. I confirm that I have read and understand the information sheet dated 3rd October 2013 for the above study. I have had the opportunity to consider the information and ask questions.
  
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. I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the study team, 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. I agree to take part in this study.

Title	Your Name	Date	Signature
Date of Birth	_ _ / _ _ / _ _ _ _ day / month / year	_ _ _ _ _ Postcode	

5. I am happy to be contacted by a researcher regarding a face-to-face interview.  
*Please leave this box empty if you do not wish to be contacted.*
  
6. I would like to receive a summary of the results by post at the end of the study.  
*Please leave this box empty if you do not wish to receive a summary*

*If you are happy to be contacted about possibly taking part in an interview and/or would like to receive a summary of the results at the end of the study, please provide your contact details below:*

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Tel Number: \_\_\_\_\_

Email: \_\_\_\_\_

## Section 1-About your symptoms

We are interested in symptoms which you think are related to your recent referral to hospital.

The following questions are about when you first noticed a symptom and when you first told your GP or nurse about it.

Please give an exact date if you can. Otherwise please give your best estimate (for example approximately how long ago, the month or the season). You may wish to refer to your diary or calendar if you have it with you.

Here is an EXAMPLE question:

Sore Toe

Did you have this symptom?

Yes  Please complete A then B or C below

No  Please go to next question

**A** When did you first notice this?

Exact Date  
dd/mm/yyyy

OR

Estimate  
"3 months ago" or  
"June"

**B** When did you first tell your GP or nurse?

Exact Date  
dd/mm/yyyy  
23/12/2010

OR

Estimate

OR

**C** Tick here if you didn't tell your GP or nurse

**1.** What was the first thing or symptom you noticed that made you think something might be wrong?

**A** When did you first notice this?

Exact Date  
dd/mm/yyyy

OR

Estimate

**B** When did you first tell your GP or nurse?

Exact Date  
dd/mm/yyyy

OR

Estimate

OR

**C** Tick here if you didn't tell your GP or nurse

## 2. Change in bowel habit

Did you have this symptom?

Yes  Please complete  
A then B or C

No  Please go to next  
question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP  
or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 3. Bleeding from back passage

Did you have this symptom?

Yes  Please complete  
A then B or C

No  Please go to next  
question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP  
or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 4. Decrease in appetite

Did you have this symptom?

Yes  Please complete  
A then B or C

No  Please go to next  
question

**A** When did you first notice this?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

**B** When did you first tell your GP  
or nurse?

*Exact Date*  
dd/mm/yyyy

OR

*Estimate*

OR

**C** Tick here if you didn't tell your GP or nurse

## 5. Unexplained weight loss

Did you have this symptom? Yes  Please complete A then B or C No  Please go to next question

**A** When did you first notice this?  OR

**B** When did you first tell your GP or nurse?  OR   
OR

**C** Tick here if you didn't tell your GP or nurse

## 6. Fatigue or tiredness that is unusual for you

Did you have this symptom? Yes  Please complete A then B or C No  Please go to next question

**A** When did you first notice this?  OR

**B** When did you first tell your GP or nurse?  OR   
OR

**C** Tick here if you didn't tell your GP or nurse

## 7. Feeling different "in yourself" from usual

Did you have this symptom? Yes  Please complete A then B or C No  Please go to next question

**A** When did you first notice this?  OR

**B** When did you first tell your GP or nurse?  OR   
OR

**C** Tick here if you didn't tell your GP or nurse  Please describe the feeling below

Please try to describe what the feeling was

.....  
.....

**8. If you had any further symptoms which you feel are relevant to your present condition, please list them below. Please describe the symptom and complete A, then B or C below. If not, please tick here  and go to Question 9.**

**8.1** .....

<b>A</b> When did you <u>first notice</u> this?	Exact Date dd/mm/yyyy	OR	Estimate
<b>B</b> When did you <u>first tell</u> your GP or nurse?	Exact Date dd/mm/yyyy	OR	Estimate
OR			
<b>C</b> Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

**8.2** .....

<b>A</b> When did you <u>first notice</u> this?	Exact Date dd/mm/yyyy	OR	Estimate
<b>B</b> When did you <u>first tell</u> your GP or nurse?	Exact Date dd/mm/yyyy	OR	Estimate
OR			
<b>C</b> Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

**8.3** .....

<b>A</b> When did you <u>first notice</u> this?	Exact Date dd/mm/yyyy	OR	Estimate
<b>B</b> When did you <u>first tell</u> your GP or nurse?	Exact Date dd/mm/yyyy	OR	Estimate
OR			
<b>C</b> Tick here if you <u>didn't tell</u> your GP or nurse	<input type="checkbox"/>		

## Section 2-People you talked to about your symptoms

The next questions are about whether you talked to other people about your symptoms.

### 9. Did you talk to anyone about your symptoms, before you went to your GP?

Yes  No

Please go to next question    Please go to question 10

### 9a. If so, who did you talk to? (please tick all that apply)

Partner	<input type="checkbox"/>	Parents	<input type="checkbox"/>
Children	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Brother/Sister	<input type="checkbox"/>	Colleague	<input type="checkbox"/>
		Other, please state...	<input type="checkbox"/>
		<input type="text"/>	

### 10. Please read all of the statements and decide how much you agree with each (1 being completely disagree and 4 being completely agree) If you do not have a partner please go to question 11

	Completely Disagree		Completely Agree	
	X	x	✓	
My partner asked about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner asked how I felt about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner suggested I go to see the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner tried to reassure me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner discussed what they thought my symptoms may be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner brushed off my worries about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner pretended nothing was wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner avoided talking about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner hid his/her worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner was not worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**11. Please read all of the statements and decide how much you agree with each:  
 (1 being completely disagree and 4 being completely agree)  
 When we say 'others' we mean children, other family members, friends, colleagues and so on**

	Completely Disagree	→		Completely Agree
	X	x	✓	✓
Others asked about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others asked how I felt about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others suggested I go to see the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others tried to reassure me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others discussed what they thought my symptoms may be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others brushed off my worries about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others pretended nothing was wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others avoided talking about my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others hid their concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others were not worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please turn over to section 3**



### Section 3-About you

The next questions relate to general information about you. This will help us to understand more about you and your answers to the questions so far.

#### 12. Which best describes your employment status? Please tick one box only

Employed full-time	<input type="checkbox"/>	Retired	<input type="checkbox"/>
Employed part-time	<input type="checkbox"/>	Student	<input type="checkbox"/>
Self-employed full-time	<input type="checkbox"/>	Permanently sick/disabled	<input type="checkbox"/>
Self-employed part-time	<input type="checkbox"/>	Temporarily sick/disabled	<input type="checkbox"/>
Unemployed (seeking work)	<input type="checkbox"/>	Looking after family/home	<input type="checkbox"/>
Unemployed (not seeking work)	<input type="checkbox"/>	Other, please describe	<input type="checkbox"/>

↳

#### 13. What is your highest level of qualification? Please tick one box only

Degree (or equivalent)	<input type="checkbox"/>	GCSE/ O' Level	<input type="checkbox"/>
Diploma (or equivalent)	<input type="checkbox"/>	None	<input type="checkbox"/>
A' Level	<input type="checkbox"/>	Other, please specify	<input type="checkbox"/>

↳

#### 14. How would you describe your ethnicity? Please tick one box only

**White**

British	<input type="checkbox"/>
Irish	<input type="checkbox"/>
Any other white background	<input type="checkbox"/>

↳ Please write in

**Mixed**

White and Black Caribbean	<input type="checkbox"/>
White and Black African	<input type="checkbox"/>
White and Asian	<input type="checkbox"/>
Any other Mixed background	<input type="checkbox"/>

↳ Please write in

**Chinese or other ethnic group**

Chinese	<input type="checkbox"/>
Any other ethnic group	<input type="checkbox"/>

↳ Please write in

**Asian or Asian British**

Indian	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>

Any other Asian background

↳ Please write in

**Black or Black British**

Caribbean	<input type="checkbox"/>
African	<input type="checkbox"/>
Any other Black background	<input type="checkbox"/>

↳ Please write in

**15. What is your religion?**

No Religion	<input type="checkbox"/>
Christian (including Church of England, Catholic, Protestant and all other Christian denominations).	<input type="checkbox"/>
Buddhist	<input type="checkbox"/>
Hindu	<input type="checkbox"/>
Jewish	<input type="checkbox"/>
Muslim	<input type="checkbox"/>
Sikh	<input type="checkbox"/>
Any other religion	<input type="checkbox"/>

Please write: \_\_\_\_\_

**16. Do you live alone?**

Yes  No

Please go to next question      Please say who you live with

Who do you live with?...  
(e.g. Wife, husband, partner, family member) →

**17. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:**

- Long-terms physical or mental ill-health/disability?
- Problems related to old age?

(Do not count anything you do as part of paid employment)

No	<input type="checkbox"/>
Yes, 1-19 hours a week	<input type="checkbox"/>
Yes, 20-40 hours a week	<input type="checkbox"/>
Yes, 50 or more hours a week	<input type="checkbox"/>

**18. Are you suffering from, or have you suffered from, any of the following in the past 2 years?  
Please tick any that are applicable to you**

Asthma	<input type="checkbox"/>
Chronic Obstructive Pulmonary Disease (COPD)	<input type="checkbox"/>
Other lung disease (e.g. fibrosis, bronchiectasis etc)	<input type="checkbox"/>
Heart disease	<input type="checkbox"/>
Anxiety or depression	<input type="checkbox"/>
Inflammatory bowel disease	<input type="checkbox"/>
Irritable bowel syndrome	<input type="checkbox"/>
Peptic Ulcer	<input type="checkbox"/>
Cancer	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>
Arthritis	<input type="checkbox"/>

**19. About smoking, Please tick one box only**

Are you a current smoker?	<input type="checkbox"/>
Are you an ex-smoker?	<input type="checkbox"/>
Are you a non-smoker (never smoked)?	<input type="checkbox"/>

**20. Do you think you are more at risk of one of the conditions listed below because of your family history? Please tick a box for each.**

	Yes	No	Don't know
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Heart Disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="text"/>		

If you would like us to write to your GP, to let them know that you have taken part in this study, please could you provide your GP's contact details below.

If you do not wish us to inform your GP that you have taken part, that is not a problem, simply leave the contact details blank.

Doctors Name: \_\_\_\_\_

GP Practice and Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Thank you for taking the time to complete this questionnaire.**

**We are very grateful for your help.**

## 7. Letter to the GP



### A Study About What Makes People Decide To Go To Their Doctor

Dr. x  
Practice address

date

**Re: Patient, address, d.o.b.**

Dear Dr. x,

I am writing to inform you that your patient, Mr. x, is participating in a research study being run by Durham University and the University Hospital of North Tees. The study will explore how social context and social support affect how quickly patients present to primary care when they have respiratory and colorectal symptoms that could indicate cancer.

The study recruits patients aged 40 and over who have been referred with respiratory or colorectal symptoms, either as a two week wait, or, in the case of respiratory symptoms, have been sent for a direct access chest x-ray. Your patient has been identified and recruited through North Tees Hospital.

Participation in the study entails completion of a questionnaire, which asks about time from symptom emergence to initial presentation for a range of symptoms and about social support during the time of symptom appraisal. A proportion of consenting patients will be contacted for interview.

We do not require any specific action from yourself in relation to this study, but we wanted to make you aware of your patient's participation in this project. If you have any questions about your patient's involvement, or about the study itself, please contact me on 0191 334 0806 or by email at [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk).

Kind Regards,

Christina Dobson  
Doctoral Researcher  
School of Medicine, Pharmacy and Health

## 8. Interview Topic Guide

Could you tell me about when you first started experiencing your symptoms?

How did you feel about your symptoms (concerned, not bothered etc)?

*Did you try to find out about your symptoms? (talk to others, reference book, online etc)*

*What did you think they might have been?*

What made you think that you might need to go to the Drs about them?

How long after your symptoms started was it that you decided you should see a doctor?

How long was it between deciding you needed to go to the doctor and actually going?

Did you do anything to help you cope with them (painkillers etc)?

Did you talk to anyone about your symptoms?

Did you tell them about your symptoms or did they bring them up?

What were their thoughts/advice about your symptoms?

Do you think what they said influenced what you thought about your symptom?

Did you mention them to anyone else?

Do you normally talk to others about your symptoms when you are unwell?

In general, is health and illness something you talk about?

How has your health been throughout your life?

Could you tell me a bit about your life at the time your symptoms started – i.e. work, family, hobbies etc?

*I'm interested in getting a bit of a picture of what your life is like: Could you tell me what a typical week looks like for you? Was it similar when you were experiencing your symptoms?*

Do you talk to your friends and family a lot about general things other than sx's?

Was life generally as normal at the time?

Did your symptoms impact any of these? Did this make you think differently about going to the doctors?

Do you know of others who had similar symptoms? Did this affect how you felt about yours?

Do you tend to go to the doctors when you are unwell? What things would you normally go for?

Do you find it easy to get an appointment with your doctor?

Do you find it easy to talk to your doctor?

Do you find it easy to talk about your type of symptom?

Did anything slow you down in going to the doctors?

Is there anything else you would like to tell me about your symptoms, or the time between getting them and going to the doctors?

## 9. Interview Participant Information Sheet



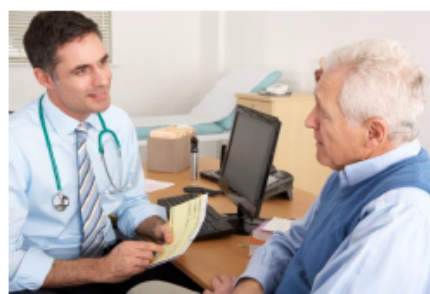
### A Study About What Makes People Decide To Go To Their Doctor

#### Interview Participant Information Sheet

*We would like to invite you to take part in our research study. Please read this information, and discuss it with others or the researcher if you wish, before you decide to take part.*

#### What is the purpose of the study?

People often spend some time deciding whether their symptoms are important and whether they should see their GP about them. We are hoping this study will help us to understand some of the reasons why people may decide to go to the doctors quite quickly or may decide to wait longer before going.



#### Why have I been invited?

You were invited to take part because you have recently been referred to the hospital with symptoms we are interested in and you kindly completed and returned a questionnaire. The researcher will have recently been in touch about the possibility of an interview, after ticking your questionnaire consent form to say you were happy to be contacted.

#### Do I have to take part?

No. It is up to you if you would like to be interviewed. If you agree to take part but then feel you no longer want to, you are free to withdraw at any point. This will not affect your healthcare in any way.

#### Who is doing this study?

The research is being organised by the School of Medicine, Pharmacy and Health at Durham University. Christina Dobson is leading the research as part of her PhD. The study is also being supervised by Prof. Greg Rubin and Dr. Andrew Russell, from Durham University.



Mrs Christina Dobson



Prof. Greg Rubin



Dr. Andrew Russell



### What will I have to do?

If you are happy to be interviewed you will need to complete the consent form provided by the researcher when they come to interview you at the time arranged. If you wish to be interviewed at the University (Queens' Campus, Stockton) we will cover your travel costs. The interview will last roughly 1 hour but varies for each interview.

In the interview we will ask about when you first noticed your symptoms and what you thought about them. We will ask you if you talked to people about your symptoms and also how and when you decided to go to your GP about them.

The interviews will be recorded and transcribed and your interview will remain anonymous.



### Will my taking part in this study be kept confidential?

Yes. Both your interview transcript and audio file will be anonymised and stored securely at Durham University. Your personal details will be kept separately to your interview data, so you cannot be identified. Any quotes we use from your interview will be anonymous. Twelve months after the end of the study your personal contact details will be securely destroyed. We will keep your interview data for 3 years after the end of the study but this is anonymised and so will not identify you.

In the unlikely event that you tell the researcher information that puts yourself or someone else at risk of harm or disclose illegal behaviour we may have to breach confidentiality, in accordance with legal and ethical guidelines.

### What will happen to the results of the research study?

The results will form part of Christina Dobson's PhD thesis and will be presented at conferences and published in journals, but you will not be identified.

If you would like to receive a summary of the study's findings at the end of the project then please tick box 6 on your consent form.

### Some Frequently Asked Questions (FAQ's)

**What are the disadvantages of taking part?**

Taking part means giving up some of your time to be interviewed.

**What are the benefits of taking part?**

This study will not directly help you but the information we get from the study could help patients with similar symptoms in the future.

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

If you wish to withdraw from either part of the study (questionnaire or interview) your data will be destroyed and the researchers will not contact you again. If you wish to withdraw please contact the researcher, Christina Dobson (0191 334 0806). You will not be expected to explain your reasons for withdrawing.

**What if there is a problem?**

If you have any concerns about the study please contact Christina Dobson (0191 334 0806) who will do her best to address your concerns. If you are still unhappy or wish to make a formal complaint you can contact the Patient Experience Team on 01642 624719 or by email at [patientexperience@nth.nhs.uk](mailto:patientexperience@nth.nhs.uk)

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the York Research Ethics Committee (REC).

**Who is paying for this study?**

The research is funded by the Evaluation, Research and Development Unit (ERDU) at Durham University, as part of a PhD studentship.

#### Additional Information

For further information of public involvement in research and the NHS you can contact INVOLVE on 023 8065 1088 or visit their website at [www.invo.org.uk](http://www.invo.org.uk)

If you have any questions about this study please contact Christina Dobson on 0191 334 0806 or [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)

***Thank you so much for taking the time to read this information sheet and for considering taking part in the study.***



*Wolfson Research Institute, Durham University, Queens Campus*

## 10. Interview Consent Form



### A Study About What Makes People Decide To Go To Their Doctor

#### Interview Consent Form

Please initial each box

1. I confirm that I have read and understand the information sheet dated 03/10/2013 for the above study. I have had the opportunity to consider the information and ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my medical care or legal rights being affected.
3. I understand that by taking part in this research I will be interviewed and I agree that the interview can be audio recorded.
4. I agree to the use of my anonymised quotes when this research is published.
5. I agree to take part in the study.
6. I would like to receive a summary of the results, at the end of the study  
*Please leave this box empty if you do not wish to receive a summary*

Participant Name:

Participant Signature:

Date:

Research Name:

Researcher Signature:

Date:

## 11. Coding Theme Matrix

### Code Matrix – 24th July 2014

Symptoms & Sx Appraisal:	From recognition to consultation:	Social Context:
Nature of symptoms	Self-Medication	Familial influences on help-seeking
<ul style="list-style-type: none"> <li>- Blood</li> <li>- Not feeling ill</li> <li>- Pain</li> </ul>	No time to be ill	Social responsibilities
<i>Changing Symptoms</i>	Tipping point	Work
Responding to symptoms	Help-seeking delays	Culture/Ethnicity
Living with/Tolerating/Managing Symptoms	Needing to know	Stigma
<ul style="list-style-type: none"> <li>- Altering diet</li> <li>- Monitoring diet</li> </ul>	Considering cancer	Family history (of cancer)
Rationalising symptoms	Considering cause/diagnosis	Lifestyle
Monitoring symptoms / Time limits	Coming to a decision	<ul style="list-style-type: none"> <li>- Family</li> <li>- Socialising</li> <li>- Church</li> <li>- Holidays</li> <li>- Hobbies</li> </ul>
Impact of symptoms	Prioritising	Friends' influence on help-seeking
<ul style="list-style-type: none"> <li>- Symptoms interrupting daily life</li> <li>- Soiling</li> </ul>	Lay illness beliefs	Be Clear on Cancer
Feelings/Attitude towards symptoms	Self-diagnosis	Previous experiences with cancer
<ul style="list-style-type: none"> <li>- Symptoms unnerving</li> </ul>	e-health/googling	<i>Lifestyle Risk Factors</i>
People's views of & relationships with their bodies:	<i>Researching Symptoms</i>	<b>Gender</b>
Illness as weakness	<i>Justifying Help-Seeking</i>	<b>Interactions with Others:</b>
Changing identity	Health Care Interactions:	Discussing bowel symptoms
'Healthy' identity	Making an appointment	Discussing health & illness
Running multiple lives	Consulting behaviour	Discussing symptoms
'why me'	GP/Dr. interactions	<i>Discussing a Cause</i>
Ageing	Model Px Behaviour/Patient	Seeking reassurance
Healthy, except	Stereotyping	Predicting other's responses
	<ul style="list-style-type: none"> <li>- Being a good patient</li> <li>- Wasting Dr.'s time</li> </ul>	Avoiding worrying others
	<b>Expectations of consultation</b>	'being bloody minded'
	<b>Being Examined</b>	Patients role in others' health behaviour

Codes in Italics added 08/08/14 – code highlighted yellow to query removing red text added 26/08/2014

## 12. School of Medicine, Pharmacy & Health Ethical Approval



Shaped by the past, creating the future

**Rebecca Maier**  
Research, Development and Trials Manager  
Chair, School of Medicine, Pharmacy and Health Ethics Sub- Committee

**Christina Dobson**  
PhD Student  
School of Medicine, Pharmacy and Health  
Durham University

8<sup>th</sup> August 2013

Dear Christina,

**Re: Ethics Application ESC2/2013/09**  
**A Symptom appraisal and help-seeking among patients with symptoms indicative of lung or colorectal cancer: an exploration of the importance of social context.**

Thank you for sending the above application to the School of Medicine, Pharmacy and Health Ethics Sub-Committee and for attending the meeting in May where this was discussed. The committee agreed that there were no major ethical issues with your proposal and requested some minor amendments. I have reviewed these amendments today and I am satisfied that all of the points raised by the committee have been addressed. I am therefore pleased to confirm Durham University ethical approval for the project.

Please note that as custodian of the data generated for this study you will be responsible for ensuring it is maintained and destroyed as outlined in this proposal and in keeping with the Data Protection Act.

Please do not hesitate to contact me should you have any questions. Good luck, I hope that the study goes well.

With best wishes,



Rebecca Maier

## 13. UHNT R&D Peer Review Approval

16 December 2013

Mrs Christina Dobson  
PhD Student  
ERDU  
School of Medicine, Pharmacy & Health  
Wolfson Research Institute  
Queens Campus  
University Boulevard  
Thornaby  
TS17 6BH

Dear Mrs Dobson

**Study Title: Social context and help seeking among patients with symptoms of cancer**  
**R&D Ref No: MED-156**  
**REC Ref: 13/NE/0319**

I am pleased to confirm NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

• Protocol	Version 4	03.10.13
• Respiratory invitation letter	Version 1	29.04.13
• Colorectal invitation letter	Version 1	29.04.13
• Relative interview invitation letter	Version 1	29.04.13
• Interview consent form	Version 3	03.10.13
• Respiratory questionnaire	Version 4	19.11.13
• Colorectal questionnaire	Version 4	19.11.13
• Questionnaire participant information sheet	Version 3	03.10.13
• Relative's & friend's participant information sheet	Version 3	03.10.13
• Patient interview participant information sheet	Version 3	03.10.13
• Relative's or friend's interview schedule	Version 1	27.06.13
• Patient interview schedule	Version 1	27.06.13
• Letter confirming no interview	Version 1	13.11.13
• NHS Ethics approval letter	Dated	22.11.13
• SSI Form	128918/538736/6/794/199910/287371	
• Caldicott approval	Dated	12.12.13
• CV	Christina Dobson	

D16 Version 3 04.04.11

Professor Volker Straub  
**Research & Development Director**  
Harold Macmillan Chair for Medicine, FRCPCH  
Direct Line: 01642 624090

Professor Samir Gupta  
**Deputy Research & Development Director**  
Consultant Neonatologist  
Direct Line: 01642 624090

Paul Garvin  
Chairman

Alan Foster  
Chief Executive

NTH115

NHS permission for North Tees & Hartlepool NHS Foundation Trust applies to University Hospital of North Tees and University Hospital of Hartlepool.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, GCP and NHS Trust policies and procedures (full list of relevant Trust SOPs will be given to PI at the study start up meeting).

Permission is only granted for the activities for which a favourable opinion has been given by NHS Ethics (and which have been authorised by the MHRA).

Approval is conditional upon adherence to study related protocols and Standard Operating Procedures (SOPs), in addition to Trust R&D SOPs.

The research sponsor, Chief Investigator, or the local Principal Investigator at the research site, may make appropriate urgent safety measures in order to protect research participants against any immediate hazards to their health or safety. The R&D Office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Office should be notified within the same time frame of notifying NHS Ethics and any other regulatory bodies.

It is the sponsor's responsibility to notify participating sites of any information relating to a change to the status of the project.

**It is important that you inform us of any of the following:**

- **Change in CI/PI: 30 days notice is required in order to arrange NHS Ethics approval of change in CI/PI.**
- **Changes in protocol.**
- **Changes to study documentation.**
- **Changes to the time frame of the study.**
- **Any substantial amendments**

We require you to provide regular updates on request and a final report on completion of this project.

Please note that your project may be subject to an audit from Research & Development at any time in line with Trust R&D SOP 14.

We wish you every success with your research project.

Best Wishes



Professor Volker Straub  
Director of Research & Development

**Cc**

D16 Version 3 04.04.11

Professor Volker Straub Research & Development Director Harold Macmillan Chair for Medicine, FRCPCH Direct Line: 01642 624090	Professor Samir Gupta Deputy Research & Development Director Consultant Neonatologist Direct Line: 01642 624090
--	--



Professor Greg Rubin  
Evaluation, Research & Development Unit (ERDU)  
School of Medicine, Pharmacy & Health  
Wolfson Research Institute  
Queens Campus  
University Boulevard  
Thornaby  
Stockton on Tees  
TS17 6BH

Russell Hill  
Sponsor Contact  
Department of Anthropology  
Dawson Building  
South Road  
Durham  
DH1 3LE

D16 Version 3 04.04.11

<p>Professor Volker Straub <b>Research &amp; Development Director</b> Harold Maomillan Chair for Medicine, FRCPCH Direct Line: 01642 624090</p>	<p>Professor Samir Gupta <b>Deputy Research &amp; Development Director</b> Consultant Neonatologist Direct Line: 01642 624090</p>
---	---

## 14. NRES Favourable Opinion



### Health Research Authority

#### NRES Committee North East - York

Room 002  
TEDCO Business Centre  
Viking Business Park  
Rolling Mill Road  
Jarrow, Tyne & Wear  
NE32 3DT

Telephone: 0191 4283563

22 November 2013

Mrs Christina Dobson  
Durham University  
Evaluation, Research and Development Unit (ERDU)  
School of Medicine, Pharmacy & Health  
Wolfson Research Institute, Queens Campus  
University Boulevard  
Thornaby, Stockton-on-Tees  
TS17 6BH

Dear Mrs Dobson

<b>Study title:</b>	<b>Understanding how and why social context affects symptom appraisal and help-seeking, among patients with symptoms indicative of lung or colorectal cancer</b>
<b>REC reference:</b>	<b>13/NE/0319</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>IRAS project ID:</b>	<b>128918</b>

Thank you for your letter received 20 November 2013, 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 myself as Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Helen M Wilson, [nrescommittee.northeast-york@nhs.net](mailto:nrescommittee.northeast-york@nhs.net).

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting

A Research Ethics Committee established by the Health Research Authority

documentation [as revised], subject to the conditions specified below.

The Interview Scenarios are a most helpful addition to the application and thank you for providing them.

#### **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).

##### **Conditions of the favourable opinion**

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

*Sponsors are not required to notify the Committee of approvals from host organisations*

##### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database 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](mailto: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).

#### Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		
Evidence of insurance or indemnity	Durham University Professional Indemnity	15 July 2013
Evidence of insurance or indemnity	Durham University Public and Products Liability	11 July 2013
GP/Consultant Information Sheets	V1	19 November 2013
Investigator CV	Christina Dobson	
Other: CV	Prof Greg Rubin	
Other: Letter of Invitation - Respiratory Invitation Letter	V1	29 April 2013
Other: Letter of Invitation - Colorectal Invitation Letter	V1	29 April 2013
Other: Letter of Invitation - Friend and Relative Invitation Letter	V1	27 June 2013
Other: R & D approval		11 October 2013
Other: Peer review comments from Prof James Mason and Dr Fiona Walter	Emails	
Other: Patient Interview Schedule	Version 1	27 June 2013
Other: Relative or Friend Interview Schedule	Version 1	27 June 2013
Other: Distressing Interview Scenarios		
Other: Letter confirming No Interview	V1	13 November 2013
Other: Lung Flow Chart		
Other: Colorectal Flow Chart		
Participant Consent Form: Interview	Version 3	03 October 2013
Participant Information Sheet: Questionnaire Participant	Version 3	03 October 2013
Participant Information Sheet: Participant Interview	Version 3	03 October 2013
Participant Information Sheet: Friend and Relative Interview	Version 3	03 October 2013
Protocol	V4	03 October 2013
Questionnaire: Respiratory	V4	19 November 2013
Questionnaire: Colorectal	V4	19 November 2013
REC application	Version 3.5	15 October 2013
Referees or other scientific critique report	Durham University	08 August 2013

Response to Request for Further Information		
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#### 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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

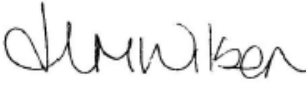
Further information is available at National Research Ethics Service website > After Review

13/NE/0319	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely

pp 

Professor Peter Heasman  
Chair

Email: [nrescommittee.northeast-york@nhs.net](mailto:nrescommittee.northeast-york@nhs.net)

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Russell Hill, Durham University

Mrs Jane Greenaway, North Tees and Hartlepool NHS Foundation Trust

NIGB Ethics & Confidentiality Committee Secretariat

## 15. School of Medicine, Pharmacy & Health Minor Amendment Approval

You replied to this message on 06/02/2014 14:03.

Sent: Wed 05/02/2014 13:20

From: MAIER R.H.  
To: DOBSON C.M.  
Cc:  
Subject: RE: Minor Ammendment Ref: ESC2/2013/09

Dear Christina,

Thanks you for sending this to me and for discussing the amendment with me. I am happy to confirm continuing ethical approval for the project from the Durham University perspective, incorporating this amendment.

Good luck with getting approvals from the REC and R&D departments.

Best wishes,  
Rebecca

**Rebecca Maier**  
School of Medicine, Pharmacy and Health,  
Queen's Campus, Durham University  
Stockton-on-Tees  
TS17 6BH

Please note: my email address has changed to [rebecca.maier@durham.ac.uk](mailto:rebecca.maier@durham.ac.uk)

---

**From:** DOBSON C.M.  
**Sent:** 05 February 2014 10:39  
**To:** MAIER R.H.  
**Subject:** Minor Ammendment Ref: ESC2/2013/09

Dear Rebecca,

Please find attached an updated version of the study document GP letter, for consideration for approval as a minor amendment. The document has been amended to include a REF line (highlighted) which will indicate patient name, d.o.b and address. This has been necessary as the original letter, does not contain sufficient information (name only) for the GP practice to identify the patient within their records.

Kind Regards,  
Christina

Christina Dobson  
Researcher  
Evaluation, Research & Development Unit (ERDU), School of Medicine, Pharmacy & Health,  
Room E106, Wolfson Research Institute, Durham University Queen's Campus,  
Stockton-on-Tees, TS17 6BH

## 16. NRES Minor Amendment Approval



### Health Research Authority

NRES Committee North East - York

Room 002  
TEDCO Business Centre  
Viking Business Park  
Rolling Mill Road  
Jarrow, Tyne & Wear  
NE32 3DT

Tel: 0191 4283548

07 March 2014

Mrs Christina Dobson  
Durham University  
Evaluation, Research and Development Unit (ERDU)  
School of Medicine, Pharmacy & Health  
Wolfson Research Institute  
Queens Campus  
University Boulevard  
Thornaby  
Stockton-on-Tees  
TS17 6BH

Dear Mrs Dobson

**Study title:** Understanding how and why social context affects symptom appraisal and help-seeking, among patients with symptoms indicative of lung or colorectal cancer  
**REC reference:** 13/NE/0319  
**Protocol number:** N/A  
**Amendment number:** Amendment Number 1, 05.02.2014  
**Amendment date:** 18 February 2014  
**IRAS project ID:** 128918

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	Christina Dobson	18 February 2014
GP/Consultant Information Sheets	Version 2	05 February 2014
Notice of Substantial Amendment (non-CTIMPs)	Amendment Number 1, 05.02.2014	18 February 2014



### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

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

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

13/NE/0319:	Please quote this number on all correspondence
-------------	--

Yours sincerely



pp

**Dr Giles McCracken**  
Chair

E-mail: [nrescommittee.northeast-york@nhs.net](mailto:nrescommittee.northeast-york@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Mrs Jane Greenaway, North Tees and Hartlepool NHS Foundation Trust*

*Russell Hill, Durham University*

*NIGB Ethics & Confidentiality Committee Secretariat*

**NRES Committee North East - York**

**Attendance at Sub-Committee of the REC meeting in correspondence**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Steve Chandler	Retired Consultant Medical Physicist	Expert
Dr Giles McCracken (chair)	Senior Clinical Lecturer	Expert

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Christie Ord	Covering REC Assistant
Mrs Sally Dunn	REC Assistant

## 17. Participant Study Summary Sheet



### A Study About What Makes People Decide To Go To Their Doctor

Last year you kindly took part in a study about when and why people visit their GP about certain symptoms, by completing a questionnaire and possibly taking part in an interview as well.

The study has now ended and we are writing to you because in your questionnaire you said that you would like to know about the findings of the study once it was completed.

#### Who took part?

In total, 164 people completed and returned a questionnaire. Of these, 93 people completed a questionnaire about bowel symptoms, and 71 completed a questionnaire about chest symptoms.

From the people who returned questionnaires a small number also took part in an interview. There were 14 people with bowel symptoms and 12 people with chest symptoms who took part in an interview.

The people who took part came from all over the area served by the University Hospital of North Tees. They ranged age from 40 to 89, and there was a roughly equal mixture of men and women.

Study Summary Sheet

#### What did we find?

##### *People's symptoms*

People experienced lots of different symptoms, but the most common symptoms were a change in bowel habit or bleeding from the back passage for people with bowel symptoms, and a cough or breathlessness for people with chest symptoms.

There was a wide range in how long it took people to see the GP about their symptoms, from the same day to over five years later, with an average time of 2 months.

People with chest symptoms tended to see their GP slightly sooner than people with bowel symptoms. People who had blood as a symptom, (bleeding from the back passage or coughing up blood) went to see the doctor the quickest, whereas those who had changes in bowel habit, cough or breathlessness took longer.

Version 2 – 27/05/2016

#### *Talking about symptoms with others*

Most people (over 80%) talked to others about their symptoms before going to see their doctor. On average, people talked to two people about their symptoms, with six being the greatest number of people that someone discussed their symptoms with.

People most often discussed their symptoms with their partner or children, but also with friends, colleagues, other family members, and sometimes a pharmacist, at their local chemist.

People who discussed their symptoms with someone else went to the GPs quicker than those who did not discuss their symptoms but only by an average of four days.

#### *Deciding to see the Doctor*

The interviews looked at people's experiences of their symptoms and their decision to go and see a doctor about them.

There was a range of things that encouraged people to go to the doctors, including changes in symptoms, symptoms affecting their lifestyle or activities, worries their symptoms might be cancer, or encouragement from family members to see the GP.

There were also a number of things that discouraged people from going to see the doctor, such as work, caring responsibilities, or worry about wasting the doctor's time.

People's decisions about if, and when, to see the GP were based on many different factors in their life, which also changed over time.

#### *What Now?*

The results of this study are discussed in my PhD thesis and will go on to be included in papers which will be published in academic journal and presented at academic conferences.

It is hoped that the findings will be helpful for those designing public health campaigns, as it identifies some of the reasons why people might put off going to the doctor. Public health information could then focus on some of these issues to help to encourage people to go to the doctor's sooner when they are unwell.

If you would like more information about the findings, or would like to discuss them, then please contact me, Christina Dobson, on [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk) or 0191 334 0806, and I will be more than happy to discuss them with you.

## 18. 'Patient delay in cancer diagnosis: what do we really mean and can we be more specific?'

Dobson et al. *BMC Health Services Research* 2014, **14**:387  
<http://www.biomedcentral.com/1472-6963/14/387>



DEBATE

Open Access

### Patient delay in cancer diagnosis: what do we really mean and can we be more specific?

Christina Mary Dobson<sup>1\*</sup>, Andrew James Russell<sup>2</sup> and Greg Paul Rubin<sup>1</sup>

#### Abstract

**Background:** Early diagnosis is a key focus of cancer control because of its association with survival. Delays in diagnosis can occur throughout the diagnostic pathway, within any one of its three component intervals: the patient interval, the primary care interval and the secondary care interval.

**Discussion:** A key focus for help-seeking research in patients with symptoms of cancer has been the concept of 'delay'. The literature is plagued by definitional and semantic problems, which serve to hinder comparison between studies. Use of the word 'delay' has been criticised as judgemental and potentially stigmatising, because of its implications of intent. However, the suggested alternatives (time to presentation, appraisal interval, help-seeking interval and postponement of help-seeking) still fail to accurately define the concept in hand, and often conflate three quite separate ideas; that of an interval, that of an unacceptably long interval, and that of a specific event which caused delay in the diagnostic process. We discuss the need to disentangle current terminology and suggest the term 'prolonged interval' as a more appropriate alternative. Most studies treat the patient interval as a dichotomous variable, with cases beyond a specified time point classified as 'delay'. However, there are inconsistencies in both where this line is drawn, ranging from one week to three months, and how, with some studies imposing seemingly arbitrary time points, others utilising the median as a divisive tool or exploring quartiles within their data. This not only makes comparison problematic, but, as many studies do not differentiate between cancer site, also imposes boundaries which are not necessarily site-relevant. We argue that analysis of the patient interval should be based on presenting symptom, as opposed to pathology, to better reflect the context of the help-seeking interval, and suggest how new definitional boundaries could be developed.

**Summary:** The word 'delay' is currently (confused) to describe diverse conceptualisations of 'delay' and more mindful, and discerning language needs to be developed to enable a more sophisticated discussion. By stratifying help-seeking by presenting symptom(s), more accurate and informative analyses could be produced which, in turn, would result in more accurately targeted early diagnosis interventions.

**Keywords:** Delay, Cancer, Early diagnosis, Help-seeking, Symptom appraisal

#### Background

Research into earlier diagnosis is a key focus for cancer control because of the growing evidence for an association between the time from symptom onset to diagnosis and both stage at diagnosis and subsequent survival [1-4]. There are several models of the diagnostic pathway that describe the stages from symptom onset to commencement of treatment, with these stages often being referred to as stages of delay [5-7]. The diagnostic pathway has been broken down into three component intervals: the

period from symptom recognition to first consultation with a health care professional, generally a GP (termed by Olesen et al. [6] as patient delay), the period from first consultation with a health care professional to initiation of investigations for cancer related symptoms (doctor delay) and the period from initiation of investigations to commencement of treatment (system delay). Within the patient interval there are two component intervals; symptom appraisal (the period between detecting a bodily change and deciding that there is a need to discuss the symptoms with a health care practitioner) and help-seeking (the period from perceiving a need to discuss the symptoms with a health care practitioner to the first consultation) [7].

\* Correspondence: [c.m.dobson@durham.ac.uk](mailto:c.m.dobson@durham.ac.uk)  
<sup>1</sup>School of Medicine, Pharmacy & Health, Durham University, Durham, UK  
Full list of author information is available at the end of the article



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An understanding of the nature and duration of these intervals is crucial to research on cancer diagnosis, but also raises important questions about what constitutes 'normality' and where the temporal and behavioural boundaries of normality lie. We argue that the term 'delay' as currently used is both semantically and definitionally problematic and propose an alternative way of conceptualising variation in the patient interval based on symptom rather than eventual diagnosis.

A considerable body of research has sought to understand if, and how, a range of factors modify the patient interval, examining how the frequency, impact, and causes of such factors result in variation in its duration. Studies of the relationships between particular demographic characteristics and the duration of the patient interval have produced inconsistent findings [8-14], possibly because of the influence and diversity of barriers to presentation which have been shown to exist across demographic groupings [15]. Symptom misinterpretation is frequently reported, with patients believing their symptoms are the result of minor ailments [16-19], physical exertion [20,21], stress [22], connected to pre-existing conditions [23], ageing [19,24] or expected bodily changes [25]. Fear plays an important yet ambiguous role in help-seeking, acting as a prompt for some people and deterring presentation for others [26-29]. Fear can manifest itself as a fear of cancer or of the investigations and treatments associated with it [30,31]. Fear of embarrassment and shame can also act as a barrier to presentation, particularly when symptoms are located in 'private' areas of the body [12,20,31]. Concern about wasting the doctor's time, and appearing to be neurotic or hypochondriac, has been cited as a barrier to presentation [31,32]. Some patients only report their symptoms during consultations for other conditions, or monitor their symptoms in order to accumulate 'evidence' to justify presentation [24,31-34]. Social context has been shown to influence the timing of help-seeking, particularly the prioritisation of other life events [22,26,33-35]. Social networks are also thought to be influential, through the sanctioning of help-seeking [9,36-38], and/or identification of symptoms [21,39,40].

Much of the public, and research, discourse around cancer diagnosis has been centred on the concept of 'delay'. This body of research highlights the complexity of symptom appraisal and help-seeking processes, an issue which, it has been argued, has not been acknowledged in many previous studies [41].

Comparisons between studies of 'delay' within the patient interval are plagued with definitional and semantic inconsistencies [42]. We review these problems below. Our intention is not to jettison the term 'delay'. We consider there to be great value in retaining the concept of delayed presentation as a function, or a tool, to guide future research, while recognising that help-seeking in

particular occurs within the context of contending considerations, priorities and contexts. However, our conclusion is that 'delay' is better conceptualised based on symptomatology rather than diagnosis or eventual outcome.

## Discussion

### Specifying delay: semantic issues

There are common approaches within early diagnosis research for classifying the periods which constitute the diagnostic pathway, but there is less consistency in the language used to talk about it. Some authors refer to the periods within the diagnostic pathway as 'phases of delay' whereas others refer to them as 'intervals' [7,43]. We will use the term patient interval, instead of phase, to refer to the period from symptom recognition to first consultation, and the terms appraisal interval and help-seeking interval to refer to its constituent parts. The word interval is also felt to be more precise in its scope than the much vaguer concept of a phase.

Use of the terms 'delay' and 'patient delay' is common but has faced criticism, as such terms are felt to be value laden, pejorative and judgemental [40,44]. By labelling patients as 'delayers', there is felt to be an attribution of blame to the individual, which is potentially stigmatising. Critics of the use of the term 'delay' have suggested that other phrases, such as 'appraisal interval', 'help-seeking interval' or 'time to presentation' [40,42] are preferable alternatives.

Although we agree that the language currently used is fundamentally flawed these proposed alternatives are also inaccurate, as they describe something which is conceptually different: that of a discrete interval within the diagnostic pathway. Most symptomatic patients will have an appraisal interval (the exceptions being those who have not identified a change in bodily sensations as abnormal), and all patients who consult a health care practitioner will also have a help-seeking interval, regardless of how long it takes them to consult. 'Time to presentation' is not clearly defined by those who have proposed the term. However, if we assume this phrase refers to the period from symptom onset to first presentation to a health care practitioner, which we have referred to as 'the patient interval', we are faced with the same issues inherent in the previous two suggestions. These three phrases all effectively describe intervals in the diagnostic pathway but tell us nothing about their nature, whether their length is necessary or undesirable or, if the latter, how their duration could have been reduced.

The term 'postponement of help-seeking' [29] has recently been used, which fits this purpose more precisely, as it clearly distinguishes a group who have taken longer to present. However, the use of the word 'postpone' still implies intention on the part of the patient (the Oxford English Dictionary entry for postpone states: 'cause or

arrange for (something) to take place at a time later than that first scheduled), which we know is often not the experience for patients in reality.

Current suggestions for alternative ways of referring to 'delay' appear to conflate three different concepts: that of an interval; that of an interval which is judged to have been unacceptably long; and that of an event which has caused a delay in a patient's diagnosis.

We already have language which enables us to refer to discrete time periods, in the form of 'intervals', which are clearly defined. If we wish to treat the patient interval as a categorical variable in our analyses, we need to impose a boundary after which point symptom appraisal, help-seeking, or the patient interval in its entirety, are judged to be unacceptably long. This approach creates two groups within the dataset which have previously been conceived of as 'delayers' and 'non-delayers'. These terms infer intent and we cannot suppose that these patients made a conscious decision to 'delay'. We propose that more accurate and less value-laden terms to use when referring to this group are patients with an 'acceptable' or 'prolonged' interval (be it an appraisal, help-seeking or patient interval).

Dividing datasets into acceptable and prolonged intervals would enable us to examine the experiences of patients with prolonged intervals in greater detail. The purpose of such examinations would be to ascertain events which caused a delay in consulting a health care practitioner. Delays, in this context, are events within the help-seeking interval which interrupt the patient's intended course of action, i.e. consultation. We refer exclusively to the help-seeking interval as, it has been argued that framing non-recognition of symptoms as an example of delay is merely an analytical construct based on biomedical understandings of symptomatology that bears little relation to individual experience and belief [45].

When identifying causes of delay, as well as being clear about our use of the word itself, we must be mindful as to how statements about causes are phrased. For instance, to say that a patient *delayed* because they were not able to get an appointment for four days after requesting one would be inaccurate, as it implies that an objective decision was made by the patient, and that they are at fault, when in reality the delay was beyond their control. However, if we said that a *lack of available appointments caused delay* within this patient's help-seeking interval, we are shifting culpability from patient to context. This is particularly important because not all delays are avoidable. It is the avoidable delays which are of most interest, as these are the factors which have the greatest potential for modification.

To summarise, we may wish to describe data in its entirety, as the patient interval, or break it down further, into the appraisal interval and help-seeking interval. We

may wish to understand how many patients present in a timely manner, and how many take an undesirably long time to present, requiring us to impose boundaries within our data. The cases which fall beyond the agreed cut off point would be best referred to as having prolonged intervals. To understand why these patients took longer to present we could explore individual cases, most appropriately using a qualitative approach, to ascertain the causes of delay in presentation whereby the focus is on the event, or context, as opposed to the individual.

#### Specifying delay: methodological issues

There has been criticism that the approach commonly used to ascertain the duration of the patient interval (i.e. subtracting date of first symptom from date of first presentation) is too empirically grounded, as it assumes that there are objective, definitive dates when events occurred, which are readily collectable [41]. In reality, there is ambiguity in the individual, embodied experience of symptom development (i.e. from sensation to symptom), because of its grounding in social context [22], meaning that dates reported are more akin to interpreted estimates. Despite the subjectivity of the dates we collect in such studies, we believe that there is still value in using such data. However, we must be mindful that the dates provided are often 'best estimates' and will be influenced by the point that the patient has reached on the diagnostic pathway, as well as by recall bias. It is imperative that a theoretically and methodologically robust approach is adopted and best practice guidance should be followed. A good example is the Aarhus Statement [42], which states that the date of first symptom and the date of the first presentation should be consistently measured and described in order to facilitate comparison between studies.

Examinations of the patient interval often impose judgements as to the acceptability of its length. The duration of the patient interval is largely treated as a dichotomous variable, with a defined time point beyond which the interval has previously been classified as 'delayed'. Many studies, following Pack and Gallo's seminal work [46], adopt three months, or twelve weeks, as their definition of 'delay' [27,30,43,47]. However, others have used time points of one month [48], thirty days [49], eight weeks [34], or patient intervals greater than the median [35,50]. Not only does this make comparison between studies problematic [42], it also imposes an arbitrary judgement on timeliness of help-seeking across cancer sites that will have very different patterns of symptom development. It has been suggested that a preferable alternative would be to treat the patient interval as a continuous variable, with the median, as opposed to the mean, being presented because these data are usually positively skewed [15,51]. However, using medians of study-specific datasets is also problematic, as it produces a relative, as opposed to absolute,

judgement on the point signalling 'delay', making comparison between studies and generalisation from findings difficult.

Pedersen et al's (2011) [37] approach was to generate quartiles from their patient interval data, and use the 25th and 75th quartiles to represent short and long 'delay' respectively. Although this approach is less indiscriminate than the selection of time points discussed above, it remains problematic as the quartiles were computed using a dataset which contained information for patients with a range of cancers. Producing categorisations of short and long 'delay' based upon data for multiple cancer sites can be misleading, since individual cancer sites have different biological and symptomatic progression, and also have a different likelihood of 'delay' [10,52]. To assess 'delay' in patients with cancers which are known to be rapidly developing or more symptomatically troublesome using the same categories as for patients with cancers whose pathological development is more insidious, does not provide any greater insight into the appropriateness or otherwise of the length of the patient interval.

Another approach has been to attribute a label of 'delay' based upon the presenting symptom. Patients presenting with 'red flag symptoms' (i.e. change in a mole, a lump, or unusual bleeding) have been categorised as having 'delayed' if they did not present within one week of symptom onset, whilst patients reporting any other symptom have been categorised as having 'delayed' if it took them longer than four weeks to present [38,53]. This approach is preferable, as it considers the nuances of symptom severity and development. However, the grouping of symptoms has been constructed within a biomedical framework; it is likely that an individual may not perceive all 'red flag symptoms' to be immediately threatening, or all 'non-red flag symptoms' to be of no immediate threat. The time points selected for these 'alarm' and 'non-alarm' symptoms are also quite arbitrary and, in fact, are not always clinically relevant, at least within the UK context. For instance, presenting with rectal bleeding of one week's duration would be unlikely to result in a referral to secondary care, based upon the NICE referral guidelines for suspected cancer [54].

Low et al. [50] investigated the patient interval by symptom, in relation to ovarian cancer, and found that anticipated length of help-seeking did vary by symptom, with women reporting the longest anticipated help-seeking for non-specific symptoms, such as fatigue and bloating, and shorter time to help-seeking for persistent abdominal pain. Although this study considers help-seeking by symptom, the analysis is based upon the responses of asymptomatic women to hypothetical situations. These responses are unlikely to mirror actual behaviour since such a methodology does not account for the numerous potential barriers to presentation discussed previously.

#### **A symptom-based approach to defining delay**

Symptom appraisal and help seeking take place in specific social and temporal contexts and in response to the symptoms experienced as opposed to the condition ultimately diagnosed. Identification and analysis of prolonged patient intervals based upon presenting symptom, as opposed to pathology, would reflect more accurately the patient's rationalisation and behaviour, which is ultimately based on their embodied experience of that symptom and perceptions of symptom severity.

Taking a generalised approach to their description, across cancer sites, or in relation to a particular cancer site, is problematic. Some patients would be characterised as 'delayers' when a period of watchful waiting may have been appropriate for the symptom they were experiencing. For instance, an acceptable period of watchful waiting for hoarseness would be much longer than an acceptable period of watchful waiting for haemoptysis (coughing up blood), yet if we examine the length of the patient interval by cancer site (i.e. lung), as opposed to presenting symptom these two examples are not currently differentiated.

Symptoms, even those termed alarm symptoms, have different predictive risks for cancer [55]. Campaigns to raise public awareness of cancer symptoms have been predicated largely on a clinical view about the importance of responding promptly to alarm symptoms, rather than on insights into which alarm symptoms are associated with less prompt action on the part of the patient [56]. Examination of the patient interval by symptom could produce a more useful basis upon which to consider areas for this type of intervention.

If we wish to analyse data by acceptable and prolonged intervals, definition of such boundaries is more easily achieved when focusing on individual symptoms. However, there is a lack of agreement among clinicians as to what constitutes an appropriate patient interval for particular symptoms and the clinical perspective often fails to take into account the patient's understandings of symptoms and their implications. Defining new boundaries of prolonged intervals, based upon symptomatology, could be achieved through the analysis of secondary data sets, deriving quartiles from datasets of individual symptoms [37]. Such quartiles would act as a starting point from which to develop consensus around acceptable interval durations, seeking clinician and patient input to incorporate both biomedical and lay understandings in the definition of new boundaries.

Symptoms may develop concurrently and therefore the processes used to analyse multiple presenting symptoms need to be transparent [42]. Patients may identify two or more symptoms as arising simultaneously, or within a short period of time, reflecting the non-linear nature of symptom development and interpretation. Analytical approaches need to be mindful of this and should analyse the length of patient intervals both in relation to each



symptom and combinations of symptoms. This would enable identification of individual, or combinations of, symptoms which are prone to prolonged help-seeking intervals.

Analysis of the patient interval by symptom, and identification of individual symptoms, or symptom clusters, which are associated with prolonged intervals, creates a foundation from which further research can seek to understand why such associations exist and to explore causes of delay more rigorously, with a view to reducing its effects in future.

### Summary

Current approaches to 'delay' within the patient interval, both in terms of linguistic definition and categorisation, are inconsistent and often atheoretical. Researchers in the field of early cancer diagnosis need to be more mindful of the terms they use, in particular 'delay', and consider their nuances and implications. Stratifying categorisation of prolonged intervals by symptom would result in more accurate and informative analyses of timely and prolonged symptom appraisal and, or, help-seeking. Results of such analyses can then function as starting points, from which we can attempt to understand barriers to presentation from a perspective more akin to that of an individual's experience, i.e. one that is symptom-based as opposed to disease-based. Such an approach would not only be of relevance within the field of cancer, but could also be extrapolated to other conditions as well. In this way, we may be able to more accurately target interventions to address the obstacles faced by individuals most in need of support to facilitate their earlier presentation.

### Ethics statement

No ethical approval was sought, or obtained, as this discussion piece is conceptual, and not based on any specific study.

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

CD conceived the argument and drafted the manuscript. GR helped to shape the argument and helped to draft the manuscript. AR helped to shape the argument and helped to draft the manuscript. All authors read and approved the final manuscript.

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