David Winston Hamilton

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Institute of Health and Society, Faculty of Medical Sciences

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Abstract

Head and neck cancer (HNC) confers a poor prognosis and patients face complex treatment decisions. As with every cancer in the UK, recommendations for treatment are made through a multidisciplinary team (MDT). This thesis critically analyses the working of the MDT: data are presented from an ethnographic study across three head and neck cancer treatment centres.

Data collection comprised non-participant observation of 35 MDT meetings and 37 MDT clinic appointments and semi-structured interviews with 19 patients pre- and post-treatment and nine staff members of the MDT. Data generated were analysed using a Constructionist Grounded Theory approach, drawing on symbolic interactionism and dramaturgical analysis.

This thesis provides an in depth account of the backstage behaviour of the MDT members. Although an assessment of which treatment is considered 'best' drives their discussion, there is often disagreement or uncertainty surrounding this assessment. On delivering the recommendation to the patient, this backstage work often remains hidden, contributing to problems when offering treatment choice. Even when a choice of treatment is acknowledged, the MDT faces barriers in delivering and supporting this in the MDT clinic. For the patient, the majority of the work of decision making takes place away from the MDT clinic, a process which is not always supported by the MDT

The difficulties of actively involving patients in the MDT decision process have never been explored, but the complexities of offering treatment choice in the MDT need to be recognised to support patients in this setting. The guiding principles, purpose and limitations of the MDT meeting and the resultant treatment recommendation need to be

clear. A process of collaborative MDT decision making should allow effective communication of treatment risk and uncertainty, structured elicitation of patient preferences and support for patients to make decisions in line with their preferences and values.

For Preet, Cameron and Leela

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Chapter 1: Head and Neck Cancer

Head and neck cancer (HNC) is a group of tumours which may arise from multiple anatomical sites. In this chapter I provide an introduction and overview of the disease, how it presents and how it is investigated and staged. I then discuss the multiple treatment options which are available to patients and clinicians, the trade-offs associated with radical treatment and the difficulties of engaging patients in treatment decisions which make this disease uniquely challenging.

1.1 Definition

HNC is a large group of cancers originating from sites including the voice box (larynx), throat (oropharynx, hypopharynx and upper oesophagus), mouth (oral cavity), nose (nasal cavity, sinus and nasopharynx) and salivary glands. Over 90% of HNC are squamous cell carcinomas (SCC) (DAHNO 2011).

1.2 Epidemiology

The World Health Organisation estimates that worldwide there are 560,000 new cases of HNC each year, and 300,000 deaths (WHO 2008). In 2011 there were an estimated 7354 new cases in the UK DAHNO 2011 with incidence rates in England varying from 0.39 per 100,000 population for nasopharyngeal cancer (208 cases per year) to 3.01 per 100,000 for laryngeal cancer (1729 cases per year) (OCIU 2010). Depending on the site of the disease, the male:female ratio varies between 2:1 and 15:1. Most patients are older, with 98% of cancers being diagnosed in the over 40s, and 50% in the over 60s (Mehanna *et al.* 2010). The recent rise in the incidence of disease secondary to human papilloma virus (HPV) infection (discussed later) has led to HNC being diagnosed more commonly in younger patients (Mehanna *et al.* 2010; OCIU 2010). HNC is more

commonly diagnosed in patients with characteristics associated with lower

socioeconomic status such as unemployment or lower educational attainment, but much

of this difference is due to increased rates of smoking (Conway *et al.* 2010a; Conway *et

al.* 2010b).

1.3 Risk Factors

Tobacco and alcohol use account for around 75% of cases of HNC. Their effects are

not isolated but multiplicative (Mehanna *et al.* 2010). Smoking alone has a clear dose-

response relationship for the frequency, duration, and number of pack-years of cigarette

smoking. When drinkers are compared to never-drinkers, people who take more than

three drinks per day have twice the risk of pharyngeal and laryngeal cancer (Hashibe *et

al.* 2007); this effect is found to be more pronounced if drinking beers and spirits than if

drinking wine (Purdue *et al.* 2009). A family history of HNC in first-degree relatives,

especially siblings, also increases the risk of HNC (Negri *et al.* 2008).

Despite an overall decline in the incidence of all head and neck cancers in recent years

(NCI 2013), in the UK, the incidence of oropharyngeal tumours has increased by 51%

(CRUK 2013). This rise is thought to be a consequence of the increased incidence of

tumours secondary to HPV infection. There has been a significant increase in the

proportion of oropharyngeal cancer biopsies which show evidence of HPV (Nasman *et

al.* 2009). HPV related HNC is viewed as a distinct disease entity which has a better

prognosis (Fakhry *et al.* 2008; Worden *et al.* 2008) however smoking decreases survival

in oropharyngeal cancer, and this effect is independent of the HPV status. This means

that patients with HPV positive disease who smoke have a similar survival to those with

HPV negative disease (Gillison *et al.* 2012). Sexual transmission is considered to be

the primary route of HPV transmission – there is an increased rate of oropharyngeal

cancer in those with a history of six or more lifetime sexual partners, four or more lifetime oral sex partners or an earlier age at first sexual intercourse (Heck *et al.* 2010). The emergence of HPV related disease has cast doubt over previous research in oropharyngeal SCC which did not stratify for HPV infection. Additionally there has been debate about a standardised test or cut-off point for reliably detecting HPV in oropharyngeal biopsies and specimens (Mehanna *et al.* 2010), with the most widely used methods being in situ hybridisation and identification of p16, a downstream product of HPV expression (Singhi and Westra 2010). Although HPV testing is now routinely used in HNC practice, there is limited evidence that these patients should have substantially different treatment regimens to non-HPV patients (Mehanna *et al.* 2010) and trials for optimal treatment are ongoing.

1.4 Presentation

UK Guidelines from the National Institute for Health and Clinical Excellence (NICE 2005) state that patients should be referred for specialist assessment if they have more than three weeks' of symptoms of sore throat, hoarseness, difficulty swallowing, lump in the neck or unilateral ear pain. Doctors should also refer if they find a persistent red or white patch in the mouth, oral ulceration, cranial nerve palsy or effusion in the ear. Patients in the UK who fit these criteria are referred for an urgent specialist opinion via the two week wait rule (NICE 2005). Once referred, patients are assessed by full history, examination and a flexible nasolaryngoscopy. Formal endoscopy under general anaesthetic for examination of the site and biopsy is arranged if cancer is suspected, and all patients have a CT and/or MRI scan to improve the accuracy of tumour staging (Mehanna *et al.* 2010).

1.5 Investigation and staging

All head and neck tumours are graded using the tumour, nodal status, metastases (TNM) grading system (AJCC 2010). The tumour (T) stage concerns the size, position and local invasion of the tumour, and is graded between T1 (small tumours) and T4 (large, invasive tumours). HNC is locally invasive, and commonly spread via lymph. The nodal (N) stage depends on the number, position and size of the lymph nodes that the cancer has spread to and is graded between N0 (delineates no detectable spread to lymph nodes) and N3. Patients with HNC rarely have a distant metastasis at first presentation. If no metastasis is present, the tumour is graded M0, if the cancer has spread to distant structures (most often the lung) it is graded M1.

Pathological features which are associated with a poorer survival are histological grade of the cancer, pattern of invasion, proximity of the surgically resected cancer to the resection margins and presence of extranodal spread (RCP 2005). Extranodal spread is spread of the cancer through the outer capsule of an affected lymph node; this more than halves a patient's chance of surviving five years (Dunne *et al.* 2006). Concomitant disease also leads to a poorer prognosis, with this effect being more pronounced in younger patients. Additionally, comorbidity is associated with a higher incidence of complications following treatment, and a poorer quality of life after treatment has finished (Paleri *et al.* 2010).

1.6 Treatment

The survival associated with HNC varies globally (WHO 2008), but in the UK, the five year survival is around 65%. Just over 20% of patients die within a year of treatment and 30% die within two years (DAHNO 2011). Curative treatment of HNC is difficult

to achieve, and often requires radical treatment regimens which have profound effects on a patient's quality of life, most notably swallow and voice function. Good quality, randomised evidence to guide treatment decisions is severely lacking. Treatments can be broadly divided into surgical and non-surgical regimes. I shall divide the discussion of treatment into early disease and advanced disease and focus on laryngeal and pharyngeal cancer.

1.6.1 Early disease

Early cancers of the larynx and pharynx were traditionally treated with radiotherapy or cold surgical excision, however the management of early cancers has been revolutionised by the advent of laser surgery. In early oropharyngeal cancer, evidence comparing the use of laser with radiotherapy is lacking, but survival is thought to be similar (Robson and Paleri 2010). Evidence supporting the use of laser in early pharyngeal cancer is limited mainly to retrospective case series (Grant *et al.* 2009; Karatzanis *et al.* 2010).

In early laryngeal cancer, a recent Cochrane review found there to be no good quality randomised controlled trials available comparing mortality, disease-free survival, quality of life or voice outcomes for laser resection or radiotherapy (Dey *et al.* 2002). Clinical practice has been informed by a number of case series and other non-randomised research (Hirano *et al.* 1985; Ton-Van *et al.* 1991; McGuirt *et al.* 1994; Keilmann *et al.* 1996) which suggest that survival is similar between the two treatments, but with a different side effect profile and a slightly better voice outcome with radiotherapy (Higgins *et al.* 2009). Treatment pathways between the two options are also very different; radiotherapy involves travelling every day to hospital for treatment for 4-6 weeks, whereas laser surgery can be performed in one day. This difference in

treatment process is one of the main barriers to recruitment to randomised trials and the most recent attempt to conduct a UK randomised controlled trial failed as a result (Hamilton *et al.* 2013).

1.6.2 Advanced disease

In advanced disease, single modality treatment is generally associated with a poorer survival (1991; Bhalavat *et al.* 2003) but improved quality of life (Bjordal *et al.* 2001). Patients are usually treated with a combination of surgery and radiotherapy or radiotherapy and chemotherapy. Often, the choice between radiotherapy, chemoradiotherapy and surgery, on the face of it, seems simple: surgery has obvious detrimental effects on speech and appearance, whereas radiotherapy allows the patient to retain their voice box and produce speech normally, and the addition of chemotherapy increases survival. Survival (1991) and quality of life (Hanna *et al.* 2004) are reported to be the same between the two treatment options. However, the choice of treatment in advanced disease necessitates trade-offs between survival and function with the treatment selected affecting aesthetics, communication, nutrition and psychosocial functioning.

Radiotherapy to the larynx or pharynx allows preservation of the voice box which has the obvious benefits of improved cosmesis and normal speech production. Dry mouth can be one of the most troublesome side effects, but is significantly reduced by the use of intensity modulated radiotherapy (IMRT) (Nutting *et al.* 2011). Although other methods of delivery of external beam radiation such as accelerated or hyperfractionated radiotherapy have shown improvements in local tumour control (Fu *et al.* 2000), the lack of effect on overall survival, and the increased local toxicity have meant they have not been adopted widely in the UK. Survival is increased if chemotherapy is added to

radiotherapy (Pignon *et al.* 2000; Bonner *et al.* 2006), as is the rate of organ preservation (Lefebvre 2006). Survival is also increased for post-surgical patients who have positive resection margins or extracapsular lymph node spread, who go on to be treated with a combination of cisplatin and radiotherapy (Bernier *et al.* 2004; Cooper *et al.* 2004). However, radiotherapy has significant side effects which are dose dependent and worsened when combined with chemotherapy (Abendstein *et al.* 2005). The main short term side effects include skin reactions, inflammation of the lining of the mouth and throat and infection; in the long term pharyngeal stenosis leads to difficulty swallowing and laryngeal scarring causing hoarse voice. In the most severe cases this may lead to a requirement for tracheostomy. Difficulties with teeth and oral hygiene, mouth opening, dry mouth or sticky saliva (Abendstein *et al.* 2005) may be severe and debilitating. Difficulty swallowing is now recognised as one of the major side effects of non-surgical management (Wilson *et al.* 2011) and many patients require supplementary enteral feeding or nutritional assistance with permanent gastrostomy or naso-gastric tube (Moor *et al.* 2010; Paleri and Patterson 2010). Severe late radiation toxicity can be present in as many as 82% of patients at 5 years and may result in dry mouth, scarring of soft tissues and osteo-radionecrosis of the mandible (Denis *et al.* 2003). In the Radiation Therapy Oncology Group 91-11 trial, 82% of patients treated with radiotherapy and cisplatin-based chemotherapy experienced a severe toxic effect (Forastiere *et al.* 2003).

There are many potential surgical treatments of advanced HNC and a lack of consensus amongst clinicians about how much functional loss is considered 'unacceptable' to achieve complete resection of the tumour (Kreeft *et al.* 2009). Large resections are commonplace, and microvascular free flaps are often used to improve post-operative function, cosmesis and quality of life (Schliephake and Jamil 2002; Genden *et al.* 2003).

Advanced oropharyngeal cancer is traditionally treated with radiotherapy (Forastiere and Trotti 1999; Finnegan *et al.* 2009) which is thought to produce improved functional outcomes (Parsons *et al.* 2002), however there are many advocates of surgery for these tumours (Rich *et al.* 2009; Haughey *et al.* 2011). Again, decision making in advanced oropharyngeal cancer is limited by a lack of good quality, randomised, supportive evidence, leaving the choice of optimal management open to debate.

In advanced laryngeal cancer, the standard of care was traditionally complete removal of the voice box (total laryngectomy). Total laryngectomy renders the patient a neck breather with a tracheal stoma in the midline of the lower part of the anterior neck. This has obvious cosmetic consequences, but can also cause problems with mucus production, crusting, sputum production and daily activities (in particular bathing and swimming). After total laryngectomy, a patient speaks by occluding the stoma with a finger or thumb and forcing air through a one way valve, surgically created between the tracheal stoma and the gullet, thus creating a voice. Total laryngectomy patients are now offered primary surgical voice restoration, and their voice scores have been shown at least in one series to be no worse than those of patients with mild functional voice dysfunction referred to voice clinics (Robertson *et al.* 2012). Surgery also has significant potential complications: due to comorbidities, many patients pose a significant anaesthetic risk. Post-operative infection rates can be as high as 20-40% (Liu *et al.* 2007; Varghese *et al.* 2009). The advent of chemoradiotherapy means that

surgery is increasingly being undertaken on previously irradiated patients, a situation which leads to a fistula[1] rate of up to a third (Weber *et al.* 2003).

Almost 30 years ago, McNeil *et al* (1981) published a study scrutinising the trade-off between quantity and quality of life faced by patients with T3 laryngeal cancer. They performed a simple time trade-off between speech and survival asking small groups of firemen and executives how many survival years they would "trade-off" in order to maintain a near normal voice with non- surgical management. The premise of the utility analysis presented to participants, none of whom was a laryngeal cancer sufferer, was that radiotherapy was associated with a poorer survival, but a better voice. Using expected utility theory they suggested that on this basis, 20% of healthy controls would opt for the non-surgical management. The results of this work were widely accepted by the clinical community and so began a sea change in clinical opinion. Today, the standard of care for the treatment of advanced laryngeal cancer is radiotherapy with or without chemotherapy (Paleri and Roland 2011).

Practice has been heavily influenced in laryngeal cancer by large randomised controlled trials comparing surgery and radiotherapy and chemotherapy. The first of these, conducted by the Department of Veterans Affairs Laryngeal Cancer Study Group showed similar short term survival between radiotherapy and TL (1991). However,

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[1] A fistula is a communication between the larynx, pharynx or oral cavity and the neck tissues or skin surface which causes leakage of saliva and has obvious cosmetic consequences.

only estimated survivals for 2 years were ever reported and informal data presentation suggests a longer term surgical survival advantage, which failed to achieve statistical significance due to sample size attrition (Wolf 2010). Subsequently, the concurrent administration of chemotherapy was found to provide an added survival advantage to radiotherapy alone (Forastiere *et al.* 2003). Again, analysis of the long-term survival results shows that the concurrent chemoradiotherapy group had a lower overall survival, although many of these deaths were not attributable to larynx cancer (Forastiere *et al.* 2013). This led some recently to advocate the selection of patients on the basis of response to a single dose of induction chemotherapy, a strategy which has demonstrated encouraging results (Urba *et al.* 2006). Survival in laryngeal cancer has been found to be decreasing in the United States in the past two decades, coinciding with the steady increase in the use of non-surgical treatments (Hoffman *et al.* 2006). It is hypothesised by a number of authors that survival may be higher in those patients who are treated surgically (Hashibe *et al.* 2007; Olsen 2010; Dziegielewski *et al.* 2012), but the difference may be insufficient to support the performance of further substantive, randomised comparisons. Thus some recent commentators argue that we should extrapolate the results of early, closely controlled trials to the general patient population with caution (Olsen 2010).

As a result of these findings, recent research has now come to focus on quality of life as a treatment outcome (Abendstein *et al.* 2005; Rogers *et al.* 2007) and even as a predictor of survival (Mehanna and Morton 2006). Treatment for advanced HNC has profound effects on a patient's quality of life, especially their voice and swallow function. Quality of life is greatly reduced during treatment and starts to improve about 3 months following this. This improvement in quality of life persists until around two years, at which point there is no further improvement (Bjordal *et al.* 2001); in fact there

may be a further deterioration in quality of life in the long term (Mehanna and Morton 2006). Despite the obvious difference in treatment regimes, quality of life does not seem to be significantly different for patients treated surgically and non-surgically in early (Goor *et al.* 2007) or advanced disease (List *et al.* 1996; Hanna *et al.* 2004); however, this population based data may obscure wide variations between individual patients. Quality of life is significantly reduced in those patients who have salvage surgery after the failure of non-surgical treatment (Weber *et al.* 2003).

So far in this chapter, I have outlined the complexities of treatment choice in HNC. Many treatments, especially in advanced disease, have a limited chance of survival and a profound effect on many aspects of a patient's quality of life. For this reason, information giving is an important part of involving patients in decisions about their care and preparing patients for the treatments which lie ahead. In the next section, I discuss the difficulties in delivering information effectively, and through this, outline some of the initial challenges of patient involvement in decision making.

1.7 Patient information about treatment

The diagnosis of and treatment for HNC is known to cause significant psychological morbidity (Rapoport *et al.* 1993; de Leeuw *et al.* 2001) which can persist in the long term (Bjordal and Kaasa 1995). Psychological distress is almost three fold more than that found in other cancers (Singer *et al.* 2011). Anxiety levels are associated with the ability to cope (Elani and Allison 2011) which in turn can be affected by degree of perceived control (de Maddalena and Zenner 1991; Dropkin 1999). Quality of life has been considered as the extent to which "the hopes of an individual are matched and fulfilled by experience" (Calman 1984, page 124-125). In this paper, Calman argued that to improve quality of life, health care professionals should "narrow the gap between

a patient's hopes and aspirations and what actually happens" (ibid, page 125). Through

tailoring information to the individual, the mismatch between unrealistic expectations

and experience could be narrowed thus potentially improving outcome.

The expectations that patients have about their treatment are largely based on the

information that they receive. In a qualitative study of 15 HNC patients, treatment

expectations were clearly linked to the information given by health professionals before

therapy began. Participants described a 'knowledge gap' between a full understanding

of what was going to happen and what information can convey (Llewellyn *et al.* 2005).

In turn, expected symptom severity rated before oral surgery was the primary predictor

of symptom severity immediately post-operatively and at follow up. Pre-operative

expectations predicted not only symptom severity, but also psychological distress, speed

of return to work and healing ratings after oral surgery (McCarthy *et al.* 2003). The

perception of adequate information from the specialist can be associated with a better

long term rehabilitation outcome in laryngeal cancer (de Boer *et al.* 1995) and improved

quality of life in oropharyngeal cancer (Moore *et al.* 1996). Less satisfaction with

information provision pre-treatment has also shown correlation with lower emotional

functioning and higher levels of depression at follow up (Llewellyn *et al.* 2006).

Satisfaction with information is a significant predictor of quality of life in patients

undergoing radiotherapy for nasopharyngeal carcinoma. In a simple questionnaire

study, the score from the five item Medical Interview Satisfaction Scale (MISS)

questionnaire (a questionnaire designed to assess the satisfaction of a patient with a

consultation) was found to significantly predict the Functional Assessment of Cancer

Therapy, General Scale (FACT-G) score, suggesting that those patients who had more

satisfaction with the medical information provided had a better quality of life 4 months

later. This finding maintained significance when adjusted for disease stage (Yu *et al.* 2001).

The amount of information regarding surgery required by an individual patient varies enormously and patients express the need for information individualised to their particular case (NCA 2002; Newell *et al.* 2004; Llewellyn *et al.* 2005). The information received from professionals often does not reflect the diversity of their needs. This means that many patients turn to alternative sources of information to help them understand what they have been told. Patients report that they are ill-prepared for the functional changes associated with surgery (Newell *et al.* 2004) and express a requirement for more information on communication and swallowing, length of time in hospital, psychological adjustment (Newell *et al.* 2004), side effects and prognosis of surgery (Chen *et al.* 2009) financial support, access to support groups and how the treatment would affect quality of life and the ability to work (Llewellyn *et al.* 2006). After treatment for HNC, patient requirement for information changes, with the most common topics requested for discussion at follow up being fear of recurrence, dental health, chewing, pain and fatigue (Ghazali *et al.* 2013). Nonetheless, before treatment, clinicians often focus on the technical specifications of the operation (Edwards 1998). Patients report that they often have too little information or information that they cannot understand (Newell *et al.* 2004; Llewellyn *et al.* 2006). On the other hand, too much information about the effects of treatment may lead to a perceived fear and lack of ability to cope (Llewellyn *et al.* 2005). Half of the 82 HNC patients investigated by one group of researchers stated that they required more information than that provided pre-treatment. Post-treatment this figure had risen to two thirds, with 48% of patients reporting lower satisfaction with information post-treatment and in the follow up period than pre-treatment (Llewellyn *et al.* 2006). This may be because patients often prefer

verbal over written information, but verbal information diminishes during follow-up, as contact with clinicians becomes less frequent (Pollock *et al.* 2008). Patients often report a poor experience of involvement in their treatment decision and a large number of patients say that they were given no choice in the choice of treatment (Edwards 1998; Newell *et al.* 2004). Many patients feel that the choice of treatment is the responsibility of the doctor (Newell *et al.* 2004; Pollock *et al.* 2008), while others want to be more involved in decisions about their care than they are currently, but lack the requisite information (Edwards 1998).

An inherent problem with assessing the information needs of HNC patients is that the concept of information need is difficult to define. Various techniques are employed in an attempt to address this, resulting in an abundance of questionnaires assessing satisfaction with the consultation, treatment decision or information provision. Qualitative research allows a deeper understanding of the patient experience, but comparison and combination of study findings is difficult. When qualitative and quantitative techniques are used on the same cohort of patients at different time-points it is found that patients' claims of "satisfaction" with information was largely a result of the questionnaire methods rather than real, lived experience. Negative experiences gleaned through interview were not expressed adequately via questionnaire; in fact, it was suggested that "information satisfaction" holds little importance to patients who are facing life-threatening illness and treatment (Pollock *et al.* 2011).

1.8 Current practice

A nationwide survey of information giving prior to laryngectomy demonstrated a large variation in the information giving practices among different clinicians. Surgeons reported taking an average of 15 minutes to discuss the treatment options (range 1 to 45

minutes); all discussed the effect on voice and communication, but fewer discussed effects such as psychological sequelae (38%) and effect on relationships (22%); 84% of surgeon respondents discussed the diagnosis and treatment options at the same consultation; 79% agreed that there should be a second consultation to discuss treatment options, however only 64% reported its routine provision. Worse, 40% of the surgeons failed routinely to discuss cure and survival rates for the treatment available, possibly calling into question the quality and validity of the informed consent for the procedure (Stafford *et al.* 2001). Patients prefer their information to be delivered verbally by a health care professional (Pollock *et al.* 2008; Davies *et al.* 2010) and the relationship with the doctor and trust in their experience is an important part of the treatment decision making process. Patients often exercise a positive choice to delegate responsibility for the treatment decision to the doctor (Pollock *et al.* 2008; Davies *et al.* 2010; Pollock *et al.* 2011); however it is important that such delegation is not presumed by the clinician, nor used as a reason not to involve the patient in decisions regarding their care. In a focus group study of 33 HNC health-care professionals, most found it difficult to impart information in the limited time available. They agreed that, whilst patients should be involved in decisions regarding rehabilitation and palliative care, those about the choice of primary treatment were regarded as the province of the consultant in charge. Patients stated that they found talking to health professionals with experience of managing the disease helpful, but professionals often 'protected' their patient by underplaying the severity or longevity of side effects, leading to anxiety when the symptoms arise. Many patients are therefore steered towards a particular treatment course by the consultant (NCA 2002). This presents the patient and clinician with a difficult problem: the choice of treatment has profound effects on a patient's survival and quality of life, but there are barriers to effective information provision.

There is a dearth of good quality research to guide decisions and the choice of treatment is not a value free exercise: important trade-offs are faced between survival, speech and swallow.

1.9 Values and preferences

To make a decision on behalf of a patient a clinician assumes that they hold shared values and priorities for treatment. Gill *et al* (2011) argue that this is the case: in a small study of 30 patients, 30 companions and 25 members of the MDT, all groups ranked 'being cured of my cancer', 'living as long as possible', 'having no pain' and 'being able to swallow all foods and drinks' as their top priorities. However this finding is contested by many other groups: for example, when Mohide *et al* (1992) compared the treatment priorities of 20 HNC health care professionals and 20 patients, they did not match. Professionals rated communication, self-image and esteem as most important, whereas patients were more concerned about the physical consequences of surgery such as tracheal mucus production (Mohide *et al.* 1992). Other authors have found significant differences in ratings for the work and social functioning or pain (Grossman *et al.* 1991; Jalukar *et al.* 1998). A comparison of the views of patients who had undergone laryngectomy with those of health care providers found that more than twice the proportion of health care providers would compromise survival in order to preserve voice and quality of life compared to patients (Otto *et al.* 1997). In a similar study, 130 newly diagnosed stage II to IV HNC patients were asked to rank a series of 12 potential HNC treatment outcomes. As expected, three quarters of patients ranked "being cured" as the top priority of treatment, however one fifth ranked it as second or third. Rankings given were highly variable and generally unrelated to patient or disease characteristics, except for the perhaps unsurprising observation that older patients

generally placed a lower priority on cure and living longer, and a higher priority on avoidance of pain (List *et al.* 2000). When patient findings were compared with the responses given by non-patients, it was concluded that non-patients also valued survival highly; however patients were more likely than non-patients to accept aggressive treatment in order to achieve survival benefit (List *et al.* 2004). This is in agreement with another study of attitudes towards chemotherapy which demonstrated that a group of newly diagnosed cancer patients expressed willingness to undergo very aggressive chemotherapy with an extremely limited survival advantage. In contrast, non-patients, oncology doctors and nurses were much less likely to opt for such a treatment with the expectation of minimal gain (Slevin *et al.* 1990).

1.10 Decision making

The majority of the work around decision making in HNC thus far has concentrated on expected utility theory. One of the first applications of decision analysis to a clinical situation explored whether radical neck dissection was beneficial to patients with oral cancer with no local spread of disease (Henschke and Flehinger 1967). Paleri and Kelly (2008) constructed a decision tree for patients presenting with recurrent disease, analysing the decision between re-irradiation and chemotherapy and symptom palliation. One of the most widely quoted uses of expected utility theory was the work undertaken by McNeil *et al* (1981). In her study, 37 normal participants (firefighters and middle managers) were asked to "trade-off" years of survival against retaining a normal voice. The authors concluded that 20% of these volunteers would choose radiation to treat a T3 laryngeal tumour despite the treatment having a poorer survival rate than laryngectomy at the time. However, the primary aim of these studies was to assign utility values to HNC treatment outcomes. They draw on a 'normative theory' of

decision making, based on the philosophy that under ideal conditions, an individual will make the choice with the maximum expected utility: this however is arguably not a reflection of the real-life process of decision making for patient or clinician (Edwards *et al.* 2006). Thus, although they provide a useful insight into the trade-offs which HNC patients face when choosing treatment modalities, they do not provide significant insight into the actual process of decision making.

1.11 Conclusion

HNC is a broad term which incorporates cancers from multiple anatomical sites. A diagnosis of HNC is often associated with a poor prognosis and almost a third of patients will die of their disease within two years. Not only this, but successful treatment may cause persistent and debilitating effects on swallow, voice and quality of life: patients and clinicians are therefore forced to trade-off function against survival. Research underpinning the effectiveness of the treatments available is open to criticism, interpretation and debate. The patient population are often long term drinkers, with concomitant health problems and lower educational attainment, presenting patients and clinicians with a unique challenge in effectively engaging patients in treatment decisions. This combination of factors makes treatment decision making in HNC fraught with difficulty. The requirement for patients to contribute to decision making seems clear: many decisions are based on values and attitudes to survival and quality of life, but when the values of patients and clinicians are compared, they differ. Although the provision of treatment related information is related to patient expectations and quality of life, there are significant challenges in delivering information to patients which is effective and individualised. Some patients express a requirement for more of a role in the treatment decision, whereas others actively delegate the responsibility of

decision making to the clinical team. Thus, the degree of desired involvement in decision making varies from patient to patient, and this should be acknowledged in the decision making process. In the next chapter I shall describe the increasing role of the patient in treatment decisions and outline the rationale for effective patient engagement in healthcare decision making.

Chapter 2: Decision Making in Healthcare

The relationship between doctor and patient is complex (Ong *et al.* 1995) and has been the subject of many reports (Roter and Hall 1992). In cancer management, treatment decisions can have far-reaching effects on survival and quality of life. As I discussed in the previous chapter, HNC in particular presents the patient and doctor with multiple, complicated treatment options and little high-quality research evidence to act as guidance. Not only does this make treatment choice difficult; it also places further importance on effective communication and decision making between clinician and patient.

In this chapter, I discuss how treatment decisions are made in medicine. Through the course of the chapter, I do not aim to give an in depth view of all of the different types of physician-patient encounter, as these are discussed in detail elsewhere (Emanuel and Emanuel 1992). I shall provide a history of the rise of patient involvement in healthcare decisions, as well as the drivers for this. I will then define and discuss shared decision making (SDM) and its use in making healthcare decisions.

2.1 Paternalism

Since the era of Hippocrates there has been a generally accepted view that doctors make decisions on behalf of their patients; they decide what is in their best interests, and patients are sometimes informed of these decisions. "The old Hippocratic ethic saw the patient as a weak, debilitated, childlike victim, incapable of functioning as a real moral agent" (Veatch 1987, cited in Miles 2009, page 1322)

The description of the paternalistic model of decision making emerged from the account of the "sick role" (Parsons 1951). In this, Parsons viewed the doctor-patient

relationship as one which is similar to that between parent and child. The temporary sick role status is granted to the patient and its award involved both rights and obligations on the part of the patient. The patient is excused from usual responsibilities and duties, including family and work, but must attempt to return to health by seeking medical help and complying with the recommendations of the physician. Although there are examples of this role in society today, this model does not serve modern medicine well. We attend our doctors for many things other than solely when we are ill (e.g. pregnancy, disease screening) and many chronic conditions cannot be assumed to be temporary (Maguire 2002).

However, the paternalistic model of healthcare decision making was widely practiced. In this model, the physician, on behalf of the patient, assessed the stage and degree of disease, and formulated a treatment plan which he believed was most likely to lead to cure of, or improvement in the condition. The amount of patient involvement in this process varied, from being delivered selected information to enable agreement and consent, to where the clinician "authoritatively informs the patient when the intervention will be initiated" (Emanuel and Emanuel 1992 page 2221). It was assumed, for this model to be successful, that the physician was knowledgeable and up to date, leading to the correct treatment being applied consistently to patients with the same problem. Physicians were considered to be best placed to evaluate the trade-offs and pitfalls of treatment, and applied these to the decision process based on their evaluation of the best interests of the patient (Charles *et al.* 1999).

There are situations where it is still appropriate to employ the paternalistic decision making model. It is often used in emergency situations, or when the patient is unconscious or cannot make their wishes known. As medicine has evolved, however,

its shortcomings have been exposed (Charles *et al.* 1997). This model cannot adequately incorporate the wishes and autonomy of a patient, and to practice using paternalism assumes that that the physician and patient place the same value on clinical outcomes (Deber 1994). Although paternalistic decision making relies on the beneficence of the physician, physicians may give limited information in order to influence the patient to agree with their assessment of best interests (Emanuel and Emanuel 1992). Not only this, but there have been several driving forces to increase the role of the patient in the medical encounter away from that of a passive recipient. In the following section, I shall discuss in turn the major influences on increasing patient involvement in decision making.

2.2 Evolution of medicine

Modern medicine has witnessed an explosion in the number of treatments available for existing conditions and an increase in the number of conditions for which treatments may be administered. For example, it has been long recognised that a profoundly elevated blood pressure is damaging to health, however the increased cardiovascular risk associated with mild to moderate hypertension have only been more recently realised (Kannel *et al.* 1972). Hypertension is usually asymptomatic and gives sufferers an increased risk of future negative health events. Treatment options were once limited but now there is a huge number of drugs available, organized into five main classes. Published guidelines are complicated, stratifying patients by age and comorbidity (NICE and BHS 2011), and have, over time, recommended treatment of increasing proportions of the population (Thomson *et al.* 2005). The development of guidelines however creates a bias towards effectiveness and places less importance on adverse effects. Clinical practice guidelines may rarely take account of patient preferences

(McAlister *et al.* 2000; Thomson *et al.* 2005; Joyce *et al.* 2013), or not concentrate on outcomes which are important to patients (Joyce *et al.* 2013). Even when published, the content and recommendations of the guidelines are often the subject of scrutiny and debate (Sofat *et al.* 2012). Thus a consultation deciding on the appropriate treatment for a hypertensive patient involves complex skills in clinical evaluation, critical appraisal and risk communication. Each potential treatment has effects on mortality and morbidity, making an assessment of 'best' far more complex. If guidelines' recommendations are applied without consideration of patient preference, a large proportion of patients may receive treatment which is not in line with their preference (Protheroe *et al.* 2000). Guidelines which take into account the values of the patient for complex decisions can be more responsive to the individual preference of the patient (Thomson *et al.* 2000). Despite this, professionals often feel pressure to adhere to them (Matlock *et al.* 2011) which has led to suggestions to adapt guidelines to include the patient more effectively (van der Weijden *et al.* 2013), or even be developed in conjunction with decision support tools (van der Weijden *et al.* 2012).

2.3 Variation in care

Wide geographical variation in the treatments administered for common medical conditions have previously been noted (Roos 1984; Chassin *et al.* 1986) and this variation was often found to be independent of population and disease characteristics. Wennberg described this as 'unwarranted variation' as it cannot be explained by illness or patient preference (Wennberg 2010). Although this variation is dependent on geography to an extent, it is more dependent on clinical uncertainty related to the outcome of the treatment (McPherson *et al.* 1982). Unwarranted variation in care is particularly evident in 'preference sensitive' decisions: those which have more than one

generally accepted treatment option, such as elective surgery. Unwarranted variation can be significant; the rate of knee replacement can vary by a factor of 4.7 and the rate of mastectomy by 7.3 across regions of the United States. In England the rate of variation is lower but occurs in procedures such hysterectomy or hip or knee replacements (Wennberg 2011). The UK Atlas of Variation documents variation across a range of outcomes in England: for example the length of admission following an elective breast procedure has a six-fold variation across the country (RightCare 2011). Policy makers and clinicians have attempted to reduce this variation in care by tackling clinical uncertainty. Research is performed to quantify and measure clinical outcomes and these are then used to produce management guidelines with the intention of standardising disease treatment. Although this seems to makes sense, it is not wholly effective. When producing a practice guideline based on research on clinical outcomes, the importance that a particular patient places on that clinical outcome and its risks and consequences may be ignored (Joyce *et al.* 2013) and therefore variation may persist as a result. For example the rate of surgery for benign prostatic hypertrophy is not dictated by the severity of symptoms, rather by the extent to which the patient is troubled thereby (Barry *et al.* 1995). Also, in a population study of 2,128 individuals, time to joint replacement was more strongly predicted by "willingness to consider surgery" than symptom severity (Hawker *et al.* 2006). Clinical guidelines may act to mask the uncertainty which often underlies the treatment decision for many conditions (Mulley 2009), which clouds risk communication. Not only this, but whilst central planning and delivery of healthcare might be expected to reduce variation across countries, this is not the case (Westert *et al.* 2010). Rates of tonsillectomy are particularly affected by variations in care, famously noted by Glover in 1938 (Glover 2008). The publication of guidelines based on ample good quality evidence (SIGN 2010) clearly outline the risks

and benefits of intervention but have failed to eradicate the variation in operation rate which persists over 70 years after the publication of Glover's findings (Burton 2008; Suleman *et al.* 2010).

If healthcare delivery variation cannot be explained by difference in disease patterns, geography or patient population alone, it must represent unwarranted variation in clinical practice between regions. If the balance of power in the treatment decision lies with the healthcare provider, then this variation will persist (Wennberg 2010). Ideally, variation should depend on the clinical characteristics of the population and the attitude and preferences of the patient (Wennberg 2011); so called warranted variation. The use of decisions aids significantly changes the rates of intervention across a broad range of conditions (Mulley 2009). Thus informing and empowering patients by involving them in decisions about their care should act to lessen this clinician-driven unwarranted variation in care.

2.4 Legislation

The increasing recognition of the role of patients in the medical consultation has gradually been recognised by the legislative and regulatory authorities. In June 2008 the General Medical Council (the regulatory body for UK doctors) changed the guidance on informed consent. The old booklet "Seeking patients' consent: the ethical considerations" (GMC 1998) was replaced with "Consent: patients and doctors making decisions together" (GMC 2008). The guidance extended the concept of consenting patients beyond informing patients of the alternatives, risks and benefits of interventions and instead instructed doctors to work in partnership with patients and "maximise patients' opportunities, and their ability, to make decisions for themselves" (ibid, page 6). In the same way, successive governments have placed more and more emphasis on

patient choice, culminating in the recent proposed NHS reforms championing "No Decision About Me Without Me" (DoH 2010A; DoH 2010B). These documents not only support the involvement of patients in decision about their care, but recommend a wholesale change of culture of the NHS where patient involvement in every decision is ingrained as routine practice. Implementation of such recommendations requires more than documents alone: for culture change to come about the traditional view of the doctor patient relationship is challenged. For this reason, implementation is slow, as it is difficult to embed patient involvement into routine practice (Elwyn *et al.* 2010). Professionals and clinicians may need to be incentivised to involve patients or the quality of decision making should be measured to provide feedback (Coulter and Collins 2011). Each approach faces challenges, however, not least the difficulty in defining and measuring decision quality (discussed later). Nurses and doctors sometimes feel that they are already involving their patients in decisions (Gravel *et al.* 2006) and hence that there is no need to change; however, this view is not always echoed by the patients they treat (Stevenson *et al.* 2000). Nevertheless, real implementation of patient involvement in all treatment decisions requires effective leadership, good quality care commissioning and substantial investment (Elwyn *et al.* 2010).

2.5 Patient preference

One of the main driving forces behind greater patient involvement in the medical encounter has come from the patients themselves (Stevenson *et al.* 2004). Patients expressed an unmet need for information about their care and value information about treatment choices (Waitzkin 1984; Beisecker and Beisecker 1990; CQC 2010).   This strong desire for information was independent of the socioeconomic status of the

patient, and the need for health information appeared less dependent on patient factors than on situational factors, such as the length of consultation and the cues from the doctor (Haug and Lavin 1979; Beisecker and Beisecker 1990), all of which were modifiable in the consultation. Bringing a patient viewpoint into the consultation involved two separate but interlinked concepts: patient information about the disease and treatments, and patient involvement in the treatment decision. These two concepts were not always correlated and at first it seemed there was a need for one and not the other. Ende *et al* (1989) measured patient preference with a scale of 0 to 100, where 0 is very low, 50 a neutral attitude and 100 a very high preference. Their 303 patients reported a mean score of 33.2 +/- 12.6 with regard to involvement in the treatment decision, however they expressed a higher information requirement of 79.5+/-11.5. It was also found that the level of preferred involvement in decisions decreased with increasing severity of the illness. This work was supported by others: in a study of 210 patients with hypertension, 47% felt that they preferred the clinician to make the therapeutic decisions, 31% felt that the clinicians should make the decision after taking an opinion from the patient and 19% felt that decisions should be made on an equal basis (Strull *et al.* 1984). This was supported by work performed in college students (Krantz *et al.* 1980) and low income diabetes sufferers (Pendleton and House 1984). Even if patients did express a desire to be involved in medical decisions, this failed to predict their actual behaviour in the consultation (Haug and Lavin 1981). Larsson showed that 73% of patients were as involved in decisions as much as they wished to be (Larsson *et al.* 1989).

It would be simple to conclude from this research that although patients were expressing a need for information about their disease process, the majority were happy for the doctor to lead the decision process. This conclusion however has its flaws: in order to

understand the issue of patient participation in the consultation, it must be clear what "participate" means. Two processes are required in order to make a decision: "problem solving" and "decision making". Problem solving requires the doctor to know the problem, and have knowledge of the options which are available to solve it. Decision making requires the ascertainment of values and preferences to decide which of the options is preferred for that specific patient. Patients often cannot be involved with the "problem solving" stage – they will not be aware of the range, effectiveness and associated morbidity and mortality of the treatment options available, but they could be central to the "decision making" (Deber 1994). A variation on this model was also described by Eddy: he divided the consultation into two stages, an "objective" stage where the treatment options are presented and the prognosis, mortality, morbidity and risk associated with the options are discussed. This is followed by the "subjective" phase, where the values and preferences of the patient are discussed in order for a decision to be made (Eddy 1990).

In more recent years, patients have expressed an increasing (often unmet) requirement for involvement in treatment decisions. One in three patients in primary care and one in two following inpatient hospital treatment state that they would prefer more engagement in decisions about their care (Garratt and Boyd 2008; Martin 2008). In a large, qualitative study of HNC patients and professionals, Edwards found that most patients wanted to be more involved in the decisions about their care than they currently were (Edwards 1998). Not only this, but patients' perception of their own involvement does not always correlate well with that observed by researchers (Martin *et al.* 2003); some patients felt that they had been involved in the decision process but were not given a menu of options or did not significantly influence the course of action (Beaver *et al.* 2005). In a study videotaping consultations, doctors appeared poor at eliciting the

concerns or priorities of the patient, and even when elicited, these were often not acted upon (Campion *et al.* 2002). Importantly, this is not to argue that all patients want more involvement in decisions about their care; more that desire for involvement is individual, and thus varies from patient to patient. Indeed, desire of a patient to be actually involved (so called 'meta-preference') varies according to many patient characteristics such as age, education, experience of ill health and relationship with the clinician (Say *et al.* 2006). Hence if treatment decisions are to be patient centred, clinicians must be able to respond to this variation and adapt the decision process accordingly.

2.6 Variations on paternalism

Waterworth and Loker (1990) expressed concern that involving patients in decisions may be inadvertently forcing them to "toe the line" in order to please the practitioner, and therefore patient involvement should be resisted. This gave rise to forms of "sensitive paternalism" (Deber 1994) where the patient actively gives permission for the practitioner to make a decision on their behalf ("paternalism with permission") (Cross and Churchill 1982) or the practitioner makes the decision, and then provides the patient with information about the benefits, risks and alternatives in order to allow them to potentially withdraw permission. Hence, although sensitive paternalism seems to increase the amount of information conveyed to a patient, it does not allow active participation in the decision making process (Deber 1994). To achieve decision participation, patients need to have knowledge not only of the option being presented, but alternative options, as well as the uncertainty which may underpin the decision (Birke *et al.* 1990).

The driving forces which I have outlined so far in this chapter meant that the importance of involving patients in decisions was beginning to be recognised. In breast cancer, Ashcroft was one of the first to look at not only the psychological impact of choice of treatment, but also the effect that patient choice had on this, providing a clinical psychologist to guide patients through the decision process. It was noted that the feeling of personal control over outcome was expressed by the participants as being important and concluded that:

> The best predictor of a good psychological adjustment to breast cancer treatment is to establish, before surgery, the importance to the woman of a complete body image. Treatment, preferably with consultation with the patient herself, can be adjusted accordingly (Ashcroft *et al.* 1985 page 45, 46).

This was echoed by work in 1988 which concluded that patient involvement in the choice of treatment had greater relevance to the psychosocial outcomes than the type of operation performed (Morris and Ingham 1988). Much of the debate centred on whether a patient should be involved in healthcare decisions and, if they were involved, how much of a role should they have and how this should be achieved.

2.7 Informed choice

It has been proposed that patients should have complete control over the decision, sometimes described as informed choice. The patient overcomes the problem of information deficit by receiving information, and therefore is able to make the decision alone and no longer needs to share the process or have decisions made for them (Levine *et al.* 1992). In this model, the physician's preferences for the treatment options do not come into the discussion and the decision relies on information provision as the sole basis of the decision making process. Although this means that a patient is better informed, patients may not necessarily want all the responsibility for the decision (Ende

et al. 1989; Beisecker and Beisecker 1990). Informed choice allows control for patients

if they choose to assume the role of "agent" (Bishop and Yardley 2004), but is

problematic as it assumes the patient is a "rational actor" in the relationship – due to the

emotional and complex nature of the decision, this is not always the case.

Thus began an endeavour to shift the paradigm of the physician/patient encounter,

striving to construct a model of decision making which is positioned between the poles

of paternalism and informed choice. The constant difficulty faced was the power and

information imbalance between patient and physician summarized well by Hurley:

> The crux of the information problem is that while the health care
> provider possesses better knowledge regarding the expected
> effectiveness of health care in improving health status, the individual
> knows best how improvements in health status affect his or her well-
> being (Hurley *et al.* 1992 cited in Charles *et al.* 1997, page 683)

2.8 Sharing decisions

In order to resolve the power imbalance and encourage a mutual style of decision

making between doctor and patient, shared decision making (SDM) was first

conceptualized by Charles and Gafni (Charles *et al.* 1997). SDM allows the patient

choice and information about the treatment option which they prefer and the doctor a

role of transferring information and participation in, but not domination of, the decision

process. In the next section I discuss theory and practice of SDM as a model of health

care delivery, and present the evidence for its effectiveness.

2.9 Shared Decision Making

2.9.1 Definition

The precise definition of shared decision making (SDM) is subject to debate (Makoul

and Clayman 2006), and the terminology used to describe the involvement of patients in

decisions about their health range from consumerism, informed decision making, through patient-centred care and partnership to informed consent and autonomy (Edwards and Elwyn 2009). The definition of SDM is not merely semantic; a lack of understanding of what exactly SDM means and how it is carried out can stand in the way of implementing it in practice and studying its effectiveness (Mead and Bower 2000A; Mead and Bower 2000B). The most widely accepted conceptualization was the original description by Charles *et al* (1997) who described a decision which had involvement of both the patient and the doctor, a sharing of information by both parties to achieve a consensus and resultant agreement about which treatment to implement. In simpler terms, SDM is "involving the patient in decision making to the extent that they desire" (Edwards and Elwyn 2006 cited in Edwards and Elwyn 2009 page 5). In the original description of SDM, the steps required to adequately share a decision were described. The patient's preferences and values should be elicited so that the options discussed are compatible with the patient's lifestyle and values. Information on the treatment available, its risks, benefits and possible outcomes should be transferred to the patient in an understandable and unbiased way and the physician should recommend the course of action which they consider to be the best (Charles *et al.* 1997). It may be argued that this model of SDM gained dominance as this is the most straightforward to train, observe and measure in clinical practice, but potentially neglects key relational and subjective-affective aspects of the patient's involvement in the process, as well as a broader range of decision making activities and health-related behaviours (Edwards and Elwyn 2009). SDM is about more than presentation of a series of options and exploring the patients values but a broader conceptualization that attends to how patients and health professionals think and feel about their relationships, rather than simply how they communicate health care options (Edwards and Elwyn 2009). The most recent and

clear conceptualisation of decision making in healthcare is broader (Elwyn *et al.* 2012), and explains the process of patient engagement in healthcare in three steps:

- **Choice talk:** this involves discussing with the patient that a choice in fact exists, and emphasises the importance of recognising preference and the role of uncertainty in the choice

- **Option talk:** the treatment options are listed together with their respective risks and benefits. This stage continues for the amount of time the patient wishes

- **Decision talk:** this involves asking the patient if they are ready to make a decision or receive a recommendation. If a decision is made, the doctor must check that this is in line with the patient's priorities, and if a recommendation is made, the doctor must confirm their own understanding of the patient's preferences

If SDM is to become routine practice, the definition and process of a shared decision must be broad and adaptable. A holistic view of making decisions is required, with an appreciation of the lived experience of ill health and the anxiety and uncertainty which underpins healthcare decisions (Olthuis *et al.* 2012). To achieve this, clinicians require an understanding of the patient's perspective of making a decision. Rapley (2008) describes how much of the work of decision making for a patient takes place outwith the clinical consultation, distributed in time and amongst people and information sources. Acknowledging this makes SDM more than informing patients about choice, and in doing so makes it relevant to many aspects of healthcare delivery.

2.9.2 Effectiveness

The culture of modern medicine demands that practice should be informed by evidence. The fundamental barriers to providing evidence for the effectiveness of SDM are: difficulty in defining what SDM is (Mead and Bower 2000A; Mead and Bower 2000B)

and how the 'patient-centredness' of a consultation is observed or measured. Although

attempts have been made to measure decision sharing (Elwyn *et al.* 2005), much

research into the effectiveness of SDM concentrates on patient decisions aids. Decision

aids are information sources which can be in the form of pamphlets, videos or computer

programs which are designed to give information about healthcare options to the patient

and facilitate the elicitation of values and priorities for treatment from the patient. They

may be employed with a clinician during a consultation, but are usually used elsewhere,

either alone, or with support. Decision aids provide information on and help patients to

clarify their values and preferences (IPDAS 2012).   In a recently updated Cochrane

review of 115 randomised controlled trials the use of a decision aid was associated with

improved patient knowledge, lower decisional conflict, a decreased proportion of

patients who were passive in decision making and fewer patients remaining undecided.

There was also a reported increase in patient satisfaction with the decision making

encounter and improved perception of risk (Stacey *et al.* 2014). Although this evidence

is noteworthy, most of the improvements are more about the consultation process and

less about clinical outcomes such as survival or quality of life. Also, if clinicians use

decision aids, this does not automatically mean that SDM has taken place; a decision aid

is an adjunct to communication rather than a guarantee that a decision is shared. Indeed

SDM is more dependent on the interaction between doctor and patient rather than on the

use of a specific tool (Kaner *et al.* 2007)

The question of how to measure the quality of a decision is highly complex. The latest

update from the International Patient Decision Aids Standards Collaboration (IPDAS)

states that in order for effectiveness of a decision to be measured, the quality of the

decision making process and the quality of the choice that was made must be measured.

The quality of the choice made is measured by assessing the knowledge of the patient

and the patient choice/preference concordance. There are difficulties in using clinical outcomes in this measurement of decision quality: the outcome of the treatment may be poor (i.e. the patient may experience a complication), but the decision process may still be of good quality. Decisions are also made in conditions of uncertainty, and patients may trade-off certain clinical outcomes (for example quality of life) in order to preserve others (for example survival) (IPDAS 2012).

Even if clinical outcomes were to be used to assess the quality of a decision, the optimum outcome remains in doubt. Quality of life is often measured via instruments which may narrow its conceptualisation to merely the presence or absence of disease, excluding the perspective of the individual patient (Bowling 2001). The definition of health can be interpreted in various ways by different individuals depending on their values and preferences. Any measure of quality of life should therefore incorporate these broader conceptualisations of health status such as quality adjusted life years (Thomson *et al.* 2005). For example, Popay *et al* (2003) found that, although people were aware of the health risks of engaging in smoking and excessive drinking, they engaged in these behaviours in order to counteract the stress associated with other areas of life; optimization of health was not the prime determinant of their quality of life. To use other clinical outcomes, such as symptom severity, can be clinician-centred: the quality of a decision should not be based on the severity of the symptom or outcome, rather the importance that the particular patient places upon it. This means, rather than using clinical outcomes to determine the quality of a decision, the patient goals for treatment should be considered. When the stated patient goals of treatment are compared with those of clinicians, there is a disparity (Sepucha *et al.* 2008), meaning that the goals used to measure decision quality must also be patient derived. This is reinforced by the work of Barry *et al* (1995): this group found that patient reported

symptom severity in prostate disease did not match the treatment choice made. The most important indicator of the treatment chosen was how bothered men were by their symptoms. Men who were bothered by their prostatic symptoms were seven times more likely to opt for surgery. In the same way, "willingness to consider replacement" was the best predictor of time to knee replacement in osteoarthritis patients rather than the patient reported pain score (Hawker *et al.* 2006). Hence the choice of the most appropriate measure to assess the quality of a decision is fraught with difficulty. At the same time, the difficulties described in assessing the quality of a decision constitute one of the barriers to implementation of SDM, as many clinicians feel that the time and effort required to change their clinical routine to incorporate SDM is not justified by the outcome (Coulter 2010).

However, the argument for SDM transcends this. Ethically, making good, individualised healthcare decisions which respond effectively to the needs of the patient is important. It empowers patients to involve themselves in treatment decisions and challenges the concept that the doctor knows best (Elwyn *et al.* 2010). It is seen more as the meeting of two experts: the clinician brings expertise and knowledge about the treatments, their risks and benefits and the patient brings an understanding of their attitudes, preferences and values. SDM allows patients, especially those with chronic diseases, to resist the possible ulterior motives of drug companies and other organisations or individuals with a conflict of interest, or those who are potentially well-placed to gain financially from ill-health or illness avoidance (Moynihan 2011).

If not effectively involving patients in decisions about their health, doctors are assuming that they know what is important to the patient (e.g. survival, effect on quality of life). This is not always the case, however, as if treatment priorities are compared between

professionals and patients there is often a disparity. For example, in breast cancer, doctors thought that 71% of women would rate keeping their breast as a top priority for treatment, but this was only the case for 7%. More doctors were also concerned about the effect of radiation on the success of reconstruction (60% vs 24%) whilst patients placed a greater priority on avoiding a prosthesis (30% vs 0%) (Lee *et al.* 2010).

Well-informed patients make different decisions to those who are not as well informed (Volandes *et al.* 2009), may perceive risk in a different way (Steel 2000) and adhere better to treatment (Joosten *et al.* 2008). In a study of patients with dementia, clinic attenders were asked about the goals they had for treatment. Groups of patients were compared with and without access to a decision support tool. The majority (86%) of patients with access to the tool chose comfort care and only 4% chose life prolonging care. In the group without access, 64% chose comfort care and 14% life prolonging care. At a follow up interview six weeks later, these choices were also found to be more stable in the group accessing the decision aid (Volandes *et al.* 2009). In a group of patients who had already been consented for an elective out-patient percutaneous coronary intervention, 88% believed that it would decrease their risk of a heart attack. In contrast, only 17% of the cardiologists who had consented them shared this belief, which was also in direct contrast to the published literature which shows no benefit (Boden *et al.* 2007). Around half of the patients who were consented felt that the physician dominated the decision process (Rothberg *et al.* 2010). Generally, informed patients are less likely to choose surgery: for example once patients are informed about the risks of surgery for sexual dysfunction, 40% fewer choose it (Wagner *et al.* 1995). Prior to the use of a decision aid, 48% of women would choose surgery for abnormal menstrual bleeding, but this reduces to 38% after the use of a decision aid (Kennedy *et*

al. 2002) and there was a 20% relative decrease in the uptake of surgery for stable angina after the use of a decision support tool (Morgan *et al.* 2000).

Although it can be demonstrated that SDM is popular, effective and ethically requisite, it is often not standard practice and implementation has been difficult (Elwyn *et al.* 2010). Although many physicians will have been trained in patient-centred communication, this does not always correlate well with SDM (Wensing *et al.* 2002). Indeed, despite the fact that many professionals report that they already practice SDM, this is not always supported (Elwyn *et al.* 2005). Mulley alludes to the problem of "silent misdiagnosis"; clinicians are trained principally to diagnose disease in order to recommend effective treatment, but fail to diagnose the preference or priorities of patients in order to make an effective decision (Mulley *et al.* 2012). Many health care professionals see SDM as a threat to their professionalism, almost "political correctness gone too far" (Carvel 1999, page 783). Increasing SDM may increase the number of patients declining treatments for conditions which are not immediately affecting their health (e.g. hypertension), leading to an increased incidence of adverse health events and failure to meet treatment targets for some conditions.

In the context of HNC, Davies *et al* (2010) argue that the traditional SDM model of decision making is ill-suited to patients facing life threatening disease. Her ethnographic study was based in a United States ENT department and included 39 patients' clinic appointments and 22 semi-structured patient interviews. Here, a 'conventional' SDM model of decision making was followed for those with benign or non-urgent disease. However, a "non-adherent" group, commonly with a diagnosis of HNC, relied heavily on the trust in their physician and made decisions through a series of conversations with physicians and relatives; many of these discussions took place

outside of the office setting. This non-adherent group made decisions to "do something" about their disease, but relied heavily on the treatment recommendation to inform their treatment decisions. The authors conclude that this places the responsibility for decision making with the treating physician. However, a statement of trust in the doctor, and a consequent reliance on the treatment recommendation should not be confused with an argument for paternalism in this disease. Instead, a consideration of *why* patients rely heavily on recommendation and trust, and *how* their personal values, aims and preferences can be built into such a complex decision should be scrutinised.

In a systematic review, Gravel *et al* (2006) described that the most commonly reported barriers to SDM were time constraints, lack of applicability of the model due to patient characteristics or the clinical situation, provider motivation, and perceived impact on the clinical process and patient outcomes. In a systematic review, Elwyn *et al* (2013) found that indifference from health care providers was a major barrier to SDM implementation which originated from a lack of confidence in the content of decision support tools or a disruption to established patterns of work leading to organisational inaction. Nonetheless, Towle *et al* (2006) found that SDM was a well-accepted and welcome addition to the clinical encounter in a group of six family physicians. In this study, the physicians were specifically trained in SDM and consultations were then observed. Although the physicians felt that they integrated the model into the consultation, this was not always observed by the researchers. The values of the patient were often not elicited and the choices not always given. They found that the largest barrier to implementation was the well-established communication methods of the physicians involved. In another study of primary care consultations, Longo *et al* (2006) found that patients valued SDM less than other attributes such as a having a doctor who listens or who gives understandable information. However, experience with a practitioner trained

in risk communication or SDM had a positive effect on the value patients placed on those attributes, suggesting that SDM may gain importance once patients have experienced it.

2.10 Conclusion

Through the course of this chapter I have discussed the rise of patient involvement in the medical consultation. Modern medicine presents many different treatment options, all with risks to mortality and morbidity, and effective and safe healthcare delivery demands a broad conceptualisation of patient-centred healthcare. SDM allows the sharing of information between the patient and the clinician: the clinician provides information about the risks and benefits of the treatment options; the patient provides information about their values and preferences. There is a strong clinical and ethical argument for SDM but, despite this, it is not yet viewed as routine practice in the NHS. Also, the variations in care which acted as one of the catalysts for involving patients in decisions about their care persist today. In order for patients to be truly central to the delivery of healthcare, barriers to patient involvement in decision making must be identified, recognised and addressed. In order to do this, SDM needs to be flexible and adaptable to real-life clinical decision making and not only one-off interactions within the physician-patient dyad.

Healthcare teams are increasingly used to decide upon and deliver treatment; indeed in cancer treatment they are the standard of care. If patients are to be effectively involved in real-life clinical decisions, the delivery of patient-centred care in healthcare teams must be addressed. In the next chapter I discuss the development of healthcare teams, the reasons for their popularity and the challenges which teams face if they are to effectively engage patients.

Chapter 3: Multidisciplinary Team Working

Multidisciplinary team (MDT) working is seen as the modern standard of care in cancer treatment decision making (NICE 2004). This means that every cancer treatment decision in the UK should be made using an MDT. In this chapter, I discuss the history and development of the MDT as a way of working. I present the evidence for the effectiveness of MDT decision making, and the effect that MDT working has on decision making and treatment outcomes. I also present the attempts that have been made to analyse the process of decision making and patient involvement in the MDT.

3.1 The history of MDT working

It is generally agreed that the origin of MDT working is a report published in 1995 by the Chief Medical officer for England (Dr Kenneth Calman) and the Chief Medical Officer for Wales (Dr Deidre Hine) (Calman and Hine 1995). Following its publication, similar reports were produced in Northern Ireland (Campbell 1996) and Scotland (SODoH 1996). However, the "Calman-Hine report" was not the first time MDT working had been suggested, nor did its publication lead directly to the implementation of MDTs. The report is credited with their development because its recommendations laid the foundation for MDT decision making in England and Wales.

The report was written as a response to the increasing weight of evidence which suggested that those patients who were assessed and treated in specialist, centralised cancer centres, which had expertise in a disease area, had better outcomes than those who were not. For example, in breast cancer the caseload of the operating surgeon had a significant effect on treatment outcome (Sainsbury *et al.* 1995) and in paediatric cancer, centralisation of care improved survival (Stiller 1988). It was also noted that

there was a persistent, unaddressed variation in treatment practice across England and Wales (Morris 1992; Harries *et al.* 1996) and British cancer survival statistics compared unfavourably with the rest of Europe (Sant *et al.* 2003). Improved quality of care was advocated by patients themselves, with vocal pressure from increasingly influential patient groups such as the Radiotherapy Action Group Exposure (Hanley and Staley 2006).

The Calman-Hine report was not detailed and did not provide strict plans for implementing its recommendations. However, its central message tackled many of the problems with cancer care, and resonated with clinicians and patients at the time. There was a clearly stated requirement for cancer services to be "patient-centred", but the key recommendations of the report were to provide centralisation of care to high-quality, specialist care units, with early diagnosis and monitored outcomes (Calman and Hine 1995). Centralisation of care to "Cancer Units" and "Cancer Centres" across central and district hospitals in the UK was thus established as the future of treating cancer. There was a minimum standard set for patients to be seen by cancer health care professionals with a subspecialist interest in the specific disease type, rather than more general clinicians who saw only a small number of cases per year.

The concept of providing this service via an MDT was recommended in the Calman-Hine report, but this was by no means the first time that it had been advocated as a way of organising cancer care. The report made structural recommendations to change the way cancer treatment was delivered, with an emphasis on multidisciplinary working but making decisions in healthcare teams was already established in some cancers, especially breast (BBG 1994). Despite this, the recommendations of the report faced significant difficulties in their implementation, as a result of various problems such as

manpower issues (Haward 2006). A large part of the report's eventual successful

implementation was due to the fact that it triggered the preparation of disease-specific

evidence-based guidelines for each cancer, now referred to as the Improving Outcomes

Guidance (Haward 2006). In each Improving Outcomes Guidance, the MDT approach

was further reinforced as the standard of care in cancer treatment. Specifically in HNC,

the Improving Outcomes Guidance was published, by the National Institute for Clinical

Excellence and clearly stated that:

> Multi-disciplinary teams (MDTs) with a wide range of specialists …
> will be responsible for assessment, treatment planning and
> management of every patient (NICE 2004, page 8)

This established MDT working as the standard of care in HNC. The latest audit of

HNC treatment confirmed that 97.5% of those who had a cancer care plan created were

discussed in an MDT (DAHNO 2011).

3.2 Definition

There is no one definition for an MDT and definitions vary depending on the setting and

the disease. Inter-professional care is seen as "a process by which professionals from

different disciplines collaborate to provide an integrated and cohesive approach to

patient care" (Legare *et al.* 2011, page 18). MDT working is commonly linked with

inter-professional care, but an inter-professional team is not necessarily the same as an

MDT. An inter-professional team involves multiple professionals in the care of the

patient potentially at different time points: the MDT involves a single interaction or a

series of interactions which usually take place at one time point or over a short space of

time. The UK Department of Health defines the MDT as:

> a group of people with different healthcare disciplines which meets
> together at a given time (whether physically in one place, or by video
> or tele-conferencing) to discuss a given patient and who are able to

contribute independently to the diagnostic and treatment decision
about the patient (DoH 2004, page 3)

Specifically in HNC, the NICE Improving Outcomes Guidance specifies that an MDT

is:

a comprehensive range of professionals …. These MDTs should deal
with minimum of 100 new cases of upper aerodigestive tract cancer
per annum, which implies a population base of over a million; most
will be based in Tertiary Centres which have radiotherapy facilities
(NICE 2004, page 38)

The make-up of the HNC MDT varies between centres depending on the funding and

expertise available. The NICE Guidelines state that all MDTs should be attended by

three or more dedicated surgeons, some of whom are skilled in reconstruction. The

team should also include clinical oncologists, restorative dentists, pathologists,

radiologists, clinical nurse specialists, speech and language therapists, palliative care

specialists, dieticians, an MDT secretary, team manager and coordinator (NICE 2004).

A national audit published in 2003 highlighted that this was not being achieved:

although over 95% of meetings were attended by an oncologist and/or a surgeon and

80% were attended by a speech and language therapist, fewer MDTs had access to other

specialists. Only around half included dieticians and/or clinical nurse specialists, and

the role of other specialists was even more variable, with teams having a mix of plastic

surgeons, restorative dentists and palliative care physicians (Birchall *et al.* 2003).   The

list of recommended attendees is by no means exhaustive, and modern HNC MDTs may

include dental hygienists, clinical psychologists, lymphoedema nurses, anaesthetists,

social workers, benefits advisors and psychiatrists. The roles of the MDT are clearly

laid out in the NICE guidelines:

The MDT should take overall responsibility for assessment, treatment
planning and management of all patients. The MDT should take
responsibility for deciding what form of treatment should be offered,

where the proposed treatment should be carried out, and by whom
(NICE 2004)

In stating this, the shared responsibility of the MDT in managing patients with HNC is emphasised. Importantly, it states that treatments should be "offered", therefore the outcome for an MDT discussion should be a treatment *recommendation*, rather than a treatment *decision.*

3.3 Benefits of MDT working

MDT working is popular amongst the members of staff who attend it. In a national survey by the National Cancer Action Team (NCAT), 2054 members of staff who attend an MDT completed a comprehensive questionnaire. Over 90% of participants felt that the support of fellow members was important and that working in this way was beneficial to the well-being of the members. Over 80% felt that the MDT saved time and felt that this form of working improved job satisfaction (NCAT 2009). Specifically in HNC, a qualitative study of 33 professionals in four focus groups found that the team provided an inclusive environment for planning care. Staff members reported that the team gave support, a chance to stay up to date and an opportunity for discussing difficult cases (Edwards 1998). Although interesting, this study used focus groups of MDT members to collect data. MDT members were in the presence of others and therefore their vocal support may be a reflection of social acceptability or the awareness of colleagues rather than true support. Nevertheless, MDTs are thought to increase recruitment to clinical trials (Twelves *et al.* 1998; McNair *et al.* 2008), improve adherence to care quality indicators (such as dental or nutritional assessments) (Kelly *et al.* 2013) improve patient satisfaction and shorten the time between diagnosis and treatment (Gabel *et al.* 1997).

MDT teams have a variety of clinicians and allied health professionals from a range of backgrounds. Although some of these members have well-recognised roles within the team, others' roles are more ambiguous. Individual members of the team demonstrate high levels of exhaustion and members with a lesser role in the discussion, such as pathologists and radiologists, perceive that they have lower levels of accomplishment at work (Catt *et al.* 2005). The proportion of UK hospital consultants with psychological morbidity and emotional exhaustion rose between 1996 and 2002, coinciding with the rise in MDT working. This was thought to be attributable to increased stress without a similar increase in job satisfaction, a finding which was most pronounced in clinical and surgical oncologists (Taylor *et al.* 2005).

Despite MDT working being uniformly viewed as the standard of care in cancer management, evidence for its effectiveness is sparse (Fleissig *et al.* 2006; Taylor *et al.* 2010). Despite this, the MDT has persisted as a way of working, which may be due in part to the reported benefits expressed by the majority of staff members who attend it. In a similar way, the implementation of the Calman-Hine report was reliant on the warm reception it received from clinicians. Nevertheless, researchers and policy makers continue to strive to demonstrate the effectiveness of MDTs, not least because they are expensive and time consuming. Best practice guidelines estimate that a radiologist will take two hours and a pathologist 2.4 hours to prepare for each hour of team meetings (Kane *et al.* 2007) putting the estimated cost of all UK MDT meetings at £50 million a year for preparation and the same amount again for attendance (Taylor *et al.* 2010). In HNC, Mullan *et al* (2014) recorded the time taken for the team to discuss each patient over 10 meetings. They reported it varied between 15 seconds and eight minutes, with increased discussion times for older patients or in those with more advanced disease. As the majority of cancer care is delivered in large central hospitals, this represents a

considerable time burden for attendees. In the age of evidence-based medicine, most health interventions must demonstrate effectiveness to earn their place in routine practice. In the next section I discuss the evidence of effect that MDT working has on the decisions made and ultimately the clinical outcomes of the patient who are treated by them.

3.4 Effect on decision making

The primary problem with assessing the effectiveness of the MDT is deciding what the measure should be and from which viewpoint it should be measured. In one American study, the treatment recommendation of the referring clinician was compared with the MDT recommendation in 75 breast cancer patients. It was found that in 32 patients (43%), the recommendation of the MDT was different to that of the referring clinician. In a third of the cases where the treatment plan was changed, more clinical information was needed for a decision to be reached. Importantly however, 13 patients (17%) had the recommendation of mastectomy (from the referring clinician) changed to breast conserving therapy (from the MDT). However, it must be noted that this study was conducted in the United States, where the 'referring clinician' may not have been a member of the MDT; indeed the expertise and experience of the referring clinician is not specified (Chang *et al.* 2001). In a similar study in HNC, Brunner *et al* (2014) found that in almost a third of cases, the treatment plan of the referring clinician was changed by the MDT. Treatment plans were more frequently altered if the original plan from the referring clinician did not include surgery or if the histology was not squamous cell carcinoma or skin malignancy. This study was conducted in Australia, which has a similar referral pathway to the United States, and hence it applicability in the UK is again limited. Interestingly however, the authors included details about the expertise of

the referring clinician, and found that those from oncologists were more likely to be changed than those from surgeons. In the UK, Kee *et al* attempted to ascertain if, when a clinician presents their patient at the MDT, the ensuing discussion changes the reported preference of the clinician. In a similar proportion of cases (39%) the preference of the referring clinician did not match the final decision of the MDT. Interestingly however, they also showed that in only 26% of cases where the team and individual clinician disagreed did the referring clinician finally concur with the decision of the team and present it to the patient (Kee *et al.* 2004).

Thus, although it can be said that different decisions are made by teams than are made by individual clinicians, it is still more complex as to whether this difference is even expressed to the patient. Also, judging whether these altered decisions are 'better' is a much more difficult and complex task. In the study by Kee *et al* above (ibid.), the authors also made an attempt to quantify the 'quality' of the decisions made using expected utility theory. To do this, the maximum expected utility of all the available treatment options was compared with the expected utility of the preferred treatment of the referring clinician and then of the MDT in 50 cases. The effect of the discussion on the net difference between the "maximum" utility score and the utility score of the selected treatment was found not to be significantly different from zero. Although an interesting method of assessing this question, it is difficult to judge the quality of decisions based on this small study. Not only this, but although the survival estimates were individually estimated by the physician, the utility values on which the analysis was based were derived from the literature, which assumes that all patients had the same utility for the different outcomes.

MDT working not only affects the treatment recommendations made, but also the diagnoses given. In gastro-oesophageal cancer, there are many potential different methods of accurately staging patients such as CT scanning and trans-oesophageal ultrasound. Davies *et al* (2006) found that an assessment taking into account multiple different methods of staging at an MDT meeting was closer to the post-resection staging when compared with the single staging modalities alone. Although this resulted in fewer patients being under treated it could be argued that this improvement is due to the combination of staging technologies rather than the MDT meeting per se. There is little doubt however that the MDT facilitates the discussion and combination of modalities such as that demonstrated here. A systematic review of lung cancer teams found MDT decision making increased the number of patients being treated aggressively with surgical resection, chemotherapy or radiotherapy with a curative intent (Coory *et al.* 2008). Morris *et al* (2008) used cancer registry data for 11,919 breast cancer patients to compare the diagnoses and treatments given over a five year period with the degree with which the treating centres had implemented the recommendations from the Calman-Hine report. The degree of Calman-Hine implementation was estimated by the caseload of the operating surgeon and the make-up of the MDT. Implementation was found to be variable (the study was conducted between 1995 and 2000) but it was associated with a reduction in the use of breast conservation surgery and an increase in the use of radiotherapy following breast conserving surgery. This study provides interesting data which shows a change in practice over time, but it is difficult to unpick how much of this was due to the introduction of MDT working, how much due to the other recommendations of the Calman-Hine report (such as centralisation of care), or indeed how much was due to a change in the way patient preferences were incorporated into the decision.

The evidence presented so far suggests that since the introduction of MDT working, practice has changed. It is impossible to go on to conclude how much of this change was due to the MDT, the other Calman-Hine recommendations or temporal trends. The literature presented allows the conclusion that MDT working results in a change to the decisions made. Although this demonstrates that decisions are *different* it is more difficult to define whether they are *better*. It is also still not clear whether this change in management has any positive effects on the eventual treatment outcome. In the next section I discuss the evidence assessing the effect of MDT working on clinical outcomes.

3.5 Effect of MDT working on survival

The challenges faced when assessing the impact of MDT working on survival in cancer was outlined by Hong *et al* (2010) in their systematic review on this subject. Similar to the problems faced when studying the effect of SDM, the definition of MDT is applied variably across centres. Benefits may reflect a selection bias of patients with a better prognosis, rather than a real effect, and any improvements highlighted may be due to other advances in screening, diagnosis or treatment which happened in the same time period. Hong's review included 21 studies which were categorised broadly into retrospective studies and those with cohorts before and after the introduction of an MDT, usually in a single centre: it was not able to demonstrate a link between MDT working and survival. Although the incorporated evidence suggested a survival advantage for the MDT, this could not be confirmed as causal due to the difficulties in defining the MDT and heterogeneity of study designs.

The only UK study of the effect of MDT working on survival in HNC compared two retrospective cohorts of patients in the South West of England. The first cohort of (566

patients) was treated in 1997 and the second (727 patients) was treated in 2000.   Over
85% of cases were captured in each audit, but collection relied on clinicians completing
paper-based protocols. The authors reported a number of process improvements
between the two audits. The proportion of patients seen in an MDT increased from
46% to 74% between the two audits and the number having pre-treatment imaging and
accurate staging work-up also increased. However, perhaps as a result of this, waiting
times also increased. The overall survival between the two cohorts was not
significantly different (64.1% increased to 65.1%), but analysis revealed that those
patients were assessed in an MDT had a statistically significantly better survival than
those who were not. Although MDT working could have improved the 'non-temporal'
standards such as pre-treatment imaging, the correlation between MDT working and
increased survival cannot be assumed to be causative. The authors discussed that
survival data was probably incomplete, as the deaths reported did not match those of
death registrations in the area. Also, temporal trends were not accounted for and
confounding factors such as patient selection were not acknowledged (Birchall *et al.*
2004).

In Australia, MDT decision making is not mandated, and hence Friedland *et al* (2011)
were able to compare the treatment and outcomes between HNC patients who had been
referred to the MDT (395 patients) and those who had not (331 patients) over a 12 year
period in a single hospital. The authors found that those patients who had been seen in
an MDT were less likely to have single modality treatment and more likely to receive a
combination of chemotherapy and radiotherapy and/or surgery. Also, those patients
who had very advanced (stage IV) disease had significantly improved survival.
However, the allocation to management within or outwith the MDT was not
randomised, but chosen by the referring clinician; also the MDT patient group had a

higher age and more advanced disease. Most importantly however, it is not made clear why some patients were selected to be managed by the MDT whilst others were managed by individual clinicians.

There are no randomised controlled trials of MDT working and as it is now ubiquitous, randomisation of this complex intervention is impossible. This means that patients cannot be randomised to be treated by a team or an individual. However, during implementation of the findings in 1995, MDT working was introduced into one health board in Glasgow (the "intervention area"), but not in other health boards in the west of Scotland (the "non-intervention area"), allowing a comparison between two similar populations. Before MDT working was introduced, breast cancer mortality was 11% higher in the intervention area than in the non-intervention area. After MDT introduction, breast cancer mortality was 18% lower than the non-intervention area. There was also a reduced variation in survival between hospitals in the intervention area. This study used cancer registry data on 13,722 patients, and the authors adjusted for temporal trends. This large study was published after the systematic review above and the authors provided detail about the definition of MDT working used. Although only a single study in one cancer, the size of the effect is noticeable and it provides the strongest evidence of a positive effect of MDT working on cancer survival to date (Kesson *et al.* 2012).

Despite this, given the overall weight of evidence and the difficulty in accurately answering this question, it is not known if MDT working has an effect on cancer survival. Importantly however, there is equally no convincing evidence of a negative effect. Even if MDT working did improve survival, the aspect of the process which was responsible for such effects is not known. This lack of effect on cancer survival

outcome has driven researchers to search for alternative ways to assess the effectiveness of the MDT. As I discussed in the previous chapter, a treatment decision is far more than the clinical outcome it produces, and therefore in order to assess the MDT as a method of making a treatment decision further exploration is required.

3.6 Assessment of the MDT decision making process

Various different general quantitative measures have been developed to attempt to objectively record the broad 'effectiveness' of MDTs. Many of these have been based on clear guidelines, issued by the National Cancer Action Team (NCAT) following its survey of MDT members entitled "The Characteristics of an Effective Multidisciplinary Team" (NCAT 2010). One tool developed by Taylor *et al* (2012), covered many "observable" features of MDT working such as attendance, administration and patient-centredness of the clinical decision making. The authors measured the patient-centredness of the MDT decision by counting the number of cases where there was a mention in the discussion of patient-based information. Patient based information in this study was defined as patient demographics, comorbidities, supportive needs or patient and family preferences. Ten colorectal MDT meetings were video-taped and scored by three observers using a standardised proforma developed by the authors. Teams scored highly in measures of attendance, dealing with conflict and administration. However eight out of the ten meetings observed scored "poor" or "very poor" for patient centred care. The patient information which was included was frequently confined to demographics and most teams rarely considered other patient-based factors. Other authors have produced similar tools, usually designed to be used by an independent observer or by the team itself as a means of self-assessment. Lamb *et al* (2011) developed a tool which used Likert scales to quantify 11 aspects of MDT

team discussion, including information about the patient, contribution of members of the team and the incorporation of patient views. Five MDTs were observed discussing 164 patients. Teams scored highly in the amount of information given about the clinical history, and radiological information. Also, the "quality" of the input from surgeons and oncologists was rated to be high. The Likert scale for "patient views" ranged from "no provision of patient views" through "patient views from a report or account" to "fluent, comprehensive account of the patient views". MDTs were assessed by an observer who attended one meeting of five different MDTs and team members were asked to complete a similar survey individually online. Teams were found, using this scale, to incorporate patient views into the discussion quite poorly. Moreover, the self-assessment questionnaires completed by the team members suggested that they over-estimated the 'patient-centredness' of their decisions. This may of course merely reflect the difficulty of defining 'patient-centredness', or the inadequacies of this scale. This study provides an interesting insight into the content of the MDT discussion, but provides little information on the exact nature of patient-centred information included or the reasons for the difficulties in incorporating it into the discussion. Questionnaires and observation frameworks such as these provide user-friendly, quantifiable measures which can be used by team members to assess themselves and ultimately improve their practice. However, only a superficial account of the discussion is provided and many aspects are based on a subjective assessment of the MDT meeting alone. It cannot be concluded that MDTs which mention details about a patient more frequently involve their patient more in the treatment decisions, but both studies highlight a similar theme: within the team discussion, information about a patient is sparse, especially that regarding patient values and preferences.

Placing the patient at the centre of the decision is reportedly important to the members of the MDT. In the NCAT Survey of MDT (2009), 95% of respondents felt that "Patient views should always inform the decision-making process" and "Patient views/preferences should be presented to the MDT by somebody who has met the patient". At the same time, 96% of participants felt that it was not practical for patients to attend their own MDT meeting. Although interesting, these data represent the views of the MDT members, but do not provide detail of actual practice in each MDT. When the free-text responses from the NCAT survey were analysed, lack of information about the patient or lack of knowledge of the patient views were seen as the main reason for MDT decisions not being implemented (Lamb *et al.* 2013). Although the authors state that patient presence at the meeting would "undoubtedly inhibit discussions" they conceded that little is known about how patients' preferences and values should be represented in the MDT.

The potential for patients to attend their own MDT meeting has been explored previously. In a questionnaire survey of 135 breast cancer patient advocates and 294 health care professionals, only a minority (between 24% and 32%) of clinicians were supportive of involving women in the treatment planning meeting, compared with 93% of breast cancer advocates. Advocates felt that that it would lead to information and empowerment for the patient, but professionals felt that it would inhibit the discussion and cause patient anxiety (Butow *et al.* 2007). Although interesting, this study provided little information (other than demographic data) about who the breast cancer advocates were: one third had "health training" and 70% had been diagnosed with breast cancer within the past 10 years.   Martin *et al* (2011) reported almost insurmountable difficulties in incorporating service users onto healthcare provider teams. In this study, users attended health service-development team meetings over a considerable length of

time. Existing team relationships were built largely on trust, either secondary to long-standing relationships or pre-existing hierarchies, which presented barriers to user integration. Additionally, if users were successfully integrated, the distinction between professional team members and lay members was reduced, which acted to lessen the unique insight and input that users were originally intended to bring. Nevertheless, if successful, user integration took place over a period of years; when applied to the MDT setting, there is no opportunity such relationships to develop . A small qualitative study interviewing ten MDT members reported that, although meeting a patient in the MDT setting allowed for better information giving, one to one consultations provided superior communication and trust-building (Bellardita *et al.* 2011). Another small qualitative assessment of the patient experience of attending their own MDT agrees that it improves information giving, but not involvement in the decision (personal communication, Adam Potts). Choy *et al* (2007) conducted an interesting pilot study in which 23 breast cancer patients were invited to attend their own MDT meeting. Included women completed a questionnaire before and after the meeting and gave a short qualitative interview. The authors used a small control group of seven patients who refused to attend. It is not possible to draw any conclusions from this study owing to the small sample sizes but the findings were nonetheless interesting: attending the MDT seemed to have no effect on anxiety and improved information gathering and communication. The small qualitative component also highlighted some negative aspects of MDT attendance including the intimidating nature of the radiology and pathology information and the potential difficulty of hearing bad news in that setting. Encouragingly, professionals also gave a positive response to the intervention, despite feeling that the time required made it quite resource-intensive.

Omitting, or not incorporating, patient preference information into the treatment discussion potentially has an effect on decision implementation. Rajan *et al* (2013) analysed 3230 documented breast cancer MDT discussions and found that 146 (4.5%) of these were discordant with the final agreed patient management plan. Of the discordant decisions, 61 (41.7%) were due to 'patient choice': the nature of this choice and how it was elicited is not specified. In a similar way, Blazeby *et al* (2006) analysed 273 upper gastrointestinal cancer MDT decisions over five months and compared the documented MDT decision with the final treatment performed to see if treatment decisions made in the MDT are actually implemented. In all there were 41 decisions (15%) which were changed: of these, 18 (44%) were due to comorbid disease not discussed, 14 (34%) were "related to patient choice" and 8 (20%) were because "new information" came to light. The group undertook a similar investigation of the colorectal MDT at the same hospital. In an analysis of 201 decisions, 20 (10%) were not implemented. Of these nine (40%) were due to comorbidity and seven (35%) were due to "patient choice" (Wood *et al.* 2008). These retrospective studies provide interesting data, but relied on review of the case notes, exposing the data to bias. They also examined a case load with a very high number of patients being treated without curative intent. For both of these studies, the vast majority of the changed decisions were to a more conservative plan, with curative treatment being changed to palliation, or palliation being changed to best supportive care. It could be argued that decisions such as this rely even more heavily on patient values, and hence it is not surprising that so many decisions were changed. Nevertheless, the studies highlight the consequences of not incorporating patient preference information into a treatment discussion. They do not however provide the necessary detail as to how a decision change occurred, or indeed why.

This means that despite the fact that MDT members reportedly value patient information such as values and preferences, such patient centred information is often omitted from the discussion. At the same time, MDT members feel it is not practical for patients to attend their own MDT meeting. If information about the patient preferences and values are not included in the discussion, this leads to difficulties with making appropriate recommendations and decision implementation. This presents the MDT with a challenge in effectively engaging their patients in the decision process. A large review of effectiveness of MDT working stated that "there is no consensus about how best to involve patients in the clinical decision making process in team meetings" (Taylor *et al.* 2010, page 744). The issue of patient involvement in MDT decision making warrants further exploration.

3.7 Patient involvement in the MDT

Successful incorporation of the views of the patient into a discussion between professionals at a meeting where the patient is not present is a challenging concept. In order to do this, an analysis of *how* the team make decisions is required, a question particularly suited to qualitative techniques. Kidger *et al* (2009) performed an ethnographic study of a gynaecological MDT. Ten meetings in one centre were observed and this exercise combined with 16 interviews with members of staff. The results echo and build upon the problems with MDT working which have been alluded to with the survey and questionnaire research presented above. The authors found that the consideration of patient related factors such as comorbidity information, psychosocial issues and patients' wishes was unstructured when compared with the very structured manner in which the biomedical information was presented. MDT members recognized the importance of 'seeing' a patient rather than an objective representation

through information; however information about patient preferences was only really presented when these were strongly held, or ran counter to the recommendation of the team. This lack of information about patient preferences was at odds with the MDT members' recognition of its importance. The team exhibited uncertainty about when and how this kind of information should be incorporated into the discussion.

Lancely *et al* (2008) performed another ethnographic assessment of a gynaecological MDT. Sixteen MDT discussions in one centre were observed, and used to create questions for semi-structured interviews which were conducted with 12 members of the team. Again, the biomedical details of the patient were at the forefront of the discussion, packaging patients into a semi-predictable 'case' which consisted mainly of their biomedical data. Although information such as the ethics of treatment selection or the individuality of the patient was sometimes presented, the team struggled to incorporate this into the 'case' and therefore into the decision. The authors observed that this often led to two strands of narrative about a single patient, which the team had significant difficulties combining. The authors spoke about one of the effects of this in the team; allied members of the team who hold the non-biomedical information (for example Clinical Nurse Specialists) were silenced or ignored.

These two ethnographies suggest a dominance of the biomedical view of the patient in the MDT discussion despite acknowledgement from the members about the role of other patient information. The biomedical dominance may however be a symptom of the difficulty in incorporating other sorts of information into the discussion, and when incorporated, the challenges in how it should be used to influence the decision or recommendation. Both of these studies provide a fascinating insight, not only into the fact that patient preferences are not incorporated into the discussion, but also why this

may be the case. However, the ethnographic studies were each based in a single centre, and relied solely on researcher generated notes, rather than audio or video recording of the interaction. Although this methodology provides much more depth of analysis than survey data, the intricacies and subtleties of the team interaction which influence the course of the discussion and the decision made may have been lost. Although it is not without its downsides, recording of the decision making conversation would provide a further increased level of detail (Hammersley and Atkinson 2007). It is also unclear about which of the decisions were implemented and how the included cases were sampled. Nevertheless, both studies act to highlight one of the major challenges facing the MDT at the moment: how does the MDT involve the patient in treatment decisions?

The most striking limitation of all of the literature examining the effectiveness of the MDT is that it ignores the interaction of the team members with the patient. Although they demonstrate a dominance of biomedical information in the MDT meeting it cannot be concluded that teams who have more information about a patient involve their patients better in decisions. In order to reach a conclusion such as this, more data are needed. The observations must extend beyond the MDT environment to include, at the very least, the next stage in the decision process, the clinic appointment. In omitting this, these studies are not an analysis of MDT decision making, rather an analysis of team dynamics and negotiation. Importantly, however, if we are to truly address how involved patients are in MDT decisions, one of the richest sources of data would be the patients themselves. It seems counter-intuitive that in all the studies so far of the 'patient-centredness' of MDT decision making, the voice of the patient is all but absent.

3.8 Conclusion

The MDT is currently the standard of care in cancer treatment decision making, and the vast majority of patients who have cancer will have their case discussed in this forum. The MDT is popular among its members but requires the time and expertise of a wide range of clinicians and, as a result, has huge financial implications. There have been many studies looking at the outcome of the MDT discussion, perhaps because this is more easily quantifiable; despite this there is very little evidence on how effective MDT decision making is. It is known that when treatments are decided through an MDT, different decisions are often made than when they are not; it is more difficult however to ascertain whether the resultant decisions are in fact better.

If patients' values and preferences are not included effectively in MDT decisions, a proportion of the recommendations from the MDT may not be implemented. The members of the MDT also recognise the importance of incorporating patient preferences into the decisions. At the same time, the team struggles with how and when to incorporate individual patient information such as treatment preference into the discussion. If any intervention is to be successful in improving patient engagement in treatment decision making in this setting, there needs to be a clear understanding of the process of MDT decision making. However, in order to gain this clear understanding, an examination of more than just the team discussion is required.

In order to truly explore how a patient is involved in an MDT treatment decision it is essential at least to observe how the team interacts with the patient. The difficulty faced is that the majority of the work on involving patients in healthcare decisions has centred on the interaction of one clinician with one patient. At the same time, the majority of the work looking at MDT decision making focuses on the clinicians and their

interactions with each other. It is argued that a patient preference is not a static piece of information, but the result of an interaction (Epstein and Street 2011), therefore any research which is looking at how it is incorporated must respect this. There is also a glaring lack of studies examining the patient experience of the MDT decision process, and there is no account of how the patient makes a decision in conjunction with the MDT. An appreciation of how the patient engages with the recommendation of the team, as well as the team with the patient, is essential to understand how a decision is made and to identify opportunities for improvement. The interaction between the two would provide us not only with an account of how the team make a recommendation, but also with a fuller picture of how, together with the patient, they make a decision.

Aims and Objectives

In Chapter One, I discussed the complexity of the treatment decisions in HNC. Patients often have a low chance of survival, uncertainty about the outcome of the treatment and a significant functional trade-off if cure is to be achieved. In Chapter Two I discussed the rise of patient involvement in the medical consultation and the drivers for this change in practice. I discussed the clinical and ethical argument for SDM as a method of achieving patient-centred decision making, and the barriers which exist to implementing this into routine practice. In Chapter Three, I discussed how, in the UK, HNC decisions are currently made through an MDT. I discussed the history of the MDT, the scarcity of evidence for its effectiveness and outlined the difficulties that the MDT face when considering the values and preferences of the patient in decision making.

In this thesis, I aim to examine critically patient engagement in the MDT treatment decision making process in HNC. In order to achieve this aim, I have the following three objectives:

Objective one: To examine critically the current function of the MDT meeting in HNC

Objective two: to evaluate the experience and practice of decision-making by patients and clinicians and to elicit their views on current and preferred involvement in the treatment decision making process

Objective three: To use the findings from objectives one and two to determine the requirements for decision support in the context of the MDT.

In the next chapter I discuss the methodological approach which I employed to achieve these aims and objectives.

Chapter 4: Methodology and methods

In this chapter I outline the theoretical and philosophical standpoint that I have adopted to address the question under study. I detail the assumptions which acted as the foundation for my methodological approach and the implications that this had for the data collected and its analysis. I then discuss the methods of data collection and the challenges which I faced when gathering data. I also explain the approach, recruitment and consent of participants and close the chapter by describing my process of data analysis.

The MDT meeting and clinic is not defined by a geographical space, but rather by the interactions of multiple members of the team with each other, with the patient and with the pieces of information which are available to them. The treatment decision is the result of various social processes within the MDT, between MDT members and the patient and between patients and their supporters. In analysing this process, I am attempting to describe something which has no physical form and no parameters. The process of investigation presented me with multiple, complex, variable, sometimes conflicting accounts of decision making in this setting (including my own). In order to gain an understanding of this process, I needed an appreciation of the multiple viewpoints and interactions which make it up.

4.1 Theoretical perspective

A philosophical and theoretical basis was required which enabled me to explore the multiplicity of perspectives which existed during an MDT meeting, clinic and treatment decision. To begin the explanation of the theoretical perspective that underpins this work, I will briefly discuss the ontological and epistemological foundations I adopted.

The setting under study and the product of this process, a decision, is a construct of an interaction. In order to explore the different and sometimes divergent perspectives in decision making I require an acceptance that 'truth' or reality is something which is interpreted by the observer. One ontological perspective which acknowledges this is termed *relativism:* the relativistic standpoint accepts that there are multiple realities and each reality constructed has equal validity (Crotty 1998). Relativism is in direct opposition to *realism*, or the belief that an object exists in one, true, objective reality, waiting to be discovered. Realism is often suitable for the study of physical but perhaps not social phenomena. Kuhn argued that there is no theory-neutral observational stance which can be used to describe one universal truth; data will always be viewed through a lens consisting of the observers theoretical standpoint, and if another lens is used to look at the same set of data by another observer, another conclusion may be reached (Kuhn 1970 cited in Crotty 1998). This creates an acceptance that 'truth' is something which is interpreted by the observer, and suggests that one overarching law cannot be arrived at. I acknowledge that my appreciation of the research question is relativistic; multiple realities may exist, guiding the behaviour of the participants, and my method of enquiry must respect this. However, to adopt a purely relativistic viewpoint would also potentially lead to a conclusion that my analysis is merely a result of my own cultural influence, and no more valid a representation of reality than any other observer. In order to resolve this I will draw upon Hammersley's description of "subtle realism" (Hammersley 1992). He argues that whilst certain validity of any finding or generation of knowledge is impossible, this does not mean that one cannot have any confidence in its validity. Hence, there is a 'reality' but this reality can never be known completely. My research aims to represent 'reality', but not reproduce it; indeed there will always potentially be other, perhaps contradictory accounts which may be equally valid.

However my claims should be judged by the extent to which they represent or reflect reality based on interpretation of plausibility and credibility.

The *constructionist* epistemological viewpoint acknowledges that the production of knowledge (or what we can know about reality) is socially constructed, therefore an unimpeded or 'raw' view of reality is impossible. Constructionists argue that meanings are constructed and objects are defined by the meaning that we assign to them; in other words "all objects are made and not found" (Fish 1990 cited in Crotty 1998, page 52). This is not to say that we *create* meaning as an asocial individualistic achievement; this would be a subjectivist viewpoint. A constructivist viewpoint argues that meanings are embedded in culture and convention. Therefore as a social group of humans, we generate our own collective meaning which is shaped by our culture, background and previous interactions (Shwandt 1994). In accepting this, we can place the constructionist viewpoint between the opposite poles of objectivism and subjectivism (Crotty 1998).

So, in conclusion, my ontological standpoint is one of subtle realism and my epistemological standpoint is constructionism. This allows me to explore the various perspectives in the MDT decision process, where multiple perspectives are important, valid, and require investigation and analytic attention. I will now go on to describe the effect that this position has on my choice of methodology and the way that I will enact this methodology by way of my techniques of data collection.

4.2 Symbolic Interactionism

I adopted a scientific methodology that assumes that there is a reality which cannot be known about directly, as different meanings can be ascribed to objects and social

encounters. Symbolic interactionism has its origins in pragmatism which developed as an alternative to the stimulus–response theory of action (Strauss 1993). Pragmatism theorised that an organism is not passive, awaiting a stimulus before action can be generated, but has an on-going activity which the stimulus plays into; the response witnessed is the reaction between the two (Charon 1995). Pragmatism was developed into progressive 'theories of action' by successive generations of sociologists at the University of Chicago. Although it was the work of Dewey and Mead in which pragmatism takes it roots, it was Herbert Blumer who developed and crystallised this into practical theory, and first coined the term "symbolic interactionism" (Travers 2001). This provided the basis for symbolic interactionism to develop as a research perspective.

Blumer developed symbolic interactionism as a direct contrast to "variable analysis". Variable analysis is the idea that an individual can be broken down into a number of "variables" or complex dimensions which vary. Blumer argued social phenomena cannot be described and measured in this way and variable analysis removed context and merely acted to simplify social life (Blumer 1956). At the time, this quantitative analysis of social life, conducted through surveys, questionnaires or statistical analysis was popular and mainstream (Travers 2001). Blumer contested that symbolic interactionism provided insight into "the real operating factors in group life, and the real interaction and relations between factors" (Blumer 1969 cited from Travers 2001, page 24). In keeping with the pragmatic viewpoint, symbolic interactionism relies on the subject being active; in fact interaction is the unit of study. As humans, we are interacting all the time and our actions have an effect on those around us. In turn, we take each other's actions into account as we act. Importantly, we do not only interact with those around us, but also within ourselves; we think and define situations then act

according to our assessment. The resultant action is not pre-programmed; although we can predict how a certain situation is going to develop based on our past experience, we cannot guarantee the reactions or cooperation of others (Charon 1995): this is especially true in groups of people. Joint action does not simply arise from a set of pre-given relationships, although these may be well known and long standing. The situation may not develop as expected thus the capacity to reproduce joint action is:

> subject to pressure as well to reinforcement, to incipient dissatisfaction as well as to indifference; they may be challenged as well as affirmed allowed to slip along without concern as well as subjected to new vigour…. A gratuitous acceptance of the concepts of the norms, values and social rules and the like should not blind the social scientist to the fact that any one of them is subtended by a process of social interaction – a process that is necessary not only for their change, but equally well for their retention in a fixed form. It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life (Blumer 1969 cited from Cuff *et al.* 1998, page 115)

Therefore action and interaction can be described, but are not defined by rules, norms and values; instead they are endlessly rebuilt and re-worked. This is a necessary feature of social life: although rules and norms influence our behaviour they are not concrete and solid. This is especially true at the level of an organisation such as a hospital where the rules and policies which govern behaviours are subject to frequent modifications and changes.

In line with central themes of symbolic interactionism, I conducted my research using ethnographic methods which places importance on the *observation* of interaction. Ethnography is a method of qualitative study which places the researcher directly in the setting under analysis; observing and interpreting the actions of the participants. It stays true to the central concept of symbolic interactionism that the contents of the mind are displayed in action (Cuff *et al.* 1998).

4.3 Ethnography

"Ethnography" was originally an anthropological methodology and would involve the researcher travelling and living with a foreign culture in order to produce a rich and detailed description of a non-western culture (Hammersley and Atkinson 2007). It gained popularity and in time was used to describe Western cultures, often the villages or towns of Western Europe or the US (Lynd *et al.* 1929). Ethnography is a central example of *naturalistic* enquiry; here, participants are studied in their natural environment, so the observer respects the social world or the context in which the actions are performed. In the 50s and 60s the practice of ethnography was developed by the 'Chicago School' of interactionist sociologists to use as a method of studying human social life (Wirth 1928; Blumenthal 1932 cited in Atkinson *et al.* 2001). Ethnography requires the researcher to participate in the daily life of the studied participants rather than in experimental conditions; the research takes place 'in the field'. Data are gathered from a range of sources via watching, listening and asking questions through formal and informal interviews. The study is in-depth, and hence there is a concentration on fewer cases, and data is gathered in a relatively unstructured way. Analysis of data gathered via ethnographic methods is not pre-defined and focuses on the meanings, functions and consequences of human behaviour (Hammersley and Atkinson 2007). In essence, ethnography is a development of what we already do as human beings to make sense of the world around us.

In order to undertake ethnography, there is an underlying belief in cultural relativism: that individuals construct their own world based on their interpretation of what is around them (Hammersley and Atkinson 2007). The effect that the researcher has on this process cannot be denied, as their cultural background and worldview will have an

effect on their interpretation of the data. By using ethnographic methods, I did not have to rely on retrospective accounts gleaned through participant interviews which may provide an idealised account of events from one perspective (Strauss 1993). My observations allowed me to study the participants as a group, meaning that I could begin to analyse the complex process of negotiation which is used to attempt to achieve a position of consensus in the team. I was able to directly observe how individuals in the team used the information available to them and interpreted it. The setting under study presented multiple examples of this and thus provided interesting and illuminating data. I saw how the aim of the MDT discussion varied amongst teams, and how the outcome of the discussion was packaged and taken to the patient in various forms by individual members. I was able to observe how objects or information (e.g. scans, pathology reports) were interpreted and then used by various members of the team to inform and strengthen their argument for a particular treatment option.

In this thesis, I aimed to examine critically the process of MDT decision making with an emphasis on patient engagement. Ethnographic methods have previously been conducted in complex settings such as medical environments (Pope 2005), by clinicians as well as social researchers (Zaman 2008). By placing myself in the setting under study, I did not have to rely on retrospective idealised accounts provided by participants. However, I have previous experience of being one of the participants under study, and therefore I had to ensure that my analysis reflected the data collected as far as possible. Although this is not to say that I exerted no influence over the resultant analysis, more that the description that I produced was a construct of the data and my interpretation of it, rather than my pre-formed ideas or theories. For this reason I chose to adopt Constructionist Grounded Theory for my data analysis and use the next section to describe this.

4.4 Constructivist Grounded Theory

Grounded Theory provides a systematic strategy for the analysis of qualitative data and resulted from the work of Glaser and Strauss (Glaser 1967) during their studies of dying in hospitals. In this section I describe the central tenets of Grounded Theory, the similarities and differences that my approach has to the original description, the reason for my choice of Constructionist Grounded Theory and how this reflects on the epistemological standpoint of the thesis.

The original description of Grounded Theory in the book "The Discovery of Grounded Theory" (Glaser 1967) was novel because it challenged the dominant positivist epistemological viewpoint of the era, but at the same time provided practical guidelines for the management of qualitative data. The central tenets of Grounded Theory are the coming together of data collection and analysis. Analytic "codes" are assigned to small segments of data and these codes are derived from the data rather than pre-conceived. Emerging codes are constantly compared and the outcomes of these comparisons are used to guide further collection. The categories generated are then elaborated upon and explored using memo writing. Data sampling is done with the aim of developing theory rather than to represent populations. In developing this methodology Glaser and Strauss had the aim of constructing theory from data rather than beginning with theory or hypothesis and using data collection and analysis to prove or disprove this. Originally it was proposed that the resultant theory needed to be testable and reproducible, and used to create "formal generalisations" that could be, in turn, used to predict future events (Glaser 1967). It was argued that this made qualitative analysis more than "soft science and journalism" (Blumer 1969 cited from Travers 2001, page 41)

If staying true to this original form of Grounded Theory, literature review should take place following analysis, in order for the ideas or interpretations of the researcher to have little or no effect on the theories emerging from the data. Although the emergence of this approach provided legitimacy to qualitative analysis it has often been criticised for having positivistic assumptions; researchers were assumed to be neutral to the data, with no effect over it rather than to report it. As a consequence of this, since its original description, Grounded Theory has been modified by some researchers. (Charmaz 2006, Bryant 2002). The approach that I adopted was Constructivist Grounded Theory (Charmaz 2006) which recognises the origins and purpose of Grounded Theory in generating theory from data, but also recognises the effect of the researcher on the data. In her 2006 book, Charmaz states:

> My approach explicitly assumes that any theoretical rendering offers an interpretative portrayal of the studied world, not an exact picture of it. Research participants' implicit meanings, experiential views – and researchers finished grounded theories – are constructions of reality….I argue for building on the pragmatist underpinnings in grounded theory and advancing interpretative analysis that acknowledge these constructions (Charmaz 2006, page 10)

In following these principles, the inherent effect that I had on my data was reported transparently, rather than denied. This was particularly relevant in my position; I was observing and interpreting action in a setting in which I used to be one of the actors. I was transparent about the effect that this starting point may have had on my resultant analysis. This transparency was reflected in fieldnotes and memos which themselves formed data for analysis. This approach observes the central principle that data analysis takes place as the field work progresses, rather than after it, which means that generated ideas are tested as the data collection continues, allowing for unanticipated and new issues raised to be explored. This means that it is both inductive and deductive. It begins by being inductive; I was not testing a theory with the data, but building

theoretical concepts from it. The data guided the emergent concepts, but was then

tested by the further data collection. When this was tested (either by theoretical

sampling or data analysis) it became more deductive. Purposive sampling (discussed

later) was used to test the concepts which were emerging from the data, seek out deviant

cases and maximise the differences between cases. Whilst performing the data

collection and analysis, the division of the MDT meeting and clinic into areas where the

patient was and was not present led to me adopting elements of dramaturgical analysis

as a lens through which to interpret the data.

4.5 Dramaturgical Analysis

The MDT meeting is an area where the professional members of the team meet to

discuss the patients, and the patient is not physically present in this space. The MDT

clinic is where one or more members of the team meet the patient. Through the course

of data collection and analysis, I found that the nature and content of the discussion

varied according to the forum in which the interaction occurred. With this in mind, I

drew upon the work of Goffman (1959) who detailed how people present themselves to

others in a similar way to a theatrical performance. We, as social beings, portray an

image to fit with the setting we are in, so that we can influence the impression that

others make of us. This also applies to 'team performances' where a cast of various

members are engaged in a joint performance, intended to portray a certain image to the

audience (which in this case is the patient and their supporters). *Dramaturgical*

analysis divides social settings into areas where the performance takes place ('front

stage') and areas where the actors can relax ('back stage'). With respect to symbolic

interactionism as described earlier, Goffman effectively identifies attempts by

individuals and groups to manipulate interpretations of social interactions though their

actions in different settings. The limits of this analysis must be made clear: it is contestable as to whether the MDT meeting is indeed a true 'backstage'. It could be argued that it is merely another frontstage, where the individual actor is the MDT member and the audience becomes the other members of the MDT, or me. Nevertheless, it is where the actors prepare for the performance, and 'impression manage', thus deciding how they are going to project themselves to the audience, and hence for the purposes of studying decision making in this setting, it is sufficient. I used dramaturgical theory as a tool to analyse, conceptualise and report the data.

4.6 Validity and Generalisability

As I have a background in quantitative research, at the beginning of the research I sometimes struggled to defend my methods to a clinical audience. Indeed, a criticism levelled at the qualitative methods of enquiry is that they are too subjective and cannot be extrapolated to apply to any other population than that which was studied (Mays and Pope 2000). To address this, I have found the description about the reliability of qualitative research by Seale (1999) provides a clear and accessible response. According to Seale, internal validity is the extent to which research conclusions are supported by the population or setting directly under study, and external validity is the likelihood that these conclusions will hold true in other settings. Seale argues qualitative research provides detail or depth of analysis into the phenomena being described - a 'thick description' - and therefore potentially greater internal validity than a quantitative analysis. I aim for my findings to be applicable to other settings, however I accept that this decision of generalisability is one for the reader to make, and not an assumption made by the author. I am making no claims that the population that I am studying is an accurate reflection of another population seen in another MDT, but my

conclusions will be credible to a reader familiar with the phenomena under study, who can then judge whether the study results are applicable or useful in similar (but not identical) situations. In other words, whilst the population may not be generalisable, the emergent conclusions will be.

4.7 Data collection

I gained ethical approval from the Newcastle and North Tyneside 2 committee (reference 11/NE/0200) in September 2011. I also gained approval from the institutional Research and Development board for each data collection centre. The two main methods of data collection were non-participant observation and interviews. For clarity, I describe the methods of data collection before discussing the approach and recruitment of participants. This is because the nature and timing of the observations presented me with ethical issues and describing the way in which data was collected will cast light on the reasons why the approach and consent procedure was chosen.

4.7.1 Observation

The collection of observational data was central to this piece of work; it allowed me to directly observe meaning through action rather than via retrospective accounts. I performed non-participant observations in the MDT meeting and the MDT clinic in three HNC centres in the north east of England (see figure one). The MDT meeting is a gathering of healthcare professionals involved in the care of HNC patients which lasts between one and two hours. Following the meeting is the clinic (usually on the same day, but not in all centres) where some members of the team meet the patient. I observed the MDT meetings and clinics for 30 patients in total: there were 23 males and seven females, aged between 38 and 87 years. Most patients had one MDT meeting and

one clinic appointment, however sometimes patients had more than one: there was a total number of 35 MDT meetings and 37 clinic appointments over three centres (Centre A, Centre B and Centre C). The details of the included participants are included in table one:
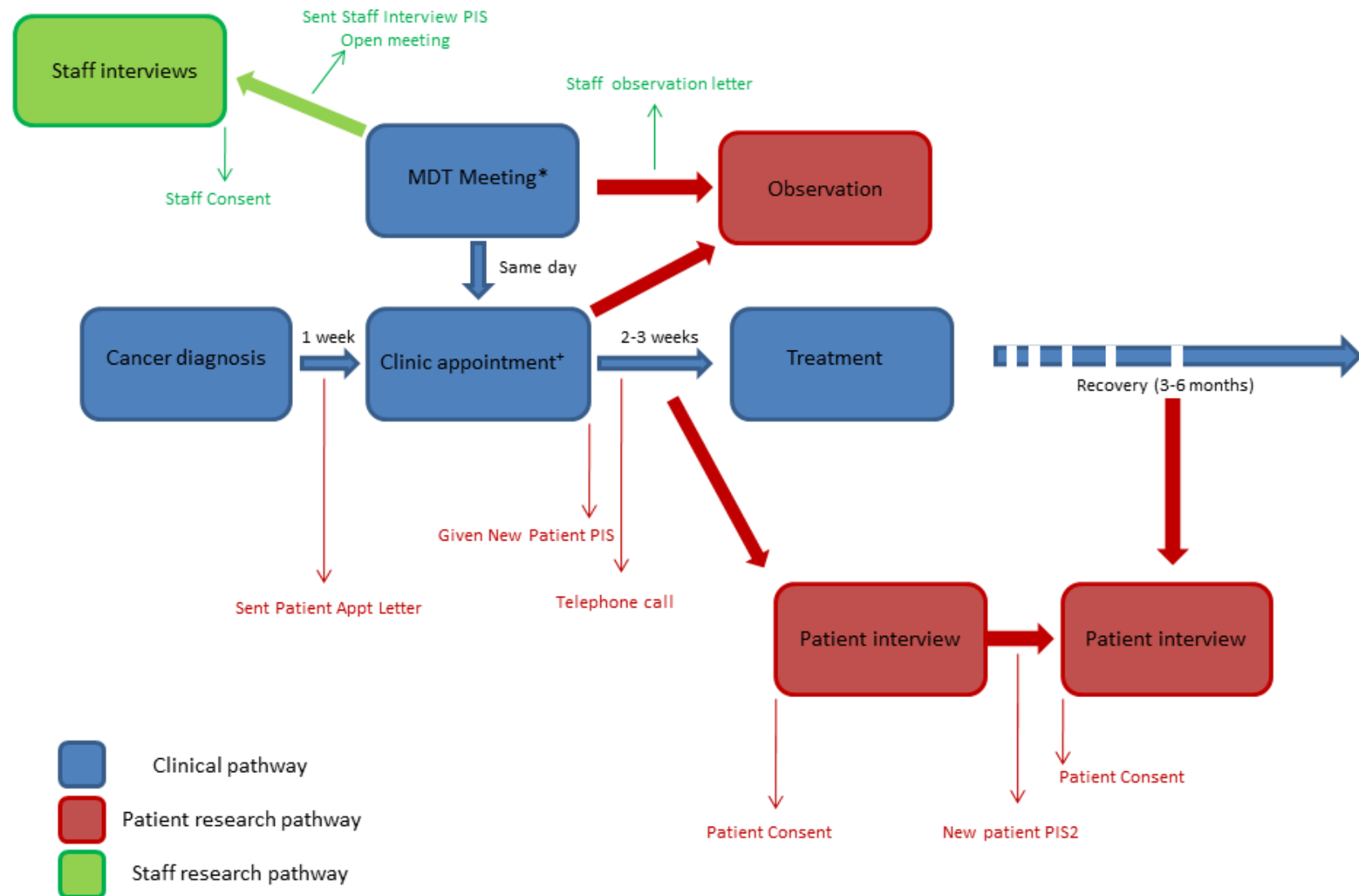
Figure 1: study flow chart

*MDT meeting between staff members: patient is discussed, imaging and pathology reviewed but patient is not present
+ Clinic appointment between some members of the MDT and the patient, where treatment decision is made

| PATIENTS: Group 1 | Centre | Age | Tumour site | Observation | | Int 1 | Int 2 |
				MDT	Clinic		
James Cain	A	68	Pharynx	1	1	1	1
Frances Cotton	A	82	Pharynx	1	1	x	x
Philip Vase	A	61	Parotid	1	1	x	x
Fred Barnes	A	71	Lip	1	1	x	x
Deborah Dolphin	A	54	Pharynx	1	1	1	x
Vincent Lowry	A	80	Pharynx	1	1	x	x
David Forcett	A	72	Pinna	1	1	x	x
Stanley Wright	A	87	Pharynx	1	1	1	x
Daniel Carding	A	64	Larynx	1	1	1	x
John Winton	A	61	Larynx	1	1	1	x
Bobby Older	A	52	Pharynx	1	1	x	x
Samuel Black	A	55	Pharynx	1	1	1	1
Keith Down	A	62	Larynx	1	1	1	x
William Runman	B	73	Pharynx	3	1	1	x
Andrew Driver	B	49	Pharynx	1	1	1	x
Donna Childs	B	52	Pharynx	1	1	1	x
David Jobling	B	63	Larynx	1	1	x	x
Sophie Leicester	B	49	Larynx	1	1	x	x
Edward Doman	B	73	Mouth	3	1	1	x
Eric Francais	B	65	Larynx	1	1	1	x
Gary Duck	B	57	Pharynx	1	1	x	x
Jean Dixon	B	63	Pharynx	1	2	1	1
Jane Doe	C	69	Pharynx	1	2	1	x
Margaret Brigstock	C	81	Mandible	1	2	x	x
Roy Dayson	C	60	Pharynx	1	1	1	x
Dana O'Malley	C	67	Pharynx	1	1	x	x
Gary Nicholson	C	46	Pharynx	1	2	x	x
Tracey Burnham	C	38	Larynx	1	1	x	x
James Matfield	C	70	Larynx	1	4	1	x
David Dale	C	84	Larynx	1	1	x	x
PATIENTS: Group 2 (interview only)							
Kevin Hair	A	82	Pharynx				
David Newman	A	57	Larynx				
Frank Sunnyman	A	52	Pharynx				
Phil Gardener	B	65	Larynx				
STAFF (interview only)		**Staff role**					
Mr Red	A	ENT surgeon					
Dr Orange	A	Oncologist					
Mr Surton	A	Maxillofacial surgeon					
Miss Salt	A	Speech and Language Therapist					
Tessa Darling	A	Clinical Nurse Specialist					
Mr Halifax	B	Maxillofacial surgeon					
Mr Blaydon	B	ENT surgeon					
Mr North	B	ENT surgeon					
Dr Goodier	C	Oncologist					

Table one: details of included participants

The MDT meeting and clinic only took place for around five to eight hours per week and therefore I was not able to spend extended periods of time immersed in the field in line with previous landmark ethnographies (Wirth 1928; Whyte 1943). At each meeting, I audio-recorded the entire discussion and took field notes. Often, in a single MDT meeting, only one or two patients were included in my study (discussed further in the section on sampling). The recording of the discussion of patients who were not included in this study was discarded, however I kept my reflections and field notes for the entire MDT meeting discussion. Once a patient had been selected for inclusion into the study, I approached the clinician who was due to see the patient in clinic, and asked for permission to observe this encounter. I then attended their clinic appointment, and audiorecorded the interaction between the member(s) of the MDT and the patient. I would often then observe the rest of the clinic, without taking any further recordings but sometimes made some field notes.

The main aim of the observations was to witness the real-life interaction of the team with one another and with the patients. I was interested in the way in which the available evidence was interpreted by members of the team, the way in which this evidence was mobilised and used to form a treatment recommendation and the way in which this recommendation was delivered to the patient. I was also interested in the way in which the team interacted with the patient and the role that patient had in the formation of a treatment decision. The audio-recorded data for the selected patients were transcribed word for word and data were anonymised by changing names before analysis. Before, during and after the meeting I had informal discussions with many of the staff members and asked questions about their thoughts or actions which I recorded in field notes. These notes also contained details of the context of the observed actions

of team members, non-verbal actions or visual observations and reflections at the time. I then transcribed all field notes into a 'reflective diary' immediately following the meeting, together with my own reflections on the situation.

4.7.2 Challenges when observing

I have worked as a clinician in some of the research sites, sometimes alongside clinical staff who participated in this study, which has both positive and negative effects. The main beneficial effect was that my background eased access to the setting as my key participant who negotiated access on my behalf required little explanation of the study. In his 1943 book, Whyte explains that his relationship to a key member of a studied group and the standing of this individual within the group was more important to the members of the group than the researcher themselves (Whyte 1943). I certainly found this when starting my research at Centre B. One of the MDT members wanted to ask some questions about the ethical process and the destination of the recordings, but directed these questions to one of the HNC consultants rather than me. Although he contacted me for the answer, it was clear that the assurances of this consultant to his colleague about my credentials were a more important factor than my answers alone. This is in direct contrast to the advice of Goffman, who feels that this 'top-down' approach to access can lead to problems; a point that he describes as the "affiliation issue".

> You can't move down a social system. You can only move up a
> social system. So, if you've got to be with a range of people, be with
> the lowest people first. The higher people will 'understand', later on,
> that you were 'really' just studying them. But you can't start at the
> top and move down because then the people at the bottom will know
> that all along you were really a fink – which is what you are (Goffman
> 1989, cited from Travers 2001, page 36)

I did not find that problems arose from this. Firstly I am already a member of the group of "people at the bottom" and so did not have trouble affiliating with them. I am a surgical registrar who attended the meeting before this research began, but I was rarely called upon to speak, in a similar way to many other members. Secondly I made it clear to all participants throughout that my role was not one of "fink"; rather it was to examine how they function from a critical (not criticising) perspective; part of this involved having a sympathetic view of the work and challenges involved. Participants often knew me, which lead to minimal suspicion about my presence and often honest or frank insights during informal interviews. The language used in the MDT meeting was also often highly complex; the meeting moved quickly and complex, detailed conversations took place simultaneously. Through the course of the research I found that even when using technical language, the members of the team negotiated and manipulated with the same turn of phrase or nuance as when they used everyday language. As a clinician-researcher I found that I did not need to 'learn' this language and therefore had immediate access to these discussions.

My background also had potential drawbacks when performing observations. The fact that I felt that there were challenges in effectively involving patients in decisions led me to asking the question which led to this thesis. This means that I approached this work from the unavoidable viewpoint that there was a problem which needed to be solved. This concept is not unique and was termed by the anthropologist Malinowski as "foreshadowed problems"

> Preconceived ideas are pernicious in any scientific work, but
> foreshadowed problems are the main endowment of the scientific
> thinker (Malinowski 1922 cited in Hammersley and Atkinson 2007,
> page 21)

Also, the fact that I have worked previously in this setting as a clinician meant that I may have already constructed my own meaning for the objects that the group are drawing on to make a decision; it may be that I don't see the situation through the eyes of the "stranger" (Schutz 1944). This has the potential to mean that I would struggle to gain analytical distance from the data and hence struggle to treat the data theoretically (Green and Thorogood 2009). Smaller but vital details may go unnoticed and as a result I strived to continually ask questions of the participants and my data. This is mentioned by Whyte:

> I had to balance this familiarity with detachment….whenever life flowed so smoothly that it was taking it for granted, I had to try and get out of my participating self and struggle again to explain the things which seem obvious (Whyte 1943, page 357)

I do not draw attention to these challenges to highlight deficiencies in the collected data, rather to demonstrate that I was aware of the challenges integral to ethnographic research and took steps to acknowledge or address them. My aim was that by acknowledging the challenges which I faced when collecting data and attempting to address them, the quality of the data which I collected would improve as a result. Thus, I tried to ask the obvious, 'taken for granted' questions, those questions which at times I felt I already had the answer to: "Why did you make that decision? What did you draw upon?" I strived for my field notes to not only reflect my own viewpoint, but the viewpoint of the participants, something which has previously been covered by Mitchell:

> The sociological observer must exercise sufficient discipline on himself to ensure that it is indeed the actors meanings that are recorded in his notebook and not merely his own (Mitchell 1977, cited from Crotty 1998 page 75)

When analysing data, I tried to make sense of the data and ground my analysis in the data collected rather than my own preconceived ideas (Green and Thorogood 2009), in

effect staying true to the data as far as possible. I led data analysis and report sessions where I explained my emerging analysis to supervisors and supported my interpretations by reference to the data, ensuring that the analysis did not drift into convenient or preconceived arguments.

4.8 Interviews

I conducted interviews with members of the MDT and patients at all three centres. Hammersley and Atkinson divide interviews or oral accounts into those which are "solicited" and those which are "unsolicited" (Hammersley and Atkinson 2007) and this is a useful distinction to draw here. Unsolicited accounts are naturally occurring explanations heard by the ethnographer and sometimes occur because the actual events are not in keeping with the normal run of events or the values of the group (Hewitt and Stokes 1976). Unsolicited accounts were captured with the audio-recorded data or the field notes. Solicited accounts are produced as a result of formal questions of the researcher to the participant however many feel that these accounts are affected too much by the researcher (Becker and Geer 1957). These solicited accounts were collected 'formally' and 'informally'.

4.8.1 Informal interviews

In the field, I regularly asked informal questions of participants to gather their views on a situation, or question their reasons for a certain course of action, and recorded the resultant data in my field notes. Similar to previous accounts (Hammersley and Atkinson 2007), I found certain times and settings were suitable for gleaning these. Between the MDT meeting and the clinic there was often a 10-15 minute period when MDT members would speak informally with one another. This was a good opportunity

for me to join conversations and ask informal questions. Equally in the MDT clinic

there is a lot of the time spent waiting for patients to come in or between patients

(writing notes, dictating letters etc.) where staff members would debrief from

particularly difficult decisions or prepare for the next consultation; here some very

interesting data would be gathered.   This time spent informally interacting, was a real

opportunity to get inside the experience of working in a team. I was made to feel as part

of this, and my membership sometimes allowed me some insight into the gossip around

the table. These data provide an invaluable, unsolicited insight into the possible

motivations for particular courses of action.

4.8.2 Formal interviews

I conducted formal interviews with patients and health care professionals. These

interviews took place in a setting removed from the MDT room and clinic and were all

semi-structured. A semi-structured interview is a method of interviewing which allows

depth of investigation, but with a clear framework to guide questions. The interviewer

has a topic guide with the topics of discussion or specific questions on it (Green and

Thorogood 2009). Although the topic guide provided me with a framework to work

around, the format of the semi-structured interview allowed the participant to talk in

more depth on certain subjects and allowed me the opportunity to pick up on these cues

and probe if necessary. This means that the resultant data is comparable, but rich and in

depth. The development of the interview guide was iterative; as data collection

continued, the content of the guide evolved in order to explore emerging themes. I

performed interviews whilst going through the process of transcribing and analysing

observational data which allowed me to ask the participant specifically about their

feelings on certain points, or their reasons for a particular course of action. As the

research progressed I found I could also explore their accounts by highlighting competing accounts from other participants (anonymously) and their reasons for this. I found this was a much less threatening method of probing the participants which yielded interesting data. In the next section I describe the groups of participants that I interviewed and give some details of their characteristics. I describe some of the challenges which I encountered, particularly whilst performing the patient interviews, how I dealt with these, and the potential effect that they had on the data gathered.

Staff interviews

I performed formal interviews with nine members of staff (five surgeons, two oncologists, one speech and language therapist and one clinical nurse specialist: see table one) at three centres. Staff interviews took place with an individual staff member, usually in a clinical environment such as an office or a clinic room. I was aware that the interview data sometimes provide "idealised/motivational accounts" (Strauss 1993) meaning the perspectives elicited from participants were not always directly related to the actions of participants in the setting under study (Hargreaves 1977). However, the fact that I had observational data as well as interview data allowed me to compare the actions of participants in the field with the accounts given in interview. I always conducted interviews after I had spent some time observing in the fields, and never the other way round. I often used specific cases, conflicts or discussions as 'anchors' to talk about their feelings on a particular subject and this proved a useful way of exploring participants' views.

Patient interviews

Patient interviews took place with the patient and sometimes a relative or carer, usually at the home of the patient unless they were an inpatient at the time. This meant that the

atmosphere was usually more informal than the staff interviews. The aim of the patient interviews was to explore their experiences of making the treatment decision. I used the interviews to gain an understanding of the patients' perspective of the process, and the ways in which they feel it could have been improved. I interviewed two groups of patients

Group 1, prospective group: these were patients whom I had observed in the MDT clinic. I interviewed these patients at two time points: firstly between the treatment decision and the treatment itself, and again 6 months following the treatment. At the first interview I explored participants' views on the communication between them and the MDT regarding the diagnosis and treatment, and their experience of their interaction with the team and the decision process. In total I interviewed 15 patients between the treatment decision and treatment; of these 15 patients, there were 12 men and three women, aged between 49 and 87. I interviewed three of these patients between eight and nine months after their treatment (see table one). I interviewed fewer follow-up patients as a large number either were uncontactable, or felt that they were not yet ready to be interviewed again. The interview allowed me the opportunity to assess the patients' attitudes towards the quality of decision making before the bias effect of treatment related morbidity, but still recent to the clinic appointment, ensuring richness of the data and minimising re-call bias (Edwards and Elwyn 2009). During the second interview I explored the extent to which, and in what ways, participants' views may have changed following the treatment (Murray *et al.* 2009). I asked them about the treatment related side effects, their quality of life and their function following treatment and the correlation of their pre-treatment expectations with these.

Group 2, retrospective patients: I interviewed four patients (all male, aged 57-82) who had their treatment within the last 5 years. Again in this interview I explored the change that patients may have experienced in their view of the MDT decision following the completion of their treatment.

4.8.3 Challenges when interviewing

Although ethnographic methods provide an interesting and rich analysis of the MDT decision making, patient interaction with the MDT could be minimal. The patient often had little role in the consultation, and therefore there was sometimes little interaction to draw upon to aid analysis. This made it more difficult to draw on the patient's perspective of the process of decision making. Although the lack of data here helps to illustrate the problem, it makes patient interviews challenging, as the patient has had very little to draw upon whilst making the treatment decision. Not only this, but my dual role of clinician-researcher surfaced as a challenge time and again during interviews, and was something that affected me in many ways. I first noticed it during my very first patient interview:

> He preferred to resort to stories or sayings when talking about the experience, and often gave short answers with no elaboration. I got the impression this may have been because to elaborate would have unlocked feelings and emotions which he did not want to unlock before the operation. I felt it would not be in his best interests to push too hard for answers – it was not something he wanted to do, and may have spoilt the rapport we had built up (Field Notes, 3rd January 2012)

The patients were often in a frame of mind where they were being brave before entering into treatment and had sometimes built a wall before entering into a very scary and daunting process. I often felt that I should not dismantle this wall just for the sake of good quality data. The issue of knowing how 'deep' to probe was also linked to my background as a clinician:

> I am very used to interviewing people in a clinic setting in a short space of time. The aim of that interaction however is to convert the stories of the patient into a scientific piece of writing, or a single piece of information, a diagnosis, in order to understand the story. If I am unable to understand the story, or fit it into a pattern, then the story is of no use to me and it is discarded. I will have picked up many bad habits, which must be shed. I am used to taking copious notes in order to fill in records, and being limited by time. I think it will help, in that I am used to talking to patients about sensitive matters, and used to covering difficult subjects such as cancer and death. I must make sure I shed bad habits though, and encourage good ones (Field Notes, 13th October 2011)

I sometimes felt that were I to ask too many questions and explore their decision making process, they may feel that, as a clinician, I was questioning whether or not it was the correct decision to make:

> I don't feel that my interview technique is yet up to scratch. I am trying to open up my questions, but I don't think I am really peeling back the layers of the onion and finding out the true feelings of the patient. This is partly because it may upset them – I don't see my role as being one where I go along and upset the patient and their family; perhaps make them doubt that the decision that they made is a bad one – I think I am constantly aware that I don't want the patient to feel that I think (as a doctor) that they have made a bad decision (Field Notes, 9th March 2012)

I found that the main challenge of being a clinician-researcher was the role that the patient saw me as having when carrying out semi-structured interviews. The patient was often confused, anxious and in need of information which in itself illuminated the nature of the problem under study. As participants knew that I was a doctor, they often used the interview as an opportunity to ask questions and explore anxieties, which can lead to a consultation rather than a research interview – this is a problem which has been previously described (Richards and Emslie 2000). I adopted various techniques to minimise the impact of this, but I was constantly aware of the effect that this behaviour may have on my data. I had the choice between providing the required information, which would potentially compromise the nature and quality of the data I was gathering,

or to come back to these questions at the end. I found that to delay things sometimes led to me appearing unhelpful and evasive and the discussion which ensued following information giving was interesting, but sometimes off the recorder. For this reason I would sometimes give some information during the interview but found I had to carefully balance my roles of information giver and receiver.

Without doubt, the most personally challenging aspect of my interviews was when I didn't agree with the treatment decision which had been made. This presented me with a direct choice: to act as a clinician or researcher:

> ....the main thing was my own ethical dilemma which distracted me for most of the interview - "this chap is making the wrong decision" - this is I suppose the clash between clinician and researcher. As a clinician I would have struggled to let him make that decision in the first place, and may have even persuaded him out of it as I think it is based on misinformation, but as a researcher I am there to find out why he made it. I find the case interesting but also quite frustrating. .... he is now too far down the line to change his decision anyway. I also know that my role in that situation is certainly not one of clinician, but I can't just drop it - I think I saw myself as having a 'duty'. I think that meant that I did the interview half as a clinician, and half as a researcher. What resulted was the worst of both though. As a clinician, I would have quite happily have said I don't agree with your decision and then taken it from there (he may of course have stuck with his guns), but I didn't feel I could say that here. But his decision (radiotherapy) doesn't match his priorities (cure). (Field Notes, 19th March 2012)

In all of these situations I primarily acted as a researcher as this was the role that I was taking whilst interviewing. Most patients knew that I was a doctor; this was sometimes because I had been introduced as such during the clinical encounter, sometimes because I had used my profession to facilitate access and sometimes because it was an assumption by the patient. I neither advertised nor hid my identity as a clinician, however I often found during interviews that it was necessary to reveal it, mainly because I was in a position where I could help.

By pointing out the multiple challenges in gathering interview data, my aim is not to give the picture that it is of poor quality; rather that I have strived to be aware and open about the challenges of interviewing as a clinician so that I tackled the problems and difficulties I faced, and improved the quality of the data that I gathered. My clinical background did have unexpected benefits: a number of the patients included in this study had a very poor voice, or no voice at all as a result of the cancer or its treatment. This presented me with a unique methodological challenge in carrying out qualitative interviews which are reliant on the spoken word. I used various methods to get around this. Firstly, I am very used to working with patients in this position, so feel confident in talking to patients with these limitations. I often ensured a relative or carer was present for the interview, to help with interpretation of what the patient was saying. It was important in these situations not to let the carer take over; I made sure that the patient answered my questions as well as the carer, and I constantly checked if they agreed with what was being said. I used pieces of paper for the patient to write on, and kept these at the end of the interview. I always transcribed these interviews myself, and inserted in the written notes at the appropriate points in the transcript. Also, I sometimes had to guess what was being said during the interview based on lip reading and gesticulations of the patients. When I was correct, I said it out loud (with the patient agreeing), and then transcribed it as being said by the participant.

4.9 Recruitment and consent

The process of recruitment and consent for the observations presented me with multiple challenges: I was collecting highly personal data about patients before they had met the clinical team, and sometimes before they had even been given their diagnosis of cancer. This meant that I had to exercise caution when approaching them for inclusion in the

study and adopted an approach which I felt was patient-centric rather than designed simply to meet the minimum guidelines set by the ethics committee. In this section I discuss the approach, recruitment and consent of participants.

4.9.1 Patients

Inclusion/exclusion criteria

Patients were excluded from the study if they did not understand written or spoken English, or they did not have the capacity to consent. Patients were eligible for inclusion into the *observation* phase of the study if they had a decision to make about treatment for a HNC – there is more detail about this later in this section. For the *interview* phase of the study, I concentrated on patients with laryngeal and pharyngeal cancer (see table one). The reason for limiting the interview phase of the study to these cancers is to allow any recommendations as a result of this study to be more applicable to patients in these groups. As I discussed in Chapter One, the term "head and neck cancer" encompasses a large range of different cancers. There is great variability in the types of decisions that these different groups of patients face. The largest proportion of patients in the MDT clinic have cancers of the larynx and pharynx, and face similar trade-offs between survival and function.

Group 1, prospective patients

At the end of the MDT clinic consultation, the clinician informed the patient about the study and provided the Participant Information Sheet. At least 48 hours after the information had been given, I contacted the patient by telephone. During this telephone call I presented the patient with three options:

1) Have no further involvement in the study and have all data collected so far concerning them securely destroyed.

2) Have no further involvement in the study but allow all data collected so far to be retained in the research project.

3) Continue with the study and agree to an interview.

If the patient was willing to continue in the study, I arranged to meet them at a location of their choice (usually their own home) where I obtained written informed consent for the first interview. At the end of the first interview I asked them if they were willing to be contacted again regarding a second interview six months following their treatment. If they were in agreement, I contacted them by telephone around six months after they completed their treatment. Prior to this telephone call I liaised with the clinical team to ensure that it was appropriate for a given patient to be re-contacted. As with the first interview, I arranged an appropriate location and gained written informed consent for the second interview.

Group 2, retrospective patients

I recruited patients from the follow up MDT clinic who have had laryngeal or pharyngeal cancer treatment within the last five years. Patients were identified with the help of the clinical team from the MDT coordinator and follow up clinic lists. Patients were sent an information sheet which contained a slip which they returned if they agreed to take part in the research. Prior to the interview I gained written informed consent.

4.9.2 MDT members

Inclusion/exclusion criteria

Any staff members attending the MDT were eligible for inclusion

Observation

I collected data from one centre at a time, beginning at the Centre A, then Centre B, then Centre C. To gain access at each centre, I approached one of the lead ENT consultants and told them in detail about the work. The consultant then sent an e-mail (composed by me), to the members of the MDT. Two or three weeks following this I attended my first MDT meeting where I collected no data, but spoke briefly about the project and answered any questions. In addition to this, MDT members were provided with my contact details so they could ask me any questions more privately if required. The week following my first MDT meeting attendance, I began data collection.

Interview

Potential interviewees were contacted by e-mail which invited them to be included in the study, with a participant information leaflet attached. Staff members registered their interest by e-mailing a reply. I gained written consent before the start of the interview. Various different staff members attend the MDT meeting, and the following brief descriptions will help to contextualise the data gathered from observations and interviews:

ENT surgeons: involved in the diagnosis and investigation of the HNC. They carry out many surgical resections of HNC.

Maxillofacial (Max facs) surgeons: similarly involved in the diagnosis and investigation of the HNC patients. They carry out surgical resections and surgical reconstruction

Plastic surgeons: involved in surgical reconstruction following cancer removal which means they often have an advisory role to the surgical team.

Oncologists: treat all types of HNC, and specialise in the delivery of non-surgical treatment; radiotherapy and chemotherapy. Many oncologists also have an interest in cancers of other regions of the body

Clinical Nurse Specialists (CNS): usually assigned a number of patients each, and act as support to the patient throughout treatment and recovery. They have a nursing background and specialise in the care of HNC patients. They are the first contact for a patient in the community and often form close relationships with patients.

Radiologists: doctors who show the radiology images and discuss their report and opinion with the team in the MDT meeting

Pathologists: interpret the specimens which have been taken either during biopsy or resection of the cancer. They give information about the type of the cancer, the size, and whether the cancer has been completely removed.

Speech and language therapists (SALT): involved in assessing the swallowing and speech patients before treatment and in the rehabilitation of these functions following treatment

Dietician: involved in optimising the nutritional intake of a patient in order to prepare for treatment and to rehabilitate successfully.

Registrars: A registrar is one grade below a consultant in the medical hierarchy; registrars from all of the medical specialities attend. There is one 'lead' registrar for the ENT and max facs team, who usually take a principal role in providing clinical information about a patient at the start of the MDT meeting discussion.

Administrators: the administrators for each team have slightly different roles and backgrounds. Administrators ensure that all patients are being seen by the correct consultant, and all clinical data from the clinic is entered correctly into the database

Palliative care: There is a Palliative care consultant at the Centre B, a physician who specialises in the care of the patient for whom treatment is not with curative intent

Restorative dentists: Centre A and B included a restorative dentist who helped patients deal with the effect of treatment on their dentition

Clinic staff: Often a small number of nurses from the clinic that day will attend the meeting as observers

Students: There are medical, nursing and SALT students who attend the meeting as observers for educational purposes

4.10 Sampling

Throughout this study I have used purposive sampling to select participants for recruitment. The aim of purposive sampling is to develop the concepts and themes which were emerging from the data (Charmaz 2006). It was intended to build concepts and allowed me to continuously ask questions of the data. When sampling I was interested in performing an analysis of how decisions were negotiated in this setting, which altered the way I sampled between and within cases. My sampling strategy loosely followed a three stage procedure previously described by Strauss and Corbin (1990). Firstly, a convenience sample was collected; participants were included opportunistically in order to begin analysis. I took an interest in a wide range of decisions; treatments in early disease, advanced disease, adjuvant therapy or palliative decisions. In doing this I achieved a wide spread of patients, ages, comorbidities and

socioeconomic classes.   As the analysis unfolded and I began to think and write

critically about these decisions, I searched for cases which would test the concepts and

themes which were emerging. For example, in the early cases, I noted that palliative

options were often not discussed or offered in the clinic, and I was keen to explore why

this might be the case. I often had a choice of patients to include from each clinic, and

so I searched for a patient to include who had options for treatment, one of which was

palliative; I then used this case as a basis for formal and informal discussions with the

clinicians and patients about their attitudes towards palliative care and decision making.

In his study of paediatric consultations, Strong (1979) also had to consider how to

sample within cases – decisions needed to be made about whom to talk to, what to

observe and what questions to ask. This was one of my considerations: I was interested

in the decision process, rather than the patient experience of cancer and rehabilitation or

an in-depth view of patient experience of receiving cancer treatment. This altered the

way I interacted with and asked questions of the staff and patients. In the later stages of

the study, sampling was used to test the concepts which were emerging from the data,

seeking out deviant cases and maximising the differences between cases. Similar to

previous ethnographies (Skolnick 1966; Moffatt 1989) I also sought to see how my

concepts would hold up in other settings by visiting MDTs abroad to see if my analysis

of decision making was generalisable to other groups. The outcome of some of these

comparisons and observations are discussed in Chapter Nine.

After finishing data collection in one centre I would stop fieldwork for two to three

months in order to further my analysis, write memos about emerging themes, and

discuss my emerging findings with supervisors. Initially, my aim for sampling was to

achieve *theoretical saturation*; this is the point at which sampling and analysing is

continued until nothing new is found (Charmaz 2006). Although this may be possible with smaller, or more straightforward projects, the notion that this can be achieved is controversial and it has been suggested that it may inhibit exploration of data (Dey 1999). In my setting, the large range of patients, clinicians and potential treatment decisions made this task almost impossible; hence rather than claiming saturation, a more appropriate term would be *theoretical sufficiency* (Dey 1999)

I did encounter challenges when sampling. There were a large number of patients discussed at each MDT meeting, sometimes more than 30, meaning that many patients potentially could be included in the study. Firstly, I had to be careful not to only select straightforward examples of radiation therapy vs. surgery. Although these cases are important and provide a picture of decision making in this setting, to limit my analysis to these dichotomous decisions may provide a simplified picture of the challenges faced in this setting. At the same time by only concentrating on more sensational, problematic or crisis patients I would give a view which was not representative of the routine work of the clinic. More exceptional patients were included from time to time as their cases could also serve to cast light on the more mundane phenomena (Hammersley and Atkinson 2007), but I was careful that they did not form too large a proportion of my sample. Secondly, my primary inclusion criterion was a patient with "a decision to make". In essence, every patient had a decision to make; to be treated or not, indeed to turn up to clinic or not, therefore all patients in the clinic potentially meet this criteria. Nonetheless, some patients, on the face of it, did not seem to have a decision to make as they were provided with a single, clear treatment recommendation by the MDT. However, I sometimes viewed the patient accepting the radical treatment as a decision, or included cases where treatment options were the subject of a long discussion in the MDT meeting, but not then offered to the patient in the MDT clinic.

Thus in the MDT clinic, it may have appeared to a patient that they did not have a decision to make, but the patient was included because the discussion cast light on the process of making a treatment recommendation and a decision in this setting. Hence, my process of patient sampling aimed to provide an analysis that presented a credible representation of routine MDT meetings. This required a combination of my clinical experience, my data and analysis so far and the discussion which was unfolding in front of me.

4.11 Data Analysis

I have described previously the theoretical and methodological foundation of my data analysis. In this section, I describe the practical process I followed to perform data analysis.

Stage 1, reading

All data was collected by me, and detailed field notes were made at the time, and transcribed immediately afterwards. I transcribed all MDT meeting observations, seven MDT clinic appointments, and all patient interviews where the patient had no voice or severe problems communicating. All other observations and interviews were transcribed by others, but I read though and listened to each transcription on at least two occasions before coding. This stage also involved some informal analysis as I recorded my observations and attempted to make sense of them in my field notes.

Stage 2, open coding

Following the reading and familiarisation, the data were coded. The first stage of this was 'open coding'. To do this, I read the data and then assigned a 'code' to each line. At the start of data collection assigned codes were very descriptive, however as data

collection and analysis continued, I developed a sense of the data and was able to apply more analytic codes. I aimed for the codes to be analytical rather than descriptive (Charmaz 2006), to say what the data was about; not just a summarising word, but a conceptual label (Charmaz 2006; Green and Thorogood 2009). In practice, assigning analytical, conceptual codes, especially to observational data was challenging. The observational transcripts contained a lot of people speaking in short, overlapping and sometimes unfinished sentences. The language used was often highly technical with lots of interruptions which made the codes assigned quite descriptive at times. This meant that coding this type of data presented me with challenges demonstrated in the example below:

| Observational data	Assigned open codes
MR JUNIOR: On examination there was a right level 2 lymph node, which was about a couple of centimetres on fibreoptic endoscopy he had swollen retromolar area with a hole…. on direct questioning he said he had a tooth inspection recently. He was found to have a large tumour which was filling the right piriform fossa going to the posterior cricoid area, right supraglottis, up to the right vallecula. So he was brought in for panendoscopy and biopsies, and I think the findings were confirmed to be the case. There was a large T3 tumour arising from the right piriform sinus going onto the right pharyngeal wall and biopsies were taken at the time Dr Slide: They showed a moderately differentiated invasive keratinising squamous cell carcinoma and that was HPV negative MR JUNIOR: He has also had a CT scan	Cancer spread Cancer position Cancer size/extent Treatment so far Staging of cancer Cancer type

DR WINDOW: He had the scan in South Tyneside, here it is…. So as we are coming up and we are coming down, there are bilateral necrotic level 2 3 and 4 lymphadenopathy, so the largest one on the right is 2.5 by 2.1 and the left 2.1 by 1.6 cm. With regards the tumour, there is a tumour which is there in the vallecula, abutting onto the epiglottis and then down to the right side in the right aryepiglottic fold involving the entire piriform fossa. Coming out of it laterally, but probably still within the confines of the….no extra laryngeal spread. There's the tumour, and then going posteriorly, just coming across the midline and then we're going further down, it looks like it is involving the right side of the post cricoid space. So a large, measuring about 3.5 by 2.4 by 5 cm. Piriform fossa and post cricoid and aryepiglottic fold involving paraglottic space, part of the vallecula above the epiglottis and tongue base, oesophagus is fine. With regards the rest of him with regards M, he's got… lungs are fine, no hepatic abnormalities, we've got an incidental adrenal adenoma and that's it. Considering he's got so much, it doesn't look too bad really. Liver's a little enlarged, the spleen's normal, so there we are	Cancer spread Cancer position/extent Cancer staging information Cancer size Cancer spread Other health problems Using previous experience
MR BLONDE: Thank you. That's T4 then, N2c	Cancer staging
DR WINDOW: N2c and er….	
MR BLACK: I scoped him and I'm sorry the pictures are not there, it's on my desktop. It's a very large tumour. There is nothing in the vallecula that I can see in….	Dealing with practical difficulty Staging disease

In the example above, the focus of the discussion was to build up a clinical picture of

the patient, or a 'case', at the start of the MDT meeting. In order to move beyond

descriptive tags I tried to concentrate on the mechanisms that shape these encounters.

Here, the code "case building" suggests the gradual accumulation of evidence and this may be used to group and define the codes above. In this sense, I have coded the process rather than specific topic of speech.

Stage 3, axial coding

After the open coding of four or five transcripts, a coding framework was drawn up. This is a framework which details the common, important or recurrent codes. Codes are linked together if they are similar, and a group of connected and interlinked codes are gathered together in to a 'theme'. An example of this is the code "interaction" (figure two):

Figure 2: interaction code
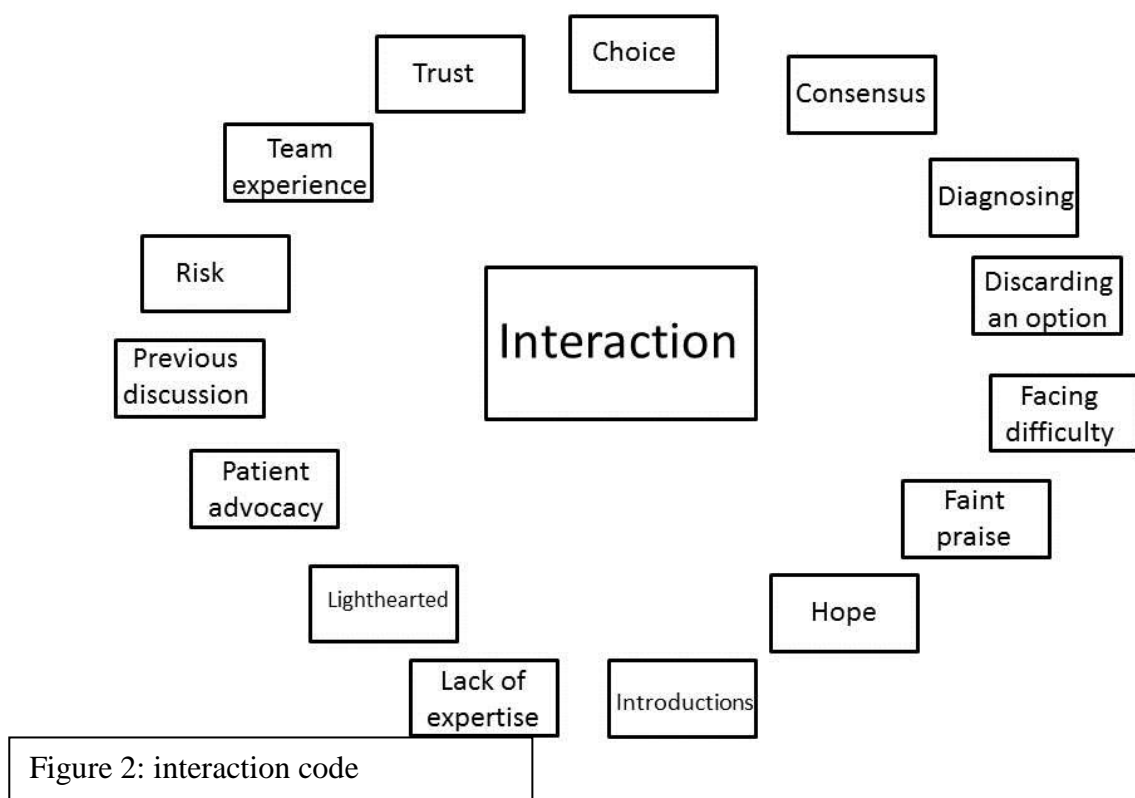
As analysis went on, new codes were generated. These were added to the framework, and transcripts which had already been coded were re-coded to incorporate these. As I

had many different forms of data, there was a potential issue with how many coding frameworks there should be. To have separate frameworks for interviews with different patient and staff groups, and observations from different settings would be unwieldy and would act to fragment the data and emergent concepts. With this in mind, I attempted to code the data into as few frameworks as possible in order to emerge with a coherent joined-up message.

The codes used were derived completely from the data, and were not pre-determined. The coding was organised using the NVivo computer package. This package allows short segments of data to be logged under a particular code and kept in electronic files, rather than having to physically cut and paste the hard copies of the transcripts. The ongoing process of coding did not take place in isolation; the framework was constantly adjusted and clarified according to the transcripts being coded and the new data collected

Stage 4, memo writing

Memo writing was a central part of my analysis. A memo is a piece of writing about a code which detailed my interpretation of a code, and the idea or concept which it demonstrated (Strauss and Corbin 1990). Memos included ideas about the data, details about the analysis of the data or hypotheses and theories about how the codes inter-related and the relationships between them (Green and Thorogood 2009). Memos were used to develop a deeper description of the codes and the data. In this way, memos allowed the development of theory; this was used to guide further sampling and as a basis for the emerging data chapters. These memos were presented to supervisors and colleagues and then improved upon by collecting more data.

Stage 5, generating testable propositions

The process of data analysis provided a rich description of the process of treatment recommendation and treatment decision making, from the perspective of the MDT and the patient. In describing the process of decision making I discussed the rationale for increasing patient involvement in treatment decision making and highlighted the challenges in achieving this. I used the analysis to build an alternative model of the structure of decision making in the MDT. In addition to this, and in order for the work to provide a solid platform for further improvement in decision making in this setting, I described a series of barriers to patient involvement and provided clear recommendations to overcome these barriers. The findings can then be used as the basis for further work in this setting and hence ultimately lead to an improvement in care.

4.12 Conclusion

In this chapter I have described the epistemological and ontological foundation of the thesis and how this theoretical standpoint was enacted via my techniques of data collection. As the MDT meeting and clinic only exists for half a day a week, I was not able to continuously immerse myself in the field as with some 'classic' ethnographies. However, my method of inquiry respected the principles of naturalistic enquiry by placing me directly in the setting under study, allowing me to observe meaning through action. My position as a clinician researcher presented me with multiple expected and unexpected challenges; however I firmly believe that this status has awarded me with more benefits than problems. Importantly, my previous status as a participant in the MDT allows me to conclude that the discussion and actions which unfolded were a true representation of the routine work of the clinic. The methods which I have described in

this chapter provided me with multiple, rich sources of data. This means that my analysis, by being grounded in the data, provides a detailed analysis of the real practice of MDT decision making rather than an idealised account. The data shed light on the barriers to effective patient involvement, but importantly, allow me to explore the reasons why such barriers exist, and in doing this provide insight into how these barriers may be overcome. Thus, the thesis should provide a solid foundation for care to be improved in this setting. In the next chapter I will present the first part of my analysis: the way in which the MDT team interact with each other and the information which is available to them.

Chapter 5: The MDT Meeting: Laying the Foundation

At face value, the aim of the discussion at the MDT meeting seems simple: to make treatment recommendations for patients with HNC.   Through the course of the next three results chapters I use the data that I have collected to illustrate the complexities and challenges in this process, and go on to demonstrate the effect that these complexities have on clinical decisions and patient engagement in MDT decision making. Specifically in this chapter I describe the evidence that is used by the team as a basis of the treatment recommendation. I discuss how different pieces of evidence hold different levels of importance in the room and how this hierarchy is continually re-worked through interaction among members of the team.

Before continuing, I will explain the terminology used in this chapter. For the purposes of clarity, and to reflect the prevailing viewpoint, I refer to the outcome of the MDT discussion as a treatment *recommendation*, and the outcome of the interaction of the team with the patient in the MDT clinic as a treatment *decision*.

5.1 Information about the patient

A treatment recommendation cannot be made without information about the patient. In order to begin to understand this, it is helpful to have an understanding of the process through which a patient moves before reaching the MDT clinic. Most patients attend the hospital with a symptom, such as a change in their voice or difficulty swallowing, and are then seen by a surgeon (who may or may not be an MDT member), who takes a history and performs an examination. The surgeon then organises an examination under anaesthetic (EUA). During this procedure, the surgeon looks closely around the mouth, throat and voicebox in order to assess the size and position of the cancer. Biopsies

(small pieces of tissue) are taken during this procedure, and these are reviewed by the pathologist. Around the time of the staging assessment the patient also has scans of the head, neck and chest and these are reviewed by a radiologist. The MDT meeting is the culmination and amalgamation of all of this work.

In the MDT meeting, all centres observe certain conventions as a matter of routine. The meeting is chaired by one clinician and is brought to order. The first patient's name is read aloud and one of the clinical team (almost always a surgeon) gives the details of the clinical history, examination and the EUA. This clinician may have been the person who performed these assessments, or may refer to the notes of the person who did. The pathologist then reads out the results of the biopsy, confirms that this is a cancer, and sometimes gives information about the type of cancer or its aggressiveness. Finally, the radiologist talks through their opinion on the scan, whilst showing the scan images to the team on a screen. Although more evidence than this is often presented, the evidence detailed here is given at all meetings and appears to be viewed as the minimum dataset – without all of this information, the patient discussion is postponed until this information is available.

Following this routine presentation of clinical data, a discussion takes place about the treatment recommendation. Most of the discussion, especially at the early stage, is about the cancer: the precise anatomical site, size, extent and spread. This information is put together to form the tumour, nodal and metastasis (TNM) stage (see Chapter One). The reports that the pathologist and radiologist give are pre-prepared and often accepted as undisputed fact within the team, which usually leads to very little discussion about their source or content. These 'facts' directly form the TNM status, the foundation of the recommendation. The following are observational data from a case of

Vincent Lowry, an 80 year old male with a cancer on his soft palate. The radiologist

gives his report during the meeting:

> Dr McCain [radiologist]: On the right hand side, he's just got this
> slightly increased enhancement in the tonsillar fossa, and little sort of
> cystic focus in there of fluid, just sitting there, about a centimetre in
> size. The degree of enhancement is very mild, I'm not sure what I
> would call this, the thickening also is pretty mild. ....the soft palate
> appears normal in CT [computerised tomography], the tongue base
> appears normal on CT, and there's nothing extending down into the
> hypopharynx; it's very much just a localised area in there, that
> tonsillar fossa. He's got a couple of very tiny little retropharyngeal
> lymph nodes like that, but they're within normal limits. And then,
> again, the deep cervical chain nodes down here are not enlarged, so I
> think we can say that it's N0 [referring to N stage zero], on the basis
> of this.....
>
> (Vincent Lowry, Observation, MDT meeting, Centre A, 19th January
> 2012)

I observed that the role of the radiologist in this situation was to report the scan and, in

doing so, describe the cancer as accurately as possible. The radiology report leads

members of the MDT to convert the radiological information into a TNM status, in this

case T1N0M0. The criteria for assigning a TNM status are well-documented (AJCC

2010) and well-known in the team. When the TNM status has been assigned it is

sometimes said aloud by any member of the team. At other times it is assumed by the

MDT members that others will have come to the same conclusion and there is only an

implicit conversion to a TNM stage. The TNM status, when decided, is used as a basis

of the treatment discussion, and I observed that this information is usually not

questioned. However, when looking closely at the language used, the members of the

MDT cannot treat this information with absolute certainty: "and little sort of cystic

focus" and "I'm not sure what we would call this". Although the radiologists'

observations are converted into a simple objective fact (T1 stage), the specific language

used demonstrates the subjectivity underlying them. The team use the radiographic

staging as a foundation for the ongoing discussion, and the uncertainty which underpins it is ignored in order to facilitate the negotiation. To calculate the N (nodal) stage, the radiologist reports the number and size of the lymph nodes in the neck; this gives the team information about whether the cancer has spread. At the end of the report, the radiologist clearly concludes that this is N0, something which I observed was taken forward by the team as fact. However, the language used to reach that conclusion is again open to interpretation. "He's got a couple of tiny little retropharyngeal lymph nodes, but they are within normal limits". If it was absolutely certain that these small lymph nodes were of no significance, they would never have been mentioned. The language used is not unequivocal, and the concerns about lymph nodes which are enlarged but "within limits" are voiced, perhaps with the intention of displaying the difficulty in reaching a conclusion of N0, or perhaps to absolve the radiologist of responsibility if the patient is under treated as a result of the report. In most cases, the TNM status is decided during the pathology and radiology reports, and is used as an undisputable basis of the entire discussion about treatment. At points of conflict, however, when one or other member of the MDT needs to reinforce a point, the openness of these facts to interpretation is revealed.

Later in the MDT discussion about Vincent Lowry, I observed there was a conflict between MDT members about whether the treatment should be laser therapy (suitable if the lesion is smaller) or radiotherapy (suitable if the lesion is larger). In the following observational data extract, Mr Red, an ear nose and throat (ENT) surgeon felt that radiotherapy was the best option and was therefore insisting that the lesion was not small and localised. Mr Black is another ENT surgeon, who felt that the tumour was indeed small enough to be treated with laser therapy. During their exchange they return

to the radiology report and reveal how the information provided within it can be interpreted differently by individual members of the team:

> Mr Red [ENT surgeon]: This is the level of the tonsil and soft palate, it's not T1
>
> Dr McCain [radiologist]: well as I say I think it's quite difficult to see on the CT because
>
> Mr Red: You can't call that T1!
>
> Dr McCain: All we can make out is actually going on up in the palatine/tonsillar fossa, round here where it is more thick, and you've got that little cystic space. So it's quite difficult to differentiate the margins.
>
> Mr Red: That little cystic space isn't going to be just a little cystic space I wouldn't have thought would it? Do you think it is? Just a little, innocent, little cystic space that you can just take a 5mm margin round?
>
> Mr Philips [plastic surgeon]: But this is when the TNM classification is inadequate
>
> Mr Red: No this is where you don't treat an x-ray, you treat what they look like!
>
> Mr Black [ENT surgeon]: The margins for a tonsil will be the superior constrictor muscle, it won't be a smaller margin for a lateral oropharyngectomy procedure. The soft palate will be superficial tumour, I'll go down to muscle, and then I'll come up [describing surgical removal of cancer]
>
> Mr Red: I know how to do the operation, you don't need to…. All I'm saying is I don't think it's an adequate operation, I think it's an operation instead of more adequate treatment, which in my opinion would be radiotherapy …. You've never scoped him have you? Mr Black? You're just treating the x-ray and the histology aren't you?
>
> Mr Black: And that picture
>
> (Vincent Lowry, Observation, MDT Meeting, Centre A, 19th January 2012)

The discussion leading up to this point had centred solely on the details of the cancer and the TNM status. When directly questioned, the radiologist revealed the difficulty with giving the precise answer required and this uncertainty was used by Mr Red to

argue that this tumour was larger than had been reported. This provides a clear example of the MDT members using their interpretation of the available evidence to negotiate and reinforce their notion of the 'best' treatment for the patient. The argument between Mr Red and Mr Black became heated at times, which suggests both parties feel strongly about their perceived 'best' treatment, something which I recorded in my field notes:

> [Mr Black's suggestion for laser] caused a raised eyebrow and a smile from Mr Red – he is sitting directly in front of Mr Black and so this is not seen. There was some very robust debate… Mr Black was keen to laser the lesion, but almost everybody else at the meeting felt that radiotherapy was the best treatment. The pro-radiotherapy group was headed by Mr Red and some of the comments made between Mr Black and Mr Red were scathing.
>
> (Field notes, MDT meeting, Centre A, 19th January 2012)

Mr Black was facing opposition from a number of his clinical colleagues, but persisted with his assertions for laser, despite the weight of opinion to the contrary. There are many questions raised by these data: why is there such a disparity in the recommended treatment options between two surgeons of the same discipline? What it is that drives this and leads professionals to vehemently oppose one another? The answers to these questions are multi-faceted; they lie partially in the way in which MDT members interpret other evidence, which is not specifically related to the patient in question and partially in the way in which the clinician perceives a treatment as 'best'. I will explore these concepts later in this chapter and in Chapter Six.

It can be seen from the discussion above that the characteristics of the patient in the MDT meeting up until this point consists solely of the details of the cancer. None of the clinicians involved in the discussion have met or assessed the patient. The discussion includes the soft palate, the tonsil and the neck but nothing beyond this. The cancer TNM information is regarded by the team as the top of a hierarchy of evidence about a patient. There are obvious downsides to this, and some of these are alluded to in the

MDT meeting observation data above. For example, Mr Red argues that to confine assessment of a patient solely to the TNM information is substandard: "this is where you don't treat an x-ray, you treat what they look like!" Whether he alludes here to inspection to a visual assessment of the cancer or of the patient is uncertain, but it highlights the concerns of some members of the MDT in limiting the information about a patient to that which can be gleaned from an x-ray, histology report and clinical history and examination. This sentiment is perhaps not shared by Mr Black as his statement "and this picture" (when referring to a projected picture of the tonsil) suggests that this dataset, combined with the picture, is adequate.

It is false to suggest that the MDT relies solely on the TNM status to inform the treatment recommendation and the data above reinforces this. In many ways, the difficulty with providing the evidence to inform the recommendation is summed up simply by Mr Red in his interview:

> I think people need to appreciate that the MDT is advised on the information that is available, and probably the most important piece of information isn't available….which is the patient

(Mr Red, ENT Surgeon, Interview, 8th May 2012)

In this short passage, Mr Red makes a simple but informative statement which outlines one of the fundamental challenges of MDT decision making. The MDT is making recommendations based on the information and evidence which is available to them at the time of the meeting. The patient is, however, absent from the MDT room and therefore all evidence that is incorporated into the discussion must be gathered before the meeting takes place. This presents the MDT with a challenge: how should the absent patient be represented in the room? Different MDT meetings grapple with this problem in different ways. This in itself is an indication that teams are aware that clinical TNM information alone is inadequate and in doing so they acknowledge the requirement for

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more information to build their picture of the patient in the MDT meeting.   Firstly, the

MDT members must decide the nature of the extra information required and secondly,

they must decide how this information should be presented and then incorporated into

the discussion. Mr Red is not alone is his assertion that the MDT needs to treat more

than just the TNM status and there is wide agreement from members of the MDT that

focussing purely on information about the cancer provides an inadequate picture of a

patient. The following extract is taken from an interview with Sally, a speech and

language therapist from centre A:

> You're just making decisions based on scans and guidelines as
> opposed to an individual and having somebody ever having had the
> opportunity to explore not just their physical and psychological status,
> but their feelings about treatment.... it would be nice to have much
> more of a feel and a knowledge of the patient before it gets to that
> MDT.

(Sally, Speech and Language Therapist, Interview, 3rd July 2012)

Her reference here to the "physical" status refers to the description I have outlined thus

far: clinical information about the cancer and the patient's general health. She goes on

to widen her definition of what a patient 'looks like' by extending the patient identity to

"psychological status" and even "feelings about treatment". This introduces an opinion

which is shared by many at the meeting: treatment decisions cannot be made with

details of the cancer alone and more information is required. Her statements reveal that

the information provided does not give the members of the MDT a "feel" of the patient

being discussed, or provide the team with information about the patient's lifestyle,

context, values and preferences. At the same time, the task of representing the "feel" of

a patient using pieces of information about them is difficult. Before continuing, I will

tackle one of the most obvious possible solutions to this problem: allowing the patient

themselves to attend the meeting. Direct patient presence at the meeting would provide

potentially incontestable evidence about the 'feel' of the patient, but it is an idea which

faces strong opposition from most members of the MDTs which I have observed, and

has been reported in the wider literature (see Chapter Three); this is the reason it is not

current practice. To demonstrate this clearly, I provide data from Sally again, in order

to juxtapose her views on patient attendance with her earlier statement:

> [if the patient attended] I don't think you could have a free and full
> discussion, particularly if you're thinking that the prognosis might not
> be very good for a patient. I think that it would inhibit what your
> thoughts were and so you wouldn't be having a proper discussion then
> I don't think. It would have to inhibit it, because sometimes you'd
> have some quite distressing things that you might want to talk about
> and you wouldn't discuss that with a patient in the room
>
> (Sally, Speech and Language Therapist Interview, Interview, 3rd July
> 2012)

In this statement Sally is clear that she feels it is not a good idea for the patient to attend

the MDT meeting. It is not clear what she means by a "proper discussion" or whether

she is protecting her patients unnecessarily, but it can be assumed that she anticipates

her colleagues would not share all the information and opinions at their disposal, which

would be detrimental to the treatment discussion. These data also introduce the idea

that the team view the meeting as a safe space, where they can share frank views with

each other without having to concern themselves with upsetting the patient in question.

This 'backstage' area is created by having a team meeting before the clinic appointment

with the patient. Potentially, moving the patient into this area would lead the backstage

to be temporally and geographically relocated to a new space, further 'back' thus

creating another forum and fragmenting the discussion. This problem explains the

resistance of the MDT to this idea, but it must be highlighted that the views of Sally

originate from her assessment of a patient being present at a meeting in its current form.

This does not mean that the idea of a well-supported patient attending an MDT with a

sympathetic team is something that would never be possible, rather that it is regarded by the members of the team as an unfavourable option. I will discuss further the 'backstage' and 'frontstage' organisation of the MDT meeting and clinic, together with the effect this has on decision making, in Chapter Six.

5.2 Building the 'evidential patient'

I have discussed so far how MDT members agree that providing information pertaining only to the cancer is insufficient to inform a treatment recommendation about a patient, but at the same time there is strong opposition to the patients themselves attending the meeting. MDTs in different centres introduce various pieces of extra information to solve this problem, in an attempt to construct the patient identity in the room via information provision: the 'evidential patient'. The information included in the meeting varies between teams: in centre A they concentrate on the medical details of the patient, previous health problems and comorbidities which have been obtained during the initial clinic appointment at first presentation. In centre C, a clinical specialist nurse (CNS) is present at the appointment where the cancer diagnosis is given for every patient. Following the clinic appointment, the CNS sees the patient in a separate room, offers support and collects information about their support network and home circumstances which is presented at the MDT meeting later that week. In this centre, this information gathering is always delegated to the CNS, rather than the consultant in charge. By contrast, in centre B one of the surgeons always holds a meeting with the patient before the MDT in order to deliver the diagnosis. Sometimes at this 'diagnosis meeting' they discuss with the patient the treatment options and present this, usually as a patient preference, at the MDT meeting. I will discuss centre B in more detail to illustrate the point that when this information is presented at the meeting, members of the team

interpret it in different ways. This is not surprising, as it is already evident that the TNM status information is subject to interpretation. These interpretations, and their influence on the clinical recommendation, are externalised and made visible at points of conflict.

The following data segment is about a patient called Donna Childs, a 52 year old female who had a small cancer of the tonsil surgically removed with a laser, together with the removal of some lymph nodes from the neck. She was the subject of an MDT discussion as the team needed to decide whether any further (adjuvant) treatment was needed. It was clear from the discussion that post-operative radiotherapy was recommended in her case, however it was less clear as to whether chemotherapy should be given at the same time. The pathologist presented the results of the examination of the surgically resected specimen and told the team that one of the lymph nodes had a small amount of extracapsular spread[2]. As discussed in the introduction chapter, there is clear research evidence that patients with extracapsular spread have a five-year survival advantage of around 4% if post-operative chemotherapy is combined with post-operative radiotherapy (Cooper *et al.* 2004). However the addition of chemotherapy to radiotherapy significantly increases the side effects of treatment, particularly the effect on swallowing. The data presented below are observational from the MDT meeting and the discussion takes place after the pathology result is known:

> Mr Ilkley [ENT surgeon]: Er, yes. Now pre-operative discussion
> with this lady. She was keen to try and avoid the use of
> chemotherapy, either the primary or the adjuvant setting. So would

---

[2] Extracapsular spread means that the cancer has spread out of a lymph node into the surrounding structures.

you consider not giving it? Would you consider just using radiotherapy?

Dr King [Oncologist]: Just with the lymph node….

Mr Ilkley: And she's HPV positive as well [these cancers are known to be more responsive to radiotherapy]

Dr King: You know my opinions, there are some rules which I have to respect [giving chemotherapy to patients with extracapsular spread is recommended in the guidelines]. And if it is reported like this, I can't do that

Miss Dutch [ENT surgeon]: I think the thing is, you can offer her chemotherapy, and I know this is how you put it, is that you offer her it, and tell her what the risks and the benefits are, and she makes her own choice. You know people have the right to refuse these things. I know Dr King won't say….unless you have this I'm not going to treat you! If she feels that strongly about it once all the evidence is….

Mr Halifax [Maxillofacial surgeon]: I would view them as guidelines, not rules.

Mr Ilkley: I don't know if you were here when we discussed her first time around, but her husband died, and her daughter's partner died in Afghanistan, so she…. I think she's very keen not to die.

Shannon [Clinical Nurse Specialist]: That's always the case!

Mr Ilkley: Exactly, that's the other side of the…. She may want to have that added survival benefit that chemotherapy adds, given what the histology shows.

Mr Halifax: She needs [to be given] just the full picture, and then make a decision. We can't decide that for her now

Miss Dutch: No

Mr Halifax: All we can decide is that she needs to decide

(Donna Childs, Observation, MDT Meeting, Centre B, 1st June 2012)

In the extract above, Mr Ilkley clearly presents that the preference of the patient is to avoid chemotherapy, and the priority for treatment is not to die, which presents a potential quandary: the MDT must either make a recommendation to maximise the chances of survival or to avoid adding chemotherapy to her treatment. It could be deduced from this that Mr Ilkley's expressed assessment of Mrs Child's preference does

not match her priority simply because of the survival advantage that chemotherapy offers. It may be that Mr Ilkley is not prioritising one preference over the other, but is sharing this uncertainty with the team. However, because of the statement of preferences, the team appear to shy away from offering a clear treatment recommendation of chemotherapy, and instead opt to offer the options to the patient as an equal treatment choice. The disparity between treatment preference and priority is not explored, nor could it be in this setting. It could effectively be argued that the conclusion of "all we can decide is that she needs to decide" is not necessarily correct, and the priority/preference disparity needs to be made clear to the patient. Her preferences need to be explored, and if necessary, a treatment recommendation given which are in line with these. The team react to this by taking a step back, and giving all the work of the decision making to the patient. The way in which teams handle these positions of choice will be discussed further in Chapter Six, but the excerpt above demonstrates the power that expressed patient preference can hold in the meeting. Without this information, I observed other patients being clearly recommended chemotherapy by the team. A more cynical viewpoint would be that offering choice allows Mr Ilkley the opportunity to control the consultation with the patient and to frame the discussion toward his own preference. In a similar way to Mr Black earlier in the chapter, the reasons that clinicians choose to champion one particular treatment option over another often extend beyond the patient in question; this is something I will discuss later in this chapter and in Chapter Six. There is also ambiguity in the team about the role of the treatment guidelines and how they should be incorporated into the decision. Should they be treated as rules, with which compliance is essential, or a guide to strengthen the argument for a particular course of action? Clinical guidelines are

usually produced with the aim of reducing clinical uncertainty, although in this situation

the issue of how rigidly to apply them to an individual patient has the opposite effect.

The reaction of the other members of the MDT to the information about Mrs Child's

treatment priority and preference is of further importance. The following is an extract

from my reflective diary for the day, following some informal discussions with other

members of the team:

> I had some interesting discussions with one of the clinical nurse
> specialists (Kim). During the meeting Donna Childs was discussed.
> It was discussed whether she should have chemotherapy or not – the
> surgeon (Mr Ilkley), during the meeting, reported that she did not
> want chemotherapy. When I was discussing this with Kim, I repeated
> what he had said. "Get with the program Winnie!" was her reaction
> [Winnie is my nickname]. She feels that it isn't the patient, but the
> surgeon who doesn't want the chemotherapy – the surgeons aren't
> keen on the chemotherapy and therefore they gear the discussion so
> the patient doesn't choose it. This means that they feel that the
> opinions which are presented at the table [MDT meeting] are those of
> the clinicians, and not of the patient, and that patients are often
> presented as "not wanting it" because either the surgeon doesn't want
> it or the patient will be persuaded out of it. This was echoed by Dr
> Dean [Palliative Care consultant] who echoed that it is "clear" what
> the patient was going to choose because she was "talking to a
> surgeon".

> [during the consultation the patient chose not to proceed with
> chemotherapy]

> On talking to Mr Ilkley after the patient had left the room, it was clear
> that his personal preference was not to have chemo, as it added a lot to
> morbidity for only a "small survival advantage".

> (Field notes, MDT Clinic, Centre B, 1st June 2012)

It is not possible to conclude from these data whether the surgeon misrepresented the

patient at the MDT meeting. It is possible to conclude that other members of the team

often treat information such as this with suspicion. Although information about

priorities and preferences may be included in the MDT discussion (as well as other

information which is patient-centric) there is more potential room for different people to

interpret it in different ways around the MDT table, perhaps even discard and ignore it due to concerns over its source. This not only has an effect on the unfolding discussion, but also the recommendations which are made by the team to the patient; the way in which the options are presented to the patient and ultimately, the decisions made. This however presents a potentially dangerous balance. As demonstrated, a presentation of the perceived preferences of patients seems to hold quite a lot of 'power' over the treatment recommendation made and yet, at the same time, there is suspicion about how it was gathered and then presented in the meeting, and confusion about the emphasis it should be given during the discussion. I have no data from the 'diagnosis appointment' between patient and surgeon; however, possession of this data would not provide the answer as to how this sort of information should be treated by the team and incorporated into the decision. The preference information being presented by Mr Ilkley is a representation of an earlier interaction between him and the patient. Through this interaction it seemed that Mr Ilkley tried to reach an understanding of what he thought the patient wanted or feared, and interpreted this in the light of what matched with his own clinical interpretation of best practice, finally overlaid with other personal preferences. My own interpretation of this interaction (if it were available) would provide no 'truer' a representation, merely another construction of the patient's preference. This emphasises the interactional nature of a patient preference and reinforces that it should not therefore be treated as a fixed informational commodity which can be passed from person to person or presented as a fact in a meeting (Slovic 1995; Epstein and Peters 2009)

As I mentioned earlier in the chapter, the patient's preference is not the only piece of 'non-clinical' information which is sometimes included in the discussion. Depending on the centre and the patient, members of the MDT may present information about a

patient's home circumstances, support network or even character. Although this is often interesting, I sometimes observed how it is difficult to incorporate into the decision making discussion, other than via an assumption. To demonstrate this, the following is observation data from an MDT meeting at centre A. The patient is called Stanley Wight, and he has a large tumour of his tonsil.

> Mr Blonde (ENT surgeon): He's a very sort of straightforward sort of man, who doesn't worry too much, but he will probably cope with [the diagnosis] very well. But, he needs a lot of radiotherapy
>
> Dr Orange: What age is he?
>
> Mr Blonde: He's 87, I mean he's a very good 87
>
> (Stanley Wight, Observation, MDT meeting, Centre A, 2nd February 2012)

When Mr Blonde refers to his ability to 'cope', he is talking about his reaction to the diagnosis. In this extract there is a judgement made by Mr Blonde about the patient being a "very 'good' 87" year old. On one level this provides more information about the 'feel' of the patient, and helps to form a more holistic picture of the person that he is. On another level it is a judgement which subtly sways the team in one direction, towards radical management (this is what the team offered to the patient). These subtleties occasionally arise when speaking about patients, their drinking or smoking habits, their character or their age. They sometimes have a small but vital guiding effect on the tone of the discussion, which pushes the direction of the MDT decision making towards or away from treatment options. This means that the subjective judgements which are made by the speaker and the listener when transferring information of this nature, potentially lead to assumptions about which treatment would be best.

In order to continue the analysis of the discussion that takes place in the MDT meeting, I will turn attention to the other information that the team consider when making

treatment recommendations. The MDT is a gathering of expertise, designed to create a

pooling of experience in the same room at the same time to inform treatment

recommendations. I alluded earlier in the chapter to how information which is not

directly relevant to the patient being discussed has an effect on the interaction of MDT

members; in the next section, I will explore in more detail how the team incorporate this

information into the treatment recommendations.

5.3 Incorporating other information

HNC has a paucity of good quality research evidence to guide treatment decisions and

the research literature is of variable quality (see Chapter One). Although this does not

mean it is of no use, it does mean that different members of the team place different

levels of importance on the outcomes of the research. In order to demonstrate this, I

shall return to the discussion reported above, which took place primarily between Mr

Black and Mr Red, about the patient, Vincent Lowry. The discussion had become quite

heated, and Mr Black had quoted some research evidence to reinforce his choice of best

treatment. The following is the angry response from Mr Red:

> Mr Red: Aaaah well, I don't care what the publications say Mr Black,
> because Mr Blonde [another ENT surgeon] and I, and Mr Smithson
> [another ENT surgeon] over the years have never published anything,
> and we've probably done a whole load more cases than the people
> who have published things. So whatever's published is only a small
> proportion of the total number of cases that are done. …. So you
> can't take one or two publications in isolation by people who can talk
> the talk as gospel. And whichever the latest publication which comes
> out, that seems to be the one that we are following, and that is
> inherently wrong. That's the point I'm making, I think evidence
> based medicine is appropriate, but only in the full context of the whole
> of the evidence available and that includes the personal experience of
> yourself, and everybody around you, and everybody that you know,
> and everybody that you discuss with things with, not everything that is
> put on paper…. And a lot of people who put things on paper are doing
> it for their own personal reasons rather than the future of the specialty.
> And you know that, and I know that, and everybody else knows that.

So don't bleat to me about publications indicating that you should have a certain direction for treatment, because that isn't true.

Mr Black: Will you let me come back on that?

Mr Red: Yeah….

Mr Black: So the publications I'm talking about are ones coming out of… a single centre. But then I've seen such cases here, and the last paper to come out of this was a truly multicentre work across seven different centres in spread across the US and Germany, and the outcomes exceed those of T1 and T2 tonsil tumours treated by primary radiation. You're talking about 20% increase in local control, compared to giving primary radiotherapy alone. And I think we need to give that something of consideration. As an MDT if we believe that this tumour is not treated ideally by transoral resection, I abide by that, and we'll offer him radiation therapy. But we can't not take notice of the excellent outcomes that have been published.

Mr Red: There's no point having an MDT is there? You might as well wrap up MDTs tomorrow and just forget it. If people's experience don't matter

(Vincent Lowry, Observation, MDT meeting, Centre A, 19th January 2012)

The angry discussion demonstrated here may be viewed as a negative occurrence, but these data demonstrate the role of conflict in externalising the views of the MDT members and giving them opportunity to make clear what they see as important or express their interpretation of the hierarchy of evidence. Garrety (1997) highlighted that conflicts are often a window into the underlying assumptions and priorities of particular groups, and allow the observer to see what is 'really' at stake beyond the immediate issue being discussed. The interaction is a clear example of experience and research competing for a position of importance in informing the discussion of which treatment would be 'best'. In this situation, radiotherapy is an established treatment for cancer of this size and laser is a new treatment which, although it may improve some patient outcomes, has not got a large weight of evidence to support it. There is some research evidence from the other cancer centres that it can produce good clinical outcomes but,

as it is new, many clinicians have little experience with it. This means that to choose

radiotherapy in this situation would be to follow a conventional treatment pathway for

cancers such as these. To choose laser therapy would be to believe and trust the

preliminary data from other centres and have a goal to move forward the treatment of

cancer. Either way, the persistence for laser or radiotherapy depends in part on the way

in which the members of the team interact with the wider research literature and

combine it with their own experience and practice. Some of the comments by Mr Red

were raised when I interviewed him two weeks prior to this meeting.

> I certainly don't think that some of the decisions made [in the MDT]
> are necessarily the right ones, because I think sometimes personality
> and persistence outweigh pragmatism, common sense and
> experience…. I think, it seems that the people who are persistent are
> often those who have least experience, but have probably done the
> most recent reading. I think some of them might have a hidden
> agenda because they want to be trying out new things. And they
> might be right because that's how you make progress…. I remember
> when I first started I was a lot more aggressive than I am now because
> I've seen what happens to people. You go to national meetings and
> people will always present their fantastic results, and their fantastic
> new operation and their fantastic new operation will disappear 5 years
> down the line. ….I think some people [are] doing it for an ego thing.
> And you've heard it all in there; you hear the egos, people quoting
> papers. And the other point is of course that people who work in units
> like ours ….they don't publish papers about all the cases because they
> don't have time, so all those papers that are published by definition
> are done by people who have the time to do that which makes you
> question whether or not they've actually done the cases in the first
> place, or they're just collating somebody else's. We haven't got the
> time or the inclination to. So all the evidence that you read in the
> journals probably comprise, I don't know, fewer than 1 or 2 percent of
> the number of cases that have ever been done.

(Mr Red, ENT Surgeon, Interview, 8th May 2012)

These data highlight a multitude of issues concerning the interpretation of research data.

They demonstrate the way in which members of the team may doubt the validity of the

research or question the motives of the authors of the research. Additionally, even if the

data are to be accepted as valid and applicable, the way in which new research data

should be amalgamated with the considerable existing experience of the surgeons and other MDT members, and hence incorporated into the recommendation, is not clear. Not only this, but the actual act of presenting research data in the meeting can be interpreted in a negative light, linked to self-aggrandisement and a "hidden agenda" . Mr Red even suggests that the underlying principle of medical research, to "make progress", leads to fashionable new surgical procedures waxing and waning in popularity, something which he has had the benefit of witnessing due to many years in practice.

Together these data highlight some of the considerable complexities of applying research data to individual patients. From the viewpoint of Mr Red, this suspicion immediately devalues research evidence as a tool to make decisions. He quite clearly states that research evidence should come within the hierarchy of evidence, but most certainly not at the top. It is also evident that he disagrees with the idea that this information should be given priority over the experience of the team. His views are not shared by all members of the team and the presentation of this data is not intended to suggest that this is the case. Instead, the data provides insight into the ways in which the research literature may be interpreted. His comment "And you know that, and I know that, and everybody else knows that" was not supported by other data, and highlights a common misconception expressed by many different members of the team: that everybody else in the team sees things from the same viewpoint. It is often stated during dialogue or interview that viewpoints are widely held or agreed with when this is not the case, mainly because the differences in the viewpoints and the reasons for them have never been explored. The data also demonstrates the other factors which drive a clinician's conviction for a particular course of action, other than the current clinical situation. Although the discussion above centres on Mr Lowry, the outcome of the

discussion (and the final recommendation made) will have implications for future patients with a similar cancer. Thus, the MDT discussion for an individual patient provides a platform for wider debate and how the knowledge which informs the discussion is formed and how the different sources and types of knowledge are aggregated is a complex process.

The experience of the individual members of the team has a large number of effects on treatment decisions across the centres. On one level, the experience of the members of the team effects the clinical opinion that they provide, and I shall explore the effect of this next. The clinical opinion and knowledge of the members of the MDT is a valued commodity. To demonstrate this I will present observational data from Centre A. The discussion is about the patient, Bobby Older, who had been recently treated with chemotherapy and radiotherapy for a cancer at the base of his tongue. Following the treatment he had a PET CT (positron emission tomography computed tomograph) scan: this is a relatively modern type of scan which highlights groups of cancer cells by changing their colour on the scan. Confidence in the use of this scan is growing as it is used more frequently. The patient had a residual lymph node in his neck, shown on a conventional CT scan, after completing his treatment. Before the advent of PET CT, the lymph node would have been removed as the likelihood of it being residual cancer is high. The PET CT scan had been performed however, and it had not changed colour; the scan suggested that it was not cancer. To believe and proceed on the basis of it would have been to trust the results of the PET CT scan implicitly. These data are from the discussion where the team are deciding whether or not they should proceed with removal of the lymph node: the operation to remove it is called a neck dissection:

> Mr Black [ENT surgeon]: This is a point for discussion around the
> group. In this man's case clearly, Mr Surton, what do you think, this

man, as a group we need to discuss this, this man has a neck node on the left hand side, very metabolically active pre-treatment [on the PET CT scan]. Post-treatment, it's not active at all….

Mr Surton [maxillofacial surgeon]: You're thinking of doing a neck dissection?

Mr Black: We have a series of 20 or so far, we haven't found viable tumour in any. The last guy we did was Bob Tressey, quite a chunky, 4 cm node, again non-viable tumour cells, so as a group, are we actually ready to decide that….?

Mr Surton: ….we're not going to dissect on the basis that….

Mr Black: ….sit on it and not do anything.

Dr Winter [radiologist]: Well, I think it, I mean every case is different isn't it. There is a case, the residual node is solid and it's not necrotic [necrosis in a node is a sign of cancer]…. and there wasn't any activity, but the problem we have is, we have some patients where we have not done a PET CT, it's a necrotic node and my worry is you might have a bit of tumour in a necrotic node…. a lot of evidence shows that you can, you know, sit on these, a lot of papers can come up

Mr Surton: ….if we've made a decision we're not going to do it, obviously, a little bit at the back of the mind says, are we not going to miss a chance to do something earlier on? But if we do an ultrasound now, as a baseline, and then an ultrasound at three months, and then maybe another PET CT scan…that will give us an idea of whether there are any further change

Mr Blonde [ENT surgeon]: Yeah, I think that is the question, about how we should decide to follow these up if we're not going to operate on them. And does that sound reasonable, if we had an ultrasound, at the time of deciding not to operate?

Dr Winter: It would be nice to know what the ultrasound would look like, as Mr Surton said, what it looks like now, then in three months, you say well I know what it looked like….

Mr Surton: So if the decision is not to operate, and a baseline ultrasound within a week to ten days and another at three months.

Mr Blonde: Yeah, OK

Mr Black: OK

(Bobby Older, Observation, MDT meeting, Centre A, 16th February 2012)

The extract shows the team actively adapting their care as they discuss. It is a drastic new change to their management plan, and a very different potential treatment course for the patient. Trusting the negative PET CT results means that the team would recommend that the patient should not proceed to neck dissection. This means that he avoids the risk of the operation, but takes on the small risk of persistent cancer which was missed by the scan. The patient was primarily under Mr Black, but his use of the MDT was evident when he said "This is a point for discussion around the group", "as a group we need to discuss this" and "so as a group, are we actually ready to decide that?". This repeated referral to the decision as one which is made by the group shows Mr Black sharing responsibility and spreading the decision across the team. As the discussion continues, the team can be seen gradually shifting from 'what should we do' to 'this is what we should do' as the various members voice their support for the conservative management plan. At the same time, an important question is raised by the data, which I will answer in the coming chapters. Where does the patient come into this? Following a conservative management plan avoids the risk of the neck dissection, but accepts the risk of a missed cancer. It could be argued that whether or not to proceed is in fact a value judgement based on attitude to risk, and this judgement should be made by a patient, not a professional team[3].

These data demonstrate one of the main benefits of working in the team, a shared responsibility or 'safety in numbers'. Mr Black is not reporting his decision to the MDT team, but clearly asking for advice. The extract shows treatments being adapted in real-time, and provides an example of research evidence being actioned in practice.

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[3] In the MDT clinic, the treatment decision was to proceed with conservative management

It also shows how new technologies move within the hierarchy of evidence and become incorporated into the discussion. Here, the PET CT scan (a relatively new advancement) has little high quality evidence to guide decision making and it is jostling for position in the hierarchy through the interaction of the members with each other. A long journey lies ahead until the technology gradually becomes 'trusted' by the team, but through this journey, the findings of the scan become less of a discussion point and more of a 'fact'. As a result the scan results slowly move up or down the hierarchy of evidence over time.

The data I have presented shows that the clinical opinion of the MDT members as a resource on which to base decisions is not as open to interpretation as the use of research evidence. As a result of this, the team sometimes find it easier to incorporate their own opinions into the decision discussion. In the data above, research evidence is used loosely to inform the discussion, but the clear driver for the change in management plan is the opinion of the individuals in the team. Team experience in the form of clinical opinion shapes the behaviour of a team and provides the individual members with support in following management plans, especially those which are alternative to standard care. However team experience has effects which extend beyond the opinion of the clinicians. When visiting the different centres, I noticed that there seemed to be a considerable variation in care between centres across one, quite small geographical region, which did not seem to be explained by the patient population. Patients who would probably have been treated radically in one centre, were treated palliatively in another. I found that, when watching patients being counselled, I sometimes formed my own clinical opinion as to how they should be treated; when the opinion of the team members was very different to mine it sometimes shocked or surprised me. As a result of this, the reasons for this perceived variation in care therefore became one of the

focuses of my investigation. In centres A and B the vast majority of patients were treated with curative intent, with extended courses of chemotherapy and radiotherapy, or large operations and surgical reconstructions. Two and sometimes even three of these therapies (surgery, radiotherapy and chemotherapy) were combined and patients suffered debilitating side effects as a result, impinging upon many aspects of their quality of life. In HNC treatment it is well-documented (DAHNO 2011) that around a third of patients die within two years of developing their cancer despite the hardships endured during radical treatment.

When I visited centre C, a greater proportion of patients seemed to be treated with palliative intent that in the other centres. The team were happy to give a treatment recommendation of "best supportive care", and when they recommended radical management they usually included "..or best supportive care" as an alternative treatment recommendation. In centre A and B, the option of "best supportive care" would often not be mentioned or discussed, even in patients with advanced disease. During his interview, Dr Goodier, an oncologist in centre C, gave some insight into the reasons for this:

> There is a school of thought that if you want to get control of head and neck cancer you have to bold, aggressive. And I don't disagree with that… and I came into head and neck cancer very much, I think with those views. It didn't take long to learn that that isn't an appropriate approach for everybody I'm afraid. Partly because some of the patients just can't withstand too much intervention. … And if it goes wrong, you know if you push patients in for aggressive treatments who really can't stand it, my gosh. If you're a human being at all you do regret that. I mean there will be some patients at the margin where we do all agree, "Let's go for aggressive treatment." But it turns out half way through treatment or whatever that actually, that was not a very clever decision. …. death from advancing cancer in patients who've had multimodality of treatments is probably even worse…. the only blowouts from carotid arteries I've seen in head and neck cancer are patients who've had high dose radiation to the neck. And you

know that patient may not have had a carotid blowout if they'd not
had the intervention in the first place.

(Dr Goodier, Oncologist, Interview, 18th January 2013)

A "carotid blowout" is a hole quickly developing in the main artery of the neck, the
carotid. It is almost universally fatal, as the resultant haemorrhage bleeds the patient's
entire blood volume in under a minute. It can occur as a result of HNC or its treatment
and is an extremely unpleasant mode of death to experience or witness. In this data
extract, Dr Goodier describes the experiences he has had when treating patients with
advanced cancer and not succeeded in curing them. In his statement "my gosh. If
you're a human being at all you do regret that" his language changes from the rather
clinical, factual tone which characterises the rest of the interview to one which is quite
emotional. The language and tone in this part of the interview gives insight into the
emotions which he has experienced which drive his practice. This shows the lasting
effect that the interaction between patient and clinician can have on clinicians, and
hence on future patients, and the human, emotional response which clinicians have to
experiences which fundamentally shape their practice. Importantly however, Dr
Goodier is referring to quality of death rather than to quality of life, and he makes a
judgement that dying after treatment is 'worse' than dying without treatment. Besides
the fact that this is value judgement, one can perhaps sympathise with this viewpoint
when he talks about mode of death. Given the dramatic nature of a carotid blowout, it
could be understood that if Dr Goodier, rightly or wrongly, felt responsible, that would
be a highly unpleasant experience and therefore highly likely to affect his future
practice. This highlights an interesting concept, as when speaking of SDM, clinicians
often refer to the anxiety that decision responsibility may invoke in patients. However
here is an example of the weight of decision responsibility on the clinician. Rather than
invoking anxiety, this may invoke an equally powerful emotion, regret. To demonstrate

this further, I will juxtapose words of Dr Goodier with those of Mr Halifax, a surgeon

from centre B:

> We can technically always do an operation…. Statistically you ain't
> going to do very well because you're T4 with a big tumour, but it
> doesn't mean to say that some of them haven't done okay. …I mean
> we will say to them "Prognosis is 25%," but they'd rather have 25%
> of something than - essentially palliation means, "I'm dead." They're
> going to make it as comfortable as possible for him, but "I'm dead".
> Why not? See the other thing as well is, it's bloody horrible, it's a
> horrible death. So however mutilating and horrible the surgery is, it's
> often better than the death. I mean I have seen a few who have had
> nothing, it's grim. Absolutely grim. Well you just get a big hole in
> your head. You can't eat, all your food comes through it, all your
> saliva comes through it, it stinks. It's nasty to care for. ….and yet it
> doesn't kill you instantly, ….you don't blow out until you catch your
> carotids which is often …a long time away.. So not having – having
> half your head removed is bloody horrible, but it doesn't smell as
> much and it's generally not as bad. Trouble is in your heart of hearts,
> as a clinician you know that, so you tend to push a bit on the treatment
> side because you know, by God, if I don't, it's bloody horrible. You
> know, and they bloody live with you, the ones you don't treat you
> know, oh my God.

(Mr Halifax, Maxillofacial surgeon, Interview, 5th October 2012)

In this passage, Mr Halifax talks about the times he has not treated radically and the

effect this has had on him. Again, Mr Halifax, in a similar manner to Dr Goodier, uses

quite emotional language to describe the lasting effect that these decisions have, and the

language is out of character with the rest of the interview. Again, he refers to the quality

of the death, and expresses how he sees death after treatment, as a "better" death than

one without treatment. To illustrate his point he gives distressing details of the nature

of a cancer death without treatment, but provides us with no similar information about

one with treatment.   Interestingly, whilst illustrating this point, he emphasises the

process of dying as opposed to Dr Goodier, who spoke more about the mode ("carotid

blowout"), but it is clear which of the deaths Mr Halifax feels is preferable. He also

goes on to provide an indication of the sort of effect that this has on his practice "so you

tend to push a bit on the treatment side because you know, by God, if I don't, it's bloody horrible": his more radical approach is supported by my observations.

These two pieces of data are shown to demonstrate that a concept which is shared between centres, the experience of watching patients die, can have completely opposing effects on the delivery of care in different settings. In one centre, the talk of regret and quality of death drives the team to palliate more, in another, to treat more radically. The previous two pieces of data have some remarkable similarities: an emotional response to death, but coupled with a feeling of responsibility for the nature of these deaths. Both express feelings of "regret" or patients that "live with you" and, with this in mind, it is not surprising that the clinicians allow this to affect their practice. Both also refer to the quality of death, either the process of dying, or the mode of death, and the effect that this, coupled with the feeling of responsibility, has on the clinician. It exposes the practice of medicine as an emotional process; the resultant emotions have a powerful effect on future actions.

The data presented in this chapter demonstrate the variable effects that the previous experience of members of the MDT team has on the recommendations made. On a superficial level, prior clinical experience forms clinical opinion which can be used as a source of information for other members of the team to draw upon. This kind of experiential knowledge, although largely anecdotal, stands high on the hierarchy of evidence informing treatment recommendations. However, the effect of the prior experience of team members extends beyond this: it shapes the way the members of the team interpret research evidence and clinical guidelines, and incorporate them into treatment decisions. Additionally, on a more fundamental level, the human reaction of clinicians to clinical experiences guide their practice over time, and feelings of

responsibility or regret for past decisions have a major influence on the nature of the care delivered in a particular centre. If I return to my question earlier in the chapter, "What is it that drives a clinician's conviction for a particular treatment plan?", previous experience, would certainly seem to provide part of the answer.

So far in this chapter, I have highlighted how the team use the evidence available to them to inform their discussion about making a treatment recommendation. Some of the information is related to the patient, and some is related to experience of the team or the wider HNC community. I have discussed the way in which this evidence is viewed by the team and interpreted, and have given some examples of the effect of this on the recommendations made. This process of evidence 'mobilisation' is complex but, as I have outlined, the team interaction is governed by more than just the patient in question. In the final section of this chapter I will go on to demonstrate how the environment or atmosphere in which the MDT discussion takes place exerts further, over-arching effects on the behaviour of the team and the decisions made.

5.4 Team behaviour

When I visited each MDT, there were similarities between them and conventions observed by each team. The MDT was always chaired by a surgeon, and the clinicians always dominated the discussion. The order of the discussion was always the clinical details of the patient, followed by radiological and pathological information to form the TNM status, and then further discussion to form a treatment recommendation. However, I also observed that there were subtle differences between teams which altered the behaviour of the members. Each team which I visited had a different atmosphere and this had an effect on the discussion: not only its content, but also its length, the degree of conflict and the 'position' of the patient in relation to the team

recommendation (I will discuss the patient 'position' further in Chapter Six and Seven).

I observed the team atmosphere to be affected by many different factors; this was always most evident to me when joining a team, as after repeated attendances the atmosphere became less obvious, as it had done for the MDT members over time. To demonstrate how the atmosphere of a team was generated, I present the following extract from my reflective diary after my first attendance at Centre B:

> The room is much quieter than it was at the Centre A. There were fewer people present – everybody in the room had more of a role. There were few people who said absolutely nothing at all. There were many less phones ringing – there are no dect phones in Centre B [a dect phone is a mobile phone which is carried in the hospital. In centre A these rang frequently and often people spoke quietly on them during the meeting], and people are contactable by pager. This means that they not only have to leave the room to answer this but also that the conversation takes place away from the room. It has the added benefit that people are not as likely to contact people in the MDT for more trivial matters. The room is quite small, and the tables are arranged in a square. …. There is coffee and juice available in the corner, which everybody makes use of. The nurses… seemed to be in the central 'gang' of the team, and were very pally with each other. At the end of the meeting there was a 'round the table' where everybody was invited to speak, even if it was just to say that they had no issues. …It was obviously something that [the nurses] were waiting for and they told the team about issues with patients or news. This exercise took almost as long as the meeting itself. … It helped to generate more of a team atmosphere.

(Field notes, MDT Meeting, Centre B, 18th May 2012)

These data document my initial impressions of the MDT at centre B, but also outline many of the factors which generated the atmosphere. As mentioned previously, although there are many aspects of the discussion which were the same, small differences in the set-up of the room, the facilities available and the attitude of the members generated an atmosphere which I observed as being more inclusive to the allied health professionals. In contrast to this, Centre A provided an occasionally combative, sometimes quite threatening atmosphere. Most of the observational MDT

meeting data in Centre A included discussions between consultant clinicians, but there

were a large number of other people present in the room, sometimes as many as 40.

This means that speakers were greatly out-numbered by non-speakers and at times the

MDT meeting turned into an 'observed conversation' rather than a group discussion.

To demonstrate some of the reasons for this, as well as the effect that it had, I will

present interview data from Tessa, a CNS in centre A:

> But as soon as that one person walks in the room it all clams up ….
> Which is … quite worrying. I think some of the conflict can be very,
> very uncomfortable at times…. embarrassingly uncomfortable. I
> don't think that an MD meeting is the place to be like that. It should
> be a comfortable atmosphere where everybody feels comfortable to
> speak…..the atmosphere I think needs to be very relaxed. I don't
> think the pressure that we're under …helps. I think we're all under so
> much pressure. Even things like …. we don't even get a cup of coffee
> now. I think part of it is that we have very complex patients and I do
> feel the complexity of the patients has increased…. you're pulled in so
> many different directions. I just don't feel that I'm doing a
> particularly good job because I just can't do it all.   I can hopefully
> speak out for the patient if I know the patient well enough. But then I
> think sometimes that, that becomes hard …. because of the workload I
> don't think we have as much insight as we'd like to have.

(Tessa, Clinical Nurse Specialist, Interview, 23rd October 2012)

In these data, Tessa describes the atmosphere of the room in a negative way, but goes on

to outline the reasons for this. On an individual level, high workload means that she

doesn't know her patients as well as she feels she should, which leads to a poor

perception of her own ability to perform her role and "speak out" for the patient. At a

group level the workload means that the atmosphere that she feels would help to form

an inclusive discussion is not achieved. The people present in the room additionally

affect the atmosphere, sometimes in a negative way, presumably due to strained

relations with the rest of the group. These data demonstrate that the MDT meeting is not

a 'socially neutral' space, but subject to the same requirement for understanding,

inclusiveness and acceptance as another social situation. Stripping back these social

niceties (even to the extent of failing to provide coffee), whether due to workload pressures or other reasons, affects the atmosphere and decreases the quality of service provision in the eyes of the members as a result. The resultant atmosphere, at least in centre A, provides a challenging environment in which to make treatment recommendations which, as I have discussed so far, are already complex. Importantly, many of the factors which generate this atmosphere, such as the attitude of members, set-up of the room or facilities available are modifiable. The provision of coffee, team exercises such as 'round the table' at the end of the meeting and the exclusion of phones are simple additions to the MDT meeting. Other factors such as personal differences and historical interactions between individual members are more difficult, but certainly not impossible, to address. The workload of the MDT and allied health professionals is also a more significant challenge to rectify, merely because of the investment and personnel which is required to achieve this.

The data above allow us to begin to see the perspective of the members of the MDT who speak less regularly and provide evidence of the effect that the atmosphere may have on the team decision making. In centre A, other allied health professionals (such as speech and language therapists) echoed the sentiment that the atmosphere is not conducive to their input. In order to demonstrate this, I present data from Sally, a speech and language therapist in centre A:

> I don't think it is always a full and frank discussion. Because when it becomes threatening like that….for some people in the room anyway, it just results in silence doesn't it? [You just] keep your mouth shut because you're going to say the wrong thing. I know from my own perspective, I would be much less likely to talk some weeks than others. But that's because I've had my hands burned and I've contributed sometimes and said the wrong thing and been in the line of fire, and I'm not prepared to do that….Even if the patient were my relative and it was for the best outcome for them, I wouldn't put myself through that now.

These data provide a stark demonstration of the effect of the atmosphere on the contribution of the allied health professionals. Speech and language therapists provide specific expertise about the pre-treatment function of patients with regards to their voice and swallow, and have an intimate knowledge of the functional outcomes in the months and years after treatment. Here Sally states that, although the atmosphere varies, an atmosphere which is not conducive to her input results in her not adding anything to the discussion; by silencing her, vital details about the patient may be omitted. The grave negative effect that the atmosphere has on her input is clear from her words when she states that she would not add to the discussion "Even if the patient were my relative and it was for the best outcome for them". These data provide insight into the detrimental effect that the atmosphere of a room has on the input of the allied health care professionals. It is not only an effect on their feelings; they are present to provide expertise, often of a different nature to the evidence presented by the doctors. An atmosphere which is not conducive to including these allied health professionals in the discussion will have consequences on the evidence available to inform the recommendation.

The data presented in this section outline two important concepts about the atmosphere of the team. Firstly it is modifiable, and secondly, it has a significant effect on the input of the allied health care professionals. If the modifiable factors which encourage inclusion in the team are ignored, this potentially limits the input of allied health professionals and hence the nature of the discussion and potentially the recommendations made. It is not possible to conclude that treatment recommendations would be different if the atmosphere were different. However, my observations support the account above that the atmosphere of each centre I visited changed the way in which

MDT members interacted and hence the nature of the discussion. This means that implementing changes to facilitate the input of these members would help to provide a more inclusive atmosphere, which would in turn increase the contribution of the allied members, and with it the information that they bring.

5.5 Conclusion

Through the course of this chapter I have discussed the initial stage of the work of the MDT team. The aim of the MDT meeting is to produce a treatment recommendation and, in order to do this, the members need information and evidence on which to base this decision. There are two main sources of information: firstly, information about the patient being discussed and, secondly, information gleaned from elsewhere, such as the research literature or the previous experience of the team. These discussions do not take place in contextual isolation; they are framed by the atmosphere, history and culture of the team. All discussions take place with a backdrop generated by the people present, their history together, their previous discussions and the pressures which they are facing, both individually and as a group.

Different pieces of evidence hold a different importance in the room to the various members. This is not a pre-defined list or rank ordering, it is a hierarchy which is continually defined and re-defined depending on the patient and the negotiation that the team is having. There are pieces of information which are less contestable, but certainly not immune to discussion, such as the size and extent of the cancer, and the clinical opinion of the team. The other evidence varies in importance, depending on the patient, the disease and the proposed treatment. The importance of these pieces of evidence also varies over time, as new technology is introduced and new research performed. Much of the research evidence available to the MDT members in HNC is of limited quality

which allows members to sometimes alter their interpretation to reinforce their argument.

The experience of the team has a substantial effect, which governs not only the individual decisions made, but also the behaviour of the team over time. The members of the team appear to value the 'safety in numbers' that team experience brings but, at the same time, previous experiences, especially those which are negative, shape the pattern of the discussion and the treatment recommendations made. Thus experience has positive and negative effects on the discussion, but potentially creates a clinician–driven variation of care between teams.

In this chapter I have shown that before the point is reached where the 'decision talk' can even take place, the evidence underpinning the decision needs to be made available and mobilised.   In order to do this, the team attempt to construct the 'evidential patient' out of a number of pieces of information about the patient. This 'evidential patient' is designed to reproduce the patient in the room via information. There is disagreement, not only about which evidence should be used, but also how it should be drawn upon. Even in teams where there is less conflict, and the evidence used to construct the patient is more stable, one wonders whether it is possible to produce a patient identity in the room by providing information. The "feel" of a patient is not a fact which can be presented, but rather is a product of an interaction. This means that any attempt to represent it, other than via interaction with the patient, is potentially doomed to fail.

The data presented in this chapter represent an extra layer of complexity in the process of decision making in teams. In a clinical encounter between one doctor and one patient, the evidence and information used and its hierarchy is clearer. This is partly because the work involved is performed by one individual (the clinician) rather than a

group. The patient is also well-represented; they may not always be called upon, but the information required to get the "feel" of the patient is available to the clinician via interaction with them rather than via the 'evidential patient'. Hence, I have outlined an additional complexity of team decision making; a step before treatment recommendation, where the foundation blocks for the decision are put in place. Whilst presenting the data so far, I have not given details about how the recommendation is made, how this is communicated to the patient and ultimately how a decision is reached. I will discuss these aspects of decision making in the chapters which follow.

Chapter 6: Delivering the Treatment Recommendation

In Chapter Five I described how the evidence which is used as the basis for a treatment recommendation is mobilised and negotiated within the MDT. In this chapter I move the focus to the next phase of the decision making process: delivering the treatment recommendation to the patient. I discuss the motivations of the team to arrive at a treatment recommendation, the challenges that the team face in order to acknowledge and then offer treatment choice and the effect that these challenges have on the treatment decisions made.

6.1 Assessing 'best'

The basis of the MDT discussion is to come to a recommendation of which treatment is 'best' for the patient and when I observed the MDT meeting and clinic, the mention of 'best' was commonplace. In the following extract Mr Halifax describes his view of the aim of the MDT discussion:

> [The team] need to leave the MDT [meeting] with the treatment options ….prioritised. So a rank order of [the] best treatment clinically – slightly irrespective of the patient's wishes. From a clinical point of view to try and get best outcome, this would be our first, this would be our second, this would be third and fourth and fifth. Then you discuss it with the patient and say, "This is what we think."

(Mr Halifax, Maxillofacial Surgeon, Interview, 5th October 2012)

In this data extract, Mr Halifax clearly states his view that the aim of the MDT discussion is to decide the "clinically" best treatment for the patient and even goes as far to say that this could be "irrespective" of the patient's wishes. It could be argued that in restricting his view of best to 'clinically best' he is accepting the limitations of making recommendations in the MDT setting and adapting his clinical practice to suit.

However, Mr Halifax's reference to "best treatment clinically" is open to interpretation.

In the MDT meeting the patient is not physically present, but this does not mean the patient is not present in any form. I discussed previously how the team build the 'evidential patient' in the MDT meeting; in this way the patient is present through case-related information, much of which is non-clinical. The patient is also present as a manifestation of collective past patients, hence more 'patient-related' factors become an integral component of this 'clinical' assessment. This means the distinction between an assessment which is 'clinically best' and that which is more 'patient related' is unclear. Even if 'clinically best' were to exist, individual clinicians, in varying situations, have differing views on what they would consider it to be; it is certainly not an objective entity which exists as one, incontestable truth. Hence, although Mr Halifax may have his own clearly held view, this may not be shared by other members of the team. In this quote Mr Halifax does not refer to how this assessment of best interests should be made, what its basis should be and who should perform the assessment. He also does not acknowledge the difference of opinion which may exist when assessing what is clinically best, perhaps because he does not recognise it.

As I mentioned, many clinicians have a view of what they feel is best in certain clinical situations which is formed through a combination of clinical opinion, experience and research. This view of what is best is often quite strongly held:

> In general head and neck there often isn't an option; you've got the best treatment that there's an evidence base for that… once you've decided on that option it's not that I'm deciding on it as a non-surgical oncologist or a surgical oncologist deciding on it; that is the truth as far as we know it…that is at present universally thought to be the best treatment for the patient. So once that decision has been made that's it…… the patient's decision….may not be I want radiotherapy, I want surgery, it's do you want the best treatment we know of or not.
>
> (Dr Orange, Oncologist, Interview, 18th January 2013)

In this extract, Dr Orange clearly states that one treatment option is often "best" and thus, from his perspective, the only choice which exists for the patient is whether or not to accept this. He refers to this assessment of the best as being something which is "universally thought". My observations support his assertion that MDT members often see their own assessment of the 'best' as incontestable, indeed this is one of the reasons why conflict arises. At the same time the MDT often decides that two options could, equally, be considered as the 'best'. However, in a similar way to Mr Halifax, Dr Orange does not acknowledge the difference in opinion which may exist or indeed the difficulty in defining the 'best' treatment. What does 'best' mean? Who should decide this? Which part of the treatment is being referred to? Is it a value judgement? Unlike many others, Mr Blaydon, an ENT surgeon, discussed some of these difficulties in the assessment of 'best':

> Mr Blaydon: I don't think you can have one definition [of best]… I think clearly there are different potential definitions. One definition would be that you actually look at what statistically their best survival outcome might be. And you could quite legitimately say, "That's in their best interests." But that is only their best interests if survival is their key objective. If their key objective is lifestyle and function then it may not be that that's in their best interests. So it very much depends upon what the patient's wishes are, and actually getting that information out of them is actually quite difficult. In some people they are very clear, but in the majority of people my own experience is that it's actually quite difficult to get them to actually impart that information. And we probably aren't that good at asking the question directly, "What's most important to you? Is it survival at all costs or is the quality of your life more important than your absolute survival?"

> (Mr Blaydon, ENT Surgeon, Interview, 25th October 2012)

Here, Mr Blaydon refers to what is commonly accepted as the 'best' treatment by many members of the MDT: "what statistically their best survival outcome might be". However, he goes on to discuss other aspects of treatment outcome which may be considered to alter an assessment of best, such as lifestyle or function. Most

interestingly however, he gives insight into the difficulties he faces in extending the conceptualisation of best outside of the optimum chance of survival. In order to extend the concept of what is best for a particular patient, information is required about what the patient's wishes are, what is important to them, and what their aim is for treatment. He gives the reasons why integrating this information into an MDT discussion is difficult: the MDT "aren't that good at asking" but also even when asked, "it's actually quite difficult to get them to actually impart that information". It is difficult to ascertain whether he thinks this is a result of the patient group and their characteristics, the complex nature of the disease, the format and structure of the MDT meeting or a combination of these factors. Also, even when information of this nature is forthcoming, the task of trading off one outcome (e.g. survival) for another (e.g. quality of life) is not straightforward, and varies between patients (Jalukar *et al.* 1998; Hamilton *et al.* 2012; Laccourreye *et al.* 2012). Nevertheless, the data highlight the difficulties that the MDT members face when deciding what is 'best' for a particular patient and thus the challenges that exist in using this as a basis for a treatment recommendation. However, this treatment *recommendation*, or consensus view, is the culmination of the MDT discussion.

6.2 The treatment recommendation

At the end of the MDT discussion, the team come to a 'consensus' view, or treatment recommendation. The recommendation is sometimes deliberately repeated or emphasised by the chairman or other member of the MDT, but sometimes it appears that the recommendation is assumed to be known in the team and therefore not articulated. Importantly, this does not mean that everyone agrees with this recommendation, rather that this is the message to be delivered to the patient in clinic.

In keeping with Goffman's original description, the MDT meeting room is in this sense a 'backstage' area for the actors (MDT members) to prepare for the performance on the 'frontstage' (the MDT clinic). The 'line' that the team are going to take during the performance is agreed and a unanimous 'front' is therefore presented. After the treatment recommendation is stated, the performance is set, and dissent from the members is no longer allowed, even if there is still disagreement. Here, to illustrate the 'setting' of the performance, I again use the case of Vincent Lowry: in the previous chapter I included the MDT discussion of this patient. Mr Black felt very strongly that laser treatment was 'best' for the patient, however Mr Red felt equally strongly that the 'best' would be radiotherapy. The discussion between the clinicians was protracted and at times heated. The following data are from the end of the meeting; Mr Blonde is the chairman of the MDT:

> Mr Black (ENT surgeon): [Laser is] amazing…. I can pull the patient data, I have a database of the [laser resections] I have done, I've done about 12 so far, tonsil and soft palate tumours, and it's just….it's something we need to take notice of

> Mr Blonde (ENT surgeon): Yeah, I think we'll need to, we'll have to discuss it another time or we'll take up the whole morning on one case. But, I think there are arguments for and against...

> Dr Orange (oncologist): I would suggest he has radiotherapy, because he will have a slightly better functional outcome, and he's 80 and …because of his age, and because of the possibly better function…. But you know we have had these patients and we've given them radiotherapy and the radiotherapy has failed….Soft palate seems to be more radio resistant. But the tonsil, I think radiotherapy would be much better. But then, I'm a radiotherapist. But I think the guy should have radiotherapy without chemotherapy. ….would you Dr Yellow?

> Dr Yellow (oncologist): Yes

> Mr Blonde: I think there is a consensus view of the MDT, would be for radiotherapy

> MR Black: OK

There was clearly uncertainty and disagreement about which of the treatments would be 'best' and Dr Orange alludes to this when he is summing up the role of radiotherapy. However, the data demonstrate clearly the chairman of the MDT (Mr Blonde) bringing the discussion to a close and plainly stating that the treatment recommendation (here described as the "consensus view") should be radiotherapy. In stating this, the performance is set; the 'front' is decided and a unanimous team performance promoting the certainty and expertise can be provided for the audience in the MDT clinic. These data show how the MDT meeting is treated by the MDT members as a 'backstage' area. It is where the performance to the audience is "painstakingly fabricated, illusions and impressions are openly constructed" (Goffman 1959, page 114). The data show how, in this case, all members of the MDT 'agreed' that one option was the 'best' and once this agreement was in place, dissent was not longer allowed. When this is the case, this treatment option is delivered to the patient as a clear, single treatment recommendation. In the majority of cases this treatment is accepted by the patient.

The first step between a treatment recommendation and a treatment decision is the delivery of the recommendation to the patient. The process of delivery varies slightly between centres. In centre A and B, an individual member of the MDT, the 'lead', is usually chosen to deliver this message to the patient. Sometimes it is decided that the patient should see two leads, usually an oncologist and a surgeon, either separately or at the same time. The decision about who should be the lead depends on various factors: whom the patient is under, who is available in the clinic and the nature of the treatment(s) being recommended. In centre C, the majority of the patients are seen in the 'combined clinic'. The combined clinic takes place on a different day to the MDT

meeting, and is staffed by at least one surgeon and one oncologist. In all included centres, at the MDT/combined clinic, many of the allied health care team such as the dietician, SALT or CNS are either present at the consultation or available to be called upon. The role of the allied health professionals is variable from week to week and depends on how many staff and patients are present at the clinic. Sometimes they are present for the entire clinic consultation, sometimes they move between consulting rooms. This usually means that the clinic is quite busy and it is not unusual for staff to be entering and leaving rooms as a consultation is ongoing

The MDT does not always make a recommendation for one treatment alone. At other times, the MDT concludes that there is more than one option which could be considered as 'best' for the patient. Two treatment options may have similar or equal survival but differing side effects and functional deficits associated with them. One option might be seen as 'better' with regard to clinical outcomes such as survival, voice or swallow but a second option with a different pattern of outcomes and side effects may be regarded as being good enough to offer as a second option. In these situations, the expression of treatment recommendation at the end of the MDT discussion is sometimes accompanied by a description of how it should be presented (or performed) to the patient in clinic. The following data come from the end of the MDT meeting discussion about James Cain, who has a large tumour of the voice box:

> Dr Orange: One question here is, if we give him chemoradiotherapy and we can rid of this tumour, which I doubt, am I going to leave him with a functional larynx [voice box]?

> MR BLONDE: And swallowing yes,

> MR BLACK: His larynx is compromised as it is

> MR BLONDE: It actually…. If you're going to have a chance of curing of this disease he needs combined treatment, probably surgery first

Dr Orange: If he's agreeable to that, if he's not agreeable to that, I would regard this as palliation

MR BLONDE: Yeah, so I think it's really from his point of view, if he wants…. The advice to him would be the best is to have a very big operation, but it's…

Dr Orange: I think if he were to have the operation he needs radiotherapy [after the operation]

MR BLACK: OK?

MR BLONDE: Yep, OK

Dr Orange: And if he turns down the operation we can give him chemoradiotherapy

MR BLONDE: Yep, OK, thank you

(James Cain, Observation, MDT meeting, Centre A, 22nd December, 2011)

These data show how the MDT decides not only on their performance, but on the role of the audience; the rules of how the actors and the audience should interact are clearly stated. The recommendation which would be offered in this case was surgery with post-operative radiotherapy, and the patient would be given the power of veto over this. If this veto were used, chemoradiotherapy would be offered as a second option. Although the members of the MDT voice the uncertainty associated with the outcome of Mr Cain's swallowing after the treatment, by planning to make clear recommendations they potentially obscure this uncertainty in order to deliver a convincing performance to the audience[4]. These data show how the MDT sometimes reacts when there are two treatment options which could be recommended, however this is not the only way in which the MDT handles this situation. MDT members may acknowledge that there are two options available which could *equally* be regarded as the best, or perhaps that the

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[4] Total laryngopharyngectomy (removal of the voice box and part of the throat) was offered to, and accepted by, Mr Cain

assessment of which of them is best cannot be made in the backstage area (and hence without the patient). In this position, the MDT has a situation of treatment *choice* and in the following sections, I will discuss how the team manages this.

6.3 Treatment choice

The challenges in the assessment of 'best' and the difficulties of how to effectively involve patients in treatment decisions are most pronounced when there is treatment choice. Clearly treatment choice always exists: patients may choose not to attend clinic, or they may refuse the clear recommendation of the team. When I refer to choice here, I refer to treatment choice being *offered* by the MDT to the patient. However, in order to offer choice, its existence must be *acknowledged*.

6.3.1 Acknowledging choice

If choice is not acknowledged by the MDT it can never be offered to the patient. The MDT acknowledges choice by recognising that two or more options are indeed available for a particular patient. Stanley Wright is an 87 year old gentleman with a large tumour of his tonsil. During the MDT meeting the team decided to give a clear recommendation of radical radiotherapy:

> Dr Orange: Right, so it stops at the soft palate
>
> Mr Reggie: T4a….
>
> Dr Orange: Why doesn't he have any nodes with a tumour this size?... What symptoms did he have?
>
> Mr Blonde: Just a sore throat, and some difficulty swallowing.
>
> Miss Salt: He has had some weight loss, and what have you, so it sounds like he's already losing weight, got swallowing troubles.
>
> Dr Orange: Obviously he needs radiotherapy then. If you actually put him in a slot, whoever's finished first will see him

Mr Blonde: Well it's T4 N0 M0, as far as we can tell, yeah. Erm, thank you

(Stanley Wright, Observation, MDT meeting, Centre A, 2nd February 2012)

In this extract, it can be seen that the team has come to a clear recommendation of radiotherapy. To Dr Orange, this is 'obvious' as clearly radiotherapy is the 'best' treatment to cure this particular grade of tumour in this anatomical location. However, of interest in this extract is the data which is *missing*. Radiotherapy can only be regarded as the 'best' treatment in this case if the aim is to cure the disease. In order to achieve cure the patient has to withstand the risks and morbidity (and potential mortality) associated with treatment: radiotherapy will have a profound effect on his swallowing and nutrition, and probably lead to a requirement for a feeding tube. The trade-off needed to achieve treatment cure, the risk of treatment effects being overwhelming or cure not being achieved may not be acceptable to Mr Wright. Indeed the chance of achieving cure in T4 oropharyngeal cancer in an elderly patient is low. In this way, by not discussing the palliative option, treatment choice is not *acknowledged* by the members of the MDT. When choice is not acknowledged, it can never be offered. I spoke informally to Mr Blonde after the meeting about why this was the case:

> They discussed an 87 year old with large disease of the oropharynx. They decided that he should be treated with radical radiotherapy, however looking at the disease, I was doubtful whether this was going to be curative, and again I wondered if he should be offered a palliative option. I asked Mr Blonde … he said that the prognosis is often so poorly known (as in the data isn't available), that it is difficult to tell what his chances are and therefore whether to give him the palliative option

(Field notes, MDT meeting, Centre A, 2nd February 2012)

These data suggest that the reason the prognosis associated with treatment was not discussed was because this information was not available [5]. There is well accepted evidence that one in three HNC patients will die of the disease (DAHNO 2011); the difficulty that faces many clinicians is predicting which of any three patients has the poor prognosis. Mr Blonde reacted to this lack of information by treating the patient radically; this reaction to the lack of prognostic data is commonplace:

> The best chance of curing someone's the first chance. We don't know which third is going to be…. so how do you choose that third [of patients who will die of their disease]?. In the future we may have better tumour markers, we may have better co-morbidity marks and just basically genetic markers showing how well a patient is going to live…. Really, we do not have the prognostic markers on head and neck

(Dr Orange, Oncologist, Interview, 18th May 2012)

A prognostic marker is a clinical indicator used to estimate the likelihood of success of a treatment or the reaction of the patient or the tumour to certain treatments. These data clearly show that Dr Orange feels that the lack of prognostic markers leads him to treat more radically. If he is presented with three patients with HNC, he is therefore unable to estimate which of these patients has a poor prognosis. This, coupled with the belief that the best chance of cure is the first time that a patient is treated, drives him to treat all three with radical therapy in order to provide the best chance of cure. However, a 'trial by treatment' approach advocated here means that a lot of patients are treated for disease when they are very unlikely to survive the disease or the treatment. I was able to put Dr Orange's opinion directly to the oncologist at centre C, Dr Goodier, and the following was his response:

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[5] In the MDT clinic, it was decided to proceed with radical radiotherapy. Palliative management was not discussed

Ha ha! But if you look at the decades of reporting……and compare that with the sort of shall we say, the more softer approach, the overall five year survivals are not that different. And in my own experience …we can recognise which patients are going to tolerate treatment and which are not and our predictions are usually right…if you treat aggressively you can see the damage you're doing and they don't recover. There still will be one or two patients who we've made the wrong decision. We've gone for an aggressive, you know potentially a curative approach and we've regretted it.

(Dr Goodier, Oncologist, Interview, 18th January 2013)

Dr Goodier's views are in direct contrast to Dr Orange, who strives for more concrete, perhaps 'scientific', markers of prognosis on which he can base decisions. Dr Goodier referred again to the emotional effect of pushing patients through radical treatment which has a further effect on his treatment recommendations. These data demonstrate how the lack of availability of prognostic information can be interpreted in a completely different way by two individuals; this interpretation has a fundamental effects on the treatments recommended to patients.

The data presented so far in this section demonstrate how a lack of prognostic data can lead to treatment choice (in particular palliative options) not being acknowledged. This lack of prognostic data is interpreted in different ways by different clinicians, but nonetheless if clinicians and patients are not aware of the prognosis of treatment, this potentially acts as a barrier to offering choice. However, this is not the only barrier to offering choice: even when choice is acknowledged by the MDT as a group, it is not automatically offered to the patient. In the group setting the disagreement of which option is 'best' (and hence which option should be recommended) can lead to a unique situation where the *group* acknowledge that treatment choice exists, but there is no one individual in the meeting who feel that two (or more) options could be viewed equally as the 'best'. Mr Vase had a rare tumour of the parotid gland which had been removed

surgically. Below, the MDT are trying to decide whether or not it would be 'best' to give him radiotherapy post-operatively:

> Dr Orange (oncologist): He's had quite a lot of tumour manipulation as well; I'd give him radiotherapy but….
>
> Mr Surton (maxillofacial surgeon): There was no sense that we actually breached the tumour or saw the tumour, it was always encapsulated….
>
> Dr Orange (oncologist): Would you keep him under observation then?
>
> Dr Yellow (oncologist): [nods]
>
> Dr Orange: I think you would cause not really very much morbidity [with radiotherapy], it's so peripheral and so lateral. So Mr Surton, if you want him treated, send him to me, if you want him under observation, send him to Dr Yellow
>
> (Philip Vase, Observation, MDT meeting, Centre A, 15th December 2011)

Here, Mr Surton asks for advice from Dr Orange and Dr Yellow, the oncologists who have attended the MDT meeting that day. There is a clear difference of opinion between the two: Dr Orange feels Mr Vase should be offered radiotherapy, and Dr Yellow feels that he should not. Here, the MDT acknowledges that choice exists: the group feel that two options are available. However, both the individual oncologists feel that one option is 'better' than the other. In such a situation, the selected lead may stick rigidly to the performance and recommendation decided by the team, and dutifully deliver the balanced view of the MDT, or he / she may deliver a recommendation based on their own view of 'best'. At the time of selecting the lead, it is impossible to say how rigidly they will stick to the 'party line'. This makes the group's choice of lead to deliver the recommendation to the patient a proxy for the recommendation which will be delivered.

When choice is acknowledged by the MDT, the choice of lead is not the only problem; there is further disagreement as to whether choice should be offered at all Samuel Belton was a 55 year old male with a moderately sized (T2) cancer of the tonsil which had not spread to any lymph nodes in the neck. The MDT discussed the available treatment options, and different members felt that two different treatment options would potentially be the 'best' for him. Mr Surton (maxillofacial surgeon) felt that the lesion could be removed surgically and then reconstructed using tissue from the patient's forearm. Dr Orange (oncologist) felt that the patient should be treated with radical chemotherapy and radiotherapy ('chemoradiotherapy'). We join the discussion at the point when the two treatment options have been verbalised by the respective consultants:

> Mr Surton [Maxillofacial surgeon]: So shall we see him together
>
> (Silence 10 s)
>
> Mr Blonde [ENT surgeon]: Depends how you put it to the patient isn't it, you know!
>
> Mr West [Plastic surgeon]: It's one of these things, we've done this before, and you see the patient, and you have two people there, and you confuse the patient even more. I think….
>
> Tessa [Clinical Nurse Specialist]: It's horrendous, I think it is the worst thing you can do for a patient
>
> Mr West: I agree. I think it's a terrible thing
>
> Tessa: Patients just don't know, they just don't know what to do
>
> Mr Surton: But are we not supposed to give the patient choice?
>
> Mr West: And if we can't decide, I think it's really unfair, I know we've been here before and we've spoken about it, but this is…
>
> Tessa: Hey I've seen…., you know it's picking up the pieces afterwards, because they're really cannot make that decision
>
> (Samuel Belton, Observation, MDT Meeting, Centre A, 1st March 2012)

This is the start of a lengthy argument in the MDT meeting about whether this treatment choice should be offered to Mr Belton and if so, how. The majority of the conflict involves how (or whether) to offer the choice to the patient, rather than specifically which modality should be chosen. The situation is a stark representation of the difficulties that the MDT encounters once choice has been acknowledged: the group feel that there are two options available, but each individual has a clear view of which of these two options is best. So how should the team proceed? It is easy to initially judge the viewpoints expressed as being paternalistic or over-protective, but in order to understand them, they need to be explored further. The following data extract is taken from later in the discussion:

MDT coordinator: So you want to see him separately? See him first, and then oncology or….

Tessa: This is where it becomes difficult for the patient

Mr West: Yeah, I don't think we're doing the patient any favours to be honest.

Tessa: It traumatises them, they don't know what to do

Mr West: I've been in these discussion before, and I don't agree with them, … I don't think we're helping the patient… I think we should decide what we think the best option for the patient is, we mention a different option for treatment, and we say as an MDT, with all of our experience we feel this is the best way to go

Mr Blonde: …I think with most of these things, your first chance is your best, and I think he stands a better chance of getting away with less treatment from primary radiotherapy, with consideration of chemo. That's what I would say. Tessa, you're dispassionate if you like, in terms of the modality of treatment?

Tessa: I'm just…. I'm not bothered about necessarily the modality of the treatment, I just don't think we should be going in there and saying you need to decide….

Mr Blonde: No, no, no, I didn't mean that, I mean if he's your family

Mr Surton: You have a duty to tell the patient what the treatment options are

> Mr Blonde: I think that is right. I think in this day and age, I don't think you can say to the patient you should have this, and not to allow the patient to ask the question is there an alternative

> (Samuel Belton, Observation, MDT Meeting, Centre A, 1st March 2012)

In this extract, the evidence has been mobilised and assessed by each member of the team, and different members of the team have come to different conclusions about how to proceed. One is vocalised by Mr Surton "You have a duty to tell the patient what the treatment options are" and the other is vocalised by Tessa "I just don't think we should be going in there and saying you need to decide". When I interviewed Mr Surton, his feelings on the aim of the MDT and the relationship of the MDT with the patient were clear:

> I truly believe in our role being one of providing information and supporting people in their decision making process... I think you just have to be sensitive to the individual, …The MDT as a concept cannot be aware of the subtle things to do with what makes a patient tick, what makes a patient happy, what makes a patient feel comfortable. We present, really a history, an x-ray, a biopsy and therefore a diagnosis and we are offering treatment based upon that, but that really isn't enough to make these important decisions, otherwise we could just be using an algorithm

> (Mr Surton, Maxillofacial Surgeon, Interview, 28th May 2012)

At the beginning of this data extract Mr Surton states his view of the aim of the MDT meeting. He goes on to detail his reasons for these assertions; that the MDT is not aware of the more subtle patient factors which affect decision making. The information which is available (mainly clinical information about the cancer) is not enough to make a decision in the room on behalf of the patient. With this in mind, he is stating that when choice is acknowledged by the MDT it should then be offered to the patient. However, in order to explore the opposite viewpoint, I will present data from Tessa, the clinical nurse specialist:

I just think the patient is looking to us all the time. And of course then everybody is sort of saying, "Well, it's not really for us to make that decision, it's for you. All I can do is give you the information that we've got." And I just think that's very, very difficult… I always worry that if that treatment that they decide then turns out to be potentially the wrong decision they could potentially blame themselves. And that's what worries me, I just think that, that would be awful.

I definitely think we should have an idea as to what treatment we offer. So, I don't think whether the patient should be told, "We can offer radiotherapy or surgery and then the outcomes is potentially going to be the same. But if one doesn't work then we'll go on and do other." That's terrible and I really don't agree with that

(Tessa Darling, Clinical Nurse Specialist, Interview, 23rd October 2012)

Tessa clearly feels that the patient is dealing with the diagnosis and impending treatment and should not be laboured with all the work of decision making in addition to this. In the interview, it was difficult to unpick whether this viewpoint stemmed from a belief that decisions should not be shared with patients or previous experiences of witnessing it being done poorly. In saying this, she is recognising the anxious situation in which the patient is in, faced with multiple experts and with limited time. The view point which she holds is widespread, both by MDT members and patients. When speaking to the patient in question, Samuel Belton, about the situation, he said the following:

From the patient's point of view having two sets of professionals who disagree on something wouldn't make me feel very good…. it might make me say well look can we have another opinion….you know if I was put into that situation I would want the medical people to make the best decision for me because they would know that

(Samuel Belton, Patient, Interview, 6th March 2012)

Here, Mr Belton holds a common stance with Tessa and feels that the members of the MDT should make the decision for him. I will discuss the patient experience of decision making in the next chapter, but present this data here to show that the view of

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Tessa, although it could be interpreted as being paternalistic or over-protective, is widely held, even amongst patients included in this research. Indeed, it is difficult to disagree with the argument that patients are in need of support and guidance during the time of their cancer diagnosis. The data presented in this section demonstrate that when choice is acknowledged by the team, there is disagreement as to whether it should then be offered to the patient. This disagreement centres on whether, by presenting two or more options without a recommendation for one, the team are *offering choice* or *presenting uncertainty*. In order to explore this further, I will focus on the end of the MDT discussion about Samuel Belton. Of particular interest is the way in which the chairman of the meeting, Mr Blonde, achieves consensus within the team, allowing the resolution of the discussion:

> Mr Blonde: I think with patient communication, what you're doing is you should make the patient feel that they can trust you to do what's in their best interests. And in this situation, you say that the surgery's going to be big, and you'll have difficulties with it and we, as a team, will do our best to look after you through all that. You could have a big operation, but it is a big operation with quite a lot of healing up, and it is possible that you could need some radiotherapy after it. There is the alternative to have radiotherapy and chemotherapy, but it's unlikely that you'll get away without significant difficulties with your swallowing, and I think it would be unfair not to add that last bit. But I think if you put it in that way so the patient feels that they can trust the team
>
> Tessa: Yeah
>
> Mr Blonde: I think when they fall apart is if we say we can't decide, and we don't know what we're doing
>
> Tessa: Yes, and that's when it becomes difficult
>
> Sally [Speech and language therapist]: That we're arguing yeah….
>
> Mr Surton: No, I agree entirely with what you say
>
> (Samuel Belton, Observation, MDT Meeting, Centre A, 1st March 2012)

In this extract, Mr Blonde emphasises that they should allow the patient to feel that they can "trust the team". This reframes the problem from one about whether or not to present uncertainty to one about instilling confidence and is the linchpin that the whole team feel comfortable signing up to. By advocating that the MDT should instil "trust", Mr Blonde does not address how this uncertainty should be presented in the frontstage, but rather how it should be hidden. Nevertheless, the mention of "trust" gives the MDT a common purpose to move forward with. Importantly he makes it clear that they should not present the patient with uncertainty: this is the point which brings wide agreement from the team. It is clear that uncertainty exists: none of the information which underpins the decision could be viewed as certain and there are very few, if any, 'facts' which can be seen as undisputed. It is widely accepted amongst the MDT members that patients should not be exposed to uncertainty and equally wide agreement that the patient should be given choice, but the two concepts are closely interlinked[6].

The data presented provides valuable insight into the backstage behaviour of the actors. The conflict presented above about Samuel Belton centres on how the performance should be delivered with uncertainty viewed as 'destructive information'. Goffman (1959) refers to destructive information as "facts which, if attention is drawn to them during the performance, would discredit, disrupt, or make useless the impression that the performance fosters" (ibid, page 141). This leads to uncertainty being kept from the audience in order for the performance to be convincing. In order to explore why uncertainty is viewed in this way, I will turn to Mr Halifax, the maxillofacial surgeon.

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[6] In the MDT clinic the patient was offered chemoradiotherapy. Surgical resection was mentioned at the end of the consultation, but there was a clear recommendation for chemoradiotherapy

I think they need to know there is uncertainty, I don't think that's unfair. You can say, "Well it isn't clear cut in your case, x or y or z, but we think this, this or this." I think you have to have the bollocks to rank them in order. I really do not believe it's fair to say to the patient, "We're quite uncertain, we don't know what to do, these are the options, what do you want?" I mean that is just shit because you're the bloody expert, that's what they're paying you for, "What would you do?" and you have to be able to say, "I would – if this was my mum, that's what I'd do." I think they should leave with a degree of certainty about their treatment…. that is beneficial psychologically to them. And they have to walk away with that. They can't walk away thinking, "Christ, even the experts don't know what to do." That's desperately wrong. How you'd bring [a patient into the MDT meeting] more, productively – saying, "Here we are, come to the MDT, we'll all bloody – we all shout at each other over the table, you're completely involved from square one." How's that going to help them? They're just going to see uncertainty and general larking about, which isn't great. But out of [the MDT meeting] comes, you'd hope, some reasonably….clear decisions and that's the aim of it I think…. What comes out at the end of it is a fairly useful decision making order of priorities for the patient that they can then go away with.

(Mr Halifax, Maxillofacial Surgeon, Interview, 5th October 2012)

In this extract, Mr Halifax links the provision of certainty to his status as a professional or expert. Uncertainty, on the other hand, is seen as not knowing what to do, and is viewed by him as something which should be avoided. At the same time, Mr Halifax does not think that it should be a 'secret': he clearly says that the patient should know there is uncertainty. This apparent paradox is in part resolved by the effect of presenting the patient with a professional recommendation in the face of uncertainty. This makes the 'art' of the professional to be delivering a reasonable and justified recommendation frontstage despite the challenge of uncertainty. This viewpoint is widely held, and presents the MDT with a challenge. The team frequently face situations where two options are available, with only the conviction of the various individuals around the table separating them. There is no way of saying, with the evidence and expertise available, which of them is 'best', partly because of the difficulty in defining 'best' that I have already discussed. Whether the team perceives

this as a position of uncertainty, or a position of choice is central to how they deliver the message to the patient.

6.3.2 Offering choice

So far in this chapter I have discussed the challenges that the MDT face when acknowledging that choice exists for a particular patient. However, even when choice is acknowledged, it is not always offered to the patient. Nevertheless, situations do arise where the team acknowledge that choice exists and agree that it should be then offered to the patient. In this section I discuss the complexities that the MDT members face in *offering* choice effectively. As already noted at the end of the MDT discussion, the team select a lead to deliver the treatment recommendation to the patient. The lead has ultimate control over how the performance plays out to the audience and thus how the recommendation of the MDT is delivered. Leads usually have a clear individual view of which treatment they think is best and this view may be different to the recommendation of the MDT. If the MDT has acknowledged choice and agreed that it should be offered, the lead may still feel that one treatment option is 'better' than the other. Their own views/opinions may shape how rigidly they stick to the MDT recommendation, and means that when delivering the recommendation for two or more treatment options, the description of the treatments are 'framed'.

Framing is when the emphasis of the treatment recommendation is presented in such a way so as to provide bias, or at least make it very difficult for the patient to do anything other than comply with the lead's assessment of best. To demonstrate this, I present two extracts, both involving a consultant oncologist talking to a patient about radiotherapy. In the first extract the patient (David Dale) had advanced disease

involving the lymph glands of the neck and had a choice between surgery and

radiotherapy. The following is Dr Green's description of the treatment to the patient:

> Dr Green: The first thing that would happen …they would make you a
> plastic mask ….because it's a very accurate treatment.. …. And then
> when you start the treatment you're just lying down like as if you're
> having a scan, wearing that plastic mask. They shine the radiotherapy
> at you. You don't feel anything. You just lie there and then you go
> home again. …But, the radiotherapy does cause some side effects and
> they can be quite nasty, the side effects. Obviously the aim of the
> radiotherapy is to try and get rid of this cancer and to do that we have
> to give quite big doses of the radiotherapy. And the way it works is,
> it's a little dose each day and it builds up. So your skin on the outside
> will start getting red like it's had a sun burn-type reaction and on the
> inside it starts getting red and inflamed as well. And that means that
> you'll start having problems like a sore throat and some problems with
> your swallowing… And that means that you'll need lots of support as
> you go through the treatment. So, you'll be put on special mouth
> washes and you'll need to be on pain killers and things to help you
> with that. …. You'll feel more poorly if you're not keeping your
> strength up so we would arrange [a gastrostomy] before you started
> the treatment….It's just a little tube that's put in your tummy. It goes
> under your clothes and you'd be taught how to use it and you can
> put… They give you special food and you can put medicines and
> things down it as well…. I can't pretend that it's anything other than a
> hard treatment because it is a hard treatment….But the aim, obviously,
> is to get you through and out the other side.

(David Dale, Observation, MDT Clinic, Centre C, 21st February 2013)

Here Dr Green's emphasis on the positive aspects of the treatment can be seen

throughout. The simplicity of the radiotherapy treatment process is emphasised and

comparisons are made to previous experiences which are undoubtedly unpleasant and

difficult, but certainly not overpowering such as "sunburn", "sore throat" or "feeling

poorly". The rest of the description given also seems positive and non-threatening: the

verb used for delivering the radiotherapy is "shine", the treatment is "accurate" the food

given is "special". In addition, each time a side effect is mentioned, the efficacy of the

treatment, or the support that will be provided to overcome it is emphasised. Also, the

statement "… get you through and out the other side" implies that there will be a period

of unpleasantness followed by normality on the 'other side'. This seems to suggest that despite the hardship the patient will encounter, help will be provided, and he will probably be cured of his cancer as a result. From the description above, it is clear why a patient may agree to proceed with this suggested therapy and this was indeed what the Mr Dale did.

In the second piece of data the consultant oncologist is Dr Goodier, and the patient Gary Nicholson, who had a large (T4) cancer of the soft palate but no sign of spread. He had a history of alcohol abuse but was quite young (46 years old) in comparison to most patients with HNC. In the MDT they acknowledged that the recommendation should be an offered choice between radiotherapy and best supportive care. The following is Dr Goodier's (oncologist) explanation of radiotherapy:

> Dr Goodier: To do that, we need to spread it out over six weeks of daily treatment. That means you coming up from home, Monday to Friday, every day for six weeks with just gaps at the weekend. You'd be with us for half an hour or so each day. We would lie you on a couch on your back, wide awake and this machine would rotate around you and deliver radiation – a dose of radiation – every day to exactly the same area for a few minutes. Then you get off the couch and off you go, home and you'd come back every day 'til you've had 30 treatments. As the treatment goes through, your body starts reacting to the radiation that we're giving it. We don't like radiation. Our bodies don't like it. Everything becomes inflamed and sore. The outside of your skin and the inside of your throat will all become quite red and hot and sore and that's why swallowing will become very, very difficult – probably impossible. Even swallowing your own saliva will be impossible by the time you get to the end of that six weeks. And during that time, also, you're made very tired, increasingly tired as you go through the treatment. ….
>
> The risk is, you know, we could start off with treatment, you coming every day. The first couple of weeks you'd probably be okay but as this soreness – we'll call it that – develops, it saps your energy. Even the strongest guys struggle, believe me and by the time they get to six weeks, life is very difficult; made worse if you're used to drinking alcohol and used to smoking. You have relied on alcohol for your nutrition for a long time and to reverse that and then to have the protein that you need to heal up… because what happens is, you lose

the lining of your throat. All the protection that we have from bugs disappears, so infection gets into your throat no problem and you're overwhelmed and that's what usually happens with guys like you who just haven't got that reserve. And we cause it. We end up putting people through this harm because we want to treat to you. We want to try and get this better, but sometimes we've just got to be sensible I think; sit back and say "Actually, is this really going to work and is this in your best interests?"

(Gary Nicholson, Observation, MDT Clinic, Centre C, 31st January 2013)

Here, the striking contrast between the descriptions of exactly the same treatment can be seen. Some of the emphases that are given are quite subtle: the treatment is "spread out" and "every day", a description which sounds more laborious and less simple than that provided by Dr Green. When describing the side effects, the emphasis becomes less subtle. Where Dr Green describes a "sore throat", Dr Goodier describes "swallowing will become very, very difficult – probably impossible. Even swallowing your own saliva will be impossible". Dr Green describes "poorly", Dr Goodier describes "overwhelmed". Also Dr Goodier makes several references to Mr Nicholson's dependence on alcohol which may have shaped his bias away from recommending curative radiotherapy[7]. The comparison of these data extracts demonstrates how the description of a treatment can have a fundamental effect over the treatment choice made by the patient. A doctor can offer choice, without ever really offering choice at all. It would be understandable for the patient to choose Dr Green's description, and turn down Dr Goodier's, and yet both are the same. Both descriptions are also correct – some patients have the experience which Dr Green described, and some have the experience which Dr Goodier described. The main difference between the two scenarios is that Dr Green's description is to a patient whom the clinician wants

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[7] Mr Nicholson was managed palliatively

to accept the radiotherapy treatment, and Dr Goodier's is to a patient whom the clinician wants to turn it down. Importantly though, neither doctor is lying, both are informing their patients; indeed both doctors may feel that they are giving their patient choice. The data illuminate how offering choice consists of far more than describing two options and explaining them verbally.

During my fieldwork I observed many different motivations for framing a treatment description. The lead may be adhering to the agreed performance of the MDT, or may be manipulating the performance in order to guide the patient into agreeing with their individual assessment of best. Sometimes they are describing to the patient the 'mechanism' for the MDT recommendation and using framing to explain why an option is viewed by the MDT as being unfavourable. In this way they are describing the treatment in order to paint it in a dim light, and hence justify the team's decision to not recommend it. Sometimes it is done unintentionally or subconsciously, when attempting to present treatment options equally, and sometimes it is done to frame the treatment in a positive light and hence protect the patient and engender hope. Nevertheless, the use of treatment framing is a barrier to offering choice to patients. Framing a treatment description does not always lead to a patient agreeing with the clinician but the existence and effect of framing must be explicitly acknowledged before choice can effectively be offered in the MDT clinic. The effect of framing is most pronounced when discussing palliative or non-curative treatment options as I discuss in more detail below.

Discussing palliation

I have discussed the influences on the rate of palliation between different clinicians previously. Here, I examine how the way palliation is described is sometimes a major

barrier to pursuing non-curative treatment options. The extract below relates to David

Forcett, a 72 year old patient who had a recurrent cancer which was invading one of the

muscles of the neck. Palliative management was briefly mentioned and hence

acknowledged in the MDT meeting, and the following extract is from the end of the

clinic appointment, and takes place between Mr Phillips (plastic surgeon) and the

patient:

> Mr Phillips (Plastic surgeon): What kind of pastimes do you enjoy?
>
> Pt: Oh I go fishing
>
> Mr Phillips: Fishing, well hopefully many years of fishing to enjoy hopefully…so our aim will be to cure you
>
> Pt: Right. Thank you
>
> Mr Phillips: And, so as long as you don't want to give up, we're not going to give up
>
> (David Forcett, Observation, MDT Clinic, Centre A, 26th January 2012)

Here, the language used to express the prognosis, the expectations of the success of the

treatment, and palliation is of particular interest. It can be seen that Mr Phillips

expresses the prognosis of the treatment in broad terms: "hopefully" and "aim". These

are very general words which do not give the patient any clear indication of their actual

likelihood of survival. The use of words such as 'hope' and 'aim' is widespread in the

MDT clinic, indeed it is difficult to find examples of where prognosis is discussed in

any other terms. The use of these words may be as a result of a paucity of prognostic

data, but also, both 'hope' and 'aim' are quite positive words, which are likely to give a

message that survival is something which should be expected. Of particular interest

with regard to offering choice is the way in which Mr Phillips implies that the palliative

option is to "give up": this description is beyond framing of the treatment options and

the words are close to offering no choice at all. To "give up" implies that if the

palliative option is selected, then the patient may be abandoned, with no actual care offered. However, the language used to describe palliation is more complex than this; the context in which a discussion takes place is central to whether palliative management plans are selected by patients, as I now explore.

Edward Doman was a 74 year old patient with two synchronous cancers in the oropharynx and the mouth. The operation being proposed to remove the cancer was extensive, and likely to require post-operative radiotherapy to achieve cure. The cancer was also invading the bone of the jaw which meant that radiotherapy was not going to offer a curative treatment. Mr Doman attended clinic on three successive occasions; on the first two occasions further scans and opinions were required to assess his suitability for surgery. During the third MDT meeting, the team recommended that palliation should be offered to him as a first line therapy. It is important to note that up until this point, over successive clinic appointments the focus of discussions between Mr Halifax and Mr Doman had been to provide cure. The following extract is from when this was discussed with him in clinic:

> Mr Halifax: My concern as I mentioned to you last time is surgery would be very extensive and would still lead on to radiotherapy. Radiotherapy…wouldn't be a walk in the park …and the disadvantage of radiotherapy is that we know there's some bone involvement there so they would increase the dose on where the bone is, it would probably kill the bone to some degree but surgery would actually completely remove it…And we obviously need your opinion as well... Any form or treatment to try and completely cure this is going to be extremely extensive, do you see what I mean? And I think, as I say we've discussed this at some length and there may be some merit in going for the radiotherapy first to try and control what's there. That was in essence the upshot of the discussion.
>
> Patient: Could that cure it, my disease?
>
> Mr Halifax: Certainly the idea it would certainly delay it. I don't think we could sit here and offer you a cure with any form of treatment. That just isn't...

Patient: With any form of treatment? Even the surgery wouldn't?

Mr Halifax: I couldn't sit here and guarantee you a cure with anything. That's just a fact. I would be an idiot to do so. ….And the first thought is whether we can try and contain that with radiotherapy and see where we are at that point.

(Edward Doman, Observation, MDT Clinic, Centre B, 15th June 2012)

In this passage Mr Halifax is offering choice: the first is complete removal of the cancer, reconstruction and post-operative radiotherapy. This is extensive treatment, and would have a significant impact on the Mr Doman's quality of life; indeed the MDT doubted whether he would survive this. However, the surgical option is the only way Mr Doman could achieve a cure. Radiotherapy would not provide cure and would also cause side effects, although not as severe as those he would experience during surgery. The mismatch between this presumed aim of achieving cure and the treatment of radiotherapy means that the consultation was long, drawn out and confusing and Mr Doman struggled to accept radiotherapy as a treatment option. Importantly, Mr Halifax was not dismissive of the palliative option at any point but despite this, the patient had difficulty in accepting it. At the conclusion of the consultation, Mr Halifax felt that Mr Doman should speak to the oncologist, as he felt that the source of the confusion was the details of the treatment itself. However, during this meeting, the same confusion arose again:

Pt: I did get the impression that Mr Halifax thought that radiotherapy would be the best way to go

Perdy (Clinical Nurse Specialist): But the radiotherapy would not cure you of the cancer

Pt: So what would it do, the radiotherapy, would it just delay it?

Dr Strong: It may slow the progression of the cancer

Pt: But it couldn't cure it?

Dr Strong: No

Perdy: No, it won't cure it. The cancer's gone into the bone, and radiotherapy doesn't work very well when the cancer's in the bone

Pt: It is in the bone is it, the cancer?

Perdy: Yeah.

Pt: Then the only chance I've got is to go through the operation isn't it….It's the only chance I've got?

(Edward Doman, Observation, MDT Clinic, Centre B, 15th June 2012)

In this passage the focus of the discussion between the MDT members and the patient is on curing the cancer. Mr Doman is not aware that the key difference between the two options is that surgery provides some (albeit small) chance of cure, whereas the radiotherapy provides none. If the aim of the discussion and treatment was more explicit, this would provide the clinician and patient with a foundation for palliative decision making. However, because the aim of the treatment has not been made explicit or discussed, Mr Doman presumes both treatments are with the aim of cure. Dr Strong realised that the patient's aim of treatment did not match the treatment which was being offered, and so Mr Halifax was invited into the room to resolve this:

Mr Halifax: So we are trying to preserve as much as what you have already got for as long as possible, given the extent of the cancer that you've got. And that's why, on balance, it's not a question of "Can we do an operation". Yes you can do an operation; you can always do an operation, but is that going to be of any great benefit to you?

Pt: That's what I'm worried about

Mr Halifax: And that's what I'm worried about, because I'm not sure it is….So as I say, you are going to send an inordinate amount of time in hospital recovering from your surgery and going through radiotherapy. Whereas the design of the radiotherapy that is proposed which is essentially to shrink the tumour and keep it at bay for as long as possible, will keep you doing as you're doing for as long as possible…. It's not going to cure you, but neither am I. But given the fact that neither of us are saying that we can cure you, we are then in the situation where we need to try and keep you going doing whatever you are doing for as long as possible.

> Pt: So the radiotherapy from now on will be the best bet, really, that's what you're saying?
>
> Mr Halifax: So therefore it's: do you have a big operation and spend a lot of time in hospital, potentially, if we looked at the next 6 months or a year or however long, how much percentage of that time are you going to spend in hospital, with an operation and radiotherapy to follow, it's going to be a heck of a lot of it. With radiotherapy which is basically designed to shrink the tumour and keep on top of the symptoms, you're going to weather that a lot better and spend an awful lot more time doing whatever you're doing at the moment.
>
> (Edward Doman, Observation, MDT Clinic, Centre B, 15th June 2012)

These data demonstrate Mr Doman shifting towards an acceptance of palliative management once the aim of the treatment is made clear. With the statement "to try and keep you going doing whatever you are doing for as long as possible" Mr Halifax is shifting the aim of treatment from cure to preservation of quality of life. At the start of the clinic discussion, the assumption of Mr Doman was that cure was the aim of treatment: in that case, palliation will always be seen as failure. These data highlight that the aim of the treatment must be absolutely explicit for effective decision making, especially when discussing palliative options. Not only this, but when the aim of the treatment is clear, the care that is available to the patient in order to carry out the palliation can be openly discussed. This converts palliation from a passive process of 'not treating radically' to an active process of caring for a patient with non-curative interventions. Making the aim of treatment clear is not only to inform discussion of palliative management plans but also to help inform assessments of which treatment is considered 'best'. It is difficult to conclude from this data why the aim of the discussion was not clear: it may reflect an unwillingness or reluctance to discuss palliation. Nevertheless, if the aim of the treatment is always assumed to be cure, even if the words used to describe palliation are positive, the non-curative option will always be considered second best.

6.4 Conclusion

The purpose of the MDT discussion is to come to a recommendation of which treatment is 'best'. This assessment is difficult to make as many aspects of treatment outcome may be considered to alter an assessment of best such as survival, lifestyle or function. In order to decide what is best for a patient, information is required about what the patient's wishes are, what is important to them and what their aim is for treatment. The MDT faces difficulty in incorporating information of this nature into the backstage MDT discussion. Not only this, but even when this information is available in the backstage (as I discussed in Chapter Five), the MDT members have difficulty incorporating it, meaning the resultant recommendation cannot adequately take it into account. In order to involve patients the aim of the MDT discussion and the unavoidable limitations of the MDT recommendation must be clear to MDT members and patients. Although this only strengthens the argument for a central role for the patient in HNC decision making, how this should be enacted in practice remains a challenge. I will continue this analysis by describing how the treatment recommendation is used by the patients and clinicians to make a treatment decision in the next chapter.

Once a recommendation has been made, the nature of the interaction between patient and MDT member, and the effect that this interaction has on the final decision reached must be understood. Framing is commonplace, and acts as a barrier to patients being allowed real opportunity to build in their own values and preferences into a decision. Also, the aim of the proposed treatment is not always clear, leading to an inhibition of the decision discussion, especially with respect to palliative decisions. Thus, in order to present choice effectively, more than a mere verbal description of two treatment options

is required. The aims of the proposed treatment and the effect that this has on the decision made must be recognised. The MDT must understand how to effectively engage patients in this interaction in order to conduct a fair discussion of the options available.

The challenges in the assessment of 'best' and the difficulties of how to effectively involve patients in treatment decisions are most pronounced when there is treatment choice. If choice is to be offered in the MDT setting, the complexities of acknowledging and offering choice must be explicit and understood. To offer choice is sometimes to expose the uncertainty underpinning a recommendation to a patient. Although uncertainty is often seen as 'destructive information' which should be kept in the backstage, it could equally be used as an opportunity to acknowledge and incorporate the preferences and values of a patient. In this way, the presence of uncertainty could provide a basis on which patients build in their own opinions and views to a treatment recommendation in order to form a treatment decision which takes them into account.

If the MDT is to involve patients in decisions the limitations of the recommendation, the effect of the interaction with the patient and the uncertainty associated with treatment choice must be recognised. However, even if patients are offered choice effectively, this does not mean that they are involved in decisions about their care in the MDT. In order to further understand how we can involve patients we must gain an understanding of the perspective of the patient and the way in which a patient makes a treatment decision. Only by understanding this can the team facilitate the process of patient engagement and then *support* choice, after it has been offered. In the next chapter I shift the emphasis of the analysis away from the team and towards the patient. I explore

further the way in which choice is seen and dealt with by the patient, and highlight further the challenges that the healthcare team and the patient face together in making effective treatment decisions

Chapter 7: Enabling Patient Involvement

The analysis in previous chapters has concentrated on how the MDT negotiates and delivers a treatment recommendation. In this chapter I move the focus of my analysis to consider how a patient makes a decision within the current MDT care pathway. To conclude the chapter I outline how MDT decision making could change, so that the perspective of the patient becomes an integral part of the structure of the clinic.

A diagnosis of HNC presents patients with treatment options which will have a fundamental effect on their appearance, swallow, voice and survival. The available treatment options are often complicated with complex changes to the anatomy of breathing or eating, or grafting of tissue from one part of the body to reconstruct another. The complexity of the decisions being made often leads patients to turn to the members of the MDT for support and guidance. The following data is from Eric Francais a 65 year old patient with a cancer at the top of his larynx:

> Pt: You know, they're the doctors, they're the professional people. And I'm just Joe Bloggs off the street. Well, let's face it, they're the people…who know. I mean, for a lot of years, I was a steel erector. I wouldn't expect you as a doctor coming along and doing what I could do. Do I? I mean, you're the people that know how to do the job and what to do.
>
> DWH: You feel a decision should be the doctor's decision?
>
> Mr Francais: Oh, definitely, without a doubt. It's got to be the doctor's decision. How could I make a decision like that?
>
> (Eric Francais, Interview, 29th June 2012)

In this extract Mr Francais acknowledges that his own area of expertise is far removed from the world of medicine and therefore he cannot have responsibility for the treatment decision. In this situation this has led to him delegating the decision to the MDT as to him, decision making is an expert process. Although this does not mean that Mr

Francais is disengaged from the decision making process, it means he is allowing the assessment of 'best' performed by the MDT to act as the basis for his treatment decision. The view expressed by Mr Francais is widely held by patients included in this study, which endorses and perpetuates a sometimes paternalistic viewpoint which is expressed by MDT members:

> I think one of the questions is, is shared decision making the right model for head and neck cancer? And it may not be…..I think it's not the right model for head and neck cancer. I suppose what we're doing is informed benign paternalism. Paternalism again has got negative connotations and it doesn't necessarily always need to have, in that you know a real father will look after a three year old child and stop them running into the road and stop them sticking their hand in the fire….that is paternalism but it's not necessarily bad I think. [The MDT] is good for reaching a decision for what's the best treatment for a patient and then it's up to the patient to either accept that or turn it down.

(Dr Orange, Oncologist, Interview, 18th May 2012)

Dr Orange uses the concept of shared decision making to talk about patient involvement in the broader sense. He not only states that he feels shared decision making is not happening in the MDT decision process at the moment, but makes the assessment that shared decision making is something which should not happen in this disease and setting. Through the course of his argument he highlights that paternalistic decision making, in some form or another, is a viable alternative. The scenario he provides, of a father protecting a 3 year old child, presents an irrefutably 'good' application of paternalism. However, it also implies a similarity of relationship between doctor/patient and parent/child which reinforces the opinion of 'doctor knows best'. Nevertheless, the acceptance of the complexities of the disease and decision making in this setting, could justifiably lead any observer to the same conclusion, as the following entry from my reflective diary highlights. This entry was made after I observed a maxillofacial surgeon attempting to involve the patient in a decision about how to treat a small cancer

on his lip. The surgeon had offered treatment options of surgery or radiotherapy to the

patient, but had offered no support to help him to make the decision. Also, he had used

various verbal and non-verbal cues to bias the patient in favour of surgery. The patient

and his wife left the clinic room far more anxious than when they entered it:

> There was an imposition of the SDM [shared decision making] model
> on the paternalistic model, ending in the worst features of both. I left
> [the observation] with the distinct feeling that [the surgeon] should
> either share the decision properly, or not at all – to do it poorly is more
> destructive to the patient than taking a paternalistic approach. To take
> a paternalistic approach is not necessarily 'wrong'. When reading the
> transcripts, researchers in healthcare are not able to understand some
> of the nuances of the decision, so how should a patient be expected to?
> Is it right …. to dumb down the decision, or make the options more
> simple and straightforward (and therefore perhaps falsify them) in
> order just to 'tick the box' that you have shared the decision? It
> should not be assumed that SDM is what 'should' happen in this
> setting …. perhaps SDM is not the way to go forward.

(Field notes, MDT clinic, Centre A, 8th December 2011)

This is my reaction to observations of MDT members attempting to involve patients in

decisions. I worried that involving patients in these complex decisions was potentially

an impossible task, and concluded that paternalism was the safest way of making

decisions. I would emphasise this is not the view which persisted throughout the course

of this work, but present the data to demonstrate how taking part in, or observing the

MDT decision process in this disease can and does sometimes feasibly result in this

conclusion. To agree that this is the way to proceed with decision making in the MDT,

is to accept that the recommendation made as a result of the MDT discussion should be

accepted by the patient, and hence converted directly into a treatment decision. This

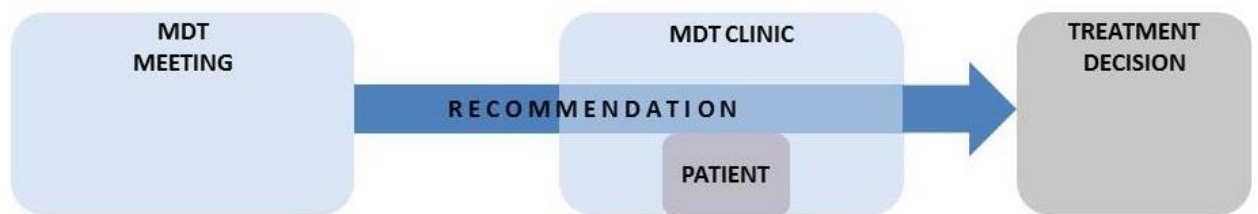results in a decision process as depicted in figure three:

Figure 3: paternalistic model of MDT decision

In this simple model of decision making, the recommendation comes directly from the assessment of 'best' from the team, based on expertise and current evidence. In this model, the patient accepts that the MDT's assessment of best is accurate and thus the recommendation is representative of their aims for treatment. Arguably, this model of decision making is well suited to the MDT structure of working. The paternalistic model accepts that there are parts of the decision making process which are less accessible to patients: in the MDT meeting the clinical information is mobilised backstage, negotiated and combined with other evidence to decide which treatment options are available. The patient can have little role in this step unless they have expertise in HNC. However, the paternalistic model has limitations in its utility in MDT decision making. I have discussed previously how to accept the recommendation of the MDT without question is to accept that the assessment of 'best' can be made in the backstage. In previous chapters I have discussed the significant problems with this: the backstage recommendation is based on the 'evidential patient' and the various MDT members' interpretations of the relevant research and experience available to them. MDT members have difficulty in incorporating information other than the clinical details of the cancer into the 'evidential patient' and thus into the recommendation: the resultant 'clinically best' recommendation cannot adequately incorporate the values, preferences and opinions of the patient. The MDT recommendation is sometimes based on considerable uncertainty, and the presence of treatment options may not have been

acknowledged or offered by the team. This model also awards no role to the patient apart from the Parsonian 'sick role' (Parsons 1951): accepting the recommendation of the doctor. In order to better understand the role of the patient in the MDT decision process, and to further explore the limitations of the paternalistic model of MDT decision making, I shall begin to describe the process through which a *patient* makes a treatment decision. Jean Dixon is a patient who had a cancer of the base of the tongue:

> Husband: It's lack of experience. I mean really, we don't really know what cancer is any road
>
> Pt: Well I do, as my mam died of cancer.
>
> Husband: Yeah, but we're not people that have had it….We don't really understand it. It would be better… from our point of view if we didn't have the choice…Everything's brand new so we can't really, you can only judge things from experience and we don't have the experience…
>
> Pt: Yeah, it was [hard to make the decision]. I mean I still keep thinking "Have I done the right thing?". … He said I didn't have to [make the decision] straight away, I could think about it. But if I had come home I still wouldn't have known
>
> (Jean Dixon, Interview, 2nd July 2012)

Mr and Mrs Dixon have had family members with cancer, however they recognise that this experience is not applicable to their current decision. In recognising this they were left with nothing to draw upon, and hence they were struggling to have any active role in the decision. Their reaction to this was to search for a recommendation from the surgeon and even to wish that no choice had been offered. During the decision consultation, this delegation of the responsibility for the decision could easily be interpreted by the clinician as an endorsement of the paternalistic model. These data reveal how their delegation of the responsibility for decision making was a reaction to the disempowered situation in which they found themselves, with nothing to draw upon to help them to take part in the decision making process.. Although patients may

justifiably actively delegate some or all of the responsibility for the decision to the MDT members, at the same time, the MDT have a duty to ensure that this is not due to disempowerment as demonstrated here. However, patients do not always discard their existing knowledge, experience and opinion in the MDT clinic. John Winton was a 61 year old patient with a large cancer of his larynx; when the MDT examined the CT scan, it appeared that the laryngeal cartilage was being invaded by the cancer, which identified the cancer as T4. As the tumour was so invasive, the MDT decided that a single recommendation of total laryngectomy should be delivered to the patient in clinic. The following is data from this appointment:

> Mr Black (ENT surgeon): This tumour in your throat is a fairly big tumour, and it's spread to the neck as well. And we had a to and fro discussion at the multidisciplinary team meeting. We believe that there are two possible ways that we can manage this. At some parts of the scan, there is evidence that the tumour may have gone into the Adam's apple cartilage. It's not entirely certain, but it looks like it. If that is the case, surgery would be the only option to get rid of the tumour. But surgery would involve you losing your voicebox, losing part of the swallowing passage, you would need a big neck operation. We'll take some tissue from your forearm, and use it to reconstruct your throat. Once we do the surgery, your speech will be different, you won't be speaking the same. You will have a hole in the centre of your neck, a tracheostomy
>
> Pt: Nah, nah [shakes head]
>
> Mr Black: You wouldn't fancy that?
>
> Pt: No
>
> Mr Black: That's the surgical option. On the other side is the option of radiation therapy
>
> Pt: I would rather take a chance with that
>
> Mr Black: The only concern with the radiation we have was, where I mentioned on the scan, where the Adam's apple is slightly….
>
> Pt: Aye
>
> Mr Black: With the tumour, if you have radiation, radiation doesn't nicely tackle when there is tumour inside the cartilage. So when that

happens, your tumour may not completely go away. You will be left behind with a bit of tumour, and you may still need surgery after that

Pt: I'll take a chance with the radiotherapy and progress from there

(John Winton, Observation, MDT Clinic, Centre A, 23rd February, 2012)

At the start of the extract, Mr Black mentions that there are two options for treatment, despite the recommendation of the MDT being that only total laryngectomy should be offered. As I discussed in Chapter Six, presenting two options and then outlining why one was recommended rather than the other was a common method of delivering the treatment recommendation to patients. In the extract above Mr Winton took control of the consultation by clearly stating that he did not want surgery and he would rather "take his chances" with radiotherapy. In doing this, he made a decision to *reject* the recommendation of the MDT. Mr Winton was adamant that he did not want a total laryngectomy throughout the consultation, and eventually the treatment decision was made to instead treat the cancer with radiotherapy. In the paternalistic model of decision making, if a firm treatment recommendation is given to the patient they usually accept this recommendation. However, a problem arises for this model when the patient becomes an active participant in the decision process rather than a passive receiver of the recommendation. Few would disagree that patients should be allowed to participate in their decision in this way; indeed, it is not possible to perform a treatment on a patient if they refuse it. When I interviewed Mr Winton, we discussed the rationale for his decision:

Pt: Well you see my mother died of cancer… my father died of cancer, and I've seen the way cancer works. I'm not being cheeky, and I'm not being horrible once they cut you open, it's like your letting fresh air into a bulb, it then just spreads, and they stitch you back up again and "We've cured it", right, for how long? And then it comes back again…

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DWH: And what's important to you when you're making that decision?

Pt: Surviving as long as I can…, I mean if you get the year, 18 months it's better than getting two weeks isn't it?

(John Winton, Interview, 5th March 2012)

These data provide insight into some of the thought processes which guided the decision processes for Mr Winton: his *work* of decision making. In the case of Mr Winton, the basis of this work was his experiences of relatives' cancer. At the time of the clinic appointment this was the only information which he had available to draw upon to make his decision.   Although this information is personally relevant, it is not clinically relevant to the situation in which he finds himself; as a result of this his aim of treatment (cure) potentially did not match his treatment decision (radiotherapy). If patients are to become active participants in the MDT clinic, this work of decision making needs to be acknowledged in the decision process. If this work is not acknowledged, this does not mean that it does not take place; instead, patients perform the work based on limited experiential information. Alternatively, as demonstrated in the next data extract, they perform it after the decision has been made. Keith Down was a 62 year old with a recurrent cancer of his larynx. In his MDT clinic appointment a recommendation for partial laryngectomy (removal of part of the voice box) was made and accepted by the patient. The following week, the patient returned to clinic with his sister as his family had doubts about whether it was the best decision for him:

Pt: And my daughter didn't agree with that about having the thing in your throat [surgery] and I said, as I said to you on Friday, if that's better, the more chance and everything… and she says "Oh we don't want this". And they got talking to each other and everything and…. It's just what they're thinking, and they're talking to different people and everything

Sister: Will he get his voice back?

Mr Black: Yes, he'll have voice, he'll have a serviceable voice, but his voice will be something like this [whispers]. It'll be a strain initially. Patients tend to do differently; we have one or two who are doing fairly well

Sister: Will it stay like that? Or will it get any better?

Mr Black: It will stay like that, yes.

Sister: And does he have to ... have a tube in for a long time?

Mr Black: He'll have a tube to feed for about six weeks I reckon. That's the average among these patients.

(Keith Down, Observation, MDT Clinic, 15th March 2012)

Mr Down attended the previous clinic appointment alone. On returning home he had discussed his decision with his sister and two daughters who raised concerns about the decision and ordered Mr Down to return to clinic. In clinic, the surgeon was able to address the family's questions, and eventually the same treatment decision was made as the week previously. These data demonstrate that this work of decision making still takes place, even if the MDT structure does not make provision for it. The opportunity to report the results of their work to the MDT clinic was something which was beneficial for his family:

Sister: Well he went himself, and his daughter rang me and she said "Well I'm not very happy about this", and I thought here we go again… I had… got myself wound up, and I was crying, and I felt as if …. I didn't understand, and I said to Keith, I don't understand, can I come with you? Do you really know what you're doing?.... I thought that maybe …he had closed up a little bit and he was just going for the operation because it was easier….but no, I heard what the doctor said, …. I'm happier now, and I can go back, and I can tell the daughters…. I phoned them up and I said, no, I says he's going for the best option

DWH: And what are his daughters like now?

Sister: Alright, she said as long as we know that there was somebody there, and you've heard clearly what they're saying you know. And I explained about what the radiotherapist had said. I mean we've got

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other family as well, he's got a brother and sister who live in
Thailand, and it's just been so hard.

(Keith Down, Interview, 22nd March 2012)

Here, Mr Down's sister describes how the patient reported the decision to his family

and they had expressed concern about whether the choice of treatment was 'best' for

him. It demonstrates a picture of 'relational autonomy': a view that humans are not self-

sufficient and independent and instead generate autonomy through interaction with

others (Keller 1997). Hence Mr Down and his close family discussed and negotiated

what was 'best' for him amongst themselves. Rapley (2008) described how patients

enact relational autonomy by distributing their decision across people, encounters,

situations and technologies. Hence decision making is not a one off episode, but a

process in which patients make decisions over a range of encounters, rather than just

one. In this way, Mr Down does not complete the work alone; he involves those around

him. They had little to base this discussion on and this led to anxiety about whether he

had made the 'right' choice, and unanswered questions about alternatives. In this case,

a concerned family requested a further appointment to report back the results of this

work, and clarify the decision. However this would not always be the case; in some

cases this patient work of decision making may come to a conclusion which agrees with

the decision made, in others the work may change the decision and in others again it

may lead to doubt and anxiety for the patient and their supporters. Nevertheless, the

MDT decision process cannot ignore this work: it is required for the patient to construct

treatment preferences and hence is an essential part of involving patients in treatment

decisions. Acknowledging the patient work changes the model of the clinic (see figure
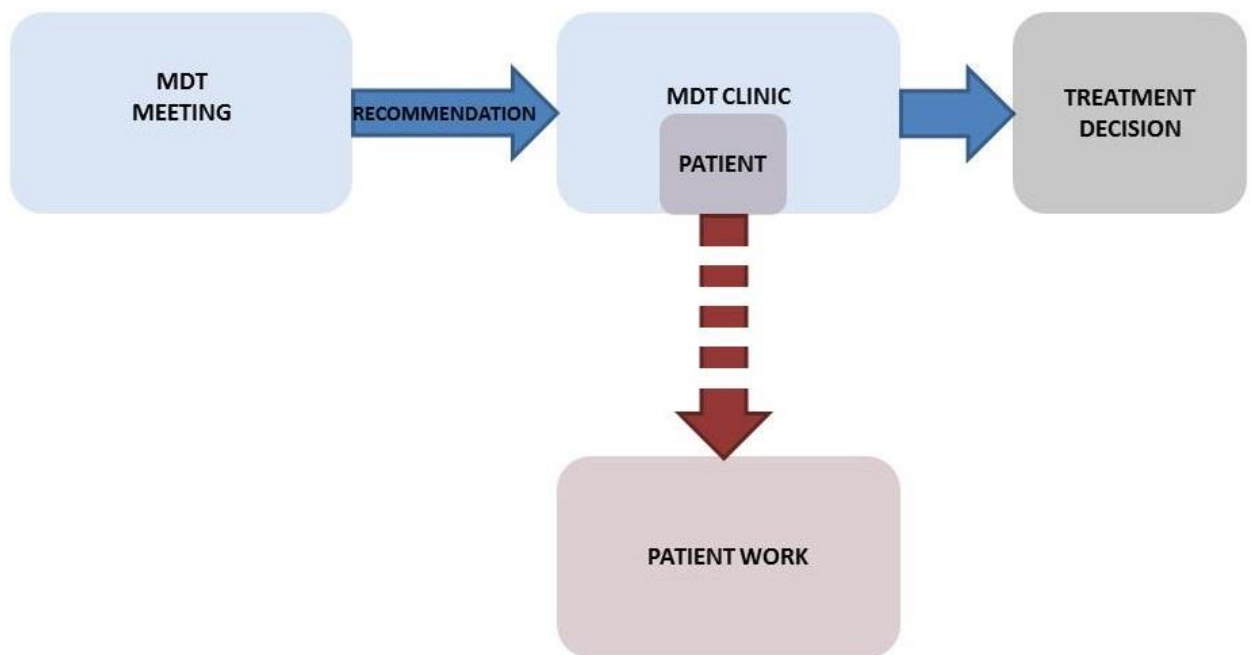
four):

Figure 4: building the patient work of decision making into the clinic structure

By building the patient work of decision making into the MDT decision process, this model includes a step in MDT decision making that a patient can have a central role in As I have demonstrated, this work is often based on prior experience or knowledge and can have a significant effect on the treatment decision made. Thus the model introduces *two* processes which contribute to the formation of a treatment decision; that of the MDT and that of the patient. Importantly, acknowledgement of patient work is only the first step toward inclusion, and is not in itself sufficient for patient involvement.   The patient process needs to be *incorporated* into the MDT pathway, rather than just acknowledged. In this section, I will show data to demonstrate how the MDT can ensure that this work is worthwhile, relevant to the decision being made and coordinated with the MDT process.

To facilitate the patient work, we need an understanding of how, where, when and by whom it is performed and an acceptance that this may vary between individuals and

over time. To begin, I will turn to James Matfield who, despite the constraints of MDT decision making, was given the opportunity to become involved in the decision. Mr Matfield was a 70 year old patient with a large cancer of the voice box who had been offered a choice of radiotherapy or total laryngectomy. Radiotherapy would affect his swallow function and may mean that he needs tube feeding in the short or long term. It would also involve six weeks of daily travel to the hospital for treatment, but would allow him to retain his voice box and therefore his voice (although his voice would be hoarse as a result). Total laryngectomy would involve a two week stay in hospital; the effect on his swallow would be potentially less, however he would breathe through a stoma in the neck and his speech would be affected as a result. In addition to this, having surgery involves being admitted as an inpatient, but radiotherapy is usually performed as an outpatient. He attended the clinic appointment with Mr Cove (ENT surgeon) and Dr Green (oncologist) to discuss the decision. Mr Matfield had the choice of two options, and Mr Cove and Dr Green had not made a firm recommendation for either. At the time of the appointment, Mr Matfield was very keen to make the decision on the day of the clinic appointment:

> Pt: I like to make my decision straight away.
>
> Dr Green (oncologist): Yeah, but it's a big… It's a life-changing decision and you don't want to just make a snap decision and then regret it either.
>
> Mr Cove (ENT surgeon): I think it might be beneficial to come back next week.
>
> Pt: You see, my wife … I'm going into hospital for a fortnight, leaving her alone in the place, like
>
> Wife: Either way, you're… you know.
>
> Pt: I know, but I'll be coming back on the night-time, like.
>
> Wife: I know you will.

Mr Cove: There's a lot going….

Pt: The chances are I can keep my voice?

Mr Cove: I think you've got a lot going on in your head. Okay? I really think this is such a big decision that you should go away and have a week … and think about it.

(James Matfield, Observation, MDT Clinic, Centre C, 21st February 2013)

Mr Matfield was very keen to make the decision in the clinic room, but, as demonstrated, Mr Cove and Dr Green felt that he needed more time to weigh up the options. Despite the protestations of Mr Matfield, the clinicians strongly discouraged him from making the decision that day. They arranged for him to have a separate discussion with the clinical nurse specialist, during which she reiterated the decision to be made and made clear what his role should be. She also provided further information for him, and arranged to ring him during the week to ask if he had any questions. They arranged for him to be seen again in clinic, in a week's time, and organised the ambulance transport for him and his wife to travel to this appointment. In this way, the team almost forced Mr Matfield to take time, talk to others, find out more then make his decision; this is something he later told me he appreciated:

Pt: And then when he says to give yourself a week to make the decision, which was a good thing because I was going to make it there and then…. and to come back and really think about it and read…. everything about it again. It gave us time to think. And I decided, if I can save me voice box rather than have the stud thing in your neck, I'd rather have it, try the radiotherapy first.

DWH: So you found that week valuable?

Pt: Yeah, yes I did, really. And very, I thought the doctors were great and all, very good.

DWH: What did you do during that week?

Wife: Well you read through the book didn't you?

Pt: Aye, I read through the books yeah.

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Wife: And we talked about it.

Pt: Yeah, and I had a good talk with you.

Wife: Asked the family.

Pt: Asked the whole family what they thought.   And they said it came down to my decision. But our [daughter] said, "Dad, if you can save your voice box and that, you know, to try and save it." And hopefully they can. That's all I'm hoping for now.

(James Matfield, Interview, 4th March 2013)

In this situation the MDT had acknowledged that there were treatment options for Mr Matfield and agreed that these options should be offered in the clinic by Dr Green and Mr Cove. Mr Cove and Dr Green felt that he should be offered more support. Hence the extra time and support that Mr Matfield was afforded was not due to a particular MDT or treatment decision, but rather the specific clinicians that he happened be seeing. The clinicians acknowledged that the patient work of decision making needed to take place and facilitated this work by giving him information, support from the CNS to ask questions, a geographical area outside of the clinic room to consult with family and time in which to perform the work of decision making. The data reveal more detail about how this work is done and reinforce that for the patient, much of the work of decision making may not be done in the clinic room, but rather it is done outside of it:

[Mr Cove] says, "No, no, this is my advice, you away and think about it." And that was good advice he give us because when I come back home and I read everything again and that, I said "I'm pleased Mr Cove said to go away".   I read [the information] again [and] I made my decision then within about two days. I'd made my decision after I spoke to the family and everything. So yeah, that was good.

(James Matfield, Interview, 4th March 2013)

It could be argued that Mr Cove behaved in a paternalistic manner by strongly instructing Mr Matfield to engage with the decision in this way; nevertheless Mr Matfield was "pleased" to be afforded this opportunity. Importantly, the structure of the

decision making process in Mr Matfield's case meant that when performing the work, the decision was still his to make. Hence he had the opportunity to use this work to contribute to the final decision, rather than justify a decision already made. He discussed the decision with other people, and valued the opportunity to consult with his wife and other members of the family. The information was interpreted by the patient in the light of his own values and preferences; in doing so he sought to gain an understanding of the effect of the treatment options on his daily life and his relationship with others:

> And the, the worry I had is, if I was going to get admitted to hospital me family were going to have to travel to get there …. And I might not see anybody, 'cause [my wife] doesn't drive. So she would have to rely on our children coming up here to get her, to get her and fetch her down to hospital, probably. That was the other worry to me than most things. But then, with her being on her own… but obviously it's not going to be that way 'cause I'll be brought back every night and whatever for the chemotherapy. And that was one of the other decisions why I had my other decision too because I was going to be admitted to hospital.
>
> …
>
> Except, of course, me voice is never going to be the same, and it's that me voice will never get back to normal. I mean, I know it's nice to have your voice you've had all your life, but it had to change, it's just, at least I'm not, the main thing is I'm not going to die.
>
> …
>
> The longer I live the better because I love life and I love to be, like, this morning walking through the fields seeing the deer and things, that's the sort of thing I like. And I like nature and that, I love fishing. I like me fly fishing, you know. I just hope I can continue with that.
>
> (James Matfield, Interview, 4th March 2013)

These data are taken from different points in the interview, but show that Mr Matfield had different pieces of information available to him, and placed a different importance on each of these. Mr Matfield weighed up the trade-offs he had to make, but at the same time incorporated them into his own way of life. In the clinic room, the common

considerations are survival, swallowing and the presence or absence of the voice box. The data show that Mr Matfield's quality of life was not necessarily linked to his voice, but instead to his ability to be there for his wife, walk in the countryside or fish, all pursuits which arguably are not reliant on the presence of a voice box. He lived in the countryside and therefore the practicalities of the actual treatment were important such as the availability of transport to the hospital or the working arrangements of his daughter. Thus the preference of whether or not to keep the voice box was included in a hierarchy of other considerations. In the clinic room, some statements included in the above data extract could be interpreted by the clinician as meaning that Mr Matfield was willing to lose his voice box to achieve cure. However, through the course of performing this work, other considerations (such as caring for his wife) were considered, by him, to be more important. Nevertheless, in the clinic appointment, the decision was reported as one being dependent on the presence or absence of the voice box:

> Mr Cove: And, so, we, we left you with some difficult thoughts.
>
> Pt: Yes you did.
>
> Mr Cove: Are you glad you had the week to go..?
>
> Pt: Yes I did in a way 'cause I read through them both again and then I decided to take the radiotherapy.
>
> Dr Green: Okay.
>
> Pt: If it saves me trying to save some of my gear up here like - like, you know?
>
> Mr Cove: Yes…You could, you could do either, but you're right. If you want to have a chance to save your voice box-
>
> Pt: Yes I do, yes.
>
> Mr Cove: We'll not take it out.
>
> Pt: It's worth taking the chance.

Mr Cove: Yes, exactly. So, I think that's, I think that's entirely reasonable. That's very good

(James Matfield, Observation, MDT Clinic, Centre C, 28th February 2013).

These data demonstrate a brief confirmation of Mr Matfield's treatment decision as well as reassurance from Mr Cove. The rest of the clinic appointment was a discussion of the practicalities and risks of the treatment which lay ahead. These data extracts provide valuable information about the work of decision making for patients, and how they incorporate facets of the decision into their own worldview and circumstances. This data is not intended to show how much importance Mr Matfield placed on his voice box, rather that by being given the opportunity to perform the patient work, he was able to place it in a hierarchy of other considerations. They also present a new backstage area: the patient's backstage. The actors in this backstage are the patient and their family or supporters and the setting is outside of the clinic room, in multiple areas including the patient's home. The actors use the information available to them, and negotiate its importance amongst themselves. At the clinic consultation, Mr Matfield and his wife present a team performance with the clinicians as the audience members; it was a short confirmation that he had made his decision rather than a protracted discussion again of the options. Mr Matfield appeared to have become more confident during the week away from clinic and as such was able to be an active participant in the decision making discussion on his return. Thus, in this case, the work of Mr Matfield was acknowledged and then successfully incorporated into the decision process. If the support that the MDT provides is to be incorporated into the model of decision making, it changes again (see figure five):
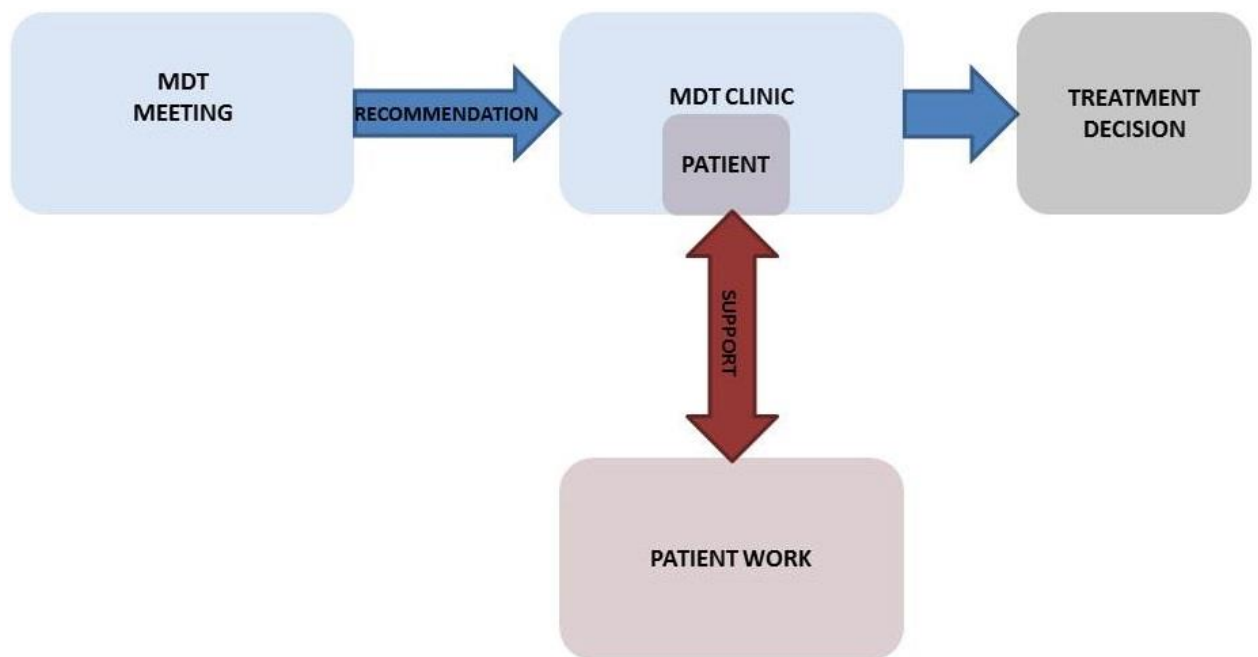
Figure 5: an engaged model of MDT decision making

In order to discuss further the challenges in enacting a model such as this in practice, I will firstly discuss how the MDT can support the work of decision making for the patient and secondly discuss the role of the treatment recommendation in this process.

7.1 Supporting the work of decision making

To support his work, Mr Matfield was offered information, time to understand and discuss the information, an area outside of the hospital to perform the work, support from the CNS to interpret the information and a route back to clinic to report back his work and ask further questions if required. The MDT already recognise that information provision is an important part of supporting patients thought their treatment process and hence a large amount of information is already provided for patients about the disease process and outcome; but most of this is provided after the treatment decision has been made. Stanley Wright was an 87 year old patient with a large cancer of the tonsil who attended the MDT clinic where the decision was made to treat the

cancer with radical radiotherapy. Mr Wright received large amounts of verbal information about the process of treatment and large booklets of information to return home with. At the time of his interview, I asked him about his expectation of the treatment:

> Interviewer: Do you have any vision of where you will be in [a couple of months]?
>
> Pt: Well I hope to be on top of the bill...... [coughs]…I hope to be back to normal…..I do sincerely hope to be back to normal.
>
> Interviewer: Back to where you were in say October last year [before the illness]?
>
> Pt: Well, exactly, yes.. I mean I had everything to live for and I used to go to the shop and I used to say "I'll have that, I'll have that" you know….I hope [the gastrostomy is] a temporary measure. I hope within the next month or so, that I've got a resemblance of weight back.
>
> (Stanley Wright, Interview, 21st February 2012)

Here, Mr Wright is expressing a lot of hope for the treatment which lies ahead: he expects to survive the treatment, and for his function to return to pre-treatment levels. Mr Wright was a cheerful and positive patient, and so it was difficult to determine whether these words were the result of hope or expectation. However, at the time of interviewing him, his responses concerned me, as I knew that his expectations were also very unrealistic. He was an elderly patient with advanced disease: he had a low chance of survival, and if he did survive the effect of the radiotherapy on his quality of life was likely to be significant. When trying to follow him up six months later I was saddened to hear that he had died of his disease. These data provide a striking example of a patient's expectations being far removed from the clinical course which lay ahead. It could be argued that the fact that his outlook for treatment was far more positive than it turned out to be is not detrimental and allowed him to enter into treatment with a positive frame of mind. At the same time, it perhaps denied him the opportunity to

come to terms with his own mortality, make preparations for the difficulties which lay ahead or even make the necessary arrangements and say good bye to members of the family.

Nevertheless, it is important to explore why his expectations were so unrealistic. At no point during the clinic appointment or information giving session was Mr Wright given any real indication of the small chance of short or long term survival. I have discussed the effect of this lack of prognostic data on decision making in previous chapters. However immediately following his clinic appointment Mr Wright attended another appointment with a CNS, speech and language therapist and dietician. At this appointment, a large amount of written and verbal information about the process and outcome of his cancer was given:

> Tessa: Now we are going to give you this booklet it's called understanding head and neck cancers, okay? And there is a section in here about radiotherapy okay, and I have written on their five appointments prior to starting treatment okay? And it goes through the side effects that may occur okay? We warn you about all of them, because obviously we don't know which ones are going to affect you and the worst scenario for us, is that you might require …. some morphine based medication towards the end of treatment alright?
>
> Pt: I hate morphine
>
> Tessa: You might not like it, but you will like it if you need it
>
> (Stanley Wright, Observation, MDT Clinic, Centre A, 2nd February 2012)

The pathway of treatment and rehabilitation facing Mr Wright would have a severe detrimental effect on his quality of life, however the Tessa was unable to describe how severe his individual reaction to treatment would be. This is because it is difficult, if not impossible to predict the severity of the side effects that a patient may experience from HNC. Undoubtedly if more prognostic information were available it would facilitate information giving in this setting. However even if this were to happen, it must

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be acknowledged that true *individualisation* of information is an impossible task. This does not mean that the MDT should not attempt to risk stratify their patients; more that if this is done, it should be combined with an acceptance of the limitations of this. Thus instead of attempting to provide a patient with a picture of certainty, the MDT should instead address and present the uncertainty associated with survival and outcome (I discuss further how this may be achieved in Chapter Eight).

Additionally in the data above, it can also be seen that the effect of the side effects of treatment on Mr Wright's life was not clear. Tessa states that "the worst scenario for us is that you might require some morphine": it is not clear in this statement why the morphine may be needed. The pain from treatment may be so severe that Mr Wright would be unable to swallow effectively, perhaps leading to him not being able to take any food or liquid by mouth. Although morphine may be given to help with this symptom, the real "worst scenario" is arguably his inability to swallow, rather than the provision of morphine. It is understandable for the MDT members to concentrate on the methods which will be used to alleviate symptoms, rather than the symptoms themselves. However, in doing this, they sometimes present a barrier to the patient developing an understanding of the real effect that the treatment may have on them. The outcome of this was that although Mr Wright was provided with a large amount of information, he was not provided with an insight into the 'experience' of treatment.

In HNC, the MDT often strive to provide information about the 'experience' of cancer by encouraging new patients to meet other patients who have already gone through treatment. Jean Dixon was just about to enter into treatment for a cancer of the base of the tongue:

> Well I'm not really bothered about [meeting a patient]. Because everybody's different. … If I was to meet somebody and, and they said "Oh it was great" …I would think "Oh well, I should be all right.". And I might not be. So I'm not really bothered about meeting anybody, because I think my experience is gonna be different. Everybody's different.

(Jean Dixon, Interview, 2nd July, 2012)

Here, Mrs Dixon recognises that the experience of the patient she meets may be different to hers, and therefore she discards it as a method of information gathering. If she is told by the patient that treatment will be straightforward, and she then experiences side effects, then this may lead to more anxiety. Indeed she may be frightened to meet a patient in person and hence come face to face with her own possible future. Importantly, this does not mean that information or experiences of this nature are of no use to new patients, more that if they are to be used, a range of patients or experiences may provide new patients with a broader range of outcomes and information.

The data presented reveal information giving as a far greater challenge than merely presenting a patient and their supporters with verbal and written information, or indeed meeting a single patient. Instead, information needs to be provided with opportunity, encouragement and support to interpret, engage with and understand this information. Although at first this seems straightforward, in this disease and setting, further challenges emerge. Sometimes when patients are given treatment related information, they are also given the contact details for the Clinical Nurse Specialist (CNS). This allows the patient opportunity to ask questions and potentially helps them interpret the information available to them. On the face of it, the provision of contact details for the CNS appears to be a simple and effective intervention to support patients in performing the work of decision making, however there are some hidden challenges. Mrs Brigstock was an 82 year old lady with a large tumour of her jaw bone. The cancer of the jaw

bone is resectable, and hence potentially curable, but this would have a significant effect on her function and quality of life post-op. Additionally, the MDT felt that she may not survive the general anaesthetic and the immediate post-operative period and therefore the option of best supportive care was also discussed. The following data extract shows Mr Siddell (maxillofacial surgeon) discussing the available treatment options and explaining to the patient what her role in the decision is:

> Mr Siddell: Have you got any thoughts yourself about those two routes? In other words, trying to help control the symptoms without doing anything big or doing something big with the hope of trying to get rid of it? ….So those are the good sides and the bad sides, and it's not really for me to sort of say one way or the other if you see what I mean. I can see both sides of that and obviously because we've been – I've been here a lot with other patients, I know the good parts and the bad parts for each of those routes. I can't predict what's allotted to you; I don't know if you go down one route is it going to be much better than the other route because I've given the balance.
>
> …. There isn't a right answer, there isn't a wrong answer, but if all of a sudden you turn round to me and say, "Well I do not want a big operation," then that's easily done, or you might turn round to me now and say, "Actually I want you to do absolutely everything possible to try and get rid of this, no matter what the risk," then that's fine.
>
> (Margaret Brigstock, Observation, MDT Clinic, Centre C, 17th January 2013)

Mr Siddell clearly avoids making a treatment recommendation and presents both options as being completely viable to the patient. In this extract and in the discussion during the rest of the appointment, there was no framing of the treatment description; the risks and benefits of both treatment options were patiently discussed without emphasis or bias, and in doing so, Mr Siddell awarded nearly all the control for the decision to Mrs Brigstock. Mr Siddell told the patient that she should go away and discuss with the family, and that Jane, the CNS, would contact her in the next week to answer any questions and help her through the decision process. On the face of it, this seemed like he was providing a supportive and inclusive environment for the patient to

perform the work of decision making. However, the following is taken from my reflective diary after the patient had left the room:

> Once the patient [and her son in law] left, the message changed. After saying to the patient that she had equal choice and a chance of surviving the operation, he said afterwards her chances of surviving it were basically zero. It was obvious that he thought she should go for best supportive care, however did not make this recommendation to her during the consultation. The patient's son in law said [during the consultation] that they would go for the option which meant she could "live as long as possible" but [after both had left the room] Mr Siddell said to the nurse, "but I think…." And the nurse said "yes I know" – it wasn't explicitly said, but it was clear that both [Jane and Mr Siddell] thought that best supportive care was the way forward and I can't see her making any other decision. It was almost as if the choice was a charade - a process through which they should go. It was done very well….but if that was the way he felt, why did he not tell the patient that? Why make them equal?
>
> (Field Notes, MDT Clinic, Centre C, 17th January 2013)

During the clinic appointment, the statement from the son in law of "live as long as possible" was interpreted by Mr Siddell and Jane as meaning that he would prefer to pursue radical treatment. When Mr Siddell said "but I think…." he did not finish his sentence, but it was clear that he disagreed with this, and felt that Mrs Brigstock should be treated palliatively. Thus, in this case, the patient was given support but its aim was to ensure that she chose the option that the Mr Siddell and Jane felt was best. I have no access to the discussion which took place between the Jane and the patient (this was mainly on the telephone), but the decision for best supportive care was indeed what was decided in clinic the following week; her return appointment was a very brief confirmation that she had complied with the Mr Siddell's ideas of the 'best' treatment. In this case, Mr Siddell thought that the recommendation should be best supportive care, however instead of explicitly stating this to the patient (and hence allowing a full discussion about the options with this information available), the provision of 'support' was used as an additional method of persuading the patient via framing. Although Mr

Siddell is correct to provide a treatment recommendation, if this is to be done, the provision of support should not be viewed as an opportunity to frame the decision or manipulate the patient into complying with the clinician. Rather the recommendation should be explicitly communicated and discussed with the patient and their supporters. These data highlight the significant implications of the nature of the support provided for the decisions made. Close consideration should be given to which members of the MDT support the patient, how the patient accesses them and the specific role and training that the supporting MDT member has.

The nature of MDT decision making and HNC presents barriers to the provision of time in which patients can perform the work of decision making. Mr Blaydon is an ENT surgeon:

> I suppose the ideal is … that you probably shouldn't delay decision making too long otherwise you may undermine the patient's prognosis, that it would be nice to come up with a decision sooner rather than later. … It's prognostic things, but it's also logistic things as well in that you may have a situation whereby there may be a clock ticking in terms of the cancer waiting…. times timeline. You may also have a situation whereby for logistical reasons there may not be a clinic the following week with an oncologist there. I think there's a general principle to – to arrive at a decision sooner rather than later would be good, but it's not unreasonable to – for example if the patient needs more time, to actually give them that time to maybe talk it over with their family, if necessary meet other patients who have had similar treatments or whatever to help them come to a decision.

(Mr Blaydon, ENT Surgeon, Interview, 25th October 2012)

Mr Blaydon agrees with the concept of providing patients with time, but outlines some of the prognostic and logistical barriers to this. The disease being treated is unrelenting hence the commencement of treatment is time sensitive. The make-up of the MDT changes from week to week, so the patient may have a discussion with a clinician who is not available the following week, or indeed there may be no MDT clinic. Also, patients are often referred to the clinic as part of the cancer waiting times national

strategy, which dictates that treatment must be started with 62 days of their first presentation, a target which is often referred to as a "clock ticking". Thus, although he agrees that although providing time is beneficial, the barriers to this, particularly those which are organisational, need to be acknowledged in order for time provision to be routine practice. In addition to this, if the engaged model of MDT decision making is to be enacted in practice, the role of the treatment recommendation also needs to be clear.

7.2 The role of the treatment recommendation

The case of Vincent Lowry has provided insight into the backstage actions of the MDT members throughout the preceding data chapters. In Chapter Five, I discussed how there was disagreement about whether laser or radiotherapy was 'best' to treat his tonsillar tumour. In Chapter Six I discussed the conclusion of the MDT discussion, where they decided to offer him radiotherapy as a single treatment option. Here, frontstage data from the clinic appointment reveals how the recommendation was delivered to the patient:

> Mr Black: After a lot of discussion, the consensus…. would be to give you radiation therapy…. that was what we jointly decided. And we think with that treatment there is a very good chance of controlling your disease completely. I'll stop here and you can ask me more questions if you and the family want to ask any further questions.
>
> Pt: Well, I'll do as you say
>
> Daughter: So there's no other operation, it would just be radiotherapy?
>
> Mr Black: We discussed this at length at the meeting, and in fact there was a significant discussion, and the majority of people in the audience felt that to be frank, except for me, felt that radiation would be the way forward. And Dr Yellow was the oncologist, and that's what we are offering to you as first line treatment. Unless you have any reservations, then we can think about other options.
>
> Pt: I'll do as you say….

Daughter: Right. So he would have to come into hospital every day?....he's a really bad traveller. He feels sick, and really bad travelling

Pt: You know when I come here I get all tensed up and travelling....

Daughter: He doesn't really go out the house to be honest.

Mr Black: Really? Is it likely you may then stop the treatment midway for whatever reason, because that would backfire very badly.

Pt: I wouldn't do that

Daughter: No he wouldn't do that

Mr Black: I know you asked about the surgical option. I promised people I wouldn't say anything. But it is feasible to take it out surgically, and there is an option available, but the consensus at the MDT was to go ahead with radiation. Unless, as a family or yourself very strongly object to it and feel that you can't go ahead with that, then of course the surgical options is always there. But as a group we felt that the best way forward was to offer you radiation

Pt: Well. I'll go with you

(Vincent Lowry, Observation, MDT Clinic, 19th January 2012)

In the MDT discussion, Mr Black was clearly in favour of laser (referred to here as "surgery"). Mr Black was instructed by the MDT meeting to deliver radiotherapy as a single treatment recommendation: the data reveals the inflexibility of this instruction. This limited his freedom to express his opinion; as a result of this Mr Black struggled to address the questions and concerns of the patient and his family as the clinic appointment progressed. The challenge faced by Mr Black with respect to the recommendation is similar to the one faced by the MDT as a whole when attempting to incorporate clinical guidelines (discussed in Chapter Two). Is the recommendation a 'rule' which should be adhered to at all costs, or is it to guide a conversation of the options available? If it is the latter, then how should it be used in this way? In these data, Mr Black struggles with the questions from the patient's daughter about whether there are any other treatment options available. In this way, the rigidity of the treatment

recommendation acts as a barrier to an open discussion between Mr Black, the patient and his daughter about the real options that exist to treat his cancer. The discussion of the surgical option was limited to "it is feasible to take it out surgically" which would be offered only if the patient 'strongly objected' to radiotherapy. However, without any means of knowing the risks, benefits and trade-offs, the patient is not provided with anything to form the basis of these objections.

If patients are to be truly involved in the decisions about their care, and the MDT is to embrace an engaged model of decision making, the role of the team discussion, and hence the resultant recommendation needs to be clear. I have already discussed the fundamental flaws with using the recommendation as a paternalistic 'instruction' for a treatment decision. Here, the data show the difficulties of limiting the recommendation to 'clinically best' and then attempting to use the clinic appointment to build into the decision the patient's preferences. Therefore, the aim of the team discussion, the role of the recommendation, and the manner with which it is delivered to the patient needs close consideration by individual MDTs and clinic structures if patient participation in treatment decision making is going to be enacted. I will discuss some of the methods for achieving this in Chapter Eight.

7.3 Conclusion

I have outlined two separate processes in MDT decision making; that of the clinicians and that of the patient. In the clinician process, the MDT meets to produce a treatment recommendation and then this recommendation is delivered to the patient in the MDT clinic. In the present chapter, I examined the patient work of decision making: patients base this work on the information and experience which is available to them and distribute it across people, places and time.

In its current form, decisions are usually made in the MDT clinic immediately following the MDT meeting and this patient work is rarely acknowledged. If the patient work is not acknowledged, this does not mean it does not take place: instead patients may have to base it on limited experiential information, or perform the work after the decision has been made. Thus, by not including this patient work in the decision making pathway, detrimental outcomes range from causing the patient and their family increased anxiety to patients using unrelated information to inform their decision.

For patients to be truly engaged in decisions about their care, their work of decision making must be recognised and supported. The MDT can support the patient work of decision making by proving information, support and time. In this chapter, I have highlighted the numerous challenges to providing this. Information giving is more complex than the presentation of large amount of verbal or written information. Patients must be allowed to engage with and understand the process and outcomes of treatment. They must be given information in understandable and accessible forms, with representations of a range of patient experiences. They must be informed of the uncertainties regarding the outcome and success of treatment. In this way, uncertainty is regarded as an opportunity to gather the preferences of patients and build these into the decision rather than being seen as a barrier to patient involvement. Patients must be given time to discuss this information with those around them, and weigh up and trade-off options depending on how important the outcomes are to them, or how they fit into their way of life.

If the MDT is to engage patients in decisions, acknowledging and supporting the patient work of decision making alone is not sufficient. The MDT has to be clear about the aim and the outcome of the MDT meeting. The resultant recommendation cannot be a

paternalistic instruction for treatment. Neither can a 'clinically best' recommendation be produced, which the patient is then expected to build their own values and preferences into, partly due to the difficulties in defining 'clinically best'. The team need to be explicit about what the role of the patient is in the decision process and how they are going to support this role. Also, although providing support to the patient to engage in decision making work could potentially create a lot of time and expense to organise in the first instance, the benefits to both patients and clinicians could potentially far outweigh the costs of this restructuring.

In the next chapter I will discuss the findings in close relation to the objectives which I set out at the start of the thesis. I will then discuss how these findings impact on the structure and function of the MDT, and outline the ways in which MDT working can move towards a more involved model of decision making.

Summary of Results

Chapter Five: the MDT meeting, laying the foundation

In this chapter I discussed the backstage interaction between MDT members in the MDT meeting; here, the MDT members use the information and evidence available to them with the aim of producing one or more treatment recommendations. I argue that the team build an 'evidential patient', designed to reproduce the patient in the backstage via information. They combine this with their interpretation of the research evidence and the previous experience of the team. These discussions are framed by the atmosphere, history and culture of the team. The variable interpretation of the relative importance or reliability of the pieces of information varies across the individuals in the team, and forms a loose hierarchy which is continually defined and re-defined through negotiation between the members. Some information is less contestable, but certainly not immune to discussion, such as the size and extent of the tumour and clinical opinion of the team. Other evidence (such as patient preference, social circumstances and use of research literature) varies in importance. There was a perceived variation in the recommendations made by the team between centres, dependent on the atmosphere of the team and the experience of the individual members.

Chapter Six: Delivering the Treatment Recommendation

The aim of the backstage MDT discussion is to decide which treatment is 'best' for an individual patient. Information about the patient's values and preferences are central to this assessment of 'best', and yet the MDT faces difficulty in incorporating information of this nature into the backstage MDT discussion. Nevertheless, when the assessment of 'best' has been made, the resultant MDT recommendation is delivered to the patient

by one or more selected member(s) of the MDT. During this exchange between clinician and patient the aim of the proposed treatment is not always explicit and the description of the treatment options is often 'framed' in order to guide the patient to complying with the clinician's recommendation. The challenges in the assessment of 'best' and how to effectively involve patients in decisions are most pronounced when there is treatment choice. To offer choice is sometimes seen as exposing to a patient the uncertainty underpinning the treatment recommendation; this is something many members of the team feel is undesirable.

Chapter Seven: Enabling Patient Choice

Here I explored the patient's perspective of the MDT decision process. In a similar way to the MDT members, patients base their 'work' of decision making on the information and experience which is available to them at the time and distribute it across people, places and time. Currently, decisions are made in the MDT clinic immediately following the MDT meeting and thus the patient work is rarely acknowledged. This often has detrimental consequences: patients may have to base their work on limited experiential information (which may not be applicable to the clinical situation), or perform it after the decision has been made. When patients were encouraged and facilitated by clinicians to engage in this work, they were able to interpret the information, discuss it with those around them and consider the effect that the treatment process or outcome may have on their day to day life. For patients to be truly engaged in decisions about their care, their work of decision making must be recognised and supported. The MDT should be clear about the role of the patient in the decision and how they are going to support this role. Importantly, the MDT should be clear about the treatment recommendation and the way it is used in clinic to help decision making.

Chapter 8: Discussion

Towards a new model of MDT working

In this thesis I have presented a detailed analysis of the process of treatment recommendation and decision making in the HNC MDT, with a particular focus on patient engagement. The data has highlighted that, despite being widely viewed as a UK standard of care, MDT working creates multiple barriers to effective patient involvement. To maintain the status quo is unsatisfactory: attempting to involve patients in decisions, whilst working with an MDT structure which does not adequately allow this, can and does result in decisions which are not in line with the values and preferences of the patient. The MDT is therefore compelled to improve care in this setting: in the present chapter I outline the ways in which this may be achieved. I discuss how the current model of MDT working encourages and perpetuates a paternalistic form of decision making. I summarise and discuss the main findings with reference to the aims and objectives which I set out at the start of the thesis. I draw on the wider literature to discuss how these barriers may be overcome in this setting and outline a new model of MDT working, with MDT members and patients working as partners to make individualised cancer treatment decisions.

This thesis has one aim: to examine critically patient engagement in the MDT treatment decision making process in HNC. There were three objectives of this work which I will use below to begin the discussion of my findings:

Objective 1: To examine critically the current function of the MDT meeting in head and neck cancer

I discussed the function of the MDT in Chapter Five. The MDT makes treatment recommendations based on the information and evidence which is available to members at the time of the meeting. The patient is, however, absent from the MDT meeting and therefore all evidence that is incorporated into the discussion must be gathered before the meeting takes place. In order to represent the patient in the backstage, the team construct an 'evidential patient' out of a number of pieces of information about the patient. This 'evidential patient' is designed to reproduce the patient in the MDT meeting room via information. The pieces of information which form the evidential patient are hierarchical: all pieces of information are interpreted in different ways by individual members, indeed some are even manipulated to reinforce a particular opinion or line of action. Thus, the hierarchy is continually negotiated and redefined by interaction between the members of the MDT. The evidential patient is made up of multiple different pieces of information: the size, extent and spread of the cancer, comorbidity information, the clinical state of the patient (swallow/voice function) or information to provide a more holistic view of the patient such as their social situation or their values and preferences.

The evidential patient is not the only source of information which the MDT draws upon during the meeting: the recommendation is also based on the MDT members' clinical experience and their interpretation of the wider research literature. At times, research findings from other centres are interpreted as being reliable and trustworthy, and as such are relied upon to inform a strong recommendation for an individual patient; at other times research findings are discarded due to concerns over their validity, or even

assumptions about the motivations of the authors. Whether a piece of research should be trusted or discarded depends partly on the quality of the research; however in practice it also depends on the individual MDT member interpreting it and the argument that they are attempting to reinforce. In contrast to the interpretation of research evidence, the clinical experience of the members of the MDT is less open to interrogation amongst the members; experience, anecdote and opinion are often therefore trusted as a reliable source of information. This reliance on individual clinician's experience creates a variation in recommendations made between MDTs both between and within centres depending on the individual clinicians present at any given MDT meeting.

Thus, before the point is reached where the team can begin discussion of the treatment recommendation, the evidence underpinning the recommendation needs to be made available and mobilised. This process of mobilisation represents an extra layer of complexity in the process of team decision making, a step before treatment recommendation, where the foundation blocks for the decision are put in place. Some MDTs attempt to increase the 'patient-centredness' of their discussion by introducing as much information as possible about the patient into this backstage area. However, much of this attempt to re-produce the "feel" of a patient (without the opportunity for face to face interaction) is potentially doomed to fail. It is difficult to incorporate some information - for example, "the patient lives alone" - into a clinical recommendation without making an assumption. Information about the preferences of the patient was variably presented and had a sometimes significant guiding influence on the backstage discussion and recommendation. However, many MDT members treated this type of information with suspicion about its source or elicitation. Not only this, but when preference information was presented in a similar manner as a T stage or pathology

result, there was an assumption that preference information can be incorporated into the discussion in this way. However the preference of a patient is not an information commodity which can be passed from person to person in order to make a decision. If MDT decisions are to incorporate patient preferences into the treatment decision, the nature of patient preferences and how they are formed needs to be explored.

Patient preferences

I have discussed how, in the MDT meeting, when patient preference information is available, it is often presented in a similar way to information such as the tumour stage or comorbidities. However, preferences which are formed in life threatening situations, particularly cancer, are unlikely to be pre-formed or pre-existing (Lichtenstein and Slovic 2006). Patients diagnosed with HNC are faced with considerable uncertainty, and as a result their preferences may be unstable (Epstein and Peters 2009). This means patients are not deemed to opt for the treatment which maximises their expected utility (with resultant preferences to match), but rather that their expressed preferences are labile, dynamic, reversible and sensitive to option description. When patients assess their preferences, they may rely on heuristics, emotion or intuition; preferences formed in this way are often more unstable and changeable (Epstein and Gramling 2013). The 'ordeal' associated with treatment is difficult for a patient to imagine (Little *et al.* 2008); also, when this unimaginable health state is encountered, patients tend to rate their quality of life as being higher than they expected it to be (Ubel *et al.* 2005). This means that when the patient meets the surgeon before the MDT meeting, the preference that they express is unlikely to be pre-existing or strongly held. Hence, an attempt to include a preference as a stable piece of information making up the 'evidential patient' is misusing information of this nature.

A patient preference is formed from a process of interaction with their physician: it is *constructed* (Slovic 1995; Lichtenstein and Slovic 2006). Preferences are constructed during elicitation and are therefore responsive to the way in which the options are presented, described or even framed by the physician. Slovic describes the process of preference formation:

> "Construction strategies include anchoring and adjustment, relying on the prominent dimension, eliminating common elements, discarding non-essential differences, adding new attributes into the problem frame in order to bolster one alternative, or otherwise restructuring the decision problem to create dominance and thus reduce conflict and indecision" (Slovic 1995, page 369)

The response to this should not be to minimise the effect of the physician on this preference, as the interaction itself can be therapeutic (Epstein and Street 2011). Rather, the acknowledgement that patient preference is the product of an interaction should be recognised in the structure of the clinic. Epstein (2013) proposes that in life threatening disease, with complex choices in situations of uncertainty, models of decision making do not always acknowledge the instability of patient preferences and the process of construction. He argues that a decision process should therefore place the relationship between patient and health care professional at its centre.

In relation to MDT decision making, the recognition of 'constructed' preferences has significant implications for the way in which decisions are made in this setting. If it is acknowledged that patient preferences are constructed from an interaction with clinician(s) then the structure of the decision making process should respect this. However, even if the resultant patient preferences are adequately incorporated into the decision making processes, this does not mean that patients are involved in their care. If properly constructed patient preferences are to be central to the MDT decision process,

next it must be ensured that patients have a foundation on which to base them. I will discuss how this should be achieved later in the chapter.

Objective 2: to evaluate the experience and practice of decision-making by patients and clinicians and to elicit their views on current and preferred involvement in the treatment decision making process

The outcome of the backstage MDT discussion is a treatment recommendation which is delivered to the patient in the MDT clinic. The basis of the recommendation discussion is the MDT members' consideration of which treatment option is 'best' for the individual patient. MDT members do not always recognise that the 'best' treatment is not a single objective clinical fact which can be viewed as indisputable. Although a particular site and stage of tumour may have an established treatment modality which research evidence has shown to provide a superior survival, recommending this option without discussion with the patient may result in a treatment decision which does not adequately account for the values and preferences of the patient.

The 'best' treatment for an individual patient is dependent on their aims for treatment, their values and their preferences. I have discussed already how preferences are not fixed informational commodities, but rather are constructed through a process of interaction with members of the MDT and supporters. This means that any decision of which treatment is 'best' for an individual patient can only be made after interaction with them. In this section I will discuss the other key component of the MDT clinic interaction: the available treatment options.

In Chapter Six I explored the reasons why the MDT may limit or withhold a discussion of alternative treatment options from patients. Firstly, MDT teams may not

acknowledge that alternative treatment options exist: commonly, this is because the MDT assumes that the aim of the patient is cure and hence recommends radical treatments. This leads to little or no discussion of palliative options, best supportive care or other non-curative options. Secondly, the MDT as a *group* sometimes acknowledges that two (or more) options may be considered 'best'; however, no one *individual* MDT member agrees that both could equally be regarded thus. Because each individual has a clear preference for one or other option, the MDT is presented with difficulties when selecting a clinician to deliver the treatment options to the patient, as the chosen individual may only deliver their own view of 'best', or perhaps frame the discussion to reflect this. This makes the choice of clinician to deliver the recommendation to the patient a proxy for the recommendation itself.

The data presented in Chapter Six demonstrate that MDT members sometimes viewed the offering of treatment options to the patient as revealing uncertainty to the patient. However, many MDT members view their role as being one of providing expertise (and hence certainty); to offer treatment options is seen to be 'not knowing what to do'. The desire of MDT members to conceal uncertainty sometimes meant that treatment options were not discussed with the patient. Thus, the perceived requirement to conceal uncertainty acted as an additional barrier to offering treatment options and hence involving patients in treatment decisions[8]. Hence, the question of how to deal with

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[8] I recognise that treatment choice exists even if alternative treatment options are not offered to the patient: the patient can choose not to accept a treatment recommendation, indeed they may choose not to attend clinic at all. Equally, MDT members are not the only participants in the decision who can instigate a discussion of treatment options.

uncertainty and whether or not to present it to patients is central to any discussion of patient involvement in this setting.

Clinical uncertainty

HNC is a heterogeneous disease with low survival and a large range of treatment outcomes which have a significant effect on the quality of life of a patient; as a result the choice of treatment involves considerable uncertainty. One source of this uncertainty is a distinct lack of prognostic data available to MDT members to guide decision making. In the studied centres this lack of numerical prognostic information led some clinicians to treat more patients radically, so any patients who had a chance of survival were treated, at the expense of some patients who had a very low chance of survival being treated unnecessarily. Other clinicians reacted to this lack of prognostic information by using more heuristic judgements to attempt to predict which patients were unlikely to survive treatment and hence which patients should not be offered radical management. These alternative interpretations of the same problem (lack of prognostic information) led to a variation in the treatments offered between clinicians.

A common reaction to uncertainty is to attempt to reduce it by providing data about the risk of treatment where it was previously absent. Indeed some diseases and treatments have extensive, peer-reviewed research and outcome data to guide management decisions. Importantly however, even when this is available, uncertainty still exists. For example, if the HNC community gathered the data available, and were able to inform a patient with laryngeal cancer that if they were to be treated, given their age, sex, cancer and comorbidities, their chance of survival would be 30%, this would be considered by many to reduce the uncertainty associated with treatment, or perhaps even eliminate it. However, there is considerable difficulty in applying an objective probability estimate

(30%) to a single event (survival) in an individual patient (Han 2013); arguably there cannot be a 'frequency' of a single event. This stated risk is postdictive, rather than predictive and as such is a record of past events in similar patients rather than a true prediction of the future (Politi *et al.* 2007). The issue of how population based risk data applies to an individual patient is described as 'first order' or 'probability' uncertainty (Han *et al.* 2011). An expression of probability is a description of the degree of confidence of an event happening in an individual with similar characteristics: an expression of personal confidence in numbers. However, it is not possible to have '30% survival': the patient will either survive or not (Thomson *et al.* 2005). These probabilities are interpreted by individual patients (Han 2013); this interpretation is affected by factors such as their prior beliefs, their interpretation of the context in which the physicians beliefs were formed, the perceived credibility of the clinician, the patient's understanding of the risk, how it was provided and the context in which the information was given (Fox and Irwin 1998). These interpretations must be taken into account and explored when risk information such as this is being given.

First order uncertainty can be reduced to an extent by ensuring that the presentation of risk information is clear. Strategies to achieve this include presenting the absolute risk of an event occurring (rather than a relative risk), a common denominator when comparing treatments, a clear reference class and an accompanying time frame (Paling 2003). However, first order uncertainty when using risk estimates is the not the only type of clinical uncertainty.

'Second order' uncertainty or *ambiguity* refers to either imprecision of the expressed probability estimates or disagreement about their validity or evidence base (Han *et al.* 2011). Communicating ambiguity is challenging; a common method is confidence

intervals, although there is disagreement regarding the optimum interval range, clinical usefulness and patient interpretation of these (Han 2013). The GRADE system presents the evidence for the effectiveness of an intervention with a qualitative indicator of the strength of the recommendation and the quality of the evidence, allowing patients and clinicians to judge the probability and ambiguity of the evidence simultaneously (Balshem *et al.* 2011). However, separating the likelihood of an event from the confidence in it occurring is difficult: for example it is challenging to express to patients that there is a low confidence that something is highly likely (Han 2013). Also, it can be argued that ambiguity cannot exist, as an expression of probability cannot be viewed as a true 'fact' (Han *et al.* 2011). In addition to probability and ambiguity, there are multiple other potential sources of uncertainty, all of which are present in HNC. Whereas probability and ambiguity encompass the likelihood of an event, 'complexity' encompasses the severity and the effect that it will have on the patient's life. Thus complexity is both objective and subjective: it depends not only the outcome itself, but the perceived effect of the outcome on the patient and their supporters and their judgement of its severity and its effect on relationships, work etc. (Han *et al.* 2011).

Concealing uncertainty

In the centres included in this research, members of the MDT often attempted to present a 'front' of certainty. In order to achieve this, the uncertainty associated with treatment was sometimes concealed in the backstage, and not revealed to the patient. This is an understandable reaction and is not uncommon (Parascandola *et al.* 2002). Uncertainty is abstract and difficult for patients to conceptualise and understand, hence communication of uncertainty may be time and resource intensive, and may lead to increased confusion for patients. Patients sometimes have a preference for known risks

and avoid decisions with unknown risks: so called "ambiguity aversion". This persists even when the odds favour the ambiguous option (Ritov and Baron 1990). Uncertainty can lead to a heightened perception of risk and worry for patients (Viscusi *et al.* 1991; Han *et al.* 2011) or decreased satisfaction with decisions (Politi *et al.* 2007). A combination of these negative reactions to uncertainty may lead to patients withdrawing from involvement in decision making. Therefore is concealing uncertainty as far as possible preferential? In order to answer this question, it must first be considered whether adequate concealment is indeed possible. Concealing uncertainty is not eliminating it; a clinician may conceal uncertainties about risk information but the patient may still be uncertain about their interpretation of this data or the effects of treatment on their quality of life or relationships. Not only this, but to conceal uncertainty is to ignore the potential *positive* effects on the decision consultation. Revealing uncertainty may lead to an increase in patient information gathering, or a renewed interest in engaging with the decision process. Ambiguity (as described above) may be used positively, to facilitate the discussion about how the probabilities presented are not necessarily "true" for that individual, or even as a source of hope that a particular side effect may not happen to that patient (Han 2013). Uncertainty could act as a useful cue to gather the values and preferences of patient and build these into the decision. This means that instead of being viewed as a barrier, the existence of uncertainty could be viewed as an *opportunity* to further involve patients (Han *et al.* 2011).

Informing patients about uncertainty associated with treatment is respecting their autonomy: it allows patients to judge for themselves the strength of a recommendation and therefore whether to accept it. Indeed, to provide a picture of certainty is potentially to provide an inaccurate or even misleading picture of risk (Edwards 2003).

Hence, the concealment of uncertainty is not a solution for dealing with uncertainty in decision making. This means that if patients are to be adequately informed, an open discussion of the clinical uncertainty which underpins the recommendation and decision is required.

Communication of uncertainty

If it is accepted that uncertainty should no longer remain a backstage concept and instead be presented to the patient, next it must be considered how this uncertainty should be presented to the patient and used to make treatment decisions. It must be understood that decisions under conditions of uncertainty involve different cognitive pathways than decisions with better known outcomes and risks. Indeed, the use of utility optimisation and statistical thinking in decisions with imperfect information can lead to decisions which are worse than those using heuristics alone (Gigerenzer and Gaissmaier 2011). In situations of uncertainty, this makes logic less useful that the brain's adaptive 'toolbox' of heuristic processing (Volz and Gigerenzer 2012). However, decisions in situations of uncertainty are common in everyday life and as such are well-rehearsed in human decision making (Volz and Gigerenzer 2012). Thus, when making decision under conditions of uncertainty, rather than denying or eliminating the role of instinct and heuristics, these should be explicit, challenged and discussed. In a similar way to the discussion above about eliciting patient preferences, this makes the discussion of uncertainty a dynamic interaction between patient and physician, rather than a presentation of risk and uncertainty information alone.

There are relatively few methods developed of communicating uncertainty to patients visually (Han *et al.* 2011). Han *et al* (2012) developed visual dynamic random icon arrays to demonstrate an uncertainty for a 9% risk of colon cancer. This consisted of

100 icons, nine of which were highlighted; the highlighted icons were randomly distributed, and this random distribution changed every two seconds, in an attempt to represent the uncertainty of outcome. Ancker *et al* (2009) attempted to reproduce the uncertainty and also the 'feeling' of risk by using game graphic icons. Users 'discovered' if icons were affected by a health outcome by clicking on them and affected outcomes were randomly allocated. The authors found that the use of interactive graphics helped patients to understand not only what the risk was, but also how it felt. This in turn helped to demonstrate high risk and reduce anxiety of low risk. Although these methods of representing the 'randomness' of clinical outcomes change patients' perception of risk, the effect on patient understanding is not known (Han 2013).

In the settings under study, MDT members relied on verbal communication when discussing the risks and uncertainties associated with treatment and very few communication adjuncts were used. Potentially, the discussion of the risk and uncertainty associated with treatment could be improved by using adjuncts to communication such as those described above. Decisions aids are also an established tool to help improve communication which provides a platform for discussion of the clinical uncertainties. Decision aids are "tools designed to help people participate in decision making about health care options [which] provide information on the options and help patients clarify and communicate the personal value they associate with different features of the options" (IPDAS 2012). Decision aids are designed to be used before, during or after a clinical consultation by the patient with or without a clinician. In a systematic review of 115 randomised controlled trials studying the effectiveness of decision aids, the use of a decision aid was associated with improved patient knowledge, lower decisional conflict, a decreased proportion of patients who were

passive in decision making and fewer patients remaining undecided. There was also a reported increase in patient satisfaction with the decision making encounter and improved perception of risk (Stacey *et al.* 2014). If MDT members were provided with a tool to facilitate the communication of risk, then this may improve communication of uncertainty, and consequently improve patient involvement.

So far in this section, I have described the difficulties of concealing and communicating uncertainty. However, to complete this discussion, the effect of uncertainty on the clinician should also be considered. A physician's reluctance to deal with uncertainty can lead to over-investigation in the pursuit of certainty, or indeed a refusal to talk about the future ("there is no way of telling") (Smith *et al.* 2013). A higher intolerance of clinical uncertainty in clinicians is associated with their fear of death or dying (Merrill *et al.* 1998) and often leads to misplaced optimism about the future in terminally ill patients (Christakis and Lamont 2000) . There is a large variation in clinicians' reluctance to disclose uncertainty and uncertainty related stress (Gerrity *et al.* 1990). A reluctance to discuss uncertainty was associated with physicians not recruiting eligible patients to trials (Taylor *et al.* 1984) and a reluctance to engage with SDM (Politi and Legare 2010). The attitude of physicians to uncertainty in turn affects the number of expressions of uncertainty to patients during clinic appointments (Gordon *et al.* 2000). The relationship of the physician's reaction to uncertainty and the decision made is complex but important: it has been suggested that the physician's reaction to uncertainty has a greater effect on patient satisfaction in decision making than the patient's reaction (Politi *et al.* 2011). Whether the development of better tools to share uncertainty would modify these factors remains to be seen, however if communication of uncertainty is to be commonplace, the effect of this interaction on patients, clinicians and the decision made requires scrutiny.

Objective 3: To use the findings from objectives one and two to determine the requirements for decision support in the context of the MDT.

The data presented in this thesis demonstrate that the complexities and uncertainties of treating HNC and the consequences of treatment led many clinicians and patients to conclude that patients cannot and perhaps should not be more involved decisions about their care. Hence, a paternalistic model of decision making is dominant in this setting. In the paternalistic model, the evidence is discussed in the MDT meeting, and a clear treatment recommendation is delivered to the patient. As the patient is often not supported in decision making, they have very little to draw upon to make the decision. This results in patients requesting and then accepting this recommendation from the MDT, which endorses the paternalistic ('expert') decision process and allows it to continue unchallenged.   Although some clinicians and patients advocate an increased role for patients in treatment decision making, the paternalistic model predominates as MDT working lends itself well to this model. The two main reasons for this predominance are uncertainty about how the MDT can adequately incorporate patient preferences and difficulties in understanding how to support patients in making decisions. This results in (sometimes strong) disagreement between members of the MDT as to what the role of the patient is in the treatment decision, how a patient should be involved and hence what the aim of the MDT meeting discussion is.

The behaviour of the MDT members appeared to be strongly influenced by the attitude of the MDT members and in Chapter Five I describe a distinct difference in the 'atmosphere' of the MDT from centre to centre, based on my observations. The MDT atmosphere appeared to be influenced by the make up of the group, such as the personalities present, the leadership style and previous discussions. The atmosphere

was also influenced by the setting in which the discussion took place: the layout and set up of the room, the time available and the number of patients. The atmosphere impacted on how the discussions unfolded and how individual members, especially allied healthcare professionals, engaged with the team during the backstage discussion. A particularly combative or hostile atmosphere often silenced allied health professional members, and with it the information and expertise that they brought. Allied health professionals were included in some centres with exercises such as 'round the table', led by the chairperson at the end of the meeting, where all members were encouraged, one by one, to raise questions or issues to the group. Importantly, by affecting the behaviour of the MDT members, team atmosphere seemed to significantly shape not only the discussion which unfolded but also the recommendations the MDT made and how these recommendations were delivered to the patient in clinic.

Paternalistic MDT members found their argument for paternalism supported when patients were offered treatment options, but not then given supplementary support to help to make this decision. In the studied centres, this led to either a request from the patient to the clinician for clear guidance, and hence a reversion to paternalism, or a decision made by the patient based on limited experiential information which may not have been relevant to the situation at hand. However, the paternalistic model assumes a passive role for the patient in accepting the treatment recommendation; this is not always the case. Patients sometimes refuse or question the recommendation being put to them, providing a rare challenge to paternalism in this setting. Offering treatment options to patients without supporting them in their choice is delegation of the decision and abandonment of the patient. Thus, if patients are to be involved in a treatment decision, acknowledging and then offering choice is not enough. Instead, patients need to be *supported* in making decisions. To offer treatment options and support choice is

to value the autonomy of the patient. Hence, before continuing with my discussion of decision support, I shall discuss the way in which the MDT may respect the autonomy of the patient

Patient autonomy

Respecting the autonomy of a patient is a legal, ethical and moral requisite. Patients are encouraged to make autonomous decisions, and this is seen to improve quality, accountability and choice (DoH 2010B). Although it is clear that the autonomy of the patent should be respected, this concerns more than merely allowing and offering choice (Entwistle *et al.* 2010). For example, to offer treatment options would be to respect the autonomy of the patient, however this may constitute "naïve consumerism" (merely giving patients what they ask for) or "abandonment" (delegation of the decision to the patient) (Epstein and Peters 2009). In relation to the data presented in this thesis, the concern amongst MDT members that offering choice is delegating and abandoning the patient is a significant barrier to choice being offered in the first instance. Also, to offer choice without supporting and enabling that choice may alienate groups of patients who are vulnerable, marginalised or who lack confidence (Davies and Elwyn 2008); these are the patients who are in most need of support and the group who often present with HNC. Thus, if patient autonomy is to be respected, the independence of the patient should perhaps be de-emphasised, and their relationship with the doctor and other members of the healthcare team emphasised (Struhkamp 2005). A consideration of this 'relational autonomy' recognises that humans are not self-sufficient and independent, meaning that involving patients in decisions requires more than presenting options and awaiting a verdict. Relational autonomy emphasises the importance of the interaction with the clinician, encouraging questions, correcting misunderstanding, constructing

preferences and allowing disagreement (Entwistle *et al.* 2010). In this way, autonomy is generated through interaction with others.

In relation to decision making, Rapley (2008) describes how patients demonstrate a relational autonomy by distributing their decision across multiple encounters with different doctors, supporters and family members. Some encounters are prolonged dialogues, others short chance meetings. In this way patients turn to others for knowledge, understanding, dependency and for support and care during the time of illness. This takes place over a period of time and involves gleaning information from a range of sources. The recognition of the 'mundane' patient work of decision making not only alters the way in which the autonomy of a patient should be considered but also highlights the way in which patient preferences are formed through a process of interaction with others.

The data presented in this thesis strengthens this viewpoint. For the patient, a lot of the 'work' of decision making took place away from the clinic setting, distributed amongst people, encounters, places and information sources. Patients performed this work in their own homes or communities, with family members and other supporters, after the clinic appointment. Patients interpreted the information if it was provided to them, but combined it with a host of other considerations when choosing which treatment option to pursue. They interacted and negotiated with their supporters to interpret the options which were available to them and considered the process, risks and uncertainties of treatment options in the context of their everyday and family life.

If this work is not supported by the MDT it does not mean that it is not performed. Patients instead use anything that they have available to them to form the basis of the decision: this is often limited, experiential information which is not clinically

applicable. Also, if the decision is made immediately in the MDT clinic, much of this work must be performed after the decision has been made. This sometimes leads to increased anxiety and confusion and other times results in decisions which are not in line with patient preferences, or in line with ill-formed preferences (Elwyn *et al.* 2012).

In this thesis, I have demonstrated that the provision of information is central to offering support to patients. However, in this disease and setting, information giving presents a far greater challenge than merely presenting a patient and their supporters with verbal and written information, or indeed meeting a single patient. Instead, information needs to be provided with opportunity, encouragement and support to interpret, engage with and understand this information. Here, I will discuss the ways in which the MDT may provide the patient with this.

Information giving

Information giving is central to patient involvement in decision making, not only to guide patients expectations of disease (Llewellyn *et al.* 2005), but also to facilitate the process of preference construction (Slovic 1995). Providing accurate treatment related information to patients presents clinicians with significant difficulties. Data presented in this thesis highlight the uncertainty surrounding the prognosis and expected outcome of treatment for an individual patient. Although information on outcome figures may sometimes be available nationally, clinicians did not always feel that this was applicable at the local level due to differences in patient characteristics. Additionally, these data were often not routinely collected at the level of the hospital or geographical region, impacting on the availability of information of this nature. Not only this, but even if accurate outcome data were available, there exists debate over which outcome measure most accurately represents the functional outcome after treatment for HNC, with

established outcome measures often not representing patient experience or patient perception of the symptom (van der Molen *et al.* 2009). This causes difficulties when researching the differences between different treatments and when providing patients with comparative information about the effect that treatment may have on them. This lack of comparative and prognostic data creates challenges when discussing which treatment is 'better' with regard to survival, function or quality of life which, in turn, may add to the framing effect from the presenting clinician.

At the same time, information giving is about more than the provision of copious amounts of written information (Semple and McGowan 2002). The data presented in this thesis demonstrates that currently, patients are provided with a large amount of treatment related information, but this is usually only after the treatment decision had been made. Patients were rarely supported to understand and interpret this material which often led to either the information being discarded or misunderstood. Hence, even if comprehensive information about the risk and uncertainty of treatment is provided, patients should also be *supported* in its understanding and interpretation. Patients should be provided with information about the aspects of treatment which are important to them, or practical in their situation. In the next section I will discuss a possible method of providing such support: decision coaching.

Decision coaching

The role of a decision coach is to assess the decisional needs of the patient and then support the patient through decision making, using decision aids and adjuncts if available. The decision coach can monitor the progress of the patient in their decision and identify barriers to the implementation of the decision (Stacey *et al.* 2008). Decision coaching or decision navigating can be provided by a member of the team who

is "trained in decision support and [is] supportive but relatively neutral in the decision" (Stacey *et al.* 2008, page 28). In the cancer centres included in this thesis, a variation on the decision coach role was often provided by the Clinical Nurse Specialist. However the guidance sometimes offered instead functioned as an added opportunity for the MDT to bias the patient's decision. These nurses do not fulfil the role of decision coach as outlined in the literature as they are not trained in decision support; also the structure of the MDT does not currently support nurses to take a decision coach role

Decision coaches can help to improve confidence in decision making and prepare for the decision consultation (O'Connor *et al.* 2008) with positive effects on knowledge, information recall and participation in decision making (Coulter and Ellins 2007). However, in a recently published systematic review, only 10 randomised controlled studies were identified and thus conclusions about the effectiveness of decision coaches were limited. The authors found that although decision coaching can improve patient knowledge, it is difficult to unpick how much of this improvement is due to decision coaching, and how much to the decision aid which is often simultaneously used. The effect on other outcomes such as cost effectiveness, values-choice concurrence and patient satisfaction varies, with some studies reporting a positive effect, and others reporting no difference (Stacey *et al.* 2012). A variation on the role of decision coach is decision "navigator": a navigator meets the patient before the clinical appointment and prepares them for the consultation with the physician. The training of the navigators is based on the SCOPED checklist for consultations (Situation, Choices, Objectives, People, Evaluation, and Decisions) (Belkora 2014). In a large randomised controlled study of the use of navigators in prostate cancer, navigators provided pre-consultation preparation, accompanied the patient to the clinic appointment and produced recorded and written documentation of the consultation. 'Navigated' patients were more

confident in making decisions about cancer treatment and had less decisional regret than those who received usual care (Hacking *et al.* 2013). If a decision coach or navigator role is included in team decision making, the MDT must incorporate this individual: such models have previously been developed.

Shared decision making in healthcare teams

In Chapter Two, I examined the effectiveness of shared decision making (SDM) as a method of delivering patient centred healthcare and outlined the strong clinical and ethical argument for SDM as a method of engaging patients in treatment decisions. Therefore, before I discuss further how the MDT may improve patient engagement in decision making I will consider the work which has already been done around SDM and healthcare teams. First, I will discuss an SDM model which has already been proposed for involving patients in healthcare teams; this model incorporates a 'decision coach' role as discussed above. Second, I will discuss the role of team training in promoting an environment of SDM in a healthcare teams.

Inter-Professional Shared Decision Making (IP-SDM) is in its infancy (Legare *et al.* 2008) as the majority of the research on SDM concentrates on the physician/patient dyad (Makoul and Clayman 2006). In two recent systematic reviews of measures to help the implementation of SDM, only 3/40 studies focussed on the interdisciplinary approach (Legare *et al.* 2010; Legare *et al.* 2012).   Stacey et al (2010) performed a large literature review and theory analysis which identified no models of SDM in the interprofessional context. This led the same group to develop a conceptual model for an interprofessional approach to SDM, shown in the figure six below.
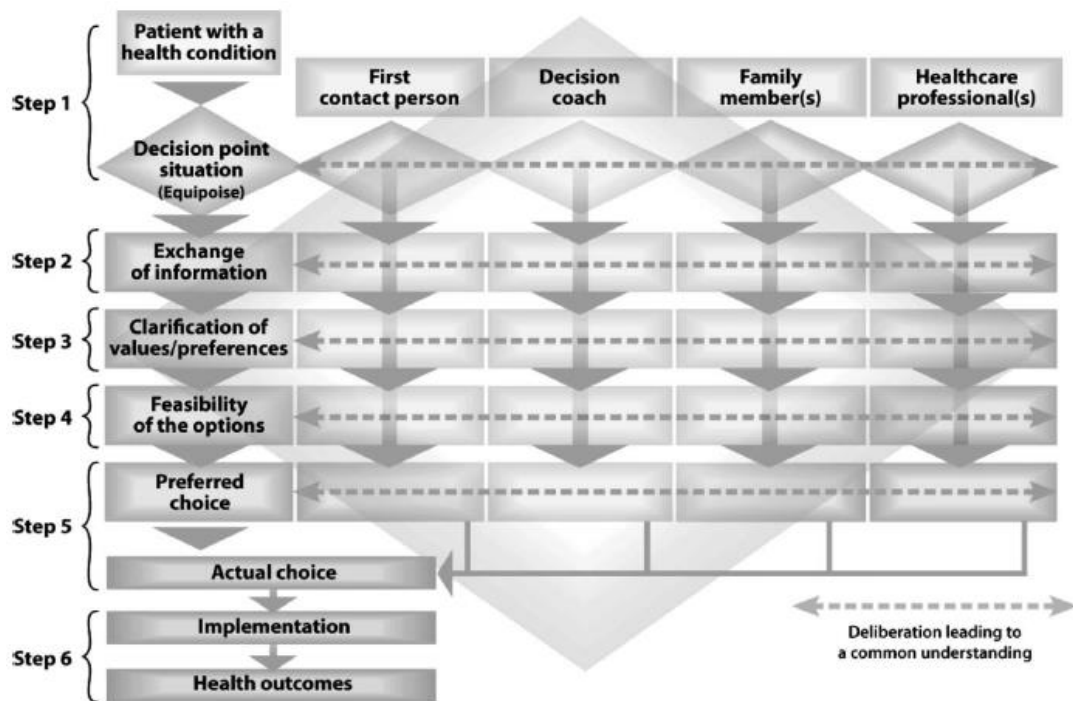
Figure 6: inter-professional shared decision making model, from Legare, 2011

This model is based on various assumptions: the definition of 'inter-professional' is when "professionals from different disciplines collaborate to provide an integrated and cohesive approach to patient care" (Legare *et al.* 2011, page 18). The model assumes that all members of the team understand and agree that SDM is the optimal method of achieving patient-centred care, and are aware of the steps required to enact it (and of their role in each step). The model also acknowledges a view of relational autonomy of the patient, in stating that that the team of the patient (family and supporters) and their preferences should be involved in the shared deliberation. In this model, the rows represent the experience of the patient as they move through the decision process, and the columns are the people involved in the step. The model outlines the six steps of SDM in teams. This is a conceptual model, providing a platform on which to base further research about how interprofessional teams collaborate with each other and the patient, and the relationships which are essential for SDM to take place in a team

setting. In order to achieve inclusiveness, the model lacks detail as to how each step may work in practice, but it acts as a useful framework for considering how patients may be involved in their care when working in teams (Legare *et al.* 2011). When validating this model with 79 stakeholders, the main barriers for the implementation of SDM in an inter-professional team were seen to be time, resources for implementation, organisational structures and imbalance of power within the team. The main facilitators were inter-professional training and the sharing of knowledge within the team. However, only half of the 79 stakeholders felt that the model was clear, while 41% felt they would be willing to test it in the clinical setting (Legare *et al.* 2011)..

The proposed conceptual model is, by the authors' own admission, more a recognition of the individual roles and inclusive environment needed to implement SDM than a guide of how a healthcare team should engage a patient in the clinical setting. Importantly, the model highlights the people, processes and shared understandings which are required if patient involvement in decisions is to be improved. However, the majority of the work done in developing this model was in the primary care setting and the reference to an interprofessional team is not necessarily the same as an MDT. Interprofessional teams involve multiple professionals taking part in the care of the patient, potentially at different time points and different parts of the healthcare system (e.g. primary and secondary care). The MDT is a unique example of interprofessional care: it involves a single interaction or a series of interactions which usually take place at one time point or over a short space of time. This means that a lot of the steps shown occur simultaneously in the MDT meeting and clinic rather than sequentially; indeed this is one of the reasons why difficulties in patient engagement arise. When studying MDT decision making, the central effect of the interaction of the members of the team with each other must also be acknowledged, as well as the interaction of the members

with the patient. This thesis has provided a level of detail for the individual steps in the model above in relation to the MDT, and in doing so has added to it by casting light on the barriers which exist between the steps. However, this model could not be applied to the MDT without adaptation. Also, as I have already briefly discussed; imposing a new model of working is not sufficient alone to change the behaviour of the team. If the MDT is to effectively implement a more patient centred approach to decision making, a shared understanding of how to do this effectively needs to be in place. Team training potentially has a role in achieving this

Team training

Team training potentially has a role in achieving more patient centred care however, few IP-SDM training programs exist: in a review of 80 training programs in 14 countries and 10 languages, only five were aimed at a professional group other than doctors only, and only one adopted an inter-professional approach (Legare *et al.* 2012). Also, a recent systematic review of the effect of inter-professional training on team interaction and patient related outcomes was inconclusive (Reeves *et al.* 2010). Although the included papers showed inter-professional training to potentially decrease the clinical error rate (Morey *et al.* 2002), improve teamwork (Young *et al.* 2005) and increase patient satisfaction (Campbell *et al.* 2001), the six studies identified were of variable quality with heterogeneity of methodology.

Korner *et al* (2012) developed one of the only training models aimed at inter-professional teams, which divided SDM into 'internal' and 'external' participation. 'External' participation involved communicating treatment options with the patient, discussing values and preferences and delivering a treatment recommendation. 'Internal' participation concerned the communication within the team needed to create

shared decisions; this included training on communication and cooperation within the team, feedback between members, leadership style and tools to facilitate communication. This training program was evaluated positively by the included teams, and implemented successfully, however the authors did not investigate the effect of the training on the process or outcome of decision making.

Hence, although team training in SDM seems to make sense, there are few training programs available and even fewer studies evaluating its effect on the decision making process, patient experience and outcome. At the same time, team training is in its infancy, so the obvious paucity of studies assessing the effectiveness of training in teams should not lead automatically to the conclusion that it is of no benefit, rather that the benefits are unknown. Also, whilst recognising there is a need to better evaluate such specific team SDM training, more broad communication training is known to develop key communication skills in clinicians (Fallowfield *et al.* 2002). Similar training techniques are therefore likely to be useful for improving communication (and patient involvement) in the MDT setting.

Role of the recommendation

Finally, if the MDT is to embrace patient centred care as a routine way of working, the role of the backstage MDT interaction and the resultant recommendation needs to be scrutinised. If the MDT meeting and clinic follows a paternalistic pathway, the way in which this recommendation is used is clear: it is delivered to the patient with an assumption that it will be accepted. However, if patients are involved in decision making, the data presented in this thesis highlights a unique problem with the MDT recommendation: its inflexibility. In the clinician/patient dyad the recommendation can be adjusted and changed depending on the ongoing interaction with the patient and the

preferences expressed. An MDT recommendation on the other hand, presents the members of the MDT with difficulty when trying to combine it with the preferences of the patient. Is it a rule which must be adhered to? If the patient disagrees with the recommendation, what action should the MDT member take? It is not possible to provide an absolute answer to these questions, as it will vary from team to team and patient to patient. However, the role of the recommendation and the way it is delivered to the patient needs to be explicit and agreed within each team. Importantly, the recommendation should not be delivered until after the physician has discussed the options available and ascertained the values of the patient. Also, after the recommendation has been given, the way in which the recommendation was generated and the values which underpin it must be explicitly discussed (Epstein *et al.* 2004).

Through the course of this discussion, I have highlighted the steps which need to be taken to acknowledge a treatment choice, offer it to a patient and then support the patient in making a decision about their care. The interaction between members of the MDT and the patient has been central to this discussion: it is a therapeutic relationship where preferences are constructed, risk and uncertainty are communicated and the process of decision making takes place. As a conclusion to this discussion, I will outline the ways in which the MDT might change in order to achieve a more patient-centred approach to decision making.

A new model of MDT working

The MDT must be aware of the barriers to offering choice to patients and the importance of the interaction between physician and patient; this interaction should be central to the structure of the clinic. At the end of Chapter Seven, I presented a model of decision making in the MDT which allows interaction of the team with each other and with the patient and acknowledges and supports the patient work of decision making. In light of the discussion in this section, the model can now be expanded (see figure seven):
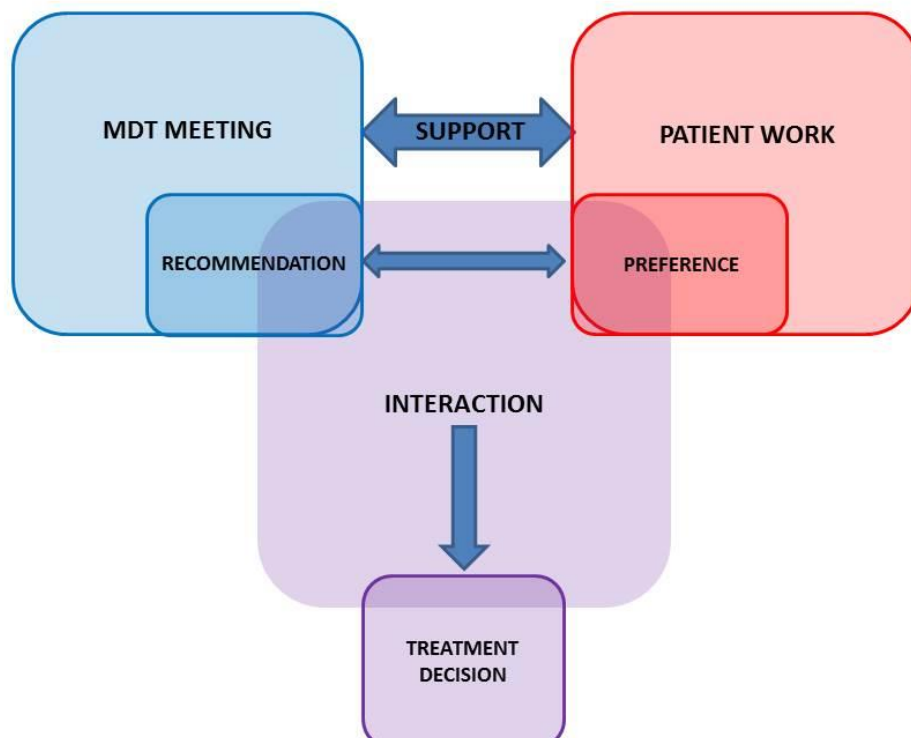

Figure 7: a new model of multidisciplinary working

Firstly, I will discuss the assumptions which underlie this model. Members of the team must agree that the patient is to be involved in the decision if the patient desires it.

Then, members should be aware of the steps which are required to involve a patient in a decision and the role that they, as an MDT member, should have in this. Team training may have a role in establishing these assumptions. Lastly, they must be aware of the barriers to decision making in this setting and how these should be overcome if choice is to be offered to the patient in clinic.

At the centre of this model of MDT working is the interaction between MDT members and the patient and their supporters. This interaction takes place within the MDT clinic, and is driven by the outputs of two work processes: the MDT meeting and patient work. The MDT meeting is the interaction of the team members with each other (mainly in the backstage), and the product of this is usually a treatment recommendation. Patient work is the interaction of the patient with the MDT and their own supporters, and the product of this work is a patient preference. I will discuss each of the steps in the decision process, in turn, below.

The MDT meeting

The aim of this meeting should be one or more treatment recommendations or a communication of alternative treatment options. The members of the MDT should discuss the clinical information about the patient, review the radiology and pathology reports and discuss which treatment options are available for a particular patient. The MDT should allow a patient a role in choosing the best option for them as an individual. At all times, the aim of the treatment recommendation and the values which underpin the discussion should be explicit. This includes a consideration that survival at all costs is not always the patient's main aim of treatment. It should be clear that the MDT discussion is not a discussion of which option is 'best' for a particular patient as this assessment cannot be made backstage in the MDT meeting. Instead it should be clear

what the recommendation is, why it was formed and which values underpin it. The team should also explicitly state how it should be used in the MDT clinic and the MDT member who delivers the recommendation should be clear about how and when it is delivered in relation to the description of the options and the patient's preferences.

Patient work

The aim of patient work is to form preferences which are stable and in line with their values and beliefs. The patient work can take place at any time: it may be spread between information sources, places and people. The MDT members should recognise this and enable it by providing support, resources and personnel to discuss the treatment options, communicate the risk and uncertainty, elicit preferences and explore them: a decision aid may support this work. Some of the work may take place during the clinic appointments, some between the patient and their supporters and some between the patient, their supporters and a member of the MDT. The team may consider providing an individual who is independent of the clinical team to act as a decision coach or navigator.

Interaction

The aim of the interaction between the MDT members and the patient is to form a treatment decision. Here, the MDT members help the patient to construct their treatment preference, give information about the risks and benefits of treatment options and discuss the uncertainty and risk associated with the choice of treatment. The treatment recommendation should be delivered, together with the reason for the recommendation, its aim and a discussion of why other options are not recommended. The timing of the delivery of the treatment recommendation is challenging: on one

hand, if could be delivered after the description of the options. This could present difficulties in combining the recommendation and the patient view. Alternatively, the recommendation could be given at an early stage to inform the patient preferences: however this must be done with the acknowledgement that this recommendation was formed without the patient perspective. Again, a decision aid may work in facilitating this discussion.

This interaction can happen once, or multiple times in relation to the patient and staff work. For example, the MDT member and patient may have a first consultation focussed on information exchange and a second concentrated on decision making (with support between the appointments). As I discussed in Chapter Seven, the provision of time has prognostic and logistical barriers. The disease being treated is unrelenting, the make-up of the MDT meeting changes from week to week, and patients are often referred to the clinic as part of the cancer waiting times national strategy, which dictates that treatment must be started with 62 days of their first presentation. Thus, although providing time is beneficial, the organisational barriers must be acknowledged and overcome in order for time provision to be routine practice.

Importantly, this model does not have a time line. The three work processes (MDT meeting, patient work and interaction) should take place, but there is no requirement for them to take place in any particular order. This allows flexibility for various teams to format their clinic in various ways. The patient may be enabled to come to the initial consultation more informed and prepared for the discussion. The MDT meeting may take place in a small 'combined clinic' setting around the interaction with the patient. I observed this practice during informal observations in other centres. A small group of treating physicians of various specialities meet together briefly, and then meet the

patient as a group. They can then leave the patient to continue backstage discussions which are then delivered to the patient again or the patient is allowed into the backstage. This structure breaks down the barrier between the backstage and frontstage, allows maximal interaction with the patient, and is dynamic, so the decision making model can be guided by the preference of the patient. It allows short, interlinked discussions to take place in quick succession between the physicians with or without the patient with a resultant recommendation which is more dynamic and therefore responsive to the patient needs. The result of this interaction and discussion could then be delivered to a larger MDT on a different occasion.

The patient work can take place before the MDT meeting, after it, or within the clinic appointment. The patient may legitimately delegate all or some of the responsibility of the decision to the members of the team, or turn down the opportunity to distribute this work. MDT members should encourage the patient to engage in this work, but the patient must be able to exercise a right to take very little part in the decision if required.

There is flexibility in the model above to allow patients to attend their own MDT meeting if required. As I discussed in Chapter Three, this idea is popular amongst patient advocates (Butow *et al.* 2007), but not clinicians (Butow *et al.* 2007; NCAT 2009). There is little data documenting the patient experience of involvement in MDTs, as it is rarely routine practice: small studies have concluded that patients attending their own MDT allows for better information giving but not necessarily improved involvement in decision making (Choy *et al.* 2007; Bellardita *et al.* 2011). This means the area of patients attending their own meeting is relatively unfamiliar as an intervention, making conclusions about its worth difficult. However, the concept of a

well-prepared and supported patient attending a sympathetic MDT is worth further exploration.

The model allows MDTs to identify the processes required to enable patients to become involved in decisions about their care. It is flexible enough to act as a guide for the organisation and format of team decision making, but at the same time clearly states the essential work processes which should take place. If this model is to be enacted in practice, the barriers to offering and supporting choice need to be acknowledged and overcome. Only by achieving this, can the MDT begin to move towards improving the process of patient engagement.

Strengths and weaknesses

This data presented in this thesis provides an in depth account of the process of decision making in MDTs, with a particular focus on patient engagement in this process. The analysis of observational data provides a detailed, in depth description of the backstage activity of the staff participants and, when combined with the staff interviews, a novel insight into the challenges facing MDTs when involving patients in decisions. My role as a clinician researcher allowed me to understand the complex MDT discussions and enabled informal and formal interviews with participants which were perhaps more frank than they would be with a non-clinician researcher.

However, the methods of data collection, analysis and sampling also present limitations which should be acknowledged. This thesis highlights significant problems with patient participation in MDT decision making, and because of this, patient interaction with the team can sometimes be minimal. As I detail in Chapter Four, data were analysed using a theoretical basis of symbolic interactionism, where interaction between participants is

the unit of study. Sometimes the lack of patient interaction with the MDT members in decision making consultations led to difficulties when attempting to gather data on the patient experience of making decisions. To an extent, I tried to counteract this by conducting interviews with the patients themselves, but this presented more problems. If patients delegate the decision to the members of the MDT, their process of decision making may have been very short; merely a process of asking somebody else to make the decision for them. This sometimes made for challenging interviews when trying to discuss a patient's process of decision making, as they sometimes had no such account to draw upon. With this in mind, I sought to gather further data about the patient experience by conducting semi-structured interviews with two groups of patients at various time points. However, this only went part of the way to providing a richness and depth to the account of the patients' decisions. I followed up group one after an average of nine months, however patients were hard to reach at this time: they were often still suffering the acute effects of radical cancer treatment and, understandably, were not interested in talking to a researcher. Protective carers usually took phone calls rather than the patients themselves which sometimes compounded this effect. When I did manage to interview patients from this group, they usually gave a detailed account of the process of treatment and rehabilitation, but often did not see the decision as a defined 'event' to be expanded upon. I encountered the same problem with group two patients (who had received treatment within the last five years). Group two were a difficult group to access; I was reliant on patient names being given to me by the clinical team and the selected patients were often happy with their treatment and felt that the decision process was excellent, which perhaps meant that they were not representative.

With respect to data collection, my sampling criteria meant that some interesting decisions and patients will have been missed. One of my criteria was a "patient with a decision to make". In specifying this, a group of patients - those who are offered just one option which they must accept or turn down - which make up a significant proportion of the clinic, were omitted. Importantly, this group is not absent from the thesis as sometimes I included patients for whom treatment options existed, but only one option was actually presented to the patient in clinic. However, the experience of these patients, in accepting or refusing the clear treatment recommendation is under represented.

Finally, data collection occurred over three centres, each with a more "classical" structure of MDT clinic (as I have described through the course of the Chapter Seven and Chapter Eight). It is assumed, but not clear, if this structure is indeed universal amongst other centres and cancer areas. Thus some of the issues highlighted in this thesis may not exist, be different, or even solved by varying clinic structures elsewhere.

Chapter 9: Conclusion

The MDT was introduced after the Calman-Hine report highlighted the value of centralisation of cancer care (Calman and Hine 1995). In subsequent NICE Improving Outcomes Guidance in various cancer subsites, the obligation to make every cancer decision using an MDT was repeatedly reinforced (NICE 2004). MDT decision making is now the gold standard of care in cancer treatment delivery in the UK. However, despite the central importance of the MDT in cancer care and the significant cost associated (Taylor *et al.* 2010), evidence for its effectiveness is sparse (Fleissig *et al.* 2006). There is no proven effect on survival (Hong *et al.* 2010), and although it is established that different decisions are made within an MDT than by individual clinicians, it is unknown as to whether these decisions are better (Blazeby *et al.* 2006). There is little doubt that the MDT is popular amongst its members (NCAT 2009): indeed this may be a primary reason for its longevity. However, it is difficult to ascertain how much input allied health professionals have on the resultant treatment recommendation: is the MDT discussion truly 'multidisciplinary' or is it merely an 'observed conversation'?

Patient involvement in decision making is ethically, morally and clinically necessary. HNC has a low survival (DAHNO 2011), and patients face a significant functional trade-off if they are to achieve cure (Abendstein *et al.* 2005). The data presented in this thesis highlight the multiple barriers to effective patient involvement that MDT working presents. Indeed, it could be argued that, with respect to patient involvement in decisions, the MDT paradigm is a backwards step from the physician-patient dyad. The format of the meeting and clinic often leads to strong recommendations and decisions of 'best' being made in the backstage without the patient, primarily focused on a bias

towards cure, and ill-informed by patient preferences. Concerns about decision delegation and risk communication discourage clinicians from offering choice to patients and lack of relevant knowledge and experience lead patients to delegate the decision to the MDT members. This encourages and perpetuates the paternalistic process, with apparent assent from both patients and staff.

Progression towards patient centred decisions in an MDT clinic cannot be achieved by introducing increasing amounts of information about the patient into the backstage. Instead, the interaction between MDT members and patients should be central to the structure of the clinic. The product of the backstage MDT discussion, the recommendation, suffers from inflexibility, creating problems when attempting to combine it with the values and preferences of the patient. These values and preferences are difficult to represent adequately in the traditional MDT structure, and therefore to incorporate into the decisions. There is little understanding of the patient work of decision making, and thus patients are not adequately supported in making decisions about their care.

If MDT working is to remain the gold standard of care, it should continually adapt to meet the needs of the patient population that it serves. If patient involvement is to be improved, close consideration should be given to the structure of the clinic, the content and aim of the MDT backstage discussion, the support provided to patients and the central importance of the interaction between members of the MDT and the patient. Moreover, a wider consideration of the quality of care that the MDT provides, coupled with a desire to continually improve this standard of provision, should perhaps lead MDT members to reflect on whether their current mode of working is achieving the high standard of individualised care required for every cancer patient.

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Appendix 1: Glossary

CNS   Clinical Nurse Specialist

CT scan   Computed tomography scan, a detailed cross-sectional scan which is performed on all patients with head and neck cancer to delineate the size and spread of the cancer

ENT   Ear Nose and Throat, the surgical speciality which encompasses the treatment of head and neck cancer

EUA   Examination under anaesthetic

HNC   Head and neck cancer

HPV   Human Papilloma Virus

IP-SDM   Interprofessional shared decision making

Larynx   The voicebox

Max Facs   Maxillofacial surgery

MDT   Multidisciplinary team, the collection of professionals who gather to make treatment recommendations

MRI   Magnetic Resonance Imaging, a detailed cross sectional scan using strong electromagnets. Provides details of different internal structures than the CT scan.

M stage   Metastasis stage. Denotes the presence of distant metastases (rare in head and neck cancer). If no metastases are present, the tumour is graded M0, if the cancer has spread to distant structures (most often the lung) it is graded M1.

NCAT   National Cancer Action Team

NHS   National Health Service

NICE   National Institute for Health and Clinical Excellence

N stage   Nodal stage. The number, position and size of the lymph nodes that the

cancer has spread to: graded between N0 (no detectable spread to lymph nodes) and N3

Oncology   Medical speciality concerned the treatment of cancer

PET CT   Positron emission tomography computed tomograph scan: similar to a

CT scan, but highlights groups of cancer cells by changing their colour on the scan

Pharynx   The anatomical area at the back of the mouth and nose which links the

mouth to the oesophagus and windpipe. Consists of nasopharynx (back of the nose),

oropharynx (back of the mouth, where the tonsil and the back of the tongue is) and

hypopharynx (lower down in the throat, at the top of the oesophagus, behind the

voicebox)

SALT   Speech and language therapist

SCC   Squamous cell carcinoma, the most common histological diagnosis of

head and neck cancer

SDM   Shared decision making

T stage   Tumour stage. Concerns the size, position and local invasion of the

tumour: graded between T1 (small tumours) and T4 (large, invasive tumours).

Total laryngectomy   Complete removal of the voice box

Appendix 2: Ethical Approval

05 September 2011

Mr David W Hamilton
NIHR Research Doctoral Fellow
Newcastle University
Institute of Health and Society
Baddiley-Clark Building
Newcastle upon Tyne   NE2 4AX

Dear Mr Hamilton

Study title:	Decision making in head and neck cancer: an ethnography of the multidisciplinary team
REC reference:	11/NE/0200
Protocol number:	Protocol: version 7

Thank you for your letter received 25 August 2011, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information was considered [in correspondence] by a sub-committee of the REC A list of the sub-committee members is attached.

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).

Conditions of the favourable opinion

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

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

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

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

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

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

Approved documents

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

Document	Version	Date
Covering Letter		
Covering Letter		----
Evidence of insurance or indemnity		01 July 2010
Investigator CV	Mr David Hamilton	30 June 2011
Letter of invitation to participant	Staff Observation Letter Version 1	30 June 2011
Letter of invitation to participant	Patient Appt Letter Version 3	15 August 2011
Other: CV – Catherine Exley		30 June 2011
Other: CV – Janet Wilson		08 July 2011
Other: New patient Interview Schedule	Version 1	05 July 2011
Other: New patient Interview 2 Schedule	Version 1	05 July 2011
Other: Retrospective patient Interview Schedule	Version 1	05 July 2011
Other: Staff member Interview Schedule	Version 1	04 July 2011
Participant Consent Form: Patient Consent	Version 2	30 June 2011
Participant Consent Form: Staff Consent	Version 2	30 June 2011
Participant Information Sheet: New patient PIS	Version 2	30 June 2011
Participant Information Sheet: New patient PIS2	Version 2	30 June 2011
Participant Information Sheet: Retrospective patient PIS	Version 2	30 June 2011
Participant Information Sheet: Staff interview PIS	Version 2	30 June 2011
Protocol	Version 7	30 June 2011
REC application	Version 3 1	07 July 2011
Response to Request for Further Information		
Summary/Synopsis	Recruitment Table Version 1	08 July 2011
Summary/Synopsis	Group 1 and staff pathway Version 2	30 June 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

<u>Reporting requirements</u>

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

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

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

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/NE/0200	Please quote this number on all correspondence

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

Yours sincerely

[signature]

Mr Paddy Stevenson
Chair

Email: Helen.Wilson@suntpct.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	"After ethical review – guidance for researchers"
Copy to:	Miss Amanda Tortice, Newcastle Hospitals NHS Trust

Appendix 3: Interview Guides

Staff Interview Schedule

Introduce researcher and purpose of the study

Obtain consent to proceed and to record the conversation

- What do you see as the best way of making decisions in head and neck cancer?
- The MDT
    - What is it for? What is its primary aim?
    - What works well, and what works not so well?
    - How could it be improved?
    - No decision about me without me in the MDT…. Is this possible?
- Treatment decision
    - Why do you regard a treatment as the best for a patient?
    - What factors do you take into account when making treatment decisions?
- Patient involvement in decisions/shared decision making
    - What does it mean to you?
    - Do you think there are barriers to patient involvement? What are they? Why do they exist?
    - Why do clinicians struggle to involve their patients effectively?
    - Do you think we need to improve patient involvement? Why?
- Uncertainty/conflict
    - Is it a problem or is it healthy/required?
    - How should uncertainty and conflict be presented to the patient? Should they know that you don't know?
    - If there are options, how should they be communicated?
- Decision for treatment
    - What is the role of the patient in the treatment decision?
    - How much of a role should the patient have? Can patients know enough?
    - How much of a role should a patient have in the decision
        - Should we give power of vito?
        - Should you allow a patient to make a decision which is considered wrong?
        - how much should a patient know before treatment
    - How much of a role should the family have
- Palliation/prognosis
    - Do we palliate enough? Do we treat too many people radically?
    - What are the barriers to good palliation?
    - Do you think we have a range of palliative options available to us?
    - Do you have prognostic information available to you?
    - Would you use this information if it was available? How would you use it?

New patient interview 1 schedule

Introduce researcher and purpose of the study

Obtain consent to proceed and to record the conversation

The interview will cover the following broad areas:

- Previous experience of making healthcare decisions
  - What does shared decision making mean?
  - Have you had to make big healthcare decisions before?
- Experience of making this decision
  - What was your process of making the decision? Talk me though it
  - What did you draw upon?
  - What factors did you take into account?
  - Did you turn to anybody/anything for information or help?
  - How did you come to your final decision?
  - What was the MDT like?
  - Did you understand what was going on?
  - Could it be improved?
- Information given about the disease and treatment options
  - Do you think you had enough information?
  - Where do you get your information from?
  - Do you think you need more information?
  - Did you understand all the information
- Patient involvement in the decision about care
  - Should patients be involved in decisions about their care?
  - How should we involve patients?
  - Were you involved? How?
  - Would you have liked more say/less say?
  - How this made the participant feel, and further exploration
- What are your expectations of treatment?
  - Are you expecting side effects? What sort?
  - Do you have any idea of your prognosis? Do you want to know?
  - Where will you be in 6 months time?
- In the perfect world, how do you think decisions should be made?

New patient interview 2 schedule/retrospective patient interview schedule

Introduce researcher and purpose of the study

Obtain consent to proceed and to record the conversation

- Experience of the treatment
    - What has happened so far, story of the treatment
    - Correlation with expectations – worse, better
- New normal
    - Do you have a good quality of life?
    - How do you cope with swallowing?
    - How is your voice, how do you get on with communication?
- MDT and decision process
    - When you look back did you understand the treatment decision?
    - Did you understand the consequences of the decision?
    - Did you have enough information to base the decision on?
    - Should they have allowed you more or less control over the decision?
    - Do you wish the decision had been made differently?
    - Do you feel you made the right or the wrong decision?
    - Do you have any regrets?
    - How could they improve the clinic/the decision process?
    - In the perfect world, how do you think treatment decisions should be made?
- Palliation/prognosis
    - Were you ever aware of the chances of the treatment being successful?
    - Would you want to be aware?
    - Was palliation ever an option for you? Is it now?
- Information giving
    - Do you think you had enough information about treatment?
    - Did you understand what you were entering yourself into?
    - Should they give more information? Could they?