# A qualitative multiple case study investigating information exchange at lung cancer consultations

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**Declaration**

I declare the work in this thesis to be my own, except where otherwise stated.

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## Abstract

**Title**:

A qualitative multiple case study investigating information exchange at lung cancer consultations.

**Background**:

Effective information exchange is an asset to effective lung cancer care. Although a considerable body of evidence informs the approaches to 'diagnostic bad news delivery', the exchange of information that takes place between patients with cancer and professionals with whom they interact thereafter is less well documented. Information exchange has an influential role throughout the lung cancer care continuum, providing patients and professionals with details relative to the cancer diagnosis and the subsequent choices to be made in its management. Information on disease extent, treatment and related side-effects, rehabilitation and prognosis are judged by patients as the most prominent for them. Despite awareness of the specific categories relevant to information exchange needs, there is little evidence available exploring the information exchange process, per se, within cancer generally and even less within the lung cancer context.

**Aim**:

To investigate information exchange processes during lung cancer consultations, specifically exploring information content which is both exchanged and not exchanged.

**Design**:

Qualitative, multiple case study design.

**Methods**:

A case centred on a patient with lung cancer. Within the case were the patients, the health professionals they consulted with and accompanying companions. Seven cases were recruited, which included 12 companions. Data were collected in outpatient clinics between 2010 and 2011. Data were digital recordings of consultations; debrief interviews immediately post-consultation and later in-

depth patient interviews. All interviews were transcribed and analysed for pattern matching and coding.

**Findings**:

Analysis of categorical data indicated cases were typical of the Scottish lung cancer population across all demographic domains, accept age and performance status. The preliminary analysis showed across cases, almost universal satisfaction with the level and content of information exchange for the main *a priori* categories of diagnosis, treatment and treatment outcome. Substantive analysis revealed that information content across the *a priori* categories was influenced by the presence of the accompanying companion. Within the clinical consultation, companion influence on information exchange was shown to be mediating, moderating or neutral. A key finding which emerged showed companion accompaniment to be a negotiated process, with three identifying levels of accompaniment. Non-negotiated companion presence at the clinic was associated with influential and expert companions who significantly moderated the content, direction and flow of information exchange, using the constructs of companion control, companion agenda and companion as expert. Persuasive influences further shaped non-negotiated accompaniment and were identified as demographic characteristics and relationship alliances. Patient and professional perspective regarding companion accompaniment was shown to be discordant.

**Conclusions**:

The level of negotiated companion presence at lung cancer clinics has direct implications for clinical care. There needs to be greater understanding among professionals of ways in which information exchange can be influenced by companions.

**Key words**: lung cancer, information exchange, patient-professional-companion interaction, negotiated accompaniment, mediating and moderating influence.

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# Chapter 1: Introduction and overview of the thesis

## 1.1. Introduction to the thesis

Lung cancer is a disease with many biomedical and psychological symptoms and for many patients diagnosed with the disease there remains few possibilities of being cured (Salander and Henriksson, 2005). This underlines the need for personalised or patient-centred care, tailoring communication to the specific needs, values and preferences of each individual patient (Kissane, Bultz, Butow and Finlay, 2010). Quality lung cancer care includes effective patient-healthcare professional communication and information exchange about the disease and treatment, patient preference and goals of care (Griffin, Koch, Nelson and Cooley, 2007). To inform rational decision-making about therapy and adequate planning for expected outcomes, patients and their families need information about the extent of the disease and the chances that it may be cured (Hagerty, Butow and, Ellis, 2005). Additionally, whether the prognosis is favourable, poor or uncertain healthcare professionals should elicit each patient's values and preferences to offer a concordant plan of patient-centred care (Nelson, Gay, Berman, Powell, Salazar-Schicchi and Wisnivesky, 2011).

In the context of patient-centred cancer care, communication with healthcare professionals can be important to help patient need for information and other forms of support. It can influence a wide range of cancer care outcomes both positively (Neumann, Wirtz, Bollschweiler, Mercer, Warm and Wolf 2007; Clayton, Butow, Arnold and Tattershall, 2005; Roberts, Benjamin, Gavigan, Gesme and McCarthy, 2005; Schneider, Kaplan, Greenfield and Wilson, 2004; Schofield, Butow, Thompson, Tattershall, Beeney and Dunn, 2003) and negatively (Thorne, Hislop, Armstrong and Oglo, 2008), impacting for example on treatment adherence (Roberts et al, 2005; Schneider et al, 2004;), patient anxiety and depression (Fogarty, Curbow, Wingard, McDonnell and Somerfield, 1999; Schofield et al, 2003), and patient satisfaction (Kim, Kaplowitz and Johnston, 2004; Schneider et al, 2004).

There is a tangible body of evidence which suggests that communication with healthcare professionals can affect the extent to which patients feel cared for, respected and involved (Burkitt-Wright, Holcombe and Salmon, 2004; Step, Rose, Albert, Cheruvu and Siminoff, 2009; Kruijver, Kerkstra, Bensing and van de Wiel, 2000; Thom 2000). These latter studies can be interpreted as suggesting that patients seem to value communication at least in part because of what it signals about healthcare providers' attitudes towards them, with inference about the importance of the interpersonal aspects of healthcare provider-patient relationships (Skea, MacLennan, Entwistle and N'Dow, 2014). Evidence points to the significance of what has been referred to as health professionals 'seeing the person in the patient' (Goodrich and Cornwell, 2008) or treating patients 'as persons' (Entwistle and Watt, 2013). Good clinical communication can be valued both in its own right as a key element of patient-centred healthcare delivery (Street, Makoul, Arora and Epstein, 2009; Epstein and Street, 2007) and for its contributions to patients' health status and abilities to lead the kinds of lives they want to live (Entwistle, Firnigi, Ryan, Francis and Kinghorn, 2012).

Clinical communication can be defined as the dynamic, interpersonal process of mutual influence that occurs during the exchange of verbal and non-verbal messages between patients and healthcare professionals (Albrecht, Penner, Cline, Eggly and Ruckdeschel, 2009). Ong, de Haes, Hoos and Lammes (1995), signalled the scope of this influence and noted three basic communication functions in the cancer context, creating effective interpersonal processes, exchanging information and facilitating appropriate treatment decisions.

Despite the growing body of evidence above, the literature is less clear on certain fundamental aspects of communication such as information exchange processes. Thus, within lung cancer management I believed there was a need to better understand the fundamental aspects of patient-centred care and communication and to choose to explore information exchange between healthcare professionals and patients owing to a particular lack of research in this area.

## 1.2. Background to the thesis

This study developed from my clinical experience within lung cancer nursing, where for the past twenty years I have practised as a clinical nurse specialist. In this time I have witnessed the influence of information on patient care and the changes that have taken place both through transformations in patient-professional interaction and importantly patient-centred care, mainly as a consequence of policy directives and a strong desire to place patients and their families at the heart of healthcare. I was also cognisant of the key role that clinically usable information and information exchange plays in helping patients with lung cancer manage the impact of their health or ill-health, especially in relation to their diagnosis and subsequent treatment. Unless patients have insight into and understanding of their situation and are able to share their opinion and perspective then they are unable to make decisions about their care (Fallowfield, 2010). However, in my experience exchanging information about diagnosis and prognosis to patients with cancer who are ill and frightened is never easy.

In lung cancer management, there is a clear need to embed patient-centred care – an approach which ensures that all lung cancer patients are offered a co-ordinated package of advice, information, treatment and support, tailored to their ongoing needs and preferences (United Kingdom Lung Cancer Coalition [UKLCC], 2013). To inform practice at local and national level, I believed it was imperative to investigate the most fundamental aspect of this approach, namely the information exchange process as it occurred between patients and professionals. I was primarily interested in both the information which was exchanged and that which may have not have been exchanged by patients (and their companions and professionals). Cancer patients are often reluctant to disclose their concerns to the healthcare team, often believing that depression, pain, fatigue etc. are inevitable consequences of their illness (Bakker, Fitch, Gray, Reed and Bennett, 2001); or that nothing can be done to alleviate problems, so there is no point in mentioning them (Arora, 2003). This avoidance of information exchange perhaps reinforced by the reluctance of professionals to inquire about patient concerns

(Ford, Fallowfield and Lewis, 1996) and by their evasion of certain information, especially relating to treatment outcome (Quirt, Mackillop, Ginsburg, Sheldon, Brundage, Dixon and Ginsburg, 1997).

A significant catalyst for undertaking this research was identifying that there was no empirical evidence about information exchange within the specialist area of lung cancer. Consequently, after discussions with clinical colleagues, it was agreed that this would be an area worthy of investigation to inform practice

### 1.3. Rationale of the thesis

Increasingly, across the spectrum of cancer care literature, there is an awareness of the impact of clinical encounter information exchanges on the illness experience (Albrecht et al, 2009; Baile and de Moor, 2005). Although a considerable body of evidence informs the approaches to 'diagnostic bad news delivery' (Barclay, Blackhall and Tulsky, 2007; Bredart, Boulec and Dolbeault, 2005), the exchange of information that takes place between patients with cancer and professionals with whom they interact thereafter is less well documented (Beach, Easter, Good and Pigeron, 2005). While psychosocial support is identified as essential to quality cancer care, it is often interpreted as access to specialised services of psychologists, counsellors and psychiatrists, by the subset of cancer patients who have serious psychosocial distress, and not as a component of general oncology care (Bultz, Thorne and Fitch, 2004). Subsequently, much of the communication research emphasis has originated in the specialised psychology support domain and not the general cancer care context (Surbonne, Baider, Weitzman, Brames, Rittenberg and Johnson, 2009).

Patient-centred research consistently reveals that information exchange encounters with professionals who manage and deliver oncology care can have a profound influence on many aspects of a patient's wellbeing (Epstein and Street, 2007). Essentially, information exchange impacts many domains of care, including emotional wellbeing and quality of life. Fundamentally for this thesis,

information exchange has an influential role throughout the cancer care continuum, providing patients and professionals with details relative to the cancer diagnosis and the subsequent choices to be made in its management (Thorne, Hislop, Armstrong and Oglov, 2008; Jenkins Fallowfield and Saul, 2001).

With reference to lung cancer care, Earle (2004) audited the literature on lung cancer outcomes and determined that although there is rapid growth in quality of *life* and cost analyses studies, quality of *care* studies, including doctor-patient communication and decision-making, appear in publication less often. This weak evidence base has been blamed on myriad reasons, including a mix of disease characteristics, discouraging treatment outcomes, as well as, professional nihilism (Holtz, 2003). Lung cancer is the UK's biggest cancer killer and the equivalent of 96 people die of the disease every day. This is more than breast, prostate, bladder cancer and leaukaemia combined (www.info.cancerresearchuk.org/cancerstats/types/lungcancer-accessed01.02.2009).

Consequently, outcomes research in lung cancer, by virtue of the disease's poor prognostic outlook, is largely focused on the palliative/end of life care trajectory. The irreconcilable difference for lung cancer researchers is that, in a cancer with an unpredictable care pathway, where information exchange is critical and often predicated by additional complexity and urgency, patients may be excluded from participation, or pertinent stages of the care journey neglected from research (Thorne et al, 2008; Earle, 2004). Consequently, information exchange in lung cancer care required further investigation.

### 1.4. The importance of information – the evidence and policy context

Although the exploration of information exchange within the cancer context is important, a particular lack of research in the context of lung oncology has been noted. Of eighteen reviews of cancer communication carried out in the past 10 years none provide specific evidence of information

exchange in lung cancer care that can be used to inform practice (Rodin, Mackay, Zimmerman, Mayer, Howell, Katz, Sussman and Browers, 2009). Although they confirm that patients have information needs across the continuum of care, they conclude that the diversity among patients in terms of their needs and preferences means it is impossible to conclude that any one method of communicating information is necessarily guaranteed to be superior (Rodin et al, 2009).

Two systematic reviews conducted a decade apart, summarised the categories of information which patients with cancer thought were most relevant to their requirements. Patients judged information on disease extent, treatment and related side-effects, rehabilitation and prognosis as the most prominent for them (Rutten, Arora, Bakos, Aziz and Rowland, 2005; Mills and Sullivan, 1995). Despite awareness of the specific categories relevant to information exchange needs, there is little evidence available exploring the information exchange process, per se, within cancer and even less within the lung cancer context.

However, investigation of the information exchange process within lung cancer is important as there is a wealth of policy initiatives recommending professionals target specific patient-centred categories of information (UK Lung Cancer Coalition [UKLCC], 2007; National Institute Clinical Excellence, 2005; Scottish Intercollegiate Guidelines Network, 2005). In order to realise the ambition of providing people with lung cancer patient-centred care, there are a number of challenges that the NHS must meet to deliver quality care, the most central being: responding to patients' full range of care and treatment needs as a result of the physical, psychological, practical and informational impact of the disease (UKLCC, 2007). A key feature of the UKLCC directive was ensuring patients have a positive cancer experience, facilitated through information exchange to enable patients to be fully involved in decisions about treatment and care, in turn, supporting patients to exercise choice about how and where they receive care and treating patients as individuals, 'not a set of symptoms'.

Providing care based on the needs of individual service users/patients is one of the fundamental principles of the NHS (Department of Health, 2012a). The provision of patient-centred care is now

regarded as an integral part of efforts to improve the quality of services (Department of Health, 2012b). Efforts to improve the quality of NHS services are underpinned by the NHS Outcomes Framework which sets out the indicators for measuring health outcomes at national and local level (Department of Health, 2012b). Patient-centred care is defined as care that is respectful of and responsive to individual patient preferences, needs and values, that ensures that patient values guide all clinical decisions (Institute of Medicine, 2001). It involves putting patients and their families at the centre of all decisions. This principle objective is both contemporary and crucial within the UK healthcare system, especially in light of the Francis Inquiry Report (2013) which renewed and reaffirmed personal and organisational commitment to the patient-centred values of the NHS, following the concerns and subsequent public enquiry of poor patient care and high mortality within an NHS hospital in England. Francis (2013) recommended a patient-centred, collaborative approach to healthcare, where patients come first in every aspect of care.

Healthcare professionals should create collaborative patient-centred relationships with patients (and their families) in which clinical decisions are made using best available information and evidence from all participants. However, this ideal is rarely achieved (Epstein, Alper and Quill, 2004). Typically less than 1 minute out of a 20 minute consultation is spent discussing treatment and planning (Epstein et al, 2004) and although patients generally want more information from their healthcare professional this is not always achieved.

Given policy directives and lack of evidence in the lung cancer context, there is clear need for more research. The imperative for research was also influenced by the knowledge that the exchange of information between patients and professionals is often fraught with problems. In her review of physician communication behaviour, Arora (2003) stated physicians cannot assume patients will volunteer all relevant information. Equally, professionals are often reluctant to give full disclosure about cancer and its treatment (Jenkins et al, 2001). This non-exchange of relevant information within

the clinical encounter, by either party, may theoretically impact the quality of the cancer diagnosis and treatment decisions taken (Liang, Burnett, Rowland, Meropol, Eggert, Hwang, Silliman, Weeks and Mandelblatt, 2002; Gafni, Charles and Whelan 1998).

## 1.5. Conceptualisation of information

Epstein and Street (2007) advocated that healthcare professionals embrace a process model of information exchange that focuses on the reciprocal efforts of both patient and professional to manage information and achieve, even negotiate, a shared understanding of the medical and personal issues underlying the patient's health condition. The imperative being to assist patients to understand the clinical information required for informed decision-making.

It was not the intention of my research to focus on information exchange within the related context of shared decision-making (SDM). However, there are important parallels regarding the process and conceptualisation of information exchange found in the extant literature on SDM, hence at this point it is important to conceptually explore information, as it is the central focus of this thesis.

Shared decision-making is the most dominant and widely advocated model used in contemporary healthcare policy and practice (Charles, Gafni and Whelan, 1999, 1997). SDM is increasingly advocated as an ideal model of treatment decision-making, and this interactional model is distinguished from the other widely discussed models of paternalistic and informed (patient) decision-making (Bugge, Entwistle and Watt, 2006). Sharing decisions in healthcare is dependent on an approach where professionals and patients share the best available evidence when faced with the task of making decisions, and patients are supported to consider options to achieve informed preferences.

There are three analytical stages identified for treatment decision making:

1. Information exchange
2. Deliberation about treatment options
3. Decision on the treatment to implement

Information exchange is important for professionals to formulate diagnoses and recommend treatment and for patients to have the opportunity to make choices about their therapy options (Elwyn and Charles, 2001). More significantly for my research, information exchange has three distinct features:

- Flow and direction – two way flow of information (professional ↔ patient)
- Type – medical and personal
- Amount – all relevant for decision-making

Information needs to flow between the participants, whether dyadic, triadic or more. Additionally, the lay knowledge of the patient and the expert knowledge of the professional are equally as important (Edwards, Davies and Edwards, 2009). At a minimum, the professional must communicate biomedical information to the patient regarding the diagnosis, as well as all available treatment options and potential side-effects. Patients might exchange information about their values and preferences for the above, as well as personal health details, such as past medical history and presenting complaints. The amount of information conveyed is theoretically infinite and difficult to determine. However, it is usually understood to require professionals to communicate medical knowledge about healthcare options and associated outcomes and patients to communicate their values (Bugge et al, 2006; Coulter, 2002).

Within SDM information exchange and content is influenced by several factors ranging from professional expertise and ability to elicit and exchange information, often impacted by medical training and professional culture, to clinical environment, constrained by time and conflicting clinical commitments (Feldman-Stewart, Brundage and Tishelman, 2005). Information exchanges can be significantly influenced by the dynamics and interactions of participating members. Although dyadic encounters remain common, frequently in healthcare practice more than two participants, both professional and lay, are part of the clinical consultation (Charles et al, 1999).

A key consideration in clinical practice is that information may not be exchange by professionals and patients during encounters, which impacts on the professional's ability to arrive at an appropriate diagnosis and treatment prescription and limits patient ability to fully engage in decision-making. As information provision by all participants is essential to the development of partnerships within the clinical encounter, it is therefore important to recognise (i) what information is not exchanged and (ii) possible explanations for non-exchange. This would provide a more comprehensive understanding of both patient and professional constraints on information exchange and contribute to the development of interventions aimed at achieving a more equitable encounter (Edwards, et al, 2009).

Therefore, in my thesis information exchange was conceptualised as a process of information flow during the clinical encounter, between participants with individual knowledge (lay and expert), as well as values and beliefs about that knowledge. Each participant brings to the interaction information content that is material to the success of the consultation. The process relies on the conveying and receiving of information, an iterative process driven by the information exchange, including not only what was said, but also what was left unsaid. The concept recognises that information exchange does not occur in a vacuum and that during the clinical encounter, information exchange may be impacted by external factors including environment, individual perspective and the presence of additional participants.

Consequently, the following research question was devised:

*What information is exchanged and what information is withheld between patients with lung cancer, healthcare professionals and any companions patients bring to the clinical consultations?*

## 1.6. Organisation of the thesis

In the second chapter of the thesis, the evidence concerning information exchange from the perspective of lung cancer care is reviewed and clinical context provided. The literature review will start by overviewing the literature on lung cancer epidemiology. To provide policy context the literature is reviewed in relation to Government and NHS initiatives directed at improving the information experience of patients with cancer. The primary aim of the review is to consider the evidence relevant to information exchanged and not exchanged. Additionally, the literature examines the evidence pertaining to the importance of information within the clinical encounter. Further it appraises the evidence concerning the positive and negative influence of information exchange on patient care.

Chapter three outlines the methodological approach I adopted to answer the research question. The rationale underpinning the use of a case study design, which adopted a qualitative, constructivist approach, is described. A specific focus of the chapter is to illustrate the case study design for data collection and analysis.

In chapter four the practical and procedural aspects of the study, namely case identification and recruitment, recruitment challenges, data collection methods and data analysis strategies are described. The processes of ethical approval are also described, alongside consideration of the ethical aspects of the study.

Chapter five presents the initial findings of the first two stages of data analysis. Firstly, the ordering and comparison of the primary descriptive, categorical data for the cases, both within and across cases, is illustrated. Assignment and ordering of *a priori* categories around the identified themes of diagnosis, treatment and treatment outcomes are described. Then, from this data, the emergence of the key theoretical proposition is explored in chapter six.

Substantive analysis is presented in chapter seven. Here, leading on from the key theoretical proposition identified in chapter six, the theory building process is developed and outlined, namely - companion influence. Companion influence, as a mediator or moderator of information exchange is described, alongside patient preference for companion presence at consultations.

Chapter eight is the substantive discussion considering the findings of the thesis which generated new knowledge. The discussion considers the extant literature as well as the strengths and limitations of the study. Finally, chapter nine concludes with the implications of the findings in relation to clinical practice and future research.

# Chapter 2: Literature review

## 2.1. Introduction to literature review

Chapter 1 outlined information exchange within the context of the clinical encounter. Information exchange was conceptualised as a mutual exchange of information between primarily the patient and the professional(s) they consult with during lung cancer consultations. The two-way mutual exchange of information is fundamental to this thesis. Equally the information content which is exchanged during clinical encounters is a primary consideration for my research and is further underpinned by policy directives. In this chapter, the literature was reviewed with consideration to the process of information exchange, with information content explored in detail. Such exploration is important to underpin the research question and to consider patient perspective of the information exchange process.

The literature review is outlined in individual sections with each intended to add specific components to support my thesis. Section 2.3 will provide clinical context by detailing lung cancer from an epidemiological perspective. Similarly, section 2.4 will present evidence relating to the healthcare policy priorities surrounding lung cancer management. In section 2.5 the literature will be reviewed investigating the importance of information which is exchanged. Finally, in section 2.6 the literature will be explored with specific focus on information content which is not exchanged during clinical interactions.

## 2.2. Search strategy

The literature in relation to information exchange was searched using the following key words and concepts; lung cancer, out-patient clinic consultations, professional-patient relations, communication, information and information exchange. The following electronic databases were searched; Medline, Medline in Process, Embase, PsycInfo, British Nursing Index, AMED, CINAHL, Cochrane Library, Ebsco Biomedical and Health Sciences. Both information and clinic consultations were not searched with

exclusivity to the lung cancer or cancer literature. Concepts were combined using AND or OR. The search was exploded to include the PUBMED database and Synonyms were introduced and included– clinical encounters/clinic consultations/interactional analysis studies. Literature on decision-making, shared decision-making and information needs was further accessed for background information and cross-referencing.

Retrieval was limited to articles in English and excluded letters, but did allow editorials primarily for information, as the evidence base for data relating specifically to lung cancer was so scarce. Cancer sites on the Internet were also investigated for general information on the most recent cancer publications. Sites searched were CancerWEB, Cancer ResearchUK and all lung cancer sites such as Global Lung Cancer Coalition, Roy Castle Foundation were also regularly accessed. Additional references were located searching the bibliographies of related papers and using search engines such as Google.

Context setting concerning lung cancer epidemiology and current policy initiatives will be addressed first. Then the main areas of the literature relating to information exchange between patients and professionals at consultations with relevance to this thesis will be reviewed.

## 2.3. Epidemiology of lung cancer

Lung cancer is the most prevalent cancer in the world (International Agency for Research on Cancer [IARC], 2007). With 1.8 million new cases diagnosed and 1.2 million deaths every year, it accounts for over 13% of all new cancer cases (IARC, 2007). The disease is responsible for more cancer deaths than prostate and breast cancer combined and every 30 seconds, someone, somewhere in the world dies from the disease (IARC, 2007). With approximately 400, 000 new cases annually it is the most common cancer in Europe. With just under 350, 000 deaths per annum it is accountable for 20% of Europe's total cancer mortality (Ferlay Autier, Boniol, Heanue, Colombet and Boyle, 2007). In the United

Kingdom, lung cancer is liable for 1:7 new cancer cases and approximately 40,000 people are diagnosed yearly. Prognostic outlook is poor in the UK and over 75% of those diagnosed will die within one year of diagnosis (www.info.cancerresearchuk.org/cancerstats/lungcancer-accessed10/02/2009). Lung cancer is a formidable health problem in Scotland and leads the international tables in both incidence and mortality. In 2005, whilst there were 4, 500 newly diagnosed cases, 4, 000 deaths were recorded (Information and Statistic Division [ISD], 2008).

### 2.3.1. Pathology of lung cancer

Small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) are the two main histological types of lung cancer. More than one in ten lung cancer cases are classified as SCLC. It is commonly associated with a history of smoking (Janssen-Heijnen and Coebergh, 2003). Without treatment SCLC is the most aggressive type of lung cancer, with median survival from diagnosis only 2-4 months (National Cancer Institute [NCI], 2009a). Because of its high proliferation rate, SCLC is responsive to chemotherapy and radiotherapy. However, relapse and recurrence are common and cure seldom possible (Moore, 2009). SCLC is often disseminated at diagnosis.

The majority of lung cancer cases (approximately 75-80%) are classified as non-small cell lung cancer (Moore, 2009). Classification includes adenocarcinomas, squamous and large cell sub-types (Hoffman, Mauer and Vokes, 2000). In early stage NSCLC surgical resection offers the best chance of cure. However, when surgery is not feasible, combination chemo-radiation has been shown to offer survival benefit in fit patients with locally-advanced disease (Jassem, 2002).

### 2.3.2. Clinical presentation of lung cancer

Regardless of cell pathology, patients with lung cancer may present with many different symptoms, both respiratory specific and generally systemic. Dyspnoea, cough, haemoptysis and chest pain are the predominant presenting features. Additionally systemic symptoms may be present such as weight

loss, anorexia and fatigue (Tod, Craven and Allmark, 2008). Often symptoms are insidious and non-specific (Corner, Hopkinson and Fitzsimmons, 2005). Such subtle and vague symptoms can often remain unrecognized by patients and professionals resulting in late presentation and subsequent advanced disease (Hamilton, Peters, Round and Sharp, 2005; Koyi et al, 2002). Approximately one-third of patients present to their General Practitioner (GP) within one month of new symptoms, one-third present between 1 and 3 months and one-third present later than 3 months after their new symptom (Kesson, Bucknall, McAlpine, Milroy, Hole, Vernon, MacBeth and Gillis, 1998). In international and national studies the median duration from first tumour related symptom to hospital referral has been shown to be 43 and 45 days respectively (Koyi, Hillerdal and Branden 2002; Fergusson, Gregor, Dodds and Kerr, 1996).

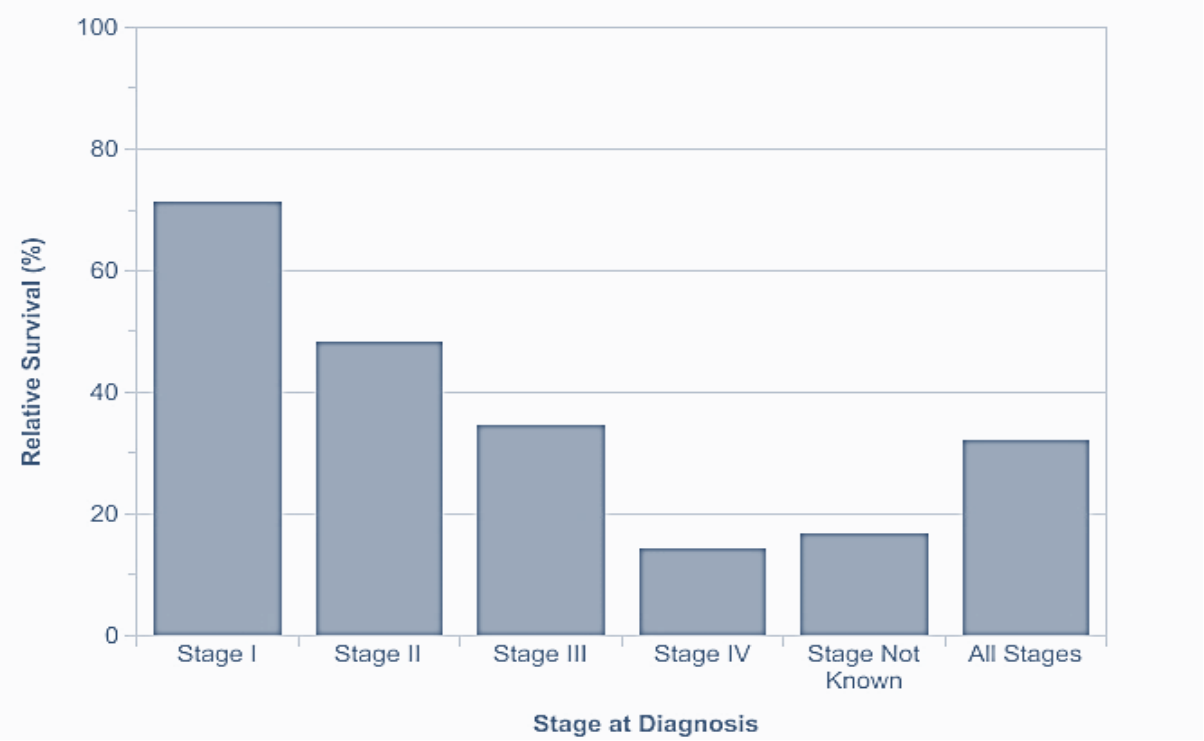
International research has shown that patient reported delays of symptoms from 7 days in Italy and 6 months in United States (Jensen, Mainz and Overgaard, 2002). A UK study revealed a delay of over a year among patients (Corner et al, 2005). To explore the pathway to diagnosis, Corner et al (2005) interviewed 22 men and women from two cancer centres in the north and south of England. Patients remembered having symptoms for many months, typically over the year, before a diagnosis was established. Patients experienced both respiratory and systemic symptoms which disrupted their quality of life but did not interpret them as serious and hence failed to take action.

Patients minimize or explain symptoms away, through a combination of stoicism, fear or because of other health-related issues (Tod et al, 2008). Tod et al's qualitative study investigated diagnostic delay in lung cancer in community and hospital settings in England. Twenty patients reported a wide variation in symptoms. However, as symptoms were often not as severe as expected and patients had a fatalistic view of cancer therapy, they delayed reporting their concerns to the GP. Delay to diagnosis, whether it be patient or professional, was recognized as an important factor in overall outcome of treatment (Bowen and Rayner, 2002; Bozcuk and Martin, 2002).

### 2.3.3. Relationship of disease stage and survival within lung cancer

In lung cancer, the most important factor for survival is the stage of disease at diagnosis, which in turn, depends on how early the tumour is discovered. Eighty per cent of patients with lung cancer present with locally advanced or metastatic and therefore incurable stage disease (Gregor and Milroy, 2001). The majority of those diagnosed present at stage III or stage IV (www.info.cancerresearchuk.org/cancerstats/lung-accessed05/04/2008). One-year survival from lung cancer is strongly related to the stage of the disease at diagnosis. Patients presenting at stage I have the highest survival rates (71%). Survival is much lower for those diagnosed with stage IV disease (14%) (www.info.cancerresearchuk.org/cancerstats/lung-accessed05/04/2008). One year survival in relation to disease stage is shown in table 1.

**Table 1: One-year Relative Survival (%) by stage**




Reproduced with permission from: www.info.cancerresearchuk.org/cancerstats/lungcancersurvival-accessed05/04/2008

### 2.3.4. Management of lung cancer

Management of lung cancer is based on pathology of the cancer, stage of the disease and the performance status (PS) of the patient. PS is an attempt to quantify a cancer patient's general well-being and activities of daily living to determine suitability for treatment (Oken, Creech, Tormey, Horton, Davis, McFadden and Carbonne, 1982). Surgery, radiotherapy and chemotherapy, used as individual therapies or combination modalities, are treatment options for lung cancer. More recently biological therapies have become part of the management profile (Moore, 2009). Management guidelines for lung cancer were first published in 2005 in England and Wales, with concurrent guidance produced in Scotland by the Scottish Intercollegiate Guidelines Network [SIGN], (2005). A basic summary of treatment interventions for both cell types is detailed in table 2. Although cited references are dated, treatment interventions and survival benefits are still largely applicable, as notwithstanding the use of more advanced cytotoxic regimens and targeted therapies overall survival in lung cancer has remained unchanged and poor.

**Table 2: Summary of treatment interventions**

**(Gregor and Milroy, 2001)**

| Population | Intervention | % Survival benefit | Reference |
|---|---|---|---|
| **SCLC + chemotherapy** | Thoracic Irradiation | 9.2 vs. 17.4% at 2 years | Pignon et al (1992) |
| | Post Cranial Irradiation | 15.3 vs. 20.7% at 2 years | Auperin et al (1999) |
| **NSCLC** | Platinum chemotherapy | Range of benefit | NSCLC collab. Group (1995) |
| **NSCLC**<br>**Localised**<br>**Regional** | Addition to surgery/RT | <br>-1-10% at 5 years<br>1- 4% at 5 years | NSCLC collab. Group (1995) |
| **NSCLC**<br>**Metastatic** | Addition to best supportive care | 5-15% at 1 year | NSCLC collab. Group (1995) |
| **NSCLC without chemotherapy** | CHART compared to standard RT | 21 vs. 32 % at 2 years | Saunders et al (1997) |

### 2.3.5. Summation

Lung cancer is one of the main causes of cancer death in the Western world. This malignancy is associated with significant morbidity and in 80% of patients with lung cancer the disease is inoperable due to advanced stage at presentation (Tod et al, 2008). Receiving such a diagnosis will be for most patients an overwhelming experience. In these circumstances, the provision and exchange of appropriate and understandable information is important. Consequently, information exchange in the general cancer and specific lung cancer context has been informed by a plethora of policy initiatives aimed at improving the care experience and importantly, the provision of information therein. The following section will discuss some of the current policy drivers.

## 2.4. Current policy initiatives in cancer communication

Patients with lung cancer face an ever increasing amount of new and complex information, at a time when their ability to process and understand it can be impaired by the physical and emotional stress of their illness (National Institute Clinical Excellence [NICE], 2011). The amount, nature and content of the information required by patients and given by professionals will change throughout the care continuum, as additional information is gathered about diagnosis, stage of disease and suitability for treatment (NICE, 2011). Clinical encounters with patients with lung cancer should facilitate patient choice about treatment decisions (assuming the patient wishes to participate in the decision-making process). Information provided should be appropriate to patient wishes and level of understanding (SIGN, 2005).

In the current NICE guideline (2011) on lung cancer management, good communication is recognised as vital at all stages of the care pathway. In accordance with other policy directives (Department of Health, 2010; Department of Health, 2007; Scottish Executive, 2000), the guideline chose to focus its communication section on information in relation to decision-making in lung cancer. A key guideline statement was issued stating, *in deciding treatment, patients (and carers) require information that*

*they can understand, so they can make an informed decision*. Yet, the volume of evidence for this subject was extremely limited and of poor quality and evidence, with no clear indication of what information was required. The recommendations for practice were based on limited and poor phase 1 studies and cross sectional surveys (Gabrijel, Grize, Helfenstein, Brutsche, Grossman, Tamm and Kiss, 2008; Dubley, Brown, Esmond, Bowers, Healy and Schiller, 2005; Brundage, Feldman-Stewart, Cosby, Gregg, Dixon, Youssef, Davies and MacKillop, 2001). Subsequently, lack of specific evidence limited the recommendations to several good practice points, none of which indicated the most appropriate communication methods in helping patients make informed decisions about treatment options.

The Cancer Reform Strategy (DOH, 2007, p71), stated that stakeholders consulted '*had strongly recommended that the issues of information, better face-to-face communication and support for decision-making should be given the highest priority with regards to actions to improve the patient experience*'. Yet an overview of the research evidence for the Reform Strategy conducted by Coulter (2007) found that although the evidence suggests shared decision-making is beneficial, it is not widely practiced. In essence, patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanation about their condition and the likely outcomes, with and without treatment (Coulter, 2007).

Guideline recommendations have been formulated by leading lung cancer advocacy groups and charities with specific emphasis on important information and communication aspects in the lung cancer context. Working in partnership with UK governments, health departments and NHS professionals, the UK Lung Cancer Coalition [UKLCC] (2007) developed a 12-point plan to improve lung cancer patient care, advocating for a group of patients they describe as disenfranchised. A key priority stated:

Information and support*: we call on the UK governments to ensure lung cancer patients feel informed about their disease and the support available, and empowered to make decisions about their*

*treatment options in partnership with health professionals. Every lung cancer patient should be offered high quality information at key points in their cancer journey, tailored to their individual needs. Information should be evidence based.*

In 2009, the UKLCC revisited the plan nationally and for the key point above, although some improvement had been made, progress was limited. Specific reasons for limited progress were not discussed, but the UKLCC called for greater government involvement and support of the key recommendation in the next review period.

The importance of information provision and exchange was further highlighted in key policy documents devised and subsequently revised by the British Thoracic Society [BTS] (2008, 2013). The documents were developed to advise professionals on sharing information with lung cancer patients. The intention of the guidance is to standardise and complement the information that is delivered by professionals and aimed to assist with information exchange around the diagnosis and therapeutic options available (BTS, 2013; BTS, 2008). There was unequivocal recognition from the BTS that this is an area where robust evidence is difficult to come by. Therefore, the document contained evidence-based guidance where it existed but also expert opinion from experienced practitioners (BTS, 2013). Key recommended subjects for information sharing included; diagnosis, treatment options, potential treatment related side-effects and prognosis.

### 2.4.1. Summation

The central recommendation in the drivers set by both UK and Scottish governments and leading lung cancer patient advocates is the importance of clear and open communication shared between patients and professionals (BTS, 2013; UKLCC, 2009; Scottish Executive, 2008; DOH, 2007). Yet, sharing information with people affected by cancer is complex, patients often finding it difficult to take in information given during consultations, especially immediately after hearing a diagnosis of cancer

(Scottish Executive, 2006). Despite recognition of the importance of information exchange written as policy guidelines, recommendations are at times difficult to realise in clinical practice.

## 2.5. Information exchange

### 2.5.1. Introduction

Patients with cancer seek information about the cause, diagnosis, treatment, prognosis, and psychosocial aspects of the illness (Epstein and Street, 2007). Attending to information needs is important to help the patient gain knowledge about their illness, to develop a strong patient-professional relationship, reduce uncertainty and assist with decision-making (Wolff, Chan, Harris, Sheridan, Braddock , Kaplan, Krist A and O'Connor 2005). Information is essential for decision-making, as without accurate and current information on diagnosis, all potential treatment options and prognosis, it is not possible for patients to be part of the decision-making process or give informed consent (DOH, 1998).

### 2.5.2. Information exchange in lung cancer

Despite information exchange being central to the delivery of cancer care (Dieppe, Rafferty and Kitson, 2002), there have been no studies found informing the process within lung cancer patient management. Review of the literature uncovered little evidence about information exchange in connection to lung cancer and no studies were identified which investigated the process during patient and professional interaction at clinic consultations. Research concerning the content and conduct of the lung cancer consultation is limited even though patients indicate that their healthcare professional was the major source of their information and the clinic encounter remains an important component of healthcare which impacts on health outcomes (Tattershall, 2003). Whilst none of the studies examined in the current literature review explored the information exchange process per se, they did emphasise the importance of accurate information for assisting patients with understanding their diagnosis and stating a preference for treatment options.

A Canadian prospective study investigating how much patients with recently diagnosed lung cancer knew about their disease revealed that misunderstandings are common (Quirt, Mackillop, Ginsburg, Sheldon, Brundage, Dixon and Ginsburg, 1997). One hundred patients undergoing radiotherapy or chemotherapy were interviewed to determine their view of the diagnosis, the extent of the cancer, the intent of treatment, and the risks and benefits of therapy. Their physicians' views were elicited using a self-administered questionnaire. Patients tended to underestimate the extent of their cancer and overestimate the effectiveness of therapy. Patients failed to recall side-effects of treatment, with many stating they had never been informed of treatment related toxicities (even though the doctors maintained they had exchanged this information). Doctors frequently believed that patients understood more than they actually did about both the diagnosis and treatment and failed to recognise patient misconception about the intent of treatment and prognosis. Many patients did not understand their situation well enough to make a truly autonomous treatment decision. Why such discrepancies existed between patients and professionals in this study remain unclear. A possible explanation is that patients did not have the key issues explained to them. Equally, patients may either chose to interpret information selectively, or simply their recall of events may be poor. Regardless of the reasons for incongruence, overestimation of treatment benefits led patients to accept treatment which was inappropriate for them and their doctors often failed to recognise this.

Using semi-structured interviews, Sell, Devlin, Bourke, Munro, Corris and Gibson (1993) conducted a qualitative study of 50 patients with lung cancer, one week after the diagnostic consultation. Despite having been told the diagnosis, two patients appeared unaware that they had lung cancer. One patient had difficulty understanding the diagnosis and one was in denial. Ninety-two per cent of patients indicated that it was right to be told the full extent of the diagnosis. Despite being told 'bad news,' 62% of the patients felt more reassured after the consultation, whereas 10% were less assured and 28% were uncertain. Importantly, 26% of the participants felt they were not given enough information pertaining to survival and prognosis. The study by Sell et al was conducted within a week of diagnosis,

with professionals perhaps preferring to defer exchanging information about prognostic outcome so soon after diagnosis and prior to treatment. Nonetheless, when information concerning health issues are not given or given but not understood, the health implications can be considered as potentially problematic (Elwyn and Charles, 2001).

Gabrijel et al (2008) examined the extent to which patients acquire and recall accurate information regarding diagnosis, therapy procedure, and aim of treatment, after initial disclosure of lung cancer. Structured interviews were conducted with 71 consecutive patients newly diagnosed at a large teaching hospital in Switzerland. Ninety per cent correctly recalled information about diagnosis. Proposed treatment modality was known by 83% of the patients. Only 49% accurately recalled the treatment intent. Even when the aim of treatment was curative, 42% could not recall being told this. Nearly three-quarters of the participants were satisfied with the exchange of information about diagnosis, yet only 39% were satisfied with communication about prognosis. The authors proposed the main reasons for low congruence between patients and physicians may have been that although professionals provided accurate explanations to patients, it was not suited to individual patient's momentary needs. Another possibility was that professionals informed patients but patients were unable to process the information due to the stressful circumstances.

Despite the incongruence noted in the studies above, evidence suggests that the majority of patients newly diagnosed with lung cancer want information on diagnosis, treatment and outcome (Pardon, Deschepper, Stichele, Bernheim, Mortier and Deliens, 2010; Davidson, Brundage and Feldman-Stewart, 1999). In a study examining lung cancer patients' desire for information and participation in treatment decisions, across the 21 patients interviewed there was a breadth of information required. Davidson et al (1999) found that regardless of desired roles in decision-making, patients preferred maximal information, with highest priority on information about treatment regimens, side-effects, survival and effect of therapy on disease symptoms.

In considering the preferences of patients with lung cancer for patient-centred information and decision-making, Pardon et al (2010) reported findings mirroring those of Davidson et al (1999). Ninety-nine percent of patients interviewed desired information about the diagnosis, 97% wanted treatment related details and 96% wished to know if the cancer could be cured. These findings are also consistent with evidence from general oncology studies (Hagerty, Butow, Ellis, Lobb, Dimitry and Tattershall, 2005), but contrast to earlier data which indicated that patients with lung cancer inherently seek less information from professionals than other cancer sub-groups (Blanchard, Labrecque, Ruckdeschel and Blanchard, 1988). Some caution is required generalising from Pardon et al's data to the wider lung cancer population as the sample was younger (mean age of 64 years) and had a better performance status (p=0.0006), with evidence to support that younger, fitter patients desire a higher level of information exchange and involvement in clinical consultations than older, less well patients (Street, Gordon, Ward, Krupat and Kravitz, 2005).

Importantly, many patients with lung cancer either do not have sufficient information or there is significant misunderstanding of the issues, to preclude an autonomous decision. To be autonomous a decision must be made intentionally, without controlling influences, but also with true understanding of the relevant information (Faden and Beauchamp, 1988). Of relevance to my research is that these studies failed to capture the actual content of the information exchanged. The primary focus of these studies was retrospective analysis, using semi-structured interviews or questionnaires that relied on patient recollection of events and these methods fail to capture the interaction to the best extent. Without audiotaped transcriptions of the information exchange process, it is impossible to accurately report what information the professionals and patients exchanged (Hagerty et al, 2005; Gattellari, Voigt, Butow and Tattersall, 2002).

A significant consideration within my research was recognising the specific information content important to the individual patient, with focus on the type, direction and flow of the exchange between the participants at the encounter. As there was no evidence to inform this crucial aspect of

the clinical encounter in the literature, I identified this as a key requirement for further investigation. Importantly, as there was insufficient empirical evidence within the speciality of lung oncology regarding the specifics of information exchange, the cancer literature was explored more generally.

### 2.5.3. Information exchange in general cancer

With respect to information exchange, the key requirement of patients is the need to know and understand (Ong et al, 1995). International studies have consistently reported that the majority of cancer patients desire detailed information on a variety of topics such as diagnosis, treatment options, associated side-effects and prognosis (Cox, Jenkins, Catt, Langridge and Fallowfield, 2006; Jenkins et al, 2001; Sanson-Fisher, Grigis, Boyes, Bonevski, Burton and Cook, 2000).

The majority of patients with cancer in the UK want to receive all information, good or bad, regarding their diagnosis and treatment (Cox et al, 2006; Jenkins et al 2001). A 250 patient stratified sample, typical of West of Scotland cancer patients (Meredith, Symonds, Webster, Lamont, Pyper, Gillis and Fallowfield, 1996) and a more heterogeneous study of 2331 patients across the UK (Jenkins et al, 2001), showed that patients wanted to know the diagnosis and specific details about treatment and prognosis. Results from the Scottish survey conducted at a regional cancer centre showed that 79% of patients wanted as much information as possible, and 96% had a need or an absolute need to know if they had cancer. Most patients (91%) wanted to know the chance of cure, with 94% wanting details about treatment side-effects. When results were cross tabulated according to age, sex, deprivation score and type of treatment, there was a linear trend for patients from more affluent areas to want more information. There was a strong preference for diagnosis information to be given by a hospital doctor [60%] (Meredith et al, 1996).

Similar findings were seen in the multi-centre study exploring information preference of patients with cancer, attending 34 hospital oncology consultations (Jenkins et al, 2001). Of this sample 87% wanted all possible information, both good and bad, with 98% preferring to know if the diagnosis was cancer.

In agreement with Meredith et al's findings, 95% wished to know their prognosis and 97% wanted to know all possible treatment options. Cross tabulation of responses revealed no significant differences in information preferences for tumour site or treatment aims. In contrast to the Scottish study, preference was influenced by age and sex where, in comparison to men, women preferred to know the specific name of the illness.

A multi-centred UK study evaluated multidisciplinary communication, information needs, decision-making preferences and information experiences of 394 cancer patients (Cox et al, 2006). In line with previous research, the majority of patients wanted all possible information, both good and bad (87%), with 39% wishing to share responsibility for decision-making. The majority of patients rated the information they received as helpful, and 7.6% as unhelpful. All patients indicated they had been given information about diagnosis and treatment, with 87% recalling information exchange about prognosis, a slightly lower figure than previous studies (Jenkins et al, 2001; Meredith et al, 1996). Respondents were recalling the type of information they received retrospectively, therefore there was no objective measure of information exchange content.

In all of the studies cited, a small minority of patients expressed reservations about professionals exchanging completely frank information about diagnosis and prognosis. Among the sample of Scottish patients, 4% of people did not wish to know they had malignant disease. And approximately 10% did not wish information about chance of cue (Meredith et al, 1996). Within the Jenkins et al (2001) study 13% of patients preferred 'to leave it up to the doctor' or 'to have information only if it was good', thereby signalling significant reservation about overall truth disclosure. Schattner and Tal (2002) cautioned that because of the heterogeneity of patients, professionals should realise that a substantial minority may not want to know everything about their condition, especially if the information is pessimistic or threatening.

A body of research identifying cancer patients' information needs and the professional sources with who they exchange cancer-relevant information has emerged (Rutten et al, 2005). The significance of information exchange in the consultation is readily apparent. For the professional, information is crucial for formulating diagnoses and prescribing treatment. For the patient, the benefits of information include increased involvement in decision-making and greater satisfaction with treatment choice (Arraras, Wright, Greimel, Holzner, Kuljanic-Vlasic, Velikova, Eisemann and Visser, 2005); improved ability to cope throughout all stages of the care pathway (Davidson and Mills, 2005); decreased anxiety (Deane and Degner, 1998; Ream and Richardson, 1996) and increased satisfaction with the cancer experience with subsequent reduction in disruption to quality of life (Arora, Johnson, Gustafson, McTavish, Hawkins and Pingree, 2002).

Information exchange research focusing on cancer patients' health outcomes has been dominated by site specific cancers, predominantly breast, gastro-intestinal and prostatic malignancies. For example, Bakker et al (2001) used a qualitative research methodology to describe the experience of women with breast cancer interacting with professionals. Two key features were identified. Firstly, information was viewed as a valuable asset to get through the various phases of the cancer journey. Possessing information equated with power and control. Secondly, they viewed professionals as 'information experts' whom they expected to play a major communication role throughout the cancer journey. Information was especially crucial, as in line with other literature, it allowed women to take on active self-care roles, all of which promoted control and participation (Galloway Graydon, Harrison, Evans-Boyden, Palmer-Wickham, Burlein-Hall, Rich-van der Bij, West and Blair 1997; Ream and Richardson, 1996; Grahn and Danielson, 1996). Although the women in this study perceived the professionals as the primary source of information, they viewed themselves as equal partners, with the focus on sharing information and being active consumers of care, rather than passive recipients (Bakker et al, 2001). The study emphasised the significance of the 'interactional' nature of the breast cancer consultation. However, findings may not be immediately generalisable between the young

(most were between 40-50 years old) and well educated (62% had a college/university education) women with breast cancer, historically high information seekers, and other site specific groups such as lung cancer.

Davison, Parker and Goldenberg (2004) found that the majority of men with prostatic cancer attending out-patient clinics in Vancouver had a strong preference for detailed information about their cancer, with 43% wanting an active and 47% wanting a collaborative role in decisions about their treatment. Evidence suggested that the clear majority of men (90%) wanted detailed information about their cancer, investigation results, treatment options, side-effects of treatment and effect on quality of life. They had high expectations about the knowledge, skills and expertise of their physicians to deliver this information during out-patient consultations.

Parker, Baile, de Moor Lenzi, Kudelka and Cohen (2001) reported similar findings when assessing patient preference for communication among patients with various cancers. However, lung cancer patients were not sampled therefore the opportunity was lost to assess lung cancer patient preference regarding information exchange, and to compare their perspective with those of other cancer groups.

### 2.5.4. Summation

In conclusion, there is little evidence to inform information exchange within lung cancer care. The available data provides evidence that although patients have a desire for information, following information exchanges there is incongruence between patients and professionals understanding, with the possibility patients misunderstand the status of their disease and the aim of treatment. Within general oncology evidence suggests that patients desire information on diagnosis, treatment and treatment outcomes, with professionals the preferred source of information. Importantly, whereas these studies are influential in identifying patient preference for information, they utilised retrospective data collection to elicit opinion and the actual content of the interaction (the

information both given and withheld) has yet to be investigated. Directly observed discussions capture actual interactions and allow for an analysis of the process of the information exchange.

## 2.6. Information not exchanged

### 2.6.1. Introduction

Information exchange can be problematic. It relies on patient and professional each providing the information required by the other. However, evidence suggests that information is sometimes not exchanged (Bugge et al, 2006). This section will explore information that is not exchanged in lung cancer care specifically and cancer care more generally.

### 2.6.2. Non exchange of information in lung cancer

Given that cancer patients who have more concerns and unresolved issues are likely to experience worse health outcomes, disclosure and exchange of information is vital (Maguire, 1999). However, within lung cancer care the lack of empirical data makes it difficult to confirm or contest this hypothesis, with only one study found investigating the concerns of newly diagnosed lung cancer patients. Hill, Amir, Muers, Connelly and Round (2003) interviewed 80 patients with lung cancer within a fortnight of diagnosis. Patients were asked to rate 17 specific items of concern. Diagnosis and concerns for the future were the two most dominant concerns. Unmet psychosocial needs in patients with lung cancer appear unchanged since Houts, Yasko, Kahn, Schelzel and Marconi (1986) found that patients with the malignancy had more unresolved concerns than any other cancer group. Psychosocial concerns were more worrying for patients than physical symptoms yet the ones least likely to be discussed and addressed between patients and professionals. Patients do not mention psychosocial issues during consultations as they are often diverse and not thought to be relevant. Professionals often do not elicit concerns of this nature, as they are viewed as time consuming (Elwyn, Edwards and Kinnersley, 1999). Subsequently, information remains un-exchanged.

Only one other study was identified which focused on the role of collusion (The, Hak, Koeter and van der Wal, 2000). This ethnographic study of 35 patients with small cell lung demonstrated that patients with a limited prognosis showed a 'false optimism' about their recovery, in that patient interpretation of the prognosis was considerably more optimistic than what they had been told. Many patients informed their relatives that they have been told they were 'cured' when in fact their life expectancy was a maximum of two years (The et al, 2000). The authors argued that professionals colluded, using 'medical activism', sustaining the optimism through ongoing chemotherapy sessions and limiting discussion on prognostic information. Patients, focused on current activity (chemotherapy), preferring to 'forget' the uncertain future. The authors portray collusion as a strategy by which professionals and patients sidestep information relevant to treatment outcome. Other studies have found similar collusive tendencies in patient-professional communication in oncology more generally (Kirwan, Tincello and Lavender, 2003). Evasion of information allowed patients not to acknowledge explicitly what they should know about cancer, its therapy and outcome and it may thus have implications for the treatment choices patients made.

Collusion and complicity are important considerations in information exchange and as such will be discussed in the results chapter. However, a wider perspective was required to consider specifically information which is not exchanged in cancer care. The lack of evidence relating to lung cancer particularly necessitated a need to widen the search field to include general cancer.

### 2.6.3. Non exchange of information in general cancer

Within the general oncology literature there is a small body of evidence that non-exchange of information is prevalent. Thorne, Bultz and Baile (2005) reviewed literature which suggested professionals often failed to recognise psychiatric morbidity in cancer patients (Fallowfield, Ratcliffe, Jenkins and Saul, 2001) and neglected to elicit patient's psychosocial concerns (Rogers and Todd, 2002). Further studies suggested professionals may neglect the psychosocial concerns of patient,

whilst concentrating on the biomedical aspects of disease (Cox et al, 2006; Hack, Degner and Parker, 2005). Information exchange in outpatient clinics is organised according to a hierarchy and used to make treatment decisions and not primarily for addressing either symptom or psychological concerns of the patient (Rogers and Todd, 2002).

Fagerlind, Linbald, Bergstrom, Nilsson, Naucler, Glimelius and Ring (2008) found that in a gastro-intestinal oncology clinic little attention was given to psychosocial concerns. Mean time for consultation was 19 minutes – mean proportion of time spent discussing clinical and medical information was 78%, with only 16% of time spent on patient-centred topics. Although, cancer patients predominantly want information about their disease, its treatment and possible side-effects and prognosis (Cox et al, 2006; Rutten et al, 2005), some also want to discuss psychosocial aspects of care (Sanson-Fisher, Girgis, Boyes, Boneveski, Burton and Cook, 2000). Similarly, Stead, Fallowfield, Brown and Selby (2002) reported that while all but one of 43 professionals participating in their ovarian cancer study agreed they should discuss patient psychosexual concerns, only 25% actually engaged in such discussions.

Studies have reported the importance of reconciling the findings of research, which often measure patient outcomes weeks or even months after potentially critical exchanges, with the results of research generated during real-time consultations (Hack et al, 2005; Beach and Anderson, 2003a). Of critical importance to studies investigating information exchange within cancer consultations is that what participants say about the process often stands in contrast to how interactions actually happen (Beach and Anderson, 2003b). Previous interactional research by Hack et al (2005) revealed that the primary emphasis has been individuals' self-reported experiences rather than observing naturally occurring interactions between cancer patients and professionals. What has been absent has been a thorough explication and understanding of the information exchange during consultations (Beach and Anderson, 2003b). As there was no empirical data identified at literature review, I deemed observing

this naturally occurring exchange of information crucial to understanding the information which was both exchanged and not exchanged within lung cancer consultations.

### 2.6.4. Non exchange of information in general practice

Studies within the general, non-cancer literature have informed clinical practice relating to information exchange (Charles et al, 1997; Roter, Stewart, Putman, Lipkin, Sytiles and Inui, 1997). Resonating with the findings reported in the cancer literature, the general research has also found reluctance from both patients and professionals in primary care to present all relevant information, especially concerning psychosocial issues. Patients commonly fail to mention emotional or psychological concerns, for fear of wasting the doctor's time (Cape and McCulloch, 1999), and even fear of stigmatisation or because of embarrassment (Hirschfield, Keller, Panico, Arons et al, 1997). Across general and primary care settings, professionals report that the process of eliciting emotional and psychosocial concerns takes time, which they feel they do not have. They argue they often lack the training and expertise to deal with such issues; they lack the informational skills to convey the correct and appropriate information and they lack the skills needed to 'share' information with patients (Elwyn, Edwards, Gwyn and Grol, 1999; Marteau, 1989).

When patients do not exchange all relevant information concerning past medical history, life style or opinions and concerns, they are forcing professionals to diagnose and treat when full disclosure has not been achieved. Studies have confirmed that both patients and professionals feel there have been times within the clinical consultation when they have not exchanged sufficient information, that may have been important for decision-making (Bell, Kravitz, Thom, Krupat and Azari, 2001; Barry, Bradley, Britten, Stevenson and Barber, 2000; Britten, Stevenson, Barry, Barber and Bradley, 2000). Equally, professionals are reported to have withheld information pertaining to alternative treatment regimens and survival outcomes at consultations (Entwistle, Williams, Skea, MacLennan and Bhattacharya, 2006; Britten et al, 2000).

Bugge et al (2006) investigated the significance for decision-making when both patients and professionals did not exchange information. Across 5 diverse clinic settings, including general and cancer contexts, their findings concurred with previous research and found that patients withheld information because the clinician's behaviour was off putting (Kaplan, Greenfield, Gandek, Rogers and Ware, 1996), the clinic environment was not conducive to the exchange (Fadiman, 1997), or patients did not think that the information was relevant or appropriate (Barry et al, 2000). Health professionals felt they lacked the skills to adequately deal with certain types of information (Lampic and Sjoden, 2000) or they judged that the decision was theirs alone to make (Fagerlind et al, 2008). Significantly, the evidence highlighted that patients felt they gave insufficient information to professionals. Likewise professionals did not provide all relevant information about diagnoses and treatment options that patients would have liked and which they deemed important for participation (Bugge et al, 2006).

### 2.6.5. Summation

Information exchange between professionals and patients is a critical component of clinical encounters. It is especially challenging in cancer care where the complexity of the medical information, the uncertainty regarding the disease, and the treatment outcomes add a potentially greater emotional dimension to the interaction. Information exchange difficulties between patients and professionals have been investigated by researchers from different disciplines and clinical contexts who have tried to explore why these occur. If either professionals or patients refrain from full exchange of information about their concerns, relating to the patient's problem within the interaction, they may not reach a shared understanding of the issues that need to be addressed. The lack of a shared understanding about the nature of the problem is a poor basis for effective shared working towards decisions about a course of action to deal with the presenting problem (Bugge et al, 2006).

Studies in cancer care focusing on the actual information exchange process during the clinical encounter are relatively limited, informed by general and primary care evidence and frequently

retrospective (Arora, 2003). Additionally, despite the focus on interactions within the oncology context, a review of the literature revealed that the primary emphasis has been individuals' self-reported experiences rather than observing naturally occurring interactions between cancer patients and professionals.

As there was no empirical evidence investigating the phenomenon of information exchange within the lung cancer context, my research explored this premise. My study was conducted with the expectation of making a contribution to current practice by providing an understanding of information exchange within this specialised area. By providing accounts of individual patient perspective of the information exchange process, it was hoped that such evidence would not only help professionals to better understand the patient experience, but also provide useful data to inform practice and policy regarding the process in general.

# Chapter 3: Rationale for methodology

## 3.1. Introduction

The following chapter will describe the rationale underpinning the use of the qualitative case study methodology used in this thesis. The case study method is grounded in a constructivist paradigm guiding the empirical inquiry of the contemporary phenomena of information exchange (Anthony and Jack, 2009). The rationale for the use of this paradigm to address the research question will be explored and the basis for this approach will be examined, with particular emphasis on case study processes in research design, data collection and data analysis.

## 3.2. Justification for a qualitative approach

A qualitative case study is a potentially valuable approach to conducting investigations aimed at understanding the complexity of care situations (Hewitt-Taylor, 2002). Chapter 2 illustrated that information exchange is highly complex and despite the centrality of the clinical encounter to patient and professional information exchange, its true scope and nature have not been well articulated (Dieppe et al, 2002). There is a paucity of empirical literature on which to formulate and develop local and national policy and also a lack of qualitative research to inform professional practice within the specialist area of lung cancer.

My thesis aimed to explore the complex process of information (both that exchanged and not exchanged) and further required to investigate the process from a participant perspective. A qualitative methodology suited to describing and explaining complex issues of relevance to healthcare and nursing and one which involved specific focus on the richness of the real-life context, seemed the most appropriate for my research (Yin, 2009). This method is concerned with developing explanations of social phenomena, eliciting the opinions and experiences of individuals and offering both richness and depth of information in order to understand participant perspective within their social and situational context (Hancock, 2002).

Miles and Huberman (1994, p10) stated that a major strength of qualitative data is the focus on *naturally occurring ordinary events in natural settings so that there is a strong handle on what 'real life' is like*. The empirical literature I reviewed lacked a clear understanding of this real life situation concerning information exchange between patients with lung cancer and professionals. Consequently, the cornerstone of my thesis concerns itself with the clinical context and is buttressed by what Miles and Huberman (1994) termed local groundedness, whereby data is collected in close proximity to the specific real life situation and embedded within its context. Within this situational context, rich descriptions, with a ring of truth are revealed, leaving a strong impact on the reader. It was this description and the lived experience of the lung cancer patient that qualitative methodology would channel. Consequently, the use of the method was considered key for my research.

There were other mitigating factors which led me to conclude that a qualitative method was the most appropriate approach to address the research question. These are detailed in table 3.

**Table 3: Advantages of a qualitative research method**

| | |
|---|---|
| Provides depth and detail | looks deeper than analysing ranks and counts by recording attitudes, feelings and behaviours |
| Creates openness | encouraging people to expand on their responses can open up new topic areas not initially considered |
| Stimulates people's individual experiences | a detailed picture can be built up about why people act in certain ways and their feelings about these actions |

My research required a methodology which would allow me to study a complex, yet unexplored area of cancer within the real-life context of the patient perspective.

## 3.3. Justification for a constructivist paradigm

Maxwell (2004) portrayed four alternative paradigms which compete for acceptance as the paradigm of choice in informing and guiding qualitative inquiry; *Positivism, Advocacy, Pragmatism and*

*Constructivism* (table 4). Paradigms may be viewed as a basic belief system or worldview that philosophically guides the researcher to make claims about what knowledge is (ontology), how we know it (epistemology), what values go into it (axiology), how we write about it (rhetoric) and the process for studying it (methodology) (Cresswell, 2004).

**Table 4: Alternative paradigms**
**(Maxwell, 2004)**

| Positivism | **Constructivism** |
|---|---|
| Determination | Understanding |
| Reductionism | Multiple participant meanings |
| Empirical observation & measurement | Social & historical construction |
| Theory verification | Theory generation |
| Advocacy | Pragmatism |
| Political | Consequence of actions |
| Empowerment issue orientated | Problem centred |
| Collaborative | Pluralistic |
| Change –orientated | Real-world practice orientated |

A constructivist approach seemed to me to be an appropriate method by which to explore the concept of information exchange from the perspective of the participants. Positivism reflects a deterministic philosophy where intent is to reduce the ideas into discrete theories to test. Therefore, I rejected this, as the aim of my study was theory generation. Researchers using an advocacy paradigm believe inquiry needs to be intertwined with a political agenda, aimed at reforming the lives of the participants and although policy initiatives have an important role within my study they are not the sole orientation. Within the pragmatic paradigm, instead of methods being important, the problem takes precedence and for my research I needed a paradigm which was more holistic and contextual than problem-solving. Assumptions identified within the constructivism paradigm hold that individuals seek interpretation of the world in which they live and work. They develop subjective meanings of their experiences which are varied and multiple, leading the researcher to look for meaning in complex

situations (Cresswell, 2004). My research would be best explored using this paradigm as it allow me to 'reveal the multiplicity of factors which have interacted to produce the unique and complex character of the entity that is the subject of the study' (Yin, 2009, p82).

Constructivism maintains that the truth is relative and dependent on one's perspective. It recognises the importance of the subjective human creation of meaning and is built on the premise of a social construction of reality (Searle, 1995). As I was concentrating on exploring and giving an account of how people make sense of a situation (information exchange), at a particular point in time (lung cancer consultations) this paradigm was an obvious choice (Blaxter, Hughes and Tight 2006).

Additionally, constructivist research focuses on the meanings embedded in textual and verbal accounts and generally involves the analysis of archival materials, documentary sources and/or oral and personal histories and narratives, garnered through data collection strategies such as interviews. It was very much in tandem with the data collection methods which my research would employ. The utilisation of a constructivist approach would allow me to give meaning to the way things are within the real-life experience of the clinical encounter and to identify factors that otherwise could not be described through metrics and statistics. The goal of the research is to rely on the participants' views of the situation and the construct and meaning which is forged through information exchanges (Cresswell, 2004). The constructivist paradigm was chosen as the most appropriate because the focus was on subjectivity, where the research was attempting to understand the phenomenon of information exchange through directly observed data collection, but also what the participants create and associate with their own subjective meanings of information, as they interact with the world around them, including at times the researcher (during de-brief interviews and more comprehensively at the in-depth interview) (Walsham, 2006).

### 3.4. Justification for case study design

A research design is the logic that links the data to be collected and the conclusions to be drawn to the initial questions of a study: essentially, it ensures coherence (Rowley, 2002). The case study design

is defined as 'an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident' (Yin, 2009, p 13). Importantly for my research, the design draws upon the principles of an inquiry, seeking to understanding complex social systems (Bennet and Elman, 2006; Denscombe, 2003), where the intention is to comprehend the nature of current processes in a previously little-studied area (Cresswell, 2004; Eisenhardt, 1989).

Given the nature of the research problem as outlined in Chapter 2, I judged this design as the most appropriate for this study. It is well suited to new research areas for which existing theory seems inadequate, as demonstrated in the literature review section, which highlights the paucity of data to guide information exchange in lung cancer. Furthermore, I realised that this design was compatible with my research as there were three distinctive factors of key consideration and these are identified in table 5.

**Table 5: Key factors guiding the use of case study design**

| | | |
|---|---|---|
| **Research question being posed** | Case study design is the preferred research strategy when 'how', 'what' and 'why' questions are being asked | My research question is: what information is exchanged and not exchanged between patients with lung cancer and healthcare professionals at clinic consultations |
| **The extent of control over behavioural events** | Case study design is valuable when the researcher has little or no control over the event | My research seeks to investigate the phenomenon of information exchange from a participant's perspective, without controlling either the clinical encounter or the meaning people ascribe to the experience |
| **Research is being carried out in the real life context** | Case study is beneficial for contemporary events | My research was conducted within the real-life contemporary context of the clinic consultation |

As with paradigm justification there are numerous alternative research designs to select, as figure 1 displays:

**Figure 1: Alternative research designs**

| |
|---|
| CASE STUDY |
| Experimental |
| Grounded theory |
| Action research |
| Ethnography |

However, Yin (2009) stated there are distinguishing features of case study design which discern it from the other strategies. In particular case study design:

- Copes with the technically distinctive situation in which there will be many more variables of interest than data points
- Relies on multiple sources of evidence, with data needing to converge in a triangulating fashion

As such, as my research, congruent with clinical practice and concerned with investigating complex situations, where the real-world context is central and when multiple perspectives are required, judged that this design has much to recommend it over other research methods.

In summary, a case study design was appropriate to this research because the questions posed were of the 'what' type genre; the focus was on contemporary as opposed to historical events and, as a researcher, I did not seek to control events or behaviours. Importantly, case study design was relevant to use because the phenomenon of information exchange would be studied in a total, contemporary

and real-life context. The constructivist paradigm was chosen as the most applicable for my research because the focus was on subjectivity – exploring meanings, experiences and perspectives of the participants in relation to information exchange.

### 3.5. Case study design

The case study provides a form of inquiry that elevates a view of life and its complexity (Thomas, 2009). Stake (2005) suggested that the case study is not a method in itself, but rather a focus on one thing, looked at in-depth and from many angles. However, Yin (2009) argued that the design must relate to the context of the study and importantly, the research question. With particular reference to my research, concerned with exploring multiple perspectives within the real-life context of information exchange processes, I was persuaded by the literature to consider this definition of case study design. For my thesis the definition which encompassed the fundamental premise of my research was:

*Case study design is an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, programme or system, in a real life context. It is research-based, inclusive of different methods and is evidence led. The primary purpose is to generate in-depth understanding of a specific subject to generate knowledge and /or inform policy development or professional practice* (Simons, 2009, p21).

There are several proponents of case study design (Eisenhardt and Graebner, 2007; Gillham, 2001; Merriam, 1998; Miles and Huberman 1994; Eisenhardt, 1989). The two most prominent Yin (2009) and Stake (2005) used different terms to describe a variety of cases. According to Stake (2005), three categories of case study can be identified in terms of their broad purpose, namely; intrinsic, instrumental and collective. Yin (2009) categorised case studies as explanatory, exploratory or descriptive. He further described the primary distinction in case design being between single and multiple case designs based on either holistic or embedded designs.

The use of a single case design is considered when studying unique or extreme cases, or to confirm or challenge a theory or for cases where the researcher did not have access to before. Multiple (or collective) case designs are preferred as analytical conclusions from more than one case will provide more powerful data than from a single case, with more compelling evidence. Consequently, multiple case designs are useful for predicting similar results (literal replication) or predicting contrasting results but for predictable reasons (theoretical replications) providing valuable information for the study (Baxter and Jack, 2008).

Within my research, multiple case study design would enable investigation of a case, utilising informative and contextual data to interpret my findings about the phenomenon being explored. My interpretation would lead to a more complete understanding of the process of information exchange and provide effective data that could not be collected otherwise (Brown, Hill, Burant and Siminoff, 2008). As such, I required a multiple case study design which would provide varied real-life perspective as well as rich description and insight and one which necessitated the identification of diverse cases from a range of:

- patients (male and female)
- healthcare professionals
- accompanying companions
- types of lung cancer
- stages of the disease
- proposed treatment options
- potential treatment outcomes

The application of a multiple case design would allow me to analyse each individual case and would have the potential to provide a unit of analysis to be analysed within case. Additionally, throughout the aggregate of cases, a multiple case design would allow more robust and compelling evidence across-cases (Yin, 2009). As such, the design I employed was the collective or multiple design, ideal

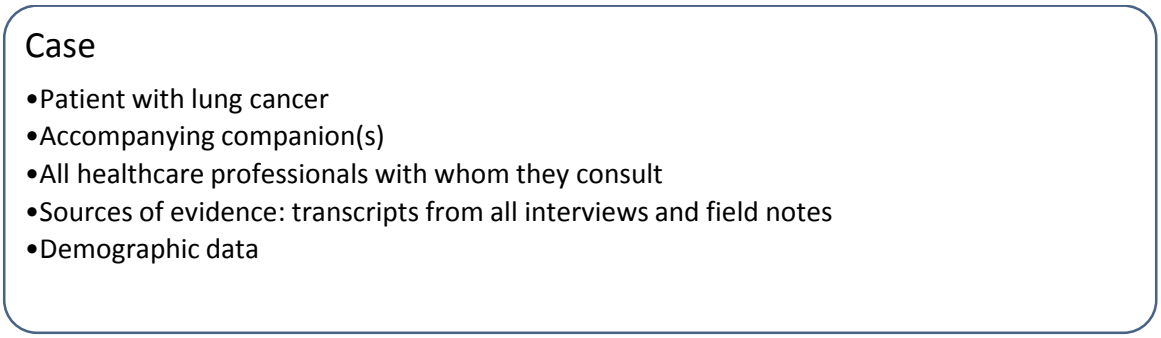
for comparative cross case analysis, to understand and explore the similarities and difference between the cases.

### 3.6. Case definition

Case selection is a primordial task for the case study researcher. In choosing cases, one also sets out an agenda for studying those cases (Seawright and Gerring, 2008). The case is defined by Miles and Huberman (1994, p25) as, 'a phenomenon of some sort occurring in a bounded context'. The case is, in effect, the unit of analysis, the major entity being analysed in the study and its bounded components. Subsequently, case selection should reflect the characteristics and problems identified in the empirical literature and the underlying research question (these were defined in Chapter 2) whilst representing the topic of the study.

As stated by Simons (2009) the case study is the in-depth exploration from multiple perspectives of the complexity of a particular case. Consequently for my research, the patient with lung cancer needs to be seen within the complexity of a case, coming to understand the activity within the full and important circumstances of the process of information exchange (Stake, 2005). Thomas (2009) viewed the case as a container composed of objects, which intermesh in myriad ways and the result is inherently highly complex data. A case study is about seeing the case in its completeness, looking at it from many angles (Thomas, 2009). Stake (2005) reasoned if qualitative research requires that cases to be chosen, making a proper selection of cases is crucial. The composition of a case in my research is delineated in figure 2.

**Figure 2: Case composition**




For my research I referred to some of the principles offered by Miles and Huberman (1994), namely that:

- Case selection should be relevant to the conceptual framework and address the research questions
- Each case should be likely to generate rich, contextual information on the type of phenomena which need to be studied
- Cases should produce believable descriptions and explanations

Additionally, within the Miles and Huberman (1994) teachings, the case is the 'heart' of the study and a somewhat indeterminate boundary defines the edge of the case: what will not be studied. This boundary will be defined further by sampling or case selection, which for my study is outlined below.

## 3.7. Case selection strategy and case binding

Researchers define this particular section, which I have named case selection, as sample selection. I made the decision to follow the principles of Thomas (2009) and Stake (2005) and viewed the cases, not as a sample of a population, but cases drawn from one. The point of a case study is not to find a portion that shows the quality of the whole, but to look at case 'selection', focusing on one, two or a few, without any expectation that it represents a wider population. In case study design, the researcher is trading breadth of coverage (i.e. case numbers) for depth of understanding (Thomas, 2009). It is in the multi-faceted nature of the case design that the opportunity arises to relate one

piece of data to another (within case) whilst offering explanation based on the interrelationships between them (across case).

In case study design a common pitfall is the tendency to attempt to answer a question that is too broad or has too many objectives and includes an unrealistic number of cases (Baxter and Jack, 2008). Yin (2009) and Stake (2005) suggested placing boundaries on cases, hence preventing this explosion from happening. Suggestions for binding a case include; by time and place (Cresswell, 2004), time and activity (Stake, 2005) definition and context (Miles and Huberman, 1994). Binding ensures the study remains reasonable in scope, by indicating what will and will not be studied in the research. Binding is closely aligned to inclusion and exclusion criteria (see chapter 4) as well as assisting with the selection strategy which the research employs.

Multiple cases are regarded as equivalent to multiple experiments; the more cases/experiments that can be marshalled to establish or refute a theory, the more robust and compelling the research outcomes (Rowley, 2002). My study will follow the principles of qualitative case study selection that commends researchers to work with small case numbers, nested in their context and studied in-depth. Essentially my research will explore a small lung cancer population, their companions and professionals, all with expert experience and insight into the disease.

Thus, there is a need to select context-based cases which answer the research questions determined by the study. To accomplish this I utilised a purposive selection technique. The research question exploring the information exchange process and individual case perspectives would be best answered, more meaningful and context laden, if drawn from a strategically and purposively selected group of cases (table 6).

**Table 6: Criteria for purposive case selection**

| **Patients with lung cancer** | | | | |
|---|---|---|---|---|
| | **Gender** | **Age** | **Performance status** | |
| | Male & female | <65 years<br>>65 years | 1 – 3 | |
| | | | | |
| **Lung cancer** | **Type** | **Stage** | **Treatment** | **Treatment intent** |
| | NSCLC<br>SCLC<br>Mesothelioma | Limited<br>Advanced | Chemotherapy<br>Radiotherapy<br>Surgery<br>Combination<br>Best supportive care | Palliative outcome<br>Curative outcome |
| | | | | |
| **Healthcare professionals** | Clinical nurse specialist | Respiratory consultant | Oncologist | Thoracic surgeon |
| | | | | |

Within my research the multiple case design would be subject to purposive case selection allowing comparison among diverse components of the selected cases. Despite the dangers of selection bias when researchers employ a purposive technique to select cases, yet more serious problems would likely be encountered if one chooses a very small case group in a completely random fashion (Seawright and Gerring, 2008). Randomised selection will often produce cases which are substantially unrepresentative of the population. It is true that purposive selection cannot entirely overcome the inherent unreliability of 'generalising' from small case sizes, however, it can make an important contribution to the inferential process by enabling the researcher to choose the most appropriate cases for a given research strategy (Seawright and Gerring, 2008).

## 3.8. Case size

Within multiple case designs it is suggested that, to increase the quality of the research, the selection of cases needs to be driven by two issues:

1. Appropriateness: demonstrating a fit to both the purpose of the research and the phenomenon of inquiry
2. Adequacy: concerned with how many cases are enough (Kuzel, 1999; Miles and Huberman, 1994)

Within this design a significant principle, guiding both case selection and size, is the prospect of literal or theoretical replications. Multiple cases allow for within and across case comparison, particularly in diverse settings (Darke, Shanks and Broadbent, 1998). However, Stake (2005) cautioned that the number of cases to allow this is crucial. Benefits may be limited if there are fewer than four cases or more than ten to fifteen because the researcher could be overwhelmed by data.

Case size is contentious, ambiguous and no simple solution is provided (Patton, 2002; Rowley, 2002). Cases need to be carefully selected so they either produce similar results offering corroboration with each other (literal replication), or generate contrasting results but for predictable reasons (theoretical replication). The replication logic requirement of the multiple case design provides suggestions to determining the number of cases (Shakir, 2002). The ability to conduct 6-10 case studies, arranged effectively within a multiple case design, is analogous to the ability to conduct 6-10 experiments on related topics. A few cases (2 or 3) would be literal replications, whereas a few more (4 to 6) might be designed to pursue different patterns of theoretical replications (Yin, 2009).

I took a pragmatic stance early in the research to select study sites with access to multi-professional healthcare teams (respiratory physicians, lung cancer clinical nurse specialists, oncologists and thoracic surgeons), who as individuals, could provide expert knowledge and insight into information exchange, from a specialist, oncology perspective. Equally, they were selected for their experience in

the complex management of patients with lung cancer. These would be selected using a purposive technique, to provide diversity within the cases, with the aim of providing the greatest coverage and best chance of identifying patterns of difference or similarity (Shakir, 2002).

I judged that the research may provide literal replication, with similarities evident in the cases. Equally during data analysis, theoretical replication may be apparent. I used the replication logic strategy developed by Yin (2009) [table 7] and, as overall theoretical replication may have been evident, decided that 6 to 10 cases was considered the number of cases required for my study.

**Table 7: Replication logic strategies for determining case size in multiple case design (Yin, 2009)**

| **Replication logic strategies** | **When the….**<br>▸ Difference between rival theories is<br>▸ Degree of certainty required is<br>▸ Differences between the cases is | **Initial number of cases** |
|---|---|---|
| **Literal replication** | Low | 3- 4 |
| **Theoretical replication** | High | 6-10 |

## 3.9. Data collection

Case study research excels at conveying an understanding of a complex issue and emphasizes detailed contextual analysis of a limited number of events and their relationships (www.ischool.utexas.edu/case study research method-accessed 14.11.2009). As such, case study data collection features which are thought to benefit complex evaluations require the use of multiple data sources (Baxter and Jack, 2008). Each data source is one piece of the puzzle, with each piece contributing to the researcher's understanding of the whole phenomenon. This convergence adds strength to the findings, as various strands of the data are woven together to promote a greater understanding of the case and its relationships with other cases (Baxter and Jack, 2008).

Yin (2009) considered the case study's unique strength is its ability to deal with a full variety of evidence, including documents, artefacts, interviews and observations. The benefits of these multiple data sources can be maximised if three key principles are followed:

- Use of multiple sources of evidence
- Creation of a case study database
- Maintaining a chain of evidence

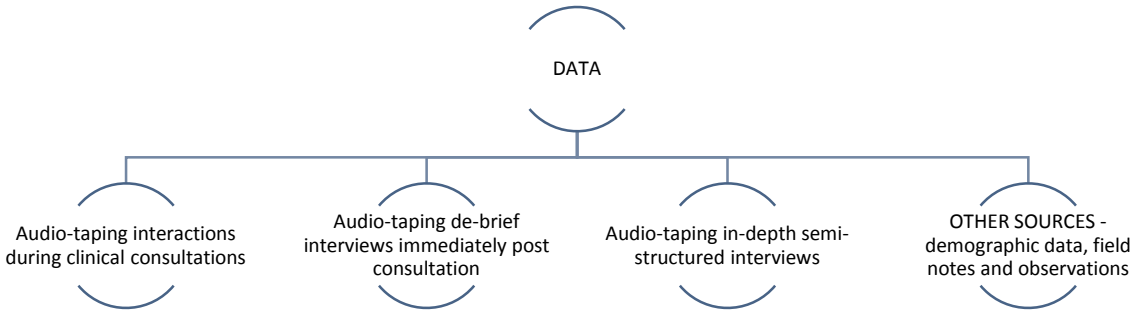
### 3.9.1. Use of multiple sources of data

A major strength of case study data collection is the opportunity to use different sources of evidence, to address a broader range of contextual and behaviour issues (Thomas, 2009; Yin, 2009; Baxter and Jack, 2008). The most important advantage is the development of converging lines of inquiry, a process of triangulation and corroboration (Yin, 2009). Conclusions drawn from case study design are likely to be more convincing and accurate, if based on several different sources of data, corroborating the same phenomenon (Yin, 2009; Hewitt-Taylor, 2002).

My research was principally concerned with exploring the information exchange process and capturing the actual communication taking place between the participants, gaining a description of the meaning and perspective that the participants themselves placed on the information they either exchanged or did not. To gain an accurate picture of the phenomenon and its related complexities, data required to be collected from multiple perspectives. A useful strategy when the contemporary health problem has complexities which are not clearly understood or has little researched evidence, as was the case with my research (Thomas, 2009). Each of the various sources employed would require a different approach to their interrogation but would consequently yield diverse but converging insights into the phenomenon of information exchange. The strategies I employed are illustrated in figure 3.

The principle of triangulation followed within my study pertains specifically to data and not investigator, theory or methodological triangulation (Patton, 2002). The use of triangulation in order to undertake the pattern-matching analysis used in case study design strengthens the credibility (construct validity) of the research – the establishment of the correct operational measures for the concepts being studied (Bergen and While, 2000). Yin (2009) asserted that, with data triangulation the potential problems of construct validity can also be addressed, because multiple sources of evidence essentially provide multiple measures of the same phenomenon (Yin, 2009).

**Figure 3: Convergence of multiple sources of evidence**




### 3.9.1.1. Audio-taped interactions during clinical consultations

The main strength of audio-taping the interaction between the participants during clinical consultations was the provision of direct access to the social phenomena under consideration. Instead of reliance on self-report, interactions within the clinical context are recorded verbatim. An audio-taped recording of the interaction and information exchange between the study participants was a key requirement for providing factual accounts of the information both exchanged and not exchanged. The intention was to record the clinical encounters as they occurred as real-life events, where the focus is on understanding the meanings participants, in the contexts observed, attribute to events and

actions. This type of observation is viewed as interpretative and fits with the constructivist paradigm important to my study design.

This strategy permits a permanent record of the interaction, events and behaviour. It also allowed further analysis or subsequent comparisons across time where the data was not subject to memory and bias recall of the participants. Additionally, observer bias whereby the researcher records not what actually happened, but what they either wanted to see/hear, expected to see/hear, or merely thought they saw/heard, with the potential to undermine study reliability and validity, was reduced in my study as I was not present during the clinical consultation whilst data was being collected. The very act of being observed poses a risk of influencing the participants during the process, such as the Hawthorne Effect whereby people modify their behaviour as they know they are being studied (Cormack, 2000). Researcher influence, bias and reflexivity are explored in Chapter 4.

#### 3.9.1.2. De-brief interviews

De-briefing was critical to capture the immediate perspectives of the participants post consultation. A de-briefing is a semi-structured conversation with an individual who has just experienced or witnessed an event. It is used to refer to the process whereby qualitative feedback is sought from the participants, usually about interviews conducted beforehand (Lavrakas, 2008). The immediacy of the interaction yields useful information regarding people's motivations and concerns about the consultation. Additionally, it also provided a platform on which to base additional questions and acted as an aide memoire at the in-depth interview.

#### 3.9.1.3. Semi-structured in-depth interviews

Interviews are an ideal method of data collection as they are a highly efficient way to gather rich, empirical data when the phenomenon of interest is highly complex yet episodic (Eisenhardt and Graebner, 2007). In contrast to other data collection strategies, interviews are insightful and focus on

the meanings individuals assign to events and the complexity of their attitudes, behaviours and experiences. Stake (2005) described interviews as the road to multiple realities where the decision to use face-to-face interviewing implies a value on personal language as data (Ritchie and Lewis 2003). To arrive at a description of the meaning of information exchange for patients with lung cancer, and their companions, gaining an accurate picture of the phenomenon from their perspective, semi-structured, yet in-depth, interviews were a key source of data collection. This strategy in conjunction with data collected from the clinical consultations provided breadth and depth to the study and ensured complete and thorough findings (Speziale and Carpenter, 2007).

Yin (2009) described interviews as guided conversations rather than structured queries. Although pursuing a consistent line of enquiry between all cases, the actual stream of questions is likely to be more fluid than rigid (Rubin and Rubin, 1995). Albeit a sense of conversation is ideal in interviewing, the research question dictated specific *a priori* topics which required to be addressed. Whilst flexibility and latitude are evident in case a study method, an interview guide was devised (Appendix 1) to ensure that all participants were asked to discuss the same topics, ensuring similar types of data were collected (Holloway and Wheeler, 2002). Standardisation of at least some of the questions added to data reliability, as unstructured interviewing with spontaneous questions, makes the data difficult to quantify and analyse (Thomas, 2009). Questions used in the interview guide were formulated following consultation with an Advisory Group. All patient related documentation was reviewed by members of a Focus Group, set up in consultation with the Roy Castle Foundation (a leading lung cancer advocacy group). They assisted me in developing the content of the guide and reviewed all patient materials for suitability of language and content.

**3.9.1.4. Field notes and case sheets**

In addition to data collected during the clinical encounter and interviews as transcribed material, other forms of data would be collected via case sheet compilation and researcher observation recorded as field notes. Case studies use a combination of case sheets, field notes, and databases to categorise

and reference data so that it is readily available for subsequent reinterpretation. Case sheets allow the recording of all categorical data for individual cases and their composition will be discussed in chapter 4. Similarly researcher observation, recorded as field notes throughout all periods of interaction with study participants, records testimonies, stories and illustrations which can be used in later reports (www.ischool.utexas.edu/case study research method-accessed 14.11.2009). Keeping a record of the interview is part of the artistry (Stake, 2005).

#### 3.9.1.5. Case demographic data

Demographic data collection was instrumental in the study. It was necessary to determine whether the cases were a typical representation of the wider population and essentially as it provided important data relating to the characteristics of the participants. All demographic data provides contextual background information and it further informs data analysis in relation to within and across case analysis.

The triangulation of these data collection strategies; audio-taped observed interaction, de-brief interviews, in-depth interviews, field notes, case sheets and demographic data documentation, essentially provide multiple measures of the same phenomenon. In so doing, the depth and quality of data offered to answer the research questions should be increased.

## 3.10. Creating a case study database

Multiple sources of data are required to be organised, documented and stored, comprehensively and systematically, in formats that can be referenced, in order that converging lines of enquiry and patterns can be uncovered (Baxter and Jack, 2008). Categorised and referenced data should in this way be readily available for subsequent re-interpretation and the design of the databases should be such that other researchers would be able to use the material based on the descriptions contained in the documentation (www.ischool.utexas.edu/case study research method-accessed 14.11.2009).

The main proponents of case study design recognise the importance of database creation in the organisation of complex and multiple sources of data (Yin, 2009; Stake, 2005). Its omission within the research design is viewed as a major shortcoming (Yin, 2009). Its construction essentially establishes a data warehouse for subsequent cross case analysis (Davis, 2010). I used the software package Nvivo 9® which facilitated the recording of source detail, including all key documents, tabular materials, audio files and narratives. The software allowed accurate recording of time and date of data collection, storage and search capabilities, and importantly, for retrieval of patient narratives, which were referenced and identifiable (Wickham and Woods, 2005).

### 3.11. Chain of evidence

The final principle advocated by Yin (2009) was maintaining a chain of evidence, the predominant aim of which is to further ensure reliability of the evidence. An evidence chain essentially allows an external observer to follow the derivation of the study evidence and to trace the steps in either direction. Yin (2009) suggested that the links between the report and the database are transparent and my research adhered to this principle. All evidentiary sources were stored and organised within Nvivo 9® software and remain available for independent inspection. These three key principles of case study design will be explored in more detail in chapter 4.

### 3.12. Data analysis

Case study analysis is driven by one of the realities of this design: a staggering volume of data. To prevent 'death by data asphyxiation' (Pettigrew, 1988), case study researchers recommend coding data to allow unique patterns of each case to emerge prior to further across case analysis (Yin, 2009; Miles and Huberman, 1994; Eisenhardt, 1989). In this way large volumes of data can be reduced into manageable units (Miles and Huberman, 1994). Software programmes, such as Nvivo 9®, are beneficial in coding and categorising raw data derived from patient narratives, verbatim transcripts of interviews and written materials, where the research is attempting to derive meaning from words and

patterns (Yin, 2009). Yet, to systematically analyse and identify themes and patterns, a clear analytical strategy is essential to convey data from preliminary coding to reasoned and compelling conclusions (Yin, 2009).

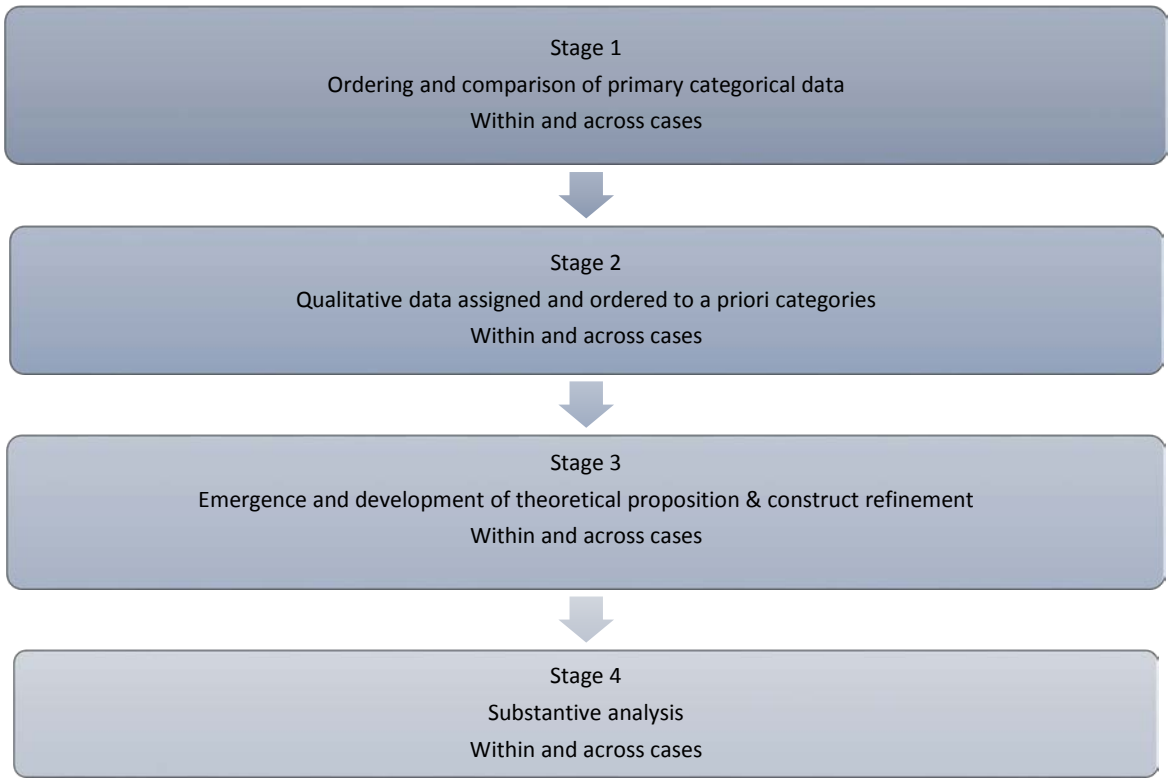
To prevent being initially overwhelmed by considerable amounts of raw data and to aid initial pattern identification *a priori* specification of categories is useful to shape the primary design and to permit the researcher to measure constructs more accurately (Eisenhardt, 1989). Relying on predetermined or *a priori* categories helps to focus the attention on certain data, whilst ignoring data less relevant to the research. Yin (2009) considered the prioritising of data based on categories which relate to the original research questions as the preferred approach in case study design.

Once a pattern or category is identified, it is interpreted in terms of the social situation in which it occurred and the researcher moves from describing the social context to a more in-depth interpretation of its meaning (Neuman, 1997). The ultimate goal of case study analysis is to uncover patterns, determine meanings, refine constructs and build theory (Patton and Appelbaum, 2003). Similar analytical strategies, for analysing case study evidence, have been advocated by Yin (2009) and Eisenhardt (1989). Whereas Eisenhardt (1989) described the process of building theories inductively from the data, Yin (2009) proposed explanation building from the initial theoretical propositions. In both strategies the process is highly iterative and closely linked to the extant literature. The approach is especially appropriate in new topic areas, with resultant theory often novel and empirically valid (Eisenhardt, 1989).

Utilising principles from both Yin and Eisenhardt's analytical strategies I identified four key stages of data analysis relevant to my own research and these are shown in figure 4. Whilst these are discussed in more detail in chapter 4, the stages described here identify the analytical strategy to be used from

initial *a priori* category specification and categorical data ordering through to substantive analysis of the theoretical proposition.

**Figure 4: Stages of data analysis**




## 3.13. Quality in case studies

Although I have used terms such as validity and reliability especially in relation to Yin's (2009) criteria for judging quality in case study design in this thesis, I am more persuaded by the work of other researchers. The quality of a case study depends less on ideas of validity and reliability and more on conception, construction and conduct (Thomas, 2009). Assessing the standards for the quality of a study's conclusions, Miles and Huberman (1994, p277) considered that there are countless possibilities and definitions. Subsequently they remained in the 'critical realist' tradition and focused on issues of confirmability, dependability, credibility and transferability. Other exponents of qualitative design reflected that the following key issues were predominant criteria for evaluating

design in the constructivism paradigm, and as my research is grounded in this concept, I considered them valid measures to apply to my work (Lincoln and Guba, 2005; Denzin and Lincoln, 2003; Riege, 2003).

i. **Confirmability**: is analogous to objectivity and the basic issue of freedom from unacknowledged research biases. It closely corresponds to external reliability (Miles and Huberman, 1994) and construct validity (Riege, 2003). The test assesses whether the interpretation of data is drawn in a logical and unprejudiced manner to ensure the conclusions are the most reasonable ones obtained from the data. Confirmability, within my research, was enhanced through the selection of appropriate operational measures, data collection tools and methodology for the study under investigation. In accordance with the principles advocated by Yin (2009), three tactics were employed to increase reliability throughout this research. Firstly, to encourage convergent lines of enquiry, triangulation of multiple sources of evidence was used and was observable with the inclusion of all interview transcript narratives, field note annotations as well as demographic data compiled for each individual case. Such data established a chain of evidence throughout data collection whereby all documentation was computerised and all stages of the analytical process logged both within document folders and in the software package Nvivo 9®. Finally a case study database was established and stored in this manner for peer review and scrutiny. Additionally, transcripts and drafts of the evolving case study were reviewed by university supervisors for consistency and accuracy.

ii. **Dependability**: is analogous to the notion of reliability and the purpose is to show indications of stability and consistency in the process of the study (Riege, 2003). I judged that dependability was primarily enhanced through strict adherence to the approved study protocol, which reported the entire conduct of the case study accurately and transparently. Although the protocol was revised on two occasions it was subject to Ethical committee approval and is available for peer review. The development of a case study database not only inferred dependability but also enhanced reliability

with the provision of transparent and accurate documentation. Within the database all data collected during the study was organised to facilitate retrieval for peer review (Yin, 2009) and to facilitate replication of the study. To enhance the reliability of interview data management I audio-taped all interviews, carefully transcribed the narratives and presented each case's experience and perspective with extracts of pertinent statements in the research report. My familiarity of the subject matter and geographical setting for the research also lent itself to the reliability of the research findings.

iii. **Credibility**: is analogous to internal validity and the purpose is to demonstrate that the study was carried out in such a way it ensures the account 'rings true', makes sense or seems convincing (Miles and Huberman, 1994). I considered that the use of triangulation techniques, such as the use of multiple sources of evidence during data collection, would enhance my data's credibility. Also credibility was evidenced in my study through pattern matching and constant comparative analysis of the data. The data followed a credible line of evidence from recognition and analysis of original *a priori* categories to the emergence of the theoretical proposition, all documented and analysed in Nvivo. Use of peer debriefing techniques, such as presenting the data analysis and emerging themes to university supervisors, also fostered credibility within my own research. Miles and Huberman (1994) stated credibility is also synonymous with achieving an authentic portrait of what we are studying where the researcher captures meaningful, context-rich descriptions. Within my research capturing the perspectives of the participants verbatim, accurately and comprehensively as audio-recordings, ensured I had access to the lived experience of information exchange and a plausible personal account of the phenomenon.

iv. **Transferability**: is analogous to the function of external validity or generalisation and is achieved when the research shows similar or different findings of a phenomenon amongst respondents (Riege, 2003). Generalisability is grounded in the intuitive belief that theories must be shown to account for phenomena, not only in the setting in which they are studied, but also in other settings (Gibbert and Ruigrok, 2010). The aim of my study was not to generalise the results to the wider Scottish lung cancer

population but, instead, lean more towards the development of theory that could inform future research and practice. Generalisation of the case study so that it contributed to theory was an important driver.

Each case was the starting point for theory development, with theory tested, replicated and analysed within and across cases. In my study, when two or more cases were shown to support the same theory, replication could be claimed. Replication logic allowed knowledge to accumulate across cases and strengthened the opportunity for analytical generalisation, in which a previously developed theory was used as a template with which to compare the empirical results of the case study. The study represented analytical rather than statistical generalisation denoting the process of generalisation from empirical observations to theory, rather than inferring conclusions about a population (Lee and Baskerville, 2003). Researchers advise that transferability is enhanced by data and analysis which facilitates a 'fix' on where the cases fit with the wider population (Hammersley, 2008; Lincoln and Guba, 2005). Consequently, the study strength was the demographic diversity of patients and companions who participated. Case selection was purposive to select a group of patients with lung cancer, who would be typical, in terms of their demographic variables, of the wider Scottish population and who were, therefore, more likely to illuminate the research questions.

## 3.14. Methodological strengths

Case study methods have a number of specific advantages. Primarily, by restricting the focus to a relatively small number of cases the research can facilitate the construction of an in-depth understanding of the subject under study. Hodkinson and Hodkinson (2001) judged case studies to be grounded in the lived reality of personal experiences whereby complexity and the real-life context may be explored in detail. Multiple data collection methods, such as interview transcripts, demographic data and directly observed behaviours can produce robustly evidenced understanding of social processes. In addition, multiple case studies can enable research to focus on the significance

of the idiosyncratic. Across case comparison of individuals or groups can focus on the unique as opposed to the shared experience (Hodkinson and Hodkinson, 2001). Case studies can show the processes involved in causal relationships, demonstrating the depth and complexity of the ways such correlated factors influence each other.

Case study methods can facilitate the exploration of the unexpected and the unusual, revealing significant issues which were unanticipated when the research commenced, with the complexity and depth of the data generating new theoretical concepts. A major strength of theory building in case study method is its likelihood of generating novel theory. Bartunek and Seo (2002) argued that an attempt to reconcile evidence across and between cases types of data and literature increases the chance of creative reframing into a new theoretical vision.

An additional strength is the emergent theory is likely to be testable with constructs that can be measured, because they already have been during the theory building process. Also, Eisenhardt (1989) argued the resultant theory is likely to be empirically valid. The likelihood of valid theory is high because the theory-building process is so closely aligned with evidence that it is very likely the resultant theory will be consistent with empirical observation. In well executed theory-building case study research, researchers answer to the data from the beginning of the study. It is this intimate interaction with the actual evidence that often produces theory which closely reflects reality (Eisenhardt, 1989).

## 3.15. Methodological limitations

Case study methods have a number of specific disadvantages. Foremost as this method concentrates on relatively small case numbers a common concern is they provide little basis for generalisation to larger populations (Yin, 2009). It is generally agreed that case studies, like experiments, are generalisable to theoretical propositions and not to populations or universes (Hammersley and Gomm, 2000). Case study researchers are more interested in finding the conditions under which

specific outcomes occur and the mechanisms through which they occur, than uncovering the frequency with which they arise (George and Bennett, 2004, p31). Eisenhardt (1989) cautioned that theory building from cases may result in narrow theory where the risk is that it describes a very distinctive phenomenon and the researcher is then unable to raise the level of generality. Likewise, selection bias can occur and cases can be skewed towards having or not having a particular attribute; for example patients with lung cancer with limited stage disease or better performance status.

Case studies can take too long to complete and result in massive, unreadable documentation (Yin, 2009). Given the typically staggering volume of rich data, there may be a temptation to build theories which attempt to capture everything. The resultant effect is a theory rich in detail but one that lacks the simplicity of overall perspective (Eisenhardt, 1989). Researchers lose their sense of proportion as they confront voluminous data and are unable to assess which are the most important relationships and which are peculiar to a particular case (Eisenhardt, 1989). Equally, Hodkinson and Hodkinson (2001) cautioned that when case studies are successful in revealing the complexities of social contexts there are difficulties presenting accessible and realistic representation of that complexity in writing.

### 3.16. Summation

Case study methods have both strengths and limitations. An important consideration for my research, with an interest in theory-building processes, related to case study size and subsequent issues of generalisation. With respect to generalisability, my case study, with seven cases, fitted with the replication logic proposed by Yin (2009). My case study, like the experiment does not represent a sample and the goal was to build, expand and generalise theories (analytical generalisation) and not to enumerate frequencies (statistical generalisation). Such theory development in case study research may have important strengths like novelty and testability, which arise from the intimate linkage with empirical literature (Eisenhardt, 1989). Correspondingly, given the strengths of this case study approach and its independence from past empirical observation it is particularly well suited to new

research or research areas for which existing theory seems inadequate (Eisenhardt and Greabner, 2007).

Despite the fact my case study cannot be representative of all patients with cancer or even lung cancer it can provide more than a simple idiosyncratic understanding. The issue is what the cases can tell about each individual case itself and about situations beyond the actual cases studied (Hodkinson and Hodkinson, 2001). Where case studies generate new thinking, that thinking has a validity that does not entirely depend upon the cases from which it is drawn, but with findings which 'ring true' in other settings.

This chapter described the rationale for my chosen research design strategy. It outlined why the case study approach was appropriate to this research because the questions posed were of the 'what' type: the focus was on contemporary events and the researcher had only limited control over actual behavioural events. Furthermore, a constructivist paradigm allowed for a broader and deeper understanding of the process of information exchange as constructed by each individual participant.

The chapter further detailed the overall research design from case definition and selection, through data collection and analysis. Chapter 4 will explore the research design in more depth from a practical and logistical stance.

# Chapter 4: Research methods

## 4.1. Introduction

The justification for choosing a qualitative, constructivist approach and case study design was defined in chapter three. This chapter will now describe the practical and procedural aspects of the study. The chapter will begin with a description of the ethical approval considerations required for this investigation. This will be followed by discussion of the processes relevant to ethical considerations for my research. Discussion will also demonstrate the processes undertaken in relation to case identification and recruitment, data collection methods and data analysis strategies.

## 4.2. Ethical approval application and access to cases

Ethical approval was sought and granted from the Department of Nursing and Midwifery at the University of Stirling and simultaneously from the Health Board Research Ethics Service (REC 1) and Research and Development (R & D) Management. More details of the process are outlined below.

### 4.2.1. University Ethics Department

The Research Proposal and an Integrated Research Application System (IRAS) form were submitted to the Department of Nursing and Midwifery at the University of Stirling on 18th March 2009. Committee approval was granted on 14th May 2009. As per University guidelines, annual progress reports were submitted, specifying both progress and changes.

### 4.2.2. Health Board Research Ethics Service (REC 1)

Original submission of IRAS form (REC ref 09/S0703/106) was submitted to the Health Board Research Ethics Service (REC 1) for consideration on 10th September 2009. This submission and all accompanying documentation were reviewed at an Ethical Review meeting on 6th October 2009. Following attendance at the meeting where the study was discussed and questions answered to committee

satisfaction, a favourable opinion was granted on 11th November 2009, subject to minor amendments (Appendix 2).

In the initial stages of recruitment and data collection it was recognised that in the majority of cases, patients with lung cancer were accompanied to the consultation. Additionally the literature identified companions often accompany patients to the consultation to provide practical, emotional and informational support, as well as participate in medical decision-making (Clayman, Roter and Wissow and Bandeen-Roche, 2005). There was recognition that companions were an integral part of the clinical encounter, with the potential to have a significant contribution and influence on the information exchange process. After discussion with study site clinicians and on further reflection a Substantial Amendment Form (1) was submitted on 5th July 2010, requesting REC approval for the submission of documentation relating to Companion Accompaniment. Ethical approval was granted for Amendment 1 on 19th July 2010.

An important and salient explanation of the original research question and its aims is required at this point. The original research proposal submitted to the Ethical Committees initially sought to explore information exchange between women with lung cancer and healthcare professionals at clinic consultations. There was both scientific justification and a deep sense that women's informational issues were of significant consequence and worthy of further research in this specialist oncology field.

However, this gender specific study was not without challenges. Notably for the first six months of the study recruitment was gender specific and uptake was poor. Clinically there were also concerns raised among clinicians at the exclusion of males, and at a time when recruitment was poor overall, a decision was made to change study criteria to allow both genders to be approached for participation. Recruitment difficulties are discussed in more depth in section 4.4.4

A revised Study Protocol and Substantive Amendment Form (2) were submitted for ethics committee consideration on 22nd November 2010 for the inclusion of male participants. A favourable ethical opinion was granted on 14th December 2010.

#### 4.2.3. Research and Development (R & D) Management Approval

All stages of the approval process for REC shown in section 4.2.2. were paralleled for Research and Development (R & D) Management. Dates of submission and approval were synchronous (Appendix 3). R & D management approval granted access to all clinical study sites. Written approval was also sought from the Director of Nursing. Additionally, as well as seeking approval from Lead Nurses and Service Managers within the local Directorates for Medicine and Acute Emergency Services, I presented my research proposal to the Director of Nursing and all Lead Nurses at their monthly scheduled meeting in December 2009.

#### 4.2.4. Ethics Committee at National Waiting Times Centre Board (NWTCB)

Concurrent ethical approval was also requested and granted for access to the tertiary thoracic centre, as there was potential for participants to receive surgical resection at this third study site. Ethical approval was sought on 7th September 2009. As this site was an independent Health Board, with an autonomous Ethics Committee review procedure, I required a letter of access, which was granted on 27th October 2009. An application to Disclosure Scotland, allowing the NWTCB to access details of any cautions and convictions was also submitted and returned approved on 20th October 2009. Management Approval for the study was granted at this site on 11th December 2009 (Appendix 4).

### 4.3. Ethical considerations

Epidemiological data suggests that patients with lung cancer, especially those with advanced disease, can present with poor performance status (Sethi, 2004) and, also, be a very vulnerable group (Montazeri, Hole, Milroy, McEwen and Gillis, 2003). I was cognisant of the fact that all potential participants were at a particularly vulnerable stage of their cancer journey immediately following

diagnosis. Vulnerability is inferred by virtue of health status, position on the disease pathway and even communication skills (Phipps, 2002). Ethical debates exist in the literature surrounding the suitability and acceptability of approaching such vulnerable patients (Hopkinson, Wright and Corner, 2005; Casarett and Karlawish, 2000). In this current study careful consideration was given to strategies to minimise risk and these are defined below.

### 4.3.1. Informed consent

I considered informed consent to be the major ethical consideration for minimising risk and protecting the participant's right to autonomy within this study (Beauchamo and Childres, 2001). As such particular consideration was given to these aspects of informed consent:

- Information sheets: Availability and distribution of clear written information sheets for all potential patients, companions and professional participants. Potential patient and companion participants were approached and made aware of the study by a professional they were already familiar with, usually the CNS or respiratory consultant.
- Written consent: Obtained from all participants – patients, companions and professionals with copies given to each individual.
- Recruitment protocol: Recognising the importance of patients not being coerced into study participation. Both participant information sheets and informed consent procedures articulated that participation was voluntary, with participants retaining the right to withdraw from the study at any stage. It is widely recognised that, in order to avoid coercion or undue influence, the recruitment process should allocate sufficient time to both communicate a thorough explanation of the study and to give the potential participant adequate time to consider the information before making a decision to participate. A period of 48 hours was allowed between receiving study information and contact by the researcher.

### 4.3.2. Beneficence

My over-riding duty, as a researcher, was not to cause harm to any of the participants, or indeed myself. Disclosing intimate and sensitive details about their lives can increase the sense of vulnerability and anxiety by participants (Ford and Reutter, 1990). Equally, learning such details can impact significantly on researchers. Support networks for participants, in the form of ongoing contact and assistance from their own medical and nursing professionals were available throughout the duration of the study. Participants were notified and gave consent that their general practitioner would be informed of their entry into the study and additional support existed in the primary care setting if required. For researcher support, academic supervision via regularly scheduled meetings at Stirling University was ongoing throughout the research period. Additionally, I have worked within this specialty for two decades, dealing with this patient, companion and professional group and felt I had the necessary skills and attributes required.

### 4.3.3. Confidentiality and anonymity

The issue of confidentiality is closely aligned with beneficence. Potential participants were informed, within the patient information sheet and informed consent form, that their right to anonymity and confidentiality would be protected throughout the study's duration. The management of confidential data was of primary concern, with any data sheets stored securely in a locked drawer, separated from all other data, in the researcher's office, which no one else had access to. Participants' identity was not linked with personal responses but identified through an alias. The participant's right to confidentiality and anonymity was in congruence with the Data Protection Act (Scottish Executive, 1998) and in adherence to the NHS Code of Practice on Protecting Patient Confidentiality (Scottish Executive, 2003).

## 4.4. Recruitment process

As I considered a case to be inclusive of patients, companions and professionals, the recruitment process naturally involved participation of all members of the triad (chapter 3). The natural order of

recruitment suggested study sites and professionals were identified and approached first, with the healthcare team then responsible for identification of patient and companion participants.

### 4.4.1. Study site and professional recruitment

Two study sites were selected on the basis of my prior knowledge of lung cancer service management in the geographical area. I identified two acute teaching hospitals, which operated different clinic consultation models, for patients with lung cancer. Another inherent feature for site selection was the high incidence rate of lung cancer in the geographical areas they covered.

Study Site A is an acute teaching hospital with approximately 450 beds, serving a population of more than 200, 000 people. Three Respiratory Consultants offer specialist respiratory care, including lung cancer patient management. The multidisciplinary team includes a respiratory physician, a lung cancer CNS, a clinical oncologist from the regional cancer centre, a specialist palliative care team member and thoracic surgical team support. This site operates a multidisciplinary clinic model, where patients are reviewed at clinic, following a multidisciplinary meeting. In 2007 at this hospital, 131 patients were diagnosed with lung cancer [60 females and 71 males] (Office for Audit and Clinical Effectiveness, 2008).

Study site B is a large acute teaching hospital with over 1000 beds, serving a population of 300, 000. There are a total of 4 Respiratory Consultants divided across respiratory sub-specialities, which include lung cancer patient management. The multidisciplinary team includes a respiratory physician, a lung cancer CNS, a clinical and medical oncologist from the regional cancer centre, specialist palliative care team member and thoracic surgery team support. This site operates a sequential clinic model, where patients are reviewed following the multidisciplinary meeting by the respiratory consultant and then referred to the most appropriate speciality clinic thereafter. In 2007 at this site, 187 patients were diagnosed with lung cancer [82 females and 105 males] (Office for Audit and Clinical Effectiveness, 2008).

Formal introductions were made by letter to the Lead Lung Cancer Clinician and Lung Cancer CNS as well as Lead Nurses and Service Managers at each site. An invitation to meet the researcher was extended via a recruitment pack (Appendix 5: Healthcare Professional Introduction Letter; Appendix 6: Healthcare Professional Information Sheet; Appendix 7: Healthcare Professional Consent Form) and followed by informal discussions with the researcher. Written consent was obtained from all identified professionals who agreed to participate.

The same process was followed for Study site C, which is a national resource centre for Scotland, offering regional and national heart and lung surgical procedures. This acute surgical site has over 200 beds and offers thoracic surgery to patients. Potential patient participants considered for surgical resection were cared for at this tertiary site.

#### 4.4.2. Patient and companion recruitment

Participants were selected explicitly to encompass instances in which the phenomenon under study was likely to be found (Zach, 2006). I wanted to select a broad range of patients with lung cancer (with or without their companions) who possessed particular qualities or characteristics and specific knowledge about the disease. They would thus be an important source of experience and expertise regarding information exchange.

Patients with primary lung cancer (and their companions) attending clinical consultations at both Study site A and B, referred for any treatment modality and deemed by their professional team to be (i) well enough to be selected and (ii) met eligibility criteria, were considered for study participation. Professionals were asked to purposively select cases to include the following range of characteristics and demographic variables where possible; age (range from 18 years on), gender (male and female), performance status (0-3), disease classification and stage (range of lung cancer type and range of stages local to advanced), treatment types (all ranges from palliative therapy to resection), treatment

outcome (range from palliative therapy to curative), educational level (range from secondary to higher education), socio-economic (range of deprivation scores scores).

### 4.4.3. Method of recruitment

Potential participants were identified by the healthcare team following discussion at the multi-disciplinary team meeting (MDTM) and again when they initially attended the diagnostic clinic to be informed of a lung cancer diagnosis. Professionals used their clinical discretion to determine patient suitability for the study and applied the following eligibility criteria to assist with case selection:

Inclusion criteria:

- Patients will have a diagnosis of primary lung cancer and be aware of the diagnosis
- Patients will be attending lung cancer clinics at the outpatient department
- Patients will be 18 years of age or over and agree to participate in the study
- Patients will be able to understand English

Potential participants were not approached at the diagnostic clinic, but were contacted 24-48 hours later by the CNS (as per standard practice at both sites). Consequently, potential participants were initially approached by a member of staff known to them. Then using their professional judgement and their knowledge of the individual, the CNS introduced the study to potential participants and determined if:

1. Potential participants would be willing to consider having the Patient Information Pack (Patient Introduction Letter; Appendix 8: Patient Information Sheet, Appendix 9 and Patient Consent Form, Appendix 10) sent to them by post

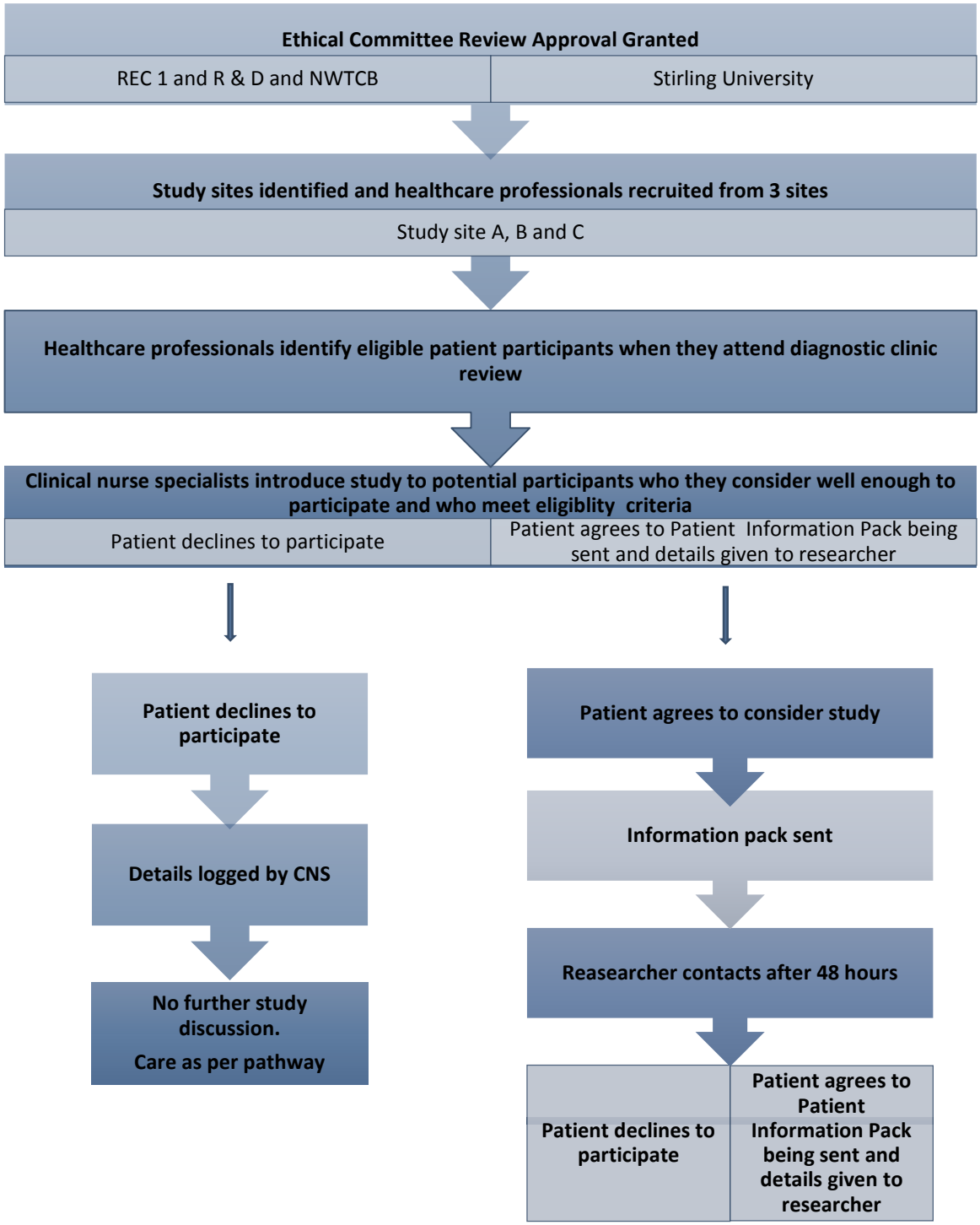
2. Potential participants would require a Companion Information Pack (Companion Introduction Letter, Appendix 11, Companion Information Sheet, Appendix 12 and a Companion Consent Form, Appendix 13) to be sent along with their Patient Information Pack

3. Potential participants would be willing to consent to their contact details being given to the researcher.

The CNS completed a log of all potential participants approached to participate in the study (Appendix 14: Potential Participants Data Sheet). The details of potential participants willing to consider study participation and who gave permission for their details to be given to the researcher then had a Patient Information Pack (+/- the Companion Information Pack) sent to them, using first class mail. The CNS also informed the potential participant that the researcher would contact them in the next 48 hours to answer any queries about the study and if they were agreeable and discuss the next stage of the process with them.

Potential participants were contacted by telephone within the specified time period by the researcher. Patients who agreed to participate in the study consented to meet the researcher at their next clinical encounter for more detailed discussions regarding the research study. They were also given contact numbers should questions arise in the interim. At the first meeting between the researcher and the participants, written informed consent was taken, after the study rationale was explained in person and the opportunity for questions was given. This above process is illustrated in Figure 5.

**Figure 5: Recruitment process**



### 4.4.4. Recruitment challenges

#### 4.4.4.1. Study site and healthcare professional recruitment

Initial recruitment of both study sites and healthcare professionals ran well as I was familiar with the sites and gaining access to clinical teams was facilitated by my knowledge of the local managed clinical networks. The initial period of recruitment required comprehensive preparation and included numerous meetings with medical, nursing and managerial staff members, as I established relationships with professionals who were crucial to site access approval. I disseminated study information using mediums such as letter, secure email, telephone and face to face meetings. When requested I gave presentations to staff-side colleagues to facilitate a more precise overview of study requirement and impact on clinical sites. However, on reflection as uncomplicated as this preliminary phase of recruitment was, perhaps establishment of an advisory group consisting of managerial representation may have offered strategies to assist me with collaborations and partnerships.

Table 8 shows the challenges considered relevant to study site and professional recruitment and illustrates methods to overcome the challenges faced, as well as my reflections on the specific considerations.

**Table 8: Study site and healthcare professional recruitment challenges**

| Points to consider | Methods to overcome | Reflections |
|---|---|---|
| **Relationship establishment with study site communities**<br><br>**Strategies to ensure collaboration** | o Formal written approach to management colleagues to achieve 'buy-in'<br>o Presentations to senior management to reassure clinical impact from study would be minimal<br>o Ensure researcher is readily available and contactable to answer any ongoing queries | Could have established an Advisory Group with representation from managerial, clinical and lay members to facilitate ongoing planning and updates<br><br>Suggested regular updates / progress |
| **Clinician concerns re study protocol** | o Regular meetings, emails or phone calls to raise issues and deal with concern<br>o Presentation of study protocol and scientific rationale for gender specific study | Could have established an Advisory Group with representation from managerial, clinical and lay members to facilitate ongoing planning and updates. This group then may have been able to facilitate an expedited solution to clinicians concerns<br><br>This concern was discussed for some months, with all scientific justifications presented. However, impasse was reached which had to be overcome in order for the study to progress (see table 9) |

Recruitment of healthcare professionals likely to be present during clinic consultations (including specialist palliative care team members) was also unproblematic. All professionals approached provided written informed consent. The three clinical nurse specialists at each of the study sites were identified as Site Specific Investigators and were instrumental identifying potential patient participants and completing study documentation. Preliminary discussions with study site teams and available audit data suggested potential patient participant numbers (6-10 patients) would be achievable.

Throughout this period of negotiation with clinical and managerial teams the research proposal for the original research 'exploring information exchange between women with lung cancer and healthcare professionals' was discussed and consented to by all healthcare participants. Unfortunately as the study progressed despite written informed consent there was a concern raised by a member of the team regarding female only recruitment. Gender-specific recruitment was felt to be to the detriment of the male population, who would then be denied the opportunity to participate and have their perspective voiced. The objection was sustained for some months with arguments raised from both viewpoints re inclusion of men. Impasse was reached and I had to make a decision which had the potential to impact the whole ethos of the study.

#### 4.4.4.2. Patient and companion recruitment

Overall study patient/companion recruitment was prolonged and ran from January 2010 to December 2011. Challenges faced within this period were multifactorial and described in table 9.

The major consideration was the objection to gender-specific recruitment. Whilst this discussion was ongoing and unresolved there was no recruitment taking place within one site. In addition the study was slow to recruit any participants and with only one site fully engaged the decision was taken to include men in the study.

**Table 9: Patient recruitment challenges**

| Points to consider | Methods to overcome | Reflections |
|---|---|---|
| **Barriers to patient recruitment**<br>- **Gender specific participants**<br><br>**A suspension of the study occurred at one of the study sites during discussion re gender concerns**<br><br>**As a direct result this site effectively only recruited and participated in the final 6 months of the data collection period**<br>- **Study slow to recruit** | o Regular discussion re scientific justification for studying female only population<br>o Frequent meetings with university supervisor, allowing progress/situation updates as well as suggestions for way through impasse<br>o Decision taken to either include male participation or recruit another study site with other HCP<br>o AS STUDY SLOW TO RECRUIT – DECISION WAS TO INCLUDE MALES IN THE STUDY<br>o Continual discussion and updates with study sites re changes to research protocol<br>o Substantial amendment submitted to REC<br>o Weekly communication (email and telephone) with CNSs regarding potential participants identified at MDT and diagnostic clinic<br>o Regular email correspondence to all HCP reminding of eligibility criteria etc.<br>o Communication re recruitment completion date and target enrolment numbers | There was recognition and empirical evidence that information exchange was not examined across both genders. However, as a researcher and clinician with an interest in women's lung cancer issues I was initially keen to investigate cancer communication and information exchange from a female perspective. However, despite the methods described to overcome challenges, recruitment was slow and I thought the inclusion of men (although costly in terms of time and effort for substantial ethics amendment) was preferable to a stalled study, which was recruiting few patients at the time or a new process of study site and HCP recruitment<br>I instigated weekly contact with the CNSs at both sites, to facilitate discussion re potential participants. Despite the large numbers of lung cancer patients being diagnosed across the Health Board, recruitment was slow. I was keen to reinforce eligibility criteria to ensure all potential participants were identified. There were times despite initial contact I was unaware of progress or stage of communication. As a CNSs I was cognisant of how busy the clinicians were and at times did not push too hard for potential numbers, preferring to leave it to the discretion of the recruiters.<br><br>A noteworthy consideration was how I viewed my role both a researcher and CNS. I was keen to recruit patients to the study, but anxious not to upset the clinicians by appearing pushy. On reflection there may have been a familiarity between us, as were colleagues and lung cancer networks are small, which in fact hindered rather than enhanced recruitment. I may have initiated more contact with colleagues I was unfamiliar with.<br>Advisory Board perspective may have highlighted such a situation and offered alternative strategies |

Additionally, there were external influences and challenges which necessitated a study length extension, over which I as a researcher had little control and thus little in the way of strategies for overcoming them. These are listed as follows:

1. Researcher ill health which required a leave of absence.
2. The study sites merged their services between February 2011 and July 2011 and no recruitment took place during this time to allow for the transition.
3. The CNS at study site A had maternity leave during the recruitment period and there were periods of sick leave.
4. There was no clinical nursing cover when the CNS began her maternity leave.

## 4.5. Data collection

A key strength of case study design is the use of multiple sources and techniques in the data collection process. In the following sections I will define the practical processes of multiple data source use, employed alongside the other two principles of database creation and maintaining an evidence chain (Yin, 2009).

### 4.5.1. Multiple data sources

To address the aims of the study it was essential that the research accommodated a rich variety of data sources, which would in turn strengthen the research process. Significant volumes of data would be collected from the clinical encounters where the information exchanges were being executed and from the interviews (both de-brief and in-depth). The process of data collection for each is detailed.

### 4.5.2. Audio-taping of clinical consultations

In person introductions to patient and companion participants was facilitated by either the CNS or the respiratory physician at the start of the clinic. A clinic room was provided to take written consent and

answer questions, as well as conduct any de-brief interviews. I remained in the clinic area, (but not the consultation room) for as long as necessary to collect data for all participants in each case. All participants gave written consent for the clinical consultations and interviews to be audio-taped. I opted to audio rather than video-tape consultations and interviews. Although video is recommended researching professional-patient interaction, as it captures all modalities of the exchange (Haidet, Tate, Divirgilio-Thomas, Kolanowski, Eberly and Happ, 2009), I was concerned the intrusiveness of video recording equipment and the presence of a camera might alter the consulting behaviours of participants. I was conscious of the potential, modifiable, Hawthorn Effect that both my presence and that of the recording equipment may have on patient and professional participants alike and tried to minimise the impact (Cormack, 2000). At no time was I present during the consultation. The device used for audio was digital and discrete and placed away from the participants but it still accurately recorded the exchange. The professionals were asked to operate the equipment, after a period of instruction by the researcher. If for any reason during the interview the participant wished to terminate the study, the professional would halt the audiotape and the clinic consultation would proceed as normal. This situation never arose during data collection at clinical encounters.

### 4.5.3. Audio-taping of debrief interviews

De-brief interviews were viewed as a powerful means of extracting valuable information from patients and professionals in the immediate aftermath of their clinical encounter, when recall of events is strong and first impressions can be captured (Appendix 15: Patient Debrief Interview Guide and Appendix 16: Professional Debrief Interview Guide). Additionally, information could then inform further in-depth interview questioning. De-brief duration ranged from 1 – 5 minutes and was always carried out post-consultation in privacy. No patient or companion declined to be de-briefed. Only one professional de-brief was declined due to clinical commitment.

### 4.5.4. Audio-taping in-depth semi-structured interviews

The third process of data collection within this study was the semi-structured interviews. One of the most important sources of case study information is the interview (Yin, 2009). As the study was interested in exploring the experience of information exchange from the perspective of the participants, the use of semi-structured, but in-depth interviews was an ideal data collection method to address the aims of the research question. It has been shown that patients with lung cancer (96% of those surveyed in a Glasgow study) indicated that they found being interviewed acceptable (Montazeri, Milroy, Gillis and McEwen 1996). Importantly, patients with similar demographic and geographic backgrounds to those in my research reported they found interviews conversational and relaxing. Montazeri et al (1996) also found that of the 126 patients they surveyed over half preferred to be interviewed at home.

Following the de-brief interview with patients and companions I secured a date, time and venue for the in-depth interview. All cases were given the option of interview location. Five cases wanted to be interviewed at home, one at work and the remaining case during his hospital stay. In order to facilitate greater clarity of recall and reduce the potential for bias following the clinic encounter, the in-depth interview was scheduled to take place as soon as possible after the final consultation but prior to treatment commencing. This was a pragmatic decision whereby it was hoped that, if carried out before therapy patients, would be more focused on the events of the consultation and conversation would not be complicated by treatment related information issues, or by potential treatment related side effects such as pain, nausea and lethargy.

Prior to beginning the interview I ensured that all present were happy to proceed with the research and agreeable to the interview being audio-taped. Written informed consent was taken from any companion participant joining the study at this point (this applied to Cases A and E). Interview duration was variable but approximately an hour long in the majority of cases.

## 4.6. Reflexivity in research practice

Parahoo (2006) defined reflexivity as the continuous process of reflection by the researcher on his or her values, preconceptions, behaviour or presence and those of the participants, which can affect the interpretation of responses. Essentially it requires researchers to recognise that they are part of the social world under study, whilst acknowledging one's position in relation to the research (Herr and Anderson, 2005). Qualitative researchers are interested in how meanings are produced and reproduced within particular social, cultural and relational contexts, with the interview itself as one such context of interactive meaning-making. Therefore, interpreting qualitative data requires reflection on the entire research process (www.utsc.utoronto.ca/reflexivity-accessed29/10/2014). Reflecting on the research process and trying to understand how one's values and views may influence research findings adds credibility to the research (Jootun, 2009). In order that trustworthiness, dependability, transferability and credibility can be established the research process must be transparent, with an integral aspect of this being reflexivity, an in-depth self-awareness of one's perspective, strengths and limitations (Patton, 2002).

Hall and Callery (2001) suggested that to fulfil these quality expectations throughout the research thesis, the researcher should make explicit how data was constructed and questioned their preconceptions throughout the process. To fulfil this recommendation I kept a reflexive diary. Within my diary I logged my thoughts, opinions and field notes relating to the research process and cases. I also entered any concerns or questions for my supervisors as they arose. In this manner, the intention was to provide particular detail to the understanding of real-world research (Anthony and Jack, 2009). For the purpose of the thesis I have chosen to reflect on three major areas of concern which required a great deal of reflection at particular time frames during the research.

### 4.6.1. Recruitment

As previously discussed in chapter 4.4.4. recruitment to the study was challenging. Despite a successful Ethics submission with a scientific rationale for exploring information exchange in a gender-specific lung cancer population, at the point of recruitment a concern was raised that the exclusion of men would fail to allow the perspective of the full lung cancer population to be voiced. Whilst debate was ongoing over the issue, recruitment was suspended at one site. In order to progress recruitment (which was slow at the first site too), there were two choices presented to me; either recruit an alternative study site with new healthcare professional participants (which necessitated a Substantial Amendment to Ethics and perhaps transfer of the study to a different location in the city) or include men in the study. After a prolonged period of time and much deliberation I opted for the second option. This major issue was discussed via email with the medical clinicians, with periods of inactivity in correspondence, prompting me to turn to other HCP participants for assistance, as this email excerpt and my notes reflect:

**VIGNETTE 1**

EMAIL:

I am sorry to ask this of you, but do you know if there has been any more consideration of my study. I have written a few times asking if involvement isn't possible can I approach another HCP

NOTES:

Staff failed to respond to several emails and I have now been forced to contact another member of staff for assistance. This feels awkward and I do get concerned that I am playing on goodwill and familiarity by doing so, but I am pretty desperate for a solution!

As shown in table 9, I hypothesise that my familiarity with the HCP participants made me cautious in my approach to them. On reflection I was attempting to preserve my nursing professional relationships with them and not have them judge me as overbearing researcher. In comparison to several other researchers I assumed that all my preliminary meetings and presentations prior to the

research had fully engaged the HCP participants and that knowing staff and the environment would make recruitment easier (Larkin, 2013; McNeill and Nolan, 2011). Like Larkin (2013) I found that the insider status of my role as researcher was more complex than I anticipated. In some respects I was an insider, knowing all the HCP participants and gatekeepers. Yet, as Labaree (2002) stated insiderness is transformed by the situation and decided by the participants not the researcher. Importantly for me as a researcher I learned that despite considering myself an insider, this did not prove advantageous when it came to recruitment.

### 4.6.2. Duality of role at interviewing

The duality of my role as researcher and nurse was made transparent to patients and companions as my professional title and the nature of the research was explained on all Information Sheets. I was aware that I was entering the research process with my own history and experience, which could influence how I understood and managed data collection and analysis. However, Colbourne and Sque (2004, p303) stated, 'if the nurse cannot be removed from the researcher, why pretend?' It was my clinical experience and judgement, in addition to reviewed literature, that identified the paucity of evidence underpinning information exchange in this specialist area and which ultimately, led me to conduct the research. I aimed for reflexivity which Dowling (2006) described as 'closing the door on the belief that distance between researcher and participant is paramount, and providing momentum for a move towards a position where the boundaries between the two are surrendered'.

The duality of my role had strengths and limitations during the data collection period and more specifically during interviews. I aimed, where possible, to appear neutral when I conducted data collection. Aside from Health Board identification worn during clinical encounters I had no other sign of professional status. I dressed in my normal working clothes (non-clinical) (Allen, 2004) and, during interviews conducted at patients' homes; I aimed for a relaxed approach, using first names if patients and companions were comfortable with this. I have 20 years of experience undertaking home visits as

part of my routine clinical practice and hoped this was evident during data collection. As a lung cancer nurse interacting with patients and their companions living with a condition I am accustomed to, I was in familiar territory. I understood the processes they were talking about and this allowed them to communicate their perspective without interruption. My familiarity provided insight into the experience that might not have been evident to a researcher without an oncology background.

However, the nature of my clinical background may have created assumptions for the patients and companions. There were instances (discussed in chapter 5) where participants asked me clinical questions. They understood my clinical role and, in some cases, took the opportunity to ask probing questions regarding diagnosis, treatment and treatment outcome.

In a study carried out by Anderson (1991) where she interviewed Chinese and Anglo-Canadian women with diabetes about their illness experience, the participants asked her for clinical information based on her social role as a nurse. The realities of the participants' lives, coupled with their requests for help, were addressed by Anderson through a reciprocal process. She obtained information and provided information in return. Whilst some research approaches, such as participatory action research and feminist methodologies highlight the importance of reciprocation (Kemmis and McTaggart, 2000) I was conscious of my social part of the research process. Therefore, exchanging information about prognosis with companions, when I was not part of the clinical team and the patients themselves were uncomfortable with the direct line of questioning, was inappropriate.

Undertaking the reflexive process allowed me to be aware of what was influencing all of our responses, while simultaneously being sensitive of relationships to the research topic and the participants needs (Dowling, 2006). The possibility of becoming clinically enmeshed with participants may have led to me having difficulty maintaining the neutral role I had originally aimed for.

**VIGNETTE 2**

Agnes even asked clinical questions of the researcher, which at times Alex appeared uncomfortable with, especially in view of the positive perspective he had taken regarding his treatment outcome.

| | |
|---|---|
| ***Agnes:*** | ***Now, after the second radiothera…, eh, chemotherapy, if it hasn't shrunk, is there any other type of chemotherapy that he can get that would be a different kind of treatment?*** |
| ***Researcher:*** | ***It's difficult for me to say, because I don't work for Dr Allan.*** |
| ***Agnes:*** | ***No, uh huh..*** |
| ***Alex:*** | ***That's right – see, that's how I says to you, it's getting over the first one and moving on from there. That's the best thing. A lot depends on how much it shrinks (In-depth interview/Alex/Agnes, Ref 16)*** |

### 4.6.3. Companion role – influence on professional practice

Research activity is recognised as a principle ingredient to the potential success of future healthcare practice and service provision (Department of Health, 2010). Consequently there is increasing emphasis within contemporary health care for practitioners/researchers to actively engage in practice orientated research with a view to making inroads into influencing mainstream patient healthcare and practice (Clark and Thomson, 2013). An important aspect of reflexivity is identifying specific ways in which my own perceptions and clinical practice may be influenced by the research, those researched and the research findings.

The novel finding of negotiated companion presence impacted my clinical practice on a fundamental level. Prior to undertaking the research, within my sphere of clinical practice the multi-disciplinary team endorsed the recommendation from national organisations and suggested to patients they bring a companion to consultations to discuss the diagnosis and management of their condition (BTS, 2013; NICE, 2005; SIGN, 2005). There may now be a need for lung cancer clinicians to be cognisant of and

responsive to patient preference for accompaniment above the universal recommendation of companion accompaniment.

Reflecting on this innovative finding for my own practice I believe it is imperative to be aware and respect patient preference for accompaniment. To achieve individualistic, patient-centred care I recognise that, for some patients, being un-accompanied to consultations fulfils their informational and decision-making needs and as a clinical nurse specialist my role is to be aware and respect patient preference.

**VIGNETTE 3**

Post research practice

- Within my clinical practice instead of universally recommending that patients bring a companion to their diagnostic consultation, I instigate conversation outlining options for accompaniment, emphasising that patient preference is paramount and will be supported by all team members.
- Raising awareness among colleagues that as clinicians we should review national guidelines in relation to patient accompaniment to consultations and adopt a patient-centred and patient-preference approach to accompaniment.

The development of a decision trail explaining the impact on data collection and analysis throughout the study were logged within my field notes. All instances were documented in my journal and field notes to raise awareness of such influences on my interpretation of the data and their relationship to the research themes and case studies. Multiple sources of evidence including interview transcripts, reflexive journal notes, field notes and audit trails, documented and organised in this manner further strengthen the study's credibility and are available for inspection by examiners (Hammersley, 2008).

## 4.7. Case sheets and field notes

Collation of case sheets (Appendix 17) began when initial demographic data relating to Case A was sent by the CNS at Study Site A. Seven case sheets were developed in total. Each case was assigned an individual case sheet which included demographic data, checklists, field note summaries, a case study, thematic frameworks and all other relevant documentation. These were categorised and stored in individual databases in Nvivo 9® and were updated frequently. Case sheets were finalised after completion of all data collection and were entered as important documentation into the case study database.

Field notes allowed me to record feelings and intuitive hunches, pose questions, and document the work in progress. I prepared field notes after each case encounter, listing key features which struck me about the patients, their companions and professionals. I detailed ideas about the clinical and home environment, noting aspects of the information exchange process requiring clarification, observing the minutiae of what happened, when and how others reacted. Essentially, I prepared an interpretive commentary (Stake, 2005). These first analytical notes gave rise to the start of data analysis at the beginning of the interpretative process providing insight and depth to my early across case evaluations (Hammersley and Atkinson, 2007; Payne, Field, Rolls, Hawker and Kerr, 2007).

## 4.8. Demographic data

Participants gave permission for demographic data to be collected (Appendix 20: Demographic Data Sheet.). Data was obtained either from patients or their healthcare team. Evidence suggested that variables such as gender, age, educational status and stage of disease impact on information exchange between patients and professionals (Street, 1991). Demographic data had a valuable role within this study, for direct comparison with existing research findings and as illustrated in Chapter 6. Both patient and companion categorical data was thought to influence information exchange within this study. Demographic information was entered into the individual case sheets.

My prior knowledge, as a nurse specialist, did afford me insight into disease aspects but I verified all clinical demographic data during the course of the discussions with the healthcare team. I neither sought permission for nor planned on accessing documentation such as case files for any demographic data verification.

### 4.9. Data management

Patient's personal details such as name, address and CHI number were initially required to allow the researcher and the professional to track the number, sequence and timing of clinic consultations and importantly, to facilitate interviews carried out in the community setting. This information was separated from all data collected and held in a locked cabinet, in a secure location at all times. Patients were coded with an ID number and an alias, which was used on all study documentation. Immediately after the recruitment of Case A data collection and subsequent data management commenced. All audio-tapes were transcribed personally by me. Although this was both, labour and time intensive, the advantages of personally transcribing ensured there was accuracy and clarity in the transcripts and it allowed me to become immersed in the data. Similar to patient details, all audio was stored in a secure locked drawer, with all electronic transcriptions stored on password encrypted computers.

### 4.10. Case study database

Database creation permits organisation and documentation of all study data. Observing the second principle of case study data collection, I created an electronic research database using Nvivo 9®. Within this database I organised and stored all documentation relating to the cases and primarily ordered these around nodes for each individual case. Additionally, entries to the database folders recognised the original *a priori* categories which I established to answer the research questions. As analysis unfolded emerging sub-categories were added to reflect areas of information exchange. Then as the research developed and data analysis identified the emerging theoretical proposition the constructs relating to companion influence were also documented within specific nodes and categories. The

database included all field notes, demographic data, transcripts and audio recordings, as well as, a journal of my interpretative analysis notes. It was a valuable resource tool during comparative analysis.

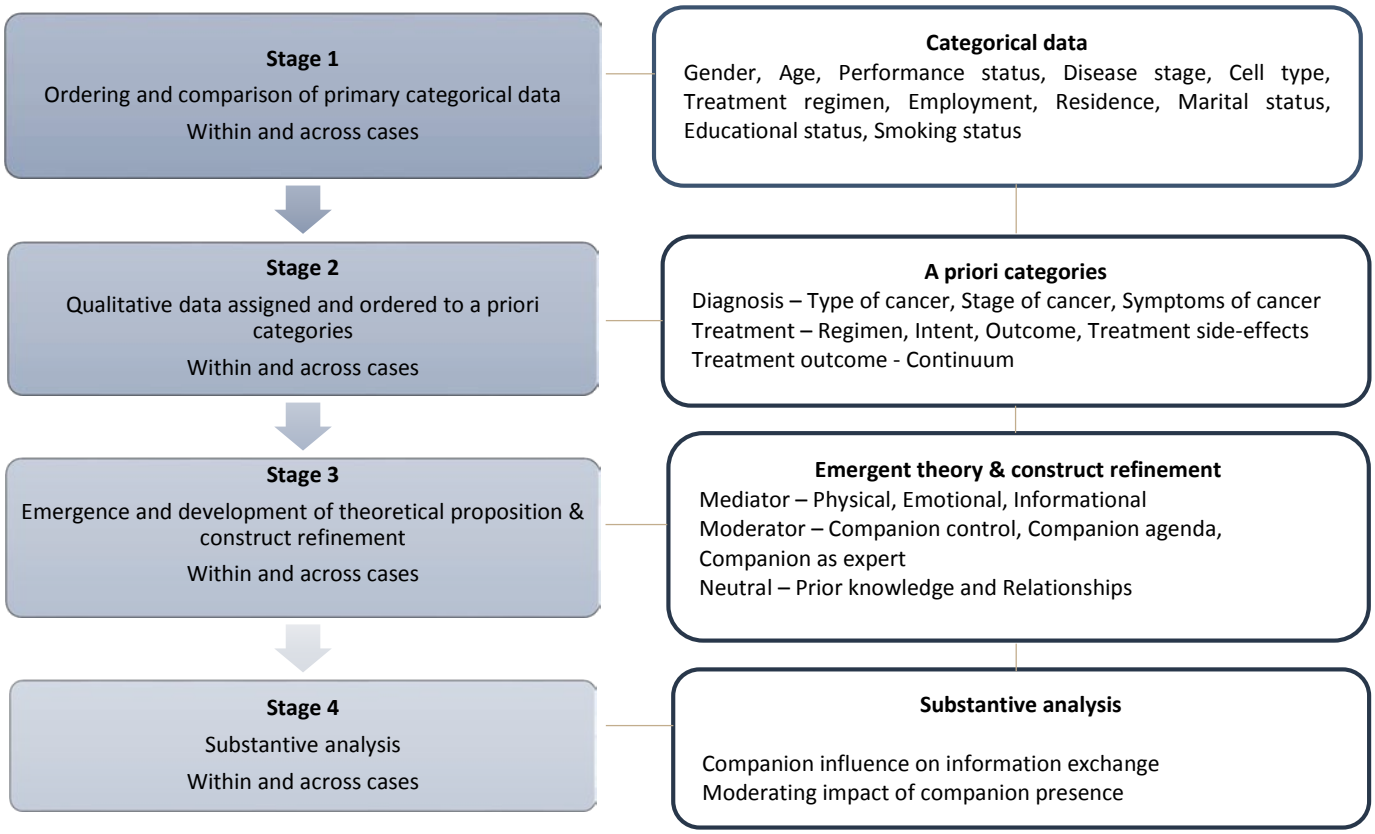
### 4.11. Maintaining a chain of evidence

Demonstrating a clear evidence trail further enhances the reliability of case study data and, importantly, is the third principle of case study data collection. In my study, all data relevant to individual cases, from potential case identification through to all transcribed interview data was made available for observer review. Correspondingly, all study material, including audio-tapes, transcriptions and case sheets were reviewed and discussed with my principle university supervisor and remain available for inspection.

### 4.12. Data analysis

Chapter 3 illustrated the theoretical approaches to data analysis in case study research, with specific reference to multiple sources of evidence that require to be referenced and coded in order that converging lines of inquiry and patterns can be uncovered (Stake, 2005). This section will detail the actual data analysis process undertaken in this study describing the four key stages of analysis and is represented in figure 6.

**Figure 6: Data analysis process**




Before embarking on coding and pattern matching in order to initially manage the volume of data generated and to provide a robust and clear synthesis of the raw data I followed basic principles (Box 1) stipulated by Thomas (2011, p171). These were useful at the start of data analysis to put the evidence into preliminary order.

**Box 1: General process of analysis**

**Thomas (2011, p171)**

- Examine all of your data – read the transcripts, diaries, notes and listen to audio-recordings
- Make copies of all raw data – keep one uncorrupted and use the other as a working data document
- Re-examine the data, highlighting important parts to give an impression of recurring and emerging themes (as I originally used a priori categories such as diagnosis, treatment and treatment outcome I used these as broad themes and ordered emerging categories around these)
- Read the data again, using the list of original constructs draw up a grid and reference the evidence and make notes and observations
- Identify second-order constructs which seem a good fit with the data and use to summarise the important themes
- When you are satisfied these constructs capture the essence of the data – label as themes
- Think about how the themes connect across cases, look for comparisons, contrasts, contradictions
- Find ways to map your themes
- Select appropriate quotes/narratives

### 4.12.1. Stage one - analysis of categorical data

Stage one analysis involved the ordering and comparison of demographic characteristics relating to each case. Each case was assigned both a case sheet and database file within Nvivo 9®. Within the software database it was then possible to develop and review nodes for all categorical variables within and across cases. The twelve demographic variables analysed are shown in table 10 - chapter 5. The aim of this stage of analysis was to provide descriptive data about the cases being studied, whilst more specifically identifying and describing particular attributes such as age, disease stage and performance status, and how these compared across the cases to determine if the cases were typical or atypical of the wider population. This stage of analysis compared data between participant cases, cases that declined to participate and cases not approached by professionals.

### 4.12.2. Stage two – analysis of qualitative data

Qualitative data was assigned to *a priori* categories based on key stages of the cancer care continuum and identified, empirically, as the recommended topics for information exchange and communication between professionals and patients. These were recognised as:

- Diagnosis
- Treatment
- Treatment outcome

During analysis and coding of the consultation transcripts it was apparent that the primary focus for participants was not solely the three broad categories detailed. Inductive data analysis revealed that information was exchanged around sub-themes for each category, with the exception of treatment outcome, where information was either exchanged or not. Such sub-categorisation (again within Nvivo 9®) permitted large amounts of data to be more easily managed and identified for across case comparison, providing essential units for further analysis (Thomas, 2011).

### 4.12.3. Stage three – emergence & development of theoretical proposition & construct refinement

Stage three of the analysis marked a shift of emphasis within the data. To this point, analysis identified data which encompassed categorisation of the information exchange process as it occurred between the participants within the cases. Constant comparative analysis indicated that across cases information exchange, per se, was regarded as important but performed to a level which each case found suited their needs. Analysing the data relationships within cases and comparing across cases within Nvivo 9® I detected that actual information content was impacted by other factors which consequently determined what course information exchange assumed.

Companion influence emerged as a significant consideration impacting information exchange during both clinical consultations and the in-depth interview process. As this new data occurred I reviewed the audio-tapes and transcriptions again to identify, more inductively, any themes or connections to substantiate the new emerging theory. I followed the explanation building process considered by Yin (2009) whereby the eventual theory is likely to be series of iterations:

- Make an initial theoretical statement or proposition
- Compare the findings of one case against the proposition
- Revise the proposition
- Compare the revision of the facts with a 2nd, 3rd or more cases

The final explanation or theory may not be the one stipulated at the beginning of the study and, therefore, differs to an extent to the pattern-matching process described in chapter 3. As I became more familiar with and compared the data across cases the new proposition of companion influence began to emerge (Yin, 2009). Then, as the next step in iterative analysis is the constant comparison between the emerging data from the cases and the empirical literature (Yin, 2009; Eisenhardt, 1989), I re-examined the evidence relating to both, factors impacting information exchange and the specific constructs impacted. A 'close fit' is important to the development of a theoretical proposition because it takes advantage of the new insights emerging from the data and the literature and yields an empirically valid theory, which in my study was linked to companion influence (Eisenhardt and Graebner, 2007).

#### 4.12.4. Stage four – substantive analysis

Before substantive analysis could be undertaken, I refined the constructs pertinent to companion influence and these are explored in chapter 6. Reasons for this were two-fold:

1. To further refine and describe codes relating to the new theory
2. Build evidence between my data and that reviewed empirically to support the constructs I had identified – moderating, mediating and neutral companion influence

I considered it important to further re-define the broad concepts of companion influence and investigate what specific features or attributes of companions and the patients they accompanied to consultations might additionally impact information exchange processes. From this further data analysis it emerged that although patient attributes (such as age, gender) could not be considered as influential considerations overall, companion characteristics were. These were further characterised in a novel resultant theory – *negotiated companion presence* – the detail of which will be illustrated in chapter 7.

## 4.13. Summation

In chapter 4 the study design and method described in chapter 3 has been operationalised. The specific processes relevant to case identification and selection via the recruitment process have been documented. Subsequently, the methodological processes of data collection and analysis have been illustrated, with attention to the three principles of case study design, multiple data sources, creation of a study database and maintaining a chain of evidence.

# Chapter 5: Results

## 5.1. Introduction

The following chapter will present two of the three stages of data analysis. The first stage, described in section 5.2, is the ordering and comparison of primary categorical data for the cases. Within this analysis two methods were utilised to inform the data:

1. Within-case analysis - this involves organising the data by specific cases for in-depth study
2. Across-case analysis - used to explore similarities and differences across cases.

Section 5.3 reports on the second stage of analysis where qualitative data was assigned and ordered to *a priori* codes, identifying and developing themes from more inductive analysis, leading to the key substantive theoretical proposition. The third stage of data analysis development of the key theoretical proposition will be the focus of chapter 6, whereby its emergence will be detailed and reported. This will be followed by a more extensive analysis of the substantive theoretical findings in chapter 7, before an in-depth discussion in chapter 8.

Chapter 5 will begin with an overview of the recruitment summary as well as a brief overview of categorical data for the non-participant cases to add context and investigate reasons why certain patients may not be approached for study participation.

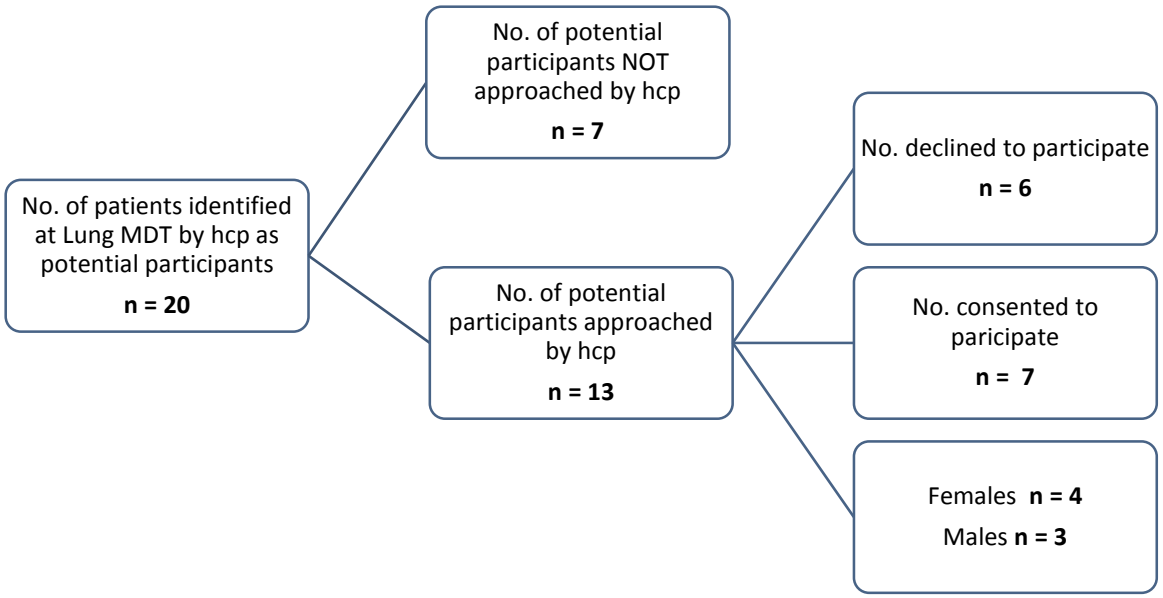
## 5.2. Primary categorical data analysis

Before detailing the categorical data from the cases, this section will firstly give some contextual background and descriptive detail on recruitment. Recruitment to the study continued for an extended period of time, January 2010 to December 2011. The reasons for prolonged recruitment were multifactorial and discussed in-depth in Chapter 4.

### 5.2.1. Recruitment summary

Twenty patients were identified as potential participants, with 7 cases recruited to the study. A summary of recruitment is shown in figure 7.

**Figure 7: Recruitment summary**




### 5.2.2. Non-participation in the study

Of the non-participants (both not approached and approached but declined) 13 were female. This reflected the time line within the recruitment process where Study Site A only approached women and Study Site B only started to recruit in the last six months of the recruitment period. Basic demographic data were collected using the previously described Potential Patient Demographic Sheet. Additional demographic information was collected from professionals at the clinical consultations. The seven demographic domains are displayed in table 10 alongside the explanations given by professionals for not approaching potential participants. The reasons given by those patients who were approached, but declined are also listed.

**Table 10: Baseline demographic characteristics of non-participant patients**

| Characteristics | No of non-participants | |
|---|---|---|
| | | |
| **Gender** | | |
| Male | 1 | |
| Female | 12 | |
| **Age** | | |
| < 50 | 0 | |
| 50-59 | 0 | |
| 60-69 | 2 | |
| >70 | 11 | |
| **Performance status** | | |
| 0 | 0 | |
| 1 | 5 | |
| 2 | 5 | |
| 3 | 3 | |
| 4 | 0 | |
| **Disease stage** | | |
| Limited | 2 | |
| Advanced | 11 | |
| **Histological cell type** | | |
| NSCLC | 9 | |
| MESO | 1 | |
| SCLC | 2 | |
| NO HISTOLOGY | 1 | |
| **Treatment regimen** | | |
| Chemotherapy | 4 | |
| Radiotherapy | 5 | |
| Surgery | 1 | |
| Combined | 2 | |
| Palliative care | 1 | |
| **Treatment intent** | | |
| Curative | 2 | |
| Palliative | 10 | |
| Best supportive Care | 1 | n = 13 |
| **Reasons for non-approach by healthcare professionals (n = 7)** | | |
| Severe memory impairment due to dementia | 1 | |
| No cell type and decision taken not to pursue diagnosis | 1 | |
| Too upset at diagnosis | 3 | |
| Severe confusion due to brain metastases | 1 | |
| Patient diagnosed with mesothelioma | 1 | n = 7 |
| **Reasons for non-participation cited by patients & companions (n = 6)** | | |
| Too overwhelmed by all information | 5 | |
| Too much other things to cope with at moment | 1 | n = 6 |
| | | |

A significant number of cases (n = 9) were diagnosed with non-small cell lung cancer. All of the non-participant cases were over 60 years old, with the majority older than seventy and 6 were in their

eighties. This combined with poor performance status (PS); where 8 patients had a PS of 2 or above, advanced stage of disease (n=11) and the palliative intent of therapy (n=11) could explain why this group of patients were either not approached to participate or declined when asked.

### 5.2.3. Case study participants

This section will concentrate specifically on data pertaining to the characteristics of the cases who did participate in the study. The focus is initially on the study sites and professionals before discussing the cases studies comprehensively within and across case.

#### 5.2.3.1. Study site and healthcare professional participants

The study had the potential to be carried out across three hospital sites. The main study sites were two acute teaching hospitals (Study Sites A and B). Cases referred for surgical intervention would be seen within the third Study Site (C) which provides Thoracic Surgical Services. During the study period the Health Board launched a major service redesign which included the amalgamation of Study Sites A and B into a central unit. Redesign had an impact on recruitment, which was temporarily postponed, but otherwise the study remained unaffected.

All healthcare professionals approached to participate in the study gave written consent. The main Study Sites and healthcare participants are listed in table 11.

**Table 11: Characteristics of the study sites and healthcare professionals**

| Study site | Geographical & demographic data | Clinical modality | Healthcare professionals who participated | Gender |
|---|---|---|---|---|
| | | | | |
| **A** | Large teaching hospital, with 440 in-patient bed capacity, delivers a broad range of regional, supra-regional and national acute clinical services | Joint respiratory/oncology clinics<br>Patients seen by team in one afternoon | Respiratory physician<br>Clinical oncologist<br>Clinical nurse specialist<br>Clinical trials nurse | M<br>M<br>F<br><br>F |
| | | | | |
| **B** | Large teaching hospital, with 1077 bed capacity, delivers a broad range of regional, supra-regional and national acute clinical services | Separate modality clinics<br>Patients seen by specialists in sequential clinics | Respiratory physician<br>Clinical oncologist<br>Clinical nurse specialist | M<br>F<br>F |
| | | | | |
| **C. Thoracic centre** | 200 bedded hospital provides regional and national services for cardiac and thoracic services | Specialist thoracic clinics only | | |

Despite the Thoracic centre being a potential site for information exchange, the opportunity for their inclusion was not realized. No case at Study Site A was considered suitable for resection and only one case [Case F - Flo] (Study Site B) was seen by the Thoracic Surgeon. Unconventionally, due to industrial action, she did not attend an out-patient consultation and was reviewed on admission to the thoracic centre. Although the patient consented to the audio-taping of the in-patient consultation, the surgeon declined and the opportunity to record what would have been the only surgical-related information exchange encounter was missed.

#### 5.2.3.2. Within-case data analysis of participant cases

Seven patients were recruited to the study: 4 women and 3 men. All seven consented to the audio-recording of their out-patient consultations, de-brief interviews post clinical encounter and later to an in-depth interview. Seven healthcare professionals consented to the audio-recording of the consultation and post-consultation de-brief. A total of 12 companions consented to participate in the

study and gave permission for audio-taping of consultations; de-brief interviews and in-depth interviews they may have participated in. All participants were assigned an alias.

Baseline demographic data were collected using the Patient Demographic Sheet. Originally demographic data captured information on eleven domains. However, following discussion with university supervisors, another domain of smoking status was included. Although smoking history was never requested, all 7 cases mentioned smoking at some point during data collection. Consequently, as tobacco use is linked to the development of lung cancer and a very contemporary issue, another domain was created to record this data. Each case will be analysed within-case, incorporating the 12 domains, whilst considering multiple sources of evidence relating to them. Table 12 illustrates the categorical data for each case.

## Table 12: Baseline demographic characteristics of participant cases

| Cases Alias | M/F | Age | PS | Cell type | Stage | Smoking status | Treatment | Intent | Employment | Residence | Marital status | Educational status | Study site | Healthcare professional seen | Companion(s) present | Debrief interviews | In-depth interview |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **A Alex** | M | 71 | 0 | NSCLC | T4 N0 | Ex-smoker | Chemotherapy + / - radiotherapy | Curative | Retired (caulker-burner) | City | Widowed | Secondary school | A | Dr Andrews Respiratory physician<br>Dr Allan Clinical oncologist<br>Sr Alcorn Clinical nurse specialist | Daughter (Ann) (consultation)<br>Partner (Agnes) (in-depth) | Alex<br>Dr Andrews<br>Dr Allan<br>Sr Alcorn | Alex<br>Agnes (contributed) |
| **B Ben** | M | 69 | 0 | MESO | None/not recorded | Never smoker | Chemotherapy | Palliative | Self-employed mechanic | City | Widowed | City & Guild Cert | A | Dr Andrews Respiratory physician<br>Dr Allan Clinical oncologist | Daughter (Betty) (consultation)<br>Alone (in-depth) | Ben<br>Dr Andrews<br>Dr Allan | Ben |
| **C Celia** | F | 71 | 1 | NSCLC | T4 N2 | Smoker | Radiotherapy | Palliative | Retired (sales assistant) | City | Widowed | Secondary school | A | Dr Andrews Respiratory physician<br>Dr Allan Clinical oncologist<br>Sr Alcorn Clinical nurse specialist | Brother (Colin) (consultation)<br>Alone (in-depth) | Celia & Colin<br>Dr Andrews<br>Dr Allan<br>Sr Alcorn | Celia |
| **D Delia** | F | 55 | 0 | NSCLC | T4 N2 | Smoker | Chemotherapy | Palliative | Unemployed (car valet) | City | Married | Secondary school | A | Dr Andrews Respiratory physician<br>Dr Allan Clinical oncologist<br>Clinical trials nurse | Husband & daughter (Davie & Denise) (consultation)<br>Husband (in-depth) | Delia & Davie<br>Dr Andrews<br>Dr Allan | Delia<br>Davie (contributed) |
| **E Eve** | F | 65 | 0 | SCLC | T4 N2 M1 | Smoker | Chemotherapy | Palliative | Retired (engineering plant worker) | City | Divorced | Secondary school | B | Dr Boyd Respiratory physician<br>Dr Brown Clinical oncologist<br>Sr Baxter Clinical nurse specialist | Son (Eric) (1st consultation)<br>Son & daughter (Eric & Elaine) (2nd consultation)<br>Son & 2nd son ( (Eric & Ewen) in-depth) | Eve & Eric<br>Dr Boyd<br>Sr Baxter<br>Dr Brown | Eve<br>Eric (later – Ewen) (contributed) |
| **F Flo** | F | 67 | 0 | NSCLC | T2 NO | Ex- smoker | Surgery | Curative | Retired (clerical assistant) | City | Married | Secondary school | B | Dr Boyd Respiratory physician<br>Sr Baxter Clinical nurse specialist | Husband & daughter (Frank & Fiona) (consultation)<br>Husband (Frank) (in-depth) | Flo & Frank<br>Dr Boyd<br>Sr Baxter | Flo<br>Frank (contributed) |
| **G Gordon** | M | 53 | 0 | NSCLC | T4 N2 | Smoker | Chemotherapy + / - radiotherapy | Palliative | Sick leave (from full time employment as a carer) | City | Divorced | Secondary school | B | Dr Boyd Respiratory physician<br>Dr Brown Clinical oncologist | Ex-wife (Grace) (consultation)<br>Alone (in-depth) | Gordon & Grace<br>Dr Brown | Gordon |

#### 5.2.3.3. Case study A (Alias Alex)

Alex was a 71 year old man diagnosed with T4 N0 non-small cell lung cancer. He presented to his general practitioner with a persistent cough. Despite a history of prostatic cancer for which he had radical radiotherapy, he was well with a PS of 0. He was an ex-smoker, having stopped 10 years ago. Alex left school with secondary education qualifications and worked as caulker-burner in the construction industry before retiring due to a back injury. Widowed, he lived in a large inner-city area. Primary treatment was chemotherapy, followed by adjuvant radiotherapy, if the cancer responded. Treatment intent was considered curative. He attended Study Site A with his daughter (Ann) and together they had consultations with a respiratory physician (Dr Andrews), a clinical oncologist (Dr Allan) and the Clinical Nurse Specialist (Sr Alcorn). Case study data was collected at de-brief interviews from Dr Andrews, Dr Allan and Sr Alcorn as well as Alex. At in-depth interview, the patient was accompanied by his partner (Agnes), who was not present throughout other data collection encounters.

#### 5.2.3.4. Case study B (Alias Ben)

Diagnosed with mesothelioma (not staged) Ben was the only case with this diagnosis. He was a 69 year old man, who continued to work as a self-employed car mechanic. He left secondary school and then gained City and Guild Certification. He was a non-smoker. Widowed, he lived in an inner city area. His main presenting symptom was chest pain. He was not physically debilitated by pain and his PS was recorded at 0. He had no significant past medical history. The treatment modality was chemotherapy, with the intent being local control and palliation. Ben attended his clinic consultations at Study Site A with his daughter (Betty) and they consulted with Dr Andrews and Dr Allan. Data was also available from de-brief interviews with both doctors and the patient. At the time of the in-depth interview, Ben was un-accompanied.

#### 5.2.3.5. Case study C (Alias Celia)

Celia was a 71 year old lady, with a history of breast cancer, who had been diagnosed with non-small cell lung cancer, after developing posterior chest pain. Her PS was 1. Celia was a retired shop assistant, who had secondary school education. At the time of data collection she lived alone in an inner city area and was a widow. Celia was a current smoker. As her cancer was staged as T4 N2 Celia was offered palliative radiotherapy. When she attended Study Site A, her brother (Colin) was present and they consulted with Dr Andrews, Dr Allan and Sr Alcorn. Additional data was collected at de-brief interviews with Celia and the three professionals. Celia was un-accompanied at the in-depth interview.

#### 5.2.3.6. Case study D (Alias Delia)

Diagnosed with T4 N2 non-small cell lung cancer, Delia was a 55 year old woman who presented with pleuritic chest pain. This was a new symptom on a background of severe Chronic Obstructive Pulmonary disease (COPD). Delia was unemployed due to ill-health as a result of her airways disease. She previously worked as a cleaner and car valet. She left school with secondary school qualifications. She was married and lived with her husband (Davie) in an inner city area and her PS was described as 0. At the time of data collection Delia was a smoker. Treatment regimen was chemotherapy, with the intent being symptom control and palliation. The patient attended clinic consultations at Study Site A and was reviewed by Dr Andrews, Dr Allan and the Clinical Trials Nurse. Data was collected at the consultations with these professionals and also at de-briefs with the patient, her husband and her daughter (Denise), Dr Andrews and Dr Allan. At the in-depth interview Delia was again accompanied by her husband.

#### 5.2.3.7. Case study E (Alias Eve)

Eve was a 65 year old woman who presented with increasing dyspnoea and pain. She had been diagnosed with small cell lung cancer, staged at T4 N2 M1. Despite the extent of her disease the patient's PS was 0. Eve lived with her son, Eric (as he moved home to look after her) in an inner city

area. She was divorced and left school with secondary school qualifications and worked in an engineering plant until she retired. Eve was a current smoker, with co-morbid conditions which included oesteo-arthritis and COPD. Originally Eve consented to a local clinical trial involving concurrent chemotherapy and radiotherapy, but this was altered to chemotherapy when she was diagnosed with cerebral spread. The intent of therapy was palliative. This lady attended Study Site B and was seen at sequential clinics by Dr Boyd and Dr Brown, as well as Sr Baxter (the CNS). She was accompanied by Eric to the first consultation and then by both Eric and daughter Elaine to the second. All consultations were recorded and data collected. Debrief interviews included all members of the healthcare team and the patient and her companions. At the in-depth interview Eve was accompanied by her sons (Eric and Ewen).

#### 5.2.3.8. Case study F (Alias Flo)

The fifth case of the study was Flo, a 67 year old lady diagnosed with T2 N0 non-small cell lung cancer. Her cancer was diagnosed following investigation of recurrent chest infections. She had no significant past medical history and stopped smoking over 20 years ago. PS was 0. Since leaving school with secondary school qualifications, Flo worked as a clerical assistant until she retired. She was married and lived with her husband (Frank) in a suburb. The treatment modality was surgical resection with a curative intent. Flo was diagnosed at Study Site B and attended consultations there with Dr Brown and Sr Baxter. She was accompanied by Frank and daughter (Fiona). De-brief interviews were recorded and data collected from Flo and her companions and her health team. As a surgical candidate, she was reviewed at the thoracic centre as an in-patient but this consultation and de-brief were not part of data collection. The in-depth interview data was collected from Flo and her husband.

#### 5.2.3.9. Case study G (Alias Gordon)

Gordon was a 53 year old man who presented with painful knees, but his GP was concerned about accompanying weight loss and anorexia. Investigations revealed a T4 N2 non-small cell lung cancer.

Gordon was previously well, with no significant past medical history and with a PS of 0. He worked as a carer, but was on sick leave. He left school with secondary school educational qualifications. He was a current smoker. He lived on his own in an inner city area. Chemotherapy was the treatment prescribed, with additional radiotherapy if there was a good anti-cancer response. Treatment intent was palliative. Gordon attended consultations at Study Site B with his ex-wife Grace. Although this was a sequential clinic site he was seen at the same session by Dr Boyd and Dr Brown. De-brief interviews were conducted with Gordon and Grace and with Dr Brown. Dr Boyd was called to an emergency. The in- depth was carried out in the cancer centre ward, at the patient's request and he was un-accompanied.

## 5.3. Across-case analysis of categorical data

All seven cases recruited were Caucasian and diagnosed with primary lung cancer. These were a rich and diverse group of cases, with all seven presenting a varied categorical data set for analysis. Yin (2009) considered that between 6 to 10 cases are sufficient to provide compelling support for the initial set of propositions. These cases were selected purposively and defined as critical to the study, due to their knowledge of the phenomenon under research.

### 5.3.1. Gender

During the period of data collection, more women (n=421) than men (n=405) were diagnosed with lung cancer across both study sites (Office for Audit and Clinical Effectiveness, 2008). During data collection 4 women were recruited to the study which allowed for a comparable division of gender and permitted data to be gathered and analysed from both male and female cases.

### 5.3.2. Age

Although lung cancer is strongly correlated to age and usually diagnosed in patients over the age of 65 years (www.cancerresearchuk.org/lungcancer/keyfacts-accessed 09.03.2013) this study recruited

cases from a diverse range of age groups. Cases ranged in age from 53-71 years, with median age being 64 years.

### 5.3.3. Performance status (PS)

Six cases were classified as having PS 0, indicating they were fully active and maintained close to pre-diagnosis performance with no or minimal restriction (Oken et al, 1982). Performance status is shown in Appendix 21. PS classification is vital as it determines a patient's fitness and suitability for therapy. The prevalence of poor PS (3 or above) among lung cancer patients is generally high (Lilenbaum, Cashy, Hensing, Young and Cella, 2008). Conversely, in this study all but one of the cases recorded good PS (PS 0). Celia was classified as PS 1 due to co-morbid disease and stage of current diagnosis. This was the only domain with little variation across the cases, in relation to standard functional status.

### 5.3.4. Cell type

Five of the seven cases were diagnosed with non-small cell lung cancer, paralleling national statistics, where approximately 75% of the lung cancer population has this cell type. However, differentiation across cases was noted, as small cell and mesothelioma classifications were included in analysis.

### 5.3.5. Disease stage

Only 2 cases were identified as having limited stage disease - (Alex – T4, N0 and Flo - T2, N0). Five cases in the study were diagnosed at an advanced stage, compatible with the vast majority of lung cancer cases throughout Scotland. Ben's mesothelioma was never assigned a classification as historically pleural mesothelioma is only formally accurately staged post mortem. Variable data in such an important domain, which impacts directly on treatment and treatment intent, has the potential to influence the type and content of information exchanged at the clinical encounter between all case participants.

### 5.3.6. Treatment

Treatment decisions are based on many of the categorical data listed, as well as the risk to the patient from therapy related toxicity, with any potential benefit in survival balanced against the risk of additional toxicities (NICE, 2005). Five cases received chemotherapy as first line treatment, with two cases (Alec and Gordon) scheduled to have adjuvant radiotherapy, depending on the outcome of the initial therapy. Celia was too frail for systemic chemotherapy and had palliative radiotherapy. Only Eve was considered for a chemotherapy clinical trial. Study protocol indicates patients undergo CT imaging of head and at this conjuncture Eve was found to have cerebral metastases and therefore was ineligible for the trial. She received standard chemotherapy. Across cases, only Flo was considered for resection. Again across cases, there is heterogeneous data for this domain, with the possibility to impact information exchange on many levels.

### 5.3.7. Treatment outcome/intent

Two cases (Alex and Flo) were reported as having potentially curative treatment: chemo-radiation and surgery respectively. For the remaining five cases the prognostic outlook following treatment could be measured in terms of months, with median survival of 4 months in patients with advanced disease (BTS, 2008).

### 5.3.8. General demographic data

Two cases (Ben and Gordon) were in employment, although Gordon was incapacitated by his symptoms and on sick leave. Ben continued to work, but carrying out less manual labour then pre-diagnosis. Delia was unemployed due to long-standing ill health and the rest of the cases were retired. Other than Ben, who has City and Guild Certification, everyone else had secondary school educational qualifications. Two patients were married, 3 were widowed and 2 divorced. Four of the cases lived alone. All cases lived in a large urban area of Scotland, with 6 of them residing in the most deprived areas of the city (DepCat 7). The Carstairs and Morris Index of Deprivation is a measure of quantifying

socioeconomic deprivation or affluence in different localities across Scotland. Deprivation scores are derived by combining four census variables which best indicate material disadvantage (proportion of households with male unemployment, lack of car ownership, overcrowded housing and the head of household being in social class IV or V) for each postcode sector in Scotland (McCloone, 2004). There are seven deprivation scores, with DepCat 1 being the most affluent and DepCat 7 being the most deprived.

Originally smoking status was not one of the original categorical domains but throughout the data collection period smoking history was referred to by all of the cases. Consequently, data on the domain could be recorded. Six of the seven cases were either current or ex-smokers. Only Ben was a never smoker and his mesothelioma was directly attributable to asbestos exposure.

### 5.3.9. Study site demographic data and data collection episodes

Cases A - D were diagnosed at Study Site A. Every case was reviewed by a respiratory physician (Dr Andrews) and a clinical oncologist (Dr Allan). At the consultations, Cases A and C were also reviewed by the CNS (Sr Alcorn). Cases C and D were reviewed by the clinical trials nurse. All cases were accompanied to the consultation by a companion.

Similar findings were in evidence at Study site B where Cases E, F and G were diagnosed. Clinic consultations are usually sequential at this site. All cases were reviewed by a respiratory consultant (Dr Boyd) and 2 cases by a clinical oncologist (Dr Brown). Data was not captured for information exchange between Gordon and Sr Baxter, as she was not at clinic on the day. Flo was the only case assessed off site at the thoracic centre. All cases were accompanied by companion(s). Table 13 illustrates all data collection episodes for each case.

**Table 13: Data collection episode for each case**

| Study site | Case | Clinical consultations (separate clinical encounters) | De-brief interviews | In-depth interviews | Demographic details/Field notes |
|---|---|---|---|---|---|
| **A** | Alex | Dr Andrews (Respiratory physician)<br>Dr Allan (Oncologist)<br>Sr Alcorn (Clinical Nurse Specialist) | Dr Andrews<br>Dr Allan<br>Sr Alcorn<br>Alex and Ann | Alex & Agnes | √ |
| **A** | Ben | Dr Andrews (Respiratory physician)<br>Dr Allan (Oncologist) | Dr Andrews<br>Dr Allan<br>Ben & Betty | Ben | √ |
| **A** | Celia | Dr Andrews (Respiratory physician)<br>Dr Allan (Oncologist)<br>Sr Alcorn (Clinical Nurse Specialist) | Dr Andrews<br>Dr Allan<br>Sr Alcorn<br>Celia & Colin | Celia | √ |
| **A** | Delia | Dr Andrews (Respiratory physician)<br>Dr Allan (Oncologist)<br>Clinical Trials Nurse | Dr Andrews<br>Dr Allan<br>Delia, Davie & Denise | Delia & Davie | √ |
| **B** | Eve | Dr Boyd (Respiratory physician)<br>Dr Brown (Oncologist)<br>Sr Baxter (Clinical Nurse Specialist) | Dr Boyd<br>Dr Brown<br>Sr Baxter<br>Eve, Eric & Elaine | Eve, Eric & Ewen | √ |
| **B** | Flora | Dr Boyd (Respiratory physician)<br>Sr Baxter (Clinical Nurse Specialist) | Dr Boyd<br>Sr Baxter<br>Flo, Frank & Fiona | Flo & Frank | √ |
| **B** | Gordon | Dr Boyd (Respiratory physician)<br>Dr Brown (Oncologist) | Dr Brown<br>Gordon & Grace | Gordon | √ |
| **No of data collection episodes** | **Cases n = 7** | **Consultations n = 18** | **De-briefs n = 23** | **In-depth n = 7** | **Demo/notes n = 7** |

### 5.3.10. Summary of categorical data

Overall the data illustrated more similarities than differences, between the non-participant and participant cases, and generally within the most significant categorical domains. Data for all the cases in the study reflect the Scottish population. Across cases (both non-participant and participant) patients were diagnosed with advanced stage lung cancer, usually non-small cell type, where definitive treatment consisted of palliative therapies (usually chemotherapy and/or radiotherapy).

There were notable differences with regard to age and performance status between the groups. For example, patients in the non-participant group were older – with 11 aged over 70 years and the other 2 cases over sixty. The non-participant group had poorer health status with 8 of the 11 cases classified as PS 2, with advanced stage disease recorded in all cases. The implications that recruiting younger and healthier patients to the study and the influence, if any, this has on information exchange will be considered further in chapter seven.

It is not the aim to generalise these cases to the rest of the lung cancer population. However, it is apparent that the cases in the majority of domains reflect the Scottish lung cancer population. As such they are an appropriate group of cases on which to expand and generalise theories (analytical generalisation) and upon which to base further analysis. Additionally, across cases there is also a degree of heterogeneity with each case providing valuable and rich data which impacts on information exchange.

## 5.4. Assignment and ordering of qualitative data from *a priori* codes

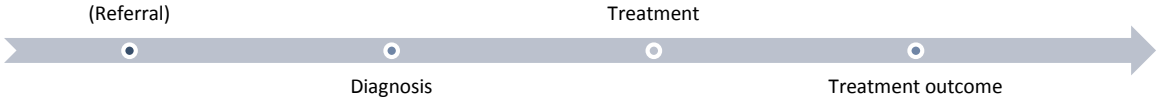
### 5.4.1. Introduction

The second stage of data analysis involved the ordering and coding of qualitative data. The study explored information which was either exchanged or not exchanged between professionals and patients, as they met along the cancer care continuum (shown in figure 8). The current model of the lung cancer continuum divides the patient journey and periods of information exchange into discrete stages; namely diagnosis, treatment and treatment outcome. Information is exchanged at these key

stages of the care continuum. I reflected that a sound foundation for categorical data collection and subsequent analysis should focus on specified *a priori* categories. I judged information *per se* to be a vast and complex area to study and after careful review of the empirical literature, deemed diagnosis, treatment and treatment outcome as the most important stages of the patient care pathway, where patient-professional information exchanges were crucial. These key categories informed the *a priori* codes during data collection in my research.

At the time of data collection for this study, the referral stage of the pathway was complete and thus not influential in forming the *a priori* codes.

**Figure 8: Cancer care continuum**
**(BTS, 2013)**




The following three sections and corresponding subsections describe the second stage of data analysis, where qualitative data was assigned and ordered to key *a priori* codes. The section will detail the findings, observations and selected quotes in relation to the three *a priori* codes outlined above.

### 5.4.2. Analysis of diagnosis related information

The first *a priori* code developed, was information relating to the diagnosis of lung cancer. The study began after the referral and investigation stages of the pathway and in all cases the diagnosis of lung cancer had been communicated at earlier consultations, with some patients having more information than others. For Cases A through D, the patients had been made aware of diagnosis specific

information at clinics the week before. Cases E, F and G, although aware they had lung cancer, were returning for discussions relating to this specific aspect of their disease.

From the original *a priori* code of diagnosis other sub-codes emerged inductively, as the data was analysed. Sub-codes for diagnosis are shown in table 14.

**Table 14: Sub-codes for diagnosis**

| Key a priori code | Sub-code |
|---|---|
| | |
| **Diagnosis** | Type of lung cancer |
| | Stage of lung cancer |
| | Symptoms of lung cancer |

### 5.4.3. Type of lung cancer

A histological diagnosis of lung cancer was confirmed in 6 cases. Ben had a histologically proven diagnosis of pleural mesothelioma. For example:

***Mesothelioma, that's what the pathology has shown, so we know exactly what it is (Consultation/Dr Allan/Ben, Ref 6)***

During the period of data collection, three of the patients were informed of the specific cell type of their cancer (Cases A, B and E). Moreover, the level of detailed information exchanged about the diagnostic cell type, varied significantly across cases. In some cases very little histological detail was provided as shown below:

***And that test has confirmed it's cancer and it's told us what sort of cancer it is (Consultation/Dr Andrews/Delia, Ref 1)***

In contrast to the above, Eve's information exchange regarding cell type was significantly more in-depth, with the exchange occurring across both clinical consultations. The patient continued to talk

about her cell type at her de-brief and in-depth interview, with her understanding of her cancer, its treatment and treatment outcome, developing from one consultation to the next:

***We've got a sample back and there's a bit of a surprise…we were expecting one type of lung cancer, but we saw another type of lung cancer, and the type of lung cancer you have is called a small cell lung cancer yeah? (Consultation/Dr Boyd/Eve, Ref 5)***

***OK, so there's two types of lung cancer – one is a faster growing cancer, and one is a slower growing cancer, and you have the one that is a faster growing cancer. And it's called small cell lung cancer (Consultation/Dr Brown/Eve, Ref 7)***

***But the biggest shock I've got the day is she's just telt me I've got fast track cancer . He said 'small cell cancer'. He didn't say it was a fast growing cancer. He didn't say I was snuffing it quicker, put it that way (De-brief interview/Eve, Ref 8)***

The inference to the growth rate of the cancer was mentioned in only two cases (E and A). In the latter case the patient and more so his companion, referred to his cancer type as slow growing on numerous occasions, perhaps seeking reassurance that the outcome from this particular 'slow growing' cell type would be more favourable:

***A non- small cell or something, very slow growing (In-depth interview/Agnes, Ref 1)***

Ben was diagnosed with a malignant tumour affecting the lining of his lung, almost exclusively caused by exposure to asbestos. Although cell type is an important prognostic indicator there was limited information exchanged regarding classification. For example:

***So that's what the pathology has shown, so we know exactly what it is. And that's, we know it's a tumour that can affect the lining of the lung, and I think he's talked to you about asbestos does seem to be a factor in it (Consultation/Dr Allan/Ben, Ref 6)***

The classification of cancer is an important issue, with correlation of tumour type and biological behaviour vital in cancer management. However, there is no evidence across cases, apart from Eve and to some extent Alex, that the presence or absence of information about this, made a significant difference to how patients viewed their cancer diagnosis. It is possible that for the rest of the cases, just knowing they had a lung cancer was all the information they required. For these cases, there appeared to be more importance placed on information regarding the stage and extent of the cancer, and this will be discussed in the next section.

Overall, both professionals and patients, when questioned, expressed the view that they had exchanged all of the diagnosis related information they wanted to or to a level that was satisfactory for them.

### 5.4.4. Stage of lung cancer

All cases in this study received information regarding the location and extent of their disease and subsequently, there was some type of justification given by the healthcare professional for a treatment rationale based on tumour location:

***Yes – it starts off on what we call the pleural lining of the lung, rather than the middle of the lung itself, and that's got swollen and it's affected by a sort of tumour, like a rind in the lung, Now, because of where it is, and it is quite stuck onto the lining of the lung, it can't be removed (Consultation/Dr Allan/Ben, Ref 1)***

Whereas cell classification did not seem relevant for some of the cases in the study, as discussed previously, the extent and location of the cancer appeared to be germane for all of them:

***Well you were doing it to see how far it's spread, if it's on the other side of my lung or if it's just in my lung, or behind it or around about it…. (Consultation/Dr Boyd/Flo, Ref 19)***

Although all patients had information exchanged regarding staging, similar to cell classification there were differences in the amount and detail explained. Some clinicians would explain disease staging comprehensively whilst showing the location on the CT monitor:

***We had a look at your PET scan today, and that did not show up anything on the left. And the other tiny nodules on the right also did not show up much….. It's a tiny nodule, it could be unrelated, it could be a scar, it could be nothing. And we know that your lymph glands are swollen in the midline, and again that would be, really making us think of other treatments than surgery. You have got quite a nasty aggressive-looking tumour on the right side, which is close to the main line (Consultation/Dr Boyd/ Gordon, Ref 24)***

However in other cases there was very little information exchanged in relation to disease extent:

***There's a tumour affecting the left lung and it's obviously it's a little bit stuck to the where the rib is (Consultation/Dr Allan/ Celia, Ref 2)***

Additionally, when healthcare professionals were giving information about the diagnosis there was variation in the language employed. In some cases there was evidence of strong, descriptive language used by the healthcare professionals. For example:

***Lung cancer is a very nasty cancer (Consultation/Dr Brown/Eve, Ref 12)***

Whereas for others euphemistic descriptions were employed:

***Well, it's in a very important area. A busy traffic area, it's very near major blood vessels and such (Consultation/Dr Andrews/Alex, Ref 2)***

The reasons for the variation were not investigated and remain unclear. It could simply be related to the communication style of individual practitioners and their educational and experiential backgrounds, regarding the communication of diagnosis. There was no data suggesting that patients were influenced or distressed by either too much or too little detail, about the stage of their disease

or by the language used. But staging information did seem to be an important component of their cancer care, with many recalling information regarding this theme at their in-depth interview. For example:

***Well, it's near the spine as well you see? It's going near the spine he says. It's a very, very sensitive area. There's a lot of tissue there he says, so em, he says you need to be careful (Celia, in-depth interview, Ref 13)***

Information concerning staging was significant for these patients as it was directly related to both treatment and treatment outcome. This will be discussed in greater detail in section 5.5. Also, whereas there is evidence that companion input was limited during information exchange regarding cell classification, their input was more noticeable when discussion focused on staging.

Alex's companion Agnes appeared to have insight that the location and staging of his cancer signified that surgery was not an option. She independently raised the subject of disease extent during the in-depth interview:

***Agnes:*** ***Yeah, it's 5 cms***

***Alex:*** ***I'm not too sure if that's big or small***

***Agnes:*** ***Well, where it is, it's near the heart and the aorta, so they can't operate. It's too dangerous, so it is (In-depth interview/Agnes & Alex, Ref 6)***

By contrast Delia's husband, whilst stating he felt that explanations regarding diagnosis and stage of disease were carried out well, did not appear to fully understand the significance of the information. It would appear for this family that despite understanding the diagnosis, there is misunderstanding in relation to the significance of a few spots actually representing disseminated disease.

***I think they explained it well to us, yes. I understood it, my daughter understood it. We were actually relieved a bit relieved it was only spots…I was expecting a big mass! (In-depth interview/Davie, Ref 10)***

Study data indicates that information is exchanged along a continuum, with the capacity for professionals to exchange information with patients and their companions at a variety of clinical encounters. As previously stated, this study only collected data at specific and pre-determined information exchange interactions and cannot comment on further information which may have been given regarding staging elsewhere. That said, when questioned all participants comment that they exchanged the information which was suitable for their current needs.

### 5.4.5. Symptoms of lung cancer

Another inductive theme to emerge from analysis of the qualitative data was that of symptoms of lung cancer. Effective diagnosis of lung cancer relies to a great extent on identifying symptoms. Unfortunately few patients will be or will remain asymptomatic through the cancer continuum. Across cases, every case presented with symptoms. Flo was the least symptomatic, with her cancer essentially found coincidently. That said, she was being treated for pneumonia and had been treated for recurrent chest infections, a common symptom of the disease.

Although all seven cases in this study presented with one or more cancer related symptoms (summarised in table 15) there was great variation in the time devoted to discussing these. One limitation of this study is that data collection commenced after the diagnosis was established. Therefore it cannot comment on clinical encounters where information on symptoms may have been discussed extensively, especially in the referral stage of the pathway, when it can be theorised that symptom related information would be exchanged more comprehensively.

**Table 15: Symptoms reported**

| | A | B | C | D | E | F | G |
|---|---|---|---|---|---|---|---|
| **Dyspnoea** | | ✓ | ✓ | ✓ | ✓ | | |
| **Pain** | | ✓ | ✓ | ✓ | ✓ | | ✓ |
| **Cough** | ✓ | | | ✓ | | | ✓ |
| **Weight loss** | | | ✓ | | | | ✓ |
| **Chest infection** | | | | ✓ | | ✓ | |
| **Anorexia** | | | ✓ | | | | ✓ |

Analysis showed that whereas study site B exchanged detailed information regarding stage of lung cancer, in all cases, little emphasis was placed on information exchange about symptoms. Eve and Flo had no symptom related conversations with the healthcare team. A potential reason for Study site A spending time in this type of information exchange, could relate to the fact that almost all the cases diagnosed had high symptom burden and treatment intent was palliative [aside from Alex who had only one symptom and a curative intent].

***So I was going to just have a chat to you first, just to find out how you, what your symptoms have been. So you had a sort of pleurisy type illness? And did you get pain and a cough with that? (Consultation/Dr Allan/Delia, Ref 2)***

Significantly Gordon, the youngest patient, with one of the highest symptom burdens across the cases, did not appear to have his symptoms discussed at either of the two clinical consultations. When exchange did take place it was at the instigation of Gordon's companion:

***He's been eating and sleeping less…but that's more about stress and there's the cough (Consultation/Dr Brown/Grace/Gordon, Ref 1)***

Without companion intervention these symptoms may not have been highlighted. Across cases this

appeared to be the trend. Accompanying companions were noted to intervene during exchanges about symptoms, often prompting patients or answering for them when questioned. In this way companions contributed to the clinical encounter either to provide information requested or at times investigate their own information agendas. For example:

***I think you've found that, haven't you…if you do too much… you get pain [Betty in response to Dr Andrews asking Ben about symptoms] (Consultation/Ben/Betty, Ref 1)***

This issue of companion agenda will be explored in more detail in chapter six. However, there were examples of their influence throughout all aspects of the information exchange encounters, for all *a priori* codes. This will continue to be considered as data analysis is examined.

## 5.5. Treatment related information analysis

The second *a priori* code relating to treatment was analysed. As with data related to diagnosis, analysis identified treatment data inductively and led to the classifications of treatment type and treatment side-effects.

**Table 16: Sub-codes for treatment**

| Key a priori code | Sub-code |
|---|---|
| | |
| **Treatment** | Treatment type |
| | Treatment related side-effects |

### 5.5.1. Treatment type analysis

For all cases, information about type of treatment was exchanged. Across cases, every medical professional exchanged information about treatment to a lesser or greater extent. When the CNS was

present at clinic they too exchanged treatment related information, but it was the medical staff who consistently gave more in-depth communication. For example:

***Small cell lung cancer is very difficult to treat, because sometimes, some of the cells, they are kind of immune to the chemotherapy and they kind of survive and then start up trouble at a later stage. So sometimes, although your chemotherapy is very successful, initially, you can have more trouble later on and that would require more treatment. And in order to reduce the chance of that happening we would like to combine radiotherapy and try to catch everything we know is there right now and use a double treatment, yeah? (Consultation/Dr Boyd/Eve Ref 28)***

The CNS built on the data given by their medical colleagues across cases, often supplementing biomedical information with practical advice. When chemotherapy was the modality of choice, only one of the physicians named the chemotherapy drugs they planned to prescribe (Dr Allan/Ben). In all other chemotherapy cases (for Cases A, B and E) this data was given by the clinical nurse specialist, who also gave thorough information about the actual regimen. For example:

***Now, we've got the information about the chemotherapy for you as per Dr Allan ok? Now this tells you about it. It's Vinoralbine and Cisplatin – so it's two drugs given together (Consultation/Sr Alcorn/Alex Ref 10)***

Each professional gave discrete amounts of detail when discussing this category. The observed routine of the clinics favoured an initial discussion from the respiratory physicians, leading to a more detailed exchange at the specialist oncology clinic. This observed practice was evident in all cases at study site A where Cases A to D were reviewed on the same day by both the respiratory and oncology consultant. For some cases the routine was made explicit, as could be seen in the following:

***But I'm hoping that Dr Allan, the cancer specialist from the cancer centre will be able to advise on some potentially quite good treatment, and I'm not the cancer specialist (yeah) – I'm not going to tell him his job, but I think it may well be he would want to use anti-cancer drugs called chemotherapy, first of all (Consultation/Dr Andrews/ Alex Ref 1)***

There was evidence that patients demarcated the roles and specialism of the healthcare teams. Two cases (Eve and Gordon) commented on the fact that information exchange regarding treatment evolved between the generalist and specialist clinic consultations. And as witnessed in the case of Eve the news moved from generally positive to negative:

***See when we spoke to Dr Boyd? Just, obviously he's no a cancer specialist, but he was saying that Dr Brown was, like the specialist, and she would explain it a lot better than, you know what I mean? So fae last week, everything is positive, like, do you know what I mean? There was good treatment then. But on Friday, it was eh… a bit of a shock, like, know what I mean? (In-depth interview/Eric, Eve's companion, Ref 7)***

There was one example where the generalist exchanged more information regarding diagnosis and treatment than the specialist did. The reasons for this could be multi-factorial and not necessarily relevant to the study but just reflected the information Dr Boyd exchanged at this particular consultation:

***So we, we're always talking about other treatments than surgery, and the treatments we are talking about would be chemotherapy and radiotherapy, and the question now is in what order, and what do we do first, and how much do we do of each? The idea is that we're giving you some chemotherapy upfront, and we'll give you a couple of cycles of chemotherapy and then do another scan and see what's now left for treatment. Because it may be that the area that we need to treat with the radiotherapy has shrunk considerably. We will also be able to see whether the small nodules that we looked at have changed or not (Consultation/Dr Boyd/ Gordon Ref 42)***

As with the category of diagnosis, this study lacks data regarding previous consultations held between the cases and their general physicians. It assumes that there may have been previous information exchanged on the subject of treatment. This is corroborated by the clinical nurse specialists in particular, who alluded to the fact they have spoken with the patients on many previous occasions at the generalist clinics:

***I think I did. I think coz I've had a couple of conversations with him before, with his results appointment, we'd kind of covered some things then (Consultation/Sr Alcorn/ Alex Ref 2)***

It is beyond the remit of this study to comment with any certainty on the reasons for the varying amounts of data from each healthcare professional and it could merely allude to their differing communicative styles, as well as clinical time commitment and clinic model.

When information exchange concerning treatment was taking place, patient involvement was varied. As expected, at consultations where professionals hold expert knowledge about therapy they, exchanged more information as patients and companions listened. Patient exchange ranged from declining to question (such as Ben summarised below) to frequently asking for information:

| | |
|---|---|
| ***Dr Andrews*** | ***Would it be helpful if I summarised things again?*** |
| ***Ben*** | ***Not really.*** |
| ***Dr Andrews:*** | ***Not really?*** |
| ***Ben*** | ***Because you've already told me everything that I need to know, doctor. I'm not being disrespectful, but you've already told me everything about it – there's really nothing more I can ask you without…without getting depressed (Consultation/Dr Andrews/Ben, Ref 15)*** |

Like Ben, Gordon and Flo participated very little in the treatment related exchange, whereas Delia and Eve asked some questions, although these were not consistent throughout the encounter. That said, Eve did seem to have a firm grasp of the CONVERT trial which she had been asked to consider and came to her second consultation having decided that she would start the trial. Not having full insight into the process of randomisation, she incorrectly decided which of the therapies she would take, only to be told that was not her decision as the trial was randomised:

***See this trial thing….to get the two treatments- the chemotherapy plus the radio….taking both at once. What I'd like to do is try the two at once the first time and if it's kinda heavy on me, just go back to daeing wan at a time. OK? (Consultation/Eve/ Dr Brown Ref 29)***

Delia had prior knowledge of lung cancer and chemotherapy, having nursed her mother in law with the same condition and this may have meant she already felt informed about treatment options. Of

all the cases, Alex engaged the most with his healthcare team when discussing his treatment. His questions ranged from length of inpatient stay, how many courses were required, to how the chemotherapy is given and finally what effect treatment would have on him between courses? His discussion may have been fuelled by his perceived lack of knowledge and apprehension regarding chemotherapy. Unlike Ben who stated that asking questions and having more information served to depress him, Alex believed that information relieved his anxiety and gave him hope:

***Now, that's fine. I've got everything I want to hear anyway Dr Allan. It's actually put my confidence right, the way it's always been (Consultation/Alex/ Dr Brown Ref 10)***

Across cases, Flo was the only patient referred for consideration of surgery. Unfortunately due to industrial action which forced clinic cancellations, her consultation with the surgeon was not recorded. However, her respiratory physician did exchange detailed and comprehensive information regarding the rationale and process involved in surgery. A detailed exchange was necessary as Flo's case was complex with lymph node involvement and may have required a one or two stop approach to surgery:

***So it could be a two-step approach or a one-step approach. What we want to avoid is surgery that is done for the wrong reasons and is basically not achieving its target, which is to cure you. Yeah, because that's a disaster, when you do surgery and you don't – you then find you have to close up again because it goes all wrong. Yeah, we don't want to do that, yeah. So we're doing all these tests to really make sure that we find the right patients for the surgeon, yeah? And we rule out those that aren't right for them beforehand, before they get on the table (Consultation/Dr Boyd/Flo, Ref 38)***

In three cases information was exchanged about entry into a national clinical trial. Cases C and D were given information concerning the FRAGMATIC study and Case E was considered for the CONVERT Trail. There was no data available to inform why Case A and G were not considered for trial entry. There were not trials open for consideration for Case B and F.

Despite the concern at having to undertake anticancer therapy, for some patients there was also relief that they were offered treatment. Some expressed the concern that there may have been no

treatment options available to them:

***So you're actually walking on cloud nine, coming out of there, because you're saying 'brilliant, I'm going to get treatment', instead of turning round and saying, 'there's nothing'. At the end of the day I'm happy I'm getting treatment (In-depth interview/Alex, Ref 15)***

Whereas others were glad that they were offered one type of treatment over another:

***No, well I was glad they didn't say chemo, right enough, I was glad. I'd have been bitterly disappointed, if they had said chemo. I felt ok about getting radiotherapy. I was actually delighted it was radio and not chemo (In-depth interview/Celia, Ref 23)***

When questioned immediately post consultation, all cases stated that they had exchanged the information that they wanted to in respect of treatment:

***Aye well, I know what's happening now. D'you know? I know what's going on now. Whereas, I know he told us some of it the last time, we know mair now (De-brief interview/Delia, Ref 14)***

Similarly de-brief interview analysis for the professionals showed that, all but one commented that they had exchanged the information which they wanted and had planned to with the patients during the consultation. For example:

***That was the main things I wanted to talk to them about, and then we've covered the issues that they were concerned about (Consultation/Sr Alcorn/ Celia, Ref 6)***

However, Dr Brown had concerns that her consultation with Eve was not conducive to adequate exchange of information regarding the planned chemotherapy treatment:

***No, I think what I wanted, what I normally have done also, is gone through the actual chemotherapy treatment. Sometimes I mention the drugs and explain to patients that it's given over 3 weeks and that they***

***receive 4 cycles. I didn't really get the opportunity to do that. Most of the consultation was dominated by the stress of her smoking and her family (Consultation/Dr Brown/Eve, Ref 8)***

As previously recorded, professionals and patients reported they had exchanged the treatment related information they wanted to or to a level that was satisfactory for them. Although for professionals their views were only elicited transiently at the de-brief interviews, nonetheless the immediacy and unsolicited nature of their opinions immediately post consultation, permitted important insight into their perception of the exchange. Aside from Dr Brown's consultation with Eve, all were by and large satisfied with the exchange. There were other unsolicited comments regarding companion involvement but this will be expanded in chapter 6. Where information was not exchanged in relation to treatment it usually took the form of:

- Naming the chemotherapy agents
- Introducing clinical trials
- Discussing adjuvant therapy

In relation to exchanging information regarding adjuvant therapy, professionals may conceivably have felt that it was too soon to enter into discussion on a second treatment when the response to the first was unknown. Initial tumour response to chemotherapy would dictate dose and ultimately outcome of radiotherapy and, at this time, that was an unknown quantity. An exception to this was when Dr Boyd did exchange information with Flo about the possibility of adjuvant chemotherapy post operatively. However, this exchange was not initiated by either the patient or the professional. Instead it was prompted by Flo's companion (her daughter Fiona) who was asking questions which appeared to be based on her own information needs agenda:

***And you don't think any chemo or radiation after it? But again it all depends on what there…? (Consultation/Fiona, Dr Boyd, Ref 9)***

Data analysis highlighted that across cases companions influenced information exchange relating to the main *a priori* categories. Their influence was witnessed in the majority of cases but to varying degrees, depending on the agenda that each companion appeared to have.

Whereas data showed the main therapy modalities were identified and categorised as chemotherapy, radiotherapy and surgery, there was no instance where *best supportive care* or *no treatment option* were included within therapy domains. It is logical that for these seven cases, with symptomatic disease and good performance status, all would be offered a therapeutic treatment option, to not only relieve symptoms but to confer survival benefit. Hence for these cases there was no rationale for best supportive care or no treatment.

Of relevance is that across all cases there appears to be a strong indication from patients that they wanted some type of therapy. In some cases patients stated that they were relieved to be offered treatment, with the concern being that there may have been no therapeutic option available for them. Throughout data collection there is no discussion with any case of a *no treatment option* or *active surveillance*, whereby their cancer is closely monitored but not actively treated. Indeed, there is no data from the analysis which identified any active exchange between patients and professionals regarding patient preference for a specific therapy. Data did not identify any instance of shared decision-making in relation to treatment modalities throughout this study. Professionals did not enquire about patient preference and patients did not volunteer their opinion.

### 5.5.2. Treatment related side-effect analysis

Treatment related side-effects vary considerably across the three therapies used to treat lung cancer. Across all cases there was evidence that information relating to treatment side-effects was exchanged. Consequently, as the proposed first line treatment for five of the cases was chemotherapy, the majority of the information exchanged concerning treatment related side-effects, focused on this modality. However, each professional discussed treatment related side-effects differently.

In some cases the information was superficial:

***It can cause a bit of tiredness, can affect your immunity, so you might be a bit more prone to infection. Sometimes this particular one can cause a bit of thinning to the hair, although it's not always a problem (Consultation/Dr Allan/Delia Ref 9)***

Contrastingly for other cases the exchange was fairly detailed:

***With the chemotherapy, the side-effects are based upon the fact that the chemotherapy works on fast-growing cells. So anything in your body that normally grows quite fast will be affected. That is your hair cells, so your hair might fall out; the lining of your gullet and your stomach and your bowel gets normally replenished quite quickly, so that may suffer and you may get nausea and vomiting and diarrhoea. And your bone marrow cells grow quite fast, so you may not be making as much blood as usually, and your immune cells may suffer and you may be open to infections, sometimes severe enough to go into hospital (Consultation/Dr Boyd/ Gordon Ref 19)***

In certain cases when discussing potential therapy related side-effects, the direction the exchange took and subsequent information exchange was influenced by questions from companions. For example:

***Colin:*** ***I know this is a naïve question, but if the radiotherapy can shrink the tumour to some extent, why can it not destroy it altogether? Is it because of the harsh side-effects?***

***Dr Allan:*** ***Well, no, it's a very good question. Sometimes we can destroy and get rid of tumours with radiotherapy. The difficulty with this one is, partly, it's a relatively large tumour and it's very close to the spinal cord which is the nerves going down the back, and we always have to take into …( Consultation/Dr Allan/ Celia/ Colin, Ref 4)***

There was no indication from the transcriptions that patients appeared upset or voiced any objection to the influence of their companions for this category.

There was some prior knowledge of anti-cancer therapies noted during data collection. Alex and Celia both had cancer previously and were aware of the side-effects of radiotherapy and chemotherapy respectively. As mentioned in the last section, Delia had nursed her mother in law who had lung cancer

and was treated with chemotherapy and radiotherapy.

It was never the intention of this study to explore prior insight and knowledge. However significantly, data analysis revealed that both patients and companions could be described as 'expert', with some cases displaying either previous experience or acquired knowledge of the disease and/or anti-cancer therapies. The relevance of 'expert' may have significance in relation to information exchange and will be considered in chapter 6.

Data showed that across cases patients varied, not only in their previous cancer and therapy knowledge but also in their desire to know about therapy side-effects. Of all cases, Ben exchanged the least information and asked very little in connection with treatment side-effects:

***Dr Allan*** ***So can you think, it's an awful lot of information about treatment and such – can you think of anything else you want to ask?***

***Ben:*** ***Not really. You've explained it wonderfully well. You've explained it wonderfully well.***
***Dr Allan:*** ***Mm hmm. So there will be leaflets you can have as well, that you can take away with you and read about it.***
***Ben:*** ***I think things like that will probably just depress me (Consultation/Ben/Dr Allan Ref 7)***

By contrast having information about potential side-effects had a positive effect in other cases:

***Aye I feel a lot better after that… Aye well I'm quite happy with what I've been told you know what I mean. And what's gonnae happen wie the treatment and what to expect in the way of side-effects (De-brief interview/Delia Ref 10)***

When the CNS was present they reinforced information exchanged between the patient and the doctor. In the majority of cases they offered written information about treatment and side-effects, in line with national guidelines (NICE, 2005):

***So I'll give you that to start off with. This wee booklet just gives you a bit of detail about the radiotherapy and some side-effects you might get. It's just so you can refer back to it, because you've had a lot of info today and it's hard to take it all in (Consultation/Sr Alcorn/Celia, Ref 4)***

All patients have access to the CNS throughout the cancer journey, with the CNS role viewed as pivotal in maintaining contact and support for patients and their companions. Therefore, these cases could have theoretically contacted the CNS at any time point for information regarding treatment related side-effects.

Throughout other periods of data collection treatment related side-effects were mentioned but not extensively. Nausea was the most common side-effect identified and one that certain cases expected to experience as a consequence of chemotherapy. Alec based his fear on prior knowledge:

***Well, actually, I'm a bit apprehensive about that, coz the people, from what I've seen, have been very sick (Consultation/Alex/Dr Allan Ref 1)***

Whereas Alex feared being sick, Eve took it for granted that she would be:

***Alright, so I'm gonna be sick. I'm gonna be very sick through it. Well, that's that (De-brief interview/Eve, Ref 1)***

For others, avoidance of the issue was the preferred stance:

***I didnae really want to ask any questions. I think I, I just wanted tae come in and get us on the first set of treatment and that kind of stuff, and that and then. Just get through it, do you know what I mean, and see what the next day brings, see how it makes me feel, do you know what I mean? (In-depth interview/Gordon, Ref 24)***

During the interview with Eve her companion (a second son Ewen, who was not present during her clinic consultations) raised his own concerns regarding short and longer term effects from chemo. These concerns appeared to be related to Ewen's information needs agenda and had not been raised by Eve or any other companion prior to the interview:

***Aye, I know. And that was another one, an aw. It said there, when I read it to you, see that one there – it said something aboot, some patients don't have any of the symptoms, nausea and feeling ill all the time, and some of them, you might be kind of a, and some people get bad. That wan said something about in your body, years later, you can get like growths and all that, or like lumps and that…tumours (In-depth interview/Ewen, Ref 17)***

Despite the forthright nature of his enquiry, linking chemotherapy effects to life threatening illness and to secondary cancers, there was no indication that Eve was unhappy with this type of information exchange.

The same qualification applies to information not exchanged in this category as that of the preceding categories. This study was a snapshot of only some consultations for these cases and can only comment on the data exchanged or not exchanged witnessed during these. When questioned professionals and patients stated they had exchanged treatment related side- effect information and to a level which was satisfactory for them. The exception was Dr Brown and the consultation with Eve and her companions, where companion information agenda was a significant and important influence on the information exchange. Instead of discussing chemotherapy and its potentially life changing/ life limiting side-effects, the opportunity for dialogue on this category was lost, as the companion agenda of smoking and treatment outcome took precedence. This is more appropriately discussed and analysed under treatment outcome in section 5.6.

## 5.6. Analysis of treatment outcome

The final *a priori* code identified was treatment outcome. Data demonstrated patients are individuals and the desire for this type of information by patients and their companions was as variable as the provision of it by healthcare professionals.

**Table 17: Sub-codes for treatment outcome**

| Key a priori code | Sub-code |
|---|---|
| | |
| **Treatment outcome** | Information exchange continuum |

Information exchange relating to outcome appeared to flow along a continuum. It varied from cases, who asked direct questions about treatment outcome (or their companions did), to others who commented it was something they could not or would not enquire about. In the continuum there were also cases that may have mentioned the issue but did not appear to focus one way or the other on the significance. There was also a noticeable distribution of information exchange regarding outcome from individual professionals. In some cases patients asked a very open and frank question:

***And what's the outlook in your opinion (Consultation/Flo/Dr Boyd, Ref 84)***

The clinician replied in an open and honest manner, providing a detailed amount of information. For example:

***If we do the operation and we take this bit of cancer out that we know is cancer and they take out all the other lymph glands when they do the operation and they check them, and there isn't any cancer in the lymph glands, then we would regard it as a curative operation. And the chances of being cured for lung cancer are then quite high. Yeah? (Consultation/Dr Boyd/Flo, Ref 85)***

Notably, Flo appeared engaged on this topic of information exchange. Later, during the in-depth interview, she commented that she never asked any questions of professionals in the past and on no occasion would she have used the word cancer:

***I would just, whatever he, whatever he told me, I would have accepted it and that was, I wouldnae have questioned it or asked or prodded into it or anything like that. I would just have went with the flow. I wouldnae***

***ask any questions. Never entered my head. Never entered my head…it was a word I would never use (In-depth interview/Flo, Ref 88 & 89)***

Contrary to her later stated opinion Flo was engaged on this category and appeared content with information provision by the clinician:

***And it wasnae, it wisnae bad, if you know what I mean, what he told me you know and, like, he gave me that wee bit of hope, do you know? Like maybe they've got it in time. You know, and you're gonna have a few years, you know and…? Well, I think, well I think he explained it quite well, really, you know? He didnae paint, you know, a garden. But no, I think, he didnae, he didnae frighten me either, sorta thing, like, you know? (In-depth interview/Flo, Ref 93)***

Gordon was equally to the point:

***How bad is it? (Consultation/Gordon/Dr Boyd, Ref 99)***

The information given in response to this question was fairly detailed and involved data about prognostic outlook and chance of cure:

***…..and it may be possible at that point to give you what's called radical radiotherapy, that's called high-dose, which has a better chance of keeping the disease at bay for longer. Yeah? And perhaps even curing it…But a cure is not guaranteed with what we're doing here..It's, you know, it's, it's a long shot, but we're trying. Yeah? So I think you're still in with a shout. I mean it's, but it's never 100 per cent, it's never 100 per cent guaranteed. For any treatment in this case, yeah (Consultation/Dr Boyd/ Gordon, Ref 100)***

By contrast Eve did not personally seek information regarding outcome. However, for her companions prognostic information seemed an important component of their information agenda, with their questions and exchanges influencing and controlling the content and direction of the consultation:

***She says the chances of curing you are very small. So it's pretty bad then? (Consultation/Eric/ Dr Brown, Ref 71)***

For Eric the importance of knowing treatment outcome was a significant consideration during exchanges and he re-iterated this during the in-depth interview:

***I think the only burning question any of us has got is 'time', innit? That's it (In-depth interview/Eric, Ref 83)***

Information exchange during the consultation with the oncologist, Dr Brown, was intense and entirely companion led at the start. There is no indication that Eve would have asked for this type of information. It was only after a long exchange about percentage survival between the oncologists and her companions did she ask:

***But there's nae chance of cure wae me, basically? (Consultation/Eve/ Dr Brown, Ref 73)***
***There is a chance, and that's why I'm recommending you have this treatment or them both together – it's to give you the best chance. But I don't know what your, I can't predict how you're going to react to this, and how your tumour is going to react to this. So we would have to wait and see, but it at least gives you some idea of what the chances are (Consultation/Dr Brown/ Eve, Ref 74)***

Case E demonstrated not only the changing emphasis, but also the impact of information given across consultations, by different professionals. The previous week Dr Boyd explained prognosis as such:

***Well, in a way, it's good news because you've got what we call limited stage disease, and there is, at least, a chance of curing you, although it's hard to achieve that in the longer term. But you're very likely to respond well to treatment, initially, and perhaps you won't need any further treatment after. That's what we're hoping for, yeah (Consultation/Dr Boyd/Eve, Ref 10)***

One week later the oncologists quoted:

***It's more a 20% chance of cure and 80% chance of not (Consultation/Dr Brown/Eve, Ref 71)***

For Eve and her companions this change was difficult to comprehend:

***So fae last week, everything is positive, like, do you know what I mean? There was good treatment then. But on Friday, it was eh… a bit of a shock, like, know what I mean? (In-depth interview/Eric/ Ref 78)***

In other cases (Celia and Delia) information appeared more subliminal, with no direct exchange of survival statistics but still reference to the incurable nature of the cancer:

***Oh, he can't cure it. But they say you may recommend radiotherapy and then I said 'is that not just prolonging the inevitable (Consultation/Celia/ Dr Brown, Ref 45)***

***As Dr Allan said, we can't get rid of it, we can't take it away, but we can shrink it down (Consultation/Dr Brown/ Celia, Ref 46)***

For Alex, who had a *potentially* curable cancer, data showed information was impacted by the ability to recall and understand the information. The following narratives show Alex's comprehension of the exchange. Dr Allan exchanged the following information:

***And he's explained to you that we feel it's not going to be possible to remove it all, but there are treatments that can help to shrink it. So there's no guarantees (Consultation/Dr Allan/ Alex, Ref 1)***

However, less than a week later Alex's recall of the information is different to that discussed:

***No, well that Dr Allan has gave me all the confidence when he said that – "once we shrink it". It's not a case of 'if', it was "once we shrink it down so far, then we'll concentrate and get the radiotherapy and try and get rid of it altogether" (In-depth interview/Alex, Ref 17)***

Analysis showed like Eve's companions, Alex's companion Agnes, appeared to have her own information needs agenda and this at times appeared to control the content and direction of information exchanges. Agnes asked clinical prognostic questions of the researcher, which at times Alex appeared uncomfortable with, especially in view of the positive perspective he had taken regarding his treatment outcome:

***Agnes:*** ***Now saying it's a slow growing one – a non-small cell, if the treatment shouldn't work, with it being a slow growing one, does that give you an specific length of time, if the treatment doesn't work (In-depth interview/Agnes/ Alex, Ref 23)***

***Alex: Ach well, it's just a case of waiting to see, that's all, nothing else for it (In-depth interview/ Alex, Ref 17)***

At the opposite end of the continuum was Ben. Contrasting to all other cases, Ben was not prepared to enter into exchange about treatment outcome. Neither he nor his companion Betty asked about treatment intent or survival. Betty was a registered nurse working in oncology and her knowledge and expertise may have negated the need to engage in discussions. Equally, she may have maintained the role of daughter and not nurse and deliberately decided to limit her contribution to only prompting Ben, allowing him to engage and exchange information for himself. Ben was informed that his disease was incurable:

***Now because of where it is, and it's quite stuck onto the lining of the lung, it can't be removed – but we…there are treatments that can help to shrink it a bit and firstly help to get it under control (Consultation/Dr Andrews/ Ben, Ref 27)***

Both professionals at the de-brief interviews commented Ben was not keen on exchanging information regarding his prognosis and they respected his wishes:

***He didn't want to talk about prognosis, so we didn't focus on that specifically (De-brief interview/Dr Allan, Ben, Ref 30)***

Across cases, Ben appeared to want the least information exchange, especially in relation to treatment outlook. Malignant pleural mesothelioma is a rare aggressive tumour, with very little prospect for cure and Ben often referred to his cancer as a living thing. For example:

***The thing wouldn't bother me, as long as I wasn't, the monster within wasn't just eating away at me and doing things it shouldn't be, I need to keep my other organs are kept away from it (In-depth interview/Ben, Ref 28)***

Ben declined Dr Andrews's invitation to discuss the diagnosis further. During the in-depth interview he was quite vociferous, stating his opinion that there was no point to asking questions about any aspect of his cancer, especially this feature:

***Well, I'm never going to ask them 'how long am I going to live'. I'm definitely not going to ask them that. I wouldn't put anyone in that position. I could be here in 10 years' time, I could be here in a year's time – I don't know. I don't want to know (In-depth interview/Ben, Ref 40)***

Specifically within this category there were polarised information exchanges shown across cases, with evidence that desire for outcome information was at times a companion and not patient agenda. Analysis identified companion role and influence was a central emerging theme throughout the information exchange process relating to all *a priori* codes, with a significant role identified in connection with treatment outcome in particular.

## 5.7. Summary of *a priori* coded qualitative data

The preceding sections of this chapter have presented the preliminary results of the data analysis and key findings have emerged, which will be summarised below. The intrinsic aim of the research was to explore information both exchanged and not exchanged between the cases, which essentially comprised the *a priori* codes of diagnosis, treatment and treatment outcome and the associated sub categories along the cancer care continuum.

From this analysis key findings have emerged:

### Diagnosis

- **Type of lung cancer**: all cases were made aware of a lung cancer or mesothelioma diagnosis. Although the histological cell type may not have been explained to patients, they did not appear to have any complaints about this aspect of information. Overall, both patients and professionals expressed the view that the information exchange process concerning diagnosis was conducted to a level at which they appeared content. A significant emerging influence on diagnostic information exchange was the role of the companion and the effect of their information agenda on the process.
- **Stage of lung cancer**: all cases were made aware of the cancer stage. The level of descriptive detail

given by professionals varied but on the whole, all cases stated the information exchanged regarding lung cancer stage suited their needs. Data emerged that, whereas patients may not always seek information regarding this category, it was frequently a companion who did.

- **Symptoms of lung cancer**: although all cases were symptomatic from their cancer, there was variation in the depth and amount of information exchanged on this category. However across cases, patients and professionals did not raise any concerns about the details of information for this category. Companions were again influential in guiding the content of the exchange, often answering for patients by prompting them, regarding their presenting or current symptoms.

**Treatment**:

- **Type:** across all cases information was exchanged relating to treatment type but to varying levels. Patient exchange differed depending on the amount of explanation each desired. Nonetheless, patients felt they gave and received the right treatment related information to suit their needs. A consideration influencing this category was companion information agenda, with notable inferences from professionals expressing concern that information exchange was greatly impacted by companion presence.
- **Treatment related side-effects**: similar to other *a priori* codes, information exchange concerning this category differed for all cases, with some patients being very involved in discussion and others preferring not to. That said, all cases stated they had the type and amount of information exchanged which suited their needs. Comparable with other categories, companion information agenda was evident during discussion concerning side–effects and influenced the content and direction of the exchange.

**Treatment outcome:**

This *a priori* code appeared to contrast with the others in some respects, perhaps due to the emotive nature surrounding prognostic information concerning one's own mortality, from patients as well as

professionals. Information exchange ranged from comprehensive to minimal, with professionals stating they followed patient agenda thus avoiding prognostic information disclosure (discussed in chapter 2). The variation in information exchange across cases can be attributed to the influence of both the patient and professional and to companion effect.

Across cases, data demonstrated that, from a patient and professional perspective, there was almost universal satisfaction with the level and content of information exchanged. Aside from one oncologist expressing the view that important elements of her exchange were not appropriately addressed, in all other cases, information appeared to be exchanged to a level which suited the information needs of the participants. Chapter seven will discuss these findings in greater detail.

However, a key finding which emerged was the influential role that companion presence exerted on both the content and direction of information during the consultation. Chapter six will examine the emergence and development of the theoretical proposition which arose from the substantive analysis of the *a priori* codes namely, companion influence.

# Chapter 6: Emergence of the theoretical proposition – companion influence

## 6.1. Introduction

A key component of healthcare delivery is the patient-healthcare professional encounter and the exchange of information which takes place therein. Information exchange accounts for a large percentage of time within the clinical consultation, at which patients with cancer, seek information about their diagnosis, treatment and prognosis (Epstein and Street, 2007). As such, my case study developed the original *a priori* codes around these three main constructs, in order to answer the research question. Yin (2009) stated that original theory development as part of the design phase is essential.

However, because the case study strategy used in my research is suited to exploration of issues in-depth and, following leads into new areas of innovative constructions of theory, the theoretical framework at the beginning was not the one that survived to the end (Hartley, 2004, p 328). Theory was emergent in that it was situated in and developed by recognising patterns of relationships among constructs within and across cases and their underlying logical arguments. There was no pre-determined theory underpinning the potential emergence of factors which might influence information exchange in the current study. Instead, the theory-building process occurred via recursive cycling among the case data, emerging theory and later extant literature (Eisenhardt and Graebner, 2007).

Traditional models of human interaction suggest that communication occurs on content [i.e. transfer of information] (Albrecht et al, 2009). The data from my study suggested that information content is important. Clinicians required contextual information from patients about past medical history, presenting symptoms as well as previous experience and current expectations to formulate a diagnosis and treatment plan. Likewise patients needed information regarding all available therapies, potential side-effects and expected outcomes to make informed choices.

Preliminary findings recognized the importance of the content of the information between patients and professionals. As summarised in section 5.4, analysis of the data demonstrated that across all seven cases, information exchange took place throughout all *a priori* codes (to a lesser or greater extent). Importantly, from both patient and professional perspectives, to a level which they felt suited their information exchange needs at the time. Furthermore, none of the participants expressed the opinion that they were given or gave too much or too little information during the consultations.

However, my research revealed a shift of focus. Whilst consideration of the content of the exchange was important, there appeared to be factors across cases which influenced how content was determined and ultimately, what form the information exchange process assumed. As this tentative theme began to emerge it was important to re-interrogate the literature, as the next step in iterative analysis is the constant comparison between the emerging data from the cases and the empirical literature (Yin, 2009).

The content of information is influenced by a number of practical and contextual factors. Challenges professionals confront interacting with patients at oncology consultations highlight potential influencing factors effecting information exchange, among them; lack of clinical time to deal effectively with communication issues (Spiece, Harkness, Laneri, Frankel, Roter and Kornblith, 2000), lack of specialist knowledge and training (Slort, Schweitzer, Blankstein, Abarshi et al, 2011), poor continuity of care from the healthcare team (Kendall, Boyd, Campbell, Cormie et al, 2006), use of medical terminology by health professionals (Gattellari et al, 2002) as well as employment of avoidance techniques by doctors and nurses (van Bruinessen, van Weel, van Gouw, Ziljlstra et al, 2013).

At patient level, a systematic review identified barriers and facilitators to effective information exchange between patients and general practitioners, ranging from patient characteristics such as

age, gender and medical condition to language and cultural factors (Slort et al, 2011). These specific demographic traits have been identified in other general oncology literature as having an impact on communication within the clinical consultation. Schilling, Scatena, Steiner, Albertson, Lin et al (2002) found that communication was not significantly impacted by patient gender but was related to age. Older patients with cancer are often more deferential to professionals and less likely to complain that their communication needs were unmet. Patient passivity and limited exchange of information has been identified as a cultural/racial trait, whereby doctors are perceived as less informative (Gordon, Street, Sharf and Souchek, 2006) and use less supportive communication when interacting with non-Caucasian patients (Street et al, 2005).

The literature examining the patient–professional communication interface is large, challenging to integrate, and of varying quality (Rodin et al, 2009). Overall, the evidence suggests the way in which a professional relates to and exchanges information with patients can be profoundly impacted by wide-ranging, external factors such as those previously mentioned (Edwards et al, 2009). It is beyond the scope of my research to investigate all the influencing factors impacting on information exchange, but my data demonstrated there were potential areas worth consideration.

Preliminary analysis from my study revealed that, across cases, a significant influence on information exchange at the clinical encounter was the presence of the patient companion. As overwhelmingly patients with cancer are accompanied to the clinical consultation by companions (Shepherd, Tattershall and Butow, 2008), their potential to influence the exchange, either in a facilitative or non-facilitative manner warrants further analysis. My research indicated that companions have the potential to add extraordinary dynamics to the clinical interaction and the reasons for this are myriad and will be discussed in more depth in the discussion chapter 8.

Examination of the contemporary literature on medical communication found that research has primarily focused on professional–patient exchanges, leaving the influence of companions relatively

unexplored (Arora, 2003). Despite this, a diverse, albeit disjointed research base has begun to highlight the potential role companions play during clinical consultations. The major problem with existing literature is there has been little synthesis of data in this area, potentially due to diverse disciplines investigating the subject matter (medicine, linguistics, sociology, psychology) as well as the range of consultations under investigation (care of the elderly medicine, primary care, diabetes) (Laidsaar-Powell, Butow, Bu, Charles, Gafni, Lam, Jansen et al, 2013). The current pool of literature informing companion influence in the cancer care context is small with only a few in-depth studies. None have focused specifically on the information exchange process or, more pertinently, have studied the influence of companions within the context of lung cancer care.

This paucity of data guiding companion role in relation to cancer communication was cited in the National Cancer Institute's Monograph (Epstein and Street, 2007). It concluded that, not only does cancer have a major impact on families, but companions play a crucial role in communication in cancer settings. Thus, the strength of findings from my study suggested that companion influence was a significant avenue of analysis to pursue and one which would offer a clear and original contribution to the literature.

My data showed that companions can have both a negative and positive impact on information exchange within the lung cancer consultation, often influencing the communication process. As there did not appear to be deficiencies or concerns with content level (either in relation to information exchanged or not exchanged) there needed to be analysis which could explore the data beyond information per se, analysing the factors which influenced and guided the content itself. The central design of my case study was to constantly compare theory and data – iterating towards a theoretical proposition drawn from and 'fitting' both. Eisenhardt (1989) commented that a 'close fit' is important to the development of a theoretical proposition, because it takes advantage of the new insights

emerging from the data and the literature, and yields an empirically valid theory. In the following section data analysis supporting companion influence as the theoretical proposition will be described.

## 6.2. Development of the theoretical proposition and construct refinement

The research questions explored information which was exchanged and information not exchanged during clinical encounters between professionals and patients (with or without companion accompaniment). As discussed in section 5.7, the data established that there were instances throughout the *a priori* codes where information was given across all categories analysed and others where certain information was not exchanged (for example in relation to cell type, disease stage and eliciting presenting symptoms). The professional-patient interaction is frequently situated in a triadic relationship consisting of the healthcare clinician, the patient and a third party, usually at least one key family member or companion (Tsai, 2007). Evidence from my study showed the presence of a third party/companion fundamentally influenced information exchange by impacting (either positively or negatively) on the complexity of the clinical encounter. It was this influence and the dynamics that were produced in terms of information exchange between the participants in the 'triad', which emerged as a theoretical proposition for consideration.

My data analysis led to the theoretical proposition of companions as a persuasive influence on information exchange. The substantive theoretical proposition was not specified at the beginning of my study but the theory emerged iteratively through discovery and manipulation of themes and categories, in an attempt to present a rational view of the phenomena and explain the relationships among the cases. Before this theoretical proposition could be used to augment the substantive analysis within and across cases, the theme of companion influence had to be described more inductively. A significant step in shaping the theoretical proposition is the sharpening or refinement of the codes, or constructs as Eisenhardt (1989) preferred to describe them. According to the work of Eisenhardt and Graebner, (2007) and Eisenhardt (1989) this a two part process involving:

1. Refining the definition of the constructs

2. Building evidence which measure the constructs in each case

## 6.3. Refining the definition of the constructs

### 6.3.1. Refining the concept of companion

Throughout this thesis companion has been used to describe the family member, relative or care-giver. A companion could be defined as any group of persons who are related biologically, emotionally or legally (Dokken and Ahmann, 2006). For the purpose of this study I broadly define companion as a person with a significant interest and role in the patient's life who were present during the consultation and/or de-brief and/or in-depth interviews. Table 18 summarises the companion combinations participating in the study.

**Table 18: Companion combinations**

| Cases | Consultation 1 | Consultation 2 | In-depth interview |
|---|---|---|---|
| | | | |
| **Alex** | Daughter - Ann | Daughter - Ann | Partner - Agnes |
| **Ben** | Daughter - Betty | Daughter - Betty | |
| **Celia** | Brother - Colin | Brother - Colin | |
| **Delia** | Husband - Davie<br>Daughter - Diane | Husband - Davie<br>Daughter - Diane | Husband - Davie |
| **Eve** | Son - Eric | Son - Eric<br>Daughter - Elaine | Son - Eric<br>Son - Ewen |
| **Flora** | Husband - Frank<br>Daughter - Fiona | | Husband - Frank |
| **Gordon** | Ex-wife Grace | Ex-wife - Grace | |

Within the oncology setting companions are likely to be present at initial visits when the diagnosis is being given and treatment options discussed, immediately after cancer recurrence and in the terminal phase of the disease (Jansen, van Weert, Wijngaards-de Meij, van Dulmen et al, 2010).

As discussed in chapter 3 there was a substantive amendment to the research proposal submitted to the Health Board Ethics Committee, allowing companions to consent to study participation. Original submission protocol was designed to capture the information exchange between patients with lung cancer and professionals alone. There was recognition that as patients are accompanied by companions to clinical consultations, their inclusion in the study was important to capture all data pertinent to each case (Street and Gordon, 2008; Ellingson, 2002).

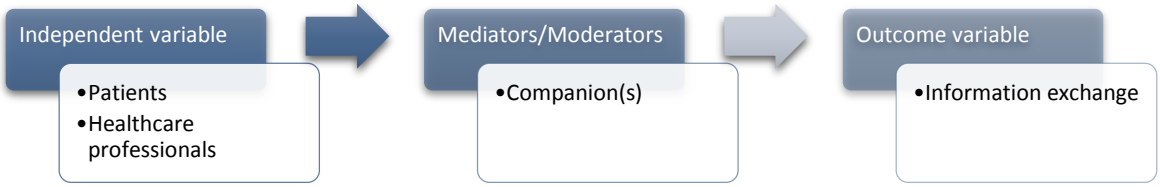
Accompanying companions are predominantly spouses, followed indeterminately by children, parents or siblings (Beisecker and Moore, 1994; Labreceque, Blanchard, Ruckdeschel and Blanchard, 1991; Adelman, Green and Charon, 1987). My data confirms the literature with companions comprising spouses/ex-spouse (cases D, F, G), children (cases A, B, D, E, F) with only Case C accompanied by a sibling.

### 6.3.2. Refining the constructs influenced by companions

The constructs of controlling influences impacting the communication pathway are central to The National Cancer Institute's Monograph: Patient-centred communication in cancer care: promoting healing and reducing suffering (Epstein and Street, 2007). The monograph was a critical synthesis of existing literature which focused on optimising communication processes between healthcare delivery teams, patients and companions (triads) and not solely the patient-physician dyad (Arora, 2003). In the monograph's section appraising communication pathways, of 197 studies referenced only 4 directly mentioned patients with lung cancer and none of these were germane to companion influence. Within the processes and pathways, from communication to health outcomes, the theme which underpinned the work was the influence of Mediators and Moderators. A mediator or a moderator is a third variable that changes the association between an independent variable and an outcome variable (Baron and Kenny, 1986). Analysis of mediator and moderator effects may provide

more in-depth information about a phenomenon under investigation, with consideration of these processes allowing a more precise description of the relationship between the variables (Bennett, 2000). This process can be identified for my data in the schematic below.

**Figure 9: Mediating and Moderating companion influence**




In the meta-synthesis describing mediators and moderators, an essential mediator within the communication pathway is family and social support, with companions providing instrumental help, encouragement and advocacy in gaining access to and effectively utilising health services (Epstein and Street, 2007). Companions are seen as mediators providing direct (when present with the professional) or indirect (when they suggest topics for the patient to discuss) input into clinical conversations to facilitate communication between patient and clinician (Shields, Epstein, Fischella, Franks, McCann, McCormick and Mallinger, 2005). Equally, companions (and the social environment) were also identified as essential moderators who served to operate at multiple levels, influencing the link between communication and health outcomes. Subsequently, the patient's social environment consisting of companions can both mediate and moderate the relationship between patient-professional communication outcomes (Epstein and Street, 2007).

It was not the intention of my study to investigate or measure health outcomes as a direct result of information exchange. What was evident in my data was that information exchange was more complex than merely negative and positive companion influences. In addition, the exchange was impacted across almost all cases and throughout all *a priori* codes and at times, entirely companion agenda led. A more in-depth analysis will be described in chapter 7.

The NCI monograph conceptualised the positive and negative influences on information exchange within cancer care communication, using the mechanisms of mediating and moderating concepts and these rich descriptors seem to have more resonance with my study data (Epstein and Street, 2007). Within my findings I considered that the analysis of mediating and moderating companion influences could elicit data about how the process of information exchange occurred and was realized. These particular conceptual codes could be used to facilitate substantive analysis as they allow a more precise description of the companion influence during the clinical encounter.

An essential feature of theory building and refinement is comparison of the emergent proposition with the extant literature. Therefore the empirical literature was again investigated utilising Epstein and Streets' themes of mediating and moderating influences on communication pathways and, information exchange as an initial theoretical framework to develop analytical codes encompassing companion influence, in order to further refine the data constructs. Before companion influence could be used to underpin the substantive analysis, the mediating (facilitating) and moderating (controlling) constructs had to be refined into a more coherent set of themes (Ryan and Bernard, 2003). As previously stated, an essential feature of theory building is comparison of the emergent constructs with extant literature (Eisenhardt, 1989).

A literature review was performed to identify analytical sub-constructs relating to companion influence. It was conducted using the databases EMBASE, MEDLINE, PubMed, Psych-INFO, CINAHL, SCOPUS and Cochrane Library. Clayman and Morris (2013) reported, despite the vast literature on patient-physician communication, examination reveals that companion role and influence has been sparsely studied. The intention of my review was to permit delineation of the companion role and any potential influence and was facilitated by two significant meta-analyses (Laidsaar-Powell et al, 2013; Wolff and Roter, 2011).

Wolff and Roter (2011) presented a meta-analytical review of family presence in routine medical visits. Theirs was the first review of studies investigating the dynamics and consequences of patient accompaniment. They reviewed quantitative information describing the medical visit interactions, illustrating attributes of accompanied versus unaccompanied patients, medical visit processes and outcomes. Electronic data bases PsychInfo and Pubmed were searched 1949-2009. In all, 17 studies were identified (10 observational and 7 surveys). Rationale for companion accompaniment was identified as both facilitating and controlling and is shown below. Participant perspective of companion role was also included in their analysis.

**Facilitating**

- Emotional: providing reassurance
- Informational: helping patient remember, assisting with recalling symptoms, prompting patient to speak and facilitate their questions, providing information to healthcare team (clarify patient history), helping patient to understand information and translation if necessary

**Controlling**

- Discouraging: controlling exchange
- Discussing own agenda

The systematic review conducted by Laidsaar-Powell et al (2013), essentially built upon the analysis by Wolff and Roter, but was more inclusive and not restricted to quantitative research. They explored physician - adult patient - adult companion (triadic) communication within medical encounters, searching PsycInfo, Medline, Cinahl, Embase and Scopus from 1950 to 2011. Literature synthesis resulted in 52 studies for inclusion. In agreement with Wolff and Roter they found that companions regularly attended consultations and assumed a variety of roles and influenced the encounter both in

a facilitating and controlling manner. In parallel to the previous review they reported that perspectives regarding companion accompaniment varied widely.

**Facilitating**

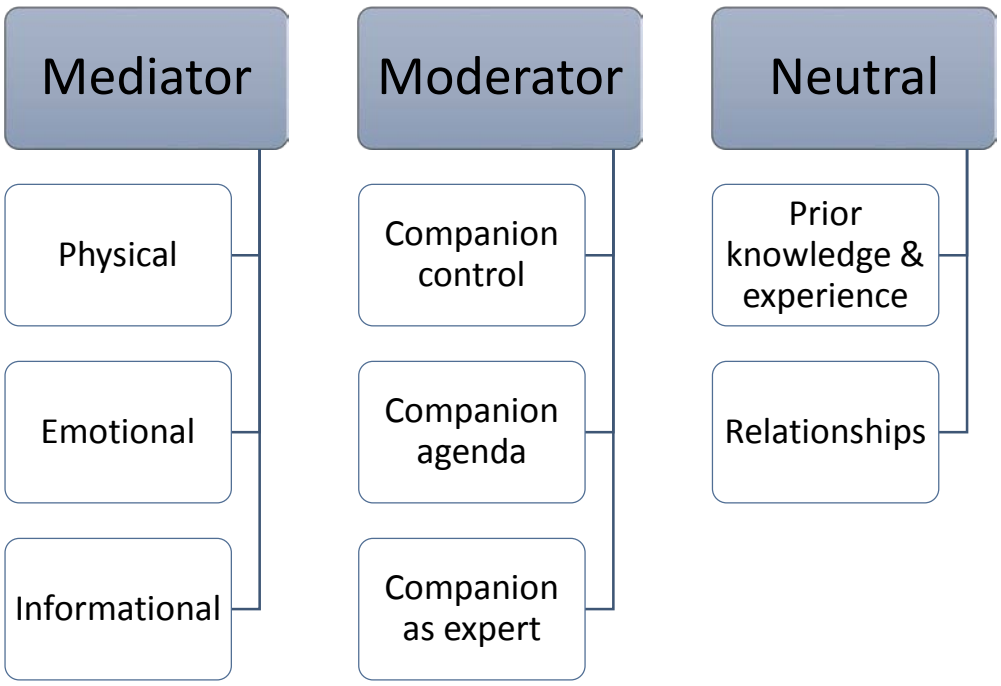
- Emotional: providing companionship and comfort
- Informational: clarifying patient history, remembering information, ensuring patient understanding
- Physical: transportation and physical assistance

**Controlling**

- Companion agenda: discussing own issues
- Companion control: dominating and controlling exchange

Based on the empirical literature in the meta-analyses, I theorised mediators and moderators could be refined into the sub-constructs shown in figure 10 and used to underpin the substantive theoretical proposition. Iterative analysis of my study data identified a further sub-construct (***companion as expert***) which was not revealed within the meta-analyses but which emerged as a significant theme for consideration. Equally, although not recognised within the current literature, my data identified a third construct NEUTRALITY – with two cases displaying neither a wholly mediating nor moderating influence on information exchange. However, as data outliers the construct warranted inclusion and the reasons for neutrality merited discussion.

**Figure 10: Substantive analysis constructs**




Epstein and Street's monograph provided a theoretical framework on which to base further analysis and on which to both:

1. refine the construct definitions

2. build evidence to measure the constructs of each case (Eisenhardt, 1989).

## 6.4. Summation

This analysis considered the theoretical proposition of companion influence as a mediating and moderating impact on information exchange. It recognised patterns of relationships among constructs with the opportunity to explore companion presence and influence at the clinical encounter within and across cases. The emerging theoretical proposition of companion influence as a mediator or moderator, in relation to information exchange within clearly defined constructs, will be the main focus of the substantive analysis explored in detail in chapter 7.

# Chapter 7: Substantive Analysis

## 7.1. Introduction: Substantive replication analysis

The following section will describe the substantive within and across case replication analysis. Companion influence will be demonstrated by describing constructs related to mediating and moderating effect. Additionally, as my study data identified, outlier cases showing neutrality as a third construct, will be described within the substantive analysis (summarised in table 19). Three case summaries will highlight companion influence for each construct. Participant perspective on companion presence was identified both in my data and the empirical literature and will be used to explore preference for involvement within and across cases. The section will conclude with a synthesis of the constructs, leading to the key findings of the substantive analysis. Participant narratives are highlighted with Nvivo 9® references (see section 3).

**Table 19: Mediating, moderating and neutral influences on information**

| Influences | Constructs | Actions | Cases |
|---|---|---|---|
| **Mediating (facilitative) influence** | Physical | Logistical – provides transport<br>Physical presence | C G<br>A B C D E F G |
| | Emotional | Provides reassurance<br>Seeks reassurance<br>Being supportive<br>Physical comfort | A B<br>D G<br>G<br>F (Frank only) |
| | Informational | Remembering/ Aid memoir<br>Clarification/seeking<br>Provides context | A B C D E F G<br>A C D E F G<br>A C D E G |
| | | | |
| **Moderating (controlling) influence** | Companion control | Answers for patient<br>Interrupts<br>Dismissive | C E F G<br>C E F<br>C F |
| | Companion agenda | Companion agenda setting | A C E F G |
| | Companion as expert | Healthcare profession education<br>Previous experience in cancer<br>Learned expertise | B C F<br>A D<br>E |
| | | | |
| **Neutral** | Prior knowledge & experience | | B D |
| | Relationships | | B D |
| | | | |

## 7.2. Mediating companion influence

Analysis of mediating influences focused on any aspects of companion involvement which might confer a facilitative or positive impact on information exchange, during the clinical encounter, and also to an extent during other periods of data collection (de-brief and in-depth interviews). For the three main constructs identified *physical, emotional and informational,* data suggests that within and

across all cases, companion mediating influences were witnessed to varying degrees and for divergent reasons (table 16).

### 7.2.1. Physical role and influence

Despite the majority of the patients having advanced cancer they were identified as good performance status (PS). Celia was classified as PS1 but all others were 0 which denoted them as fully independent. There were two cases where companions provided logical assistance in the form of transportation. Colin provided Celia with a means of getting to the consultation. Celia had attended her breast cancer consultations on her own, but was younger and fitter then. She now admitted that despite wanting to be unaccompanied, pragmatically she relied on Colin for assistance:

***I've got a walk. And the walk was telling on me, so it was, because my brother has got the car, he says, "I'll come and get you – it's no problem." (In-depth interview/Celia, Ref 1)***

However, for Gordon having Grace provide transportation was a significant issue as he commented that he felt able to drive himself but because of Grace's concerns about his physical health she refused to let him drive his own car. Although companion influence in Gordon's case correlates as a mediating influence, from Gordon's perspective it may easily be viewed as moderating as well, as Grace exerts her own agenda and control:

***Sometimes she nips my heid aboot it, know what I mean? "you're no driving". And I'm sitting there and I'm going, "Oh." You know, I've got a fifteen thousand pound motor sitting there and I cannae drive it (In-depth interview/ Gordon, Ref 7)***

There was very little evidence in my data to support that the presence of companions was influential in or required for active physical care needs, aside from the logistics of transportation. However, notably the data did show that, although not required for direct physical support, companion presence at the consultation could theoretically impact on the encounter. Universally across all cases

companions provided physical presence. In certain cases companion presence not only provided companionship but allowed patients to just listen during the exchange:

***For a start I didn't know what questions to ask you know? But eh, like through listening to them being there, through listening to them asking questions and then listening to the answers, I kinda found out more that way. If I had been on my own, I wouldnae have asked any questions (In-depth interview/Flo, Ref 2)***

### 7.2.2. Emotional influence

Data from the study shows that for some cases companion physical presence was closely associated to the emotional influence which they exerted. The companion's role in assisting patients to articulate their information needs, whilst expressing concern and offering reassurance and encouragement during the exchange of information was identified. Although not prevalent in all cases, there were instances where companion influence had a mediating effect on information exchange through their use of support and assurance; as witnessed in consultation between Dr Allan, Alex and Ann.

| | |
|---|---|
| ***Alex:*** | ***Aye, the radiotherapy. It's just the chemo…..I'm actually quite apprehensive about that coz the people from what I've seen have been very sick*** |
| ***Dr Allan:*** | ***Have they?*** |
| ***Ann:*** | ***Dad, I don't think Auntie Alice was too bad*** |
| ***Alex:*** | ***But she's still not recovered*** |
| ***Ann:*** | ***Her treatment was a lot longer and her symptoms were much worse*** |
| ***Alex:*** | ***Aye, you might be right…I might be strong enough….(Consultation/Alex, Ann, Dr Allan, Ref 11)*** |

Companions adopted a reassuring and supportive role, often in reply to concerns raised by patients and most times answered before the professionals had the opportunity to do so:

| | |
|---|---|
| ***Ben:*** | ***Wonder how that affects you, that.*** |
| ***Betty:*** | ***What?*** |
| ***Ben:*** | ***The vitamins and the injection.*** |

***Betty:*** ***The vitamins and the injection are just to build up your immune system to reduce the possibility of side-effects, and if you went in next week and hadn't had them, then you wouldn't get it. So we need to make sure that you get them, so you are prepared and strong.***

***Ben:*** ***Okay. Yeah. (Consultation/Ben, Betty, Dr Allan, Ref 6)***

Information exchanges within the lung cancer setting can be highly emotive and companions may be called upon to provide both physical comfort and verbal support in the form of reassurance and encouragement for the patient. Within my study there was no opportunity during the consultations for me to observe non-verbal behaviour of this nature, such as holding hands, embracing, offering tissues etc. Moreover, there was no robust evidence identified from the audio-recordings that patients required this level of support. The only case which became emotionally upsetting and interrupted data collection was Flo, where during the interview she became too upset to carry on and both Frank and I offered her physical contact and support. Prior to becoming upset, Flo and I were discussing her diagnosis and she offered that at times exchanging information about it was difficult:

***Flo:*** ***I know, I know, but it's just..it's…I think if I don't talk about it.. if I don't discuss it, then it isn't really happening… that I'll wake and they'll say 'we got it wrong…it's not cancer' (Flo, in-depth, Ref 10). HERE FLO BREAKS DOWN AND CRIES.***

***Frank:*** ***It's alright…you've been very good (In-depth interview/Frank, Flo, Ref 10)***

In three cases there was no evidence of any emotional influence, in the form of reassurance or supportive behaviours (Cases C and E and F). Interestingly, these were the companions who exerted a more moderating influence during information exchanges. Data identified that no emotionally supportive language was given to either Celia or Eve. Although Flo was given reassurance by her husband Frank during the in-depth interview, there was no evidence of this during the clinical consultations from her daughter Fiona.

Data indicated that female companions (daughters and partners) offered more supportive language or emotional input. This could be explained by the fact that proportionally, females were the

predominant accompanying companion (females, n=7; males n= 5). Likewise, although controversial, there may be an argument that female companions adopted a nurturing, caring role and were more suited to providing this type of reassuring and supportive communication in an emotive consultation. As there were such wide-ranging companion characteristics, each with the potential to impact on the relationship between patients and companions and ultimately the clinical encounter, there may be relevance investigating how these complex features interact.

### 7.2.3. Informational influence

Across the three major constructs, companions appeared to demonstrate informational influence most appreciably. As information is the basis for discussion regarding diagnosis and is important in exchanges concerning treatment decisions, it seems logical that companion influence within this construct was so significant. Within this construct, all cases were affected by companion informational influence which included remembering and clarifying/seeking information, both of which provided important contextual detail for the exchange.

#### 7.2.3.1. Remembering

In all cases companions influenced the exchange of information by acting as an aide memoire. They recalled medication use, symptom presentation and provided contextual information on health issues:

***Don't forget the anti-depressants (Consultation/Dr Brown, Eve and Eric, Ref 1)***

Likewise, companions contributed a mediating role by encouraging patients to speak about their symptoms, especially when patients themselves had not exchanged information on this theme. For example:

***But sorry, you did comment to me, when we were sitting outside, waiting, you did comment that you had, during the past week, you had just once coughed up some blood (Consultation/Dr Anderson/Celia/Colin, Ref 1)***

Instances were noted where companions volunteered pertinent information in response to questions from professionals and did so before patients could answer for themselves. In the example provided, although Grace's behaviour was mediating, there was also a suggestion of a slightly more moderating effect as well, demonstrated by her taking control of the exchange. Mediating and moderating influences during a single consultation were not uncommon:

| | |
|---|---|
| ***Dr Brown:*** | ***Okay. Good. And how are you in yourself?*** |
| ***Grace:*** | ***I think it's understandable...*** |
| ***Gordon:*** | ***What can I say?*** |
| ***Grace:*** | ***He's been eating, sleeping less the last few days.*** |
| ***Gordon:*** | ***Aye.*** |
| ***Grace:*** | ***That's more about stress than it is….and there's the coughing*** |
| | ***(Consultation/Dr Brown/Gordon/Grace, Ref 1)*** |

Analysis using original *a priori* qualitative data demonstrated that companions, more than patients, prompted information exchange about symptoms. Patients may be reluctant to discuss symptoms for fear that professionals perceive their disease too advanced for treatment. Analysis showed that companions also corroborated in a symptom minimising behaviour. They provided what they thought was positive context by offering explanation to justify or even diminish the impact that symptoms had on the everyday lives of the patient. The link between symptoms, within the context of daily activities and social situation, seemed germane across cases and was evident in Davie describing Delia's physical health and ability to carry on as normal:

***No, no. As she said doctor, she no in any pain, you know. She's still going aboot doing her day to day activities. She's still walking doon to the nursery to get the grandson. It's no actually hindered you has it? (Consultation/Davie/Dr Allan, Ref 9)***

In contrast, in Case C, contextual information regarding symptoms was discussed with the aim of escalating the degree of symptoms endured, in order to influence management. Although information was provided in two distinct ways, both were still mediating behaviours designed by companions to

influence the dialogue on symptom management. Colin appeared determined to convey this information as he did so one more than one occasion:

***Colin:*** ***I do think Celia is much more breathless than even just a few weeks ago. Is oxygen a consideration? (Consultation/Colin/Celia/Dr Anderson, Ref 1)***

***And***

***Colin:*** ***This is the problem, the stairs and her breathing. Celia would need carrying up all those stairs in one of the wee chairs; she's just too breathless now to manage on her own (Consultation/Colin/Celia/Dr Allan, Ref 3)***

Symptom information is essential to inform diagnosis, symptom control and dictate treatment planning. Chapter five discussed information relating to symptoms and highlighted that information on this specific code was not well exchanged during this study. This study was a 'snap shot' of the patient care pathway and symptoms may have been discussed in more depth when patients first presented to the team at the referral stage.

**7.2.3.2. Clarifying/seeking information**

The majority of companions engaged in question asking behaviour for this construct with only Cases B and D not engaging in this type of activity. The reasons for this neutrality will be discussed later. Within this construct, companions demonstrated various mediating influences. They supplied additional information regarding comorbidities and past illnesses and contributed important information to the exchange. Data suggested that when companions clarified information on past medical history, they alerted medical staff to previous ill health and treatments which had the potential to impact on current therapies:

***Dr Anderson:*** ***Radiotherapy, which is strong x-rays shone at the local area – that's done at the cancer centre***

***Ann:*** ***He's had that before***

***Dr Anderson:*** ***Oh yeah, that's right – was it for the prostate?***

***Alex:*** ***Yeah, my prostate***

***Dr Anderson:*** ***And that brings to mind the prostate business…but it does sounds to me as if this stuff is for radiation proctitis (Consultation/Dr Anderson/Alex/Ann, Ref 5)***

There were also instances across cases where companions advocated for patients, asking treatment related questions with the aim of facilitating patient understanding:

***So – I know you're talking aboot the mediastinoscopy – can he no just do them both? Like the, would it be a VATS procedure, would you do the video-assisted thoracotomy or would you do...? (Consultation/Fiona/Flo/Dr Boyd, Ref 1)***

However, for some, the incentive may have been to gain greater personal understanding of the situation. Ann revisited her questions regarding radiotherapy for Alex on a number of occasions seeking clarity perhaps more for her own information agenda than his, for example:

***Will he definitely need radiotherapy? (Consultation/Dr Allan/Alex/Ann, Ref 7)***

Ann's need for clarity may have been coupled with her understanding and expectation of treatment. She commented during the de-brief interview that she hoped treatment would have been a single therapy:

***At the start, though, I thought, with Dr Allan, when he was talking about the treatment, I thought he might just get away with the chemo – but I realise, now, that you're going to have to get both of them (De-brief interview/Ann, Ref 2)***

During this dialogue Alex did not contribute to the process but data demonstrated he appeared satisfied with the content of the information exchange:

***No, that's fine cos I've got everything I want to hear and it's actually put my confidence right the way it always has been, you know what I mean? (Consultation/Alex/Dr Allan, Ref 10)***

Across cases there was evidence that companions influenced the mediating constructs in diverse ways. For the majority of cases there was no data indicating that patients had a negative perspective on this mediating influence. The next section will explore perception of companion involvement in more depth.

#### 7.2.3.3. Perception of companion accompaniment – mediating influence

Significantly data analysis illustrated that although patients appreciated companion accompaniment and involvement, in some cases the actual preference of the patient would have been to be unaccompanied. A key finding in this study indicated that companion accompaniment to the clinic consultation was often a negotiated process, with three levels of negotiated entry. Accompaniment was shown to have been:

- Never negotiated: a mutual understanding without discussion where companion accompaniment was taken as an absolute from either party
- Partial negotiation/negotiated coercion: a negotiated discussion between patient and companions where companion petition prevailed
- Non-negotiable: where companions did not broker discussion or consent of patient

In Case D, Davie and Delia never discussed Davie or Diana's presence at the clinic. Theirs was a mutual understanding that companions would be present:

***No, no, no I woulda wanted them there beside me. And if it had been Davie, the only…if it had been him that was in..he would have wanted me and my daughter there. Know what I mean like (In-depth interview/Delia, Ref 11)***

In other cases, although it was thought that accompaniment was mutually agreed, there was a degree of negotiated coercion by companions:

***Well, when I told her, she [Grace] was one of the first ones I told, do you know what I mean. And eh… no, it wasnae a conscious thing, know what I mean? When I says to her, and she says, "right, I'll just come up to the hospital with you. I'll dae this wi' you. I'll dae that wi' you," and that kind of stuff, know what I mean? And that was it, know what I mean? (In-depth interview/Gordon, Ref 1)***

This narrative seemed to imply that Grace did not broker any discussion when she insisted "***I'll dae this wi' you. I'll dae that wi' you,"***

Celia's reason for accompaniment did have a strong logistical component. However, data analysis showed she would have happily attended the consultations unaccompanied had Colin not been fairly insistent about transport and entered into negotiation with her. Alex had also previously attended his prostate oncology appointments unaccompanied and was keen to do so for his current diagnosis. In Alex's case, analysis showed that in an attempt to shield his companions from the severity of the disease, he would have attended on his own. However when they found out they entered into negotiation, with Alex finally agreeing to let them be present:

***Plus the fact, I think the reason why my daughter's coming up a lot now, I don't tell them everything. I keep a lot to myself. It's the same when I was first thingmied with prostate – I tried my best not to tell them, but when we heard it was… how bad it was, then they had to know, coz you don't know the outcome of it by that time. And coz she wanted to come now, coz of the difference in it, that's how (In-depth interview/Alex, Ref 2)***

Another negotiated case was Ben. He would have been unaccompanied, however at his family's insistence; he acquiesced, albeit it appeared under some duress:

***Aye, I'd probably have broke it to them in my own way, coz they would have eventually found out with me having to go to the, obviously down to the cancer centre and that, my daughter works there, you know? She'd have found out. But the first day that Dr Anderson told me in that old place, broke her heart, and I didn't think it was fair on her, you know? I said, "I told you not to come with me and you did, so what can you do? (In-depth interview/Ben, Ref 4)***

The remaining Cases E and F were non-negotiated. Companions were insistent on Eve and Flo being accompanied:

***We wouldnae let her go up hersel', coz she would come back and tell us a bunch of lies (In-depth interview/Eric, Ref 10)***

Another crucial finding to emerge from the data identified that the level of negotiated accompaniment appeared to be associated with companion moderating influence on information exchange. This feature will be discussed in more detail in chapter 8.

**7.2.3.4. Mediating construct summation**

In conclusion, there were examples in every case where companions exerted a mediating influence on information exchange. Data demonstrated that mediating influences were identified across three constructs, *physical, emotional and informational.* However, companion mediating effect was not consistent across themes and ranged from limited to enhanced influence. Informational influence was the most significant construct identified. Companions exerted positive influence acting as an aide memoire and also within the role of clarification and information seeking.

The study indicated that there was a diverse mix of companion characteristics [gender, personality traits and past experiences], as well as relationship types, within and across cases. Explaining the demographic variables of companions was not a requisite of this study. However, evidence emerged that such features may, in fact, impact on the inter-connectedness of information exchange and patients and companion preference for accompaniment. As such this again was a consideration worthy of exploration, especially in light of emerging data, demonstrating that the negotiated involvement of companions could theoretically influence the constructs identified. Importantly, from a patient perspective, companion presence and involvement was appreciated in the majority of cases, particularly in relation to informational constructs.

In one case, Ann, all three mediating constructs were in evidence during the clinical encounter and these are summarised in the case summary below.

**Case summary 1: Mediating companion influence**

**COMPANION CASE SUMMARY: ANN**

Alex was a 71 year old man diagnosed with T4 N0 non-small cell lung cancer. He originally presented to his general practitioner with a persistent cough. Despite a history of prostatic cancer for which he had radical radiotherapy, he was well with a performance status of 0. He was an ex-smoker, having stopped 10 years ago. Alex left school with secondary education qualifications and worked as caulker-burner in the construction industry before he retired due to a back injury. Widowed, he lived in an inner-city area of a large urban city. Primary treatment was chemotherapy, followed by adjuvant radiotherapy if the cancer responded. Treatment intent was considered curative. He attended Study site A with his daughter Ann and together they had consultations with a respiratory physician (Dr Andrews), a clinical oncologist (Dr Allan) and the Clinical Nurse Specialist (Sr Alcorn). This was the second out-patient appointment Ann had attended. Ann was present only during the clinical encounters and not at the in-depth interview. Ann was between 35-45 yrs old, married and had school age children. She lived close to Alex. Her mother died of metastatic breast cancer.

Initially in this case the companion role was minimal and very little mediating influence was apparent during the first clinical encounter with Dr Anderson. The only mediating construct which was identified was emotional, whereby Ann attempted to encourage Alex to see that chemotherapy was not necessarily as negative a treatment as he envisioned (Ref 1). This was Ann's only contribution throughout the encounter. However, at the second consultation with the clinical oncologist, there was data to suggest that Ann was more involved and active within the exchanges. Her main role firstly was that of aide memoire prompting Alex with medication use (Ref 3, 16). Her influence then extended once again into emotional constructs where she urged Alex not to compare his present situation with that of family members who had undergone anticancer treatment (Ref 9). Ann employed reassurance and encouragement as a mediating influence to support Alex with treatment decisions. Additionally, she influenced the exchange by providing information regarding past medical history, important for healthcare professionals for verifying facts which might be relevant to current therapies (Ref, 11). Extending her role Ann's influence moved to the dual constructs of clarification and information seeking, whereby through a sequence of questions she sought to gain a better understanding of the proposed treatment (Ref 3, 4, 5). Ann's motivation for her informational influence appeared twofold - for clarification and reassurance for Alex and primarily for her own understanding. Throughout all exchanges with the professionals, Ann used supportive and affirmative language in an effort to encourage and comfort Alex during the consultations, referring to both his positive attitude and his general physical fitness (Ref 6, 10, 11, 13). There was no data to suggest that Ann had a moderating influence on information exchange during the consultations and the de-brief interview. Likewise there was no evidence that Ann was following her own agenda to the detriment of Alex's information needs. There is no data found to show that Alex was unhappy with any aspect of Ann's involvement during the encounter. Indeed her influence was viewed as mediating and positive for him, in that the conversation between Ann and the oncologist looked to give him confidence and support his decision to undergo therapy (Ref 10). Overall, despite Alex expressing concern regarding companion accompaniment (he feared Ann would be burdened and upset by the diagnosis [Ref 3]), and companion presence being negotiated in this case, her presence served as a positive and mediating influence in general.

## 7.3. Moderating companion influence

Analysis of moderating influences focused on any aspects of companion influence which might impact information exchange in a controlling or non-facilitative manner, throughout any encounters where communication took place between the participants. The main constructs identified with regards to moderating influence were *companion control, companion agenda and companion as expert.* As with

mediating influence, companions were shown to influence information exchange to different extents across these constructs and for diverse reasons. These will be considered in this section and are summarised in table 16.

### 7.3.1. Companion control

Companions were seen to exercise control over the exchange of information in various ways, but predominantly by answering patient intended questions and through interruption. Although the majority of cases (five overall) exhibited this behaviour, some companions did so consistently throughout all encounters with various healthcare professionals, as witnessed in Celia's case with her sibling Colin, whereby he frequently controlled the information exchange and Celia's answers:

***Dr Allan:*** ***Is there anything else you think we haven't talked about that you wanted to ask about, or anything you haven't remembered?***

***Colin:*** ***No, you spoke to Dr Anderson and the, your about your analgesics to your painkiller (Consultation/Dr Allan/Celia/Colin, Ref 14)***

Despite this behaviour being evident, there was no evidence to suggest that Celia was upset by it. Throughout the exchanges she only ever interjected once to correct his answer:

***Researcher:*** ***Did you speak about your treatment?***

***Colin:*** ***Ten treatments, yeah.***

***Celia:*** ***Twelve treatments.***

***Colin:*** ***Oh, I beg your pardon, aye, twelve, twelve (De-brief interview/Celia, Colin, Ref 17)***

Data revealed that companions moderated information exchange and applied control to varying degrees. In the most moderating cases (C, E and F) companion control was exhibited throughout the clinical consultation or period of data collection. Fiona's controlling influence was shown in her tendency to interrupt and control the content and flow of information in this manner, regardless of the clinical encounter:

***Flo:*** ***I'm just doing my normal day, I don't feel sick. I've had my down days as well, when you….***

***Researcher:*** ***Yeah of course, can you say more about this***

***Interrupted by Fiona***

***Fiona:*** ***But we're going home now and Dad's got two sisters, so there you go, you're gonna get nae sympathy! (De-brief interview/Flo/Fiona, Ref 1)***

Additionally Fiona was seen at times to undermine Flo and her replies suggested a dismissive tone:

***Flo:*** ***It'd be better if they just say, "right, I'm gonnae bring you in tomorrow and do it." Not to give me time to think about it, if you know what I mean?***

***Researcher*** ***yes I……***

***Interrupted by Fiona***

***Fiona:*** ***You've had enough time to think aboot it! (De-brief/Researcher/Flo/Fiona, Ref 5)***

In my study, companion controlling influence which directed information exchanges was subject to variability and occurred for different reasons. It could theoretically be linked to many variables both of the companion and the patient. As with mediating influences, companions could essentially be moderating information to ensure that patient care was not compromised.

Key characteristics impacting control of the informational process could theoretically be companion personality type, as well as relational aspects between patients and companions. An exemplar is Colin, a retired paramedic and the younger, often vocal brother of Celia, attempting to make sure his elderly frail sister received the best possible treatment. Likewise, Fiona a registered nurse who had experience in dealing with healthcare teams was outspoken and strong-willed, advocated for her mother Flo, who by her own admission never usually asked questions and preferred to leave treatment decisions to the medical team.

A significant finding in the data was that the moderating constructs appeared to be closely associated; with companion control interconnected to companion agenda, which in turn was linked to companion as expert.

### 7.3.2. Companion agenda

In the cases where companions used controlling behaviour to moderate information exchange, they regulated the clinical content of the exchange by addressing their own information agenda. In certain cases there was evidence that companions raised concerns and discussed topics which appeared to satisfy their own communication and information needs. Such agenda setting was evident throughout the clinical consultations and in one Case (A) also present during the in-depth interviews. The data also illustrated that in some cases the companion recognised they were addressing their own agenda:

***And we needed to talk, and because we have both got perhaps a different take on, on it...now we can kinda, I don't know, clear things up with the others (Consultation/Dr Boyd/Grace/Gordon Ref 2)***

Despite this being Grace's agenda there was evidence in her narratives that she felt she was raising this agenda for Gordon. However, there did not appear to be any concern for patient autonomy and self-determination:

***No, because if you don't hear it, you're gonnae do it, and I'm not gonnae know, so that's why I thought, I'm gonnae have to. I've got a wee checklist of questions, and they're all about things I know you're gonnae do! And that was the major one, because I know what you're like…( Consultation/Dr Brown/Grace/Gordon, Ref 4)***

In case A, Agnes was present at the in-depth interview but absent from the consultation. Data demonstrated Agnes had her own information needs agenda and this was manifest by the clinically related questions she asked of the researcher, which she did not have the opportunity to do previously. Agnes was fully aware of my clinical role of nurse specialist and attempted to capitalise on this with numerous questions:

***Well, it's only sort of, like, ninety, ninety percent don't survive it, isn't it? I mean, that's the sort of ratio, isn't it? (In-depth interview/Agnes/Alex, Ref 11)***

Whereas the data reflected that Gordon never appeared disgruntled with Grace's moderating influence, in case A there is evidence that Agnes's direct line of questioning regarding treatment outcome and prognosis appeared to make Alex uncomfortable:

| | |
|---|---|
| ***Agnes:*** | ***Now, after the second radiothera…, eh, chemotherapy, if it hasn't shrunk, is there any other type of chemotherapy that he can get that would be a different kind of treatment?*** |
| ***Researcher:*** | ***It's difficult for me to say, because I don't work for Dr Allan.*** |
| ***Agnes:*** | ***No, uh huh..*** |
| ***Alex:*** | ***That's right – see, that's how I says to you, it's getting over the first one and moving on from there. That's the best thing. A lot depends on how much it shrinks (In-depth interview/Alex/Agnes, Ref 16)*** |

It is unknown if Agnes would have exchanged this type of information had she been present at the clinic. However, had she done so the content and direction of the information exchange within the consultation for Case A would have certainly altered, as there had been no prognostic information exchanged. The evidence demonstrated Agnes's agenda appeared essentially to satisfy her own need for information around this theme. It did not appear to be a protective mechanism borne of the need to facilitate information exchange regarding prognosis for Alex, because as the narrative above highlighted, he was uncomfortable with the content of the discussion.

The previous section described the controlling influence that Colin showed towards Celia, where he moderated the exchange with his own predetermined information agenda. It could be argued his control and agenda setting was a protective mechanism designed to shield Celia from the difficulties of cancer and its therapy. Equally there is evidence he may have sought to control and influence certain aspects of her care. An example of this control was witnessed when Celia was introduced to

the clinical trials co-ordinator, who gave her Patient Information Sheets to consider for a national trial. Colin took this information with the intention of reading it for Celia:

***Colin:*** ***Och, a lot of this is just, you know, it's information sheets – it's just to give you an idea of what it's about. But it's just confirming what they've already told you, that's all. It's just to see if… It's just to tell you what it is. Honestly, I'll take these papers home, have a wee look through them – there's no point in you having more paperwork than you need. Yeah, it's just information. There's nothing that has to be filled out. I'll just hang on to that for you. If you particularly want to look at them, then I'll…(Consultation/Dr Allan/Celia/Colin, Ref 11)***

Later, Colin attempted to control and limit researcher access to Celia for the in-depth interview. Conceivably his actions may have been protective and an attempt to reduce any stress he perceived from too much intervention. However conversely this action could have theoretically also impacted Celia's autonomy and decision making as well as her ability to set her own agenda:

***Researcher:*** ***What I was going to do is, perhaps, give you a call in the next day or two…***

***Celia:*** ***That's fine, uh huh.***

***Colin:*** ***Well, if you're alright with that?***

***Celia:*** ***Aye.***

***Colin:*** ***Well I hope that's, bearing in mind Celia was actually saying that she's desperate to get time to herself. She's had an awful lot of visitors and an awful lot of phone calls, and I know people mean well – she's finding it overwhelming and she went out yesterday and got the bus into town just to escape. She talks about, it's interesting terminology – she uses terms like, "to escape, I got the bus into town to escape." So she wants to escape from the house. Why don't you leave it until next week? (De-brief interview/Celia/Colin, Ref 3-6)***

Corresponding with Case G, the data did not provide evidence that in either case the patients had a negative view of their companion's moderating influence. On the contrary, Celia's narrative praised her brothers (Colin's twin often accompanied her as well) and their input, despite earlier suggestions that she would have happily been unaccompanied:

***Celia:*** ***I'm quite happy for my brothers to be there. We're quite a close family. They've got kind of experience of nursing, the ambulance side of it, you know? (In-depth interview/Celia, Ref 17)***

My data revealed that companion agenda can exert a significant moderating influence both on the content and direction of information. In addition, it showed that a predetermined companion agenda can moderate the direction and content of the exchange and lead to a totally different discussion. In the example highlighted below - Eric and Elaine's concerns regarding Eve's smoking led to an exchange about prognosis. During the clinical encounter the exchange was animated and could have been exacerbated by the family discussing this agenda prior to the consultation and their very differing views regarding smoking:

***Eric:*** ***The doctor said last week – the smoking has got to stop, and it's got to stop now because…***
***Eve:*** ***Easier said than done.***
***Eric:*** ***……of the treatment (Consultation/Dr Brown/Eve/Eric, Ref 4)***

***And***

***Dr Brown:*** ***Ok, right. Hmm. Ok, good. Right, so I think, I understand that you've probably been lectured about the smoking. He's right, yeah. The side-effects will be much worse.***
***Eric:*** ***Yeah, as soon as the treatment starts the smoking has to stop…***
***Dr Brown:*** ***And the chances of curing you will be cut. The chance of curing you is very small, but you're going to make it very, very small. So I don't want to lecture you, but I just want to confirm what Dr Boyd said (Consultation/Dr Brown/Eve/Eric, Ref 6)***

Dr Brown introduced the theme of treatment side-effects and outcome to highlight that smoking cessation will impact positively on both these aspects of therapy. However, this served to lead the companions to another agenda, which Eve had not noticed:

***Eric:*** ***She says there that 'the chances of curing you are small'.***
***Elaine:*** ***So it's pretty bad, then?***
***Dr Brown:*** ***Em… In what sense is that?***

***Elaine:*** ***You've just said there, the chances of curing her are small but the chances of curing her if she's smoking is even smaller.***

***Dr Brown:*** ***Yes, so the chance of, I mean, what do you think the chances of cure are for this?***

***Elaine:*** ***We're hoping that it's a good percentage.***

***Dr Brown:*** ***What would you think is a good percentage?***

***Elaine:*** ***I don't know. 80/20.***

***Dr Brown:*** ***(Laughing.) No.***

***Elaine:*** ***No, 50/50?***

***Dr Brown:*** ***It's more 20% chance of cure and 80% chance not.***

***Eve:*** ***So, you mean that's whether I smoke or whether I don't smoke?***

***Dr Brown:*** ***No, if you smoke it will be a lot less than that.***

***Eric:*** ***So you've got to stop smoking to gie yourself the best chance (Consultation/Dr Brown/Eve/Eric Ref 7)***

This case appears to highlight the complex narrative that develops during exchanges of information between patient and clinician, when the content and direction of information is impacted by the influence of other participants, namely Eve's children. The exchange began as a discussion on smoking and therapy outcome, and despite Dr Brown providing data that the chance of cure were small and continuation of smoking would lessen the chance further, Eve either never heard this crucial piece of information, or she knowingly chose not to pursue this line of information directly. If the latter proposition was evident, then Eve and Dr Brown could be determined to be complicit in their collusion where neither of them pursued communication regarding the often difficult subject of prognostic outcome. Collusion relating to prognostic information was evident elsewhere.

In Case B, Ben was reluctant to exchange information about several aspects of his management, particularly outcome, during his clinical encounters:

***Well, I'm never going to ask 'how long am I going to live'. No, no, no….I wouldn't annoy anybody with questions like that. I don't see a point to it (Consultation/Dr Anderson/Ben/Ref 3)***

Moreover, both clinicians where complicit in the collusion actively avoiding prognostic information exchange, with both offering justification for this stance, based on ideals of following patient agenda and being respectful of patient-centred care:

***So that's…he's very, he's very down to earth. He didn't want to discuss the prognosis and he really didn't want to go over things again. So I was led by his agenda (De-brief interview/Dr Anderson/Ben/Ref 1)***

***Yes, I mean from previous discussions, I knew what his expectations were likely to be. He didn't particularly want to talk about prognosis and therefore we didn't focus on that specifically – but that was his, that was the way he wanted the conversation to go (De-brief interview/Dr Allen/Ben/ Ref 1)***

The very obvious difference in these two cases was that Ben's companion adopted a neutral influence during the information exchanges and did not impact or control any aspect of this particular encounter. Contrastingly, Eve's companions adopted a different perspective and chose to question aspects of the information given by the oncologist, thus influencing the content and direction of the exchange. Significant influence was consequently exerted within the prognostic information domain, with the oncologist compelled to justify her rationales.

Companion influence in Case E could essentially be viewed as moderating. Companions controlled and moderated the content and direction of the exchange and as they picked up on prognostic information in advance of Eve, they did so without her initial consent and theoretically against her wish to collude with medical staff to avoid precise information about outlook. Equally in this case companion influence could also confer a mediating role whereby the actions of the family lead to a more in-depth discussion and analysis of prognostic indictors which would otherwise have been missed by Eve and ignored by Dr Brown.

In three of the five Cases (C, E and F) where moderation was evident in relation to companion control and companion agenda, there was also persuasive links with the third construct of companions as experts.

### 7.3.3. Companion as expert

In this study *expert companion* was conceptualised within a broad categorisation and ranged from companions who had a healthcare background (Betty, Colin and Fiona) to those with previous knowledge and experience of caring for someone with the illness (Agnes, and Davie). Importantly there was also evidence that in some cases (Eric), companions became 'expert' through reading and familiarisation around the subject matter. Colin, a retired paramedic, was a compelling example of a companion with a healthcare background who moderated the content and direction of information by utilising his knowledge of breathlessness management:

***Dr Anderson:*** ***Is there anything that I've not made clear that you'd like to ask me at all?***

***Colin:*** ***No, well, I don't know if this is your department, or if it would be this other fellow – but I think there's just a few wee things. Sorry, I don't mean to be rude by writing things down. Yeah, I do think Celia is much more breathless than even just a week ago. Is oxygen therapy a consideration?***

***Dr Anderson:*** ***I think it's unlikely. I can measure the oxygen level in her blood quickly with a wee machine, so I'll do that in two minutes. I think that's unlikely to be necessary, but it's certainly something that I'll check just now.***

***Colin:*** ***Or a nebuliser of some kind (Consultation/Dr Anderson/Celia/Colin, Ref 1)***

In his attempts to improve Celia's health status Colin's moderating 'expert' knowledge and information agenda could have impacted negatively on her care. He failed to take full account of her current contextual situation - Celia continued to smoke:

***Dr Anderson:*** ***You've stopped smoking then, haven't you?***

***Celia:*** ***Not really, no, doctor***

***Dr Anderson:*** ***Well, there's no question of oxygen on someone who still smokes***

***Celia:*** ***I had heard that doctor. Is that for health and safety doctor?***

***Dr Anderson:*** ***It's health and safety and there's no benefit from oxygen if people go on smoking***

***Colin:*** ***But em…Oh right. (Consultation/Dr Anderson/Celia/Colin, Ref 8)***

In other cases companions did not recommend therapy. Applying control with expert knowledge to moderate the content and direction of the exchange was evidenced by monopolising the conversation with the consultant:

***Fiona:*** ***Cos obviously, d'you know what I mean, I'd like... just to know, like...the bronch was…Cos the bronch was inconclusive, you know, the...***

***Dr Boyd:*** ***All the tests that are inconclusive are good. Yeah.***

***Fiona:*** ***mmm...d'you know what I mean, it's all looking good. I know it's all looking good, but it's still, like, and I know you're never gonnae know until you go in and look, but...***

***Dr Boyd:*** ***What we want to avoid is surgery that is done for the wrong reasons and is basically not achieving its target, which is to cure (Consultation/Dr Boyd/Flo/Fiona, Ref 3)***

In Eve's case, Eric did not have a healthcare education, but his moderating expert influence was evidenced by him becoming a knowledgeable companion through research and studying the written information supplied:

***Eric:*** ***Yeah, I read it over, like. It's 230 patients or something just now. She actually read the booklet herself, last week, and what put her aff was the side-effects – but it doesnae matter. I said to her, it doesnae matter what you have, you're still gonna get the side-effects. Is it just a case of if she takes both treatments at the same time it'd be quicker?***

***Dr Brown:*** ***It doesn't make any difference.***

***Eric:*** ***Does that not make any difference?***

***Dr Brown:*** ***So do you have any questions about it?***

***Eric:*** ***No. I just like to know how far on this cancer is (Consultation/Dr Brown/Eve/Eric, Ref 11)***

Eric skilfully shifted between his understanding and knowledge of the trial literature to moderating the information flow and content to suit his own information needs and agenda concerning Eve's prognosis.

In all other companion Cases (A, D and G) there was no significant evidence of companions as experts. Yet prior knowledge regarding the experience of cancer, such as caring for someone previously with

the illness, could also imply a level of 'expertise' which might subsequently influence the process. In Case A, Agnes expressed an opinion regarding outlook, based on Alex's experience of prostate cancer. Agnes projected that the outlook from lung cancer would be similar to that of his previous cancer and this prior knowledge and experience (as incorrect as it was), allowed her to adopt a moderating influence on her current opinion and viewpoint:

***Well, I feel as if, because he responded so well with the prostate, (yeah) you know, from such an aggressive one that he had and he beat it…that he will be the same here (In-depth interview/Alex/Agnes, Ref 12)***

Data suggests that, although companions moderated across the three main constructs to differing degrees, aside from minimal comments from Alec and Gordon, no other patient expressed their discontent at the influence of companion presence. However, perspective on companion moderating influence was evidenced, not from patient perception but from that of professionals and the next section will explore perception of companion involvement in more depth.

### 7.3.4. Perception of companion accompaniment – moderating influence

Within the mediating influence construct, patients expressed positive opinions regarding companion impact on information exchange. But, professional perspective was absent for this domain. However, the reverse was identified for moderating influence. Despite evidence that companions influenced information exchange in a moderating fashion, overall patient perspective was not critical of this effect. Professionals were more vocal for this domain and study data illustrated that, for some cases, there was a negative perception noted regarding companion accompaniment.

Professionals' views were elicited directly after the consultation to capture the immediacy of their opinions. Analysis of de-brief interview data showed for most cases, the professionals responded to the questions in the affirmative, stating they had covered the pertinent areas which they had intended to. Some professionals commented that they tended to follow the patient's agenda:

***Well, the answer to that is yes, I hope so, but I don't always follow my agenda, I follow the patient's agenda (Consultation/Dr Anderson/Alex, Ref 1)***

Whereas professionals confirmed they exchanged the amount and type of information which they hoped to during the consultation, they also identified that at times there was large volumes of information to communicate to patients and their companions:

***But... no, it's quite, they've had a bit of a rollercoaster. It's funny that... sometimes there's an advantage in seeing patients quickly. But sometimes....It's too, too much. Too much time, too much information (Consultation/Dr Brown/Gordon, Ref 3)***

In only one case (Case E) did the oncologist feel that the content of the information she provided was inadequate:

***No. I think what I wanted, what I would normally have done, also, is gone through the actual chemotherapy treatment. Sometimes, I mention the drugs and …explain to patients that it's given over three weeks, and that they receive four cycles. I didn't really get the opportunity to do that. Most of the consultation was dominated by her stress, regarding smoking. …and I mentioned that it'd be four treatments. But I would have liked to have gone through that, because, obviously, there's neutropenia sepsis, …which you want to warn the patient of…so that is something that I'm gonna have to follow up on (Consultation/Dr Brown/ Eve, Ref 1).***

Significantly, without being asked directly, professionals made unsolicited comments regarding the accompanying companions as evidenced with these exemplars:

***The brother is a bit intense, actually – he got a bit wearing (De-brief interview/Dr Anderson/Colin, Ref 1)***

***There seems to be a lot of antagonism between her and the son…and is nagging her …regarding smoking…and harassing her, and she's feeling very stressed with that. So the consultation was interrupted about three times just for that (De-brief interview/Dr Brown/Eric, Ref 2)***

***They had a daughter here that I had not met before, so we had to go over everything again. The daughter seemed well-informed, was mentioning VATS procedures and things like that, so...It was more the relative***

***that wanted to know stuff and not the patient. She didn't think of much (De-brief interview/Dr Boyd/Fiona, Ref 2)***

In the data there is association shown between the companions who influenced the exchange of information in a moderating manner and whom professionals chose to comment, particularly, Colin, Eric and Fiona. There is no indication from the medical staff that the presence of the companions was so moderating that it made information exchange untenable. Yet, companions altered the content and direction of the exchange to suit their information agenda. Professionals mentioned certain companions spontaneously but not necessarily in a positive light. The unsolicited nature of their comments appeared to confirm that the data accurately assessed these companions as persuasive moderators of information exchange. Importantly, data revealed that the most vocal and moderating companions did not negotiate their accompaniment but insisted on their presence at the consultations.

### 7.3.5. Moderating construct summation

The negotiated presence of companions and more importantly, the moderating role of non-negotiated companions, emerged as a major finding in the data. A moderating influence was shown in five of the seven cases and could be categorised into three main sub-themes of *controlling companion, companion agenda and companion as expert*. Evidence also showed the sub-themes were linked with recurring patterns, demonstrated across all three constructs. The more controlling the companion, the more they influenced the information exchange process with their own information agenda. This was particularly so when the companion may have a perceived expert companion role. Conversely, companions did not need to have a healthcare background to exert their own agenda, only a persuasive desire to have their questions answered. Moderating influence was thought to be partly driven by companions desire to enhance their loved one's care and not solely for their own advantage.

Iterative data analysis also revealed that professionals and patients held views and attitudes about companion moderating influence, which warranted analysis and exploration. There were no negative comments elicited from patients regarding companion influence within this construct. Although narratives indicated patient disquiet in two cases (A and G), professionals commented more specifically about the most moderating companions.

Similar to mediating influence, diverse companion demographic characteristics [gender, personality traits and past experiences] as well as relationship types within and across cases (shown in table 16) may have had a significant role to play in the information exchange process for moderating constructs.

Case summary 2 described below, illustrates all three moderating constructs which were evident during the clinical consultation for Case F.

**Case summary 2: Moderating companion influence**

**COMPANION CASE SUMMARY: FIONA**

Flo was a 67 year old lady diagnosed with T2 N0 non-small cell lung cancer. Her cancer was diagnosed following investigation of recurrent chest infections. She had no significant past medical history and stopped smoking over 20 years ago. Performance status was recorded as 0. Since leaving school with secondary school qualifications, Flo worked as a clerical assistant until she retired. She was married and lived with her husband in a large urban suburb. The treatment modality was surgical resection with a curative intent. Flo was diagnosed at Study site B and attended consultations there with Dr Boyd and Sr Baxter. She was accompanied by her husband Frank and daughter Fiona. Fiona was present only during the clinical encounters and not at the in-depth interview. Fiona was aged 35-45 yrs, married with no children. She lived in the USA and was a registered nurse, practising abroad and had flown home specifically to be present when Flo was given her results and proposed treatment plan.

At the outset of the consultation, in this case the companion was quiet and did not exchange any information with Dr Boyd whilst he explained specifics relating to the cancer type and stage. Approximately half way through the consultation, data showed that Fiona began to engage in the exchange and became more involved exerting a strong moderator influence throughout the communication process in the second half of the discussion. Her influence was evident through all three moderating constructs (control, agenda and expert). Data identified that Fiona controlled the exchange of information by employing the three sub-constructs of companion control. She spoke directly to Dr Boyd throughout the exchange, with no attempt to engage Flo in the discussion between them, either with prompting or asking her questions or seeking her opinion. Likewise, Fiona exerted a strong control over elements of the exchange, often interrupting the dialogue to interject (Ref 5) or answering for her mother unsolicited (Ref 1). There was data to suggest that Fiona used a moderating influence to marginalise Flo, which included use of the third person, with Fiona referring to her mum as 'she' (Ref 2) and her tone appeared dismissive at times during the exchanges (Ref 1). Extending her moderating behaviour, Fiona controlled the exchange by direct questioning of the physician. Her line of candid questioning suggested a companion agenda devolved of an enhancing or protective behaviour towards Flo (Ref 8). A further moderating or inhibiting effect was Fiona's use of her expert knowledge often displayed in the language used. As a nurse she asked direct medicalised questions (Ref 6), and her language further prohibited the inclusion of Flo and Frank from the exchange as it often included terminology that they would have been unfamiliar with i.e. mediastinoscopy and VATS (ref 4), 'bronchoscopy was inconclusive' (Ref 3).Despite Fiona's moderating influence, this style of exchange appeared to suit Flo. It fitted with her desire not to ask direct questions herself and to allow Fiona to control the content and direction of the information (Ref 2). Although her moderating influence did not render the consultation difficult and information exchange untenable, and despite Flo appearing content with Fiona's presence, Dr Boyd mentioned her role when questioned at the de-brief (Ref #). Aside from being a physical presence there was no data indicating that Fiona exhibited any other mediating influences within this case. Additionally, Fiona's accompaniment to the clinical encounters was non-negotiable. She had taken leave from work in America and had a specified time to accompany her mother to the consultations.

## 7.4. Neutral companion influence

The previous sections explored the data relating to both mediating and moderating companion influence. However, analysis identified a more non-aligned influence in two cases (Case B and D). Aside from acting as a physical presence and memory aid, these companions appeared to have so little influence on the information exchange that their input could be regarded as neutral. Analysis of neutral influences focused on any aspects of companion influence, which could explain the rationale for why, in these two cases specifically, there was neither a significant mediating not moderating influence. Two main constructs were identified which could theoretically explain the influence; *past experience and knowledge* and *relationships.*

### 7.4.1. Past experience and knowledge

These two cases were completely dissimilar in terms of companion characteristics relating to experience and knowledge. Ben's daughter Betty was his accompanying companion. A registered oncology nurse she had a minimal mediating influence on the exchange when she acted as an aide memoire, only reminding Ben which medications he took. Likewise Betty then had a minimal moderator effect on the discussion when she answered a question about Ben's understanding of his condition and used the word mesothelioma when he struggled to pronounce it. Aside from minor interjections, Betty appeared to keep her counsel and remained neutral for significant amounts of time, with Ben predominantly exchanging information with both professionals. When invited to ask questions she declined (Dr Anderson, Ben, Betty, Ref 3). Her reasons for adopting a more impartial role are unclear. However, it could be proposed that Betty as an experienced cancer nurse already knew the treatment pathway, expected treatment side-effects and potential prognostic outcome and did not need to engage in an exchange for more information.

Delia was accompanied to her consultations by Davie her husband of thirty years and their daughter Diane. Davie was also present at the in-depth interview. Davie had no healthcare education but had

personal experience of lung cancer with his mother, who subsequently died of the condition. The couple also experienced the death of their son. Davie conferred a mediating influence by his physical presence and had a further mediating role as an aide memoire. Similar to Betty, Davie seldom asked direct questions. Feasibly, he may already have understood the proposed treatment plan and potential side-effects from past experience.

### 7.4.2. Relationships

In both cases, relationship factors may have been a significant influence. It is possible that Betty maintained the role of daughter, setting aside her nursing experience, and taking the lead from her father. Ben was reluctant to ask too many questions, especially in relation to the themes of treatment and treatment outlook, and Betty may have thought it inappropriate to discuss these subjects in his presence. In case D, Davie and Delia's long-standing marital relationship may have provided the easy and relaxed communication between them, witnessed even in the cancer setting.

A case summary 3 describing the dual constructs of past experience and relationships of Case D is summarised below.

**Case summary 3: Neutral companion influence**

**COMPANION CASE SUMMARY: DAVIE**

Diagnosed with T4 N2 non-small cell lung cancer, Delia was a 55 year old woman who presented with pleuritic chest pain. This was a new symptom on a background of severe Chronic Obstructive Pulmonary disease (COPD). Delia was unemployed due to ill-health as a result of her airways disease but worked as a cleaner and car valet previously. She left school with secondary school qualifications. She was married and lived with her husband in an inner city area and her performance status was described as 0. At the time of data collection Delia was a smoker. Treatment regimen was chemotherapy, with the intent being symptom control and palliation. The patient attended clinic consultations at Study site A and was reviewed by Dr Andrews, Dr Allan and the Clinical Trials Nurse. Delia was accompanied by her husband Davie to both clinic consultations and he was present when the in-depth interview was conducted. Davie and Delia had been married for 30 years. They had two adult children. Their daughter Diane, a mother of two, was present during the consultation with Dr Andrews. Diane's only exchange of information was to ask if the situation was 'hopeless' (Ref #). Their son died 13 years ago from an unintentional overdose of Ecstasy tablets at a rave. They spoke of him frequently throughout the in-depth interview, especially in relation to avoidance of companions and avoidance of communication. The family had experienced loss from their son's death and Davie's mother died of lung cancer (she was under the care of the same healthcare team that was currently caring for Delia). As a couple they both exchanged information throughout all information exchange encounters (consultations, de-brief and in-depth interviews).

Davie never exerted control over Delia and never answered questions intended for her. He rarely asked any questions, preferring instead to make statements (Ref 3, 4, 6). Data showed that as a couple Delia and Davie had a very easy-going communication style, often completing sentences for each other (Ref 10). There was no dismissive tone adopted and Davie never seemed to be controlling the information exchange with his own agenda. Field notes and researcher observations noted Davie adopted a fairly relaxed, laid back stance, and his exchanges were almost conversational. His calm composed manner seemed at odds with the gravity and emotive nature of the situation. Across all cases he was the only companion who constantly thanked the staff and he praised them repeatedly (Ref 9).

This style of communication could be related to many variables including personality trait, strength and longevity of relationship and also prior experience of cancer with Davie's mother. In this case Delia appeared comfortable with Davie's influence (neither mediating nor moderating) and commented that she needed his accompaniment at the information exchanges (Ref 2).

### 7.4.3. Neutral construct summation

Specific conclusions for the reasons for a more passive stance within these two cases could not be determined from the data. Data did identify a broad spectrum of features which could effectively impact neutrality. Comparing data within and across the two cases, there is an assertion that the recurring sub-constructs found related to prior knowledge and experience. Betty was an oncology nurse and Davie had past experience with his mother's lung cancer and son's death. Within the relationship sub-construct Betty's deferential role as daughter and Davie and Delia's long and comfortable marriage, were identified as central tenets (see table 16).

There is no evidence that companions in cases B and D significantly influenced the exchange of information between patients and professionals. Nevertheless, their actual physical presence at the clinic may have impacted positively as a source of emotional support and this is borne out in Delia's narrative (Ref 2).

### 7.5. Comparison across all constructs

Across the three major constructs of mediating, moderating and neutral influences, further sub-construct analysis has been presented, both within and across the cases. Whilst it is recognised empirically that companions influenced information exchange along similar broad constructs (Laidssar-Powell et al, 2013; Wolff and Roter, 2011), there was no meaningful evidence to inform which constructs were more influential than others or why and how companions did indeed mediate or moderate within each specific domain.

This study recognised that all companions displayed mediating influences, primarily and significantly across the informational construct. They provided clarification, context and vitally recalled information to enable professionals to provide care based on current communication and knowledge. Whilst a physical role was not relevant in this study, all companions were recognised as providing a physical presence and a sense of 'being there' for the patient. Whereas physical presence was associated with emotional support, not all companions offered reassurance and encouragement in this study. The data illustrated, within this construct that companion variables, including personality traits and relationship alliances, may account for the way that companions as individuals and as a collective, influence the information process.

In relation to moderating constructs, evidence suggested that although all companions regulated information exchange to some extent, certain cases did so across all three sub-constructs. Evidence further demonstrated that companion control, companion agenda and companion as an expert were

correlated and inter-connected. The evidence also indicated that companion personality traits may significantly influence which cases displayed more moderating behaviours. The interaction of relationship variables, as well as knowledge and past experience, were also illustrated as prominent explanations why certain companions adopted a more neutral influence on the process.

There was clear evidence that companion accompaniment to the clinical consultations was a negotiated process. Companions who exerted a more moderating influence appeared to be placed in the non-negotiable end of the spectrum, with patient preference receiving little consideration. Across all cases, the evidence showed that patients valued companion involvement even when it was shown to moderate the information content and exchange. Professionals did not voice opinion regarding any mediating companion influence but were vocal about moderating companion behaviour.

Policy initiatives dictate that companion accompaniment is recommended at consultations. Recognising what constructs relating to information exchange are influenced by companions within clinical consultations is essential for informing information exchange between patients, companions and professionals. Subsequently, identifying what characteristics impact on preference for companion accompaniment is important; as is an understanding of the reasons for particular companion presence. There is also a requirement to investigate the impact of participant perspective on companion accompaniment and the implications this has on clinical practice. These key findings will be discussed in the following sections.

From this analysis key findings have emerged from construct synthesis which requires further analysis and exploration:

- What specific constructs relating to information exchange in lung cancer are influenced by companion presence? And how is it impacted by characteristics (both patient and companion) and relationships?
- What is the preference for companion accompaniment and how is it impacted by patient and companion characteristics and relationships?
- What is the participant perspective of companion presence and are there implications for clinical practice?

This study has used within and across case analysis of the mediating, moderating and neutral constructs and associated sub-constructs to explain the influence of companions on information exchange. Additionally companion and patient characteristics are described in conjunction with participant perspective. These are summarised in table 20.

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Table 20: Associated constructs & characteristics

| Case | Patient variables | Companion relationship | Companion variables & attitude | Preference for accompaniment | Influence | Constructs influenced | Participant perspective on accompaniment |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| **A** | Independent man.<br>Living with prostate cancer.<br>Did not want to burden companions with his cancer. Did not want specific information (i.e. prognostic info). Would have attended alone. | Daughter | One of 2 siblings (brother was a drug addict). Married with young children. 30-40 yrs old. Some previous cancer experience as mother died of cancer + Alex had prostatic CA. Fairly quiet and appeared respectful during exchange. No obvious agenda noted | Negotiated | Mediating | Physical - presence<br>Emotional - reassurance<br>Informational - aide memoire, seeks clarification | Patient content<br>Professional no comment |
| | | Partner | In relationship with Alex for 12 years. Age between 65-75 yrs. Experience of looking after Alex with prostatic CA. Was not present at clinic and had an informational agenda at in-depth interview. Vocal and strong personality | Negotiated | Moderating | Companion agenda setting<br>Expert companion - past experience | Patient displayed some disquiet but overall content<br>Professional no comment |
| **B** | Independent man.<br>No past history of cancer and was still grieving for his wife who died in the past year.<br>Did not want to burden companions with his cancer. Adamant he did not want to know too much and did not want specific information (i.e. prognostic info).<br>Would have attended alone. | Daughter | One of 3 siblings. Married with 2 young children. 30 - 40yrs old. Registered oncology nurse. Fairly quiet and appeared respectful during exchange | Negotiated | Neutral | Prior knowledge and experience<br>Relationships<br>Physical - presence | Patient content<br>Professional no comment |
| **C** | Fairly frail elderly lady.<br>Past experience of breast cancer and good grasp of information. Would have attended alone but brother was persuasive and she logistically needed transport | Brother | One of 2 of Celia's younger brothers. A retired para-medic with some healthcare knowledge. 65-75 yrs. old. Vocal and strong personality | Partially negotiated | Moderating | Physical - logistical, presence<br>Informational - aide memoire, seeks clarification, provides context<br>Companion control - answers for patient, interrupts, dismissive<br>Companion agenda<br>Expert companion – education | Patient content<br>Professional mentioned moderating influence |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **D** | Independent lady.<br>Past experience of cancer and family bereavement.<br>Never gave thought to attending alone or negotiate companion presence | Husband<br><br>Daughter | Married to Delia for > 25 years. Previous experience of cancer with his mother. Age 55-65 yrs. Never vocal or opinionated during exchange.<br>One of 2 siblings (brother died of OD). Married with 2 young children. 25-35 years old. Previous experience of cancer with her grandmother. No obvious agenda and fairly quiet and respectful throughout exchange | No discussion<br><br>No discussion | Neutral<br><br>Mediating | Prior knowledge & experience<br>Relationships<br><br>Physical- presence<br>Emotional - seeks reassurance<br>Informational – seeks clarification, provides context | Patient content<br>Professional no comment<br><br>Patient content<br>Professional no comment |
| **E** | Independent lady.<br>Some experience of friends with cancer. Strong personality and recovering alcoholic. Argumentative and strong personality.<br>Family did not appear to give option of attending alone. | Son<br><br>Daughter | One of 3 siblings. Age 30-40 yrs. No previous family history of cancer but gained insight into the condition, treatment and trial data. Vocal and strong personality. Argued with Eve during consultations<br>One of 3 siblings. Age 30-40 yrs. No previous family history of cancer and was not as versed as her brother about condition and treatment. Vocal and strong personality. Argued with Eve during consultations | No negotiation<br><br>No negotiation | Moderating<br><br>Moderating | Physical - presence<br>Informational - aide memoire, seeks clarification, provides context<br>Companion control - answers for patient, interrupts, dismissive<br>Companion agenda - agenda setting<br>Expert companion - learned | Patient and companion argue but overall content<br>Professional mentioned moderating influence |
| **F** | Independent lady.<br>Cancer found co-incidentally and she appeared to be still coming to terms with diagnosis. Did not like to use the word cancer and never asked questions of healthcare professionals.<br>Family did not appear to give option of attending alone. | Husband<br><br>Daughter | Married to Flo for > 30 years. Retired. Age 65-75 yrs. Did not comment much during clinics. Quiet with no obvious agenda.<br>One of 2 siblings (brother lived in London). Fiona lived and worked as a RGN in the USA. Age 30-40 yrs. Vocal and strong personality | No negotiation<br><br>No negotiation | Mediating<br><br>Moderating | Physical – presence<br>Emotional – physical comfort<br><br>Physical – presence<br>Informational – aide memoire, seeks clarification<br>Companion control - answers for patient, interrupts, dismissive | Patient content<br>Professional no comment<br><br>Professional mentioned moderating influence |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | Companion agenda - agenda setting<br>Expert companion - education | |
| **G** | Independent man.<br>Worked as a carer and looked after his father who died of upper GI cancer.<br>Did not want many family members to know about diagnosis.<br>Companion appeared persuasive re accompaniment | Ex-wife | Divorced from Gordon, but still friends. They have a son. Age 45-55 yrs. No past experience of cancer. Had informational agenda, vocal but not overly so. Strong personality. | Partially negotiated | Moderating | Physical – presence<br>Emotional - seeks reassurance<br>Informational - aide memoire, seeks clarification, provides context<br>Companion control - answers for patient<br>Companion agenda - agenda setting | Patient displayed some disquiet, but overall content<br>Professional no comment |

## 7.6. Constructs influenced by companion presence

Data from the study illustrated that, across cases, companion presence at clinical consultations is universal. Inherently the presence of another individual alters the dynamics, focus and exchanges that take place within non-dyad or triad consultations. This is not disputed in either my study data or the empirical literature. What was more equivocal was the influence that companion accompaniment had on information exchange, specifically within lung cancer consultations. Exploring the interconnectedness of companion influence on information exchange and the implications this has on clinical practice, was relevant and appropriate as there was a paucity of data within this arena.

Although my data did not find persuasive evidence that practical, physical influence was significant, there were incidences (Cases C and G) where companions fulfilled a logistical role by transporting patients to consultations. In this study patients were more robust and younger than the 'typical' lung cancer patient. For all cases performance status was 0 or 1 and this may reflect the stage of the illness when patients were not encumbered by treatment and its related side-effects and therefore less reliant on companions for physical support. More notably, my data indicated actual companion physical presence or 'being there' inferred a more significant mediating influence and in my study, evidence revealed this was closely connected to the second construct of emotional support. Even when companions did not exchange significant amounts of information their company and companionship provided reassurance and emotional support and an overall mediating effect. Companion presence gave patients the confidence to attend an emotionally laden consultation. Conversely, physical presence was also identified in the study as a moderating influence. In case E, argumentative exchanges regarding smoking diverted the discussion from clinically important information exchange regarding treatment and potentially life-limiting side-effects.

Study data revealed that companions exerted the most influence within the informational construct. Across all cases companions aided memory recall, with the exception of Case B, all sought clarification

of information and every case, except Cases B and F, provided the healthcare team with contextual information. The impact that the provision of pertinent information from companions regarding current symptoms, past medical history and the social/situational context has on patient care and management, can be significant. In Case A cough was alleviated, Case B pain control was tackled and Case C, breathlessness and anorexia were addressed. Noticeably, data from the study suggested that patients themselves seldom highlight their own symptoms or social context. Therefore, companion influence within this construct can be influential in assisting in overall patient management.

Although the majority of companions influenced the physical/emotional and informational constructs, some were more involved in information exchange than others. One hypothesis for this difference was the actual range and diversity of companion characteristics. Data illustrated that companion characteristics such as confidence level and life experience, may have an impact on information exchange within the consultation.

More notably patient/companion relationship may have a significant influential role within mediating influences. As table 18 summarised, there were a wide range of companions represented with more female companions accompanying patients. Evidence suggested within the sub-constructs of emotional and informational domains, the majority of companions influencing the exchanges were daughters or spouses and these and other relationship traits inform the second key finding and will be discussed within section 7.7. When companions did mediate within the physical/emotional and informational sub-constructs, data indicated that their influence was intended to enhance patient health status. The provision of current, contextual health details added to the clinical picture and provided improved knowledge for professional, enhancing care for the patient.

In contrast, when companions were seen to moderate the information exchange process, there was the potential for patient care to be compromised. Data demonstrated that the majority of companions

moderated information within three main constructs and sub-constructs with evidence identifying that it was difficult to isolate companion control, companion agenda and companion as expert. Each construct appeared interconnected. Whereas five companion cases demonstrated moderating influence in relation to information exchange via a combination of the constructs, three cases were identified where there was significant moderating influence seen throughout all three domains, with constructs inter-dependant.

In the three most principal moderating cases (C, E and F) data demonstrated the exchange of information was primarily regulated during the consultations by companions exercising control. Control was implied through companions answering for the patient, interrupting discussions and at times by dismissive behaviours (Cases C, E and F). Although conceivably not intended, such companion control could be seen to side-line patient control of information exchange. In turn this then has the potential to diminish patient autonomy and decision-making capabilities. Study data showed across these three cases companions used control and agenda setting to moderate the direction and content of information exchange.

There is further evidence that other companions also employed information agenda setting effectively. In Case A, companion agenda centred on treatment outcome and prognostic information, with manipulation of the discussion focusing on this aspect of communication. Equally throughout both consultations, Case G's companion effectively constructed her own agenda of symptoms and contextual information (working and driving) into the discussions. Notably in all five cases patients did not raise these issues independently and thus data showed the respective companions choose their own schedule and moderated the content and flow of the information to suit their own and not necessarily the patient agenda.

Of the five most moderating companions there was evidence, in certain cases, that control and agenda setting were associated with and impacted by companions as experts. This construct comprised three sub-constructs which the majority of cases fitted; *health education background* (Cases B, C and F), *past experience* (Case A and D) *and learned/self-taught expert* (Case F). My study indicated that companions with a healthcare education moderated information exchange more appreciably. Case C and F appeared to take advantage of their professional education to control information content, with the data showing they often monopolised the discussion. Further indications were that expertise can be taught and Case E was able to control information exchange through his learned knowledge of lung cancer and proposed therapies. Experiential knowledge, although shown to moderate the exchange in Case A, was not a moderating feature in Case D, with theoretically, relationship characteristics explaining the difference in this sub-construct. Data analysis highlighted that Case B was an incongruous case within this construct. Here the companion had more knowledge of oncology, practising as a senior nurse within the field, yet had no moderating effect on information exchange, aside from minor corrections of the diagnostic terminology. Consistent with Cases A and D, relationship traits may explain this variance.

As with mediating influences, patient and companion characteristics, as well as relationship types, should be considered as having a significant and persuasive impact on information exchange within moderating constructs. Companions who moderated information exchange were vocal and confident in their relationships with other members of the triad. In order to control and at times direct the information agenda companions exercised strong personality characteristics. Likewise due consideration of the family relationships is warranted; this identified that adult children and siblings were more moderating than spouses.

In contrast to mediating influence, data analysis revealed when information exchange was moderated by companions, it had the potential to impact adversely on patient care, by diverting from clinically

relevant information. During consultations where companions controlled information content with their own agenda, there was evidence that professionals did not discuss information pertinent to treatment and side-effects, both potentially life limiting scenarios (Case E). Similarly as in case C, the professional was forced to discuss inappropriate therapy which would not have been beneficial to the patient or indeed the patient may have been distressed and upset by the topic under discussion (Cases A – prognosis, Case G, activity limiting discussion).

However, moderating influence could also be perceived as a protective mechanism whereby companions attempted to engage with professionals to ensure patients had enhanced care. By leading and controlling the information exchanges relating to treatment modalities and treatment outcome, companions could theoretically be looking to push for the most beneficial therapy for their loved one. Companions may notionally be acting as an advocate for the patient exchanging information with healthcare professionals on many aspects of the disease process, including symptomology, as well as, therapy options and treatment outcomes. An important core feature of this companion advocacy role was identified as collusion reduction, where companions recognised that patients either failed to discern important information relating to key discussions such as prognostic communication or they in fact engaged in complicity with their healthcare professional preferring to avoid difficult to discuss subjects.

This study provided new evidence that companions mediated and moderated information exchange within and across six major constructs. It further identified and synthesised new knowledge relating to which specific sub-constructs were more impacted by companions within lung cancer consultations. Additionally, data explored in the substantive analysis reflected that there was a wealth of characteristic variables (companion and patient) which might impact this influence across the major constructs. This in turn might theoretically impact the preference for companion accompaniment. This was the second key finding to emerge from synthesis and is explored in section 7.7.

## 7.7. Preference for companion accompaniment

Although companion presence was universal, data revealed that companion accompaniment was not an absolute certainty. A key, innovative finding was that companion accompaniment occurred along a continuum, from negotiated to non-negotiated. In two Cases A and B, patients would have preferred to have been unaccompanied to the consultations. Reasons cited for preferring to be unaccompanied were; to protect companions from the diagnosis and believing any information was their private business. However, within these cases, even when patients expressed a desire to be unaccompanied, companions appeared to negotiate with them and secured their attendance. As summarised in table 20 another level of negotiation was identified as partial negotiation.

Data for Cases C and G identified a mix of pragmatism and logistical need (i.e. transportation), some negotiation and ultimately companion presence, which was not fully consensual from the patient viewpoint (Case C) and slightly coerced (Case G). Atypically, in Case D, data showed there was no debate about accompaniment. This patient and her companions attended all consultations as a family unit and gave no consideration to the situation being otherwise. Across the remaining cases there was neither discussion nor negotiation. Companions did not give patients the option of their presence. Data showed there was direct association between non-negotiated accompaniment and moderating influence. In cases where companion presence was non-negotiable (E and F and to a lesser extent C) companions appeared to exert a moderating influence on information exchange. These three cases exercised important influence throughout the three constructs, controlling information exchange, following their own information agenda and applying expert knowledge. A common justification for accompaniment from companions was patients would not tell them all the information (case E) or would not ask for any information during the consultation (case F). Research demonstrated patient preference for accompaniment appeared to be compromised by vocal companions, with strong personal characteristic traits which did not allow patients to broker objection regarding accompaniment.

As substantive analysis occurred after the completion of data collection, with data explored retrospectively, I was unable to adapt my data collection to gather prospective evidence to inform patient selection/preference of companion for accompaniment. However, within the data there is evidence to suggest that the companions who were present may have influenced information exchange because of the very nature of their relationship with patients, in addition to defining characteristics of both patients and companions.

### 7.7.1. Patient and companion characteristics

Analysis of the data hypothesised that certain aspects of personal characteristics render some companions more mediating, moderating or neutral than others. Across cases there were 5 moderating companions (3 women and 2 men). Of this number, 3 were identified as more influential moderators (1 woman and 2 men). As case study numbers were small it is important to note that no one gender appeared more significantly moderating than another. Of more significance was that all moderating companions were very vocal throughout the information exchange process, with strong opinions and forceful personalities, with an ability to control information content and direction. Likewise, where mediating or neutral influence was noticed, companions tended to be from both genders and from different age groups. In contrast, when they exchanged information they did so less frequently and used more supportive behaviours with little or no attempt to control the exchange process.

It is unknown how much of an impact educational level had on the mediating or moderating companion influence, but professional status showed mixed effect. There was an identified association between companions with expert knowledge (Colin a retired paramedic and Fiona, a registered nurse) and moderating influence. Yet, the companion with the most oncology professional knowledge (Betty) adopted a wholly neutral influence. On reflection it could be considered that Betty's

neutrality stemmed more from relationship influence than professional knowledge as highlighted in section 7.4.2.

The data did not suggest that specific patient variables were strongly influential across the six constructs. Overall, patients were neither elderly, of poorer health or performance status nor cognitively impaired by disease processes. Likewise there were no discerning or segregating features relating to educational level or socio-demographic status, which could be seen to differentiate the patients along identifiable demographic differences. The majority of patients had some prior experience of cancer or ill health. Equally, few of the patients were overly passive recipients of their own care. Despite Celia being older and frailer than the other cases, she exchanged information and participated in the dialogue. Similarly, data showed that Eve was very vocal herself, appeared to have a volatile relationship with her companions and often argued during consultations. Of the three cases where significant moderating influence was dominant, Flo exhibited the most passivity. Her personality might explain this reticence, as she never historically exchanged information with the healthcare team and, fundamentally, she was reluctant to speak about her cancer. A notable feature, but of questionable significance, was the fact that of the three most moderating companion cases, patients were female.

### 7.7.2. Patient and companion relationships

Patients were never accompanied by more than two companions throughout data collection. Theoretically, there may have been some type (however negotiated) of selection from a wider group of companions, but the opportunity to explore patient preference for companion selection in greater detail was not capitalised. Patients were never explicitly questioned about the nature of the relationship with their companions. They were asked during the in-depth interview under the heading of *support at clinic* if there was a conscious decision taken pre consultation to take a companion to the clinic and also questioned on the rationale for this decision. As negotiated accompaniment was

not an original consideration of the thesis this line of enquiry was not investigated extensively at this point in data collection. However, in some cases patients commented that their original preference would have been to be un-accompanied. In hindsight exploring the concept of patient preference for specific companion accompaniment and deeper exploration of the familial relationship and domestic affiliations between the patients and their companions could perhaps have allowed a deeper understanding of the reasons why certain patients wished to attend clinics alone and why for others the thought of being unaccompanied never entered their thoughts.

In addition, the study did not take the opportunity to consider patient perception of the roles they believed their companions should play during the consultation. This was principally because the study did not primarily set out to explore this domain and instead the influential roles and constructs influenced by companions only emerged as a theoretical proposition as the study unfolded and the data was analysed in-depth.

Data illustrated when patients had a spouse or partner (Cases A, D and F), or ex-partner (Case G) these appear to be the preferred companion. Other accompanying companions comprised adult children (Cases A, B, D and F) or as in case C a sibling.

Two of the most moderating companions were adult children. These companions appeared to be more controlling of the content and direction of information exchange and their recorded interactions revealed they used moderating behaviours which often interrupted and at times side-lined patients. Data does not suggest that these companions were not caring towards the patients, as their presence at the consultation may in itself signify, concern and consideration. Nonetheless, data demonstrated that their behaviours contrasted to other accompanying adult children (Cases A and B) who appeared to show different levels of respect and deference to their parents. Additionally, in relation to three of the accompanying daughters, data indicated that notable differences were seen in both their

relationships with the patients and their effect on information exchange process. Case A (Ann) was respectful and exerted a significant mediating influence on information exchange. Case B (Betty) was deferential and shown to be more neutral, whereas Case F (Fiona) was a strong moderator of information, often controlling both content and direction of the exchange. Reasons for such contrasting influences could be explained, in part, by companion-patient relationships and also companion-patient characteristics.

Spousal/partner companions were present in Cases A, D, F and G. Consistent with children relationship effect, data showed that spousal/partner/patient relationship appeared to impact differently on information exchange. Partner companions A and G both displayed moderating influence on information, but data suggested to a lesser extent than other moderating cases and not across all constructs and although they followed their own information agenda there was less controlling dismissive influence. By contrast in Case D, companion influence was neutral with no moderating behaviour witnessed. In Case F, Flo's husband would have been considered a neutral influence had he not exhibited a more mediating, emotionally supportive role. It is conceivable that divergent influences across these cases could be explained by relationship dynamics. In Case A, the couple had never married and lived separately. Equally in Case G the couple had divorced and lived apart and therefore their relationship characteristics may not mirror that of married couples (Cases D and F) with marriage longevity and different attitudes to their relationship. Additionally, although not fully understood, female partners appeared to have a more moderating influence on the exchange.

Attitudinal influence can only be hypothesised from data analysis in certain cases, as patients and, more importantly, companions were never directly questioned regarding these constructs. Although conjecture, a reason for moderating influence could have been that companions felt that, as immediate and close family members it was their 'place' to advocate for the patient, ensuring symptoms were detailed (Case C), or contextual information given regarding smoking behaviour (Case E) and clarification sought regarding surgery [Ref 6] (Case F). Likewise, companions may have assumed

that a level of patient passivity allowed them to be vocal and speak on patient behalf. In Case C the companion may have viewed the patient, as elderly and frail and unable to make autonomous decisions. Hence the reasons he was controlling the information exchange and his rationale for taking away her right to see patient information regarding clinical trials. Equally, in Case F, companion dominance of the exchange; may have been mitigated by her knowledge that the patient historically displayed avoidance behaviour in order to escape discussing her cancer diagnosis with the healthcare team.

Data illustrated that companions and patients are complex yet individual humans with differing opinions, personalities and attitudes about their relationships. Consequently, they interact with others in complex and different ways which consequently impacts information exchange processes. The evidence did not specify categorically, what specific companion and patient characteristics were more influential than others across the constructs, but considered the rationale for their interaction across cases. Importantly, the study contributed new evidence of the association between companions who were significant moderators of information exchange and their level of negotiated presence at clinical consultations. Evidence showed these companions to be opinionated and vocal, controlling information via their own agenda by utilising their expert knowledge.

Such companion influence has the potential to influence important constructs of the information process. Therefore, exploring companion accompaniment and influence from the perspective of patients and healthcare professionals appeared to be the next logical step within data synthesis and this emerged as the third key finding.

### 7.7.3. Perspective and implications of companion presence

The interview schedule for patients asked if it was a conscious decision to have a companion present during the consultations. There is evidence that some cases would have preferred to have been

unaccompanied and in the narratives, there is further evidence that patients felt uneasy with the informational content that companion agenda discussed. Yet, pertinently, there was no data analysed which showed that any of the cases were profoundly dissatisfied with companion presence. Notably data showed that patients only commented on companion mediating influences, using affirming language to reinforce the positive aspects of their accompaniment. Even when companions did not negotiate their presence and moderated the exchange of information with controlling behaviour, patients did not raise any issues with the level of moderation.

Conversely, data demonstrated that healthcare professionals were cognisant of companion presence and offered their perspective on accompaniment in certain cases. Significantly, healthcare professionals who did express their view on companion presence only did so when the influence displayed was moderation. Additionally, professionals offered their perspective at the de-brief interviews, unsolicited. In Case E the oncologist expressed concern that companion agenda distracted from clinically relevant information exchange and could potentially have life-limiting consequences, if the opportunity was lost to redress the imbalance. In other cases, professionals were aware that companion agenda was controlling the exchange of information (Case F), or that companion control was wearisome (Case C). Despite comments from professionals regarding companion influence, there was no evidence from the narratives to suggest that moderating behaviour made information exchange untenable.

On this third key finding, data suggested there was a clinical impasse between patient and professional perspective on companion accompaniment. In certain cases, professionals thought moderating behaviour had a negative influence on information exchange during the consultation. However, from a patient perspective, data did not identify this moderating influence as significantly impacting the exchange. Data could not offer specific explanation as to why there should be disparity between patients and healthcare professionals on this unique finding.

It can be theorised that, at this emotive type of clinic consultation, patients were less conscious of the moderating, mediating or neutral influence of their companions. Although never questioned prospectively regarding their perspective of companion role, there was evidence from the narrative data, that patients did not view moderating behaviour as impacting on their care. Even Eve did not mention the heated debate she had with her companions regarding her smoking habit and how this led onto a sensitive discussion regarding her prognostic outlook. It may not have fundamentally mattered to her. The information was now there and she was dealing with it. Conceivably, patients may just be accepting of their own particular family traits, even if that includes moderating behaviours. Equally, patients may just be grateful to have someone there with them throughout this time and as such, are prepared to tolerate moderating behaviour.

Although not able to draw any robust conclusions from the data, the study has highlighted the emotive nature of lung cancer care, the poor prognostic outlook and the fear and uncertainty in which patients live their lives. It might be theorised that the severity of certain conditions and the poor outcome of specific diseases mitigates against patients being too unhappy with any influence which companions exercised.

Impasse between patients and professionals could signal an important deficiency in patient clinical care (Epstein et al, 1985). For communication and information exchange to be effective, the professional must gain an understanding of the patient's perspective, with values and preferences explored (Teutsch, 2003). The empirical literature and national policy directives recommend that professionals suggest to patients that they should be accompanied to clinic consultations by a companion, based on evidence which has shown the positive, mediating influence they exert on the exchange. Significantly, my data now challenges the clinical assumption that companion accompaniment should be recommended universally. Additionally, my findings also highlight that

companion accompaniment is not only a source of mediating influence within the clinical encounter, but needs to be considered from moderating and neutral constructs simultaneously.

## 7.8. Summation

Substantive data analysis could be described through three distinct stages in my study.

1. The first stage refined the substantive analysis constructs relating to companion influence, naming mediating, moderating and neutral constructs
2. In stage two the influences of the substantive within and across case analysis related to the three major constructs and their associated sub-constructs were described
3. The third stage identified the key findings which emerged from construct synthesis

Data was analysed between all constructs, in an attempt to synthesize the key components of the domains and describe the influence that companions exert within and across each construct. Analysis illustrated that patient, and more significantly companion, characteristics and relationships may have been instrumental in further influencing information exchange. The data could not claim to have categorically investigated all such variables. However, within the constraints of small case numbers, the evidence demonstrated that both personality traits and relationship alliances appeared to influence the information exchange process. Also, although this is important data in itself, and an area which also warrants future investigation, it primarily underpins the innovative finding of negotiated accompaniment.

The study generated new knowledge, identifying the association between preference for companion accompaniment and negotiated presence at the clinical encounter. Pertinently, data illustrated that companions with a non-negotiated accompaniment to the consultation subsequently exerted a significant moderating influence on the information exchange process, which had the propensity for

both negative and positive outcome. Consistent with influencing factors within the construct domains, personal characteristics and relationships could theoretically impact preference for accompaniment as well. Companion accompaniment is universally recommended and accepted at the clinical encounter. Therefore, focusing on understanding the perceptions of all participants seems both timely and germane.

# Chapter 8. Discussion

## 8.1. Introduction

My study has generated new and original knowledge related to negotiated and more specifically non-negotiated companion accompaniment at the clinical encounter. This thesis described information which was exchanged or not exchanged between patients with lung cancer, the companions who accompanied them to clinic consultations and the professionals with whom they consulted. The principal finding to emerge from the data, illustrated the influential role of accompanying companions, especially those with a non-negotiated presence who were identified as influential and expert with a moderating influence on the information exchange process. Secondary study data also suggested that preference for accompaniment was impacted by a variety of factors, such as patient and companion characteristics as well as relationship alliances. Perceptions of companion accompaniment also was a significant aspect of secondary data worthy of consideration, especially as my data highlighted that patient-professional perspective on companion accompaniment and influence on information exchange were both inconsistent.

This chapter considers explanations for these findings with reference to the wider corroborating or contradictory literature. The chapter will begin with an analysis of the study's strengths and limitations.

## 8.2. Strengths of the research

To my knowledge this study is one of the first to investigate information exchange between patients with lung cancer, their companions and professionals at clinic consultations. The study explored a previously under-researched subject, describing in detail the content and type of information important and relevant to each participant within triadic clinical consultations. This research identified, for the first time, the influential role that companions played in negotiating their presence

at clinical encounters and the subsequent impact accompaniment has on the information exchange process.

It was the absence of empirical evidence on information exchange within the lung cancer context that primarily guided the use of a case study design. The strength of this method allowed exploration of the *richness of the phenomenon and the extensiveness of the real-life context* (Yin, 2009, p2). One of the key strengths was the decision to employ a research method which allowed an in-depth understanding of the specific and contemporary topic of information exchange. The study was concerned about information exchanges between the participants and all relevant behaviours, but as it was not motivated with manipulating either behaviours or variables, adopting a case study method added to the strength of the research design and the ability to answer the research questions. Demonstrating the experience of information exchange from the insider's perspective was an integral element of the research and another key strength of the study was the use of multiple methods of data collection techniques (detailed in chapters 3 and 4).

The decision to audio-tape all clinical consultations and interviews was both considered and pragmatic. Capturing all information exchanges precisely and truthfully promoted rigor and trustworthiness of data and provided an accurate unbiased record of events which did not rely exclusively on retrospective participant recall (Coleman, 2000). An added strength of utilising multiple methods of data collection in the study, specifically debrief and in-depth interviews, allowed focus on participant perspective. The effect of this was twofold in that de-brief interviews captured the immediacy of participants perceptions and semi-structured interviews permitted the individual to explore their experience of the information exchange process from their own personal perspective, whilst standardisation of at least some questions increased data reliability and replication across cases. The overriding strength of the study was the multiplicity of participant perspectives and

triangulation of data which allowed an in-depth and extensive exploration of the information exchange process.

## 8.3. Limitations of the research

One limitation related to sample size. Yin (2009) stated that one replication can support analytical generalisation and Eisenhardt (1989) specified each case serves as a distinct experiment that stands on its own as an analytical unit. Although each of the seven case studies in my research emphasized the rich, real-world context in which information exchange and companion influence occurred, case size was limited and, although innovative, the findings must be considered judiciously.

A second limitation of the study was the number of patients who were younger and in better health recruited to the study. Case selection bias by professionals could have contributed this limitation. Although overall cases were a heterogeneous group in terms of gender, cell type, treatment options and potential survival outcomes, data analysis showed that patients with advanced cancer could have been excluded from the study because their physicians believed it is not in their interest to participate or that they were too frail to do so. Professionals are frequent gatekeepers during recruitment and wish to protect the more vulnerable, frail and elderly patient population (Holloway and Wheeler, 2002; Polit et al, 2001). This was evidenced in the current study and cited as a common justification for not approaching certain patients. Professionals often face dilemmas when recruiting patients with life-threatening illness to research studies and although supportive of the research process have concerns about exacerbating anxiety at such a sensitive time in the illness journey (Ewing, Rogers, Barclay, McCabe et al, 2004). Such challenges with recruitment resulted in a less than typical case selection for this research with the overall effect that the study was unable to present evidence regarding both information exchange and companion influence and roles in patients who were elderly and with poorer performance status.

The final limitation concerned collection of companion demographic data. Both companion demographic information and data exploring their perception of the interaction was never requested formally. Some companion data was collated retrospectively from transcription narratives and researcher field notes. Collection of additional demographic data such as age, professional background and educational status would have been valuable when analysing companion demographic effect on preference for accompaniment and companion influence on information exchange and consequent roles. However, this reflects in part, the true nature of case study research, that the true significance of negotiated companion accompaniment and subsequent companion role and influence were only identified during the substantive analysis period when emerging theoretical propositions were inductively identified.

## 8.4. Negotiated accompaniment

This study generated new knowledge regarding the concept of negotiated companion accompaniment prior to clinical encounters. Whilst exploring the information exchange process between patients, companions and professionals, the study found that companions exerted an influential role on many constructs of information exchange. Those companions with a non-negotiated accompaniment to the consultation were shown to exert the most significant moderating influence. Within the study patient: companion negotiation divided into three distinct categories:

- Reciprocal: accompaniment was mutually agreed by both participants
- Partial: accompaniment partially coerced following companion petition
- Non-negotiable: accompaniment was immutable where companions did not broker discussion or consent.

My findings indicated when accompaniment was reciprocal or partially negotiated; companions predominantly demonstrated a mediating or enhancing influence on information exchange.

Conversely non-negotiated accompaniment was associated with vocal and expert companions with a significant moderating and controlling influence on information exchange.

Effective negotiation enhances the prospect of purposeful and meaningful communication. Conversely, ineffectual or non-negotiation is associated with conflicts and adversarial relationships which restrict the full potential of communication and information (Botelho, 1992). Although my data could not be informed by empirical evidence on negotiation between patients and companions prior to the consultation, investigation of the wider negotiation literature, although limited, demonstrated that companion negotiation can increase the dynamics and complexity of both information exchange and clinical care in other contexts. Rosenthal, Marshall, MacPherson and French (1980) emphasised the problems of both conflict and control, in the negotiated relationship between all care participants (patients, companions and nurses) or triads. Patients, companions and professionals came from different worlds, brought individual definitions of the clinical situation, as well as various goals. Professionals seek to control the clinical conditions of their work, whereas patients and companions seek to control the conditions of the clinical experience. Negotiation of control takes place in a situation of unequal power between the participants, with professionals operating from the most dominant position. In order to control companions within the clinical setting professionals cast them into three roles.

- *Visitor*: the preferred role as it is the least threatening to professionals
- *Worker*: companions adopting a more involved but still subordinate role
- *Expert*: orientated to patient care needs and as a consequence their actions could lead them to disrupt the fundamental features of ward clinical work

My research correspondingly identified the 'expert' role of non-negotiated companions who moderated and consequently altered the fundamental features of the information exchange process. The companions in my study adopted the role of expert, independent of any other individual, in direct contrast to Rosenthal and colleagues' findings that professionals cast companions in the expert role. My research showed that expertise was often conferred through a companion's established relationship and intimate health knowledge of the patient (Allen, 2000); past experience, healthcare training and the self-development of disease and treatment related knowledge (Nolan, Grant and Keady 1996). All factors which could theoretically have been instrumental in determining the moderating companion's decision not to negotiate their presence at clinic in the first place.

There was no indication in my study these expert companions felt subordinated, with a need to negotiate or relinquish control to other members of the triad. Companions came to the clinical encounter without negotiating their presence and guided their own information agenda by directing and controlling information exchanges. Importantly, they did so independently of any other member of the triad. Study evidence suggested that as singular individuals, they were both confident and influential in their own right to control the information exchange process, independent of coalition formation.

Coalitions occur when two individuals in a triad adopt a common strategy to achieve a mutually-desired decision despite the active or passive resistance of the third individual (Coe and Prendergast, 1985). Coe and Prendergast's analysis of interactions among physicians, elderly patients and their companions revealed each encounter involved several coalitions, where the majority of companions made efforts to form coalitions with physicians. Physicians are viewed as an important ally for companions because of their power and status within the triad. This is contrary to my study data which demonstrated that companions seemed unconcerned about the amount of power and expertise held by other individuals, relying instead on their own perceived expert status within the triad.

In a study exploring ways in which nurses, patients and companions negotiated care and the division of labour when patients were in medical wards in the UK, expert companions were found to constitute a special case in the understanding of negotiated care (Allen, 2000). Drawing on the three companion roles defined by Rosenthal et al (1980), Allen found that expert companions posed challenges to the basic features of the social organisation of the clinical work. Fundamentally the negotiation and subsequent integration of expert companions was described as problematic because companions perceived they were negotiating and delegating care for the patient and subsequently relinquishing control to professionals. Companion roles within the triad were identified as the third member and stated they were:

- *mediator* (negotiating equally and impartially between the other two)
- *exploiter* (seeking to turn a disagreement between the other two to their own advantage)
- *oppressor* (using a divide and conquer process, creating conflict to achieve their own ends).

My data showed, in contrast to Allen (2000), the expert companions in my study portrayed none of these roles. Likewise there was no indication of negotiation within the triad at the oncology out-patient consultation. Clinical context may be an important consideration for negotiating and relinquishing control. Allen's study was in-patient based where triadic exchanges could be more prolonged (over days and weeks). Within this clinical context, companions may recognise the severity of the patient's condition and the nature of continual care renders the patient particularly dependent on other members of the triad. Subsequently companion expert role is less defined.

My data was consistent with the findings of Hasselkus (1992) whereby companions have moved beyond viewing themselves merely as fonts of medical information and historical details, content with either forming coalitions with or relinquishing control to other triad participants. In her study Hasselkus analysed topical themes and exchanges of meaning between physicians, older patients and

family caregivers during medical appointments. Unexpectedly, she found that caregivers contributed to traditional physician domains of care such as diagnosis, interpretation of symptoms and treatment recommendations much more than anticipated. In line with my findings, companions exchanged information around medical aspects of care whilst bringing very little social context to the exchange. Companions viewed themselves as integral primary healthcare providers, with their long-term experience in monitoring symptoms, controlling medication and taking an active role in the health of the patient. This presentation of their role and place within the clinical consultation differs markedly from the model of coalitions (Coe and Prendergast, 1985).

Correspondingly, in my study companions acted more as independent practitioners, often as an expert and vocal individual for the purpose of fostering their own information agenda rather than in contention or even negotiation with the other members of the triad. In her study Hasselkus's sample was derived from an elderly population and it could be considered that companions would be more engaged in care activities requiring a high level of involvement when patients were both elderly and of poorer health status (Wolff and Roter, 2008). The clinical context within which negotiation transpires is an under-researched area and one worthy of further consideration.

My findings of the expert, controlling and non-negotiating companion were distinct to research undertaken by Morris and Thomas (2001). The overreaching aim of their qualitative study which interviewed 79 carers and patients was to obtain an account of the cancer experience from the carer's perspective. The research primarily focused on how carers negotiated their relationship within the medical setting. Unlike my research there was no indication that patients and companions negotiated companion presence *pre*-consultation. Also in direct contrast to the non-negotiated accompaniment found within my study, companions in this work were diffident about their place at the consultation and required to be 'invited in' both by the patient and the professional. Morris and Thomas found carers were reticent of entering the consultation, 'stood back' without contributing to the exchange,

were uncertain of their role and reserved about disturbing the privilege of the doctor-patient relationship. Carer diffidence about their role and accompaniment was due to concern about issues of confidentiality as well as maintaining a sense of independence for the patient. In my research even when companions displayed more neutral influence (Cases B and D) they still contributed to information exchange within the clinical encounter, although there was a greater sense of deference to the patient rather than diffidence. However, this respect for patient self-determination found in the neutral cases in my study was not evident in the replication analysis of some of the mediating cases and appeared to be absent in the moderating cases.

Although the primary focus of my study was not on exploring the carer's place within the clinical consultation, my data did not identify with any of the concerns of negotiated identity, support and sharing, among the moderating companions, recognised in the research by Morris and Thomas (2001). There is no immediate explanation as to why companions in my study were different to those of Morris and Thomas (especially as their sample included 10 patients with various stages of a lung cancer diagnosis). I have previously hypothesised that both personal characteristics and relationship alliances may have a significant influence within my study and the contrast between the two studies points to such variables.

My research data also illustrated an important consideration of moderating companion role, namely that of reducing collusion between patient and healthcare professionals, especially in relation to dialogue surrounding prognostic information. Within my study I viewed collusion in the terms and definition postulated by Helft (2005) whereby faced with a sensitive and uncomfortable situation (i.e. prognostic information exchange) patients and their clinicians often come to a tacit or explicit avoidance of dialogue. Within my study certain companions recognised this situation and altered information content and direction accordingly. Moderating companions were identified as patient advocates or surrogates, 'speaking-for' their loved one on a sensitive and emotive subject. Mazer,

Cameron, DeLuca, Mohile and Epstein (2014) examined pseudo-surrogacy among 46 companions accompanying patients with life-limiting cancer to clinical encounters where treatment options and outcomes were discussed. They identified a range of companion roles from pseudo-surrogacy (companions speaking as if the patient were unable to speak for himself), hearsay, and conflation of thoughts to co-experiencing and facilitation. In line with previous research that suggested companion role can be both influential but also dominant during clinical encounters (Karnieli-Miller, Werne, Neufeld-Kroszynski and Eidleman, 2012), Mazer et al found that companions often advocated and spoke on behalf of patients even when the patient was capable of engaging in the exchange. This companion role could be seen to either inhibit or enhance patient-centred care (Shepherd, Tattershall and Butow, 2008). Mazer et al (2014) warn that such moderating companion influence and perspective might sometimes allow him/her to communicate patient held values and concerns often more articulately than the patient. At other times is can be unclear whether it is the patient's or companions perspective that is being expressed.

The principle finding which emerged from my data was non-negotiated accompaniment was undertaken by expert, moderating companions with the ability to influence meaningful information exchange. Within my study, moderating companions often followed their own agenda to achieve their individual informational needs independent of other members of the triad. Also study data, in agreement with empirical research, demonstrated that companions had both expert knowledge of the patient and the healthcare context and viewed themselves equal partners in the information exchange process. In contrast to empirical data, moderating companions influenced information exchange without forming coalitions with or appearing subordinate to professionals and as referenced above, often felt confident to confront collusive situations.

Study findings revealed there may be other factors influential in shaping non-negotiated companion accompaniment. In particular, the clinical context appeared germane, as was the timing of

information, i.e. around the time of diagnosis and treatment. Within my analysis participants' characteristics, attitudes and interpersonal relationships with each other were further shown to be considerations relating to information exchange and companion presence during consultations. Consequently, there is an identified need for ongoing research focusing on negotiation within both the cancer and non-cancer context, at various stages of the patient journey and with all participants involved.

## 8.5. Factors impacting preference for accompaniment

The evidence presented in chapter 6 indicated that there were three distinct levels of negotiated accompaniment prior to the clinical consultation. There is further evidence that the level of negotiated accompaniment was associated with companion influence and impacted on the constructs of information exchange within the clinical encounter. My data analysis indicated the level of negotiated companion presence may be affected by other considerations namely, participant characteristics and interpersonal relationships which exist between them and these will be considered in the next three sections.

### 8.5.1. Patient characteristics impacting companion accompaniment

Although tentative, a key finding in my data is that although patient demographic characteristics are important and worthy of consideration, their companions are still likely to accompany them to the consultation irrespective of patient attributes or functional status. A significant difference between my data and empirical evidence is the influence that patient demographic characteristics have on companion accompaniment to clinical encounters. Although evidence in the literature is inconsistent, results from some studies indicate that accompanied patients are more likely to be older, female, less educated and in worse physical health (Wolff and Roter, 2008; Schilling et al, 2002; Glasser, Prohaska and Gravdal, 2001). My data contradicts these findings especially in relation to age, gender and physical functioning.

#### 8.5.1.1. Accompaniment rate: clinical context and age

Companion accompaniment rate in my study was high (100%). Theoretically there could be a number of justifications for such universal accompaniment. The majority of acute teaching hospitals throughout the United Kingdom adhere to national cancer guidelines recommending patients are accompanied to clinical consultations when information concerning the diagnosis and treatment will be exchanged (BTS, SIGN, NICE). Evidence from my study demonstrated that patients may need their companion to be present primarily as the diagnosis is cancer, regardless of age and physical functioning or because it was recommended.

Wide variation in the rate of accompaniment has been demonstrated according to clinical context and population studied. Low rates of accompaniment are found in studies when adult patients attended primary care or out-patient clinics (Schilling et al, 2002; Brown, Brett, Stewart and Marshall, 1998; Bothelo, Lue and Fiscella, 1996). Accompaniment rate was reported to rise when older patients (> 60 years of age) visited primary care or care of the elderly clinics (Ishikawa, Roter, Yamazaki and Takayama, 2005; Glasser et al, 2001). Accompaniment rate increased within oncology encounters (Street and Gordon, 2008) and more so when diagnosis was disclosed (Eggly, Harper, Penner, Gleason, Foster and Albrecht, 2011).

In an observational study by Brown et al (1998) to determine the proportion of accompanied patients and demographic characteristics, approximately a third of patients were accompanied to family practice visits. Children and patients over the age of 75 years were the most frequently accompanied. Adelman, Green and Ory (2000) commented that the one major characteristic that distinguished the geriatric medical visit from many other encounters was that often the older patient is accompanied by a third person. Accompaniment in this age group is associated with additional difficulties encountered by patients such as sensory deficits, cognitive impairment and functional limitations (Ishikawa et al, 2005; Wolff and Roter, 2008). Despite two of the patients in my study being

over 70 years there was no indication of any significant functional deficits requiring physical assistance aside from transport (Adelman et al, 2000).

In a study carried out by Street and Gordon (2008) 64% of newly diagnosed lung cancer patients were accompanied to Veterans Affairs medical centre consultations. This figure is markedly lower than the accompaniment rate in my study, but may in part be explained by the fact that Street and Gordon recruited mainly male Veterans from culturally diverse backgrounds. A small but not insignificant number of their sample was African-American men who are less likely to bring a companion to cancer consultations (Eggly et al, 2011; Gordon et al, 2006).

Importantly my study demonstrated there was no difference in accompaniment rates with respect to age, underpinning the findings by Street and Gordon (2008) who also demonstrated this. My data, although comparable with Street and Gordon consisted of a younger group of patients with lung cancer (median age = 64 years). It is not possible from the evidence presented here to state categorically why the cases in my study were younger (but selection bias at recruitment may be a factor), but age was not a significant influence impacting the rate of companion accompaniment.

**8.5.1.2. Accompaniment rate: gender**

Gender did not influence the rate of accompaniment in my study. However my data was based on small case numbers and did not reflect the power differentials seen for gender influence in other larger studies. There are also inconsistencies highlighted regarding gender within the empirical data. In the systematic review conducted by Laidsaar-Powell et al (2013) two studies found that accompanied patients were more likely to be female (Glasser et al, 2001). Brown et al (1998) concurred with this finding that female patients were more likely to be accompanied to family practice visits. Nevertheless, in the Brown study, accompanied females were often elderly and accompanied by elderly female siblings. Equally, gender was found to have no bearing on rate of accompaniment in

other studies (Eggly et al, 2011; Ishikawa et al, 2005; Labrecquel Blanchard, Ruckdeschel and Blanchard, 1991). Ishikawa et al (2005) reported male patients were frequently accompanied more than their female counterparts. However, cultural differences and the collectivist culture in Japan may have influenced male accompaniment rate in this study where, out of elder respect, it may be the norm for elderly males to be accompanied. Further research is required to determine if demographic variables, influential in some international studies, reflect cultural and historic practices (Andrades, Kauser and Ambreen, 2013; Ishikawa et al, 2005).

#### 8.5.1.3. Accompaniment rate: educational status

My findings suggested educational status to have little influence on accompaniment as across cases there was homogeneity within this domain (i.e. the majority of cases had secondary school education). Empirically it has been shown that patients with less educational status are most frequently accompanied to clinical encounters (Ishikawa et al, 2005; Wolff and Roter, 2008; Schilling et al, 2002). Of relevance to my data is that two of three studies which showed no influence by educational level were conducted in the oncology setting. My findings paralleled those of Street and Gordon (2008) who failed to identify any relationship between educational status and companion accompaniment in a lung cancer setting.

#### 8.4.1.4. Accompaniment rate: disease and physical status

Two key findings emerged from my research concerning physical status and accompaniment. Firstly, the majority of patients (n=5) in my research were diagnosed with advanced disease with treatment intent palliative. Uncharacteristically, despite advanced disease, all of the cases had good performance status and functional ability. Disease classification and poorer health status are two of the most significant factors influencing the frequency of companion accompaniment to clinical encounters (Street and Gordon, 2008). Contrary to existing research although all patients in my study experienced good health and physical function, they were all accompanied to all of their consultations.

Secondly, despite awareness that information exchange within the clinical encounter would involve discussion concerning complex therapies and treatment outcomes, some patients did not wish to be accompanied to the consultation. This finding contradicted literature which suggested when patients are faced with uncertainty and anxiety they seek companion presence at consultations (Labrecque et al, 1991) and companion presence at oncology consultations is seen as normative among cancer patients (Beisecker and Moore, 1994). The negotiated nature of accompaniment identified in my study indicates this is not universally the case for all patients within this clinical context.

In conclusion, my analysis revealed that despite advanced disease and uniformly poor prognostic outlook, none of the patients had poor functional ability, yet there was universal accompaniment. By contrast other research showed patients are more likely to be accompanied to consultations when they have worse physical health and poorer functional status (Wolff and Roter, 2008; Ishikawa et al, 2005; Schilling et al, 2002; Labrecque et al, 1991). I consider that the nature of the disease itself is a key feature of accompaniment even in the absence of poor health status. Data analysis would suggest that of patient related characteristics, health status and more pertinently the nature of the disease are the principal variables influencing companion accompaniment, as there is no overall effect noted from the other variables discussed above. Even when patients are functionally well and wish to be unaccompanied, companion presence still prevailed.

#### 8.5.1.5. Companion characteristics and interpersonal relationships impacting accompaniment

Although my data did not demonstrate patient characteristics as a major influence on negotiated accompaniment, companion characteristics and interpersonal relationships between patients and companions appeared to have been a more persuasive influence on companion presence. My findings corresponded with recent literature in terms of companion gender but contrasted with relationship characteristics. Wolff and Roter (2011) in their meta-analytical review of 17 quantitative studies investigating the dynamics and consequences of patient accompaniment found that companions were

on average 63 years of age and predominantly female (79.4%). Patients were accompanied in 54.7% of cases by spouses followed by adult children (32.2%). Systematic review of mixed method research also identified the same companion demographics and interpersonal relationships internationally (Laidsaar-Powell et al, 2013).

A higher accompaniment by adult children in my research may have reflected both divorce and widowed status. In my study only two of the cases were currently married (Case D and F) and they were accompanied by their spouses. Case G was accompanied by his ex-wife. The remaining cases were either widowed (Cases A, B and C) or divorced (Case E). Theoretically these cases may have been accompanied by spouses under different circumstances. Instead adult children and a sibling fulfilled the role of accompanying companion, with information exchange ultimately impacted by accompanying companion composition and moderating behaviour.

Of the three cases in my study with the most moderating companions with non-negotiated presence, two were males (an adult son [Case E] and a brother [Case C]) and two were females (adult daughters [Cases E and F]). Likewise my data analysis showed that in other cases where moderating behaviour was demonstrated and presence was partially negotiated (Case A – Agnes and Case G, Grace) female companions were more verbally dominant. This is consistent with other studies which demonstrated that female companions tend to be more assertive and dominant than men when interacting at consultations (Glasser et al, 2001). Contrary to research which suggested that verbally dominant companions facilitated patient involvement in the medical visit by prompting patients to ask questions and interact in dialogue, subsequently promoting patient autonomy; among the most moderating companions in my study there was no indication that patient autonomy guided the agenda (Clayman et al, 2005).

Substantive data analysis allowed significant themes to emerge inductively which showed some companion personalities as expert, controlling and moderating. Identification of these companion personality traits allowed my research to illustrate behaviours had significant influence on negotiated or more pertinently non-negotiated accompaniment and consequent information exchange. Data demonstrated these companions were vocal and often opinionated even in clinical encounters with experienced professionals. Despite widespread agreement regarding the importance of companion involvement and support in the context of cancer consultations, a review of the literature discloses a relative dearth of research investigating the personality traits and behaviour of companions during clinical consultations (Eggly, Harper, Penner, Gleason et al, 2011). Despite recognition that companion behaviour affects the dynamics of all stages of the triadic interaction, where even in a single visit, companions may range from facilitative and supportive to argumentative and controlling (Albrecht, Eggly and Ruckdeschel, 2010), research has focused less on companion personality traits and more on demographics such as race and age (Street and Gordon, 2008).

My findings appear to correspond with the perspective of earlier researchers who presented ideas on the nature of both negotiation and triad behaviour whereby interactions may change depending on a variety of factors, not least the characteristics and relationships of its members (Kleinman, 1979). My analysis indicated that both negotiated accompaniment and the information exchange process was more moderated when the patient was female and the accompanying companion was an adult child (of either gender) or a male sibling. Yet as discussed in chapter 6, none of the female patients with moderating companions were passive recipients of care, in poorer health or elderly. My data failed to highlight specific patient characteristics which could account for such moderating influence from companions.

Therefore, it could be suggested that the interpersonal relationships between these three patients and companions influenced accompaniment. Relationships co-existed or ‘fitted’ without negotiation

of their mutual relationships, but were also persuasively governed by strong, expert companions who were likely to attend the consultations as a direct result of their own personalities and agendas, irrespective of patient preference or characteristics.

Co-existence and negotiated care were themes identified when Coeling, Biordi and Theis (2003) described the ways in which companions and patients negotiated the rules that influence the care experience. Their qualitative study was part of a larger examination of 60 care dyads and their use of respite care in the Midwestern United States. Using content analysis they analysed the data from interviews conducted between caregivers and care-receivers to suggest how the care experience 'fits' into their lives. They constructed the theory of caregiver and care-receiver dyadic identity, which was mutually agreed upon when both parties negotiated a set of rules about their conduct together and their relationship. Importantly, the rules which govern the relationship can be consciously decided or implicit and taken for granted (Botelho, 1992). In comparison with my findings, Coeling et al found that relationships can co-exist regardless of whether the contributions from each member are equal. Conceptually, one party can be more controlling and give more than the other. Dyadic negotiation and relationships take place within an important social context, with its attendant conditions, which include both individual perceptions of the relationship and the issues which are important to each individual (Morley, 1986).

Although Coeling et al (2003) advanced the theory of both dyadic negotiation and the influences on care processes and outcomes; they failed to investigate the ways that processes are influenced by age, gender, ethnicity and other demographic and relationship variables. Like other empirical studies and my own research, the opportunity was lost to capitalise on this significant area of research. What my study provided was an important opportunity to identify moderating companions and the influence of their behaviours on both negotiated-non-negotiated accompaniment and information exchange within the triad encounter. Future research should focus specifically on what aspects of companion

demographic variables and patient-companion relationship alliances impact on dyad negotiation relating to companion accompaniment.

## 8.6. Perception of companion accompaniment

This study provided an important opportunity to advance the understanding of companion accompaniment at clinical consultations and their subsequent influence on information exchange. It specifically identified six constructs which were moderated and mediated by companions within triadic encounters. Additionally, the opportunity to understand the perception of patients and professionals regarding companion accompaniment and influence was afforded during this research. There has been little research exploring triadic relationships and what evidence there is historically focused on encounters involving care of the elderly (Haug, 1994). The patient-physician-companion interaction at consultations is complex. Each member of the triad brings different perspectives to the encounter (Quinn, Clare, McGuinness and Woods, 2012). My study demonstrates the divergent viewpoints of patients and professionals and provides new knowledge relating to triadic perception within the oncology context.

### 8.6.1. Patient perception

In my study there was no indication that patients perceived companion accompaniment negatively. Even when companions moderated the information exchange process there was no suggestion that patients were dissatisfied with companion input. Equally in cases where companions either negotiated their presence (Cases A, B and G) or where accompaniment was non-negotiated (Cases C, E and F), patients appeared content with companion level of involvement.

Analysis revealed that Cases A and B wanted to attend the clinical consultation on their own. Both men viewed accompaniment as an additional burden for companions. They felt strongly about the avoidance of companion burden. Self-perceived burden is an important issue faced by patients with

cancer, with over 70% of patients with advanced cancer reporting mild to extreme levels (McPherson, Wilson and Murray, 2007). Posing a burden to companions has emerged consistently in qualitative research as a domain relevant to quality care at end of life (Singer, Douglas, Martin and Kelner, 1999); the maintenance of dignity and is an important consideration in actual treatment related decisions (Ashby, Kellehear and Stoffell, 2005).

However, despite strong feelings regarding non-accompaniment and following negotiation with companions, both cases acceded to companion presence. This finding was in contrast to Beisecker and Moore (1994) who found that although patients generally preferred accompaniment, they also believed they should be the one who decided whether companions attend. Additionally Case B strongly believed he alone should have autonomous ownership of information exchanged about his diagnosis and treatment with the inclusion of family members at his discretion.

Benson and Britton (1996) found that overwhelmingly patients opposed companions influencing information that was provided to them, with notions of ownership of body, illness and information mentioned by over 60% of the patients they surveyed. Acknowledgement of the needs and wishes of their loved ones was the reason for A and B finally acquiescing and agreeing to accompaniment.

Allowing for different levels of negotiated accompaniment in my study, overall patients commented favourably on companion involvement across cases. Patients appreciated companion involvement in information seeking, clarification and retention. This is consistent with the existing literature examining patient preference for companion involvement in consultations which also demonstrated that companion participation is generally accepted and welcomed (Repetto, Piselli, Raffaele and Locatelli, 2009). Patients in my study commented that emotional support or being present were also important companion roles and again this finding is illustrated empirically (Repetto et al, 2009; Kimberlin, Brushwood, Allen, Radson and Wilson, 2004).

Notably none of the patients in my study reported that companion accompaniment impacted negatively on any aspect of information exchange. Similarly, none of them wished in hindsight to be unaccompanied, even in the most moderating and non-negotiated cases. My findings reflect those of Schilling et al (2002) who found 84% of patients attending primary care consultations stated companion presence very helpful. Of the patients who were unaccompanied, 16% regretted their decision and thought in hindsight having a companion would have been beneficial (Schiling et al, 2002). Data described in section 7 noted that even in the most moderating of information exchanges; patients did not comment that the process was made untenable by companion influence. However, several other studies have shown companion presence and role within the consultation can impact negatively on information exchange (Brown et al, 1998; Hasselkus, 1992; Labrecque et al, 1991). Companion involvement can reduce direct interaction between patient and professionals; with patients in accompanied visits found to be excluded from companion-professional conversations and ultimately less involved in joint decision-making (Greene, Adelman, Friedman and Charon, 1994).

Within my study there seemed to be an implicit acceptance of moderating companions and as illustrated this may be a direct consequence of patient-companion established relationships. Exploring the association between patients' expectations regarding the communication role of companions, it was found that while patients varied in their ratings of companion helpfulness, few reported any disadvantage to having a companion present (Ishikawa, Roter, Yamazaki, Hashimoto and Yano, 2006). A caveat of the Ishikawa and co-workers' study is that the setting was a Japanese geriatric clinic where cultural and traditional deferential views of relationships may strongly influence outcomes. That said, reflecting my data, these same relationship factors may account for the fact that patients are often routinely accompanied to their hospital visits by companions where relationship bonds are firmly established and the interplay of family relationships and individual personality 'quirks' and traits are well known to both patient and family (Ishikawa et al, 2006).

Within my research there appeared to be an implicit acceptance and understanding of companion dynamics and relationships. Difficulties and strategies of involving family members with dysfunctional dynamics in cancer care was a theme explored by Speice et al (2000). They found while companions are an integral part of patient care, they bring with them a range of emotional reactions, interpersonal dynamics and expectations. Often these dynamics exist prior to the diagnosis and frequently become exacerbated by it. However, as disruptive and dysfunctional as companion personality traits and family relationships are, they are often interconnected and more likely accepted by patients. Patients are used to dealing with their own family dynamics and any chaotic responses and behaviours (Speice et al, 2000).

My data analysis indicated even when companions exhibited moderating influences within the consultation; this may be their usual dynamic. Consequently patients accepted and allowed without complaint moderating behaviour and its subsequent effect on accompaniment and information exchange.

### 8.6.2. Professional perception

A central finding in my data analysis was the difference between the patient and professional's perception of companion accompaniment. Analysis showed whereas patients were accepting of companion accompaniment and influence on information exchange, professionals appeared less so. Three professionals gave unsolicited opinion concerning the most moderating behaviours of companions, explicitly Cases C, E and F, the three non-negotiated accompanying companions identified in the study. My data demonstrated patient and professional perception of companion accompaniment were polarised. Essentially, patients remarked only on mediating and supportive influence, whereas professionals expressed opinion exclusively on moderating behaviours.

Companion expertise, control and agenda were identified as the three principal influences inextricably linked and affecting the dynamics of information exchange within the current study. Analysis demonstrated professionals also perceived companions used control and their own agenda to moderate and influence the direction and content of information. Companions within my study were shown to promote their own information agenda, which at times appeared different to that of the patient's and the professional's. Agenda setting and the companion as an expert practitioner are issues identified as potentially problematic both in my data and elsewhere in the literature.

Hasselkus (1992) explored family caregiver-professional relationships in the medical setting when the patient was elderly. In line with my findings Hasselkus's data showed whereas companions believed they acted as primary care givers interacting as a second practitioner with the professional, physicians viewed the companion as a patient substitute and an alternate source of information. Similarly, my results showed companions acted as independent practitioners to further their own information agenda. Also the more attention given to companion information agenda the less consideration was given to patient and professional agenda.

My data showed that departure from professional clinical agendas can cause discord with physicians who perceived that clinical information was neglected in pursuit of a different agenda by companions. The relationship between agendas and physician stress was noted in a study by Yaffe and Klvana (2002). Exploring family physician attitudes to interfacing with family caregivers, they found that although most family doctors believed it was their responsibility to address companion concerns within triadic encounters, 81% found this activity stressful. A significant cause of stress was different agendas or conflicting responses from patients and companions. Differing care needs between the two was a cause of much concern for doctors which created additional complex challenges as companion agenda took precedent over those of the patient (Yaffe and Klvana, 2002).

Companion agenda was a significant construct identified in my data and comparable to research by Schilling et al (2002). These authors discovered that whilst companion accompaniment favourably influenced patient and physician understanding, it could also add greater social and medical complexity. Echoing earlier studies, my research identified companions discussed their own agendas, and influenced the encounter with moderating or controlling behaviours towards the patient (Labrecque et al, 1991).

There was no evidence of stress among professionals in my study. However companion presence appeared to increase the complexity and dynamics of the consultation resulting in moderating and controlling influences which altered the content and direction of the encounter. Although data showed that companions were vocal and influential and pursued their own information agendas, there was no evidence in my research that companion accompaniment rendered information exchange untenable.

Still, Greene et al (1994) cautioned that the presence of a companion can impact on clinical practice significantly. Investigating the effects of the presence of a third person on the physician-older patient medical interview, these researchers concluded companion presence can limit the exchange of information and the establishment of good rapport between patients and physicians. Green et al also found that patients often raised fewer issues and are less assertive in the presence of a companion, thus potentially failing to address their own agenda. Importantly when companions do raise concerns they may not reflect the patient's needs and current concerns. In accord with my data these researchers concluded that patients and companions may attend the consultation with very different agendas and the presence of a companion could undermine the development of a trusting patient-physician relationship which consequently compromises patient care (Greene et al, 1994).

## 8.7. Patient – professional discordance

My analysis revealed a measure of patient and professional discordance as a consequence of differing perceptions of companion accompaniment. Results showed that patients and professionals had polarised perspectives especially pertaining to moderating companion behaviours. Importantly patients did not voice any concerns regarding moderating behaviours such as companion control or more specifically companion agenda, which influenced both accompaniment and the information exchange process. In contrast, in some cases professionals expressed opinions on moderating behaviours which impacted the content and direction of the consultation information exchange. Recognising the negative impact of moderating behaviour, one professional within my study also recognised the potential impact on clinical patient care. Understanding patient healthcare beliefs, values and preferences is a fundamental feature of patient-centred care (Epstein and Street, 2007); with any lack of agreement or impasse potentially signalling a deficiency in patient clinical care (Epstein and Peters, 2009).

Current evidence indicates that professionals often have a poor understanding of patient perspective and little insight into the patient as person, including prior behaviour or family involvement (Duggan, Geller, Cooper and Beach, 2006). Street and Haidet (2011) explored factors affecting physician understanding of patient health beliefs using a cross sectional, observational method of 207 patients and 29 primary care physicians. They determined that the physician's perceptions of health beliefs differed significantly from patients. Similar to my data, physicians had a relatively poor understanding of patient perception of health beliefs; believing patient beliefs mirrored theirs with a level of shared understanding. Additionally, physicians perceive the quality of their interactions with patients differently from patients with a tendency to under-estimate patient desire for information (Willems, De Maesshalck, Deveugele, Derese and De Maeseneer, 2005) and shared decision-making (Bruera, Sweeney, Calder, Palmer et al, 2001).

However, in parallel with my findings, there was a recognised discord between physicians and patients not just on the outcome of the medical encounter but also the nature of the health condition being addressed. Street and Haidet (2011) suggested physicians may misperceive how patients understand medical issues and point to the need for both parties to develop shared understanding within clinical encounters. This would seem especially relevant within the oncology context where complex information is exchanged at triadic encounters.

## 8.8. Summation

Within lung cancer management this study made a new contribution to the body of evidence by exploring information exchange between patient, companions and professionals. The findings discussed in the sections above suggest that companion accompaniment to lung cancer consultations is often a negotiated process. When the accompaniment is identified as non-negotiated it is predominantly by companions who moderate the information exchange process. Persuasive influences shaped negotiated accompaniment and are summarised as (i) factors impacting preference for accompaniment (ii) perception of companion's accompaniment and (iii) patient-professional discordance. Having identified these influences and discussed them in relation to the wider literature each of these will be explored in relation to implications clinical practice and future research in the concluding chapter.

# Chapter 9. Conclusions and recommendations clinical practice and future research

## 9.1. Introduction

The aim of the final chapter is to summarise the key findings and relate them to implications for clinical practice. The chapter will conclude with my recommendations for future research.

The research used a multiple case study design, informed by a constructivist paradigm, to explore the exchange of information between patients, companions and professionals at lung cancer consultations. It is a design appropriate to investigating new subject areas, when resultant theory is often novel and empirically valid and this approach to lung cancer management had not been reported previously in the literature.

## 9.2. Conclusion of the thesis and key findings

Findings in the preceding chapters suggest that, whilst exploring the original concept of information exchange between study participants during lung cancer consultations, new emerging theoretical propositions were identified in relation to influential factors impacting the information process during these clinical encounters. Information content (what information was exchanged and not exchanged) was an important consideration, but across cases, was carried out to a level which appeared to have utility for all triad participants. Data showed there may have been other contextual factors influencing the content and direction of information exchange. Results from the analysis demonstrated that accompanying companions emerged as an influential factor during the clinical encounter.

The findings provided new insight into companion presence during cancer consultations as mediating, moderating or neutral influences, adding to an existing knowledge base regarding the specific constructs impacted. However, in terms of emerging theory my study further conceptualised and refined these constructs to specify the distinctive role companions of patients with lung cancer

assumed. Data analysis showed that in some cases companion presence at lung cancer consultations was found to be a non-negotiated accompaniment.

Significant interrelating factors influencing non-negotiated companion accompaniment emerged from my research and I considered these emerging concepts to have clinical relevance in terms of contemporary cancer practice.

## 9.3. Summary of key findings

### 1. Content

Recognising the influence companions have on the content and direction of the information exchange process, as conceptualised by Charles et al (1999), was crucial. The positive influence of accompanying companions, identified in the literature, on patient-professional interactions supports the value of companions being present during consultations. Equally useful is identifying when the role is non-supportive and challenging to both patient and professional information exchanges and deviates from important clinical interactions, as was the situation in the most moderating of cases in my study.

### 2. Demographic characteristics

There was universal accompaniment to consultations. Although accompaniment to consultations appears to be unanimously accepted, some patients would prefer to be unaccompanied to the clinic encounter. Accompaniment occurs via a process of negotiation. Non-negotiated companion presence is associated with expert companions who moderate the information exchange processes with skilful use of their own information agenda. Importantly companion presence was determined by a range of variables connected to levels of negotiation and characteristics of patients and companions. The breadth of studies in triadic clinical encounters addressing negotiation is narrow, unreported in the out-patient oncology setting and rarely concentrates on the demographic variables of all participants. However, it was specifically companion attributes as well as interpersonal relationships which

appeared to determine the level of both negotiated presence and moderating companion behaviour. Of particular interest is that healthcare teams recommend to patients with lung cancer that they are accompanied to clinical consultations. Such recommendations are endorsed in national policy directives (BTS, 2013; NICE, 2005; SIGN, 2005).

**3. Preference for and perspective of accompaniment**

Despite the dynamics and complexities of the consultation being moderated by companions, there was no evidence to demonstrate that patients found companion presence and subsequent influence untenable. Even among those patients who stated their original preference was for an unaccompanied consultation, moderating companion presence was accepted. However, within the study professional perceptions of moderating influence conflicted dramatically, with recognition that the complexity and direction of clinical information could be compromised by companion presence.

**4. Discordance**

Discordance between patient and professional perception of the utility of companion accompaniment was evidenced during this study. In some encounters incongruence was manifest between the perceptions of two key members of triad, with a potential to impact clinical care at a fundamental level. Such discordance identified within my data may well illustrate that patients and professionals assess the clinical encounter and the component parts of it, differently, ultimately leading to divergent perceptions and goals during the consultation and process of information exchange.

## 9.4. Implications for practice

The results of this study have clinical implications for practitioners involved in the informational and care needs of patients and companions within the oncology setting. Although companions are often perceived as helpful within the consultation and their presence can result in perceived benefits such as increased patient understanding and improved quality and quantity of information, based on the

findings of my study there needs to be a greater understanding among professionals of the ways in which information exchange can be influenced by companions.

The emerging theory suggested that expert companions adopted a significant moderating role and controlled many aspects of informational content. Findings suggest that professionals should be aware of and respect patient preference regarding companion involvement. This in some ways contradicts policy initiatives which recommend, often universally, that patients should be actively encouraged be accompanied to the clinical encounter (BTS, 2013, NICE, 2005, SIGN 2005), when in fact unwanted accompaniment may result in negative outcomes for patients.

The following key points are drawn from the findings of the substantive analysis of the emerging theoretical proposition:

- Professionals may find it worthwhile to seek clarification of companion role and purpose of accompaniment at the outset of the consultation. Ascertain from the patient and/or the companion why the companion has accompanied the patient to the clinic encounter, especially as there may be discordance between the patient and companion perception of accompaniment
- Be aware and respect patient preference for accompaniment – if patient preference is to retain control over the informational content and decision-making role then this should be respected. Professionals should be cognisant that companion accompaniment is often non-negotiated and has the express aim of satisfying companion and not patient agenda.
- If companion led agenda is evident, it may be useful to highlight helpful companion behaviours and discuss the various supportive roles companions can adopt
- Reflect upon your own practice, recognising where discord may be apparent and communication blocking techniques may be employed

- Consider national guidance which recommends almost universal accompaniment to consultations and respect patient preference for accompaniment.

## 9.5. Recommendations for future research

Several implications for future research were identified. They come with the caveat that the sample size in my study was small.

1. The clinical and social context of the disease process and the stage of the care pathway is worthy of further investigation. For example, are companions more involved and influential in the diagnostic phase of the disease process or does moderating influence continue into post-therapy follow up and survivorship stages of the continuum?
2. Companion roles appear to vary considerably and do so depending on perceived need of individual patients. Other characteristics and variables, such as companion personality and demographic attributes, as well as relationship alliances, may also influence information exchange. These require further assessment.
3. There is little contemporary evidence to inform both the role and impact of negotiated companion accompaniment at out-patient clinical encounters. This needs to be studied further.
4. A study documenting the characteristic attributes and preferences of patients who prefer to attend consultations unaccompanied would be recommended. A clearer understanding is required of how the specific needs and characteristics of patients influence companion accompaniment.
5. There is a paucity of data within oncology settings relating to the impact of patient-professional discordance and its effect on information exchange and clinical care processes. As discordance has the potential to negatively impact clinical care further research in this vital area would be valuable.

## Reference List


Adelman RD, Green MG, Charon R (1987) The Physician-Elderly Patient-Companion Triad in the Medical Encounter: The Development of a Conceptual Framework and Research Agenda. *The Gerontologist*. 27 (6) 729-734.

Adelman RD, Green MG, Ory MG (2000) Communication between older patients and their physicians. *Clinics in Geriatric Medicine*. 16 (1) 1–24.

Albrecht TL, Eggly SS, Ruckdeschel JC (2010) Communicating with relatives/companions about cancer care. In Kissane DW, Bultz BD, Butow PM, Finlay IG (Eds) *Handbook of communication in oncology and palliative care*. New York. Oxford University Press.

Albrecht TL, Penner L, Cline R, Eggly S, Ruckdeschel J (2009) Studying the process of clinical communication: issues of concepts, context, and research directions. *Journal Health Communication*. 14, 47–56.

Allen D (2000) Negotiating the role of expert carers on an adult hospital ward. *Sociology of Health and Illness.* 22 (2) 149-171.

Allen D (2004) Ethno-methodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. *Nursing Inquiry*. 11. 14-24

Anderson JM, Blue C, Lau A (1991) Women's perspectives on chronic illness: ethnicity, ideology and restructuring of life. *Social Science and Medicine.* 33 (2) 101-13.

Andrades M, Kausar S, Ambreen A (2013) Role and Influence of the Patient's Companion in Family Medicine Consultations: 'The Patient's Perspective'. *Journal of Family Medicine and Primary Care*. 2 (3) 283-287.

Anthony S, Jack S (2009) Qualitative case study methodology in nursing research: an integrative review. *Journal of Advanced* Nursing 65 (6) 1171–1181.

Arora NK (2003) Interacting with cancer patients: the significance of physicians' communication behaviour. *Social Science and Medicine*. 57, 791-806.

Arora NK, Gustafson DH, Hawkins RP, McTavish F, Cella DF, Pinigree S, Mendenhall JH, Mahvi DM (2001) Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: a prospective study. *Cancer.* 92, 1288–1298.

Arraras JA, Wright S, Greimel E, Holzner B, Kuljanic-Vlasic K, Velikova G, Eisemann M, Visser A (2005) Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. *Patient Education and Counselling*. 54 (2) 235–241.

Ashby, MA, Kellehear A, Stoffell, BF (2005) Resolving conflict in end-of-life care. *Medical Journal of Australia*. 183 (5) 230-1.

Aupérin A, Arriagada R, Pignon JP, Le Péchoux C, Gregor A, Stephens RJ, Kristjansen PE, Johnson BE, Ueoka H, Wagner H, Aisner J (1999) Prophylactic cranial irradiation in patients with small-cell lung cancer and complete remission. *New England Journal of Medicine*. 341. 476-48.

Baile WF, de Moor C (2005) Breaking bad news to patients: physicians' perceptions of the process. *Current Opinions in Oncology*. 17, 331–335.

Bakker DA, Fitch MI, Gray R, Reed E, Bennett J (2001) Patient-health care provider communication during chemotherapy treatment: The perspectives of women with breast cancer. *Patient Education and Counselling*, 43 (1) 61-71.

Barclay JS, Blackhall LJ, Tulsky JA (2007) Communication strategies and cultural issues in the delivery of bad news. *Journal of Palliative Medicine*. 10 (4) 958-77.

Baron RM, Kenny DA (1986) Moderator-Mediator Variables Distinction in Social Psychological Research: Conceptual, Strategic, and Statistical Considerations. *Journal of Personality and Social Psychology*. 51 (6) 1173–82.

Barry CA, Bradley C, Britten N, Stevenson F, Barber N (2000) Patients' unvoiced agendas in general practice consultations: Qualitative study. *British Medical Journal*. 320, 1246–1250.

Bartunek J, Seo M (2002) Qualitative research can add new meanings to quantitative research. *Journal of Organizational Behaviour*. 23, 237-242.

Baxter P, Jack S (2008) Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report.* 13 (4) 544-559.

Beach WA, Anderson J (2003a) Communication and cancer? Part I: The noticeable absence of interactional research. *Journal of Psychosocial Oncology.* 21 (3) 1-23.

Beach WA, Anderson J (2003b) Communication and Cancer? Part II: Conversation Analysis. *Journal of Psychosocial Oncology*. 21 (4) 1-20.

Beach WA, Easter DW, Good JS, Pigeron E (2005) Disclosing and responding to cancer "fears" during oncology interviews. *Social Science and Medicine*. 60 (4) 893-910.

Beauchamo TL, Childress JF (2001) *Principles of Biomedical Ethics*. Oxford. Oxford University Press.

Beisecker AE, Moore WP (1994) Oncologists' perceptions of the effects of cancer patients' companions on physician–patient interactions. *Journal of Psychosocial Oncology*. 12. 23–39.

Bell RA, Kravitz RL, Thom D, Krupat E, Azari R (2001). Unsaid but not forgotten—Patients' unvoiced desires in office visits. *Archives of Internal Medicine*. 161. 1977–1984.

Bennett JA (2000) Mediator and moderator variables in nursing research. *Research in Nursing and Health*. 23 (5) 415-20.

Benson J, Britten N (1996) Respecting the autonomy of cancer patients when talking with their families: Qualitative analysis of semi-structured interviews with patients. *British Medical Journal*. 313. 729-731.

Bergen A, While A (2000) A case for case studies: exploring the use of case study. *Journal of Advanced Nursing*. 31 (4) 926–934.

Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB (1988) Information and decision-making preferences of hospitalized adult cancer patients. *Social Science and Medicine.* 27 (11) 1139–1145.

Blaxter L, Hughes C, Tight M (2006) *How to Research*. Buckingham. Open University Press.

Botelho RJ (1992) A Negotiation Model for the Doctor-Patient Relationship. *Journal of Family Practice*. 9 (2) 210-218.

Botelho RJ, Lue BH, Fiscella K (1996) Family involvement in routine health care: a survey of patients' behaviours and preferences. *Journal of Family Practice*. 42 (6) 572–576.

Bowen EF, Raynor CFJ (2002) Patient and GP led delays in the recognition of symptoms suggestive of lung cancer. *Lung Cancer*. 37. 227-228.

Bozcuk H, Martin C (2002) Does treatment delay affect survival in non-small cell lung cancer? A retrospective analysis from a single UK centre. *Lung Cancer*. 34. 243–52.

Bredart A, Boulec C, Dolbeault C (2005) Doctor-patient communication and satisfaction with care in oncology. *Current Opinion in Oncology.* 17. 351-4.

British Thoracic Society (2008) *Giving information to lung cancer patients*. London. British Thoracic Society.

British Thoracic Society (2013) *Sharing information with lung cancer patients*. London. British Thoracic Society Reports.

Britten N, Stevenson F, Barry CA, Barber N, Bradley C (2000). Misunderstandings in prescribing decisions in general practice: Qualitative study. *British Medical Journal*. 320. 484–488.

Brown JB, Brett P, Stewart M, Marshall JN (1998) Roles and influence of people who accompany patients on visits to the doctor. *Canadian Family Physician*. 44, 1644–1650.

Brown RF, Hill C, Burant CJ, Siminoff LA (2008) Satisfaction of early breast cancer patients with discussion during initial oncology consultations with a medical oncologist. *Psycho-Oncology*. 18 (1) 42-9.

Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S (2001) Patient preferences versus physician perceptions of treatment decisions in cancer care. *Journal of Clinical Oncology* 19: 2883–2885.

Brundage MD, Feldman-Stewart D, Cosby R, Gregg R, Dixon P, Youssef Y, Mackillop WJ (2001) Cancer patients' attitudes toward treatment options for advanced non-small cell lung cancer: implications for patient education and decision support. *Patient Education and Counselling*. 45 (2) 149-57.

Bugge C, Entwistle VA, Watt IS (2006) The significance for decision-making of information that is not exchanged by patients and health professionals during consultations. *Social Science and Medicine*. 63. 2065–2078.

Bultz BD, Thorne S, Fitch MF (2004) Who owns emotional care of the cancer patient? Untangling the conceptual confusion. *Oncology Exchange*. 3. 32–35.

Burkitt-Wright E, Holcombe C, Salmon P (2004) Doctors' communication of trust, care and respect in breast cancer: qualitative study. *British Medical Journal*. 328. 864.

Cape J, McCulloch Y (1999) Patients' reasons for not presenting emotional problems in general practice consultations. *British Journal of General Practice*. 49. 875-879.

Casarett DJ, Karlawish JT (2000) Are Special Ethical Guidelines Needed For Palliative Care Research? *Journal of Pain and Symptom Management*. 20 (2) 130–139.

Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science and Medicine*. 4. 681–692.

Charles C, Gafni A, Whelan T (1999) Decision-making in the physician–patient encounter: Revisiting the shared treatment decision-making model. *Social Science and Medicine*. 49. 651–661.

Clark AM, Thompson DR (2013) Succeeding in research: insights from management and game theory. *Journal of Advanced Nursing*. 69 (6) 1221-1223.

Clayman ML, Morris MA (2013) Patients in context: Recognizing the companion as part of a patient-centered team. *Patient Education and Counselling*. 91 (1) 1-2.

Clayman ML, Roter D, Wissow LS, Bandeen-Roche K (2005) Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science and Medicine.* 60 (7) 1583-1591.

Clayton JM, Butow PN, Arnold RM, Tattersall MHN (2005) Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer*. 103. 1965-1975.

Coe RM, Prendergast R (1985) Research note: the formation of coalitions: interaction strategies in triads. *Sociology of Health and Illness*. 7. 237–247.

Coeling HV, Biordi DL, Theis SL (2003) Negotiating Dyadic Identity Between Caregivers and Care Receivers. *Journal of Nursing Scholarship*. 35 (1) 21-25.

Colbourne L, Sque M (2004) Split personalities: Role conflict between the nurse and the nurse researcher. *Nursing Times Research.* 9 (4) 297-304.

Coleman T (2000) Using video-recorded consultations for research in primary care: advantages and limitations*. Family Practice*. 17. 422-427.

Cormack D (2000) *The research process in nursing* (4th Ed). Oxford. Blackwell Science.

Corner J, Hopkinson J, Fitzsimmons D (2005) Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. *Thorax.* 60. 314-319.

Coulter A (2002) *The autonomous patient: Ending paternalism in medical care*. London. The Stationery Office.

Coulter A (2007) Shared decision-making: The debate continues. *Health Expectations*. 8. 95–96.

Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L (2006) Information needs and experiences: an audit of UK cancer patients. *European Journal of Oncology Nursing.* 10 (4) 263-272.

Cresswell JW (2004) *Research design: qualitative, quantitative and mixed methods approaches* (2nd). London. Sage Publications.

Darke P, Shanks G, Broadbent M (1998) successfully completing case study research: combining rigour, relevance and pragmatism. *Information Systems Journal*. 8. 273-289.

Davidson JR, Brundage MD, Feldman-Stewart D (1999) Lung cancer treatment decisions: patients' desire for participation and information. *Psycho-oncology*. 8. 511-520.

Davidson R, Mills ME (2005) Cancer patients' satisfaction with communication, information and quality of care in a UK region. *European Journal of Cancer Care*. 14 (1) 83–90.

Davis RJ (2010) Case study database. In Mills A, Durepos G, Wiebe C (Eds). *Encyclopedia of Case Study Research*. London. Sage Publications.

Davison BJ, Parker PA, Goldenberg SL (2004) Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *British Journal Urology.* 93 (1) 47-51.

Deane KA, Degner LF (1998) Information needs, uncertainty, and anxiety in women who had a breast biopsy with benign outcome. *Cancer Nursing*. 21 (2) 117–126.

Denscombe M (2003) *The good research guide for small-scale social research projects* (2nd Ed). Philadelphia. Open University Press.

Denzin NK, Lincoln YS (2003) *Collecting and Interpreting Qualitative Materials*. California. Sage Publications.

Department of Health (1998) *Guidance on commissioning cancer services: improving outcomes in lung cancer*. London. Department of Health.

Department of Health (2007) *The Cancer Reform Strategy*. London. Department of Health.

Department of Health (2010) *Equity and Excellence: Liberating the NHS*. London. Department of Health.

Department of Health (2012a) *A consultation on strengthening the NHS Constitution.* London. *Department* of Health.

Department of Health (2012b) *The NHS Outcomes Framework 2013/14*. London. Department of Health.

Dieppe P, Rafferty A, Kitson A (2002) The clinical encounter – the focal point of patient centred care. *Health Expectations*. 5 (4) 279-281.

Dokken D, Ahmann E (2006) The many roles of family members in 'family-centred care' – Part I. *Paediatric Nursing*. 32 (6) 562- 565.

Dowling M (2006) Approaches to reflexivity in qualitative research. *Nurse Researcher*. 13 (3) 7-21.

Dubey S, Brown RL, Esmond SL, Bowers BJ, Healy JM, Schiller JH (2005) Patient preferences in choosing chemotherapy regimens for advanced non-small cell lung cancer. *The Journal of Supportive Oncology.* 3. 149-154.

Duggan PS, Geller G, Cooper LA, Beach MC (2006) The moral nature of patient centredness: Is it "just the right thing to do"? *Patient Education and Counselling.* 62. 271– 276.

Earle C (2004) Outcomes Research in Lung Cancer. *Journal of the National Cancer Institute Monographs.* No. 33. 56-76.

Edwards M, Davies M, Edwards A (2009) What are the external influences on information exchange and shared decision making in healthcare consultations: A meta-synthesis of the literature. *Patient Education and Counselling.*75. 37-52.

Eggly S, Harper FW, Penner LA, Gleason MJ, Foster T, Albrecht TL (2011) Variation in question asking during cancer clinical interactions: a potential source of disparities in access to information. *Patient Education Counselling*. 82 (1) 63–68.

Eisenhardt KM (1989) Building Theories from Case Study Research. *The Academy of Management Review.* 14 (4) 532-550.

Eisenhardt, KM, Graebner ME (2007) Theory building from case studies: opportunities and challenges. *Academy of Management Journal*. 50 (1) 25-32.

Ellingson L (2002) The roles of companions in geriatric patient–interdisciplinary oncology team interactions. *Journal of Aging Studies*. 16. 361–382.

Elwyn G, Charles C (2001) Shared decision-making the principles and competencies. In Edwards A and Elwyn G (Eds) *Evidence based patient choice: Inevitable or impossible?* (pp. 118–143). Oxford. Oxford University Press.

Elwyn G, Edwards A, Gwyn R, Grol R (1999) Towards a feasible model for shared decision making: Focus group study with general practice registrars. *British Medical Journal*. 31. 753–756.

Elwyn G, Edwards A, Kinnersley P (1999) Shared decision-making in primary care: The neglected second half of the consultation. *British Journal of General Practice*. 49. 477–482.

Entwistle VA, Firnigl D, Ryan M, Francis J, Kinghorn P (2012) Which experiences of healthcare delivery matter to service users and why? A critical interpretive synthesis and conceptual map. *Journal Health Service Research Policy*. 17 (2) 70-78.

Entwistle VA, Watt IS (2013) A capabilities approach to person-centred care: response to open peer commentaries. *American Journal Bioethics*. 13 (8) 29-39.

Entwistle VA, Williams B, Skea Z, Maclennan G, Bhattacharya S (2006) Which surgical decisions should patients participate in? Reflections on women's recollections of discussions about different types of hysterectomy. *Social Science and Medicine*. 62. 499–509.

Epstein RM, Peters EP (2009) Beyond information: exploring patient preferences. *Journal of American Medical Association* 302 (2) 195-197.

Epstein RM, Alper BS, Quill TE (2004) Communication evidence for participatory decision making. *Journal of American Medical Association*. 291. 19. 2359-2369.

Epstein RM, Street RL (2007) *Patient-Centred Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: NIH; 2007. NIH Publication 07-6225.

Ewing G, Rogers M, Barclay S, McCabe J, Martin A and Todd C (2004) Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliative Medicine*. 18. 452-459.

Faden RR, Beauchamp TL (1988) A history and theory of information-exchange in consultation: the patients' view of performance and outcomes. *Patient Education and Counselling*. 25. 237-246.

Fadiman A (1997) *The spirit catches you and you fall down*. New York. Farrar, Straus and Giroux.

Fagerlind H, Lindblad AK, Bergstrom I, Nilsson M, Naucler G, Glimelius B, Ring L (2008) Patient-physician communication during oncology consultations. *Psycho-Oncology*. 17 (10) 975-985.

Fallowfield L (2010) Foreword. In Kissane DW, Bultz BD, Butow PM, Finlay IG (Eds) *Handbook of communication in oncology and palliative care*. New York. Oxford University Press.

Fallowfield L, Ratcliffe D, Jenkins V, Saul J (2001) Psychological morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer*. 84. 1011– 1015.

Feldman-Stewart D, Brundage MD, Tishelman C (2005) A conceptual framework for patient-professional communication: an application to the cancer context. *Psycho-oncology*. 14 (10) 801–809.

Ferguson RJ, Gregor A, Dodds R, Kerr G (1996) Management of lung cancer in South East Scotland. *Thorax*. 51. 903–906.

Ferlay P, Autier M, Boniol M, Heanue M, Colombet M, Boyle P (2007) Estimates of the cancer incidence and mortality in Europe in 2006. *Annals of Oncology*. 18 (3) 581-592.

Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR (1999) Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology*. 17. 371-379.

Ford JS, Fallowfield LJ, Lewis S (1996) Doctor-patient interactions in oncology. *Social Science and Medicine*. 42. 1511-1519.

Ford JS, Reutter LI (1990) Ethical dilemmas associated with small sample sizes. *Journal of Advanced Nursing.* 15 (2) 187-91.

Francis R (chair) (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.* The Stationery Office.

Gabrijel S, Grize L, Helfenstein E, Brutsche M, Grossman P, Tamm M, Kiss, A (2008) Receiving the diagnosis of lung cancer: patient recall of information and satisfaction with physician communication. *Journal of Clinical Oncology.* 26. 297-302.

Gafni A, Charles C, Whelan T, (1998) The physician as a perfect agent for the patient versus the informed treatment decision-making model. *Social Science and Medicine.* 47. 347-354.

Galloway S, Graydon, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, Rich-van der Bij L, West RN, Blair B (1997) Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *Journal of Advanced Nursing*. 25 (6) 1175-1183.

Gattellari M, Voigt KJ, Butow PN, Tattersall, MHN (2002) When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *Journal of Clinical Oncology,* 20 (2) 503-513.

George Al, Bennett A (2004) *Case Studies and Theory Development in the Social Sciences*. Cambridge. MIT Press.

Gibbert M, Ruigrok W (2010) The 'What' and 'How' of Case Study Rigor: Three Strategies Based on Published Work. *Organizational Research Methods.* 13 (4) 710-737.

Gillham B (2001) *Case Study Research Methods.* London. Continuum.

Glasser M, Prohaska T, Gravdal J (2001) Elderly Patients and their Accompanying Caregivers on Medical Visits. *Research on Aging*. 3 (3) 326-348.

Goodrich J, Cornwell J (2008) *Seeing the Person in the Patient*. London. The King's Fund.

Gordon HS, Street RL, Sharf BF, Souchek J (2006) Racial differences in doctors' information-giving and patients' participation*. Cancer*. 107 (6) 1313–1320.

Grahn G, Danielson M (1996) Coping with the cancer experience. II. Evaluating an education and support programme for cancer patients and their significant others. *European Journal of Cancer Care.* 5. 182-187.

Greene MG, Adelman RD, Friedmann E, Charon R (1994) Older patient satisfaction with communication during an initial medical encounter. *Social Science and Medicine*. 38 (9) 1279–1288.

Gregor A, Milroy R (2001) Lung Cancer. In: Scottish Executive Health Department *Cancer Scenario: An Aid to Planning Cancer Services in Scotland in the next decade*. Edinburgh: The Scottish Executive. http://www.show.scot.nhs.uk

Griffin JP, Koch KA, Nelson JE, Cooley ME (2007) Palliative care consultation, quality-of-life measurements, and bereavement for end-of-life care in patients with lung cancer: ACCP evidence-based clinical practice guidelines (2nd edition). *Chest.* 132 (3 suppl). 404S-422S.

Hack TF, Degner LF, Parker PA (2005) The communication goals and needs of cancer patients: a review. *Psycho-oncology*. 14 (10) 831–845.

Hagerty RG, Butow PN, Ellis PM (2005) Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis*. Journal of Clinical Oncology*. 23. 1278-1288.

Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MHN (2005). Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology*. 16 (7) 1005–1053.

Haidet K, Tate J, Divirgilio-Thomas D, Kolanowski A, Eberly ER, Happ M (2009) Methods to Improve Reliability of Video Recorded Behavioural Data. *Research in Nursing and Health*. 32(4) 465–474.

Hall WA, Callery P (2001) Enhancing the rigour of grounded theory: incorporating reflexivity and rationality. *Qualitative Health Research*. 11 (2) 257-272.

Hamilton W, Peters TJ, Round, Sharp D (2005) What are the clinical features of lung cancer before the diagnosis is made? A population based case-control study. *Thorax*. 60. 1059-1065.

Hammersley M (2008) *Questioning qualitative research*. London. Sage Publication.

Hammersley M, Atkinson P (2007) *Ethnography: Principles in Practice* (3rd) edition. London. Routledge.

Hammersley M, Gomm, R (2000). Introduction. In Gomm R, Hammersley M, Foster P (Eds), *Case study method: Key issues, key texts*. London. Sage Publication.

Hancock B (2002) *Trent Focus for Research and Development in Primary Health Care: An Introduction to Qualitative Research*. Trent Focus Group.

Hartley J (2004) Case study research. In Cassell C, Symon G (Eds.) *Essential guide to qualitative methods in organizational research*. London. Sage Publication.

Hasselkus BR (1992) Physician and Family Caregiver in the Medical Setting: Negotiation of Care? *Journal of Aging Studies.* 6. 67-80.

Hasslekus B (1994) THREE-TRACK CARE: Older Patient, Family Member, and Physician in the Medical Visit. *Journal of Ageing Studies*. 8 (3) 291-307.

Haug MR (1994) Elderly patients, caregivers, and physicians: theory and research on health care triads. *Journal of Health and Social Behaviour*. 35 (1) 1–12.

Helft PR (2005) Necessary Collusion: Prognostic Communication with Advanced Cancer Patients. *Journal of Clinical Oncology*. 23. 13. 3146-3150.

Herr K, Anderson GL. (2005). *The Action Research Dissertation: A Guide for Students and Faculty*. California. Sage.

Hewitt-Taylor J (2002) *Case study: An approach to qualitative enquiry. Nursing Standard* 16 (20) 33-37.

Hill KM, Amir Z, Muers MF, Connolly CK, Round RG (2003) Do newly diagnosed lung cancer patients feel their concerns are being met? *Journal of Cancer*. 12 (1) 35-45.

Hirschfeld RM, Keller MB, Panico S, Arons BS, Barlow D, Davidoff F, Endicott J, Froom J, Goldstein M, Gorman JM, Marek RG, Maurer TA, Meyer R, Phillips K, Ross J, Schwenk TL, Sharfstein SS, Thase ME, Wyatt RJ (1997) The National Depressive and Manic-Depressive Association consensus statement on the under-treatment of depression. *Journal of American Medical Association*. 277 (4) 333-340.

Hodkinson P, Hodkinson H (2001) *The Strengths and Limitations of Case Study Research.* Paper presented to the Learning and Skills Development Agency conference. Making an Impact on Policy and Practice. Cambridge. 5-7 December 2001.

Hoffman PC, Mauer AM, Vokes EE (2000) Lung cancer. *Lancet*. 355. 479–85.

Holloway I, Wheeler S (2002) *Qualitative research in nursing*. (2nd Ed). Oxford. Blackwell Publishing.

Holtz A (2003) Lung cancer: why doesn't it get the respect its gargantuan toll demands? *Oncology Times* 11. 25 (21) 27-28.

Hopkinson JB, Wright DNM, Corner JL (2005) Seeking new methodology for palliative care research: challenging assumptions about studying people who are approaching end of life. *Palliative Medicine* 19 (7) 532–7.

Houts PS, Yasko JM, Kahn SB, Schelzel GW, Marconi KM (1986) Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. *Cancer*. 58 (10) 2355-61.

Information and Statistics Division (2008) Cancer In Scotland. Edinburgh. Information and Statistics Division Scotland.

Institute of Medicine (2001) *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC. National Academy Press.

International Agency for Research on Cancer (2007) *Cancer Incidence in Five Continents*. No 160. Lyon, France. IARC Scientific Publication.

Ishikawa H, Roter DL, Yamazaki Y, Hashimoto H, Yano E (2006) Patients' perceptions of visit companions' helpfulness during Japanese geriatric medical visits. *Patient Education and Counselling.* 61. 80-6.

Ishikawa H, Roter DL, Yamazaki Y, Takayama T (2005) Physician–elderly patient–companion communication and roles of companions in Japanese geriatric encounters. *Social Science and Medicine.* 60 (10) 2307–2320.

Jansen J, van Weert JC, Wijngaards-de Meij L, van Dulmen S, Heeren TJ, Bensing JM (2010) The role of companions in aiding older cancer patients to recall medical information. *Psycho-oncology*. 19. 170-9.

Janssen-Heijnen MLG, Coebergh JWW (2003) The changing epidemiology of lung cancer in Europe. *Lung Cancer*. 41 (3) 245-258.

Jassem J (2002) Combined chemotherapy and radiotherapy in inoperable non-small cell lung cancer. *Lung Cancer*. 3. Suppl 3. S43-46.

Jenkins V, Fallowfield L, Saul J (2001) Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer*. 84. 48–51.

Jensen AR, Mainz J, Overgaard J (2002) Impact of Delay on Diagnosis and Treatment of Primary Lung Cancer. *Acta Oncologica*. 41 (2) 147–152.

Jootun D (2009) Reflexivity: promoting rigour in qualitative research. Nursing Standard. 23.23. 42-46.

Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware A (1996) Characteristics of physicians with participatory decision-making styles. *Annals Internal Medicine*. 124 (5) 497-504.

Karnieli-Miller O, Werner P, Neufeld-Kroszynski G, Eidleman S (2012) Are you talking to me? An exploration of the triadic physician-patient-companion communication within memory clinics encounters. Patient Education and Counselling. 88. 381-390.

Kemmis S, McTaggart R (2000) Participatory Action Research: communicative action and the public sphere. In Denzin NK, Lincoln YS (Eds) *Strategies of Qualitative Inquiry*. California. Sage Publications.

Kendall M, Boyd K, Campbell C, Cormie P, Fife S, Thomas K, Weller D, Murray SA (2006). 'How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers'. *Family Practice*. 23. 644–50.

Kesson E, Bucknall CE, McAlpine LG, Milroy R, Hole D, Vernon DR, Macbeth F, Gillis CR (1998) Lung cancer-management and outcome in Glasgow, 1991-92. *British Journal of Cancer.* 78 (10) 1391-5.

Kim S, Kaplowitz S, Johnston M (2004) The effects of physician empathy on patient satisfaction and compliance*. Evaluation Health Professional*. 27. 237-251.

Kimberlin C, Brushwood D, Allen W, Radson E, Wilson D (2004) Cancer patient and caregiver experiences: communication and pain management issues. *Journal of Pain Symptom Management*. 28. 566–578.

Kirwan JM, Tincello DG, Lavender T, Kingston RE (2003) How doctors record breaking bad news in ovarian cancer. *British Journal of Cancer.* 24 (6) 839-42.

Kissane DW, Bultz BD, Butow PM, Finlay IG (2010) *Handbook of communication in oncology and palliative care*. New York. Oxford University Press.

Kleinman A (1979) Recognition and Management of Illness Problems: Therapeutic Recommendations from Clinical Social Science', Massachusetts General Hospital Review for Physicians: *Psychiatric Medicine Update*. New York. Elsevier.

Koyi H, Hillerdal G, Branden E (2002) Patient's and doctors' delays in the diagnosis of chest tumours. *Lung Cancer*. 35. 53–7.

Kruijver IPM, Kerkstra A, Bensing JM, van de Wiel HBM (2000) Nurse-patient communication in cancer care: a review of the literature. *Cancer Nursing*. 23. 20-31.

Kuzel AJ (1999) *Sampling in Qualitative Inquiry*. In Crabtree BF, Miller WL (Ed). *Doing Qualitative Research*. Thousand Oaks, CA. Sage Publications.

Labaree R (2002) The risk of 'going observationalist': negotiating the hidden dilemmas of being an insider participant observer*. Qualitative Research* 2 (1) 97-122.

Labrecque MS, Blanchard CG, Ruckdeschel JC, Blanchard EB (1991) The impact of family presence on the physician-cancer patient interaction. *Social Science and Medicine*. 33 (11) 1253–1261.

Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WW, Jansen J, McCaffery KJ, Shepherd HL, Tattersall MH, Juraskova I (2013) Physician-patient-companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Education and Counselling*. 91. 3-13.

Lampic C, Sjödén PO (2000) Patient and staff perceptions of cancer patients' psychological concerns and needs: a review. *Acta Oncologica.* 39. 9–22.

Larkin V (2013) Encounters in the field, challenges and negotiations in midwifery research. *Evidence Based Midwifery.* www.rcm.org.uk/content/encounters-in-the-field-challenges-and-negotaitions

Lavrakas P (2008) *Encyclopaedia of survey research methods*. California. Sage Publications.

Lee A, Baskerville R (2003) Generalizing Generalizability in Information Systems Research. *Information Systems Research.* 14. 3.

Liang W, Burnett CB, Rowland JH, Meropol NJ, Eggert L, Hwang Y, Silliman RA, Weeks JC, Mandelblatt JS (2002) Communication between physicians and older women with localized breast cancer: Implications for treatment and patient satisfaction. *Journal of Clinical Oncology.* 20 (4) 1008–1016.

Lilenbaum RC, Cashy J, Hensing TA, Young S, Cella DP (2008) Prevalence of Poor Performance Status in Lung Cancer Patients: Implications for Research. *Journal of Thoracic Oncology*. 3 (2) 125-129.

Lincoln YS, Guba E (2005) *Naturalistic Inquiry*. London. Sage Publications.

*Maguire P (1999) Improving communication with cancer patients.* European Journal of Cancer. 35. 1415-1422.

Marteau TM (1989) Framing of information: Its influence upon decisions of doctors and patients. *British Journal of Social Psychology*. 28 (1) 89–94.

Maxwell J (2004) Casual Explanation, Qualitative Research, and Scientific Inquiry in Education. *Educational Researcher* 33 (2) 3–11.

Mazer BL, Cameron RA, DeLuca JM, Mohile SG, Epstein RM (2014) 'Speaking-for' and 'speaking-as': Pseudo-surrogacy in physician-patient-companion medical encounters about advanced cancer. *Patient Education and Counselling*. 96. 36-42.

McCloone P (2004) *Carstairs Scores for Scottish Postcode Sectors from the 2001 Census*. Glasgow. MRC Social and Public Health Sciences Unit.

McNeill J, Nolan A (2011) Midwifery research buy midwifery researchers: challenges and considerations. *Evidence Based Midwifery*. 9 (2). 61-65.

McPherson CJ, Wilson KG, Murray MA (2007) Feeling like a burden: exploring the perspectives of patients at the end of life. *Social Science and Medicine*. 64 (2) 417-427.

Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, Fallowfield L (1996) Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *British Medical Journal.* 313 (7059) 724-6.

Merriam S (1998). *Qualitative research and case study applications in education*. San Francisco. Jossey-Bass.

Miles MB, Huberman AM (1994) *Qualitative data analysis: An expanded sourcebook*. London. Sage Publications.

Mills M, Sullivan K (1995) The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *Journal of Clinical Nursing*. 8. 631-642.

Montazeri A, Hole DJ, Milroy R, McEwen J, Gillis CR (2003) Quality of life in lung cancer patients: does socioeconomic status matter? *Health and Quality of Life Outcomes.* 1. 19-24.

Montazeri A, Milroy R, Gillis CR, McEwen J (1996) Interviewing cancer patients in a research setting: the role of effective communication. *Supportive Care Cancer*. 4. 447–54.

Moore S (2009) Lung cancer: causes and management. *Cancer Nursing Practice*. 8 (9) 27-34.

Morley I (1986) Negotiating and bargaining. In Hargie O (Ed) *A handbook of communication skills*. New York. New York University Press.

Morris SM, Thomas C (2001) The carer's place in the cancer situation: where does the carer stand in the medical setting? *European Journal of Cancer Care*. 10. 87–95.

National Cancer Institute (2009a) Small cell lung cancer treatment. www.cancer.gov/cancertopics/treatment/small-cell-lung/healthprofessionals-accessed October 5th 2009.

National Cancer Institute (2009b) Cancer of the Lung and Bronchus (Invasive). SEER Cancer Statistics Review 1975-2006. http://seer.cancer.gov/csr/1975_2006/results/sect_15_ table.25.pdf- accessed October 5th 2009.

National Institute for Clinical Excellence (2005) *Lung Cancer*: NICE guidelines. http://www.nice.org.uk/CG024NICEguidelines

National Institute for Health and Clinical Excellence (2011) *Lung Cancer: Diagnosis and Treatment*. Clinical guideline 121. London. NICE.

Nelson JE, Gay EB, Berman AR, Powell CA, Salazar-Schicchi J, Wisnivesky JP (2011) Patients rate physician communication about lung cancer. *Cancer.* 117 (22) 5212-20.

Neuman LW (1997) *Social Research Methods: Qualitative and Quantitative Approaches'.* Needham Heights, MA. Allyn and Bacon.

Neumann M, Wirtz M, Bollschweiler E, Mercer S, Warm M, Wolf J (2007) Determinants and patient-reported long-term outcomes of physician empathy in oncology: a structural equation modelling approach. *Patient Education and Counselling*. 69. 63-75.

Nolan M, Grant G, Keady J (1996) *Understanding family care*. Buckingham. Open University Press.

Non-Small Cell Lung Cancer Collaborative Group (1995) Chemotherapy in non-small cell lung cancer: a meta-analysis using updated data on individual patients from 52 randomised clinical trials. *British Medical Journal*. 311. 899-909.

Nvivo 9®. Qualitative Data Analysis Software. www.qsrinternational.com

Office for Audit and Clinical Effectiveness (2008) *Statistics & incidence of lung cancer in men and women in North Glasgow.* Greater Glasgow and Clyde NHS Trust.

Oken MM, Creech RH, Tormey DC, Horton J, Davis TE, McFadden ET, Carbone PP (1982) Toxicity and Response Criteria of the Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*. 5. 649-655.

Ong LM, de Haes JC, Hoos AM, Lammes FB (1995) Doctor – patient communication: a review of the literature. *Social Science and Medicine*. 40. 903–918.

Parahoo K (2006) *Nursing research: Principles, Process and Issues*. London. Macmillan Press.

Pardon K, Deschepper R, Stichele R, Bernheim A, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, van Kerckhoven W, Deliens L (2010) Preferences of patients with advanced lung cancer regarding the involvement of family and others in medical decision-making. *Journal of Palliative Medicine.* 13. 1199–1203.

Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L (2001) Breaking bad news about cancer: patients' preference for communication. *Journal of Clinical Oncology*. 19 (7) 2049-56.

Patton E, Appelbaum S (2003) 'The case for case studies in management research'. *Management Research News.* 26 (5) 60–71.

Patton MQ (2002) *Qualitative Research and Evaluation Methods*. California. Sage Publications.

Payne S, Field D, Rolls L, Hawker S, Kerr C (2007) Case study research methods in end-of-life care: reflections on three studies. *Journal of Advanced Nursing*. 58 (3) 236-45.

Pettigrew, A (1988) *Longitudinal field research on change: Theory and practice*. Paper presented at the National Science Foundation Conference on Longitudinal Research Methods on Organisations. Austin. Texas.

Phipps EJ (2002) What's End of Life Got to Do With It? Research Ethics with Populations at Life's End. *The Gerontologist*. 42 (suppl 3) 104-108.

Pignon JP, Arriagada R, Ihde DC, Johnson DH, Perry MC, Souhami RL, Brodin O, Joss RA, Kies MS, Lebeau B, Onoshi T, Osterlind K, Tattershall MHN, Wagner H (1992). A meta-analysis of thoracic radiotherapy for small-cell lung cancer. *New England Journal of Medicine*. 327. 1618-1624.

Polit D, Hungler B (2001) *Nursing Research, Principles and Methods*. Philadelphia. Lippincourt.

Quinn C, Clare L, McGuinness T, Woods RT (2012) Negotiating the balance: The triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. *Dementia.* 12 (5) 588-605.

Quirt CF, Mackillop WJ, Ginsburg AD, Sheldon L, Brundage, Dixon P, Ginsburg LM (1997) Do doctors know when their patient don't? A survey of doctor–patient communication in lung cancer. *Lung Cancer*. 18. 1–20.

Ream E, Richardson A (1996) The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. *European Journal of Cancer Care.* 5.132–138.

Repetto P, Piselli M, Raffaele C, Locatelli (2009) Communicating cancer diagnosis and prognosis: when the target is the elderly patient – a GIOGer study. *European Journal of Cancer*. 45. 374–383.

Riege AM (2003) Validity and reliability tests in case study research: a literature review with "hands-on" applications for each research phase. *Qualitative Market Research: An International Journal*. 6 (I) 275 – 86.

Ritchie J, Lewis J (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London. Sage Publications.

Roberts C, Benjamin H, Chen L, Gavigan M, Gesme DH, McCarthy P (2005) Assessing communication between oncology professionals and their patients. *Journal of Cancer Education*. 20. 113-118.

Rodin G, Mackay JA, Zimmermann C, Mayer C, Howell D, Katz M, Sussman J, Browers M (2009). Clinician-patient communication: a systematic review. *Support Care Cancer*. 17 (6) 627–644.

Rogers M, Todd C (2002) Information exchange in oncology outpatient clinics: source, valence and uncertainty. *Psycho-oncology. 11. 336-345.*

Rosenthal C, Marshall VW, MacPherson AS, French SE (1980) *Nurses, patients and families*. London. Croom-Helm.

Roter D, Stewart M, Putnam S, Lipkin M, Stiles W, Inui L (1997) Communication patterns of primary care physicians. *Journal of the American Medical Association*. 277 (4) 350-356.

Rowley J (2002) Using case studies in research. *Management Research News*. 25 (1) 16-27.

Rubin HJ, Rubin IS (1995) *Qualitative Interviewing: The Art of Hearing Data*. California. Sage Publications.

Rutten LF, Arora NK, Bakos AD, Aziz N, Rowland J (2005) Information needs and sources of information among cancer patients: a systematic review of research (1980–2003) *Patient Education Counselling*. 57 (3) 250–261.

Ryan GW, Bernard RH (2003) Techniques to Identify Themes. *Field Methods***.** 15 (1) 85-109.

Salander P, Henriksson R (2005) Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. *Lung Cancer*. 50. 155-162.

Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P (2000) The unmet supportive care needs of patients with cancer. *Cancer*. 88 (1) 226–237.

Saunders M, Dische S, Barrett A (1997) Continuous hyper fractionated accelerated radiotherapy (CHART) versus conventional radiotherapy in non-small-cell lung cancer: a randomised multicentre trial. CHART Steering Committee. *Lancet*. 350. 161-5.

Schattner A, Tal M (2002) Truth telling and patient autonomy: the patient's point of view. American *Journal of Medicine*. 113 (1) 66-9.

Schilling LM, Scatena L, Steiner JF, Albertson GA, Lin CT, Cyran L, Ware L, Anderson RJ (2002) The third person in the room: frequency, role, and influence of companions during primary care medical encounters. *Journal of Family Practice*. 51 (8) 685–69.

Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB (2004) Better physician patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal General Internal Medicine*. 19. 1096- 1103.

Schofield PE, Butow PN, Thompson JF, Tattersall MHN, Beeney LJ, Dunn SM (2003) Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology*. 14. 48-56.

Scottish Executive (1998) Data Protection Act. Edinburgh. Scottish Executive.

Scottish Executive (2000) Our Nation Health: A plan for action, a plan for change. Edinburgh. Scottish Executive.

Scottish Executive (2003) NHS code of Practice on Protecting Patient Confidentiality. Edinburgh. Scottish Executive.

Scottish Executive (2006) Cancer in Scotland: Action for change. Edinburgh. Scottish Executive.

Scottish Executive (2008) Better Cancer Care. Edinburgh. Scottish Executive.

Scottish Intercollegiate Guidelines Network (2005) Management of Patients with Lung Cancer. A National Clinical Guideline. Edinburgh. SIGN.

Searle JR (1995) *The Construction of Social Reality*. London. Penguin.

Seawright J, Gerring J (2008) Case Selection Techniques in Case Study Research A Menu of Qualitative and Quantitative Options. *Political Research Quarterly*. 2008 61 (2) 294-308.

Sell L, Devlin B, Bourke SJ, Munro NC, Corris PA, Gibson GJ (1993) Communicating the diagnosis of lung cancer. *Respiratory Medicine*. 87. 61–3.

Sethi T (2004) Lung cancer specialist calls for cash to beat 'Cinderella' disease. *www.scienceblog.co/community*

Shakir M (2002) The selection of case studies: Strategies and their applications to IS implementation cases studies. *Research Letters Information and Mathematical Sciences.* 3. 191-198.

Shepherd HL, Tattersall MHN, Butow PN (2008) Physician-identified factors affecting patient participation in reaching treatment decisions. *Journal of Clinical Oncology*. 26. 1724–1731.

Shields CG, Epstein RM, Fiscella K, Franks P, McCann R, McCormick K, Mallinger J (2005) Influence of accompanied encounters on patient-centeredness with older patients. *Journal American Board Family Practice.* 18. 344-54.

Simons H (2009) *Case study research in practice*. London. Sage Publications.

Singer P, Douglas K. Martin, DK, Kelner M (1999) Quality End-of-Life Care Patients' Perspectives. *Journal of American Medical Association.* 281 (2) 163-168.

Skea ZC, MacLennan SJ, Entwistle VA, N'Dow J (2014) Communicating good care: A qualitative study of what people with urological cancer value in interactions with health care providers. European *Journal of Oncology Nursing*. 18. 35-40.

Slort W, Schweitzer BPM, Blankstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, Van der Horst HE, Deliens L (2011) Perceived barriers and facilitators for general practitioner – patient communication in palliative care: A systematic review. *Palliative Medicine*. 25 (6) 613-629.

Speice J, Harkness J, Laneri H, Frankel R, Roter D, Kornblith AB (2000) Involving family members in cancer care: focus group considerations of patients and oncological providers *Psycho-oncology*. 9. 101–112.

Speziale S, Carpenter HJ, (2007) *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia, PA. Lippincott Williams and Wilkins.

Stake R (2005). *The Art of case study Research*. London. Thousand Oaks.

Stead ML, Brown JM, Fallowfield L, Selby P (2002) Communication about sexual problems and sexual concerns in ovarian cancer: a qualitative study. *The Western Journal of Medicine.* 176. 18-9.

Step MM, Rose JH, Albert JM, Cheruvu VK, Siminoff LA (2009) Modelling patient-centred communication: oncologist relational communication and patient communication involvement in breast cancer adjuvant therapy decision- making. *Patient Education and Counselling*. 77. 369-378.

Stevenson FA , Barry CA, Britten N, Barber N, Bradley CP (2000) Doctor–patient communication about drugs: the evidence for shared decision making. *Social Science and Medicine*. 50 (6) 829–840.

Street RL (1991) Information-giving in medical consultations: the influence of patients' communicative styles and personal characteristics. *Social Science and Medicine.* 32 (5) 541-548.

Street RL, Gordon HS (2008) Companion participation in cancer consultations. *Psycho-Oncology.* 17 (3) 244–251.

Street RL, Gordon HS, Ward MM, Krupat E, Kravitz RL (2005) Patient Participation in Medical Consultations: Why Some Patients are More Involved Than Others. *Medical Care*. 43 (10) 947-1064.

Street RL, Haidet P (2011) How well do doctors know their patients? Factors affecting physician understanding of patients' health beliefs. *Journal of Geriatric and Internal Medicine.* 26 (1) 21-27.

Street RL, Makoul G, Arora NK, Epstein RM (2009) How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counselling*. 74. 295-301.

Surbone A, Baider L, Weitzman TS, Brames MJ, Rittenberg CN, Johnson J (2009) Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Support Care Cancer*. 18 (2) 255–263.

Tattershall M (2003) Enhancing communication in the lung cancer consultation. *Lung Cancer.* 41.1.

Teutsch C (2003) Patient-doctor communication. *Medical Clinics of North America*. 87 (5) 1115-45.

The AM, Hak T, Koeter G, van der Wal G (2001) Collusion in doctor-patient communication about imminent death: An ethnographic study. *Western Journal of Medicine*. 174 (4) 247–253.

Thom DH (2000) Training physicians to increase patient trust. *Journal of Evaluation in Clinical Practice*. 6. 245-253.

Thomas G (2009) *How to do your case study. A guide for students in education and applied social sciences.* London. Sage Publications.

Thomas G (2011) *How to do your case study. A guide for students and researchers*. London. Sage publications.

Thorn SE, Hislop TG, Armstrong EA, Oglo V (2008) Cancer care communication: the power to harm and the power to heal? *Patient Education and Counselling*. 71. 34-40.

Thorne SE, Bultz BD, Baile WF (2005) Is there a cost to poor communication in cancer care? A critical review of the literature. *Psycho-oncology*. 14 (10) 875–884.

Tod A, Craven J, Allmark P (2008) Diagnostic delay in lung cancer: a qualitative study. *Journal of Advanced Nursing.* 61 (3) 336-343.

Tsai MH (2007) Who gets to talk? An alternative framework evaluating companion effects in geriatric triads. *Community Medicine*. 4 (1) 37-49.

UK Lung Cancer Coalition (2013) *Putting patients first: Understanding what matters most to lung cancer patients and carers*. London. UKLCC.

United Kingdom Lung Cancer Coalition (2007) *Lung cancer plan: improving lung cancer survival in the UK*. London. UKLCC.

United Kingdom Lung Cancer Coalition (2009) *Reviewing the lung cancer plan: are we emerging from the shadow of lung cancer?* London. UKLCC.

van Bruinessen IR, van Weel, EM, van Gouw H, Zijlstra JM, Albada A, van Dulmen S (2013) Barriers and facilitators to effective communication experienced by patients with malignant lymphoma at all stages after diagnosis. *Psycho-Oncology*. 22 (12) 2807-2814.

Walsham G (2006) Doing interpretive research. *European Journal of Information Systems*. 15. 320–330.

Wickham M, Woods M (2005) Reflecting on the Strategic Use of CAQDAS to Manage and Report on the Qualitative Research Process. *The Qualitative Report.* 10 (4) 687-702.

Willems S, De Maesschalck S, Deveugele M, Derese A, De Maeseneer J (2005) Socio-economic status of the patient and doctor–patient communication: does it make a difference? *Patient Education and Counselling*. 56. 139–146.

Wolff JL, Chan EC, Harris R, Sheridan SL, Braddock CH 3rd, Kaplan RM, Krist A, O'Connor AM, Tunis S (2005) Promoting informed choice: transforming health care to dispense knowledge for decision making. *Annals Internal Medicine*. 143 (4) 293-300.

Wolff JL, Roter DL (2008) Hidden in plain sight: medical visit companions as a resource for vulnerable older adults. *Archives Internal Medicine*. 168 (13) 1409–1415.

Wolff JL, Roter DL (2011) Family presence in routine medical visits: a meta-analytical review. *Social Science and Medicine*. 72 (6) 823–831.

Yaffe MJ, Klvana J (2002) Physician perspectives on the elderly patient-family caregiver-physician encounter. *Israel Medical Association Journal.* 4. 785-789.

Yin RK (2009) *Case study research: Design and methods*. London. Sage Publications.

Zach L (2006) Using a Multiple–Case Studies Design to Investigate the Information-Seeking Behaviour of Arts Administrators. *Library Trends*. 55 (1) 4–21.

(www.cancerresearchuk.org/cancerstats/lung-accessed05/04/2008)

(www.cancerresearchuk.org/cancerstats/types/lungcancer-accessed01/02/2009)

(www.cancerresearchuk.org/lungcancer/keyfacts-accessed09/03/2009)

(www.ischool.utexas.edu/casestudyas aresearchmethod-accessed14/11/2009)

(www.utsc.utoronto.ca/reflexivity/a process of reflection. accessed29/10/2014)

## Appendices

UNIVERSITY OF
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**Gentle reminder to patients about their immediate debriefs interview answers.**

Clinic consultation

Main topic question

Generally looking back over your clinic visit(s) how do you think they went?

Prompts & supplementary questions

Is that what you expected?

Who did you see?

Support for you at clinic

Main topic question

Was it a conscious decision to take …companion to clinic?

Prompts & supplementary questions

Can you tell me why this was the way you did it?

Was that the right decision to attend in this manner?

Information which the healthcare professional gave to or withheld from you

Main topic question

Can you remember what things you spoke about?

Prompts & supplementary questions

Was the hcp more interested in physical problems (such as breathing or pain)?

Did they discuss other concerns i.e. emotional matters, psychosocial concerns, and financial problems?

Is this really what you expected to be discussed?

Thinking back to the visit do you think the healthcare professional(s) gave you as much information as you would have liked?

Was there too much or too little information?

Do you remember what information you did receive?

Was there information, which you were expecting to get that perhaps you, didn't (can you give me any examples?).

Did you ever experience a sense that they were holding back from you?

Can you please give me any sense in what way this was apparent?

How did this make you feel?

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Information which you gave to or withheld from the healthcare professionals

Main topic question
Can you tell me if you covered all the points you wanted to on the day?

Prompts & supplementary questions
Was there information you knew you had to tell the hcp and why it was important?

Was it more important for you to discuss the physical/psychosocial aspects of your illness?

Did you feel you held back telling them everything? And if this was the case why did you do so?
A week or two down the line do you wish you had given them this information?

Effect if any of withholding information

Main topic question
If you have felt that information has been withheld on both sides; is it possible for you to say if withholding any information has in anyway had an impact (positive or negative) on your care?

Prompts & supplementary questions
Do you for example think you could have had your concerns/needs discussed and addressed properly if there had been a fair exchange of info?

Do you think it would have led to you making different decisions regarding treatment or your care in general?

**Interacting with clinicians**

Main topic question
For you personally is interacting and exchanging information with your clinician important to you

Can you explain your answer please?

[redacted]

[redacted]

13 October 2009

Mrs Allison Smith
Lung Cancer Clinical Nurse Specialist
Greater Glasgow and Clyde NHS Trust
Gartnavel General Hospital
1053 Great Western Road
Glasgow
G12 0YN

Dear Mrs Smith

**Study Title:** **Information exchange between women with lung cancer and healthcare professionals at diverse clinic consultations.**

**REC reference number:** **09/S0703/106**

**Protocol number:**

The Research Ethics Committee reviewed the above application at the meeting held on 06 October 2009. Thank you for attending to discuss the study.

**Ethical opinion**

The committee discussed this study at length and had several questions for the investigator which were answered to their satisfaction namely:

a) Clarification of the numbers in each group.
b) Is each site/clinic involved in the tape recording. Are they going to tape the whole clinic consultation?
c) Are they comparing like with like?
d) Has the researcher got some back-up in case of upset?
e) Are they going to provide a copy of the tape recording of the consultations to the participants if requested?
f) How are healthcare professionals being approached?
g) The committee thought that the interviews with healthcare professionals would last more than 5 minutes?
h) Question 6.2 - how many sites involved?
i) The committee wondered why men are not being included?

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.

**Ethical review of research sites**

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

**Conditions of the favourable opinion**

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

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

*For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

***Other conditions specified by the REC***

The committee require the undernoted minor clarifications/amendments to both the Study Design and Information Sheets

Study Design:

a) Question A71-2 should read 2 sties - not 1.
b) Data should be stored for longer than 3 months.
c) Do patients know that the researcher is getting information about them from their consultant?
d) The committee noted that the Insurance Certificate is out of date.

Information Sheets for Healthcare workers.

a) Participants should be informed whether they will be using own time or work time for this research.
b) Section "Who has reviewed this Study"- delete any reference to the "IRAS system and any reference to the "Ethics committee at the [redacted]" etc (there is no Ethics committee at the Golden Jubilee). The wording in respect of Ethics Committee should read "This study has been reviewed by the [redacted] (1) REC". Any reference to "Trust" should read "Board".

Information Sheet for Patients:

a) Under "Purpose of the study" - delete 4th line from "such as one stop clinics" etc up to "sees the patient" i.e. 4th line should read "whether or not different clinic designs makes any difference to the amount and type of information exchanged".
b) Section "Who has reviewed this study" - amend as per Healthcare section above.
c) Patients should be informed of the exchange of information between their healthcare professional and the researcher.

Consent Form for Patients:

a) A further box should be added in respect of their agreeing to the exchange of their information between healthcare professional and researcher.

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

**Approved documents**

The documents reviewed and approved at the meeting were:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering Letter | | 07 September 2009 |
| REC application | | 07 September 2009 |
| Protocol | | 07 September 2009 |
| Investigator CV | | 20 August 2009 |
| Participant Information Sheet: Healthcare Professional | 4 | 24 August 2009 |
| Participant Information Sheet: Patients | 4 | 24 August 2009 |
| Participant Consent Form: Healthcare Professionals | 4 | 24 August 2009 |
| Participant Consent Form: Patients | 4 | 24 August 2009 |
| Letter of invitation to participant | Healthcare Professional s V 4 | 24 August 2009 |
| GP/Consultant Information Sheets | 4 | 24 August 2009 |
| Evidence of insurance or indemnity | | 01 May 2009 |
| Letter from Sponsor | | 01 May 2009 |
| Interview Schedules/Topic Guides | 4 | 01 May 2009 |
| Letter of invitation - Patients | 4 | 24 August 2009 |
| CV for supervisor | 4 | 25 August 2009 |

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

**09/S0703/106** **Please quote this number on all correspondence**

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

[redacted]

Andrea

[redacted]

*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" SL-AR2*

*Copy to:* *Carol Johnstone,*
*Business Development Manager*
*University of Stirling*
*Stirling FK9 4LA*

Appendix 3. R&D Approval

[redacted]

Our Ref: EP/LR
Enquiries to: [redacted]
Direct Line:
e-mail:

26th Jan 2010

Ms Allison Smith
Lung Cancer Clinical Nurse Specialist
Dept of Respiratory Medicine
Gartnavel General Hospital
1053 Great Western Road
Glasgow
G12 0YN

## R&D Management Approval

Dear Ms Smith

**R&D Reference:** GN09ON371
**REC Ref:** 09/S0703/106
[redacted]
**Chief Investigator:** Ms Allison Smith
**Project Title:** Information exchange between women with lung cancer and healthcare professional at diverse clinic consultations.

I am pleased to confirm that [redacted] is now able to grant **Management Approval** for the above study.
As a condition of this approval the following information is required during the lifespan of the project:

1. SAES/SUSARS – If the study is a **Clinical Trial** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004 (CTIMP only)
2. Recruitment Numbers on a quarterly basis (not required for commercial trials)
3. Any change of Staff working on the project named on the ethics form
4. Change of CI
5. Amendments – Protocol/CRF etc
6. Notification of when the Trial / study has ended
7. Final Report
8. Copies of Publications & Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Yours sincerely

[redacted]

[redacted]

11 December 2009

Mrs Allison Smith
Lung Cancer Clinical Nurse Specialist
Gartnaval General Hospital
1053 Great Western Road
Glasgow
G12 0YN

Dear Mrs Smith,

**Management Approval for a non-commercial research project**

I am pleased to tell you that you now have Management Approval for the research project entitled: **Information exchange between women with lung cancer and healthcare professionals at diverse clinical consultations**. I acknowledge that:

- The project is sponsored by the **University of Stirling.**
- Research Ethics approval for the project has been obtained from the **West of Scotland Research Ethics Committee 1** (reference number: **09/S0703/106**).
- The Site Specific Form for this project has been reviewed and there is no objection to it proceeding at this site.

The following conditions apply:

- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.
- All amendments (minor or substantial) to the protocol or to the REC application should be forwarded to the NWTCB Research Office with a copy of the amendment application and approval letter.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the National Waiting Times Centre Board Research Manager, Dr Catherine Sinclair (0141 951 5440, catherine.sinclair@gjnh.scot.nhs.uk).

Further information about research at the National Waiting Times Centre Board can be found at the following website: www.nhsgoldenjubilee.co.uk/home/research.php.

Yours sincerely,

[redacted]

UNIVERSITY OF
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**NURSING AND MIDWIFERY**

Dear Dr

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

You are invited to participate in a study to explore the exchange of information between patients with lung cancer and healthcare professionals at clinic consultations. The researcher is a lung cancer clinical nurse specialist currently undertaking a clinical doctorate at the University of Stirling investigating the research title listed above.

You and your colleagues have been identified as being involved in the specialised management of patients with lung cancer within Glasgow and as such are in an ideal environment to assist with this research study.

For your information I have enclosed a **Healthcare Professional Information Sheet**, which incorporates the purpose of the study, as well as the methodological design to be used. Once you have had the opportunity to read and consider all the information, I would like to invite you to take part in the study. I have also enclosed a **Consent Form**, so that you can tell me whether or not you wish to participate in the study

If you have any questions about the research study you can contact me by telephone or email at the above listed numbers and addresses. I would be happy to visit your department to discuss the study in more detail personally.

The study and all relevant documentation have been reviewed by the West of Scotland (1) Research and Ethics Committee.

Thank you for your attention and with your permission I look forward to undertaking my research within your department.

Yours sincerely

**Allison Smith.**
**Doctoral Student**.

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## Appendix 6: Healthcare Professional Information Sheet

**Project title**

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

**Introduction**
I would like to invite you to participate in a research study, which aims to explore the exchange of information between patients with lung cancer and healthcare professionals at clinic consultations. You and your clinical colleagues have been identified as health professionals who are involved in the management of people with lung cancer and are thus best qualified to take part in this study.

You should only participate if you want to. Choosing not to take part will not disadvantage you in any way. Before you make your decision it is important for you to understand why the research study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with other people, including your colleagues. Please get in touch if there are any areas you feel need clarified.

**Thank you for reading this.**

**What is the purpose of the study?**
The aim of the research study is to explore how patients with lung cancer and healthcare professionals exchange information in the clinical consultation setting. The research will focus on what information is exchanged between patients and healthcare professionals and what information is not exchanged

**Why have I been asked to take part?**
You have been asked to take part in the research because you are a health professional involved in the speciality of lung cancer.

**Do you have to take part?**
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign and return the consent form enclosed. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will remain confidential.

**What will happen to me if I take part?**
If you decide to take part, you will be asked to take part in the audio taping of your clinic consultation with patients with lung cancer. You will also will be asked to take part in a short (5 minute) debrief interview, with the researcher, following the clinic consultation. During this interview you will be asked about the information you gave to the patient during the consultation and whether or not you felt you may have withheld certain types of information and if so, what type of information and why.

With your permission, the interview will be tape-recorded.

The researcher may also ask for some demographic information about the patient with lung cancer who will also be taking part in the study.

Participation in consenting to the study and any data collection will take part within the normal working day and you will not be asked to participate in any part of the study in your own time.
The researcher will securely store all data. Electronic data will be stored in a password-protected computer and written transcripts will be secured in a locked drawer within a locked office. The researcher and her supervisor will be the only people with access to the data. Your identity will be coded and anonymised.

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**What are the possible benefits of taking part in the research study?**
You may not benefit personally from taking part in this research. However, with your assistance and participation in this study, you will be able to contribute, as a professional, in a research project examining the information exchange between patients with lung cancer and healthcare professionals. Your involvement may assist the research to identify areas in patient care that can be improved for the future management of this patient group.

**What are the possible disadvantages of taking part in the research study?**
The disadvantages are that there may be the inconvenience of having your consultations with patient's audiotaped and the time (no longer than 5 minutes) taken to participate in a debrief interview with the researcher after the clinic consultation.

**What will happen to information about me?**
All of the information/data generated at clinic consultation and debrief interview will be anonymised. Neither you nor the patients will be identified in any publication.

**Who is funding the research study?**
The research is part of a doctoral study, self-funded by the researcher.

**Who has reviewed the research study proposal?**
This study has been reviewed by the West of Scotland (1) Research and Ethics Committee.

If you do wish to take part, please sign and return the consent form and return it to the researcher in the stamped addressed envelope provided.

**Thank you.**

*Contacts for further information*

- *Should you wish to talk to someone or have the researcher visit you in person to go over any aspect of the study, please contact*

***Allison Smith. Doctoral Student.***
***C/O Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN***
***0141 211 0182 or 0777 198 2110***
**allison.smith@ggc.scot.nhs.uk**

- *Should you wish to contact someone other than the researcher, please contact the research supervisor:*

***Dr Carol Bugge. Senior Lecturer.***
***Department of Nursing & Midwifery. University of Stirling. Stirling. FK9 4LA***
***01786 466109***
**carol.bugge@stir.ac.uk**

- *Should you wish to raise a concern about the study with someone who is independent from the research team, please contact the Head of Department:*

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***Department of Nursing & Midwifery. University of Stirling. Stirling. FK9 4LA***
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**william.lauder@stir.ac.uk**

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DEPARTMENT OF
**NURSING AND MIDWIFERY**

**Appendix 7: Healthcare Professional Consent Form**

**Title of project**

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

**Researcher**
Allison Smith
Doctoral Student

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. ☐

2. I confirm that I have discussed the study with those people whom I regard as appropriate and have had the opportunity to ask questions. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

4. I agree to the clinic consultation and the debrief interview being audio taped. It has been explained to me that disks and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐

5. I agree to the use of anonymised quotes in reports and publications ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |

For further information please contact

Allison Smith, Doctoral Student.
Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN.
Telephone: 0141 211 0182 or 0777 198 2110
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1 copy for participant
1 copy for researcher

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## Appendix 8. Patient Introduction Letter

DEPARTMENT OF
**NURSING AND MIDWIFERY**

Dear

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

I am a clinical nurse specialist currently undertaking a clinical doctorate at the University of Stirling. You are invited to take part in a research study exploring the exchange of information between patients with lung cancer and healthcare professionals at different clinic consultations.

As you have been receiving care from a team of health professionals specialising in lung cancer care you have been identified as eligible to take part in this study.

I have sent you the study Patient Information Pack. It contains this letter, as well as a Patient Information Sheet, which has more details about the study. The information sheet explains exactly what you would be required to do if you decide to take part in the study.

Once you have had the opportunity to read and consider all the information, I would like to invite you to take part in the study. The research is interested in how patients and health professionals (such as doctors and nurses) exchange information when they meet at the outpatient clinic consultation.

Your doctor or nurse will have asked for your permission for me to contact you by telephone, which I will do 48 hours after you receive the Pack. This will to allow you time to consider the information and discuss the study with your family and friends if you would like to. When I phone we can discuss any questions about the research study you may have.

You can contact me by telephone or email at the above listed numbers and addresses if you or your family and friends have any questions in the meantime.

I look forward to speaking with you.

Yours sincerely

**Allison Smith**
**Doctoral Student**

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DEPARTMENT OF
**NURSING AND MIDWIFERY**

**Project title**

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

**Introduction**

I would like to invite you to take part in a research study, which aims to explore the exchange of information between patients with lung cancer and health professionals at outpatient clinic consultations.

You should only take part if you want to. Choosing not to take part will not disadvantage you in any way. Before you make your decision it is important for you to understand why the research study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with other people, including your hospital doctors and nurses and your own GP.

Please ask me if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part in the study.

**Thank you for reading this.**

**What is the purpose of the study?**

The aim of the study is to look at what information patients with lung cancer and healthcare professionals exchange with each other at the outpatient clinic consultation. The study plans to describe the information they DO give and the information that they DO NOT give.

**Why have I been asked to take part?**

You have been asked to take part in the research because you are a patient affected by lung cancer, who is attending outpatient clinic consultations. We want to gather your views on your experience of the clinic consultations and your thoughts and opinions on the information that is given to you by health professionals and the information that you give in return to them.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. The decision you make (to take part or not) will in no way affect any care you receive. If you do decide to take part you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed consent form to keep. You are free to stop taking part at any time during the study, without giving a reason. Please ask your own General Practitioner and your care team at the hospital for their advice if you need it

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**What will happen to me if I take part?**
If you might be interested in taking part, the researcher will tell you more about the study. You can contact the researcher by telephone (the number is on this letter) and arrange to have the researcher call you back for a telephone discussion, or if you prefer arrange, for the researcher to visit you at home.

If you do agree to take part you will meet with the researcher when you attend the outpatient clinic on your next visit. At this time the researcher will discuss the Consent Form with you and if you are still willing to take part in the research ask you to sign the form at this time. The consultation you have with the doctors and nurses at this clinic visit and any other clinic consultations relating to your condition will be tape recorded, with your permission.

The researcher will NOT be present when you are having your consultation with your medical and nursing team.

After the consultation, the researcher will ask you to take part in a 5 minute debrief interview. If you do not feel up to this debrief interview after your consultation, this can be arranged to be done at another time, if you prefer. With your permission this short interview will be tape-recorded as well.

On the day of your consultation, the researcher will arrange with you a date, time and convenient location for a more in-depth interview, which will discuss the consultation in more detail and, which will last approximately 30-60 minutes. With your permission this interview will be tape-recorded.

Any clinic visits you have after the in-depth interview with the researcher will no longer be part of the research study and will therefore not be tape-recorded.

The researcher may ask your healthcare professional for health-related information about you, such as details about your illness, the expected treatment plan, as well as your age and place of residence. All recorded information will be stored securely. Electronic data will be stored in a password-protected computer and written transcripts will be secured in a locked drawer within a locked office. The researcher and her supervisors will be the only people with access to the data. Your identity will be anonymised and your confidentiality will be guaranteed at all times.

**What are the possible benefits of taking part in the research study?**
This study may not benefit you personally, but the information we get might help other patients with lung cancer in the future by letting us understand what people need in terms of the information that is exchanged between them and their health professionals. It will also give you the chance to say what you think about information that is exchanged and how it exchanged and what things affect it in your opinion and we will listen to your views.

**What are the possible disadvantages of taking part in the research study?**
You will have your conversations with your health professionals tape-recorded. It is possible you may find this intrusive. If you feel it is affecting your consultation in anyway, the recording can be stopped at anytime.

You may find you feel anxious about discussing your care and if this is the case you can stop the interview with the researcher at any stage and you can withdraw from the study if you are unhappy with any aspect of it. However, some people find it helpful to discuss their opinions and feelings.

There are no other disadvantages to the study foreseen.

**Will my details be kept private if I take part? Will anyone else know I'm doing this?**
If you consent to take part in the study, all information about you and all information that you give will be anonymised and will be kept **strictly confidential**. No one will be able to recognise you from any report about the study – your name and anything, which could lead to anyone being able to recognise you, will be removed. Any quotes used in reports and publications will be anonymised and referenced

using a confidential coding system. All recorded data is stored securely and is destroyed following strict NHS guidelines after a suitable time period.

**What will happen to the results of the project?**
A summary of the findings can be sent out to you if you wish to see them. The researcher will also be preparing a manuscript for publication in academic and scientific journals and all participants in the study can read this. You will not be identified in any report or publication.

**Who is funding the research study?**
This research is part of a doctoral study, self-funded by the researcher.

**Who has reviewed the research study proposal?**
This study has been reviewed by the West of Scotland (1) Research and Ethics Committee.

**Thank you once again for taking the time to read this.**

Contacts for further information

- Should you wish to talk to someone before deciding to take part, or at any time during the study you can contact

**Allison Smith. Doctoral Student.**
**C/O Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN**
**0141 211 0182 or 0777 198 2110**
**allison.smith@ggc.scot.nhs.uk**

- Should you wish to contact someone other than the researcher, please contact the research supervisor:

**Dr Carol Bugge. Senior Lecturer.**
**Department of Nursing & Midwifery. University of Stirling. Stirling. FK9 4LA**
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- Should you wish to raise a concern about the study with someone who is independent from the research team, please contact the Head of Department:

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DEPARTMENT OF
**NURSING AND MIDWIFERY**

**Researcher**
Allison Smith
Doctoral Student

**Appendix 10: Patient Consent Form**

**Title of project**
Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I agree to my GP being informed of my participation in the study. ☐

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

5. I agree to the clinic consultation(s), the debrief interview and the in-depth interview being audiotaped. It has been explained to me that disks and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐

6. I agree to my healthcare professional exchanging health-related information about me to the researcher ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |


For further information please contact

Allison Smith, Doctoral Student.
Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN.
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Email: allison.smith@ggc.scot.nhs.uk


1 copy for participant
1 copy for researcher
1 copy for case notes


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## Appendix 11: Companion Introduction Letter

DEPARTMENT OF
**NURSING AND MIDWIFERY**

Dear [carer's name inserted]

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

I am a clinical nurse specialist currently undertaking a clinical doctorate at the University of Stirling. You are invited to take part in a research study exploring the exchange of information between patients with lung cancer and healthcare professionals at clinic consultations.

As you have been recognized as a carer, who is likely to attend clinic consultations with a patient receiving care from a team of health professionals specialising in lung cancer care you have been identified as eligible to take part in this study.

I have sent you a **Companion Information Pack**. It contains this letter, as well as an Information Sheet, which has more details about the study. The information sheet explains exactly what you would be required to do if you decide to take part in the study.

Once you have had the opportunity to read and consider all the information, I would like to invite you to take part in the study. The research is interested in how patients and health professionals (such as doctors and nurses) exchange information when they meet at the outpatient clinic consultation. As you may be present with a friend or relative at these consultations it is important that you are aware of the study and if you are part of the consultation it is important that you have all the relevant information and that you give your consent to take part in the study.

The hospital doctor or nurse looking after your friend or relative will have asked for their permission for me to contact them by telephone, which I will do 48 hours after they receive The Patient Information Pack. Therefore I also wanted to send you details of the study as you may be with the patient on the day of clinic. This will to allow you time to consider the information and discuss the study with your friend or relative, or anyone else you like. When I phone we can discuss any questions about the research study you may have.

You can contact me by telephone or email at the above listed numbers and addresses if you or your family and friends have any questions in the meantime.

I look forward to speaking with you.

Yours sincerely

**Allison Smith.**
**Doctoral Student**

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DEPARTMENT OF
NURSING AND MIDWIFERY

**Project title**

**Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.**

**Introduction**
I would like to invite you to take part in a research study, which aims to explore the exchange of information between patients with lung cancer and health professionals at outpatient clinic consultations.

You should only take part if you want to. Choosing not to take part will not disadvantage you or your friend or relative in any way. Before you make your decision it is important for you to understand why the research study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with other people, including the hospital doctors and nurses or anyone else.

Please ask me if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part in the study.

**Thank you for reading this.**

**What is the purpose of the study?**
The aim of the study is to look at what information patients with lung cancer and healthcare professionals exchange with each other at the outpatient clinic consultation. The study plans to describe the information they DO give and the information that they DO NOT give.

**Why have I been asked to take part?**
You have been asked to take part in the research because you may be attending the clinic consultation with a friend or relative who is affected by lung cancer. Sometimes other people present influence the exchange of information between the patient and the healthcare professional, therefore it is important that your participation in the consultation is recognised.

**Do I have to take part?**
No. It is up to you to decide whether or not to take part. The decision you make (to take part or not) will in no way affect any care your friend or relative receives. If you do decide to take part you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed consent form to keep. You are free to stop taking part at any time during the study, without giving a reason. Please ask the care team at the hospital for their advice if you need it

**What will happen to me if I take part?**
If you might be interested in taking part, the researcher will tell you more about the study. You can contact the researcher by telephone (the number is on this letter) and arrange to have the researcher call you back for a telephone discussion, or if you prefer arrange, for the researcher to visit you at home.

If you do agree to take part you will meet with the researcher when you attend the outpatient clinic with your friend or relative at their next visit. At this time the researcher will discuss the Consent Form with you and if you are still willing to take part in the research ask you to sign the form at this time. The consultation your friend or relative has with the doctors and nurses at this clinic visit and any other clinic consultations relating to their condition will be tape recorded, with theirs and your permission.

The researcher will NOT be present during the actual consultation with the medical and nursing team.

After the consultation, the researcher will ask your friend or relative to take part in a 5 minute debrief interview. If you are there after the consultation you may be part of the de-brief interview and therefore your permission will be asked to tape-record this short interview alongside your friend or relative. If either the patient or you do not feel up to this de-brief interview after the consultation, this can be arranged to be done at another time.

On the day of the consultation, the researcher will arrange with your friend or relative a date, time and convenient location for a more in-depth interview, which will discuss the consultation in more detail and, which will last approximately 30-60 minutes. You may be present at this interview and with your permission this interview will be tape-recorded.

Any clinic visits which you have with your friend or relative after the in-depth interview with the researcher will no longer be part of the research study and will therefore not be tape-recorded.

All recorded information will be stored securely. Electronic data will be stored in a password-protected computer and written transcripts will be secured in a locked drawer within a locked office. The researcher and her supervisors will be the only people with access to the data. Your identity will be anonymised and your confidentiality will be guaranteed at all times.

**What are the possible benefits of taking part in the research study?**
This study may not benefit you personally, but the information we get might help other patients with lung cancer and their carers in the future by letting us understand what people need in terms of the information that is exchanged between them, their carers and their health professionals. It will also give you the chance to say what you think about information that is exchanged and how it exchanged and what things affect it in your opinion and we will listen to your views.

**What are the possible disadvantages of taking part in the research study?**
The conversations between the patient, you and the health professionals will be tape-recorded. It is possible you may find this intrusive. If you feel it is affecting your consultation in anyway, the recording can be stopped at anytime.

You may find you feel anxious about discussing your friend or relative's care and if this is the case you can stop the interview with the researcher at any stage and you can withdraw from the study if you are unhappy with any aspect of it. However, some people find it helpful to discuss their opinions and feelings.

There are no other disadvantages to the study foreseen.

**Will my details be kept private if I take part? Will anyone else know I'm doing this?**
If you consent to take part in the study, all information about you and all information that you give will be anonymised and will be kept **strictly confidential**. No one will be able to recognise you from any report about the study – your name and anything, which could lead to anyone being able to recognise you, will be removed. Any quotes used in reports and publications will be anonymised and referenced using a confidential coding system. All recorded data is stored securely and is destroyed following strict NHS guidelines after a suitable time period.

**What will happen to the results of the project?**
A summary of the findings can be sent out to you if you wish to see them. The researcher will also be preparing a manuscript for publication in academic and scientific journals and all participants in the study can read this. You will not be identified in any report or publication.

**Who is funding the research study?**
This research is part of a doctoral study, self-funded by the researcher.

**Who has reviewed the research study proposal?**
This study has been reviewed by the West of Scotland (1) Research and Ethics Committee.

**Thank you once again for taking the time to read this.**

Contacts for further information

- Should you wish to talk to someone before deciding to take part, or at any time during the study you can contact

**Allison Smith. Doctoral Student.**
**C/O Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN**
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**allison.smith@ggc.scot.nhs.uk**

- Should you wish to contact someone other than the researcher, please contact the research supervisor:

**Dr Carol Bugge. Senior Lecturer.**
**Department of Nursing & Midwifery. University of Stirling. Stirling. FK9 4LA**
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- Should you wish to raise a concern about the study with someone who is independent from the research team, please contact the Head of Department:

**Professor William Lauder**
**Department of Nursing & Midwifery. University of Stirling. Stirling. FK9 4LA**
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**william.lauder@stir.ac.uk**

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**Appendix 13: Companion Consent Form**

DEPARTMENT OF
**NURSING AND MIDWIFERY**

**Title of project**
Information exchange between patients with lung cancer and healthcare professionals at clinic consultations.

**Researcher**
Allison Smith
Doctoral Student

Please initial box

1. I confirm that I have read and understand the Companion Information Sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I agree to the clinic consultation(s), the debrief interview and the in-depth interview being audiotaped. It has been explained to me that disks and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐

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

| _____ | _____ | _____ |
|---|---|---|
| Name of Participant | Date | Signature |
| _____ | _____ | _____ |
| Name of Researcher | Date | Signature |


For further information please contact

Allison Smith, Doctoral Student.
Gartnavel General Hospital. 1053 Great Western Road. Glasgow G12 0YN.
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1 copy for participant
1 copy for researcher
1 copy for patient case notes

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DEPARTMENT OF
NURSING AND MIDWIFERY

## Log of Potential Participants

**Patient ID CODE**

Performance Status ☐ Disease stage ☐

Gender ☐ 5 Digit post code ☐

**Q1 Treatment regimen**

Surgical resection ☐ Surgery & CT ☐ Surgery & radiotherapy ☐

Radiotherapy ☐ RT & CT ☐

Chemotherapy ☐ & RT ☐

**Treatment intent**: Curative ☐
Palliative ☐

Best supportive care ☐

**Q2. Age (years old)**

| | | | |
|---|---|---|---|
| 18-25 | ☐ | 56 -65 | ☐ |
| 26- 35 | ☐ | 66 - 75 | ☐ |
| 36-45 | ☐ | Over 75 | ☐ |
| 46 – 55 | ☐ | No reply | ☐ |

**Q3. Reason for not participating**

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1. Can you tell me what you talked about today?

2. Did you mention everything you wanted to?

3. Do you feel that there was any information that you held back

4. Can you say why?

5. Do you think the healthcare professional covered all the main points that you expected they would?

6. Was there anything you hoped they would talk about but didn't?

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DEPARTMENT OF
**NURSING AND MIDWIFERY**

1. Can you tell me the main things you discussed today?

2. Did you tell the patient everything you had intended?

3. If not – why not?

4. Did you feel the patient gave you all the information you would have expected them to on this visit?

5. If not can you say why they may not have?

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## Appendix 17: Case summary E

Pseudonym: Eve

Demographics:

Case E - Eve

| | |
|---|---|
| Code/Gender | GR05/E |
| PS | 0 |
| Symptoms | L sided chest discomfort, increasing dyspnoea |
| Disease stage | Limited stage |
| Histological type | Small cell lung cancer (L upper lobe) |
| Treatment intent | Palliative, concurrent chemo-radiotherapy |
| Age | 63 |
| Employment | Retired engineering plant worker |
| Residence | City. Usually lives along. Son staying at present |
| Marital status | Divorced but newly engaged to her partner |
| Educational status | Secondary school education |
| Smoking status | Current smoker |

**Field Note Summation (1): Consultation 1**

**Location**: Study site B Resp clinic

**People present**: Eve & companion (son - Eric)

**Patient & companion demeanour**: They were both very relaxed and patient was making jokes throughout time at clinic (she got her hair done to impress the doctor). ? Coping mechanism. Eve's partner did not come into clinic – he was too anxious. Patient had already been informed of diagnosis – was returning for histology and provisional treatment plan.

**Listening to the tapes post clinic**: patient did appear to be given sound relevant clinical information and Dr Boyd did spend time (20-30 mins) discussing all the issues with the patient and her son. Chemotherapy given in the context of curative therapy (despite small cell lung cancer).

Son initiated conversations, asked frequent questions, answered questions for Eve. Son seemed to have his own agenda re smoking and almost bullying his mother into stopping. Treatment outcome seemed the most important subject for companion. Atmosphere was volatile (?) at times

**De-brief summations**:

- Dr Boyd described Eve as 'flighty' but felt she was happy with level and content of information exchanged as was he.
- Sr Baxter confirmed she had exchanged the information she felt was required and patient was given written information on clinical trials.

**Emerging themes**:

Information discussed around *a priori* categories

No obvious disquiet at content, flow or direction of information from any participant

Companion role

**<u>Field Note Summation (2): Consultation 2</u>**

**Location**: Study site B – oncology clinic

**People present**: Eve, Eric and Elaine (daughter)

**Patient and companion demeanour**: A second companion was present this week. There was a somewhat tense atmosphere between the 3, as they had been arguing about patient's smoking habits and I think they had fallen out over certain things. Eve continued to make jokes but I felt she was more anxious this week. Consultation aim was to discuss therapy with oncologist and it had been a week since they last attended.

**Listening to tapes post clinic**: Patient and her family had read the written information and did ask viable questions, even quoting stats! Dr Brown spent time (approx. 30 mins) going over and building on info re trial. First mention that treatment has no 'guarantees'. Content, flow and direction of consultation and information exchange influenced significantly by companion agenda, asking questions (specifically about treatment outcome). Specific a priori categories becoming more relevant - treatment outcome

**De-brief summations**:

- Sr Baxter stated she had exchanged the information she intended and thought she pretty detailed info and the opportunity to ask questions – but all declined. Backed up verbal info with written information. Felt she had covered all aspects of therapy and that son did most of talking at this time, as patient declined to ask too much.

- In contrast, Dr Brown stated there were topics she did not cover (ie clinical aspects of chemotherapy) as family argued and dominated consultation with smoking and prognosis agenda. Normally she would prefer to discuss chemo s/e in more depth.
- Patient shocked to learn she had 'fast track cancer'
- Companions comment that tone of discussion had changed from positive, with a chance of cure (they thought in terms of 80:20) to negative (20:80) in the space of 1 week.

Family were very vocal and led and controlled exchanges the majority of the time. Their agendas concerning smoking and prognosis dominated. Atmosphere was tense and son walked out of consultation at one point.

**Emerging themes**:

- Strong, dominant role of companions
- Companion led agenda (smoking and prognosis) – not patient agenda
- Companion knowledgeable re aspects of trial and chemotherapy
- *A priori* categories were covered to participants required level

**Field Note Summation (3): In-depth interview**

**Location**: Eve's home

**People present**: Eve, Eric (and Ewen, 2nd son later)

**Overview**: Family dynamics play a significant role in the interactions of this family. Arguments and antagonism are evident but appear to be part of their family dynamics. No negative comments from companion re the significant companion led agenda witnessed at clinic. Eve originally said she would prefer to be unaccompanied to clinics but then admitted she would forget things, so needed companion presence.

Despite dynamics witnessed at clinic, patient and companion felt well informed – felt the level of information exchange suited them – felt they were given all relevant information and gave information in return.

Tone of information and the impact of the news re prognosis was apparent and left the family 'shocked'.

**New emerging themes**

- Exchange of information (content of *a priori* categories overall) appeared to suit participants
- Content controlled by vocal companions
- Family dynamics
- Original reticence by patient to be accompanied to consultation

**Information exchanged**

| | | | | | |
|---|---|---|---|---|---|
| **Diagnosis** | Lung cancer | Small cell | CT shown | Limited stage | 'Nasty cancer' |
| **Symptoms** | pain | breathlessness | headaches | | |
| **Treatment** | Depends on cell type | Trial discussion | Rationale | Cisplatin/Etoposide | Eve does not want surgery as it 'spreads' cancer |
| **Treatment side-effects** | Nausea | Hair loss | Tired | Reduced immunity | |
| **Treatment outcome** | Chance of cure | Difficult to cure | Likely to respond to chemo | Companions initiate discussion and ask prognosis | Prognostic information change dover the course of 1 week |
| **Miscellaneous** | Family history | Employment | Social input | Physical exam | SMOKING! |

**Information not exchanged**

| | | |
|---|---|---|
| **Diagnosis** | Eve stated she originally did not want companions present at diagnosis | Eve originally wanted only her son to have information about her diagnosis |
| **Symptoms** | Not discussed | |
| **Treatment** | Dr Brown disappointed with her exchange of information about chemotherapy | Opportunity to discuss issues not given as companions changed flow, content and direction of exchange with their own agenda |
| **Treatment side-effects** | Dr Brown disappointed with her exchange of information about chemotherapy side-effects | Opportunity to discuss issues not given as companions changed flow, content and direction of exchange with their own agenda |
| **Treatment outcome** | Specific focus on outcome altered the dynamics of the exchange significantly | |
| | | |

UNIVERSITY OF STIRLING

## Appendix 18. Patient Demographic Sheet

DEPARTMENT OF
**NURSING AND MIDWIFERY**

**Patient ID CODE** ☐ **Gender** ☐

Performance Status ☐ Disease stage ☐ Histological Cell Type ☐

**Q1 Treatment regimen**

| | | | | | |
|---|---|---|---|---|---|
| Surgical resection | ☐ | Surgery & CT | ☐ | Surgery & radiotherapy | ☐ |
| Radiotherapy | ☐ | RT & CT | ☐ | | |
| Chemotherapy | ☐ | & RT | ☐ | | |
| Best supportive care | ☐ | | | | |

**Treatment intent**: Curative ☐
Palliative ☐

**Q2. Age (years old)**

| | | | |
|---|---|---|---|
| 18-25 | ☐ | 56 -65 | ☐ |
| 26- 35 | ☐ | 66 - 75 | ☐ |
| 36-45 | ☐ | Over 75 | ☐ |
| 46 – 55 | ☐ | No reply | ☐ |

**Q3. Employment**

| | | | | | |
|---|---|---|---|---|---|
| Works F/T | ☐ | Unemployed | ☐ | Retired | ☐ |
| Works P/T | ☐ | On sick leave | ☐ | No reply | ☐ |

**Q4. Residence**

| | | | |
|---|---|---|---|
| A town/city | ☐ | Other (please state) | ☐ |
| Village/rural | ☐ | Postcode | ☐ |

**Q5. Marital status**

| | | | |
|---|---|---|---|
| Married | ☐ | Divorced | ☐ |
| Living with a partner | ☐ | Widowed | ☐ |
| Single | ☐ | Other | ☐ |
| Prefer not to say | ☐ | | |

**Q6. Educational status**

| | | | |
|---|---|---|---|
| Secondary school education | ☐ | Other | ☐ |
| College or university education | ☐ | Prefer not to say | ☐ |

**Appendix 19: WHO Performance status**

| Grade | Explanation of activity |
|---|---|
| 0 | Fully active, able to carry on all pre-disease performance without restriction |
| 1 | Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work |
| 2 | Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours |
| 3 | Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours |
| 4 | Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair |
| 5 | Dead |

## Appendix 20: Article for submission

### Title

Non-negotiated companion influence on information exchange at lung cancer clinic consultations


### ABSTRACT

**Aim**: To investigate information exchange processes during lung cancer consultations

**Background**: Effective information exchange is an asset to effective cancer care. The way in which a professional relates to and exchanges information with patients can be impacted by wide-ranging, external factors, including the presence of an accompanying companion. Patients with cancer are frequently accompanied to the clinical consultation by companions. Their potential to influence the exchange, either in a facilitative or non-facilitative manner warrants further investigation.

**Design**: Qualitative, multiple case study design

**Methods**: A case centred on a patient with lung cancer. Within the case were the patients, the health professionals they consulted with and anyone else who was present within the consultation. Seven cases were recruited, which included 12 companions. Data were collected in outpatient clinics between 2010 and 2011. Data were digital recordings of consultations, debrief interviews immediately post-consultation and later in-depth patient interviews. All interviews and audio-recordings were transcribed and analysed for pattern matching and coding.

**Findings**: All patients took at least one companion to a consultation. Three levels of negotiated companion accompaniment were identified. Companions mediated and moderated information exchange within and across six major constructs. Companions who did not negotiate their presence at the clinic were powerful and expert companions who significantly moderated the content, direction and flow of information exchange, using the constructs of companion control, companion agenda and companion as expert.

**Conclusions**: The level of negotiated companion presence at lung cancer clinics has direct implications for clinic care. There needs to be greater understanding among professionals of ways in which information exchange can be influenced by companions.



**Key words**: lung cancer, information exchange, patient-professional-companion interaction, negotiated accompaniment, mediating and moderating influence

**Introduction**

Effective communication is an asset to effective cancer care (Thorne, Bultz and Baile, 2005). Communication between patients and professionals can impact the effectiveness of the clinical encounter and influence quality of care and clinical outcomes for patients with cancer (Aiello Bowles, Tuzzio and Wise, 2008). Clinical communication can be defined as the dynamic, interpersonal process of mutual influence that occurs during the exchange of verbal and non-verbal messages between patients and healthcare professionals (Albrecht, Penner, Cline, Eggly and Ruckdeschel, 2009). A seminal review (Ong et al, 1995) signalled the scope of this influence and noted three basic communication functions in the cancer context, creating effective interpersonal processes, exchanging information and facilitating appropriate treatment decisions. This paper is concerned with one of these functions: information exchange.

The evidence suggests the way in which a professional relates to and exchanges information with patients can be profoundly impacted by wide-ranging, external factors (Edwards et al, 2009). One significant influence on information exchange at the clinical encounter is the presence of patient companion(s). As overwhelmingly patients with cancer are accompanied to the clinical consultation by companions (Shepherd et al, 2008), their potential to influence the exchange, either in a facilitative or non-facilitative manner warrants further analysis.

**Background**

Lung cancer is one of the main causes of cancer death in the Western world. It is associated with significant morbidity and in 80% of patients with lung cancer the disease is inoperable due to advanced stage at presentation (Tod et al, 2007). Receiving such a diagnosis will be, for most patients, an overwhelming experience. In these circumstances, the provision and exchange of appropriate and understandable information is important.

A key component of healthcare delivery is the patient-healthcare professional encounter and the exchange of information which takes place therein. Information exchange accounts for a large percentage of time within the clinical consultation, at which patients with cancer, seek information about their diagnosis, treatment and prognosis (Epstein and Street, 2008).

Traditional models of human interaction suggest that communication occurs on content [i.e. transfer of information] and that information content is important (Albrecht et al, 2008). Clinicians required contextual information from patients about past medical history, presenting symptoms as well as

previous experience and current expectations to formulate a diagnosis and treatment plan. Likewise patients needed information regarding all available therapies, potential side-effects and expected outcomes to make informed choices.

Examination of the contemporary literature on information exchange found research has primarily focused on professional–patient exchanges, leaving the influence of companions relatively unexplored (Arora, 2007). Despite this, a diverse, albeit disjointed research base has begun to highlight the potential role companions may play during clinical consultations. The major problem with existing literature is there has been little synthesis of data in this area, potentially due to diverse disciplines investigating the subject matter (medicine, linguistics, sociology, psychology) as well as the range of consultations under investigation (care of the elderly medicine, primary care, diabetes) (Laidsaar-Powell et al, 2013). The current pool of literature informing companion influence in the cancer care context is small with only a few in-depth studies. None have focused specifically on the information exchange process or, more pertinently, have studied the influence of companions within the context of lung cancer care.

The professional-patient interaction is frequently situated in a triadic relationship consisting of the healthcare professional, the patient and a third party, usually at least one key family member or companion (Blanchard et al, 2000). A companion could be defined as any group of persons who are related biologically, emotionally or legally (Dokken and Ahmann, 2006). Within the oncology setting companions are likely to be present at varying stages of the care pathway, at initial visits when the diagnosis is being given and treatment options discussed, and immediately after cancer recurrence and in the terminal phase of the disease (Jansen et al, 2010).

The National Cancer Institute's monograph (Esptein & Street, 2007) is a critical synthesis of existing literature focussing on optimising communication processes between healthcare delivery teams, patients and companions (triads) and not solely the patient-physician dyad (Arora, 2007). Communication pathways are appraised (Esptein & Street, 2007), but of 197 studies only 4 directly mentioned patients with lung cancer and none of these were germane to companion influence.

The monograph used the concepts of Mediator and Moderator to explain links between communication and health outcomes. A mediator or a moderator was defined as a third variable that changes the association between an independent variable and an outcome variable (Baron and Kenny, 1986). Analysis of mediator and moderator effects may provide more in-depth information

about a phenomenon under investigation, with consideration of these processes allowing a more precise description of the relationship between the variables (Bennett, 2000).

An essential mediator within the communication pathway was identified as family and social support, with companions providing instrumental help, encouragement and advocacy in gaining access to and effectively utilising health services (Epstein and Street, 2007). Companions are seen as mediators providing direct (when present with the professional) or indirect (when they suggest topics for the patient to discuss) input into clinical conversations to facilitate communication between patient and clinician (Shields et al, 2005). Equally, companions (and the social environment) were also identified as essential moderators who served to operate at multiple levels, influencing the link between communication and health outcomes. Subsequently, the patient's social environment consisting of companions can both mediate and moderate the relationship between patient-professional communication outcomes (Epstein and Street, 2007). Further evidence of the potential for mediating and moderating companions comes from two systematic reviews (Wolf and Roter, 2011; Laidsaar-Powell et al, 2013) which each outline some facilitative and controlling components related to companion presence.

Thus companion influence may have a mediating or moderating impact on information exchange, but there is little evidence relating to cancer care generally or within the lung cancer context specifically. The objective of the study was to explore the information exchange process within lung cancer consultations. This paper will explore the analytical construct that emerged of companion influence on the consultation.

**The Study**

**Aim**

The aim was to investigate the information exchange process within lung cancer consultations. Within case study design theoretical propositions are used to direct analysis. In this study an iterative theoretical proposition relating to companion influence emerged. The proposition aimed to specify which particular constructs of information exchange companions influenced with their presence at the clinical encounter and to describe the perspective of study participants to companion accompaniment.

**Design**

A qualitative, multiple case study methodology grounded in a constructivist paradigm guided the empirical inquiry (Anthony and Jack, 2009). The case study design sought to understanding complex social systems (Bennet and Elman, 2006; Denscombe, 2003), with the intention to comprehend the current processes in a previously little-studied area (Cresswell, 2004). Multiple case designs was used as analytical conclusions from more than one case provided more powerful data than from a single case (Yin, 2009). Multiple case design was useful for predicting similar results (literal replication) or contrasting results but for predictable reasons (theoretical replications) (Baxter and Jack, 2008).

**Composition of a case**

A case included the patient with lung cancer, the health professionals they consulted with and anyone else who the patient brought with them to the consultation. Multiple sources of evidence relating to each case were considered relative and important to case composition and these included demographic data and transcripts from consultations and interviews. Researcher field notes and case sheets devised for each case were also considered essential to the case.

**Participants**

In total 12 companions accompanied 7 patients with lung cancer to clinical consultations in two study sites. Patients were accompanied by companion combinations which comprised, adult children (n=7) spouse or ex-spouse or partner (n= 4) or a sibling (n=1). Companion combinations are shown in table 1.

**Table one here**

**Ethical considerations**

The study was approved by the Ethics Review Committee at the Department of Nursing and Midwifery at the University of Stirling and permission was granted from West of Scotland Research Ethics Service (REC 1) and Research and Development (R & D) Management. Informed consent was obtained from all participants prior to the clinical consultations. Participants were aware of their right to withdraw from the study at any time. Pseudonyms were used to protect their identities.

**Data collection**

The data collection was carried out from January 2010 to December 2011. A key strength of this case study design was the use of multiple sources and techniques in the data collection process (Yin,

2009). Significant volumes of data would be collected from the clinical encounters where the information exchanges were being executed and from the interviews (both de-brief and in-depth). A clinic room was provided to take written consent and answer questions, as well as conduct any de-brief interviews. The researcher (AS) remained in the clinic area, (but not the consultation room) for as long as necessary to collect data for all participants in each case.

***Clinical consultations***

With permission consultations were recorded, using a digital recorder placed away from the participants, but able to still accurately record the exchange. The professionals were asked to operate the equipment, after instruction by the researcher.

***De-brief interviews***

De-brief interviews were viewed as a powerful means of extracting valuable information from participants in the immediate aftermath of the clinical encounter, when recall of events is strong and first impressions can be captured. De-brief duration ranged from 1 – 5 minutes and were carried out post-consultation in privacy. No patient participant declined to be de-briefed. Only one professional de-brief was declined due to clinical commitment.

***In-depth interviews***

In-depth interviews were digitally recorded with patient participants. They were conducted in a place of the participants choosing and focussed on the patients (and if present their companions) views on the information exchange in the consultation.

**Case sheets and field notes**

Field notes permitted a record of researcher feelings and intuitive hunches, in addition to allowing a reflective document of the work in progress. They were prepared after each case encounter. Annotations were made about aspects of the information exchange process requiring clarification, observing the minutiae of what happened. An interpretive commentary was prepared (Stake, 1995). These first analytical notes gave rise to the start of data analysis at the beginning of the interpretative process providing insight and depth into early cross case evaluations (Payne, Field, Rolls, Hawker and Kerr, 2007; Hammersley and Atkinson, 2005).

**Data analysis**

These multiple sources of evidence required to be referenced and coded in order that converging lines of inquiry and patterns could be uncovered (Stake, 1995). All data were transcribed, checked for accuracy and organised using the software package NVivo 9. To start the analysis the basic principles stipulated by Thomas (2011, p171) were followed in order to manage the volume of data generated and to provide a robust and clear synthesis of the raw data. Case study analysis involving coding and pattern matching was then undertaken (Yin, 2009).

The analysis involved an iterative process of description, analysis and interpretation (Liu, 2013). The first stage involved reading the transcripts and assigning a code to each construct. In the second stage it was important to look for similar codes, whilst discarding those deemed redundant. The major themes of the coding were guided by the principle themes of Mediating and Moderating influences (Epstein and Street, 2007). Constant comparison of the data allowed for identification of relationships between the codes. Data collected from both consultations and all de-brief interviews for each case were analysed collectively. When coding was complete across all companion cases, they were then compared across cases and categorised using NVivo9.

The audio-tapes and transcriptions were reviewed again to identify, more inductively, any themes or connections to substantiate any new emerging theory. The explanation building process (Yin, 2009) whereby the eventual theory is likely to be series of iterations was the guiding principle:

- Make an initial theoretical statement or proposition
- Compare the findings of one case against the proposition
- Revise the proposition
- Compare the revision of the facts with a 2nd, 3rd or more cases

Before substantive analysis could be undertaken, the constructs pertinent to companion influence were refined. Reasons for this were two-fold:

1. To further refine and describe codes relating to the new theory
2. Build evidence between data and that reviewed empirically to support the constructs identified – moderating and mediating influence

**Quality**

Quality was assured using three concepts:

**(i)** **Confirmability**: was enhanced through the selection of appropriate operational measures, data collection tools and methodology for the study under investigation. Three tactics were employed to increase confirmability (Yin, 2009). Firstly, convergent lines of enquiry with triangulation of multiple sources of evidence was observable with the inclusion of all interview transcript narratives, field note annotations as well as demographic data compiled for each case. A chain of evidence was established whereby all documentation was computerised and all stages of the analytical process logged both within document folders and in Nvivo 9®. Finally a case study database was established and stored for peer review and scrutiny. Transcripts and drafts of the evolving case study were reviewed by university supervisors for consistency and accuracy.

**(ii)** **Dependability**: was enhanced through adherence to the study protocol. Development of a case study database not only inferred dependability but also enhanced reliability with the provision of transparent and accurate documentation. Within the database all data collected during the study was organised to facilitate retrieval for peer review (Yin, 2009) and to facilitate replication of the study (Leonard-Barton, 1990). To enhance the reliability of interview data management, all interviews were audio-taped, carefully transcribed and the narratives presented for each case's experience and perspective with extracts of pertinent statements in the research report

**(iii)** **Credibility**: was enhanced with the use of triangulation techniques. Credibility was further evidenced through pattern matching and constant comparative analysis of the data. The data followed a credible line of evidence which was documented and analysed in Nvivo.

**Findings**

Theory was emergent in that it was situated in and developed by recognising patterns of relationships among constructs within and across cases and their underlying logical arguments. Data analysis led to the theoretical proposition of companions as either a mediating or moderating influence on information exchange. Mediating and moderating companion influences are shown in table 2.

**Mediating influence**

There were examples in every case where companions exerted a mediating influence on information exchange. Data demonstrated that mediating influences were identified across three constructs, *physical, emotional and informational.* However, companion mediating effect was not consistent across themes and ranged from limited to enhanced influence. Informational influence was the most

significant construct identified. Companions exerted a positive influence acting as an aide memoire and also within the role of clarification and information seeking.

Significantly data analysis illustrated that although patients appreciated companion accompaniment and involvement, in some cases the preference of the patient would have been to be unaccompanied. A key finding in this study indicated that companion accompaniment to the clinic consultation was often a negotiated process with three levels:

- Never negotiated: a mutual understanding without discussion where companion accompaniment was taken as a given
- Partial negotiation/negotiated coercion: a negotiated discussion between patient and companions where companion petition prevailed
- Non-negotiable: where companions did not broker discussion or consent

A crucial finding identified that the level of negotiated accompaniment appeared to be associated with companion influence on information exchange.

**Moderating influence**

The negotiated presence of companions and the strongly moderating role of non-negotiated companions, emerged as a major finding in the data. A moderating influence was shown in five of the seven cases and could be categorised into three main sub-themes of *controlling companion, companion agenda and companion as expert*. The sub-themes were linked with recurring patterns, demonstrated across all three constructs. The more controlling the companion, the more they influenced the information exchange process with their own agenda. This was particularly so when the companion may have a perceived expert companion role. Companions did not need to have a healthcare background to exert their own agenda, only a persuasive desire to have their questions answered.

- **Companion control**

Companions were seen to control the exchange of information in various ways, predominantly by answering patient intended questions and through interruption. Although five cases exhibited this behaviour, in some cases it was seen to be throughout all encounters with various healthcare professionals. In one case (C) the companion controlled patient access to clinical trial material:

***Och, a lot of this is just, you know, it's information sheets – it's just to give you an idea of what it's about. But it's just confirming what they've already told you, that's all. It's just to see if… It's just to tell you what it is. Honestly, I'll take these papers home, have a wee look through them – there's no point in you having more paperwork than you need. Yeah, it's just information. There's nothing that has to be filled out. I'll just hang on to that for you (Case C companion, Ref 11)***

- **Companion agenda**

In the cases where companions used controlling behaviour to moderate information exchange, they regulated the clinical encounter by addressing their own agenda. In certain cases there was evidence that companions raised concerns and discussed topics which appeared to satisfy their own communication and information needs. Such agenda setting was evident throughout the clinical consultations:

***No, because if you don't hear it, you're gonnae do it, and I'm not gonnae know, so that's why I thought, I'm gonnae have to. I've got a wee checklist of questions, and they're all about things I know you're gonnae do! And that was the major one, because I know what you're like…(Companion Grace, Ref 4)***

- **Expert companion**

In this study *expert companion* was conceptualised within a broad categorisation and ranged from companions who had a healthcare background (Companions B, C and F) to those with previous knowledge and experience of caring for someone with the illness (Companions A and D). There was also evidence that in some cases (E), companions became 'expert' through reading and familiarisation around the subject matter:

***No, well, I don't know if this is your department, or if it would be this other fellow – but I think there's just a few wee things. Sorry, I don't mean to be rude by writing things down. Yeah, I do think Celia is much more breathless than even just a week ago. Is oxygen therapy a consideration? (Companion C, Ref 1)***

When companions did mediate within the physical/emotional and informational sub-constructs, their influence seemed intended to enhance patient health status. The provision of current, contextual health details added to the clinical picture and provided improved knowledge for professional, enhancing care for the patient. In contrast, when companions were seen to moderate the information exchange process, there was potential for patient care to be compromised.

**Perception of companion accompaniment**

Within the mediating influence construct, patients expressed positive opinions regarding companion impact on information exchange. But, professional perspective was absent for this domain. However, the reverse was identified for moderating influence. Despite evidence that companions influenced information exchange in a controlling and moderating fashion, overall patient perspective was not critical of this effect. Professionals were more vocal for this domain and study data illustrated that, for some cases, there was a negative perception noted regarding companion accompaniment:

***There seems to be a lot of antagonism between her and the son…and is nagging her …regarding smoking…and harassing her, and she's feeling very stressed with that. So the consultation was interrupted about three times just for that (Oncologist, Companion E, Ref 2)***

**Discussion**

When accompaniment was reciprocal or partially negotiated; companions predominantly demonstrated a mediating or enhancing influence on information exchange. Conversely non-negotiated accompaniment was associated with powerful and expert companions with a significant moderating and controlling influence on information exchange.

The current research identified the 'expert' role of non-negotiated companions who significantly moderated and consequently disrupted features of the information exchange process. The companions in this study adopted the role of expert, independent of any other individual, in direct contrast to Rosenthal and colleagues' (1980) findings that professionals cast companions in the expert role. In line with the findings of others, study data suggested that expertise was often conferred through a companion's established relationship and intimate health knowledge of the patient (Allen, 2000); as well as past experience, healthcare training and the self-development of considerable disease and treatment related knowledge (Nolan et al, 1996; Taraborelli, 1994; Twigg and Atkin, 1994). All factors which could theoretically have been instrumental in determining the moderating companion's decision not to negotiate their presence at clinic in the first place.

There was no indication in this study that the expert companions felt subordinated, with a need to negotiate or relinquish control to other members of the triad. Companions came to the clinical encounter without negotiating their presence and promoted their own agenda for structuring information exchange and in some cases, directly organising and controlling communication. They

did so independently of any other member of the triad. As singular individuals, they seemed both confident and powerful in their own right to control the information exchange process, independent of coalition formation.

Coalitions occur when two individuals in a triad adopt a common strategy to achieve a mutually-desired decision despite the active or passive resistance of the third individual (Coe and Prendergast, 1985). Coe and Prendergast's analysis of interactions among physicians, elderly patients and their companions revealed each encounter involved several coalitions, where the majority of companions made efforts to form coalitions with physicians. Physicians are viewed as an important ally for companions because of their power and status within the triad. This is contrary to current study data which demonstrated that companions seemed unconcerned about the amount of power and expertise held by other individuals, relying instead on their own perceived expert status within the triad.

In contrast to Allen (2000) and Simmell and Wolff (1950), findings suggested that the powerful, expert companions did not play any of their identified roles. Likewise there was no indication of negotiation within the triad at the oncology out-patient consultation. Clinical context may be an important consideration for negotiating and relinquishing control. Allen's study was in-patient based where triadic exchanges could be more prolonged (over days and weeks). Within that clinical context, companions may recognise the severity of the patient's condition and the nature of continual care renders the patient particularly dependent on other members of the triad. Subsequently companion expert role is less defined.

Data was consistent with the findings of Hasselkus (1992) whereby companions have moved beyond viewing themselves merely as fonts of medical information and historical details, content with either forming coalitions with or relinquishing control to other triad participants. In her study Hasselkus analysed topical themes and exchanges of meaning between physicians, older patients and family caregivers during medical appointments. She found that caregivers contributed to traditional physician domains of care such as diagnosis, interpretation of symptoms and treatment recommendations much more than anticipated. In line with current findings, companions exchanged information around medical aspects of care whilst bringing very little social context to the exchange. Companions viewed themselves as integral primary healthcare providers, with their long-term experience in monitoring symptoms, controlling medication and taking an active role in the health of

the patient. This presentation of their role and place within the clinical consultation differs markedly from the model of coalitions (Coe and Prendergast, 1985; Roscoe, 1981).

In this present research companions acted more as independent practitioners, often as an expert and powerful individual for the purpose of furthering their own agenda rather than in contention or even negotiation with the other members of the triad. In her study Hasselkus's sample was derived from an elderly population and it could be considered that companions would be more engaged in care activities requiring a high level of involvement when patients were both elderly and of poorer health status (Wolff and Roter, 2011; Wolff, 2008). The clinical context within which negotiation transpires is an under-researched area and one worthy of further consideration.

Current findings of the expert, powerful and controlling, non-negotiating companion were distinct to research undertaken by Morris and Thomas (2001). Their research primarily focused on how carers negotiated their relationship within the medical setting. Unlike our study there was no indication that patients and companions negotiated companion presence *pre*-consultation. Also in direct contrast to the non-negotiated accompaniment found within our study, companions in their work were diffident about their place at the consultation and required to be 'invited in' both by the patient and the professional. Morris and Thomas found carers were reticent of entering the consultation, 'stood back' without contributing to the exchange, were uncertain of their role and reserved about disturbing the privilege of the doctor-patient relationship. Carer diffidence about their role and accompaniment was due to concern about issues of confidentiality as well as maintaining a sense of independence for the patient. In my research even when companions displayed more neutral influence (Cases B and D) they still contributed to information exchange within the clinical encounter, although there was a greater sense of deference to the patient rather than diffidence. However, this respect for patient self-determination found in the neutral cases in our study was not evident in the replication analysis of some of the mediating cases and appeared to be absent in the moderating cases.

Our data did not identify with any of the concerns of negotiated identity, support and sharing, among the powerful, expert companions, recognised in the research by Morris and Thomas (2001). There is no immediate explanation as to why companions in our study were different to those of Morris and Thomas (especially as their sample included 10 patients with various stages of a lung cancer diagnosis). It has previously hypothesised that both personal characteristics and relationship

alliances may have a significant influence within our study and the contrast between the two studies points to such variables.

**Limitations**

One limitation of the study relates to sample size. Yin (2009) stated that one replication can support analytical generalisation and Eisenhardt (1989) specified each case serves as a distinct experiment that stands on its own as an analytical unit. Although each of the seven cases studies emphasized the rich, real-world context in which information exchange and companion influence occurred and the aim was not to generalise the findings to the wider population, and while new knowledge emerged from the analysis, case size was limited and the findings considered judiciously.

Another limitation concerned collection of companion demographic data. Companion data was collated retrospectively from transcription narratives and researcher field notes. Collection of additional demographic data such as age, professional background and educational status would have been invaluable information when analysing companion demographic effect on preference for accompaniment and companion influence on information exchange and consequent roles. This reflects the true nature of case study research in that the true significance of companion role and influence was only identified during the substantive analysis period when emerging theoretical propositions were inductively identified.

**Conclusion**

The findings provided new insight into companion presence during cancer consultations as mediating and moderating influences. In terms of emerging theory this study conceptualised and refined these constructs to specify the distinctive role companions of patients with lung cancer assumed. Companion presence at lung cancer consultations was often found to be a non-negotiated accompaniment. Three significant interrelating factors influencing non-negotiated companion accompaniment emerged. These emerging concepts had clinic relevance in terms of contemporary cancer practice.

Recognising the significant yet fundamental influence companions have on information content and direction is crucial. The positive influence of accompanying companions on patient-professional interactions supports the value of family members being present during consultations. Equally useful

is identifying when the role is non-supportive and challenging to information exchange and deviates from important clinical interactions.

**Table 1: Companion combinations**

| Cases | Consultation 1 | Consultation 2 | In-depth interview |
|---|---|---|---|
| | | | |
| **Alex** | Daughter Ann | Daughter Ann | Partner Agnes |
| **Ben** | Daughter Betty | Daughter Betty | |
| **Celia** | Brother Colin | Brother Colin | |
| **Delia** | Husband Davie<br>Daughter Diane | Husband Davie<br>Daughter Diane | Husband Davie |
| **Eve** | Son Eric | Son Eric<br>Daughter Elaine | Son Eric<br>Son Ewen |
| **Flora** | Husband Frank<br>Daughter Fiona | | Husband Frank |
| **Gordon** | Ex – wife Grace | Ex-wife Grace | |

**Table 2: Mediating and moderating influences on information exchange**

| | Constructs | Actions | Cases |
|---|---|---|---|
| **Mediating (facilitative) influence** | Physical | Logistical – provides transport<br>Physical presence | C G<br>A B C D E F G |
| | Emotional | Provides reassurance<br>Seeks reassurance<br>Being supportive<br>Physical comfort | A B<br>D G<br>G<br>F (Frank only) |
| | Informational | Remembering/ Aid memoir<br>Clarification/seeking<br>Provides context | A B C D E F G<br>A C D E F G<br>A C D E G |
| | | | |
| **Moderating (controlling) influence** | Companion control | Answers for patient<br>Interrupts<br>Dismissive | C E F G<br>C E F<br>C F |
| | Companion agenda | Companion agenda setting | A C E F G |
| | Companion as expert | Healthcare profession education<br>Previous experience in cancer<br>Learned expertise | B C F<br>A D<br>E |
| | | | |
| **Neutral** | Prior knowledge & experience | | B D |
| | Relationships | | B D |