

SHARED DECISION MAKING IN CONSULTATIONS ABOUT TREATMENT FOR
NON SMALL CELL LUNG CANCER

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ABSTRACT

Lung Cancer accounts for between 10-15% of all new cases of cancer in the UK. Considering treatment for lung cancer is a complex process involving balancing the trade-off between quality and quantity of life. Guidelines (NICE 2005) emphasise that treatment decision making is an endeavour to be done jointly between doctors and patients. Current evidence suggests that involvement in decision making is beneficial for patients and can be achieved through using a shared decision making model. It is unclear how treatment decisions are currently made in lung cancer and what patients' views on the process are.

The current study aimed; first to examine the patient, companion and doctor interaction within lung cancer decision making consultations; second to explore if shared decision making is present; third to investigate patient satisfaction with the decision making process.

A mixed method cross sectional survey design was used. A qualitative method was used to observe fourteen consultations, which were then coded for content using thematic analysis. A questionnaire was used to elicit patients' views about the consultation. Data was analysed using descriptive statistics.

Findings suggest that shared decision making was not routinely implemented in current practice. Seventeen themes were extracted around making sense of the patient's lung cancer, discussing treatment options and their consequences, aspects of related care and social expectations. Consultations were largely focused on the exchange of information, which did not happen fully. Patients' values were not elicited and participants did not deliberate the decision together.

Consultations consistently helped the patient to understand their prognosis, and the best clinical direction to take and consent to. However patients are not actively involved in the decision making. If shared decision making is to be used in clinical practice the structure of the consultation needs to be adapted to create space for patients to be supported through deliberating the decision in addition to talking about options and choices.

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ABBREVIATIONS

COM	Companion
DCS	Decisional conflict scale
DOC	Doctor
LCNS	Lung cancer nurse specialist
PAT	Patient
SDM	Shared decision making
SWD	Satisfaction with decision scale

CHAPTER 1: INTRODUCTION

1.0 Literature review

Every year approximately 39,500 people in the UK will be diagnosed with lung cancer. Around 35,300 people will die from the disease. This makes lung cancer the most common cause of cancer death in the UK and a leading cause of mortality in people under the age of 75 (Cancer Research UK, 2010). The majority of lung cancer cases cannot be cured; only 7% of lung cancer patients in England and Wales are alive five years after diagnosis (Cancer Research UK, 2004).

The facilitation of patient involvement in their healthcare by staff is a key component of current NHS policy (The NHS Plan, 2000). National Institute for Clinical Excellence Guidelines (NICE, 2005) on the treatment of lung cancer stated that treatment options should be discussed with the patient and decisions on treatment and care should be made jointly with the patient. This model of health care can be delivered through a framework of shared decision making (Charles, Gafni & Whelan, 1997).

The following sections explore a description of lung cancer, its treatment and the empirical evidence available about the experience of living with lung cancer, communication within consultations and decision making about treatment.

1.1 Lung Cancer

Lung cancer is a term used to describe uncontrolled cell growth in lung tissue. A tumour is created when abnormal cells stick together. If abnormal lung cells detach they can circulate to other areas of the body via the blood or lymphatic system. The cells may start to grow in other areas. This new secondary growth is called a metastasis (National Lung Cancer Forum for Nurses, 2010). Lung cancer is the most common cause of cancer death for men, who account for 60% of cases (NICE 2005).

In women, lung cancer is the second most common cause of cancer death after breast cancer (NICE 2005). Lung cancer is uncommon in people younger than 40, but incidence rates increase thereafter and is most common in people aged 75-84 years (Office for National Statistics, 2010).

Lung cancer is one of the few cancers with a known carcinogen being partly responsible for its development. Around ninety percent of lung cancer deaths can be attributed to smoking (Cancer Research UK, 2010). Deprivation is strongly linked with smoking and with incidence and mortality rates in lung cancer. Carstairs' deprivation index analysed lung cancer incidence data for England and Wales (1993). It was found that in the most deprived male groups the incidence rate was 2.5 times higher compared to the least deprived (Quinn et al., 2001).

Lung cancers are classified into two types: small-cell lung cancers (SCLC) and non-small-cell lung cancers (NSCLC).

- 1) SCLC account for about 20 % of cases. Small cell carcinoma is more likely than NSCLC to have spread by the time of diagnosis (Cancer Research UK, 2009).

- 2) NSCLC account for the other 80 % of lung cancer cases. There are three types of NSCLC: Squamous cell carcinoma, Adenocarcinoma and Large-cell (undifferentiated) carcinoma. These are categorised together because they behave similarly and respond to treatment differently to small cell lung cancer (Cancer Research UK, 2009).

This thesis will focus on NSCLC because it is the most prevalent. The treatment options for NSCLC are described below.

1.2 Treatment for lung cancer

The three main treatments for lung cancer are chemotherapy, radiotherapy and surgery (Cancer Research UK, 2010). Chemotherapy is the main treatment choice for patients with NSCLC. Chemotherapy can be used to reduce symptoms, extend length of life or shrink the cancer enough to allow further treatments, such as, surgery or radiotherapy. Chemotherapy is found to be effective in reducing mortality rates in patients with stage III or IV NSCLC to improve disease control, relieve symptoms, and improve quality of life (NICE 2005). First line chemotherapy for patients with advanced NSCLC improves survival by up to nine months in comparison to best supportive care (Shepard et al., 2000).

1.3 Experience of having and adjusting to lung cancer

There is a paucity of research in the lung cancer arena when compared to other cancers. Much less funding is awarded for lung cancer research than for other cancers, respective of both mortality and incidence rates (NCRI Strategic Analysis, 2002). The research that exists suggests that the experience of having and adjusting to lung cancer is a difficult and complex process. Some of these aspects are discussed below.

The physical symptoms of lung cancer include pain, tiredness, coughing and lack of appetite (Akin, 2010). Chapple et al (2004) interviewed 45 patients in different stages of lung cancer to investigate their experiences. Many patients experienced stigma and shame related to the public perception of it being a self-inflicted disease caused by smoking and their self-image was negatively affected. Fear related to the prospect of death is also a major component, with regular hospital visits dominating their lives (Murray et al., 2002).

The experience of patients diagnosed with lung cancer is often one of uncertainty (Sharf et al., 2005, Murray et al., 2002). This uncertainty can include doubting medical procedures, remembering unpleasant past experiences and complaints of

insufficient information (Sharf et al., 2005). Recently, diagnosed lung cancer patients have many unmet psychosocial needs such as concerns about their future and worries about the impact of their illness upon their family (Hill et al., 2003). Often prognosis is poor, the available treatments predominantly only prolongs life for a relatively short time; and these treatments may negatively impact upon the patients' quality of life. Individuals may try to adjust by positively envisioning the situation, emphasising self-efficacy, increasing their will to live, and setting aside physical discomfort (Sharf et al., 2005).

Central to the experience of metastatic NSCLC is that it is a mortal illness. Evidence suggests that patients do not have a full awareness of their prognosis and the goals of therapy, perceiving their disease more optimistically than doctors (Sagan et al, 2011). For example, Quirt et al (1997) found that only 36% of lung cancer patients agreed with their doctor's view about their likelihood of cure, with most patients being overly optimistic. Temel et al's (2011) study of patients with metastatic NSCLC found that many patients retained their inaccurate view of prognosis, even following discussion with their doctor. There is evidence that patients and their companions collude with doctors in false optimism (The et al., 2000). Patients inaccurate perceptions of their prognosis may have implications when discussing treatment options.

The experience of having lung cancer involves discussions around treatment options. Treatment decisions that need to be made in oncology consultations may include whether to start chemotherapy or radiotherapy. The toxicity of cancer treatment may be significant and the side effects can have a pronounced detrimental impact on the patient's quality of life. For example, of patients being treated with Cisplatin/Pemetrexed or Cisplatin/Gemcitabine (the most widely used chemotherapy drugs) 12- 21 % will suffer alopecia and 4 - 7 % will experience vomiting caused by the therapy (Scagliotti et al., 2008). However, chemotherapy may also relieve symptoms, especially pain (Bircan et al., 2003) and improve the quality of life for those with advanced NSCLC.

Lung cancer patients often have complex management needs; this underpins the importance of partnership in decision making. Patients, their families and doctors are required to balance the side effects of treatment against length of life. Decisions involve an assessment of the trade-off between quality and quantity of life. Without such a discussion, patients would risk abandoning patient centred aspects such as an emphasis on quality of life in favour of longer life at an expense. Evidence in support of this shows that patient choice of further treatment may be based less on information received from doctors and more on their personal experiences or those of significant others (Jonsen et al, 1998). Similarly, past studies have shown that some doctors have been prepared to treat cancer patients aggressively for little benefit (Brundage et al, 2001). This trade-off between the extension of life and quality of life makes lung cancer a particularly appropriate area for investigating decision making. This is because the treatment choice is a complex process where specialists can lack consensus about what is optimal (Brundage et al, 1996).

1.4 Decision Making in Lung Cancer treatment

1.4.1 Making good decisions

Current NHS policy recognises the importance of making good decisions (Department of Health, 1995; The NHS Plan, 2000). A good patient decision can be conceptualised as one that is made well, i.e. the decision making process (Bekker et al., 1999). A good decision process requires the patient to be aware of the consequences of all options, assess the different options in accordance with their beliefs and trade-off these evaluations when making the choice (Bekker et al., 1999). Informed decision making is another term for ‘good’ decision making. In practice people rarely make well-informed decisions (O’Conner 2009) as individuals have limited processing capacity (Loh et al., 2007). In order to still make choices despite this people use modes of thinking and reasoning that simplify the issues (Bekker et al., 2010). Decision making requires people to incorporate information from sources external to them with their internal existing thoughts and feelings (Bekker et al., 2010). People selectively attend to external factors to create their own internal

representation of the issue, which is then evaluated (Payne & Bettman, 2004). Rather than the facts themselves influencing decision making, it is the way information is presented and the individual's past experiences that influence their decision making (Bekker et al., 2010). People are often unaware of their biases when creating their internal mental representation of the issue. Heuristic or systematic strategies are used to evaluate their representations and make decisions (Chaiken et al., 1980). The way that people selectively process information in this way may result in poorly made decisions.

1.4.2 Evidence of patients' decision making about lung cancer treatments

There has been little systematic investigation of patients' decisions about lung cancer treatment. However, there is some evidence that patients may not be making treatment decisions for lung cancer well. From the aforementioned definition, there is an expectation that patients making good decisions must be aware of all the treatment options available and their consequences. Patients often report that they did not perceive there to be a choice of treatments, with length of life being paramount in many patients' view (Koedoot et al., 1996). When it comes to decision making in the palliative setting, active treatment seems to be valued over best supportive care (Yellen, 1995). This may be because doing something provides people with a sense of control (Levine et al 1988). Indeed, cancer patients have been shown to choose aggressive treatments even when the chance of cure is as little as 1 % (Slevin et al., 1990; Yellen et al., 1995). In another study, Koedoot et al (1996) interviewed patients after the decision whether or not to start chemotherapy was made. The patients reported feeling that they did not have a choice '...with their back up against the wall' implying that chemotherapy was the only option if they wished to survive. When discussing treatment options with patients and their companions this preference to opt for treatment should be taken into account by the doctor.

Koedoot et al's (2003) prospective study of treatment preference concluded that patients generally make up their mind about chemotherapy before seeing their oncologists and receiving information relevant to their treatment. This may indicate

that the patient has already decided what they want before the consultation and that the doctor does not have much influence on their eventual decision. This finding also suggests that people are relying on existing beliefs and schema. Perhaps it is the doctor's role to challenge these beliefs with their evidence-base and clinical expertise. Koedoot et al's (2003) study highlighted the important proactive role that doctors can take in helping patients to unpack and understand their preferences and values. Patients may often have investigated their condition and different treatment options before the consultation where decision making happens (Diefenbach, 2009) and have a clear preference for treatment.

Whilst some people may have a treatment preference, there is also evidence that some patients with cancer want to leave medical decisions to their doctor (Degner & Sloan, 1992). Female sex, younger age and having a higher educational level are predictive of desires to engage actively in decision making (Gaston & Mitchell, 2005). As noted earlier, lung cancer is a disease that largely affects people over the age of 75 and is more prevalent in men (Office for National Statistics, 2010). It is therefore possible that lung cancer patients are less likely to actively engage in decision making than some other cancer patient groups. As patient involvement is more important when the decision made is more crucial for the patient (Loh et al., 2007) lung cancer patients may need more active support from health care professionals to actively engage them in the decision making process.

1.4.4 Patient Centred Care and Shared Decision Making

Patient centred care has many definitions. Mead and Bowers' (2000) model which is one of the most widely regarded, describes five dimensions of patient centredness: 'doctor as person', 'patient as person', 'sharing power and responsibility', 'therapeutic alliance' and having 'a biopsychosocial perspective'.

Shared decision making (SDM) has been referred to as the crux of patient centred care (Godolphin, 2009). SDM can be defined as a process by which healthcare professionals and patients work together to make healthcare choices (Charles et al., 1997; Makoul, 2006). SDM is considered to be desirable in healthcare

communication. There is evidence suggesting that it increases satisfaction, increases involvement and adherence, and is associated with reductions in anxiety and depression (Fallowfield et al., 1990). Despite the benefits that can result from SDM as a part of patient centred care, it is not routinely implemented in clinical practice (Elwyn et al., 1999a; Stevenson et al., 2000 O’Conner et al., 2007). The next section explores the concept of SDM in more detail.

1.4.5 Shared decision making about treatment

The interaction between the health care professional and the patient, and the roles and responsibilities around the sharing of information, preferences and decision making are key to SDM (Bekker, 2010). A SDM framework differs from the traditional hierarchical doctor centred-approach (Glasgow et al, 1999) where doctors’ behaviour comprises mainly of directives and closed questions (Street, 1992). Edwards and Elwyn (2006) suggested a difference between the process of involvement (option portrayal, exchange of information and exploring preferences for who makes the decision) and the actual decisional responsibility (who makes the decision). It appears that most beneficial for patients is the process of involvement itself, rather than the action of making the decision (Edwards & Elwyn, 2006).

SDM involves a complex set of behaviours that both patient and professional must adopt in consultations in order for SDM to be achieved (Legare, 2007). Currently there are variations in the conceptualization of SDM and its characteristics and core elements. Following Makoul and Claymans’ (2006) systematic review of the literature they proposed an integrative model for the elements of SDM (see *Table 1*).

Table 1: The elements of Makoul et al's (2006) integrative model of SDM

Essential Elements
Define/explain problem
Present options
Discuss pros/cons
Patients values/preferences
Discuss patient ability/self efficacy
Doctor knowledge/recommendations
Check/clarify understanding
Make or explicitly defer decision
Arrange follow up
Ideal elements
Unbiased information
Define roles (desire for involvement)
Present evidence
Mutual agreement

The essential elements in this model are those that need to be there for patients and health professionals to engage in the process of SDM. On the other hand, whilst the ideal elements may enhance the decision-making experience, they are not considered necessary for SDM to take place (Makoul & Clayman, 2006).

Another such model is Towle et al's (2006) competencies for SDM which was formulated from information obtained by literature review, interviews and focus groups (see *Table 2*).

Table 2: Competencies for informed and SDM (Towle et al., 2006).

Competency	
Partnership	Develop a partnership with the patient
Information	Establish or review the patient's preferences for information
Role	Establish or review the patient's preferences for role in decision making
Ideas	Ascertain and respond to patient's ideas, concerns and expectations
Choices	Identify choices (including ideas and information patient may have) and evaluate the research evidence in relation to the individual patient
Evidence	Present (or direct patient to) evidence taking into account information and role above, framing effects (how presentation of the information may influence decision making), etc. Help patient to reflect upon and assess the impact of alternative decisions with regard to his or her values and lifestyles
Decision	Make or negotiate a decision in partnership and resolve conflict
Plan	Agree upon an action plan and complete arrangements for follow up

A criticism of both the above models is that they were developed to train health professionals to develop competencies and are about what the doctor must do. A list of tasks the professional must complete does not consider how patients interact in the consultation or translate into a model to explain how decision making is shared between parties. These models of SDM only focus on the doctor's side of the dyad and do not fully consider the patient's role and responsibility in the communication process. Moreover, they do not consider patients individual factors such as capacity to understand and attend to information, mood or outside influences e.g. family or systemic factors. Similarly Makoul & Clayman's (2006) systematic review failed to consider how to accommodate principles of inter-professional collaboration into SDM (Stacey, 2010).

A further criticism is that these models were developed for use in certain contexts, for example in primary care or for prevention and screening decisions. Some types of decisions are more complex than others. For example, a preventative decision to have a flu jab is fundamentally different to a treatment decision to start chemotherapy. It is possible that models such as Towle et al's (2006) and Makoul's (2006) that analyse the SDM process in primary care cannot be generalised to all medical consultations.

Stacey et al's (2010) concepts of SDM may be a more useful structure to conceptualise SDM; it was found to be common to all existing models and can be operationalised to everyday medical decision making. Moreover, it attempts to include the interaction and exchange which should be present between health professionals and patients in SDM.

Stacey et al's (2010) theory analysis of fifteen SDM models revealed eighteen core concepts organised into four main themes: features of the SDM process; individuals involved in SDM; factors influencing the process of SDM (e.g. relationships, policies, services) and outcomes of SDM at the level of patients, practitioners and the healthcare system. Stacey et al (2010) analysis of concepts found four features in the SDM process that were common across all models of SDM:

1. Knowledge transfer and exchange
2. Expression of values/ preferences
3. Deliberation
4. The decision

In order to establish if SDM is used in medical encounters researchers have used various tools which are discussed in the next section.

1.5 Investigating SDM

The different ways of defining and conceptualising SDM has resulted in inconsistent measurement and makes measuring the constructs of SDM a challenge (Simon et al., 2006). Few instruments have been designed to measure the whole process of SDM because the concept is relatively new. SDM can be explored by observing and analysing the content of the decision making consultation and by using a questionnaire to elicit participants' perceptions of the decision making process. Both are explored below:

1.5.1 Observing shared decision making

Observing consultations is the most objective way of measuring SDM because it allows access to the process that naturally occurs in consultations. There are several coding scales that set out to objectively measure the presence of decision making in medical encounters. These are summarised below:

- Street's (2001) method of analysing patient participation in medical encounters breaks down expressions of both doctor and patient in the discourse into units which are then coded. These consist of the extent to which patients ask questions, express concern and give assertive responses, and the extent to which doctors use partnership-building and supportive talk. It has an inter-rater reliability of 0.71 (patient behaviours) and 0.76 (practitioners behaviour). It is generally viewed that this tool is most relevant when measuring patient-centredness (Street, 2001).
- The Roter Interaction Analysis system (RIAS) (Roter & Larson, 2002) was designed to reflect the principles of medical dialogue and codes the contributions of both patients and health care professionals in the medical exchange. It is usually performed without the use of a transcript, directly from audiotapes of the consultation. It has an inter-rater reliability of 0.85 (Roter & Larson, 2002).

- The Rochester Participatory Decision Making Scale (RPAD) (Shields et al., 2005) is based on a patient involvement model which focuses on the physician's behaviour that encourages patient participation. It is a 9-item scale in which coders rate how adequately a health care professional demonstrated a particular behaviour, such as discussing uncertainty and clarifying agreement. It is a reliable tool (correlation coefficient = 0.72).
- The Decision Analysis System for Oncology (DAS-O) (Brown et al., 2010) was developed to evaluate SDM in breast cancer consultations. The system consists of two subscales: 1) creating a SDM context, 2) Providing unbiased and clear information. The DAS-O captures doctor behaviour only. It is reliable tool with high inter rater reliability (correlation coefficient = 0.88).
- Singh et al's (2010) coding system was designed to be an oncology-specific system for shared decision making. It has eighteen items and six constructs; establishing a problem, doctor-patient relationship, research evidence, patient perspective, decision making and time issues. It has intra-rater reliability, satisfactory internal consistency (Chronbachs alpha = 0.77) and construct validity (Singh et al, 2010). However, it has been acknowledged by the authors that this coding system requires further validation (Singh et al., 2010).

The above coding systems vary in terms of their clinical relevance for measuring shared decision making and in their applicability to the lung cancer setting. The RPAD system focuses on the behaviour of physicians' encouragement of participation and therefore does not fully record the patient's role. Street's (2001) measure is one of patient participation which is not the same as shared decision making and excludes the true nature of the decision making interaction. Equally, it presents coding difficulties when a third person is present. Usually studies using this measure exclude consultations in which a patient's companion was present (Street et al., 2008). It is unlikely that this measure could be used to assess the true nature of the

interaction in most lung cancer consultations given that, as clinically observed, patients rarely attend alone.

Ong et al (1998) analysed the properties of the RIAS in oncology consultations. They concluded that the RIAS was acceptable for use in oncology settings, with acceptable content validity, and high inter-rater reliability. Whilst the RIAS does allow for the coding of a third party, such as a patient's companion or second health care professional, it does not focus on constructs of SDM. Rather it is used to operationalise patient centredness (Mead & Bower 2002). Thus neither of these coding systems are thought to be adequately specific for the decisions which need to be made by cancer patients (Singh et al., 2010).

Whilst the DAS-O is cancer specific it was developed for use with breast cancer patients. The sample used to develop the tool consisted of only female patients, most of whom were already cured and were debating having adjuvant treatment (Brown et al., 2010). This is very different to other cancers such as patients with metastatic lung disease who must make decisions as their health and survival prospects decline. Moreover, the DAS-O places an emphasis on information important to clinical trial decisions rather than specifically focusing on SDM in the consultation in general.

Singh et al (2010) stated that cancer consultations have some specific characteristics which require a targeted approach from the health professional and that existing coding frameworks are more suitable for primary care or when investigating patient centredness. Whilst Singh et al's (2010) coding system is oncology specific, it is concerned with doctors' impact on patient outcomes and it focuses on doctors' rather than patients' behaviour. Using this measure would therefore not reflect the true interaction that occurs in the SDM process either. Despite SDM involving both clinician and patient there is a lack of measuring instruments which focus on both parties. However, it would be possible to create an oncology specific framework to include patient utterances. This would then enable the true nature of the interaction between doctor and patient to be captured regarding how decisions are made in

consultations.

1.5.2 Measuring people's perception of SDM

Most studies assessing SDM have used questionnaires to assess satisfaction with the decision making process (Roter, 1977; Gattellari et al., 2001; Ford et al., 2003; Kriston et al., 2010; Singh et al., 2010;) and preferences for involvement in decision making (Butow et al., 1997; Stewart et al., 2000; Koedoot et al., 2003; Pardon et al., 2009). The strengths of these questionnaires are that they result in standardised data and allow anonymity which can encourage honesty when asking about sensitive issues. However, the limitations are that some questionnaires can encourage people to answer in a socially desirable way rather than to express their true views (Robson, 2002). A necessary consideration when measuring participants' perceptions of SDM is the need to use a reliable, brief and acceptable measure that is applicable for patients. This would aid questionnaire completion and produce meaningful data (Robson, 2002).

There are several self report questionnaires designed to measure the extent of shared decision making in medical encounters. These include the Perceived Involvement in Care Scale (PICS) (Lerman et al., 1990), Shared Decision Making Questionnaire (SDM-Q) (Simon et al., 2006) and the dyadic OPTION instrument (Melbourne, 2010) described below:

- The PICS consists of 13 questions designed to measure patients' perception of doctor-patient communication during medical consultations. It investigates three categories of activities during the medical encounter: doctor facilitation of patient involvement; patient information provision; and patient participation in decision making. It is widely regarded to have satisfactory internal consistency (Cronbach's alpha = 0.73) (Lerman, 1990).
- The SDM-Q is an 11 item theory driven instrument which elicits the extent of patient involvement in decision making. It was developed based on existing skills and competency models of SDM. It too has acceptable reliability

(Cronbach's alpha = 0.77). A shorter version with nine items has also been developed (Kriston et al., 2010).

- The Observing Patient Involvement in Decision Making (OPTION) scale aims to measure the overall shared decision making process. This has primarily been used to assess the extent to which clinicians involve patients in decision making in general practice. The OPTION instrument has been modified (Melbourne et al., 2010) to a 12 item dyadic questionnaire which can be completed by both practitioner and patient following a consultation. However, validation studies need to be carried out on clinical populations to assess the modified instrument's validity and reliability in practice.

The above measures are open to criticism as pure measures of SDM. They have largely been developed for different illness populations and with differing study aims, such as patient involvement and patient centredness, rather than primarily for SDM. SDM is much more than how clinicians involve patients. A limitation of the PICS is that it does not include an appraisal of doctor behaviours related to the information-exchange process. Neither the PICS or the SDM-Q were designed to assess interdependence between participants in consultations.

It may be more useful to assess patients' perception of the decision that has been made, for example by using the Decisional Conflict Scale (O'Connor, 1995). Decisional conflict in patients is an expected result due to the inherent difficulty and uncertainty in decision making. Uncertainty can be lowered when the patient a) feels informed about the alternatives, benefits and risks; b) is clear about their own values; c) feels supported in the decision making process. Interventions that help patients to feel more informed lower decisional conflict. People may feel more supported in decision making if they are guided in the steps of SDM. As a result, they may feel they have made a better choice and be more satisfied with the decision. Satisfaction with the decision that has been made can be measured by using the Satisfaction with Decision Scale (Homles-Rovner et al., 1996). This is an attitude scale which assesses

how satisfied patients are with a health care decision.

The existing tools available for assessing SDM in medical interactions do not seem to capture adequately the interaction involved in the process. Tools need to be developed which take into account the nature of the oncology setting and be based on the theoretical SDM concepts of transfer and exchange (Stacey et al., 2010).

A central component of the shared decision making model is how health professionals communicate with their patients (Bensing et al., 2000). This is explored in the next section.

1.6 Doctor - patient communication in medical consultations

The consultation between doctor and patient is a key interaction. This exchange can encourage patient participation, and impact upon patient satisfaction and facilitate improved health status (Ong et al., 1995; Stewart, 1995). Normal decision making medical consultations are patient centred and evidence based. In these consultations the majority of patients accept doctors' recommendations (Sharf et al., 2005) whilst feeling that they owned the decision (Mendick et al., 2010). When involved in discussion about treatment options uncomfortable symptoms and side effects must be weighed against potential benefits to assess potential impact on patient's quality of life. This deliberation requires doctors and patients to navigate uncertain information that is based on probabilities and may not be meaningful for the individual. Patients are unable to make sense of the uncertainties and take part in decision making as much as they may want unless they are given the right kind of information. Effective communication skills are a crucial constituent of patients' participation in life prolonging treatment decisions (Street, 1992). The concept of mutuality in communication is where both doctor and patient are partners in the relationship and decisions are negotiated (Roter, 2006). Good communication is an important prerequisite for SDM.

Good communication resulting in shared understanding does not always seem to be present in medical consultations. Quirt et al (1997) interviewed one hundred recently diagnosed lung cancer patients. At the same time their consultants completed questionnaires to try and elicit the level of agreement between doctor and patient about the disease. The findings indicated that misunderstandings were common, such as the purpose of treatment and its probable outcomes. These misunderstandings usually went unrecognised by the doctor, therefore it may be unwise to assume that patients are in a position to make an informed decision about their treatment. This mismatch between the patient and doctor perceptions may indicate that true SDM is an unlikely event in consultations.

Much of the prior literature on doctor-patient communication focuses on patients' preferences for involvement in decision making and not on how patients are actually involved. Evidence suggests that some patients may not want to take part in medical decision making. Patient variables seem to play an important role within this. Patients' socio-demographics such as lower income, lower level of occupation, fewer years in education and older age all seem to be associated with a preference for less involvement in the consultation and for them to take a more passive role (Ende et al., 1989; Pendleton & House, 1984; Waitzkin, 1985). Illness severity is also a major determinant in the type of communication that is present in consultations. Ende (1990) found that as illness severity increased, both patients and doctors relied more on the doctor making decisions about treatment. As lung cancer progresses it is possible that communication changes, but there is little evidence regarding this.

Most research studies on consultations focus on communication skills such as levels of understanding, rapport building, doctor-patient relationship and interruptions. These are important elements of care and are patient centred, however, they are not essential parts of SDM. Singh et al's (2010) framework demonstrates that patient centred care is different to SDM by having different items which tap into these different factors.

The present study aims to extend previous literature and investigate the specific SDM skills demonstrated in consultations, rather than focusing on patient centered techniques.

Communication in consultations does not just exist in the patient-physician dyad. Other influences need to be considered when investigating treatment decision making, such as the significant others who may be present. It is currently unclear what role companions play in decision making, however, the available evidence will be presented below.

1.7 The companion in decision making consultations

The presence of a companion in consultations is found to be valuable for patients (Roter, 2006). Given the numerous treatment decisions that need to be made in a short time period, families' impact on patients' treatment decision making can be profound. Most lung cancer patients are older in age (median 72 years). This places limitations on their capacity to withstand suffering and habituates them to being more passive when making treatment decisions than younger patients (Petrisek et al., 1997; Siminoff et al., 2000). Egglis' (2006) study of information seeking in oncology consultations found that 86 % of patients brought a companion into their consultation, suggesting that most patients bring someone along to their oncology consultation. Clayman et al (2005) found that companions appeared to be particularly active in consultations (routine geriatric consultations) the more ill the patient was. In these cases companions facilitated patient involvement in their own care. Patients were four times more likely to be active in decision making than compared to when the companion did not act as facilitator. It may be the case that companions become more involved in decision making as a disease progresses.

Companions may not always agree with the patient as to what is the most appropriate course of action. Zhang et al (2003) found that 65% of families studied disclosed numerous disagreements, and that these mostly concerned routine treatment decisions, discontinuation of therapeutic treatment and the use of hospice care. Zhang et al (2010) found that patients and caregivers reported significant disagreement on

the trade-off between treatment side effects and benefits as care givers were more concerned about the patients' quality of life. Family disagreements about treatment decisions are highly situation-specific (Lobchuk & Degner, 2002). Although families agree on many matters regarding care, disagreements on minor issues had a significant effect on the stress levels of patients and caregivers (Zhang et al., 2010). Helping patients and their companions to discuss and process decisions together may be beneficial to both parties wellbeing.

The companion's role in cancer consultations is little understood (Street et al., 2008). There is evidence that they fulfil several roles, including a functional role of asking questions, information seeking and, providing emotional support (Schilling., 2002). However, it is possible that companions are supportive simply by their presence, rather than through active engagement (Street et al., 2008). The companion's involvement is often that of monitoring the interaction and putting forward questions and concerns when they feel particular issues need to be addressed (Street et al, 2008). Some companions have recounted their experience in decision making as a meaningful but difficult experience (Jacob, 1998). Beisecker and Moore (1994) asked oncologists about their views of cancer patients' companions and found that they perceived companions behaviours as differing greatly from assertive to passive. They also noted that the patient and companion often had different agendas.

The role of the companion has also been explored in the child-parent dyad where involving the family members in decision making is seen as greatly beneficial. Miller's (2009) qualitative analysis investigated the decision making process in children with a chronic illness. It was found that decisions made collaboratively between the parent and child resulted in many positive outcomes. Perceived advantages included a closer bond between family members, everyone knew what was happening and, this resulted in both the patient and family members being happier. It may be the case that this finding can be generalised to other family relationships such as spousal or sibling involvement. However, a companion's presence may not always be beneficial. Research has found that in some situations

companions have a negative effect on the consultation. For example they could forcibly seek to follow their own agenda or interfere with the patient's communication (Beisecker et al., 1989; Greene et al., 1994; Jansen et al., 2008). In addition accompanied patients reported lower levels of attention during the consultation than unaccompanied patients (Jansen et al, 2008).

A companion or various other people being present in the decision making consultation can alter the structure of the relationships in the room and make SDM a more difficult task (Charles et al., 1997). It would be useful to measure what input companions make in oncology settings to assess what would be most helpful to all involved in the decision making process. The role of the companion in SDM in lung cancer settings has not been explored thoroughly and it is unclear how and when during the consultation companions will contribute.

1.7.1 Measuring companions' involvement

There is little insight from theories of (individual's) decision making and prior evidence on how to develop the concept of the patient-physician dyad to include the participation of others who may be involved in the SDM process (Stacey et al., 2010). Although some decision making models state that companions may be included in the shared decision making process, the companion is usually contained within the patient role rather than as a separate entity. Moreover, there is seldom any debate about how the companion may contribute to the process (Stacey et al., 2010). Existing studies have asked for companions' perceptions of the consultation process after the event (Smith et al., 2009; Zhang et al., 2003 & 2010; Lobchuck & Degner 2002). Accuracy of recall may depend on how large the time delay was between the choice being made and reporting of their experiences.

Studies in the companion literature have usually only included primary caregivers who were predominantly spouses. It may be useful to look at a more diverse support network than spouses as various members of family and friends may attend consultations and influence decisions. The methods used to explore companions'

roles in medical consultations usually involve audio taped telephone interviews where the patient and companion are interviewed separately. This has the advantage of people not tailoring their answers to what they want the other person to hear. However, this kind of research also presents practical difficulties, as interviewees may be reluctant to talk to unseen strangers over the telephone about personal and emotive aspects of their lives.

In order to see when and how companions contribute to the decision making process consultations could be recorded and a framework for decision making could be created to capture their input. This would help to clarify where the companion interjects into the discussion, and what the purpose is e.g. whether it is for clarification of information, expressing their own values, to agree/disagree with what is being said or for emotional support. This would allow for the patient and companion contributions to be assessed whilst minimising the demands placed upon them.

1.8 A Summary of SDM research within cancer consultations

There is evidence that the use of SDM in clinical practice is limited. Shepard, Butow & Tattersall (2011) interviewed oncology doctors about their attitudes towards SDM. They found that although all doctors said they were comfortable with the approach, the use of SDM differed depending on cancer specialization, context and stage of the disease. Discrepancies may exist between doctors' subjective assessments of their own consultations and the actual communicative reality. Towle et al (2006) analysed transcripts of consultations to see if any competencies for SDM (see page 19) were present. When asked, the doctors thought that they had put the SDM competencies into practice. However, the analysis of the transcripts of consultations illustrated that doctors practice of the competencies were in fact limited. If this discrepancy regarding SDM practice in lung cancer consultations exists it may have implications for professional training.

Singh et al (2010) analysed 63 cancer consultations and found that although patient satisfaction with the consultation was high it had no relationship with the presence of SDM. On average doctors displayed fewer than 11 of 18 SDM constructs. However, a criticism of this study is that the coders of the transcripts for SDM behaviour were two oncologists, and the likelihood of bias when oncologists rate oncology consultations is high. In Singh et al's (2010) study just under half the participants had breast cancer. It would be interesting to see if similar results were found in patients with lung cancer.

A number of studies have investigated how decisions are made in the lung cancer context. For a summary of the studies investigating lung cancer patients as decision makers please see Table 3. A criticism of previous studies in the lung cancer literature is that many have looked at desired roles and participants' preferences (Brundage et al., 1998; Brundage et al., 2001; Davidson et al., 1999; Pardon et al., 2009; Silvestri et al., 1998). A desired role does not predict a treatment preference and treatment preference does not predict the decisions that patients will actually make. This method does not access the real world scenario of SDM.

A further criticism of previous research is that they studied relatively "well" populations (Brundage et al., 1998; Brundage et al., 2001). These populations may be able to understand and complete decision making tasks better and in a different way than NSCLC patients. In addition, past research has used hypothetical scenarios rather than participants' real life choice (Brundage et al., 1998; Brundage et al., 2001; Silvestri et al., 1998). There may be differences between what people think they would do in a hypothetical scenario and what they would actually choose to do when presented with that situation in real life when their values have been affected by their experience of illness.

Author	Study Design & Method	Summary of Findings
Brundage et al (1998)	56 patients (previous lung or prostate cancer) and 20 staff participated in treatment trade-off interview to find out how patients weigh quality of life against survival when choosing treatment options.	A wide variation of survival advantage thresholds was observed. Patients were more willing than staff to have toxic treatments.
Silvestri et al (1998)	91 patients previously treated with chemotherapy for NSCLC were interviewed to examine the trade-off between the survival benefit of chemotherapy and its toxicities. Hypothetical scenarios were used.	Patients' willingness to accept chemotherapy for the treatment of metastatic NSCLC varies widely. 25% did not want chemotherapy in the circumstances they had already received it.
Davidson et al (1999)	21 outpatients with lung cancer participated in treatment trade off interviews to assess their preferences for hypothetical treatment options.	Patients rated details of treatment regimen, early and late side effects, survival, and effects of treatment on symptoms to be essential information for making treatment decisions. 57% of patients desired an active or collaborative role in DM.
Brundage et al (2001)	60 people previously treated for a cancer (other than lung cancer) were interviewed as surrogate decision makers balancing the risks and benefits of chemotherapy for lung cancer and looking at role preference.	Participants' attitudes ranged greatly regarding choosing chemotherapy for treatment of NSCLC. NSCLC patients should be offered more than one treatment option. A systematic process such as an interview as a decision-support strategy would be useful for educating patients and for eliciting their preferences.
Sharf et al (2005)	Interviews with 9 patients with lung cancer to explore their reasons for declining treatment options recommended by their doctors.	Patients commented on poor communication with health care professionals, discontinuities in health systems, and impact of social support. Explanations of patients' reasons for refusal reflected several ways of coping with an undesirable situation, such as strategies for reducing uncertainty.
Harrington et al (2008)	Case study of Mr L with NSCLC. Examining perspectives of Mr L, spouse, oncologist and palliative care consultant regarding treatment decisions.	Moving on to third or fourth line chemotherapy may be easier for all involved in the decision than discussing hospice care. Patient and family members may not wish to discuss the issue with the oncologist. Approaches to communication about treatment options are discussed.
Pardon et al (2009)	128 patients with NSCLC were interviewed about information and participation preferences, participation level achieved and satisfaction with DM process.	Participation preferences for control of DM differ depending on the type of decision. 14.8% want control for treatment decisions whereas 49.2% for end of life decisions. In addition 78% of patients would prefer relatives present when information is given and 68% want relatives involved in the DM process.

Table 3: Table to illustrate research in the lung cancer and decision making field

All of the research in Table 3. utilised interview based methods to elicit data from participants. A semi-structured interview gives the participant greater flexibility in what they wish to discuss and allows the interview to uncover novel areas the researcher has not previously considered (Lubursky,1994). A criticism of interviews is that they can be demanding for the participants. The initial consultation following lung cancer diagnosis is a demanding experience in itself, involving the consideration of new information and potentially being full of uncertainty and anxiety (Temel et al., 2008). In order to minimize patient disruption and distress it may be more appropriate to use a briefer measure than an interview to assess patients' views. A questionnaire would enable the collection of data on patient satisfaction with decision making whilst placing minimal demands on them.

Street (1992) suggested that when investigating processes in medical consultations it is appropriate to use multiple measures, for example, both observational and self report measures. An observation of the consultation gives a detailed record of the decision making process whereas a questionnaire can be used to obtain patients' opinions.

1.9 Research aims and objectives

The above review and discussion of ideas surrounding doctor-patient communication, decision making and companion involvement shows that there is a broad platform from which consultations with patients with lung cancer may be examined.

This study aims to describe how participants with lung cancer are involved in the decision making about treatment choices in consultations with health professionals. An observational method will be used.

The objectives are:

- To describe the contributions of patients to the consultation.
- To describe the contributions of companions to the consultation.
- To describe the contributions of doctors to the consultation.
- To investigate patient satisfaction with the decision making process.
- To assess whether this involvement is in accordance with current guidelines on shared decision making practices.

CHAPTER 2: METHOD

2.1 Clinical Context

This research was carried out in a regional oncology centre in the North of England. The service receives about six new lung cancer referrals each week. In accordance with guidelines, patients are seen by a consultant oncologist within 14 days of their referral from general practice (NICE, 2005). Within this 14 day period, patients are referred for scans and/or biopsies, the test and/or scan results are assessed and discussed at a multidisciplinary team meeting, and the patient is invited to attend a consultation with an oncologist and discuss the surgical, radiotherapy or chemotherapy treatment options available. Before their initial consultation with the oncologist patients are informed of their cancer diagnosis. The diagnosis is usually given by a respiratory physician at the ‘fast track’ clinic. There are four oncology clinics each week with four different consultant oncologists and their specialist registrars (SPRs). Patients have an initial consultation within which the doctor discusses a range of treatment options around a) deciding whether or not to start treatment, and b) making choices about which treatment to have including palliative care. The consultation length depends on the individual patient’s needs and concerns but is approximately half an hour. Immediately following this consultation, patients may have a consultation with a lung cancer nurse specialist (LCNS) to go through these issues in more depth.

2.2 Research Design

The study has a cross-sectional survey design using mixed methods. A qualitative method is used to observe the content of the consultation. Consultations were audio tape recorded, transcribed, and then analysed. A questionnaire was used to assess patients’ views about their choice and the consultation. These two methods provide data on both the content of the consultation and perceptions about the consultation.

2.2.1 Consultation

The content of initial oncology consultations was audiotape recorded. This method is

known as an observational method and has the advantage of recording directly what people say and do in the real-world setting (Robson, 2002). Audiotaping cancer consultations has been found to be an acceptable method to both doctors and patients (Knox et al., 2002). A limitation of this method may be that when participants are aware that what they are doing is being observed they may change their behaviour (Mayo, 1933). However, Singh et al (2010) suggests that when recording real life consultations participants are fully involved in the consultation process and quickly forget they are being audiotaped.

Alternatives to audio recording were considered. Video recording would have enabled a study of body language and any unspoken meaning in the room, adding to analysis of the interaction. However, video recording is more intrusive than tape recording and participants may feel less comfortable and alter their behaviour more with a video recorder than a tape recorder (Willig, 2008). Video recording is used in communication studies to provide clinicians with feedback about their skills for training purposes. This is not the purpose of the current study, rather it is interested in the verbal content of the consultation. Another option would have been for the researcher to have been present during the consultation and taken notes. However, this may have distracted the participants and the researcher's presence during consultations was not judged to be appropriate by the ethics committee.

2.2.2. Questionnaire

A questionnaire was used to assess patients' perceptions of how the decision was made (see materials section 2.4). An advantage is that questionnaires can be reliable ways of eliciting cognitions and emotions. A disadvantage is that poorly designed questionnaires may elicit socially desirable responses (Robson, 2002). In addition, response rates to questionnaires are often low (Robson, 2002), this may affect this population more so due to lower educational and literacy levels in the lung cancer population in general (Peto et al., 2000; Cancer Research UK, 2010). Aiming to minimise this effect patients were able to complete the questionnaire in the clinic, however, they were also given the option to take the questionnaire home and post it

back to the research nurse. All patients chose to take the questionnaire home, this could be due to the highly emotive nature of the consultation they had just been in.

Ethical Approval

Ethical Approval was granted by Yorkshire and the Humber Ethics Committee in August 2011. A copy of the letter confirming ethical approval can be found in appendix 1.

2.3 Sample

All members of the lung oncology team were made aware of the research by RL and CM during several multi-disciplinary meetings. Staff supported the study. The sample included oncologists delivering lung cancer services, patients receiving treatment for metastatic NSCLC and the patients' companions. All new patients with metastatic NSCLC (stage IV) were able to take part. Patients were only excluded if the clinical team judged them to be unsuitable to take part in the research, e.g. a non-English language speaker or not competent. Suitable patients from all oncologists' clinic lists were invited to participate. This enabled the study to include a cross section of NSCLC patients, as from discussion with clinicians it was clear that different doctors have slightly different patients. The disadvantages of analysing different doctors' consultations are that their differing methods of communication and method of conducting the consultation may be a confounding variable.

In total 23 patients were approached and given information about the study; 14 patients participated in the study. There were several reasons for non-participation: declined to take part (n=1), did not attend their consultation (n=2), health deteriorated and transferred to inpatients (n=2), went down different treatment routes due to test results (n=4). The patients in the study were affiliated with six different oncologists, (4 consultant oncologists and 2 specialist registrars).

2.4 Materials

The following set of materials were developed for this study:

- 1) Study information sheets for patients and companions in accordance with ethical guidelines (see appendix 2)
- 2) Study consent forms for patients, companions and staff (see appendix 3)
- 3) A questionnaire (see appendix 4)
- 4) Coding frames to analyse the content of the consultation (see appendix 5 for sample).
 - Singh et al's (2010) oncology specific shared decision making coding frame.
 - Three coding frames developed by the researcher to code doctors', patients' and companions' contributions to the consultation.

All materials (apart from the coding frames) were piloted on the lung cancer service user group that meets monthly at the oncology centre. The advantages of including service users' views in material development are that it increases validity of the materials and reduces researcher bias.

Information sheet and consent form

The information sheet describing what the study involves and its potential impact was given to patients and companions by their LCNS when they attended the fast track clinic at the oncology centre. In order to comply with research governance patients then had at least 24 hours before they were asked to participate. To conform to good research practice consent forms were given to patients and companions to sign before their consultation. Participating oncologists also filled out consent forms before the study began.

Questionnaire

The questionnaire included:

1). Demographic details such as sex, age and relationships of companion/s present in the consulting room. These details were gathered in order to establish if the patient demographic was similar to those in other studies. Gathering data about who accompanied patients was done to enable the researcher to see if there was any link between who accompanied the patient and the contributions patients and companions made during the consultation.

2). The decisional conflict scale (DCS) (O'Connor, 1993) is a 16 item Likert style questionnaire which measures personal perceptions surrounding the decision which has been made. The scale is scored from 0 -100 where higher scores reflect decisional conflict. The questionnaire consists of five subscales:

1. Personal uncertainty
2. Feeling uninformed
3. Unclear values
4. Inadequate support
5. Perception that an ineffective choice has been made.

The DCS was chosen because it was developed for and is widely used in studies of decision making. Medical decision making in the lung cancer context is complex and involves deliberating potential gains and losses, trade offs between potential symptom relief and survival gain and risk. When confronted with such difficult decisions uncertainty is more likely. Due to this inherent uncertainty in medical settings decisional conflict is a vital component of decision making. The DCS was thought to be most appropriate to address the research aim of investigating patients satisfaction with the decision making process, as Holmes-Rovner et al (1996) found that lower levels of decisional conflict correlated with higher levels of satisfaction. The available evidence indicates that the DCS has satisfactory psychometric properties, with internal consistency being Cronbach's alpha ranging from 0.78 to 0.92 (O'Connor, 1995).

3). The Satisfaction with Decision Scale (SWD) (Holmes-Rovner et al., 1996) is a 6 item Likert style questionnaire which assesses patient satisfaction with the health care decision itself, before the consequences have been experienced. The SWD has satisfactory reliability (Cronbach's alpha = 0.88). This scale was thought appropriate to use to address the research aim of investigating patient satisfaction with the decision making process.

Coding framework

In order to answer the research aims for this study a realist method of qualitative data interpretation was used. Coding frameworks were used to categorise data; A thematic framework analysis to interpret findings (Ritchie and Spencer, 1994).

Coding frame – shared decision making

Singh et al's (2010) coding frame was used to analyse the consultations. However, Singh et al's (2010) coding frame does not include the patients' contributions in the consultation (please see earlier critique, section 1.5.1). In addition it was felt that it did not adequately capture all aspects of decision making that were present in lung cancer consultations. Therefore three additional coding frames were developed (see section 2.6 Analysis).

Coding frame – decision making conversation

The purpose of the coding frames developed by this research was to classify doctor, patient and companion utterances into categories that reflected the information sought, provided and deliberated around the diagnosis and treatment of this lung cancer. The three coding frames aimed to classify the emotions, cognitions, reasons for/or against certain options mentioned by all people in the consultation separately. Thematic framework analysis (Ritchie and Spencer, 1994) was used to develop these coding frames. Thematic framework is a qualitative method where data is systematically and comprehensively classified in accordance with themes.

It is distinct from other analytic qualitative methodologies such as grounded theory and interpretative phenomenological analysis (IPA) because it was developed as an efficient way of processing information and obtaining meaningful results in order to address a specific research question and from which recommendations could be proposed (Richie and Spencer, 1994). Grounded theory aims 'to generate or discover a theory' from the data (Glaser and Strauss, 1967). IPA aims to explore people's personal experience of their world and the meaning they give it, it is interested in their perception of reality rather than aiming to develop an objective view of the experience (Smith and Osborn, 2008).

The primary aim of the current research is to describe how patients are involved in the decision making process about treatment choices in lung cancer consultations. Framework analysis is driven by, and grounded in, the original observations of the people it is about. Furthermore framework analysis is dynamic, changes can be made to the framework with themes added or collapsed as new ideas emerge throughout the analytical process. In addition to this inductive approach framework analysis permits a priori issues and concepts from existing research to guide the framework and be coded for. Additional advantages of framework analysis are: the transparency of the process (MORI Social Research Institute, 2003); it enables analysis within and between cases.

2.5 Procedure

This section describes the study procedure (Figure 1)

2.5.1 Recruitment and consent

The LCNS's identified all new patients eligible for participation and invited them, and their companions, to participate in the research.

Patients and companions were asked for their consent to participate by the research nurse before their consultation. Patients who participated were provided with a study number to anonymise their consent forms, tape and questionnaire. All doctors completed consent forms before data collection began.

2.5.2 Data Collection

Participants' consultations were tape recorded using a digital voice recorder, switched on by the doctor. The clinical team suggested they have responsibility for turning on the tape recorder rather than requiring the researcher to be present as it would be less disruptive to clinic practice. Patients were provided with a questionnaire and stamped addressed envelope after their consultation.

The consultations were transcribed verbatim. The researcher transcribed six recordings and eight were transcribed by a third party who had signed a confidentiality agreement. Advantages of the researcher transcribing the data include that it allows the researcher to immerse themselves in the data from an early stage, becoming aware of recurrent themes. Advantages of a third party transcribing the data include that they are not invested in the findings and therefore bring impartiality. All transcripts were anonymised, study numbers were used for identification. All computer files were password protected.

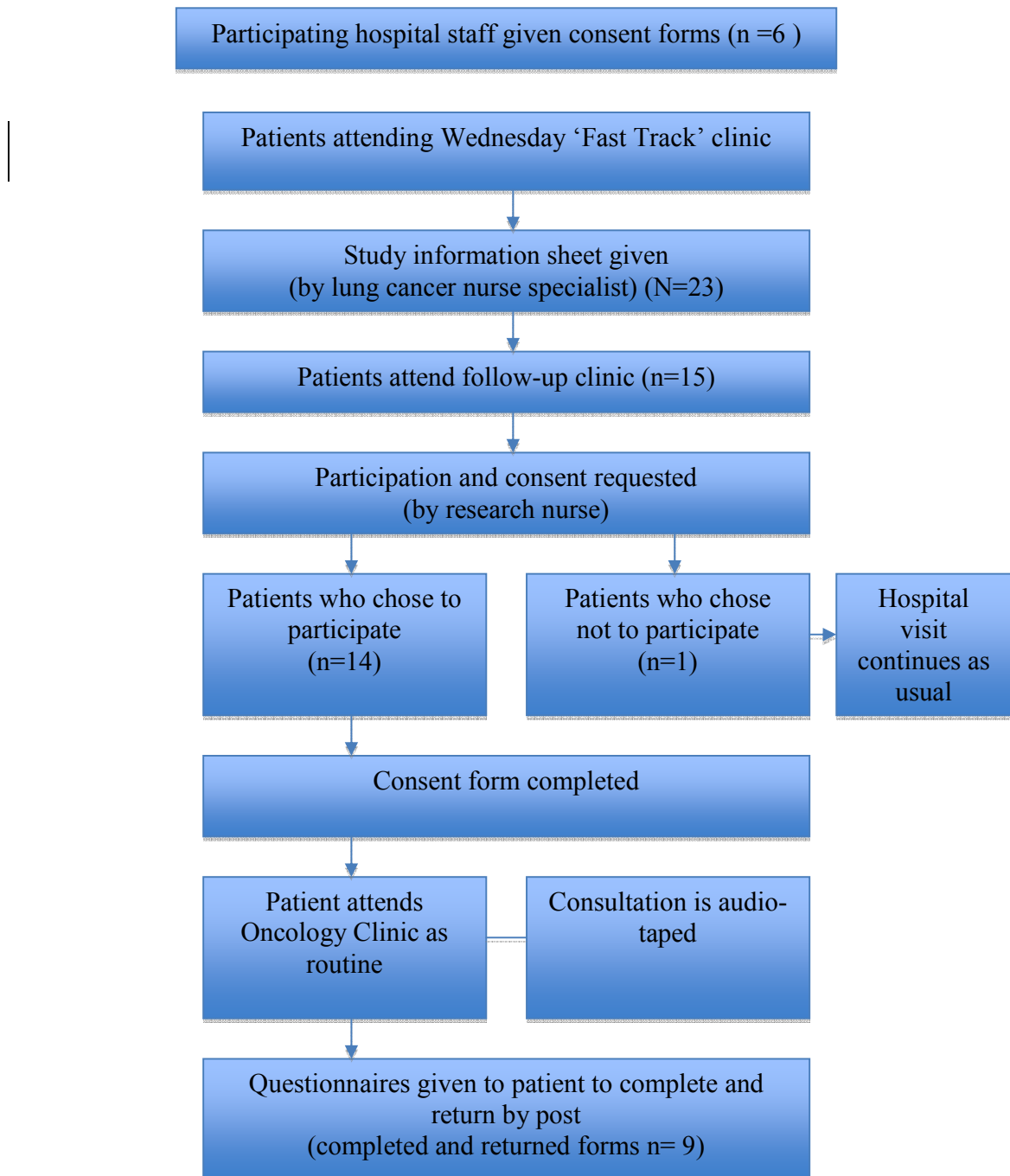


Figure 1: Flow Chart illustrating procedure

2.6 Data Analysis

The data from the consultations were analysed using thematic analysis. The data from the questionnaires were analysed using descriptive statistics.

2.6.1 Analysis of consultations

Analysis was conducted using the following five steps (Richie, Spencer & O'Connor's (2003): Familiarisation; Identifying a thematic framework (initial themes; indexing the data; sorting the data by theme or concept; synthesizing the data); Indexing; Charting; Mapping and interpretation (see below).

Four coding frames were applied to each consultation to capture the utterances of doctors, patients and companions. Singh et al's (2010) coding frame was intended to capture doctors' verbalisations associated with shared decision making. To capture the interaction between all participants within the consultations and classify more fully the discussion, three additional coding frames were developed, one each to code doctors', patients' and companions' utterances. The content of these coding frames are discussed in more detail below.

2.6.2 Shared decision making coding frame

Each of the themes identified by Singh et al (2010) is described and an example provided from the application of the coding frame to this data set.

1. Reason for consultation established: Items where the doctor states explicitly the reason and aims of the consultation. An example is: "So what we're going to do [patients name] is we're going to spend about 40 minutes together and I'm going to ask you lots of questions first about what's been going on and how you are and then I may want to examine you I may not need to examine you, but either way when we've finished that we'll then sit down and talk about where I think you are, what your position is and what I hope we can be able to offer you.

Then we can have a chat about you know whether that's what you want, what your options are that sort of thing".

2. History reviewed: Items where the doctor reviews and elicits information from the patient about their medical history that is relevant to the current cancer. Examples are: "Ok, when did that wheeze start to erm kick in?"; "And do you still smoke?"; "and you're on Tamoxifen for your breast cancer chemo?...yeah and you had radiotherapy and was that on the right or left?"; "any other surgery apart from what you've told me already?"

3. Social circumstances reviewed: Items involve the doctor finding out about the patient's social situation. Examples are: "can I just ask who lives at home with you now? Is it just the two of you at home?"; "ok, when did you retire?"; "so you can get up and down the stairs...how about washing and dressing?"; "But you still get round the shops and do your own shopping and cleaning and cooking and things?"

4. Interruptions: The item refers to when the consultation is interrupted e.g. by a pager, another member of staff or the doctor being called out of the room.

5. Rapport building: Items refer to the doctor building a rapport with the patient and companion through social exchange. Examples include: "the next thing is obviously you know especially in your situation thinking 'oh my goodness how could this be me because I've never smoked'"; "Sorry, I'm asking you all these questions"; "So, it's cold outside isn't it? You wrapped up well?"

6. Evidence presented: Items from when the doctor presents evidence from studies about the treatment options. Examples are: "there's a trial that looked at the two bigger doses given a week apart or the twelve, thirteen treatments and that showed that you got quicker response to the bigger dose but that response didn't last quite as long, and people who had the bigger dose tended to do little bit

better”; “we know that distinction’s important because people in a trial, we’ve done recently, if they’re non squamous they did better with one combination, if they were squamous they did better with the other combination.”

7. Quality of research discussed: Items referring to the doctor commenting on the strengths of the research referred to. There were no examples of this theme in the current study. An example that Singh et al (2010) gives of this theme is: “Only one fairly small study has shown that [drug x] is better than standard treatment.”

8. Physician appraisal of data: This item refers to the doctor making a clear recommendation based on their evaluation of the information. Examples include: “At this point the right thing to do is to consider having a systemic treatment, a drug treatment to try and keep it under control”; “the best way to treat all the areas at once are with a drug treatment, so that goes through the blood stream and would hopefully...attack the cancer cells in all of those areas”; “what we need to think about is giving chemotherapy and then reassessing”.

9. Research relevant to the patient: This item refers to the doctor individualising the evidence base to the patients’ circumstances. Examples of utterances coded to this theme include: “what’s little published that if you look at non-smoking related lung cancer it’s still about the 8th most common cancer in the world so it’s more common than you would imagine so obviously the vast majority of lung cancers are due to smoking but you take all the other cancers it’s about the 8th most common cancer is non-smoking related lung cancer”; “2 or 3 years ago we had one recipe that was for all types of what’s called non-small cell lung cancer which is another time there has been some work now that’s showing that if you’re a non- squamous type of lung cancer, which you are, you’d be better with this new recipe rather than the old recipe that’s what we need to talk about today”.

10. Patient views enquired upon: This item refers to when the doctor asks about the patients' treatment preferences. Examples of utterances coded in this theme: "what are your gut feelings about chemotherapy?"; "you'd be interested in chemotherapy?"; "How would you feel about coming in now? Or would you rather go home and get some stuff and come back?"

11. Asked regarding amount of information wanted: This item refers to the doctor asking for the patients preference regarding how much they want to be told. Examples of utterances coded in this are: "And have you seen your pictures? Is it something you want to see?"; "I can go through averages today if you'd like me too?"; "What we've not done today is we've not talked about life expectancy and that sort of thing...ermm...now I'm happy to do that at any time that you want to, if you want to, I'm happy not to do it if you don't want to."

12. Asked regarding decision making preference: This item refers to the doctor asking the patient how involved they want to be in the decision making process. There were no examples of this theme in the current study. However, Singh (2010) gives the following example: "Would you like to have a think about what I have said and let me know what you decide, or would you rather I choose the treatment for you, based on what I know about you? Or we could decide together now what we both think is the best course."

13. Physician ensured patient understanding: This item refers to when the doctor checks that the patient has understood the information presented. Examples of utterances coded to this theme are: "Does that make sense?"; "did you understand all that?"; "I just want to recap that with you and see where we are at the moment."

14. Treatment option presented: This item refers to when the doctor states that there are at least two options (including no treatment). Examples of utterances coded in this theme include: "In terms of further treatment, which might be

further draining of the fluid or chemotherapy and that obviously comes in lots of different forms”; “Now the 2 options in this situation from your point of view is either some radiotherapy which would shrink things down and help with the pain. Or some chemotherapy to shrink things down first and then follow up with some radiotherapy”; “At this point the right thing to do is to consider having a systemic treatment, a drug treatment to try and keep it under control... or actually doing nothing might be a reasonable thing to do if its not causing you any great bother.”

15. Multiple options presented: This item refers to when the doctor presents multiple appropriate treatment options. An example of an utterance coded in this theme is: “Now that’s the chemo, now the other option is you might say I don’t like the sound of that, I don’t want the chemotherapy and your other option is to have some radiotherapy only...and then there’s a 3rd option that patients sometimes say is I’d rather not have any treatment at all, no radiation, no chemo I just want to manage things with pain killers.”

16. Treatment process described: This item refers to when the doctor explains the procedures involved with having treatment. An example of utterances coded in this theme is: “you lie down with your arms up, the machine is... they use something call photons and they go into the bone and leave a dose inside the body. When you’re having it it just feel like a normal x-ray, it just takes a little bit longer and because we have to get you in the right position the majority of time is sitting on a not that comfortable couch, getting you in the right place and they’ll use lasers and tattoos to make sure its in the right place, they scan about 15 minutes, for the treatment about 15 minutes.”

17. Side effects discussed: This item refers to when the doctor describes the side effects of the treatment options. Examples of utterances coded in this theme are: “the side effects of that are tiredness, inflammation of the skin, it can flare the pain up in the short term and the worse side effect of that is that it can cause

inflammation of the healthy lung” ; “It varies greatly in patients with this chemotherapy, some patients don’t even notice, some patients get more hair loss it always grows back after its never permanent, you can feel nauseous or sick with chemotherapy.”

18. Possible benefits discussed: this item refers to when the doctor states the benefits of each option. Examples of utterances coded in this theme include: “They have been shown to improve peoples quality of life as well”; “we can have you feeling a lot better than you are now.”

19. Patient values in decision considered: this item refers to when the doctor clearly states that the patient’s values play an important role in the optimal treatment choice. The following are examples of utterances coded in this theme: “and from a quality of life point of view that might mean that first week you might not feel like going dancing which is obviously a really important thing for you so it’s, it’s all about balance here”; “and I understand that your husband has Parkinson’s urm, and urm Dr X mentioned that as well that it was something we needed to keep in mind as well.”

20. Option given to defer treatment decision to next visit: this item refers to when the doctor states that there is time to think about the options before making the decision. An example of an utterance coded in this theme is: “you don’t need to make a decision today you can go away for a week we’ll be getting the final result and we can talk again in a week’s time and of course I’ll give you some written information as well today so you can have a think.”

2.6.3 Decision making conversation coding frame

Three coding frames were developed to code all utterances by doctor, patient and companion about the treatment decision for lung cancer. These coding frames focused on coding utterances around the options, consequences, individual’s judgments and other decision-related factors such as affect. The initial coding

frames were developed from six completed consultation transcripts. These were selected to represent consultations from different doctors and length of consultation. The transcripts formed the basis of the coding frame which were developed in accordance with Richie, Spencer & O'Connor's (1993) guidance, specifically:

1. The researcher read over the transcripts several times to familiarise herself with the text. The text was then broken down into meaningful units. Meaningful units varied in length from phrases to a paragraph which conveyed one meaning.
2. The meaningful units were interpreted and given a code. Item lists were created (see appendix 6). The codes were considered in relation to each other and codes with similar meanings were grouped together under titles.
3. HB and RL discussed the differences and similarities between the titles with reference to the data and research on people's decision making in order to identify themes and categories.
4. The preliminary coding frame (see appendix 7 for sample) was piloted by applying it systematically to six transcripts. Some changes were made including removing the separate theme 'uncertainty' and adding it as a subcategory to each 'option' theme.
5. The reliability of the coding frame was checked. RL and two independent raters trained in using the coding framework were also employed. Two colleagues coded two transcripts and the results were compared and differences noted, inter-rater reliability was calculated at Kappa coefficient 0.81 (within the 'good' range). Inter-rater agreement, measured by a concordance measure such as Cohen's Kappa protects against 'observer drift' where increased familiarity with the coding framework may result in differences in examples of category membership over time (Robson, 2002).
6. Following further discussion and debate with HB about the coding of items and the frameworks face validity categories were added to, merged, or further separated out. The final framework (see appendix 5 for sample)

was a result of this discussion which formed the final themes and sub categories.

7. The final framework was applied to all 14 transcripts. Each unit was coded into only one subcategory. No new sub categories or themes occurred during this stage of the analysis. A description of each theme and an example is provided below.

Themes and titles: coding frame development.

Three separate coding frames were developed to categorise the utterances of all participants in the consultation. However, there are more similarities across the coding frames than differences because the content is the same, only people's experiences and evaluations are different. In total there are 16 themes within the doctor's coding frame and 17 themes within each of the patient's and companion's coding frames, however themes and subcategories vary. All themes from the coding frames are described below. When the theme is present across all three coding frames, quotes from each participant are presented.

1.Disease: all three coding frames have a section to code for the disease.

Doctor: The theme included items referring to the status of the disease and that treatment was an option. Within the theme were 4 sub categories: neutral comment; positive evaluation; negative evaluation; uncertainty. The following are examples of the neutral comment items coded within this theme: "its gone over to the liver and your adrenal glands"; "so the lung cancers spread to the lymph glands". The following are examples of positive comments about the disease: "only about a 1 in 10 to 1 in 20 people have this mutation, so its rare, but it's a good thing"; "I suspect from the way that's its behaved with you all along that the cancer has been quite slow growing and it may actually have been around since then but it is a good thing for you because if that is the case it means its quite slow." An example of a negative evaluation of the disease is: "lung cancers traditionally have not been a very positive cancer and I think that's still the case". An example of items coded uncertainty within this theme include: "Yeah not

100% at the moment, it's most likely looking at a type of cancer called Adenocarcinoma, its most likely that."

Patient: Within the theme were 4 sub categories: neutral comment/question; positive evaluation; negative evaluation; uncertainty. An example of a neutral comment/questions is: "Is it round?" An example of a positive evaluation is that after the patient has been told by the doctor that his cancer has a positive mutation on it: "oh, very good anyway, yeah, well that's it then, yeah, very good." An example of an item coded uncertainty within this theme is: "Well, yes, I'm not sure about the type that he said it is."

Companion: the theme had the same 4 sub categories as the patient frame. Examples of neutral comments/questions are: "is it bad in his liver then?" ; "Is any spread of er the cancer being erm has everything spread, the cancers spread why it hasn't shown up already, would there be any further spread?"

2. Option Surgery: all three coding frames have a theme for surgery.

Doctor: The theme included items referring to the possibility of patients having a surgical procedure to remove the cancer. Within the theme were 5 sub categories: neutral comment/question; positive evaluation; negative evaluation; uncertainty; individualized information. The following is an example of the neutral comment items coded within this theme: "unlike the previous occasions when they've found the cancer and they were able to just do a little wedge to remove, this time where it is it wouldn't be possible to do that.". An example of a negative evaluation of surgery is: "I don't think surgery is the way to go".

Patient: Within the theme were 4 sub categories: neutral comment/question; positive evaluation; negative evaluation; uncertainty. Examples of neutral comment/questions about surgery are: "nobody's mentioned surgery so I guess they can't take it away"; "if I'd have caught this earlier could you have operated?"

Companion: The companion frame had the same sub categories as the patient frame. An example of a neutral comment/questions item coded in this theme is: "and surgery has definitely been ruled out?"

3. Option gefitinib: all three coding frames have a theme for gefitinib. The theme included items referring to the possibility of taking the drug gefitinib as a treatment for lung cancer. Gefitinib is a tablet that is only given if the patients cancer has tested positive for an epidermal growth factor receptor (EGFR) mutation.

Doctor: The same 5 subcategories as the surgery option were retained, as they are for all treatment options within the doctors framework to enable a comparison of information giving. The following is an example of a neutral comment item coded within this theme: “Because if that test is positive we can give you a tablet instead of the chemotherapy”. The following is a positive evaluation of this option: “[taking gefitinib]... is good and its very well tolerated.”

Patient: The same four sub categories as the surgery option were retained as they are for all treatment options within the patients framework to enable comparison. An example of a neutral comment question within this theme is: “Well which is best, negative or positive?”. An example of an utterance coded as uncertainty in this theme is: “I think its to do with erm, growth hormone, and whether, the err tumour has got that mutation on it so they can use that, I’m not sure how it changes treatment.”

Companion: The same four sub categories as the surgery option were retained as they are for all treatment options within the companions framework to enable comparison. Examples of neutral comments/questions are: “yeah, so in that instance would you not recommend the, the what’s the drug called, gefitinib?”; “Right, so it’s not looking as though it will be that mutation.”

4. Option Chemotherapy: all three coding frames have a theme for chemotherapy. The theme included items relating to having chemotherapy to treat the patient’s lung cancer.

Doctor: It included the same 5 sub categories as the other treatment options. The following is an example of a neutral comment item coded within this theme: “Chemotherapy is drugs given through a drip in the arm, given once every three

weeks for upto six lots of the treatment”. An example of an utterance coded as a negative evaluation within this theme is: “I think that we know that chemotherapy ...sometimes it’s not that great”. An example of an item coded as uncertainty within this theme is: “but the chemotherapy that we ended up giving you might be different depending on how well you were and what the problems were that you had”. An example of an item coded as individualised information within this theme is: “the difficulty with chemotherapy is that chemotherapy is strong drugs and the body has to be strong enough to withstand them and the rough rule of thumb is that if you’re well enough to be up and about for more than half a day then you’re well enough for chemotherapy ... now, I don’t think you are at the moment, you can’t stand for long.”

Patient: The same 4 sub categories as the other treatment options were retained. The following is an example of a neutral comment item coded within this theme: “So its like a 5 week cycle?”. The following is an example of an uncertainty item coded within this theme: “then ok, I’ll take drugs. If its either going to stay, or with a bonus, reduce it...but that, none of us know.”

Companion: The theme included the same 4 sub categories as the other treatment options. Examples of neutral comments/question items coded within this theme are: “So, could you perhaps explain what the chemo options are, assuming it’s an adeno, and EGFR negative.”; “When would you know if its not working?”

5. Option drain fluid: all three coding frames have a theme for draining fluid. The theme included items related to pleural effusion (when fluid builds up in the chest) and its treatment. Treatment involves performing a pleurodesis: draining the fluid to relieve the symptoms and limiting the accumulation of further fluid, this is often achieved through doing video-assisted thorascopic surgery (VATS).

Doctor: The same 5 subcategories as the other treatment options were retained. An example of an item coded as a neutral comment within this theme is: “what they would sometimes do is do what’s called a VATS procedure where they put a cannula in to that space. So it’s a general anesthetic but it’s quite a small

procedure they then can take all the fluid out, and then if they feel that they can what they call pleurodesis they can put some talc into the space and what the talc does is it causes it to stick down and stop fluid coming back”. An example of an utterance coded as a positive evaluation within this theme is: “a pleurex drain...is a good way of draining the fluid, keeping you breathing well, hopefully can help you play golf, they don’t have that much restrictions on your motion and erm in time it tends to dry up”. An example of an utterance coded as a negative evaluation is: “I know it doesn’t sound doesn’t sound that pleasant.”

Patient: The same 4 sub categories as the other treatment options were retained. An example of an item coded as neutral comment/ questions is: “so will they leave the drain in then?”. An example of an utterance coded as a negative evaluation is: “I don’t like the sound of bags hanging off and things like this, I don’t like the sound of that.”

Companion: The same 4 sub categories as the other treatment options were retained. An example of an utterance coded as a neutral comment/question is: “and presumably if they glue the lung together that will stop a lot of the coughing and the problems that she’s having?”

6. Option Radiotherapy: all three coding frames have a theme for radiotherapy. The theme included items about the treatment option radiotherapy.

Doctor: The same 5 subcategories as the other options were retained. Examples of items coded as neutral within this theme are: “its using x ray treatment. Erm, we can do that in a number of treatment schedules to try and focus on the area that’s causing problems. Spot bowling I call it, to try and shrink that down”. An example of an item coded as a positive evaluation in this theme is “Radiotherapy may be a better option...it doesn’t have the risk of infection, it doesn’t tend to make you feel as poorly”. An example of an item coded as a negative evaluation is: “the size of it makes it too big to give a big dose of radiotherapy to it. Which is what we’d need to be able to do”. An example of an item coded as uncertainty in this theme is: “In this situation there’s, because of uncertainty, I’d be happy to go

with the higher dose, or I'd be happy to go with the lower dose and we just keep an eye on things and then if things change we then go down a different track.”

Patient: The same 4 sub categories as the other treatment options were retained. An example of a neutral comment/question coded in this theme is: “what, how do they give you this radiotherapy?”; “oh, its an x ray is it?”

Companion: The same 4 sub categories as the other treatment options were retained. Examples of items coded as neutral comment/question are: “do they erm, they don't use boards any more to hold?”; “can't she have it on both sides?”

7. Option - come into hospital now: all three coding frames have a theme for coming into hospital now. The theme included items referring to the option for the patient to be admitted to hospital that day due to their physical deterioration in health.

Doctor: The theme was broken down in to the same 5 sub categories. An example of an item coded as neutral is: “I'm just wondering whether we should bring you in for a general sort out? Into hospital?”. An example of an item coded as a positive evaluation within this theme is: “yeah, its better, it'll be a quicker sort out”. An example of an item coded as personalized information within this theme is: “We'll look at doing the transfusion tomorrow...erm...and erm we could put a pump up tonight, this little needle that would just give you anti-sickness medication. Build you up bit.”

Patient: The same 4 sub categories as the other treatment options were retained. An example of an utterance coded as a neutral comment/question is: “So I don't do any of that till I'm sorted out?... so, come in and get sorted out?”

Companion: An example of a neutral comment/question is: “how much longer will he be in?” An example of a positive evaluation of this treatment option is: “I think you'll be better off cos you've looked ill for a few days now.”

8. Option - No active treatment: all three coding frames have a theme for no active treatment. The theme included any utterances about the option of not pursuing treatment, and letting the disease run its natural course.

Doctor: this theme included the same 5 sub categories as the other options. An example of an utterance coded as a neutral item in this theme is: “the other option for treatment for you is to not treat the cancer and to treat any symptoms the cancer might be having on you. Ermm...and so that is a valid choice that’s something for you to think about as well”

Patient: The same 4 sub categories as the other treatment options were retained. An example of a neutral comment item within this theme is: “to leave it alone, which is satisfactory to me cos like you say its only slow progressing at the moment, as far as you know.”

Companion: The same 4 sub categories as the other treatment options were retained. An example of a neutral comment item within this theme is: “you can live with it for a while, is that your view?” An example of an utterance coded as a negative evaluation of not having active treatment is: “Well its [an active treatment] better than doing nothing isn’t it?”

9. Option - Consent: all three coding frames have a theme for consent. The theme refers to any items that are about the patient consenting to a treatment option.

Doctor: The theme was split into the same 5 sub categories as the other options. An example of an utterance coded as a neutral item in this theme is: “Ok so I’ll just take you through the consent forms, again its erm basically what we’ve just talked about so that’s your name and my name, so its chemotherapy with Carboplatin Gencytobin”

Patient: Within the theme were 4 sub categories: neutral comment/question; positive evaluation; negative evaluation; uncertainty. Examples of utterance coded as neutral comments are: “I’ll have to sign it won’t I?”; “I haven’t consented yet have I?”

Companion: The theme was split into the same 4 sub categories as the patients frame. An example of a neutral statement was: “the nurse last week said that coming here today might help a decision, rather than having to decide or sign forms.”

10. Treatment consequence – side effects: all three coding frames have a theme for side effects. The theme refers to any items where a participant mentions the side effects that choosing a treatment option may have. The theme was split into the same 3 sub categories across the 3 coding frames: neutral comment/question; positive evaluation; negative evaluation.

Doctor: Examples of items coded as neutral are: “the general side effects can make you feel a bit achy and a bit fluey. Sometimes you can have a little bit of sore mouth a bit of diarrhoea not very often.”; “Not all patients develop all side effects”. An example of an item coded as a negative evaluation within this theme is: “...some of which are unpleasant, some of which are very serious”. An example of an item coded as a positive evaluation within this theme is:

“sometimes people are sore and have swelling [lists side effects]...but I don’t think that will be the case for you...people generally tolerate it quite well”.

Patient: examples of items coded as neutral comment/question are: “he said I’ll have a rash”; “will I be poorly after I’ve had it?”

Companion: an example of an utterance coded as a neutral comment/question within this theme is: “Will she glow in the dark afterwards?”

11. Treatment consequence - will feel better: all three coding frames have a theme for feeling better as a treatment consequence. The theme included items which referred to treatment having the positive consequence of the patient feeling better by their symptoms lessening in severity.

Doctor: Examples include: “but in three or four weeks after the treatment symptoms should get better, that’s the intention.” and “ it can as I say shrink the disease down and make you feel better”

Patient: An example of this theme in the patient’s frame is the patient acknowledging the doctors statement that there symptoms will improve; “yeah, oh that’s very good then”.

Companion: An example of this theme in the companions frame is: “but you’ll feel better after you’ve had it.”

12. Treatment consequence – risk: all three coding frames have a theme for risk. The theme included items which highlight the potential risk of a treatment option to the patient's life.

Doctor: An example is “chemotherapy er that it does put you at risk of real serious infection and even life threatening infection, because with your lungs, you know, there is a risk with treatment. You're just about ok at the moment, but we could easily upset the applecart.”

Patient: An example of a patient utterance within this theme is when a patient acknowledges that there is a risk “yes, I know.” Or finding out details about the risk: “What kind of infection would one get?”

Companion: An example of an utterance coded within this theme is: “yeah, its just a small amount of people, not everyone gets that like though”.

13. Prognosis: all three coding frames have a theme for prognosis, although sub categories within it differed. The theme included items referring to the outcome of the disease and probable life expectancy (survival).

Doctor: The theme had 3 sub groupings: neutral comment/question about prognosis; uncertainty; provides average life expectancy information. An example of a neutral comment/question about prognosis item coded within this theme is: “Its palliative, so its just two aims to control the disease, so its to help your symptoms and er to actually if you like prevent or delay the development of further problems, so as I say give you actual improvement in your life span”. Examples of providing average life expectancy information item coded within this theme are: “if you give it to people, if you look at people who don't have it and compare, on average those who have chemotherapy tend to live for two or three months longer. Obviously, if you respond that could be longer, if you don't respond that can be less”; “The average is around 3-4 months prolongation compared to baseline”. An example of a item coded as uncertainty within this theme is: “its incredibly difficult because of the uncertainty of your situation”;

“Its difficult to know because we don’t know how fast its been changing. I don’t, I think, I can quote averages but averages are meaningless.”

Patient: The theme had three sub-categories; neutral comment/question; uncertainty, requests life expectancy information. An example of an item coded as a neutral comment within this theme is: “so, you can only treat me now, there’s no cure.” An example of an item coded as requests life expectancy information is: “Right, I mean do you know how long I’ve got or?”

Companion: This theme had the same three sub-categories as the patients frame. Examples of a neutral comment/question are: “Is the treatment erm ...active or palliative?”; “It’s not totally the end is it?”

14. Preference stated: The theme included when a participant clearly stated what their preference was for an option, this was sometimes in the form of a directive and sometimes phrased more in terms of an opinion.

Doctor: The theme had two sub groupings: treatment option and timing of delivery of care. The following are examples of the treatment items coded in this theme: “so I think come in for a sort out”; “what I think we ought to do while we are waiting for these further tests and particularly with the holiday coming up is seeing if we can get some radiotherapy into that left chest”; “So chemotherapy or radiotherapy for either local or systemic of symptoms would be the thing that I would recommend”. The following are examples of the timing of delivery of care items coded within this theme: “I think we don’t want to start any treatment at the moment until we know what’s the right treatment for you, it’s more important to work that out.” “also starting you on some vitamin tablets because the normal chemotherapy, the one through a drip, requires you to be on vitamins for a week before, so we should get that started while we are waiting for the other procedures so we don’t lose any time.”

Patients: This theme is broken down into 4 sub themes: treatment; timing of delivery of care; consent; end of life. An example of an utterance coded as treatment within this theme is: “oh yeah, I can’t do medicine, tablets I can take, but drinking, oh no no”. The following is an example of an utterance coded in the

consent sub category of this theme: “but then that’s, whether that’s my choice or not. Do you know what I mean? Urm, as to what I want to do”. An example of an utterance coded as end of life within this theme is: “But I don’t want to be grapped in pain and them trying to bring me round, I don’t want that.”

Companion: this theme is broken down into the same 4 sub themes as the patient frame. An example of an utterance coded as timing of delivery of care is: “we should get going with some kind of drugs as soon as possible really.”

15. Expressed affect: This theme is only included in the patient and the companion coding frame, not the doctors coding frame. The theme included items referring to an expression of emotion during the consultation.

Patient: The theme had 3 sub categories of shock; anxiety; sadness/crying. The following is an example of a shock item coded within this theme: “I mean I’m really shocked”. The following is an example of an anxiety item coded within this theme: “Well it’s, it’s erm, it’s the worry really and the apprehension, not knowing”. The following is an example of an upset coded item: “it’s been you know, bit upsetting”.

Companion: The theme had the same 3 sub categories as the patient frame with the addition of the sub category: acknowledges emotion. Examples of items coded as shock within this theme are: “It’s a bit of a shock that it’s gone into the other lung I thought it was all contained.”; “I nearly died, I couldn’t believe it when you had this diagnosis.” An example of an utterance coded as upset within this theme is: “But it’s also his aunty so we’re all very upset.” An example of items coded as acknowledges emotion is: “I knew you were shocked, you weren’t expecting it in the lymph.”

16. Social Expectations: The theme includes items that are part of the human interaction, utterances that are essentially a reaction that would be expected in normal social circumstances.

Doctor: The theme had three sub groupings: social mores; reassurance; acknowledges emotion. The following are examples of the social more items

coded within this theme: “I wish I could be more specific”; “yes, yes, it’s a lot, a lot to take in, I know an awful lot”. The following are examples of the reassurance items coded within this theme: “don’t worry, we’ll go over it again and again and again until you’ve got it”; “that’s fine, if you think that you want to think about it that’s also fine. Honestly”. The following are examples of the acknowledges emotion items coded within this theme: “You alright? do you want some tissues?”; “so a bit of a bolt out of the blue?”

Patient: The theme included items that conform to the social norms of what a patient should say in a consultation situation. The theme had two sub groupings: social mores; comments/questions on doctor role. Examples of items coded within the social mores sub category include: “ah well love, when I go for it I go for it!”; “I’m going to give it a damn good fight”; “Anyway, I haven’t had a bad innings, I’m 73 in April”. Examples of items coded within the comments/questions on doctors role included: “which do you think best then?”; “See, whatever decisions you chaps come up with I go with”; “Yeah, you’re the experts.”

Companion: This theme had three sub categories: social mores; reassurance, and encourages the patient. An example of an utterance coded as a social mores within this theme is: “You know, there’s also the point of view that if its your time to go its your time to go”.; “I think we just need to know what we’re facing”. An example of an utterance coded as reassurance is: “just cos they say it might happen doesn’t mean its going to happen but its to be aware of.” An example of an utterance coded as encouraging the patient is: “right, can you remember? what facts have you been told?”

17. Aspects of related care: The theme included items referring to other aspects of care that surround the treatment choice. The theme had three sub groupings which were common to all three frameworks: future decisions; mentions other health professionals/support; comments on adjustment to disease/treatment.

Doctor: The following are examples of the future decisions items coded within this theme: “once we get some response from the chemotherapy we can reserve

radiotherapy for the future, that's certainly, we can think about that in the future"; "so it's likely we will need to get to this fluid off and get some better samples and then once we've got that done we can then think about the chemotherapy". The following are examples of mentioning other health professionals/support: "and the other team which I think is useful to get involved is the Macmillan team because they can give you advice on, you know, financial things"; "and you know you can phone and talk to (the lung cancer nurse specialist) and ask us any questions over the phone". The following are examples of comments on adjustment to disease/treatment: "and you know you've got a good quality of life at the moment so enjoy it while you've got it and if that changes we'll give you something to try and help with it"; "You don't necessarily need rest, rest is important yes erm do, do rest but don't over rest."

Patient: The following are examples of the future decision items coded within this theme: "Cos you're going to check up on me in six weeks and see where we go from there"; "yeah, so, think about radiotherapy for the future, after the chemo". The following are examples of utterances coded as mentioning other health professionals/support: "a senior nurse or something... yeah, he seems nice"; "but I've been told to contact Parkinson's people and see if they can arrange...". The following is an example of an utterance coded to comments on adjustment to treatment/disease: "if I got a symptom that I thought that was worse, then I'd ring that number yeah, but if it went away a while then I wouldn't, I'd manage."

Companion: The following is an example of a future decision item coded within this theme: "if you try it and you decide you don't like it, don't want it once you've started it then that's another decision to make". The following is an example of a adjustment to disease/treatment item: "exercise and that it doesn't harm does it?"; "and we might have to look at practical help for you both, you might need a home, I think realistically you are going to need some help and you need to get to the toilet, I mean realistically mums not going to be able to pull you up, all I'm saying is we need to consider these things."

2.6.4 Applying the coding frames to categorise utterances.

For both the SDM and shared conversation coding frames, the following method was adopted to classify participant's utterances. The text of the participant was broken down into a meaningful unit. The coding frame used to assign a code to the meaningful utterances. The code was recorded on the text to identify it within the text for analysis purposes. A mark applied against the code in the framing when it was identified. In this way, a pattern of responses could be ascertained per participant.

In addition, a case analysis was conducted (see appendix 8 for example). This involved collapsing sub categories of themes and mapping the frequency data of overall themes across all participants for each consultation. This was done to create a broader picture of the communication and identify where there were gaps in the information discussed. This enabled the researcher to see where there was congruence across participants' contributions and how shared communication was.

2.6.5 Plan of analysis

Responses from the questionnaire were entered into excel spread sheets and descriptive statistics (frequencies, means and standard deviations) were used to describe the characteristics of the sample.

The data from the qualitative analysis are reported using narratives and frequencies to illustrate patterns of responses in two ways: a cross-sectional analysis synthesizing the range of utterances raised by different stakeholders in the consultation (SDM and consultation conversation); a case analysis to illustrate the content of the conversation between the doctor-patient-companion (consultation conversation).

CHAPTER 3: RESULTS

Fourteen patients were approached and participated in the study; seven males and seven females; one patient declined participation. Participants' mean age was 70 years (s.d. 10.5, range 46-83). Consultations lasted on average 41 minutes (s.d. 12.4, range 21-64 minutes). The doctors speak about a third more in the consultation than the patient and companion combined. With frequency of utterances on average being; doctors 69 (range: 41-105); patients 27 (range: 16-49); companions 20 (range: 2-59). All but one patient brought a companion with them to the consultation. Most patients brought one companion (n=7), followed by 2 companions, (n=4), then 3 companions (n= 2). Decisions about treatment were made by the end of 13/14 consultations, 43% signed a consent form. Nine patients out of the fourteen returned the questionnaires (64% response rate) (see table 4 for summary).

Table 4: Summary of consultation outcome

Consultation	Treatment Decision	Outcome/consent	DCS total score	SWD total score
1	Come into hospital now	Admitted to hospital	-	-
2	Radiotherapy (then chemotherapy)	Consent form signed	0	30
3	Watchful waiting until symptoms develop	Come back in 6 weeks	0	30
4	Consider chemotherapy (choice postponed)	Return next week with decision	-	-
5	Radiotherapy	Consent form signed	-	-
6	Chemotherapy	Consent form signed	-	-
7	VATs (drain fluid with aim of doing chemotherapy)	Verbal consent for Dr to ask surgeons about VATs	9.4	30
8	Chemotherapy	Consent form signed	26.5	22
9	Chemotherapy	Consent form signed	-	-
10	Chemotherapy	Awaiting further results	25	24
11	Chemotherapy	Provisionally booked	0	30
12	Gefitinib	Consent form signed	0	30
13	Chemotherapy	Provisionally booked	0	30
14	VATs (drain fluid with aim of doing chemotherapy)	Verbal consent for Dr to ask surgeons about VATs	0	30

3.1 Decisional conflict and satisfaction

Out of the nine patients who returned the questionnaire, 6 scored zero on the DCS, which indicates that 67% of respondents felt no decisional conflict. O'Connor (1993) states that total scores lower than 25 are associated with implementing decisions whereas scores exceeding 37.5 are associated with feeling unsure about decision implementation. The data indicates that no patients in this sample would feel unsure about the treatment decision that was made. The sample mean for total decisional conflict was low at 5.4 (s.d. = 9.3), reflecting there to be little decisional conflict. The mean values for the five decisional conflict sub category scores were: uncertainty with the decision made, 11.1 (s.d.= 17.2); perception made an informed decision, 4.6 (s.d.=9.4); clarity of personal values, 4.6 (s.d.=9.4); inadequate support, 3.7 (s.d.=7.3); perceived efficacy in decision making, 6.9 (s.d. = 11). Out of the nine respondents seven scored the highest possible score (30), this indicates that 50% of the current sample were very satisfied with the decision that had been made. Five patients did not send back their questionnaire this makes it difficult to interpret the connection between the content of the consultation and the outcome, it is possible that patients may be more dissatisfied than the current data indicates.

The data from the two participants who scored themselves as being less satisfied and experiencing some decision conflict (consultation 8 and 10) were explored in more detail. These participants had different consultation outcomes, saw different doctors and contributed to the consultation in different amounts from each other. It seems as if there was a slight difference in the pattern of themes in these patients conversations (please see section 3.3)

3.2 Shared decision making synthesis

This section describes the results of Singh et al's (2010) coding frame. Out of a total of 18 shared decision making behaviours the mean score for the current consultations was 10. Figure 2 illustrates the frequency with which each item occurred across all consultations. In general the doctors took a detailed account of the patient's current situation (items 2 and 3) and demonstrated good communication skills (items 1, 4, 5, 13, 10). Not all treatment options were presented in all consultations (items 14 and 15). However, the option patients were presented with was explored in depth with details given about process, side effects and possible benefits (items 16, 17 and 18). The evidence base was usually poorly described (items 6 and 7). Equally so were eliciting patients preferences and values (items 12 and 19). Although all doctors provided information about side effects, procedures and benefits not all treatments were discussed in detail.

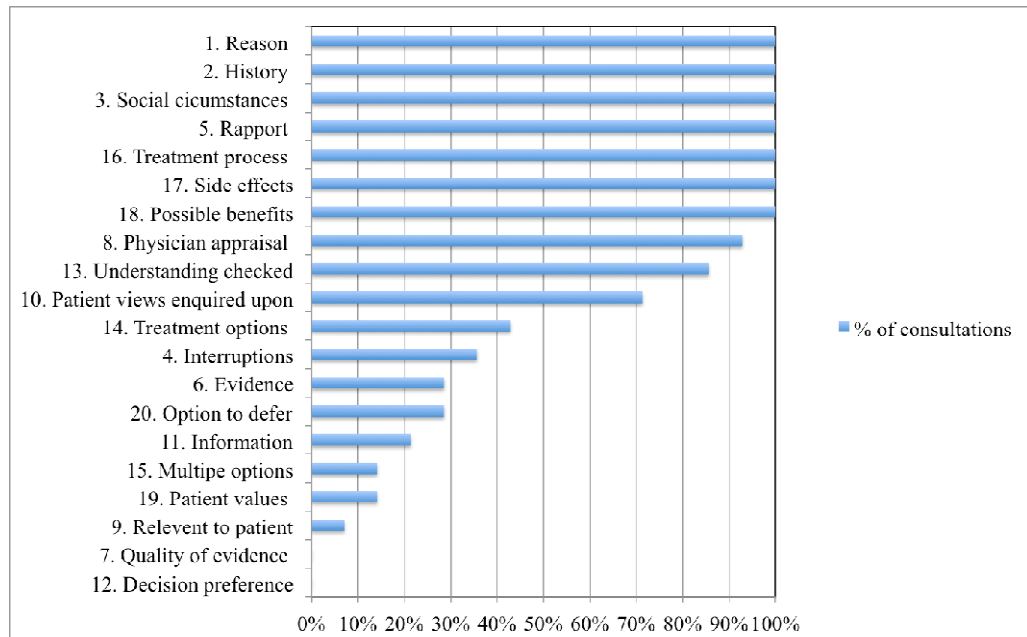


Figure 2: Graph summarizing results from Singh et al's (2010) coding frame

Singh's framework illustrated that much of the consultation focuses on talk about patients' symptoms, history and current circumstances and that many elements necessary for SDM are missing. There is a discrepancy between shared decision making as conceptualised by Singh et al (2010) and current practice. The data suggests that doctors are able to appraise the situation and recommend an appropriate treatment. However, that patients are not explicitly involved in the decision making process.

3.3 Within consultation conversation synthesis

The case analysis was conducted to look at the relationship between the participants' contributions within the consultations. This analysis enabled the patterns of contributions both within and across consultation to be identified (see appendix 8 for example case analysis).

The pattern of information doctors communicated during each consultation was fairly consistent. Similar themes were always talked about, whilst specifics around treatment options varied appropriately with the patient's disease status. Patients and companions were led by the content of the doctor's contribution. The doctor provides the information and talks about certain aspects which the patients and companions then reflect on and respond to. If the doctor does not mention a theme then in general the patients are unlikely to mention it (e.g. the risks treatment poses to life). This suggests that the information the doctor gives is key to topics that are then discussed. Doctors talk most about the delivery of care of an option, its side effects, and how to cope with that option, this drives the consultation. Discussion is based around the option that the doctor prefers based on their knowledge of the patient's disease. All treatment options are not raised in all consultations. Few doctors raise the option not to have an active treatment. The patients were not fully involved in the deliberation of treatment options in the decision making process. In part, they were unable to do so because they were not informed of the full range of options and prognosis details. In addition, there was little explicit prompting to encourage evaluation from the patient's life.

The two consultations where patients reported less than maximum satisfaction and a degree of decisional conflict differ slightly in their conversational pattern. In general the above patterns hold, however, when combining the number of utterances about affect and social expectations there is a slight difference. In most consultations the doctor has the same amount or slightly more utterances than the patient about these two themes, which one would expect if the doctor acknowledges any concerns raised by the patient. However, in these two consultations patients have slightly more utterances in the themes of affect and social expectations combined than the doctor does. This may illustrate that in these two consultations the patient is raising issues of importance to them.

3.4 Describing consultations using coding frames created for the study.

This section describes the range of issues raised by the participants, across all consultations. The response of the doctors, patients and companions are described together under the same theme. Tables are included in this section to illustrate the pattern of utterances by all participants. They are categorical data and are not statistically meaningful.

3.4.1 Making sense of the patient's lung cancer.

This section describes how lung cancer and its meaning is explored within consultations. Doctors, patients and companions discussed aspects of the disease, prognosis and values or emotional response they had in relation to these. The three perspectives are explained below. The content of this was the most closely aligned across all three participants in the consultation. The discussion about cancer usually had a question-answer format where the patient and companion seek out more information from facts provided by the doctor. Patients and companions do not regularly evaluate the information that is presented to them.

Table 5: Summary of participants' comments about lung cancer

Theme: Disease	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Neutral comment/question	14	100%	14	100%	10	70%
Positive evaluation	4	29%	3	21%	0	0%
Negative evaluation	5	36%	2	14%	0	0%
Uncertainty	6	43%	3	21%	4	29%

All doctors explained the patients' results and progression of the disease. For example:

“We know that there's a growth on the left upper lobe and that is the cancer. Urm, we've got some of the results back and it is non small cell lung cancer.” (Doc 2)

“Either way the cancer is now not only in the, close to the centre of the chest, but it's the glands in the middle of the chest too... and its also in one of your adrenal glands, the one on the right.” (Doc 3)

Additionally the doctors indicated their appraisal of disease severity in around a third of consultations:

“I think without treatment I think you're certainly going to become quite sick quite soon.” (Doc 10)

“you're only... about a 1 in 10 to 1 in 20 people have this mutation, so its rare, but it's a good thing.” (Doc 12)

In just under half of the consultations the doctors expressed uncertainty about the disease and that this may impact upon treatment:

“we don't exactly know which type it is and that's important to us cos each type uses a different, a slightly different chemotherapy so that's just that final result we're waiting for.” (Doc 11)

“Yes at the end of the day we are not sure what type, what cell it is and what we can do is give a drug which probably can affect both.” (Doc 6)

All patients sought out information about their disease, for example:

“The only question I have is if that happens to get bigger will that be a lot worse to get rid of?” (Pat 3)

“What does [Squamous cell] mean?” (Pat 9)

“is that purely because of the fluid?” (Pat 14)

“...ands its definitely the left lung?” (Pat 1)

Patients evaluated their disease or expressed uncertainty about it in less than a quarter of the consultations, for example:

“I had a biopsy and they said it had spread, that’s it, that’s as bad as I know.” (Pat 11)

“I’m not sure what’s going on with it actually.” (Pat 8)

Companions also commented or asked questions about the patients lung cancer, for example:

“How long do you reckon he’s had it Dr?” (Com 1)

“We were just talking about various problems with pain in the left knee, are we certain that it’s not related to the cancer?” (Com 5)

Companions never evaluated the patient’s disease and seldom commented on disease uncertainty.

“So you don’t know yet if it’s...[adenocarcinoma]?” (Com 6)

“they don’t know how fast its changing?” (Com 3)

As part of making sense of the patient’s lung cancer most consultations also included a discussion about disease outcome (see table 6). End of life or dying was seldom explicitly mentioned by any of the participants.

Table 6: Summary of participants' comments about prognosis

Theme: Prognosis	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Neutral comment/question	13	93%	13	93%	8	62%
Uncertainty	8	57%	2	14%	0	0%
Requests LE information	-	-	6	43%	2	15%
Provides LE information	4	29%	-	-	-	-

Most doctors made a neutral comment about prognosis, such as the aim being to control rather than cure the cancer, for example:

“this can't make it go away. All it can do is shrink it down to make it easier for you, to give you better quality of life to reduce any symptoms that you've got and try and lengthen life expectancy a bit as well.” (Doc 3)

“so I'm afraid we're not going to get rid of your cancer forever and a day, we haven't got a cure. We want to keep you as well as you can be for as long as possible.” (Doc 5)

Doctors stated there were levels of uncertainty around prognosis and often did not answer explicitly how long patients could expect to survive, rather they explained that prognosis depended on how the individual responds to treatment. The following are examples of doctors relating how unpredictable life expectancy was:

“I can quote averages but averages are meaningless cos you know some people do much worse than the average and some people do much better and I think that depends a little bit on how you respond to treatment.” (Doc 9)

“its very difficult to put times on things because we don't know and what we're suggesting rather than saying x months or whatever is actually seeing how things go and taking things a step at a time, and kind of a rolling horizons things of seeing how

you are and how you respond to chemo, cos if you respond and you're stable, fantastic. If we notice you're deteriorating, or you notice you're deteriorating then obviously we're measuring a shorter amount of time and I think until we get onto that sort of journey its very hard to set out where you'll be. I'm not trying to avoid answering your question, but it's a case of monitoring and watching." (Doc 10)

However, disease progression and average life expectancy was mentioned in about a third of consultations.

"With treatment its about, well less than a year being about 6-9months actually. And with treatment it's about 15 months, something like that." (Doc 3)

"Without treatment survival is usually 3-6months, with treatment you're looking at 6 – 12 months depending how you get on." (Doc 2)

"The average is around 3-4 months prolongation compared to baseline, now that's taking into account that not everyone responds to chemotherapy, so some people will not benefit and some people get much more of a benefit." (Doc 10)

Most patients asked questions about the outcome of their disease wanting to confirm that their cancer was life threatening, with 93% of patients asking about prognosis in general, examples include:

"Can we beat this? We're now looking at four different lots. So what're we saying? Can you treat me and cure me, or can you not?" (Pat 1)

"Right. So are you...you can only just keep me alive then, for so long?" (Pat 1)

"So, I'm terminally ill aren't I? eh?" (Pat 1)

Less than half of the patients specifically requested information about how long they had left to live,

"In this state that I'm in now how long have I got?" (Pat 3)

"I just want to know I'm not going to die in 6 months or... Or am I or what?" (Pat 9)

And/or expressed their own beliefs about their prognosis which tended to be over-estimates. There was:

“well, it’ll be a year, could be two? Yeah?” (Pat 12)

“ well I’m hoping they can cure it but they’re not going to.” (Pat 2)

“ well I think I can get, being optimistic, probably 4 or 5 year, at the rate I’m going.” (Pat 3)

Companions contributed less to this theme in the consultations. However, their contributions seemed explicitly to clarify options and ask for further details, in complementary way to the patient’s contribution. Issues around severity of disease, prognosis and disease management were enquired about, for example:

“I mean obviously the thing that we are hovering round is how serious a problem it is. I mean, I suppose it is serious isn’t it?” (Com 5)

“the way it is at the moment, my understanding is that this treatment my dads going to go through is to control the cancer, not to cure it.” (Com 10)

“just maintaining quality of life, I think that’s what it is isn’t it?” (Com 2)

“and what sort of, I mean, we’re talking about time frames and things like that, I mean I know that time frames on anything like that are...I mean how long a piece of string, but I think for mums benefit she needs to know.” (Com 2)

“what are you talking prognosis wise? And controlling it with the chemo? To be blunt.” (Com 10)

The theme affect contained all utterances by patients and companions around expressed emotions (see table 7).

Table 7: Summary of participants' verbalised emotions

Theme: Expressed Affect	Patient Total (n=14)	%	Companion Total (n=13)	%
Shock	3	21%	1	8%
Anxiety	3	21%	0	0%
Sad/crying	5	36%	2	15%
Acknowledges Pat emotions	-	-	5	36%

For patients, the utterances centred on their evaluation of the diagnosis and prognosis, these were minimal and contained, for example:

“I’m shocked and I don’t know what to say really I’m just, can’t take it on board.” (Pat 2)

“it’s frightening enough with what I’ve got and erm I mean I don’t sleep very well and erm anyway as I say it’s just an on-going nightmare from er 6 weeks ago whatever, I still can’t take it in.” (Pat 8)

For companions, most utterances were in response to the patient’s emotions rather than expressing any of their own feelings. Companions’ utterances were to acknowledge support and explain the patient’s reaction, often accompanied with a hug, offering tissues or expressions of comfort, for example:

“I think some of the way that you’re feeling has been a psychological reaction to it all.” (Com 2)

“It’s ok Dad, it’s ok to be upset its not a weakness being upset about something.” (Com 10)

Doctors’ utterances around affect were to acknowledge patients and companions feelings, not to prompt or enquire about emotional wellbeing. Doctors acknowledged emotions in 64% of consultations. For example in response to the patient displaying emotion doctors responses included:

“I’m sorry.” (Doc 1)

“yes, of course, and everybody would be [shocked].” (Doc 2)

“Right, ok, so it’s been quite a strain.” (Doc 5)

Once a joint understanding of the patient’s lung cancer had been reached through discussion about the disease and its outcomes the consultation progressed to discuss potential treatment options.

3.4.2 Discussing treatment options

This section explores how the patient’s options were discussed. It comprises of four parts; presenting treatment options, preferences for treatment, consequences and consent.

The categorised information regarding treatment options discussed by doctor, patient and companion in the consultation is summarized below in table 8.

Table 8: Summary of treatment options discussed

Option Category	Dr Total (n=14)		Patient Total (n=14)		Companion Total (n=13)	
	n	%	n	%	n	%
Option - surgery						
Neutral comment/question	4	29%	4	29%	2	15%
Positive Evaluation	0	0%	0	0%	0	0%
Negative Evaluation	7	50%	0	0%	1	8%
Uncertainty	1	7%	0	0%	0	0%
Personalised information	1	7%	-	-	-	-
Option - gefitinib						
Neutral comment/question	10	71%	4	29%	4	31%
Positive Evaluation	5	36%	2	14%	0	0%
Negative Evaluation	5	36%	0	0%	1	8%
Uncertainty	4	29%	1	7%	0	0%
Personalised information	2	14%	-	-	-	-
Option - chemotherapy						
Neutral comment/question	13	93%	13	93%	8	62%
Positive Evaluation	11	79%	3	21%	0	0%
Negative Evaluation	6	43%	2	14%	0	0%
Uncertainty	6	43%	4	29%	2	15%
Personalised information	4	29%	-	-	-	-

Option Category	Dr Total (n=14)		Patient Total (n=14)		Companion Total (n=13)	
	n	%	n	%	n	%
Option - drain fluid						
Neutral comment/question	2	14%	2	14%	2	15%
Positive Evaluation	1	7%	0	0%	0	0%
Negative Evaluation	0	0%	1	7%	0	0%
Uncertainty	2	14%	0	0%	0	0%
Personalised information	2	14%	-	-	-	-
Option - radiotherapy						
Neutral comment/question	10	71%	3	21%	5	38%
Positive Evaluation	2	14%	1	7%	1	8%
Negative Evaluation	6	43%	2	14%	0	0%
Uncertainty	2	14%	0	0%	0	0%
Personalised information	4	19%	-	-	-	-
Option - come into hospital						
Neutral comment/question	1	7%	1	7%	0	0%
Positive Evaluation	1	7%	1	7%	1	8%
Negative Evaluation	0	0%	0	0%	0	0%
Uncertainty	0	0%	0	0%	0	0%
Personalised information	1	7%	-	-	-	-
Option - no active treatment						
Neutral comment/question	3	21%	3	21%	1	8%
Positive Evaluation	1	7%	0	0%	0	0%
Negative Evaluation	0	0%	1	7%	1	8%
Uncertainty	1	7%	0	0%	0	0%
Personalised information	0	0%	-	-	-	-

Doctors generally provided neutral information about the options. Not all options were talked about equally. Doctors tended to present the clinically best, active treatment, rather than an exploration of all treatment options. In all cases there were real world restrictions on the treatment options that could be offered because of how the patients disease had progressed, this was made explicit in the doctors rationale for recommending another treatment. In this way treatment options would be mentioned, negatively evaluated and ruled out as a viable way forwards. This ruling out of treatment options was always accepted by the patient rather than questioned. Examples include:

“The first thing we know is that with the size of the cancer, its spread to the lymph glands so doing an operation is not possible. I don’t think surgery is an option.” (Doc 10)

“We can’t give radiotherapy in terms of, to all that area for the same reason, it has spread to the pleural space.” (Doc 8)

“We looked to see if there was a particular type of mutation on it, a mutation on one of your genes called a EGFR mutation and there isn’t, so those drugs that work in that way aren’t appropriate.” (Doc 14)

Doctors offered incomplete information about the range of options available. Whilst at least one active treatment option was presented in all consultations not having active treatment and opting instead for conservative care was only mentioned in 21% of consultations, examples include:

“Cos there’s a possibility that it might have been changing very slowly that actually doing nothing might be a reasonable thing to do if its not causing you any great bother.” (Doc 3)

“...and then there’s a 3rd option, that patients sometimes say is I’d rather not have any treatment at all, no radiation, no chemo I just want to manage things with pain killers and that is a valid decision as well you know.” (Doc 11)

Patients utterances about treatment were in response to the options raised by the doctor. The utterances were more about information searching and explanation than evaluation the options using their values and judgments, examples include:

“Yeah but its giving me other drug, chemo. That’s it, chemo’s stronger. Isn’t it?” (Pat 5)

“but if they, like on chemotherapy, which ever way it is, if I get my course in and I wait three weeks before I start your next one?” (Pat 10)

“the chemotherapy for this, is it any different from the chemotherapy for the leukaemia?” (Pat 13)

“ok, and would that procedure [draining fluid], is it surgery and under anaesthetic?” (Pat 14)

Patients' utterances about conservative care suggest it was not seen as an active treatment option:

"I don't think my option is to stand and hope for the best, that's the way I look at it." (Pat 3)

When companions contributed to the conversation about treatment options it was mainly to clarify or find out more information, examples include:

"I think I get the drift you've got to have some vitamins for a week while they are looking to see whether its squamous or adeno and depending on the outcome of that they'll, whatever you be ha-, you will know within a week and you'll have to start the treatment one week later." (Com 6)

"It's not worth having a blast of radiotherapy as well? sorry this is lay person speaking you want to sort of chuck everything at it, you can." (Com 8)

As part of the discussion around treatment options participants often mentioned they had a preferred way to proceed, this was sometimes expressed in terms of a desire, a recommendation or a directive. Participants stated their treatment preferences to variable extents (see table 9).

Table 9: Summary of participants' stated preferences

Theme: preference	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Treatment option	12	86%	6	43%	1	8%
Timing of delivery of care	10	71%	4	29%	1	8%
Consent	-	-	1	7%	1	8%
End of Life	-	-	1	7%	1	8%

In most consultations the doctor gave their expert opinion and recommended a treatment option. For example:

“what it might be worth doing is doing a more definitive procedure on the fluid, to get the fluid off putting something to try and stop it coming back or leaving a drain in permanently. So what I’d like to do today is speak to one of our surgical colleagues to think about doing a procedure to do that.” (Doc 7)

“So we’ve got a cancer on that side with a bit that has spread on the other side, ok, so obviously we need to give chemotherapy.” (Doc 6)

“so, what we need to do from today is say, I think chemotherapy is right for you.” (Doc 10)

Doctors also generally expressed that timing was important and how they would prefer to advance with treatment, such as:

“what we can do today is start the vitamins anyway, yes, so that if it is a adenocarcinoma we can go ahead with the chemotherapy next week. It will save us a week isn’t it, we don’t waste time.” (Doc 6)

“we could get that started while we are waiting for the other procedures so we don’t lose any time.” (Doc 7)

After doctors stated their preference for treatment they then checked the patient’s acceptance of their recommendation. All patients in the current study agreed with suggestions the doctor made. Patients stated their own treatment preferences in fewer consultations than doctors, this was usually in terms of wanting the most effective treatment and deferring to the doctor’s expertise:

Doctor: “so, what are you thinking?” (Doc 10)

Patient: “well, I’d like the best treatment obviously to give me the most energy and the longest time, if we can do it that way?” (Pat 10)

Doctor: “so that would, you’d be interested in chemotherapy?” (Doc 10)

Patient: “yes, yes, if that were the right way forwards?” (Pat 10)

Companions rarely stated a preference for any aspect of care, when they did it was generally supporting what either the patient or doctor had just stated as their preference. For example:

“as long as they don’t give her medicine, liquid medicine, anything that might taste bad.” (Com 2)

“my mum and I were talking about we err, feel very strongly that she should have some kind of advance directive.” (Com 2)

“In fact she was saying this morning I’d like them to get on with the treatment whatever it is. We need to get started.” (Com 8)

Discussion about treatment options involves an awareness of potential side effects and benefits. At least one consequence of the potential treatment options was mentioned in all consultations, whether this was in terms of side effects, potential risks or feeling better (see table 10).

Table 10: Summary of participants’ comments about the consequences of options

Theme: Consequences	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Side effects - Neutral comment/question	12	86%	10	71%	5	38%
Side effects - Positive evaluation	5	36%	2	14%	0	0%
Side effects - Negative evaluation	3	21%	1	7%	0	0%
Risk	11	79%	5	36%	1	8%
Feel better	9	64%	1	7%	2	15%

Doctors described the potential side effects of treatment options in most consultations, for example:

“It can sometimes make you sickly and vomit but it’s not good at that, so it’s not like some chemotherapy’s, it’s a given that you’ll feel sick, it’s not a given with this one, it can make you feel tired and washed out, chemotherapy tends to do that for the first few days afterwards, it sometimes make your mouth sore and give you a bit of diarrhoea.” (Doc 8)

“Side effects of the chemotherapy are that it can make you tired, it can affect your blood count, it can make your red cells go low which can make you anaemic. It can also make you nauseous or be sick. Although we can give you special anti sickness medicine and we can change that if it happens. And it can affect your bowels. It can also affect your fingertips and your toes, your nerve endings and it can effect your kidneys and your liver, so they’re things that we have to monitor closely with your blood tests.” (Doc 10)

Side effects were rarely evaluated by the doctor, however, when they were they were more likely to be positively than negatively evaluated, such as:

“They’re not too bad and most patients who are reasonably fit, which I think you are, tolerate the chemotherapy reasonably well.” (Doc 5)

Both patients and companions acknowledged or asked questions to clarify information about side effects. Examples include:

“and then I’ll get that rash will I?” (Pat 12)

“sounds like quite a lot of side effects that’s all.” (Pat 4)

“I’ve already got sore mouth as well.” (Pat 9)

“will this make him feel quite poorly then?” (Com 10)

Patients made very few evaluations about treatment consequences and, as was the case with doctors, when they did they tended to be positive such as:

“well, its not too bad is it? I’ll be right” (Pat 12)

“I won’t get side effects me, I’ll be ok” (Pat 4)

Doctors usually highlighted the potential risk to life that treatment brings, for example:

“...if your white cells fall you’re at risk of infection and if you get an infection your body can’t fight it so it can go from something very benign to something very serious very quickly, because sometimes chemotherapy can make people very poorly and occasionally people can die as a result of the side effect of the chemotherapy rather than the cancer.” (Doc 9)

Few patients and companion commented about the risk to life that treatment may have, this was usually in terms of acknowledging the risk information doctors provided, rather than exploring it, for example:

Doctor: “there’s a small risk, but not a big risk that it can put you at risk of infection and bleeding which sometimes can be life threatening.” (Doc 2)

Patient: “yes, I know. I’ve heard of it.” (Pat 2)

The positive consequence of treatment i.e. that the patient has fewer active symptoms and feels better was mentioned by doctors in just over half of consultations, for example:

“and it should improve your cough, and it should improve your pain.” (Doc 12)

“you may notice an improvement in your breathing as you go along.” (Doc 2)

Equally, patients and companions rarely mentioned this positive consequence of treatment, one example being:

“but you’re going feel better when they take that fluid.” (Com 7)

Once options and their consequences have been discussed the conversation may involve discussion about consenting to treatment (see table 11). This is where patients firmly agree to having a treatment option and the procedure is booked.

Table 11: Summary of participants' comments about consent to treatment

Theme: Consent	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Neutral comment/question	9	64%	5	36%	2	16%
Positive evaluation	0	0%	0	0%	0	0%
Negative evaluation	0	0%	0	0%	0	0%
Uncertainty	0	0%	1	7%	0	0%

Doctors often mentioned consenting to treatment, this was usually in the form of presenting the patient with a form, recapping the treatment option agreed on and asking them to sign it, for example:

“Right so this is the ...your name at the top [patients name] erm, the [date of birth] and its radiotherapy to the chest, to the tumour, and the reason we want to do that is to treat the tumour...its just your signature there. If you're happy to sign it today, you don't have to sign it today, erm, I don't want you to feel pressured.” (Doc 2)

All patients signed a consent form if they were presented with it. Patients and companions utterances around were consent were usually acknowledging that they were consenting to treatment rather than making any evaluation about it, for example:

“I'll have to sign it won't I?, if its going to do some good I want it.” (Pat2)

“Do you want me to print my name as well?...Yeah, that's fine...all in your box now.” (Pat 9)

When discussing treatment options the above themes were considered. In addition to the options themselves and their consequences consultations also included other factors that were related to the current decision, these results are discussed below.

3.4.3 Aspects of related care

This section describes how wider aspects of the patient's care are explored in the consultation. Doctors, patients and companions discussed possible future decisions that would have to be considered, where patients could seek support from and how to adjust and cope with the disease and its treatment (see table 12).

Table 12: Summary of participants' comments about aspects of related care.

Theme: aspects of related care	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Future decisions	12	86%	5	36%	5	23%
Other health professionals/support	12	86%	9	64%	5	38%
Comments on adjustment	12	86%	8	57%	9	69%

In most consultations doctors mentioned potential future treatment decisions that may need to be made in the patients care, for example:

“it might be that in six weeks time its grown to the point where we say, you know what, I don't think we should wait any longer. But it might be, you know, that its about the same size as it was, if it has grown we start some treatment.” (Doc 3)

“so what we need to think about is giving chemotherapy and then reassessing, we may want to give radiotherapy after chemotherapy. And the dose of radiotherapy and things will depend on the size of it and how you are and we'd consider giving radiotherapy at the end to kind of consolidate what we've done, so if things have shrunk nicely we'd use the radiotherapy to try and get longer control.” (Doc 10)

“See how you feel, if you feel that you can cope with it for a further 3 cycles that's fine we'll go with it. Or you can say thank you very much I don't want to go ahead and we'll stop it and we'll talk about radiotherapy at that time.” (Doc 6)

Both patients and companions commented on these future decisions, usually in the form of checking the information the doctor provided and reiterating that future treatment could alter depending on the patient's experience of it, for

example:

“so it’s the same then situation really?” (Pat 4)

“if its too much for you. And like he said if after a couple of doses its just too much for you then we can switch and just do the two.” (Com 2)

“if you try it and you decide you don’t like it, don’t want it once you’ve started it then that’s another decision to make.” (Com 4)

Doctors also frequently highlighted that other sources for help and assistance, such as other health professionals were available:

“get in touch with [LCNS] and even if you get home and go ‘ahh I wish I’d have asked that’ or I mean [LCNS] can answer it, [LCNS]’s super. There’s no question too small for him.” (Doc 2)

“I think the other thing we don’t underestimate is coping with cancer is not straight forward and we do have an additional support service here. There’s also something called, we have a psych-oncology group sort of, which are psychologists who are trained in helping people come to terms with cancer and dealing with cancer I’ll just say that’s available for you because it can be very, very helpful, especially if you’re not sleeping, if you’re not sleeping it means you’re more tired it then feeds into more side effects so I’d be happy to refer you to them if you wanted to?” (Doc 8)

Patient and companion utterances about other support available were brief and usually in response to the doctor making a statement or enquiry about these matters, for example:

“well, I’m expecting a call from them cos [LCNS name] said, the ‘community nurses will be contacting you’ so they’re probably coming to see me anyway.” (Pat 4)

“Erm, yes I think I need all the help I can get and I also want to know about the healing and the meditation and all that side as well, which I know is available.” (Pat 8)

Doctors commented on the patient’s adjustment and/or coping in most consultations, this was generally in the form of offering advice about medical issues and giving practical suggestions about daily living, for example:

“what we recommend to the patients is we normally give you a thermometer to monitor your temperature at home. If you feel that your temperature is up or you feel unwell in yourself its very important that you ring the hospital.” (Doc 13)

“The most important thing from what you’ve described is I think musculoskeletal, I think carrying on with the wheat packs and a bit of gentle motion is sort of good, get that better.” (Doc 7)

“So obviously if somebody’s got a hacking cough or they’re not feeling very well don’t visit them when you’re. But don’t lock yourself up in a room don’t you know.” (Doc 8)

Both patients and companions commented on adjustment and coping with illness and treatment. Patients tended to focus on their own coping strategies and planning for the future, for example:

“ah well, if I got a symptom that I thought that, (sighs) if I thought the symptom that I’d got was something that I’d never had before, then I’d be in touch with you. As regards a bit of a twitch or a bit of pain or whatever then I wouldn’t bother.” (Pat 3)

“you know, cos if I’m going to be poorly for a fortnight, your dad can’t cope with that can he? Do you now what I mean? We need to, we need to talk about what we can do.” (Pat 4)

“Is it, am I able to cope with it? it won’t be you know bad to cope with because I’m on my own.” (Pat 6)

Whereas companions utterances were generally highlighting aspects of the patients well being, advice giving and comments about how they could be of help to the patient and, for example:

“he clears peoples gardens and he likes to be active and happy, he don’t want to stay indoors, it won’t stop him will it?” (Com 12)

“I think me and [name] would be more reassured to know that other people were going in to take some of that weight off you, so you can then concentrate on being the strong one. Its going to take a toll on anybody. I think to get the support there from day one.” (Com 10)

“I know, you just, be honest, when you’re not feeling so good, tell us you’re not feeling so good, let us know. Let us help you.” (Com 7)

3.4.4 Reinforcing social expectations

This section describes how during consultations participants say certain phrases or fill conversational space in a way that helps to keep the interaction running smoothly. These utterances were present in all consultations and usually displayed a certain ‘human’ quality of warmth or humour. All doctors, patients and companions conformed to some extent to the social expectations of their role within medical consultations (see table 13).

Table 13: Summary of participants’ comments in social expectation theme

Theme: Social expectations	Doctor total (n=14)	%	Patient total (n=14)	%	Companion total (n=13)	%
Social mores	12	86%	14	100%	9	63%
Reassurance	8	57%	-	-	3	28%
Comments on doctors role	-	-	4	29%	0	0%
Encourages patient	-	-	-	-	5	38%

The item social mores was present in most consultations, examples of doctors social mores include:

“He’s thinking ‘I’ve been given too much information today’ [laughs].” (Doc 11)

“I think you know especially in a situation where there isn’t anything to blame it’s just bad luck.” (Doc 8)

“well, you know, that’s ermm [laughter] well, oh my word, I’m going to have to get my crystal ball out know aren’t I?” (Doc 3)

“we’re never going to give you the lungs of a 21 year old you know. so we just take things step by step.” (Doc 3)

Patients expressed social mores in all consultations. They used the ordinary language that surrounds cancer; talking about being positive, having a fighting spirit and a sense of control over their disease, for example:

“...even the neighbours have been fantastic so I’m very lucky in that respect so I’m going to be positive, it’s the only way I can do it.” (Pat 8)

“no I think you’ve, I mean basically, I’d like lot live a lot longer and if I have my way I’ll try my best.” (Pat 10)

“I mean I’ll fight it that’s not the problem.” (Pat 9)

“I’m a strong positive person, you know, we know people that have been said to them they’ve got weeks to live and they’ve lived for a long time.” (Pat 14)

Companions’ usually stated social mores, these comments were containing and supporting of both themselves and the patient, examples include:

“my mum is not your average 80 year old no.” (Com 2)

“there’s a lot to take in and you feel that you’ve understood it and I’ll walk out of here and I won’t remember a word you’ve said, but I know what’s going to happen, I’ve got the leaflet.” (Com 6)

“Well we have to wait and see how things turn out.” (Com 5)

Companions also encouraged patients, sometimes this was encouraging them to be active in the consultation or sometimes this was in terms of being encouraging about their attitude towards the disease, for example:

“What do you know of it mum, do you want to say what you do know?” (Com 5)

“if you’re going to give it a damn good fight then you give it a damn good fight.” (Com 10)

On occasion companions also reassured patients, for example:

“But I suppose everything’s here that’s anywhere in the world I think...you can’t get better treatment anywhere else.” (Com 6)

“when your chest is a bit better and you’re in a better frame of mind it might not seem as daunting, I don’t know.” (Com 4)

Doctors offered patients some form of reassurance more than companions did, this was usually regarding aspects related to treatment and remembering all the

facts the doctor was providing, information leaflets were often given at this stage. Examples include:

“I’ll do it for you (re: taking down info) don’t worry, at the end. I’ll do it don’t worry about that.” (Doc 6)

“Well try to put your mind at rest you know in terms of starting the treatment there’s a few cancers we need to start treatment within a week and that’s particularly small cell, the other times that we tend to do is more about you know if you waited 2 weeks it’s not going to make any difference.” (Doc 8)

Patients commented on the doctor’s role and/or asked the doctors advice in around a third of consultations. Patients’ utterances were around their confidence that the doctor was a skilled and informed expert, for example:

“I can’t deal with it myself now obviously can I? I need somebody like you whose got knowledge about this stuff and you, you’re there to direct me in the right direction, what you think’s the right direction. I don’t know what’s the right direction, only by what you’ve just said.” (Pat 3)

“Listen to them cos they know what they are doing.” (Pat 2)

“No, no, obviously it’s a very specialist...this is why you have to listen to the experts don’t you.” (Pat 6)

The above results illustrate that there are a range of themes talked about by participants in lung cancer treatment decision making consultations. Differences between how much certain themes are discussed and whether these conversations involve SDM is explored in the following chapter.

CHAPTER 4: DISCUSSION

The purpose of this study was to describe the decision making conversation in lung cancer consultations, to explore if shared decision making was taking place and to investigate patients' perceptions of the decision. A mixed method design was used to address this, using coding frames to analyse the content of the consultations and questionnaires to gather patients' views of it. The main findings are described in brief below.

4.1 Summary of consultations

The data from the consultations illustrate that communication was not equal between all parties. Doctors spoke the most, followed by patients, followed by companions. This is the norm in medical consultations because part of the doctor's role is to provide information and patients speak more than their companions because they are the focus of the consultation (Roter, Hall and Katz, 1988). The style of the consultation appears to be quite formulaic and this is independent of the patient and the doctor.

This study found that doctors provide information about the disease and present the clinically best option as the choice for patients to consent to. Doctors describe that treatment option's associated procedures and side effects. Patients and their companions are interested in understanding the disease and ask about treatment choice to 'make sense' of their illness. Patients and companions rarely make any evaluation about what the doctor is offering and express little emotion. Most patients want to know about disease outcome and prognosis but the information provided is not always complete. Doctors also signpost future decisions and offer advice about adjusting and coping with the disease and treatment. These are commented on by the patient and discussed by the companion as and when the doctor raises them. The companion's role is related to that of the patient, seeking out health related information to increase joint understanding.

The rest of this chapter will explore whether current practice reflects shared decision making, the validity of the research and its potential clinical implications.

4.2 The presence of SDM in lung cancer consultations

This section discusses whether or not the observed consultations meet the criteria for SDM. SDM as conceptualised by Singh et al (2010) is not being routinely implemented in this setting, with just more than half of the items of Singh et al's (2010) frame being raised by doctors in consultations. The data from the current consultations received the same average score of presence of SDM items in this frame as Singh et al's (2010) study of cancer patients consultations: a score of 10. This suggests that there is some continuity about the way professionals provide information in cancer consultations.

It is questionable whether Singh et al's (2010) coding frame really conceptualises SDM, rather it helps clinicians to see where they are focusing their efforts when conversing with patients. It can be used in the context of staff training to help staff improve their practice and see that they are implementing patient centred care through their good communication skills. Singh et al's (2010) frame is not competent enough to appraise all the components of SDM. The coding frames developed for this study can be used to assess whether SDM was happening because they illuminate the nature of the interactional conversation between all three parties, rather than just information given by the doctor as in Singh et al's (2010) frame.

In order to assess whether SDM was practiced in the current consultations the observed findings are discussed below in relation to the following key aspects of SDM:

- both the patient and doctor exchange information about the health problem and treatment options;
- both the patient and doctor discuss their reasoning about and preferences for the different options (patient values elicited);

- both the patient and doctor negotiate and agree on the decision to be made.

Information exchange: Doctors provide information about the patient's disease and treatment option, with patients asking questions to clarify the information provided. In general, within consultations the themes the doctors talk about the most patients also talk about the most, with patients needing to be primed about what is appropriate to discuss in that setting. Information exchange does occur, however patients are not fully informed of all options available and their potential consequences e.g. option of conservative care. The data suggests that doctors want to inform and treat and are aiming for a shared understanding of the disease and its management.

Reasoning and preferences for options: In general the doctor stated a preference for treatment based on their assessment of the patient's disease and patients agreed to doctors' suggestions. Patients did not usually state a treatment preference and did not vocalise any reasoning they had done regarding agreeing to the treatment option. Patients did not explore their personal preferences and values or use them in collaboration together with the evidence to make a decision. Little emotion was expressed; this lack of affect may suggest a lack of evaluation. The data suggests that patients were not evaluating what was happening. Patients are presented with a lot of information and it is unlikely they are able to assimilate it, reason about it and arrive at their own preference independent of the doctor.

Agreement on the decision: All patients left the consulting room knowing what the next stage in their treatment was. It was rarely explicitly stated that all parties agreed to the decision, although consent forms were signed in 6/14 consultations. Doctors tended to explain what the best course of action was and checked that the patient agreed. In this way a choice is presented rather than a decision made. There was no evidence of the information being deliberated between participants as to whether the potential side effects were worth experiencing for potential gains and patient and companion did not discuss the decision together.

The patterns above describe a normal consultation where doctors tailor information to the patient (patient centredness) and provide information about what is most clinically effective (evidence based practice). Whilst the SDM coding frame accesses this, what is illuminated by the frames created by the researcher is how the patient and companion respond to the doctor. The patient responds to what the doctor is saying and the companion contributes in complimentary ways. If the doctor does not raise an issue then neither does the patient and it is not discussed. The patient does not have the opportunity to understand all possibilities and evaluate if one suits them better. There is nothing in the current structure of the consultation that would help anything different to happen.

This study adds to the body of evidence that there is only limited use of SDM in clinical practice (Mendick et al., 2010; Shepard, Butow and Tattersall, 2011; Towle et al., 2006). SDM is a term created in primary care and it has been argued that it is not suitable in contexts such as this. For example, Pollock (2011) found that when suffering from a serious illness constructs such as SDM have little applicability for patients, as they want to trust in the professional's expertise. However, this represents a misunderstanding of the issue at stake. Whilst patients may not feel able to make the decision themselves they do state preferences that they wish to be involved in decision making (Davidson et al., 1999; Gattellari et al., 2001; Kremer et al., 2007, Pardon et al., 2009). Equally, the literature shows that patients become distressed when their wishes are not being met (Lin, 2012), for example, when end of life preferences are not followed (Crane et al., 2005). Patients' desire for involvement is illustrated by their question asking and seeking understanding of what is going on for them. Whilst this may not be conceptualised as being involved in making the decision itself, patients' actions of seeking knowledge is a desire for the process to be more shared. Patients' views about the way the decision was made are explored in the following section.

4.3 Patients' views about the consultation

Patients in this study rated their satisfaction with the consultation quite highly. However, there was data missing. Whilst questionnaire responses illustrated that 50% of the sample are completely satisfied and experience no decisional conflict the feelings of the 30% of the sample who did not respond are unknown. Due to the lack of a full data set a judgment cannot be made about the link between the content of the consultation and the outcome. It is possible that those who were less satisfied and experienced more decisional conflict did not return their questionnaire, resulting in a skewed sample of largely satisfied patients who experienced little decisional conflict.

In addition, reported satisfaction may not be a sufficient depiction of patients' experiences. Pollock et al's (2011) study about receiving information in cancer care showed that frequent interview accounts of negative experiences and dissatisfaction did not convert into scores of dissatisfaction on self report questionnaires. Patients may feel hesitant to be critical when they need continued care and treatment management (Nehring et al., 1973) and may feel obliged to make a 'grateful testimony' to the service that they received (Nguyen et al., 1983). Taking the above into account responses to the questionnaire may not truly represent patients' views.

An explanation for low decisional conflict is that patients feel informed, that their values are listened to and they that they have adequate support to make an effective choice. However, this is not evidenced in the observational data. An alternative reason for low decisional conflict is that patients are not engaging with the decision or that they do not know there is a decision to be made. There is no evidence in the current study that patients are considering options and making trade off decisions between length and quality of life. The data suggests that in the current study patients are not perceiving there to be a decision to be made,

rather patients are asked to consent to a choice the doctor has presented. If patients do not know that there is a choice they cannot express decisional conflict.

4.4 Validity of results and concordance with previous research

The current research utilised strong research methods as it was observational and without influence from the researcher (Robson, 2002). Many of the results from this study are in keeping with other literature in the communication and decision making field, this indicates that the current findings are valid. Results illustrate that doctors, patients and companions talk about the same areas in consultations as other researchers have identified, such as exchanging information about disease, treatment and deciding what would happen next (Street and Millay 2001; Roter and Hall, 2006; Singh et al., 2010) with companions, if present, contributing in complementary ways (Street, 2008). Similarities with previous research in terms of content of consultations and doctor-patient communication are explored below.

4.4.1 Information about options and treatment choice

This research indicates that doctors do not provide full information about treatment choice, supporting findings that many patients with lung cancer do not understand its treatment (Quirt, 1997). In the current study doctors did not elicit patient role or information preferences, only offering a treatment choice on occasion. This supports the findings of Braddock et al., (1999); Elwyn et al., (2003); Towle et al., (2005); Singh et al., (2010). As in other literature (Koedoot et al, 1996) patients in this study did not seem to perceive that there was a choice of treatment. Doctors stating their preference may imply to patients that there is a correct choice and only one path to follow. The choice patients are presented with is whether to consent to the doctors recommendation, rather than participate in the decision making process. All patients in the current study agreed with suggestions the doctor made, which is in line with Sharf et al's (2005) findings and may reflect patients feelings of dependence (Mendick, 2011).

Active treatment seems to be valued over best supportive care, as in other studies (Yellin, 1995; Koedoot et al., 1996; Slevin et al., 1990) with the option of conservative care raised in only 21% of consultations. Patients' utterances about conservative care suggest it was not seen as an active treatment option, this can be interpreted as being because patients are responding to how doctors present the information. In addition, generally patients did not comment about the potential risk to life that active treatment entails. This may indicate that patients do not have time to fully process this consequence or that they do not wish to consider it.

4.4.2 Realistic expectations of disease outcome

In the current study most doctors made a neutral comment about prognosis, such as it being palliative rather than curative. However, it is debatable how much patients absorb that information as this study and previous research has shown that patients have inaccurate perceptions about the prognosis of their disease (Temel et al., 2011; Sagan et al., 2011; Quirt et al., 1997). Doctors stated that there was a level of uncertainty about how long patients could expect to live, this may be necessary to maintain patients' hope and the doctor patient relationship (Mendick et al., 2011).

Patients overestimate life expectancy and the option of palliative care was not mentioned in any consultations. Without accurate information of disease prognosis patients are unable to accurately balance length of life and quality of life and may agree to unproductive or distressing treatments at the end of life (Temel, 2008). These findings agree with previous evidence that both doctor and patient prefer not to directly address patients' mortality (The et al., 2000). A discussion about palliative needs at the time of diagnosis and throughout disease progression could help raise awareness of the disease outcome and help patients consider the risks and benefits of treatment (Temel et al., 2011).

4.4.3 Conforming to traditional doctor-patient roles

This section discusses evidence from the current study in terms of 'normative' participation in consultations and decision making processes. In the current study

participants conformed to traditional information giving/information seeking roles, with nearly a third of patients commenting on the doctor's expert role or directly asking for their advice. This suggests that some patients expect the doctor to take the lead role in decision making. One interpretation of this is that in assigning responsibility to the doctor the patient may avoid responsibility and the subsequent risk of regret if the treatment option turns out to be not as expected or have negative consequences (Botti and McGill, 2006). As suggested by previous research it may be that lung cancer patients are less able to actively engage in decision making due to their socio-demographics (Ende et al., 1989; Pendleton & House, 1984; Waitzkin, 1985). However, turning to doctors for guidance does not mean that patients sacrifice their sense of agency or that SDM cannot occur (Thompson, 2007).

In the current study language that reflected and maintained traditional roles (social mores) was evident in all consultations and may have served the purpose of making doctors, patients and companions feel more comfortable and signposting that they were going to behave as expected by all. For example, patients vocalised their perceptions of personal resilience and fighting which may give a sense of perceived control (Byrne, 2002). This is unsurprising as it fits in with the social conventions around coping with the challenge of physical disease and protecting others (both the companion and doctor) from feeling uncomfortable and embarrassed (Byrne, 2002).

4.4.4 Emotionless and treatment focused consultations

It was not the norm for patients or companions to express emotions about the disease or their prognosis during consultations. Both companions and doctors responses to patients helped to contain and control any emotion expressed, rather than encouraging exploration of it. In these consultations doctors do not initiate talk about emotions. One interpretation of this is that patients and companions do not think it is appropriate to raise how they are feeling and refrain from doing so, which may lead to emotional distress being unidentified. This study found that doctors were more likely to discuss others aspects of care such as adjusting to

illness and treatment rather than discuss emotional issues. This is in line with findings of Taylor et al (2011) who suggest that doctors may view engaging with emotions as less relevant to the provision of medical care with its side effects and treatments. Doctors described other professionals and agencies patients could seek help from. An explanation of this is that doctors are highlighting that it is other people's role to provide emotional, psycho-social or practical support. As revealed by the case analysis of the consultations patients who were less satisfied have slightly more utterances than the doctor in the themes of affect and social expectations combined. One interpretation of this is that in these two consultations patients are raising issues of importance to them that are not being addressed. It is possible that there was an unresolved need in those patients.

4.5 Contributions of this study to the wider literature

This study adds to the existing evidence base about decision making in lung cancer. First by examining the presence of SDM (see section 4.2) in NSCLC consultations. Second by illuminating the role of companions in these encounters. Third by observing a discrepancy between what patients say they want (patient preference literature) and what has been observed in the current study that they receive.

4.5.1 Role of companions.

In the current study companions' purpose was to be involved in understanding and be an aide memoire to the patient rather than a decision facilitator. Whilst previous studies have demonstrated that companions' role is that of supporting patients (Street et al., 2008) and facilitating their involvement in care (Clayman et al., 2005) this study found that companions did not support patients to engage more in the conversation, deliberate the choice that is presented to them or make a decision. In addition companions rarely uttered encouraging or reassuring statements, it may be that simply their presence in the consultation was reassuring and supporting enough. Findings suggest that the companions of NSCLC patients

perform less of a supportive role, occupying instead a position alongside the patient of information gathering and clarification.

4.5.2 Patients want information that is not provided

Existing studies have illustrated patients' preferences in lung cancer (Brundage et al., 1998; Brundage et al., 2001; Davidson et al., 1999; Pardon et al., 2009; Silvestri et al., 1998), but few have observed if they have achieved their preference. A problem with previous studies that asked about achievement of patient preferences is that it was impossible to tell if patients had received information and forgotten it or whether there was a misunderstanding. This observational data shows there is a true discrepancy between what patients say they want (from the literature) and what they receive.

Information is missing from these consultations that patients would like to be included, with patients not being fully informed about their options, consequences or prognosis. Studies on patient preferences in lung cancer illustrate that most patients would like to be fully informed about treatment decisions, with nearly all patients wanting information about treatment, likelihood of cure and life expectancy (Pardon 2009). Not presenting full information may impact upon treatment choices. Brundage et al's (1998) study found that most NSCLC patients would not choose chemotherapy for a survival benefit of three months or less and when given the choice between chemotherapy and best supportive care 78% chose best supportive care. However, Brundage et al's (1998) study was conducted using hypothetical scenarios rather than a real world decision at the time that it was made. This research observed that patients preference for choosing best supportive care are not translating into the current consultations. These findings suggest that best supportive care is an option worth discussing with lung cancer patients and is currently missing in consultations. One possible result of patients not being fully informed is that they cannot participate in decision making as much as they would like, this is explored in the next section.

4.5.3 Patients are not achieving their desired level of involvement.

This study suggests that patients are not playing an active role. There is evidence that patients want to engage in the decision making process, with around two thirds of patients with advanced lung cancer wanting to share treatment decisions with the doctor (Pardon et al., 2009), which is not happening in the current study. Previous research has shown that cancer patients do not achieve their desired level of involvement in treatment decision making (Davidson, 1999; Gattellari et al., 2001), however studies are based on patients self-report. The current study adds strength to this finding through observing that patients are not fully involved.

In Davidson et al's (1999) study of lung cancer patients and hypothetical treatment options 57% of patients wanted an active role in treatment decision making. Comparing the above patient preferences to the study's observational results shows that patients are not obtaining the level of information that they want. Equally the current study highlights that patients are not asked about what is important to them or about their preference for involvement. In order to improve the match between patient preferences for involvement and how patients are involved in practice, changes may need to be made which are explored in the section below.

4.6 Clinical implications and recommendations

Data from this study suggests that for current standards of patient centred care to be maintained it is not necessary to alter communication patterns. However, if participants want more involvement in the consultation and the decision to be more shared as the evidence above indicates, the consultation structure needs to be changed. Currently the encounter is predominantly about information giving where a lot is aimed to be achieved in a short time at a relatively brisk pace. Patients may not understand or retain all information provided to them by their doctor (Bourhis et al., 1989) and it is unlikely that patients could adequately weigh up the toxicity, side effects and quality of life information if they were

presented fully. Introducing a new emphasis on deliberation with doctors supporting patients to think through their choices would require more time, as it is likely that all needs cannot be met in one consultation.

Consultations could be set up differently to support doctors to better support patients. One way to allow fuller patient participation would be to prepare patients with information before they came to the consultation. Patients could be ‘front loaded’ with information about the full range of treatment options and their consequences. This would mean that when the patient attends their consultation time that would have been spent describing treatment options could be spent having more of a joint discussion about them. In addition, decision aids could be provided. Decision aids can help patients to comprehensively represent the decision problem and have a knowledge of all options with their pros and cons and the consequences of options (Bekker, 2010). This would then enable patients to evaluate and make a trade off decision according to their own beliefs and values. There is evidence that cancer patients who have used decision aids are more satisfied (Brown et al., 2001). In addition a decision-aided consultation may enable sensitive topics such as the patient’s death to be more easily talked about at the right time. A further suggestion is that a second meeting could be used where the patient is guided through the decision, perhaps with decision coaching from their LCNS with consent forms signed at this later stage.

The above recommendations are in line with suggestions for clinical practice from the MAGIC project (making good decisions in collaboration) which puts forward that SDM can be divided into three stages: choice talk; option talk; decision talk (Elwyn et al., 2012) (please see figure 3).

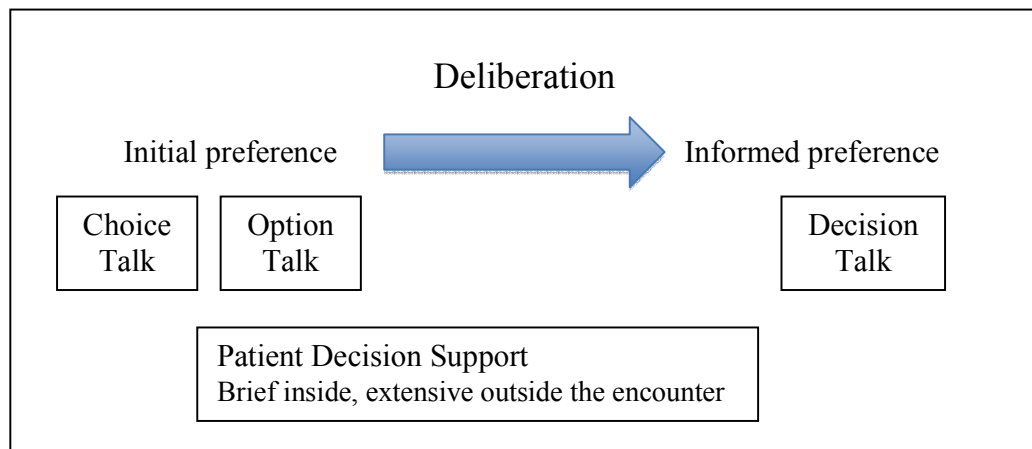


Figure 3: SDM: a model for clinical practice (Elwyn et al, 2012)

Extra space in the current system may be needed to feasibly allow time for consideration and for patients and clinicians to work together. The suggestions above would separate the choice and option talk from the decision talk allowing time for deliberation which would be supported by aids and decision coaching. This model may be able to sustain SDM.

4.7 Strengths and limitations of the study

The current research has both strong and weak points which are detailed below.

4.7.1 Confidence in the results

The mixed method design ensured that the study appropriately tackled the research objectives, enabling a detailed exploration of what actually happens in a consultation. Strengths include that the research was carried out in a real world setting, using an observational design which increased the validity of the findings because it provides objective information about this context. In addition, gaining patients' perspectives was used to get a more subjective view of the decision making consultation.

This study was well grounded in the literature. The coding frames were informed by psychological theories of decision making and evidence from prior research. Analysis has been perceivable and unambiguous through the use of coding frames. Triangulation through multiple analysis using Singhs et al's (2010) coding frame, coding frames devised for the study and case analysis method provides further assurance about the credibility of the findings. Looking at the same phenomenon in different ways strengthens confidence in the findings of the results (Patton, 2002).

4.7.2 Study limitations

A limitation of this study is its small sample size. Recruiting patients with metastatic, stage IV NSCLC was a challenge, as once a patient had been identified as appropriate to be approached a variety of factors could change in the time frame before their consultation. It was not unusual for a patient's illness projection to alter resulting in them no longer attending the consultation. For example a deterioration in health would mean that they were admitted as an inpatient. In addition, a proportion of participants did not send back their questionnaire, this is a limitation of real world research (Robson, 2002). There has been little investigation of lung cancer patients' decisions about treatment, which may partly be due to the difficult nature of recruiting patients at an advanced stage in their illness.

A further limitation of this study is that communication consists of non-verbal as well as verbal elements. This study only recorded verbal elements, which makes it possible that some meanings and messages communicated between participants were missed. Qualitative data can be affected by researcher bias, however, this has tried to be limited by utilising a thematic framework which helps to minimise researcher bias as results are grounded in the text. In addition, the research supervisor checked that results were grounded in the data through discussion with the researcher and decisions about the framework were made explicit by the researcher.

This study investigated decision making in the late stages of metastatic lung cancer, the findings cannot be assumed to be transferable to consultations about other types of cancer where threat to life is less great and outcomes potentially more positive. Patients were all from a single region in the UK and therefore may differ from practices and attitudes in other countries. However, many findings do converge with previous research.

4.8 Implications for future research

This is one of the first studies to use an observational method to assess SDM in NSCLC. Examining the studies results reveals areas for future research to investigate and extend the current findings. The exploratory nature of this research has shown aspects of the consultation that could be done differently if the desired result was to encourage shared decision making. Recommendations include a change to current practice which may result in the patient being more empowered to participate. Future research could involve developing a patient decision aid to be used in this clinical setting which could be trialled and evaluated.

In addition, there is a need to explore in more depth patients' and companions' views of these consultations. The current study cannot infer a link between consultation content and satisfaction outcome due to not having a full data set for patient satisfaction. Future research could involve conducting a semi-structured interview with the patient and companions following the consultation and decision. This would enable findings from the current questionnaire data to be unpacked to see if upon further exploration patients did feel that all their needs were met in the consultations. Interviewing patients and companions would also illuminate what aspects they consider important in the decision and if there is any concordance.

The current study has explored the decision making process at one point i.e. beginning first line treatment (decision to start treatment). There is a need to

assess if decision making consultations are different later on in the disease pathway i.e. when the patient is beginning second line treatment (decision to stop or continue treatment). It is unclear whether decision making is the same at these two points or if it is dependent on experience. It may be the case that once a patient has experienced the treatment option they state their preferences and value judgments more frequently. Future studies could involve the researcher following patients and their companions through their disease progression and treatment cycles to investigate if decisions to continue with active treatment were made in a similar manner and the evolving nature of the decision making process. It is unclear how deteriorating health may influence the manner in which people weigh up the pros and cons of treatment and make quality of life trade-off decisions. If patients and companions became more involved in decision making as disease progresses this would have implications for doctors' practice.

4.9 Conclusion

This was a rigorous study using an observational method to explore decision making in lung cancer consultations. The findings are consistent with previous research that shows current practices do not support a model of SDM. The patients are not aware of all the options, are not supported in evaluating them and a discussion deliberating choices alongside their own values is not happening in consultations. Conversations are more about patients consenting to a procedure than sharing in the decision. There are several changes in practice that could be implemented to encourage more involvement. These include prompting patients with information before consultations or using decision aids within consultations. These proposals would have minimal impact on service change. Studies indicate that patients want this increased involvement (Davidson et al., 1999; Pardon et al., 2009) and the decision literature suggests that it has positive outcomes (Brown et al., 2001; Edwards and Elwyn, 2006).

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APPENDIX 1 – Letter of Ethical Approval


National Research Ethics Service
NRES Committee Yorkshire & The Humber - Humber Bridge

Yorkshire and the Humber Research Ethics Office
 First Floor
 Millside
 Mill Pond Lane
 Leeds
 LS6 4RA

Telephone: 0113 3050127

24 August 2011

Ms Rebecca Elizabeth Lifford
 Psychologist in Clinical Training
 The Leeds NHS Teaching Hospitals NHS Trust
 Leeds Institute of Health Sciences
 Charles Thackrah Building
 101 Clarendon Road, Leeds
 LS2 9JL

Dear Ms Lifford

Study title: Assessing patients' and companions' decision making about treatment decisions in non small cell lung cancer
REC reference: 11/YH/0286

Thank you for your letter of 07 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

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

Ethical review of research sites
NHS sites

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

Non-NHS sites
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.

APPENDIX 2 – Information sheets

Patient information sheet

(copies given to patients in font size 12).

INFORMATION SHEET

Assessing patients and their companions decision making about treatment for Non small cell lung cancer.

You are being invited to take part in a research project.

Please take the time to read this information before deciding whether or not you wish to take part in this research. It is important to understand why the research is being done and what it will involve. We are happy for you to discuss this research with others who are important to you.

What is the purpose of this research?

This research will develop a greater understanding of how patients reach decisions about treatment choices for lung cancer. This research is being carried out in the Bexley wing of St. James's University hospital by Rebecca Lifford who is a student at the University of Leeds. We are interested in your views about making treatment decisions and how informed and supported you and your companions feel when making these decisions.

Am I eligible for the research?

You can take part in the study if you have lung cancer. We would like about 40 people to take part in this study.

What will happen to me if I take part?

This research has two parts to it. First the consultation between yourself, your oncologist and whoever accompanies you to the appointment will be audio taped. Second you will be asked to answer a short questionnaire given to you by the nurse specialist. This will take place at the hospital and should take no longer than 10 minutes to complete.

Do I have to take part?

No, taking part is completely up you. Your care will not be affected by your decision to take part or not. You have the right to withdraw from the study at any stage; without giving a reason.

What are the possible disadvantages and risks of taking part?

This research involves you talking about your experiences of having lung cancer. We do not think there are any risks in taking part in this study. You will be giving us your time, which some may see as a disadvantage.

What are the possible advantages of taking part?

The information gained from this study will help the service understand what information patients and their companions need to know and if more support is needed for all patients making treatment choices in lung cancer.

Will my taking part in this study be kept confidential?

All consultations will be audio tape-recorded and transcribed for analysis. Any details that may identify you will be removed from the transcript. The researcher (Rebecca Lifford) will use a number to identify your responses. This means your questionnaires will be anonymised. Information you provide on the questionnaire will remain totally anonymous.

What will happen to the results of the study?

The results from the study may help inform future practice. They will also be presented at conferences, workshops and published in academic journals. The anonymised transcripts will be destroyed.

Who has reviewed the study?

This study has been reviewed by the Leeds West Research Ethics Committee.

Consent

You will be asked to sign a consent form before you take part in the study.

What if there is a problem?

If you would like to talk in more detail about any aspect of this research, please contact your lung cancer nurse specialist or Rebecca by phone or email.

Thank you for reading this information sheet from the research team

Dr. Clive Mulatero Oncologist St. James Hospital	Hilary Bekker Senior Lecturer University of Leeds	Rebecca Lifford Research student University of Leeds
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Companion information sheet

(copies given to companions in font size 12).

INFORMATION SHEET

Assessing patients and their companions decision making about treatment for Non small cell lung cancer.

You are being invited to take part in a research project.

Please take the time to read this information before deciding whether or not you wish to take part in this research. It is important to understand why the research is being done and what it will involve. We are happy for you to discuss this research with others who are important to you.

What is the purpose of this research?

This research will develop a greater understanding of how patients reach decisions about treatment choices for lung cancer. This research is being carried out in the Bexley wing of St. James's University hospital by Rebecca Lifford who is a student at the University of Leeds. We are interested in your views about making treatment decisions and how informed and supported you and your companions feel when making these decisions.

Am I eligible for the research?

You can take part in the study if you have a family member/friend with lung cancer. We would like about 40 people to take part in this study.

What will happen to me if I take part?

This research has two parts to it. First the consultation between the patient, whoever accompanies the patient to the appointment and the oncologist will be audio taped. Second the patient and yourself will be asked to answer a short questionnaire given to you by the nurse specialist. This will take place at the hospital and should take no longer than 10 minutes to complete.

Do I have to take part?

No, taking part is completely up you. Your care will not be affected by your decision to take part or not. You have the right to withdraw from the study at any stage; without giving a reason.

What are the possible disadvantages and risks of taking part?

This research involves you talking about your views of the consultation appointment and how the treatment decision was made. We do not think there are any risks in taking part in this study. You will be giving us your time, which some may see as a disadvantage.

What are the possible advantages of taking part?

The information gained from this study will help the service understand what information patients and their companions need to know and if more support is needed for all patients and their companions when treatment choices are being made.

Will my taking part in this study be kept confidential?

All consultations will be audio tape-recorded and transcribed for analysis. Any details that may identify you will be removed from the transcript. The researcher (Rebecca Lifford) will use a number to identify your responses. This means your questionnaires will be anonymised. Information you provide on the questionnaire will remain totally anonymous.

What will happen to the results of the study?

The results from the study may help inform future practice. They will also be presented at conferences, workshops and published in academic journals. The anonymised transcripts will be destroyed.

Who has reviewed the study?

This study has been reviewed by the Leeds West Research Ethics Committee.

Consent

You will be asked to sign a consent form before you take part in the study.

What if there is a problem?

If you would like to talk in more detail about any aspect of this research, please contact a lung cancer nurse specialist or Rebecca by phone or email.

Thank you for reading this information sheet from the research team.

Dr. Clive Mulatero Oncologist St. James Hospital	Hilary Bekker Senior Lecturer University of Leeds	Rebecca Lifford Research student University of Leeds
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APPENDIX 3 – Participant consent forms

Patient consent form

PATIENT CONSENT FORM FOR RESEARCH STUDY

Patient identification number for this study:

Title of Project: Describing decision making about Lung cancer treatment

Name of Researcher: Rebecca Lifford, Psychologist in Clinical Training,
University of Leeds

Please initial box

1. I have read and understood the information sheet for the above study
2. I have had opportunity to ask questions about the study
3. I understand that if I take part in the study I may not gain any direct personal benefit
4. I consent to my consultation with the doctor being audio -tape recorded for the purposes of this study
5. If I choose not to return the questionnaire I consent to the recording still be used as data
6. I consent to anonymised results and quotes from the study being presented and published
7. I understand that I can withdraw from this study at any time without my medical care being affected.
8. I agree to take part in this study.

Name of Participant

Date

Signature

Name of Person taking
consent

Date

Signature

Companion consent form

COMPANION CONSENT FORM FOR RESEARCH STUDY

Patient identification number for this study:

Title of Project: Describing decision making about Lung cancer treatment

Name of Researcher: Rebecca Lifford, Psychologist in Clinical Training, University of Leeds

Please initial box

- 1. I have read and understood the information sheet for the above study
- 2. I have had opportunity to ask questions about the study
- 3. I understand that if I take part in the study I may not gain any direct personal benefit
- 4. I consent to my consultation with the doctor being audio -tape recorded for the purposes of this study
- 5. I consent to anonymised results and quotes from the study being presented and published
- 6. I understand that I can withdraw from this study at any time without my medical care being affected.
- 7. I agree to take part in this study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Doctors consent form

Consent form

Title of Project: Assessing patients and companions decision making about treatment for Non small cell lung cancer.

Name of Researcher: Rebecca Lifford, Psychologist in Clinical Training, University of Leeds

I understand the purpose of the above study. I understand what is expected from me in my involvement with it. I give my permission for my consultations with those patients who agree to the study to be audio-taped. Audiotapes of consultations will be anonymised. I agree to complete a brief questionnaire following each audio-taped consultation. Study data will be kept confidential and destroyed after the study has been completed. I understand that the tapes and questionnaires will only be used for the purposes of the current study.

Signed

Print name and title

Signed (researcher)

Date

APPENDIX 4 – Patient Questionnaire

Patient identification number:

Describing Decision Making About Lung Cancer Treatment

Questionnaire

Thank you for agreeing to take part in this study. Your views about how decisions regarding your treatment are made are important. We want to know your opinions and feelings about the consultation you were just in. Answers will be kept anonymous and will not effect your treatment in anyway.

Age:

Sex: (please circle) Male Female

If someone came with you to today’s appointment what is your relationship to them? (e.g. partner, daughter, friend)

Please answer the following questions:

	Strongly Agree	Agree	Neither Agree Or Disagree	Disagree	Strongly Disagree
1. I know which options are available to me.					
2. I know the benefits of each option.					
3. I know the risks and side effects of each option.					
4. I am clear about which benefits matter most to me.					
5. I am clear about which risks and side effects matter most.					
6. I am clear about which is more important to me (the benefits or the risks and side effects).					
7. I have enough support from others to make a choice.					
8. I am choosing without pressure from others.					
9. I have enough advice to make a choice.					
10. I am clear about the best choice for me.					
11. I feel sure about what to choose.					
12. This decision is easy for me to make.					

	Strongly Agree	Agree	Neither Agree Or Disagree	Disagree	Strongly Disagree
13. I feel I have made an informed choice.					
14. My decision shows what is important to me.					
15. I expect to stick with my decision.					
16. I am satisfied with my decision					

Satisfaction with the decision

Answer the following questions about your decision. Please indicate to what extent each statement is true for you AT THIS TIME.

	Strongly Agree	Agree	Neither Agree Or Disagree	Disagree	Strongly Disagree
1. I am satisfied that I am adequately informed about the issues important to my decision.					
2. The decision I made was the best decision possible for me personally.					
3. I am satisfied that my decision was consistent with my personal values.					
4. I expect to successfully carry out (or continue to carry out) the decision I made.					
5. I am satisfied that this was my decision to make					
6. I am satisfied with my decision.					

THANK YOU for taking the time to complete this questionnaire.

APPENDIX 5 – Extracts of final coding frame scoring sheets

Extract of coding frame for doctors contributions

Theme	Number of observations
1. Disease	
1.1 Neutral comment/question	
1.2 Positive evaluation	
1.3 Negative Evaluation	
1.4 Uncertainty	
2. Option - Surgery	
2.1 Neutral comment/question	
2.2 Positive Evaluation	
2.3 Negative Evaluation	
2.4 Uncertainty	
2.5 Individualised/personalised information	
3. Option - EGFR/gefitinib	
3.1 Neutral comment/question	
3.2 Positive Evaluation	
3.3 Negative Evaluation	
3.4 Uncertainty	
3.5 Individualised/personalised information	
4. Option - chemotherapy	
4.1 Neutral comment/question	
4.2 Positive Evaluation	
4.3 Negative Evaluation	
4.4 Uncertainty	
4.5 Individualised/personalised information	
5. Option - drain fluid	
5.1 Neutral comment/question	
5.2 Positive Evaluation	
5.3 Negative Evaluation	
5.4 Uncertainty	
5.5 Individualised/personalised information	
6. Option - radiotherapy	
6.1 Neutral comment/question	
6.2 Positive Evaluation	
6.3 Negative Evaluation	
6.4 Uncertainty	
6.5 Individualised/personalised information	

Extract of coding frame scoring sheet for patients contributions

Theme	Number of observations
8. Option - no active treatment	
8.1 Neutral comment/question	
8.2 Positive Evaluation	
8.3 Negative Evaluation	
8.4 Uncertainty	
9. Option - consent	
9.1 Neutral comment/question	
9.2 Positive Evaluation	
9.3 Negative Evaluation	
9.4 Uncertainty	
10. Treatment Consequence - side effects	
10.1 Neutral comment/question	
10.2 Positive evaluation	
10.3 Negative evaluation	
11. Treatment Consequence - feel better	
12. Treatment Consequence - risk	
13. Prognosis	
13.1 Neutral comment/question	
13.2 Uncertainty	
13.3 requests LE information	
14. Patients preference stated	
14.1 Treatment	
14.2 Timing of delivery of care	
14.3 Consent	
14.4 End of life	
15. Expressed affect	
15.1 Shock	
15.2 Anxiety	
15.3 Sadness/crying	
16. Social Expectations	
16.1 Social mores	
16.2 Comments/questions on doctors role	
17. Aspects of related care	
17.1 Future decisions	
17.2 Mentions other health professionals/support	
17.3 Comments on adjustment/coping	

Extract of coding frame scoring sheet for companions contributions

Theme	Number of observations
8. Option - no active treatment	
8.1 Neutral comment/question	
8.2 Positive Evaluation	
8.3 Negative Evaluation	
8.4 Uncertainty	
9. Option - consent	
9.1 Neutral comment/question	
9.2 Positive Evaluation	
9.3 Negative Evaluation	
9.4 Uncertainty	
10. Treatment Consequence - side effects	
10.1 Neutral comment/question	
10.2 Positive evaluation	
10.3 Negative evaluation	
11. Treatment Consequence - feel better	
12. Treatment Consequence - risk	
13. Prognosis	
13.1 Neutral comment/question	
13.2 Uncertainty	
13.3 requests LE information	
14. Doctors preference stated	
14.1 Treatment	
14.2 Timing of delivery of care	
14.3 Consent	
14.4 End of life	
15. Expressed affect	
15.1 Shock	
15.2 Anxiety	
15.3 Sadness/crying	
16. Social expectations	
16.1 social mores	
16.2 reassurance	
16.3 Encourages patient	
16. Aspects of related care	
16.1 Future decisions	
16.2 Mentions other health professionals/support	
16.3 Advice on adjustment/coping with treatment	

APPENDIX 6 – Extract of item lists for all participants

Describing doctors contribution to consultation – an extract

- 1. Establishing a problem/Background**
 - 1.1 Info seek current symptoms:
 - Cough
 - Sickness
 - Breathing
 - Pain
 - Blood
 - Bowels
 - Energy level
 - Weight/appetite
 - 1.2 Info seek timeline of symptoms
 - 1.3 Info seek social Circumstances:
 - living arrangements
 - family situation
 - ADL
 - employment
 - smoking
 - 1.4 Info seek any other medical problems
 - 1.5 Info seek other medical procedures
 - 1.6 Info seek family medical history
 - 1.7 Info seek - current medication
 - 1.8 Info give – current medication
 - 1.9 Info give – pain management
- 2. Physical examination**
 - 2.1.1 listen to chest/breathing/heart
- 3. Exploring P's illness**
 - 3.1 Info seek – how p currently copes with symptoms
 - 3.2 Info seek - How symptoms currently effect P life.
 - 3.3 Expression of concern re: patients symptoms
 - 3.4 Expression of concern re: impact on life.
- 4. Target Problem**
 - 4.1 Establish P current knowledge of cancer
 - 4.2 Scans:
 - offer to view scans
 - explain scans
 - size of tumour/s
 - location of tumour/s
 - Tumours spread
 - uncertainty about exact type of cancer
 - uncertainty about when cancer started
 - Check for P understanding of cancer
 - Clarifies in response to P/C queries

5. Comment about lung cancer

- 5.1 Positive comment
- 5.2 Negative comment

6. Goals of treatment

- 6.1 control of symptoms
- 6.2 not curative, delay development of further symptoms
- 6.3 palliative
- 6.4 shrink tumour

7. Comments about treatment decision

- 7.1 States that a treatment decision needs to be made
- 7.2 States decision doesn't need to be made today
- 7.3 Asks P for thoughts about treatment.

8. Comments about treatment options

- 8.1 States more than one option to choose from
- 8.2 States what treatment isn't an option:
- 8.3 Explains why not an option
- 8.4 Treatment might make symptoms better
- 8.5 Treatment might make quality of life worse due to side effects
- 8.6 Treatments better than 2/3 years ago
- 8.7 Treatments are individualised
- 8.8 Uncertainty over timeline of treatment

9. Comments EGFR option

- 9.1 EGFR mutation explained
- 9.2 EGFR statistics given
- 9.3 EGFR result given – positive/negative/uncertain.
- 9.4 difitalib tablets side effects – rash, diarrhea
- 9.5 Benefits of difitalib
- 9.6 Positive comment expressed
- 9.7 Negative comment expressed
- 9.8 Check for understanding of treatment option
- 9.9 Withholds info
- 9.10 Side effects –acne/rash, sickly, poor appetite, chest inflammation.

10. Comments chemotherapy option

- 10.1 Chemotherapy option voiced
- 10.2 Chemotherapy explained
- 10.3 Chemotherapy process described
- 10.4 Logistics/practicalities of chemotherapy discussed
- 10.5 Checks understanding of option
- 10.6 Reasons for chemotherapy
- 10.7 Reasons against chemotherapy
- 10.8 Minimises side effects
- 10.9 Positive comment re: chemo
- 10.10 Negative comment re: chemo
- 10.11 Asks P thoughts about chemo
- 10.12 professional opinion re: have chemo

- 10.13 Can stop treatment once started if change mind
- 10.14 Withholds info
- 10.15 Consequences of Chemotherapy:
 - Time in hospital
 - Consequence – ADL
 - SE hair
 - SE nausea
 - SE vomiting
 - SE tiredness
 - SE diarrhea/constipation
 - Sore mouth
 - Risk of death through lowered immunity
 - Crucial to monitor symptoms as increased risk of dying due to chemo
 - Q of L may increase due to treatment
 - Q of L may decrease due to side effects of treatment.

11. Comments drain fluid option

- 11.1 Draining fluid from lungs in order to then see if can do chemo.
- 11.2 Explains VATs
- 11.3 Positive comment VATs
- 11.4 Negative comment VATs
- 11.5 Consequence of VATs – if remove fluid may be able to have chemo
- 11.6 Check understanding of VATs

12. Comments radiotherapy option

- 12.1 Radiotherapy as option voiced
- 12.2 Radiotherapy explained
- 12.3 Radiotherapy process described
- 12.4 Logistics/practicalities of radiotherapy discussed
- 12.5 Checks understanding of option
- 12.6 States can stop treatment once started
- 12.7 Reasons for radiotherapy
- 12.8 Reasons against radiotherapy
- 12.9 Minimises side effects
- 12.10 Positive comment re: radiotherapy
- 12.11 Negative comment re: radiotherapy
- 12.12 ask P thoughts about radiotherapy

*Describing patients contribution to consultation – an extract***1-12....****13. Preferences**

- 13.1 want to keep my weight up
- 13.2 want to keep my appetite
- 13.3 don't want to be a burden

14. Comments/questions about treatment

- 14.1 whats the difference e.g. between chemo and radiotherapy?
- 14.2 States preference for intervention:
 - no needles
 - don't want to be in hospital a long time
 - don't want it to hurt
- 14.3 is it going to hurt?
- 14.4 don't want it to be uncomfortable/horrible
- 14.5 beliefs about consequences of treatment
- 14.6 concern about treatment option
 - treatment timeline i.e. too slow
 - sounds like a lot of side effects
 - impact of treatment SE on family
- 14.7 other family members need to be considered.
- 14.8 I can try it and see
- 14.9 hope for the future

15. Perception of treatment consequences

- 15.1 I'm not going to get side effects
- 15.2 I'll be fine, my family are supportive

16. Emotion expressed

- 16.1 negative emotion (fear, confusion, shock, anger, sad, worry)
- 16.2 Uncertainty about future
- 16.3 hopeful treatment will work
- 16.4 worry for family members

17. Attitude to Cancer/illness

- 17.1 I Will 'fight' cancer/not going to give in
- 17.2 I'm not going to have any side effects e.g. I'll be alright me.
- 17.3 I'm not frightened
- 17.4 perceive control over cancer
- 17.5 going to be positive
- 17.6 can always ask for extra help (e.g. macmillan nurses)
- 17.7 never been really ill before

18. Comments on DM

- 18.1 What do I need to do?
- 18.2 Uncertainty about whats 'best'
- 18.3 lots of information to take in
- 18.4 want to go home and think about it with partner/family

- 18.5 understand information presented
- 18.6 confused about treatment
- 18.7 emotionally overwhelming
- 18.8 time pressure

19. Comments on Dr's Directive

- 19.1 P clarifies Drs plan that has been made.
- 19.2 trust in Dr's expertise
- 19.3 there is no choice (e.g. all I can do is go with the chemotherapy)
- 19.4 I want to think about it first
- 19.5 seeks clarification of treatment option
- 19.6 neutral comments re: Drs directive
- 19.7 positive comments re: Drs directive
- 19.8 questions timeline of treatment

20. Life expectancy

- 20.1 raised by P
- 20.2 lack of knowledge/no-one will tell us
- 20.3 acknowledges that fatal
- 20.4 requests life expectancy info
- 20.5 prefer not to know life expectancy info
- 20.6 gives reason why want to know
- 20.7 gives reason why doesn't want to know
- 20.8 states own LE estimate
- 20.9 positive comment
- 20.10 negative comment
- 20.11 uncertainty expressed

Describing companions contribution to consultation – an extract

- 1. Comments on their purpose**
 - 1.1 want to know what's happening
 - 1.2 take notes
 - 1.3 pass on information and action plan to rest of family
 - 1.4 support P

- 2. Providing information**
 - 2.1 info give P symptoms
 - 2.2 info give symptom timeline
 - 2.3 info give medication
 - 2.4 info give past procedures
 - 2.5 info give social circumstances

- 3. Information seeks - lung cancer**
 - 3.1 details on scans
 - 3.2 size of cancer
 - 3.3 how long has cancer been there?
 - 3.4 how quickly is it growing?
 - 3.5 location of cancer
 - 3.6 type of cancer

- 4. Questions/comments treatment options**
 - 4.1 Questions/clarifies goal of cancer treatment
 - 4.2 Info seek time pressure – how quickly would that decision be made?
 - 4.3 clarifies treatment options
 - 4.4 Clarifying treatment process
 - 4.5 Past experiences/knowledge of treatment
 - 4.6 info seeks consequence of treatment options
 - 4.7 info seeks SE of treatment options
 - 4.8 what happens next
 - 4.9 what about future treatment?

- 5. Comments DM**
 - 5.1 Expresses desire for Dr to be honest with them
 - 5.2 States current level of knowledge
 - 5.3 trusts in Dr expertise
 - 5.4 lots of information

- 6. Expresses concerns**
 - 6.1 Concerns over P current health
 - 6.2 Concerns over P future Q of L
 - 6.3 Concerns about why not found LC sooner
 - 6.4 Concerns about impact on family
 - 6.5 concerns about treatment SE's

APPENDIX 7 – Example of preliminary coding frame

Doctors preliminary coding frame

Theme	Number of observations
1. Disease	
1.1 neutral comment	
1.2 positive evaluation	
1.3 negative evaluation	
1.4 preference stated	
2. Surgery	
2.1 neutral comment	
2.2 positive evaluation	
2.3 negative evaluation	
2.4 preference stated	
3. EGFR	
3.1 neutral comment	
3.2 positive comment	
3.3 negative evaluation	
3.4 preference stated	
4. Chemotherapy	
4.1 neutral comment	
4.2 positive evaluation	
4.3 negative evaluation	
4.4 preference stated	
5. Drain Fluid	
5.1 neutral comment	
5.2 positive evaluation	
5.3 negative evaluation	
5.4 preference stated	
6. Radiotherapy	
6.1 neutral comment	
6.2 positive evaluation	
6.3 negative evaluation	
6.4 preference stated	
7. No active treatment	
7.1 neutral comment	
7.2 positive evaluation	
7.3 negative evaluation	
7.4 preference stated	
8. Come into hospital now	
8.1 neutral comment	
8.2 positive evaluation	
8.3 negative evaluation	
8.4 preference stated	
9. Consent	
9.1 neutral comment	
9.2 positive evaluation	
9.3 negative evaluation	

9.4 preference stated	
10. Side effects	
10.1 neutral comment	
10.2 positive evaluation	
10.3 negative evaluation	
10.4 preference stated	
11. Feel better	
11.1 neutral comment	
11.2 positive evaluation	
11.3 negative evaluation	
11.4 preference stated	
12 Risk	
12.1 neutral comment	
12.2 positive evaluation	
12.3 negative evaluation	
12.4 preference stated	
13. Prognosis	
13.1 neutral comment	
13.2 positive evaluation	
13.3 negative evaluation	
13.4 preference stated	
14. Adjustment/coping	
14.1 neutral comment	
14.2 positive evaluation	
14.3 negative evaluation	
14.4 preference stated	
15. Emotion	
15.1 neutral comment	
15.2 positive evaluation	
15.3 negative evaluation	
15.4 preference stated	
16. Uncertainty	
16.1 Disease	
16.2 treatment	
16.3 end of life/prognosis	
17. Time	
17.1 Take time to consider	
17.2 don't waste time	
18. patient centred utterance	
19. Human response/social more	
20. DM facilitator	
21. Sign post future decision	

APPENDIX 8 – Example case analysis

Consultation 6

