



Risk of Recurrence after Lung Cancer: A Multiple Case Study of Communication

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Risk of Recurrence after Lung Cancer: A Multiple Case Study of Communication

Matthew Howard Johnson

A thesis submitted in partial fulfilment of the requirements of
Sheffield Hallam University
for the degree of Doctor of Philosophy

December 2019

Candidate Declaration

I hereby declare that:

1. I have not been enrolled for another award of the University, or other academic or professional organisation, whilst undertaking my research degree.
2. None of the material contained in the thesis has been used in any other submission for an academic award.
3. I am aware of and understand the University's policy on plagiarism and certify that this thesis is my own work. The use of all published or other sources of material consulted have been properly and fully acknowledged.
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Abstract

Surgical treatment of early stage lung cancer offers the best chance of long-term survival, either on its own, or as part of multi-modality treatment. However, the potential for future recurrence of cancer is a realistic concern and increases strongly by cancer stage. Research findings around information needs of patients with cancer are complex and contradictory and few studies have included patients with early stage lung cancer.

This study explores communication regarding risk of recurrence following lung cancer surgery using a qualitative multiple case study approach. Purposive sampling identified twelve cases centred on patients with a range of lung cancer stages and management plans. Case studies began at first post-surgical consultation and continued for six months after surgery. Patient participants followed two distinct treatment pathways after surgery, either straight into long-term follow-up, or to see an oncologist to discuss adjuvant treatment. Data collection included audio recordings of consultations, in-depth interviews with patients and their associated professionals, and collection of documentary evidence. Data were analysed using a Framework approach, with latent themes developed at a higher level using Thematic Analysis techniques.

This multi-perspectival dataset gave rich, longitudinal insights into communication around recurrence risk following lung cancer surgery. Three overarching themes were developed: 'Predicting the Future', 'Maintaining hope' and 'Hope Dances'. Fundamentally different conceptions of long-term outcome were seen amongst patient and professional participants. Discussion of recurrence risk was generally minimised during observed consultations. However, patients with more favourable prognoses tended to have more explicit discussions around the subject. Patients and professionals shared an imperative to maintain patient hope, which powerfully determined how potential recurrence was discussed. Participants engaged in active strategies to support hope, which included tacit co-construction of hope for the future. Findings are considered in terms of the clinical communication implications, supporting patients after treatment finishes and the need for further research.

To a Mouse (extract)

On Turning Her Up in Her Nest with the Plough,

(Robert Burns November, 1785)

But Mousie, thou art no thy lane,
In proving *foresight* may be vain:
The best-laid schemes o' *Mice* an' *Men*
Gang aft agley,
An' lea'e us nought but grief an' pain,
For promis'd joy!

Still thou are blest, compared wi' me!
The *present* only toucheth thee:
But Och! I *backward* cast my e'e,
On prospects drear!
An' *forward*, tho' I cannot *see*,
I *guess* an' *fear*!

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List of abbreviations

CIS	Critical Interpretive Synthesis
CT	Computerised Tomography scan
GP	General practitioner
IASLC	International Association for the Study of Lung Cancer
LCNS	Lung Cancer Nurse Specialist
(L)MDT	Lung Cancer Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NSCLC	Non-small cell lung cancer
PET	Positron Emission Tomography scan
SCLC	Small cell lung cancer
TNM	Tumour, node, metastasis – cancer staging system

Research publications and presentations

Poster presentations

- National Lung Cancer Forum For Nurses Annual Conference, Chester, November 2014.
Prognostic communication in cancer: a critical interpretive synthesis of the literature.
- Faculty Research Day, Health and Wellbeing, Sheffield Hallam University, June 2015.
Identifying research questions around disclosure of risk of recurrence following lung cancer surgery.
- 16th World Conference on Lung Cancer, Denver Colorado, USA, September 2015.
Abstract published: Johnson, M. et al. (2015). Identifying research questions in disclosure of risk of recurrence following lung cancer surgery using a critical synthesis of the literature. *Journal of Thoracic Oncology*, 10 9 (S2), S638.

Conference presentations

- Communication of risk of recurrence following lung cancer surgery – update and findings of a study. 15th Annual British Thoracic Oncology Group (BTOG) Conference, Dublin 25th - 27th January 2017
- Discussing potential recurrence after lung cancer surgery: complexity and challenges. 18th World Conference on Lung Cancer, Yokohama, Japan, October 2017

Publications

- Johnson, M., Tod, A. M., Brummell, S., & Collins, K. (2015). Prognostic communication in cancer: a critical interpretive synthesis of the literature. *European Journal of Oncology Nursing*, 19(5), 554-567.
- Johnson, M., Tod, A. M., Brummell, S., & Collins, K. (2018). Discussing potential recurrence after lung cancer surgery: Uncertainties and challenges. *European Journal of Cancer Care*, 27(5), e12870.

1. Introduction

This study explores the issues around communication between professionals and patients about possible cancer recurrence following lung cancer surgery. This brief introduction chapter sets the scene of the research, starting by identifying the initial research aims and why this particular issue was seen as a problem that required further investigation. I will then outline the study aims and objectives. In order to place this study in context, I will give an introduction to the clinical settings and indicate my own clinical and research roles. This will be followed by a few comments on writing style and end with an overview of the structure of the remainder of the thesis.

1.1 Summary of clinical problem

Patients react very differently to the news that they have a lung cancer. For many the first reaction is concern that they might die (Lehto & Therrien, 2010). The majority of patients for whom definitive surgery is feasible are keen to accept the treatment and view it as the best chance to eradicate the disease (Powell et al., 2015). Following surgery patients are commonly told that the cancer has been completely resected. Although many patients appear fully aware that cancer can recur, sometimes after a long period of time, others seem to assume that since the cancer was completely removed during surgery, there is no possibility of it coming back. Nevertheless, most seem to acknowledge that recurrence could happen, but are not fully able to understand the concept of micro-metastases and late recurrence. How recurrence might manifest is something that few patients appear to have any concept of, or if they do, they tend to think only of recurrence within the lung itself. In practice, if patients have had an optimal resection, recurrence within the area of operation (termed local recurrence) is relatively uncommon. Recurrence more often occurs in a distant organ, such as bone, liver or brain (Consonni et al., 2015; Lou et al., 2013; Uramoto & Tanaka, 2014).

My personal clinical role prior to and during this research was as a specialist cancer nurse providing a supportive care service for patients, principally during the surgical phase of their treatment. Experience of sitting in pre and post surgical consultations suggested that the

subject of potential recurrence of the cancer after surgery was often not something that was discussed in detail. Even where patients were going to be referred on to an oncologist to consider having chemotherapy, intended to reduce their risk of recurrence (known as adjuvant therapy), the subject was dealt with briefly. In my clinical role I did not routinely attend the subsequent oncology consultations, and I had assumed that a fuller and more explicit discussion about recurrence and risk would take place during that appointment. Despite this, when talking with patients more informally on a one-to-one basis, they sometimes asked questions about whether the cancer was likely to come back again in the future.

National cancer strategy advocates educating and informing patients about their condition, so they become more empowered to take an active role in their care (Independent Cancer Taskforce, 2015). However, the British Thoracic Society urges caution when discussing cancer stage and prognosis with patients with lung cancer. Their guidelines on giving clinical information to patients cite the complex nature of this information, which patients may not be emotionally or intellectually equipped to deal with (British Thoracic Society, 2013). How best to answer patients' questions and whether detailed discussions about recurrence risk should be a routine part of care left me, as a health care professional, unsure about the best strategy. These uncertainties became the starting point for this study.

1.2 Study aims and objectives

Study aim

The aim of the research is to gain an in-depth understanding of the communication of recurrence risk following potentially curative lung cancer surgery, from the perspective of both patients and professionals involved.

Objectives

1. To explore, using case study methodology, how a range of patients who have completed surgical treatment for lung cancer conceptualise their long-term risk of cancer recurrence, and how these change over time.

2. To understand how these patients perceive their communication needs about risk of cancer recurrence following surgery.
3. To explore how a range of health professionals caring for these patients conceptualise these individuals' long-term outcomes and identify the knowledge they draw on to form these opinions.
4. To investigate the attitudes and beliefs held by these professionals about priorities and principles of communication with patients after lung cancer surgery in general, and about long-term outcomes specifically.
5. To identify the nature and delivery of communication about risk of recurrence between this group of patients and their associated professionals during post-operative surgical, oncology and follow-up consultations.
6. To gain theoretical insight into the interpersonal processes occurring during these consultations that may regulate and tailor the information that is communicated.

1.3 Introduction to the clinical settings

The research study was principally undertaken in two specialist hospitals, each providing a lung cancer surgery service for a number of local lung cancer teams based in general hospitals without thoracic surgical services on site. For reasons of research governance and practicality, I needed to select local lung cancer teams that were willing to engage with the research and were relatively accessible, as a significant proportion of the data collection occurred at the local hospitals. Although surgery took place in one of the two thoracic surgical hospitals, the patients' overall pathways were managed by the lung cancer multidisciplinary teams (LMDT) based in the local hospitals. Most patients had contact from a Lung Cancer Nurse Specialist (LCNS) both from their local hospital, as well as one based at the surgical hospital during their treatment there.

1.4 The researcher in lung cancer care

The research study was undertaken on a part-time basis while I was also working as the clinical lead of a small team of specialist cancer nurses. Coming to the research relatively late in my career, I had previously worked in diverse cancer nursing roles. This has included

chemotherapy care and as an LCNS in a large general hospital. The LCNS role is an integral part of the lung cancer multidisciplinary team and provision of the role is mandated in current national guidelines on lung cancer management (National Collaborating Centre for Cancer, 2011). Central to the role is providing continuity for patients and their family members by being a point of contact, offering emotional and practical support and helping patients and their families access the information they need about their diagnosis and treatment (Leary, White, & Yarnell, 2014; Maguire, R. et al., 2013).

The research questions had direct connection to my clinical role. This factor makes the findings especially relevant at a clinical and theoretical level. Such close connection to the research subject did have a number of practical, methodological and ethical dimensions that needed careful consideration. Adoption of a qualitative methodology intensified many of these issues, due to the centrality of the researcher as the key method of data collection and analysis. Some of these issues will be considered further at points during the thesis, but they also bear brief consideration at this initial stage.

My clinical role as a specialist lung cancer nurse gave me clear insights into the pathways, management and decision-making regarding patient care, all of which make interpreting events at a superficial level easy. Seeing things as they actually are, however, sometimes requires coming into a situation with ‘fresh eyes’, avoiding preconceptions, and questioning assumptions. Being a member of staff at the surgical hospitals compounded these issues. Although strenuous efforts were taken to ensure that the study patients were not also part of my own caseload, both patient and professional participants were aware that I was a senior nurse linked with the surgical hospitals. At times there was a strong risk of blurring lines between researcher and nurse role. The implications of these issues will be explored in more depth in the methodology section.

1.5 Notes on writing style

The choice to adopt a first person writing style for the majority of the thesis was a conscious one, made at the outset of the study. Writing the researcher into the final report allows the ‘authorial voice’ to be heard and purposefully makes the reader aware of my personal and

intimate role throughout the process (Ritchie & Ormston 2014). Clearly placing myself into the account also serves to help maintain the necessary reflexivity and underline my role as a researcher and as a Nurse Specialist and the effect of these different roles in the process.

The standpoint adopted in relation to what labels to ascribe to the various participants was also given a lot of consideration. The term 'professional' was chosen to refer to a clinical practitioner of any discipline involved in the observed consultations and interviews. In practice this was consultant and trainee thoracic surgeons, consultant medical and clinical oncologists, consultant chest physicians, and LCNS working in the surgical and in the local hospitals. The term 'patient' can be seen as reflective of only the aspect of the person's life during their contact with the healthcare system and therefore negates the vast majority of time in which the 'ill person' is not being a patient (Frank, 2000). While I recognised the need to represent people as multidimensional beings, with lives outside their hospital experience, ultimately I chose to use the term 'patient' throughout. The rationale was twofold. The first was practical, in wanting to avoid the clunky 'person affected by cancer'. The second was more fundamental. The study was primarily about clinical communication in which the relationship between professional and patient was central to the research question. Recognition of this power imbalance between participants became essential to the findings.

Throughout the thesis I have made extensive use of verbatim quotes and longer extracts from the data. Quotations within the text are denoted by italicised text within quotation marks. Longer extracts are indented and single-spaced, again in italics. These direct quotes have often been edited for confidentiality, clarity and brevity, designated by use of square brackets. Full orthographic conventions used are listed in appendix 10. Professional speakers are identified by their discipline and participant number and which patient case they relate to. Patient speakers are identified by their pseudonym, and where relevant which interview (1st, 2nd or 3rd) it occurred.

1.6 Overview of thesis

In the next chapter I will set out the background to lung cancer management and the surgical treatment pathways. I will introduce some of the current national policy drivers for lung cancer and the wider general cancer agenda. I will then consider some of the background theory on clinical communication, uncertainty and hope, which underpin the later findings. In the third chapter I will present a literature review of prognostic communication in cancer care, initially done at the beginning of the study in 2014. Since further relevant studies have since been published, the review was refreshed later towards the end of the study and these findings are also presented. Chapter four provides details of the study methodology, rationale for the choices made and details of the case study methods employed and how the analysis was undertaken.

The following four chapters will present the findings. In the first I will present each of the twelve cases and their treatment pathways, with information about the patient and professional participants. The following three chapters will provide cross-case analyses, with each chapter exploring a particular theme. Chapter 6 will present the theme 'Predicting the Future', examining how professionals and patients conceived the future outcomes for the individual patient participants. The following chapter looks at the theme of 'Maintaining Hope' and explores the shared goals of patient and professional participants around hope. The final findings chapter uses the theme 'Hope Dances' to explore key clinical consultations observed during the study in-depth to identify how interactions between professionals, patients and their families play out in ways that are aimed to support patient hope. These findings are then discussed in chapter 9 in relation to the extant literature and their contribution to current knowledge is identified. Finally the implications for clinical practice and its development will be explored and opportunities for further research will be identified.

2 Background to the study

2.1 Chapter introduction

The aim of this chapter is to position my research in the context of the literature, and to provide some theoretical underpinning for the study. I will begin by describing the current management of lung cancer in the UK, focusing on the surgical pathways. I will briefly discuss current lung cancer survival statistics. Following this scene setting, the remainder of the chapter will then look at clinical communication, risk, managing uncertainty and hope. Starting by exploring the challenges of presenting information about risk to patients, I will discuss uncertainty in healthcare as a complex and multidimensional concept. I will end on an exploration of the multi-faceted nature of hope and its continuing and central place in modern healthcare.

2.2 Lung cancer and its management in the UK

2.2.1 Incidence

Lung cancer is the third most common cancer diagnosis in the UK population, with 46,388 cases diagnosed in 2015 (Cancer Research UK, 2017). The disease is almost equally spread between men and women. It is a condition that tends to affect older people, with incidence highest in the ninth decade of life (Cancer Research UK, 2017). While lung cancer is often assumed to be linked to smoking, around 10 to 15 per cent of lung cancers occur in patients who have never smoked (Couraud, Zalcman, Milleron, Morin, & Souquet, 2012). Genetic factors and pollution appear to be the most significant causes of lung cancer not linked to smoking (Molina, Yang, Cassivi, Schild, & Adjei, 2008).

Lung cancer is classified into two main groups: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). Patients with SCLC are generally not offered surgical treatment due to the high rate of disseminated disease at presentation and rapid growth rate. The role of surgery in very limited disease is being evaluated (Lim, Belcher, Yap, Nicholson, & Goldstraw, 2008). NSCLC is the commonest form of lung cancer, accounting for 89% of patients diagnosed with lung cancer (Royal College of Physicians London, 2018). NSCLC is

classified into histological sub-types. The most common are adenocarcinomas, cancers arising from glandular tissues, followed by squamous cell carcinomas, which arise from the outer, protective layers of the body (Cancer Research UK, 2017). A small proportion of lung malignancies are classified as neuroendocrine tumours, which include carcinoid tumours and large cell neuroendocrine carcinomas (Travis et al., 2015).

2.2.2 Staging and survival

Lung cancer is staged using the 'TNM' system, as devised by the Union for International Cancer Control. The current eighth edition version was published in 2016 (Brierley, Gospodarowicz, & Wittekind, 2016). The current study was initiated when the seventh edition TNM system was in use and therefore this has been used throughout this thesis (Goldstraw 2009). Details of the seventh edition staging system are available in Appendix 1. The system characterises the size and position of the primary tumour ('T' stage), the presence or absence of cancer in local and distant lymph nodes ('N' stage) and whether there is distant metastatic spread to other organs ('M' stage). The resulting TNM stage is then used to produce an 'integrated stage'. The integrated stage is generally more familiar to lay people, whereby stage I indicates the earliest stage of cancer, and stage IV the most advanced, usually indicating the presence of metastatic disease.

Survival in patients with NSCLC generally is poor. Of the patients diagnosed between 2010 and 2011 in England and Wales only 32% survived beyond one year after diagnosis (Cancer Research UK, 2014). Five-year overall survival¹ was 9.5%. This means that if you have a group of 100 patients all diagnosed at the same time with lung cancer, on average there would be fewer than ten patients alive after five years. The International Association for the Study of Lung Cancer (IASLC) developed a database of over 90,000 patients from 16 countries, treated between 1999 and 2010. This database has been used to develop and refine the seventh TNM staging system, and to produce the current eighth edition (Goldstraw et al., 2016). 'Clinical staging' is based on radiological and clinical assessment of the patient. Patients who have completed surgery will have a more definitive 'pathological

¹ Five-year survival measures the percentage of people alive after a period of five years. Overall survival is concerned only with whether the patient is alive and does not distinguish the cause of death, nor whether the patient still has active cancer.

staging', based on the additional results of the surgical histopathology reports. Significant changes may be seen between the initial clinical staging and the final pathological staging available following surgery, based on the final results of lymph node sampling and size and anatomical positioning of the primary tumour (Naidoo, Windsor, & Goldstraw, 2013). Pathological staging represents a more accurate picture of the extent of the cancer than clinical staging. Hence survival figures for pathological stage are slightly better than for clinical stage, as are displayed in table 2.1 (Goldstraw et al., 2016).

Integrated stage (7th TNM)	5-year survival (per cent) by clinical stage	5-year survival (per cent) by pathological stage
IA	82	83
IB	66	71
IIA	52	57
IIB	47	49
IIIA	36	36
IIIB	19	23
IV	6	-

Table 2.1: Five-year overall survival by clinical and pathological staging (7th edition TNM)

2.2.3 Diagnosis

Lung cancer diagnosis usually occurs when the disease is at an advanced stage. Only 27% of patients were diagnosed with stage I or II lung cancer in England and Wales in 2016 (Royal College of Physicians London, 2018). The disease is usually asymptomatic in its early stages, meaning that by the time that symptoms develop many patients already have advanced cancer. Late presentation and diagnosis of lung cancer is considered to be the principal reason for the overall poor survival figures (Holmberg et al., 2010). Significant work is going into improving early detection by means of professional and patient awareness campaigns (Athey, Suckling, Tod, Walters, & Rogers, 2012). Several trials have reported positive benefits of lung cancer screening programmes (Crosbie et al., 2019; De Koning, Van Der Aalst, Ten Haaf, & Oudkerk, 2018; Field et al., 2016; National Lung Screening Trial Research Team, 2011). The overall aim is to increase the numbers of patients offered surgical resection, and thereby potentially curing more patients (Independent Cancer Taskforce, 2015).

Current UK guidelines for the management of patients with lung cancer mandate that patients should be managed within a lung cancer MDT (National Collaborating Centre for Cancer, 2011). The MDT should include chest physician, radiologist, histopathologist, thoracic surgeon, radiation and medical oncologist, nurse specialist, palliative care and administrative support. General Practitioners (GPs) are encouraged to refer any patient with signs that might indicate a diagnosis of lung cancer to the local lung cancer MDT via an urgent 'two-week wait pathway'. These patients should be seen in secondary care within two weeks from the GP referral. The aim of the two-week wait pathway is to diagnose and treat patients as early as possible. In practice, only 28% of patients diagnosed between 2012 and 2013 were referred via two-week wait route (Cancer Research UK, 2017). The most common route of diagnosis is as an emergency, usually via a casualty department. Patients diagnosed as an emergency are more likely to have advanced cancer, while those referred to hospital as a non-urgent patient, or who were being investigated for another medical problem, are more likely to be diagnosed with an early stage lung cancer (32% stage I or II) (Cancer Research UK, 2017). Patients diagnosed without symptoms while being investigated for a different condition are referred to as having an 'incidental finding'.

2.2.4 Social dimensions of lung cancer

Several factors identified in the preceding sections lead to particular challenges faced by people with lung cancer compared with other cancer diagnoses. Cancer is known to be a stigmatising condition, with its association with alien invasion, death and visible treatment consequences (Helman, 2007; Sontag, 1991). However, people with lung cancer experience particular stigmatisation, beyond that of most other types of cancer (Else-Quest, LoConte, Schiller, & Hyde, 2009). Public perceptions of smoking and lung cancer, along with awareness of the generally poor prognosis associated with the condition, are two of the key factors that have the greatest impact for this group (American Lung Association, 2014; Conlon, Gilbert, Jones, & Aldredge, 2010; Hamann, Ver Hoeve, Carter-Harris, Studts, & Ostroff, 2018).

Over the years significant efforts have been put into public health campaigns and legislation to reduce tobacco consumption. Smoking rates have reduced from around fifty per cent of the adult UK population in 1950 to approximately sixteen per cent in 2016 (Cancer Research

UK, 2017). Changes in attitudes have resulted in smoking being perceived as undesirable, and in many areas of society, as socially unacceptable. However, smoking rates remain significantly higher amongst both male and female unskilled and manual workers, compared with those working in professional roles (Graham, 2012). While the general reduction in smoking rates has brought obvious health benefits, attitudinal changes around smoking have also led to negative consequences for those affected by lung cancer (Hamann et al., 2018). Perceptions about smoking in relation to social class and education levels further reinforce these stigmatising characteristics for people with lung cancer (Graham, 2012).

The stigma around smoking has significant influence on patients' personal feelings about their illness, wider public opinion, as well as professional attitudes towards people diagnosed with lung cancer (Hamann et al., 2018). There are a number of qualitative studies that have explored the stigmatising effect of smoking on patients with lung cancer (Chapple, Ziebland, & McPherson, 2004; Conlon et al., 2010; Lehto, 2014). These effects are multidimensional, having implications for personal, interpersonal, and societal attitudes around lung cancer (Hamann et al., 2018). People who have smoked often experience a sense of self-blame, shame and guilt due to their perceived role in causing their cancer. Such feelings are associated with increased levels of depression and feelings of lack of entitlement to, or not being deserving of, treatment and support (Else-Quest et al., 2009). On an inter-personal level, patients with lung cancer can be reluctant to disclose their diagnosis to friends and acquaintances for fear of judgemental reactions. Family members can sometimes chastise patients for their smoking following a diagnosis of lung cancer (Chapple et al., 2004). Repeated focus on smoking history in clinical interactions can reinforce the sense of self-blame felt by patients (Lehto, 2014). Those who have not smoked, or had a trivial and distant smoking history, can feel judged by implication and often want to stress their non-smoking status (Chapple et al., 2004).

On a societal level, attitudes to smoking and lung cancer can influence health funding, charities, research effort, as well as general attitudes to the condition. Professional and media debates regarding whether some treatments should be withheld for patients who continue to smoke can reinforce the sense of stigmatisation (Donnelly, 2017; Glantz, 2007). A nihilistic attitude regarding lung cancer amongst some professionals has been blamed to

some extent for late diagnosis and low rates of referral to surgeons and oncologists for active treatment (Chambers et al., 2012; Wassenaar et al., 2007). Conlon et al. (2010) argue that, with some exceptions, there is a lack of a strong advocating voice on behalf of lung cancer patients, such as is seen in the powerful breast cancer lobby, which can begin to address these inequalities and provide improvements in care and treatment. All these issues, such as stigmatisation, socio-economic and demographic factors, prognosis, social and professional attitudes, combine to create a uniquely challenging treatment landscape for lung cancer.

2.2.5 The surgical pathway

Patients referred with suspected lung cancer undergo a series of investigations aimed at achieving a diagnosis and clinical stage, and determining the optimal treatment options. Investigations include radiological imaging (e.g. CT, MRI and PET scans) and biopsy of the tumour or lymph nodes, as well as an overall assessment of fitness for surgery (Brunelli et al., 2009; Lim et al., 2010). For patients who are suitable for surgery, optimal treatment is considered to be excision of the affected lung lobe and associated lymph nodes in the mediastinum (lobectomy and nodal dissection). In patients where removal of tumour with a clear margin of normal tissue cannot be effected, a pneumonectomy (resection of the whole lung) may be an option. However, pneumonectomy carries a higher surgical risk of death and is associated with lower long-term quality of life (Lim et al., 2010). Patients with small tumours who have poor lung function may be considered for surgery removing only an anatomical portion of the lobe, known as a segmentectomy (Lim et al., 2010).

After surgery patients follow two distinct management pathways: either referral for an oncology opinion, or straight to long-term follow-up. Current guidelines suggest that patients who have evidence of cancer spread to any lymph node following surgery, or with tumours greater than four centimetres in their largest axis, should be referred to an oncologist to discuss the possibility of adjuvant chemotherapy (Lim et al., 2010). Adjuvant chemotherapy aims to treat undetectable micro-metastatic disease and circulating tumour cells in patients who have had a complete surgical resection, with the aim of reducing the chance of future cancer recurrence. Meta-analyses of clinical trials indicate that adjuvant chemotherapy can add an average of around four per cent improvement in absolute

survival at five years (Burdett et al., 2015). Postoperative radiotherapy is usually only offered to patients with incomplete resections², or with mediastinal lymph node involvement (Lim et al., 2010; National Institute of Health and Care Excellence [NICE], 2019). Patients who do not go on to have further treatment, as well as those who have completed adjuvant therapy, then undergo a period of regular surveillance. This is typically for a period of five years and is aimed at monitoring patients for signs of cancer recurrence, either locally at the site of surgery, or systemically. Follow-up appointments usually include physical examination, plain chest x-ray and often CT scans. However, there is lack of consensus on the most effective strategy and frequency for following up patients after surgery (Colombi et al., 2013; Schmidt-Hansen, Baldwin & Hasler, 2012).

Significant unaddressed psychological and physical needs have been identified in patients who have completed treatment for cancer (Armes et al., 2009; Richards, M., Corner, & Maher, 2011). The national Living With and Beyond Cancer programme forms part of the government's cancer strategy and research agenda (Independent Cancer Taskforce, 2015; National Cancer Research Institute [NCRI], 2018). Part of the Living With and Beyond Cancer strategy is the Recovery Package. This comprises of a suite of measures aimed at identifying needs, promoting self-care through education and information, and access to health and wellbeing or rehabilitation programmes (Department of Health, Macmillan Cancer Support & NHS Improvement, 2013). Ultimately the aims of the strategy are to reduce demands on secondary care services, improve patients' quality of life and ultimately assist patients to resume a meaningful role in society. One of the elements of the Recovery Package is provision of a summary of treatment that includes information for patients on potential short and long-term side effects from treatment and early signs and symptoms of recurrence or progressive disease (Macmillan Cancer Support, 2013). This measure puts the discussion of potential recurrence with patients after surgery very much on the agenda.

² An incomplete resection signifies that there is evidence of cancer being left behind during surgery. This can be where the surgeon recognises that she/he was unable to remove the entire tumour or affected lymph nodes and is designated as *macroscopic residual disease* (R2). Residual disease can also be determined by the pathologist when he/she examines the resection edge. Where there is evidence of cancer cells at the cut edge of the resected lung, this is called *microscopic residual disease* (R1). A complete resection with no residual disease is designated as R0 (Goldstraw et al., 2007)

2.2.6 Prognosis and cure

The term ‘radical management’ is defined as “... *treatment given with the intention to improve survival substantially, which may amount to a cure*” (Lim, et al. 2010 pii4). Surgery is seen as the best chance of effecting a cure in patients with stage I or II NSCLC and some patients with stage IIIA (National Collaborating Centre for Cancer, 2011). More recent guidance includes surgery as an option as part of multi-modality treatment for patients with any nodal disease (NICE, 2019). The term ‘cure’ itself, however, is more challenging to pin down. Widely used as a lay term, the Oxford English Dictionary offers one definition as “*Eliminate (a disease or condition) with medical treatment*” (OED, 2018). By undergoing lung cancer surgery, a patient can be seen to have eliminated the tumour. But surgically resecting the cancer, albeit with a wide margin of unaffected tissue around it, does not guarantee a cure.

Survival statistics represent deaths from any cause and do not necessarily indicate cancer recurrence. But in practice, the vast majority of deaths are cancer related (Colombi et al., 2013; Pignon et al., 2008). Many professionals take overall survival as a proxy for recurrence, due to the availability of large-scale data by stage. Studies that do report disease-free survival³ show slightly lower rates than for overall survival, as can be seen where disease free and overall survival are given in some adjuvant chemotherapy studies, such as Pignon et al. (2008). Five years after surgery is largely taken as being synonymous with cure. However, recurrence after this time is possible and is sometimes seen clinically. Distinguishing this from a new primary lung cancer can sometimes be a challenge (Colombi et al., 2013). For these reasons establishing when a patient is considered ‘cured’ is problematic.

The stage of the cancer can be the only prognostic indicator considered by some clinicians. There are many other factors that complicate the picture still further. Certain features not reflected in the cancer staging system, such as pathological sub-type, evidence of cancer invasion into blood or lymphatic vessels (vascular invasion), cancer grade, or presence of

³ Disease free survival measures the percentage of people alive and free from active cancer over a specified period of time.

tumour necrosis, amongst other factors, can have a bearing on risk of recurrence and prognosis (Travis et al., 2015). Co-morbidities, such as other cancer, heart or lung disease, combined with an older age group of the lung cancer population, also have an impact on survival (Friedel et al., 2013). The plethora of highly complex biomedical information available following surgery for lung cancer illustrates the challenges faced by professionals in interpreting what this means for the individual patient regarding risk of future cancer recurrence. Each element may have an implication, often conflicting, for the patient's future outcome. The professional needs to make sense of this for him or herself, before presenting this in a comprehensible manner to a patient. If professionals or patients want to discuss prognosis they inevitably need to talk about risks, possibilities and probabilities, and it is the communication of this sort of information that I will now turn to.

2.3 Risk and risk information

Information about risk or the chances of particular outcomes are integral to modern healthcare. Such information supports informed consent, medical and patient decision-making (Ahmed et al., 2012). It also has a role in patients making sense of their illness experiences and future planning (Thorne, Hislop, Kuo, & Armstrong, 2006). Understanding, interpreting and conveying this sort of information also comes with its own range of challenges and difficulties (Ahmed, Naik, Willoughby, & Edwards, 2012; Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007).

2.3.1 The complexity of risk information

Estimating risk, and thus attempting to forecast the future, is notoriously imprecise, fraught with problems, and is inherently prone to error (Han et al., 2009). Risk information is derived from historical population data. This leads to a range of sources of uncertainty arising within available risk information (Han, Klein, & Arora, 2011). Stochastic uncertainty arises from the nature of the sample and measurements used to generate the data, and to some extent can be expressed mathematically, such as using confidence intervals. Epistemic uncertainty arises from the limitations of current knowledge that underpins the models used to generate the risk data. An example could be the impact of cancer histological sub-type on long-term survival, about which there is only emerging knowledge (Ujii et al., 2015). Aleatory uncertainty, on the other hand, pertains to the *“fundamental, irreducible*

randomness and indeterminacy of natural events” (Han et al. 2011, p832). This type of uncertainty sits at the heart of arguments around the application of population data to the outcome for an individual (Spiegelhalter, 2008). Most risk information has elements of stochastic, epistemic and aleatory uncertainty.

Lay people struggle to interpret statistical information in relation to individualised risk (Han et al., 2009). Understanding personal prognostic information derived from population data can be challenging. A percentage estimate risk of dying from cancer ultimately becomes all or nothing for the person concerned. However, the match between the individual and the wider population from which the data was derived will strongly influence the precision of the risk estimate, and the credence placed on the data by the individual and his or her healthcare team. Survival data in healthcare is necessarily historical, and so may not be reflective of new medical advances and changes in practice. Ultimately, Spiegelhalter (2008) argues that all risk estimates are subjective and need to be constructed by argument, contingent on available information and dependent on the relationship between the individual and the issue in question.

2.3.2 Communication of risk

Information about future possible outcomes can be presented in many different formats. This can range from detailed statistical information about risks or chances, to implicit information, or even by the way in which someone behaves and their body language. Information exchange about risk never occurs in a purely objective manner and is always coloured by biases and subjectivity. The language used and the way that information is framed and its emotional content can substantially alter the way that patients understand their situation (Edwards, Elwyn, Covey, Matthews, & Pill, 2001). In this way the subjective and emotional aspects of the information is intrinsic to its communication, and often form a dominant part of what patients retain about their situation (Zikmund-Fisher, Fagerlin, & Ubel, 2010).

At the more explicit end of the spectrum of risk communication, a key distinction in the types of risk information lies between discussion of the possibility that an event can happen on one hand, and numerical probability estimates on the other (Zikmund-Fisher, 2013).

Possibility is simply the statement that something could occur. Such information discloses that an event could happen, but not the magnitude of the risk. Possibility information can be tailored to the needs of a specific situation by the way that the risk is presented (Zikmund-Fisher, 2013). For example, information can be made more specific by providing verbal categories, using terms such as high, medium or low risk. While a categorical evaluation of possibility can provide some concept of the degree of risk, it remains a subjective assessment made by the person giving the information, which may not match that of the recipient (Ahmed et al., 2012). Similarly, providing risk information by comparing one situation against another can be used to provide context to possibility type information (Zikmund-Fisher, 2013). An example might be “your risk of cancer recurrence is increased if you continue to smoke”. Information is not provided about the degree of risk, but the option of continuing to smoke is established as riskier in terms of cancer recurrence.

Discussions about risk can also use an estimate of probability, defining the risk with more precision using numbers. An absolute estimate of probability provides a numerical evaluation of a future event happening, such as recurrence of cancer. Numerical probabilities can also be tailored towards a particular situation in similar ways to possibility information, such as providing an estimate of change to risk given particular circumstances. An example could be “by undergoing chemotherapy your chance of living beyond five years will increase by four per cent”. The information provides no details about the underlying risk level, but focuses on the degree of benefit to be gained by having treatment. However, many authors recognise the challenges patients, and indeed professionals, have in fully understanding and interpreting numerical risk information (Brust-Renck, Royer, & Reyna, 2013; Gigerenzer et al., 2007; Thorne et al., 2006).

Fuzzy Trace Theory differentiates between ‘verbatim’ and ‘gist’ memory: two different mental representations of information presented to patients (Reyna & Brainerd, 1991). This theory proposes that gist memory focuses only on general concepts, or the ‘fuzzy’ detail, and works in parallel with the exact recall of verbatim memory. Gist level recall, however, incorporates the subjective, emotional and psychological elements in the meaning (Reyna, 2004). People seek further detail at the verbatim level when necessary, but gist information is usually preferred (Reyna, Nelson, Han, & Pignone, 2015). In the context of communication

about prognosis following surgery, most patients will work at the level of mentally processing the meaning of what they have heard, which favours gist level recall (Reyna, 2008; Reyna, 2012). This is coupled with the fact that much information is complex and unfamiliar, and is also highly emotionally charged. It is therefore likely that most patients will take away only a limited impression of the information that they were given. Zikmund-Fisher (2013) argues that due to people's preference for gist level information, where possible information should be given with the minimum level of precision that will achieve the information goal for the patient. Risk is inherently linked to uncertainty, and is both a source of that uncertainty, as well as mechanism by which we might attempt to manage it. In the next section I will explore some of the multiple layers and complexities of uncertainty in relation to health care.

2.4 Uncertainty

Uncertainty is at the core of human existence. Most agree that we do not live in a deterministic universe, or even if we do believe our future is mapped out, there is agreement that we cannot clearly know it (Eagleton, 2017). It is the mundane nature of most of our normal daily lives that prevents us considering the uncertainty inherent in our lives minute by minute. However, facing serious illness, particularly cancer, uncertainty can be thrown into sharp relief (Babrow, 2001; Shaha, Cox, Talman, & Kelly, 2008).

2.4.1 Uncertainty and Stress and Coping Theory

In their work on stress and coping, psychologists Lazarus and Folkman defined uncertainty as *"confusion about the meaning of the environmental configuration"* (Lazarus & Folkman, 1984, p103). This definition leaves the focus of the uncertainty deliberately vague. The theory of stress and coping involves a process of appraisal of both the situation and the resources available to cope with the problem. They identify this as primary appraisal of the target, to identify the nature of the threat. Secondary appraisal is then employed to determine what can be done to address the problem.

Lazarus and Folkman identify two main types of coping; 'problem focused', and 'emotion focused' coping. Problem focused coping includes strategies such as planning, information seeking and decision-making. Emotion focused coping helps to regulate negative feelings

and includes avoiding the issue, seeking emotional support, or distraction activities (Lazarus & Folkman, 1984). The process of coping is on going and involves continual re-appraisal of the threat and coping effectiveness. Folkman later added another form of coping, 'meaning focused' coping, which is associated with positive emotions and includes things such as positive re-appraisal of events and goal revision (Folkman, 1997). Lazarus and Folkman argue that uncertainty has a potentially blocking effect on anticipatory coping processes, due to the unknown future outcomes that might need to be faced. Developing a conception of what the future might hold, on the other hand, helps to facilitate planning for the future and what are known as 'contingency coping' mechanisms (Lazarus & Folkman, 1984).

Uncertainty is frequently seen as something that humans always strive to minimise (Case, Andrews, Johnson, & Allard, 2005). Minimising uncertainty is usually equated with a quest for information until the source of uncertainty is eliminated. Some questions have no known answer and are not amenable to a search for information, or just raise further questions (Bradac, 2001). Nevertheless, some communication theories have tried to reflect this desire to minimise uncertainty, for example Uncertainty Reduction Theory (Berger, C.R. & Calabrese, 1974). There is general recognition that seeking and accessing health related information is a vital part of adjusting and coping with an illness (Brashers, Goldsmith, & Hsieh, 2002). But, despite the view that uncertainty is undesirable, there is also recognition that there are times when increased levels of uncertainty can be beneficial to the individual (Babrow, Kasch, & Ford, 1998; Babrow, 2001; Brashers et al., 2002; Mishel, 1988). For example, a patient with cancer starting a new treatment with a realistic, but low chance of benefit might construe uncertainty about outcome in a positive light. Increasing mental uncertainty about the chance of benefit could allow the patient to continue to view the treatment as a good thing, despite difficult side effects. In this way the patient can maintain the (low) mental possibility of achieving the potential treatment benefits, in the face of other negative information that might be dispiriting.

2.4.2 Uncertainty models

Authors agree uncertainty is a complex and multidimensional concept (Babrow et al., 1998; Han et al., 2011; McCormick, 2002). Mishel (1988) considered uncertainty as the central psychological feature of illness and defined it as the *"inability to determine the meaning of*

illness-related events" (p225). Several researchers have created models of patient uncertainty (Babrow et al., 1998; Kasper, Geiger, Freiburger, & Schmidt, 2008; Mishel 1988). These have included aspects such as the ambiguity about the nature of the illness, the complexity of medical management, the sufficiency of information and the unpredictability of the illness and its prognosis. Han, Klein and Aurora (2011) argued that, while useful, these models often lacked precision and were limited in the reflection of the multidimensional nature of uncertainty. The team developed a model that attempted to address these shortcomings. They defined uncertainty at its most fundamental level as *"the subjective perception of ignorance"* (p830). Their description of uncertainty as a perception is key to the idea that it is experienced in many ways. The model conceives uncertainty as having three principal dimensions: first, the 'Source' of uncertainty; second, the 'Substantive issues' of uncertainty; and third, the 'Locus' of uncertainty. The model is summarised in figure 2.1.

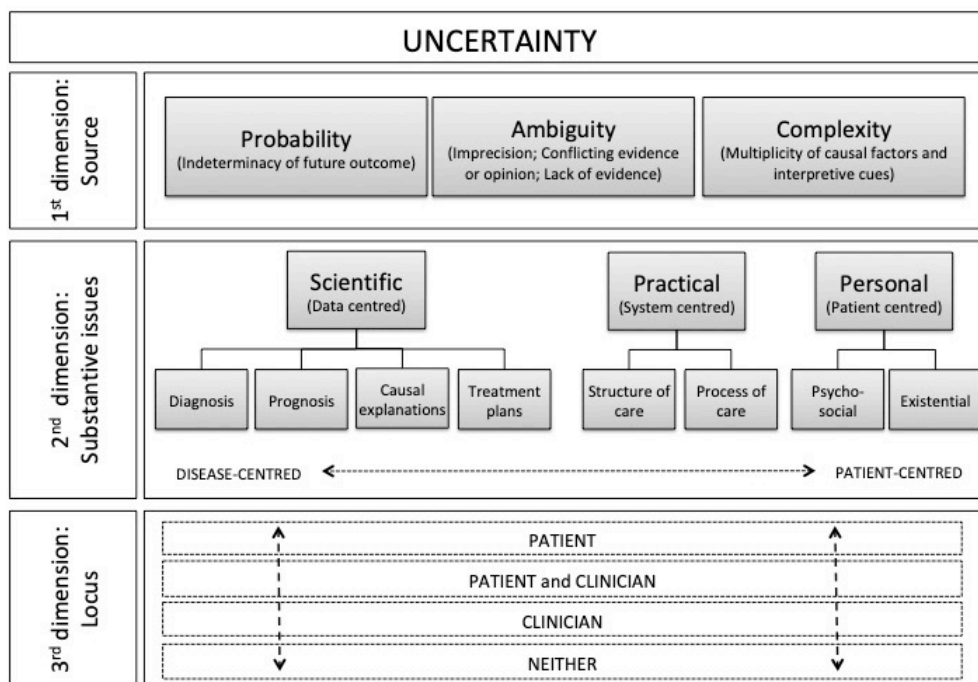


Figure 2.1 Dimensions of uncertainty

(adapted from Han et al. (2011) with permission of Sage Publishing Inc.)

In the first dimension, the Source, Han et al. (2011) identify three aspects of uncertainty: 'Probability', 'Ambiguity' and 'Complexity'. Probability is the risk or chance of something happening, for example quoted mortality risk during surgery. Uncertainty is an intrinsic element of probability. Even given specific odds of something happening, one cannot know if the event will or will not happen to a particular individual. Ambiguity covers the precision, or lack of it, of available information and might be experienced where risk data is not specific, such as when it encompasses a big range. Conflicting evidence or opinion may be

obtained, or situations where there is no available information can also lead to ambiguity. The Complexity aspect of uncertainty reflects the vast array of potential information that might need to be taken into consideration. Examples include multiple interpretive cues, such as quality of life as well as survival uncertainty, multifactorial causes and the contingent nature of information available.

The second dimension of Substantive Issues relates to the individual factors that surround the particular case. This dimension is divided into 'Scientific', 'Practical' and 'Personal' aspects. Scientific aspects include establishing and certainty of the diagnosis, prognostication, causation, treatment options and their effectiveness. These aspects are highly disease focused. Practical uncertainties relate to aspects such as accessing the right care, negotiating the care system and the competence of the healthcare staff. Personal aspects of uncertainty cover psychosocial impacts, such as potential loss of employment, effects on relationships and existential questions. These uncertainties are highly centred on the patient. In this way, the substantive aspects of uncertainty can be seen to run on a continuum from highly disease specific issues to patient centred concerns.

The third dimension, the Locus of uncertainty, relates to who is experiencing the uncertainty at any given time. A patient, their family member, the professional, all, or none may experience uncertainty about a particular aspect at any particular time. This final dimension underlines the notion that uncertainty is not just something that patients face, but is experienced by everyone involved, from his or her own perspective. It is this aspect of the model by Han and colleagues that sets it apart from less comprehensive conceptions of uncertainty in healthcare. This means that uncertainty takes on an interactional aspect, whereby how an individual experiences uncertainty will influence coping, disclosure and what information is sought. This model of uncertainty is complex, but its multidimensional structure helps to delineate the causes of uncertainty for patients and professionals.

2.4.3 Uncertainty in Illness Theory

A number of authors have developed models, frameworks and theories around uncertainty in health (Mishel, 1988; Selder, 1989). Mishel's Uncertainty in Illness Theory (UIT) was originally conceived around situations of acute illness (Mishel, 1988). Drawing on Lazarus

and Folkman (1984) Stress and Coping theory, UIT takes as the starting point the stimuli patients experience about their illness as the cause of uncertainty. This could include new symptoms, or the familiarity and congruity of the events around the illness. How people interpret these stimuli could be affected by their cognitive capacity, education, social support and access to credible information. As with Stress and Coping theory, feelings of uncertainty are characterised as essentially neutral. The uncertainty is appraised and interpreted as an opportunity or a danger. Figure 2.2 outlines the appraisal and coping phase of UIT.

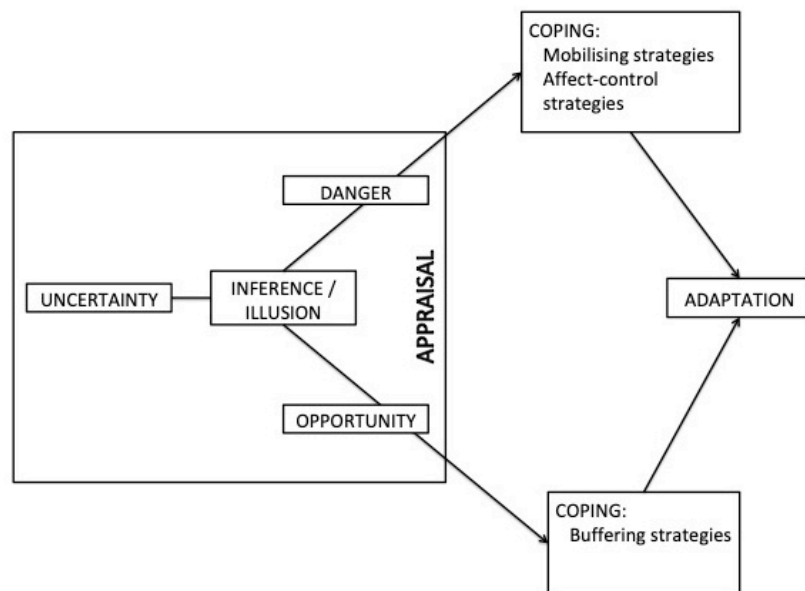


Figure 2.2 Appraisal and coping elements of Uncertainty in Illness Theory

Used with permission of John Wiley and Sons, from Mishel (1990); permission conveyed through Copyright Clearance Center, Inc.

Mishel described two processes used in the appraisal of uncertainty: 'inference' and 'illusion'. Inferences are beliefs about the self that are influenced by personality disposition, such as resourcefulness (Rosenbaum & Jaffe, 1983), mastery (Pearlin & Schooler, 1978) and locus of control (Rotter, 1966). Illusions are beliefs that are constructed out of the situation of uncertainty. Illusions emphasise the especially favourable aspects of the situation, and make use of such processes as downward comparison with others in the same position (Taylor, S. 1983). Mishel identified illusions as being important in maintaining hope in the face of negative and life-threatening information. Depending on whether uncertainty is appraised as opportunity or danger, Mishel proposed different coping strategies. If uncertainty is seen as danger to them, patients could mobilise resources, such as taking

action, vigilance and information seeking to try to reduce it. Additionally, strategies to control affect, such as redefining events, self-talk and wishful thinking might be used. Where uncertainty is seen as an opportunity, Mishel argued that buffering strategies are employed to distance contradictory information and support the sense of uncertainty that might continue to open optimistic possibilities.

In the situation of chronic illness, where uncertainty may extend over years, Mishel later adapted the theory (Mishel, 1990). The reconceptualised theory suggested that people's orientation might adapt and shift, whereby uncertainty is more likely to be viewed as an opportunity. Situations such as undergoing surveillance following cancer surgery, where people live with uncertainty of potential recurrence over years are identified as such a scenario. In these circumstances the deterministic view of acute care can give way to a more probabilistic worldview, where uncertainty is accepted as part of the natural order of things. In this way uncertainty can be viewed as something natural and to be embraced. Mishel goes on to argue that patients can be supported in fostering this approach by the network of professional and family support acknowledging uncertainty and helping them to see this as normal. However, this interactional element of the theory is not specifically developed.

Uncertainty in healthcare is clearly linked to, but distinct from, a lack of available health information. The complex multidimensional nature of uncertainty can mean that providing or searching for information alone will not address the whole problem. There remain many aspects of health that are inherently uncertain and unknowable. But provision of information where it is available about diagnosis and treatment is still core to cancer care.

2.5 Information and clinical communication

2.5.1 Cancer patient information

There has been extensive research over the last four decades and beyond regarding communication between patients and professionals and the delivery of information about cancer. This body of literature will be explored in more depth in the next chapter. Several highly influential studies have indicated that patients with cancer want to be fully informed about their condition and have shaped subsequent health service policy and guidelines

(Cassileth, Zupkis, Sutton-Smith, & March, 1980; Cox, A., Jenkins, Catt, Langridge, & Fallowfield, 2006; Jenkins, Fallowfield, & Saul, 2001). Other studies suggest that professionals are frequently poor at communicating and avoid discussing difficult or distressing information with patients (Fallowfield & Jenkins, 1999; Fallowfield & Jenkins, 2004; Maguire, P., Faulkner, Booth, Elliott, & Hillier, 1996). As a result of this, authors argue, patients with cancer can feel under-informed about their condition and treatment and want to take a more active role in their care (Cox, A. et al., 2006; Fallowfield, Ford, & Lewis, 1994; Fallowfield, Jenkins, & Beveridge, 2002).

Such research echoes a growing cultural shift towards patient empowerment and health consumerism (Salmon & Young, 2017). It has also been influential in developing current UK government health policy, and the growing movement towards Patient Centred Care (Department of Health, 2010; Goodrich & Cornwell, 2008; NHS England, 2014). Patient information provision and empowering people to take a shared role in medical decision-making also form a central element of current national cancer strategy (Independent Cancer Taskforce, 2015). However, other authors argue that many research studies do not support the idea most patients want to be consumers of information or make complex decisions about their treatment (Salmon & Young, 2017). Rather, they suggest, patients want information that sustains trust in clinical teams and enables patients and families to maintain hope. The predominant western social and moral climate values self-determination. Salmon and Young (2017) argue that these normative values have influenced the clinical communication research paradigm. In this way, research has made assumptions about how communication 'should be', rather than examining how it is.

2.5.2 Information seeking and avoiding

There is a common acknowledgement that seeking information about illness and treatment is not how all patients like to cope all of the time. Nonetheless, there is an implicit assumption that people always want to be given or look for information about their condition. In reality, many patients wish to avoid details that might be difficult to hear (Johnson, J. D., 2014; Sweeny, Melnyk, Miller, & Shepperd, 2010). One approach has been to view attitude to information seeking in terms of fixed personality traits (Miller, S. M., 1987). Patients were conceived as either having a tendency to employ a 'monitoring'

approach, and who tend to seek medical information, or to use a 'blunting' approach, and who tend to avoid medical information. People were seen to cope better when information was tailored to their underlying coping style.

In contrast to this view of fixed personality types, other researchers have proposed that seeking or avoiding information is predominantly dependent on situation and context (Barbour, J. B., Rintamaki, Ramsey, & Brashers, 2012; Germeni & Schulz, 2014; Johnson, J. D., 2003; Lazarus & Folkman, 1984). People seek information selectively; directing attention towards certain information targets, while other sources of information might be avoided (Lambert & Loiselle, 2007; Lambert, Loiselle, & Macdonald, 2009). J. D. Johnson (1997; 2003) identified context and salience of information as the central elements in his Comprehensive Model of Information Seeking. Background factors such as age, occupation, education, and previous health experience can interact with an individual's beliefs about things such as the value of knowledge, or whether one is deserving of care. However, it is the personal relevance to the person and the utility of the information that plays a key role in deciding what information is required. The person not only has to recognise that they do not know something, but they also need to see that knowing it will add value and benefit them in some way. Germeni & Schultz (2014) described how patients might choose to seek or avoid information as a way of supporting information goals around maintaining hope, their faith in the medical team and the desire to resume normality. Leydon et al. (2000) identified the need to preserve hope, and to maintain faith in their medical team's ability to make the right decision on the patient's behalf, as reasons why some people wanted to avoid information.

2.5.3 Clinical communication

Much communication theory is about information seeking, implying an active process by the seeker, such as that described above by J. D. Johnson (1997). Others account for the interactive process of information management, such as Theory of Motivated Information Management (Afifi & Weiner, 2004; Afifi & Morse, 2009). This model acknowledges that not all information exchange is because of active information seeking by patients. Information is often passively received, as well as patients actively attempting to avoid information. The roles and influence of both parties in information management is highlighted, considering

the efficacy of both information giver and information provider in comprehension, processing and transmission of information. However, the model is limited in considering the realities of communication in a clinical scenario and the range of influences on patients and professionals regarding the nature of that communication.

A conceptual framework that focuses on the particular communication encountered in clinical encounters was developed by Feldman-Stewart, Brundage and Tishelman (2005). The framework includes four elements; the communication goals of each participant, the personal attributes of the participants, the communication process, and finally the environment in which the communication takes place. Figure 2.3 gives an outline of the framework. The complexity of clinical communication is reflected by recognising the multiple messages conveyed, that the intention of the message might not be how it is interpreted, and in the range of external factors that impact on both patients and professionals. Both participants may have multiple goals they want out of a clinical encounter. Each needs to convey and receive messages. Primary goals represent the core information that needs to be conveyed, while secondary goals enable the primary goals to be achieved, such as building a rapport. Typically there will be several communication goals within an encounter, with changing priorities at different times in the interaction. When goals conflict, either between participants, or internally between the different messages a participant wants to convey, communication can become more difficult and lead to frustration.

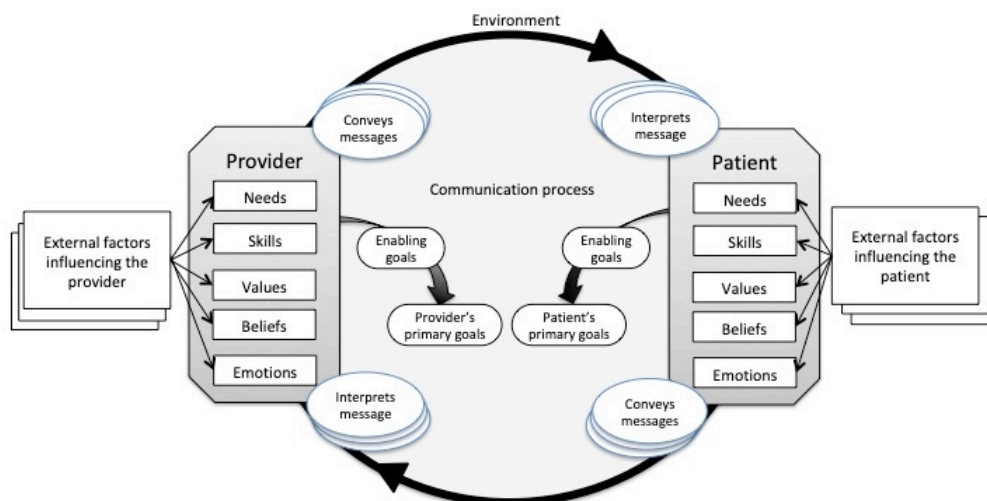


Figure 2.3 Conceptual framework for patient-professional communication

Used with permission of John Wiley and Sons, from Feldman-Stewart et al. (2005); permission conveyed through Copyright Clearance Center, Inc.

The framework highlights the intrinsic role of personal values and external factors in shaping communication for both professional and patient participants in clinical situations. It also identifies how communication occurs in a process involving simultaneous and sequential messages, conveyed intentionally and unintentionally. These dynamic processes act to provide feedback on what has been conveyed, as well as 'feedforward', so that information transmitted can influence subsequent elements of the conversation. The authors distinguish between active verbal and non-verbal messages, as well as passive messages, such as silence. Interpretation of the information conveyed can be in terms of the content, or at an emotional level.

The authors note that this framework is not intended to function as a model, with predictive qualities around communication behaviours or outcomes. Nevertheless, the framework has much to offer to the understanding of clinical communication, principally by its focus on the interactive process of communication, rather than ascribing fixed roles of information seeker, or information giver to participants, as seen in other models. In the context of communication about prognosis, the model appears to offer much to the understanding of the process by reflecting of the complexity of the process within the clinical environment.

2.6 Hope

Across much of the literature on coping with stress, uncertainty and managing information, the goal of supporting patient hope, or avoiding information that might damage hope has repeatedly been identified. However, much of the time, what is meant by hope has not been explicitly identified. In the final section of this chapter I will explore the concept of hope and try to identify and define what is meant by it in healthcare.

2.6.1 The concept of hope

Hope may seem to be self-evident. However, as reflected in its ubiquitous presence in daily speech, the concept of hope is complex and has meanings that range from trivial to profound. Hope has been explored across many disciplines, including philosophy, theology, linguistics, psychology and healthcare. In the healthcare setting, interest in the concept has come from nursing and palliative care research. I will begin to look at hope by briefly

exploring some of the wider ideas about hope from philosophy and theology and then focusing on hope in healthcare specifically.

Philosophical conceptualizations about hope vary, and are at times diametrically opposed to one another. Some see hope as an essential element to life, a comfort in misery and a force to enable people to attain goals and progress in life, while others have seen hope as a destructive and evil force⁴. One interpretation of hope is essentially passive and a block to striving, trusting that fate, or some other force, will bring about the best outcome. The opposite of hope in this scenario might be considered to be self-determination. Others view hope as negative due to its ability for self-deception and lack of awareness regarding the ultimate futility of life (Bloeser & Stahl, 2017). Nevertheless, in most Western contemporary contexts, hope has a positive orientation, linked to a desire for a good outcome (Folkman, 2010; Godfrey, 1987; Lazarus, 1999; Snyder, 2002).

Hope is both a noun (something that one can have), and a verb (something one can do). Used as a verb, hope is usually considered to have an objective; a state that the 'hoping' can achieve, such as 'I hope that X', or 'I hope to do X' (Elliott & Olver, 2002). The Oxford English Dictionary gives one definition of the verb hope as: *"To entertain expectation of something desired; to look (mentally) with expectation"* (OED, 2018). These definitions underline the future focus of hope. Hope in noun form has two senses (Elliott & Olver, 2002). Firstly, it can be understood as a feeling or emotion, and therefore a subjective experience. One can

⁴ The ancient Greek myth of Pandora and its subsequent interpretation illustrates some of the varied ideas about hope. Zeus gave Pandora a wedding gift of a jar, but with the proviso that it should never be opened. Overcome with curiosity about what the jar contained, and unable to resist, one night she prised open the seal of the jar. Realising too late that it in fact contained something terrible, she tried to reseal the jar, but not before releasing the ills of the world, sent to plague humankind. But one evil remained trapped in the jar when Pandora tried to close it. That evil was hope. Interpretations of this story have varied over the millennia. One version says that trapping hope was a further evil, by denying us the comfort of hope. Others have argued that the Greek word *elpis* signified expectation, but in the sense of foreboding. Hence by Pandora resealing the jar, it spared us the continual knowledge of our ultimate fate and meaninglessness of our existence. Another interpretation says that hope is the ultimate evil, as it deludes humans into thinking that there is a good future. Trapping it in the jar at least allows us as humans to have a degree of insight into our mortality and brief time on the earth (Bloeser & Stahl, 2017, Fry, 2017).

possess hope, as in 'I have hope that X', or used as an adjective, 'I am hopeful'. These feelings and emotions reflect an internal, personal experience (Godfrey, 1987). The direct opposite of hope in this context might be considered to be fear. The second use is that of an evaluation, for example, 'there is hope', or the opposite, 'there's no hope'. Such evaluations are frequently the subject of speculation and estimation by others, and can exist independently of the individual at the heart of the situation (Elliott & Olver, 2002).

Downie (1963) argued that hope must be within the range of that which is logically possible. He maintained that things that are desired, but perceived to be impossible (and so hopeless) were a 'mere wish'. On the other hand, it is possible to hope for things that might be improbable, but conceivably possible. However, what is considered as impossible is in the eye of the beholder and 'miracles' might sit somewhere on the cusp of these two interpretations. But improbable hope can easily be construed as 'vein' or 'faint', or as a 'false hope'. A related concept to hope – and sometimes used interchangeably – is that of optimism. Optimism is the tendency to expect the best outcomes and where there is little room for doubt about achieving them (Lazarus, 1999). Eagleton (2017) argues that optimism is a form of self-deception, adding that there is no logical reason why any individual should 'beat the odds', or why things should 'work out well in the end'. Eagleton sees this kind of optimism as essentially delusional.

In everyday usage, knowledge, beliefs and hopes are distinct states and usually imply a hierarchy of certainty (Downie 1963). Theorists largely agree that it is not possible to hope in situations where you are certain the desired outcome will occur (Eagleton, 2017). There is inherent conflict between the idea of hope and faith in a religious context, as true faith in God is axiomatically certain. In this context hope can develop a different meaning, being nearer to knowledge of future divine assistance, salvation, or attainment of eternal life (Bloeser & Stahl, 2017). Outside the religious context, it is also possible to make a distinction between a hope for a particular outcome, and a more indeterminate hope, sometimes called 'fundamental hope' (Godfrey, 1987, p64). In contrast to other forms of hope, fundamental hope is conceived to lack these specific aims, but is rather more about having a positive orientation to the future. Godfrey describes this as an "*openness of spirit with respect to the future*" (p64). He contrasts this with the opposite situation, that of despair -

the utter lack of hope. Fundamental hope can be seen to have some similar qualities to ‘will’ or ‘spirit’; a vital life-force that keeps us moving forward, fighting for life, and refusing to capitulate. To live without hope has been equated to ceasing to function as a human being (McGeer, 2004). Fundamental hope can be seen to have similar qualities to hope in the religious context.

2.6.2 Hope in healthcare

Within healthcare and psychology research there has been much interest in the concept of hope. Several multidimensional conceptual models of hope and corresponding measurement tools have been developed over the last three decades, for example Herth (1992), J.F. Miller and Powers (1988), Nowotny (1989), Snyder et al. (1991), and Stoner (2004). Other researchers contend that by selecting particular aspects of the multiple meanings of hope and trying to render it into a score, researchers risk missing the complexity of the concept in healthcare (Elliott & Olver, 2002; Folkman, 2010). Numerous reviews and concept analyses attest to the multiplicity of interpretations of hope in healthcare (Benzein & Saveman, 1998; Cutcliffe & Kaye, 2002; Kylmä & Vehviläinen-Julkunen, 1997; Tutton, Seers, & Langstaff, 2009; Wiles, Cott, & Gibson, 2008). Unfortunately, across this body of literature, there is little consensus about what hope is, and how it is distinct from other related concepts.

Hope Theory defines hope as: *“the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways”* (Snyder, 2002, p249). The definition places hope in the realms of a perception, rather than an emotion. It focuses on being goal-directed and as part of that perception, being able to conceive of achieving that specific goal. However, others view this as a limited rendering of hope (Bloeser & Stahl, 2017). Many argue that hope can be present even in circumstances where the person does not have the ability to achieve the goal (Folkman, 2010; Lazarus, 1999; McGeer, 2004; Pettit, 2004). Within the stress and coping literature, hope is seen as a vital emotion focused coping strategy (Folkman, 2010; Lazarus, 1999). Due to the inherent need to be aware of both the positive and negative outcomes that are possible, hope has the quality to allow and legitimise holding of conflicting expectations at the same time (Folkman, 2010).

In healthcare, the issue of ‘false hope’ remains particularly controversial. Eliot and Olver (2002) suggest that whether there is hope regarding a patient’s medical condition is seen to rest with the doctor. Where a discrepancy exists between medical and patient assessment of the situation, and the patient or family continue to believe in a likely positive outcome, but the medical team no longer believe cure is possible, health professionals may consider the patient or family member to be in denial and to possess false hope. Snyder (2002) considers false hopes as psychologically ‘maladaptive’, particularly where the goals of hope are illusory, too big, or there are poor strategies for achieving them. However, several writers take issue with the whole idea of false hope. Pettit (2004) identifies hope as a rational process, through which people cope with the “*turmoil of brute, disheartening fact*” by acting and reacting as though the hoped-for outcome is definite (p161). Patients and families may continue to find hope beneficial, even in the most extreme situations (Bennett, 2013). Many are able to sustain hope despite pessimistic forecasts by their medical team (Elliott & Olver, 2002). Lazarus (1999) suggests that the only rationale for giving up a hope in a ‘lost cause’ is if there is something else to hope for that is more constructive.

Del Vecchio Good, Good, Schaffer and Lind (1990) explored the centrality of hope in oncology care in the United States during the late twentieth century. They described a culture where the disclosure of a cancer diagnosis had become the norm. However, the perceived imperative to instil and maintain hope in patients, and in the professionals themselves, led to a more ambivalent approach to discussing prognosis and treatment outcomes. Doctors regulated information disclosure to patients. This led to a ‘balancing act’ between maintaining a doctor patient relationship based on partnership and open discussion of information, and the possible hazards of giving detailed prognostic information (Del Vecchio Good et al., 1990).

Perakyla (1991) described the process of ‘Hope Work’, whereby healthcare staff engaged in constructing and bolstering patients’ hope, as an automatic part of their daily work. The amount and focus of this Hope Work differed with different care scenarios. Hope Work on an acute haematology unit was focused on hope for recovery and optimism. During work caring for patients with palliative care needs, hope was directed towards short-term goals such as symptom management. At times Hope Work was also about dismantling, or

realigning hope where the outlook was poor. In contrast, in the emergency unit, Hope Work was almost absent, possibly due to the short time over which events developed, and the unknown and uncertain potential outcomes. McGeer (1994) argues in her essay on the 'Art of Good Hope', that an essential aspect of using hope in a positive manner is what she describes as responsive hope. In this she emphasises hope as an interpersonal, mutually supportive process, avoiding the excesses of hope that is dependent on pure personal agency, as well as hope that might be considered wishful.

The foregoing discussion illustrates the multifaceted nature of hope as a concept. It can be interpreted in many ways and has multiple meanings. Hope is used by many disciplines as well as being a common lay term. However, the boundaries of the term remain unclear and related terms are often used interchangeably, such as belief or optimism. Folkman summed up her perspective on hope in the following way:

Hope belongs to the arts as much as it does to the sciences; its meanings range from the ordinary to the transcendent. We can study certain aspects of hope with behavioural and social science techniques, but we cannot capture all of its aspects. (Folkman, 2010, p907).

Although difficult to pin down, hope remains a core feature of coping with illness.

2.7 Chapter summary

This background chapter has allowed me to explore and define many of the core concepts that will form the basis for the rest of the study. I began by locating the study in the context of the lung cancer surgical treatment pathway and the long-term patient outcomes. The issues of cure, survival and recurrence were examined and the limitations that are inherent in information about risk. The challenges of risk communication were then considered. Fuzzy Trace theory was identified as offering insights into patients' risk information preferences, suggesting a general preference for information in gist form. I then considered concept of uncertainty as a central element of ill health and exploring the multidimensional model of uncertainty in health by Han and colleagues. Managing uncertainty in healthcare was examined in relation to Stress and Coping literature, and Mishel's Uncertainty in Illness theory. In the next section I considered communication in the clinical setting, focusing

particularly on the conceptual framework for clinical patient-professional communication by Feldman-Stewart and colleagues. I ended the chapter by analysing the centrality of hope as a complex multidimensional concept in healthcare and introduced the idea of Hope Work. In the next chapter I will present a review using a systematic approach of clinical literature on prognostic communication between patients and professionals in cancer care.

3 Literature review using a systematic approach

3.1 Introduction

The previous chapter explored some of the wider theory that underpinned the study. This briefly touched on some of the literature around communication in cancer care. In this chapter I will present a more in-depth review of the clinically focused studies that examine how prognosis is communicated in cancer care practice and explore the patient and professional perspectives on this. The chapter will be in two parts. First I will present a critical interpretive synthesis conducted at the outset of this project of published evidence from 2004 until 2014. The results will be combined with findings from a systematic review conducted on evidence published up until the end of 2003. In the second half of the chapter I will present an updated review of evidence published since the start of my study. Some of these findings from the updated review will be influential in the discussion of findings and conclusions of the thesis. I will end the chapter by indicating the gaps in knowledge that my research is aimed to address.

3.2 Prognostic communication in cancer care: the literature to 2014

Early broad reading around my research topic identified a comprehensive, systematic literature review on communication of prognosis in cancer care (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005). The review had wide aims that included understanding patient preferences, clinician views and current practice of prognosis communication in cancer. Studies included patients treated for early stage cancer, advanced cancers, and cancer patients in palliative care settings. It explored 93 papers published between 1973 and 2003. By presenting such a large number of studies, discussion and synthesis of findings was necessarily limited. The review was also then ten years old. It was important to understand how the field had developed since, indicating a need to refresh the review. In June 2014 I therefore set out to review the literature published since January 2004. The scope was more limited than the one completed by Hagerty, Butow, Ellis, Dimitry, and Tattersall (2005), and specifically excluded discussion of prognosis with patients around end of life.

3.2.1 Review approach

Multiple typologies of literature review have been documented (Grant & Booth, 2009). Considerable methodological overlap exists between these approaches, and different methodologies may be given the same name by different researchers (Barnett-Page & Thomas, 2009). These factors make choosing an approach challenging. However, I wanted to incorporate diverse research methodologies, so as to reflect the breadth of research knowledge about prognostic communication. Although it is feasible to synthesise data from qualitative, quantitative, and mixed methods studies separately, such an approach risks failing to capture the breadth and complexity contained within the literature (Dixon-Woods, Bonas et al., 2006). Critical Interpretive Synthesis (CIS) was chosen as the review methodology that offered the best fit with my aims (Dixon-Woods, Cavers et al., 2006).

CIS was developed from meta-ethnography (Noblit & Hare, 1988). It employs strategies common across qualitative research techniques, particularly in terms of being non-linear and iterative in nature. The approach identifies key themes, metaphors and concepts from the original studies, translates them between the other studies, and then looks for wider patterns and constructs. Contradictions in findings are explored between studies. Constant comparison techniques are employed to build greater understanding by developing 'synthetic constructs', grounded in individual studies, leading to a 'synthesising argument' in order to develop new theory or insight (Dixon-Woods, Cavers, et al., 2006; Flemming, 2010). CIS is also essentially a critical process, and one where the authorial voice is acknowledged (Dixon-Woods, Cavers, et al., 2006; Mays, Pope, & Popay, 2005). This means that alternative accounts may exist of the evidence, but that the resulting synthesis is grounded in the evidence, verifiable and plausible.

3.2.2 Objectives:

I used two search questions to help identify literature relevant to clinical prognostic communication in cancer care.

1. What is known about the process of communicating information about prognosis or recurrence risk with adult patients with cancer?
2. What is known about the patient preferences and professional views about communicating prognosis or recurrence risk with adult patients with cancer?

3.2.3 Literature review method

Although I aimed to take a systematic approach to the literature, the rigour of a full systematic review was not achievable, given the limitations of time and manpower available to me as a part-time doctoral student. However, in order to ensure rigour I used the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines to conduct and report this review (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

The process of systematic review has placed much importance on rigorous and exhaustive searches of electronic databases. In contrast, methods of searching literature for qualitative syntheses have emphasised broad based searches with a sampling approach (Dixon-Woods, Cavers, et al., 2006; Thomas & Harden, 2008). However, in common with Flemming's (2010) use of CIS, I opted to use a standard search strategy of databases. This was largely due to an interest in published clinical literature, but was also due to lack of resources to undertake extensive searches of grey literature, or by snowballing techniques using personal contact with authors, that were suggested as alternatives.

Authors have developed a range of strategies and mnemonics to facilitate comprehensive searches using electronic databases (Booth, A., 2016). Some approaches specifically aim to identify qualitative research, such as the SPIDER tool (Cooke, Smith, & Booth, 2012). However, this review aimed to uncover a diverse understanding of prognosis communication, rather than focusing on qualitative research only. The PICO tool has been widely used in systematic reviews, particularly in relation to quantitative studies (Booth, A. & Fry-Smith, 2003). The mnemonic indicates **P**atient group, **I**ntervention, **C**omparators, and **O**utcome, but requires some modification in the context of observational studies, where there is no intervention or comparison group (Lockwood, Munn, & Porritt, 2015). For the purpose of this review I considered the patient group as 'patients with cancer', intervention as 'communication of prognosis to patients by professionals' and the outcome was the 'process of disclosure, patient views, professional views'.

Three databases (MEDLINE, CINAHL and PsychINFO) were searched using Open Athens. A search strategy was devised using the search questions above and followed the basic format of:

- Neoplasms (MeSH term), cancer, oncology
- Prognosis, recurrence risk, information
- Professional-patient relations (MeSH term), Truth disclosure (MeSH term)

The searches were adapted to reflect the specific database being used. The full search strategies used are available in appendix 2. The Cochrane database of reviews was also accessed and searched for suitable studies. The journal Psycho Oncology, chosen for its particular relevance to the subject, was 'hand searched' for relevant studies, as was the reference lists of included papers.

Criteria for considering studies for the review

In order to systematically review papers identified in the searches, inclusion and exclusion criteria were developed (see table 3.1). Peer reviewed research studies, published between January 2004 and June 2014 were included. Only papers published in English could be incorporated, as there were no resources for translation. Published reviews of literature, expert opinion, or best practice guidelines were also not included.

Selection of studies

Results from each of the database searches were downloaded into an Excel sheet and duplicates were removed. Records were screened for suitability by examining titles and abstracts. Potentially suitable references were then downloaded in full and assessed against the inclusion / exclusion criteria to confirm their suitability for the review.

INCLUSION:	EXCLUSION:
Papers published between January 2004 and June 2014.	Non-English language articles
Patients diagnosed with cancer as primary focus	Predominantly patients at "end of life".
	Predominantly non-cancer, or patients with borderline malignant conditions,

Early stage, locally advanced or metastatic cancer diagnosis or “all stages”	(myelodysplastic syndrome, carcinoma <i>in situ</i> , etc.)
Analysis of professional-patient communication	Studies primarily involving genetic testing to estimate recurrence risk
Significant discussion of prognosis or recurrence risk	Studies primarily involving the use of decision aids
Adult patients over 18 years	Reviews or expert opinion
	Studies exploring relatives’ communication only
	Research exploring only professionals’ perceptions of patient communication
	Hypothetical or simulated scenarios with patients or non-patients as the primary focus

Table 3.1 Inclusion / exclusion criteria for included studies

Quality appraisal

There is much controversy about the ways that qualitative literature should, or indeed should not, be appraised as part of conducting a review that includes qualitative literature (Dixon-Woods et al., 2007; Pope, Mays, & Popay, 2007; Toye et al., 2013). Nevertheless, as a process to systematically appraise each study and its contribution to my research questions, I felt it was important to use the rigour offered by established tools to evaluate the studies included in the review. Toye et al. (2013) argue that methodological flaws are more tangible than conceptual clarity and interpretation of the research. Because of this, appraisal tools tend to over-emphasise process over outcome. With this in mind, I used the appraisal tools as a way of exploring the strengths and weaknesses of the studies in more depth, rather than a method of selecting studies to be included or excluded within this review.

One commonly used tool for qualitative research is the Critical Appraisal Skills Programme (CASP) tool, using ten questions to assess rigour of the overall research, selection of subjects, data collection and analysis (CASP, 2013). This tool has been recommended in the Cochrane Systematic Review Handbook (Hannes, 2011). The version used was designed to specifically assess the quality of in-depth interview and qualitative observational studies. However, cross sectional survey and questionnaire studies were also included in this review. Boynton and Greenhalgh (2004) argue that many survey studies lack rigour, or use

inappropriate instruments, which can lead to poor quality data and misleading conclusions. There is currently a dearth of suitable appraisal tools to assess quality of questionnaire studies for inclusion in literature reviews. Boynton and Greenhalgh (2004) provide a critical appraisal checklist, but this is very detailed and requires access to the original surveys or questionnaires and is not very suitable for appraisal of published papers. Another appraisal tool for questionnaires is published by the Center for Evidence Based Management (CEBMA), but is not healthcare specific and limited in its depth (CEBMA, 2014). As neither tool provided exactly what was required for the purpose of this review, I felt that it would be appropriate to develop a composite tool, based on the questions in the Boynton and Greenhalgh and CEBMA tools, but closely modelling the format of CASP. The composite tool is displayed in appendix 3.

Risk of bias

Systematic reviews generally use a team approach to ensuring an objective approach to selection of studies, and arriving at a finalised list of papers to be included (Aveyard, 2010). Due to resources available, it is important to acknowledge that the selection of papers was singlehanded and as such risked introducing an element of bias, subjectivity and error into the review. Another concern was that resources and time only permitted an exploration of published work and hence is open to publication bias (Aveyard, 2010). It is also acknowledged that electronic databases are not good at retrieving qualitative papers due to poor indexing of qualitative terms and the elusive and complex nature of what is being sought (Dixon-Woods, Bonas et al., 2006). I have attempted to mitigate these potential biases by setting clear objectives, research questions, inclusion and exclusion criteria, and maintaining transparency in synthesis of the studies.

Data extraction and management

Data were extracted from the studies using a form developed for use by Cochrane qualitative reviews (Glenton et al., 2013), which I adopted here with only minor modifications (see appendix 3). I then coded findings from within the results, discussion and conclusion sections of the papers, and these were emergent from the studies. Thomas and Harden (2008) pointed out the importance of distinguishing between data, findings and interpretations within qualitative published reports. I checked material within each code for consistency and coherence, by reading through the material across all the studies. Where

necessary, material was then re-coded, divided if representing more than one issue, or amalgamated with another code if the material did not stand up on its own.

Data synthesis

CIS involves a process of translation of findings from one study into another, whereby the concepts, themes and metaphors are identified in the original studies and rendered so that similarities and differences can be explored. I developed a framework grid to explore the translated findings, as described by Flemming (2010). Each paper included in the review formed a row of the grid, with each thematic code forming a column. I then wrote a short summary of the material coded from each paper in the respective box where a particular theme was identified. This allowed a quick visual summary of themes within each paper and conversely to see if and how each theme occurred across the set of papers being reviewed. Reading down the columns allowed me to identify variations or divergence in themes across papers. Reasons for divergent findings were accounted for where possible (Flemming, 2010). This allowed me to develop synthesising arguments that integrated evidence from all the papers to produce new ideas that went beyond the findings of the individual studies (Dixon-Woods, Cavers, et al., 2006). At this level of analysis I incorporated original author interpretations of findings within the reviewed papers into the synthesis. However, Dixon-Woods, Cavers, et al. (2006) urge caution in incorporating such interpretations uncritically. As with many other qualitative analysis approaches, CIS is iterative and uses creative, interpretive processes that defy transparency.

3.2.4 Literature review results

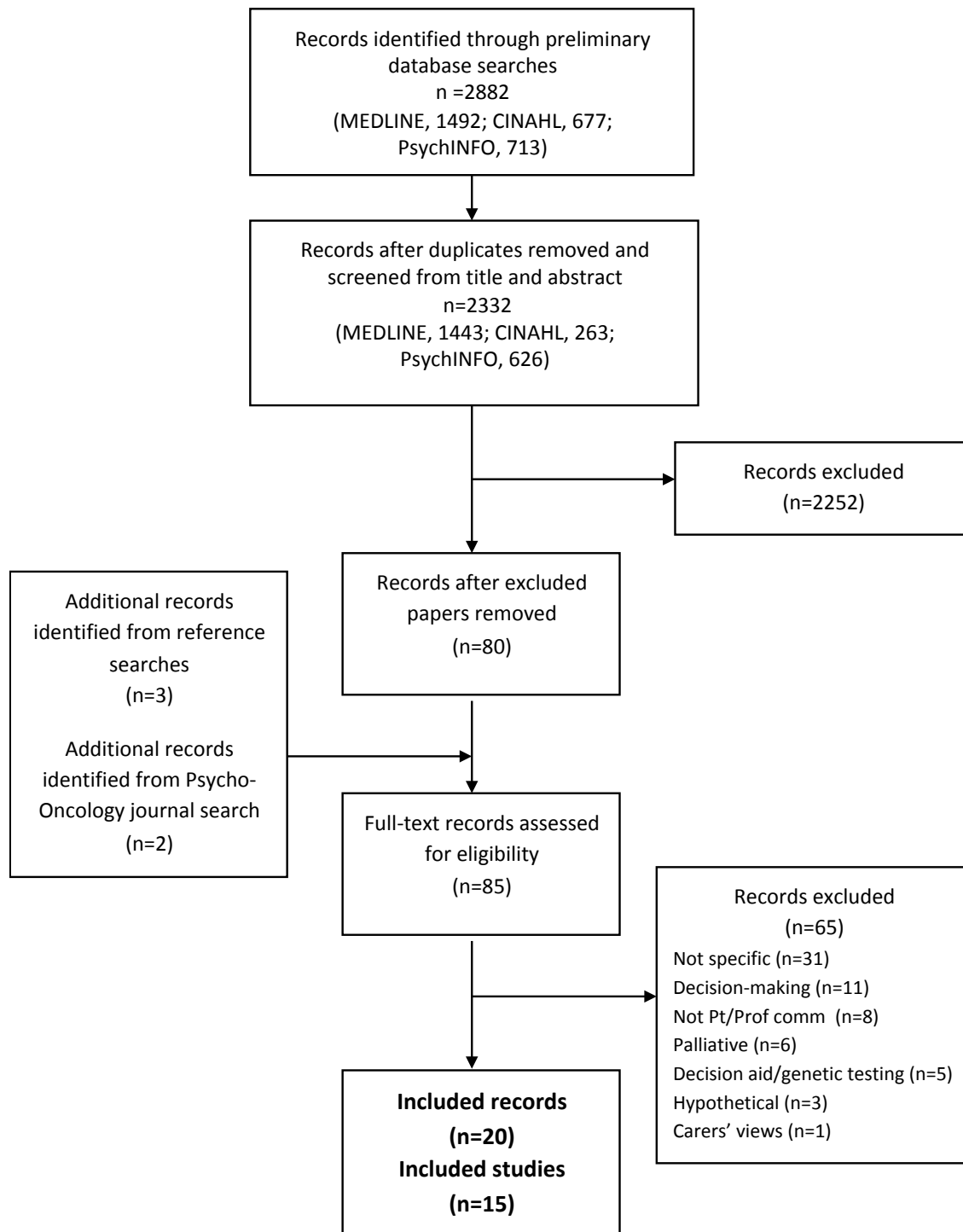


Figure 3.1 Flow chart illustrating literature search 2004 – 2014
(Reproduced with permission, Elsevier)

A total of 2332 unique papers were identified in the search. Details of the selection process for the final studies included in the review are shown in the flow chart given in figure 3.1. Twenty published papers from 15 different research studies were included in the review. A summary table of each study included in the review covering aims, methods, and findings is available in appendix 4.

Types of studies

Studies were conducted in UK, USA, Australia, The Netherlands and Canada. Eight studies used a quantitative survey approach. Of these four were patient questionnaires (Franssen et al., 2009; Hagerty et al., 2004; Hagerty, Butow, Ellis, Lobb, et al., 2005; Lagarde et al., 2008), two used quantitative analysis of consultations between patients and doctors (Alexander et al., 2012; Jansen et al., 2008), or used both strategies (Liu et al., 2014; Robinson et al., 2008). One study used mixed-methods (Kelly et al., 2013). The remaining eleven studies used a qualitative methodology; including five interview studies (Curtis et al., 2008; Goldman et al., 2009; Lobb, Halkett, & Nowak, 2011; Mitchison et al., 2012; Step & Ray, 2011), two interview and focus groups (Thorne et al., 2006; Thorne, Oglov, Armstrong, & Hislop, 2007), two observations of medical consultations (Leydon, 2008; Rodriguez, Gambino, Butow, Hagerty, & Arnold, 2008), and two studies used multiple qualitative strategies (Mendick, Young, Holcombe, & Salmon, 2011; Mendick, Young, Holcombe, & Salmon, 2013). Three studies reported on data collected as part of larger research projects (Liu et al., 2014; Robinson et al., 2008; Rodriguez et al., 2008).

Patients and settings

The studies included patients with a range of different cancer types. Eight studies recruited patients with a single cancer type. Three studies were on patients with breast cancer (Kelly et al., 2013; Mendick et al., 2011; Mendick et al., 2013), two on oesophageal cancer (Franssen et al., 2009; Lagarde et al., 2008), two in haematological malignancy (Alexander et al., 2012; Goldman et al., 2009) and one high-grade glioma (Lobb et al., 2011). Ten involved heterogeneous cancer patients, although two of these included a majority of breast cancer patients. Two further studies used a mixture of patients with cancer and other chronic health conditions, one of which involved patients with lung cancer and chronic obstructive pulmonary disease (Curtis et al., 2008). Of the 20 studies included in the review, six focused on patients being treated with curative intent, nine with palliative intent and five included patients of mixed prognoses. Nine studies recruited patients in oncology out-patient settings, three in breast cancer units, and five in specialist haemato-oncology or surgical units. The other three papers recruited patients using a range of means and were largely community focused.

Quality

Across all the papers there was limited consideration of the ethical aspects of the research, beyond ethical committee approval. None of the published accounts of the studies discussed the impact of the research on participants, despite the sensitive nature of the area. There was limited researcher reflexivity evident in the qualitative studies, although this is common in published papers. Most of the studies provided good contextual information about the location and population. The papers by Thorne et al. (2006) and Thorne et al. (2007) provided the least information on the population and location, due to the amalgamation of multiple datasets, and diverse patient groups and settings. Descriptions of participant sampling were variable. Some papers gave detailed and robust accounts of the process and had high response rates and accounted for non-responders, such as Franssen et al. (2009) and Lagarde et al. (2008). Other studies gave only vague and incomplete accounts of the process. Methods of data collection were generally clearly presented across the papers. Qualitative studies that included participant interviews varied in the detail they presented regarding interview topic guides or questions used.

There were some notable methods used amongst the papers, including one study that used excerpts of recording transcripts to help remind participants during interviews of what had been said in the consultations (Goldman et al., 2009). Two papers employed a theoretical model. Kelly et al (2013) used the self-regulation model (Leventhal, Kelly, & Leventhal, 1999), and Step and Ray (2011) used Problematic Integration (Babrow, 2001). In the quantitative papers a variety of validated and non-validated tools were employed, raising some questions regarding their validity or suitability. Low response rates in some questions in the study by Kelly et al. (2013) were interpreted as a lack of knowledge in responders. However, no consideration was given to alternative explanations, such as patients' discomfort in answering questions about prognosis.

Conveying the process of data analysis and its rigour in qualitative research is often a problem and was variable across the papers. Notably the papers by Mendick and colleagues demonstrated a high level of rigour by their explanation of the codes, testing of alternative thematic formulations and examination of divergent cases. Qualitative analysis methods within predominately questionnaire studies that included some free text response

questions were particularly poorly described (Hagerty, Butow, Ellis, Lobb, et al., 2005; Jansen et al., 2008). The paper by Thorne et al. (2007) used secondary analysis of previous studies conducted by the research team, but unlike the data presented in the 2006 paper, included cancer and non-cancer patients. The rationale for amalgamating data from these patient groups *post hoc* was unclear, and the findings presented were almost entirely from the cancer population.

A number of the qualitative papers presented large sections of original data in a powerful and compelling manner, which helped to emphasise the conceptual clarity and interpretive rigour of the papers (Goldman et al., 2009; Lobb, et al., 2011; Mendick et al., 2011; Mendick et al., 2013). Presentation of the quantitative data varied in quality. Some papers did not clearly present all relevant data, and others provided only limited statistical analysis. For example, Kelly et al. (2013) gave no data in tables, making reading and interpretation difficult. Some studies identified statistically significant associations using correlation coefficients, without a clear idea of whether this was clinically relevant. An example was Franssen et al. (2009) who made a link between a better sense of taste on a quality of life scale and a willingness to initiate a discussion regarding prognosis.

3.2.5 Themes from 2004 to 2014 review

The review and its findings have been published (Johnson, M., Tod, Brummell, & Collins, 2015). An overview of the themes, subthemes and the constructs identified from within the papers are given in table 3.2. A thematic framework was developed as a result of the synthesis of findings within this review, and which was subsequently used to help guide study research questions and to help develop the initial analytical framework.

3.2.6 Summary of findings up to 2014

The aim in the following section is to identify key themes from my own 2014 review, and to combine these with those from the relevant papers included in the review by Hagerty, Butow, Ellis, Dimitry, and Tattersall (2005). This necessarily personal analysis of the large body of diverse literature around prognostic communication identified in these two reviews reflects findings that had the largest impact on my thinking about the focus of my own research project.

Theme grouping	Theme	Constructs
Diagnostic and prognostic factors	The nature of prognostic information	Scope of prognostic information Spectrum of prognostic information Qualitative and quantitative prognoses
	Provision of prognostic information	Framing of information Format of information
	Disease factors	Temporal / cancer trajectory Disease uncertainty
Patient factors	Patient desire for prognostic information	Patient need for full prognostic disclosure Patient desire for a realistic approach Patient desire for optimistic approach Patient need for personalised information Significance of numerical information for patients
	Patient need to maintain a sense of hope	Patients strive to maintain a sense of hope Patient avoidance of negative news Patient re-framing of negative news “Beating the odds” Statistics do not reflect individuals “Doctors get it wrong”
	Patient need to balance hope with prognostic information	Avoiding “too much” information Information seeking paradox Ways patients balance hope and prognostic information Effect of professional communication on hope
	Individual patient factors	Patients are individuals Patient anxiety Patient understanding of prognostic information Patient recall of prognostic information Denial Cultural effects
Clinician factors	Clinician-patient relationship Communication ethos	Willingness to discuss prognostic information Desire to give hope preserving information Helpful and unhelpful communication strategies Clinician experience Communication guidelines in relation to prognostic disclosure
	Shared understanding	Illusion of shared meaning Prognostic concordance

Table 3.2 Themes and subthemes identified in literature review 2004 – 2014

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Diagnostic and prognostic factors*The nature of prognostic information*

Studies reflected the wide range of what constitutes prognostic information. Distinctions were made between information provided about whether or not the disease is curable, information given in numerical (quantitatively) or in verbal form (qualitatively), or information transmitted in less explicit form (Alexander et al., 2012). Indications about prognosis can be given to patients by such things as investigation results, tone of voice, or body language (Alexander et al., 2012; Goldman et al., 2009; Gordon & Daugherty, 2003;

Mendick et al., 2013; Thorne et al., 2007). Rodriguez et al. (2008) analysed recorded oncology consultations and identified how the way in which information is framed can also influence the prognostic message delivered. Examples included discussing prognosis in terms of chance of death, as opposed to chance of cure, as well as presenting information in direct relation to the patient concerned (e.g. patients like you), or in relation to a wider group of less specific patients (e.g. patients with lung cancer). Analysis of second opinion haemato-oncology consultations indicated that prognostic information might be given in several different forms during consultations (Alexander et al., 2012). Leydon (2008) analysed oncology consultations and identified how pairing bad news followed by more positive information could significantly soften and alter the message that patients hear.

Provision of prognostic information

Studies using observation of consultations, as well as reports from patients and professionals, indicated variability in whether or not patients were presented with prognostic information. Some studies suggested prognostic information was largely not discussed (Schofield et al., 2001; Sell et al., 1993), while others indicated communication about prognosis was common (Kelly et al., 2013; Leighl, Gattellari, Butow, Brown, & Tattersall, 2001; Siminoff, Ravdin, Colabianchi, & Saunders Sturm, 2000). A comprehensive observational study of surgical consultations following breast cancer surgery by Mendick et al. (2013) indicated that surgeons presented information about prognosis in non-explicit ways. Statistical estimates of prognosis were not given, and categorical and comparative statements were used to convey prognosis. Information was given on a spectrum of explicitness, with the most explicit prognostic detail disclosed to patients with the best prognoses. Such findings suggest that explicit prognostic discussions are not universal, even in with patients with early stage cancer. Notably, studies where prognostic communication was routine, the setting was either breast cancer, or consultations where adjuvant chemotherapy was discussed. This is, perhaps, unsurprising. Adjuvant treatment aims to reduce the risk of dying from the cancer following complete surgical excision. It is almost universally offered in early stage breast cancer treatment and some form of prognostic discussion would seem to be inevitable in the context of treatment decision-making.

Disease factors

Across the studies there were differences in the way prognosis was discussed at different points along the cancer pathway, as well as differences related to type of cancer diagnosis. Step & Ray (2011) used patient interviews to retrospectively recall the differences in the way prognosis was discussed with patients at the end of curative treatment and when they had relapsed. Discussion at the end of initial treatment reflected hope for cure, while at relapse this changed to one of managing a chronic condition. Hagerty et al. (2004) used a cross sectional survey design to determine the optimal timing of prognostic discussions for patients diagnosed with metastatic disease. Around half of patients newly diagnosed with metastatic disease wished to delay prognostic discussions until later on in their treatment.

The availability of reliable prognostic information from population statistics also differed across cancer diagnoses. Prognostic information was readily available for common conditions, such as breast cancer. Kelly et al. (2013) used an on-line prognosis calculator in their survey study of patients' perceptions of professionals' prognostic communication. In contrast, interviews with professionals (Alexander et al., 2012), and with patients (Thorne et al., 2007), indicated that for patients with rarer malignant conditions and for those seeking second opinions, accurate prognostic information was often simply not available.

Patient factors

Patient desire for prognostic information

Studies were consistent in recognising that patients have individual needs for prognostic information. Several studies used surveys to determine the proportion of patients who want to be given prognostic information. Most of the tools used had been developed from the Information Styles Questionnaire (Cassileth et al., 1980). More recently, similar approaches have produced remarkably consistent results (Cox, A. et al., 2006; Franssen et al., 2009; Hagerty et al., 2004; Jenkins et al., 2001; Lagarde et al., 2008; Lobb, Kenny, Butow, & Tattersall, 2001). These surveys indicate that an overwhelming majority of patients wanted to be given all available information about their condition, both good and bad, and specifically information about prognosis. Findings from the study by Hagerty et al. (2004) indicated that patients looked for a 'realistic' approach from their clinicians.

Other studies, many using qualitative patient interviews, suggested a much more nuanced requirement for prognostic information (Butow, Dowsett, Hagerty, & Tattersall, 2002; Curtis et al., 2008; Friis, Elverdam, & Schmidt, 2003; Leydon et al., 2000; Lobb et al., 2011; Mendick et al., 2013). Patients associated information about their condition with feelings of power, choice and control over aspects of their disease (Thorne et al., 2006). While findings from interview studies also indicated patients' desire to be given 'all' information and for a 'realistic' approach, patients often also expressed a preference for information presented in an 'optimistic' and hope-preserving manner (Curtis et al., 2008; Davey, Butow, & Armstrong, 2003; Friedrichsen, Strang, & Carlsson, 2000; Goldman et al., 2009; Mendick et al., 2013). Other patients indicated that detailed prognostic information could be distressing and was not what they required (Friis, Elverdam, & Schmidt, 2003; Lobb et al., 2011). Patients with acute myeloid leukaemia needed to focus on their on-going treatment and did not have capacity or desire to explore longer-term issues around prognosis (Friis et al., 2003). Factors such as maintaining hope for the future, trust and faith in the medical team were some of the reasons why patients did not want to be given details of prognosis (Leydon et al., 2000).

Several interview and survey studies also highlighted patients' need for information tailored to their individual situation (Curtis et al., 2008; Goldman et al., 2009; Hagerty, Butow, Ellis, Lobb, et al., 2005; Lagarde et al., 2008). Presentation of numerical information about prognosis appeared to have a particularly strong significance for many patients. Findings from interview studies indicated how patients who were given statistics about their prognosis found these numbers could dominate their thinking and stay with them for a long time (Step & Ray, 2011; Thorne et al., 2006). Where patients perceived odds as favourable, patients reported they found this information helpful. Where statistics were felt to be negative, this could be particularly difficult to absorb and cope with (Thorne et al., 2006). Some patients also felt that doctors could use statistics in a coercive manner to steer patients, who might be reluctant, towards a particular treatment choice (Thorne et al., 2006).

Patients' need to maintain a sense of hope

The central importance for patients with cancer of maintaining a sense of hope is well reported (Friis et al., 2003; Hagerty, Butow, Ellis, Lobb, et al., 2005; Koopmeiners et al.,

1997; Leydon et al., 2000; Lobb et al., 2011; Mendick et al., 2013; Sardell & Trierweiler, 1993; Thorne et al., 2007). Findings from patient interviews indicated how patients seek out and value information they perceived as hopeful. Such information allowed patients to attempt to manage the inherent uncertainty of their situation, and to continue to envisage positive things happening in the future (Thorne et al., 2007). Studies have described many ways in which patients try to maintain hope in the face of negative information. Examples include, discounting unfavourable odds, a belief in an ability to beat the statistics, using complex (and apparently irrational) ways to re-frame bad news in a positive light, and taking a sceptical view of any prognostic estimates given to them (Curtis et al., 2008; Lobb et al., 2011; Thorne et al., 2006; Thorne et al., 2007).

Findings by Thorne et al (2007) indicated that patients could express ambivalent attitudes to prognostic information. While it could have practical and psychologically useful aspects, prognostic information also had the ability to increase levels of anxiety. Some patients reported actively trying to limit prognostic information (Butow, Dowsett, Hagerty, & Tattersall, 2002). Other studies indicated some patients might continue to seek further details in an effort to bolster hope and reduce feelings of uncertainty (Thorne et al., 2006; Thorne et al., 2007). Step & Ray, (2011) reported accounts of patients whose search for further information only served to increase their anxiety and lead to further questions. The authors described this phenomenon as an “information seeking paradox”.

Balancing hope and honesty

Although many studies identified patients wanted honest information that reflected the realities of their clinical situation whilst also wanting information that was hopeful or optimistic, fewer studies explored the tension that this implied (Curtis et al., 2008; Mendick et al., 2011; Mendick et al., 2013; Step & Ray, 2011; Thorne et al., 2007). In their comprehensive and multi perspectival study using patient and surgeon interviews, coupled with observation of consultations, Mendick et al. (2011; 2013) found that participants carefully controlled the amount and detail of information that was given. Although surgeons and patients talked about the importance of honesty and giving all information, surgeons also wanted to limit detailed information. Similarly patients did not want to hear it. This pattern was reflected in the findings from the observed consultations. Thorne et al. (2007)

argue that a preference for positive information does not mean that patients do not acknowledge the possibility for untoward outcomes, but indicates a preference to focus on more optimistic ones. Step and Ray (2011) argue that this tension in information provision results in particular difficulties for patients who want to be involved in decisions about their care.

In an interview study with patients with advanced lung cancer and COPD, Curtis et al. (2011) identified a range of ways patients attempted to integrate honesty about their prognosis with hope. The researchers concluded that simply asking patients what information they wanted was unlikely to elicit their true requirements. Therefore clinicians need to understand individual patients' information and coping strategies in order to provide the right balance of information. Findings from several studies indicated patients reported that being presented with prognostic information in a manner that was too direct could be interpreted as brutal and damaging to hope (Koopmeiners et al., 1997; Lobb et al., 2011; Thorne et al., 2007).

Individual patient factors

A number of studies have tried to identify patient characteristics in relation to prognostic information requirements (Franssen et al., 2009; Hagerty et al., 2004; Jansen et al., 2008). Attempts to link these to socio-demographic factors have not provided any strong correlations. Fear of recurrence and general anxiety appeared to have an effect on desire for prognostic information. Patients with higher educational levels tended to want more information (Franssen et al., 2009), but age did not seem to be a factor (Jansen et al., 2008). When measured against available survival statistics, most patients were inaccurate in their assessment of prognosis, with most patients over estimating it (Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999; Kelly et al., 2013; Liu et al., 2014; Quirt et al., 1997; Robinson et al., 2008).

Clinician factors

Clinician-patient relationship

Prognostic discussions were facilitated by a good, trusting and on-going relationship between the clinician and the patient (Butow et al., 2002; Friedrichsen et al., 2000; Goldman

et al., 2009; Mendick et al., 2011). Where discussions of prognosis needed to occur at the first meeting, such as during second opinion haematology consultations, establishing a rapport and demonstrating understanding of the patient's problems immediately was essential (Goldman et al., 2009). Factors that helped establish good clinician-patient relationships included skilled communication and demonstrating respect and care towards the patient (Lobb et al., 2011; Thorne et al., 2007). In particular, patients valued professionals that were able to provide continuity for them and could help to interpret and make sense of complex medical information (Thorne et al., 2006).

Communication ethos

Findings from a questionnaire study of physicians by Liu et al. (2014) found differences between individual clinicians' reported willingness to discuss prognosis in the advanced disease setting. Doctors with more exposure to caring for patients at the end of life appeared to be more willing to initiate discussions about prognosis. Interviews studies with clinicians indicated they wanted to give patients honest and realistic information about their condition (Butow et al., 2002; Mendick et al., 2011). In particular they wanted to give information that would help to support hope in their patients. Interview findings with breast cancer surgeons in the study by Mendick et al. (2013) indicated they wanted patients to leave the consultation with a sense of hope, regardless of the cancer stage. However, an ethnographic study involving patients commencing chemotherapy for small-cell lung cancer highlighted the potential danger of a collusion of silence between patients and professionals about prognosis, which could have major implications for consent to treatment (The, Hak, Koeter, & van Wal, 2000). Similarly, Gordon and Daugherty (2003) argued that professionals often adopt a paternalistic stance when deciding when and how much information to disclose about prognosis with patients in early stage clinical trials in an effort to help patients preserve hope. However, they argue that there is a fine ethical line between providing compassionate care whilst also respecting patients' autonomy of decision-making.

Shared understanding

There was evidence indicating a lack of prognostic concordance between doctors and their patients when asked to give numerical estimates (Kelly et al. 2013; Liu et al., 2014; Robinson et al., 2008). Meanings of commonly used terms appeared to differ between patients and professionals. Additionally, Step and Ray (2011) identified how meanings might shift over

time and with changing clinical condition. Patients appeared to struggle to understand common terms used by medical teams around prognosis, such as overall survival, or median survival times (Davey et al., 2003; Lobb, Butow, Kenny, & Tattersall, 1999). Thorne et al. (2007) argued that where there was a mismatch between the information patients felt they needed and the manner and content delivered by professionals, patients frequently perceived it as unhelpful communication (Thorne et al., 2007).

3.2.7 Synthesis of evidence to 2014

Across this large body of literature there were four key issues that were significant to my study; Individual patient approach and needs, Professional individual attitudes and skills, Supporting hope, and Managing Uncertainty. The first two factors highlight how prognostic communication concerns the exchange of information between individual professionals and patients. It involves complex interpersonal interactions and partly reflects the quality of the clinician–patient relationship. Professionals differ in their communication ethos and their individual willingness to disclose prognostic information to patients. Some differences may be due to disciplinary role and clinical experience, especially exposure to patients receiving end of life care. Similarly patients have individual preferences for prognostic information and subject to distinct clinical, emotional and social situations. Ultimately, desire for prognostic information appears individual and circumstantial.

The third factor is supporting hope. Both patients and professionals appeared to want to support patients' own sense of hope. They attempt to achieve this by careful management of information and how it is exchanged. Communication strategies around prognosis are complex. Professionals may discuss prognostic information in a spectrum of different formats. The explicitness of the information can be used in varieties of ways to convey subtly different messages. Patients use numerous strategies to help them manage the information they do receive if it does not match their needs in terms of maintaining hope. Examples include re-framing information, re-appraisal, changing goals, or seeking further information. However, sometimes more information can lead to a paradoxical increase in feelings of uncertainty and anxiety for patients.

The final and related area was managing uncertainty and making sense of likely future events. Undoubtedly many patients need prognostic information for decision-making, planning, or to help make sense of their situation. Circumstances and personality differences affect the type and amount of information required. Uncertainty and ambiguity are central to the way patients and professionals manage information about prognosis. Professionals deliver information in ways that they feel is honest, but aspects of prognostic information may be withheld in order to preserve patient hope. Similarly, patients do not want to be deceived, but want information that is delivered in an optimistic and in a non-brutal manner. Several authors have described this process as balancing hope and honesty, or realism. However, this metaphor does not quite capture the complexity of the situation. Sometimes reality is itself hopeful. Conversely, patients may be able to find realistic hope in situations that may be considered negative.

3.3 Literature review 2014 – 2018

As previously outlined, the initial literature review was completed at the development stage of the study. At the point of concluding analysis and writing up, I needed to understand if there had been significant new findings around prognostic communication in the intervening period. In the following section I will briefly outline this process and highlight new findings that were relevant to my study.

3.3.1 Review objectives

The broad aim in undertaking this review was to replicate the 2004 – 2014 review to identify new research in the field. I did not want to expand, or refine the review criteria. The previous reviews had indicated that there was limited research evidence available around patients with early stage cancer, or with any stage lung cancer. I therefore kept the focus of the review general and included patients with all types and stages of cancer.

3.3.2 Review methodology

Inclusion and exclusion criteria were kept the same as the previous review, with the exception of including papers published between January 2014 and Oct 2018. An additional search strategy was used for this current review to ensure that research that was related to, or directly emanating from the 20 papers included in the 2004 – 2014 review was included.

The SCOPUS database allows a search of all citing literature and this function was used to identify all new literature that referenced these studies.

3.3.3 Search results

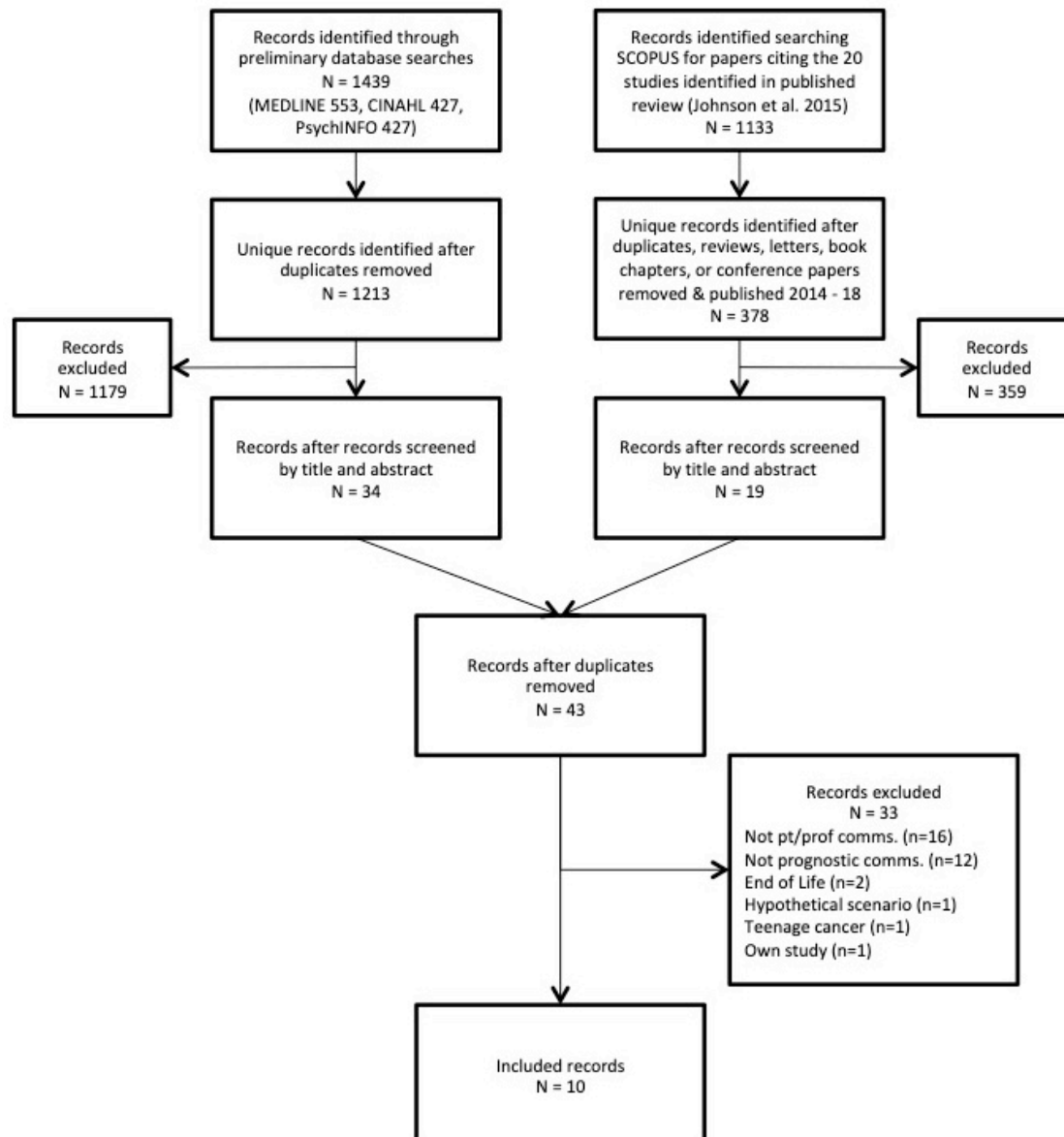


Figure 3.2 Flow chart illustrating literature search 2014 – 2018

Figure 3.2 shows a flowchart illustrating the process of searching and identifying the final papers included in this review. A total of 10 studies were included. A summary of each study and its aims, methods, and findings is available in appendix 5.

3.3.4 Description of included studies

Types of studies

Studies were conducted in USA, The Netherlands, UK and Canada. One published paper involved a large-scale postal questionnaire study analysed quantitatively (Janz et al., 2017). The remaining studies employed a range of qualitative methods. Four studies analysed recorded patient consultations: three consultations between oncologists and patients (Chou et al., 2017; Henselmans, Smets, Han, de Haes, & Laarhoven, 2017; Singh et al., 2017), one between surgeons and patients (Dronkers, Hoesseini, de Boer, & Offerman, 2018). Chou et al. (2017) used Discourse Analysis, and Singh et al. (2017) Conversation Analysis, to examine interactions between clinicians and patients regarding prognosis in detail. Two studies used in-depth patient interviews (Furber, Bonas, Murtagh, & Thomas, 2015; Gough, Ross, Riley, Judson, & Koffman, 2015), and one used in-depth interviews with patients and surgeons (Blakely, Karanickolas, Wright, & Conn, 2017). One study used patient focus groups (Cartwright, Dumenci, Siminoff, & Matsuyama, 2014). The final study analysed both recorded oncology consultations, followed up by a short telephone interview with patients and included sub-set of 15 patients who were selected for an in-depth interview (Engelhardt et al., 2017).

Patients and settings

Study patients were diagnosed with early stage (n=3), mixed stages (n=3), or advanced stage cancers (n=4). Two studies were with patients with early stage breast cancer (Engelhardt et al., 2017; Janz et al., 2017). Others included patients with surgically treated pancreatic cancer (Blakely et al., 2017), head and neck cancer at varying disease stages (Dronkers et al., 2018), advanced stage lung cancer (Singh et al., 2017), and soft tissue sarcoma being treated palliatively (Gough et al., 2015). The four remaining studies included patients with heterogeneous cancers with a range of disease stages (Cartwright et al., 2014; Furber et al., 2015), or with advanced cancers (Chou et al., 2017; Henselmans et al., 2017). With the exception of Cartwright et al. (2014), patients were recruited via their secondary care clinical teams.

3.3.5 Quality

Only three of the ten papers appeared to report on studies specifically set up to examine prognostic communication (Blakely et al., 2017; Dronkers et al., 2018; Gough et al., 2015). Three others reported on a sub-set of data from larger research projects, with broader aims (Engelhardt et al., 2017; Furber et al., 2015; Janz et al., 2017). Four studies used secondary analysis of data collected in completely separate studies (Cartwright et al., 2014; Chou et al., 2017; Henselmans et al., 2017; Singh et al., 2017).

The quality of the studies varied. In the focus group study by Cartwright et al. (2014) the rationale for the choice of methodology was not made clear, and the report appeared to suggest considerable norming of views during the focus groups. There was a lack of information about the participants and their illness backgrounds. In the study by Dronkers et al. (2018) analysis of qualitative data was limited in its depth and included quantitative analysis of the frequency of the different forms of prognostic information used in consultations, despite the small number of patient participants suitable for qualitative data analysis. Most studies were based on only a single source of data, such as only patient interviews, or recorded consultations. Blakely et al. (2017) used interviews with both patients and surgeons, which added to the breadth of insight. However, this was limited by a lack of direct clinical link between participants and no comparison to observed clinical practice, which prevented a deeper analysis being presented. The studies by Singh et al. (2017) and Henselmans et al. (2017) were particularly high quality in terms of rigour and reporting.

3.3.6 New findings

The overall focus of the papers identified in this most recent review was different from the previous one, particularly in terms of the research approaches of the included studies. More studies examined the process of prognostic communication within consultations, resulting in new findings around these interactions. New insights have also been gained about how patients conceive their prognosis. Fewer studies examining professionals' attitudes to prognostic communication conversely resulted in little new insight into this aspect. Many of these new studies served to corroborate findings of the previous review, and therefore I will

not re-state these. Rather, I aim to highlight things that are new, extend previous findings, or that change understanding.

Diagnostic and prognostic factors

Disease factors

These new studies provide further insight into the variability of prognostic communication between settings and teams. In the survey of breast cancer patients' perceptions of recurrence risk communication they had had with their doctor, Janz et al. (2017) found that most respondents felt they had discussed recurrence risk, with the majority recalling doing so using words and numbers. In contrast, studies of patients with advanced cancers suggested that doctors rarely initiated explicit discussions about prognosis. In-depth interviews with soft tissue sarcoma patients indicated it was patients who took the lead where prognostic discussions occurred (Gough et al., 2015). Nevertheless, patient views on the utility of being offered opportunities to discuss prognosis by professionals were mixed (Cartwright et al., 2014; Gough et al., 2015).

Prognostic uncertainty

The study by Gough et al. (2015) found that sarcoma patients understood they had a rare cancer and that there was a lack of detailed survival data available. Patients reported that professionals cited variability in individual prognosis and unknown response to treatment as reasons why they could not discuss prognosis. Participants reported that clinicians gave lack of evidence about prognosis as a reason not to discuss it where patients asked (Gough et al., 2015). Similarly, during observed consultations with patients with head and neck cancer, clinicians used variable or unknown responses to treatment as reasons not to talk about prognosis in detail (Dronkers et al., 2018). Engelhardt et al. (2017) found during initial consultations about adjuvant chemotherapy with breast cancer patients, oncologists frequently discussed the inability to predict an individual's future outcome from population statistics (aleatory uncertainty). In contrast uncertainty around the data itself (epistemic uncertainty) was not discussed. Oncologists in consultations with patients with advanced common cancers often emphasised the uncertain and imprecise nature of prognostic statistics (Henselmans et al., 2017). Some patients participating in focus groups questioned the validity of prognostic estimates for individual patients given by doctors, seeing it as

being “un-knowable” (Cartwright et al., 2014). In interviews with patients, most struggled to understand the concept of uncertainty in risk estimates and Englehardt et al. (2017) questioned whether raising these issues with patients might lead to greater confusion for patients.

Patient factors

Desire for prognostic information

Evidence from these recent studies has added to the understanding of the variability between individuals regarding requirements for prognostic information. Some patients conceived prognosis as being wholly negative, associated with death, and as an “expiry date” (Cartwright et al., 2014; Gough et al., 2015). Other patients wanted to have prognostic information to help with planning and treatment decision-making (Blakely et al., 2017; Cartwright et al., 2014; Gough et al., 2015). However, findings from an interview study with patients following their initial consultation with an oncologist described a much more complex and ambivalent desire for prognostic information (Furber et al., 2015). Patients reported that they did not want information if it would increase their anxiety. Nevertheless, they also wanted information if it could help them make informed decisions. The authors described patients holding a tension between “wanting to know” and “not wanting to know” prognostic information. They argued that the balance of this tension would necessarily change with time and altered circumstances. However, Furber and colleagues’ study was a cross sectional design and changes over time remain speculation on their part. They also proposed that family members’ information needs would also modify the dynamics of this balance.

Patient understanding

Furber et al. (2015) interpreted patients as having multiple understandings of their illness and prognosis during the same consultation and interview. The authors related these ambivalent and multiple understandings to the theoretical framework of awareness contexts (Timmermans, 1994). They suggested that patients find maintaining full open awareness of their situation too difficult, and can “suspend” awareness as a way of coping with their situation. Furber et al. (2015) also identified how the complex nature of medical

information can be overwhelming for patients, leading to them no longer being able to listen to or absorb further information from professionals.

Patient need for a sense of hope

Findings from the study by Furber et al. (2017) showed how patients would reframe adverse prognostic information in ways that could make it seem more hopeful when talking about it afterwards in their interviews. Information that was felt to be overly pessimistic might be rejected. Patients who were given prognostic estimates sometimes saw this as a challenge and frequently aimed to exceed these estimates (Furber et al., 2015). Evidence from the focus group studies by Cartwright et al. (2014) indicated that patients who had exceeded estimates could take great pride in “beating the odds”. Patients with advanced soft tissue sarcomas, who were told they had a poor prognosis, but nonetheless felt well, reported that they found this particularly distressing and some discounted this information entirely (Gough et al., 2015). Patients carefully tried to avoid information that challenged their positive outlook. A small number of patients in this study explicitly talked about this as an act of denial. Some believed maintaining a hopeful attitude was something positive that they could do to live longer and better with their condition.

Clinician factors

Clinician ethos

Unlike the previous review, in the ten papers being explored here only Blakely et al. (2017) reported directly on clinicians’ views. During interviews for this study, surgeons caring for patients with pancreatic cancer all emphasised the importance of maintaining patients’ hope and providing a sense of positivity in their approach. Surgeons characterised hope as particularly important in helping patients to undergo or to continue with difficult treatments, sometimes with marginal benefits. There was a tension between maintaining the hopeful stance and providing honest information when the prognosis was not good. While they wanted to maintain honesty, they spoke about limiting negative news in an effort to maintain an optimistic stance. However, they wanted to avoid supporting false hope in patients, but what this actually meant was not explored, other than surgeons would stop short of delivering false information to patients.

Communication factors

Clinician patient relationship

Surgeons in the study by Blakely et al. (2017) spoke about recognising the challenges for patients in understanding highly complex information about their condition. Some surgeons wanted to take time to explain and personalise information and respect patients' limits, while others described themselves as needing to take a paternalistic approach to information giving. Patients in the same study indicated that they valued professionals who appeared caring, gave honest, comprehensible messages that supported hope. Developing trust in the professionals was important in facilitating communication. Findings from the patient focus group study by Cartwright et al. (2014) indicted that clinicians who gave prognostic information when it was not expected, or not asked for, were considered "un-compassionate" and not to be acting as champions for their patients (Cartwright et al., 2014).

Shared understanding

Several studies indicated that patients were largely satisfied with their level of understanding (Cartwright et al., 2014; Furber et al., 2015; Gough et al., 2015). However, patients reported that they were aware that clinicians might limit discussion of prognosis in order to maintain patient optimism (Blakely et al., 2017; Cartwright et al., 2014; Gough et al., 2015). Chou et al. (2017) analysed oncologists' language during consultations with patients with advanced cancer. Prognostic information was often discussed using ambiguous and vague terms, which the authors proposed was likely to impair patients' understanding of their situation. Interviews with patients in the study by Furber et al. (2015) indicated patients often felt muddled about the information they had been given. Several patients described their condition and prognosis in broad, lay terms during interviews and avoided using explicit language. Many talked about prognosis in optimistic terms, and might give accounts with differing levels of understanding in the course of the interview, which significantly differed from information that they had been given during consultations. The authors also suggested that some patients might avoid directly engaging with the information given in consultations in order to protect themselves. Furber et al. (2017) reflected on the challenges in fully comprehending the extent of patients' understanding about their condition.

The consultation

Singh et al. (2017) used Conversation Analysis to interpret consultations between oncologists and patients with advanced lung cancer. The authors argued that the consultations were seen to be co-constructed by professionals and patients, but were disproportionately controlled by professionals. Most consultations conformed to a common flow, which the authors considered to be instrumental in controlling information delivery. Explicit discussions about prognosis, usually initiated by patients, took place in only a minority of the analysed consultations. Oncologists tended to spend comparatively little time discussing test results and to move on quickly to talking about treatment. This was more pronounced when test results were bad. Where prognostic discussions took place this usually occurred at this transition between discussing results and treatment. Professionals used a number of linguistic techniques to facilitate this transition, which were more commonly used where the results indicated stable or bad news than in good news situations. Chou et al. (2017), in their Discourse Analysis of consultations between oncologists and patients with advanced cancer, also found prognostic discussions were brief and moved quickly into discussion about the urgency and practicalities of treatment. Henselmans et al. (2017) also examined consultations about palliative chemotherapy. Patients or a family member initiated all the prognostic discussions in the consultations. There was a tendency by oncologists to minimise talk about prognosis and to highlight the uncertainty of any estimates. Breast cancer patients reported that medical staff rarely asked about worry in relation to recurrence (Janz et al., 2017).

The updated literature review identified ten further papers that build on the knowledge available at the inception of this current project. The predominance of qualitative studies in this latest review has helped to strengthen the idea that patients' requirement for prognostic information is not a straightforward matter of more information is better and has added to the understanding of the complexities of prognostic communication and the multiple and often contradictory drivers. Findings by Furber et al. (2017) regarding the complex and fluid nature of patients' conceptions of their condition and prognosis, as well as their desire to know detailed information are of particular relevance to my current study.

3.4 Identifying and addressing gaps in research knowledge

As has been demonstrated in this review, prognostic communication in cancer care is an area that has been the subject of much research activity. However, the complexity of the subject, including the multiple scenarios in which such communication takes place, means that there remain many unanswered questions. Findings suggest that patients want prognostic information that is both honest and presented in ways that support hope. Such aims at times inevitably can become irreconcilable. There remains a lack of evidence available to indicate how patients and professionals interact to manage this situation in practice, and to what extent and in what way the information given to patients is tailored around their specific needs. Further questions remain about the extent to which patients want to be given numerical information about prognosis and how this is used.

Studies conducted with patients who have early stage cancer have rarely included patients with lung cancer and to date no studies have looked at prognostic communication with patients with lung cancer treated with surgery. Many studies have focused on prognostic information practices and the needs of patients with breast cancer. In contrast to the lung cancer setting, there is almost universal use of multi-modality treatment, online risk calculation tools are widely available, and there exists a powerful lobbying force that champions patient decision-making and autonomy. Findings from such studies may not be directly transferable to the lung cancer setting, due to differences in the socio-demographic profile of the group, decision-making preferences, perceptions of the diagnosis being fatal, as well as issues of co-morbid disease, which may significantly alter patients' desire for prognostic information (Powell et al., 2015).

Studies reviewed have largely adopted a cross sectional design, aiming to gain insight into prognostic communication at a single time point. One study specifically designed to assess change in prognosis communication used a recall design, with all its methodological shortcomings (Step & Ray, 2011). Although studies have indicated that patients information needs about prognosis are fluid, there is very little research evidence that indicates how these needs change over time in relation to recovery, potential recurrence and life after treatment. In a similar way, observational studies that have examined communication

during consultations have done so within a single setting, such as surgeons giving result of surgical procedures, or oncologists talking about adjuvant or palliative treatments. There is a dearth of evidence around how prognostic communication occurs across settings where patients are managed by multiple clinical teams, as occurs frequently during the lung cancer clinical pathway. There is therefore a significant gap in the research evidence about how patients cope, and are supported to live with, the potential for cancer recurrence following the end of their initial treatment.

The study by Mendick et al. (2011; 2013) provided a particularly rich picture of the way in which patients were informed about their breast cancer. Across the two published papers the team wanted to understand what information was given to patients during consultations, what influenced the surgeon regarding information giving, what information the patients wanted to have and to explore the convergence or divergence between them. The findings were based on multi perspectival data drawn from observation of consultations, linked to in-depth interviews with the surgeons and patients involved. This research was particularly influential when it came to designing my own research approach, due to the complex multi perspectival and nuanced insights it provided of the consultations. Presenting findings from all data sources linked to a specific patient and their surgeon helped to keep the context of the interaction visible. Simultaneously, having the ability to explore cases from the point of view of a particular data type also gave the flexibility to give equal weight to patient and professional perspectives and to view the data from multiple aspects. Elements of this design were central to the methods used in my own study.

3.5 Chapter summary and conclusions

At the time of completing the review in 2014, there was a large and complex literature about prognostic communication in both the early stage disease and advanced cancer patients (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005; Johnson, M. et al. 2015). The evidence can be broadly summarised:

- Individual patients vary in their desire for prognostic information about their cancer. These preferences may vary due to demographic, psychological and disease variables.

- Patients with early and advanced stage cancer want to be given information about cancer prognosis delivered in an 'open and honest' manner.
- Patients want information that is delivered sensitively and can support hope.
- Professionals vary in their attitudes to giving prognostic information
- Professionals want to provide care that supports patients' hope.
- Patients and professionals both aim to manage the uncertainty of the patient's situation.

The latest review, in many ways, corroborates and strengthens most of the previous findings. However, further insight has been gained around the complexity of patient desire for prognostic information and in the processes by which information is regulated and managed within a consultation. The key new findings can be summarised as follows:

- Patient desire for prognostic information is complex and patients may have ambivalent requirements around having this information.
- Patients may convey multiple understandings of their clinical situation and prognosis.
- Professionals can control information during consultations by virtue of the structure of the consultations, and so limit discussion of prognosis and prioritise treatment discussions.

The reviews of the clinically focused literature discussed in this chapter have identified gaps in the knowledge base, not only in relation to patients with early stage lung cancer, but also in the wider understanding of the interplay of hope, clinical relationships and information disclosure. There is also a lack of knowledge around how prognostic information is managed across different clinical settings and how information needs change during the period after treatment has completed. Undertaking the literature reviews have helped to formulate my own research strategy and methodological approach. The next chapter will set out in detail the aims and objectives of my study, the study methodology, and the methods used to achieve this.

4 Methodology and methods

4.1 Introduction

So far I have explored a broad range of theoretical literature and reviewed recent research that focused on prognostic communication in clinical cancer situations. This has outlined the current knowledge and highlighted areas for further research, but also helped to indicate fruitful methodological approaches to studying prognostic communication in clinical situations. This chapter builds on this knowledge and sets out the methodological underpinnings of my study and demonstrates how these led to the choice of research design.

I will begin this chapter with my research aims and objectives. Following this I set out my philosophical stance. This will be followed by an introduction of case study research design and my rationale for this choice. I will then define ‘the case’, and the criteria for selecting cases for the study. The study method will then be presented, including ethical approval, participant anonymity, data collection and recruitment. Following this there is a discussion around my data analysis strategy and the stages taken to achieve this. I will conclude the chapter by looking at the steps taken to ensure quality of research and briefly reflect on my own role as a researcher and as a clinician in this.

4.2 Research Aims and Objectives

Initial research aims were identified at the outset of the project, which were refined and developed during the study.

Study aim

The aim of the research is to gain an in-depth understanding of the communication of recurrence risk following potentially curative lung cancer surgery, from the perspective of both patients and professionals involved.

Objectives

1. To explore, using case study methodology, how a range of patients who have completed surgical treatment for lung cancer conceptualise their long-term risk of cancer recurrence, and how these change over time.
2. To understand how these patients perceive their communication needs about risk of cancer recurrence following surgery.
3. To explore how a range of health professionals caring for these patients conceptualise these individuals' long-term outcomes and identify the knowledge they draw on to form these opinions.
4. To investigate the attitudes and beliefs held by these professionals about priorities and principles of communication with patients after lung cancer surgery in general, and about long-term outcomes specifically.
5. To identify the nature and delivery of communication about risk of recurrence between this group of patients and their associated professionals during post-operative surgical, oncology and follow-up consultations.
6. To gain theoretical insight into the interpersonal processes occurring during these consultations that may regulate and tailor the information that is communicated.

4.3 Research approach

4.3.1 Philosophical underpinnings

Ontology

The ontological stance taken during this research is 'subtle realism' (Blaikie, 2007). Ontology can be conceived of as the assumptions that underpin the way we approach and understand the world - the basic beliefs about what makes up reality (Giacomini, 2010). 'Realist ontology' assumes that there is an objective truth that can be discovered, and which exists independently of people's beliefs and understandings. However, subtle realist ontology maintains that this external reality cannot be directly measured and understood, except by means of human interpretation and socially constructed meanings. Hammersley (1992) argues that the most important aspect in which subtle realism is distinct from other forms

of realism is in the rejection “*of the notion that knowledge must be defined as beliefs whose validity is known with certainty*” (p52).

Epistemology

Epistemology is how we come to know and understand phenomena under investigation and how this knowledge is obtained. The approach chosen is said to derive naturally from the ontological assumptions adopted (Giacomini, 2010). I have assumed a ‘constructionist’ epistemology within this research: an approach seen to be compatible with subtle realist ontology (Blaikie 2007). The different, and often competing, interpretations of research subjects are acknowledged. This epistemological position emphasises that humans, rather than passively receiving knowledge, actively construct their understanding from information received from their environment. Meanings are not fixed and can be fluid and change over both time and with individual circumstances or background. By studying the social and personal constructions of meaning around phenomena, research knowledge is generated. However, another key factor in constructionist epistemology is the recognition that the research process itself also has an effect on the participants and the outcomes of the research. Therefore being aware of this effect and explicitly acknowledging the impact of the researcher and the research process on participants by incorporating a reflexive element within the final report, is central to this research approach (Ormston, Spencer, Barnard, & Snape, 2014).

Axiological approach

The axiological stance of the research relates to the values of the researcher that provide the rationale for the philosophical stance. Clarifying the axiological approach allows the researcher to explicitly position his or herself and make the assumptions clear relative to the research (Creswell, 2013). The choice of subtle realist ontology and constructionist epistemology can be seen to match well with the aims of this research, which seeks to take a multi perspectival approach to gaining an in-depth understanding of recurrence risk communication. No one interpretation is taken as having greater validity than any other. The critical importance of hearing the interpretations of all participants from their own points of view is central. Different perspectives will be taken together to produce an understanding of the situation in all its complexity and depth (Ormston et al., 2014).

Studies with the greatest influence on my thinking about prognostic communication and methodological approaches reviewed in the last chapter largely adopted a similar philosophical approach (Mendick et al., 2011; 2013; Thorne et al., 2006; 2007). In contrast, studies that adopt pure realist ontology and 'positivist' epistemology that values objective assessment of an external reality tend to focus on incidence of phenomena, rather than experience and meaning (Lincoln, Lynham, & Guba, 2011; Ormston et al., 2014). Examples of studies that take a more positive approach include Cox, A. et al. (2006) and Jenkins et al. (2001). Such a stance is not aimed at elucidating how prognostic communication comes about, nor is it able to help understand why communication occurs as it does. Both these factors are central to my research aims. Some researchers go as far as to argue that adopting a positivist approach to social inquiry fails to recognise the "epistemic fallacy" of equating our interpretations and sense impressions of the world with true reality (House, 1991). Nevertheless, the opposing ontological position of 'idealism' argues that there is no external reality to be uncovered, only individual constructions and perceptions of the external world (Blaikie, 2007; Giacomini, 2010). Many research approaches using an idealist perspective have done so with the express aim of empowering people to overcome adverse circumstances. Such a stance did not match with my own research approach, due to its exploratory aims to understand both patient and professional perspectives within the context of a modern healthcare system. Ultimately my goal was to identify insights that might improve clinical practice.

Research strategy

The logical process of interpreting data in order to develop or test theory also forms part of the epistemological approach (Ormston et al., 2014). Inductive logic uses data and observation to generate knowledge about the world, whereas deductive logic tests pre-established hypotheses or theories using the data collected (Blaikie, 2007). Although in theory these reflect two opposing epistemological approaches, and researchers tend to favour one approach or the other, all studies tend to have to use both approaches to a greater or lesser extent. Inductive logic grounds the research findings in the participants' world and allows emergent ideas and concepts to be developed. This approach ensures openness to new findings and ideas, and avoids being blinded by preconceived thinking and theories. A deductive approach, on the other hand, is reflected in the use of existing

literature to identify research questions and propositions, and can also influence the data analysis process. These *a priori* themes ensure emergent themes remain congruent with the study aims and largely compatible with existing theory (Pope & Mays, 2006).

Blaikie (2007) discusses another reasoning approach called abduction. This is the process of using participants' own understanding and description of events (known as first order constructs) to develop a technical account (known as second order constructs). Blaikie argues that much social life is routine and habitual, and happens on an automatic or unquestioning level. This means that participants are often not able to reveal their motivations and meanings that underpin their interactions directly. Abstraction allows a deeper exploration of lay accounts and understanding. Professionals' accounts can also provide an opportunity to gain an understanding of tacit knowledge involved in their skilled habitual actions (Blaikie, 2007). Abduction can therefore be seen as an essential process in moving findings beyond description, to a higher level of analysis, abstraction and theory development.

4.3.2 Case study research

Taking my subtle realist ontology and constructionist epistemology positions, combined with the findings from the literature, I chose to adopt a qualitative case study design in this research. I needed to understand the multiple realities of both patients with lung cancer, and the professionals involved when discussing possible cancer recurrence following surgery. The broad research aims necessitated a qualitative approach and various methodologies were considered, including ethnography or grounded theory (Bryman, 2008; Carlson, Feldman-Stewart, Tishelman, & Brundage, 2005; Creswell, 2013; Silverman, 2011). Ethnography was discounted early, due to practical considerations around ease of access to relevant points of the care pathway, as well as a need to focus on the workings of a whole system or department, rather than individual interactions. A grounded theory approach might have been a viable alternative choice for this study. Ultimately, it was a case study approach that I saw as offering the best fit with my research aims.

Case study research has been increasingly used within social science and nursing research (Anthony & Jack, 2009). The research approach has resonance with practicing nurses and

other healthcare professionals who wish to explore issues within the context of their healthcare setting (Clarke, C., Reed, & Keyes, 2015). Two principal approaches have been described, one by Robert Yin, and another by Robert Stake (Baxter & Jack, 2008; Clarke, C. et al., 2015). A commonly quoted definition of case study research is:

... an empirical method that

- *investigates a contemporary phenomenon (the 'case') in-depth and within its real-world context, especially when*
- *the boundaries between phenomenon and context may not be clearly evident.*

(Yin, 2018, p15)

There were two elements of this definition that had particular resonance with my investigation. First was investigating prognostic communication in its “real-world” context, in this situation, observed communication during clinical consultations. Second was the recognition that the boundaries between prognostic communication and the context in which it occurs would be difficult to identify. Ultimately, the case study approach emphasised maintaining the integrity of interaction between individuals within the design of the study. This meant handling the data in a way that preserved the links between patients and professionals and the context in which events occurred.

The definition of case study research offered by Yin is also reflective of Stake’s approach (Stake 2013). Both emphasise using multiple sources of evidence as the basis of the study, such as interviews, observations, and documents (Creswell, 2013). Stake’s approach sits firmly within constructivist epistemology, and is explicitly qualitative in its approach (Stake, 1995; Stake, 2013). On the other hand, Yin concedes that much of his writing about case studies often takes a more positivist line. Despite this, Yin argues his approach is capable of embracing different epistemological orientations (Yin, 2018). Commensurate with this ‘broad-church’ approach to philosophical traditions, Yin is not prescriptive about the type of evidence that might be used in a case study and identifies both qualitative and quantitative methods as suitable for inclusion. In this sense, Creswell (2013) views Yin’s case study approach as a research design, rather than a research method. In contrast, Stake sets out extensive and detailed procedures for undertaking and analysing a case study (Stake, 2013). Ultimately, Stake’s detailed methods have not been adopted in this study, and it is the principles of both approaches that have been employed in developing this research.

Whilst there are strong similarities in the overall case study design, the nomenclature they use is often divergent. Yin and Stake conceive of case studies that explore a single case, or take a multiple-case design. Yin describes the logic of a multiple-case study as that of a series of experiments, in which the researcher is attempting to replicate findings, or see divergent results for reasons that can be anticipated (Yin, 2018). Central to the case study research approach is defining what constitutes the case and its boundaries. A case is not necessarily an individual, but might be as diverse as a neighbourhood, an institution, an event, or a decision (Stake, 2013; Yin, 2018). Determining the boundaries to that case is an essential, and often challenging, step within case study research. The less concrete the case, the more difficult the case boundaries are to describe. Defining the case is reliant on the specific aims of the research, as well as reciprocally helping to clarify those aims (Clarke, C. et al., 2015).

Yin (2018) makes a distinction between what is seen as the 'case' and the 'unit of analysis' in a case study design. Whereas the case is the area of interest – in my case communication of recurrence risk - the unit of analysis is about how the data is organised, analysed and viewed. The unit of analysis for this study was taken as the individual patient and all the collected data around that patient. An alternative option might have been to take the unit of analysis as the lung cancer MDT. This would focus analysis on prognostic communication with patients within each MDT rather than at the individual patient level. Such research might then be more interested in MDT culture and practice, rather than interactions on a level of individual clinicians and patients. Each of these different ways of focusing on the research subject is valid, but the choice of the unit of analysis alters the focus of the study. Having the unit of analysis at the patient level within a multiple case study design directs analysis to this individual level, while team practice and culture remains at a more contextual level.

Stake and Yin also set out differences in the overall aims of case study designs that might change their focus. Stake described intrinsic and instrumental case studies (Stake, 1995). Intrinsic case studies aim to understand the particular issues within a case and are often single case studies. The aim is not to find out about a wider population, but to study the

case for the insight gained from the study of that specific case. Instrumental cases, on the other hand, aim to achieve a wider understanding of the subject. In a similar way Yin talks about exploratory, descriptive and explanatory case studies (Yin, 2018). Exploratory and descriptive studies tend to be focused on the particular, whereas explanatory case studies aim to shed light on wider applicability and theory building. The research design I have adopted could be described as a multiple qualitative instrumental case study.

Criticism of case study research

Case study research has faced much critical discussion, with some declaring that it does not constitute research at all (Flyvbjerg, 2006). Much of this criticism appears to come from misconceptions and confusions about what it is. Educational use of the term as a teaching tool in nursing and medicine has tended to cloud understanding of case study as a research methodology (Anthony & Jack, 2009; McGloin, 2008). However, lack of generalizability and rigour are the principal criticisms of the approach (Flyvbjerg, 2006; Houghton, Casey, Shaw, & Murphy, 2013; McGloin, 2008; Yin, 2018). Others have argued that poor methodological clarity has left the approach open to criticism (Anthony & Jack, 2009; Corcoran, Walker, & Wals, 2004).

Broader issues in research quality will be addressed below. However, the particular issue of generalizability of case study research findings to a wider context lie at the heart of concerns about the approach and is a methodological conundrum. Stake identifies a tension between generalization and particularisation in all case study research (Stake, 2013). He argues that careful framing of research questions that prioritise the wider applicability of the findings and the relationship to theory are an important element of the study design. Similarly Yin also places theory development centrally in the rationale of case study design and emphasises the role of analysis in this process (Yin, 2018). For this to occur analysis needs to take place at a higher conceptual level than simple descriptive findings of the original cases, and it is this that can provide findings that advance theory with wider general applications. Yin argues that this can be achieved by means of a single-case study, and cautions against seeing cases within a multiple-case study as being a 'sample' in the sense used in the quantitative research tradition. Such samples are carefully selected so as to be statistically indistinguishable from the total population in question. In contrast, the cases in

a case study should be selected on the basis of theoretical need within the replication logic of the methodology (Yin, 2018). The replication logic is seen to give enormous analytic benefits and to strengthen the overall case study.

4.4 Components of the research design

The initial steps of case study design include identifying the study questions, developing study propositions, or issues, and defining and bounding the case.

4.4.1 Study questions

Yin (2018) suggests that identifying 'study propositions' help to refine research questions and direct what evidence is collected. In a similar way, Stake (1995) advises the identification of 'issues' to help with focusing the research process. Researchers with some inside knowledge of the area being studied are seen to be at some advantage at this point, as they have some idea about the processes involved and a conception of the key issues. As a specialist nurse working with patients with lung cancer, my insider knowledge of the processes, access and understanding of where to look for information was invaluable at this point. This very closeness and understanding of the topic, however, also makes it easy to miss obvious issues, due to their apparent 'every day' quality. Implications of this 'emic' (insider) and 'etic' (outsider) researcher perspective will be revisited later in the chapter.

Using this emic position I identified some initial study propositions that were used in further developing the study research aims and objectives. These included:

- Professionals from different disciplines will have distinct attitudes and beliefs regarding disclosure of recurrence risk information to patients
- Patients' understanding of recurrence risk following surgery will develop over time after their surgery
- Patients who are offered adjuvant chemotherapy will be given and/or seek information about recurrence risk to aid treatment decision-making

Following completion of the literature review early in the research process I was able to use the thematic framework that was developed to help identify issues and research propositions and generate a range of preliminary study questions (Johnson, M., Collins,

Brummell, & Tod, 2015). I then developed and refined these questions in relation to the specific study focus and used the study propositions to finalise the stated research aims and objectives.

4.4.2 Bounding the case

Both Stake (2013) and Yin (2018) discuss the importance of clarifying the boundaries of what constitutes the case under investigation prior to data collection. These boundaries flow naturally from the specific research aims. Bounding the case imposes limits on what data are collected, focuses the inquiry and helps to stop the researcher getting side tracked into interesting, but essentially irrelevant issues. By bounding the case I was able to identify the important sources of data, place limits on the timescale over which data were collected, and to identify the key data collection points.

The focus of this case study was on the disclosure of recurrence risks following lung cancer surgery. Practice at the surgical units in this study was for almost all patients to be told about their surgical results and plans for onward management at the first post-surgical follow-up consultation. I therefore chose to start the cases at the point of the first post-operative surgical appointment. One of my central study aims was to understand how the issue of recurrence risk was discussed by different disciplines and also how patients coped with the risk of recurrence over time. Therefore I needed to include the subsequent oncology, or surveillance consultation. Interviews with the professionals present in these consultations also formed part of the case. I decided to follow-up patients over the first six months after surgery with patient interviews. I chose this time period as patients undergoing adjuvant therapy would have completed treatment, and so all patients would have undergone surveillance scans and recovered from their surgery. Surrounding the case itself, were things that gave context to the case, such as the surgeon's operation note, the written pathology report, and the written LMDT meeting outcome. Although not directly part of the cases, such documentary evidence was included to provide a rich background to each case. The diagram shown in figure 4.1 was developed to aid definition and in bounding the case.

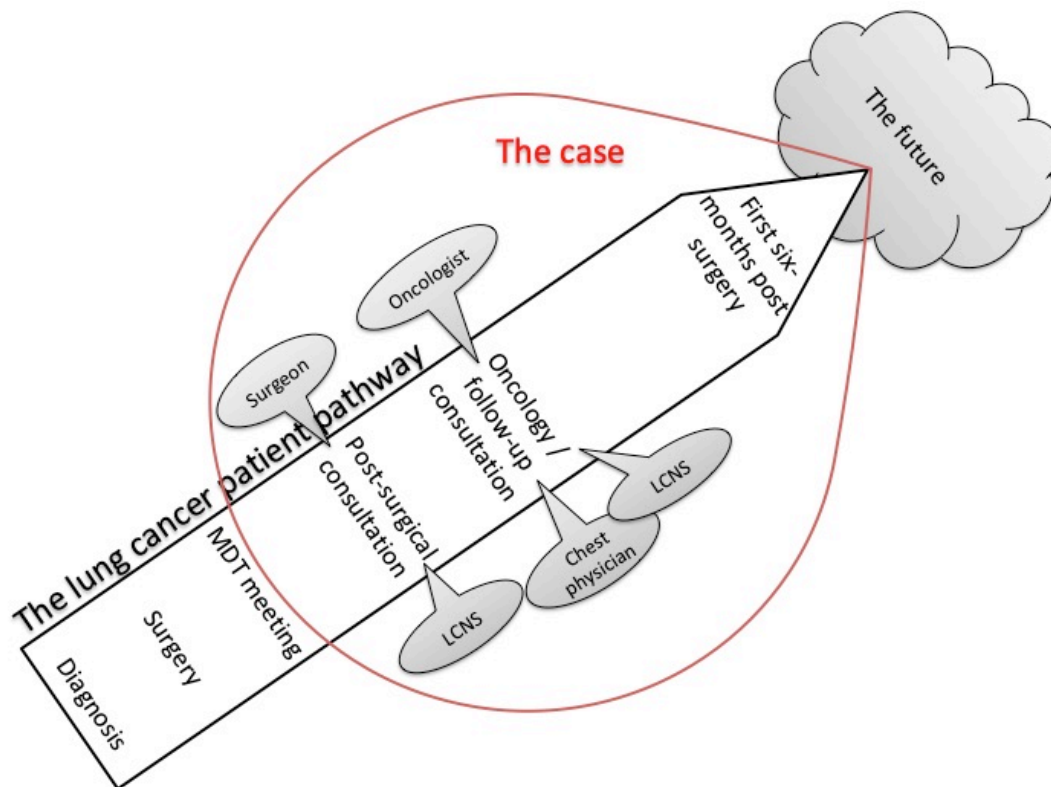


Figure 4.1 Boundaries of the case

By choosing the boundaries of the case as I did, I wanted to avoid seeing prognosis disclosure as taking place at a single time point. However, the limitations of this are evident. Patients may discuss prognosis and outcomes from the point of diagnosis of lung cancer onwards. Some surgeons may include discussion of recurrence risk and long-term survival as part of the surgical informed consent process. Some patients may be given news of their surgical pathology results during their in-patient hospital stay. Patients may also talk with their LCNS separately after the consultation, which may cover recurrence concerns. Clearly it was not possible as a researcher to be present to observe all these potential recurrence risk discussions take place. Similarly the diagnosis, adjuvant treatment visits, and subsequent follow-up consultations are occasions where discussion about prognosis might occur, but did not form part of the case itself. Information about these elements was gathered through the patient and professional interviews.

4.4.3 Case selection strategy

Determining the number of cases used within a multiple-case study design is a challenge. What constitutes 'a case' is not defined. As such, the size and complexity of each case study will vary. Nevertheless, Stake suggests a range of between four and 15 cases are ideal. Less

than four might be insufficient to illustrate patterns between cases, and more than 15 could result in such large amounts of data that researchers would not be able to deal with it effectively (Stake, 2013). I made an initial decision to recruit ten cases, as this number would allow me to incorporate a range of patients on different treatment pathways and across the study sites. The choice of ten cases also recognised the multiple sources of data within each case that would result in relatively large and complex data sets.

It was clear from the study questions and propositions that I needed to include a mixture of patients that would go on to have adjuvant therapy, as well as those who entered into long-term surveillance straight away. I therefore selected patients to approach with a wide range of preoperative clinical cancer stages. Amongst those patients who met the criteria for adjuvant therapy, I also aimed to obtain the perspective of those who actually underwent treatment, as well as those who did not. However, as this decision was made after the recruitment phase, I had no control over this element of the included cases. In order to achieve this range of cases, I therefore actively sought sufficient numbers of patients with clinical staging II or III lung cancer.

Some qualitative research approaches use the concept of ‘data saturation’ to determine when sufficient participants have been included in a study. Data saturation is the point when recruiting further subjects yields no new themes during a study. Some authors have even attempted to quantify the number of interviews required to achieve this (Hennink, Kaiser, & Marconi, 2017; Malterud, Siersma, & Guassora, 2016). Case study research, in contrast, does not follow this logic. Rather, the principal aim is to generate detailed in-depth analysis preserving the context and richness of the events under examination (Stake, 2013). Therefore, number and selection of cases in this study aimed to capture the diversity of cases and management plans and not to make claims about achieving data saturation.

4.4.4 Data collection strategy

The aim of case study methodology is to use multiple sources of data in order to build a rich picture of the cases being examined (Flyvbjerg, 2011). The process of ‘triangulation’ is commonly cited as an important factor in the robustness of qualitative case study research (Creswell, 2013; Stake, 2013; Yin, 2018). The concept comes from navigation whereby taking

two or more separate bearings can accurately pinpoint a true position. Some question the epistemological congruity of this logic in social research, arguing that we can never fully know the ultimate true version of reality (Hammersley, 1992). Others challenge the legitimacy of bringing together different qualitative methods with differing analysis approaches and assumptions (Barbour, R. S., 1998). Nevertheless, there is recognition that the use of multiple sources of data can provide diverse ways of looking at the research question, and deepens the overall understanding (Lewis, Ritchie, Ormston, & Morrell, 2014; Mays & Pope, 2006).

In this study I have used triangulation to mean the use of numerous forms and sources of data in order to build up a rich and complex picture of the events under examination. Using multiple sources can be seen to be like viewing the phenomenon through “*a variety of lenses*” in order to reveal its “*multiple facets*” (Baxter & Jack, 2008, p544). Such an approach, however, does not aim to validate or discount one particular perception or account over another and to find a unified truth. Rather it seeks to reflect the intricacy of the different perspectives and to gain insight into the way in which these interpretations come together and interact. I therefore chose to include in-depth interviews with the patient cases and their linked professionals, observation of the first two consultations after surgery, as well as collecting documentary evidence from the LMDT meeting, pathology reports and operation notes, in order to view the many perspectives involved in these cases. Figure 4.2 illustrates the data sources that were used to inform each case in the study used to fulfil the research aims.

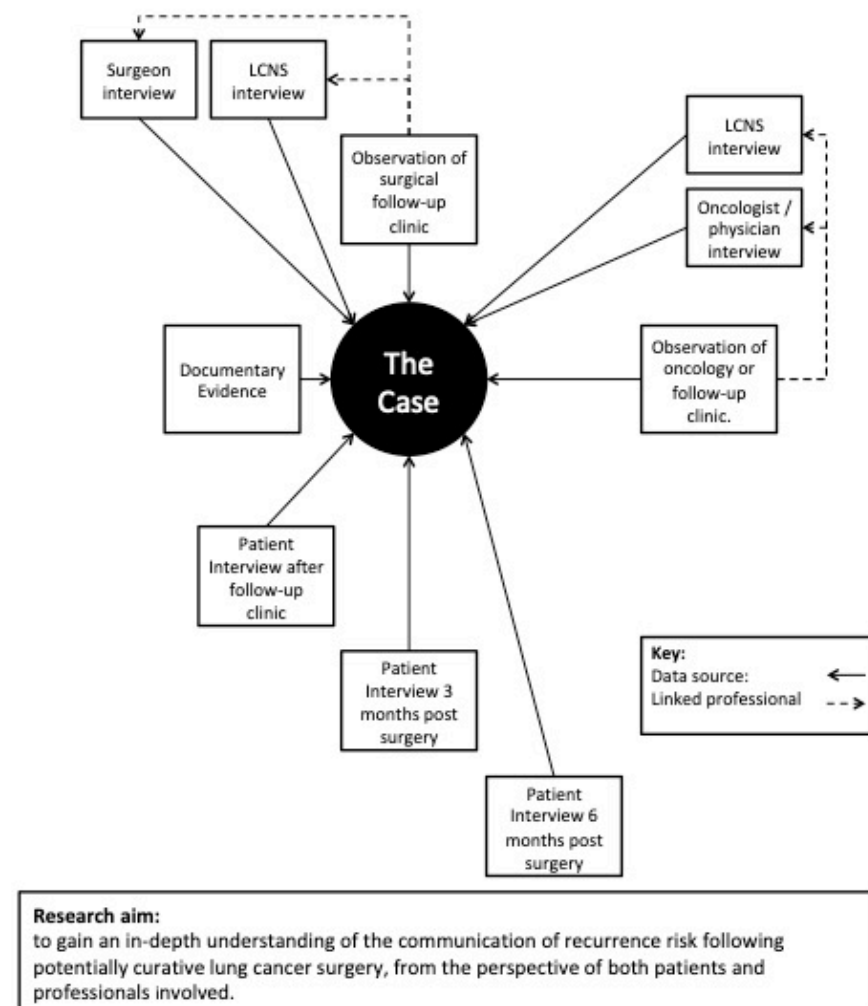


Figure 4.2 Data sources used to inform each case

4.5 Study method

The following section will outline the processes and steps undertaken in setting up the study, recruitment of participants and collection of data.

4.5.1 Ethical approval

I developed and finalised a study protocol as part of the preliminary study processes that included ethical committee and research access approval. The university Faculty Research Ethics committee approved the study on 1st June 2015 (reference: HWB-HSC-31). Health Research Authority research ethics committee (REC) gave study approval on 27th July 2015 (reference: 15/LO/1183). I later submitted a major study amendment to the REC when I wanted to include an additional study site. Approval for this was given on 24th August 2016.

I was given NHS Research and Development approval from all participating sites of the study. Copies of approval letters are available in appendix 6.

4.5.2 Research governance and access

During the conduct of all aspects of the study I applied the principles of Good Clinical Practice, as described in the Research Governance Framework for Health and Social Care (Department of Health, 2005). As a Registered Nurse, I also undertook all aspects of the research in accordance with the Nursing and Midwifery Council Code of Conduct (NMC, 2018). My university provided study sponsorship and research indemnity. I undertook research ethics and governance training through the National Institute for Health Research (NIHR) and research participant consent training via my employing hospital trust.

The research supervisory team provided formal study oversight through regular meetings to review progress and undertake reflective discussions. Research access was granted by each of the study sites where I did not have an employment contract. I compiled a study master file, which was kept securely on the main study site, according to the requirements of the principal hospital trust. I managed all study data in accordance with the university Data Management Policy, Research Data Management Policy, NHS Caldecott Principles (Department of Health, 2003), and the Data Protection Act 1998. These principles were reflected in the Data Management Plan that I developed before I began data collection (see appendix 7).

4.5.3 Treatment pathways for patient participants

The study involved three local lung cancer teams based in local hospitals, plus two separate thoracic surgical units. Figure 4.3 illustrates the relationships between the local LMDTs and the surgical pathways followed by patient participants. The local hospitals were located in socio-demographically and geographically diverse areas. LMDT 1 was at a hospital in a medium size town located in a largely rural area. LMDT 2 was in a city-based teaching hospital, and LMDT 3 was in a suburban district.

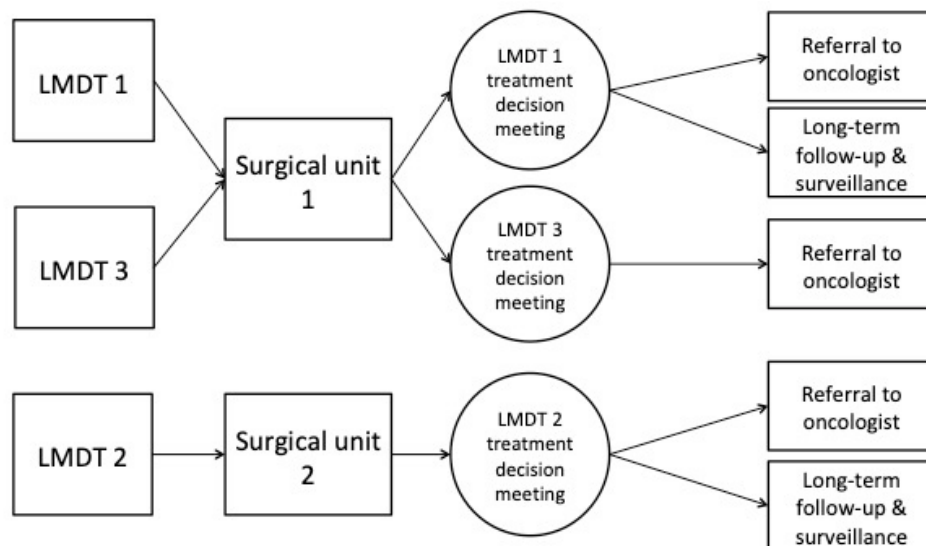


Figure 4.3 Patient pathways

Patients were referred from the local LMDT to one of two specialist units for their surgical treatment. These were both based in tertiary hospitals. Surgical unit 1 was in a suburban area. Surgical unit 2 was a city centre location. Following surgery, patients were discussed in their local referring LMDT meeting to ascertain if they would be offered an appointment with an oncologist to discuss adjuvant treatment, or commence long-term follow-up. Patients attended a post-surgical follow-up consultation two to eight weeks after their discharge, either at the surgical unit, or at their local hospital. The subsequent oncology, or follow-up consultation took place in the local hospital.

4.5.4 Participant anonymity

Throughout the conduct of the study I was conscious of the need to protect the privacy of all participants as far as was possible. Patient participants were anonymised at the point of recruitment, initially using a study code and during writing-up by pseudonym. These were alphabetically allocated according to recruitment timings (Audrey, Barbara, Cathy, Denise, Edward, Fiona, Glennis, Henry, Jane, Kamal, Len and Maggie). References to particular place names were removed. Where specific details of a patient's case might be likely to lead to identification I tried to write using more general terms, or if non-material, omitted altogether. Staff participants were allocated a number and their discipline, such as *Surgeon 1*. Full details of the locations of the study sites have been omitted during the writing-up of this study to help to prevent accidental identification of professional participants, due to the small numbers of any particular discipline working within an LMDT. However, despite such

precautions, I recognised that identification was still possible. A review by Allmark et al. (2009) highlighted the limitations to confidentiality, particularly in studies using interviews. While participants may be anonymous to a general reader, individuals might still be recognisable to people with inside knowledge. I tried to address this by adopting a reflexive and sensitive approach to the way in which I presented participants in all study output.

4.5.5 Patient participant inclusion / exclusion criteria

Inclusion and exclusion criteria were developed. The target group of patients were those with lung cancer undergoing potentially curative surgery. Although some patients did not have histologically confirmed diagnosis of lung cancer prior to surgery, patients were aware that lung cancer was a likely diagnosis. Patients who later were confirmed not to have a lung cancer would be discontinued from the study, although this situation did not arise post recruitment. No restriction was placed on the stage of lung cancer, although patients where the surgeon did not resect all visible tumour, a so-called “open and close” procedure, were excluded. Due to the qualitative nature of the study and reliance on interviews and observations of consultations, I chose to include only patients able to speak fluent English. There was no facility for translation services. The need for translation was also felt to be a significant barrier to in-depth understanding of meaning and language use, central to the methodological approach. Another major consideration was to avoid causing patients unnecessary distress, or exacerbating existing psychological or psychiatric conditions by taking part in the study. Therefore patients who were experiencing unusually high levels of psychological distress were excluded from the study. The judgement about this matter was left to the assessment of the team caring for the patient at the time they were recruited. Full inclusion / exclusion criteria are displayed in Table 4.1.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Patient has had a surgical resection for primary lung cancer • Patient is aware they have or are likely to have lung cancer • Patient has not yet been seen in the first follow-up clinic • Patient referred from hospitals that are included in the study • Able to speak fluent English 	<ul style="list-style-type: none"> • Patients who do not meet the inclusion criteria • Patients under 18 years of age • Patients unable to give informed consent to participation in the study • Patients undergoing surgery where the aim is not curative (ie surgical biopsy, tumour de-bulking, 'open and close' surgery). • Patients with a diagnosis of carcinoid tumour with no atypical features • Patients with a diagnosis of mesothelioma • Patients judged by the clinical team to be emotionally or psychologically unstable

Table 4.1 Study inclusion and exclusion criteria

4.5.6 Identification, recruitment and consent of patient participants

Potential patients were first identified during their surgical admission. Figure 4.4 outlines the process of identification and recruitment of patient participants included in the study.

I met regularly with the LCNS teams working on the two surgical units to discuss the study and recruitment. The LCNS approached suitable patients and gave them an information sheet (PIS) about the study. They then asked patients for permission for me to come to discuss the study further with them. I approached willing patients, spoke about the study and answered any questions. Interested patients were given at least 24 hours to think about participation before signing a written informed consent form (ICF). In practice, this meant written consent was usually taken just prior to the post-surgical consultation. Patients were usually aware of my clinical role and I recognised the potentially coercive influence this might have. Therefore, I particularly stressed the voluntary nature of participation in the study and emphasised withdrawal could take place at any time during the study without it affecting their normal care. Continued consent was checked at each stage of the study, such as before each observed consultation or interview they took part in. The patient PIS and ICF forms are included in appendix 8.

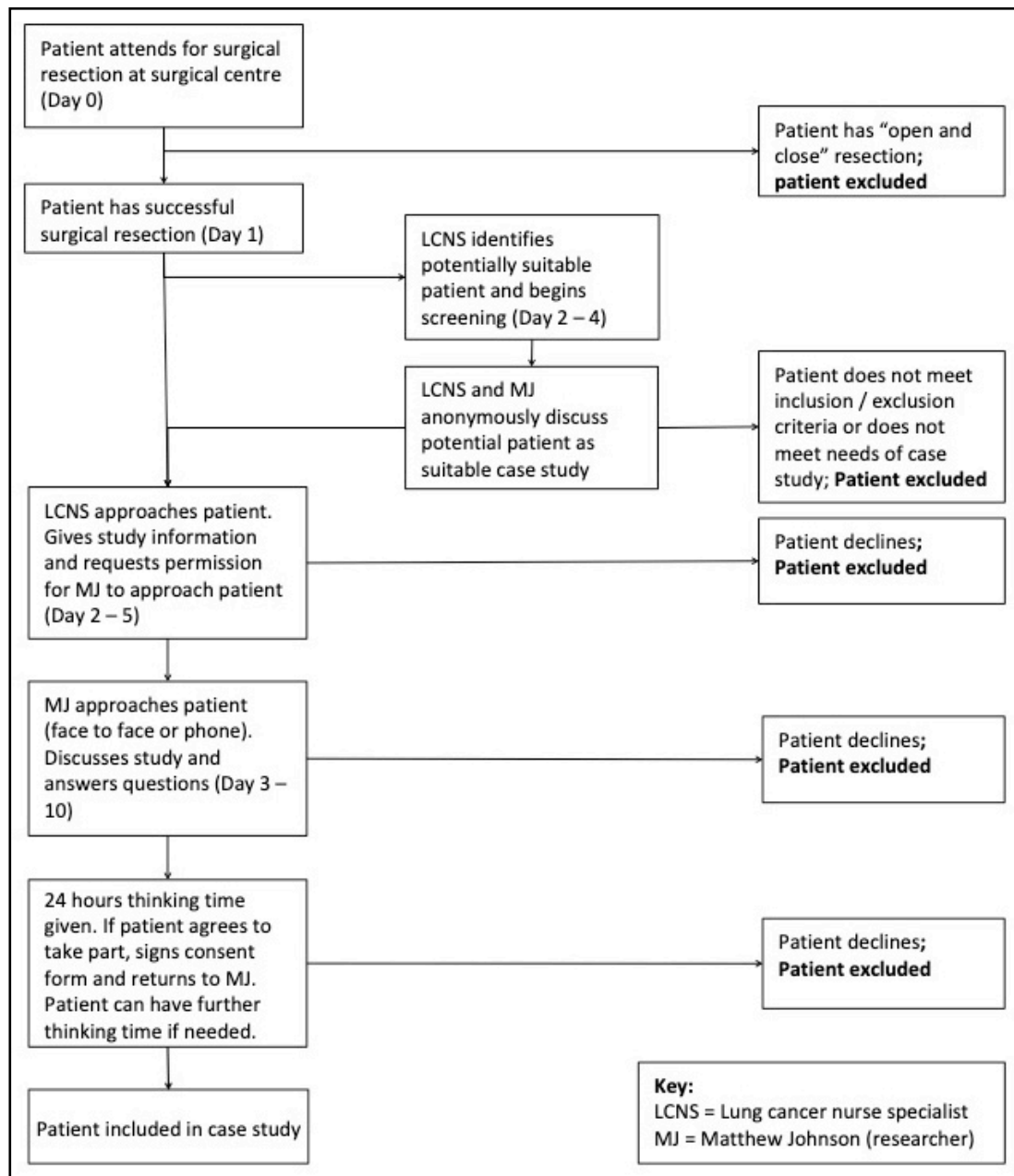


Figure 4.4 Patient participant recruitment flowchart

4.5.7 Recruitment of professional participants

Prior to commencing the study I approached members of the LMDT at the referring hospitals. A briefing sheet and professionals' PIS were given to relevant team members. I offered to meet with individuals or teams to discuss the study further. This was taken up by one LMDT, and was a chance to talk directly to the team about the project and to answer questions about their potential involvement.

When a recruited patient participant was scheduled to be seen in a clinic I approached the staff who were potentially going to see that patient to discuss the study and gave them an individual copy of the PIS. As soon as it was clear which professionals would actually see the patient in the consultation we completed written consent forms. If a member of the clinical team who was due to see a participating patient declined to take part in the study I asked if it was possible that someone else in the team might be able to see the patient. This happened on one occasion when an LCNS declined to take part in the study. PIS and ICF for professionals are available in appendix 8.

4.6 Participants

In this section I will briefly outline the 12 patients who were central to the study cases and account for patients who were screened, but were not recruited. I will then outline the professional participants who were included in the study cases.

4.6.1 Patients

Twenty-five patients were formally screened for inclusion in the study. A total of 12 patients were recruited. Eight of the participants were female. The average age was 67 years, with the youngest patient 57 and the oldest 77. Nine participants had a white British ethnic background, one was Irish, one had a non-British white background and one was Indian. Ten of the participants were married or living with a partner.

Thirteen screened patients were not included as final study participants. Basic demographic details and reasons for not including patients in the study are given in table 4.2. Five patients declined to take part in the study. Three patients did not meet the inclusion / exclusion criteria once their history was explored in more detail. Two patients were not included due to problems with my attendance at their consultation appointment and one as the study site was not yet open. One patient was excluded as they did not meet the required purposive sample because they had an early stage cancer. One patient who had consented to take part was subsequently re-admitted to hospital and died before their post-surgical consultation.

Reason for non-inclusion	Details	Age	Sex
Screen fail	Second of 2 synchronous primaries, already seen in clinic	75	Female
	Already seen in post-surgical consultation	67	Female
	Surgical outcome indicates likely primary bowel cancer	55	Female
Withdrawn	Researcher unable to attend planned surgical follow up date	76	Male
	Researcher unable to attend planned surgical follow up date	Missing data	
	Withdrawn as LMDT 3 not yet open as a site	70	Male
Purposive sampling	Clinically stage I: Does not meet purposive sampling criteria	67	Male
Patient declined	Declined first contact	75	Female
	Declined first contact	Missing data	
	Feels too unwell to take part	82	Male
	Too anxious and mentally fragile	78	Female
	"Not really my bag"	67	Male
RIP	Patient readmitted and died as in-patient at local hospital	75	Male

Table 4.2 Patients not included in case study

The recruitment target had been 10 – 12 cases. Recruitment continued beyond 10 cases partly due to two patients who did not completed the longitudinal interviews. An additional consideration in the decision to continue recruitment beyond 10 cases was the inclusion of only two oncologists talking about adjuvant chemotherapy and a single chest physician by this point. The final two cases included an extra chest physician and oncologist.

4.6.2 Professionals

Twenty healthcare professionals were recruited and took part in the study. These comprised eight surgeons, six LCNS, four oncologists and two chest physicians. Two additional professionals consented to take part in the study (Surgeon 7 and LCNS 5), but in the end they did not actually see any of the patient participants. For reasons of participant anonymity demographic details collected on professionals were very limited. An overview is given in table 4.3.

Team	Professional participant	Grade	Sex
LMDT 1	Surgeon 1	Consultant	Female
	Surgeon 3	Consultant	Male
	Surgeon 4	Registrar	Female
	Surgeon 8	Consultant	Male
	Oncologist 1	Consultant	Male
	Oncologist 2	Consultant	Female
	Chest Physician 2	Consultant	Female
	LCNS 3	Nurse (surgical consultation)	Female
	LCNS 4	Nurse (surgical consultation)	Female
LMDT 2	Surgeon 2	Registrar	Female
	Surgeon 5	Registrar	Male
	Surgeon 6	Registrar	Male
	Oncologist 3	Consultant	Male
	Chest Physician 1	Consultant	Male
	LCNS 1	Nurse (surgical consultation)	Female
	LCNS 2	Nurse (nurse-led follow-up)	Female
LMDT 3	Surgeon 9	Consultant	Male
	Oncologist 4	Consultant	Female
	LCNS 6	Nurse (surgical consultation)	Female
	LCNS 7	Nurse (medical consultation)	Female

Table 4.3 Details of professional participants by LMDT

One additional professional was approached to take part in the study, but declined participation. This was an LCNS who was due to see a patient participant (Glennis) during her surgical consultation. Another LCNS agreed to attend the consultation with the patient (LCNS 1) and was interviewed as part of the study.

Each of the 12 cases centred on a single patient participant and was associated with between two and four professional participants during the study. Many of the professionals were linked with more than one of the patient participants. The professionals associated with each case are set out in figure 4.5.

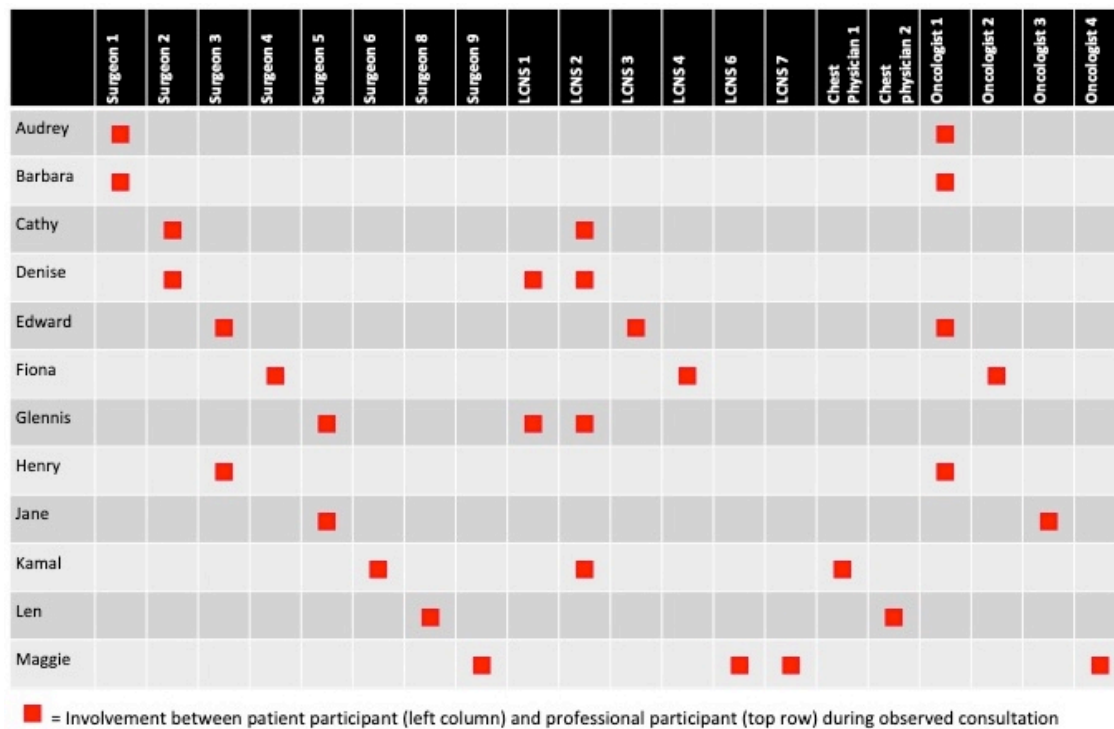


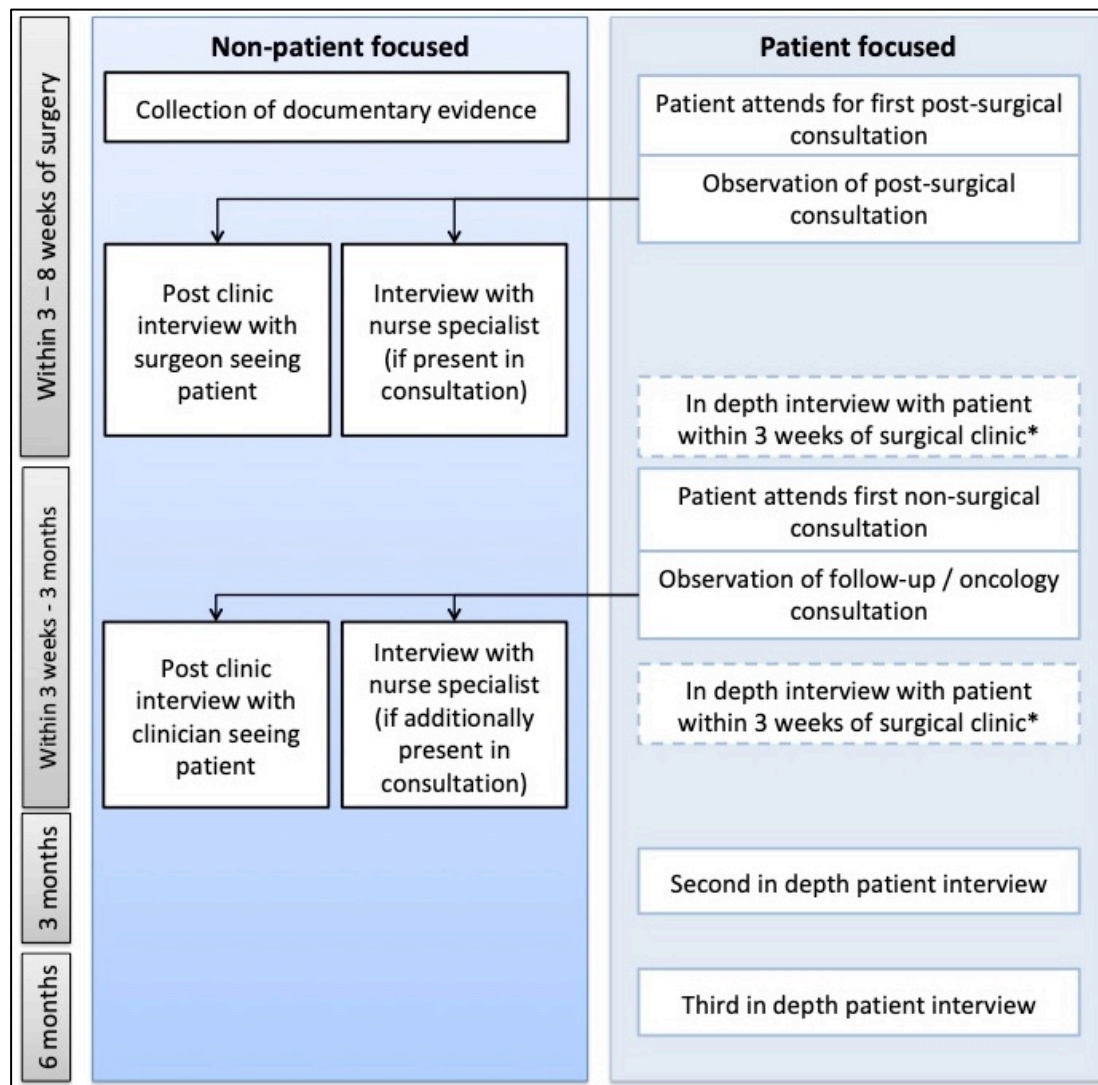
Figure 4.5 Patient participants and associated professional participants

4.7 Data collection

Data collection commenced once written patient consent had been obtained. Multiple sources of data were collected during the study. Figure 4.6 gives an overview of data collection sources and time points.

4.7.1 Documentary data collection

I collected background information for each patient participant using a standardised patient Case Record Form (CRF). This covered biographical information about the patient and details of clinical cancer staging, operation type, pathological staging and MDT outcome. The form was also designed to track subsequent clinic appointments and schedule follow-up interviews. A short CRF for each professional participant was also created that covered brief details about their role and to link them to the patient cases. A copy of a patient CRF form is available in appendix 9. Anonymised copies of the patient's operation note, pathology report, and LMDT outcome were collected.



* First patient interview may take place before or after non-surgical consultation depending on timing of clinic appointments

Figure 4.6 Data collection points and time scales

4.7.2 Observation and recording of surgical and non-surgical clinics

At the beginning of the patient's consultation I briefly reaffirmed consent from all parties for recording of the consultation and I placed a portable digital audio recorder in participants' sight. I stayed in the room during the consultation as an observer, and where possible, attempted to remain outside the discussion. However, my role as a senior nurse was widely known and it was not possible to be a true non-participant during consultations. I therefore describe my role as 'observer-as-participant' (Booth, J., 2015). I will discuss this further later in my reflexive account. I made observations about the consultation using a field note form. This included room layout, participant affect, and notes of key points that I wanted to refer back to during the subsequent interviews with participants. These notes were essential in recalling specific points, words or phrases used during the consultation, particularly if

interviews took place immediately following the clinic visit before I could listen back to the recording. A copy of the consultation observation form is available in appendix 9. After the consultation I also wrote notes in the research log, reflecting on the discussion and the roles of each of the participants.

Observed consultation recordings were transcribed as soon as possible following the event. I undertook this myself, so I could recall the events clearly and ensure I was aware of individual speaker's contributions. Transcriptions were verbatim, whilst remaining congruent with the purpose of the data. This meant including non-verbal vocalisation, such as sighs, laughs, repetitions and strong emphasis. I was able to record interruptions of speech or where more than one speaker was speaking at the same time. Pauses and hesitations were included, but pause timings and details of intonation were not. Transcription conventions used are available in appendix 10.

4.7.3 Interviews with staff participants

Following the consultation I arranged to interview the professional leading the consultation and the patient's LCNS, if they were present. Clinics were usually busy and scheduling these for the same day as the consultation was challenging at times. Depending on the timetable of the staff member and the feasibility of scheduling interviews in distant locations I carried out a mixture of face-to-face and telephone interviews. Normally there were conducted in a quiet, non-clinical environment. However, the only opportunity to interview one surgeon was in theatre between cases (Surgeon 3 about Henry). Distractions and time pressure meant this was the shortest of all interviews and yielded little useful data.

Interviews followed a topic guide and were conversational in nature (Tod, 2015). Topic guides are available in appendix 11. Guides were developed from the research questions and study aims. In total there were 30 interviews completed with 20 professional participants. Interviews lasted an average of 29 minutes (range 10 – 60 minutes). Eighteen interviews were conducted face-to-face and twelve over the telephone. The average length of interview was the same regardless of method. Field notes and reflections were captured in the research diary after each interview (see appendix 12 for an extract of the research diary).

I used a commercial transcription service to transcribe the interviews. I checked these for accuracy against the audio recordings and updated for omissions, misheard words, significant non-verbal points, as well as ensuring that the final text was anonymised. This process also assisted me to become fully immersed in the data.

4.7.4 Interviews with patient participants

After the surgical consultation, if the patient had a planned appointment with either the oncologist, or with the respiratory team within a window of three weeks, I arranged to interview the patient after the second consultation. If there was no immanent appointment, the initial patient interview took place after the post-surgical visit. Scheduling of this was flexible to try and accommodate patients' needs, so face-to-face and remote interviews were offered. Interviews were in-depth, open and conversational, and followed the planned topic guide (see appendix 11).

Eleven of the 12 patient participants completed an initial interview. One patient (Jane) declined to be interviewed and did not undertake any interviews for the study. She felt overwhelmed by her situation, both relating to her cancer treatment and also due to wider social issues, and did not feel able to undergo this aspect of the study. Average length of the first interview was 51 minutes (range 26 to 83 minutes). Eight interviews were conducted face-to-face in the hospital environment. Three patient participants elected to have a telephone interview. Interview field notes were completed about each interview and entered into the research diary.

I had not planned to involve partners in the interviews. However, excluding partners felt awkward and challenging for participants, especially when a family member had been closely involved during the preceding consultation. On four occasions the patient's partner was present during the interviews. With the first patient I interviewed, Barbara, her husband assumed he would be included and came into the interview room before I could stop him. In this circumstance I did not feel able to ask him to leave the room. This interview did give some insights that might not have occurred without her husband there. Subsequently, where a family member expressed a wish to be present, they joined the

interview. Each interviewee did undertake at least one interview without anyone else present. Unfortunately explicit written consent was not taken separately from the patient's relatives when they came into patient interviews. However, verbal consent and discussion of the recording and the use of the data was covered at the beginning of each interview. For this reason direct quotations from relatives during interviews have not been included in the thesis, although contributions made during consultations have been used.

Patients' first interviews were completed within three weeks of the post-surgical consultation with two exceptions. One patient (Len) completed their interview 31 days after the surgical consultation, due to delays during the respiratory follow-up consultation. In the end we agreed to defer the interview until the following week and it was conducted via phone. For the other patient (Cathy), scheduling an interview was particularly problematic, despite offers for a telephone interview. It was finally completed on the day of a respiratory appointment at the patient's local hospital on day 132 after the post-surgical visit. Following this appointment we made a mutual agreement not to undertake further interviews as part of the study, due to her increased levels of emotional stress caused by discussing her surgery.

4.7.5 Longitudinal patient interviews

Ten of the patient participants completed interviews on two further occasions each. Cathy only completed the first interview and Jane declined to take part in any interviews. This resulted in a total of 31 patient interviews within the study. (See appendix 11 for topic guide for the second and third interviews). Attempts were made to complete these longitudinal interviews at three and six months after the surgery. In practice, time scales slipped for many of the participants. This was particularly true of patients who went on to have adjuvant therapies. Reasons for having to delay interviews were often related to treatment schedules or periods when the patient was not feeling well and was unable to complete an interview until later.

The second interviews averaged 40 minutes in length (range 27 – 50 minutes). Four of the second interviews were conducted face-to-face; five were by phone and one via Skype. During only one interview was there a family member present (Audrey with her son). The

final interviews with patients were slightly shorter on average (37 minutes, range 17 – 58). Seven were conducted face-to-face, two by phone and one via Skype. The wives of the patients Henry and Kamal were present during their final interviews. Transcription of all the patient interviews was handled in the same manner as those with the professional participants.

4.8 Data analysis

In this section I will outline my approach to analysis of the data. As the study developed the approach to data analysis also evolved. I will outline my initial analytic strategy of Framework, and identify some of its limitations. These limitations then led me to adopting Thematic Analysis as a strategy that could assist me to provide the depth of analysis required.

4.8.1 Analysis strategy

As discussed above, the underpinning logic of multiple case studies is one of replication of a series of experiments, rather than that of a population sample. This logic then drives much of the overall analysis process. The goal of analysis is to retain the integrity of the entire case, which then enables subsequent analysis between cases (Yin, 2018). This meant that ‘the case’ became central to the analysis, with a need to maintain the origin of each element of data throughout the process of managing the data, analysis, and writing up. In order to maintain the integrity of the cases I adopted a number of strategies. Data from each case were kept together. The case was visible at each step of the analysis process to avoid losing sight of it. Individual case summaries were constructed, allowing prominence to individual context. Importantly, individual case analysis was undertaken and developed as far as possible, prior to commencing cross-case synthesis of findings by looking for patterns and divergence between cases.

An early decision in the study was to use a computer-assisted qualitative data analysis software program (CAQDAS) to manage and organise the large quantities of data from multiple sources (Silver & Lewins, 2014). NVivo 11 for Windows (QSR International, 2016) was chosen for this project largely as it contained a feature that facilitated the development of thematic matrices as part of the Framework approach to analysis. The flexibility of this

system allows data from multiple sources to be explored within cases, as well as exploring the findings across cases when required.

4.8.2 Framework analysis

Framework is a method of analysis particularly associated with applied social research (Pope, Zeibland, & Mays, 2000; Spencer, Ritchie, O'Connor, Ormston, & Barnard, 2014). It shares many of the keys steps with other qualitative analysis methods. However, it also incorporates an additional step of generating 'thematic matrices'. These matrices provide a way of visualising the data by generating summaries of themes for each case and data type. In this way data can be visualised flexibly, with the aim of detecting relationships and patterns in the data. Attitudes to the Framework approach differ amongst researchers. Some view it as a very rigorous and auditable process of analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Others regard it as laborious and time consuming to undertake (Ward, Furber, Tierney, & Swallow, 2013). Some authors, such as Braun and Clarke (2006), consider the highly structured nature of approaches such as Framework to constrain analysis. Some have associated Framework with a purely deductive approach (Pope & Mays, 2009). However, Gale et al. (2013) argue that Framework can be adapted to suit the nature of the research questions, and can take an inductive, or abductive approach as well.

The structure of Framework consists of five initial data management phases that are employed iteratively. These are 'data familiarisation', development of a 'thematic framework', a process of 'indexing and sorting', 'reviewing extracts', and 'data summary and display' (see figure 4.7). Much of these initial phases of Framework produce descriptive analysis of the research topic and it is only the final phase of abstraction and interpretation of the data that will lead to higher order findings and explanations (Spencer, Ritchie, O'Connor, Morrell, & Ormston, 2014).

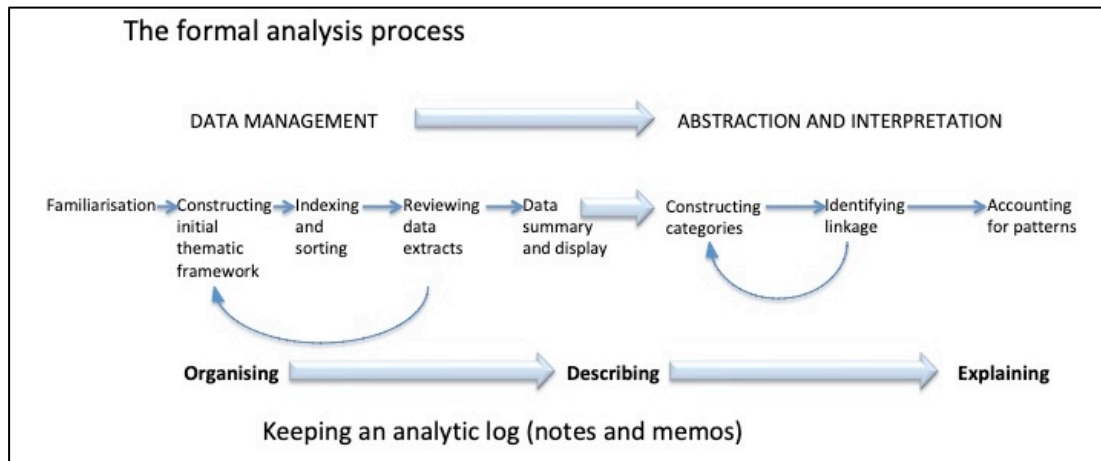


Figure 4.7 The stages of Framework approach to analysis

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Data familiarisation

Becoming fully familiar with all the data is emphasised in the Framework approach, possibly because it is often used in the context of teams of researchers, whose members may not have been involved in data collection. As a singlehanded researcher, I had collected all the data and transcribed the consultations, and had an immediate familiarity with the data. Nevertheless, analysis began with reading and re-reading, checking recordings and making notes on all the collected data.

Constructing a thematic framework

The thematic framework was developed so that it could be applied to the whole data set later in analysis. In order to keep the thematic framework grounded in the data, descriptive codes were applied by hand to the data from the first three patient participants (Saldaña, 2016). Members of the supervisory team independently reviewed three coded transcripts and suggested modifications and possible different approaches. Codes from these initial data were grouped into broad descriptive themes that were developed into a preliminary framework. A process of trying out the thematic framework on subsequent data allowed development and refinement of the framework. Emergent issues and new lines of thinking were subsequently incorporated in to the framework. This thematic framework underwent a number of iterations during the process of analysis. The final version of the thematic framework is available in appendix 13.

Indexing and sorting

Once the thematic framework was developed to a level that incorporated all initial descriptive codes, data were uploaded to NVivo and the framework trialled by applying it to further case data series. Spencer et al. (2014) refer to applying the thematic framework to the data as 'indexing and sorting', in a similar way as others might talk about 'coding'. Additional identification of *in vivo* codes within the data, such as words or short phrases that encapsulated a particular idea or point of view, helped to keep the analysis grounded in the data. *In vivo* codes were added to existing elements of the thematic framework, or if there was no match, used to help identify emergent themes. Extensive use of functions, such as notes and memos within NVivo, enabled me to capture ideas and analytical thoughts during the indexing and sorting process. An example of coding using NVivo is included in appendix 14. Once the process of indexing and sorting were complete, it was easy to generate displays from NVivo of data coded to one theme. The process of reviewing these data extracts allowed a check for consistency and a view of whether the thematic element formed one coherent block of data, or if it needed subdividing or amalgamating with another.

Data summary and display

The next step of the analysis process was data summary and display. Sorted data were used to create Framework matrices whereby the rows consisted of study cases and the columns were the elements of the thematic framework. In each of the matrix boxes a small summary of the data was written. The challenge of writing these summaries was to summarise enough so the information was manageable, but not to lose the essence of the material, or its grounding in the data. To achieve this, I included direct quotations and used original language and terminology as far as possible. A series of matrices were constructed that summarised the data in different ways and at different levels, starting with ones exploring all data sources for each individual case. An extract from one of these framework matrices is included in appendix 15. Construction of these matrices represented a significant amount of researcher time over several months. The process required immersion in the data, and this developed an in-depth understanding of the cases. Spencer, Ritchie, O'Connor et al. (2014) equate this with the end of the data management phase of analysis.

Abstraction and interpretation

At the end of these processes the findings remained at a descriptive level. The process of abstraction of data is complex and more difficult to describe. The Framework approach suggests the development of categories and typologies within the data in order to go beyond superficial description of the data (Spencer et al., 2014). Approaching the data for this study in this way had some inherent problems for case study research. Categorisation of findings requires cross case analysis at a relatively early stage, and so risked losing sight of the individual cases. Another concern was that this approach would lose the complexities in the cases essential to developing the rich picture that was required. Although Framework analysis is not rigid about the process of abstraction and interpretation, writing about the approach tends not to give much direction other than using categorisation and typologies. For this reason, other analysis techniques were explored.

4.8.3 Thematic Analysis

Thematic analysis is often seen as a straightforward and accessible technique for novice researchers (Pope, Zeibland, & Mays, 2006). Braun and Clarke (2012) describe the process of Thematic Analysis and identify six steps. These are, 'familiarisation' and 'generating initial codes', 'searching for themes', 'reviewing themes', 'defining and naming themes' and 'report writing'. Despite differences in nomenclature, the initial two steps have some similarity with those of 'data management' used in Framework. However, the two approaches have quite different terminology. In Thematic Analysis a theme is a "*coherent and meaningful pattern in the data relevant to the research question*" (Clarke, V. & Braun, 2013, p120). In this sense, themes in Thematic Analysis are not the same as the themes of the 'thematic framework' discussed earlier. Thematic analysis particularly emphasises the fluidity between these steps, and rather than this being a linear process, the iterative nature is central to achieving the best outcomes (Nowell, Norris, White, & Moules, 2017).

Searching for and reviewing themes

Braun and Clarke (2012) identify the creative processes involved in developing a clear thematic analysis, and suggest that it is a process that sometimes defies clear explanation. Above all, they argue that themes do not emerge, ready formed, from within the data. Rather, the researcher needs to engage in an active process to develop meaningful themes out of the data. They make a distinction between 'semantic' and 'latent' themes. Semantic

themes relate to the surface meanings of the data, while latent themes go beyond this, to explore the inner hidden processes and conceptualisations about what is occurring in the data (Braun & Clarke, 2006). While semantic themes should go beyond merely describing the data, it is the deeper, latent themes that help to make sense of the underlying processes involved and to develop theoretical insights.

As a result of the use of Framework, data had largely been coded using a theoretical, deductive approach, although significant inductive coding was also incorporated. As Braun and Clarke (2012) acknowledge, in reality both approaches are almost inevitable. This flexibility in the application of Thematic Analysis was important when considering my philosophical underpinning for the research, which was one of subtle realist ontology, and a constructionist epistemology. I did not re-code the data at this stage, but took time to explore the data again and to re-group existing codes to identify new linkages and patterns. In order to help identify themes I also made extensive use of charts and mind-maps to help focus thought around analysis (Pope, et al., 2006). Examples are included in appendix 16. This strategy helped to identify relevant linkages in the data between different elements (Nowell et al., 2017). I was able to then group coded data together into more meaningful patterns, not necessarily originally together in the thematic framework. Exploring these clustered codes allowed me to clearly identify areas of similarity and difference and to begin to look beyond the surface description reflected in the initial coding approach. At this level it was also essential to begin cross case analysis to identify whether nascent themes formed robust groupings that worked across several cases. This process also allowed exploration of divergence between cases, and to try and identify explanations for these divergent results within the overall analysis.

Refining, defining and naming themes, and writing the report

As I developed potential themes, it was necessary to continually review them to ensure that they remained congruent with the research aims. Each theme needed to be distinct and focused, whilst interlinking with the other themes, allowing me to build and develop a logical argument about the data collected. The process remained highly iterative, with writing forming a core part of the process of analysis, whilst moving between this and the original data, individual cases, and coded extracts, in order to preserve the context of the

data. Developing coherence was assisted by writing about each one to define and name the theme. The process of writing helped to crystallise my thinking around each theme, ensuring that it had sufficient robustness to stand up: linked, but still distinct from other areas. The theme name was important and aimed to convey an essential point about its nature and message (Braun & Clarke, 2012). The overall aim was to build a coherent story about the data, using the themes developed in a way that offered deeper insights and which was clearly grounded within the research data (Nowell et al., 2017).

4.9 Quality in qualitative research

How to judge the quality of qualitative research has been the subject of much argument (Mays & Pope, 2006; Ritchie & Ormston, 2014). Whether qualitative research can be judged on the same basis as quantitative studies is at the heart of this debate. Traditional measures of research quality have tended to use concepts such as reliability, validity and generalizability (Noble & Smith, 2015). Some qualitative researchers have argued that the epistemological basis of qualitative research is so fundamentally at odds from the positivist model that different measures of quality need to be used (Lincoln, & Guba, 1986; Schwandt, Lincoln, & Guba, 2007; Treharne & Riggs, 2015). Terms such as trustworthiness (credibility, dependability, confirmability, transferability) and authenticity of the research have been proposed. However, such terminology can be closely mapped to the more conventional ones and some researchers feel that the use of specific language relating to qualitative research only serves to muddy the waters further (Long & Johnson, 2000; Ritchie & Ormston, 2014).

Some researchers argue that the heterogeneous research approaches and the fundamental philosophical assumptions underpinning qualitative methodologies mean that external quality measures cannot be imposed, and studies should be solely judged on a subjective assessment of their own merits (Rolfe, 2006). Nevertheless, there is consensus from many health service and applied research fields that there needs to be some criteria with which to make judgements (Lewis et al., 2014). Guidelines have been produced to facilitate assessment of qualitative research, such as the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007), or the Framework for

Assessing Qualitative Evaluations (Spencer, Ritchie, Lewis, & Dillon, 2003). However, there has been criticism levelled at such tools, especially that they can lead to an unthinking and mechanistic approach and often include measures not appropriate to the research approach under review (Mays & Pope, 2006).

Term and definition	Strategy used to address
Reliability Data generation and analysis are appropriate to the aims of the research and have been collected in a thorough, careful, honest and accurate manner (Mason, 2018).	<ul style="list-style-type: none"> • Clear rationale presented for choice of methods • Purposive case selection to ensure wide range of participants from target group • Systematic collection of data - interview topic guides; verbatim transcription; CRFs; observation forms • Clear and transparent data analysis and interpretation – systematic and auditable data management; computer assisted data analysis system; initial transcripts coded by multiple people; researcher ‘data immersion’, reflexive approach to analysis and development of final themes
Validity Research accurately represents the features of the phenomena that it intended to describe, explain or theorise (Hammersley, 1992).	<ul style="list-style-type: none"> • Findings reflect research aims • Multiple case study approach across more than one setting • Multiple sources and forms of evidence (triangulation) to provide multi perspectival ‘rich picture’ • Exploration of extreme and divergent cases • Presented findings supported by data with clear rationale given for interpretation • Using well-founded and plausible arguments about the significance of the evidence generated
Generalizability The extent to which some form of wider claim can be made on the basis of the study (Mason, 2018)	<ul style="list-style-type: none"> • Analysis beyond the descriptive level to provide insights into the topic at a latent level • Sum of strategies aimed to produce reliable, valid and reflexive research
Reflexivity Being mindful of personal beliefs and values that might impact the research processes and making these explicit and understood, rather than trying to eliminate them (Hammersley & Atkinson, 2007; Long & Johnson, 2000)	<ul style="list-style-type: none"> • Maintenance of a reflective research diary and field notes throughout the study • Conscious adoption of a reflexive approach • Awareness of the role of researcher as clinician • Clear and transparent presentation of research processes and challenges. • ‘Authorial voice’ written into thesis • Awareness of ‘researcher’s position’

Table 4.4: Summary of research quality strategies

In this study I have thought about quality and research rigour using the terms validity, reliability and generalizability, adapted to match the ontological and epistemological approach that I have adopted. The way these terms have been applied are summarised in table 4.4. These inter-related concepts form the cornerstones of ethical and meaningful research. However, the use of reflexivity in all aspects of the study is the one factor above all that focuses the researcher on his or her own actions and decisions and their potential effects (Mason, 2018; Nowell et al., 2017). This means being transparent about choices in design, conduct and analysis of the study, and to take a reflexive approach to the role and impact of the researcher on participants, data collection and analysis (Seale, 2007). This latter point is described as the 'researcher's position' and includes factors such as demographic profile, professional role, power, as well as personal characteristics and standpoint (Berger, R., 2015). Throughout this current study I have tried to adopt a reflexive approach by explicitly being aware of the ways my role as a researcher influenced participants and data collection, and how my assumptions as a clinical nurse interacted with my approach to analysis (Mason, 2018; Mays & Pope, 2006).

4.10 Nurse as researcher

I was aware of the effect of my own personal impact on the way this research was undertaken and in its analysis and interpretation. I will end this chapter by reflecting briefly on some of these aspects of the study, firstly on the process of data collection and then on the approach to analysis.

The presence of the researcher and their role in undertaking the research has an impact on participants and their outcomes (Blaikie, 2007). This can throw up unique issues where the research is conducted by a clinician-researcher, as in my case (Hay-Smith, Brown, Anderson, & Treharne, 2016). I described my research role within the observed consultations as 'observer-as-participant'. I made a choice to be present during the consultations in the knowledge that it might have more impact than just audio recording the interaction and I used my research diary to reflect on these effects (see appendix 12). During one consultation I became particularly aware of a sense of 'performance' by the participants. At

points during the interaction the professional and patient became obviously aware of the digital recorder, being guarded about saying certain things, or conversely making comments aimed specifically at the recorder; essentially 'breaking the fourth wall' of their 'performance'. In other consultations comments were sometimes made referencing the recorder, often in response to expressions of thanks made by patients to professionals. Some participants made comments afterwards regarding their awareness of my writing observation notes. One professional specifically asked me to feedback on the quality of their consultation. In this situation I declined to do this, explaining that it was not part of the research objectives, but I did share the transcript of the consultation. Such issues underline the impossibility of completely 'fading into the background' as a researcher. For some professionals there was an apparent sense of being judged during the observations, a factor that was well described by Kirkham (1989) in a study on midwifery. Especially when a researcher has extended periods being 'embedded' within a research environment participants seem to quickly adapt to the observation. Behaviour appears to change in superficial ways rather than altering core behaviours and communication (Kirkham, 1989). However, my study involved relatively short periods of research activity within a given environment. It was essential to remain reflexive about the impact of this involvement and to assume that my research presence altered and influenced events to some extent.

The influence of my role as a senior cancer nurse was another key factor in this research. My clinical role was known by both professional and patient participants and was made explicit in the participant information. While I attempted to adopt the researcher role, there were examples where I also had to be a clinician. In one consultation where the surgeon was unfamiliar with the arrangements at the local hospital I was drawn directly into the consultation by being asked about referral arrangements and organising changes to the patient's analgesia. Concerns about ensuring the patient left the consultation with the right information and treatment meant I felt compelled to help with these problems, despite the conflict with the researcher role.

In interviews with patients there were also occasions where these roles clashed. For example, in one early interview with a patient, significant misunderstandings about the information she had been given became apparent to me. My first reaction was to try and

correct the confusion, as I would do in my clinical role. As a nurse I felt it was important not to ignore significant misinterpretations. In the end I decided to contact the patient's specialist nurse to ask them to pick up the issues where I felt that there were areas the patients had not fully understood. The nature of the interviews themselves can also be influenced by the perception of the participants, vis-à-vis research and professional roles (Richards, H., & Emslie, 2000; Sword, 1999). These conflicts are an inherent part of the clinician-researcher role and reflexivity is essential in dealing with the ethical, professional and research quality demands of undertaking clinical studies (Hay-Smith et al., 2016).

The emic–etic balance of the researcher role is also a significant factor in the analysis and interpretation phases of research (Berger, R., 2015). The study focused on routine encounters between professionals and patients that were part of my normal daily clinical work. One of the big challenges of the study was to see beyond this everyday encounter and to view this with 'fresh eyes' that would allow the development of insight into the process under consideration. My own assumptions about providing patients with full details of their clinical situation underpinned much of my initial conceptions of a 'good consultation'. My initial view of published population outcome data as an objective measure of patient prognosis also influenced the initial direction of the study. Much of the early analysis was spent on identifying the mechanisms of giving recurrence risk information, rather than looking at the interaction in much more broad terms. The challenge was to stop these personal and professional meanings crowding out the broader interpretations that emerged from within the data (Sword, 1999). Openly disclosing the inherent nature of the enmeshed nature of the researcher-clinician can enhance the legitimacy of the findings and interpretations.

4.11 Chapter summary

In this chapter I have set out the methodology and study processes that I followed. This research aimed to gain an in-depth understanding of the communication around recurrence risk following potentially curative lung cancer surgery using a multi perspective approach. I adopted subtle realist ontology and constructionist epistemology to undertake a multiple qualitative instrumental case study. Each 'case' centred on a patient participant following

lung cancer surgery and included the associated professionals involved during the post-surgical out-patient consultation and either the first follow-up, or oncology appointment. The boundaries of the cases began at the post-surgical consultation and ended six months after the surgery.

Recruitment using purposive sampling and data collection began once ethics and research access approval was gained. I drew on multiple sources of data that included documentary evidence, observation of consultations involving participants, interviews with participating professionals and longitudinal interviews with patients at three time points. I recruited a total of 12 cases, each centring on an individual patient participant and involved 20 professional participants across the cases. Audio-recorded data were transcribed verbatim and field notes maintained. I used the software NVivo to help manage the data. Initial analysis was undertaken using the Framework approach. Later I adopted Thematic Analysis to help to develop latent themes and concepts. Over the next four chapters I will present the findings from the study, starting with short presentations of each case.

5 Findings 1 - The cases

5.1 Introduction

In this first of four findings chapters I will provide analysis of each of the 12 study cases. It will provide context and background to illuminate and understand the findings presented in subsequent chapters. These will present key themes developed from the cross-case analysis of the data. In this current chapter I will present details of each of the study cases. After their surgery, patient participants followed two distinct pathways for their onward management, either entering a period of clinical follow-up, or being referred to see an oncologist to discuss possible adjuvant therapy. I will use these two pathways to group the cases, beginning with those who went straight into long-term follow-up. For each case I will introduce the patient and professional participants, describe the patient's diagnosis and treatment and outline the information given in the consultations relevant to recurrence risk.

5.2 Patient participants

Details of the demographics and medical history of the 12 patient participants are given in table 5.1. Pre-operative lung cancer clinical stage ranged from IA to IIIB. One patient was referred for surgery without a recorded clinical stage. Educational backgrounds varied from leaving school with no formal qualifications, to having postgraduate education. Eight of the participants were retired. Previous and current employment varied from unskilled jobs to professional roles. Smoking history ranged from negligible to recently stopped. Patient participants all had significant co-morbid illnesses, with the exception of Fiona. Of particular note was the fact that half of the participants had had a previous or concurrent cancer diagnosis, other than lung cancer. This was higher than might have been anticipated. In several cases, tests and investigations for the other cancer directly led to the incidental diagnosis of the lung cancer and may have been instrumental in early detection and thus operability of the lung cancer.

Patient case	LMDT	Education & employment	Clinical stage	Medical & smoking history
Audrey Female 74 Divorced White British	1	No formal qualifications. Retired; retail and factory work	IIB	Coronary artery bypass grafts Chronic obstructive pulmonary disease Ex smoker (stopped 10 years)
Barbara Female 68 Married White British	1	No formal qualifications. Retired; administrator	IIA	Rheumatoid arthritis Ex-smoker (stopped prior to surgery)
Cathy Female 57 Married Irish	2	Secondary education qualifications. Retired; catering manager	No staging	Recent diagnosis of chronic leukaemia Ex-smoker (stopped prior to surgery)
Denise Female 61 Married White British	2	Secretarial qualifications. Employed; medical secretary	IA	Hypersensitivity pneumonitis Breast cancer Minimal smoking history
Edward Male 73 Married White British	1	No formal qualifications. Retired; driver, ex-navy	IIIA	Pancreatitis Diverticulitis Asbestos exposure Cutaneous lymphoma Ex smoker (stopped 50 years)
Fiona Female 61 Married White British	1	Tertiary education. Not working; ex office administrator	IIIB	Treated for stage IIIB lung cancer for 2 years before surgery Ex-smoker (stopped prior to surgery)
Glennis Female 59 Partner White British	2	Secondary education qualifications. Employed; health service administration	IA	Breast cancer Ex smoker (stopped 5 years)
Henry Male 74 Married White British	1	Tertiary education. Retired; medical equipment sales	IB	Peripheral vascular disease Lumbar disc problems Ex smoker (stopped 14 years)
Jane Female 60 Single White other	2	Tertiary education qualifications. Employed; lecturer	IIIA	Thyroid cancer Auto-immune disorder Ex-smoker (stopped 10 years)
Kamal Male 77 Married Indian	2	Secondary education qualifications. Retired; small businessman	IIA	Multiple chronic conditions including cardiac and kidney disease Ex-smoker (stopped 10 years)
Len Male 73 Married White British	1	Secondary education qualifications. Retired; mechanic and foreman	IA	Recent diagnosis of localised bladder cancer Ex-smoker (stopped prior to surgery)
Maggie Female 69 Married White British	3	Secretarial qualifications. Retired; local government officer	IIIB	Diabetes Ex-smoker (stopped 6 months prior to surgery)

Table 5.1 Patient participant demographics

5.3 The Pathways

Patient participants followed two different post-surgical management pathways. None of the patients remained under the care of the surgical team after their first post-surgical consultation. Six patients were referred straight on to long-term follow-up and were seen in clinic by an LCNS, chest physician, or oncologist (Pathway A). The six remaining cases were referred to an oncologist to discuss possible adjuvant treatment (Pathway B). As a result of these consultations, three went on to receive adjuvant chemotherapy, radiotherapy, or both. The remaining three did not receive adjuvant treatment; although one went on to receive radical radiotherapy to treat a separate, synchronous lung lesion in the opposite lung. Figure 5.1 illustrates the two pathways that the patient participants followed after their surgery.

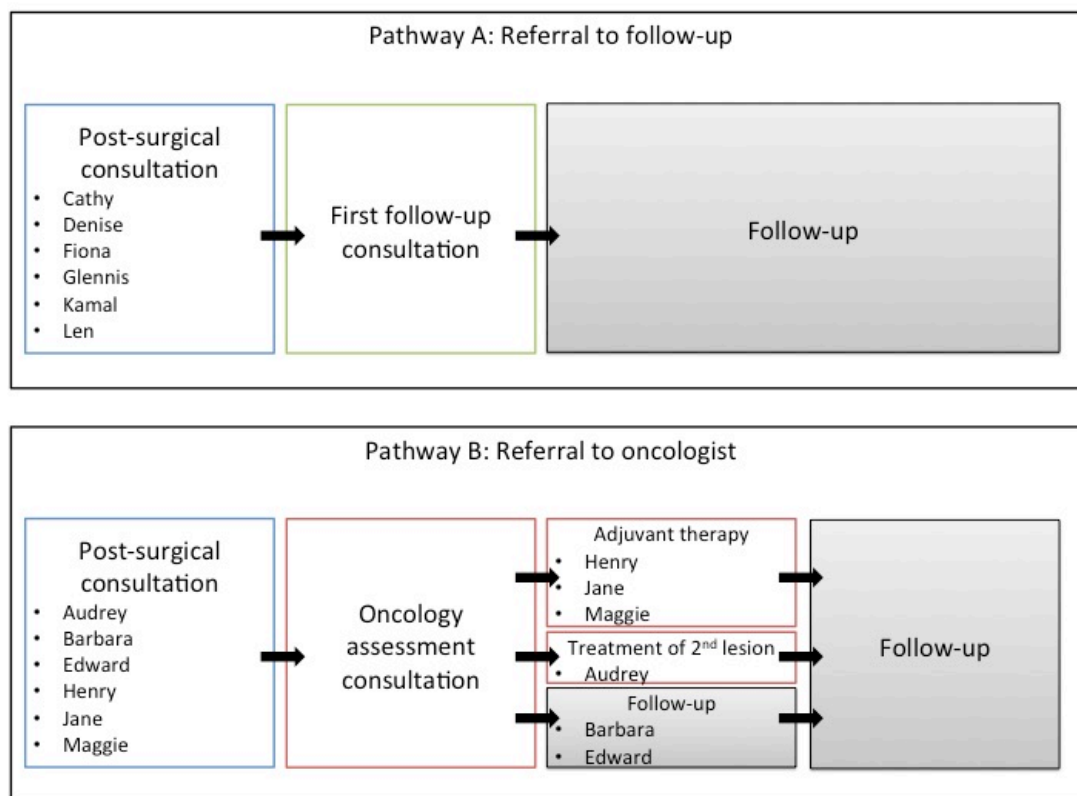


Figure 5.1 Post-surgical pathways followed by participants

5.4 Pathway A: Referral directly to long-term follow-up

5.4.1 Cathy's case

Background

Cathy was 57 when her lung cancer was diagnosed. She was married with three sons, two of whom lived at home. She had moved from Ireland in her youth, so many of her old support networks lived away. She did not rely on her husband and sons for support, but valued a circle of close female friends. Cathy had worked full-time as a catering manager until six months before her diagnosis and had left her job because she had been feeling generally unwell. Prior to this she had been a regular gym attender. Unusually, Cathy did not appear to develop any particularly supportive relationship with her medical teams.

Diagnosis and treatment

Cathy first went to the doctor with pains in her stomach. Investigations showed an abnormality in her blood tests and she said she knew straight away there was something seriously wrong with her. She was diagnosed with chronic leukaemia, which, although not curable, only required monitoring and no immediate treatment. However, during investigation for this, a lesion was revealed on her lung. She instantly knew that this was lung cancer. Cathy was referred for surgery to remove part of one lobe of her lung. The night after her surgery, Cathy experienced post-operative bleeding and had a cardiac arrest. She was taken back to theatre for bleeding and subsequently spent 15 days in hospital. The reasons for, and the consequences of, the cardiac arrest appeared to be far more significant to Cathy than the actual diagnosis of lung cancer.

Consultations

Cathy was seen in the post-surgical clinic five weeks after surgery by a registrar (Surgeon 2), who knew her from her admission. Cathy was having difficulty retaining information at the time of this consultation, which she put down to a combination of the surgery, the cardiac arrest, and painkillers. She attended with a female friend and they wanted answers to her questions about what had gone wrong during the surgery and why problems were not detected until after her cardiac arrest. They were unable to see Cathy's consultant during that visit and Cathy lacked confidence in the registrar. Ultimately the consultation did not address her concerns and she was left with mixed feelings about her surgery.

Her first follow-up appointment took place about three months after surgery with the Lung Cancer Nurse Specialist (LCNS 2) who Cathy knew from the diagnostic period. The concerns about her surgery were still evident during this consultation. A summary of the information presented in the consultations is displayed in table 5.2.

Cathy (57) Stage IA (pT1aNO MO) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	<i>"Adenocarcinoma"</i> <i>"Very early stage lung cancer"</i> Details of tumour size, cancer not spread.	<i>"Very low"</i> risk of recurrence. (Response to patient question)	No further treatment required. Follow-up at local hospital.	Not discussed
	First follow-up consultation	<i>"Adenocarcinoma"</i> <i>"Tumour very small"</i>	Not discussed	No further treatment required. Follow up with chest x-ray every 3 months.	Not discussed

Table 5.2 Key information given in Cathy's consultations

Developments

Cathy made a slow recovery from her surgery, complicated by a new diagnosis of rheumatoid arthritis. Scheduling interviews for the study with Cathy was difficult, due to her reluctance to talk about her experiences. Only one interview was completed and took place immediately after her first follow-up clinic.

5.4.2 Denise's case

Background

Denise was 61 when diagnosed with lung cancer. She was married with two children, her son still at home and her daughter married with her own children. She worked in a busy job as an administration manager. She left school with secretarial qualifications and worked in a range of administrative jobs, including as a medical secretary. Denise had been diagnosed with breast cancer three years previously. She elected to have bilateral mastectomy in order to reduce her chance of breast cancer recurrence in the future. She was still undergoing medical follow-up for her breast cancer at the time she was diagnosed with lung cancer.

Another significant health concern occurred about 12 years previously when she was admitted with hypersensitivity pneumonitis, from which she “*nearly died*”.

Diagnosis and treatment

Concerns that she might have lymphoedema as a result of her breast cancer led to a CT scan of her chest. This scan identified two lesions on her lung. She related how traumatic and shocking this news was to her. She had initially tried to keep her concerns about possible lung cancer to herself and did not tell her family. One lesion was large enough to biopsy. She chose to tell her family the day before she got the results and took her son with her to the consultation where she was told that this was an adenocarcinoma of the lung. The other lesion was too small to biopsy and she was told that this would be monitored for any further changes. Denise was very upset to find out that the larger lesion on her lung had been visible on scans she had been given when first diagnosed with breast cancer, but no one had told her about this. These experiences led her to have a more questioning attitude to doctors than previously.

Consultations

Following her lung surgery Denise was told she would have the final pathology report in a week. She described a very anxious period of time waiting for the results, particularly by the time she came back to the post-surgical clinic, four weeks after her surgery. A registrar (Surgeon 2) saw her and her two children in the post-surgical consultation. Denise had known the registrar from her admission. LCNS 1 also sat in on the consultation, but Denise had not previously met her. Due to the anxiety Denise was experiencing, the consultation felt tense at points, but Denise was relieved to hear she did not need chemotherapy.

Denise was referred back to her local lung cancer team for follow-up and was seen by LCNS 2 six weeks later. Denise had a good relationship with LCNS 2, which had commenced during the diagnostic period. Table 5.3 gives a summary of the information presented in the observed consultations.

Denise (57) Stage IA (pT1aNO/MO) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	<i>"Small lung cancer"</i> <i>"Early stage"</i> <i>"no cancer in the lymph node"</i>	Recurrence <i>"Unlikely"</i> (Response to patient question)	No chemotherapy required. Lesion in upper lobe will be monitored during follow-up at local hospital.	Not discussed
	First follow-up consultation	Not discussed	Not discussed	No further treatment required. Follow up for <i>"the next few years"</i> .	Not discussed

Table 5.3 Key information given in Denise's consultations

Developments

Denise was reassured that she would have regular scans to monitor the other smaller lesion. However, she found receiving different management possibilities for this second lesion unsettling due to the confusion it created in her mind. Although subsequent scans showed no growth in the lesion, Denise saw further surgery as inevitable at some point in the future. She viewed the fact that she had had two separate cancers (Breast and Lung cancer) as meaning that her body *"was predisposed to cancer"*.

5.4.3 Fiona's case

Background

Fiona was 61 when she underwent her surgery, but had been diagnosed two years earlier with advanced lung cancer. She was married with two adult daughters. Until her diagnosis she had led a busy life supporting her mother through cancer treatment, caring for their animals and working part-time as an office manager. However, family life was her biggest priority.

Diagnosis and treatment

Fiona's husband made her go to her GP with a cold that was slow to resolve. She knew that it was a lung cancer straight away, but it was not confirmed until she had a biopsy. Investigations revealed that the cancer had spread to a lymph node in her neck, so surgery and radiotherapy were ruled out. She said, *"You're thinking all the time, it's getting worse and worse"*. They saw an oncology junior doctor who had talked to them about palliative

chemotherapy and spoke in terms of “*buying time*”, a phrase that upset her and also stuck with her. However, it was important for Fiona to know what she was up against. Despite her family not wanting her to, she asked one of the doctors to be honest with her and tell her how long she had got. Fiona remembered, “[...] *she gave me the worst case scenario and the best case scenario. And I was just aiming for the best really [...]*”.

Fiona found chemotherapy difficult, but early scans showed a good response. She went on to have maintenance chemotherapy, but in the end she was getting a lot of side effects. She worried what would happen if she had to stop treatment. Fiona built up a strong and trusting relationship with her consultant, Oncologist 2. She also attended the local lung cancer support group and through this she cemented a supportive relationship with LCNS 4. At the group she met others in similar situations and became a reluctant role model for some. Gradually she began to see herself as an ambassador for lung cancer patients. Following a PET scan, Fiona recalled her oncologist ringing her at home and telling her that she could be offered surgery. Her initial reaction was one of elation, closely followed by feeling terrified of the surgery. However, the surgeon was “*so positive*”, that it made up her mind for her and she knew that she had to go through with it.

Consultations

Fiona attended the post-surgical consultation four weeks after her surgery with her husband and two daughters. Surgeon 4, a surgical registrar, who had operated on her, and LCNS 4 saw them. Fiona was told that the resected specimens showed no sign of cancer, only old scarring. There was an elated atmosphere, but Fiona struggled to take this momentous news in fully. Fiona was then referred back to her oncologist for long-term follow-up.

Oncologist 2 saw Fiona and her husband about two weeks later. This consultation had a similarly elated feeling. The strong relationship between Fiona and her oncologist was evident. Table 5.4 gives a summary of the information presented in the observed consultations.

Fiona (61) Presented stage IIB adenocarcinoma. Post-surgery: Localised fibrous scarring, likely response to chemotherapy		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	<i>"no residual cancer left in anything that we have taken away"</i> No specific discussion of stage.	<i>"The signs are good at the moment"</i> (Response to patient question)	No further treatment required. Follow-up with oncologist.	Not discussed
	First follow-up consultation	Surgery <i>"showed there was no cancer there"</i> and there was a <i>"complete response to chemotherapy"</i>	Prone to <i>"something coming back in the future"</i> (Response to patient question)	No more treatment required. Follow-up for five years.	Not discussed

Table 5.4 Key information given in Fiona's observed consultations

Developments

Fiona continued to make a good physical recovery. Emotionally, she struggled to come to terms with the changes in her prognosis following her surgery. In particular she knew that the surgery had indicated that the cancer had been treated by the chemotherapy, but no one would confirm she was *"cancer free"*, a situation that she described as *"being in limbo"*.

5.4.4 Glennis's case

Background

Glennis was 59 when she was diagnosed with lung cancer. She had worked in an administrative role in a health care setting for many years. Prior jobs were also health or social care related. Her and her partner had a very close, mutually supportive, relationship. She also had a daughter by a previous partner, who lived away and had a child of her own. Glennis took time out from her career several years previously to care for her sister until she died from breast cancer. She learnt a lot about her own approach to cancer from watching her sister cope with her illness. Six years before her lung cancer diagnosis, Glennis herself was diagnosed with breast cancer. She elected to undergo a prophylactic double mastectomy and not have a reconstruction in order to render her risk of recurrence as low as possible. She also went on to have her ovaries and fallopian tubes removed.

Diagnosis and treatment

In the months leading up to her lung cancer diagnosis, Glennis developed a chest infection, which was slow to resolve. Initial investigations, including chest x-rays, did not reveal

anything concerning. Glennis pushed to have further tests and finally was offered either a biopsy of a very small nodule on her lung, or to have a further scan in three months' time. She opted to have the biopsy for peace of mind and so was very shocked to be told that she had a diagnosis of primary lung cancer.

Consultations

After her surgery Glennis was very worried about coming to the surgical clinic to get the results. This was particularly focused on whether she would require further treatment, such as chemotherapy. She attended clinic with her partner two weeks after discharge and was seen by a surgical registrar, Surgeon 5, with whom she had developed a very good relationship during her admission. LCNS 1 was also present, but they had not previously met. Glennis took a strong role in the consultation, insisting she was told her surgical results right at the beginning, by saying to Surgeon 5, *"just cut to the chase"*. Glennis was referred back to her local hospital for long-term follow-up. LCNS 2, who she knew well from the diagnostic period, saw her around eight weeks after her surgery. Table 5.5 summarises the information given in the observed consultations.

Glennis (59) Stage IA (pT1AN0M0) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	Lung cancer <i>"all out"</i> . <i>"not spread to any lymph nodes"</i> . <i>"Stage one"</i> . <i>"Very early"</i>	<i>"85% chance of nothing coming back in 5 years"</i> (Response to patient question)	No chemotherapy necessary. Long-term follow-up.	Not discussed
	First follow-up consultation	No spread to the lymph nodes.	<i>"the likelihood of it having spread is low"</i> (Response to patient question)	Follow-up with chest x-rays, 3 monthly for first year.	Not discussed

Table 5.5 Key information given in Glennis's observed consultations

Developments

Glennis struggled with worry that her cancer had returned, particularly after developing a number of chest infections. During these times she tended to search for more and more information on lung cancer survival rates. This, combined with media portrayal of lung cancer, increased her worry about recurrence and her long-term future. Glennis's high level

of anxiety and search for a sense of certainty led to further increased levels of information seeking, which in turn appeared to fuel yet more anxiety.

5.4.5 Kamal's case

Background

Born in India, Kamal moved to the United Kingdom with his wife as a young man. He was 77 at the time he was diagnosed with lung cancer. He had multiple other medical conditions, and was under the care of several different teams at his local hospital. Some of his other medical conditions significantly limited his physical activity, such as walking and climbing stairs. His wife was well and looked after him at home. Their children were grown up and living abroad. Kamal left school after completing his O' levels. He ran his own small business until he retired. He described having a strong faith and believed that his future was largely pre-ordained by God. Kamal avoided looking up information about his condition to avoid encountering negative ideas.

Diagnosis and treatment

Kamal was diagnosed following an emergency admission to hospital with pneumonia. A scan showed up the lung lesion and he recalls being told the diagnosis of cancer and that it was curable with an operation. When he saw the surgeon he was told that the surgery was high risk and that there was 20 per cent risk of death during his surgical admission due to his co-morbidities. He and his wife were still keen for him to have the operation, as he did not want to consider chemotherapy. Kamal got through his surgery without major problems. However, recovery was slow, due to limited mobility and breathlessness. He acknowledged that he needed to motivate himself more to get up and do things, but admitted that he was a fundamentally lazy person.

Consultations

Kamal and his wife were seen in the post-surgical consultation one week after his discharge from surgery. They were seen by Surgeon 6, a registrar who had been involved in his care during his admission. Kamal's wife asked the majority of questions in the consultation. Although the pathology showed lymph node involvement, MDT decision was not to refer him to oncology to discuss adjuvant chemotherapy in view of his co-morbidities. Kamal was referred back to his chest physician for long-term follow-up.

Kamal and his wife attended the follow-up clinic about six weeks after surgery. Kamal knew Chest Physician 1 well from his diagnostic period. Kamal and his wife asked many questions during the consultation, mainly focused on current symptoms and management of his co-morbid conditions. There was very limited discussion focusing on Kamal's lung cancer diagnosis. Table 5.6 summarises the information given in the observed consultations.

Kamal (77) Stage IIA (pT2aN1M0) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	Tumour <i>"was a cancer"</i> It had <i>"spread to a lymph node"</i> Everything was removed at surgery.	<i>"It is a possibility it might come back"</i> (Response to patient question)	Referral to follow-up. <i>"you don't need chemotherapy"</i> Other health issues mean it would not be beneficial. (Response to wife's question)	Not discussed
	First follow-up consultation	Not discussed	Not discussed	Review in clinic again in 3 months.	Call CNS if <i>"more breathless, or [...] new persisting cough, blood in your phlegm, or anything that is concerning you"</i>

Table 5.6 Key information given in Kamal's observed consultations

Developments

Kamal continued to make very slow progress in his recovery. He had very limited mobility and was generally confined to his home and attending hospital visits. His last interview took place just after he had been sent for a new PET scan due to concerns about *"bulky lymph nodes"* in his chest. He expressed frustration that he was not told about what was wrong during that last consultation and ruminated during the interview as to whether this represented cancer coming back.

5.4.6 Len's case

Background

Len was 73 when he underwent his lung cancer surgery. He had left school at 16 after completing his exams. He had worked as a mechanic and, before retirement, as a foreman. He was married, with adult children living nearby. He was self-sufficient in terms of emotional support and attended his consultations alone. He had been relatively fit and well before his cancer diagnosis, with only minor co-morbidities. Len liked to keep a file of all his

medical correspondence, which he brought to clinic appointments. This was partly because he felt his memory was not as good as it used to be, but also as he felt that there were problems with the way he was being managed in relation to his bladder cancer. He also liked to search the Internet for information, which he felt told him more than the Macmillan Nurses could, and more than the doctors had time to tell him.

Diagnosis and treatment

Len was being investigated for an early stage bladder cancer. As part of this he had a scan that identified a lung lesion. This was subsequently biopsied and found to be a lung adenocarcinoma. The bladder cancer treatment was put on hold and he underwent surgery for his lung cancer. Len felt that he trusted his lung surgeon immediately and did not feel he needed a lot of information about his surgery. He recalled being told that the cancer could be about 15 per cent *“life-threatening”* if he had the surgery.

Consultations

Len was not concerned about coming to the post-surgical consultation, although he was not seen until about eight weeks after his surgery. Len was seen by Surgeon 8, who had operated on him and had also seen him prior to surgery. Len was effusive in his praise towards his surgeon and there was a very upbeat, positive feeling to the encounter.

Len was told by the surgeon that long-term follow-up would be under the surgeon’s care, and so he was *“totally baffled”* when he was given an appointment for follow-up with the chest physician at his local hospital. This follow-up consultation took place 12 weeks after his surgery. He and the doctor, Chest Physician 2, had not previously met. Afterwards Len commented how confused he was as to the purpose of the appointment. Delays at the clinic and interruption by a pre-assessment nurse in relation to his forthcoming bladder surgery increased the confusing and chaotic nature of the consultation. Table 5.7 summarises the key information given in the observed consultations.

Len (73) Stage IB (pT2aN0M0 – PL1) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	Tumour <i>"early stage"</i> Tumour not spread anywhere. Lymph glands <i>"negative for cancer"</i> <i>"we have taken it all without any tumour cells left in"</i>	Recurrence risk <i>"very small"</i> – <i>"about 10 – 15%"</i> (Surgeon initiated)	No further treatment required. Need to follow-up to make sure cancer does not come back.	Need to report coughing up blood, weight loss or <i>"anything that bothers you"</i> .
	First follow-up consultation	Surgery confirmed cancer diagnosis. There was a <i>"tiny deposit on the outside of the lung"</i> .	Not discussed	No further treatment required. Follow-up for next 5 years with chest x-rays.	Not discussed

Table 5.7 Key information given in Len's observed consultations

Developments

Len recovered well from his lung surgery, but there were further delays with his bladder cancer treatment. By the time he was able to go ahead with surgery he required a cystectomy and formation of a stoma. It was this, rather than his lung cancer, that caused him significant concerns and impacted on his daily life.

5.4.7 Pathway A commentary

The unifying feature of this group of cases was that none of these cases was referred for an opinion about adjuvant treatment following surgery. In each case patients were clearly informed that surgery had completed their treatment. Where patients were diagnosed with stage I lung cancer surgeons told them that their cancer was small or early stage, although only Glennis was told explicitly that she had stage I lung cancer. However, two cases could be considered divergent in relation to this pathway: Fiona's case due to her initial chemotherapy given with palliative intent, and Kamal's case, where his final pathology report indicated a stage IIA lung cancer, due to having lymph node involvement.

The only case on this pathway, and also across the whole study, where the patient was given a numerical estimate of recurrence risk without first asking for it was in Len's case. However, in each of the other cases on this pathway, patients all initiated questions to their surgeon about the chances of the cancer coming back. This occurred separately from the initial discussion about surgical findings and onward management, consistently towards the

end of the consultation. Glennis was given a numerical estimate of not having a recurrence in response to her question. Cathy and Denise were given an answer indicating the degree of risk using terms such as “*unlikely*” or “*low risk*”. Fiona and Kamal were given an answer that only indicated that recurrence was a possibility.

In the subsequent follow-up consultation, only Fiona and Glennis asked any further question about risk of recurrence, in what seemed to be a bid to ‘test’ the information they had already been told. Neither was offered a numerical probability of risk of recurrence. In the other cases, there was no more discussion of the risk of cancer recurrence. None of the professionals explicitly raised the subject of recurrence risk during the follow-up consultation with any of the patients. Only Len’s surgeon and the chest physician looking after Kamal discussed symptoms to be aware of that might indicate the early signs of recurrence. Both listed a range of alert symptoms and gave instructions to seek further advice. The other professionals did not raise this, despite the fact that most patients would not be having another routine assessment for at least three months.

5.5 Pathway B: Referral for oncology opinion

5.5.1 Audrey’s case

Background

At the time of her surgery Audrey was 74. She had left school without formal qualifications and had worked in several roles including shop work and catering. She was divorced and lived alone, and her main support was from her son who lived close by. He attended all the hospital appointments with her. Personal experience of cancer before she was diagnosed herself was through her sister who was diagnosed with breast cancer. Soon after completing chemotherapy and being told she was “*cured*”, her sister died. After this Audrey only equated cancer with death.

Diagnosis and treatment

Audrey had suffered frequent chest infections for several months prior to being diagnosed with lung cancer. Repeated chest x-rays did not reveal any problems, until finally she

coughed up blood. The number and speed of the subsequent tests made her realise that something was seriously wrong. Nonetheless she recalled the shock and devastation she felt when she was told it was a lung cancer. She met her Macmillan community support nurse at the time of her diagnosis and this became someone she went to for reassurance and information. She generally avoided telling friends and acquaintances about her diagnosis until after all her treatment was complete.

Audrey's surgical consultant (Surgeon 1) told her that her best option would be to have surgery, but she was initially worried about Audrey's breathing. Her surgeon made her climb two flights of stairs to test her breathing and her surgeon felt it was her "*sheer determination to have the surgery*" that she managed it. Although Audrey expected her operation would be to have removal of one lobe of her lung, due to the size and position of the tumour she ended up having her whole left lung removed. During her investigations in preparation for her surgery, her team also discovered another small lung lesion (a "*pin prick*") on the right lung that they told her would require treatment with radiotherapy after her surgery.

Consultations

Recovery after surgery was slow. She was re-admitted to hospital with a chest infection and struggled with breathlessness initially. It was during this admission that Audrey and her son saw Surgeon 1 in the post-surgical consultation, four weeks after surgery. Issues around pain management and concerns about infection dominated this consultation. However, Audrey and her son appeared reassured by the time they left. She was referred to oncology to discuss adjuvant chemotherapy.

Audrey and her son were seen by Oncologist 1 three weeks later. She had made her mind up to accept chemotherapy if offered, despite being something she did not want to have. In the end her oncologist did not recommend chemotherapy, due to her overall health. However, he did arrange to treat the lesion in the other lung with radiotherapy. She and her son came away from the oncology consultation confused regarding the completeness of surgery and the information about survival. Although she did not ask for clarification during

the consultation, these were things she later discussed with her Macmillan Nurse at home.

Table 5.8 gives a summary of key discussions within the observed consultations.

Audrey (74) Stage IIA (pT2aN1M0) Large cell neuro-endocrine carcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	"Large Cell Neuro-endocrine Carcinoma". No formal stage. Tumour size, separate nodule and lymph node involvement.	"a theoretical risk of recurrence" (Surgeon initiated)	Referral to oncology to discuss benefits of chemotherapy and treatment of right lung lesion.	Not discussed
	Oncology consultation	All tumour removed, but 1 lymph node affected by cancer.	"there is a possibility that this could come back again in the future" (Oncologist initiated)	4 to 6 people out of 100 having chemo would benefit. Decision for no chemo. Plans initiated to treat right lung lesion.	Not discussed

Table 5.8 Key information given in Audrey's consultations

Developments

While Audrey was undergoing radiotherapy she developed back pain, initially putting it down to the hard treatment couch. However, this got worse and she was eventually admitted to hospital as an emergency. She was very anxious that the cancer had spread to her backbone, but it was eventually diagnosed as osteoporosis. The anxiety was slow to leave her, but her sense of moving on from the treatment was summed up in her second interview by saying, *"I seem as though I've gone up a mountain, and now I'm coming down the other side"*. By her third interview she spoke about being on the flat lands on the other side of that mountain. However, the evening prior to clinic appointments she still convinced herself that she would be told that cancer had indeed spread to her bones.

5.5.2 Barbara's case

Background

Barbara was 68 at the time she was diagnosed with lung cancer. Barbara had grown-up children who lived nearby, but it was her husband who was her main support. Their strong, enmeshed relationship was evident in the observed consultations and in the first interview. For 35 years Barbara had lived with the effects of rheumatoid arthritis and she had

undergone numerous corrective operations, as well as regular treatment to help her cope with its disabling effects.

Diagnosis and treatment

Barbara had developed a cough, which was interfering with her ability to have her rheumatoid arthritis treatment and she was sent for an x-ray. She otherwise felt well, so when a “mass” was seen on the x-ray it did not feel real to her. But as she had also smoked for all of her adult life, she immediately concluded it was a lung cancer and found it frustrating when no one would confirm this for her. As a way of coping with this lack of diagnosis, she and her husband named the tumour “Brian”, from the Monty Python film ‘A Life of Brian’ and cited the song from the film ‘Always Look on the Bright Side of Life’ as their philosophy.

She had a good relationship with her consultant surgeon (Surgeon 1) from the outset and was pleased to be offered a lobectomy. While still an in-patient, Barbara was told her initial results including confirmation of the diagnosis of lung cancer. This information was important for her as she felt it helped her stay in control if she was able to understand what was happening to her.

Consultations

Surgeon 1 saw Barbara and her husband in the post-surgical clinic four weeks after surgery. The consultation was positive and upbeat. Her surgeon told her that she would refer Barbara to see an oncologist to discuss adjuvant chemotherapy.

A week later Barbara and her husband attended the oncology clinic. They were more nervous about seeing Oncologist 1 than the surgical consultation. She was not keen to have chemotherapy, as her priority was to re-start her arthritis treatment. The arthritis was still a day-to-day reality, while the lung cancer remained abstract to her. However, if there had been a significant benefit, she would have gone ahead with chemotherapy. Oncologist 1 was also not keen to offer chemotherapy and she was referred to a chest physician for long-term follow-up. A summary of the information presented is displayed in table 5.9.

Barbara (68) Stage IIA (pT3N1M0 – PL1) Squamous cell carcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	"Squamous lung cancer". Details of tumour size, and lymph node involvement. No formal stage.	"At five years [...] the chances of it coming back are such that we think that we've cured you" (Surgeon initiated)	Referral to oncology to discuss benefits of chemotherapy.	If developed "new problems" during follow-up would offer a new CT scan.
	Oncology consultation	Surgeon removed tumour, but one lymph node was affected.	"it is possible for these things to come back" (Oncologist initiated)	About 6 people out of 100 having chemo would benefit. Decision not to have chemo. Referral back to rheumatology.	Not discussed

Table 5.9 Key information given in Barbara's consultations

Developments

Recovery was slow following her surgery and she was not able to re-start treatment for her rheumatoid arthritis. She had particular trouble with worsening breathlessness. Barbara felt her anxiety made the situation worse, and blamed herself for "not doing something right". Emotionally she liked to keep her feelings private and described holding "everybody out with a bubble." Three months after her surgery Barbara was admitted to hospital with pneumonia. A CT scan revealed that she had widespread secondary lung cancer. She tried to remain positive about the future and hoped the chemotherapy she had started would keep the cancer under control. She occasionally admitted feeling low about her situation. Although she was glad that she had surgery, and it was "definitely worth a go", she came to regret not having the chemotherapy after surgery.

5.5.3 Edward's case

Background

Seventy-three years old when diagnosed with lung cancer, Edward had a number of other significant health concerns affecting his gastrointestinal system. These conditions had resulted in frequent visits to accident and emergency or being admitted to hospital. He lived with his wife. His daughter and her family lived nearby. Edward portrayed himself as being very laidback, but his wife and daughter were anxious about his health. He was retired, but had been a driver for most of his working life. However, most important to him were his years in the navy in his youth. During his naval years he was heavily exposed to asbestos

dust and was under surveillance for pleural plaques. However, recent chest x-rays had not detected his lung cancer.

Diagnosis and treatment

Edward had been diagnosed with a cutaneous lymphoma following a routine visit to a new family doctor. The news of the lymphoma diagnosis had been broken poorly and he and his family remained confused about its implications. As a result of this diagnosis he was sent for a CT scan, which revealed a lung lesion. He saw this as lucky as it led to an earlier lung cancer diagnosis. He was referred for lung surgery and immediately felt great confidence in the surgeon that he saw. Undergoing surgery was more difficult than he anticipated and recovery was slower.

Consultations

Edward, his wife and daughter attended the post-surgical consultation four weeks after his operation. The surgeon who had operated on him did not see him, but instead he was seen by Surgeon 3, a consultant not previously involved in his care. Although LCNS 3 was present during part of the consultation, she was called away at the point where information about diagnosis and treatment plans was given. Edward felt that he did not get much information about his operation during the consultation, although it was positive and good-humoured. Edward was referred on to the oncologist to discuss adjuvant chemotherapy, but the basis of this decision to refer was never clear.

Edward and his family saw Oncologist 1 about three weeks later. His oncologist advised that chemotherapy was unlikely to be beneficial for him. The consultation appeared positive and Edward felt more reassured about his lung cancer, and had also been able to clarify misunderstandings about his lymphoma diagnosis. Edward was referred to a lung rehabilitation programme, which he was keen to undertake. Table 5.10 gives a summary of the information presented in the observed consultations.

Edward (74) Stage IB (pT2aN0M0 – PL1) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	<i>"Tumour was a cancer"</i> <i>"Lymph nodes did not contain cancer"</i> No discussion of stage.	<i>"So [chemo] is more preventative to stop it [...] reoccurring?"</i> (Daughter's question)	Referral to oncologist <i>"to see if he needs something more"</i>	Not discussed
	Oncology consultation	During surgery they took samples of lymph nodes and <i>"all of the lymph nodes were okay"</i> No formal stage.	<i>"the majority of people at five years in this situation wouldn't have had a recurrence"</i> (Response to patient question)	<i>"the risk of giving chemotherapy outweighs the benefit"</i> Referral to chest team for follow-up.	Report symptoms that last more than two weeks. (Response to patient question)

Table 5.10 Key information given in Edward's observed consultations

Developments

After his consultation with the oncologist he was referred on to the chest physicians for long-term follow-up. Edward's main goal was to get back to being physically active, riding his bike and doing the garden. Over the following six months he experienced multiple emergency department admissions, possibly related to his other health conditions. He also developed pneumonia, which prompted an early CT scan of the chest. However, Edward did not appear to be concerned about this, and no further lung cancer related problems were detected.

5.5.4 Henry's case

Background

Henry was 74 when diagnosed with lung cancer. He had retired early from a job as a medical equipment salesman after he had studied science at university. He and his wife were a very close couple. She continued to work from home. Henry had always been a fit man and played rugby into his forties and was proud of only having three days' sick leave during his working career. He avoided seeking information about his health. This attitude stemmed from his experience when his mother was diagnosed with cancer. He and the family had kept his mother's diagnosis from her for about a year. One day a doctor told her the diagnosis and details about her cancer. Henry felt that she deteriorated from that moment and she died within 3 months. Since then he avoided looking for information and worrying about his health. He did not seek emotional help for himself, but he described his wife's

attitude to things as very different – a born worrier. He was pleased that there was support for her from the nurse specialists.

Diagnosis and treatment

Henry's cancer was diagnosed when he developed a cough. His wife nagged him to see his GP and he eventually went along. After diagnosis he was referred to see the surgeon and he described feeling that he had been referred to the best care in the world. He talked about his strong faith in the surgeon, oncologist and the hospitals. Recovery from surgery was quick, with very little pain and he found his breathing had improved after the surgery.

Consultations

Henry and his wife attended the post surgical consultation about four weeks after surgery. They were not able to see the surgeon in whom they had such faith, but saw someone different, Surgeon 3, who they had never met before. They found the consultation bewildering and confusing. Surgeon 3 attempted to explain his surgical outcome and the positive resection margins⁵, but Henry and his wife did not understand what they were told, and left in a state of anxiety. Following the consultation Henry's wife rang one of the LCNSs to find out more information. Henry did not personally see the need to do this and left this up to his wife to do.

Henry and his wife were seen by Oncologist 1 about two weeks later. The oncologist presented the rationale for offering adjuvant chemotherapy and possibly radiotherapy. Henry felt he was given a large volume of information about the side effects and practicalities of the treatment, which he described as “*overwhelming*”. Despite having worked in a medically related field, he did not feel that he had a good understanding of health issues. He explained that he left medical matters up to his wife. Table 5.11 summarises the information given in the observed consultations.

⁵ Positive resection margins indicated that the tissue removed during surgery showed microscopic evidence of cancer cells at the cut edge of the specimen. This means that cancer cells could be left behind in the body at the site of surgery. This is indicated in the final pathological staging report with the designation ‘R1’.

Henry (74) Stage IIA (pT2aN1M0 – R1) Squamous cell carcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	<p>"Tumour was cancer"</p> <p>"spread of the cancer to the lymph nodes"</p> <p>Cancer was "close to the margin"</p> <p>Tumour was "a little bit advanced"</p>	<p>"There is some remaining disease there"</p> <p>(Surgeon initiated)</p>	<p>Referral to oncologist to discuss chemo and radiotherapy as they can</p> <p>"guarantee better results"</p>	Not discussed
	Oncology consultation	<p>Tumour was primary cancer.</p> <p>"one of the lymph nodes was affected"</p> <p>Tumour was very close to "the edge of the resection".</p>	<p>If cancer spread to lymph nodes "it does mean that it is a bit more likely to flare up in the future"</p> <p>(Oncologist initiated)</p>	<p>Chemo aimed at reducing risk of recurrence, but not 100% guarantee.</p> <p>Radiotherapy will be given after chemo as tumour close to resection edge.</p>	Not discussed

Table 5.11 Key information given in Henry's observed consultations

Developments

Henry was happy to go along with the planned treatment advised by the doctor without wanting much information. He successfully completed the planned chemotherapy and later underwent a course of post-operative radiotherapy. He tolerated both treatments without many problems. Henry was confirmed to have relapsed soon after the final study interview.

5.5.5 Jane's case

Background

When Jane was diagnosed with lung cancer she was 60 and working as a university lecturer. She was single and lived alone. She had moved to the United Kingdom in her youth, but she still had family living in her home country. Her main social support was a strong circle of friends. Jane had been treated for thyroid cancer about 25 years previously.

Diagnosis and treatment

Jane had had shoulder pain for two years, which had gradually worsened. This had been investigated, but no cause could be found. As the pain intensified, she had asked her doctor

whether this could be a Pancoast's lung cancer⁶, but this had been dismissed. Recurrence of the thyroid cancer was also ruled out. She was eventually diagnosed following an MRI scan ordered by her physiotherapist. Jane expressed anger at the difficulties she had experienced in getting her diagnosis and treatment. She was referred for surgery and was told that in addition to the usual surgical risks, the surgeon might not be able to completely remove the tumour and that there was a risk of arm paralysis. Jane went ahead with the surgery. Although the tumour was removed there was a positive posterior resection margin. She recovered well from the surgery, with considerable improvement in her shoulder pain.

Consultations

Jane was seen in the post-surgical consultation about two weeks after her surgery. She attended with a friend for support. Her consultant briefly saw her initially to explain about the positive margin and need for radiotherapy, but this was not observed as part of the study. A registrar, Surgeon 5, who had not previously met with Jane, then saw her and this consultation was recorded. Her pre-operative pain had improved dramatically and this consultation was up beat and positive.

Her subsequent oncology consultation took place with Oncologist 3, whom she had met during her diagnostic phase. She brought a different friend to this consultation. Emotionally she found this consultation more difficult for a number of reasons, some related to her health and some external reasons. She described it as "*Not a good day*". Her focus regarding information appeared to be on practical issues of her treatment, although she did enquire about the extent of the benefit radiotherapy would give her. Table 5.12 summarises the information presented in the observed consultations.

⁶ Pancoast tumour, also known as a superior sulcus tumour, is a cancer involving the apex of the lung, often involving infiltration of local structures, such as the chest wall, brachial plexus and compression of local blood supplies and nerves. It is associated with pain and often accompanied by systemic symptoms and neurological deficit.

Jane (60) Stage IIB (pT3N0M0 – PL3, R1) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	Tumour grown into ribs. <i>“tendency to grow into nerves and blood vessels”</i> . Staging says “T2A N0”, but <i>“should say T3, because [tumour] invading chest wall”</i>	May be microscopic tumour remaining.	Referral to oncologist for radiotherapy. May consider chemotherapy after radio.	Not discussed
	Oncology consultation	Cancer cells present at one surgical edge. Unknown whether cancer cells remain behind. No cancer spread to lymph nodes.	More likely to recur if <i>“the layers of the lung are involved”</i> (Oncologist initiated)	Radiotherapy would improve <i>“local control”</i> from 50 – 60% to 70 – 80%. Potential for chemo after radio. Chemo may reduce risk of cancer recurrence.	<i>“little niggles that come and go are rarely anything to do with cancer”</i>

Table 5.12 Key information given in Jane's observed consultations

Developments

Undergoing interviews for the research study was something that Jane felt she would not be able to do, and so declined this part of the study. Jane commenced radiotherapy and subsequently had chemotherapy.

5.5.6 Maggie's case

Background

Maggie was 69 when she was diagnosed with lung cancer. She had recently retired from her job in local government and was looking forward to spending time with her family and travelling. Her husband was her main support. She had several adult children living close by with their families. She described herself as the matriarch and hub of the family. She also saw herself as a worrier and someone who thinks through the consequences of everything.

Diagnosis and treatment

Maggie was a smoker for 50 years and gave up a few months before she was diagnosed with lung cancer. She went to the GP with a cough and immediately *“knew”* it was lung cancer, due to her smoking. Her initial reaction was anger at herself for smoking and worry about

the long-term outcome. Delays in getting seen by the surgeon increased her anxiety, which she put down to “*the system*”. Her daughter looked up the surgeon on the Internet and told her he was “*the best*”. This was confirmed when they met him and she felt her surgeon had an “*aura about him*”. Her surgeon told her that the surgery was complex and that she might need a pneumonectomy, but he did not offer much detail and she did not ask any questions.

Maggie’s surgery went well and she was able to have a sleeve lobectomy⁷. She was still in hospital when the pathology results were available and the surgeon saw her on the ward before her discharge and told her that he had removed all the cancer. She was so pleased at the result that she said that she could have “*hugged him for the rest of his life.*” He also told her that she would be referred to the oncologist.

Consultations

Maggie attended the post-surgical consultation with her husband about four weeks after her surgery. She was experiencing heart rhythm problems which were making her very breathless. Her consultant, Surgeon 9, focused discussion on her heart problem, post-operative recovery and breathing. The surgical outcome and further lung cancer management were not re-visited. LCNS 6, who had been involved throughout her surgical treatment, was also present. Maggie expressed her gratitude to Surgeon 9 for what he had done for her.

Maggie’s appointment to see the oncologist happened only four days later. However, she was much more anxious on this occasion. She attended with her husband again. She was seen by Oncologist 4 and also LCNS 7, both of whom she had not previously met. The oncologist explained the rationale behind adjuvant chemotherapy, and left the final decision about going ahead with the treatment to her, a decision that she found very difficult to make. Table 5.13 summarises the information given in the observed consultations.

⁷ A sleeve lobectomy involves resection of a segment of bronchus along with the affected lobe. The remaining lobe(s) are preserved by re-anastomosis of the distal section of the bronchus to the main bronchus. The procedure is done to avoid pneumonectomy in patients with central tumours.

Maggie (69) Stage IIB (pT2bN1M0 – PL1) Adenocarcinoma		Diagnosis and staging information	Recurrence risk / long-term outlook	Management plans	Signs and symptoms of possible recurrence
	Post-surgical consultation	Not discussed	Not discussed	Not discussed	Not discussed
	Oncology consultation	<i>"Adenocarcinoma" type of NSCLC. Surgeon "got rid of" cancer "visible on this scan" Spread to lymph gland within lung, but not outside the lung.</i>	Surgery appears to have got all the cancer, but we know from studies <i>"that isn't always the case"</i> . (Oncologist initiated)	For <i>"people like you"</i> , having chemotherapy <i>"five extra people would be cured of the cancer in addition to the surgery"</i> out of 100.	Not discussed

Table 5.13 Key information given in Maggie's observed consultations

Developments

Maggie commenced chemotherapy, but found it very difficult to tolerate due to the side effects. She wanted to complete the treatment, as she sought peace of mind about future recurrence. In the end she stopped treatment after the second cycle. Despite the side effects she did not regret starting the chemotherapy and comforted herself by saying that she had had half the benefit.

5.5.7 Pathway B commentary

The cases that followed this second pathway were all referred to see an oncologist to discuss the possibility of further treatment after surgery. Most patients had stage II lung cancers. In Henry and Jane's cases the surgical outcomes were complicated by the positive resection margins. Edward can be viewed as the outlier within this group. Being diagnosed with a stage IB lung cancer he would not have normally have been considered for adjuvant chemotherapy.

Information given by the surgeons about possible future recurrence for this group of patients tended to be limited in nature. Maggie and her surgeon did not discuss surgical outcome and its implications during the observed consultation. For the others, surgeons initiated discussion about recurrence mainly in terms of it being a possibility. Rationale for referral to an oncologist and adjuvant treatment was largely left vague. None of the patients

on this pathway asked any questions about the degree of recurrence risk, or to clarify the details around the rationale for further treatment. The only question came from Edward's daughter, who did briefly ask about the nature of the possible adjuvant treatment.

During the oncology consultations oncologists had an inherent need to discuss the possibility of recurrence, at least in terms of the role of adjuvant treatment. However, oncologists like the surgeons, framed recurrence in terms of a future possibility, rather than using numerical probabilities. None of the oncologists gave patients estimates of absolute risk of recurrence, or overall survival. Some oncologists used comparative statements to give a sense of degree of risk for patients when considering adjuvant treatment. Oncologists mostly explained the potential benefit of undergoing chemotherapy to patients by talking about the numbers of extra patients who might not experience cancer recurrence, or who might survive, compared to those treated with surgery alone. In one case no numerical estimate of benefit of adjuvant treatment was given (Henry) and in another case the oncologist only focused on local control of recurrence rather than systemic control or overall survival (Jane).

Patients on this pathway did not ask for any information about recurrence risk or survival statistics and did not appear to want this detail. One exception was Edward, but only after he had been told that he did not require chemotherapy. He also went on to ask about what signs and symptoms he should look out for that might indicate a future recurrence. He was the only patient on this pathway to be given any information about what to look out for and what to do if worried about possible recurrence.

5.6 Chapter summary

During this chapter I have introduced the twelve cases that constitute the study and outlined the treatment pathways following the surgery. The twelve patients at the centre of the cases were diverse in their backgrounds and previous health experiences. Surprisingly patients in half of the cases had either a previous or concurrent malignant diagnosis and in some cases this was instrumental in the patient's early lung cancer diagnosis and surgery.

Fiona's case was atypical amongst those in the study due to her diagnosis two years previously and initial chemotherapy treatment prior to surgery.

Patients followed two distinct pathways after surgery, either referred on to long-term follow-up (Pathway A), or referred to see an oncologist to talk about adjuvant therapy (Pathway B). Patients on Pathway A were told by their surgeon that no further treatment was required after surgery. Patients then asked about their risk of recurrence. For patients with stage I cancer in this group, professionals emphasised the early cancer stage. For patients on Pathway B, professionals did initiate discussion of recurrence, but these were generally vague and often at the level of possibility rather than probability. The benefits of adjuvant treatment were usually discussed in terms of the extra number of patients who might survive or avoid recurrence, rather than discussing absolute risks. Across all of the observed consultations professionals were reluctant to enter into detailed discussion about potential cancer recurrence. Patients were rarely informed about signs and symptoms of recurrence that they should be aware about.

In the next three chapters I will present the findings from cross case analysis of the data in this study. Each chapter will be used to present one major theme: chapter 6 'Predicting the Future', chapter 7 'Maintaining Hope' and Chapter 8 'Hope Dances'. Figure 5.2 provides an overview of these themes and subthemes.

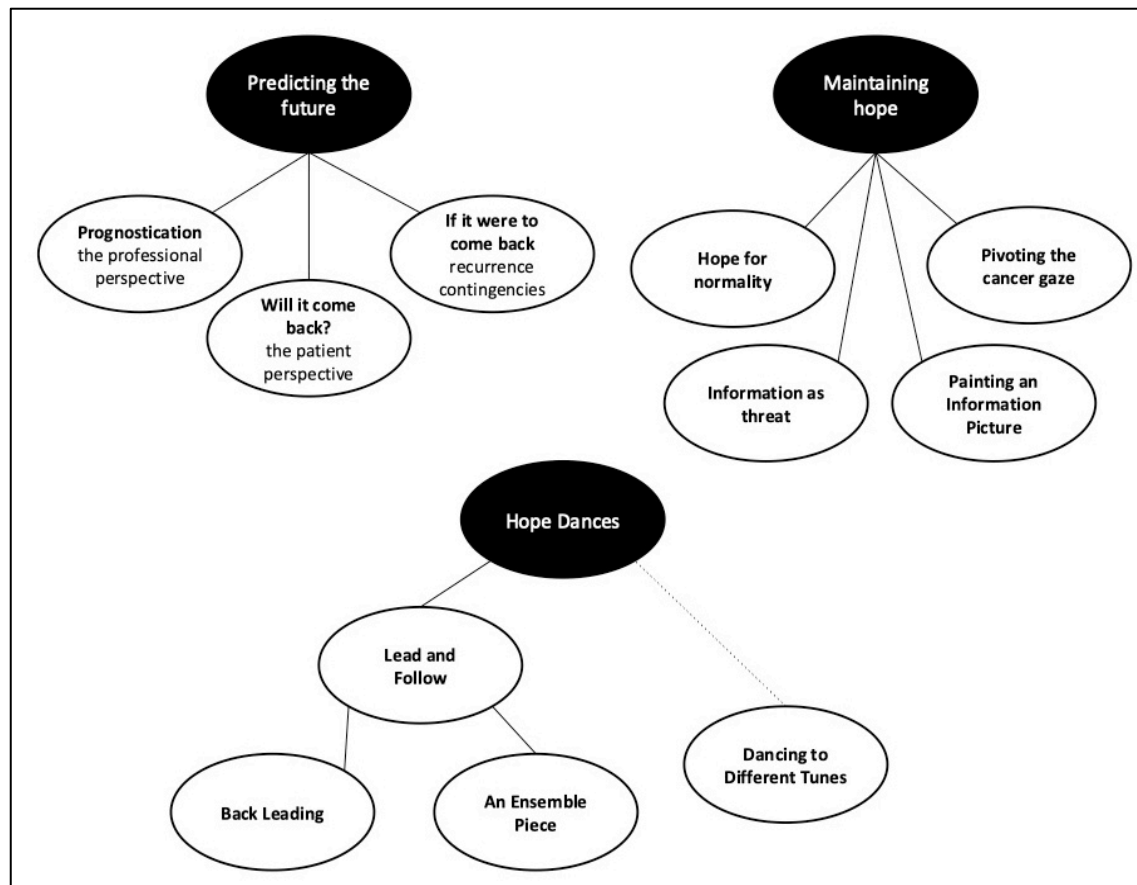


Figure 5.2 Overview of cross case themes

6 Findings 2 - Predicting the future

6.1 Introduction

In this chapter I will present the first of the study themes based on the cross-case analysis of the findings. The theme 'Predicting the future' concerns how patients and the professionals caring for them conceived the long-term outcome in relation to lung cancer. The theme covers what participants foresaw for the patients, as well as what information they drew on in order to arrive at their understanding. A schematic overview of the themes and subthemes discussed in this chapter is displayed in figure 6.1.

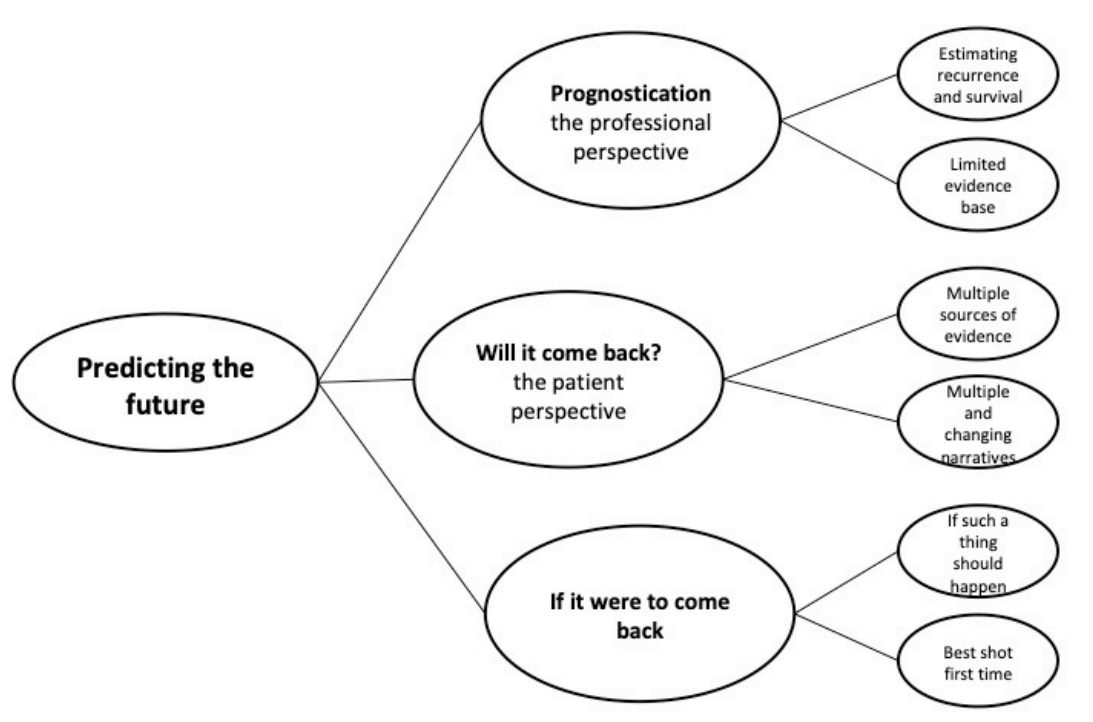


Figure 6.1 'Predicting the Future' theme and subthemes

The chapter will be organised around the three main subthemes. In the first, 'Prognostication', I will explore how professional participants conceived the long-term outcomes for patients following lung cancer surgery, based on available published data and clinical experience. The second subtheme, 'Will it come back?' will look at the patient participants' conceptions of their long-term outcomes, which were largely concerned with whether the lung cancer would recur. In the last subtheme, 'If it were to come back', I contrast the largely positive patient narratives around treating a recurrence if it were to

happen in the future, with the much more limited ideas of what treatment could offer following relapse that were expressed by the professional participants.

6.2 Prognostication – the professional perspective

During interviews with the professional participants I asked about the long-term outcomes for the patient they had seen in clinic. If not provided spontaneously, I asked professionals to provide a numerical estimation. An overview of these responses, along with the current published International Association for the Study of Lung Cancer (IASLC) survival data, are provided in table 6.1. The answers that professionals gave to this line of questioning ranged from very specific numerical estimates of prognosis to qualitative evaluations. Some professionals declined to give answers to these questions, either because they did not feel able to, or because they felt that the long-term outlook was simply unknown. These responses will be explored in more detail in the two subthemes, ‘Estimating Recurrence and Survival’ and ‘Limited Evidence Base’.

6.2.1 Estimating recurrence and survival

Professional participants made reference to published data from various sources. Many of these estimates given by professionals differed significantly from those in the IASLC survival data. However, the purpose of presenting the population data was not to establish how ‘right’ or ‘wrong’ the professional participants were in their projections, but rather to provide a baseline from which to explore the reasons for these differences. Len’s surgeon gave an estimation of Len’s five-year survival using the recent IASLC data.

[...] the current oncological literature suggests the expected survival after stage 1a, 1b, like for him, it’s 83%. (Surgeon 8: Len)

As can be seen in table 6.1, Cathy, Denise and Glennis’s surgical team members gave similar responses based on this data. However, others such as LCNS 2, who saw Cathy and Denise in the follow-up consultation, appeared to draw on earlier published studies. Her response of 70 to 75 per cent five-year survival reflected those given in the previous version of the IASLC data.

Case (Stage)	Estimation of long-term outcome				
	IASLC (2016) 5-YS	Surgeon estimate	Surgical LCNS estimate	Physician / oncologist estimate	Non-surgical LCNS estimate
Audrey (IIA)	57%	<i>"Moderately high risk of recurrence"</i>	N/A	40 - 60% 5-YS	N/A
Barbara (IIIA)	36%	<i>"Relatively high" "Real risk" of recurrence</i>	N/A	40 – 60% 5-YS	N/A
Cathy (IA)	83%	<i>"Very good" >80% 5-YS</i>	N/A	N/A	70 - 75% 5-YS
Denise (IA)	83%	<i>"Quite good, but not 100% as lung cancer"</i>	85 - 90% 5-YS	N/A	70 - 75% Disease- free survival and 5-YS
Edward (IB)	71%	<i>"Quite good". "Slight majority" will achieve 5 years 50 – 60% 5-YS</i>	Unable to give a figure	Recurrence 30 - 40% at 5 years <i>"Pretty good outlook"</i>	N/A
Fiona (N/A)	N/A	Unusual case; cannot put figure on recurrence risk.	Not able to quantify survival estimate	<i>"Optimistic survival will be good", but not able to give an estimate.</i>	N/A
Glennis (IA)	83%	85% disease free survival at 5 years	15% chance of recurrence at 5 years	N/A	Cure rate less than 100%
Henry (IIA, R1)	N/A	60% risk of getting metastatic disease within 3 years	N/A	50% 5-YS estimate <i>"an approximate one"</i>	N/A
Jane (IIB, R1)	N/A	Higher risk of both local and distant disease. Unable to give exact figure.	N/A	T3N0 Pancoast 40 - 50% 5-YS. Patient's case suggests less aggressive.	N/A
Kamal (IIA)	57%	40 - 50% 5-YS	N/A	60 – 70% 5-YS	N/A
Len (IB)	71%	83% 5-YS (based on report stating pT1bN0 PL1)	N/A	Unable to give figure. Outcome worse than if T1b PL0.	N/A
Maggie (IIB)	49%	<i>"Quite good" 35 - 40% 5-YS</i>	Unable to offer estimate.	50 - 70% 5-YS This case more like 50 - 60% 5-year disease free survival.	Generally surgical patients 60% 5-YS

Key: 5-YS = five-year overall survival

IASLC (2016) = Survival data based on pathological staging quoted in Goldstraw et al. (2016)

Table 6.1 Professionals' estimates and published data of long-term lung cancer outcomes

In response to questions about long-term outcome professional participants often made little distinction between recurrence risk and survival data. When used in clinical practice it

sometimes appeared that the two concepts were indistinct. In order to talk about recurrence risk, several participants made direct reference to the available survival data. One example was Cathy's surgeon whose answer regarding long-term outcome implied that survival was equivalent to being recurrence free.

I really think that the chance of recurrence is quite low with this kind of tumour. [...] normally survival, five years survival for these kind of tumours is very good. Over 80%. So I would say less than 20% [risk of recurrence]. (Surgeon 2: Cathy)

Glennis's surgeon also demonstrated how he used IASLC survival data to offer information to patients about the chance of not experiencing a recurrence of cancer. I asked Glennis's surgeon about the estimate he gave Glennis during her consultation of "85% chance of nothing coming back in 5 years". His answer indicated a blurring of lines between survival and recurrence in the surgeon's mind.

Interviewer: In the clinic obviously she pushed you to actually give a numerical risk of recurrence, [...]

Surgeon 5: Well I mean I just used the IASLC survival curves.

As can be seen in table 6.1, professionals appeared to be more willing to give predictions of long-term outcome for patients with early stage lung cancer, than for patients with more advanced disease. One explanation for this could simply be that statistics around early stage cancer were relatively easily recalled. However, many of the patients with more advanced cancer also had more complex clinical scenarios. As complexity of individual scenarios increased, there were increasing "grey areas" (Kamal's Chest Physician) that made interpreting available evidence more difficult and unreliable to use. Clinical complexity will be discussed further later in relation to the limitations of the available evidence.

Familiarity with and access to the relevant data appeared to be important factors in both professionals' use of these statistics in practice and the answers they gave in the interviews. Some professionals talked about seeking relevant information in relation to patients they were due to see. An example was Kamal's Chest Physician, who said: "I'd probably try and prepare myself with more up-to-date information" so he could answer questions about prognosis during consultations. Jane's oncologist emphasised that he would want to check

survival data for the individual patient “*well before any kind of appointment*” before embarking on a discussion about treatment, “*because I’m not great at keeping figures in my head long-term*”. In order to find the specific evidence required he needed to seek more specific sources of evidence than the IASLC data.

I’ll go and try and find just a review article on PubMed or something like that, that’s more contemporaneous, [...]. (Oncologist 3: Jane)

Other professional participants did not appear to see prognostic information as so important in relation to their clinical practice. Several declined to give a numerical estimation of long-term outcome during their interviews. Len’s Chest physician, for example, was aware of features in Len’s cancer staging that might impact on his long-term outlook, but she was unwilling to offer an estimate of prognosis. The reason behind this was not explicitly communicated in the interview, but her failure to recognise inconsistencies in the staging report⁸ suggested a lack of familiarity with the staging system. This may then also have been a factor in the doctor’s reluctance to offer a numerical estimate of risk. Regarding his prognosis she said:

[...] I don’t think he’s as good as he would’ve been if he’d have just been a T1a with a PLO and a R0. So I think he’s at some risk of recurrence, but I couldn’t be able to give you percentages. (Chest physician 2: Len)

Some LCNS participants were more explicit in their lack of familiarity with prognostic data and did not feel able to answer these questions. Maggie’s surgical LCNS felt that she lacked the knowledge and experience of discussing issues around treatment outcome, “*because my knowledge is relatively new compared to a lot of people around me*”. She reported that occasionally when a patient asked for this sort of information she would then call one of the medical team to speak with them. In a similar way, Edward’s LCNS recognised that she did not have confidence in talking about recurrence statistics.

⁸ All patients with pleural infiltration (PL1 or above) should automatically have a T stage of at least T2a. Len’s report should have read pT2aN0 PL1, giving an integrated lung cancer stage of IB.

I don't feel confident to state statistics about it. And I guess after doing the job for so long, I do feel that it's an area that I lack knowledge about. (LCNS 3: Edward)

Several of the professionals gave answers about recurrence risks in relative terms. Examples included Len's Chest Physician, and the Surgeon involved in Audrey and Barbara's cases (See table 6.1). The professionals compared the clinical features of the particular patients with other situations to place the risk in some form of context, while avoiding a numerical estimate of outcome. Barbara's surgeon viewed her risk of recurrence as being higher than other surgical patients, due to cancer spread to local lymph nodes. Although she identified Barbara as being at "significant" risk of recurrence, despite further questioning, she was unwilling to offer a numerical estimation. Such verbal descriptors of risk (such as "significant" or "relatively high") are inherently vague and imprecise.

I think it's quite significant. She's got N1 nodal disease. I think she's at a <relatively> high risk of recurrence. [...] I think it's all relative, I compare it to those with stage I lung cancer and I think she, you know, because she's got the N1 nodal disease [...]. (Surgeon 1: Barbara)

In several interviews professionals offered both a numerical estimation of prognosis, as well as a verbal description, as shown in table 6.1. Although some replies intuitively appeared congruent, such as the answer provide by Cathy's surgeon, others, such as Maggie's surgeon, underlined the contextual and idiosyncratic nature of these verbal estimates of outcome. The surgeon estimated Maggie's chance of survival at five years as 35 – 40 per cent: somewhat lower than the population data for Maggie's stage. Nevertheless, he described survival as "very good". Asked for more clarity to this surprising answer he responded that it was good in comparison with "what it was before". By this he meant that if she had not gone ahead with surgery, she would almost certainly have died as a result of her cancer, whereas following surgery she did now have a significant chance of cure.

6.2.2 Limited evidence base

There was a range of views amongst professional participants about the applicability of available evidence in regard to individual patients. At one end of the spectrum Len's surgeon talked about the high quality nature of the evidence and its relevance for patients.

[...] we do have very strong available evidence in terms of five-year survival for a given stage. (Surgeon 8: Len)

However, others were less whole hearted in their beliefs about the utility of this data when applied to individual patients. Professional participants saw making predictions for patients' long-term outlook as highly complex and uncertain in nature. Several factors were described as limiting the usefulness of population-based data when thinking about the outcome of individual patients. These included the meaning of average outcomes, the binary nature of survival data, the essential randomness of natural events, the complex and multi-factorial nature of prognosis, and situations where there was a lack of relevant data on which to base predictions.

Limitations of population data

The most straightforward concern was around data that gave a population average, such as mean five-year disease free survival data. Several participants cautioned against using the mean to represent a prediction of what might happen to an individual. This issue was seen to be a particular concern when attempting to convey statistical data to patients. Kamal's Chest Physician argued that a mean could obscure the spread of individual outcomes and so mask population outliers.

But also they're often based on medians, which means that, exactly. You're almost more likely to fall on one side or the other. Do better than expected or worse than expected. (Chest physician 1: Kamal)

Another basic concern about the usefulness of population data when dealing with individuals was the binary nature of the outcomes in question. Although several professionals acknowledged the existence of “good population statistics” (Oncologist 1), the relevance to the individual patient cases was less clear. Jane's Oncologist made a point about the binary nature of recurrence during their consultation, saying, “either it is going to come back, or it is not”. Several professionals felt that making predictions about whether an individual patient would, or would not experience a recurrence was an unanswerable question. For example, Maggie's surgeon felt it was “impossible to tell” what would happen to an individual. Barbara's oncologist highlighted the clinical challenge of this problem.

“[...] really what matters to the individual patient is what’s going to happen to them. And obviously she’s either going to live or die. And unfortunately we really can’t tell [...].” (Oncologist 1: Barbara).

The same oncologist, in relation to Edward’s case, expanded this point and underlined the strong sense of uncertainty that professionals themselves experienced about the patient’s future:

“[...] we really haven’t a clue, we don’t know who’s going to relapse and who won’t. And if they do relapse we don’t know when it will happen.” (Oncologist 1: Edward)

Some professionals characterised recurrence as essentially a random phenomenon, striking those for whom it was least expected. These comments underlined the aleatory uncertainty inherent in cancer recurrence. Professional participants appeared to characterise lung cancer patients as being particularly prone to surprising outcomes, at odds with the outlook suggested by the available statistics. Maggie’s surgical LCNS spoke about seeing patients with recurrence where you “*wouldn’t have expected*” it. Glennis’s LCNS saw “*no rhyme and reason*” regarding which patients would relapse, especially for those diagnosed with adenocarcinomas. Edward’s LCNS spoke about patients she had cared for with early stage cancer who had relapsed unexpectedly, highlighting the gap between available population data and the complexities and uncertainties of individual patients’ situations. These experiences led her to conclude that attempting to predict outcomes for an individual patient was not useful.

[...] as we have proven so often, statistics are actually not of any help anyway, because things just don’t fit in the boxes, do they? (LCNS 3: Edward)

Individual differences

Where professionals drew on average population data to make predictions, some used specific histology and pathological features to reflect a more individual estimate of outcome, such as the oncologists caring for Jane and Maggie (see table 6.1). Maggie’s oncologist spoke about aspects of the pathology report that could negatively influence her prognosis, such as tumour invasion into the pleura and necrosis of the tumour. However, ultimately she alluded to such adjustments owing more to professional experience and reasoning, than any particular evidence.

But the PL1 and the size and the sort of central necrosis, [...]. Again whether that's anecdotal or not. (Oncologist 4: Maggie)

Other aspects of the pathology report appeared to be given less importance. Several professionals characterised adenocarcinomas as less aggressive than other cancer types. For example, LCNS 2 said that “*the adenocarcinomas in general tend to be slow growing*” and Surgeon 2 described Denise’s adenocarcinoma as “*not a particularly aggressive type of cancer*”. But beyond this, none of the professionals identified histological sub-type in the pathology report as indicating a better or worse prognosis, despite some available evidence on the effect of adenocarcinoma subtype on prognosis. Audrey’s oncologist commented that his primary focus was to decide about whether or not to offer adjuvant chemotherapy. Histological subtype had little bearing on this decision, and was therefore largely incidental.

It's really the stage of the disease and the patients' health that drives sort of adjuvant chemo decisions. (Oncologist 1: Audrey)

Another factor that limited the reliance professional participant’s placed on the available evidence was the impact of co-morbidities on a patient’s overall prognosis. Such individual complexities meant that the available population data became increasingly unrelated to the clinical estimates for outcome. Audrey’s oncologist raised concerns about the long-term effect of having a pneumonectomy, alongside her other co-morbidities. His estimate for her prognosis included the effect of cancer stage as well as her underlying health. However, the estimate he gave for her included a large range, reflecting his uncertainty about her outcome.

Because it was an N1 tumour again, so again it is the sort of 40 to 60% at five years would be the sort of ballpark survival figure. (Oncologist 1: Audrey)

For some patients, professionals saw other health conditions as important as lung cancer stage in predicting survival, such as Kamal’s Chest physician.

[...] his survivorship is perhaps almost as much measured by his coronary artery disease or cerebrovascular risk, given his diabetes, which, from memory, I don't think is particularly well controlled. (Chest physician 1: Kamal)

Lack of relevant data

Another situation that presented a significant challenge to professionals when using the available evidence to predict long-term outcomes was for patients who had microscopically incomplete resections (denoted as R1). Table 6.1 outlines the estimates for long-term outcome for Henry and Jane. The estimate given by Henry's surgeon for risk of recurrence was unusual in providing a definitive estimate. However, the answer appeared to be based more on clinical experience rather than published data. Limitations during this interview meant I was unable to clarify how this estimate was derived.

It's going to be high, I think. [...] We know that it is a lung disease with margins not clear. He's having, let's just say, more than 60% to get a metastases within the next three years. (Surgeon 3: Henry)

There were also significant differences between the estimates given by Henry's surgeon and oncologist. The oncologist particularly highlighted the unknown significance of the microscopically positive margin finding on survival. The limited evidence base meant that this estimate was apparently an educated guess.

The difficulty we have with this one is that nobody really knows what impact the positive resection margin has, but I'd roughly guess probably about 50% five-year survival overall. That would be an approximate one. (Oncologist 1: Henry)

Jane's surgeon was more categorical about the lack of evidence to support any assessment of prognosis in her case. He indicated that staging data had less relevance in Jane's case than the effect of the incomplete resection margin.

[...] so if you look at the survival curves you only have T stages, N stages, and there's no survival curve for R. So I wouldn't know what her five-year survival is. (Surgeon 5: Jane)

The oncologist who saw Jane drew on research studies regarding outcomes for patients with Pancoast tumours to gain an indication of her likely prognosis. However, the data were of limited relevance to Jane's case, due to her positive resection margin, as well as other features that might indicate a better prognosis, such as apparent slow rate of growth and absence of lymph node spread.

[...] most of the evidence is based around those patients who have got nodal positivity, in terms of the actual values and figures and numerical values. And I think where you have got R1 and where you've got PL3⁹ that makes it much more difficult to be able to extrapolate those patients out who have got node-negative disease. (Oncologist 3: Jane)

Fiona's case was a particularly vivid example of a patient who had followed an unusual pathway to surgery, having initially been treated with chemotherapy with palliative intent. The uniqueness of Fiona's case meant that there was not a population of other patients on which to base any kind of estimate of prognosis. The professionals saw that Fiona had *"already responded in a different way to most people"* (Fiona's surgeon), and concluded that *"we can't use standard measures"* (Fiona's LCNS) to predict her future outcome. While they were optimistic about a good outlook, they felt that *"we don't quite know what's going to happen in the future"* (Fiona's surgeon). Fiona's oncologist summed up the particular challenges in predicting her future outcome.

So she's not completely risk-free, but what the percentage is... Because this is such an unusual case. I mean, in [...] the many years I worked [...] treating lung cancer, I've never seen this. We just have to watch and see. I can't put a figure on it at all I'm afraid. (Oncologist 2: Fiona)

Whether or not professionals were willing or able to offer prognostic estimates for the individual patient cases, the way in which they spoke about and conceptualised the long-term outlook drew on the available evidence and on their clinical knowledge and experience of working with numerous patients with lung cancer. Unlike the professionals, patients largely did not have access to this kind of biomedical knowledge. In the next subtheme I will explore the knowledge and information that patients used to derive their understanding of their future and the narratives they told to describe their predictions.

⁹ PL3 denotes that the tumour has breached both the visceral and parietal pleural layers and is invading the chest wall.

6.3 Will it come back? - Patient predictions of long-term outlook

In this second subtheme I will focus on how the patient participants conceived the long-term future and what information they used to form their understanding. The title of the subtheme, 'Will it come back?', reflects the concern in patients' narratives about whether the cancer would recur after surgery. I will begin by exploring the multiple sources of information that patients used to form their understanding of their long-term outlook. Next I will present findings from the longitudinal element of the study to illustrate how patients' narratives about recurrence changed and developed over time. I end this exploration of this subtheme by looking at the multiple and sometimes ambivalent nature of patients' narratives about recurrence.

6.3.1 Multiple sources of evidence

The way patients developed an understanding of their condition and its prognosis was like a collage made up of multiple pieces of evidence, gleaned from disparate sources. This included prognostic information given to them by professionals, information they had found themselves, general knowledge, experiences of family members or acquaintances, and from the symptoms they themselves were experiencing.

Specific prognostic information

Patients recalled a range of information that was given to them throughout their diagnosis and treatment and formed an understanding of their long-term outlook. Unlike other participants in the study, Glennis both asked for, and was given, an estimate of her risk of recurrence by her surgeon. She was unusual in wanting to know a numerical estimate of her prognosis, and in holding on to this information. The figure she was given was important in her initial narrative about cure. She recalled her surgeon telling her that she had an 85 per cent chance of not having a recurrence. I asked how it felt to be given this figure.

Good. I'd prefer it to be higher. (Glennis 1st interview)

While acknowledging her survival statistics as relatively good, she also implied the potential for another, more feared outcome. Her main concern remained possible recurrence of the cancer and where this might occur. In this way, the potential reassurance of this apparently positive information also became a source of anxiety and increased uncertainty for her.

You know, so I think my survival rate, if you look at my statistics is OK, but nobody's given me, is it going to pop up in another lobe of my lung? I don't know. Why did it pop up there? (Glennis 1st interview)

In contrast, Denise's surgeon had given her an assessment of her risk of recurrence as "very low". Denise felt that this amount of information was what she needed. Rather than drawing on what happened to other patients in a similar situation, she disassociated herself from the wider population of lung cancer patients.

[...] everyone's different, so let's just see how, you know, the dices roll for me. And I think that is probably the most sensible approach. I'll try and think positively and hope that this is, you know, it. (Denise 1st interview)

By emphasising her individuality and by invoking a game of chance, Denise appeared to be taking away prediction based on populations and focused more on randomness and the potential effect on her as an individual. Her position resonated with that of the professionals discussed previously who were sceptical about the applicability of population statistics to individuals. Unlike Glennis, here Denise was consciously trying to accept the uncertainty of her position and to use this as a positive force in coping with it.

For other patients information they had been given during consultations led to misunderstandings. Some patients left consultations assuming that their long-term outlook was much worse than had been intended by the professional. An example was Audrey, who spoke about what she had understood from her oncology consultation. Being referred for a PET scan made her worry that her surgeon "didn't get all the cancer out" and feared that the resection was incomplete. Discussion of the survival benefits of chemotherapy in terms of improvement in five-year survival made her think she was being given an estimate of life expectancy. She recalled, "... he said something about five years, so I think I've got five years." Other patients also appeared not to fully retain the information that they were given. When Len was asked about the recurrence risk information given during the consultation, he said, "I don't remember him saying that". Cathy had asked about the chance of the cancer coming back in her surgical consultation, but she had no recollection of asking about it, or of the answer, saying, "Did I ask that?" These examples serve to highlight

that giving patients information may not result in retention, or accurate interpretation of what professionals think they have conveyed.

Other indicators

Patient participants frequently used much broader sources of information to form their understanding of their long-term outlook beyond the direct recurrence risk or survival information given by professionals. This might include information about the nature of the surgical operation, plans for onward management, the emotional tone of the consultation, as well as factors from the wider healthcare setting, such as knowledge of how other patients with similar diagnoses were doing. The understanding patients gained from this sort of information often lacked detail and could be considered to be at the level of gist.

Information given about the surgical operation and whether the surgeon had managed to completely remove the cancer was often central to patients' positive outlook about the future. An example of this was Cathy, who was able to recall the surgical outcome and plan.

They'd taken out the cancer. And they'd had a good chunk around and they'd made sure they'd got it. So there was no cancer, so I needed no treatment. (Cathy 1st interview)

She also spoke about the rationale for the planned follow-up.

I suppose she's keeping an eye that they don't come back, hopefully. (Cathy 1st interview)

Although she acknowledged an inherent risk, albeit minimal, she remained positive about the outlook in relation to her cancer. She described her own sense of agency that would help to minimise this risk to a negligible level, which included a combination of hope, prayer and life-style changes. Describing her perceived risk of recurrence, she said:

Hopefully, zero. I hope and I pray. I don't smoke any more. I eat healthy. (Cathy 1st interview)

Other patients appeared to take the general tone of the consultation and the overall message about onward management as an indication of their outlook. A clear example of this was Len's consultation with his surgeon. Although he was not able to recall specific

details of the information given during his consultation, he took the surgeon's confident attitude as evidence of a good outlook. He acknowledged the possibility for recurrence, but this understanding came from the discussion about long-term follow-up, rather than the specific discussions about recurrence risk.

I presumed there'd be something like that [risk of recurrence] because otherwise there wouldn't be no reason to follow up. (Len 1st interview)

Several of the participants who were referred for an opinion regarding adjuvant therapy (those on pathway B) explicitly acknowledged that this referral indicated a higher risk of cancer recurrence. However, none of the patients gave any indication of the level of this risk, or any desire to know. Henry was an example of this. In his interview he explained:

And now there is the possibility of a recurrence, so therefore further treatment is recommended. (Henry, 1st interview)

However, his perception of the high cost of the treatment he was receiving was in itself taken to indicate that there was still a good chance of a good outcome.

[...] these pills must be bloody expensive [...], and so there isn't any stinting on spending money on me because my life expectancy ain't that great anyway. (Henry, 2nd interview)

Another way patients could judge their prognosis was from their fellow patients. This was a particular issue for Fiona due the length of time she had been attending the lung cancer service. In her interviews she spoke about several other patients who she had known and had died, or were currently struggling with treatment. Not only did her personal knowledge of how others had fared impact on her own view of the future at vulnerable moments, there was also a sense of survivorship guilt that she contended with in relation to other patients, with some of whom she had developed friendships. Although she strove to maintain her own positive narrative about the future, this knowledge appeared to lead to doubts.

Yeah, I feel that probably it will come back, ... maybe, you know, ... probably. It tends to, doesn't it? I'm just hoping I've got a long time before it does. [...] It just seems that way from what I've heard of other people and that, so hopefully, you know. I don't think you can get rid of that completely, can you? I don't know. (Fiona 3rd interview)

Lay understanding

In a much wider sense, patients brought their general, lay understanding of cancer to their view of their long-term outcome. Such understanding came from general knowledge, the media, as well as the experiences of family members, friends and acquaintances. Several participants, such as Audrey, Kamal and Maggie, spoke about their view that cancer was equated with death. A lay understanding also often informed participants' beliefs of why the cancer developed initially and their predisposing factors. This also influenced participants' ideas on whether the cancer might recur. Edward spoke about his assumption that his cancer was as a result of exposure to asbestos, but could not get anyone to confirm this. He saw the presence of asbestos being his primary risk of further lung cancer. Although he spoke about "*getting rid*" of his lung cancer, he viewed the presence of asbestos "*lurking*" in his body as giving him a higher risk of future cancers.

So now we've got rid of this bit [the lung cancer]. And this crept up on us. So maybe there's whatever caused that, may be lurking somewhere else. (Edward 1st interview)

Others also spoke about their vulnerability to further cancer, either due to contamination by something from the environment, or because of an inherent susceptibility within the body. Denise was particularly concerned about the underlying cause of both her lung and breast cancers.

And have I got a predisposition to both [breast cancer and lung cancer]? I'm still living in the same [area]. Is it environmental? (Denise 1st interview)

Although she raised her concern about the environment, she went on to talk about how she felt powerless to influence her risk of further cancer and being at the whim of a quixotic body. Denise describes an embodied vulnerability to the cancer that was divorced from her as a person. These concerns and a sense of things being "*unlucky*" remained with her into the third interview.

But then I think well I can't really do much. If my body decides that's the way things are and it's going to, you know, pop another one up in the other side. So it's, I just feel a bit unlucky, you know. (Denise 1st interview)

But then because of the person I am, I will never absolutely be completely convinced that that's it. There's always a chance, because I think my body is now predisposed to cancer, so I've got to be wary that it could come back. (Denise 3rd interview)

Like Denise, Glennis also saw her second cancer diagnosis, following previous breast cancer, as being “unlucky” and reflective of her predisposition to future cancers.

I just think I've had cancer twice, that's really not good. And then you do get that, am I prone to cancer? And nobody can answer that. (Glennis 1st interview)

Despite asking, she had not been able to get answers to these questions. Her questioning of medical opinion had been what had led to her early diagnosis, and this reinforced her on-going doubts about the veracity of the answers she was receiving about her risks. She began to wonder if they were unanswerable questions, or whether professionals were avoiding answering her.

I don't know if people are being evasive or if they're being honest and they just say it's just the luck of the draw or the short straw, I don't know. (Glennis 1st interview)

Fiona was another participant who saw her body as being more vulnerable to future cancers. For her, the susceptibility appeared to lie in her family being disproportionately affected by cancer, as well as her own diagnosis of lung cancer at a relatively young age. She also recognised the potential impact for her daughters if this was an inherited problem.

And like I say it does seem to be on my father's side of the family. So both my father and his sister and my Nan and me, so. I just hope my girls take after [Husband]'s side of the family. (Fiona 1st interview)

Fiona's narrative emphasised her body's vulnerability to cancer in general, which she interpreted as a weakness inherited from her paternal lineage, rather than the biomedical understanding of late recurrence due to micro-metastatic disease. She described herself as being “cancer prone”.

I'm probably more prone to, it could pop up again. So that's why they keep an eye on you. (Fiona 1st interview)

6.3.2 Multiple and changing narratives

Patient participants developed multiple narratives regarding their future after lung cancer surgery. These accounts were seen to change and different ones given greater prominence in the light of events or availability of new information. Narratives may have developed synchronously, or been present at separate time points. Participants developed predictions that focused on a positive future in which the cancer had been treated and did not return. These were characterised by a sense of hope. They also developed narratives that predicted the cancer returning. These alternative narratives sometimes appeared to be used to explore what a worst-case scenario might be like. There was an apparent fluidity between them in relation to changing circumstances, but also some patients were capable of holding on to multiple, contradictory narratives at the same time. Due to these factors participants' attitudes towards these alternative narratives could be considered ambivalent. A summary of the key narratives identified for each participant is displayed in table 6.2.

Evolving narratives

During the longitudinal element of the study patients' understanding of their long-term outlook appeared to alter principally in relation to changes in circumstances. This was particularly true where patients experienced concerning symptoms. Audrey's case provided a clear example of this, when her bodily symptoms led to a crisis point regarding the possibility of cancer recurrence. After she completed her radiotherapy to her synchronous nodule, she developed severe back pain. She initially told herself it was treatment related, but eventually, when she was no longer able to stand the pain, she presented to hospital and was told she had a collapsed vertebra. Not unreasonably, she interpreted the symptoms as representing cancer recurrence.

I thought the cancer was back. I really did. [...] I thought it had gone over my body. You know, to be honest, I thought it had hit my bones. (Audrey 2nd interview)

Case name	Long-term outcome		
	Narrative 1	Narrative 2	Narrative 3
Audrey	<i>"I equate [cancer] with death" (1)</i>	Having surgery would get rid of cancer. (1)	<i>"I thought [the cancer] had gone [all] over my body" when back pain started. (2)</i>
Barbara	Operation may be the end of the cancer and surgeon has removed everything. (1)	Cancer can come back without warning. <i>"you're still vulnerable" (1)</i>	<i>"I am never going to be cancer free. [...] I might be in remission but I will always have cancer" (3)</i>
Cathy	Hopefully risk of recurrence is zero (1)	By adopting a healthy lifestyle I can help prevent recurrence (1)	
Denise	<i>"I've got two things to worry about, whether my breast cancer returns and also whether the lung cancer returns" (1)</i>	<i>"they've caught [the cancer] early. Everything will be quite good from now on" (2)</i>	<i>"they can never say you're completely cancer free" (2) "I think my body is now predisposed to cancer" (3)</i>
Edward	Cancer could <i>"blow again" (2)</i> <i>"this thing may be lurking there" (1)</i>	<i>"[cancer] is over and done with" (2)</i>	<i>"if this thing comes back again, we're pre-armed now" (1)</i>
Fiona	<i>"there's no sign of any cancer, which is absolutely brilliant" (1)</i>	<i>"I'm probably more prone to, it could pop up again" (1)</i>	<i>"I feel that probably it will come back [...]. It tends to, doesn't it?" (3)</i>
Glennis	<i>"85% chance of no recurrence" (1)</i>	Seeing poor lung cancer survival statistics unsettling (2)	<i>"It's going to hit me somewhere. Inevitable" (3)</i>
Henry	<i>"there is the possibility of a recurrence" (1)</i>	<i>"I stand a very good chance because I'm getting good treatment" (2)</i>	Planning <i>"if things were to turn out bad" (2)</i>
Kamal	<i>"cancer never dies, never goes out of the body" (1)</i>	<i>"Operation has cleared everything [...] I don't believe that it will come back" (1)</i>	<i>"Bulky lymph nodes" on scan means the cancer has recurred (3)</i>
Len	I presumed there was a risk of recurrence due to follow-up (1)	<i>"It would surprise [me] if anything came back" (2)</i>	
Maggie	<i>"If it was operable, it was curable. If it wasn't operable then there [was treatment], which would prolong my life" (1)</i>	<i>"I know there's a chance [of recurrence]. There's also a chance I'm going to be run over by a bus" (3)</i>	Chemotherapy = <i>"Reassurance. Safety. Not having to be concerned every time I got a pain" (1)</i>

Key: (1) – First patient interview; (2) Second patient interview; (3) Third patient interview

Table 6.2 Key patient narratives around long-term outlook

Eventually Audrey was reassured that it was due to osteoporosis and not cancer, and gradually her fears of widespread metastatic cancer diminished. The old recurrence worries still returned at times, such as worsening back pain, or prior to scans and clinic appointments.

I think if anybody that has got cancer has to go and see the specialist for their next appointment, must get the same as me, you're anxious as to what they're actually going to say. (Audrey, 3rd interview)

In contrast, Glennis initially accepted the apparently “good” statistics around her lung cancer. But her growing anxiety about her situation drove her to seek further information. Glennis described using the Internet as “one of the worst things you can do”, but still ended up looking up information there.

I turned it off pretty quickly. I didn't like that. [...] I didn't like the survival rates, just that word survival rate. (Glennis 1st interview)

Her slow recovery from surgery and repeated chest infections fed growing concerns about potential recurrence. Despite her initial reaction to the Internet, her growing anxiety drew her back to seek further information, creating a vicious cycle of information searches and anxiety.

Over the follow-up period, Glennis's sense of her recurrence risk grew, and was mirrored by her growing anxiety about her respiratory symptoms. Checking for symptoms became a quotidian reality for Glennis.

I wake up and I feel like as if I've got a pressure headache, every morning, and then it goes when I'm in the shower and doing things. And I do think, have I got a brain tumour? And it doesn't really leave you, to be honest. (Glennis 2nd interview)

By the time of her final interview, a sense of hyper vigilance towards anything that might indicate recurrence of the cancer began to overwhelm her.

So when I'm coughing constantly, producing loads of sputum and feeling really tired, you just think that's, it's not good. (Glennis 3rd interview)

Chest x-rays and discussion with her medical team were unable to give her the reassurance that she longed for. She conveyed an increasing sense of distrust of the information given to

her by the lung cancer team. There was a palpable sense of overwhelming concern about what the future held for her. She reflected: *“I feel as if I’m on borrowed time”*. She described her sense that cancer would eventually *“hit me somewhere”* and that recurrence was *“inevitable”*.

Do you know quite honestly I’ve been on such a downwards spiral that I don’t think, I don’t know, actually be reassured? I am always breathless, especially walking uphill. I’ve got this cough, which is on-going. (Glennis 3rd interview)

Ambivalent narratives

Kamal illustrated particularly well how participants were able to hold on to two apparently contradictory narratives at the same time. As indicated in table 6.2, one of his narratives was his long-held belief that cancer can never be controlled completely and was inevitably fatal (*“cancer never dies”*). The opposite narrative view was that his surgery had completely removed the cancer and it could not come back (*“it’s cleared, and that’s it”*). He framed the two extreme positions together during his interview, apparently holding on to the view that there was no chance of recurrence, at the same time as seeing it as inevitable. Reflective of the reality of potential recurrence, where the event either does or does not happen, Kamal’s alternative narratives did not incorporate probability, but was capable of accommodating both possible outcomes. Despite these extremes, he still accepted recurrence sat somewhere in the realms of possibility, as was clear when talking about the potential for further treatment

Some participants, such as Cathy’s approach discussed earlier, wanted to emphasise that the lung cancer was dealt with after the surgery. In a similar way, Edward described it as being *“over and done with”*.

They call it the Big C, but B comes before the C, and D is after it. B, oh bloody hell, I’ve got it. And D, it’s done. (Edward 2nd interview)

The comment served to underline how he wished to convey his level of concern at that time: simple, non-threatening and finished. Nonetheless, Edward was cautious in the way that he interpreted his oncologist’s message about not benefiting from adjuvant chemotherapy.

They said that they didn't think that I would benefit from chemo, which is a lot different to saying you don't need it. [...] So whether they probably thought that I couldn't cope with that and therefore it's best to leave things and see how they go. (Edward 2nd interview)

Although Edward remained positive about his future, it appeared that the message he took from the oncology referral was of a greater risk of recurrence in his mind. Edward recognised the inherent risk of cancer in the future, but he consistently denied worrying about possible cancer recurrence. He described his approach as “*San Fairy Ann*”¹⁰, conveying a dismissive attitude to any worry.

Exploring and acknowledging the potential for a feared outcome appeared to be an important way of dealing with difficult ideas for some of the participants. While patients frequently maintained their positive narratives that emphasised their belief that things would turn out well, they also needed to look at other potential outcomes. Henry spoke about being able to recognise “*the two extremes*”. In his last interview he said:

[...] the future is not entirely predictable, and we just have to see how it pans out. But it looks to me to be pretty rosy. (Henry, 3rd interview)

In this way, participants wanted to look at alternative outcomes, almost as if ‘trying on for size’, and to see how they would manage them. Denise wanted to acknowledge that she could need further lung surgery if the nodule identified were to grow.

So I think I'll be more realistic thinking it's probably going to need [...] surgery, and that I will have to prepare myself more for that, rather than be very disappointed thinking, oh, everything's going to be fine. (Denise 2nd interview)

The narratives that patient participants voiced in their interviews can be seen as a way of making sense of their situation and the risks that they faced. The narratives changed as new or evolving evidence became available to the participants. Information given by professionals directly about long-term outlook seemed to only make up a small, albeit

¹⁰ Jocular form representing French *ça ne fait rien* ‘it does not matter’, said to have originated during the war of 1914–18 amongst British troops. Oxford English Dictionary <http://www.oed.com.lcproxy.shu.ac.uk> accessed 05 June 2018

significant, part of the understanding patients had. Patients appeared to use these narratives as a source of reassurance as well as a way of facing and managing fears.

6.4 If it were to come back

This final subtheme will explore how patient and professional participants conceived the implications and likely treatment options available if they were to experience a recurrence of cancer. I will start by examining the largely positive narratives patients used to talk about treating any potential future recurrence. I will then examine the contrasting ways professional participants spoke about treating recurrence, reflecting a much less positive vision of what it is to manage patients with recurrent lung cancer.

6.4.1 If such a thing should happen – patients' views

Many of the narratives patient participants told included how they would face cancer recurrence if it were to happen in the future. The function of these narratives appeared to be a process of thinking through what this would mean for them and their families and, as far as possible, mitigate the potential effect of the recurrence. Patients constructed a view where the recurrence could still be effectively managed and therefore would not be a complete disaster for them, if it occurred. In this way it was possible to see the prospect of the cancer coming back in a relatively positive light.

One example was Edward. He was very clear that if a recurrence were to occur, it would not be a catastrophe for him, because he understood that his medical team would continue to offer him all available treatment.

But then if it returns, I am hoping that I will get as much treatment then as I have now. (Edward 1st interview)

He conveyed the idea that he might almost be in a better position after relapse than he was after his original diagnosis. Although he might be facing further treatment, all the tests and treatment he had already had would not have been in vain. This view was an integral part of his positive, hopeful narrative.

And if this thing comes back again, we're pre-armed now. People know about me, things are on the system. (Edward 1st interview)

By talking about being “*pre-armed*” he wanted to suggest that he might be at some kind of advantage in the process of re-starting curative treatment. Nonetheless, doubts did creep in to his narratives about recurrence over time, especially regarding his fitness to tolerate more treatment. In order to mitigate this concern, Edward wanted to focus on maintaining his fitness levels to ensure that he would be strong enough to have further treatment if it were required.

[...] I mean everything's going fine at the moment, touch wood, but that's not to say that I'm out of the woods, and I want to make sure that I'm fit if anything else crops up. (Edward 3rd interview)

In a similar way, Barbara constructed a narrative around what things would be like if she were to later relapse. In her first interview she spoke about how important it was to her not to go ahead with adjuvant chemotherapy in order to give priority to her rheumatoid arthritis treatment. However, she stressed that she would go ahead with chemotherapy later if a recurrence were detected during her follow-up.

If such a thing should happen ..., I wouldn't hesitate to have the chemo. But as it stands at the moment, and being that I'm going to be looked after so well, at the first sign of any problems, that's where I go. (Barbara 1st interview)

The phrasing “*If such a thing should happen*” suggested something remote and probably unlikely. She appeared to view this option as equally effective as the adjuvant treatment given following surgery and that future chemotherapy was like a parachute that she could operate in the unlikely event that the cancer was to come back.

Although Maggie did commence adjuvant treatment, she was unable to complete the full course. She was able to acknowledge recurrence was a possibility and explain her contingency if she were to relapse.

And the other thing is, OK, you know, touch wood and whistle, it won't come back. It could come back anyway with my body, couldn't it? I'll cope with that when that happens and then, you know. And what they said is that is a different chemo anyway. [...] It would be different and I would do it [...]. (Maggie 3rd interview)

Maggie's narrative distanced the eventuality by saying, “*I'll cope with that when that happens*”, but also characterised chemotherapy in the future in a more positive light than

the treatment she had experienced. This continued to offer hope to her, although Maggie also never acknowledged the change of treatment aims inherent in chemotherapy treatment after relapse.

Not all patients presented such positive narratives about treating recurrence. Glennis wanted to maintain the idea of being able to have further surgery, if it was necessary. Her growing anxieties generated doubts about her ability to cope with more surgery and began to erode the idea of potentially having further curative treatment. She continued to search for further information on the Internet but the findings were not reassuring to her. Her initial assumptions that if she had a recurrence of the cancer she would be able to have further surgery became increasingly eroded by her concerns over her respiratory symptoms.

So that's why I was looking thinking, can I survive with another lobe being taken away? (Glennis 3rd interview)

Kamal was more definite about the lack of further options to treat his cancer in the event it recurred. Due to the high-risk nature of his initial surgery and discussion with the surgeon, Kamal saw the treatment that he had already had as his opportunity for a possible cure. He conveyed the idea that further treatment was a highly unlikely option. He had already been told that any more surgery was not feasible due to his general state of health. He had expressed reluctance, but did not rule out, having chemotherapy. He said:

Again chemo or operation. Operation is done. I don't think they'll need any operation that's of this kind again. [...]. There's not any other option I think. [Chemo]'s the only option. And then I'll see whether I want it done or not. (Kamal 1st interview)

6.4.2 Best shot first time – professionals' views

Some professional participants emphasised the importance of post-operative surveillance during long-term follow-up in order to detect recurrence early and offer further treatment aimed at cure. Len's surgeon stood out as being the most interventionist and positive about detecting and treating future recurrence. He stressed the importance of detecting recurrence early and to consider curative, or other active treatments for suitable patients who relapsed following initial surgery. He also highlighted the need to determine whether

any new lung lesion represented a true recurrence, or whether it might be a new primary cancer. He commented how he felt Len's care should be approached if he were to relapse.

Every option should be available to him, [...]. [...] we would formally process through the MDT channel where all the available diagnostic and therapeutic options will be discussed [...] and then we will go from there. (Surgeon 8: Len)

Although other professional participants expressed a desire to detect any recurrence early, and to actively investigate and offer treatment, many were less positive about the potential outcomes. Len's Chest physician recognised the possibility of offering radical treatment to patients who had relapsed, but went on to qualify this approach.

[...] the chances are if they get a recurrence, they probably won't be curable anyway. (Chest physician 2: Len)

Professionals distinguished the biology of lung cancer from other types of cancer, such as colorectal cancers, where isolated sites of metastatic cancer were more common. Professionals understood that patients who relapsed with lung cancer were most likely to do so with widespread metastatic disease.

I think they get the best shot first time. If they, even if they apparently relapse in a localised way, a lot of those patients will subsequently relapse further. (Oncologist 1: Barbara)

Only patients with localised disease would be suitable for curative intervention and consequently treatment after relapse was usually palliative. While he would be open to offering radical treatment if the patient were suitable, his experience suggested this was unlikely.

[...] the number of people who've been rescued by second line surgery is tiny, it's really a very small proportion. (Oncologist 1: Barbara)

Maggie's oncologist highlighted the limited good quality evidence for treating relapsed lung cancer patients.

There's a belief that treating them works, but there isn't a huge amount of evidence to back it up, or robust evidence to back it up. (Oncologist 4: Maggie)

However, she also recognised that the development of new, targeted radiotherapy techniques, had opened up treatment possibilities for patients who relapsed with only very limited disease, but she continued to be cautious about the treatment of isolated lung cancer metastases due to the lack of good evidence. Surprisingly, none of the oncologists discussed the role of the new targeted-therapy drugs in treating patients with relapsed lung cancer.

Overall, there was a general recognition by professionals that for most patients who went on to relapse, treatment was primarily offered to help manage symptoms rather than aiming at cure. Nevertheless, professionals still emphasised the importance of following up patients regularly to identify signs of recurrence early. The purpose was portrayed principally as a supportive intervention for patients and families, rather than contributing to curing patients. Findings suggested that new approaches to treatment might be beginning to influence attitudes to detecting and treating recurrence, professional participants generally remained pessimistic about the outcome if a patient was to experience a relapse following surgery.

[...] it's more about trying to pick up things before they present too much of a symptom burden to him so we can intervene at an earlier stage. (Chest physician 1: Kamal)

I think it makes managing people easier if their relapse is picked up reasonably promptly. It may not improve their survival, but I think at least they feel they've been listened to. (Oncologist 1: Edward)

6.5 Chapter summary

In this chapter I have used the cross cutting theme 'Predicting the Future' to demonstrate significant differences in the way that patients and professionals thought about the long-term outcome for individual patients. The subtheme 'Prognostication' discussed the professionals' numerical and verbal estimations of patients' chance of survival or risk of recurrence. Despite drawing on the available survival evidence, most professionals saw significant limitations in the applicability of this data to individual patients. Binary outcomes,

clinical complexities, unusual cases and familiarity with the data were all seen as factors that made professionals cautious in interpreting the available evidence.

The way in which patients understood their likely long-term outcome was described in the subtheme 'Will it come back?'. Patients' information needs about prognosis tended to focus on whether the cancer might recur after surgery. Patients used multiple sources of information to construct their views of the future, with specific prognostic information given to them by professionals only making up a small part of their understanding. Patients' narratives about their likely future were not static, but changed over time, and adapted to interpret evolving events and emotions. Patients were capable of holding multiple, sometimes conflicting narratives concurrently.

The final subtheme examined the way patients and professionals thought about the implications and management of a potential future lung cancer recurrence. Several patients maintained positive narratives about treating their cancer if it recurred and talking about this may have formed part of the way patients coped with the uncertainty of recurrence. In contrast, most professionals who discussed treating future recurrence did so in terms of palliative treatments.

7 Findings 3 - Maintaining hope

7.1 Introduction

In this chapter I will present the cross case theme 'Maintaining Hope'. This explores how patient and professional participants made active choices about the information that was disclosed and sought about long-term outcomes with the aim of supporting patients' hope. Findings will be presented using four subthemes: 'Hope for normality', 'Information as threat', 'Painting an information picture' and 'Pivoting the cancer gaze'. Figure 7.1 gives a visual overview of the themes explored in this chapter.

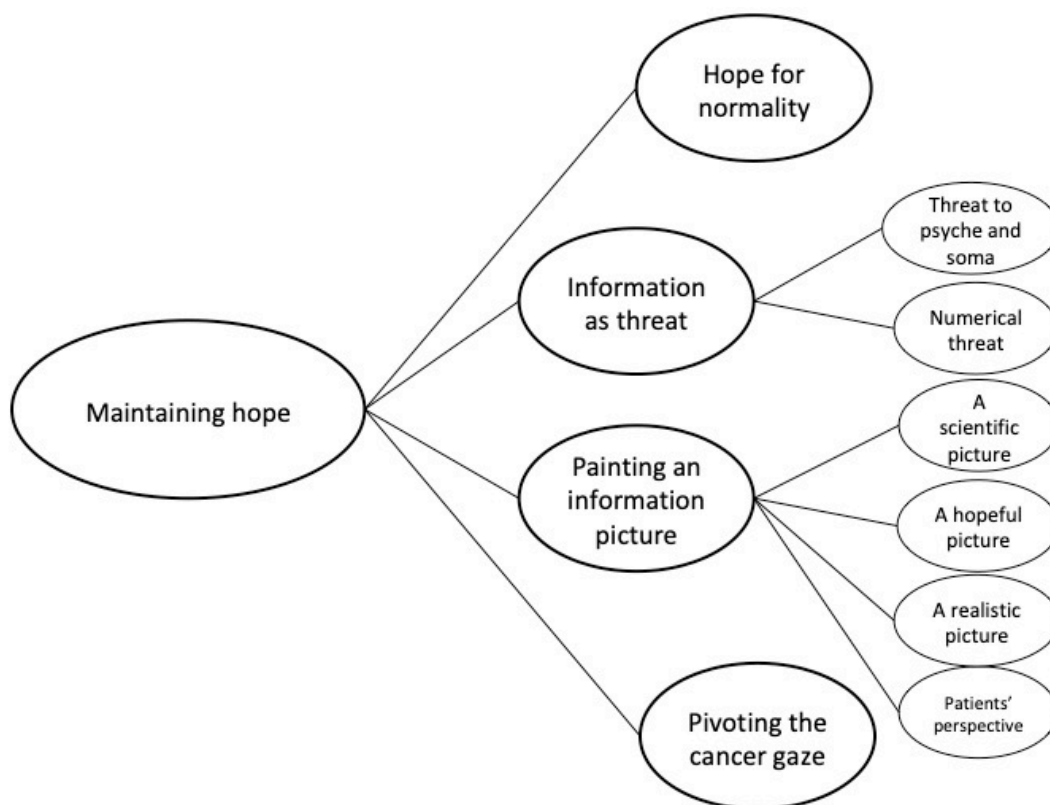


Figure 7.1 'Maintaining Hope' theme and subthemes

The subtheme of 'Hope for normality' will characterise the nature of hope as viewed by both patients and professionals and focuses on the shared aim of patients regaining a sense of normality. The second subtheme, 'Information as threat', explores how professionals and patients characterised cancer related information as potentially threatening to patients' sense of hope which impacted on both emotions and physical recovery. Numerical risk information was conceived to pose a particular danger to patients. The third subtheme

‘Painting an information picture’ considers the choices professionals made in the information they provided and patients’ choices regarding the information they sought. The final subtheme ‘Pivoting the cancer gaze’ explores how patients and professionals wanted to direct patients’ focus away from their cancer in an effort to manage uncertainty and positively influence their sense of hope.

7.2 Hope for normality

This subtheme explores how patients and professional participants shared a goal of achieving a sense of normality in patients’ disrupted lives following lung cancer surgery. In the short-term hope was centred on resumption of usual activities and the emotional stability that patients had prior to their lung cancer diagnosis. Shared hope in the long-term was for cancer fading into the background of life and no longer having an immediate impact on patients’ lives. However, the hope for cure was rarely explicitly discussed between professionals and patients, or only done with extreme caution.

During interviews many professional participants articulated the link between hope for cure and the aspiration that patients would get back to a normal life. Some professionals highlighted a sense of the vulnerability of the patient, with only fragile hope as a defence: something that might be shattered at any moment.

I think hope is [...] sometimes the only thing they’ve got, and they’ve got to hope that the cancer has been cured and hope that they will get back to a normal functioning life and that they’ll be able to do the things they wanted to do. (LCNS 2: Cathy)

Others identified the importance of the professional being part of the creation of hope for cure for the patient. An example was Barbara’s surgeon, who emphasised her role not just being a technician removing the tumour, but also creating a therapeutic encounter that fostered hope.

I think my role, not only to take it away, but it is also to be a positive influence. This is part of treatment with an end point hope of cure. (Surgeon 1: Barbara)

However, although professionals talked about the possibility of cure in study interviews, they were cautious to not imply cure when speaking to patients. ‘Cure’ could be seen as a

loaded term that promised more than was actually being offered. Nevertheless, professionals saw patients as wanting the certainty of being told they had been cured.

[...] people want to hear the cure word or use the cure word and we tread very carefully with that generally, or those of us that work in lung cancer for long enough.
(LCNS 4: Fiona)

Even with patients with relatively 'good prognoses', professionals spoke about being careful not to indicate to patients that they were cured following surgery. These concerns were particularly evident for patients with more advanced stage lung cancer.

[...] I'd hope I'd never say to her that we think we've cured you, because that's completely unreal... **(Surgeon 1: Barbara)**

Other surgeons, like those seeing Glennis and Len, included other terms they were careful of using, such as "cancer clear" or "it's all been resected". This was especially so when talking to patients with intermediate prognoses, in order to prevent giving a false impression. Such restrictions on the language being used created a paradox. Although the goal of treatment was ostensibly shared between patient and professional, it was difficult for professionals to give voice to the 'cure' word when speaking with patients, or if it was used, only with caveats and caution.

For the patient participants being given a lung cancer diagnosis and undergoing treatment was a highly significant life event, as was evident in the case presentations. In the last chapter I demonstrated how patients talked about a future where the cancer did not return and no further treatment was required. Most patients wanted to put the diagnosis of lung cancer behind them and return to normality as soon as possible, although they did not mention explicit hopes for cure.

I don't want to be wrapped in cotton wool. I want to get out and we get back as near as we can to normal. **(Edward 1st interview)**

Hope for normality was frequently conveyed in concrete hopes for the future, like going back to work, planning a holiday, or resuming a normal family life, as Maggie explained.

The plan is now we're over this, [...] we're going on a bloody good holiday. That's my future. [...] So holidays. Get another dog. Once we've done that, go on long walks. Enjoy our caravan. Enjoy our grandchildren when we want to. (Maggie 3rd interview)

However, in reality most of the participants found that their lives were inevitably changed physically and mentally as a result of the diagnosis. Getting back to 'normal' was not truly possible, even for those with the earliest staged lung cancers. For example, although Cathy did not describe her lung cancer as having a particular impact on her, the effects of her cardiac arrest, and new diagnosis of rheumatoid arthritis had altered her life significantly.

So it has affected me hugely. [...] Memory, my hands, everything about me - I'm not the same person that went into the op and came out. [...] The whole [life] has drastically changed. (Cathy 1st interview)

Similarly Glennis continued to experience problems following her surgery and she saw the change in her health as an on-going loss for her.

I still feel as if I'm in sort of mourning for how I was beforehand. (Glennis 2nd interview)

This aspect of recovery was also recognised explicitly by one of the professional participants.

[...] it's like, well, you've finished now, get back to normal. It's like, "um, well, I'm not normal. This has completely changed me". (Oncologist 3: Jane)

For some patient participants, surgery was seen as offering an end to the uncertainty of being diagnosed with lung cancer. This was especially true for Fiona. During her initial treatment with chemotherapy she had understood her cancer to be "terminal" and she worried what would happen if she stopped treatment: "as far as I knew it was just holding the cancer". It was apparent that she had hoped surgery would remove her uncertainties about her long-term future. After surgery she wanted to be told that she no longer had cancer, but could not get this answer from anyone. The certainty she had hoped to gain turned out to be just a different uncertainty about recurrence, as she explained.

Where do I stand? I felt like in limbo. [...], like I haven't got cancer but I'm not cancer clear so where am I? I suddenly thought, oh where do I stand? (Fiona 1st interview)

While all the participants spoke about hope in positive terms in relation to dealing with lung cancer, two of the patients also recognised another side to hope. Len and Fiona both at times identified hope as being too flimsy and weak against cancer, and wanted to rely on something stronger and more proactive than what they took hope to mean. Rather than relying on hope, Len wanted to seek out alternative ways of dealing with cancer.

[When] you talk about hope, you're not getting anywhere. You've got to go beyond that point. You've got to chance it. (Len: 3rd interview)

Similarly, Fiona rejected the passivity implied in mere hoping. She wanted to feel that she was relying on something stronger than just a hope and stressed the importance of her own sense of personal agency and her strong faith that she would overcome her cancer.

I will get back to normal. I just, you know, have been more positive, more than hope. [...] Because hope means you hope it's going to happen, but I'm more positive it's going to happen, and I'm going to make sure it does, sort of thing. (Fiona: 3rd interview)

7.3 Information as threat

This subtheme examines how patients and professionals both characterised much information, particularly about outcome, as potentially threatening to patients' sense of hope. Whilst some information about diagnosis and treatment was acknowledged as important, other information was seen as a threat that could impact on both patients' emotional and physical recovery. Numerical information was felt to be particularly difficult and threatening.

7.3.1 Threat to psyche and soma

The impact of information on patients' psyche, especially on factors such as, optimism, depression and maintaining hope, was the principal concern. For some patients feeling that cancer was equivalent to "death" had been particularly difficult to deal with. Often these reactions persisted long after the initial diagnosis period. These associations led some to avoid any information about cancer, such as Maggie.

I really don't want, it's a horrible thing and I don't really want to know. (Maggie 3rd interview)

She described her approach to information about her illness.

What I need to know is: what I have - no big details about it. What you are going to do about it? How are you going to do that? And am I better? [...] I don't want any finer details. (Maggie 1st interview)

Maggie described herself as a natural worrier. Information about her cancer appeared too threatening to contemplate. By avoiding information about her illness, she saw herself minimising worry.

If I don't know too much, I won't care too much. (Maggie 1st interview)

This strategy was inherently problematic. Patients often had no control over the information they received. This was particularly so when information was delivered unexpectedly, or at times of particular vulnerability. Maggie referred to an incident where she was given unexpected information just prior to going for surgery. She described it almost as a form of ambush, leaving her reeling. The difficulty of dealing with this threatening information remained with her and reinforced her desire to avoid information about cancer.

[...] I was signing the forms and the doctor was saying to me well, you know, it could be sticky. It could be stuck on a chest wall and if that's the case, there's a 35% chance of, I don't know whether he said not surviving, or them not getting it. I don't want to know. I wanted to go [...] into surgery confident that everything was going to be fine. (Maggie 3rd interview)

In a similar way, Audrey struggled to deal with the extent of the information she was given during her oncology consultation. She found herself overwhelmed by information she had received. The potential that she might be given yet further detail was too frightening for her to contemplate. She said, “*I don't want to know if it's got a life sentence*”, indicating that she did not want to be told she was not curable. The potential for this sort of information to damage her psychologically was clear. Her strategy became to avoid asking any questions, unless she felt secure of receiving reassurance. She also avoided reading cancer related

information in case she encountered anything negative, saying “*and that’s why I don’t look anything up*”.

Several of the patient participants spoke about their strongly held views that maintaining a positive attitude was vital in their ability to fight the cancer. Participants saw mind and body as one, or at least having a direct and concrete influence on each other. Patients saw having a negative attitude as adversely affecting the chances of cure. There was a strong sense of personal agency seen in the patient interviews in terms of actively blocking out negative thoughts. An example was Kamal, who linked being exposed to negative information as something that could jeopardise survival.

So it’s not a good thing to listen and understand and put in your head if you want to live. Live aside from that. (Kamal 1st interview)

Similarly, Len saw his mental attitude to the cancer as being vital to his recovery.

[...] the mind is the most important thing, and if you can get that on your side and be positive. You’ve got to be positive. Don’t let any negativeness come into it at all. (Len 1st interview)

Henry also stressed the importance of mental attitude on outcome. This stemmed from his belief about his Mother’s death after learning about her own cancer diagnosis. This experience led to him not wanting any information that might expose him to facts capable of damaging his hope.

I have a fairly positive attitude to most things and I don’t want to start reading things, which are going to give me a negative attitude. (Henry 1st interview)

Henry felt most information he was given lacked a practical value that might enable him to do something to change his situation. In particular he wanted to avoid information about survival and recurrence. He viewed thinking about a negative outcome as a direct threat to his self-image of being able to overcome this illness. When asked about information about his risk of recurrence he said:

It’s not something I particularly wanted to think about. I do have an optimism about all of this, because I do regard myself, despite my ailments, as being a relatively strong and fit person. (Henry 1st interview)

Other participants had a quasi-magical belief that thinking about cancer recurrence might make it more likely to happen.

I'm a great believer in positive energy and if you're negative about something, oh God, I might get cancer in my toe. You might well get cancer in your toe. (Maggie 3rd interview)

Barbara, on the other hand, ascribed almost conscious thought to the cancer that might detect when she let her guard down and allowed her vulnerability to show. Keeping up this defence was vital in order to protect herself and prevent the cancer 'realising' that she was vulnerable and taking advantage of this.

[...] you've got to be strong, you've got to be upfront; you can't show any weakness against it [the cancer]. (Barbara 2nd interview)

Many of the professional participants expressed similar views to the patients about the inherent threat to patients' sense of hope posed by recurrence risk information. Although often couched in more scientific terms than the views of the patients, many professional participants linked information that was a threat to patients' hope as having a direct negative impact on their chance of survival. When characterising the threat that recurrence risk information posed, several professionals linked the effect on the patient's psyche directly to a physical effect. Some argued that emphasising the good news to patients would promote a fighting spirit and help physical recovery after surgery.

It's better to give the patient positive information because it prompts them to fight better and to be active in recovery time after surgery. (Surgeon 9: Maggie)

Professionals were concerned about how negative information about recurrence and survival would "impact [the patient's] psychology" (Kamal's surgeon) and levels of hopefulness. A sense of hopelessness and depression was felt to affect the immune system, which some linked to greater risk of recurrence.

[...], I believe that [with] the cancer fight, people immunosuppress due to their psychological depression [...]. I believe that the patients who are carrying good psychology, they are getting better. I cannot prove it, but... (Surgeon 3: Edward)

Kamal's surgeon talked about the benefit of maintaining hope and having goals to aim for in relation to the philosophy of the Paralympic movement and how he applied this to recovery from surgery.

And the chances of him I think surviving would have been less in long-term, compared to if you give them hope. (Surgeon 6: Kamal)

7.3.2 Numerical threat

While patients and professionals viewed any conversation about prognosis to be potentially damaging to patients' emotional and physical outcome, numerical probability information was regarded as particularly difficult. Initiating a discussion about cure rates was likened to "opening a can of worms" (Kamal's Chest Physician). Some professionals were reticent to talk about long-term outcome statistics with patients even with early stage cancers, where statistics were viewed as being more favourable. Professionals were reluctant to "say numbers" (Cathy's Surgeon) to patients, and saw it as being "unfair" (Kamal's Surgeon) to burden patients with this type of information. Survival statistics were characterised as holding a particularly powerful significance for patients, which was viewed as unhelpful. Cathy's surgeon characterised giving statistics as a poor way to support patients.

I'm sure that you can give better support to the patient instead of just saying; [...] this is the percentage, this is the risk for you to die in five years. (Surgeon 2: Cathy)

Numerical information was seen to be too stark, and therefore unhelpful to patients. The bleak way the surgeon framed her comment underscored her negative attitude to numerical information. Others were more vivid in the language they used about the way patients could misuse the figures professionals gave them.

[...] they tend to grab those numbers and take them as the standard, and what's going to happen with them. (Surgeon 6: Kamal)

The idea of patients 'grabbing' information evokes a sense of desperation in the patients to get hold of anything that they felt was significant for them. The inference was that patients might not be capable of understanding or handling this sort of information.

Some professionals could not see any utility for patients in having recurrence statistics. They suggested that patients who were too focused on survival information, or risk of cancer recurrence were vulnerable to psychological difficulties.

I think there is a group of people who get terribly introspective, and they spend their whole life thinking am I going to be in this percentage or that percentage. And I think often they can get into real trouble doing that. (Oncologist 1: Barbara)

Professionals felt the stark nature of numerical information could lead patients to become unhelpfully preoccupied with their prognosis and for these reasons wanted to avoid giving statistics to patients, even if they requested it.

[...] I don't see the role for telling them that their risk of recurrence is 'x' per cent. I'm not sure how fruitful that would be for them to know that, other than make it something that's constantly on their minds. (Chest Physician 2: Len)

Others said they would be happy to give numerical information when asked, but apart from satisfying the patient's curiosity, could not see a direct benefit to knowing this information.

I don't think [knowing] the exact percentage is going to make much difference to how you deal with it, but some patients need the exact number. (Surgeon 5: Glennis)

Others understood patients' need to have this information and saw their role as not only providing this, but also in guiding patients to be able to understand its limitations. Kamal's chest physician wanted to make patients clear about the uncertainty inherent in the available data. Denise's surgical LCNS recognised the plethora of prognostic information available to patients and their need for guidance in negotiating this. If help was not forthcoming, patients might unwittingly seek information from incorrect or from poor sources, which she felt could be more dangerous for patients than having accurate information.

So if the patient is looking for the information we are duty bound to try and help them find it and make sure it's good quality. (LCNS 1: Denise)

7.4 Painting an information picture

This subtheme explores how participants, principally professionals, aimed to achieve the right balance in the information patients received. How professionals interpreted and

presented the available information for patients can be seen as analogous to an artist painting a picture to give a particular view of a scene, choosing an angle to present, placing certain objects in the foreground, and determining the level of detail and the lightness or darkness of the overall scene.

Following completion of lung cancer surgery, professionals had an extensive amount of biomedical information available to them. This included surgical procedure, cancer staging, pathology, management plans and the potential for future recurrence of the cancer. None of the professional participants advocated giving patients all this available information and there was an inevitable selectivity in what patients were told. Professionals varied in their approach to exactly how this information was interpreted for patients during their consultations.

Maggie's oncologist indicated that communication had been part of her specialist oncology training she had received. Beyond a boundary of always informing patients when treatment was no longer aimed at cure, which she described as "*non-negotiable*", she indicated that her training had placed emphasis on patients controlling and initiating discussions about prognosis.

[...] the oncology training is towards the patient as an individual requesting information, and being given the information at the pace they want it, at the time they want it. (Oncologist 4: Maggie)

In contrast, two surgical registrars spoke about the lack of training and preparation for giving this sort of information. Kamal's surgeon said, "*we haven't been trained to do it*". Communicating surgical outcome appeared to be given little priority in the training and development of future consultants. Surgeons learnt how to deliver such news by doing it in practice, or occasionally by observing others. Glennis' surgeon saw the way that individual professionals approached these discussions was largely a matter of personal communication ethos.

[...] there's no guidance in that [what information to give]. I think it is very much dependent on your own point of view and approach to it. (Surgeon 5: Glennis)

I will present three approaches professionals used to providing and framing information for patients. One where the balance was weighted strongly towards providing objective scientific facts (a scientific picture), one where it was much more focused on supporting hope (a hopeful picture) and one aimed at both helping patients find hope, but acknowledging risks as well (a balanced picture).

7.4.1 A scientific picture

One of professionals' first concerns was getting information that patients were able to understand. Several professionals highlighted links with smoking and an increased co-morbid disease burden that might influence information requirements. Others characterised the general population of people with lung cancer as a group that tended to be less interested in information about their condition than patients with other forms of cancer.

[...] they may not be particularly health orientated because of their lifestyle behaviour in the past. (Oncologist 3: Jane)

Socioeconomic and educational factors were seen to influence how well patients with lung cancer could comprehend complex medical information.

They may not have good literacy levels. It may be very easy for you to talk over them and talk over their heads in terms of the information you give them ... (Oncologist 3: Jane)

Len's surgeon was unusual amongst the professional participants in this study in his emphasis on giving scientific information. His priority for care involved providing patients with the best scientific evidence, not only for surgery, but for other viable treatment options as well. This approach was clearly linked to his views on the utility of survival and recurrence risk data derived from population studies, discussed in the previous chapter.

What the prognostic benefit means they need to understand. [...] And if they know that figure and they can compare with other treatment options [...] (Surgeon 6: Len)

Len's surgeon was the only professional in the study who said he routinely gave long-term outcome statistics to patients, both prior to surgery and when discussing the final pathology results. He acknowledged that patients might be looking for an optimistic message.

However, he did not feel it was his role to provide this. He was not willing to give reassuring information that was not based in fact in order to make them feel better. Len's surgeon viewed the imperative of providing the best available scientific evidence to patients as far outweighing any potential benefit of giving what might prove to be unfounded reassurance.

I'm not here to motivate the patient. I'm here to give a specific outcome from a very scientific perspective. I'm an optimistic person, but I'm not actually going to give them a fortune telling for the patient. (Surgeon 8: Len)

By talking about a "fortune telling", he appeared to be using it in the sense of telling people what they wanted to hear. While he acknowledged that sometimes giving more information about outcomes and risks could lead to increased levels of patient anxiety, he saw the goal of patient autonomy as paramount.

Often the patients said they felt more informed, had more understanding about things. But if you ask them what did it do to them, their perspective of it, did they [...] end up feeling positive or negative? Invariably they said they are informed but they were worried. (Surgeon 8: Len)

Regardless of a patient's background, however, there remained challenges in conveying complex biomedical information to people who had no medical knowledge before they became ill.

The patients are very accepting of all the information because they are new to this. Most of the patients do not know what happens if you have a cancer. (Surgeon 8: Len)

Some saw their role as an educator regarding medical matters and viewed giving biomedical information as a way of helping patients gain a sense of control.

[...] I'm trying to teach them in a way about what's happening with their body so they can understand it a bit more. Because I think if they understand it a bit more, they're more likely to feel a bit more control. (Oncologist 3: Jane)

In contrast, other professionals emphasised the need to "try and keep it as basic as I can" (Barbara's surgeon) and only give what was necessary to patients in order to "give some brief idea what it is, but not to go into major details" (Maggie's surgeon). Such views appeared to be less about educating patients, and more about giving patients the minimum

amount of information that would allow them to move on to the next stage. The aim for these professionals was to give just enough information.

[...] give them enough that they know exactly what's happened and why we're doing or proposing the next stage. (Surgeon 1: Barbara)

7.4.2 A hopeful picture

Reflecting a different philosophy, several professionals prioritised painting positive interpretations of patients' situations following surgery, to support hope for the future. They recognised the difficulties for patients when they initially heard they had lung cancer and the implications and perceptions that accompanied it. Many spoke about patients being devastated at the news of the lung cancer. For example, Glennis's LCNS wanted to recognise the challenges that her patient had faced hearing the original diagnosis, while gently trying to emphasise the good news of the current situation.

[...] they think they've got cancer and that's it. And especially lung cancer, people are really frightened of it. They think that's the end of the world, [...]. (LCNS 2: Glennis)

By trying to portray the patient's situation in the best possible light Glennis's LCNS aimed to bolster the patient's hope and to play down the negative possibilities in the future.

So you're trying to say, I've given you really bad news, but the news I've given you is the best [...]. But I think it's some way of trying to reassure them that it's not something that's not curable or not treatable or that we're not hopeful of. (LCNS 2: Glennis)

Professional participants saw patients who had a surgical resection as the fortunate ones amongst the general lung cancer population. Professionals wanted to flag this clearly to patients and place this good news into the centre of the picture. For patients who had early stage lung cancer and who did not require further adjuvant treatment discussions (following pathway A), professionals viewed this as a relatively straightforward process. For example, Fiona's surgeon wanted to make a clear link to the available biomedical information to emphasise to the good news of the situation.

Then I make that very clear in the consultation, and I'll often sort of say, you know, the points to take away are that it was early lung cancer, that we've got it all out, and that at this stage we don't need any further treatment. (Surgeon 4: Fiona)

Some professionals wanted to continue to provide a positive interpretation of the outcome for patients where the prognosis was not so good. These professionals aimed to turn the bad news of a diagnosis of lung cancer into something that might be seen as good news by re-framing it and subtly suggesting it could have been a lot worse. One surgeon aimed to portray an optimistic picture by the way information was given.

[...] I'm trying when I'm explaining to him to say that the glass is not half empty, but half full, you know what I mean? I'm saying to them yes, you are getting lung cancer. But. Always but. (Surgeon 3: Edward)

“But” underlined the contrast he wished to make with the potential bad news he was giving by drawing the patient’s attention to competing aspects that might support hope. Similarly, Kamal’s surgeon spoke about the need to emphasise areas of good news when presenting a picture of their medical situation to the patient.

[...] what I’ve learned from my previous consultant is even if the news is not that good, you need to find a reason of hope in that news. (Surgeon 6: Kamal)

In this way he wanted to create opportunities for hope in the information that he gave.

[...] he’s got T2a N1 disease, but there’s no [metastases]. [...] So that’s a good thing, because he could have been worse. (Surgeon 6: Kamal)

Rather than focusing on the cancer findings, which in these circumstances were perceived as much less positive, professionals sometimes wanted to place a more positive message into the picture that they created for patients by focusing on a more general form of hope, such as a good recovery from surgery.

I try to instil hope, but in a [...] general way, not maybe like particularly specifically for the lung cancer in itself. (Surgeon 2: Cathy)

Several professionals believed patients did not want information about the negative aspects of their condition.

I can’t say that I remember anybody was trying to find this exactly negative information; people look for positive information. (Surgeon 9: Maggie)

The justification for not disclosing information that might damage hope was their understanding that patients wanted professionals to focus on the positive aspects of what had been achieved. For these surgeons, painting a positive picture of the surgical outcome was prioritised over information about potential long-term outcome.

I believe that the majority of patients, they want to listen to the good news first. And the good news for them, it is that the tumour is out, everything is clear now and your chest X-ray's all right. The wound is well healed. These kinds of things. (Surgeon 3: Edward)

The minimum level of information about potential cancer recurrence some professionals felt was necessary to give patients was to ensure patients were aware that it was possible.

[...] my own feeling is that so long as they've got that [the understanding that relapse was a possibility], so long as if they do relapse it's not a complete surprise to them. And I think that's probably all anyone needs to know. (Oncologist 1: Edward)

Such an approach allowed professionals to provide a picture that did not focus on the negative aspects of risk and the consequences of recurrent cancer. However, oncologists who saw patients to discuss adjuvant treatment inherently needed to talk openly about possible recurrence. As a way of counterbalancing damage to hope from raising the subject of potential recurrence, professionals also wanted to stress to patients the benefits of having already undergone surgery and the potential to have already affected a cure. Barbara's oncologist consciously used positive talk to foster hope by placing the potential successful outcome of surgery into the foreground.

I think it's important to encourage, to sort of to flag up what's happened before, and acknowledge that that's a good step and obviously it's the one thing that's going to cure people, so it is the vital step for her pathway. (Oncologist 1: Barbara)

7.4.3 A realistic picture

While there was a broad consensus amongst professional participants about the importance of supporting patients' hope, several professionals did not feel it was always appropriate to paint only positive pictures for patients. For these professionals there were situations where the emphasis was on painting a more realistic view of the future. Glennis's surgeon alluded to the possibility that some professionals might avoid discussing bad news in order to protect themselves as much as protect patients.

I mean it is very easy to give good news all the time. I don't think it's always appropriate. (Surgeon 5: Glennis)

For Glennis's surgeon painting a realistic picture involved a tension between presenting positive and negative information, between providing hope and addressing the realities of the situation, and was therefore challenging to achieve.

I think our job is to make sure the patient knows or is informed about their disease process and where they are. And yes giving them hope, but also being realistic at the same time, which can be difficult. (Surgeon 5: Glennis)

Glennis's surgeon made a distinction between talking to patients with stage I cancer, where he perceived the news as “good”, and those with stage II or III, which represented a more uncertain prognosis. This distinction broadly reflected the differences between patient participants following the two pathways discussed in chapter 5. Patients following pathway B could be viewed as having an intermediate prognosis, somewhere between good or bad news. Nevertheless he viewed patients with stage II or III cancer as distinct from patients with advanced, metastatic cancer who had an unvaryingly bleak prognosis and where cure was no longer a realistic possibility. This underlined the challenges that professionals felt when creating a picture of long-term outlook for this group of patients with a more uncertain prognosis. In the following quotation Glennis' surgeon used “numbers” to refer to survival statistics.

Anything in between stage IV and stage I becomes a difficult discussion because now you're not dealing with good numbers or terrible numbers, it's somewhere in between. (Surgeon 5: Glennis)

Several professionals made a distinction between fostering “hope” and “false hope”, and characterised the latter as something to be avoided. Several professionals commented on times where they had seen colleagues being overly positive about a situation and had painted a picture that was unrealistic for patients.

I'm careful not to over reassure and careful not to give false hope. Because I have observed that in other clinicians, in a very well-meaning way, trying to give the best of news, or the best spin on something, [...] but sometimes I think delivering an inappropriate positive message. (Chest Physician 1: Kamal)

By talking about putting “*the best spin*” on something, Kamal’s physician suggested that although significant information might not be withheld, the implications and consequences of information might be painted in a way that could be considered overly positive. Where professionals saw the need to give more negative information to prevent patients having falsely positive expectations, this was something that required sensitivity.

[...] I think one of our roles is actually being honest without being brutal and to manage expectations and then those of relatives. (Chest physician 1: Kamal)

Managing expectations in this sense was about signalling the potential for negative outcomes amongst the hoped for positive outcome. Some LCNS participants felt that the consequence of some medical colleagues being “*a bit too optimistic*” was that patients could be left with “*false hope*” (Edward’s LCNS). There was a need to keep a “*happy medium*” and avoid insinuating “*this is all going to be fabulous*” (Maggie’s surgical LCNS). If this did not happen then it could fall to the LCNSs to manage the situation and deal with the emotional consequences. The continuity of the relationship between the patient and LCNS could facilitate the work of dismantling inappropriate hope across multiple contacts, helping patients to develop a more realistic understanding, without destroying all hope.

And then you’re in a position where you don’t really want to burst their bubble, but over time you may need to rein them in. (LCNS 3: Edward)

7.4.4 Patient perspective

Many of the patient participants appeared to value professionals who gave an optimistic picture of their condition, often mirroring the views of their professionals. Fiona had known her oncologist for a long time and it was this relationship that continued to provide what she saw as a hopeful view of her situation.

Well she’s very positive, and she [...] always sees the positive, gives you the good, you know. (Fiona 1st interview)

Fiona wanted to avoid pessimism regarding her treatment that might damage her own confidence.

I don’t want the negativity, no. [...] No, I like to know what <could> happen and what the good part. I don’t think I, I tried not to think of anything negative, what might go wrong, the other way. (Fiona 1st interview)

Others had similar views, with Audrey, for example, talking about wanting a “*half full*”, as opposed to a “*half empty*” approach.

Although patients talked about the benefits of being given an optimistic view, they also saw limits to professionals taking a purely positive approach in the information that they gave. Fiona, for example, needed to have confidence that she would not be deceived.

Oh yeah, I don't want to be lied to. [...] I like the truth. ... I like to know the odds. That's why I asked about timescale. (Fiona 1st interview)

The mention of timescale was a reference to her question about her prognosis asked soon after diagnosis. Fiona wanted to seek answers to challenging questions, but only when the time was right for her. This finely balanced approach had echoes of those of her oncologist. The similarities in their approaches to communication appeared to be the basis of a positive and long-standing therapeutic relationship between them. During the interview with her oncologist, she was asked how best to help patients to manage the uncertainty after lung cancer surgery.

Reassure patients when things are looking good and be honest with them when they are not. (Oncologist 2: Fiona)

Patient participants particularly valued a sense of professionals being honest or “*straight-talking*” (Barbara).

I did like [the surgeon], because she didn't pull any punches. She told me like it was, which is what I wanted. (Barbara 3rd interview)

She spoke about needing to know what was happening to her so she could “*deal with it*”. Similarly, Denise valued the sense of a candid relationship with the LCNS who saw her on an on-going basis in the follow-up clinic. She felt the nurse was not going to hide signs of things that might indicate a problem.

She's not going to sort of fluff around the edges and say, if there is a concern she's actually going to tell me the truth and be straight down the line. So I know that, you know, and that's a good thing. (Denise 1st interview)

However, she also recognised that this approach would not suit everyone and using too blunt a style might be problematic for some patients. Importantly, despite wanting the professional to help build hope for them, no one wanted to feel that they were being deceived if there was a material change in their situation. Other participants also took a pragmatic approach to difficult information. Edward spoke about dealing with information that might be considered difficult in a calm, non-emotional way, focusing on problem solving to bolster his sense of hope. He tried to identify practical steps that could be taken to address the issues raised in the information given. This approach mirrored his self-image as someone who rolled with challenges in life and his ability to cope with threatening situations. In this way it appeared that he was able to sustain hope even in the face of potentially negative information.

I won't go climbing the walls or anything. You know, this is what's happening, and how do we deal with it? (Edward 1st interview)

7.5 Pivoting the cancer gaze

In this final subtheme I use the metaphor of 'Pivoting the cancer gaze' to consider how patients and professionals attempted to focus patients' attention away from their cancer after they finished treatment, with the aim of helping to maintain hope and support coping for the future. In some situations there was a need or inevitability in focusing on patients' cancer, which provided challenges for both patients and professionals and exposed some of the limitations to this approach.

As discussed at the beginning of this chapter, the overall aim for both patients and professionals was to get life back to normal following the disruption of the cancer diagnosis and surgery. The majority of the patient participants talked during their interviews about consciously trying to remain upbeat and actively avoid thinking about their cancer by pivoting the focus of their attention away from their cancer. Some participants faced significant issues other than their lung cancer that demanded attention. After her surgery Barbara's main concerns were about her rheumatoid arthritis and the recovery from surgery. Her gaze was focused on dealing with the immediate problems she faced. By

refusing to worry about what the future might bring, she minimised the uncertainty resulting from her lung cancer.

I refuse to worry about what <could> be. What <is> is hard enough to worry about. (Barbara 1st interview)

Other patients emphasised getting on with normal things in life and moving on from their illness and treatment. Denise spoke about actively moving her gaze on to her busy family and work life and trying to avoid thinking about her lung cancer.

[...] usually it's just trying to live life and try not to think about it too much. (Denise 2nd interview)

Many patient participants conveyed a strong sense of personal agency in the way they wanted to focus their gaze away from negative thoughts associated with their cancer, as was exemplified by Fiona.

I think if you dwell on it too much, you get really down and you wouldn't have that sort of positive to get on and fight it and ... I think if you dwell on something, you can make yourself feel worse than what you actually are. (Fiona 3rd interview)

Some patients described times when their gaze was nevertheless drawn back to their cancer, such as times of “quiet reflection” (Denise), or if “there’s not a lot doing” (Audrey), and which could bring thoughts of the cancer to the fore.

Because no matter what a doctor says, or a Macmillan nurse, when you are on your own, you get all those doubts. (Audrey 1st interview)

At such times several patients talked about using an active positive thinking technique, such as giving “myself a good talking to” (Audrey). Common to these approaches was a denial of self-pity, often making comparison with others in a less enviable position than their own as a way of seeing their own situation in a more positive light.

[...] I sit there and I tell myself to pull myself together. You know, you're not the only one, get on with it. And do this. And you've got that to do. (Audrey 2nd interview)

As part of the process of patients actively pivoting their gaze away from cancer, many participants avoided seeking any further information. This was particularly true of Internet

use. The Internet was seen as a threatening and risky place, especially in relation to prognosis, or recurrence risk information. Kamal said that what he saw on the Internet did not make him feel “good or happy” and that “it’s all disturbing”. Denise talked about her experiences of searching the Internet during her earlier breast cancer treatment. She recalled a sense of relief when her breast surgeon absolved her of responsibility to seek information on line.

And it was [SIGHS] it was pretty frightening. And I thought, no I’m not going to be frightened anymore. [My surgeon]’s told me, he’s given me permission not to look, so I’m not going to look! [LAUGHS] (Denise 1st interview)

Fiona also talked about avoiding the Internet, which also included patient forums and chat rooms. Finding out about others’ experiences was of little help to Fiona.

So in my head, it’s my journey [...]. I’m not going to look and see what somebody else went through, because I’m not necessarily going to go through that. So that was me. I just wanted to take it as it came, so I didn’t look it up. (Fiona 1st interview)

Glennis was the exception amongst the participants and was the only one to search for information about lung cancer outcomes on line, as described in chapter 6. Even so, she was unsettled by what she read.

The views of professional participants regarding patients using the Internet were remarkably similar to those of the patients described above. Professionals wanted to steer patients away from searching the Internet indiscriminately. In particular they were concerned that patients could be exposed to material that they were not equipped to understand.

[...] they don’t have the background to completely understand what is written on the Internet. (Surgeon 2: Cathy)

Others, such as Audrey’s surgeon, felt that even web sites aimed specifically at a patient audience could be “doom and gloom” in the content they offered. What was common to these concerns was the fear that the Internet gave access to information that risked both being misunderstood, or overwhelming patients. Professionals appeared to want to maintain control over the information that patients received, with the aim of preventing

exposure to things that might cause unnecessary anxiety and risked damaging patients' hope.

Helping patients to pivot their gaze away from cancer at the end of their treatment was one of the key ways that professional participants felt they could support patients to maintain a sense of hope and cope with their situation. Professionals, such as Barbara's oncologist, viewed patients who could pivot their gaze and put cancer out of their mind and move on as the ones who were most likely to cope best with their situation following surgery.

*I think the people who manage this better are the slightly sort of fatalistic people who they sort of slightly shrug their shoulders and get on with it, and you know, que será, será¹¹. (**Oncologist 1: Barbara**)*

Professional participants saw a danger in patients who became fixated by their cancer, and the fear about recurrence. Len's chest physician saw the crippling nature of worry about cancer and its emotional burden could impact the patients' quality of life to such an extent that patients might become disabled by it.

*If they completely obsessed by the fact that they've had lung cancer then I think we won't have achieved anything really. (**Chest Physician 2: Len**)*

Barbara's oncologist wanted patients to simply "focus forward", away from the diagnosis and what they had been through, and to try to get "back to a more normal way of life". Other professionals saw patients that focused unduly on their cancer after treatment ended up wasting precious time that might prevent them doing meaningful things after their diagnosis. Jane's oncologist used vivid language evoking a horror movie to underline the danger of patients focusing on their cancer in unhelpful ways.

¹¹ From lyrics of a popular song sung originally by Doris Day.

Que será, será

Whatever will be, will be

The future's not ours to see

Que será, será

What will be, will be

First published in 1956, Jay Livingston and Ray Evans.

But if you spend your time looking over your shoulder for the shadow of the cancer to come and get you, you won't do anything. You won't achieve any of the things you want to do. (Oncologist 3: Jane)

Jane's oncologist described how he felt it was important to provide patients with the means to help them pivot their gaze away from being a cancer patient and towards picking up a normal life.

So in terms of pivoting one's gaze away from cancer, I think it's really important that as an oncologist, you try and give someone the tools to be able to pick the pieces of their life back up again. (Oncologist 3: Jane)

One approach used by several professionals was to provide a focus on the end point of follow-up. By explicitly discussing the five-year follow-up period and emphasising an end point, Jane's oncologist wanted to focus patients on the long-term future and help to construct hope.

[...] one of the things I think it [cancer] steals the most is the ability [...] to assume there is a future. So if you're able to build something into someone's calendar that is a fixed point in time where you say you're going to be around for that, then that helps. (Oncologist 3: Jane)

Many professional participants wanted to avoid opening up discussions about possible recurrence as a way of helping patients pivot their gaze away from their cancer. This involved avoiding discussion of not only recurrence risk, but also information about possible signs and symptoms of recurrence as well. Cathy's LCNS felt putting too much emphasis on possible recurrence during consultations and accentuating to patients that “*we might not have cured you*” was unhelpful. By minimising discussion on the subject of recurrence she felt patients would be able to focus on more positive matters.

I think patients have to [...] be allowed to forget about it [cancer] and get on with life. (LCNS 2: Cathy)

Some professionals indicated that they saw patients as being especially vulnerable to the negative effects of discussing potential recurrence in the time just after surgery. Cathy's LCNS felt that raising the issue of recurrence “*eight weeks after an operation*” was too early and said, “*I don't feel is the right thing to do*”. Fiona's oncologist was conscious that talking

about possible recurrence too much during their initial consultation after surgery could “bring things down” in what was a “good news” discussion. Denise’s surgical LCNS felt there was a risk of sending patients a mixed message when discussing signs and symptoms of recurrence in the post-surgical consultation.

If you then say, OK we want to tell you all about signs and symptoms of recurrence, even if you say at the beginning that it's really good news, we don't then want the patient to feel we're hiding something and actually we think it's going to come back [...]. (LCNS 1: Denise)

However, none of the participants offered a time frame regarding when it would be appropriate to discuss potential recurrence.

Most professionals avoided actively giving patients lists of possible symptoms of recurrence to look out for. Where patients raised questions themselves about recognising recurrence, some professionals wanted to “play it down” (Glennis’s medical LCNS and Len’s Chest physician) and to offer general reassurance. Others answered questions by telling patients to call if they experienced “any problems” (Glennis’s medical LCNS), or “anything different” (Maggie’s medical LCNS). Some professionals wanted to avoid patients becoming concerned about every new pain or cough and emphasised that it was the “duration of symptoms that’s the concern” (Edward’s oncologist), or things that lasted “more than two weeks” (Maggie’s oncologist).

In contrast, two professional participants explicitly wanted to provide specific signs and symptoms of recurrence to patients, as part of their on-going surveillance. For these professionals, focusing patients’ attention onto their cancer was seen to offer benefits that outweighed the risks of patients becoming over focused on their condition. Kamal’s chest physician explained he routinely gave patients this information.

I normally signpost them to some specific symptoms [...]. So I mention things like cough, breathlessness, haemoptysis and anything out of the ordinary. (Chest Physician 1: Kamal)

Len’s surgeon recognised that many early stage lung cancer patients may not have experienced symptoms prior to their diagnosis, and hence might not know what to look out for.

[...] if he did not have symptoms in the first place [...] he would not know what to look out for. And often lung cancer patient that's had cancer removed, they think that was that. (Surgeon 8: Len)

Recognising symptoms of potential recurrence was something that many patient participants were unclear about. Several patients expressed uncertainty about what recurrence might be like. Some felt they “*wouldn't have a clue what to look for*” (Edward), while others suggested a range of potential symptoms from cough to “*hair loss*” (Kamal) or that they would use “*common sense*” (Len). Henry said:

I suppose I have two thoughts that occasionally go across my mind. One is if it were to return would it still be lung cancer or could it be somewhere else? [...] And the other thing is how will they, if the cancer returns, what will be the symptoms of it returning? (Henry 3rd interview)

Despite these uncertainties, it was apparent that he, in common with others, had not actually asked these questions of his cancer team and he was unsure whether this was something he would want to know. Edward commented that he would not mind being told symptoms to look out for, but was concerned about the effect on his wife.

I wouldn't worry about it, but then [my wife] might. [...] she worries enough now. (Edward, 3rd interview)

While professional participants recognised these potential sources of anxiety for patients, there was a limited range of strategies aimed at addressing these uncertainties. Maggie's oncologist emphasised the importance of presenting the inherent uncertainty following lung cancer surgery as normal. By projecting the idea of uncertainty as being a natural part of life she hoped to emphasise managing, rather than reducing or denying uncertainty.

[...] part about that is I think that projecting that it's normal to be uncertain about the future. It's normal to be unsure sometimes about the future. Everybody has those uncertainties. (Oncologist 4: Maggie)

Edward's oncologist consciously wanted to end consultations with an optimistic tone in order to try and pivot patients' gaze and avoid them ruminating about possible recurrence.

So I do try and get them out on a really positive note, because even if he does fret about it, it's not going to make the relapse any more or less likely. (Oncologist 1: Edward)

Denise's surgical LCNS recognised the importance of identifying those patients who were struggling with these issues and to refer on to other services, such as psychological support, where necessary. She also recognised the role of other activities like yoga, Pilates, or relaxation that have a physical benefit, *"but also have a positive impact on the mind"*. Maggie's oncologist highlighted the role the LCNSs played in detecting patients who were experiencing emotional difficulties and intervening or referring on for further support.

7.6 Chapter summary

In this chapter I have presented findings around the theme of 'Maintaining hope'. Using this theme I have explored the choices patients and professionals made about the information they disclosed and sought about long-term outcome with the overarching aim of supporting patient hope. In the first subtheme, 'Hope for normality' I explored the goal of achieving a sense of life returning to normal that was shared by both patients and professionals. Although it was apparent that professionals and patients' also shared the goal of ultimate cure, there was reluctance and caution in explicitly discussing cure during consultations. The subtheme 'Information as threat' explored how patients and professionals shared a view that information about cancer, and particularly regarding outcomes, was viewed as posing a potential threat to patients' sense of hope. This threat was conceived as impacting on patients' emotional and physical outcomes by some patients and professionals.

In the subtheme, 'Painting an information picture', I examined how professionals achieved the right balance of information to meet the needs of patients. The personal communication ethos of the professionals appeared to be fundamental to the information they disclosed to patients. Some wished to present detailed scientific information, while others wanted to position hopeful information in the foreground. Others highlighted situations where it was important to take a more balanced and realistic approach. The final subtheme, 'Pivoting the cancer gaze', explored the way that both patients and professionals attempted to focus patients' attention away from their cancer at the end of their treatment,

with the aim of supporting hope for the future. However, there were times when turning the gaze towards cancer was necessary or unavoidable. This included where there was a need to understand more about recurrence and its warning signs, processing patients' experiences of their illness, or at times of heightened fear of cancer recurrence.

8 Findings 4 - Hope dances

8.1 Introduction

In this final findings chapter I will use the theme of 'Hope Dances' to explore the process of information exchange around lung cancer recurrence and long-term outcome within some of the observed consultations during the study. I will primarily focus on how patient hope was supported by the way in which the information disclosed was controlled and shaped by the interaction between the participants within consultations. I will use extended extracts from the consultations to explore the process of information exchange and to illustrate these exchanges. Extracts from associated patient and professional interviews will be used to provide insight into the rationale behind these communication choices. Figure 8.1 provides an overview of the themes developed within this chapter.

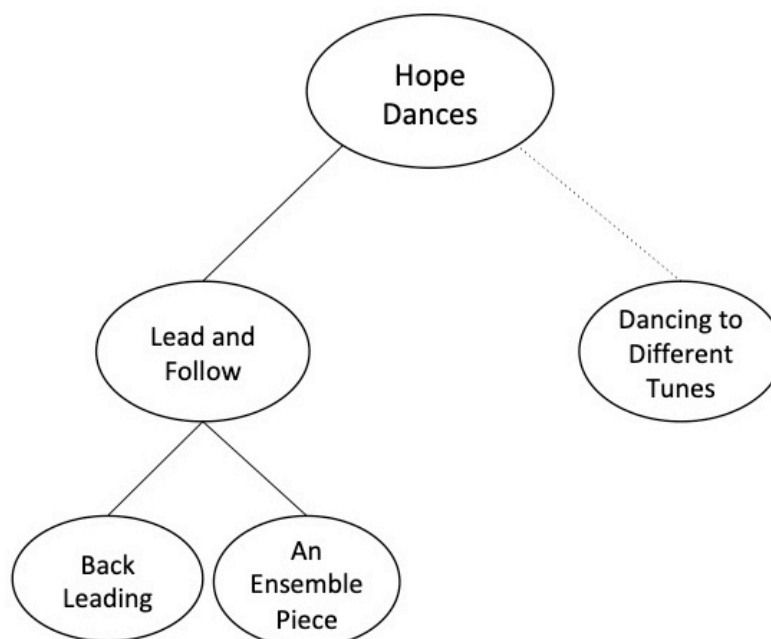


Figure 8.1: 'Hope Dances' theme and subthemes

The interactive nature of the consultations lent them to being described in terms of a metaphorical dance. The subtheme 'Lead and Follow' will be used to explore consultations where there was an interaction between a professional who took the lead in the dialogue, and the patient who assumed a more passive role in the process. In the second subtheme, 'Back Leading', I will examine variations on this basic model, where patients attempted to influence how and what information was disclosed. The subtheme 'An Ensemble Piece' will examine the interactions between multiple participants and how these different

participants related to influence the disclosure of information. The final subtheme 'Dancing to Different Tunes' provides insight into a divergent case, where participants appeared to want different things from the communication dance. Space does not permit a detailed discussion of all the observed consultations and selections have been made that best illustrate these typologies.

8.2 Lead and Follow

Many of the consultations were primarily between two interlocutors: the lead professional and the patient or their family member. This dyadic form suggested a dance involving a couple. The terms 'Lead' and 'Follow' are sometimes used as a gender-neutral description of dancing roles and serve to clarify the nature of the interactions in the consultations. The observed consultations conformed to a norm of the professional taking a clear Lead and the patients taking the Follow role. A feature of all the interactions was a sense of power imbalance, where power lay primarily with the professional by virtue of the knowledge and information they possessed. This allowed professionals to give the information they felt was appropriate for the patient. Patients varied in the extent to which they interacted or remained passive during the consultations.

These dances adhered to the unwritten rules of doctor/patient interactions in terms of structure, turn taking, and roles within the consultation. In all of the observed consultations professionals began by attempting to make an assessment of patients' current health, in terms of recovery from surgery, or fitness for chemotherapy. During most of the surgical consultations the results from the lung cancer operation were discussed in the second half of the encounter. This was then followed by discussing plans for follow-up or further treatment. In the majority of consultations, but by no means all, patients were explicitly asked if they had any questions or needed further information. This usually occurred at the very end of the consultation.

I will use two observed consultations, first Barbara's surgical consultation, followed by Maggie's oncology consultation, to illustrate two contrasting encounters that both closely followed the Lead and Follow model.

Barbara and Surgeon 1

The consultation was upbeat and friendly, made more so by Barbara's feeling that she had recovered well from the surgery. I recorded in my field notes:

Barbara is recovering well, pain settled and feeling good. A positive interaction with Surgeon 1 that was very upbeat. Bright and positive in tone. Barbara appeared to take a lot of the information in and to understand it. (Research field notes)

In common with all the other observed consultations, there was no explicit enquiry into the level of information that Barbara required. The only time that Barbara and her husband initiated any discussion was to ask about the impact of possible chemotherapy on her rheumatoid treatment, which occurred towards the very end of the consultation. Although not explored in the surgical consultation, it was later apparent in her oncology consultation and during her interviews that being able to re-start her rheumatoid arthritis treatment was Barbara's biggest priority.

Barbara's surgeon began the consultation by assessing her recovery from surgery. Following this, the surgeon began to discuss the surgical findings. This section of the consultation is shown in box 8.1. Information given that related to the surgical procedure, diagnosis and staging, further management and surveillance, recurrence and survival, and signs of recurrence have been distinguished with differential underlining. Barbara's surgeon took an unequivocal Lead role in the dance and Barbara largely only spoke in acknowledgement of the information the surgeon gave her.

A relatively large amount of information was given regarding biomedical details of diagnosis (lines 5 – 8). This included giving the specific type of cancer and its extent, including specific size (lines 12 – 15). Barbara reacted to the size of the tumour with shock (lines 13 and 16). However, her surgeon did not react to this, but moved the dance on by continuing with further biomedical information that included specific detail about her lymph nodes (lines 17 – 23). There was no discussion of Barbara's formal cancer stage.

1	Surgeon 1	Right, let me tell you what was found and [what the final-
2	Barbara	[Yes please
3	Surgeon 1	- outcome is. We told you that when you were in hospital that <u>it was a cancer</u>
4	Barbara	Yes
5	Surgeon 1	And <u>it's turned out to be what we call a squamous cancer. And that is just one</u>
6		<u>type of cancer. Umm, there are all subgroups, and it is what we call a non small</u>
7		<u>cell err lung cancer which is the common one. And is undoubtedly secondary to</u>
8		<u>smoking.</u> Okay?
9	Barbara	Right
10	Surgeon 1	It has all been removed
11	Barbara	Lovely
12	Surgeon 1	It was quite big. It was over seven centimetres [in its biggest diameter
13	Barbara	[Aghhh
14	Surgeon 1	... <u>The biggest... umm... yeah, the diameter, diameter, yeah. So it was seven and</u>
15		<u>a half by [three and a half by seven -</u>
16	Barbara	[Crikey, it was...
17	Surgeon 1	<u>[- centimetres. So we took away a whole load of the glands. Some of them</u>
18		<u>inside the lung and some of them outside of [the lung</u>
19	Barbara	[Okay
20	Surgeon 1	<u>None of the glands outside the lung contained any tumour</u>
21	Barbara	Lovely
22	Surgeon 1	<u>One or two of the glands inside the lung, within the specimen, did contain</u>
23		<u>tumour</u>
24	Barbara	Right

Key: Details of surgical procedure Diagnosis and staging Further treatment and
 Recurrence or survival Signs of recurrence surveillance

Box 8.1 Extract A from Barbara's surgical consultation

The interaction is continued in Box 8.2. Here Barbara's surgeon uses the biomedical information she had already given to lead the dance into the outcome from the MDT meeting and the plan to refer her to see an oncologist (lines 25 – 27). Her explanation about the rationale for chemotherapy was limited and extended to only suggesting there might be an unnamed benefit (line 29). By using the phrase “*some advantage*” Barbara's surgeon avoided discussing potential recurrence at this point in the consultation. She then indicated that Barbara's oncologist would explain the treatment in more detail, with the ultimate treatment decision being a joint one (lines 31 – 36). It was striking how little information or rationale she offered her about the referral for chemotherapy. In her interview Barbara's surgeon later explained that she wanted to give a simple message about the onward management plan, but not to make it overly complicated.

What I do think is that it's important that they know that there might be an advantage with [...] having chemo and why we're referring them on to an oncologist. [...] I'm sure there's bits I leave out which aren't relevant. (Surgeon 1: Barbara)

25	Surgeon 1:	Umm... and ... as such at the meeting where we discuss all the patients, <u>at the</u>
26		<u>MDT, it was decided that you may well benefit from having or being offered</u>
27		<u>some sort of chemotherapy as well as surgery</u>
28	Barbara	Okay
29	Surgeon 1	<u>It might give you some sort of advantage hhh. So I would suggest to you that you</u>
30		<u>go and talk to our oncology doctor, who will be [name]. [The consultant</u>
31		<u>oncologist], he's based here. He will talk you through chemotherapy. What he</u>
32		<u>would offer you</u>
33	Barbara	Yeah umm
34	Surgeon 1	<u>What it would do to you short term, long term. And what the potential benefit</u>
35		<u>is. And, you know, should you wish to go down that route between the three of</u>
36		<u>you, you agree. Then he will take over your care-</u>
37	Barbara	Right
38	Surgeon 1	<u>And he will follow you up with every scan that is needed. If you decide between</u>
39		<u>you, that it is not for you. Umm, then the chest doctors here will look after you.</u>
40		<u>And you will start a surveillance programme, which in most trusts last about five</u>
41		<u>years. We see you every three months to start will with a chest x-ray. And as</u>
42		<u>time goes on the risk of it coming back goes down and so we see you less</u>
43		<u>frequently. Until we see you probably once a year for the last couple of, err,</u>
44		<u>years out get CT scans usually years one, two, five,</u>
45	Barbara	Right
46	Surgeon 1	<u>However, if there is any other reason to do one, any new problem arises, we</u>
47		<u>won't hesitate, we'll get one, all right?</u>
48	Barbara	Right
49	Surgeon 1	<u>And at five years, we say, well the chances of it coming back are such that we</u>
50		<u>think that we've cured you. With fingers crossed. And we send you off to the</u>
51		<u>community. For your GP to look after you. [Okay?</u>
52	Barbara	[Okay, that's fine. Thank you

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.2 Extract B from Barbara's surgical consultation

Barbara's surgeon then quickly moved the consultation dance on to discussing long-term surveillance (lines 38 – 47). In this section she provided much more detail about follow-up plans. Her surgeon appeared to have a preference for talking about the process of follow-up, as opposed to exactly what the purpose of follow-up was. At line 42 she mentioned risk of recurrence for the first time, but only in the context of the risk falling as time after the operation increased. As a way of offering further reassurance, her surgeon mentioned that she would also offer a scan if there were "*new problems*", but she avoided naming these problems specifically (lines 46 – 47).

Finally, in this extract (lines 49 – 50) her surgeon focused attention on the point in time after five years when they might be able to say that Barbara was cured of her cancer. By bringing up the subject of cure in this way, she could pivot the dance towards this ultimate goal and away from the prospect of potential cancer recurrence, whilst still in effect having a discussion about the negative potential for what she privately admitted as "*a real risk*" for

Barbara. In the surgeon's interview she talked about using follow-up as a conscious strategy in the consultations to offer reassurance and hope.

Because they've had their cancer taken out, they know that the results of lung cancer are not <great> ... worldwide, and they want to know, you know, how we're going to look to see whether or not it's coming back. (Surgeon 1: Barbara)

During Barbara's interview she was able to confirm that she had understood and remembered most of the information she had been given by her surgeon. She also found the information reassuring and helped her feel more in control of her situation.

Yeah, she said it had all gone. [...] That was important to me. Because I know that one [lymph gland] was showing the signs of, wasn't too good. [...] so anything that was on that side has gone now. [...] Yeah, that felt reassuring to me. (Barbara 1st interview)

Asked about the information she had been given regarding the size of the tumour, she denied that the information worried her, but commented on the reason for her surprise.

[...] I just didn't understand that, how it could get so big, and like not hurt. (Barbara 1st interview)

The way in which Barbara spoke about her recurrence risk suggested that she had a basic understanding, even if couched in lay terminology. The way that the surgeon had discussed the five-year surveillance programme following surgery appeared to work well for Barbara in terms of providing a sense of on-going support, if not explicitly a source of hope.

[...] you're still vulnerable. And if you're ..., things hide and they will suddenly go, 'whoo-hoo, I'm here', you know. And just start just to be a nuisance. And that's why I think the five years [follow-up] is very good. (Barbara 1st interview)

Throughout this consultation Barbara's surgeon was able to lead the dance and Barbara appeared happy to follow. The Follow role involved indicating that she had understood the information that was being given and reacting appropriately to it. The Lead ensured that the discussion remained hopeful by curtailing, or avoiding discussion focusing on negative outcomes, like recurrence. Barbara's surgeon did this by moving the dance on to other subjects, such as follow-up and potential cure, when she felt it was necessary. At key points,

the surgeon constructed hope for Barbara, by quickly turning the discussion away from the implications of lymph node involvement and tumour size to more hopeful topics. In this way she directed Barbara's gaze towards positive aspects of her situation, such as the non-specified benefit of chemotherapy and concentrating on the end point of follow-up and potential cure. Nevertheless, the surgeon carefully ensured that cure was only discussed in terms that made it clear that cure was not part of the current situation, and only something for the future.

Maggie and Oncologist 4

Another consultation that followed the Lead and Follow model was Maggie's oncology consultation. Although superficially similar in that the professional gave a large amount of information and the patient largely only responded with single words to indicate agreement, the two consultations were very different. While Barbara appeared happy to be guided through the information about the surgical outcome and plans, Maggie's reaction to being led through the oncology consultation appeared to indicate that this was much more difficult for her. Maggie's anxiety was evident from her demeanour before and during the consultation, later noted in my research diary. In her interview she spoke about how worried she was regarding the appointment. Not only was she concerned that her oncologist might give further bad news, she also found facing a decision about having chemotherapy challenging. The consultation touched on subjects that Maggie found difficult to face and she was frequently emotional and tearful during it. The anxiety in this statement can be seen in her hesitant language.

I was very, very worried about coming today. [...] I knew he'd got all that [cancer]. But is, was, was there something somewhere else ... that might not have got looked at? (Maggie 1st interview)

An extract from Maggie's oncology consultation is presented in Box 8.3. Maggie's oncologist reiterated the pathology findings from surgery, emphasising the benefits already achieved by having undergone the surgery (lines A1 – A6). Her oncologist then highlighted the good surgical results by stressing that as far as anyone was aware the cancer was “*completely got rid of*” (line A10). But then she immediately hinted at the possibility of recurrence by saying “*that isn't always the case*” (lines A11 & A12), preparing the way to introduce the topic of

adjuvant chemotherapy. She began this by talking about the proportion of people who would see a benefit in terms of cure by undergoing chemotherapy (lines A12 – A14) and suggested that, although it was real, the benefit was quite small (lines A16 – A17).

Extract A	
A1 Onc 4	So you went off to [your surgeon] and he gave you, <u>he's done the operation.</u>
A2	<u>And he's done a very <good> operation in that he seems to have got rid of all</u>
A3	<u>the cancer that was visible on this scan. Erm, <u>the pathology results say that</u></u>
A4	<u>you have the cancer inside the lung, which was an adenocarcinoma, which is</u>
A5	<u>a type of a non-small cell lung cancer. But that one of the lymph glands</u>
A6	<u><close> to the cancer was involved with the cancer.</u>
A7 Maggie	>Right<
A8 Onc 4	<u>So you have a spread to that local lymph gland within the lung, but not</u>
A9	<u>outside of the lung, either in the centre of the chest or anywhere else. So as</u>
A10	<u>far as we are aware you have got, the cancer has been completely got rid of</u>
A11	<u>for you. However, <u>we know that looking at thousands and thousands of</u></u>
A12	<u>people that isn't always the case. And we know that if we give people like</u>
A13	<u>yourself chemotherapy, if I give a hundred people like you chemotherapy,</u>
A14	<u>five extra people would be cured of the cancer in addition to the surgery.</u>
A15 Maggie	>Right<
A16 Onc 4	<u>So there is a definite benefit to having the chemotherapy, but it is quite a</u>
A17	<u>small benefit.</u>

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.3 Extract A from Maggie's oncology consultation

In the interview with the oncologist conducted after, she commented on Maggie's lack of questions about her underlying survival rate.

[...] it endlessly fascinates me when I start off with your surgery's been very good, but we know from looking at thousands of people like you, a number of people are not cured by the surgery, and this improves it. And she doesn't ask me what her rate of cure is. (Oncologist 4: Maggie)

She went on to reflect that “*virtually nobody else*” asks for this information either. Although it could be considered that Maggie's oncologist was taking the lead from Maggie's lack of questions, in reality the professional remained in control of the information and how much was disclosed. Following this extract Maggie's oncologist then moved the discussion on to present details about the side effects and practicalities of undergoing chemotherapy. Her oncologist explained later that she felt Maggie had a good understanding of the information she had been given. This was due to her non-verbal feedback. However, she explained she did not routinely ask patients about what they had understood during consultations.

With her she was nodding and shaking her head in the right places. [...] So when I was saying stuff that was, you might die sort of thing, she kind of did do the good old, her facial expression was not pleasant. She winced at the appropriate bits.
(Oncologist 4: Maggie)

Maggie struggled to decide about treatment and asked her oncologist what she would do herself in the circumstances. The next extract from the consultation presented in Box 8.4 indicates the way in which her oncologist dealt with this query. In response to Maggie (line B1), her oncologist asked her a further question in return (lines B4 – B6). The oncologist can be seen to engage Maggie in the dance by graphically placing Maggie into a hypothetical “worst-case scenario” and asking her how she would feel. This question, apparently unconsciously, emotively used Maggie’s hope to see her grandchildren grow up as a way of getting Maggie to make a decision about her treatment (lines B14 – B20). Her oncologist commented in her interview about her choice of words to help Maggie think through her own personal decision-making.

And you heard me saying [...] you know, I don’t know [how to answer your question], because it’s about personality. If the worst-case scenario [happens], and the cancer comes back, how are you going to feel about having passed up an opportunity? And she kind of, she, it would be terrible, and you could see her thinking that through.
(Oncologist 4: Maggie)

This phrase used by Maggie’s oncologist remained with Maggie and was instrumental in her decision to accept chemotherapy.

*I think I have got to give myself the best opportunity that I can. What really fixes in my mind is when she said, how would you feel if you didn't have this and the cancer came back. **(Maggie 1st interview)***

Extract B

B1 **Maggie** [SIGHS] What would you do? [LAUGHTER] I expect everybody asks you that
 B2 **Onc 4** Not everybody, but a fair few. Er I think I think the answer is that I am a
 B3 different person to you, and what I view as important is different ... probably, to
 B4 you. What I, one of the things to think about is, in the worst-case scenario, say
 B5 the cancer did come back, how are you gonna feel if you'd given up this
 B6 opportunity to try and stop it?
 B7 **Maggie** Dreadful
 B8 **Onc 4** Some people say that they have to have everything that they can have, because
 B9 they want to do the most that they can do. And if, and therefore they will take
 B10 every chance that they can to keep the cancer from coming back. Some people
 B11 say well actually it's quite a big risk and I have had really good operation and the
 B12 benefit is so small I can live with myself, if the cancer comes back. And I think it
 B13 is where you sit, and there's a whole spectrum in between there.
 B14 **Maggie** [TEARFUL] ... >Sorry<
 B15 **Onc 4** No, that's okay ...
 B16 **Maggie** I got six grandchildren
 B17 **Onc 4** >Umhum<
 B18 **Maggie** That I want to see grow up
 B19 **Onc 4** >Umhum< [CNS GIVES TISSUES]
 B20 **Maggie** >Thank you< So...
 B21 **Onc 4** It's a difficult call, isn't it? I think the emphasis I would say is that you have had a
 B22 very good operation. And therefore the bulk of the chances of you seeing your
 B23 grandchildren growing up has already been done by [your surgeon]. What I offer
 B24 adds you a bit of extra, but not a huge bit of extra. And has with it some risks.

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.4 Extract B from Maggie's oncology consultation

Despite the oncologist's attempts to present the small but realistic benefit of chemotherapy, Maggie eventually interpreted the message in a way that supported her own hope. It was likely that Maggie's interpretation was much more optimistic than her oncologist had intended it. Maggie seemed to understand that chemotherapy would guarantee the cancer would not recur and therefore remove any uncertainty about her future.

I'm hoping that, if I manage to do the whole course, that there won't be any cancer cells in my body at all. So I won't have to live in fear every time I get an ache or a cough or a headache. Or, oh God, is this going to be something awful again?
 (Maggie 2nd interview)

By accepting that chemotherapy would give her five per-cent benefit, whilst simultaneously seeing that accepting this treatment as offering a guarantee against recurrence, Maggie then was able to estimate her chance of not having a recurrence with surgery alone as 95%.

You know, this gives you, not much ... higher chance of survival, or it not coming back. But 5% is 5%, isn't it? So then I started to look at it the other way: well, it's only 5%, so I've still got 95%. (Maggie 3rd interview)

Such an optimistic reading of the information she was given about the role of adjuvant treatment could be seen as a form of 'false hope', or denial. On the other hand, this strategy appeared to be her way of managing the overwhelming nature of the situation and the unthinkable idea of cancer recurrence. As such, it appeared to be fundamental to her coping strategy.

Maggie's oncologist attempted to deliver information in a way that she saw as supporting hope. This included emphasising having had "good" surgery as being the most important thing in achieving Maggie's goal of seeing her grandchildren grow up. Her oncologist also avoided disclosing long-term survival statistics, unless patients specifically asked for them. But there was also a desire to present a realistic view of the chemotherapy. Maggie, on the other hand, found all information about cancer a challenge, and the discussion of potential recurrence particularly so. Maggie had to follow the oncologist's Lead in this consultation. In order to counter this and to support her own personal hope, Maggie had to be very careful what information she took on board about her situation. When faced with potentially challenging information she had to construct an elaborate mental mathematical work-around for the information that she had been given to be able to continue to support her own personal hope for the future.

8.3 Back leading

There were numerous variations on the Lead and Follow dance within the observed consultations. The subtheme 'Back Leading' explores how patients or family members could influence discussions in complex and often subtle ways. The term is used in dancing whereby the person in the Follow role can indicate opportunities, such as potential space on the dance floor, or to prevent moving into danger, or colliding with another couple.

Typically, Back Leading is achieved by small subtle changes in balance or hand positioning, without directly challenging the role of the Lead. I will use two contrasting consultations from the case studies to illustrate how Back Leading might be used.

Denise and Surgeon 2

Denise had been very anxious to know the surgical findings following her operation. Her anxiety had built over the four weeks between discharge and the consultation. Although she had numerous concerns about her surgical recovery, her chief aim was to know whether she was going to need chemotherapy. In the run up to the appointment she had convinced herself that the surgeon would tell her she did require further treatment.

And they're probably going to say to me I'm afraid you've got, it's positive, has spread and afraid you're going to have to have chemotherapy. (Denise 1st interview)

This anxiety was evident during her surgical consultation, which felt tense and slightly confrontational as an observer.

[Denise] appeared anxious and 'brittle' throughout the consultation, although relaxed to some extent towards the end and with the increasingly 'good news' message. (Research field notes)

Early in the consultation Denise attempted to use Back Leading to influence the discussion by raising the issue of her surgical results.

Denise: So I am keen to know the results

Surgeon 3: Oh yes, that is why we are here for

Denise: Yeah. In fact I have been a little concerned about my um results, so umm

Surgeon 3: Good. I just want to be sure that you are okay now [...] and that you feel better.

Her surgeon acknowledged Denise's attempt at Back Leading, but avoided immediately addressing her point. Despite Denise's explicit expression of her concerns about the results in the following line, she failed to get the surgeon to change direction. Rather the surgeon maintained her own line of questioning, taking Denise with her, dealing with a number of other concerns. Denise recognised her own anxiety during the consultation.

[...] my mind was racing on, you know, and and and thinking am I going to get everything that I really need to say out? (Denise 1st interview)

Although the surgeon returned to this request about two minutes later, this delay in hearing her result was difficult for Denise. When she finally heard the results, she recalled her relief.

I thought, well ... <ah>. I've actually got my results, she's actually told me and I've got to absorb that. And yes it's all okay. So that was reassuring. I thought yes, at last. (Denise 1st interview)

The LCNS present in the surgical consultation recognised Denise's need to be given the results.

She was obviously very anxious to know the result and at one point the cue maybe for that was dismissed. (LCNS 1: Denise)

Although Denise's surgeon did recognise the high level of anxiety Denise was facing during the consultation, she did not feel that the delay in giving this information was an issue for Denise.

In the second half of her surgical consultation Denise asked another question, this time about possible recurrence. An extract of the consultation covering this discussion is presented in Box 8.5. Denise began by asking if the cancer could recur. However, she immediately followed this with comments that appeared to relate to causation, rather than recurrence (line 2). The answer the surgeon gave digressed from the information that Denise was looking for. Eventually Denise interrupted the surgeon's answer to repeat her original question more explicitly (line 18). On this occasion Denise received an answer in terms of a verbal description of possibility (Line 23, '*It is unlikely*'). Immediately after she had received this information Denise then closed down the discussion of recurrence by abruptly Back Leading again to the subject of trapped wind (line 25).

1	Denise	<u>With this type of cancer, could it pop up again?</u> Because it just seem to be
2		inexplicable that it just popped up and [my consultant] indicated at the last
3		appointment that it may be for environmental reasons or whatever, that it is
4		still not known
5	Surg 2	Yeah, yeah, the lung cancer, we still don't know a lot of things about lung
6		cancer, unfortunately. We know a few things, but not a hundred per cent ... so
7		we know that there are some environmental factors like the smoke, okay, like
8		cigarettes they can... erm, they can induce and they can, you know, help in
9		having lung cancer
10	Denise	Well, that wasn't really relevant to me. The only thing that I thought of that
11		may have been, is the fact that I had the hypersensitivity pneumonitis, so I just
12		wondered if that may have made my lungs more sensitive to the environment
13	Surg 2	They are studying a lot a lot of risk factors for lung cancer, so far they are
14		studying everything, radon, or, [gases, or pollution, -
15	Denise	[Yes, And perhaps there'll be some [unclear]
16	Surg 2	- or previous lung disease, so they are studying a lot, they are trying to study a
17		lot, they are trying to analyse a lot of [risk factors
18	Denise	<u>I was just wondered about the reoccurrence, you see, whether I could expect</u>
19		<u>possibly a re-occurrence on the other side, or whether this type can pop up</u>
20		<u>again</u>
21	Surg 2	<u>Well, it is an early stage, so</u>
22	Denise	Right
23	Surg 2	<u>It is unlikely, but we cannot say one hundred per cent that you won't have a</u>
24		<u>reoccurrence again</u>
25	Denise	Right, okay. Thank you very much, umm perhaps. Actually I do get a feeling of
26		trapped wind sometimes, which is, you've seen me where, it's it's quite painful
27		and it's, it's, it's, it is a feeling of just trapped wind, but I mean, in my mind's
28		eye, if everything is sealed, everything is fine then.

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.5 Extract from Denise's surgical consultation

After the consultation Denise spoke about the information that she was looking for when she asked about recurrence.

[...] it was whether in her experience with this particular type of cancer, whether it recurs or not. [...] But I just wondered if it had a ..., you know, if this was a common cancer that did reoccur. (Denise 1st interview)

Asked whether she had been looking for statistical data around risk of recurrence when asking her question, she replied:

Probably not, because that would be equal to me looking it up on the Internet. And she probably gave me the right information to reassure me [...]. (Denise 1st interview)

Denise had apparently taken a risk in asking the question about recurrence. Back Leading the conversation in the way that she did allowed her to move herself out of danger as soon as she had heard the information she wanted, and avoided hearing things that might threaten her sense of hope. Despite her anxiety, Denise continued attempting to back lead the consultation until she had received the information that she wanted. Her surgeon had strong feelings about not presenting too much detailed information about recurrence. During the interview after the clinic her surgeon reflected on the information that she had given to her.

[...] I've tried to reassure the patient because the prognosis for this kind of tumour at early stage is quite good, so. (Surgeon 2: Denise)

This was not an easy consultation for the participants and observer, in part due to Denise's anxiety and the surgeon's lack of flexibility in responding to Denise's concerns. Nevertheless the surgeon's assumptions about the level of communication that Denise required appeared to match closely to the reality of her requirements, despite the lack of meta-communication that might have clarified their aims early in the consultation. Nevertheless, both Denise and her surgeon were tacitly engaged in maintaining Denise's hope; trying to deliver information that would sustain hope, but avoid aspects that might be challenging to it.

Kamal, his wife and Surgeon 6

Another case where Back Leading was an important factor in the interaction was that of Kamal's surgical consultation. In this case it was Kamal's wife who used Back Leading most to try and achieve the level of information she wanted from the consultation. Box 8.6 gives an extract of the consultation where most of the information about the surgical outcome was given. Kamal's surgeon explained the surgical results and the MDT decision regarding adjuvant chemotherapy, initially portraying these results in a positive light (lines A10 – A13). Kamal's wife actively responded to this information by seeking clarification that this was really "*good news*" (line A14). Rather than just acknowledging the information, she queried it on behalf of her husband in a way that can be seen as Back Leading. The surgeon initially tried to affirm this as good news, but Kamal's wife persisted, possibly as this may have contradicted information they had previously received (line A16).

A1 Surg 6 I think [your consultant] discussed with you about the results of the histology.
A2 So the sample that we took out it was looked under the microscope and they
A3 found out what exactly what it was - and I think [your consultant] told you that
A4 it was a cancer actually. Er it was a cancer that was spread to a lymph node, do
A5 you remember that?
A6 Wife Yeah
A7 Kamal Um
A8 Surg 6 So we have discussed your case in our multidisciplinary team meeting where
A9 you have like oncology doctors or cancer doctors, radiologists and so on,
A10 respiratory physicians. And the decision was that you don't need chemotherapy
A11 Kamal Don't
A12 Surg 6 So you don't need anything else. Er, so from treatment point of view, you don't
A13 need anything else, but you are going to need to be under follow up
A14 Wife Okay, that's good isn't it?
A15 Surg 6 Yeah
A16 Wife It is good news, because I mean we was [you know
A17 Kamal [Ho ho
A18 Surg 6 The reason that they decided not to give, because as I said one of the lymph
A19 nodes was involved. But the reason that they said is it is not worth giving the
A20 chemotherapy is because of your exercise tolerance, so how much you can
A21 walk. And they don't think that you are going to tolerate the chemotherapy
A22 very well. So there is no benefit in that situation to give you the chemotherapy
A23 Wife So in that case the lymph node, that one that is left because we are concerned
A24 about it
A25 Surg 6 No no we took it out, it is not left
A26 Wife You said on because
A27 Surg 6 It was involved
A28 Wife Was involved
A29 Surg 6 Yes
A30 Wife The one that is involved or whatever and because of his health. So if they don't
A31 do chemo
A32 Surg 6 Um-hmm
A33 Wife For that one, what is the erm, damage, or what will that do?
A34 Surg 6 Well we took it out. So that is out, but we found that from the cancer that was
A35 in the lung has gone to one of the lymph nodes
A36 Wife Yeah, that is what I am saying
A37 Surg 6 Next to the lung. But that lymph node is out. So everything is out
A38 Wife Ah, I see [oh okay
A39 Kamal [So everything is clear, all done
A40 Wife So we don't need no chemotherapy. We'll just be under observation
A41 Surg 6 Yes
A42 Wife And a follow up
A43 Surg 6 Yeah

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.6 Extract A from Kamal's surgical consultation

This further Back Leading by Kamal's wife appeared to lead the surgeon to clarify the information that he had already given. In lines A18 – A22 the surgeon explained to them that rather than not requiring adjuvant treatment, it was actually Kamal's overall level of fitness that meant offering chemotherapy would probably be of no benefit. However, in his answers, the surgeon remained careful not to offer too much information regarding the implications of the lymph node status. It was evident that Kamal's wife had not fully understood, as she continued Back Leading the discussion (line A23) and the surgeon was forced to clarify the situation. Kamal's surgeon avoided making direct reference to cancer recurrence and reiterated that everything was resected (line A37). Kamal's wife concluded this part of the consultation by going back to the idea that there was no need for chemotherapy (lines A40 - A42).

In the surgeon's interview he spoke about Kamal's low mood during his surgical admission. He recognised Kamal and his wife's high level of anxiety and saw them as *"individuals that need a lot of support and a lot of guidance"*. He went on to talk about Kamal and his wife's understanding and what he hoped they had taken away with them.

So hopefully the end message, which was, 'we removed the tumour, you don't need any further treatment', I think that was well embedded in their memory [...].
(Surgeon 6: Kamal)

Kamal's surgeon emphasised the importance of presenting the information in a positive light in order to maintain hope and ultimately support Kamal's continued recovery. This meant making choices about the information he gave about the decision not to offer chemotherapy, such as avoiding discussion of the implications of lymph node spread, or possible future recurrence.

If he would have come in and I would have said we've done the operation, I'm very sorry I have bad news for you. Your lymph node had cancer. That means your cancer has spread. [...] this message for him is that his cancer is everywhere in his chest, and it's horrible, he's going to die soon [...]. **(Surgeon 6: Kamal)**

Towards the end of the consultation Kamal's wife gave him an opening to ask his surgeon a question. This section of the consultation is presented in box 8.7. In response, Kamal gave voice to his understanding that cancer is never actually curable (line B2), previously

discussed in chapter 6 (Predicting the Future). It was apparent that doubts remained in Kamal's mind about the long-term outcome following surgery. Kamal's surgeon avoided directly answering Kamal's query by initially confirming that all visible cancer was removed (line B3 – B5). In line B5 Kamal's surgeon started talking about cancer stage, but did not elucidate further how this might apply to Kamal's situation. The apparent attempt to use Back Leading to get further clarity by Kamal's wife appeared to be ignored (line B6). The surgeon immediately went on to acknowledge the possibility of future cancer recurrence, but then cited the overall rationale for surgery in a way that seemed to gloss over the potential for recurrence (lines B7 – B11). Nevertheless, the surgeon's answer did appear to provide a sense of hope for Kamal and his wife, as seen in the way that they both took up the positive messages around surgery and not being referred for chemotherapy (lines B13 – 18).

Extract B		
B1	Wife	Hum, right. Anything else that you want to know?
B2	Kamal	People say that cancer never goes, never cure. What is in that?
B3	Surgeon 6	<u>Well from what we sent- So we took out the lung- We sent it to be looked at under</u>
B4		<u>the microscope. It came back as completely removed, so everything was out. Er.</u>
B5		<u>Depends from what stage you are and what type of cancer you.</u>
B6	Wife	So er he's...
B7	Surgeon 6	<u>The reason why we are keeping you under supervision we are making sure that it</u>
B8		<u>doesn't come back. Yes, it is a possibility that it might come back. But we've. If you</u>
B9		<u>remove the cancer and it is coming back, then, then there is no point in doing an</u>
B10		<u>operation. But we are still doing a lot of operations. So it is worth it.</u> Does it make
B11		sense?
B12	Kamal	Umm, yes so far
B13	Wife	Yeah. So far you are lucky [they have done a good job
B14	Kamal	[I feel good as well in that sense
B15	Wife	And also the good thing is that you don't need chemo. Because chemo-
B16	Surgeon 6	Well, <u>I think it'll make you weaker, if you had chemotherapy</u>
B17	Kamal	Any way I feel weak now. Not doing anything or- Well it'll go slowly and will come
B18		back.

Key: <u>Details of surgical procedure</u>	<u>Diagnosis and staging</u>	<u>Further treatment and</u>
<u>Recurrence or survival</u>	<u>Signs of recurrence</u>	<u>surveillance</u>

Box 8.7 Extract B from Kamal's surgical consultation

In the interview with Kamal's surgeon after the consultation, he spoke about his reasons for not giving a response to Kamal's question in terms of survival data. Although this sort of information could have answered Kamal's question, his surgeon purposefully chose to reply with something that he saw as having the potential to support hope for the patient and his wife.

So if I tell him now in five years you might be dead or you might be alive - fifty fifty - how do you think it's going to impact his psychology? He was when he came, I remember him when he went home, he was more depressed and unwell looking. Now when he came he said I'm feeling good. And that keeps you alive. (Surgeon 6: Kamal)

From Kamal's point of view the information that he had been given in the consultation made him view his situation more optimistically and challenged his lay beliefs about cancer, as was evident from his later interview.

My opinion is different now. [...] Now the way he said, it's done. Operation has cleared everything. [...] I don't believe that it will come back. (Kamal 1st interview)

By offering the explanation he did, Kamal's surgeon appeared to match closely with the level of detail and the degree of hopefulness in the message that Kamal and his wife had wanted.

Kamal's surgeon stayed within the Lead and Follow model of consultation, remaining in control of the information that was disclosed. Kamal's wife strongly influenced the dance within the consultation by Back Leading to gain clarity in her mind, and to satisfy herself that he was not missing out on necessary treatment. She later facilitated an opportunity for Kamal to ask his own question about recurrence. However, his surgeon wanted to ensure that the message that he gave to the couple was one that could support their hope for the future. He achieved this by being selective in what information was disclosed. This meant resisting the Back Leading from both Kamal and his wife, and avoiding giving explicit details about the implications of surgical findings, potential recurrence or survival, all of which he perceived as dangerous to Kamal's morale.

8.4 An ensemble piece

Another variation on the Lead and Follow dance is described using the subtheme 'An Ensemble Piece'. This explores how multiple participants may use Leading and Back Leading to shape the consultation, and to some extent subsequent consultations. Participants engaged with and developed motifs around outcome, often initiated by others. In this way the consultations resembled a series of short sequential dances.

As was highlighted by Kamal's surgical consultation, family members could play a significant role in how and what information was disclosed. However, Fiona's surgical and follow-up consultations seemed to function in a slightly different manner and provided an example of another consultation typology. Fiona's case will be used to illustrate how multiple participants may be involved in a complex dance to manage hope that could function across settings and involve many dancers.

Fiona's surgical consultation was remarkable for the number of participants present, which besides Fiona and her surgeon also included her LCNS, Fiona's husband and her two adult daughters. Fiona's surgeon reflected that it was unusual to have so many family members in a consultation, and felt that this could put *"a slightly different dynamic on things"*. As the news had been good, she saw their presence as helpful in this situation. However, it was not just the number of family members with Fiona, but also the nature of the participants' roles in that communication that marked it out from other consultations.

Fiona's surgeon explained the surgical results to Fiona and her family early in the consultation. She specifically signalled the *"good news"* and told Fiona, *"there was no residual cancer left in anything that we have taken away"*. She reiterated this by adding, *"So that is pretty much the best news that we could have been hoping for."* There was a sense of celebration that permeated through the rest of the consultation. Afterwards I noted:

Overall, the feeling was of Fiona's shock and positive surprise at the news of there being no cancer present in the samples. (Research field notes)

This shock can be understood in terms of the process of mental adjustment between her initial bleak diagnosis and prognosis and the new post-surgical situation.

An extract from the consultation is displayed in box 8.8. Fiona's initial response after hearing the news was to ask about subsequent management (line 1). The responses from both the surgeon and LCNS of *"good question"* (lines 2 – 3) suggested a lack of clarity about her unique situation: one where there was no precedence on which to draw. Fiona's LCNS then took the Lead role and explained the plan from the MDT meeting. She was particular to underline that Fiona's lung cancer pathway was not a normal one and that there was no

clear protocol to follow (lines 6 – 11). In her interview following the consultation, Fiona's LCNS spoke about why she wanted to take the Lead at that point in the consultation. Knowing both Fiona and her oncologist well, the LCNS wanted to ensure a consistent message was given in both consultations. Fiona's LCNS attempted to pre-empt any potential threat to Fiona's hope that might occur when she saw her oncologist in the follow-up consultation, by ensuring there was an appropriate balance in the language used and she was realistic about the next steps.

I wanted to pre-warn that discussion because I think that is the sort of language that [her oncologist] might use. You know, you're not standard. You don't fit things, so actually, we don't really know. (LCNS 4: Fiona)

Fiona's LCNS continued to take the Lead and to give an outline of what the long-term follow-up would involve (lines 13 – 21), before the surgeon began to take back the Lead, beginning at line 18. Fiona then went on to ask an explicit question about the potential for recurrence; *"Is it liable to pop up again"* (line 27). The surgeon began by reiterating the unusual nature of Fiona's situation (lines 28 – 34), which echoed back to the previous comments by her LCNS. While she highlighted the positive features of the surgical findings, ultimately she was not able to provide a definite answer for Fiona (lines 34 – 37). She concluded by trying to keep a balance in her answer by saying, *"the signs are good at the moment, but we will want to be keeping a close eye on things"* (Lines 37 – 38). Fiona's surgeon expanded on the rationale for this guardedly optimistic approach during her interview afterwards.

[...] at the moment we can't find any evidence that she does have cancer, but what you don't want to sort of do is say oh yes, yes, everything's fine, completely cured. Because particularly in her case, she's done very well and the results are excellent, but we don't quite know what's going to happen in the future. (Surgeon 4: Fiona)

1	Fiona	Gosh. So where do I go from there?
2	Surgeon 4	Well, yeah, [exactly, good question
3	LCNS 4	[A very good question
4	Fiona	[LAUGHS]
5	Husband	Crikey
6	LCNS 4	Cos in truth, <u>you already don't quite fit the mould so to speak, [Fiona] because</u>
7		<u>as you know</u>
8	Fiona	No
9	LCNS 4	<u>You have gone in a quite an unusual journey with you. So in a sense we haven't</u>
10		<u>got a map as to what to do next now. But the right thing to do we are pretty</u>
11		<u>sure anyway is that you, that we put you back with [your oncologist]</u>
12	Fiona	Yes
13	LCNS 4	<u>She will certainly want that anyway initially. She may refer you back to the</u>
14		<u>respiratory team for longer-term follow-up. Because certainly we have to</u>
15		<u>follow you up for five years now</u>
16	Fiona	Umm
17	LCNS 4	<u>Because we will keep a a a track [and a trace on everything</u>
18	Surgeon 4	<u>[Keep a close eye on things</u>
19	LCNS 4	<u>We'll be re-scanning periodically and things like that. So the question is will</u>
20		<u>[your oncologist] do all of that five-year follow-up, which she may. Or will it be</u>
21		<u>her for a time and then over to the respiratory team</u>
22	Fiona	Oh I see. I've got an appointment with [the oncologist]
23	Surgeon 4	Umm
24	LCNS 4	Yeah, so
25	Surgeon 4	<u>So we'll sort of we'll leave that side of things for them to decide amongst</u>
26		<u>themselves. But certainly you won't be left</u>
27	Fiona	<u>Is it liable to pop up again, though?</u>
28	Surgeon 4	As we say, you're not, <u>you're not, you know, normal</u>
29	Husband	Normal
30	Surgeon 4	For want of a better word [LAUGHTER] You're not going to, you're not going to.
31		<u>With anyone with lung cancer we very much work on averages and what</u>
32		<u>happens in most people. So even with people who do follow what we would</u>
33		<u>expect things are never straightforward. And even more so in your case, we</u>
34		<u>just don't know the answer. The fact there was no residual disease in the tissue</u>
35		<u>that has been removed is a very good sign cos it would suggest that you have</u>
36		<u>responded to the oncological treatment. Umm, but in terms of recurrence, I</u>
37		<u>think that it is very difficult to say, but the signs are good at the moment, but</u>
38		<u>we will want to be keeping a close eye on things in the future.</u>

Key: Details of surgical procedure Diagnosis and staging Further treatment and surveillance
Recurrence or survival Signs of recurrence

Box 8.8 Extract from Fiona's surgical consultation

Towards the end of the consultation Fiona opened the floor to her daughters to join in the dance by asking if they had questions.

Daughter: *So I would be correct then, when I tell people then, I could say that my mum doesn't have cancer anymore?*

LCNS 4: *Well, you can certainly say that everything that we know about is no longer there. There is nothing see-able. But we always tread cautiously, [Daughter 2]. [...] So I think the truth is, we don't get too bold.*

This question from Fiona's daughter effectively asked whether her mother was cured. Her surgeon commented later in her interview that she saw this as a *"tricky question"* and one that made her want to *"back away"* from answering. Fiona's LCNS, who had picked up the dance with the daughter at this point, attempted to provide a guarded and cautious view of the situation and distance the idea of offering a promise of cure by avoiding *"using too bold, or strong a word at this point"*. Such an approach again emphasised the balance both professionals were trying to achieve in the message they wanted to convey.

The positive and celebratory tone observed in the surgical consultation was also evident in the subsequent follow-up appointment with Fiona's oncologist. The oncologist opened the encounter by talking about the *"absolutely fantastic news"* of the surgical results. These positive statements were reinforced a number of times. Fiona's oncologist told her, *"So it is really, really, <really> good news. I can't, I can't over emphasise that."* The oncologist contrasted Fiona's situation following surgery with that of her initial diagnosis. Fiona acknowledged this by her understated, rhetorical question.

Oncologist 2: *And, you know, this time two years ago we, I didn't expect to be saying this to you at all [LAUGHS]*

Fiona: *Well it wasn't sounding too good, was it?*

Fiona's oncologist went on to talk about her future management. This section of the consultation is reproduced in box 8.9. Her oncologist began by explaining that no further chemotherapy was indicated (lines 1 – 6). Fiona appeared to use Back Leading to raise her concerns about the lymph node in her neck, which had not been operated on (line 7). Their subsequent collaborating interaction appeared to minimise the concern about this lesion, summed up by stating the assumption that the chemotherapy had treated the neck lesion in the same way as the rest of her cancer (line 21).

1	Onc 2	We won't follow this with anything, because, I mean you've had enough chemo
2		to [LAUGHS] for anyone really
3	Fiona	Yeah, I think everything's done
4	Onc 2	<u>So you've had, so the chemo showed that the cancer has completely gone and</u>
5		<u>that has been confirmed by the operation.</u> So there will be no more treatment.
6		So everything stops
7	Fiona	<u>[And the one in the neck has probably been</u>
8	Onc 2	[Other than. Well
9	Fiona	<u>Sorted out with the chemo</u>
10	Onc 2	Exactly, <u>I mean that wasn't explored by the surgeon</u>
11	Fiona	No, because it was too near the um
12	Onc 2	Umm yeah, <u>but on the PET scan, um there was no evidence of any activity in that</u>
13		<u>area. And they specifically commented on that, because [obviously when I</u>
14		<u>requested the PET scan</u>
15	Fiona	[Because that's the way I am
16	Onc 2	<u>I said look this is where the nodes were, what's going on in them now. And there</u>
17		<u>was nothing in there. So whatever's happened here, we assume, has happened</u>
18		<u>here</u>
19	Fiona	Yeah cos it was only a tiny bit there anyway wasn't it. [Just a spark
20	Onc 2	<u>[It was small, it was small and very difficult to get to with the biopsy wasn't it.</u>
21		<u>And so yeah, we assume that there has been a complete response everywhere</u>
22	Fiona	Umm
23	Onc 2	<u>So we need to just do what we call base line scans. So just scans at this point in</u>
24		<u>time so that we have now got something to compare to</u>
25	Fiona	Okay
26	Onc 2	<u>And we need to continue to follow you up</u>
27	Fiona	>Yep<
28	Onc 2	<u>And, what we'll probably do is just annual CT scans. And three to four monthly</u>
29		<u>chest x-rays. And if there is any change on the chest x-rays or any new</u>
30		<u>symptoms, then obviously, we'd do a scan sooner and investigate it. But that</u>
31		<u>what would be the routine follow-up would be. And that continues for five years</u>
32	Fiona	Yep
33	Husband	Fantastic
34	Onc 2	<u>All being well</u>

Key:	<u>Details of surgical procedure</u>	<u>Diagnosis and staging</u>	<u>Further treatment and</u>
	<u>Recurrence or survival</u>	<u>Signs of recurrence</u>	<u>surveillance</u>

Box 8.9 Extract from Fiona's follow-up consultation

Fiona's oncologist then moved on to discuss the follow-up plan and restate that this was for a period of five years (lines 23 – 31). The oncologist's comment "*all being well*" (line 34) served to underline a sense of balance and remind everyone that there was still a possibility of the cancer returning in the future. The tone of guarded optimism set in the surgical consultation that Fiona's LCNS was keen to establish was continued during the oncology consultation. Fiona's oncologist reflected afterwards:

We're optimistic, but still there's a bit of realism there isn't there? (Oncologist 2: Fiona)

The question that was first asked by her daughter in the surgical consultation about being considered “*cancer free*” appeared to have remained at the forefront of Fiona’s mind. Towards the end of the follow-up consultation with her oncologist, Fiona raised the tentative question; “*I'm not declared cancer free, though, am I, until five years?*” After reiterating there was no evidence of active cancer, her oncologist returned to sound a note of caution.

Oncologist 2: *Um, yeah, but we never say, [completely*

Fiona: *[No, no never, cos I guess you're prone to it*

Oncologist 2: *You're prone to it, prone to umm, something coming back in the future, which is why we watch people for five years, cos the risk of it coming back having had this operation, five years down the line is then very slim*

Fiona: *>after five years, yeah<*

Fiona’s disappointment that her illness was not yet resolved, was reflected in her *sotto voce* echo of the oncologist’s “*after five years*”. Her oncologist’s repetition of Fiona’s use of the word “*prone*” also appeared to cement the idea of Fiona having an inherent susceptibility to cancer. Not being able to resolve the uncertainty of being “*cancer free*”, and somehow being “*cancer prone*” remained with Fiona, as discussed earlier in chapter 6 (Predicting the Future).

8.5 Dancing to different tunes

The final subtheme will use the metaphor of participants ‘Dancing to Different Tunes’ to examine the example of Len’s surgical consultation. The two participants appeared to have different ideas of what they wanted the consultation to be about, which they enacted with little ostensible coordination with the other dancer’s steps. Superficially the consultation could be seen to have some features in common with a Lead and Follow dance, with the surgeon giving information and the patient reacting to it. But in reality, the consultation was one of amicable chaos; two separate dances occurring, without synchrony.

Several aspects of Len's case highlight it as being slightly atypical. Some of these aspects have been identified in the preceding findings chapters. The surgeon's attitudes to the utility of lung cancer outcome data and his approach to providing and educating patients with scientific information about their condition were the most positive amongst the professional participants. He explicitly prioritised giving scientific information above that of supporting hope. It was therefore unsurprising that Len's surgical consultation stood out as the only one where a patient was given an estimation of recurrence risk probability without the patient first asking for this information.

An extract from Len's surgical consultation, where results and their implications were discussed, is displayed in Box 8.10. The consultation was short, but upbeat and positive from the beginning. Frequent verbal interruptions and cross talking between the participants were evident. Examples of Len's interruptions and subject non-sequiturs can be seen (lines 4, 8, 11, 26, and 31). Len's surgeon attempted to return the subject to surgical outcome and its implications each time. The result was frenetic, joyful, but chaotic, such that it appeared both were dancing their own dance, aware of each other, but not taking notice of all the individual steps.

1	Surg 8	You done very well. Because <u>you lost one third of the lung on that side where the</u>
2		<u>tumour was. But that is all out now. The rest of the lung, which is left in the chest</u>
3		<u>has expanded and filled that space. So, which means that you have</u>
4	Len	So everything is back to normal
5	Surg 8	Yes
6	Len	Wonderful
7	Surg 8	In fact better than normal because <u>you don't have the tumour anymore</u>
8	Len	That's right. I'm still not smoking. I haven't been smoking for ten eleven weeks
9	Surg 8	It is very good news indeed. Because that it is going to look after you, so you don't
10		have any more problems developing anymore than what
11	Len	I got a wonderful GP and a wonderful nurse look after me
12	Surg 8	Yep
13	Len	And I have had first class treatment all the way through
14	Surg 8	Thanks so [much for that [LAUGHS]
15	Len	[I cannot fault it
16	Surg 8	I'll take it as a compliment. But the important thing is that er <u>the tumour was early</u>
17	Len	Yeah
18	Surg 8	And <u>we have taken it all without any urm [tumour cells left in</u>
19	Len	[All go back to normal that sort of thing
20	Surg 8	<u>I have taken about six lymph glands</u>

21 **Len** Yes

22 **Surg 8** Which needed to come out with it. All of them are negative for cancer

23 **Len** Ahh [CLAPS AND RUBS HANDS]

24 **Surg 8** There were four. The tumour was er reliably early stage. Because we don't have

25 any proof at this stage that it has passed [anywhere else]

26 **Len** [It isn't like that at [hospital], I'll tell you, with this bladder business that's opposite

27 **Surg 8** Yes, but here from the lung point of view we have got it all out that we need to

28 have come out. And also that's the most appropriate treatment, or most affective

29 treatment you could have that is what you exactly had. And the import and [thing]

30 is to

31 **Len** [Well you are a credit to your um profession

32 **Surg 8** Well that's our job, that's our job and [we are here to offer that

33 **Len** [Well you're a credit to it, you really are

34 **Surg 8** Okay, no worries, but um, I have now discussed in our specialist meeting, as to if

35 there is any more treatment needed or not. They have confirmed that you do not

36 need any more treatment, but we still need to follow you up for the next fixed

37 length of time

38 **Len** I am at your disposal

39 **Surg 8** Yes, we will keep a close eye on things. Even though the tumour was early, we

40 removed it in time with all the lymph nodes being clear. The chances of it coming

41 back is very small. Given the early stage of tumour it is only about ten to fifteen

42 per cent if and when it does

43 **Len** So I have another twenty-five, thirty years yet

44 **Surg 8** So much more than that [LAUGHTER] But we will be following up to make sure

45 that the cancer does not come back. Because there is a ten to fifteen per cent

46 chance that it might come back even though the tumour is early

47 **Len** Yeah yeah

48 **Surg 8** That's why we we do the follow ups x-rays and scans and we'll see

49 **Len** Yeah yeah, I'm following you

50 **Surg 8** Yes, erm, if you do have any problems in er the future like coughing up blood, or

51 any unexplained cough, chest pain or unexplained weight loss, or anything that

52 bothers you. You need to report to us when you come to the clinic, or to the GP.

53 So there then we can actually examine you

Key: Details of surgical procedure Diagnosis and staging Further treatment and
Recurrence or survival Signs of recurrence surveillance

Box 8.10 Extract from Len's surgical consultation

Despite the surgeon's emphasis on a 'scientific' approach to the information that he gave to patients, as discussed in 'Painting an Information Picture' (chapter 7), the consultation was, nonetheless, highly optimistic in its tone. By line 39 the surgeon had reiterated the "*tumour was early*" for the third time. He then used this to segue into information about risk of recurrence. He used phrases such as, "*we removed it in time*" and the "*chances of it coming back is very small*", likely to engender an optimistic view of the future. He followed this with numerical estimates of probability for cancer recurrence (line 41 – 42), immediately

moderating this by saying, “*if and when it does*”. Len’s response to this in line 43 was in the form of a joke, but also may have signalled his lack of interest in engaging in the dance about recurrence statistics. In the remainder of the consultation, Len’s surgeon made numerous further optimistic references to the early stage of the cancer, his “*previous lung cancer*”, the low risk of recurrence and his “*excellent prognosis*”.

The optimistic tone was tempered by restating the risk statistics (lines 45 – 46) as well as by initiating discussion of the early warning signs of recurrence that Len should be aware of (lines 50 – 53). Despite this, Len was not able to recall the details of this information that he had been given when he was interviewed. Rather, Len suggested he would use “*common sense*” to know if there was a problem. Similarly, Len was unable to recall much of the other detail given in the surgical clinic when asked during his interviews. Len appeared happy to take away the gist of the consultation rather than retaining verbatim facts.

No, I can’t [recall the details]. But everything was as I expected it to be. It followed on from when I first met him, acted like there was no problems. Whatever was necessary to do he did [...] I wasn’t bothered about it. I had so much confidence in him. (Len 1st interview)

Ultimately, this suggested that it was the relationship and trust that Len had for his surgeon that was more important than the detail of the information that he was given. Regardless of the indication that Len might not be listening to all the details being given during the consultation, Len’s surgeon had continued to give the information he had planned to anyway. Despite this, during his subsequent interview Len’s surgeon did appear to acknowledge the limited nature of the information that Len actually required.

This gentleman was more than happy to hear that he had the well-intended operation and the well-intended outcome, so he stopped at that point. [...] But he is already happy because I had given the information that he wanted. He wanted to move on. (Surgeon 8: Len)

This subtheme particularly illustrated how, despite the intentions and the information disclosed by the professional participant, the way in which patients may understand and interpret this could be very different. Len provided a clear example of someone who had a preference for gist level information, basing his evaluation of the outcome of his treatment

at least as much on the emotional relationship he had with his surgeon. Conversely, the desire of Len's surgeon to present 'scientific', objective information about Len's condition, appeared not to be matched by the optimistic way he discussed the outcomes during the consultation.

8.6 Chapter summary

The theme 'Hope Dances' has been used to illustrate how professional and patient participants interacted to influence the information about surgical outcome and potential for future cancer recurrence during a number of selected consultations. None of the observed consultations included professionals asking patients explicitly what level of information they required. Nevertheless, it was remarkable how well professionals often appeared to meet patient participants' information needs. One of the key drivers as to how information disclosure was determined appeared to be maintaining and supporting a suitable level of patient hope. There was some evidence that patients often retained and valued the gist of the consultations rather than the exact detail. The relationship and a sense of trust between patient and professional often appeared to be an important element in the way they interpreted their situation.

By focusing on the metaphor of a dance the inevitable power imbalance between professionals and patients was highlighted using the subtheme 'Lead and Follow'. Patients and family members were able to try and influence the type and nature of the information they were given, as identified in the subtheme 'Back Leading'. The subtheme 'An Ensemble Piece' described how multiple participants, professional, patient and family members might interact to influence the information disclosed, with this effect felt even across clinical encounters. The final subtheme, 'Dancing to Different Tunes' explored an unusual consultation where the patient and professional participants appeared to have different communication aims, but carried on regardless, ultimately still providing a positive message to the patient.

9 Discussion

9.1 Introduction

In this chapter I will begin by briefly revisiting the research aims and objectives and then summarise the main findings from the preceding chapters. The study findings will be explored in relation to the current literature. Key contributions to knowledge from the study will be identified. I will then explore the practice implications of these findings and identify need for further research. The chapter will conclude with a review of the chief strengths and limitations of the study and some brief personal reflections on undertaking this project.

9.2 Research aims and objectives revisited

Study aim

The overall aim of this multiple case study was to gain an in-depth understanding of the communication of recurrence risk following potentially curative lung cancer surgery, from the perspective of both patients and professionals involved.

Objectives

1. To explore, using case study methodology, how a range of patients who have completed surgical treatment for lung cancer conceptualise their long-term risk of cancer recurrence, and how these change over time.
2. To understand how these patients perceive their communication needs about risk of cancer recurrence following surgery.
3. To explore how a range of health professionals caring for these patients conceptualise these individuals' long-term outcomes and identify the knowledge they draw on to form these opinions.
4. To investigate the attitudes and beliefs held by these professionals about priorities and principles of communication with patients after lung cancer surgery in general, and about long-term outcomes specifically.
5. To identify the nature and delivery of communication about risk of recurrence between this group of patients and their associated professionals during post-operative surgical, oncology and follow-up consultations.

6. To gain theoretical insight into the interpersonal processes occurring during these consultations that may regulate and tailor the information that is communicated.

9.3 An overview of key findings

In the course of the last four chapters I have used the twelve study cases to provide a rich picture of how information was managed regarding possible future cancer recurrence. Each case centred on a patient who had recently completed surgery for lung cancer and included associated health professionals involved in the observed consultations. An overview of the study themes and subthemes are illustrated in figure 9.1.

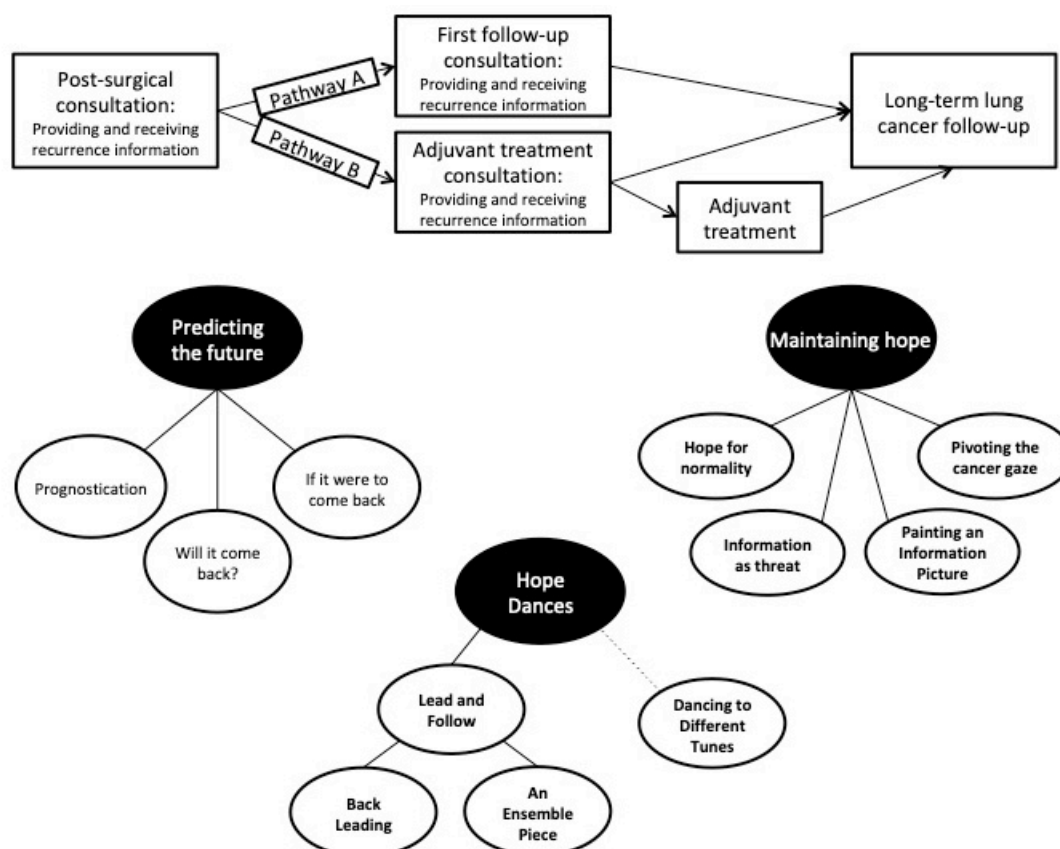


Figure 9.1: Overview of study pathways, themes and subthemes.

Cases provided a diverse range of both patient and professional perspectives. Cases followed two distinct pathways. Patients who followed Pathway A were referred from their post-surgical consultation straight into long-term follow-up. Pathway B patients were referred to see an oncologist to discuss possible adjuvant treatment after their surgical

consultation. Initial 'within-case' analysis allowed me to maintain the integrity of each case. Subsequent cross-case analysis facilitated the development of broad themes. The key findings are summarised below.

Providing and receiving recurrence risk information

- Patients were given limited explicit information regarding cancer stage, recurrence risk, or early signs or symptoms of recurrence.
- Pathway A patients asked questions about recurrence risk once told they did not need adjuvant therapy.
- Pathway B patients generally did not ask questions about recurrence or survival.
- Oncologists avoided discussing patients' underlying recurrence or survival rates, but limited discussion to the incremental benefits associated with adjuvant treatment.

Predicting the future

Prognostication - professionals predicting the future

- Professionals used verbal and numerical estimations of chance of survival or risk of recurrence when asked in interviews.
- Professionals drew on available population survival statistics, medical knowledge and clinical reasoning to form their predictions.
- Population data were viewed as having limited relevance to individual patient cases, due to the binary nature of patient outcomes, clinical complexities, and unusual cases.
- Survival statistics and recurrence risk were often used interchangeably when discussing long-term outcome.

Will it come back? - Patients predicting the future

- Patients' focus for long-term outcome was whether their cancer might recur after surgery.
- Patients used a wide range of information within and beyond the clinical environment, much of it heuristic in nature, to form their understanding of their long-term outlook.
- Patients used multiple narratives to talk about their illness and the future: sometimes these were internally inconsistent and ambivalent in nature.
- Narratives changed over time and adapted to interpret evolving clinical and life events.

- Some patients experienced significant worry or distress about possible cancer recurrence.

If it were to come back

- Patients who talked about how potential cancer recurrence would be managed largely did so in positive and hopeful terms as a way of minimising the impact of possible recurrence.
- Most professionals viewed treatment following lung cancer recurrence as unlikely to be curative and mainly given to achieve symptomatic benefit.
- Most professionals viewed lung cancer follow-up primarily as a supportive process, rather than as part of active management that could affect outcome.

Maintaining hope

Hope for normality

- Patient and professional participants wanted to support patient hope and viewed it as a central coping mechanism.
- Hope was largely directed towards achieving a sense of normality in life.
- Participants appeared to share a tacit goal of treatment being curative, but explicit discussion of 'cure' was rare during consultations and the term used with great caution.

Information as threat

- Patients and professionals both viewed recurrence risk or survival information as potentially damaging to patients' hope, particularly when given in numerical form.
- Damage to hope was seen as emotionally harmful to patients. Some saw it as having the potential to adversely affect cancer outcome.

Painting an information picture

- Professionals chose what information to disclose in order to meet patients' perceived information needs.
- Professionals' communication ethos was fundamental to the information they chose to disclose to patients – a range of views were identified.

- Patients were ambiguous about the information they wanted – honesty and straightforward communication were valued, but they also wanted a hopeful picture of their condition.
- Patients were cautious about the information they might be given by professionals and in seeking other information about cancer recurrence.

Pivoting the cancer gaze

- Professionals spoke about pivoting patients' attention away from cancer at the end of their treatment, with the aim of supporting hope for the future.
- Professionals specifically wanted to avoid talk about possible recurrence in order to prevent patients focusing on their cancer too much.
- Patients also wanted to avoid focusing on their cancer and engaged in distraction and positive self-talk when they experienced negative thoughts.

Hope dances

- 'Lead and Follow' described the inherent asymmetry between professionals and patients during consultations whereby the professionals lead the consultations and controlled the information flow.
- Patients and professionals were seen to use a range of techniques to manage the nature and extent of cancer information disclosure in the observed consultations.
- Patients appeared to retain and value the gist and emotional messages of consultations rather than the exact detail.

9.4 Discussion points arising from the findings

In this next section I will explore some of the key issues that have arisen within the findings. I will start by exploring the fundamentally different perspectives held by professionals and patients around long-term outlook following lung cancer surgery. How communication about recurrence risk is influenced by these different worldviews and the imperative to maintain patient hope regarding the future will then be examined. This will then be followed by looking at the processes by which professionals and patients attempted to control the flow of information during the observed consultations, aimed at managing patient hope. I will conclude this section by examining the implications of the study in

relation to the Living With and Beyond Cancer agenda and the particular issue of fear of cancer recurrence.

9.4.1 Recurrence risk communication across divergent worldviews

Findings presented using the theme 'Predicting the Future' indicated that there were significant differences in the way professionals and patients thought about the long-term outlook following lung cancer surgery that reflected their broadly medical and lay perspectives. These different views have implications for how risk of cancer recurrence is discussed at the end of initial lung cancer treatment.

Professionals' conception of prognosis

Imprecision and uncertainty are at the heart of prognostication (Smith, White, & Arnold, 2013). Mackillop (2006) described making a prognosis as being multifactorial and a much more subjective process than making a diagnosis. Most published studies on accuracy of prognostic estimates have been done with patients with advanced disease. There is evidence that doctors are optimistically biased in their estimates for patients with terminal cancer (Glare et al., 2003; Stone & Lund, 2007). Nevertheless, oncologists' five-year survival estimates for patients with treatable cancers against the actual outcome appear to be more accurate (Mackillop & Quirt, 1997). However, in the context of curative treatment, there appears to be relatively little published regarding professionals' attitudes to making prognoses and the utility of population data in relation to individual patients. Findings from the current study provide an insight into the attitudes to prognostication of professionals working with patients with lung cancer undergoing curative treatment. Professional views around long-term outcomes for study patients were unsurprisingly characterised by detailed medical knowledge, access to published data and insight gained from clinical experience. Such perspectives can be seen to conform to the medical perspective (Helman, 2007).

The current study did not set out to assess the accuracy of the professionals' evaluations of prognosis against population data. Where numerical estimates for outcomes were given, I took these at face value and assumed they were made in the light of the full clinical information available to the professional participants. Many of the professionals discussed their reasons for the variation between their prognostic estimates and the corresponding published population survival data. From this I was able to gain unique insights into

professionals' attitudes towards prognostic information for patients with early stage lung cancer. As identified in the subtheme 'A Limited Evidence Base', Professional participants varied in how important population statistics were to them when considering an individual's prognosis. The inherent uncertain nature of making a prognosis and the complexities of individual cases were the key factors in prognostic estimates that professionals made. The multidimensional nature of uncertainty as described by Han et al. (2011) was evident in the professionals' responses. Professional participants cited clinical situations where there was a lack of relevant data on which to form a prognostic estimate (epistemic uncertainty). Differences between average characteristics of the population sample and those of the specific individual patient (stochastic uncertainty) also limited professionals' willingness to make a numerical estimate of prognosis. Professional participants also spoke about the fundamental randomness of individual events (aleatory uncertainty) that meant population data were not useful in predicting which patients might experience a cancer recurrence. Similarly, a percentage risk estimate was perceived as unhelpful when talking about a binary outcome for an individual patient, who was "*either going to live or die*".

Professional participants demonstrated a range of beliefs about making a prognostic forecast for an individual patient and their willingness to discuss it, both in the context of a research interview, as well as with the patient. Some professional participants were comfortable drawing directly on available population data, such as the recent IASLC survival statistics (Goldstraw et al., 2016). Professionals appeared more willing to offer a definitive prognostic estimate for patients where outcomes were likely to be more favourable, such as those with early stage cancer following Pathway A. However, the complexities of individual real-life clinical situations made prognostication more challenging. Clinical complexity was often associated with patients with more advanced cancer, such as those on Pathway B. Other sources of medical complexity included patients with significant co-morbid conditions, those whose cancer had pathological features that set them aside from the norm, and where the surgical resection was incomplete. Some professionals nevertheless tried to make adjustments to published data to account for some of these factors. The resulting estimates often became unspecific and ambiguous, often encompassing a wide range, such as a five-year survival of 40 to 60 per cent. In the case of some patients,

complexity meant that there was simply no available data that related to their situation, as was seen in Fiona's case.

Patients' conceptions of the future course of their illness

Much previous research into patients' prognostic awareness has attempted to assess knowledge by asking patients to provide an estimate of prognosis in terms of chance of cure, or survival (Kelly et al., 2013; Liu et al., 2014; Robinson et al., 2008). However, others argue that asking patients to recall numerical prognostic estimates is more a test of memory and may miss patients' true understanding of their situation (Salander, Bergknut, & Henriksson, 2014). Patient narratives are recognised as a way that individuals interpret and make sense of health events and their consequences. By telling and re-telling stories about illness patients are able to construct meaning regarding their situation (Frank, 2013; Kleinman, 1988). A particular strength of case study research is the emphasis on maintaining the context of the participants' experiences. In this way, the current study has underlined the way in which patients built up their understanding of their diagnosis and risk of recurrence, described in the subtheme 'Multiple and Changing Narratives'.

Patients are known to have variable, but generally limited, understanding of cancer and wider medical matters (Fallowfield & Jenkins, 1999). In order to make sense of their health situation and its implications patients draw on a wide range of information, much of it from beyond the immediate health environment. Such wide-ranging factors are a normal part of lay understanding of illness, as described by Helman (2007). Patient narratives discussed in the findings of the current study indicated that participants formed their understanding of lung cancer and its personal impact as a process that evolved over time. Individual conceptions were formed from the experiences and information gained since diagnosis. But patients also drew on pre-existing personal and vicarious knowledge and experience of cancer, along with wider cultural beliefs. Explicit prognostic information given by clinicians during the observed consultations contributed to only one aspect of patient participants' understanding. In this way, patients' conception of their long-term outlook was not simply the product of the communication experienced in the post-surgical consultation.

Current findings indicated that patients primarily appeared to think about their prognosis in terms of whether the cancer would recur in the future, as presented in the subtheme ‘Will It Come Back?’ To sum up patient participants’ views, it would be to say, “how does this cancer affect me, my family and my plans for the future?” Despite the ostensibly positive connotation of the term survival, for some patient participants the term implicitly evoked the opposite outcome, namely death. Most participants appeared not to think about long-term outcome from surgery in relation to survival. The abstract nature of the concept, coupled with the threatening nature of the end point may be reasons for this, although the study provided limited direct evidence. Recurrence appeared to be a less threatening, more concrete and immediate concept than survival, implying the resumption of illness and all that goes with it, but not death.

The archetypal illness narrative is the restitution narrative; the plot defined as “*Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again*” (Frank, 2013, p77). To some extent, such stories can be seen as part of the socially expected discourse on recovery and a function of the way that people want to present themselves to others (Goffman, 1959). However, findings from patient interviews in the current study showed how patients formed multiple narratives about their future, not all of which conformed to the restitution model. Some narratives told of futures where patients did not see themselves as healthy again and explored what would happen if the cancer returned. In this way, patients’ narratives were often self-contradictory and ambivalent in nature.

The study by Furber et al. (2015), reviewed earlier in chapter 3, also identified these inconsistent and apparently contradictory accounts of prognosis given by patients. The team conceived patients as “*knowing and not knowing*” (p265) about their illness and its implications and used Awareness Contexts theory to explain these findings (Glaser & Strauss, 1965; Timmermans, 1994). Furber and colleagues suggested that patients knew what they had been told about their prognosis, but moved between states where they were fully aware of this information and mentally suspended awareness and temporarily ignored, or disregarded it. Awareness Contexts theory suggests that active open awareness is emotionally difficult to maintain and patients suspend this awareness as a self-protective move. Furber and colleagues treated patients’ awareness of diagnosis and prognosis as a

fixed entity, which had an objective truth. The argument around Awareness Contexts, however, does not hold up well in the situation of patients undergoing potentially curative surgery. For patients in this current study the multiple narratives they used to discuss the future did reflect the reality of multiple possible eventual outcomes; for them cancer might not return, but on the other hand it could. These multiple narratives can be conceived as a form of probabilistic thinking, where it is possible to hold on to a number of different conceptions of the future simultaneously (Babrow, 2001; Mishel, 1990).

Communicating across two separate worldviews

Bensing (2000) highlighted the potential incompatibility of the paradigms of evidence-based care and patient-centred care, with the focus of the latter on individual patient choice and the need to consider the emotional dimension of healthcare. He described the two paradigms as “*separate worlds*” (p19); with evidence-based care seen to be disease and doctor orientated, but patient-centred care necessarily illness and patient focused. The findings presented in this thesis provide further evidence that illustrates the fundamental difference between professional and patient perspectives and thinking about long-term outcomes in relation to a common cancer, such as lung cancer. Professionals discussed prognosis based on available biomedical knowledge, and often used population data. Nevertheless, most professionals also remained cautious about the applicability of population-based data at the individual level. Patient participants, on the other hand, seemed to think about their future after their lung cancer surgery as it would impact on them as an individual. They understood their situation using multiple evidence sources, of which medical information from their clinicians might only form a small aspect. Findings have demonstrated numerous ways in which patient and professional participants attempted to bridge the gap between these two worlds. One aspect was in relation to communication that aimed to support patient hope for the future.

9.4.2 Recurrence risk communication and the hope imperative

Previous studies have indicated that professionals and patients see prognostic information as something that is damaging to patient hope (Christakis & Iwashyna, 1998; Del Vecchio Good et al., 1990; Gordon & Daugherty, 2003; Thorne et al., 2006; Thorne et al., 2007). Findings from the current study coincided with earlier studies and also highlighted participants’ view that damaging patient hope could slow or threaten recovery, or even

reduce the chance of survival. Such findings are described elsewhere, but there is little hard evidence to support the idea of patients' emotions directly influencing oncological outcome (Coyne & Tennen, 2010).

Professionals' attitudes to prognostic information giving

Previous research has indicated that doctors find giving patients prognostic information stressful and difficult and they feel ill prepared for this role (Christakis & Iwashyna, 1998; Rogg, Loge, Aasland, & Graugaard, 2009). Most of this has been in the context of advanced cancer or end of life care. Research exploring attitudes to prognostic discussion with patients being treated with curative intent is more limited. Nevertheless, the importance of professionals providing a hopeful message for patients has been recognised by multiple other studies (Blakely et al., 2017; Gough et al., 2015; Mendick et al., 2011; Rogg et al., 2010). Although now thirty years old, Del Vecchio Good et al. (1990) characterised medical oncologists' views on providing hope to patients as a "*clinical imperative*" (p72). Oncologists preferentially discuss treatment and minimise prognostic discussion in order to support the hopeful message. Findings such as these have been seen more recently amongst professionals from various disciplines (Blakely et al., 2017; Gordon & Daugherty, 2003; Henselmans et al., 2017; Singh et al., 2017). A recent review of nursing attitudes to prognostic discussions has indicated that while nurses do frequently take part, it is often in a supportive capacity, with doctors leading the conversation (Newman, 2016). Common concerns expressed by nurses also include damaging patient hope through prognostic discussions, as well as concerns about going beyond the nursing remit. However, specialist oncology nurses appear to be more comfortable with initiating prognostic discussions (Helft, Chamness, Terry, & Uhrich, 2011; McLennon, Uhrich, Lasiter, Chamness, & Helft, 2013; Reinke, Shannon, Engelberg, Young, & Curtis, 2010).

Other influential studies have suggested that doctors are often uncomfortable discussing what they perceive as bad news more generally and often try to minimise or avoid explicit discussion (Fallowfield & Jenkins, 2004; Maguire, Faulkner, Booth, Elliott, & Hillier, 1996). Various training programmes to improve cancer professionals' communication skills have been developed in an effort to enhance confidence and ability to hold such difficult discussions (Fallowfield et al., 2002; Wilkinson, Perry, Blanchard, & Linsell, 2008). Some

professional participants in the current study had undergone training such as this, but most, especially surgical registrars, felt they lacked explicit training around prognostic discussions with patients treated for lung cancer. Nevertheless, it was evident that reticence to discuss recurrence issues fundamentally sat with beliefs about potential damage to hope and patient coping, rather than a lack of communication skills *per se*.

Much literature around discussion of prognosis in early stage cancer has been dominated by efforts to facilitate patient-centred treatment decision-making, often involving online cancer prognosis calculators and decision aids (Kelly et al., 2013; Rabin et al., 2013; Solowski, Okuyemi, Kallogjeri, Nicklaus, & Piccirillo, 2014). However, there has been a general reluctance amongst oncologists to adopt these into widespread clinical practice (Herrmann, Mansfield, Hall, Sanson-Fisher, & Zdenkowski, 2016). While reasons for not adopting decision aids were complex and wide ranging, reluctance to engage in detailed prognostic discussions may be one element. Evidence from the studies by Mendick et al. (2011; 2013) indicated that breast cancer surgeons limited or avoided prognostic discussion in post-surgical consultations, whilst also wanting to promote and support a sense of hope for the future in their patients.

Findings from the current study with early stage lung cancer patients broadly supports these previous findings, but significantly extends and deepens the knowledge due to the inclusion of multidisciplinary perspectives. The imperative to provide a hopeful message was seen across all the disciplines in the study and was a particular factor in the decision to limit prognostic discussion with patients. Nevertheless, despite this imperative to provide a hopeful message, professional participants expressed a range of differing attitudes to communicating prognostic information, as presented in the subtheme 'Painting an Information Picture'. Some participants did place a high value on providing prognostic data, principally in relation to helping patients with treatment decisions and making sense of their situation. However, many other professional participants remained highly reluctant to discuss prognosis with patients in this setting. While professionals discussed the limitations of the available population data in forming an individualised prognosis, most saw the information as being either irrelevant to patients' needs, or risked emotionally damaging them. In this sense, professional participants can be seen to be protecting patients from the

medical worldview of their condition, fearing that patients might not be capable or emotionally strong enough to deal with this information.

The design of the study allowed an in-depth exploration of individual values and beliefs that formed professional participants' communication ethos. Current findings indicated professionals possessed a range of nuanced attitudes and beliefs about communicating with patients about prognostic issues. These often appeared to be deeply held convictions. While these seemed to be influenced by discipline, experience and training, fundamentally it appeared that they reflected the personalities of individual professionals. It was this personal communication ethos that had the greatest influence on the information patients were provided with during their consultations.

What information about prognosis do patients want?

Previous research findings have been ambiguous about cancer patients' desire for prognostic information, beyond the idea that it is individual and varied. Large-scale questionnaire studies have tended to suggest that the majority of patients want to be given detailed information about their prognosis (Cox, A. et al., 2006; Hagerty et al., 2004; Jenkins et al., 2001; Lagarde et al., 2008). While on the other hand, most qualitative studies indicate that patients can struggle to deal with the significance of prognostic information and often do not want this level of detail (Butow et al., 2002; Friis et al., 2003; Leydon et al., 2000, Mendick et al., 2011). The current study adds to the body of evidence that casts doubt on the straightforward reading of the findings from questionnaire studies that indicate patients want 'all available' information. Patient participants wanted professionals to be honest with them and avoid lying, but they still needed to be given information that was positive and which reflected an optimistic view of their illness. In some circumstances these conflicting requirements could create a sense of dissonance in patients, such as Fiona's quest to be told she was "cancer free".

Multiple previous studies have indicated patients need to be given both honest and hopeful information about cancer, although how to resolve this tension is frequently overlooked (Blakely et al., 2017; Goldman et al., 2009; Hagerty et al., 2005; Lobb et al., 2011; Thorne et al., 2007). Other studies, such as Furber et al. (2015), described patients as simultaneously

switching between wanting to know details about their prognosis and not wanting to know. Innes and Payne (2009) characterised the ambiguity in the information patients with advanced disease wanted as a paradox that lies at the heart of communicating about prognosis. The current study suggests that this paradox is just as present in patients being treated curatively. Patients needed to feel informed, but they had a simultaneous expectation that professionals would provide information that would sustain hope. There was an expectation that professionals would process information for patients so that it was truthful and relevant, but also given in a form that was comprehensible, not overwhelming and presented in a positive light. Similar needs for information to be 'managed' by professionals have been described in haemato-oncology patients (Atherton, Young, Kalakonda, & Salmon, 2018).

Fuzzy Trace theory indicates that patients have a preference for information at the gist level, unless they have a specific need for more detail (Reyna, 2012). Studies looking at information preferences for treatment decision-making with patients with prostate cancer and older women with breast cancer indicated an inclination towards gist level and heuristic information rather than detailed, numerical risk information (Burton et al., 2015; Han et al., 2013). Treatment decision-making often appears to be made on an emotional level and many patients prefer to be guided by their medical team. Similar findings were seen amongst lung cancer patients making decisions about undergoing surgery (Powell et al., 2015). The current study involved comparatively little explicit treatment decision-making, but participants appeared happy to defer to medical recommendations. Patients largely appeared to use information to make sense of their situation and to form a broad conception of their risk of cancer recurrence. As suggested by Zikmund-Fisher (2013), current study findings indicated that information stating that recurrence was a possibility, but avoided quantifying the risk, often appeared to be sufficient for patient participants.

While most of the patient participants appeared to have little requirement for detailed information about their individual risk of cancer recurrence, there was one case who was an outlier. Glennis's on going requirement for information about risk of recurrence and apparent need for numerical data was unique amongst this group. However, the information did not give the reassurance she sought and appeared to drive further searches

in an effort to find a more reassuring view of the future, described by Step and Ray (2011) as an “information seeking paradox”. Disclosure of prognosis, even if it might be considered objectively favourable, could not help to resolve the complex and multifaceted emotional challenges of an uncertain future. There is evidence from other studies that indicates being given prognostic information does not necessarily relieve feelings of uncertainty about recurrence. Findings from another study by Hope-Stone, Brown, Heimann, Damato, and Salmon (2015) with patients with uveal melanoma suggested that even patients with good prognoses might never be able to fully accept this information, while others struggle to understand the information fully. However, there are no similar studies regarding how patients with early stage lung cancer process and understand prognostic information. The current study indicated that desire for information by patient participants was complex and fluid, but was generally about understanding the gist of the medical detail and being given a positive view of the future. These requirements appeared to be largely about supporting a hopeful view of their situation. This raises further questions about how patients with lung cancer process and use prognostic detail over the long-term in situations where they are given this information.

9.4.3 Recurrence risk communication and the co-construction of hope

The findings discussed so far have highlighted patients’ understanding about long-term outcome following their surgery that was largely about possible alternative outcomes, rather than thinking in terms of risk. Professionals on the other hand had access to the full range of biomedical understanding, but appeared to want to protect patients from accessing the medical perspective, which they felt could overwhelm patients and jeopardise hope for the future. I will now turn to explore how the multidimensional nature of the dataset in this study has given insight into how both professional and patient participants individually and jointly worked to construct hope out of the situation following the end of surgery.

Professional and patient Hope Work

The idea of Hope Work, described by Perakyla (1991), is the process of controlling and shaping discussions between patients and professionals with the principal aim of supporting hope about the future. Some researchers have argued that the reason professionals try to maintain patient hope is principally about fostering a good relationship between

professional and patient (Del Vecchio Good et al., 1990; Gordon & Daugherty, 2003). The importance of key trusting clinical relationships has been widely recognised in other studies (Burkitt Wright, Holcombe, & Salmon, 2004; Leydon et al., 2000; Salmon et al., 2012). Salmon and Young (2017) have argued, provision of hope is at the core of all healthcare provision and is fundamental to its endeavour. However, there is a note of caution sounded in some situations regarding the potentially coercive influence that professionals' use of hope can play in decision-making, particularly in treatments with marginal benefits (Gordon & Daugherty, 2003; The et al., 2000).

The current study provided examples of several patients who invested particular trust and faith in key professionals. These relationships were often central to the way in which patient participants maintained hope for the future, as described in chapter 5. There were examples in the current case study of situations where the use of hope might be interpreted as being coercive, such as Maggie's consultation with her oncologist (Hope Dances). Nevertheless, while it was clear that Hope Work was important in influencing patients to accept a particular management plan and to feel positive about previous treatment choices, its use was much more about the essential therapeutic relationship between clinician and patient. Supporting hope principally appeared directed towards helping patients 'feel better' about their situation, and at supporting patients' perceived coping mechanisms. Findings from this study indicated that professionals principally controlled information disclosure about recurrence and long-term outcome in order to ensure patients received a hopeful picture of their future in a way that could be seen as Hope Work. Patients also appeared to take an active role in the process of constructing and maintaining their hope and this too could be conceived of as Hope Work.

Previous research has identified the active mental manoeuvres patients with malignant brain tumours (Salander, Bergenheim, & Henriksson, 1996) and lung cancer (Salander, et al., 2014) use to construct hope. Authors suggest that patients do not simply passively respond to a stressful situation, but engage in Hope Work and actively create hope in response to this stress. They highlight the essential role illusion can have in creating a safe place in which to construct hope for the future. Findings from the current study suggested that patients were using multiple narratives as a way of exploring possible futures and using positive and

negative scenarios to mentally explore and try out ways of approaching difficult situations. This process was described as 'trying on for size' in the subtheme 'Ambivalent Narratives'. Patients' narratives appeared to form a contingency that had the effect of reducing the potential impact of recurrence and distancing it from thoughts of death. Lazarus and Folkman (1984) describe contingency coping as a way of planning for the future and providing individuals with a mental escape route and a source of hope. Mishel (1990) argues in her Uncertainty in Illness Theory (UIT) that coping with long-term health conditions requires acceptance of uncertainty being part of normal life and of a future with multiple possibilities. Folkman (2010) argues that this acceptance is central to the process of developing and sustaining hope for the future. Salander (2012) proposes that patients can mentally 'play' with these alternative, ambivalent stories, similarly to the way children use play to process events and make sense of their environment. Like this, patients can foster hope, without losing an appreciation of the external reality. A process of active hope is seen as an important resource closely aligned to coping strategies (Folkman, 2010; Lazarus, 1999). Hope allows the negative outcomes to be explored and acknowledged, whilst simultaneously supporting a belief in the positive outcome (Folkman, 2010).

Although patient participants did not explicitly frame hope in terms of managing uncertainty, UIT is helpful to understand the strategies used by patient participants (Mishel, 1988; Mishel, 1990). Participants appeared to appraise the uncertainty around lung cancer recurrence in various ways, as was evident in the narratives they told about their illness. According to UIT, uncertainty surrounding a situation is appraised as either an opportunity or as a threat and is interpreted through the prism of patients' inferences and illusions. Some patients, such as Glennis, Fiona and Maggie, appeared to appraise uncertainty about recurrence as a danger. Some adopted mobilising strategies, such as hyper vigilance, information seeking and attempting to access medical care. Others tried to reduce uncertainty by adopting very different coping strategies, like affect control and re-framing of information. Other participants appeared to see the uncertainty around future recurrence as more of an opportunity. UIT suggests that the predominant coping strategy in this situation is one of buffering, such as mental distancing, avoiding dwelling on things, or adopting a positive mental attitude. For these participants who saw uncertainty as an opportunity there was a greater acceptance of uncertainty as a normal part of life, such as

Denise's description of seeing how "*the dices roll for me*". UIT proposes that accepting multiple future possibilities and developing probabilistic thinking is central to adapting to uncertainty in long-term conditions, such as living after a diagnosis of cancer (Mishel, 1990). In these situations appraisal of uncertainty becomes more fluid and complex.

Findings presented in this thesis appear to support Mishel's UIT. The findings provide new insights into the processes by which both patients and professionals actively work to try and build a sense of hope, not only in situations where the prognosis is very poor, but also for patients undergoing curative treatment, such as the current participants following curative surgery for lung cancer. Professionals actively wanted to present a hopeful message to patients. At the same time patients appeared to actively create hope within the information they received. Part of this Hope Work involved apparently contradictory, overly pessimistic or optimistic narratives. However, the multidimensional data involved in this case study has also provided further understanding around the way in which professionals and patients were able to work together to co-construct a message that would support the patient's sense of hope.

Process of co-construction of hope

There is an inherent power imbalance between patients and professionals, which lies at the heart of medical interactions. This asymmetry persists despite many strategic initiatives promoting patient centred care aimed at addressing this perceived problem (Pilnick & Dingwall, 2011). However, Salmon and Young (2017) argue that the dependence and vulnerability in the clinical relationship needs to be acknowledged, and patients cannot be viewed simply as consumers of healthcare. Previous research has identified the formal structure of clinical consultations as a key factor in constraining and controlling information exchange between professionals and patients. While both parties shape the agenda to some extent, it is professionals who effectively control the process of information giving (Singh et al., 2017). Consultations rarely contain meta-communication where professionals set out an agenda and enquire into patients' information needs (Rogg et al., 2010). Professionals often justify this by suggesting their clinical experience means that they already understand what patients want to hear. Studies with both early and advanced stage cancer patients indicate that where prognostic discussions do take place, it is often in response to patients' direct

questions (Chou et al., 2017; Gough et al., 2015; Henselmans et al., 2017; Step & Ray, 2011). Findings from the study by Mendick et al. (2013), looking at interactions with breast cancer patients following surgery, indicated surgeons give prognostic information asymmetrically. Patients with more favourable prognoses were more likely to be given an indication of prognosis, whereas patients whose prognoses were poorer were given more details of surgical findings and treatment options. The range of prognostic information and the multiplicity of ways it is communicated, including the emotional and interpersonal content, has been widely recognised by other researchers (Alexander et al., 2012; Chou et al., 2017; Mendick et al., 2013; Thorne et al., 2007; Thorne & Stajduhar, 2012).

The findings presented in this thesis broadly coincide with these studies, but also provide new insight into some of the processes that occur, particularly in relation to patients undergoing curative treatment. Findings clearly illustrated how the power imbalance was present during consultations, reflected in the dance metaphor 'Lead and Follow'. Professionals led by shaping the consultations, being in possession of the required information, and principally determining the patients' onward management plans. As presented in Chapter 5, explicit information about recurrence risk and prognosis formed only a very small element of the observed consultations. Recurrence risk was conveyed to patients in a variety of explicit and non-explicit ways and these findings have been explored in more depth elsewhere (Johnson, M., Tod, Brummell, & Collins, 2018). Professionals tended to present prognostic and staging information in the least explicit manner possible; discussion about risk of recurrence was even more limited. Where information about recurrence was discussed directly, professionals largely only did so in response to specific questions from patients. Most felt that this was not information that patients usually wanted and they expected patients to ask if they needed to discuss recurrence risk. However, there was also evidence to suggest that some tried to actively shut down attempts by patients to open the topic, in order to support patient hope, as explored in the subtheme 'Pivoting the Cancer Gaze'.

A feature of this case study design was the two distinct treatment pathways. Findings indicated a distinct difference in the explicit recurrence risk information given to the two groups of patients. Those on Pathway A were given more specific information about

recurrence risks than those on Pathway B. If information was aimed at helping patients with treatment decision-making, this might seem a counterintuitive finding. But there was little evidence to suggest that professionals wanted to give, or patients wanted to use, detailed recurrence risk information in order to make choices about adjuvant treatment. While some broad, gist level information about recurrence might be part of decision-making, more explicit recurrence risk information appeared to be used to support patient hope. Evidence in corroboration of this came from the way in which explicit recurrence risk information was given. It was the patients on Pathway A themselves who largely initiated the discussion of recurrence risk, but this only happened once patients had been given sufficient gist level indication that their outlook was apparently good. The study did not give any direct explanation for this difference between the two pathways, but Mishel's UIT does provide one possible rationale for this difference.

Once information regarding the results of the surgery was conveyed to patients, further long-term uncertainties might then surface, such as questions about risk of cancer recurrence. Patients could appraise this uncertainty as an opportunity or a danger. Patients on Pathway A gained a positive sense about their situation, which allowed them to appraise the uncertainty about recurrence as something that was safe to resolve. Patients could then ask explicit questions of healthcare professionals about recurrence risk, in the expectation of hearing information that might sustain further hope. Nevertheless, although patients on Pathway A did seek recurrence risk information, they did not appear to want unlimited detail. Findings illustrated ways in which professionals and patients worked together to determine the level of detail given. The process of 'Back Leading' provided an exemplar for these processes, as illustrated by Denise's case. Professionals provided minimal information about recurrence risks, but patients could influence prognostic disclosure by Back Leading the consultation and then carefully redirecting the interaction when they achieved the level of detail they wanted. In this way patients attempted to control and constrain the level of information to match their desired level of uncertainty. Some of the cases indicated that the primary driver of information disclosed was not always the patient, but might include family members. The complexity of these processes appeared to rise as the number of active participants in the consultations increased, as was described in 'An Ensemble Piece'.

In contrast to patients who went straight into long-term follow-up, those following Pathway B appeared not to want details about recurrence risks. In the context of Mishel's Uncertainty in Illness Theory (UIT), patients who were referred to see an oncologist to discuss adjuvant therapy might interpret uncertainty around recurrence as an opportunity. Finding out more explicit information about recurrence risks could be interpreted as being unlikely to help sustain hope for the future. The tension that particularly existed for professionals when seeing patients on Pathway B was evident, as presented in the subtheme 'A Realistic Picture'. Professionals wanted to promote a sense of hope around the outcome of surgery, while at the same time raising the issue of recurrence and the potential survival benefits from adjuvant therapy. Professional and patient participants both appeared to want to limit explicit prognostic discussion. Although the aim of adjuvant therapy is to improve chance of survival, discussion of recurrence remained largely equivocal and euphemistic. Oncologists explicitly wanted to preserve patients' sense of hope about the outcome of surgery and long-term outlook. They avoided discussing overall survival statistics, focusing dialogue on potential incremental benefit of treatment, as seen in Maggie's oncology consultation described in 'Lead and Follow'. Previous studies with patients undergoing non-curative chemotherapy have shown that oncologists limit discussion around prognosis during decision-making consultations (Audrey et al., 2008; The et al., 2000).

The importance of personal values, beliefs and approaches to communication and the multiple simultaneous messages influencing the final exchange of information was identified in the conceptual framework developed by Feldman-Stewart et al. (2005). The current study findings provide empirical evidence to illustrate these processes and how both professionals and patients influence recurrence risk communication leading to a complex and interactive process. The study underlined how information exchange is tacitly 'negotiated' during consultations. Findings suggested that many professional participants wanted to limit prognostic information, even when discussing treatment options. For many patients this appeared to match their needs. If patients wanted more information they were expected to initiate this discussion. Where professionals wanted to disclose more detailed information about recurrence risks, which did not match patients' information requirements, other processes seemed to come into play that allowed patients to control

the message they took away. The consultation pattern described in ‘Dancing to Different Tunes’ illustrated how a patient (Len) might avoid engaging in the details of the information disclosed by only taking the emotional content of the encounter where unrequested numerical risk information was given. Alternatively, other patients, like Maggie, may simply re-frame and manipulate numerical information so it might seem more hopeful than the original message was intended. Other authors have identified that providing numerical information to patients is no guarantee of their understanding, or willingness to accept this information (Han et al., 2013). The findings support the idea that the salience of information to the individual recipient’s circumstance is important in the recognition and retention of the information being provided (Johnson, J.D., 2003).

The study findings raise some significant questions about the process of informed consent and treatment decision-making. Information given about recurrence risk in relation to adjuvant treatment was limited and the study also provided clear evidence about how patients conceived, re-framed, and even ignored statistical information that they were given. It was also apparent from interviews that patients had little awareness regarding the overall long-term prognostic benefits of surgery, indicating that pre-operative discussion did not form a significant element of patients’ initial decision to undergoing surgery. However, the findings also suggest that merely providing risk information may play lip service to informed consent and increases the chance that patients misunderstand and misinterpret their situation. Herein lies a clinical challenge to ensure that information is tailored to meet patients’ communication and information needs and in a level of detail that is appropriate for the purpose intended, be it making sense of their situation, or treatment decision-making and informed consent. The tension between the professional’s beliefs about disclosing prognostic information, patients’ fluctuating need for information given at the right level, and both parties’ sense of the hope imperative appears to play out in these consultations. The findings suggest that professionals need to communicate in ways that can adapt to the different needs and changing priorities of patients, to facilitate open and honest discussions with patients. Identification and awareness of the tension that is inherent in this process may be particularly helpful in ensuring communication meets the needs of both parties. The challenge for professionals and educationalists is in developing

and maintaining communication strategies that are sufficiently self-aware and flexible to respond and meet the individual patient latent, as well as expressed, communication needs.

9.4.4 Recurrence risk communication and living beyond a diagnosis of lung cancer

Supporting patients in 'living with and beyond a diagnosis of cancer' has been identified as a strategic priority for cancer care and research in the UK (Independent Cancer Taskforce, 2015; NCRI, 2018). This agenda has a wide-ranging remit covering physical late effects of treatment as well as the emotional and social impacts of a cancer diagnosis. This aspect of care has previously not received much attention within lung cancer care, primarily as the vast majority of patients were not treated with the aim of cure. However, over the last decade there has been a significant increase in the numbers of patients having curative treatment due to a more proactive approach to surgery and efforts to promote early diagnosis. Numbers are set to increase further due to two policy drivers. National lung cancer guidelines now recommend that surgery, as part of multimodality treatment, be considered in a cohort of patients previously deemed not to be suitable for surgery (NICE, 2019). At the same time, rollout of the national lung cancer screening programme has begun, which aims to detect early stage cancers, reducing the number of patients presenting with inoperable disease (NHS England, 2019). Therefore, in the future there will be many more surgically treated patients, both with very early stage cancer, as well as those with more advanced disease. The problems addressed in this study around how best to support and talk with patients about the possibility of future lung cancer recurrence will become more significant. In this last section I will explore the findings of the current study in relation to supporting patients to cope with uncertainty around recurrence, identifying and helping those who experience significant fear of cancer recurrence and looking at the implications for follow-up and cancer surveillance.

Return to normality?

Doyle (2008) characterised life after a diagnosis of cancer as being changed forever, inextricably linked to uncertainty. Others have identified how patients can anticipate life returning to normal and a sense of relief after finishing treatment, which are simply not matched by the reality of their situation (Thorne & Stajduhar, 2012). Evidence from Head and Neck cancer patients suggests that a perceived sense of certainty at the end of treatment may be replaced by the reality of growing uncertainty over the longer term

(Taylor, A., Wells, Hubbard, & Worth, 2016). Some patients argue that professionals should not collude with them about life returning to 'normality' after treatment (Thorne & Stajduhar, 2012). At the end of treatment for a serious illness patients can be seen to transition from ill-person to cured-person. Such transitions are characterised as involving a 'liminal' period, a word derived from Latin, meaning the threshold between one space and another (Little, Jordens, Paul, Montgomery, & Philipson, 1998). Frank (2013) described people who have had serious illness as being unable to return to the society of the well, but are admitted to what he called the "Remission Society" (p8). Membership of the remission society allows access to the world of the well, but those privileges might be revoked at any time and without notice, reflecting the ever-present threat of recurrence. Members continually morph between sickness and wellness in response to symptoms, anxiety, or relapse. Uncertainty around the potential for recurrence is one of multiple concerns experienced by patients after the end of initial cancer treatment. Studies report that anxiety about possible recurrence of cancer is one of patients' principal concerns (Armes et al., 2009; Jefford et al., 2008; Stajduhar, Thorne, McGuinness, & Kim-Sing, 2010; Thorne et al., 2014). However, there appears to be a dearth of research evidence available about the experiences of surgical lung cancer patients in relation to how they cope with such feelings at the end of treatment.

The ambiguous and liminal character of the period following cancer surgery was evident in the current study, particularly noticeable in the longitudinal findings. For several participants there was a sense of ambiguity about their status following surgery. Some patient participants talked explicitly about being in a state of "*limbo*", or reported how life could not just simply return to normal after their surgery, as presented in the subtheme 'Hope for Normality'. The term 'cure' was problematic for all participants. Patients avoided the term, but rather focused on more concrete, short-term goals in order to gain a sense of normal life returning. Similarly, professionals largely avoided the term when talking directly with patients, although the message remained one of hope for cure. Such findings appear in line with a survey of attitudes amongst US cancer surgeons (Winner, Wilson, Yahanda, Gani, & Pawlik, 2016). The current study indicated a communication paradox around the aim of treatment whereby both patients and professionals avoided the term 'cure' despite it being

the ultimate shared goal. This paradox serves to underline the uncertain and ambiguous nature of the period following lung cancer surgery.

Recurrence surveillance after lung cancer surgery

There remains a lack of consensus on the optimal follow-up pathways for lung cancer patients, with arguments about both cost and clinical effectiveness (Colt et al., 2013; McMurry et al., 2018; Westeel et al., 2017). Lung cancer also lags behind other tumour types, such as breast and melanoma, in terms of specific genetic tests on resected tumour that might be able to distinguish patients at higher risk of recurrence (Buyse et al., 2006; Damato et al., 2007). Despite this, patients appear to gain reassurance and support from the process of follow-up, even beyond the anxiety associated with attendance (Sandeman & Wells, 2011). Other studies indicate patients want to be followed up intensively in secondary care (Cox, K. et al., 2006; Krishnasamy, Ugalde, Carey, Duffy, & Dryden, 2011; Moore et al., 2002).

The current study did not explore the attitudes of patients regarding acceptability of the follow-up process. However, it offers unique insight into the attitudes of professionals caring for lung cancer patients towards current follow-up strategies. Professional participants largely held nihilistic attitudes to lung cancer follow-up and surveillance. These appeared to stem from their feelings about treatment for recurrent lung cancer, as discussed in the subtheme 'Best Shot First Time'. For most professional participants in the current study detecting recurrence early appeared to be primarily about managing patients' and families' sense of being cared for, rather than aiming to impact patients' long-term outcome. Some did recognise newer treatment modalities, such as stereotactic radiotherapy and biological therapies, were beginning to open up more treatment options for patient who did relapse. However, it was apparent that for many participants these newer treatment options were slow to influence attitudes to follow-up care. While these sorts of opinions were not universal, as evidenced by the proactive and interventionist approach of Len's surgeon, findings of this study indicate that for at least some professionals follow-up is not really seen as a realistic intervention to improve survival. Until there is a more widespread consensus on the optimal follow-up pathway for post-surgical lung cancer patients it is likely that this situation will not change.

Professionals' attitudes to lung cancer follow-up are also likely to influence how they perceive patients' role in self-monitoring and responding to early signs and symptoms that might indicate a recurrence. Thorne and Stajduhar (2012) argue that patients with cancer inevitably need to engage with and play a role in monitoring for potential recurrence after the end of treatment. Engaging patients necessitates a sensitive and planned discussion about the potential for and symptoms of recurrence. They recognise the challenges all parties face in communicating about possible recurrence at the transition after treatment, but they argue, simply denying the issue could risk not addressing real concerns. Professional participants in this current study were largely reluctant to discuss potential signs of recurrence explicitly with patients, for several reasons. The damaging effects on hope of discussing recurrence issues, such as focusing patients' attention unhealthily on cancer, diluting the "*good news*" of the surgical outcome and giving patients mixed messages. Another big concern centred on the non-specific and vague nature of recurrence symptoms a patient could experience. Giving patients a comprehensive list of potential symptoms was viewed as impractical and would merely increase patient worry without any clinical benefit. These concerns led to further reluctance to discuss the issue with patients.

The findings indicated a clinical challenge in how best to address the topic of signs and symptoms of possible recurrence with patients. Some professional participants tried to talk to patients not in terms of specific symptoms, but rather in relation to the duration of symptoms that would indicate the need for further investigation. However, across the findings, where discussion took place about signs of recurrence, there was little evidence that patient participants could recall the information later. There was also evidence in the findings of patients having unanswered questions about possible future recurrence that were never asked or discussed, even amongst patients who generally tried to avoid information. Concerns included where cancer recurrence might manifest in the body and how they might recognise it. Some patient participants even felt professionals deliberately withheld this information from them. On the other hand, patients were often ambivalent about the answers they might receive and were generally not comfortable to raise these concerns with their cancer team. How best to address this issue with patients in a sensitive manner that does not risk damaging patient hope and in a way which patients are willing to

engage with remains an unanswered question. Findings indicate that this subject cannot be adequately tackled within the existing format of the twenty-minute medical consultation, with multiple other competing issues.

Previous studies have indicated that patients find nurse-led follow-up acceptable and can address a wider range of concerns than conventional follow-up (Cox, K. et al., 2006; Moore et al., 2002). It is likely therefore that the solution to facilitating a sensitive and effective discussion about potential recurrence with patients will lie within an intervention led by the patient's LCNS, due to the long-term continuity offered by this role, and the focus on non-medical aspects of care. Current work to implement routine assessment and care planning of holistic needs would be an ideal starting point. Examples of approaches might include techniques commonly used in difficult discussions with patients with more advanced disease such as "hope for the best, plan for the worst" (Back, Arnold, & Quill, 2003; Mori et al., 2019). This method allows hope to be reinforced, whilst simultaneously facilitating discussion of more sensitive matters that might make a difference to patients, such as understanding of the symptoms indicating early signs of recurrence, and who to contact. Further research is also needed to address the limitations and barriers that currently exist in discussing potential recurrence with patients and to identify the utility and acceptability of strategies to patients over the long-term.

Managing recurrence concerns

The longitudinal element of the current study has given insight into the shifting uncertainty about cancer recurrence that participants experienced over time following their surgery. The narratives patients gave about their condition indicated the potentially fragile nature of their perceptions of recovery, in a way that resembled the idea of a remission society. Several participants expressed significant concerns about cancer recurrence as a response to worrying symptoms, such as back pain or recurrent chest infections. Similarly, routine scans, particularly if an abnormality was detected, could disrupt patients' sense of recovery. Others appeared to experience periods of worry about cancer recurrence that were more general and perhaps insidious, such as a persistent sense of the inevitability of further cancer and fears about being "*cancer prone*".

Study findings described in the subtheme ‘Pivoting the Cancer Gaze’ indicated that both professional and patient participants principally attempted to manage the sense of uncertainty about recurrence by directing their attention to the normal aspects of life and endeavouring to avoid thinking about recurrence issues. Professionals saw those who coped best had a “*que será, será*” attitude and did not worry excessively about what the future held. Professionals wanted to help facilitate this attitude by focusing patients’ attention beyond their cancer diagnosis, to pick up the pieces of their life, and resume meaningful activities. In this way professionals could be considered to be engaging in Hope Work with patients. Findings suggested that many of these strategies matched patient participants’ own attempts to focus their attention away from their cancer. However, such approaches appeared limited in helping patients cope when focusing on the cancer became unavoidable for patients, such as interpreting new symptoms, or for patients with high levels of anxiety leading to rumination and hyper vigilance. A real danger in the approach that only attempted to pivot attention away from cancer was the risk of creating a conspiracy of silence between professional and patient about any discussion regarding possible recurrence. Several professional participants wanted to deflect or actively close down discussion of recurrence where patients raised concerns. This was particularly true of the initial post-surgical period included in the study, but there was no real indication that professionals would be more willing to discuss these issues later during follow-up.

Lebel et al. (2016) in a consensus meeting on Fear of Cancer Recurrence, have defined it as “*Fear, worry, or concern about cancer returning or progressing*” (p3267). Such fears might be considered to be universal amongst patients diagnosed with cancer, at least from time to time. However, clinically significant worry about recurrence has been detected in as many as 40 to 70 per cent of breast cancer patients (Simard & Savard, 2015; Thewes et al., 2012). Due to the nature of the lung cancer population patients may be more reticent to raise their concerns than other patient groups. Lung cancer patients are frequently perceived to be undemanding of healthcare, potentially linked to feelings of being undeserving and stigmatisation in relation to smoking (Chapple, Ziebland, & McPherson, 2004; Conlon, Gilbert, Jones, & Aldredge, 2010; Lehto, 2014). There is little research evidence specifically looking into the extent of the problem of fear of recurrence in post-surgical lung cancer patients over the long term.

For some of the patients in this current study concerns about recurrence seemed to go beyond an expected level of uncertainty and appeared to have a significant impact on their lives. Although the study followed patients for a relatively short period after their diagnosis, it provided a valuable indication that fear of cancer recurrence might be a significant issue for patients treated surgically for early stage lung cancer. For patients with multiple cancer diagnoses the issues with fear of recurrence may well be heightened. Professionals and patients alike tended to view lung cancer patients who have had surgery as the fortunate few, against the majority that had metastatic cancer. Hence recurrence fears may be played down by patients and overlooked by professionals. Nevertheless, patients in this study who struggled most noticeably in dealing with the uncertainty of their new situation were those who might objectively be seen to have some of the best prognoses.

Many questions remain about the extent of fear of recurrence amongst patients with early stage lung cancer, the feasibility and effectiveness of any therapeutic interventions for this group, as well as the impact of different communication strategies by professionals around recurrence risk and surveillance for early signs of cancer recurrence. Practitioners need to have a greater awareness of patients who struggle to cope with potential recurrence and have available to them a wider range of strategies to help address these issues. In addition, it is important that practitioners are able to recognise when problems might require more specialist interventions and have access to timely and convenient services. Alongside this there is a need to develop interventions that are acceptable to and meet the needs of an older and potentially less well-educated patient population that is often associated with lung cancer. Early identification of those patients with lung cancer who experience significant fear of cancer recurrence and provision of interventions that make a difference is a priority. There remains a lack of evidence regarding how patients cope with the fear of lung cancer recurrence across the course of long-term follow-up and the extent of the problem in this population.

9.5 Key areas of contribution to knowledge

The findings presented in this thesis have provided a unique insight into the communication about potential recurrence after surgery in patients with early stage lung cancer. Previous research in the field has often focused on patients with advanced disease, or with those near end of life. There are fewer studies that have looked at early stage cancers in general, and none have exclusively looked at patients with lung cancer.

This study offers the first in-depth exploration of communication about recurrence risk and long-term outlook with patients following potentially curative surgery for primary lung cancer. The temporal element to the study has given new and unique insight into the process of information disclosure across sequential clinical contacts with different disciplines, as well as a patient perspective that has incorporated longitudinal interviews. This has allowed the study to capture the complexities of the process of communication with patients across teams and disciplines, and to understand how patients try to manage uncertainty about recurrence over time. Therefore, this study has provided key new insights into the care of this population of previously under-researched patients.

The study has highlighted how information about potential cancer recurrence after lung cancer surgery is disclosed according to the individual personal communication ethos of practitioners, largely surgeons, and to a lesser extent the information needs of patients and their families. Even in this group of patients with relatively good lung cancer prognoses recurrence risk communication was largely determined by the shared imperative to maintain patient hope. The study has provided insight into the way in which professionals and patients tacitly negotiate discussion around recurrence risk, primarily by professionals minimising discussion of the subject and adopting a ‘don’t ask, don’t tell’ policy. This included reluctance to discuss possible signs and symptoms of recurrence and what to do about it. This policy risked a conspiracy of silence between professionals and patients regarding discussing possible future recurrence. An asymmetry in recurrence risk information giving was seen between groups of patients, whereby patients with the most favourable prognoses felt able to ask for more explicit detail. Patients who perceived they had a less favourable prognosis did not ask for more details, possibly because this

information would not support future hope. These findings are consistent with Mishel's Uncertainty in Illness Theory. Contrary to expectations, explicit information about recurrence risks did not appear to be important for patient decision-making about further treatment.

The study has also provided new insight into patients' complex information needs about recurrence across the transition into long-term follow-up care. Some patients appeared to struggle to deal with their uncertain future, regardless of the magnitude of the risks. Even lung cancer patients who have objectively good prognoses may face significant fears about recurrence that can be a source of considerable emotional distress. Provision of statistical information in itself did not appear to allay these concerns. These insights gained over the first six months after surgery begin to suggest that fears about cancer recurrence might be a significant factor at any time after surgery, in response of a range of changing cues experienced by patients.

9.6 Recommendations for practice

The case study presented in this thesis has highlighted several key areas for developing clinical practice.

- Specific training should be offered to all professionals involved in discussing the results, management plans and the future implications following curative lung cancer surgery and should be focused on communication approaches that support patients' coping strategies, while also conveying necessary information.
- Clinicians should consider the implications of the way numerical information is used within the informed consent process and the need to be aware of the potential for patients to misinterpret and misunderstand risk information.
- Patients should routinely be offered the opportunity to have a supported conversation outside the medical consultation, probably with their designated LCNS, to allow an emotionally safe discussion about possible future recurrence, potentially following a 'hope for the best, plan for the worst' model. Discussions should include recognition of

signs and symptoms of possible recurrence and what to do about them, bearing in mind the non-specific nature of lung cancer recurrence.

- There should be routine assessment of patients for significant problems related to fear of lung cancer recurrence throughout the surveillance period. There should be adequate and timely access to specialist services for patients who experience significant fear of lung cancer recurrence.

9.7 Recommendations for future research

Many unanswered questions remain about recurrence risk communication and how best to support and equip patients to manage the uncertainty of potential recurrence following their surgery.

- Further research is needed into the communication of lung cancer recurrence risk to identify possible strategies that patients are able to engage with, in ways that do not significantly increase worry about recurrence and that are acceptable for patients. This would be particularly suitable for research using the principles of collaborative research, such as Experienced Based Co-design (Donetto, Pierri, Tsianakas, & Robert, 2015; Hinchcliff, Greenfield, & Braithwaite, 2014).
- Studies should be developed aimed at scoping the extent and significance of fear of cancer recurrence in the post-surgical lung cancer population throughout the five-year follow-up period up to ultimate discharge from the service. This should be with the aim of developing suitable methods of screening patients with clinically significant fear of lung cancer recurrence, or those at high risk of developing problems.
- In parallel there should be research aimed at identifying and trialling suitable interventions to support patients who experience significant levels of fear of recurrence that are acceptable to the demographic profile of patients with lung cancer. Again, this would be highly suitable for a collaborative research approach.

- A broader health services research challenge is how to provide coordinated and integrated follow-up care after the end of acute treatment for the growing number of patients living with multiple diagnoses, particularly those undergoing surveillance for more than one cancer primary site.

9.8 Strengths and limitations of the study

The key strength of this study lies in its comprehensive case study design; methods that were ultimately able to deliver the stated research aims. Multi perspectival data were used to gain an in-depth understanding of communication regarding recurrence risk during sequential multidisciplinary consultations. This was combined with data from longitudinal patient interviews to gain insight into patient perceptions during the first six months following surgery. The methods used allowed me to preserve the integrity of the individual cases and reflect the complexity of the interactions. Rather than trying to triangulate these different data sources with the aim of identifying a single objective truth, I have used the multiple perspectives seen in the data to enhance the richness of the findings and to see the communication from the standpoint of both the patient and the professional participants. The multiple cases in this study have also added to the overall rigour. I included a relatively large number of cases for a qualitative study, generating a large and complex dataset. My purposive sampling strategy enabled me to include a wide range of patients, which were diverse in terms of background, cancer stage and treatment pathway. Using three referring LMDTs and two surgical centres also widened the range of patient experiences and increased the diversity of professional views included in the study. Another strength was the rigour with which I approached data analysis and interpretation. Complete immersion in the data from its collection and subsequent data management resulted in a comprehensive knowledge of the dataset. This later facilitated the processes of data abstraction and interpretation and development of the study themes.

Nevertheless, there were also a number of limitations of this research. This study reported on findings generated from cases within a particular clinical context. As such it is not possible to draw direct universal conclusions from these findings, even in relation to the wider population of post-surgical lung cancer patients. However, the themes developed

focused on the broad principles and fundamental needs of participants, such that the findings may have broader application than those of the specific cases studied. In common with other qualitative studies, the potential for observer bias was a concern. I addressed these issues by adopting a reflexive approach to the study and by being self-aware of the effect of my presence as a researcher. Recording and accounting for these issues during the analysis helped to mitigate these factors. Another limitation could be considered to be the singlehanded data analysis. To some extent this is an inescapable factor of a doctoral study. However, my supervisory team were closely involved in this process throughout. Members of the supervisory team independently read and coded early interview and consultation transcriptions and were able to comment on and suggest modifications to the framework matrix. During later analysis, regular supervisory meetings were used to provide challenge and reflective dialogue regarding the robustness and rigour of the final themes developed.

9.9 Dissemination

The following points outline my planned strategy for dissemination of the study findings into practice locally and beyond.

- Presentation of findings within surgical centre lung cancer multidisciplinary team and in-service teaching sessions.
- Offer to present findings at participating local lung cancer multidisciplinary team meeting teaching sessions.
- Formal presentation at local lung cancer nursing forum.
- Presentation to Lung Cancer Nursing UK (formally NLCFN) annual conference 2020.
- Submission of abstract to British Thoracic Oncology Group (BTOG) conference 2021.
- Planned submission of paper constructed around the “Hope Dances” chapter to the journal *Sociology of Health and Illness*.
- Planned submission of paper exploring the use of case study methodology as applied to this study to the journal *Qualitative Research*.

9.10 Closing reflections

This study has offered me the chance to grow both in terms of my own skills in developing, conducting and analysing research, and in my personal and team clinical practice working alongside patients and their families undergoing diagnosis, treatment and follow-up for lung cancer. The study has also charted changes in my own assumptions and thinking about recurrence risk communication and how best to approach this with patients. I came into the research with the opinion that patients largely wanted detailed information regarding their risk of cancer recurrence, but that this was not generally given by surgeons. I assumed recurrence risk information was given as part of the process of decision-making about adjuvant therapy, due to previous experience with patients with breast cancer where patient decision-aids were routinely used. Although such data can be seen as neutral and scientific, I was surprised at how patient participants viewed it as value-laden and threatening, even where objectively it could be considered as good news. My assumptions suggested that patients with a higher objective risk of recurrence would be more likely to both want and receive detailed recurrence risk information than those where the risk was lower. The findings, however, suggested the opposite, with the information not being used in relation to treatment decision-making, but rather as a coping strategy linked to maintaining hope.

The study has allowed me to consider the complexities of providing individual prognostic forecasts based on the available population data, that I had not fully appreciated. Within this small case study, most patients had confounding factors that might impact prognosis assessments based on population data. However, it was the fundamental differences between this population data and the way patients thought about their future, extending beyond the simple differences between recurrence and survival that has perhaps changed the way in which I approach discussions with patients after their surgery the most. I have become aware of a personal willingness to disclose numerical prognoses to patients with stage I lung cancers as a way of bolstering hope and that this information may not necessarily match the needs of the patient concerned. I now appreciate the need for a more in-depth facilitated discussion with patients around the subject of possible future recurrence that helps patients to try to manage their uncertainty, provides information that

matches the patient's requirements and works in conjunction with their own sense of hope for the future. In particular I have a greater awareness of the potential for patients to experience significant unmanaged fears about possible cancer recurrence that may not match the objective statistics. How to best address such fears and support patients, however, remains a clinical challenge yet to be resolved.

The case study has both illustrated the importance of seeing a research question within its real-life context, and being able to see this background as part of the answer. The importance of qualitative methodology, such as case study, in being able to deliver nuanced and complex answers to research questions is evident in these findings. In particular, this underlines the potential danger of research that requires simple and constrained answers to questions that are multidimensional. Nevertheless, this focus on the particularities of cases provides a real challenge to the researcher in terms of dealing both with the extent and complexity of the data, as well as in being able to identify findings with sufficient universality that have applicability to a wider context. What is clear from the findings was that practice around this aspect of care is highly individual, influenced by practitioners', and by extension team ethos, as well as the clinical situation and the patients' needs at that particular time. Nevertheless, I believe that the study has resulted in rich data that have informed findings, which although remain grounded within the cases of the study, have implications for wider situations and suggest practice developments and research to address further gaps in knowledge.

10 Conclusion

The findings presented in this thesis have provided novel insight into communication between patients and professionals about the risk of lung cancer recurrence following potentially curative surgery. I believe this is the first qualitative study to explore communication involving sequential consultations between different professional disciplines and patients with lung cancer, revealing how prognostic discussions are managed across these settings. The extant literature around prognostic communication in cancer is large, but often with contradictory findings. There is no literature that specifically looked at communication in early stage lung cancer, a group of patients often seen as undemanding in terms of information requirements. This study arose out of challenges I had experienced when talking with patients about their risk of recurrence following surgery for lung cancer. The multiple qualitative case study approach was chosen as the best fit with achieving a rich, multi perspectival picture of communication in real life settings that preserved the context, background and nature of the interpersonal relationships.

The study has revealed the wide range of attitudes of both professional, as well as patient participants to prognostic information disclosure in a curative setting. Most patients wanted limited information about their risk of cancer recurrence, but their needs for this type of information were circumstantial, individual, and sometimes ambivalent. Similarly, professionals' views and behaviours varied between individual practitioners. Practice was influenced by clinical situation and patients' needs at that particular time, but primarily appeared to be a matter of professionals' communication ethos. Most professionals were sceptical about the relevance of population outcome statistics to individual patients that they saw in consultations and did not view this information as helpful to patients. Patient and professional participants generally saw prognostic information as damaging to patient hope and potentially having a negative impact on recovery. There was a clinical imperative to support patients' sense of hope for the future, which appeared to be widely shared by both patients and professionals. It was this imperative that appeared to shape communication about possible future recurrence. In this way, during consultations patients and professionals co-constructed a hopeful message about long-term outlook.

These findings have implications for how the issue of possible future cancer recurrence is discussed with lung cancer patients after surgery. While both patients and professionals are cautious about opening discussions around long-term outcomes in an effort to protect patients, relentlessly pivoting attention away from the topic of recurrence might prevent useful conversations being facilitated that could help patients deal with the uncertainty of their situation. The strategy risks developing a conspiracy of silence, where patients and professionals do not openly discuss issues around possible cancer recurrence. This could result in patients being unable to engage in their follow-up care, having no conception of early signs and symptoms of recurrence, being more likely to have misunderstandings about their condition and having unvoiced concerns. While many patients ultimately cope well with the uncertainty around the potential for future recurrence, some patients do face significant problems and may need specific support to address these.

This case study has illustrated the importance of seeing a research question within its real-life context, and being able to incorporate this background as part of the answer. The importance of qualitative methodology, such as case study, in being able to deliver nuanced and complex answers to multidimensional research questions is evident. Nevertheless, this focus on the particularities of cases provides a real challenge to the researcher in terms of dealing both with the extent and complexity of the data, but also in being able to identify findings with sufficient universality that have applicability to a wider context. However, I believe that this study has resulted in rich data that have informed findings, which although remain grounded within the cases of the study, have implications for wider situations and suggest practice implications and research to address further gaps in knowledge.

Implications for clinical practice from this study include training aimed at highlighting the importance of flexible, self-aware and responsive communication about potential recurrence after surgery that can address both professionals' and patients' communication aims and does not simply ignore this important subject. Professionals should develop an awareness of patients' perspectives of future long-term outlook. Research should aim to identify communication approaches for discussing possible future recurrence, which are also able to help maintain patients' hope. Other questions remain regarding the incidence and severity of fear of cancer recurrence in this population and how best to identify those at

risk. Co-design approaches offer an exciting research route to help develop interventions that are appropriate to the needs of the lung cancer population.

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Appendices

1. IASLC Lung cancer staging (7th edition)
2. Literature search strategies
3. Literature review data extraction and quality assessment tools
4. Literature review 2004 – 2014: summary of included studies
5. Literature review 2014 – 2018: summary of included studies
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Appendix 1: IASLC lung cancer staging (7th edition)

Definitions for T, N, and M Descriptors (Goldstraw, et al., 2007)

T (Primary Tumour)	
TX	Primary tumour cannot be assessed, or tumour proven by the presence of malignant cells in sputum or bronchial washings but not visualized by imaging or bronchoscopy
T0	No evidence of primary tumour
Tis	Carcinoma in situ
T1	Tumour ≤ 3 cm in greatest dimension, surrounded by lung or visceral pleura, without bronchoscopic evidence of invasion more proximal than the lobar bronchus (i.e., not in the main bronchus)
T1a	Tumour ≤ 2 cm in greatest dimension
T1b	Tumour ≥ 2 cm but ≤ 3 cm in greatest dimension
T2	Tumour ≥ 3 cm but ≤ 7 cm or tumour with any of the following features (T2 tumours with these features are classified T2a if ≤ 5 cm) Involves main bronchus, ≥ 2 cm distal to the carina Invades visceral pleura Associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
T2a	Tumour ≥ 3 cm, but ≤ 5 cm in greatest dimension
T2b	Tumour ≥ 5 cm, but ≤ 7 cm in greatest dimension
T3	Tumour ≥ 7 cm, or one that directly invades any of the following: Chest wall (including superior sulcus tumours), diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium; or tumour in the main bronchus ≤ 2 cm distal to the carina, but without involvement of the carina; or associated atelectasis or obstructive pneumonitis of the entire lung or separate tumour nodule(s) in the same lobe
T4	Tumour of any size that invades any of the following: Mediastinum, heart, great vessels, trachea, recurrent laryngeal nerve, oesophagus, vertebral body, carina; separate tumour nodule(s) in a different ipsilateral lobe
N (Regional Lymph Nodes)	
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in ipsilateral peri-bronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension
N2	Metastasis in ipsilateral mediastinal and/or sub-carinal lymph node(s)
N3	Metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph node(s)
M (Distant Metastasis)	
MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis
M1a	Separate tumour nodule(s) in a contralateral lobe; tumour with pleural nodules or malignant pleural (or pericardial) effusion
M1b	Distant metastasis

TNM Stage Groupings (Integrated stage)

Occult Carcinoma	TX	N0	M0
Stage 0	Tis	N0	M0
Stage IA	T1a, b	N0	M0
Stage IB	T2a	N0	M0
Stage IIA	T1a, b	N1	M0
	T2a	N1	M0
	T2b	N0	M0
Stage IIB	T2b	N1	M0
	T3	N0	M0
Stage IIIA	T1, T2	N2	M0
	T3	N1, N2	M0
	T4	N0, N1	M0
Stage IIIB	T4	N2	M0
	Any T	N3	M0
Stage IV	Any T	Any N	M1a, b

Residual Tumour (R) Classification

The absence or presence of residual tumour after treatment is described by the symbol R. TNM and pTNM describe the anatomical extent of cancer.

The definitions of the R categories are:

- RX Presence of residual tumour cannot be assessed
- R0 No residual tumour
- R1 Microscopic residual tumour
- R2 Macroscopic residual tumour.

Pleural Tumour Invasion (PL) Classification

- PL0 tumour within the sub-pleural lung parenchyma or invades superficially into the pleural connective tissue beneath the elastic layer
- PL1 tumour invades beyond the elastic layer
- PL2 tumour invades to the pleural surface
- PL3 tumour invades into any component of the parietal pleura

Appendix 2: Literature searches strategies

28th June 2014

Search History

1. CINAHL; exp NEOPLASMS/; 179575 results.
2. CINAHL; cancer.ti,ab; 112735 results.
3. CINAHL; oncology.ti,ab; 14043 results.
4. CINAHL; 1 OR 2 OR 3; 210827 results.
5. CINAHL; prognos*.ti,ab; 24758 results.
6. CINAHL; (risk ADJ3 recurrence).ti,ab; 1673 results.
7. CINAHL; information.ti,ab; 123239 results.
8. CINAHL; 5 OR 6 OR 7; 146451 results.
9. CINAHL; exp PROFESSIONAL-PATIENT RELATIONS/; 51465 results.
10. CINAHL; exp PHYSICIAN-PATIENT RELATIONS/; 15950 results.
11. CINAHL; exp NURSE-PATIENT RELATIONS/; 18115 results.
12. CINAHL; exp PROFESSIONAL-CLIENT RELATIONS/; 3672 results.
13. CINAHL; exp TRUTH DISCLOSURE/; 6454 results.
14. CINAHL; 9 OR 10 OR 11 OR 12 OR 13; 60142 results.
15. CINAHL; 4 AND 8 AND 14; 952 results.
16. CINAHL; 15 [Limit to: Publication Year 2004-2014 and (Language English)]; 677 results.

Search History

1. MEDLINE; NEOPLASMS/; 272386 results.
2. MEDLINE; cancer.ti,ab; 1048726 results.
3. MEDLINE; oncology.ti,ab; 54426 results.
5. MEDLINE; exp HEMATOLOGIC NEOPLASMS/; 9645 results.
6. MEDLINE; 1 OR 2 OR 3 OR 5; 1199768 results.
7. MEDLINE; prognos*.ti,ab; 371270 results.
8. MEDLINE; (recurrence ADJ3 risk).ti,ab; 16730 results.
9. MEDLINE; information.ti,ab; 768563 results.
10. MEDLINE; 7 OR 8 OR 9; 1124007 results.
11. MEDLINE; exp INTERPERSONAL RELATIONS/; 260678 results.
12. MEDLINE; exp TRUTH DISCLOSURE/; 12909 results.
13. MEDLINE; exp PROFESSIONAL-PATIENT RELATIONS/; 119923 results.
14. MEDLINE; 11 OR 12 OR 13; 260678 results.
15. MEDLINE; 6 AND 10 AND 14; 2611 results.
16. MEDLINE; 15 [Limit to: Publication Year 2004-2014]; 1667 results.
17. MEDLINE; 16 [Limit to: English Language and Publication Year 2004-2014]; 1492 results.

Search History

1. PsycINFO; exp NEOPLASMS/; 34777 results.
2. PsycINFO; cancer.ti,ab; 38514 results.
3. PsycINFO; exp BLOOD AND LYMPHATIC DISORDERS/; 3652 results.
4. PsycINFO; oncology.ti,ab; 4041 results.
5. PsycINFO; 1 OR 2 OR 3 OR 4; 48454 results.
6. PsycINFO; exp PROGNOSIS/; 6740 results.
7. PsycINFO; (risk ADJ3 recurrence).ti,ab; 679 results.
8. PsycINFO; exp INFORMATION/; 10767 results.
9. PsycINFO; 6 OR 7 OR 8; 18142 results.
10. PsycINFO; 5 AND 9; 998 results.
11. PsycINFO; 10 [Limit to: English Language and Publication Year 2004-2014]; 713 results.

7th November 2018

MEDLINE (7th November 2018)

NEOPLASMS/ OR cancer .ti,ab OR (oncology).ti,ab OR HEMATOLOGIC NEOPLASMS/
AND
prognos* .ti,ab OR recurrence ADJ3 risk .ti,ab OR information .ti,ab
AND
INTERPERSONAL RELATIONS/ OR TRUTH DISCLOSURE/ OR PROFESSIONAL-PATIENT RELATIONS/ OR NURSE-
PATIENT RELATIONS/ OR PHYSICIAN-PATIENT RELATIONS/
Date 2014-2018
Languages English

CINAHL (7th November 2018)

NEOPLASMS/ OR cancer .ti,ab OR oncology .ti,ab OR HEMATOLOGIC NEOPLASMS/
AND
prognos* .ti,ab OR risk ADJ3 recurrence .ti,ab OR diagnosis .ti,ab OR TREATMENT OUTCOMES/ OR
PROGNOSIS/
AND
PROFESSIONAL-PATIENT RELATIONS/ OR NURSE-PATIENT RELATIONS/ OR PHYSICIAN-PATIENT RELATIONS/
OR TRUTH DISCLOSURE/ OR INFORMATION SEEKING BEHAVIOR/ OR HEALTH LITERACY/ OR INFORMATION
NEEDS/
Date 2014-2018
Languages eng

PsychINFO (7th November 2018)

NEOPLASMS/ OR cancer .ti,ab OR BLOOD AND LYMPHATIC DISORDERS/ OR oncology .ti,ab
AND
PROGNOSIS/ OR diagnosis .ti,ab OR prognos* .ti,ab OR risk ADJ3 recurrence .ti,ab OR survival .ti,ab
AND
INFORMATION SEEKING/ OR INTERPERSONAL COMMUNICATION/ OR disclos* .ti,ab OR communicat* .ti,ab
Date 2014-2018
Languages English

Key: CAPITALS/ = MeSH term ti.ab = search in title and abstract fields * = truncation allowing inclusion of all stem words ADJ3 = words occur within 3 words of each other in any order

Appendix 3: Literature review quality assessment and data extraction tools

Quality checklist for questionnaire studies		
After Boynton and Greenhalgh 2003, CASP and Center for Evidence Based Management		
Appraisal questions		
1. Did the study address a clearly focused question?	<ul style="list-style-type: none"> Was there a clear statement of the aims of the research? What was the goal of the research? Why was it thought to be important? Is it relevant to clinical practice? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
2. Was the research design appropriate to address the aims of the research?	<ul style="list-style-type: none"> Has the researcher justified the research design (eg have they discussed how they decided which method to use)? Was a questionnaire the most appropriate research design for this question? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
3. Was the method of selection of the subjects clearly described and adequate?	<ul style="list-style-type: none"> Could the way the sample was obtained introduce (selection) bias? Was the sample of subjects representative of a wider population? Was the sample size based on pre-study considerations of statistical power? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
4. Was a satisfactory response rate achieved?	<ul style="list-style-type: none"> What was the response rate? Have non-responders been accounted for? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
5. Are the tools likely to be valid and reliable?	<ul style="list-style-type: none"> Has a validated tool been used? If the tool was locally developed, has it been piloted and modified accordingly? What claims for reliability and validity have been made and are they justified? Did the questions cover all relevant aspects of the problem in a non-threatening and non-directive way? Were open ended and closed ended questions used appropriately? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
6. Have ethical issues been taken into consideration?	<ul style="list-style-type: none"> Is there sufficient detail of how the research was explained to participants to assess whether ethical standards were maintained? Was ethical approval sought from an ethics committee? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
7. Was data analysis sufficiently rigorous?	<ul style="list-style-type: none"> Was the analysis appropriate (qual v quant) and were the correct techniques used? Was statistical significance assessed? Are confidence intervals given for the main results? Could there be confounding factors that haven't been accounted for? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
8. Have the results and analysis been presented appropriately?	<ul style="list-style-type: none"> Have all relevant results ('significant' and 'non-significant' been reported? Is there evidence of 'data dredging' (ie analyses that were not 'hypothesis driven'?) 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
9. Is there a clear statement of findings?	<ul style="list-style-type: none"> Are the findings explicit? Is there adequate discussion of the evidence both for and against the researchers' arguments? Are the findings discussed in relation to the original research question? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No
10. How valuable is the research?	<ul style="list-style-type: none"> Do the team consider the findings in relation to current practice, or relevant literature? Do they identify areas where research is necessary? Do the researchers discuss whether or how the findings can be transferred to other populations or consider other ways the research might be used? 	<input type="checkbox"/> Yes <input type="checkbox"/> Can't tell <input type="checkbox"/> No

Example data extraction form developed from work by Glenton et al. (2013)

Extraction item	Details
<i>Citation</i>	
<i>Country</i>	
<i>Aims</i>	
<i>Type of research</i>	
<i>Recruitment context (e.g. where people were recruited from)</i>	
<i>Curative / palliative / mixed setting</i>	
<i>Participants</i>	
<i>Theoretical background</i>	
<i>Sampling</i>	
<i>Sample (participant) characteristics</i>	
<i>Data collection</i>	
<i>Data analysis</i>	
<i>Themes</i>	
<i>Data extracts</i>	
<i>Author explanation</i>	
<i>Recommendations</i>	
<i>Ethics – how ethical issues were addressed</i>	
<i>Is the study context clearly described?</i>	
<i>Is there evidence of researcher reflexivity?</i>	
<i>Is sampling method clearly described and appropriate for research question?</i>	
<i>Is the method of data collection clearly described and appropriate for the research question?</i>	
<i>Is the method of data analysis clearly described and appropriate for the research question?</i>	
<i>Are the claims made supported by sufficient evidence (ie sufficient depth, detail and richness?)</i>	

Appendix 4: Literature review 2004 – 2014 - summary of included studies

Authors (year) Country	Study aims	Design and methods	Sample population	Measures analysis	and Results
Curative treatment patients					
Mendick et al. (2011) UK	Examine how surgeons manage information-giving to patients with breast cancer, and how their approach converges with what breast cancer patients want.	Qualitative Grounded Theory approach using audio recording of consultation and semi-structured interviews.	n=20. Purposeful sampling post-operative breast cancer patients and 9 surgeons within surgical breast cancer clinic (2 declined). Age 39 - 86 years (mean 60) with a range of prognostic characteristics.	Patient and surgeon interviews analysed individually and in "pairs" using a constant comparative approach within a Grounded Theory framework	Surgeons talked about needing to give patients "honest" information and not to "hide" or "withhold", but there was a potential for giving "too much" information. Patients described the need to be told "everything", but also warned of the possibility of "too much" information. Surgeons wanted patients to leave the consultation with a sense of "hope". Patients emphasised the need for "positive thinking"
Mendick et al. (2013) UK	Delineate the types of information that surgeons provide to breast cancer patients and understand the functions of this information in the tension between "hope" and "information"	As for Mendick et al. (2011)	As for Mendick et al. (2011)	Constant comparative approach within a Grounded Theory framework to analyse data within and across cases.	Surgeons gave factually explicit biomedical information at every consultation, but were less explicit in expressing judgements about implications. Surgeons gave no statistical estimates of prognosis, but presented comparisons. Evaluative comments tended to always be positive. Information given on a spectrum of explicitness. Patients did not report wanting more information than they received. Giving explicit factual information on medical findings plays a small part in the information a patient receives from their surgeon, with significant information being received in less explicit ways.
Kelly et al. (2013) USA	Explore: 1) perceptions of medical communication regarding recurrence risk, 2) patient perception of recurrence risk, 3) accuracy of recurrence risk estimates in patients	Mixed methods cross-sectional study. Patients completed quantitative questionnaires, plus open-ended questions regarding thoughts and feelings about recurrence.	n=113. (RR 80%) Women with breast cancer in university oncology clinic. Within 1 year, or between 2 - 5 years of diagnosis. . . Mean age 58.6 (SD = 10.6) years.	Profile of Mood States (POMS), modified breast cancer recurrence specific POMS, Cancer Worry Scale (CWS), 8 item perceived lifetime risk of recurrence. Individual risk of breast cancer recurrence calculated. Comparison made between calculation and patient estimate. Modified Grounded Theory used for open question responses.	Most patients expressed wish to know their recurrence risk. Almost 40% of participants felt that their health team had not discussed their risk of recurrence with them. Women were largely inaccurate in their estimate of recurrence risk, both over and under estimating the risk. Adjuvant! Online calculated risk did not correlate with the patient estimates. Patients living in rural areas, more worried, or 2 - 5 years out from diagnosis, were more likely to over estimate their risk. Affective data on recurrence came from the open questions. Women expressed more positive affective outlook (25.3%) against negative affect (5.1%).

Franssen, et al. (2009) The Netherlands	Explore how patient preferences for disclosure of prognosis relates to psychological characteristics of patients	Cross sectional postal questionnaire sent to patients between 1 and 24 months following potentially curative surgery.	n=176. (RR 86%) Post potentially curative surgery for oesophageal cancer. Average age 63 (range 30 - 80). 82% male.	As for Lagarde et al. (2008) plus involvement preferences (Information subscale of Krantz Health Opinion Survey), fear of recurrence, anxiety and depression (HADS), striving scale (Quality-Quantity Questionnaire), trust in doctors (modified Wake-Forest Physician Scale).	66% patients wanted maximum prognostic information. This group of patients had greater fear of recurrence and wanted to be more actively involved during their consultations. Patients with worse quality of life tended to report more fear of recurrence. Preferences for prognostic information not related to anxiety, depression, physician trust, or striving scores in this study.
Lagarde et al. (2008) The Netherlands	Determine preference and predictors for content, style and format of prognostic information following oesophageal surgery for cancer	As for Franssen et al. (2009)	As for Franssen et al. (2009)	Modified survey developed by Hagerly et al. (2005b). EORTC QoL 30 and OES18. Hypothetical scenario to determine type of graphical data preferred by patients.	93% patients wanted to know their average prognosis. Information preferences declined when information became more specific and more short-term. 71% wanting to know chance of recurrence within 6 months. 63% wanted specialist to initiate discussion of survival. 22% wanted the doctor to ask if the patient wanted to know first. 5% wanted to lead the disclosure or did not want the information at all. 59% wanted to have an optimistic approach. Words and numbers were preferred over visual presentations
Mixed curative and palliative treatment patients					
Leydon (2008) UK	Explore how experienced oncologists and their patients organise talk about cancer and the uncertain treatment-related outcomes of radiotherapy and chemotherapy.	Qualitative analysis of transcribed audio recordings of first oncology consultations.	n=28. Patients (6 female, 22 male) with breast, head & neck, or gastrointestinal cancer at 3 cancer centres. Most referred following initial cancer surgery. Participants aged 40 to 80 years.	Jefferson's orthography used in transcription. Analysis guided by "unmotivated looking", using Roter's Interaction Analysis System (RIAS) and Conversation Analysis (CA)	Following uncertain or bad news with relatively better news was one method used to give honest information without reducing hope and future optimism. This "proximate pairing" of information was used repeatedly across consultations at all three centres. Proximate pairing can help doctors to deliver information with both honesty and hope. However, this technique may result in patients unrealistically disregarding uncertain or bad news and could result in patients having unrealistic treatment expectations.

Jansen et al. (2008) Australia	Examine age and age-related differences in recall of information provided during oncology consultations.	Cross sectional quantitative study. Clinic consultation audio recorded with follow-up structured phone interview within 10 days.	n=260. (RR 74%) Consecutive heterogeneous cancer patients approached during initial oncology consultation. Patient age 18 to 83 years. 53% of patients having curative treatment.	Spielberger State Anxiety Scale. Information Styles Questionnaire (needs and preferences). Recall of information measured using structured telephone interview. Analysis conducted by dividing the sample into <65 years and ≥ 65.	No age difference found for information needs or preferences. Patients wanted all available information about their illness. Recall of all facts 49.5% in under 65s and 48.4% in the over 65s. Worse prognosis, more information presented and longer consultations were predictive of less %age recall. Increasing age had negative correlation with recall, but effect was masked by variation in older patients' consultations and amount of information given. The more prognostic information presented, the less patients recalled.
Robinson et al. (2008) USA	Identify communication factors that may influence concordance about chance of cure between oncologists and patients	Cross sectional quantitative questionnaire study and analysis of consultations. Part of larger study looking at educational strategies to improve oncologist communication skills.	n=187. Oncologist / patient pairs. Patients diagnosed with heterogeneous cancers where oncologist "would not be surprised if patient died or admitted to ITU in next year". No estimate of RR in this element of study. 23% of patients considered "curative". Age range 33 - 86 years, 47% male.	Patient and oncologist independently estimated chance of cure on 11-point scale of 0% to 91%-100%. Concordance graded as "good" (n=69) and "poor" (n=72). "Intermediate" concordance group excluded (n=39). Consultations coded for optimistic and pessimistic or uncertain prognostic elements. Multivariate analysis undertaken.	Where oncologists made at least one pessimistic statement about chance of cure, patients were more likely to be concordant with the oncologist about chance of cure compared to where no pessimistic statements were given (OR=2.92, 95% CI = 1.35-6.32). Patient education, age, gender and diagnosis were not independently associated with concordance. Statements of optimism, pessimism about the past or present and expressions of uncertainty did not have an effect on concordance. Oncologists only expressed pessimism in 46% of encounters and expressed optimism twice as often as pessimism.
Alexander et al. (2012) USA	1) Describe and quantify the content of second-opinion haematology consultations regarding information exchange. 2) Identify patient and provider characteristics associated with discussion elements.	Cross sectional study. Audio recording of physician - patient consultations in clinic with quantitative analysis	n=236. "Second opinion" haematology patients attending tertiary care clinic. Average age 55 (range 20 - 79).	Communication evaluation tool developed for study. Conversations coded. Prognostic discussions reported as unambiguous quantitative through to qualitative only	Prognosis discussed qualitatively and quantitatively, framing in terms of mortality, chance of cure or both. Most contained at least one quantitative estimate of cure or mortality without "hedging". Physicians discussed purpose of consultation and patient's prior knowledge. Discussions of preferred decision-making role less common. Discussion of information preference was uncommon.

Goldman et al. (2009) USA	Elucidate patient experience of second opinion consultations in haemato-oncology conditions.	Cross sectional semi-structured in-depth interviews and transcribed clinic visit. Telephone interviews at 2 - 4 wks. Sections of transcribed consultation text used to ask further questions of the subject.	n=20. Patients seeking second opinion for haemato-oncology conditions at one of three major university teaching hospitals. Subset of the patients recruited to Alexander et al 2011	Anthropological methodology using collaborative group analysis with mersion and crystallisation	Patients want expert, honest advice delivered with empathy. Amount and style of information wanted is individual. Doctors should apply expertise to specifics of individual case. Most patients wanted to contribute to agenda, but felt unable to do so. Most patients supported bringing list of prepared questions to help ensure agenda met. Demonstrating respect and care led to positive feelings, regardless of outcome. Patients wanted information to help maintain hope. Where the prognosis was not good, patients need to recognise this, but not hear too much about it.
Palliative treatment patients					
Lobb, Halkett & Nowak (2011) Australia	Elicit patient and carer perceptions of the initial diagnosis and its prognosis in high grade glioma	Retrospective cross sectional design. Semi structured interviews with patients (and carers, if designated by the patient). Interviews audio recorded and transcribed verbatim	n=19. Patients diagnosed with Grade III or IV High Grade Glioma referred to a tertiary neuro-oncology clinic within first year of diagnosis. Care givers interviewed (n=21). 11 patients approached but did not take part. Age range 31 - 74	Data analysed using the principles of Grounded Theory and the constant comparative method. Open axial and selective coding employed.	Five overarching themes emerged: shock at hearing diagnosis; understanding and processing prognostic information when in shock; perception of hope taken away; individualizing prognostic information; clinicians' lack of communication skills. Findings highlighted the inability of people to process detailed prognostic information when in a state of initial shock and distress or at the time immediate post-operative period. Some patients did not recall all the details of their diagnosis or prognosis and chose not to seek further information.
Step & Ray (2011) USA	1. What are patients' recollections of oncologists' communication about prognosis when first diagnosed? 2. What are patients' recollections of oncologists' communication about prognosis when told of cancer recurrence?	In-depth semi-structured interview study with cross sectional design.	n=30. Female cancer patients (23 breast, 4 lung, 1 colon, 1 gynaec, 1 head & neck) within 3 months of diagnosis of recurrence of stage I - III cancer. RR 68%. No male patients recruited. Age range 42 - 84 years (mean 63 yrs). Average disease free time 7.3 years.	Interviews transcribed verbatim and coded using Atlas-ti software. Research coder identified all prognosis related quotes. Authors undertook iterative analysis to identify similar and contrasting themes.	Patients described oncologists communicating optimism during the initial diagnosis. This changed at diagnosis of recurrence to one of chronic disease management. Three subthemes identified at recurrence: <i>managing the new information</i> and coming to terms with the new situation; <i>ambiguous communication</i> about the prognosis, especially relating to changing meanings in shifting contexts with an illusion of shared meaning; <i>information seeking paradox</i> medical and patient attempts to manage hope v access to detailed explicit truth. Authors propose Problematic integration as a useful model for understanding the dynamics of uncertainty in prognosis communication.

Curtis et al. (2008) USA	Examine interactions between patients' and family members' desire for hope to be supported, and the need to receive explicit prognostic information. Explore clinicians' need to provide prognostic information and the desire to foster hope	Longitudinal qualitative study. Open-ended interview questions with patients, physicians, nurses and family members.	Cascade recruitment of 31 physicians (RR 37%), 55 patients (RR 82%), 36 family members (RR 86%) and 25 nurses (RR 100%). 24 patients COPD, 30 metastatic cancer or inoperable lung cancer.	Open-ended interview questions. Participants responded to 4 diagrams of conceptual models for integration of hope and desire for prognostic information. Follow-up interview at 4 - 6 months. Subset at 12 months. Data analysed with grounded theory.	Patients and family members initially wanted "all" prognostic information. During interviews substantial minority expressed reservations about explicit prognostic information. Patients and families described changes in attitude to prognostic information and hope. Participants endorsed the models proposed.
Hagerty et al. (2004) Australia	Determine preferences of metastatic cancer patients for content and format of prognostic information and explore predictors of these preferences.	Cross sectional survey 6 weeks to 6 months after a diagnosis of metastatic cancer. Surveys completed at home or in clinic setting across 12 oncology units in New South Wales.	n=126. (RR 58%). Newly diagnosed metastatic cancer patients; 54% male, 25% breast, 18% colorectal, 15% prostate, 10% lung. Patients identified by 30 oncologists (RR 28%). Mean patient age 63 years (range 34 - 82). 92% receiving active treatment.	Krantz Health Opinion survey, HADS, prognostic information desired (15 item yes/no response with open answer). Preferred presentation of survival information (vignette and sample presentations). When and who to initiate discussion of treatment goals, symptoms and side effects, life expectancy and dying and palliative care.	Strong preference for prognostic information, strongest with longer time frames (ie 5 year survival figures), reducing with shorter time frames. Words and numbers were preferred over diagrams and charts. Patients wanted to discuss prognosis at the time of diagnosis and wanted the doctor to "just tell them". 59% wanted to know how long they would live when first diagnosed. 11% never wanted to discuss palliative or end of life issues.
Hagerty, Butow, Ellis, Lobb et al. (2005) Australia	Identify the context and way in which patients with incurable metastatic cancer wanted to be informed about their prognosis and to explore the features of this communication that patients would experience as more or less hopeful.	As for Hagerty et al. (2004)	As for Hagerty et al. (2004)	"Doctor style" (35 informational and supportive behaviours with 5-point Likert scale), Patient Definition of Hope (four suggested definitions of hope, plus open question of own definition). "What Patients Find Hopeful" (30 doctor behaviours that might convey or discourage hope, rated for hopefulness).	Patients wanted their doctor to be realistic, provide opportunity to ask questions and acknowledge the individual when discussing prognosis. Offering up-to-date treatments and being knowledgeable were seen as the most hope giving behaviours. Patients were split equally (feeling positive, negative or neutral) with regard to the hopefulness of expressing uncertainty and giving survival statistics. Patient definition of hope was wide ranging. Common themes related to quality of life and fulfilment of goals. Patients diagnosed for a longer time and those with longer expected survival were more likely to want a realistic approach.

Mitchison et al. (2012) Australia	Elicit migrant cancer patients' personal experiences of communication during consultations and their preferences for prognostic communication	Cross sectional retrospective qualitative interview study	n=73. Newly diagnosed metastatic cancer (lung 33%, breast 26%) from 4 biggest cultural groups in Australia (31 Anglo-Australians, and 20 Chinese, 11 Arabic, 11 Greek migrant patients) and 66 family members. Patients 64% female and 67% over 60 years.	Demographic data and 8-item Rissel Acculturation Scale (Cronbach α = 0.88 for Arabic population) collected. Structured interview in patient's preferred language. Thematic and comparative analysis approach used to code and elicit themes. Development of thematic tree.	Migrant patients often wanted to be informed of their prognosis. Some Anglo-Australian patients did not want their prognosis discussed, or wanted to leave discussion until they were more unwell. Some patients and families wanted the doctor to ask before disclosing this information. Others wanted the doctor to make a judgement. Migrant families sometimes wanted to withhold prognosis when the patient wanted to know.
Liu et al. (2014) USA	Test whether patients with metastatic cancer at diagnosis who have a physician who reports generally discussing prognosis earlier have a more accurate awareness of prognosis than those with a physician who delays a prognosis discussion.	Cross sectional quantitative study. Patient or carer interviews 3 - 6 months after diagnosis. Questionnaire sent to patient-nominated significant doctor regarding attitude to prognosis disclosure. Part of larger CanCORS study.	n=686. (RR 64% - eligible patients who had completed survey and identified a doctor). Stage IV lung or colorectal cancer. Average age 63 years. 49% women, 57% lung cancer, 88% had received chemotherapy at the time of the interview.	Open-ended question to elicit patient estimation of prognosis. Accurate prognosis deemed <2years (lung), <5 years (colorectal). Physicians asked to identify when they would discuss prognosis with patient with estimated prognosis of 4-6 months. Analysis of co-variables.	70% of physicians would discuss prognosis at earliest opportunity. 19% of lung patients and 14% of colorectal patients were deemed to have an "accurate" estimation of prognosis. 36% of patients stated "do not know" prognosis and 11% stated, "it was in God's hands". Patients whose "most important doctor" would discuss prognosis early were more likely to have an accurate estimate of prognosis (OR 3.23, 95%CI 1.39 - 7.52)
Rodriguez et al. (2008) Australia	How oncologists, patients with incurable cancer and their kin use framing when they discuss treatment-related and disease-related prognosis during clinic visits.	Cross sectional qualitative analysis of oncology consultations. Part of larger project looking at the effect of prompt sheets in oncology consultations on patient questioning.	n=29. Incurable cancer patients (no diagnoses given). Randomly selected transcripts from larger study of 319 new cancer patients. 51% male, age range 38 - 83 years. 23 out of 29 had a relative present.	Initial consultation digitally recorded, transcribed and analysed. Constant comparative analysis (grounded theory) to develop and apply codes and analyse data.	23 out of 29 visits contained discussion of prognosis. 166 episodes of prognostic discussion occurred; the majority were by oncologists (128). Patients made 29 prognostic utterances. 62% of prognostic talk was about the current patient or "patients like you". Oncologists talked about treatment related prognosis 72% of the time and patients 55%. 48% of utterances were framed positively and 31% negatively. During discussion of treatment outcomes, oncologists tended to address patients in personalised language and positive terms. Discussions of death or other negative outcomes tended to be framed in impersonal language.

Patients recruited outside treatment setting

Thorne et al. (2006) Canada	Examine the impact on patients with cancer of information provided in numerical form.	In-depth qualitative interviews with additional written patient accounts and focus groups. Cross sectional design (within an overall longitudinal study)	n=200. Heterogeneous cancer patients (50% breast cancer). Purposeful sampling to achieve a range of cancer sites and disease stages as well as demographic differences.	Study used an interpretive description approach. Interviews and focus groups were transcribed and all material analysed. No details of interview schedule presented, but investigators stated that the researcher did not initiate any specific questions regarding numerical data.	Almost all patients expressed a preference for being well informed about their illness. Patients used numerical information in a variety of ways and in some cases struggled to make sense of the information. Some patients used a narrative to reframe the numerical information in a way that was seen as more positive, or used it within treatment decision-making. Many patients found they received different numerical estimates from different sources. Most patients recognised the difference between population data and individual data. Some patients discounted negative odds as a means of coping.
Thorne et al. (2007) Canada	How patients with cancer or chronic illness describe the balance between hope and honesty in their communication with health care professionals, particularly in the context of information exchange associated with prognostication.	Secondary analysis of two previous qualitative studies. In-depth interviews conducted with patients was the primary source of data in both studies, conducted by the same research team.	As for Thorne et al. 2006, plus 30 patients with chronic illness (diabetes, fibromyalgia and multiple sclerosis)	Interpretive description used to analyse content using detailed coding of interview content.	Helpful and unhelpful communications; Various factors were cited as helpful, but timely, compassionate and appropriate were key features. Unhelpful communication often had a mismatch between patients' perceived need and the manner and content the professional disclosed. Impact of prognostic communications on hope; Hope was perceived as essential. Where prognostic information supported hope this was seen as positive. Where it did not, patients required significant reframing to attempt to rebuild their fragile hope. Patient recommendations for supportive prognostic communications; an overarching theme of balancing "hope" and "honesty" through individualising information, guiding interpretation and facilitating uncertainty management.

Abbreviations: n= sample size, RR response rate, CI confidence interval, OR odds ratio, HADS hospital anxiety and depression scale, QoL quality of life
(Reproduced with permission, Elsevier)

Appendix 5: Literature review 2014 – 2018 - summary of included studies

Authors (year) Country	Study aims	Design and methods	Sample	Measures and analysis	Results
Early stage cancer					
Blakely et al. (2017) Canada	Understand information needs and communication experiences of patients treated surgically for cancer of the pancreas. Identify enablers and barriers to communication and strategies to support and improve communication	Qualitative analysis of interviews with patients with pancreatic cancer and surgical oncologists	n=10 patients undergoing surveillance after being treated surgically with curative intent for periampullary cancer. Additional 2 patients declined participation. N=10 surgeons (all approached participated)	Semi-structured interviews with patients 6 - 24 months post operatively. 8 patients had a family member with them during the interview. Semi-structured interviews with surgeons. All interviews transcribed verbatim and analysed together using Grounded Theory.	Findings organised into 3 main themes. <u>Understanding</u> : Information needs to be tailored to the individual, as patients have limited capacity to understand complex medical and statistical information. Strategies were in place to manage information; surgeons tried to present information in an understandable way, avoiding jargon. Some described their approach as paternalistic. Most avoided statistics. <u>Trust</u> : relationship between professional and patient was important and aided information strategies. <u>Hope</u> : Need to maintain hope recognised by patients and surgeons. Balance between hope and honesty important. Patients desired optimistic and truthful facts that preserve a sense of hope. There was an interrelationship between truth and hope.
Englehardt et al. (2017) Netherlands	Assess whether uncertainty in statistical estimates are disclosed during consultations where adjuvant breast cancer therapy is discussed. Ascertain patients' perceptions of uncertainty in the information they were given.	Nested mixed-methods study (parent study about Adjuvant! Tool). Recorded consultations, and brief follow-up interview with patients. Selected focused in-depth interviews. Interviews within 7 days of consultation.	n=198 women with invasive breast cancer stage I - III where recorded consultation included discussion of probability. Parent study included 358 patients (overall RR 72%). 170 women completed a brief interview and 15 in-depth interview. n=20 oncologists completed surveys out of 28 involved.	References to uncertainty coded in consultations. Brief interviews and in-depth interviews coded by 2 researchers using a <i>priori</i> and open coding. Patient social demographic details and assessment of numeracy collected via questionnaire. Oncologists completed questionnaires about attitudes to uncertainty disclosure.	Uncertainties of prognostic estimates were disclosed in 49% of consultations. Of these, 79% discussed aleatory and 21% epistemic uncertainty. Allusions to precision of statistical information were generally ambiguous. 85% of patients recalled the probabilities discussed with them in the consultation. Patients had difficulties understanding interview questions about uncertainty. Most did not recognise the imperfect nature of survival data. 1 in 10 patients did not recognise probabilities given in consultations were imperfect. Eliciting patients' perceptions of uncertainty were methodologically difficult. Oncologists had low to moderate reluctance to discuss uncertainty, with 9 saying they usually discussed epistemic and 15/19 aleatory uncertainty in consultations.

Janz et al. (2017) USA	Characterise patients' perception of doctor-patient risk of recurrence discussions. Determine if characteristics of discussion are associated with understanding. Determine if approach is affected by patients' personal factors	Questionnaire study sent to breast cancer patients 2 months after surgery and linked to cancer registry data.	n=3930 (RR 68%) weighted sample of early stage drawn from cancer registry between 2013 - 15. Black Asian and Hispanic women oversampled. Women 20 - 79 with DCIS or stage I-II breast cancer. 2502 responded, 1207 did not meet eligibility criteria. Analysis on 1295 women.	Cancer treatment details derived from cancer registry. Patient questionnaire 5-pt likert scales measuring numeracy, health literacy, general worry, and recurrence worry. Recall of doctor-patient communication of recurrence. Patient estimate of recurrence risk. Multivariable regression models of doctor-patient outcomes. Accuracy of patient estimates classified as zero, reasonably accurate, or overestimation	33% of women felt doctor discussed recurrence risk 'quite a bit' or 'a lot'. 14% reported their doctor did not discuss recurrence risk at all. 51% reported their doctor talked about recurrence risk using words and numbers and 24% using words only. Patients who did not make a 'reasonably accurate' estimation of their recurrence risk were more likely to report their doctor did not discuss recurrence risk. Patients who had low numeracy reported less recurrence risk discussion. 60% of patients reported that their doctor never enquired about recurrence worry. Recommendations: enhanced training for doctors in risk communication, strategies to increase understanding (use of words and numbers and easy read information), provision of services to help women manage worry.
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Authors (year) Country	Study aims	Design and methods	Sample	Measures and analysis	Results
Cartwright et al. (2014) USA All cancer stages	Examine how cancer patients understand and discuss prognostic information	Qualitative analysis of focus group data. Secondary analysis from a larger study into health literacy	n=39 patients with cancer participated out of 83 eligible patients contacted. Patients under care of oncologist with breast haematological, colorectal, lung and other cancer types. All cancer stages were represented. Recruitment by study staff approaching patient and by means of flyers in urban "safety net" waiting room. 6 focus groups, 3 with > high school education and 3 < high school education.	Verbatim transcripts of focus groups analysed using content analysis. Preliminary themes of prognosis, diagnosis and staging were analysed using a matrix for each theme.	Understanding prognosis: discussed in terms of mortality or estimated limited survival. Patients often talked about prognosis in ambiguous terms. Some reported prognosis in terms of months or years, some talked about a 'rate', but it was unclear what was meant by this. Some did not receive any prognostic information. Only 2 patients reported using prognostic information to make treatment-decision. Communicating prognosis: Patients saw prognosis negatively and related it to a limited lifespan. Patients felt doctors were not being compassionate when they gave a prognosis. Giving prognosis linked to damaging hope. Professionals may withhold a prognosis to prevent patients "giving up". Exceeding prognosis: patients took pride if they lived beyond the prognosis given by a doctor. Attitude impacts prognosis: 10 participants spoke about beliefs that their personal attitude can influence outcome. Conclusion: Patients need greater explanation about what prognostic information can tell them, so they make use of it.
Dronkers et al. (2018) Netherlands	Investigate whether prognostic information or life expectancy is included during communication on diagnosis and treatment plans between physicians and patients with head and neck cancer. Describe professionals' communication style	Qualitative analysis of patient professional consultation using audio recordings.	n=23 patients with head and neck cancer, being treated curatively or palliatively. 7 head and neck surgeons. 8 patients declined participation. Patients undergoing consultation where treatment options were discussed and questions about prognosis were expected. Patients average age 68, 87% undergoing curative treatment	Consultations transcribed verbatim and analysed using constant comparative approach. First 7 consultations coded by 2 researchers and framework developed. Subsequent transcripts coded by one researcher using framework. No new themes identified in last 13. Coding consensus achieved by discussion.	222 episodes of prognostic discussion across 23 consultations. 5.9% of episodes were quantitative estimates of prognosis, with 94.1% of episodes were qualitative. Qualitative prognosis was discussed in all consultations. A mixture of qualitative and quantitative prognosis was discussed in 7 consultations. Six types of qualitative prognosis communication were identified: 1. Good news/bad news flow, 2. Positive framing, 3. Negative framing, 4. Implicit prognosis, 5. General counselling, 6. Scenario analysis. Surgeon communication styles identified were 1. Directive (physician centred) and 2. Affective (more patient centred). Low level of explicit prognostic discussion linked to lack of data applicable to the individual, difficulty determining what information patients want and when, and lack of surgeon communication skills to facilitate this.

Furber et al. (2015) UK	Explore patients' experiences of first oncology consultation. Explore situational and emotional factors underpinning and shaping how people make sense of the information they receive.	Qualitative analysis of patient interviews, forming part of a larger mixed methods study looking at communication and patients satisfaction.	n=182 newly diagnosed and follow-up consultations with patients with cancer. Sub-set of 36 patients selected for interview drawn from patients with high / intermediate / low satisfaction scores, with further sub-set of 5 patients having their first consultation.	Semi structured interviews with patients 1 - 4 days after consultation in patient's home. Audio recordings transcribed verbatim. Analysis used Interpretive Phenomenological analysis. Analysis initially case-by-case. Later tentatively cross case.	Two key themes were developed. <u>Knowing and not knowing</u> : Patients had a range of seemingly contradictory understandings of their diagnosis and prognosis. <u>Wanting to know and not wanting to know</u> : Patients expressed contradictory views on whether they wanted information and whether to disclose it to family members. There are differences in information requirements between individuals, but also ambivalence within individuals. Authors link these findings to Awareness Contexts theory and conclude patients have a right to know prognosis, but not a duty to know.
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Authors (year) Country	Study aims	Design and methods	Sample	Measures and analysis	Results
Chou et al. (2017) USA Advanced cancer	Describe oncologists' language during initial discussion about prognosis and treatment goals with patients with advanced cancer	Qualitative analysis using sub-set from a larger study looking at racially discordant consultations. Video recordings of consultations.	n=26 African American patients with advanced breast, lung or colorectal cancer (stage III or IV) 58% of sample had breast cancer diagnosis. Mean age 58.6. 77% female. 9 oncologist participants. 70% male.	Macro and micro level in-depth discourse analysis on transcripts of video recordings to describe and interpret oncologists' communication and linguistic behaviours	Prognosis was discussed in 19 recorded consultations. 3 communication behaviours were identified at the Macro-level: 1. <i>Minimising prognosis discussions</i> , 2. <i>Emphasising uncertainty and lack of information</i> , 3. <i>Emphasising optimism and hope</i> . At the Micro-level a further three behaviours were identified: 1. <i>Use of euphemism and linguistic hedging</i> , 2. <i>Use of modal expressions</i> , 3. <i>Use of complex language and medical jargon</i> . Missed opportunities for prognostic discussions identified. Prognostic talk was often vague and rarely included survival estimates. Prognostic conversations were frequently brief and moved quickly on to treatment talk. Observed use of ambiguous language may exacerbate patients' poor understanding of prognosis. Communication could be improved by skills training and coaching.
Gough et al. (2015)	Explore patient centred accounts of the value and timing of prognostic discussions in advanced soft tissue sarcoma patients.	Qualitative analysis of patient interviews using a cross sectional design.	n=24 patient with diagnosis of locally advanced or metastatic soft tissue sarcoma treated at one centre. 3 patients were considered to be receiving palliative care only. 36 patients approached (12 declined: 7 too unwell, 5 did not want to discuss prognosis).	Interviews followed topic guide and took place at home or in hospital and were digitally recorded. 6 interviews included a friend or partner. Transcription was verbatim. Analysis used Framework approach.	All patients were aware of their diagnosis and that they had a 'terminal' condition. Few wanted to engage in discussion about prognosis. 4 had asked about prognosis in their initial consultation. No doctors had offered prognostic information without being asked. When patients asked, doctors were reluctant to offer estimates of prognosis. 3 themes emerged. <u>Rarity causing prognostic uncertainty</u> : as condition was rare, patients believed doctors would not have reliable prognostic information. Avoiding the <u>negative</u> : patients wished to avoid information that challenged a positive outlook and helped maintain hope. Physical symptoms better guide to prognosis than doctor: Patients used the fact they felt well to mean they were not imminently dying. Doctors did not know and were only guessing. This view did not account for sudden deterioration seen in these patients. Recommendations: offering prognostic discussion at all stages of illness may help patients ask when they are ready for these discussions and help facilitate advanced care planning.

Henselmans et al. (2017) Netherlands	Examine how oncologists communicate with patients with incurable cancer about life expectancy. Observe by whom and how these discussions are initiated and their content and manner.	Qualitative analysis of audio recordings of consultations where prognosis discussed.	n=41 patients with advanced cancer (pancreas n=20, oesophagus n=5, stomach n=4, other n=11) with life expectancy of <1 year. Mean age 62; 59% male. 6 oncologists and 7 trainee oncologists were involved in a total of 62 consultations where palliative chemotherapy was discussed. 13 patients declined participation.	Consultations transcribed verbatim and fragments where oncologists, patients or companions referred to life expectancy, implicitly or explicitly, were identified. Coding was inductive.	Discussion of life expectancy was identified in 19 consultations and this was initiated by patients (17/19) or by companions (2/19). No oncologist spontaneously discussed prognosis. Oncologists rarely used 'tailoring' questions to clarify what information was required. On 12 occasions an <i>estimate of life expectancy</i> was given; either point estimates, general timeframe, or qualitative estimate. On 7 occasions no estimate was given. Where oncologists gave numerical estimates they nearly always incorporated uncertainty in the information they gave, either by explicitly saying it is not possible to predict life expectancy for an individual patient, or by giving wide ranges in their estimate. Oncologists also discussed personalising prognostic estimates by adjusting them in relation to the patients' characteristics. Oncologists did not discuss limitations of underlying evidence.
Singh et al. (2017) USA	Observe explicit and implicit prognosis communication. Explore whether conversation devices were used to shroud prognosis.	Qualitative analysis of transcribed consultations, where scan results were discussed. Study was secondary analysis of data from RCT looking at effectiveness of web-based health support system.	n=144 Lung cancer patients (NSCLC) stage IIIA, IIIB and IV. Sub-set of 33 patient / physician consultation dyads analysed in which scan results were discussed and specific conversation devices were identified. Unclear number of patients involved in 33 analysed conversations.	Conversations where scan results were discussed were categorised as 'Good', 'Stable' or 'Bad' news. Transcriptions analysed using conversation analysis techniques.	Typical oncology visits conformed to a structure that consisted of symptom-talk, scan-talk, treatment-talk, and logistic-talk, and occurred in 49 of the 64 analysed conversations. Where either physician or patient tried to skip any of the initial steps, this is often blocked. Participants co-construct and maintain the social order of these visits. Only 4 incidences of explicit prognosis-talk were identified, and on 3 occasions the patient initiated this. Significant, but unexplicated prognosis information was found in scan-talk. Conversation devices were identified that identify good news in situations not immediately seen to be that, or focus the patient on what has been achieved. These were used to transition from one phase of the conversation to another. Where news was stable or bad, oncologists moved from scan-talk to treatment-talk quickly. Recommendation: Clinicians could use the question "would you like to talk about what that means?" to allow patients to initiate explicit prognostic conversations.

Appendix 6: Study approval letters

Conditions of the favourable opinion

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

1. As discussed at the meeting, there should be a preference to meet in person for the interviews unless it is clear or the participants indicate that they wish to talk over the phone.
2. PIS mentions the follow up interviews but it does not mention that these will be recorded. The technical term like "focus groups" should be explained for lay readers and it should be clarified how many participants will be present in one group.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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.rforum.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 publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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

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

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyrequest@nhs.net. The expectation is that all clinical trials



Health Research Authority

NRES Committee London - Camberwell St Giles

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Whitefriars
Lewins Mead,
Bristol
BS1 2NT

Telephone: 0117 342 1385

27 July 2015

Mr Matthew H Johnson
Macmillan Lead Cancer Nurse
Royal Brompton and Harefield NHS Foundation Trust
Cancer Nursing Office
Royal Brompton Hospital
Sydney Street, London
SW3 6LN

Dear Mr Johnson

Study title: The process of disclosure of the risk of cancer recurrence in patients following potentially curative lung cancer surgery: a multiple case study.

REC reference: 15/LO/1183
Protocol number: HWB-HSC-37
IRAS project ID: 168907

The Research Ethics Committee reviewed the above application at the meeting held on 17 July 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Tina Cavaliere, nrescommittee.london@camberwellstgiles@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study 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).

Summary of discussion at the meeting

Social or scientific value: scientific design and conduct of the study

The Committee asked Mr Johnson why the application was submitted for a proportionate review. You explained that he was advised to do so but the PR Committee recommended that it should go for full review. The Committee advised that only the studies with no material ethical issues are suitable for PR.

The Committee noted that the 12 cases to be used in the study seem to be selected because they have similarities. The Committee queried if that was ideal or whether there should be a broader range of participants included in the study. You explained that within this selected group he will be looking to purposefully include patients from a range of different prognoses following surgery. You explained that you hope to get a small number of patients at a very early stage of cancer where risks are quite low and they are not having any extra treatment and would also seek out patients who have a more intermediate prognosis where they need to have chemotherapy in order to consolidate the surgery and therefore the study will include the full range of patients.

The Committee asked Mr Johnson if in his opinion the patients would trust their clinicians to give important information about them and the risks of cancer. You explained that this is one of the things that you would like to find out through the study. You explained that there seems to be a difference in how the oncologists, surgeons and physicians face these questions. It is generally observed that the surgeons do not tend to talk about it directly but oncologists are more straightforward about it. You explained that this is one of the aims of the study to try and capture the difference and see what is better for patients and what would the patients prefer as different patients have different preferences with regards to the way the information is given to them.

Favourable risk benefit ratio: anticipated benefit/risks for research participants (present and future)

The Committee noted that the first two observations will be audio recorded and transcribed, however it is not clear who will do the transcription. Mr Johnson clarified that transcription will be done by him, however if there is any financial support available then he might involve a professional.

The Committee asked Mr Johnson how will he make sure that they will not call someone who has died. You explained that he will check with clinical teams before calling any patients.

however it may be difficult to know if someone had died in the two weeks immediately before calling them.

The Committee noted that the study will involve asking participants if they are happy with the service and information they receive from their doctor. The Committee queried if this could affect their level of trust on their doctors. You explained that the question did not aim to look at whether the service was good or bad but more to see what the patients feel about the service they get.

The Committee asked Mr Johnson whether participants, knowing that he is a cancer nurse and an expert, might ask him about his views on their condition and if they will get any better, and therefore how would he deal with that. You explained that it may not be possible for you to answer that and he would refer them to the clinical team responsible for them. The Committee however suggested that he could be asked such questions directly as participants could be very interested to know his opinion and therefore this aspect should be seriously considered.

Care and protection of research participants: respect for potential and enrolled participants' welfare and dignity

The Committee noted that the application mentions that in case any participants are distressed they will be referred/guided to the psychology or mental health services. The Committee queried if there is any information leaflet that can be provided to the participants that they can then use as a reference. You explained that you did think about this, however this study will involve a number of trusts. The patients will always go back to their referring trust and therefore it will be difficult to know who exactly they will be referred to as he does not actually work in those trusts. However it is important the clinical team has oversight of the patients' care so he plans to link in with the nurse specialists within those trusts who will be refer on to extra support if needed.

The Committee noted that there will be a follow up of six months and before approaching the participants Mr Johnson will check if they are well. The Committee queried if those conversations will be recorded. You explained that he would record the conversations over the telephone, as it may not be convenient for some of the participants to travel.

The Committee expressed concerns that some of the patients might be severely ill and may not be able to process information properly. Moreover, discussing these issues which can have an emotional impact, and doing so over the phone can be very difficult. Even though they might have consented to be contacted over the phone, they might not be aware of the kind of questions that will be asked. You acknowledged the concerns of the Committee and explained that before he actually begins asking them any questions, he will reconfirm the consent and ask if they are happy to proceed.

The Committee however agreed it may be difficult for participants to know what it may feel like talking about issues like that over the phone, and they will also not know what questions will be asked. You agreed with the Committee. You explained that you are doing the interviews over the phone only for pragmatic reasons and for the convenience of participants and to reduce the burden of multiple visits. You mentioned that he would be happy to meet participants in person where possible or if the participants prefer. The Committee recommended that there should be a preference to meet in person unless he knows or the participants indicate that they wish to talk over the phone.

Informed consent process and the adequacy and completeness of participant information

The Committee noted that the PIS mentions the follow up interviews but it does not mention that these will be recorded. The technical term like "focus groups" should be explained for lay readers and it should be clarified how many participants will be present in one group. You agreed to clarify the same.

The Committee noted that the application mentions that Mr Johnson will receive consent training before the study starts and it queried whether that training is complete. You clarified that you will be receiving the training in August.

Suitability of the applicant and supporting staff

The Committee asked Mr Johnson what support will be available to him for the study. You explained he will have three more colleagues available to support him and several other researchers from Brompton. There will also be support available from the psychology team at the trust.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering letter on headed paper [Covering letter 09 05 15]		09 June 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]		11 June 2015
GP/consultant information sheets or letters [Consultant MDT member letter]	1.0	05 May 2015
Interview schedules or topic guides for participants [Interview topic guide first patient interview]	1	02 May 2015
Interview schedules or topic guides for participants [Interview topic guide patient subsequent]	1	02 May 2015
Interview schedules or topic guides for participants [Interview topic guide staff]	1	02 May 2015
IRAS Checklist XML [Checklist_18062015]		18 June 2015
Letters of invitation to participant [Invitation letter patient carer focus group]	1.0	31 March 2015
Letters of invitation to participant [Invitation letter MDT focus group]	1.0	02 May 2015
Letters of invitation to participant [Invitation letter NLCFN Focus group]	1.0	02 May 2015
Other [Angela Tod CV]	1	09 May 2015
Other [CV Stephen Brummell]	1	12 May 2015
Participant consent form [Staff ICF main study]	1.1	11 May 2015
Participant consent form [Patient carer focus group ICF]	1.0	04 April 2015
Participant consent form [MDT Focus group ICF]	1.0	02 May 2015
Participant consent form [NLCFN Focus group ICF]	1.0	02 May 2015
Participant consent form [Patient ICF main study]	1.2	17 June 2015
Participant information sheet (PIS) [Patient Carer Focus Group PIS]	1.0	31 March 2015
Participant information sheet (PIS) [MDT Focus group PIS]	1.0	02 May 2015
Participant information sheet (PIS) [NLCFN Focus Group PIS]	1.0	02 May 2015
Participant information sheet (PIS) [Staff PIS main study]	1.1	11 May 2015

Participant information sheet (PIS) [Patient PIS Main Study]	1.3	17 June 2015
REC Application Form [REC_Form_16062015]		16 June 2015
Referee's report or other scientific critique report [Sponsor approval and scientific review]	1	01 June 2015
Research protocol or project proposal [Protocol]	1.5	09 June 2015
Summary CV for Chief Investigator (CI)	1	01 June 2015
Summary CV for student [CV Document MHJ]	1	01 June 2015
Summary CV for supervisor (student research) [First supervisor CV]	1	25 April 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay summary and flow chart]	1	09 May 2015

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

15/LO/1183 Please quote this number on all correspondence

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

Yours sincerely

Pp 

Mr John Richardson
Chair

E-mail: nrescommittee.london-camdenwellstgiles@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mr Brian Littlejohn
Ms Vandana Luthra, Royal Brompton and Harefield NHS Foundation Trust

NRES Committee London - Camberwell St Giles

Attendance at Committee meeting on 17 July 2015

Committee Members:

Name	Profession	Present	Notes
Dr Ana Bajo	Research Psychologist	No	
Mrs Jennifer Bostock	Philosopher of Psychiatry	Yes	
Miss Tina Cavaliere	Coordinator	No	
Ms Biddy Gillman	Retired Biology Teacher/ Head of year 12	Yes	
Ms Sally Gordon Boyd	Medical Ethicist	Yes	
Ms Alison Higgs	Lecturer in Social Work	Yes	
Dr Margaret Jones	Retired General Practitioner	Yes	
Mr John Richardson	Retired Director of COREC; former Ecumenical Officer for Churches Together in South London	Yes	
Mr Evan Stone QC	Retired Queen's Counsel	No	
Dr Mark Tanner	Consultant Psychiatrist	No	
Mr James Uwalaka	Regulatory Compliance Officer	Yes	
Mr Thomas Walters	Clinical Research Charge Nurse	Yes	
Mr Jonathan Watkins	Independent Social Worker	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mr Rajat Khullar	REC Manager

Appendix 7: Data management plan

Project Name Information following surgery for lung cancer (SHU Template)

Project Identifier HWB-HSC-37

Principal Investigator / Researcher Matthew Johnson

Project Data Contact 07531978548

Description: Prospective qualitative case study looking at the disclosure of the risk of recurrence following surgery for lung cancer. Overall purpose is to identify interventions or strategies that patients may benefit from following lung cancer surgery.

Institution Sheffield Hallam University

Data Collection What data will you collect or create?

Data type and format:

- Transcribed audio recordings (Word documents with plain text copy)
- Documentary evidence (PDF files).
- Demographic and background data from CRF (Excel files with CSV file copies)

Data volumes:

Patient and staff data:

- Recruitment target 12 patients.
- Maximum number of transcriptions per patient = 10
- Documentary evidence average per patient = 10
- Average file size 500Kb

Focus groups:

- Transcriptions from focus groups = 6
- Average file size 500Kb

Demographic and background data

- One Excel file 2Mb max

Anticipated total data size:125 Mb approx

How will the data be collected or created?

Data will be collected in the form of audio recordings of clinic consultations, interviews and focus group proceedings. Audio recordings will be transcribed verbatim, checked for accuracy and the originals deleted. Transcriptions will have personal identifying information removed or anonymised. This data will be in the form of word documents with plain text copies of all files. Additional data will be in the form of documentary evidence, such as pathology reports, operation notes and MDT discussion outcomes. This will be scanned and converted to PDF files, taking care to anonymise the data. Demographic and background data will be collected on to a paper CRF and transcribed onto an Excel file, which will be kept additionally as Comma Separated Variable (CSV) files.

Data source	File name
Clinic transcriptions	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Clinic transcriptions\<Clinic type>_<Participant ID><Site>_YYYY_MM_DD.docx or .txt
Patient interviews	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Interviews\Patient interviews\<First/second/third> interview_<Participant ID>_<Site/phone>_YYYY_MM_DD.docx or .txt
Staff interviews	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Interviews\Staff Interviews\Staff_<Staff ID>_<Participant ID>_YYYY_MM_DD.docx or .txt
Documentary evidence	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Documentary evidence\<Participant ID>_<Evidence type>_YYYY_MM_DD.docx or .txt
Focus Group evidence	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Focus Groups\<focus group type>_<site>_YYYY_MM_DD.docx or .txt
Demographic	\\fs1\users\M\MJ406\Sheffield Hallam PhD\Research data\Participant

data	demographics\CRF Data.xlsx or .csv
------	------------------------------------

Research data management and analysis will be undertaken using the CAQDAS program NVivo.

Documentation and metadata

What documentation and metadata will accompany the data?

Study-level documentation:

Study meta data and contextual information will be stored within NVivo using the memoing and journal function featured. Data management and achieving will follow the MANTRA guidance for NVivo contained on the website: <http://datalib.edina.ac.uk/mantra/softwarepracticals.html> .

Data-level documentation:

Contextual details, including location and details of attending subjects at interviews or clinic observation will be embedded into textual transcripts. Further observation notes and reflections will be digitized where necessary. Research journal entries will be maintained using the function within NVivo.

Ethics and Legal Compliance

How will you manage any ethical issues?

Information sheets and consent forms will be used to ensure that informed consent is gained that allows for the preservation and sharing of the anonymised data. Clinic consultations and the interviews will be recorded and then written up verbatim. References to individuals in the transcripts will be anonymised. The researcher will check that the recording and the written transcript are the same and then erase the recording. The transcript will be kept on a password-protected computer. Any further identifying details, such as institutions, will be taken out of the final thesis and any publications.

It might be that in the interviews something of concern arises relating to patient care. If that happens, the researcher will tell the subject of this concern and consult with the supervisory team to discuss any further management, acting at all times in accordance with the Nursing and Midwifery Council professional Code of Conduct (NMC 2015). Any documentary evidence that is collected that would normally contain personally identifiable information, such as histology reports or operation notes, will be anonymised and will conform to the convention outlined above prior to storage and analysis as part of the study.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

SHU will own the primary data that it collects, but the secondary data and the copyright of the thesis submitted for examination remains will be owned by Matthew Johnson. The analysed data is owned by SHU, but will not be published without the agreement and support of the project partners.

Storage and Backup

How will the data be stored and backed up during the research?

All person-identifiable data, such as consent forms and contact details will be stored in the study site file, kept in a locked area on NHS premises. Any electronic data that contains patient-identifiable information will be stored on a networked Royal Brompton and Harefield NHS Foundation Trust computer that is password protected and accessible only to the student. Only the student will have access to person-identifiable data during the study. Only data that is anonymised will be transferred out of the NHS for the purposes of data analysis by the researcher with the support of the supervisory team.

Research data will be stored on a networked drive. Data is backed up automatically on a daily basis, and can be fully recovered in the case of accidents. All backups are securely kept on two remote locations. Additionally master copies of anonymised data files will be uploaded to the student's laptop for the purpose of analysis. This data is backed up on a removable hard drive on a daily basis whenever changes are made to the data. At project close down relevant data relating to this project will be securely archived, and all data will be deleted from the NHS files.

How will you manage access and security?

Field data will consist of digital recordings that will be held on a portable password protected device, plus paper documentation such as consent forms, CRFs and field notes. Digital files will be uploaded for transcription as soon as possible following recording. All person-identifiable data, such as consent forms and contact details will be stored in the study site file, kept in a locked area on NHS premises as soon as possible following collection. Any electronic data that contains patient-identifiable information will be stored on an NHS computer that is password protected and accessible only to the researcher. Only the researcher will have access to person-identifiable data during the study. Only data that is anonymised will be transferred out of the NHS for the purposes of data analysis by the student

researcher, with the support of the supervisory team.

All data will be handled in accordance with SHU Data management policy, SHU Research data management policy, the Data Protection Act 1998, NHS Caldecott Principles (Department of Health 2003), The Research Governance Framework for Health and Social Care, 2nd Edition (Department of Health 2005), and the conditions of the main REC approval. Interview transcripts, field notes and other data collection tools will not bear the subject's name or other personal identifiable data. The subject's initials, Date of Birth and study identification code will be used for identification.

Selection and Preservation

What data are of long-term value and should be retained, shared, and / or preserved?

All data (raw and analyzed) will be deposited in the University's Repository for Data (SHURDA) before the end of the research project. The data will be retained in the archive for a period of 10 years. When depositing the data, no further changes to data formatting will be required as all necessary actions will have been conducted as the research progresses.

The study documents including the Study Master File, CRFs, Informed Consent Forms will be kept for up to fifteen years. They will be stored in locked offices within the Royal Brompton and Harefield NHS Foundation Trust. The student is responsible for the secure archiving of study documents.

What is the long-term preservation plan for the dataset?

All 'raw' data (with appropriate documentation), and the analysed data will be made available to legitimate researchers or practitioners after the embargo period has expired. This approach to open access will ensure the legacy of the project by enabling follow-up and/or longitudinal studies to be compared with these initial raw data sets.

Data Sharing

How will you share the data?

A data sharing agreement with re-users of the data will not be required, as the raw anonymized data and the data collection methodologies will be made available on a Creative Commons with Attribution (CC-BY) or equivalent license. The only exclusion from this raw data to be shared will be the audio from interviews and clinic consultations, and was a condition of ethics approval that this was destroyed following transcription. While a robust approach to ensuring consent is received from all respondents in the study to allow raw data to be shared, should some respondents refuse permission, these data will be removed before depositing the data in the SHU Repository for Data (SHURDA). The project manager will keep the Project Director informed during data collection of those respondents refusing permission for data sharing. The responsibility for ensuring extraction of data from those declining will ultimately be the Project Director.

Are any restrictions on data sharing required?

We will deposit and share our data at the end of the project without any delay. Any research outputs that are published will contain a statement that refers to the underlying datasets and how these datasets can be accessed; any restrictions to access will be outlined and justified in this statement.

Responsibility and Resources

Who will be responsible for data management?

The DMP will be implemented by Matthew Johnson, the student researcher. Overall responsibility for its implementation rests with the Director of Studies, Professor Karen Collins.

What resources will you require to deliver your plan?

No further resources are anticipated in delivery of this plan.

Appendix 8: Participant information sheets and informed consent forms

[Institution letterhead inserted here]

Patient participant information sheet

Study title:	Information following surgery for lung cancer
Chief investigator	Matthew Johnson
Telephone number	020 7352 2181

Study Sponsor: Sheffield Hallam University

I am a qualified nurse working at Royal Brompton and Harefield NHS Foundation Trust and I am also a student studying part-time at Sheffield Hallam University for a research degree (PhD). As part of this degree I am undertaking a research project.

I would like to invite you to take part in this research study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Please ask me if there is anything that is not clear. No information for this study will be collected until you have given your written consent.

The study is looking at the information that you are given following your surgery and involves myself (Matthew Johnson) being present during some consultations with your medical teams. You would also be asked to take part in three recorded interviews following these consultations. I would also like to collect some relevant information from your medical notes relating to your treatment and the team's decision making. Further details of the study are given overleaf.

Participant name:

You will be given a copy of this information sheet to keep

1. What is the purpose of this study?

The research is being undertaken as part of my research degree (PhD) at Sheffield Hallam University. The purpose of this study is to understand the information that is given to patients following surgical treatment for lung cancer by their medical teams and lung cancer nurse specialists. I would like to compare information provided by the health professionals with information that patients want to have and see if there is any difference. The aim being to identify ways of helping patients manage the uncertainty that they may feel following their treatment.

2. Why have I been invited?

You have been invited to take part in this research because you have recently had surgery for primary lung cancer.

3. Do I have to take part?

No, your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. Your decision not to participate or wish to withdraw would not influence your current or potential future medical care in any way.

4. What will happen to me if I take part?

If you decide to participate in the study I will arrange to attend your first surgical out patient clinic with you following your discharge from surgery. I will audio record the consultation and take notes of what happens during the clinic visit.

If you are referred on to see another doctor in connection to your lung cancer or back to your original hospital team after this, I will arrange to be present during the clinic visit again. As before I will record the conversation and take notes of what happens.

I will also arrange a convenient time and place to undertake a face to face interview with you at this hospital or at the hospital you were originally referred from about your experiences soon after your initial clinic visit. I expect the interview will take between 30-60 minutes depending on the amount of issues that you want to talk about. I will also record this interview. This will take place on the same day as the clinic visit or within the next 2 weeks.

I will arrange two further follow-up interviews to take place about three and six months after your surgery. This can coincide with one of your regular appointments at the hospital, or at a separate appointment at the hospital. If this interview is very difficult to schedule due to travel or other commitments, these can be by telephone if you would like. I expect these to last around 30 minutes each and again these will be recorded.

In addition to this, I would also like to collect some information from your medical records regarding your treatment and the team's decision making.

If you chose to take part I would like to undertake all three interviews and both clinic observation sessions with each patient, where possible. However, if you are no longer able to or no longer wish to take part in the research at any point you are free to withdraw without it affecting any aspect of your medical care. If this happens, I will assume that you are happy for me to use any information that I have already collected unless you specifically ask me to remove this from the study and destroy any information that I have already collected.

Towards the end of the research I will contact patients who might be willing to take part in a focus group. A focus group would involve a meeting lasting no more than two hours with around six to eight patients and their carers who have had similar experiences to you. I would lead the group and ask people to contribute their own experiences and ideas with the aim of identifying particularly helpful or unhelpful approaches or interventions when working with patients following lung cancer surgery. I would ask you for your agreement to be involved in the focus group separately at a later date.

Although you will not be directly involved, I will also interview the doctors and nurses who were present in your clinic consultations to help me understand the events from their point of view.

5. Expenses and payments

You will not be paid for taking part in this study. However, if we arrange an interview at a time when you have to make a special visit to the hospital, I will be able to offer travel and parking expenses.

6. What are the possible disadvantages and risks of taking part?

Inconvenience of the time taken for the interviews, one following the follow-up clinic visits and two in three and six months time is one disadvantage. It is possible that the interviews could touch on topics which some people may find difficult or upsetting, as I would like to cover the long term effects of your diagnosis.

If you find the interviews difficult, you can stop them at any time. If necessary we can discuss the issues raised, or decide together whether you need to talk to another professional, or be referred on to someone specialised in providing support to patients with a cancer diagnosis.

7. What are the possible benefits of taking part?

There are no direct benefits to you from taking part in this study. However, some patients may enjoy having the chance to talk about their experiences and it is hoped the research will also identify ways of helping patients get the information they want and to manage the “uncertainty” that they may feel following their treatment.

8. What if there is a problem or I want to complain?

If you have any queries or questions please contact:

Matthew Johnson via m.johnson@rbht.nhs.uk or 020 7352 8121 x XXXX at Royal Brompton and Harefield NHS Foundation Trust.

The **Principal Investigator** for the study at [Name of institution] is [Name of PI]. He/she can be contacted on XXXXX XXXXXX.

Alternatively, you can contact my supervisor: Professor Karen Collins, k.collins@shu.ac.uk or 0114 225 5732 at Sheffield Hallam University, Centre for Health and Social Care Research.

If you would rather contact an **independent person**, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) p.allmark@shu.ac.uk; 0114 225 5727.

9. Will my taking part in this study be kept confidential?

The clinic consultations and the interviews will be audio-recorded and then written up word for word. Any names or identifying details will be removed or replaced with a code. The transcript will be kept on a password-protected computer. The recording will be erased once it has been checked. The written transcripts will have all links to you removed at the end of the study and will then be kept for as long as they might be useful in future research. In the final report and any publications relating to this study I may use direct quotes from interviews or clinic consultations. When this happens, identifying details will be taken out of the quotes so people reading these will not be able to identify you.

It might be that in the interviews something of concern arises relating to patient care. If that happens, I will tell you about this concern and will consult with my supervisor to discuss what to do. I will act in accordance with my professional Code of Conduct.

The documents relating to the administration of this research, such as the consent form you sign to take part, will be kept in a folder called a project file. This is locked away securely. The folder might be checked by people in authority who want to make sure that researchers are following the correct procedures. These people will not pass on your details to anyone else. The documents will be destroyed seven years after the end of the study.

10. What will happen to the results of the research study?

The results of this research will go to form the main part of my PhD thesis on information-giving following lung cancer surgery. The final thesis will be placed in the university library and it will also be available on a public database of research dissertations. Findings from the study will be written up in one or more academic papers and submitted for publication in medical and nursing journals, or may be presented at conferences. It will not be possible to identify you within the thesis or any academic papers or presentations.

11. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University.

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by Mr John Richardson, Chair of the London – Camberwell St Giles Research Ethics Committee.

13. Further information and contact details

Chief investigator: Matthew Johnson m.johnson@rbht.nhs.uk or 020 7352 8121 at Royal Brompton and Harefield NHS Foundation Trust.

Or **Principal Investigator:** [Name of PI], or on XXXXX XXXXXX.

Alternatively, you can contact my supervisor: Professor Karen Collins, k.collins@shu.ac.uk or 0114 225 5732 at Sheffield Hallam University, Centre for Health and Social Care Research.

If you would rather contact an **independent person**, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) p.allmark@shu.ac.uk; 0114 225 5727

[Institution logo here]

Patient participant consent form

Study title:	Information following surgery for lung cancer
Chief investigator	Matthew Johnson
Telephone number	020 7352 8121 x 4710

Participant name	
------------------	--

	Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them	Please initial each box
1	I confirm that I have read and understood the information sheet dated 28/07/15 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without give any reason and 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 Sponsor, the Research Ethics Committee and from the NHS Trust, where it is relevant to this research. I give permission for these individuals to have access to my records.	
4	I agree to take part in this study	

Name of study: Information following surgery for lung cancer
Version number of patient consent form: v 1.3
Date of patient consent form: 28/07/15

To be filled in by the participant I agree to take part in the above study		
Your name	Date	Signature

To be filled in by the person obtaining consent I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.		
Name of investigator	Date	Signature

Filing instructions
1 copy to the participant
1 original in the Site file
1 copy in the medical notes

Name of study: Information following surgery for lung cancer
Version number of patient consent form: v 1.3
Date of patient consent form: 28/07/15

[Institution letterhead inserted here]

Staff participant information sheet

Study title:	Information following surgery for lung cancer
Chief investigator	Matthew Johnson
Telephone number	020 7352 2181

Study Sponsor: Sheffield Hallam University

I am a qualified nurse working at Royal Brompton and Harefield NHS Foundation Trust and I am also a part-time student studying at Sheffield Hallam University for a PhD.

I would like to invite you to take part in this research study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Please ask me if there is anything that is not clear.

The study is looking at the information that patients are given following lung cancer surgery and involves myself (Matthew Johnson) being present during a consultation with a patient following lung cancer surgery. You would also be asked to take part in a short recorded interview at a convenient time following the consultation. Ideally this will be soon after the consultation in order to capture your experience.

Participant name:

You will be given a copy of this information sheet to keep

1. What is the purpose of this study?

The research is being done as part of my research degree (PhD) at Sheffield Hallam University. The purpose of this study is to understand the information that is given to patients following surgical treatment for lung cancer by their medical teams and lung cancer nurse specialists. I would like to compare this to the information that patients want to have and see if there is any difference. In the end I hope to identify ways of helping patients manage the uncertainty that they may feel following their treatment.

2. Why have I been invited?

You have been invited to take part in this research because you will be seeing a patient who has undergone surgery for a primary lung cancer in clinic.

3. Do I have to take part?

No, your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. If you are due to see a patient who has agreed to take part in the study, I would attempt to ask if another member of the team could see the patient instead. If this was not possible, I would then withdraw the patient from the study.

4. What will happen to me if I take part?

If you agree to participate in the study I will arrange to attend the clinic when you are seeing a patient already recruited to the study, in which they have agreed to observation of the clinic and to be interviewed afterwards. I will audio record the consultation and take notes of what happens during the clinic visit (having received written consent from yourself and the patient).

I will then arrange with you a convenient time and place to undertake an interview regarding the clinic consultation with the patient. Ideally this will be soon after the consultation in order to capture your experience. The interview will ideally be face to face, but can be done over the telephone if this is easier for you. I expect the interview will take between 20 - 30 minutes depending on the issues that come up. I will audio record the interview.

5. Expenses and payments

You will not be paid for taking part in this study.

6. What are the possible disadvantages and risks of taking part?

Some clinical staff have concerns about someone listening and recording their consultation and worry that their communication skills are being judged or held up to criticism. This is not the aim of this research, rather it hopes to understand some of the tacit skills staff use to convey complex and potentially difficult news to patients. Consultations and interviews will all be treated confidentially (see below). Another factor in taking part in the study is the inconvenience of the time taken for the interview following the clinic.

7. What are the possible benefits of taking part?

There are no direct benefits to you from taking part in this study.

8. What if there is a problem or I want to complain?

If you have any queries or questions please contact: Matthew Johnson m.johnson@rbht.nhs.uk or 020 7352 8121 x 4710 at Royal Brompton and Harefield NHS Foundation Trust, or the Principal investigator for the [Name of site], [Name of PI] via [email], or on XXXXX XXXXXX.

Alternatively, you can contact my supervisor: Professor Karen Collins, k.collins@shu.ac.uk or 0114 225 5732 at Sheffield Hallam University, Centre for Health and Social Care Research

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) p.allmark@shu.ac.uk; 0114 225 5727

9. Will my taking part in this study be kept confidential?

The clinic consultations and the interviews will be recorded and then written up word for word. I will check that the recording and the written transcript are the same. I will then erase the recording. The transcript will be kept on a password-protected computer and will not be available to any other member of the team. Identifying details will be taken out of the transcript. Patients, staff and locations will be anonymised in the final thesis and any publication resulting from this study. People reading these will not be able to identify you or your patient. The written transcripts will have all links to you removed at the end of the study and will then be kept for as long as they might be useful in future research.

It might be that in the interviews something of concern arises relating to patient care or safety. If that happens, I will tell you about this concern and will consult with my supervisor to discuss what to do. I will act in accordance with my professional Code of Conduct.

The documents relating to the administration of this research, such as the consent form you sign to take part, will be kept in a folder called a project file. This is locked away securely. The folder might be checked by the research authorities who want to make sure that the correct procedures are being followed. These people will not pass on your details to anyone else. The documents will be destroyed seven years after the end of the study.

10. What will happen to the results of the research study?

The results of this research will go to form the main part of a PhD thesis. The final thesis will be placed in the university library and are also available on a public database of research dissertations. Findings from the study will be written up in one or more academic papers and submitted for publication in medical and nursing journals.

11. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University.

12. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by Mr John Richardson, Chair of the London – Camberwell St Giles Research Ethics Committee.

13. Further information and contact details

Chief investigator: Matthew Johnson m.johnson@rbht.nhs.uk or 020 7352 8121 x 4710, or the Principal investigator for the [Name of site], [Name of PI] via [email], or on XXXXX XXXXXX.

Alternatively, you can contact my supervisor: Professor Karen Collins, k.collins@shu.ac.uk or 0114 225 5732 at Sheffield Hallam University, Centre for Health and Social Care Research.

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) p.allmark@shu.ac.uk; 0114 225 5727

Staff participant consent form

Page 1 of 2

[Institution logo here]

Staff participant consent form

Study title:
Information following surgery for lung cancer

Chief investigator
Matthew Johnson

Telephone number
020 7352 8121 x4710

Participant name

Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them

1

I confirm that I have read and understood the information sheet dated 28/07/15 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2

I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without give any reason and without my medical care or legal rights being affected.

3

I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the Sponsor, the Research Ethics Committee and from the NHS Trust, where it is relevant to this research. I give permission for these individuals to have access to the data collected about me.

4

I agree to take part in this study

Staff participant consent form

Page 2 of 2

To be filled in by the participant

I agree to take part in the above study

Your name

Date

Signature

To be filled in by the person obtaining consent

I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.

Name of investigator

Date

Signature

Filing instructions

1 copy to the participant

1 original in the Site file

Name of study: Information following surgery for lung cancer

Version number of staff participant consent form: v 1.2

Date of patient consent form: 28/07/15

Sheffield Hallam University

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Appendix 9: Study case report forms and consultation observation form

Study sponsor: Sheffield Hallam University

Patient initials: C P P

Sponsor study ID: HWB-HSC-37

Patient study number: P 08

Section one: Eligibility criteria

Name of person making first approach to patient

Position of person making first approach to patient

Participant information sheet given to the patient?

Is patient willing to be approached to discuss study further by researcher?

2

Lung C.S

18 / 08 / 2016

16: 00

Yes

No

Inclusion criteria

1. Patient has had a surgical resection for primary lung cancer

2. Patient is aware they have or are likely to have lung cancer

3. Patient has not yet been seen in the first follow-up clinic

4. Patient referred from hospital included in study (RFH or SMH / WGH)

5. Patient speaks fluent English

Yes

No

Exclusion criteria

1. Patient is under 18 years of age

2. Patient is unable to give informed consent to participation in study

3. Patient has undergone surgery where the aim is not curative (ie surgical biopsy, tumour de-bulking, "open and close" surgery)

4. Patient has a diagnosis of carcinoid tumour with no atypical features

5. Patient has a diagnosis of mesothelioma

6. Patient is judged by clinical team to be emotionally or psychologically unstable

Yes

No

Eligibility confirmed / ineligible confirmed by CI:

Name: Matthew Johnson

Signature: M Johnson

Date: 13.4.16

CASE REPORT FORM

Information following surgery for lung cancer

Study Reference: HWB-HSC-37

Sponsor: Sheffield Hallam University

Chief Investigator: Matthew Johnson

Participant initials: C P P

Participant study number: P 08

Date of Birth: 04 / 08 / 1955 (dd / mmm / yyyy)

I hereby confirm that the information supplied in this CRF is complete and accurate data. I confirm that the study was conducted in accordance with the protocol and any protocol amendments and that written consent was obtained prior collection of data for the study.

Investigator's signature: M Johnson

Date of signature (dd/mm/yyyy): 19 Sep 2016

CRF for information following surgery for lung cancer

Version: 1.1

Page 1 of 10

CRF for information following surgery for lung cancer

Version: 1.1

Page 2 of 10

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Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	LP	Patient study number:	P08

Section two: Informed consent

Has the subject freely given written informed consent? Yes ☒ No ☐

Date written informed consent given (dd / mm / yyyy)

15 / APR / 2016

Section three: Social and medical history

Patient sex ☐ Male ☒ Female

Referring MDT: ☐ RFH ☒ SMH/WGH

Age: 61

Ethnicity: white British

Main support: Husband / daughter

Marital status: ☒ M/CP ☐ W ☐ S ☐ D

Section four: pre-operative staging

Clinical staging cT 2A N3 M0

Pre-operative histology: Adenocarcinoma ☐

No pre-operative histology ☐

Section five: surgical procedure

Surgical procedure ☐ Pneumonectomy ☐ Bi-lobectomy ☐ Sleeve lobectomy

Date of surgery 16 / MAR / 2016 ☒ Lobectomy ☐ Segmentectomy ☐ Chest wall resection

Other ☐

Copy of operation note taken? Yes ☒ No ☐

Section six: discharge and follow-up

Date of discharge from surgery 17 / MAR / 2016

Date of surgical follow-up clinic 18 / APR / 2016 Location:

Date of post-op MDT discussion 01 / APR / 2016

Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	LP	Patient study number:	P08

Section two: Informed consent

Has the subject freely given written informed consent? Yes ☒ No ☐

Date written informed consent given (dd / mm / yyyy)

15 / APR / 2016

Section three: Social and medical history

Patient sex ☐ Male ☒ Female

Referring MDT: ☐ RFH ☒ SMH/WGH

Age: 61

Ethnicity: white British

Main support: Husband / daughter

Marital status: ☒ M/CP ☐ W ☐ S ☐ D

Occupational history: Administrative assistant.

Highest education qualification: A Levels - (Attended university)

Smoking history: ☐ Never ☒ Stopped - when quit (year) 2016 ☐ Current

Past medical history: Commenced Palliative Chemotherapy 01/Jan 2014
 Maintenance Chemotherapy (Pemetrexed) June 2014
 Total of 24 cycles (3/32)
 Good PR on CT scan + minimal activity on PET Jan 2014

Co-morbidities: Nil.

Study sponsor: Sheffield Hallam University	Sponsor study ID: HWB-HSC-37
Patient initials: CPD	Patient study number: P08

Section seven: post-operative staging

Pathological staging pT X N 0 M 0 Date available 21/MAY/2016

Histology No evidence of malignancy Subtype Yes No

PL 0 Vascular invasion? ☐ ☒

RQ Lymphatic invasion? ☐ ☒

Copy of final pathology? ☒ ☐

Section eight: MDT outcome

Date post-surgical MDT discussion occurred 01/APR/2016

MDT outcome: Routine follow-up Yes ☒ No ☐

Adjuvant chemotherapy ☐ ☒

Adjuvant radiotherapy ☐ ☒

Other ☐ ☒

Has first surgical follow-up occurred before MDT? ☐ ☒

If not, date for surgical follow-up clinic 15/APR/2016 Location _____

Referral to oncology? ☒ ☐

Referral to chest physician? ☐ ☒

Date of non-surgical Follow-up clinic 23/APR/2016 Location _____

Study sponsor: Sheffield Hallam University	Sponsor study ID: HWB-HSC-37
Patient initials: CPD	Patient study number: P08

Section nine: First surgical follow up clinic

Date of clinic 15/APR/2016

Visit check list

Patient re-confirms consent to study Yes ☒ No ☐

Surgeon gives informed consent Yes ☒ No ☐

CNS present Yes ☒ No ☐

CNS gives informed consent Yes ☒ No ☐

Participant No: S04

Participant No: N04

Patient interview scheduled for: Date 29/APR/2016 Time 12:45

Surgeon interview scheduled for: Location: After oncology appointment

Date 19/APR/2016 Time: ---

Location: Rescheduled via phone 6 May 15:30

CNS interview scheduled for: Date 18/APR/2016 Time 14:00

Location: via phone

Patient interview completed: Date: 15/APR/2016 (After oncology clinic)

Surgeon interview completed: Date 06/MAY/2016

CNS interview completed: Date 18/APR/2016 Face-to-face with patient

Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	U P	Patient study number:	P 08

Section eleven: Three month interview

Patient interview scheduled for: Date: 25/04/2015 Time: --:--
Location: Telephone

Patient contact log:

Follow-up contact 1 Date: 25/04/2015 Outcome Telephone interview 17-05

Follow-up contact 2 Date: --/--/-- Outcome

Follow-up contact 3 Date: --/--/-- Outcome

Interview check list

Patient re-confirms consent to study Yes ☒ No ☐

Patient interview completed: Date: 25/04/2015

Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	U P	Patient study number:	P 08

Section ten: First non-surgical follow up clinic

Date of clinic 25/04/2015

Chest physician ☐ Oncologist ☒

Visit check list

Patient re-confirms consent to study Yes ☒ No ☐ N/A

Chest physician gives informed consent ☒ Participant No: 002

Oncologist gives informed consent ☒ Participant No: 002

CNS present ☒ Participant No: N/A

CNS gives informed consent ☒

Patient interview scheduled for: Date: 25/04/2015 Time: 12:45
Location: WHH

Doctor interview scheduled for: Date: 25/04/2015 Time: 16:00
Location: Telephone

CNS interview scheduled for: Date: --/--/-- Time: --:--
Location: --/--/--

Patient interview completed: Date: 25/04/2015

Doctor interview completed: Date: 25/04/2015

CNS interview completed: Date: --/--/--

Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	<u>Z P</u>	Patient study number:	<u>P 08</u>

Section twelve: Six month interview

Patient interview scheduled for:

Date: 16/SEP/2016 Time: 11:40

Location: WGH

Patient contact log:

Follow-up contact 1 Date: 16/SEP/2016 Outcome: Interview

Follow-up contact 2 Date: Outcome:

Follow-up contact 3 Date: Outcome:

Interview check list

Patient re-confirms consent to study Yes ☒ No ☐

Patient interview completed: Date: 16/SEP/2016

Study sponsor:	Sheffield Hallam University	Sponsor study ID:	HWB-HSC-37
Patient initials	<u>Z P</u>	Patient study number:	<u>P 08</u>

Section thirteen: STUDY COMPLETION FORM and OFF STUDY FORM

Did the participant complete the study?

☒ Yes; date of last contact Date: 16/SEP/2016

☐ No; date of withdrawal Date:

Early withdrawal: Most appropriate reason

☐ Participant's decision (keep existing data) - specify

☐ Participant's decision (withdraw existing data) - specify

☐ Investigator's decision - specify

☐ Lost to follow-up

☐ Other - specify

THANK YOU CARD SENT ☒

DATE 20/SEP/2016

CRF completion:

Name: MARTIN J. BULLONSignature: MJBDate: 19/9/16

Patient & carers present:	Staff present:
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Consultation end time Length of consultation

Appendix 10: Transcription conventions

Recording	Transcription
Short pauses or hesitation (not timed)	...
Longer pauses
Very long pauses	[LONG PAUSE]
Words omitted or changed for anonymisation	[Consultant Surgeon]
Section of text omitted for space /clarity	[...] (only within thesis extracts)
Significant non-verbal content	[WRITES]
Interruptions or breaking off speech	Wor-
Two speakers speaking simultaneously	Start of overlapping [speech [Marked with left square bracket
Speech significantly louder than surrounding speech	<phrase>
Speech significantly quieter than surrounding speech	>phrase<

Appendix 11: Interview topic guides

Interview topic guide for professional participants
<ol style="list-style-type: none"> 1. Introduction to the interviews: <ol style="list-style-type: none"> a. <i>Introduction and explanation of the purpose of the interview</i> b. <i>Reiterate to participant that interviews can be stopped at any time</i> c. <i>Reconfirmation of consent to complete interview</i> 2. Risk of recurrence: <ol style="list-style-type: none"> a. <i>Explore staff member's perception of this patient's risk of recurrence</i> b. <i>Explore their perception of the role of adjuvant therapy in this case</i> 3. Disclosure choices: <ol style="list-style-type: none"> a. <i>Understand how the decision was made as to what information to present to the patient in relation to histopathology and surgical findings</i> b. <i>Use key points in the clinic encounter to ask why they chose to use a particular phrase or to give/not give particular information</i> 4. Perceived role in disclosure of diagnosis and prognosis: <ol style="list-style-type: none"> a. <i>Explore what the staff member is trying to achieve when giving information to patients regarding diagnosis and prognosis</i> b. <i>What do they see as the benefits of information giving regarding detailed clinical information and risk of recurrence?</i> c. <i>What do they see as the risks or problems with giving detailed clinical information and risk of recurrence?</i> d. <i>Explore who they feel has responsibility, or is best placed, within the patient's MDTs to discuss diagnosis and prognosis or risk of recurrence with patients</i> 5. Supporting patients to cope with the future: <ol style="list-style-type: none"> a. <i>Explore the staff member's concept of the way that <u>this patient</u> manages the emotional challenge of living with the risk of lung cancer recurrence.</i> b. <i>What does the staff member see as their role in helping patients face this challenge?</i> c. <i>Explore what the terms "HOPE" and "UNCERTAINTY" mean to the staff member in the context of cancer</i> d. <i>Explore the implications of these concepts for lung cancer patient management</i> 6. Interview close: <ol style="list-style-type: none"> a. <i>Check whether any other points they wish to make</i> b. <i>Thank the participant for their time and insight</i>

Interview topic guide for first patient interviews

1. Introduction to the interviews:
 - a. *Introduction and explanation of the purpose of the interview*
 - b. *Reiterate to participant that interviews can be stopped at any time*
 - c. *Reconfirmation of consent to complete interview*
2. Diagnosis and treatment:
 - a. *Explore knowledge and understanding of diagnosis*
 - b. *Understanding of patient's treatment to date*
3. Aim of treatment
 - a. *Explore patient's understanding of the aims of treatment*
 - b. *Understanding of planned future management or follow-up*
 - c. *Explore patient's expectations regarding reason for follow-up and adjuvant therapy (if applicable)*
 - d. *Explore patient's view of the medium to long term future in relation to risk of recurrence*
4. Information to date:
 - a. *Explore key sources of information about their condition from diagnosis onwards*
 - b. *Explore overall satisfaction with quantity, timeliness and ease of access to information*
 - c. *Explore the information have they have been given regarding the risk of cancer recurrence following surgery*
 - d. *Information seeking style and reasons for this*
5. Information presented in observed clinics:
 - a. *Explore recall from clinic(s) regarding diagnosis, treatment and risk of recurrence*
 - b. *Examine their feelings, hopes and fears regarding this information*
 - c. *Examine their feelings regarding the manner in which this information was presented*
 - d. *Explore whether the patient felt they had all the information they needed, or whether there was other information they would have liked to have*
6. The future:
 - a. *Explore how the patient sees the future in relation to their diagnosis of lung cancer.*
 - b. *Explore what the terms "HOPE" and "UNCERTAINTY" mean to the participant at the moment*
 - c. *Explore the implications of these concepts for the patient in managing their diagnosis of lung cancer and its treatment*
7. Interview close:
 - a. *Check whether any other points they wish to make*
 - b. *Check how the participant is feeling after the interview*
 - c. *Thank the participant for their time and insight*
 - d. *Explain I will be in contact to arrange subsequent interview*

Interview topic guide for second and third patient interviews

1. Introduction to the interviews:
 - a. *Introduction and explanation of the purpose of the interview*
 - b. *Reiterate to participant that interviews can be stopped at any time*
 - c. *Reconfirmation of consent to complete interview*
2. Check progress since last interview:
 - a. *Follow-up, treatment or medical developments since last interview*
 - b. *Global sense of how they are coping physically and emotionally*
3. Information presented in observed clinic (if occurred since previous interview):
 - a. *Explore recall from clinic(s) regarding diagnosis, treatment and risk of recurrence*
 - b. *Examine their feelings, hopes and fears regarding this information*
 - c. *Examine their feelings regarding the manner in which this information was presented*
 - d. *Explore whether the patient felt they had all the information they needed, or whether there was other information they would have liked to have*
4. Changes to knowledge and understanding:
 - a. *Explore any changes to patient's knowledge and understanding of diagnosis and treatment*
 - b. *Ascertain patient's current understanding of their risk of recurrence*
 - c. *Understand where patient has gained new information*
 - d. *Examine their feelings, hopes and fears about the risk of recurrence*
5. The future:
 - a. *Explore how the patient sees the future in relation to their diagnosis of lung cancer*
 - b. *Explore what the terms "HOPE" and "UNCERTAINTY" mean to the participant at the moment*
 - c. *Explore the challenges the patient has experienced in managing hope and uncertainty*
 - d. *Explore the ways in which the patient has found useful in managing hope and uncertainty*
6. Interview close:
 - a. *Check whether any other points they wish to make*
 - b. *Check how the participant is feeling after the interview*
 - c. *Thank the participant for their time and insight*

Appendix 12: research diary extract

6 Nov 2016:

First clinic observations and staff interviews. Glad to be getting going. Attended SMH MDT and caught P03 MDT discussion and initially thought that she would not be seen in clinic today, but in fact she was, so I was able to see both of them. Not sure when P03 will come back to oncology clinic as she is an in patient at the moment.

Clinic with S01 and P03

P03 was brought down from the ward as she had been admitted yesterday afternoon with an infection. She was there with her son, who I briefly met while she was I/p. She was anxious and in a great deal of pain and not really having a great hospital experience. AGE had said that she needed to have fluid drained from her chest, but they did finally manage to contact HH and were told not to! This has also slightly dented her confidence in the local team. I think she was worried that things were quite seriously wrong and that there might be an infection in the pneumonectomy space.

During the interaction with S01, she was enormously reassured that there wasn't a serious infection and that it was a minor chest infection that she can get over totally. S01 also was able to reassure her that someone can sort out her pain control and felt that S01 had been able to sort out the prescription. S01 went through all the information about the surgery, and P03 appeared to be relieved to hear this information. However, I am not too sure how much of this she has taken on board about the seriousness of the situation with the tumour being a Large Cell Neuroendocrine tumour. This has a similar prognosis to a small cell cancer, as I understand it. I also do not feel that much of this was made by S01, but in fact she did spell out the name and was aware that the patient would likely go and look it up on the internet, or at least her son. She will come back to Onc clinic once she is able to get over this infection. S01 has pointed out that she may end up with more problems with chemotherapy in relation to her pneumonectomy, although I don't think that this was said to her directly. I will try and keep an eye on when she is due back to find out when she is able to come to the clinic.

Clinic with S01 and P04

P04 turned up ahead of the appointment with her husband and she was feeling very well, seemed to be recovering well, pain settled and feeling good. Quite a positive interaction with S01. Feel that the interaction with S01 went well and that was very up beat. P04 took a lot of the information in and seemed to understand it and seemed to have some good questions about what was going on. The fact that she has also got a long term condition of RA will affect the way she and her husband approaches the matter of her cancer. She is well informed about her RA treatment and seems not to be phased by this new medical information. I have agreed that I might ring her ahead of the appointment with Oncology with the idea of trying to schedule the next appointment. She seemed very happy to take part and I feel that went really well. I have told her that the next appointment will be the time that I do the patient interview afterwards and she was OK about that.

Interviews with S01

S01 agreed to do the interviews today. I was nervous about doing these. I feel slightly intimidated. She did well to put me at my ease! I know her, but really only in a limited way. However, she has been very supportive ever since I told her about the study and PhD. I thought first interview went well, and this was the first time that I did these interviews. These will be the same questions for each patient so then following that on with the second interview was quite hard, because it was repetitive and I couldn't ask the same questions again. Some of what I had asked about in the first interview were general points about giving prognostic information and limitations and her own professional boundaries. When I came on to the second interview it felt wrong to keep asking the same questions again, going over and over

again. I'm going to have to think about this in the future if there are more patients who SO1 sees again and not by her Reg or another surgeon. I am keen to get these interviews transcribed to see how they have gone. Very relieved to get some data down. Overall, I am feeling upbeat and getting somewhere with this. The process seems good. The sheets for the clinic observations do not seem quite right and do not really have the right spaces on them in order to get the right information down and it may be helpful to rethink these and get something more structured. Just about remembering to get times down for start and finish, but will hopefully overall will improve with practice!

9 Nov 2015:

This weekend I have transcribed both the clinic encounters. I have attempted some initial coding of the surgical clinic data for P04. This is really trying to apply descriptive codes to what was happening throughout the clinics. Need to think about how to do this, as these are specifically related to the surgical clinic and I will probably end up with other specific codes for the other clinic types and the interviews. I have picked out one in vivo code "it has all been removed". I think it seems helpful to initially try and chunk the data up into smaller types of data before trying to do anything more complicated with it, but it will require a second, third etc rounds of coding to make anything more analytical out of the data. I have started out numbering them, but I think this may prove too difficult to do at the moment as the codes are all going to be pretty fluid until I am a bit further down the process.

13 Nov 2015

Some reflection on the way to SMH whilst reading the transcripts of the two clinic encounters in order to prepare questions for P04. Thinking about the interview with SO1, I may have missed out on finding out more detail on why different information is presented or not. She was fairly detailed re: type of cancer, lymph node involvement, and size. But there was no indication of the chance of recurrence. She does state that it is not her role to be negative or too gloomy. I feel that maybe she does not want to put a dampener on the proceedings by bringing up recurrence too specifically. However, in the final part of the consultation she does bring in survival advantage. I should have picked up on this and need to make sure that I am specifically identifying this and making a clear note of the context when I am jotting things down in the consultation for use later on - although this is quite hard to do! Ideally I should listen through to the tape again ahead of the interview with the professional / patient. However, this wasn't possible this time around as I didn't have earphones. Also this time around, it was not possible for the interview with P04, as there was no time as she had to get away, so this is likely to be an on going issue in this situation.

Oncology Clinic with 001 & P04

First time that I had met this doctor today. I had spoken with him on the phone yesterday and he had seemed very helpful and willing to be involved. I raised the post interview with him and he has to leave clinic promptly at 12 in order to go to another site and therefore I won't be able to schedule face-to-face interview. I have emailed him today to try and schedule a telephone interview, but I have not yet worked out how to undertake recorded telephone interview! Quite a long and thorough clinic assessment and he was very good at listening to the patient's agenda. I felt very welcome and it was easy for me to be present. Clinic room was large and not cramped and difficult for me to be there. I was involved with patient in consultation by constant eye contact and I found myself nodding and smiling a lot! The arrangement in the other clinic rooms meant that I was at more of a angle and not quite so involved in the patient's eye line.

Interview with P04

I thought that P04 might not agree to have an interview today, as she had said that she wanted to go to see her daughter for lunch after clinic and was tight for time. I think she

might not have done the interview if the outcome of the clinic had been different, as she had said that she was very anxious about this clinic, in a way that she was not before the surgical clinic. I met her in the waiting room before hand and made myself known. I raised the issue of the interview and she was dubious and I said wait and see how you feel after the clinic appointment. I was keen not to sit with her prior to the clinic appointment and chat, as I felt that this might dilute the material that she might give me in the interview and feel like she had already done the interview! It was quite a long wait and I didn't think I could keep up small talk! I went for a coffee, but was also anxious about missing her, so I came back early again!

P04 came to quiet room after the consultation and agreed to go ahead. Husband has come in too for the discussion regarding going ahead with the interview and once he was settled into the room and the decision was made to go ahead, it was too difficult to ask him to leave. He did not say a lot, but did chip in at times, usually when P04 invited him to by a look or directly. I was aware of him fidgeting and perhaps not wanting to stay too long. I wondered whether it was him that had said for P04 not to do the interview today, maybe.

I was pleased generally with the interview when it was completed (about 40 mins in length). P04 did stop the interview, but I was on the point of wrapping it up at that time any way and I told her this. I felt there were good insight into smoking, fatalism, not thinking about the future, the unreality to her of having lung cancer (you can't see it, you can't feel it, you don't have any pain...) . Does her Rheumatoid play a big actor in this attitude of STOICISM ?? Is this cause or effect? Main driver for her is to optimise QoL. She therefore values getting back onto her RA drugs as soon as possible, as she feels noticeable deterioration in her condition, the more so since the beginning of winter. Chemotherapy would interfere with this and so she was not keen to go down this route. I think that this was a lesser driver for her than the idea that RA might lead to greater complications for her with the chemotherapy, which was alluded to by O01. There was a clear sense of fatalism in her attitude to her cancer. She stated that she was surprised that she had "got away with not having cancer for as long as she had". She feels she was due this by virtue of her smoking Hx. However, she continued to smoke up until her diagnosis and her husband has continued to smoke. Interestingly he has given up in relation to various health scares, but has resumed later on saying that it had failed (ie further blockage of coronary artery post treatment) and that he might as well continue to smoke, what the hell!

Hope appears important to her. However, would this have come out spontaneously in the interview without me introducing it? Uncertainty was not there as a theme for her as she was not entertaining the idea - or she would "face it if it happens". Overall there was great relief in not having to have chemo. I feel this was not her decision, as she stated that she would have gone through with it if it had been advised. The message was clear that this was not advised from O01 and she did not argue or feel that she should have been offered it. She has been advised that the main benefit was by going through the surgery.

She will now be referred to the chest physician for follow up and she be seen again in about 3 months time and this would be about Mid February. I have put this in my work diary to chase up in Mid January.

General comments

P03 remains an in patient and I need to make sure that I keep tabs on when she goes home and when scheduled for oncology clinic.

I returned to RBH to meet a lady who had initially not felt well enough to be approached, but is well now she has had operation. Worried that if I had not gone today she would have already gone home. She was pleased to have been approached and had already declined another (RCT) study, but felt that she would be able to take part in this study. Info sheets given and I will see when she is back in clinic in 1 - 2 weeks time. NB previous Breast Ca.

Appendix 13: Thematic framework

Codes	Sub-codes
A. Patient background factors	a1 Previous health experiences a2 Other current health concerns a3 Other background issues
B. HCP background factors	b1 Professional's experience and knowledge b2 Professional roles and boundaries b3 Professional's illness attitudes b4 Professional communication ethos
C. Lung cancer pathway up to 1st clinic	c1 Route to lung cancer diagnosis c2 Initial lung cancer pathway c3 Decision to have surgery c4 Surgical episode c5 Recovery from surgery
D. Surgical outcome	d1 Surgical procedure & findings d2 Histopathology and staging
E. Recurrence and survival	e1 Risk of recurrence e2 Survival e3 Cure e4 New cancer e5 Numerical e6 Possibility e7 Fear of recurrence or actual recurrence
F. Further treatment	f1 Decision-making for further management f2 Further lung cancer treatment
G. Follow up and monitoring	g1 Follow up and monitoring g2 Perception of treating potential recurrence g3 Recognising signs of recurrence
H. Survivorship	h1 Getting back to normal h2 Treatment effects and symptoms h3 Conception of the future h4 LWBC initiatives
I. Information	i1 Patient attitudes to information about cancer i2 Information formats i3 Timing of information giving i4 Professionals' construction of patient info attitude
J. Knowledge & understanding	j1 Patient understanding and retention of information j2 Areas of uncertainty for patient
K. Patient psychosocial factors	k1 Emotional impact of illness k2 Family and friends k3 Support available k4 Patient professional relationship
L. Cancer attitudes and beliefs	l1 Attitudes and beliefs about cancer l2 Causation l3 Smoking l4 Attitudes to cancer treatments
M. Coping	m1 Illness coping m2 Managing uncertainty m3 Supporting hope
N. Miscellaneous issues	n.1 Role of the MDT n.2 Liaison with other teams
O. Observed clinic communication	O.1 & 2 Style and content reflections O.3 & 4 Information behaviour O.5 & 7 Affective behaviour O.6 & 8 Participation behaviour

Appendix 14: Example transcript coding using NVivo

Click to edit

k4 Patient professional relationship
 j2 Areas of uncertainty for patient
 i4 Professional's construction of patient info attitude
 D. Surgical outcome
 d2 Histopathology and staging
 k1 Emotional impact of illness
 Suggestions to improve care
 m3 Supporting hope
 b1 Professional's experience and knowledge
 g1 Follow up and monitoring
 b3 Professional's illness attitudes
 i2 Further lung cancer treatment
 e5 Numerical
 e3 Cure
 j1 Patient understanding and retention of information
 J. Knowledge & understanding
 i2 Information formats
 i3 Timing of information giving
 e2 Survival
 g3 Recognising signs of recurrence
 m2 Managing uncertainty
 k3 Support available
 g2 Perception of treating potential recurrence
 M. Coping
 i4 Attitudes to cancer treatments
 K. Patient psychosocial factors
 E. Recurrence and survival
 i1 Attitudes and beliefs about cancer
 O.1 Style and content reflections
 I. Information
 G. Follow up and monitoring
 b2 Professional roles and boundaries
 L. Cancer attitudes and beliefs

Quotes
 Oncologist
 Staff interviews
 O04
 P15
 Oncologist interviews
 Staff interviews
 Coding Density

i1 Decision-making for further management
 F. Further treatment
 b4 Profes
 B. HCP t

I think it's probably worth asking you at this point what you think her risk of recurrence or her five-year survival or whatever, however you want to put it would be given her stage and things.
 50 to 70% would be the quote, would be the stats. Looking at her I'd say she's got PL1 disease, she had quite a nasty looking cancer actually on the PET.
Nasty in terms of?
 Lots of collapse of the lung, a reasonable size. It wasn't hugely de-differentiated on the pathology, but the nodes were directly involved, the N1 nodes were directly involved. So I'd say, again I would have quoted her had she asked me somewhere between 50 and 70%, but the PL1 and the size and the sort of central necrosis, because there was a ring of higher white on the PET with the central necrotic area, rather than a solid, you know. The whole sheet of cancer cells to me implies that it's not growing very fast because they're not necrosing and dying with the central necrosis. Again whether that's anecdotal or not I'd say, I'd have probably said 50 to 60% for her if she'd asked me.
Chances of being alive at five years.
 Yeah, and disease free yeah.
 And in her situation the role of adjuvant chemotherapy would add, I mean you were very explicit in the meeting, another 5% on top of whatever the surgery's done.
 Yeah, so if you're saying 50 to 70% I'd say 50 to 75%, 55 to 75%. So for her 55 to 65% probably I think is nearer the mark.
 I'm quite interested, you said earlier on that in a way you expect somebody to ask you, well if it gives me 5% what would have been my underlying chance of

Annotations
 Item
 Content
 3
 Distinctly different from the evaluation of the surgeon here which was about 35% five year survival

Appendix 15: Framework Matrix example

Glennis (P09) within case analysis of Risk of Recurrence Theme

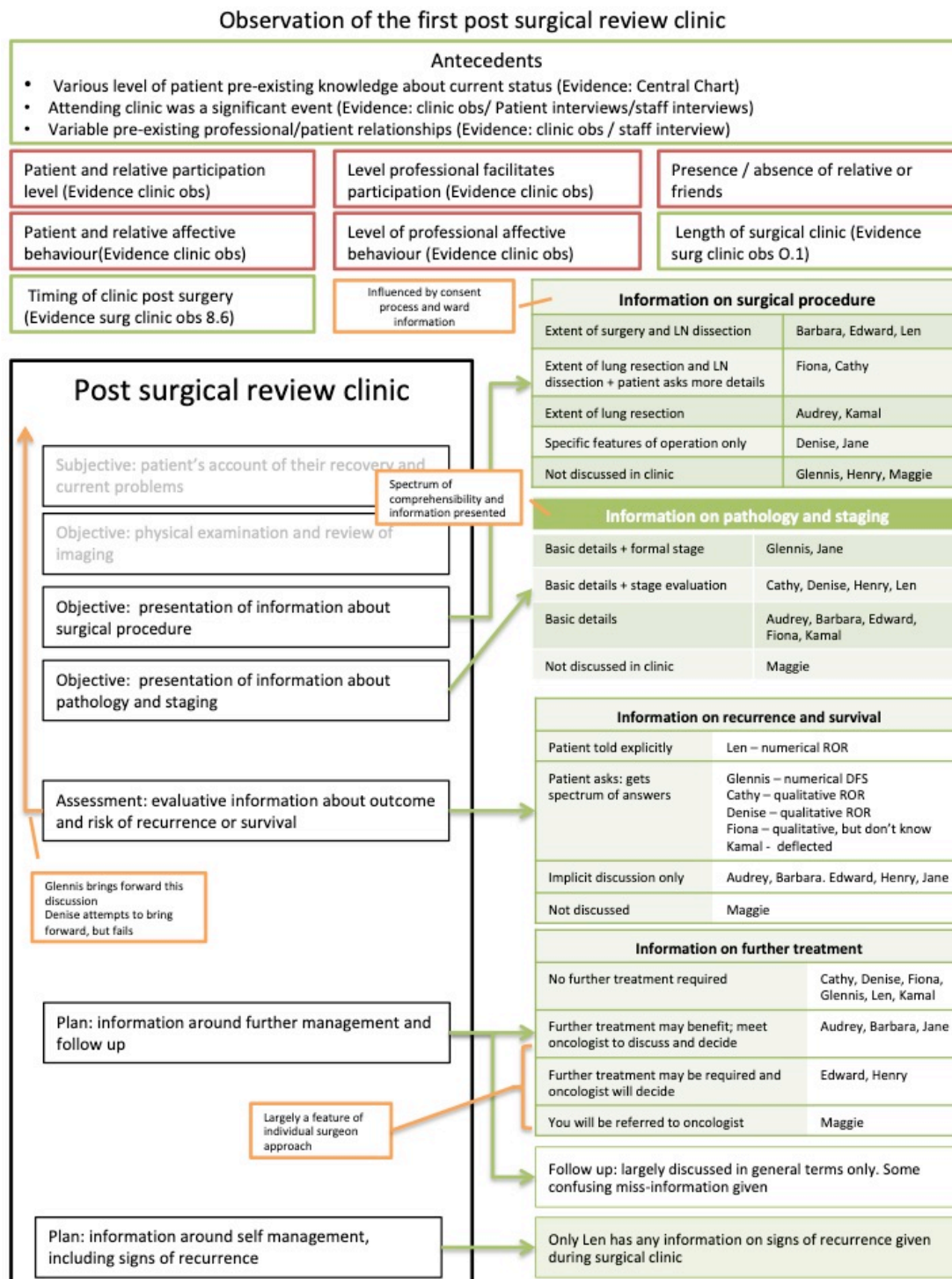
	A : E: Recurrence and survival	B : e1 Risk of recurrence	C : e2 Survival	D : e3 Cure	E : e4 New cancer
1 : Non-surgical clinic	P09 asks about chance of recurrence in the lung at some point. Cure rates high, but can't promise a cure or that cancer has not spread to somewhere else. Not 100%.	P09 asks about recurrence, but prefaces this with it being an "impossible question". N02 says it is unlikely that cancer has spread elsewhere, but "I can't promise you"	Not discussed	"the cure rate is relatively high, but it is not one hundred per cent "	Not discussed
2 : Surgical clinic	Towards end of consultation P09 initiates a question about whether to expect any recurrence. This was answered both qualitatively (think personally this done and you don't have to worry about this again) and by giving a numerical estimate of disease free survival (85%). NB - did not specifically ask for a number	P09: Will they expect any sort of reoccurrence? S05: It is all about statistics, but when it is this size, the very best, we er, the figures suggest that you have an eighty-five per cent chance of nothing coming back in five years [...]. Okay, so that's why we follow up, just to make sure But I think, I think that personally, this is done and you don't need to worry about this again	Not specifically discussed	Not discussed	Not discussed
3 : Documentary evidence	N/A				
4 : Patient interviews	T=0 Asked in clinic about risk of recurrence, told 85% chance on no recurrence. Felt good, but would prefer higher. Didn't ask where it would recur lung or somewhere else. Avoided looking survival rates on Internet. Concerned about being more cancer prone due to Hx. T=3 Unsettling if survival rates not very good. Cannot unsee it. Unsure what she would do if told WAS more cancer prone. T=6 Recalls being told risk of cancer in other lung lobes is as good as anyone else. Seeing poor survival figures unsettling and stayed with her. Concerned by current symptoms and not reassured by CXR, so asked for CT. Thinks inevitable will have another cancer at some point.	T=0 Asked in clinic about risk of recurrence and was told 85% chance on no recurrence. Felt good, but would prefer it to be higher. Didn't ask where it would recur lung or somewhere else. T=6 Recalls being told that cancer removed within lobe and there was no cancer in the lymph nodes. Cancer in any other part of the lung risk is as good as anyone else	Survival in lung ca not as good as breast ca. T=0 Avoided looking survival rates on Internet T=3 Unsettling if survival rates not very good. Cannot unsee it. T=6 Found poor survival figures given during Stand up for Cancer unsettling (particularly as had another chest infection) and figures stayed with her.	Not discussed	T=0 Concerns about being more cancer prone T=3 But no one can answer this. Unsure what she would do with the information if was told was more prone. Would remove organs that were not essential ie ovary. T=6 Feeling unwell and feels inevitable that will have further cancer at some point.
5 : Lung CNS	Question asked at end of clinic may reflect that P09 did not want an answer. P09 was concerned about both recurrence and new cancer possibilities. Wants to avoid giving a false expectation that this could never recur, but also avoid having them scared most of the time. Need to play it down and reassure. Patients do worry as they have been told they have lung cancer. No discussion in the interviews of estimations of risk of recurrence or survival. Implication was that this was slow growing and therefore the risk of recurrence would be very low, but we did not actually discuss this.	P09 asked about possible recurrence at the very end of clinic N02 feels this may be because she didn't really want an answer. P09 was concerned about both recurrence of this current lung cancer and getting another primary. N02 does not want to give a false reassurance that this would never recur, but also doesn't want them "to live the rest of their life in fear that another lung cancer's going to come"	Not discussed	Even though patients have a potentially curable cancer, they will worry about symptoms and need reassurance or investigations.	She was also concerned about getting a new cancer as well as recurrence
6 : Surgeon	Uses IASLC survival curves to estimate. Does not feel giving exact numbers will help a patient cope, but she is someone who needed to know this. Statistics are population figures, which does not say how an individual will be. P09 unusual in asking for exact (recurrence) percentage(asked, but not for numbers). Statistics can be hard to interpret. Patients will interpret figures differently; what seems good to someone will seem bad to someone else. Patients want to hear "cancer free" or "cure", but S05 only uses these with care and won't say "cured".	Question was phrased about risk of recurrence, but answered as survival	When someone asks survival statistics, uses IASLC curves. In her case there are 15% [who don't survive] which you can't predict. But she didn't ask about that bit. NB P09 asked about recurrence and he has given survival statistics.	Patients want to hear those words often they're free of cancer or it's all been resected or you are cured which I don't think you can actually say in any cancer. [...] I've always used them carefully. So really only in the Stage 1a when I say it's all out, and I won't say it is cured.	Not discussed
7 : Surgical CNS	I was important for P09 to be given figures, not just reassurance. P09 was happy with these. Way surgeon put risk of recurrence emphasised the positive and not the 15% who might see recurrence. Surgeon did not say anything about possible recurrence after 5 years.	P09 was not happy to just be reassured all okay at the beginning of the consultation, but wanted to know more details. She seemed happy with the statistics she was given. S05 did not talk specifically about the proportion of patients where this could recur ie this was presented positively.	Not discussed	S05 did not specifically say that he could not promise cure ie not being able to promise that the cancer will never come back Also did not discuss the implication that still theoretical risk of recurrence after 5 years.	Not discussed

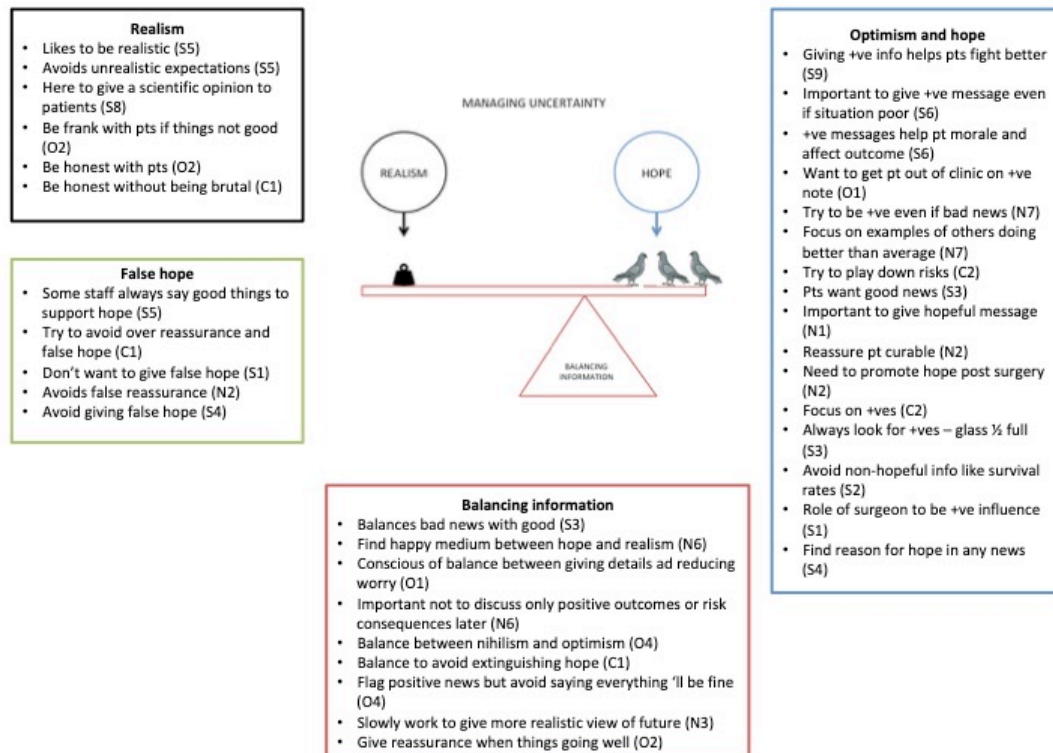
Appendix 15: Framework matrix examples

Glennis (P09) within case analysis of Risk of Recurrence Theme

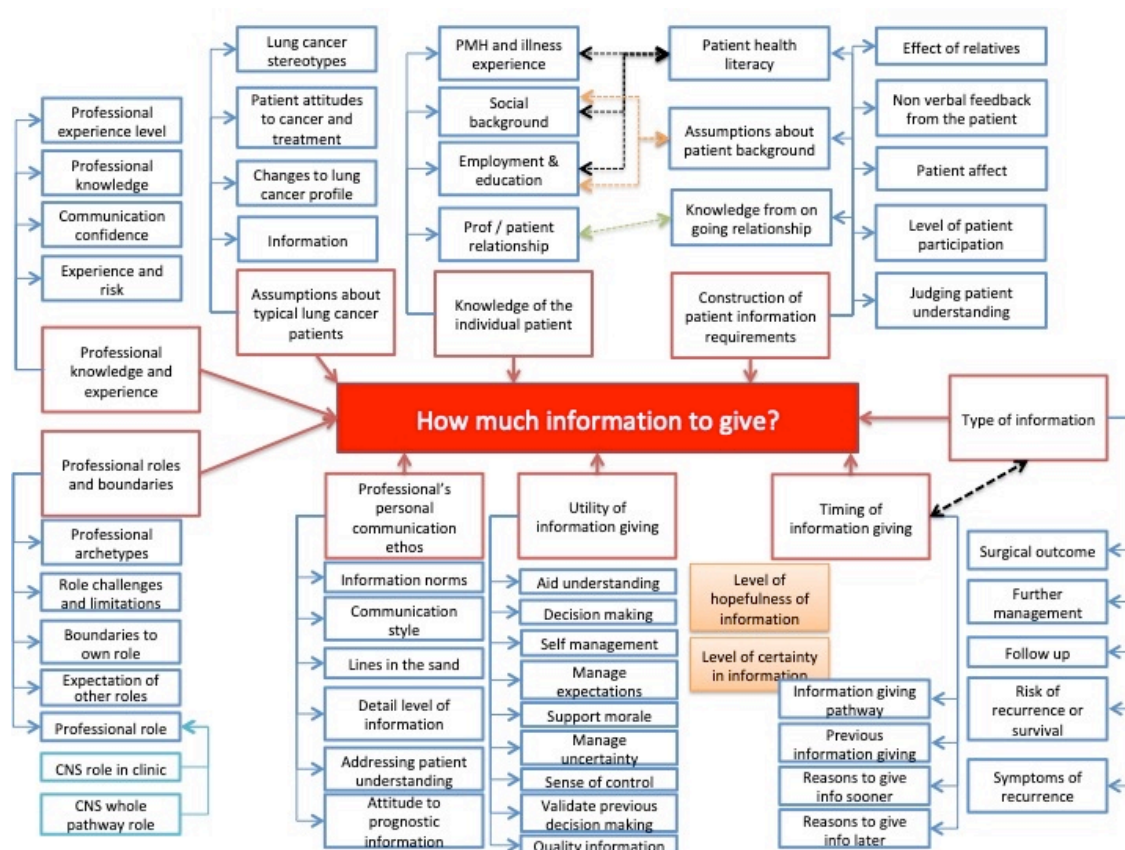
	F : e6 Numerical	G : e6 Possibility	e7 Fear of recurrence or actual recurrence	I : f1 Decision-making for further management	J : f2 Further lung cancer treatment
1 : Non-surgical clinic	Cure rate less than 100%	Likelihood of it having spread is low. Cure rate relatively high, but not 100%	Not discussed	P09 discusses her relief that she does not need chemo. N02 reflects on rationale for telling patients that they might need chemo, even when probably is that they would not. <i>N02 has a practice of telling patients that they might need chemo ahead of the operation to help manage expectations and to ease in the subject if there were to require chemo. There is an assumption that being later told the good news that this is NOT required is better than</i>	Not discussed
2 : Surgical clinic	<i>when it is this size, the very best, [...] figures suggest that you have an eighty-five per cent chance of nothing coming back in five years</i>	<i>I think that personally, this is done and you don't need to worry about this again</i>	Not discussed	Not discussed	No chemotherapy
3 : Documentary evidence				For routine post operative follow up.	
4 : Patient interviews	T=0 Recalls 85% chance of no recurrence T=6 Recent TV programmes flashed up survival statistics 85% lung cancer patient do not survive 5 years. Figure stayed with her and increased her anxiety.	Not discussed	T=0 not discussed T=3 Talks about general symptoms that make her think cancer T=6 Current chest infection is worrying her. Not satisfied by CXR in clinic (in view of experience at diagnosis) and has pushed to have a scan	Not discussed	Biggest concern was whether lymph nodes were involved and so would not need chemo or radiotherapy
5 : Lung CNS	Not discussed	Not discussed		Not discussed	Not discussed
6 : Surgeon	<i>"I don't think [knowing] the exact percentage is going to make much difference to how you deal with it, but some patients need the exact number"</i> <i>"it's all population-based so you can never say that an individual patient will follow the curve".</i> <i>"without a statistical background it's difficult to interpret those numbers"</i> <i>"most patients [...] don't ask for the exact number but I think she's unusual in the fact that she did"</i> <i>"Some patients won't be happy until they know the exact number, and I think she's definitely one of them"</i>	Not discussed		Decision for "follow up care" is straightforward in this case (stage 1) and does not need to wait for MDT outcome	Not discussed
7 : Surgical CNS	S05 gave statistics and she seemed happy to hear these. Stats are 5 year survival figures and match the standard FU period. He mentioned the 85% positive outcome, but not the 15% that is the "other way"	Not discussed		S05 has said does not need chemo. In this case decision was clear cut. However, MDT may feel it is worth seeing oncologist just to discuss risks and benefits. If the situation had been more borderline, then could risk confusing patient if given conflicting advice about need to see oncologist.	S05 was able to reassure her that no chemotherapy was required according to guidelines

Appendix 16: Mind map examples





Professionals' views of realism and hope



Mind map of How Much Information to Give - 14 05 17

