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The experiences of people living with head and neck cancer

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The Experiences of people living with head and neck cancer

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ABSTRACT

This qualitative study involved an exploration of the journey from diagnosis through to life post restorative surgery for people with Head and Neck Cancer (HNC). The aim was to understand how patients adapt to life post treatment and rehabilitation exploring how they adjust to changes in look and function. This work also focused on cultural schemas, and attitudes about the mind and body.

Methods: This is a qualitative study using ethnography as its methodology. It employs a combination of documentary analysis, observations and in-depth interviews to explore the experiences of people with HNC, looking at patients using the Southeast London Community Head and Neck Cancer Team (CHANT). The research was conducted in three stages. To capture the macro view a document analysis of policy documents was carried out, observations of the key settings provided a meso level and the individual narrative was captured by in-depth interviews (the micro level). Some observations took the form of mini focused ethnographies, which observed key clinical encounters but also observed the day-to-day clinical environment in which patients step into. This was used to inform the interview stage, create relationships with interview participant, set the scene and embed the researcher in the clinical environment. All interviews were recorded and transcribed verbatim. Data was analysed using a thematic framework analysis developed through the literature and further through the analysis process.

Results: The three strands of work coalesce to provide a picture of the experiences of people undergoing their HNC journey through diagnosis, treatment and rehabilitation. This study identified some key themes including, the traumatic elements of treatment such as radiotherapy and dental extraction, the importance of effective information giving, the impact of loss of function on the whole self and a better understanding of how individuals manage rehabilitation. The study also captures the pivotal role that networks play in facilitating a better experience of HNC. Participants highlighted that families, partners and friends are key to supporting rehabilitation. Participants further highlighted that the CHANT community-based, multidisciplinary approach is an exemplar of how to provide personalised, tailored care for this cohort of patients.

What this research shows in policy terms is that HNC is a particular type of condition that is ideally suited to being treated at a local community level within a model of integrated care. At an individual level, however, it is a catastrophic diagnosis which turns people's lives upside down and for some people, once they have gone through the treatment and rehabilitation, they are never going to be quite the same as they were when they started. This is demonstrated in observations where the reality of the environment and interactions that patients are involved in can be seen and through the individual stories that came out of the interviews.

Conclusion: More research needs to be conducted to better understand the long-term needs of patients with HNC as there is currently little qualitative research into the patient perspective. This study provides a new insight into the narrative of the patient journey for those with a diagnosis of HNC. This study is important because it provides a voice for a group of patients, which is not captured holistically in the existing literature. Through a document analysis it is apparent that the national and regional ambitions can be effectively implemented into a community-based service, however this is not replicated across the country. This piece of research affects policy and the way we go forward with service design for this group of patients and others who may have parallels as it highlights the efficacy and success of providing a cancer rehabilitation service structured in this way. This is important because it enables us to gain insight into the sheer mess, noise, urgency and confusion of the process on an individual and provides a uniquely contextualised account of the biological, social, political and psychological impacts when providing care for this group of patients.

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LIST OF ABBREVIATIONS

CNS – Clinical Nurse Specialist

HNC – Head and Neck Cancer

HPV – Human Papillomavirus

HPVOPC - Human Papillomavirus-positive oropharyngeal cancer

IMRT – Intensity-Modulated Radiotherapy

LTC – Long Term Condition

MDT – Multidisciplinary Team

MND – Motor Neurone Disease

OMFS - Oral and Maxillofacial Surgeon

ORN – Osteoradionecrosis

PTG – Post-Traumatic Growth

QoL – Quality of Life

SSC – Squamous Cell Carcinoma

1. INTRODUCTION

This thesis explores the patient journey following a diagnosis of Head and Neck Cancer (HNC). Using ethnography, I draw on individual accounts of the journey from diagnosis to rehabilitation, observations of the locations and processes of care and an analysis of the policies that shape the provision of care for people with HNC. This allows for the creation of a detailed and contextualised account of a patient's journey through HNC. To further illuminate the complexities of patient experience, this thesis examines the interactions, networks, roles, goals and images of self-identity of people with HNC and reflects on the roles health professionals and other actors play in supporting the patient journey.

In this introductory Chapter, I outline the current landscape of HNC, looking at incidence, mortality and survival rates, risk factors, waiting times for diagnosis and treatment and prevention elements to set the scene and outline the complexities of this group of cancers in terms of physiology and etiology. This Chapter then outlines existing clinical guidance in the UK, with a focus on best practice, which provides the backdrop for this research study.

1.1 CURRENT CONTEXT

1.1.1 INCIDENCE OF HNC

HNC is a term that captures a varied and heterogenous group of Cancers with origins/locations in more than 30 sites in the head and neck region, however the main sites are the mouth and lips, larynx, pharynx, salivary glands, nose and sinuses, the nasopharynx the respiratory tract and upper digestive tract, including tumours of the larynx (Fitchett *et al.*, 2018) and includes oral cancers. In 2016-2018, Cancer Research UK highlight that the most common specific location for HNC, in the UK, is the tongue.

The various definitions of HNC are relevant for contextualising some of the core data around the broad term of HNC. The World Health Organisation defines HNC by a number of classifications based on topography, morphology and histopathology, reflecting the diversity in the term and what it covers. The International Classification of Diseases for Oncology uses codes in the ICD-O-3 range to describe head and neck cancer (HNC). The International Classification of Disease (ICD-10) classifies HNC as a malignant neoplasm of the head, face or neck (World Health Organisation, 2021). The 11th revision of the International Classification of Diseases has further classified HNC with the code ICD11 (World Health Organisation, 2021). For this study, the term HNC is used broadly as it captures the complexity and variation of the cohort of patients seen by the service examined in this thesis.

In 2016-2018, Cancer Research UK confirmed that HNC is the 8th most common type of cancer in the UK, accounting for 3% of all new cancer cases. The number of new cases grows every year with oral cancers (World Health Organisation, 2018) being identified as the sixth most common cancer worldwide, accounting for 4% of all cancers. Although incidence and prevalence rates vary geographically and regionally. Research reports that in the UK from 2015-2018, there are around 12400 new HNC cases every year (2015-2018) (Cancer Research UK 2022). In 2012 300,000 patients, (2.1% of the total cancer cases), were diagnosed with cancer of the oral cavity worldwide (Dhanuthai et al., 2017) with a higher incidence rate in men, attributed to greater exposure to risk factors, and belonging to lower socio-economic groups (Warnakulasuriya, 2009). Incidence rates for HNC in the UK are highest in people aged 70 to 74 (2016-2018) with 22% of HNC diagnosed people being 75 years older or over (Cancer Research UK, 2022).

HNC is the 13th most common cancer in UK females (Cancer Research UK [CRUK]+date). CRUK figures from 2016-2018 suggest there are 3900 new cases diagnosed for women annually. In contrast, HNC is the 4th most common cancer for UK males, with 8600 new cases diagnosed annually (CRUK+ date). Incidence rates for HNC are lower in the Asian and Black ethnic groups, and in people of mixed or multiple ethnicities, compared with the White ethnic group, in England. However, incidence rates are higher compared with the White ethnic group in females in the Asian ethnic group (2013-2017).

The UK incidence of HNC is steadily rising and compared to 2007, with a 75% predicted rise by 2030 (Fitchett *et al.,* 2018). CRUK suggests a 45% increase in females and 22% in males (CRUK + date). Factors for these increases include an aging and growing population and the rise of Human Papillomavirus (HPV) related cancers (Fitchett *et al.,* 2018).

1.1.2 MORTALITY RATES

Cancer Research UK reported that between 2017-2019 there were approximately 4000 HNC deaths in the UK). HNC is the 15th most common cause of cancer death in the UK, accounting for 2% of all cancer deaths (2017-2019). There is a skew towards males in mortality rates within the UK, with HNC being the 10th most common cause of cancer death in males with (around 2,800 deaths in 2016) compared to females (17th most common, around 1,200 deaths in 2016) (Cancer Research UK 2022). Whilst there was a downward trend from the 1970s in the last decade, HNC mortality rates have started to increase (Gormley *et al.*, 2022) by around a seventh (14%) in the UK. Rates in males have increased by more than a tenth (12%), and rates in females have increased by around a seventh (13%).

Research suggests that rising mortality correlates with increased incidence rates and attributes this to a growing and aging population and a rising HPV related cohort (Fitchett et al., 2018). This must also be considered within the context of other non-biomedical factors that may change the incidence and prevalence. These include social determinants that are associated with increasing the risk. For example, health literacy, language, education and socioeconomic background (Nilsen *et al.,* 2020; Shehan *et al.,* 2022) These factors can have an impact on early diagnosis, treatment choices, adherence and consequently survival rates.

HNC survival in England is improved in the younger age cohort, under 49, compared with other age groups, though the association with age varies by the cancer subtype. Most who receive a diagnosis of HNC survive for 1 year or more (61-86%), with survival rates dropping for ten years or more (15-59%). “The five-year relative survival *rates in the UK for both men and women is similar to or higher than the European average.”* (Cancer Research UK, 2018).

1.1.3 RISK FACTORS

There are many factors, including age, genetics, and exposure to risk factors (including some potentially avoidable lifestyle factors) that contribute to causes of HNC. Incidence is associated with social deprivation and heavy consumption of tobacco and/or alcohol (Fitchett *et al.*, 2018) and this is the traditional profile of an HNC patient. However, much work is being carried out to unpick the complexities around the etiologies of these types of cancer and how we can better predict incidence through identifying risk factors and intervening to improve outcomes. It is important to note that these risk factors are more pronounced depending on gender, for example, for women HPV and other hormonal factors (Hashim *et al.*, 2017) are more likely to influence incidence. Tobacco is the greatest risk factor for all HNCs but has the highest risk for laryngeal cancers (Hashibe *et al.*, 2007) and the wider risks around smoking are discussed next.

1.1.3.1 Smoking

Cigarette smoking is independently associated with risk of HNC. The strength of these associations differed among HNC subtypes and it most associated with laryngeal cancer (Maasland *et al.*, 2014). An evaluation of the joint effects of intensity and duration of cigarette smoking on the risk of HNC using data from 33 case-control studies of INHANCE (International Head and Neck Cancer Epidemiology) consortium showed *"the joint effect of intensity and duration of cigarette smoking on HNC risk, further stressing the need of smoking cessation policies"* (Di Credico *et al.*, 2019 p.48). For oral-cavity/pharyngeal (OCP) cancers, an odds ratio >5 was reached after 30 years in current smokers of ~20 or more cigarettes/day. The study showed that patterns of OCP cancer risk in those who were current smokers differed across levels of alcohol intensity. For laryngeal cancer, ORs>20 were found for current smokers of ≥20 cigarettes/day for ≥30 years. In those who were currently not smokers and who had quit ≥10 years ago, the odds ratios were approximately halved for OCP cancers, and ~1/3 for laryngeal cancer, as compared to the same levels of intensity and duration in current smokers (Di Credico et al., 2019).

It Is important to note the populations who ingest tobacco via other routes. A number of studies were identified on HNC cancer epidemiology from the International Head and Neck Cancer Epidemiology (INHANCE) consortium. The INHANCE studies looked at ingestion of tobacco in other ways i.e. not smoked but chewed or powdered, which is associated with an elevated, near two-fold risk, for oral cancer, to include those who had never smoked (Wyss *et al.*, 2016). A type of smokeless tobacco often chewed in South Asia is known as Betel quid and contains tobacco and areca nut (Bernstein, 2021). People using this with tobacco were 8.4 times more likely to develop oral cancer versus the 9.9 times for those using betel quid alone (Merchant *et al.*, 2000).

1.1.3.2 Alcohol

HNC, including oral, pharyngeal, and laryngeal cancers, and coupled with tobacco use, accounts for 75% of oral cancers (Marziliano, Teckie and Diefenbach, 2020). Hashibe *et al.,* (2009) detailed that among the heavier drinkers (those that consumed at least three or more drinks per day) who had never smoked, there was a two-fold risk for oral cavity and oropharyngeal cancer. There is an identified symbiosis, in terms of causing HNC, between alcohol consumption and smoking and where people both drink alcohol and smoke there is a significant, positive, cumulative interaction between both factors (Maasland *et al*., 2014) and therefore their risk was significantly elevated by up to a fivefold. (Hashibe *et al.*, 2007). A retrospective analysis of 9,950 HNC patients in India (Dhull *et al.*, 2018) supports this, however it should be noted that this study does not clearly differentiate between cigarettes or bidis and there are known implications for bidi due to how they are made. This would need to be explored further to accurately map relationships.

Furthermore, research indicates that alcohol consumption can be a risk factor to secondary cancers. HNC patients with secondary cancers may struggle to reduce or change habits around alcohol consumption and with continued alcohol intake further cancers may occur alongside other complications of alcohol consumption (Marziliano, Teckie and Diefenbach, 2020). However, the definition of excessive is not easy to quantify. The Centre for Disease Control and Prevention stating 3 to 4 drinks per day can increase cancer with risks elevating with increasing consumption. The National Cancer Institute state that *"Moderate drinkers have 1.8-fold higher risks of oral cavity (excluding the lips) and pharynx (throat) cancers and 1.4-fold higher risks of larynx (voice box) cancers than non-drinkers, and heavy drinkers have 5-fold higher risks of oral cavity and pharynx cancers and 2.6-fold higher risks of larynx cancers."*

1.1.3.3 Socioeconomic deprivation

The relationship between risk of HNC and socioeconomic status is complex. Around 2,300 cases of HNC each year in England are linked with deprivation (around 520 in females and around 1,800 in males). Cancer Research UK highlight that in England (2013-2017) the most deprived quintile, compared with the least shows that incidence in females are 64% higher and in males are 101% higher 2013-2017) (Bernstein, 2021). In a study by Conway *et al.,* (2015) low educational achievement and low income is defined as high risk factor for HNC, doubling the risk, comparable to that for smoking and alcohol (Conway *et al.,* 2015). Extricating these influences is difficult as socioeconomic deprivation influences the likelihood of a number of risk factors. These include smoking, drinking, poor diet and risks around occupations that may expose individuals to environmental toxins (Bernstein, 2021). This INHANCE study demonstrated that certain occupations elevate risk of developing HNC. This is due to exposure to environmental and occupational toxins e.g., Asbestos. These are often associated with lower income service workers such as cooks, waiters, cleaners, tradespeople, those in textile production (Khetan *et al.*, 2019) firefighters and agricultural workers (Paget-Bailly *et al.*, 2013).

1.1.3.4 Human papillomavirus (HPV) infection

Since 1983, an etiological agent of carcinogenicity for HNC has been identified as the Human papillomavirus (HPV) (Gillison, 2000; Näsman *et al.*, 2009). This newly identified HPV-positive oropharyngeal cancer (HPVOPC) or HPV related HNC, enabled the identification of a new demographic of HNC patients. A 37.5% increase in females in the UK, and a 47% increase in potentially HPV-associated cancers in males was reported between 2002-2011. (McCarthy *et* *al.*, 2015). It is now known that there are two types of squamous cell carcinoma of the head and neck. Squamous cell carcinoma of the head and neck can be of the keratinized or nonkeratinized type. Keratinized types tend to occur in the more common demographic for HNC Patients - older male, alcohol and smoking cohorts. In these populations, HPV is not usually involved. However, nonkeratinizing squamous cell carcinoma occurs most commonly at age 40–55 years in men and some women without these defining lifestyle traits (excess smoking and drinking).

HPV is a sexually transmitted virus, which is currently on the rise. The annual number of HPV-associated OPC cases is forecast to overtake the annual number of cervical cancer cases in the US by 2023 (Chu *et al.*, 2013). HNC currently affect approximately 11 200 people in the UK, with an increasing proportion known to be caused by the human papillomavirus (HPV). A caveat to this form of transmission is that some cases of direct transmission from mother to child during pre-natal, perinatal and postnatal periods have been documented (Syrjanen and Puranen, 2000).

Exploration of the nuances involved in the experiences of patients with this subset of HNC is vital to ensuring the best patient experience and most appropriate approach to treatment. In doing this it is important to note prognosis expectations specific to this cohort, which several studies have shown are significantly improved for HPV-positive oropharyngeal cancer. As the practice of HPV testing (as recommended by The National Comprehensive Cancer Network) becomes more commonplace, it becomes even more critical that those involved in treating patients or developing policy and government systems are able to address the nuances in treatment and approach that may be required for people diagnosed with HPVOPC or HPV related HNC.

Other lesser factors have been identified with some still not having clear causal elements identified. They include exposure to solar or other forms of radiation, poor nutrition, marijuana use, environmental or occupational inhalants, poor oral and dental hygiene, and certain medical conditions (e.g., Epstein-Barr Virus, GERD, LRPD or a weakened immune system) have also been highlighted as having a correlation to a risk. Furthermore, INHANCE studies have shown an increased risk of oropharyngeal cancer with early sexual activity (< 18 years) and six or more lifetime sexual partners (Heck *et al.*, 2010). Therefore, with reference to the above, In the UK, a profile for HNC can therefore be demonstrated. This relates to age, gender risk behaviours and socio-economic background.

1.1.4 PREVENTION

Statistics suggest that 46% of oral cancers, 88% of pharynx cancers and 73% of laryngeal cancers in the UK are preventable (CRUK 2022). There are likely to be many habitual and socially entrenched patterns of behaviour that could reduce chances of developing primary or secondary cancers. These preventative behaviours may include smoking cessation, reducing or stopping alcohol consumption and a balanced diet high in fruit and vegetables. There is an increasing, global evidence base that diet can have a positive impact on HNC risk (Chuang *et al.*, 2012; Chang *et al.*, 2017; Galvão De Podestá *et al.*, 2019) as low levels of fruit and vegetables has been linked to an up to 50% of certain HNC subtypes.

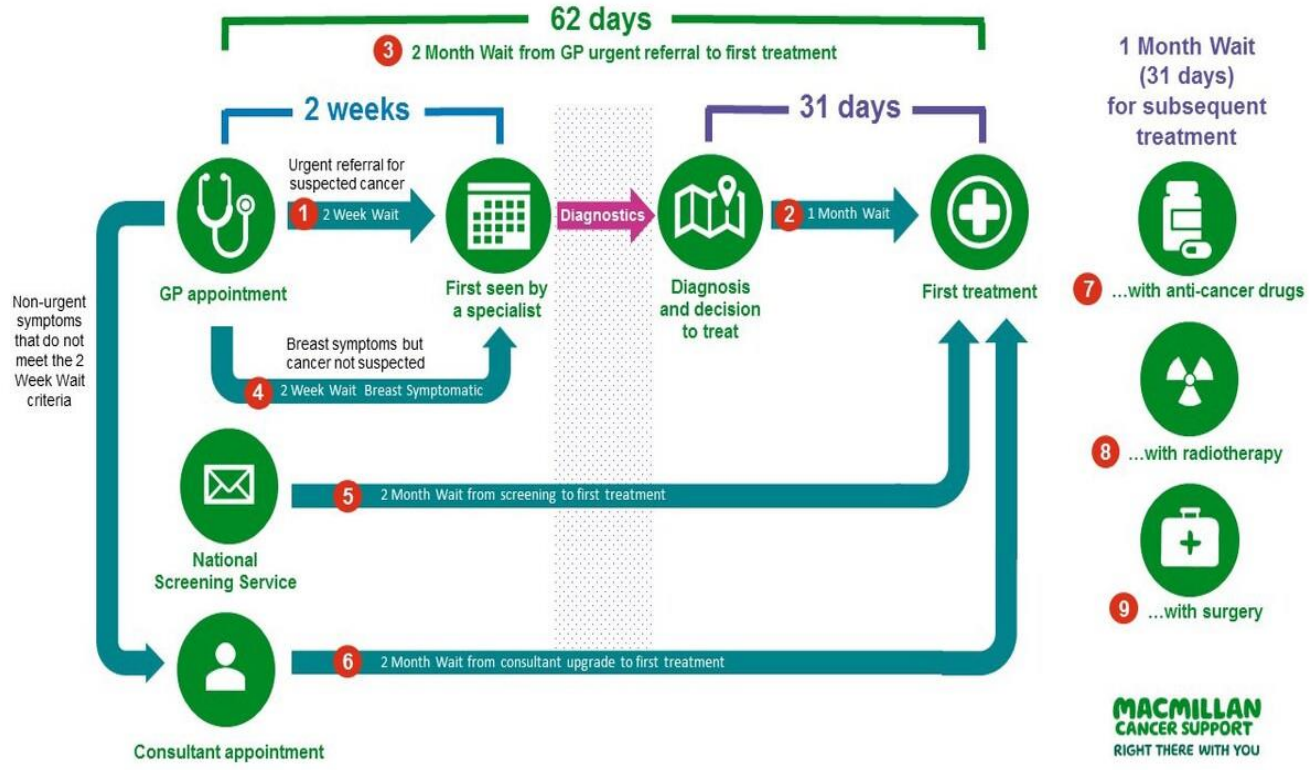
This highlights the importance of understanding what factors contribute to these statistics. Understanding the patient journey could not only improve services on diagnosis but elucidate valuable information around why and how patients manage their health before diagnosis, the societal and personal factors that make a person more likely to develop HNC and how they can be better supported preventatively and post diagnosis with these behaviours.

1.1.5 WAITING TIMES FOR DIAGNOSIS AND TREATMENT

In England, there are targets set for waiting times for an urgent referral on suspected Cancer diagnosis and commencement of treatment for Cancer. In England, there is a two-week waiting time target to first see a specialist (urgent referral). 'Two-week wait' supports early diagnosis as spotting cancer early is crucial for improving survival, so it is important that patients with potential cancer symptoms are referred promptly, and in the case of HNC referred to a specialist Oral and Maxillofacial Surgeon (OMFS).

NHS England has introduced a target called the Faster Diagnosis Standard (FDS). The target sets out that someone should not wait more than 28 days from referral to finding out whether they have cancer or not. There are also waiting time targets to start treatment. In England, Scotland and Northern Ireland, a person should wait no more than 2 months (62 days) between the date the hospital receives an urgent referral for suspected cancer and the start of treatment and then no more than 31 days wait between the meeting at which you and your doctor agree the treatment plan and the start of treatment (NHS England, 2022). This is captured in Figure 1 below.

Figure 1: A diagram sourced from Macmillan Cancer showing Cancer waiting time pathways



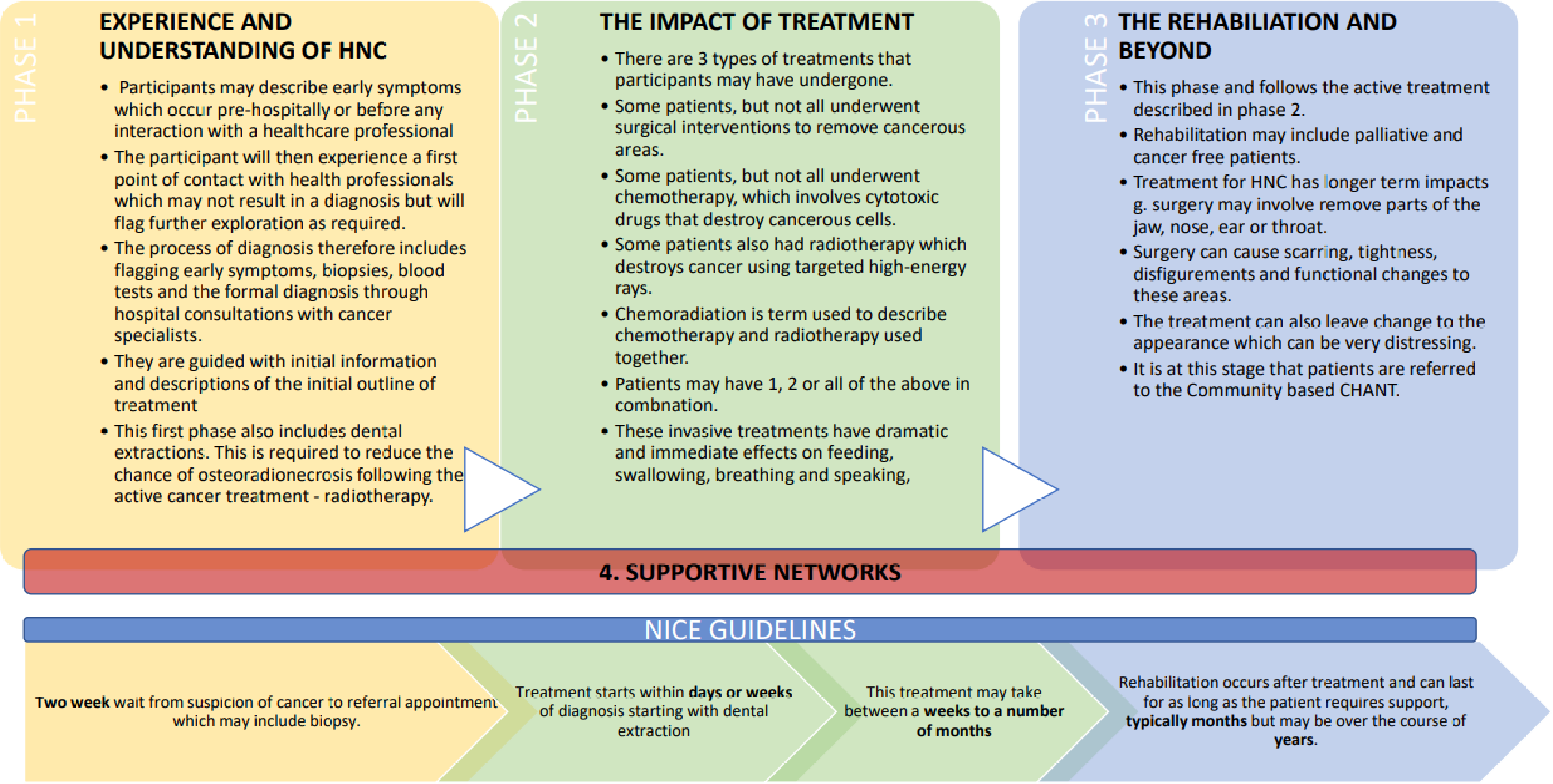
Partly due to disruptions caused by the COVID-19 Pandemic recent data shows that these targets are being missed, reflecting the pressures in recovery of services and the need for increased resource and capacity to meet the shortfall in these life-saving pathways. Referrals have increased to higher than pre-COVID 19 the proportion being seen by a specialist within the two-week target of an urgent GP referral is low (73% in September 2022, lowest on record) and the 93% target has not been met since May 2020. The target around receiving their first *treatment "within two months of attending a screening service dropped dramatically during the initial few months of the pandemic, and despite some improvement remains well below the operational standard"* (NHS backlog data analysis (bma.org.uk).

1.1.6 TREATMENT AND THE CLINICAL PATHWAY

The treatment (acute phase) for HNC involves surgery, radiotherapy, chemotherapy or a combination of these options. The clinical pathway is outlined in Figure 2: Phases of treatment with key milestone and features. A treatment plan is informed by the site of the cancer, stage of cancer (i.e., severity of the cancer I, II, III or III) age and health of the patient as those who are older with existing health conditions may find the treatment too challenging (Marur and Forastiere, 2008).

In contrast, oral pharyngeal cancers often present at a later stage and primary treatment is likely to involve radiation or chemoradiation. Surgery may involve the removal of the tumour and require reconstructive surgery at a later date. Surgery may be followed by radiotherapy or chemoradiotherapy. But some patients may require surgery and only require radiotherapy with some involving chemotherapy too. *"Many patients will receive all 3 treatments during their trajectory of care, but because each is intrinsically different to the others, failure to consider them in isolation may have meant important concepts were missed"* (Fitchett *et al.*, 2018 p.2078). Radiotherapy is used to treat locally advanced disease (Stage III+) ad an adjunct to surgery or as part of a chemoradiation approach. Radiotherapy side effects can include dysphagia, xerostomia, chronic aspirate and other conditions.

Figure 2: Phases of treatment with key milestone and features



PHASE 1

EXPERIENCE AND UNDERSTANDING OF HNC

- Participants may describe early symptoms which occur pre-hospitally or before any interaction with a healthcare professional
- The participant will then experience a first point of contact with health professionals which may not result in a diagnosis but will flag further exploration as required.
- The process of diagnosis therefore includes flagging early symptoms, biopsies, blood tests and the formal diagnosis through hospital consultations with cancer specialists.
- They are guided with initial information and descriptions of the initial outline of treatment
- This first phase also includes dental extractions. This is required to reduce the chance of osteoradionecrosis following the active cancer treatment - radiotherapy.

PHASE 2

THE IMPACT OF TREATMENT

- There are 3 types of treatments that participants may have undergone.
- Some patients, but not all underwent surgical interventions to remove cancerous areas.
- Some patients, but not all underwent chemotherapy, which involves cytotoxic drugs that destroy cancerous cells.
- Some patients also had radiotherapy which destroys cancer using targeted high-energy rays.
- Chemoradiation is term used to describe chemotherapy and radiotherapy used together.
- Patients may have 1, 2 or all of the above in combnation.
- These invasive treatments have dramatic and immediate effects on feeding, swallowing, breathing and speaking,

PHASE 3

THE REHABILIATION AND BEYOND

- This phase and follows the active treatment described in phase 2.
- Rehabilitation may include palliative and cancer free patients.
- Treatment for HNC has longer term impacts g. surgery may involve remove parts of the jaw, nose, ear or throat.
- Surgery can cause scarring, tightness, disfigurements and functional changes to these areas.
- The treatment can also leave change to the appearance which can be very distressing.
- It is at this stage that patients are referred to the Community based CHANT.

4. SUPPORTIVE NETWORKS

NICE GUIDELINES

Two week wait from suspicion of cancer to referral appointment which may include biopsy.

Treatment starts within **days or weeks** of diagnosis starting with dental extraction

This treatment may take between a **weeks to a number of months**

Rehabilitation occurs after treatment and can last for as long as the patient requires support, **typically months** but may be over the course of **years**.

exploring the perceived optimum clinical outcome for types of treatment (Yerit *et al.*, 2006; Clough *et al.*, 2018) there is less known about the patient outcome i.e. patient satisfaction and the impact on the quality of their lives and longer term impact and consequences of living with a particular treatment pathway (Clough *et al.*, 2018). The rehabilitation phase involves enabling patients to recover from the impacts of treatment which is intensive, traumatic and result in profound changes. This phase requires further support from a multidisciplinary Team (MDT) with a diverse range of specialties to help with functional impairments relating to swallowing, moving, chewing, speaking, eating/nutritional support. Patients are left to adapt to physical changes and altered facial appearance which can be psychologically distressing and have a negative impact on their well-being (Katz, Belkora and Elwyn, 2014). The literature review in Chapter Two explores current research on the patient experiences of living with HNC.

1.2 CLINICAL GUIDELINES AND DEVELOPMENTS

In May 2005, the 58th World Health Assembly Resolution on Cancer Prevention and Control urged Member States consider the importance of developing and reinforcing cancer control programmes that focus on addressing risk factors and emphasizing the importance of prevention elements (*'Strengthening the prevention of oral cancer: the WHO perspective'*, 2005) further emphasizes the global challenges in oral cavity cancer prevention. In terms of UK national health policy, the National Institute for Health and Care Excellence (NICE) guidelines issued in November 2004, highlight the following in relation to patient care. The key recommendations were:

- *"Cancer networks should decide which hospitals will diagnose, treat and care for patients*
- *Multidisciplinary teams should be responsible for every patient*
- *Clear systems should be in place for patients to be seen quickly by specialists*
- *Support services should be available to all patients who need them*
- *Local support teams should provide long-term support in the community*

- *Information should be collected*
- *More research should be done"*

In 2013, NHS England produced a national specification for the care of HNC patients. Its aims were to cover the whole pathway for HNC, while specifically focusing on the specialist elements. The specification aimed to clarify the need for the specialist HNC multidisciplinary team service, to deliver the key service standards, as specified in the Improving Outcome Guidance in Head & Neck Cancer (2004), the National Cancer Peer Review Programme Manual for Cancer Services: Head & Neck Cancer measures (2011) and Cancer Waiting Times.

Further to this, the British Dental Association produced a guide to *"Early detection and prevention of oral cancer: a management strategy for dental practice*" (published in November 2010) with the aim to offer practical advice on preventing, detecting and managing oral cancer. The guidance also addresses both the clinical aspects of the condition and the approaches to creating and managing a relationship with the patients. The document details the risk factors for the disease and provides pragmatic guidance on talking to patients about examinations. *"It also explores taboos around the practitioner's right to explore patients' lifestyle choices that can cause oral cancer, such as drinking, smoking and chewing tobacco, and offers advice on how to overcome them"* (British Dental Association).

Most recently, The Royal College of Surgeons of England and The British Society for Disability and Oral Health produced an updated Clinical Guideline (2018) entitled, The Oral Management of Oncology Patients Requiring, Chemotherapy and/or Bone Marrow transplantation which provide an overview of the current recommendations in relation to dental care for all patients undergoing cancer therapy. This guidance highlights the importance of considering oral health in context acknowledging not only the physiological detrimental effects of the diagnosis but also the impact on the quality of a patient's life citing the implications for normal social adaptation (Kumar *et al.*, 2013). The guidelines suggest that, following major head and neck surgery, approximately 70% of patients reported at least one unmet need, the most common being oral and eating problems (Ringash *et al.*, 2018).

This guidance sits alongside the complimentary guidelines, specific for patients receiving surgical and non-surgical treatment for HNC produced by Restorative Dentistry UK in 2016 (RD-UK, 2016), entitled *'Predicting and Managing Oral and Dental Complications of Surgical and Non-Surgical Treatment for HNC.'.* The guidelines address issues relating to oral and dental care at the pre-, peri- and post-treatment stages. Importantly the guidelines suggest that the optimal approach to providing the best oral care for HNC patients is *"an holistic, pathway-based and multidisciplinary team-based approach"* (p.4) and the significance of involving restorative dentistry. The guidance summarises the impact on patients undergoing both chemotherapy and radiotherapy, stating that radiotherapy causes unavoidable radiation damage to normal tissues surrounding the tumour.

This means that the function of these tissues both can be affected in the short-term and long-term (for months and years after treatment or lifelong). Furthermore, chemotherapy can cause acute mucosal and hematological toxicity, and side effects can be made more severe if chemotherapy is delivered concurrently with radiation therapy ('Predicting and Managing Oral and Dental Complications of Surgical and Non-Surgical Treatment for HNC', 2016). The RD-UK guidance provides recommendations for oral and dental management of HNC considering the retention of teeth. The Consultant in Restorative Dentistry is pivotal to this. Guidelines provide a framework for practically implementing a carefully planned oral and dental assessment, citing early intervention and reconstruction as significant pillars to improving the prognosis and quality of life of the HNC patient. (Butterworth *et al*., 2016).

1.3 SUMMARY OF THESIS

What is outlined in this introduction is the context within which we look at the experiences of people diagnosed with HNC. The guidelines introduced here hint at the importance of looking at the experiences of people receiving treatment. What is interesting and unique to HNC is that they come not just from Medicine but also from Dentistry. This is the starting point for this study, which seeks to understand the complex and harrowing experience of an under-researched group of cancer patients that have unique elements.

Chapter Two presents existing research, covering the small body of work that is most relevant to this study (the experiences of people living with HNC). In doing this the evidence gap is highlighted. Building on this, the literature review strategy sought to review other frameworks for understanding the experiences of patients with long-term conditions (LTC). This led to purposively seeking literature in the wider chronic illness and cancer studies space. The process and findings of the literature review are set out in this Chapter.

Chapter Three sets out the aims and objectives of the study, based on the identification of a gap in knowledge in the previous chapter. Three key areas of enquiry are identified. The first is around understanding the policy context at a national, regional and disease level (Chp. 5). This provides the context for clinical care pathways the recommended models of care. The second objective is to understand the settings and interactions at a local level (Chp. 6) and the third is to understand the individual experience (Chp.7).

Chapter Four outlines the core principles around the chosen methodology. Ethnography as a methodology captures the cultural experiences of people living with HNC and study a phenomenon holistically. A multi-method approach captures different vantages. Document analysis unpicks the complexity of the context. The local setting is understood through participant observation, and individual experience through interviewing patients. Each method maps to an objective (see Figure 4).

Chapters Five sets out the process of the document analysis, and systematically reviews the findings at a national, regional local and disease level demonstrating that patient-centered care, multidisciplinary working and community-based interventions are recommended for this cohort of patients, at a national and regional level.

Chapter Six presents the observations through a series of vignettes of observed clinical interactions with the rehabilitation team. This chapter also outlines observations of group settings and dental extraction clinics. This aims to provide observational data that adds to the contextual document analysis providing layers of detail that coalesce to provide an immersive narrative account of the experiences of patients with HNC.

Chapter Seven presents interviews with 12 participants. 12 semi-structured interviews were thematically analysed, and results are presented under overarching themed sections of (1) "*Experience and Understanding of HNC",* (2) "*The Impact of treatment and rehabilitation*", (3) *"The rehabilitation and beyond"*. and (4) *Supportive Networks*.

The thesis ends with Chapter Eight outlining discussion, recommendations, and conclusions from this study. Chapter Eight outlines the core themes identified across Chapter Five, Six and Seven, demonstrating findings that do not exist in the current literature. The implications for policy and practice are detailed, highlighting the potential for this study to impact on treatment pathway and ways of working with this cohort of patients. The strengths and weaknesses of this thesis are also discussed, with future research opportunities highlighted.

2. LITERATURE REVIEW

This review starts with a broad research question around what we know about the experiences of HNC patients, and what, if any, gaps there are in our current understanding. More specifically, this literature review aims to identify the depth of research focusing on the experiences of people with HNC around diagnosis, treatment, impact and rehabilitation. The review starts with an overview of the search strategy adopted before providing a detailed overview of research on HNC specifically and, finishing with an overview of sociological research on cancer more broadly within the framework of the sociology of chronic illness.

2.1 SEARCH STRATEGY

This literature review starts by outlining the search strategy implemented (outlined in Table 1 below). This is a scoping review, seeking to understand the types and breadth of evidence in this area, following an iterative approach. The search strategy utilised OVID (Embase, Medline, PubMed and PsycINFO). Web of Science and Google Scholar were also reviewed to ensure thoroughness and capture anything missed in the other databases. The search focused on publications from the last two decades, however the criteria included papers published from 1990 onwards as relevant, burgeoning work was identified in this decade. The eligibility criteria are outlined in the table below.

Table 1: Inclusion and exclusion criteria for literature review

	Inclusion	**Exclusion**
Language	Studies available in full text English or translation	Not available in full text or not available in English
Time period (Data range)	Studies published between 1990-2022 to capture most recent publications	Studies published prior to 2022 or in press/abstract or proceedings.

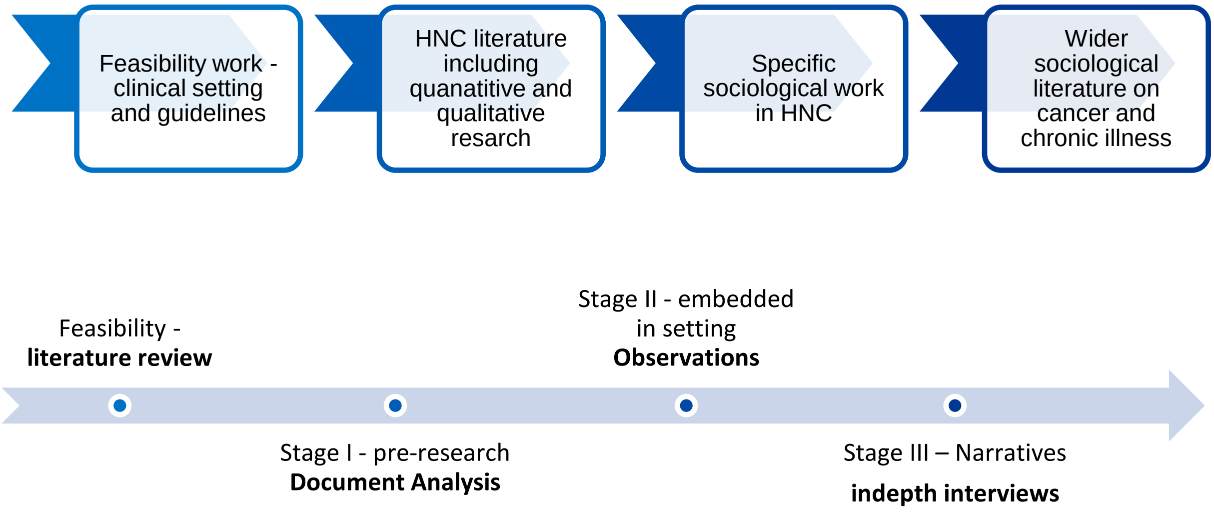
Focus of Study	I. Experiences and/or belief/views of people with HNC or their carers **II.** the wider impacts of HNC and/or HNC treatment **III.** Studies on people who have, or have had, HNC **IV.** Studies on living with cancer and its impacts V. Studies on disability or chronic illness that may be a useful parallel	I. **Grey literature** - grey literature will not be searched as it has not been peer reviewed. * **Some relevant clinical documents are included for understanding, however policy documents, reports will be examined as part of the document analysis in Chapter Four* II. **Clinical studies** – studies that do not have an experience element that focus on the aetiology or physiology of HNC
Sources	Peer-reviewed evidence	
Geographical location	All countries	
Study Design	**Qualitative -** If qualitative: ethnography, narrative, phenomenology, grounded theory, descriptive qualitative. **Quantitative** – Including systematic reviews, narrative reviews, meta-analyses studies	Studies that are not part of a peer reviewed, ratified publication process

In total over 16,000 articles and studies were returned from the criteria and 74 were included in the literature review for detailed exploration. Searches were conducted using a number of key search terms including Head and Neck Cancer; Cancer; impact; Quality of Life; lived experience; qualitative; rehabilitation; treatment; patient; coping; caregivers. This provided a broad response and therefore articles were included using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

The search started with the HNC literature where a strong body of Quality-of-Life literature exists and a smaller body of more sociological and qualitative research, then to wider cancer examples. This approach has been a key element of this thesis and is also part of the process for developing and evolving the methodology of the study as research began.

This iterative and reflexive process adds a strength to the thesis, which routes its analysis from an ethnomethodological approach to its rationale for enquiry and chosen evolved methodology and works on the premise of starting with a broad open enquiry that evolves and is data led. This means that the literature review started with a broad question and then evolved, informed by assessment of the previous stage. This was also the approach taken with the methods outlined. The pre-research document analysis sought to understand the political and societal elements before the active phase of ethnographic exploration. The observations became an important part of the immersion process and informed the interviews and contextualisation of the pre-research. Specifically, this is in line with the aim to provide a holistic model and to be person-centered in approach.

Figure 3: Showing evolution of lines of enquiry throughout the literature review



The studies extracted informed the background to the key research questions and objectives of the literature review. Data was synthesised based on a review of relevance, context and quality and the methodology a study used. This review therefore starts with exploring what we currently know about HNC. I start by examining the "Quality of Life" literature (n=165 with 6 selected for discussion in this review). This provides a broad idea of some of the key themes and challenges for patients. This section also explores how this evidence has then been used to inform clinical practice.

Following this, the review summarises the qualitative research into the patient journey for HNC, looking at studies that begin to unpick the patient experience. I then explore the growing body of research looking at the differing dynamics in the HPV cohort of patients and how this impact on the pre-existing literature, adding a complexity to the narrative around HNC. The HNC specific literature (n=38) is divided into a number of core themes and detailed in section 2.2.2.

A small number of studies (n=3) explored the impact of ethnicity and as this may capture specific needs associated with specific populations it is therefore discussed in the final section. It is also important to note that the patient experience needs to be contextualised and framed within the arena of patient and societal influences. I therefore explore the specific studies looking at international comparisons and the impact of ethnicity, as these two areas are somewhat under reviewed in discussions around HNC. This review highlights the lack of exploration of how different groups approach this journey and also how different health care systems may approach support and health care practices, potentially highlighting a need for comparative work with harder to reach groups and across different countries. The literature review finishes with introducing bodies of work that may provide useful parallels. These include comparing the themes found in the examination of other cancers, from a sociological perspective and finally touching on the broader, but usefully similar impacts on those with chronic or long-term conditions (n=28).

2.2 CURRENT LITERATURE ON HNC

2.2.1 QUALITY OF LIFE EXPLORATION

One of the largest bodies of work exploring the experiences of people living with and being treated for HNC focuses on the concept of quality of life. This remains a significant area of interest, particularly within the psychology literature, with most studies using standardized tools for assessing the quality of life of HNC patients (Hammerlid and Taft, 2001). There are various approaches for assessing health-related quality of life, used on the HNC cohort.

The Karnofsky scale and SIP have various characteristics that make them quite different in their approach (one is crude and simple whilst the other is sensitive and lengthy). The three questionnaires were compared for 3 elements, validity, reliability and acceptability with the UWQOL measuring most favorably in all areas, demonstrating the that the methodology used for capturing quality of life information can influence both the quality of the data received and the actual findings of the study. The study showed that the UW QOL scale was better than the Karnofsky and the SIP scale in showing and demonstrating change.

Such work demonstrates the importance of research to ensure that the tool used to capture information is suited to its audience and settings (Hassan and Weymuller, 1993). Broader literature exists on the use of Oral Health related QoL measures (OHrQoL. According to Sicho and Broder (2011) *"OHRQoL is a multidimensional construct that includes a subjective evaluation of the individual's oral health, functional well-being, emotional well-being, expectations and satisfaction with care, and sense of self"* (Sischo and Broder, 2011 p.1264) and is referred to as Oral Health-related Quality of Life OHrQoL but these studies were not included in the literature review as they do not focus on HNC patient experience.

A structured review and theme analysis of papers published on 'quality of life' in HNC was produced in 2007 by Rogers *et al.,* providing a seminal piece for understanding work in this area. The search terms were; quality of life, questionnaire, and HNC and studies between 2000-2005 were included. Studies were placed in to one of five themes. These are Predictors of HRQOL: (ii) Functional outcome around eating and speaking. (iii) Questionnaire development/Questionnaire validation: psychometric properties of the questionnaire. (iv) Randomised clinical trials/clinical trials: studies using HRQOL assessment as a key outcome parameter. (v) Review/editorial: The publications that have critically reviewed the QOL literature in HNC.

There were 165 studies identified. The systematic review summarised that over the past 10 years, quality of life (QOL) has been increasingly recognised as an important outcome parameter in HNC. Many validated questionnaires have emerged and this area of research is continuing to increase and expand (Rogers, Ahad and Murphy, 2007) . This study did not break down the different factors to look at them in more detail or develop them further. The findings of the studies that have broken down the different elements of QoL in relation to HNC are discussed below, Alongside, more recent studies in the area. One further questionnaire based study was identified, (Rinkel *et al.*, 2014) in 88 patients looking at voice, speech, and swallowing and the impact that this has on quality of life and distress during treatment, recovery and rehabilitation. The study found that the *"prevalence of voice, speech, and swallowing problems is high, and clearly related to quality of life and distress."* (Rinkel *et al.*, 2014 p.559). These studies suggest that the impact of not being able to communicate has a dramatic and profound impact on the well-being of a patient. This impacts on their ability to rehabilitate and creates anxiety, distress and often depression or other psychological impacts on the patient.

Considering such a larger body of studies take this approach it was important to include this in the literature review however, this approach does not provide the detail needed to illuminate the patient experience and these types of exploration do not disaggregate the factors they are looking to document. This therefore does not capture what lived meaning might be to an individual and what the impact of these assessments or statements about a person's quality of life have on them and others. This can only be elucidated through a detailed explorative narrative such as this study, a multifaceted broader inquiry taking an ethnographic approach.

2.2.1.1 Clinical application of tools to predict patients' challenges

In 2005 Scharloo *et al.,* carried out a prospective study exploring quality of life and illness perceptions in patients with recently diagnosed HNC. The purpose of this study was to investigate which illness perceptions of patients recently diagnosed with HNC explain variance in their quality of life (QOL) to identify potential targets for interventions aimed at improving QOL (Sixty-eight patients (mainly with stage III and IV disease) completed the Illness Perception Questionnaire- Revised (IPQ-R) and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30). Results showed, after controlling for age and comorbidity, that illness perceptions were significantly related to the QLQC30 physical, role, emotional, cognitive, social functioning, and global health subscales. Patients with increased attention to symptoms, who believed in a greater likelihood of recurrence, were more likely to engage in self-blame, had a stronger emotional reaction to the illness and lower QOL scores.

This study highlighted the potential predictive power of using these types of tools in clinical practice, suggesting that helping patients to restructure their 'negative pre-treatment illness perceptions' may make it easier for them to cope both during treatment and rehabilitation (Scharloo *et al.*, 2005). This could have an impact on how HNC patients handle rehabilitation. With adequate, clear, compassionate approaches to information giving expectations can potentially be managed to minimise shock and trauma.

Epstein *et al.,* (2001) investigated the quality of life and oral function in patients treated with radiation therapy for HNC using general quality of life survey (the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30) with an added oral symptom and function scale. Patients completed surveys at the beginning of radiation therapy, immediately after, and 6 months after treatment. This research demonstrates the importance of assessing oral dysfunction after HNC therapy, in order to provide the most effective treatment or *"best palliation of the malignancy with the least impact on oral function and* quality *of life is chosen".* (Epstein *et al.*, 2001 p.389). This study therefore supports the use of a standardised tool such as the EORTC questionnaire with the addition of disease/ site-specific scales. It provides useful data that can be used to support treatment and rehabilitation decisions as well as management strategies in these patient populations.

This body of work provides a standardised basis for designing and tailoring treatment and rehabilitation for HNC patients. Whilst this provides insight into areas of concern, the detailed narrative is lacking. Therefore, complimentary qualitative work is needed to further unpick identified issues or themes. Existing qualitative research in this area is explored next. The qualitative studies in the review used a range of approaches to reveal a broad range of themes of concern. These were mainly and consistently around cognitive or information overloads

(Bolt *et al*., 2020), coping methods (Isaksson *et al.,* 2016), therapeutic education (Parker *et al.*, 2014), and many aspects of social roles and identities (such as those of mother, carer, employee etc.). A focus on quality-of-life measures, whilst useful, may not capture elements that a more contextual framing would provide. Some potential limitations of this body of work are that it does not offer a broader focus, understanding the day-to-day experience that is contextualised and nuanced. These aspects may be *"difficult to dissect from a psychological vantage point"* (Wagner and McLaughlin, 2015 p.202) that focuses largely on individuals.

2.2.2 QUALITATIVE RESEARCH ON THE EXPERIENCE OF LIVING WITH HNC

Qualitative research focusing on specific elements of the patient experience of HNC have been identified in this section. Whilst there is no extensive exploration of the entire journey with its complex interdependencies and nuances, there are studies focusing on particular topics including a number of studies on HNC patients' experiences of impairment in relation to the intake of food and speaking/communicating. There are also qualitative studies that have focused on the impact of dental extractions, psychological impacts and changes to personal identity, communication changes, HPV related factors, the role of caregivers and networks, the fear of reoccurrence, and potential longer term positive impacts of the diagnosis and treatment. The impact of treatment and specifically radiotherapy is also explored.

The main outcome variables of interest are distributed fairly evenly with only a small number of relevant studies identified in each. The aspect of social eating is specifically addressed which could suggest that it is swallowing and nutritional intake which are of interest in the papers and not the social impact of eating, mealtimes and sharing food (n=8). The next domain categorised is around communication, and voice (n=3) and the challenges specific to this cohort, whilst only a small number of studies were identified it was important to include this to reflect the lack of in-depth exploration on the profound impact of HNC. A larger proportion of studies also focused on the changes to personal identity and the drastic change for HNC patients (n=6) The review then highlights an emerging body of work around HPV related HNC (n=3). Most studies identified focused on the importance of social support networks, looking at themes of loneliness, caring relationships is explored (n=8).

Understanding the particular trauma of radiotherapy were the focus in a small number of studies but are included as this is a fundamental part of treatment for HNC (n=3). Another interesting body of studies demonstrate the potential for positive impacts following a diagnosis of HNC (n=4). The understanding of the impact these elements have on recovery are critical to informing the best way for healthcare professionals to support patients and for healthcare systems to design pathways that are evidence-based, and person centered and sets the scene for this study. Finally, two reviews were examined to understand if there were any key themes and parallels to draw from this literature (n=20). Finally, I reflect on wider parallels with chronic illness (n=8).

2.2.2.1 Food and eating

Eating food is an everyday activity and alongside the importance of nutrition for the body, food and eating can have a wider impact on how a person feels as well as their daily practice. One qualitative interview based study was identified looking at this specifically in the NHS (n=17 participants) (McQuestion and Fitch, 2016). They found that in treatment, recovery and rehabilitation, there are disruptions caused to eating patterns, which fundamentally changed the meaning of food and the way it was seen by participants. The impact of treatment and rehabilitation on the relationship with food requires tailored support and this has also been identified in a range of studies in European settings (Ottosson, Laurell and Olsson, 2013; Kristensen *et al.*, 2019; Sandmæl *et al.*, 2019).

Kristensen *et al.,* (2019) carried out a study to explore HNC patients' experiences of everyday life with eating problems after cancer treatment in a Danish setting (Kristensen *et al.,* 2019).The study showed that patients frequently felt that there was an impact on their nutrition and identified unmet needs in supporting this. They experienced a feeling of loss due to losing functionality in terms of eating and this resulted in changing attitudes to eating. Participants felt a sense of it becoming an obstacle and obligation. Furthermore, it had a wider social implication challenging their relationships and habits with their families and friends. Their support was sometimes felt as pressure and a burden. (Kristensen *et al.,* 2019). This study specifically explores a Multidisciplinary Team (MDT) residential setting in Denmark. This type of residential facility is not part of the NHS pathway of treatment in England, but the findings are still of relevance where MDT rehabilitative care is provided within the community in the UK as in the case of the CHANT model, which is the focus of this study. This study shows that a multidisciplinary residential rehabilitation program may be beneficial to providing intense support and cater to HNC patients' rehabilitation needs. Exploration into this area could help to shape rehabilitation services, build on our existing care provision and improve clinical practice going forward.

Ottoson, Laurell and Olsson (2013) provide a descriptive exploration of the eating and nutritional intake problems that face HNC patients in the short and longer term, through semi structured interviews (3 case study participants following radiotherapy). This study found that there were a number of key elements to food intake following HNC treatment and this captures some of the wider, less, biomedical issues such as reducing enjoyment of eating. They suggest 5 areas of focus for HNC patients that sit under the umbrella of an acknowledgement that this will be a long journey with an uncertain prognosis requiring small steps for gradual progress. Alongside this the authors suggest patients need to learn a different way of eating which may be about managing nutritional intake rather than enjoying food, that they will encounter specific challenges eating outside the home and that receiving information and specialised support are key.

Finally they suggest patients will need to accept that things may not return to how they were previously, that they may need to accept a new, changed version of themselves (Ottosson, Laurell and Olsson, 2013). This study was again not based in the NHS but in the Swedish Healthcare framework. These themes form the basis of unpicking more detail from participants in the NHS setting in England that is explored in this thesis. This study provided the beginnings of a rich, more granular account of the impact of struggling with food and nutritional intake. The social element is a particular loss to HNC patients and could lead to patients not participating in social activities, feeling like withdrawing and isolating themselves. *"HNC signifies a long journey with problems affecting physical, psychological and social aspects of food. Information and support and the use of strategies are important for patients with head and neck cancer to adapt to new possibilities for living after cancer treatment."* (Ottosson, Laurell and Olsson, 2013 p.1041)

In 2003 Larrson *et al.,* explored the lived experiences of those undergoing radiotherapy and the eating problems they may face. The study involved interviews with eight patients from two radiation therapy departments in mid-Sweden. Only a small proportion of cancer patients undergo radical radiotherapy to the head and neck, but their needs are particularly complex. Although extensive research describes the side-effects of radiotherapy to the head and neck, there is a scarcity of studies focusing on patients' subjective experiences of eating problems and how this effects the patients' daily life. In this study a phenomenological approach was used, as the purpose was *"to acquire deeper understanding of HNC patients' lived experiences of eating problems, their consequences in daily life and patients' strategies of coping with these problems"* (Larsson, Hedelin and Athlin, 2003 p.562).

The study was able to identify two main themes relating to eating, which included many facets including struggles with chewing and swallow, the appetite and enjoyment around eating and the wider daily impact on life and how newly acquired impairments affect life. (Larsson, Hedelin and Athlin, 2003). Coping strategies were divided into a theme defined as "*trying to see the end to survive"*. The study is useful in identifying the need to view eating problems as a very contextual and complex problem, which should be understood on an individual basis with exploration of the patient's specific situation. The research suggests that developing nursing interventions based on patients' own needs, highlighting the importance of the specialist nurse in reviewing patients regularly throughout radiation therapy.

This is echoed in a qualitative study of patients (n=16) with HNC conducted by Molassiotis and Rogers (2012) which aimed to look at the nutritional and physical impacts of HNC following radiation treatment. This is one of the small group of qualitative studies conducted in England (Northwest). They found that changes to eating due to dysphagia, xerostomia and taste have a huge impact and can result in weight loss and debilitating tiredness and fatigue. They conclude that intensive support is much needed in this area.

2.2.2.2 Communication, voice and speech

HNC patients often lose their voice as a consequence of treatment whether that be temporarily, or they require technological aids to able to speak, or speech and Language therapy support. They may experience physical voicelessness but what also may come with this is a sense of psychological silencing (Gibson *et al.*, 2022). In a study by Bolt *et al.* (2020), they took a phenomenological approach, using semi-structured interviews with five HNC survivors to explore the experience of cognitive changes. Looking at how these changes affect communication in their daily lives. The study reported that patients struggled with memory, attention verbal fluency and processing speeds and this could sometimes last and persist for the long term and impacts in many spheres including work, home and other social environments. The self-perception of a person's cognitive function is outlined as being a predicting factor in the outcomes, highlighting the importance of mindset (Bolt *et al.,* 2020). There is a need to advocate for HNC patients to receive appropriate information, support and had four key findings in this respect. The first is highlighted above around the loss of cognitive functions, the unpreparedness that they felt in losing these functions. It further highlighted that participants often don't feel supported in terms of these cognitive changes which has an impact on how they can follow complex rehabilitation regimens. Finally, this study recommends rehabilitation staff should be able to have access to specialties and support to patients, specific to their cognitive function. *(Bolt et al.,* 2020). Providing this support could help to support progress in regaining communication, voice and speech.

A recent study conducted by Gibson *et al.,* 2022 captures the silencing of this cohort of patients, as a consequence of their treatment. This piece captures the notion that the literal silencing (a lack of voice) brings with it the metaphorical silencing that results in a feeling of powerlessness. Gibson et al., (2022) discussed the distressing psychological impact that can leave patients feeling a sense of disempowerment and the silencing of their perspectives, feeling voiceless not just physically but through a lack of power to communicate or control their function around speech, voice and eating. There is a loss of agency alongside the physical loss (Gibson *et al.*, 2022). This study is important in beginning to unpick the complexities around how HNC makes patients feel, however broader questions need to be answered and further work is needed to understand how to prevent this happening. On a practical level, with healthcare professionals' communication can be incredibly inhibited and therefore individualised, tailored care should be designed to optimise creative ways to communicate and focus on listening to the needs of the patient. to allow for the expression of their preferences and needs.

2.2.2.3 Personal identity changes

In 2008 Semple *et al.,* wrote about the changes and challenges to patients' lifestyle patterns following treatment for HNC using. This was a qualitative study using semi-structured interviews with a purposive sample of 10 participants who had completed treatment 6–12 months earlier for HNC. Five areas of changes and challenges to participants' lifestyles following treatment were identified in this study. These were: physical changes, concerns about cancer, work and day-to-day tasks, interpersonal relationships and social functioning. This study discussed the interwoven nature of the themes and the complexity of the context in which the individual sits, compounded by the complex treatment pathway for this specific cohort of cancer patients. Two further themes identified outside of challenges focused around particular characteristics or attributes that may have predisposed or helped to facilitate or prove to be a detriment/barrier to coping with the consequences of treatment, Finally Semple *et al.,* (2008) highlighted that patients may also have specific informational needs and ways of facilitating it. (Semple *et al.*, 2008). This study highlights that specific posttreatment concerns and challenges *"cannot be viewed as unitary or discrete aspects of life"* (Semple *et al.*, 2008 p.87), emphasising the need for exploration to be considered within a biopsychosocial context, re-enforcing the need for the work outlined in this thesis. This study had a small number of participants and fostered one method of data collection. A larger methodological approach would be useful in exploring this more rigorously.

In 2003 Crossley *et al.,* documented the narrative of one patient's experience of HNC (John Diamond's posthumously published serialised diary entries in The Times), based on the way in which cancer potentially threatens a patient's *"sense of ontological security by throwing into doubt assumptions about time and the future"* (Crossley, 2003a p.439). Crossley highlights that people learning to live with a cancer diagnosis, use a process defined as *'therapeutic emplotment"* first developed by Del Vecchio Good et al. (1994). This concept refers to "*the way in which oncologists are taught to structure temporal horizons for their patients in a particular way in order to instill and maintain hope in the context of arduous and toxic treatments"* (Crossley, 2003b p.439).

The paper goes on to highlight four stages of adaptation that take place in the patient employing a therapeutic employment process encouraging the patient to concentrate on the present and to place hope and faith in the efficacy of individual treatments as they happen. Conversely, Crossley (2023) acknowledges that this approach can cause enormous anxiety for patients, and how these feelings are juxtaposed with the 'unspoken narratives' of uncertainty, fear and skepticism in relation to ideas about the power of medicine. For the first time this paper explores how key a narrative account of HNC may be in elucidating how a patient navigates their way through a process of treatment and rehabilitation in HNC. It should be noted that Crossley writes from the position of a prominent journalist with particular social, professional and educational privilege. Whether this reflects a more generalizable account is therefore questionable. What this study does offer is an interesting insight into a theoretical framing of therapeutic emplotment. It captures the complexities of the interactions between patient and professional within the context of social, psychological and economic spheres.

A Swedish research group led by Roing *et al.*, (2009) produced an insightful discussion, creating a classic phenomenological account using hermeneutics, to explore how those who have experiences HNC *"make new meanings of being in the world"*. The study consisted of interviews with five patients with HNC with a median time of 4 years after the beginning of treatment. A hermeneutic research approach was taken, and discussion was set against the background of the philosophy of Martin Heidegger. The research examines the difficulties in maintaining simple human functions such as eating, tasting, swallowing, and speaking that are compromised by the onset of HNC treatment and rehabilitation. It interestingly takes this exploration a step further extending their examination to understanding the more *"existential significance of the mouth"* asking *"How it feels to live with these difficulties?"* and *"What does it mean to be a human being living with the consequences of oral cancer?*" (Röing *et al.*, 2009 p.1076). This an interesting finding and it would be useful to apply this questioning to this study. The results of Roing *et al.,* (2009) showed how the consequences of oral cancer affected the participants in three main ways: *"existing as oneself, "existing in the eyes of others",* and *"existing with others"* (Röing *et al.*, 2009 p.1076). The authors conclude that these findings demonstrate how essential the mouth is to a human being's identity and existence. It could be suggested that experiential accounts cannot be used to alter policy and amend services because they are individual experiences. However, there is growing consensus that it should inform development where possible.

There were a number of further studies that identified personal identity themes *(O'Brien et al.,* 2012; Nund et al., 2014; Bickford *et al.,* 2019). O'Brien (2012) explored themes around "*identity*", 're-establishing social networks' and "*intimate relationships".* This study explored the "*person as an individual and their perceived changes to self-esteem and image*". One facet of this is rooted in the changes to voice and speech. What these studies demonstrate is that these functional impairments, and disfigurements form the essence of one's identity. The embodiment of personhood is rapidly, profoundly changed with treatment and diagnosis and this can create a trauma and a need for rehabilitation to support the patient through this process.

2.2.2.4 Human papillomavirus (HPV) related HNC

There are currently few relevant studies focusing on this population, existing literature on HPV-infected women focuses on cervical cancer. Patients with HPV-positive oropharyngeal cancer (HPVOPC) need education to best address concerns such as self-blame, Guilt, intimacy, and interpersonal relationships (Chu *et al.*, 2013). Physicians need evidence-based management strategies to effectively manage psychosocial outcomes when diagnosing patients with HPV-associated OPC.

Further to this, in 2013, Baxi *et al.,* conducted semi structured interviews with ten survivors of HPV-related oropharyngeal cancer. A clear theme that came out of this work was that Clinicians play a pivotal role in the dissemination of information as they hold a trusted source of information, therefore framing the conversations appropriately can have a significant impact. Communicating the diagnosis in terms of prognosis helps to provide perspective to the patients and it was reported that the uncertainty about transmission, latency, and communicability could be confusing and harder to process when having a dialogue about HPV. (Baxi *et al.*, 2013) . Partner risk was a prominent theme, therefore highlighting the need for a deeper understanding and educational support of prevalence and transmission information. This particular study formed part of an evidence base that resulted a tailored approach to

education and treatment was taken for HPVOPC and consequently a patient-education handout was developed in response.
Therefore, in terms of practice and policy it is clear that additional educational resources explaining the facts about HPV in HNSCC in a consistent way including content of highest priority to patients may improve understanding of HPV. However, it should be noted that Baxi *et al.,* (2013) used a small, single method sample, as is the case for many of the studies in this area. They did not address, methodologically, the chosen approach or whether the information gleaned from the sample was generalisable. This thesis therefore ensures that a multi-method approach addresses weaknesses in single method studies. It also considers why the sample is sufficient to draw conclusions. See Chapter 4 for further detail on this.

Dodds, Waller and Marlow (2016) carried out a systematic review to examine the specific psychosocial impact on patients with HPV associated HNC and studies measuring knowledge about the link between HPV and HNC among different populations. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed. 51 papers met the inclusion criteria; 10 measuring psychosocial aspects and 41 measuring knowledge of the link between HPV and HNC. Quality of life in those with HPV-positive HNC was found to be higher, lower or equivalent to those with HPV-negative HNC. The review shows that longitudinal studies found QoL in patients was at its lowest 2 to 3 months after diagnosis and some studies found quality of life almost returned to baseline levels after 12 months. (Dodd, Waller and Marlow, 2016). The study explores knowledge of the increased risk of HPV and HNC and a comparison with the general population carried out. The study demonstrated that lowest knowledge exists in the general population and most proficient in the medical/dental professionals. This study therefore highlighted that there is a lack of research and published studies exploring the psychosocial impact of a diagnosis of HPV-positive HNC.

To gain an insight into the perspectives of health professionals Dodd, Waller and Marlow (2016) carried out further study in this area, conducting a qualitative study with fifteen health professionals caring for patients with oropharyngeal SCC. The study found that professionals expressed mixed views about explaining the causal role of HPV to their patients. Normalizing HPV and emphasizing the positive prognosis associated with it were identified as important in terms of communicating messages. Experiences identified as challenging, included managing couples in a consultation and patients' concerns about transmitting HPV to their partners. A need for further information and training so that patients can be provided with more information. This study points to the need for clinicians' experiences and challenges of talking to patients about HPV to be further scoped to ensure better support for their patients and that there are some key messages that need to be conveyed.

It is therefore clear that further work is needed with the HNC patients, partners of HPV-positive patients and health professionals caring for them to ensure they understand the implications and experiences of head and neck cancer. The evidenced limited knowledge of the association between HPV and HNC among the general population also highlights the need for clear information, awareness and education in this area. Furthermore, clinical guidance for health professionals and further information for patients about HPV-positive oropharyngeal SCC are needed. This study also highlights the pivotal work that explores professionals' views. This has wider relevance to HNC in general, however the professional perspective is beyond the scope of this thesis. Other important actors in an individual's HNC experience are discussed next.

2.2.2.5 The role of caregivers and networks

In considering the patient journey, it is important to reflect on the role of the caregivers in the journey for HNC patients. HNC patients are often profoundly changed in terms of their perception of themselves and this can affect how they react, re-engage and interact with former intimate relationships such as family and partners (O'Brien *et al.*, 2012). Due to the nature of this type of cancer, many sufferers rely heavily on informal carers, partners and family members. Their experience of the journey through diagnosis is therefore shaped by this element in a way that will form a key part of their narrative. There is small but growing body of work exploring the role, perceptions, impact and experience of this group. The significant majority of caregivers fall into the spousal category and specific studies have explored their role in the rehabilitation of HNC patients.

Longacre *et al.,* (2011) carried out a study seeking to summarise current findings regarding the psychological distress and psychosocial wellbeing of HNSCC caregivers, including factors that may be associated with poorer psychological health. This review identified eleven papers. The study concludes that caregivers often experience poorer psychological health, "*including higher levels of anxiety, compared to other patients and to the general population*" (Longacre *et al.*, 2012 p.18). The 6-month interval following diagnosis was identified as a significant time of stress for caregivers, this finding could help to shape when supportive interventions are targeted. The paper further highlighted that there have been relatively few reports on the psychological health of caregivers of HNSCC patients.

Kejkornkaew *et al.,* (2016) carried out a grounded theory study to investigate the meaning and characteristics of the quality of relationships between Thai family caregivers and persons with HNC. The study carried out in-depth interviews with 15 family caregivers: 13 spouses and two sons using the constant comparative method to analysis. The results concluded with the construction of a theory around the quality of relationships in caring roles around the individual with a diagnosis of HNC (Kejkornkaew *et al.*, 2016). Emergent themes centered around quality relationships, which were further sub-coded into 4 elements: feeling of love, sympathy, caring and connectedness.

Love was defined as *"the caregiver's desire to return the care-receiver's love"*. Sympathy was defined as *"the caregiver's feeling toward their care-receiver's having cancer and suffering from the disease and feeling sad for their care-receiver"* (Kejkornkaew *et al.*, 2016 p.161). Caring was defined as *"the caregiver's feeling of concern and worry about their care-receiver"* (Kejkornkaew *et al.*, 2016 p.161). Finally, connectedness was defined as *"the caregiver's feeling of becoming closer to the care-receiver than before they started caregiving*". Furthermore, the paper highlights that quality relationships between caregivers and HNC suffers as a dynamic process, which occurred in stages; the reason to be a caregiver, quality relationship, and provision of care. As discussed earlier, this study draws particular attention to the Thai cultural and religious contexts providing a uniquely reflective study of cultural influences. This culturally competent care is somewhat lacking in reflection in other studies. The study concluded that patients benefited from healthcare practitioners (specifically nurses) taking an integrative approach which coalesces scientific, religious, and cultural knowledge into daily clinical practice. Understanding cultural schemas may be an important part of designing personalised services for HNC patients.

In 2016, Hoda Badr *et al.,* (2016) conducted a qualitative study, using semi-structured interviews with 6 HNC patients and their spouses, to understand patient and spouse unmet needs and relationship challenges during curative radiotherapy for HNC. The study cites using a grounded theory analysis. The interviews highlighted the need for more support for the emotional wellbeing of spouses. Patients and their spouses would benefit from clear articulation of what physical symptoms to expect and the level of severity. Clear timelines of how rehabilitation is likely to look would enable partners to provide the best support possible (Badr *et al.*, 2016). Interviews elucidated that *"balancing competing roles/responsibilities, making time for self-care, and finding effective strategies for encouraging patient's self-care"* were key themes. The study concluded that *"couple-based interventions that emphasize the importance of managing physical and psychological symptoms through the regular practice of self-care routines may be beneficial for both patients and spouses."* (Badr *et al.*, 2016 p.336) Strategic approaches should therefore centre on teaching spouses' ways to effectively motivate and encourage this. The aim would be to improve the patient and carers' well-being, reduce conflict and engender a team approach to treatment of HNC.

Most recently, studies by Balfe *et al.,* (2016) explored the caregivers' perspective and understanding the key issues. In one study, thirty-one HNC caregivers were interviewed about their experiences of accessing social support from networks; difficulties that they experienced accessing this support; and strategies that they used to overcome or challenge these obstacles. (Balfe, Butow, *et al.*, 2016). The study concluded that HNC caregivers strongly value social support and networks. However, some found that after diagnosis social networks did not respond in supportive or positive way, leaving them isolated and struggling to find support. An interesting element of this work draws attention to the supplement of human support with other coping mechanism, such as pets, spiritual figures or medication.

With HNC, this could be particularly pertinent as the changes to their physical self are so profound and a shock to themselves as well as their close relationships. Other infrastructures such as religious groups, or pets are likely to provide very helpful support as they are less likely to be dealing with the trauma and loss alongside the individual. A further study by the same authors sought to identify and describe the triggers of emotional distress among long-term caregivers (more than 1-year postdiagnosis) of people with HNC. This study took a qualitative cross-sectional approach carrying out in-depth semi-structured interviews via telephones in 31 long-term caregivers. It should be noted that no justification for sample size or the use of telephone to conduct these interviews, was given. Telephone interviews can be limited and not give a full picture of the experience. Neither does this method tend toward elucidating the most comprehensive, sincere account that comes with face-to-face interviews. Telephone interviews tend to create an environment where it is difficult to ask sensitive question. One cannot pick up on physical cues. Furthermore, you cannot access those that do not use or have phones, which is more likely in specific cohorts of patients. (Seale 2004).

The study identified six key triggers of emotional distress: understandings and fears of illness, lifestyle restrictions and competing demands, facial disfigurement, financial problems, comorbid health problems and witnessing suffering and a cross cutting theme of loss. The study highlighted that, caregivers became *"considerably distressed by their caring role, although distress appears to decline with time for many caregivers, some continue to be distressed for years following the patient's diagnosis."* (Balfe, Maguire, *et al.*, 2016 p.2316). Support that could be provided by health professionals were identified on two levels; including providing resources and signposting for support services e.g., Financial support and reducing distress if they can by unpicking personal value or significance from their experience of loss and suffering. To further illuminate the most tailored support a deeper investigation with caregivers' experiences of loss would be beneficial and whilst this thesis does not focus on the narrative around caregivers, who they influence the individual narrative will need to be understood to contextualise their experience.

There are a number of studies that have focused on gleaning the perspective of carers for HNC patients (Schaller, Liedberg and Larsson, 2014; Badr *et al.,* 2018). Families struggled with witnessing the pain felt by HNC patients finding it difficult to comprehend the suffering they may be going through and being overwhelmed with emotions. They reported struggling with the much changed daily routine due to the illness has a profound impact on family (Schaller, Liedberg and Larsson, 2014) Psychological impacts, a lack of information, awareness and knowledge were experienced and therefore relatives could benefit from more information around how to help an HNC patient mange pain. The perspective of carers, families, partners and friends is not the direct focus of this thesis. However, exploring the perspectives of people involved in the lives of people living with HNC, offers a holistic view in terms of their varying roles and levels of support. Carers and networks need to be provided with information, education and psychological support about practical and emotional concerns that they may have, in supporting an individual with HNC.

2.2.2.6 Radiotherapy

One qualitative study looks at radiotherapy. A qualitative study of patients (n=16) with HNC was conducted by Molassisiotis and Rogers (2012) in the North West of England, uncovered a number of issues relating to the trauma of radiotherapy and the use of a mask which can often come as a profound shock (Molassiotis and Rogers, 2012). They also looked at the impact of radiation on nutritional intake, as highlighted in a previous section.

Wells (1998), also explored the experience of radiotherapy to the HNC journey through a qualitative study of patients after completion of treatment. The study emphasised the 'hidden' nature of the experience of HNC and the lack of awareness and knowledge of the patient narrative, highlighting fact that HNC patients' needs are particularly complex. The study details that the "*radiation reactions often exacerbate existing functional difficulties and may severely limit `normal' life."* (Wells, 1998 p.840). Furthermore, the study documents that there is a dearth of existing studies examining what happens following radiotherapy, exploring the consequences and side effects as well the trauma of treatment. Well's highlights that post radiotherapy is when hospital visits and that acute infrastructure is ceased, there may be a peak in emotional distress or processing. (Wells, 1998) highlighting the specific gap that this thesis seeks to fill in the research.

This study is framed as a *"naturalistic inquiry"* using a combination of methods to explore the experiences of 12 patients after completion of radiotherapy to the head and neck. The study identified that radiotherapy had a profound impact on daily life characterised by uncertain and unpredictable symptoms, and the loss of 'self-integrity' through the treatment process

(Wells, 1998). This study highlights the importance of continuity and consistency of care and draws attention to the need for a narrative holistic view of the patient journey including post-treatment for this unique cohort of cancer patients. The interventions must be accessible as this cohort are also prone to not ask for help.

Molassiotis and Rogers describes analysis being informed by using manifest content analysis. However, the study does not frame its methodological approach and simply articulates a need for qualitative exploration in this area. This study lacks a justification for chosen methodology based on the research enquiry. It does however provide a much-needed UK-based qualitative reflection. Wells (1998), in contrast, describes a more complex methodology, first being grounded in a naturalistic paradigm. This captured the notion of not searching for single truth but rather a nuanced, multi reality bigger picture. This was mirrored in the layered method. Diaries were taken, these were unstructured and provided to patients to freely capture their accounts. These were used as data source in themselves and as the context for interviews. Interviews were conducted and allowed to flow with prompt cards used at the end to prompt symptom-focused discussion. This provided thick and rich descriptive data that both strengthened the findings and justified a smaller sample size.

Donavan and Glackin (2012) conducted an examination of the literature with the aim to understand the experiences of those receiving radiotherapy for HNC through a systematic literature review. The review identified a limited number of high-quality research papers focusing on this topic, with only ten papers fitting the inclusion/exclusion criteria. The authors highlight that the majority of the studies were not generalisable owing to small sample sizes (under 10 participants) and many of them being conducted in only one centre. However, those studies identified provide a useful examination of the unique physical, social, and psychological difficulties this group of patients face. The paper identifies a need for further research into these patients, particularly focusing on the provision of support and information prior to, during, and following radiotherapy highlighting the necessity to prepare patients for the potentially slow recovery process following chemotherapy and radiotherapy. Finally the article indicates that interventional studies are required to develop clinical guidelines and protocols that can assist health professionals in meeting the holistic needs of this patient group (Donovan and Glackin, 2012).

2.2.2.7 Long term positive impacts

Finally, it is important to acknowledge the literature, which raises what is perhaps an unintended consequence of treatment for HNC and a little explored theme in the emerging research. A study by Ruf *et al.,* (2009) suggests an individual who goes through a life-threatening journey which can increase distress but can conversely (either sequentially, in phases or following reflection) result in feelings of positive change (Ruf *et al.*, 2009). Interestingly this work highlighted that positive personal changes are frequently reported by patients and by significant others. This highlights that with the right support and framework the experience can have beneficial consequences for patients and caregivers.

This positive impact is sometimes termed Post-Traumatic Growth (PTG) and a small group of studies explore this specifically in HNC (Holtmaat *et al.*, 2017; Sharp *et al.*, 2018; Nik Jaafar *et al.*, 2022). A study by Sharp *et al.,* 2018 highlights that a notable proportion of HNC survivors report PTG but growth is, lower than reported for other cancers. Higher PTG was noted as related to better HRQoL. Research in this area highlights that further research would provide a better understanding of how HNC may lead to PTG and therefore develop strategies to support and encourage PTG via improvements to service design and healthcare pathways (Sharp *et al.*, 2018). Holtmaat *et al.,* 2017 identified that among distressed HNC survivors, higher PTG was associated with lower tumor stage, absence of an anxiety disorder, absence of an alcohol use disorder, and better social functioning (Holtmaat *et al.*, 2017)and therefore this could serve to inform the beginnings of identifying which patients may require further support. This thesis also uncovers the more detailed narratives of those who report PTG and others who do not.

2.2.2.8 International comparisons and the impact of ethnicity

A qualitative study conducted by McQuestion and Fitch (2016) carried out face-to-face interviews with 17 patients. A broad topic guide was used that mapped to the chronology of the experience and aimed to prompt participants. The study took an interpretative descriptive methodological approach. This is rooted in inductive analysis that aligns with the empirical study of complex human interactions in a way that can inform practice. This study revealed five main themes:

1) making sense of the diagnosis,

2) distress from disrupted expectations,

3) heightened awareness of self, others and the health care system,

4) strategies to 'get through' treatment,

5) living with uncertainty." (McQuestion and Fitch, 2016).

Findings from the study have contributed to the development of HNC-specific patient support and education programs for patients and families in Canada and this provides another useful international comparison for the utility of the proposed study. It is clear from this literature review that there is a small body of work looking at models of care and impacts of HNC across the world but that the examination in the English NHS is much smaller and there is a dearth of detailed exploration. The health systems in Canada, America and Europe (Larsson, Hedelin and Athlin, 2003; Ottosson, Laurell and Olsson, 2013) do have key differences so it is very important that similar work is conducted to help inform services for these patients in the UK.

Whilst considering international comparisons it is also key to consider the role that ethnicity plays in the experiences that shape the rehabilitation and treatment journey for HNC patients. Whilst this area of research is small there are some emerging studies the psychosocial elements of the pathway and how key themes in these patient narratives, such as stigma may be particularly relevant in specific groups of patients. In 2016 Lebel *et al.,* highlighted the lack of exploration for how stigma can cause varying and differing experiences of emotional distress cross-culturally. Lebel *et al.,* hypothesized that*:*

(1) Asian-born Chinese immigrants (AI) would report more perceived cancer-related stigma than Western-born Caucasians (WBC);

(2) The impact of stigma on emotional distress and well-being would be greater in AI as compared to WBC. Contrary to our hypotheses, WBCs and AIs did not differ in reported stigma nor did we detect differences in its psychosocial impact.

Stigma creates a negative psychosocial impact on HNC patients and therefore the impact of cultural influences may be useful in helping us to understanding the optimal pathway to rehabilitation. This body of literature around HNC explores a number of important facets of the HNC experience, some explore the QoL looking at very defined parameters, a smaller body of work explores HNC using qualitative methods such as interviews and focuses on particular elements of the HNC pathway e.g. Food, swallowing, speaking, the role of partners, the impact of radiotherapy or the changes to their personal identity. What does not exist is a more holistic contextualized account of the experience that can serve to understand what needs are unmet and how service provision can best support the needs of this cohort of patients and understand their experiences.

2.3 SOCIOLOGICAL STUDIES OF CANCER

The literature reviewed to this point focuses specifically on studies that have been conducted to look at HNC. It is clear, however, not just that this is a limited pool of research from a sociological perspective, but also that there are potential overlaps with other long-term conditions and other cancers. The current research in this area focuses primarily on addressing more prevalent cancers and it is here that we find a useful discourse that may inform the direction of enquiry in this project. A large number of studies were identified in this space, some relevant illustrative studies are used to demonstrate important parallels that could help inform this study.

There is currently a wealth of detailed qualitative work that explores the experiences of those who have been diagnosed with more prevalent cancers such as breast, lung, prostate and colorectal cancers, with high profile charity backing from organisations such as Cancer Research UK, Macmillan UK and Prostate Cancer UK. Within Britain, there have been large scale programs such as the National Cancer Patient Experience Survey (CPES). The most recent survey (2011/12) covered both inpatient and day-case patients, 36% were inpatients and 64% were day cases. The survey highlighted that cancer inpatients reported significantly better experience of care than do hospital inpatients generally. Significant improvements were noted since 2010, to the quality of cancer services (measured by the views of patients themselves). The questionnaire identified the improvement of satisfaction scores with patients who are assigned a Clinical Nurse Specialist (CNS). However, the report also noted great variation in satisfaction between cancer types and by ethnicity.

Sociological literature in this area focuses on understanding how patients cope with their diagnosis (Schofield *et al.*, 2003) and the long-term impact on their life (Gaton-Johansson *et al.*, 2015). There are studies that examine the cancer treatment and rehabilitation journey from a narrative perspective (Halldorsdottir and Hamrin, 1996; Benzein, Norberg and Saveman, 2001; Mohlin and Bernhardsson, 2021) acknowledging that these narratives exist within further meta-narratives i.e., wider discourses which map to the individuals experience and are constructed within social and political arenas (Atkinson and Rubinelli, 2012). Conceptualising this to capture the holistic experience is an important part of this study design and the theoretical framing is discussed In Chapter Three (micro, macro and meso spheres). There are many sociological analyses of a diversity of patient and practitioner experiences and accounts of Cancer during the last decade focusing on care practices and themes around identity, adversity, coping and living beyond cancer treatment. Two key reviews were identified (Kerr *et al.*, 2018; Le Boutillier *et al.*, 2019) and are discussed next to capture the broad themes in the literature.

In a review of living with and beyond Cancer, Le Boutilier *et al.,* (2019) identified three themes, defined as describing the experience of living with and beyond cancer. These are adversity, restoration, and compatibility. This study then creates a framework that aims to provide an empirically informed grounding for future research and practice in supportive cancer care for this population (Le Boutillier *et al*., 2019).

Adversity - This refers to the trauma and distress experienced with the life-changing impact of a cancer diagnosis, symptoms and subsequent treatment and rehabilitation. In particular, studies identified how the journey (healthcare pathway) to cancer diagnosis contributes to the personal experience post cancer (Le Boutillier *et al.*, 2019). Even before diagnosis, some participants in one study, looking at those diagnosed with cancer of the vulva, faced challenges when getting their symptoms explained or noticed by professionals, which could result in symptoms being trivialised and then delay in diagnosis, or lead to misdiagnosis

(Jefferies and Clifford, 2012). This is likely to be a theme paralleled in the HNC experience. Communication experienced by healthcare professionals was also an attributing factor in terms of shaping adversity, found in a range of studies looking at breast cancer (France *et al.*, 2000; Obeidat, Lally and Dickerson, 2012) and a range of others which could form part of the challenges HNC patients face.

Restoration - The theme “Restoration” captures a body of research that explores the experience of readjusting or adapting one's life to manage the new context of cancer and recovery (Le Boutillier *et al.*, 2019). Studies in breast cancer and blood cancers identified factors that were formative to the readjustment experience. These were confidence in health care, participation in treatment planning and decision making (Beynon *et al.*, 2015), and creating new habits and lifestyle changes (France *et al.*, 2000). Societal attitudes and stigma associated with cancer were found to be involved in the readjustment experience too. For example, *”participants spoke about managing the challenges of “whispers in public” and about a desire to be able to appraise illness and talk about cancer openly”* (Le Boutillier *et al.*, 2019). This is likely to be specifically mirrored in the HNC cohort of patients due to the stark impact on the physical appearance of an HNC patient. Readjustment was also facilitated by a short-term outlook on the period of cancer treatment, i.e. a transient view of the period and also the importance of support from other people which is found in many cancers including breast cancer and prostate cancer (Davies and Sque, 2002; Aunan, Wallgren and Hansen, 2021)

Compatibility - The theme “Compatibility” explored the experience that relates to reconciling and rebalancing, creating new priorities and outlooks. For some participants, *“cancer is just something else in life, a contained, concrete medical event without complex ramifications”* (Foley *et al.*, 2006; Le Boutillier *et al.*, 2019). There are some facets to this concept of compatibility, around the idea that problems assume other proportions and a realignment takes place, steering to a more positive shift in priorities that may mean day-to-day life joys are re-envisaged. Benefits finding and a focus on what you have rather than what has been lost was also highlighted (Trusson, Pilnick and Roy, 2016) along with an increased self-awareness, acceptance of a new personality and improved personal worth (Kucukkaya, 2010).

A further review article captured themes across research in cancer over the decade between 2007-2017, carried out by Kerr *et al.,* 2018. These themes were around the professional practice, policy and regulation and the involvement of patients in research. A person's individual approach to risk around cancer frames how they might approach screening, preventative behaviours or seeking early medical intervention. These are intrinsically linked to the beliefs and practices as well as wider citizenship and governmentality framings. Several articles explore media representations of cancer risk, which can help to set a person's perceptions of risk and contribute to the likelihood of rapid diagnosis. One theme captures the body of work exploring the *"formations and social actions of scientific knowledge communities and technologies, drawing from the tradition of socio-historical, laboratory and Actor Network Studies in STS"* (Kerr *et al.*, 2018 p.561). These studies look at how professionals work and engage with different arenas, develop and implement new approaches and make decisions around diagnosis and treatment. (Zetka Jr., 2011; Gort, Broekhuis and Regts, 2013)

There is an identified move to an approach to organisational operationalisation that is evidence-based and considers professional hierarchies and specialities and how multidisciplinary working can happen effectively (Abel and Thompson, 2011). Research showed that there is *"complexity of professional approaches, organisational tools and processes deployed to improve cancer treatments and diagnosis in this period, but they do not suggest that any particular strategy such as specialisation or standardisation were easily achieved or especially influential".* (Kerr *et al.*, 2018). The studies therefore highlight complex, dynamic networks of tools, and pools of expertise and knowledge, which are in constant flux. Much of this work focuses on the ways in which cancer research and clinical teams, institutions and organisations in the developed world, particularly the USA and Europe, are coordinated, and therefore draws useful parallels to the structure of care for HNC. Policy and regulation play into this arena and was identified in articles on evidence-based medicine in cancer service development, using a frame of governmentality (willing participation in development of the system that governs them) (Ferlie *et al.,* 2012).

The involvement of the patient in developing policy is another element of this. The cancer literature also explores patient and public involvement in developing services and participating in research. The literature identified examination of the biases that can arise in research seeking to explore people’s experience, with respect to who is involved and how (Martin and Finn, 2011). Furthermore, Sinding *et al.,* (2012) highlights that inequalities in patient involvement can be obscured because of not being aware of the resource or privilege that is required to be involved in research, and Martin and Finn (2011) considered the challenges in bringing patients into another professional sphere. These are issues that will very much apply to HNC and therefore this study uses ethnography to enable the researcher to observe the treatment environment and the patient pathway.

Blurred boundaries between treatment and research, allows patients to participate in the research agenda (Morris, Armstrong and Balmer, 2009; Armstrong and Morris, 2010). Some research also explores the mirroring of social inequalities in research contexts and infrastructures, concluding that research attracts those participants who have better access to medical facilities due to having more social resources at their disposal (Joseph and Dohan, 2012). Whilst these themes are useful and help to glean what common themes may be apparent, HNC treatment brings with it complexities around visual changes to the appearance of the head and neck and functional impairment around speech, eating, swallowing and saliva production depending on type of cancer, position and type of treatment. These can be far-reaching and long term. This study seeks to explore this in more detail and therefore there are some parallels to long-term chronic conditions.

2.4 KEY THEMES IN THE SOCIOLOGY OF LONG-TERM CONDITIONS

This body of research is beyond the scope of the literature review, but it is useful to touch on the parallels and useful translations that may inform the findings and discussion of this thesis. We know that sociological enquiry is vital in this area as there are a vast array of ways that an individual is socially impacted upon when living with a chronic condition. However, often studies often do not explore the social context, there is an identified gap in studies that embed their reflections in the context of the wider social world. Whilst this thesis can draw useful thematic comparisons, it is beyond the scope of this literature review to assess and review the research systematically.

A body of research in medical sociology that may render useful parallels is that of the experience of patients with other forms of long-term condition, e.g., Parkinson's disease, Multiple Sclerosis, Arthritis and stroke, which often result in degenerative physical and mental impairments (Nettleton, 1995). As with many forms of cancer, these conditions last over an extended period of time, affecting many areas of daily life and require long term treatment, suggesting that parallels may be drawn between some cancers and the experiences of people with other long-term conditions, who need to live with their changing self over time.

Key themes identified in sociological literature include, uncertain and unpredictable futures (Scambler, Newton, and Asimakopoulou, 2014) where a useful parallel can be drawn with the work conducted in the management of HIV and how the uncertainty of the length of prognosis and how treatments will impact their daily life mirrors the HNC experience (Laryea and Gien, 1993). Further to this, the impact on social relations is key as the literature suggests that the impact on family and close friends can be profound in relation to after and ongoing care and rehabilitation. Moreover, Anderson (1988) highlight that this can compromise set traditional roles, e.g., the domestic role of the women who may experience chronic illness. Here, Anderson and Bury also begin to develop ideas around the stigma and identity (Anderson, 1988) and the compromising of one's image is further discussed by Scambler (2004) where the dichotomy of the fear of stigma and its actualisation is highlighted (Scambler, 2004).

Assaults on self-image and self-esteem (Scambler 2014) is another area to consider when discussing long-term illness and how the biological impairments of a disorder, impact in a multifaceted way. Affecting social and psychological spheres that can spread into every aspect of daily life, and even further than the individual in the context of heritable conditions. Scambler and Newton (2010) reflect on this in the context of Batten's disease, a hereditary neurodegenerative metabolic disease, using the theory of Bourdieu. However, it is the biomedical nature of the tools used to empower suffers that poses another dilemma. One may need to consider if these tools are somewhat neutralised in that they are governed and controlled by health professionals who therefore maintain a power balance that disempowers the patient and empowers the medical professionals (Scambler, Newton and Asimakopoulou, 2014; Watson and Vehmas, 2020). This leads us onto the final theme, relating to biomedical concerns.

This theme is an issue for many who live with chronic illness, and this is likely to be very similar in the case of HNC cancer patients. The theme of biomedical concerns encapsulates the notion that a sufferer must absorb extensive biomedical information relating to drug regimens and treatments and therefore dually deal with both the symptoms and complexities with undergoing treatment and the complicated intersection with the biomedical world, alongside dealing with the ailments of the disease itself and the emotional and psychological consequences. As referenced above, this theme therefore highlights the importance of the doctor/patient dynamic (May *et al.*, 2004) In helping the patient navigate this unfamiliar biomedical arena. This will be considered in more detail during the course of this study, looking at the role clinicians play in information giving and decision making.

2.5 SUMMARY

We can see from the identified literature that the current sociological and detailed qualitative research in this area is limited, small scale and mostly not UK focused. There is therefore a clear gap in the literature for a much more in-depth interview-based study exploring the experience of HNC patients in order to illuminate and/or confer some of the early work that has been conducted in this area. All the studies highlighted reiterate that exploratory work should be used to inform and develop intervention-based studies, to help guide clinical practice and protocols and utilise the knowledge and insight that this group of people play in shaping the patient journey. Existing studies of people living with HNC fail to explore their experiences in any depth. Frequently omit to use any methodological justification for the methods employed, or justify the sample size. Instead, they focus on quality of life or functional issues.

Therefore, a clear gap can be articulated. There is no account of the full journey of the patient experience and research only focuses on specific themes including swallowing, nutrition, speaking, radiotherapy or the role of caregivers, as outlined. There is a need to understand if their experience is optimal and what elements might contribute to a better experience or be the reason for challenge and trauma. This study looks at the whole picture of what it is like to receive a diagnosis, go through the treatment process and be rehabilitated, providing a narrative approach. No previous work, cited in this literature review has embedded a person's individual experience in the service they are using, providing the context of the service design and the wider national picture.

What is missing from the literature is a study, which seeks to embed the stories of individuals being treated for HNC in the context in which they are receiving care, both physically and in relation to the policy context. Therefore, what is needed is an ethnographic study, which seeks to explore the experiences of this patient group from a multi-level, contextualised perspective. This sets the scene for the study to follow. This study can help to inform tangible change to structure and models of care that is authentically informed by the patient experience. Therefore, a number of broad research focuses can help to articulate this gap in research. These are discussed in the next chapter and split into three core areas for exploration, these layers of questions come together to provide a holistic view.

3. AIMS AND OBJECTIVES

This section outlines the core research aims followed by a breakdown of the research objectives which have been distilled into key research questions. These aims and objectives have been formed through the process of the literature review where the gap and missing holistic narrative has been identified. These research questions have informed Chapter 4, Method and Methodology and therefore this is set out next.

3.1 RESEARCH AIM

As discussed in the previous section, the literature suggests that there is a gap in the research. More needs to be done to understand the long-term needs of patients (Rogers *et al.,* 2010) and provide the wider context. The ethnographic picture needs to be elucidated by placing the individual story within the context of the care that is being provided, and within the wider context of the policy documentation on how cancer care should be provided which was outlined in the Introduction. The aim of this project is to understand and explore the experiences of people who have received a diagnosis and completed treatment for HNC, throughout the clinical pathway and the long-term consequences of this complex and invasive treatment pathway.

An understanding of the patient’s perspective is essential for implementation of patient centered care and this work would therefore seek to inform and shape the design of future care pathways, acknowledging the nuanced, social implications of suffering from HNC, undergoing treatment and rehabilitation. This research will seek to understand how patients adapt to life post-treatment and after rehabilitation exploring how they adjust to their new looks and oral function. We will focus on cultural schemas, and attitudes about the mind and body.

On a practice and policy level, the research aims to identify barriers and facilitators to creating effective, patient sensitive, healthcare pathways and provides a novel conceptualisation of the key actors and processes involved in this journey, through the use of qualitative methods. Furthermore, in conducting the project it is hoped that participants will benefit from feeding back their opinions of the care pathway as this data will be used to inform the clinical team, make recommendations for improving outcomes for patients and potentially lead to training and development within the team.

3.2 RESEARCH OBJECTIVES

As highlighted in summary of the literature review (section 2.4), there is a clear gap in the research around the patient experience of HNC as a contexualised journey. The contexualised experience of the entire clinical pathway is explored using an ethnographic multimethod study and therefore the research has some clearly defined areas of focus, around (1) understanding the political context and ethos behind the specific community-based model of care that is under evaluation in this study (2), understanding the community and acute settings in which individuals experience the clinical pathway and healthcare professional interactions and finally (3) the narrative as articulated by those experiencing it. Therefore, the main research objectives have been identified as below:

1. **What is the national picture for services designed and provided for people with HNC and what are the core principles behind this?** *(Chapter 5: results, Chapter 5: section 8.2.1 Discussion and key findings)*

    a. What is the national ambition for wider cancer services and HNC services specifically and what are the principles behind this?
    b. What are the regional infrastructures that have been created to support these national ambitions?
    c. How have the regional infrastructures been used in reality at a local placed based level?

2. **What are people's experiences of the care pathway for HNC, in relation to the settings and clinical interactions?** *(Chapter 6: results, Chapter 8: section 8.2.2 Discussion and key findings)*

    a. Is the community integrated care model set up as the national and regional policy outlines?
    b. How do participants experience these settings and traverse a pathway designed in this way?

3. **What are peoples understanding and experiences of HNC?** *(Chapter 7: results, Chapter 8: section 8.2.3 Discussion and Key findings)*

    a. What are people's expectation, experiences and understanding of the treatment and rehabilitation options available to them once a diagnosis of HNC has been received?
    b. What are the short and long-term impacts and consequences of receiving a diagnosis, and treatment of HNC?
    c. What elements of the journey were most challenging and what were the drivers to surviving and thriving?
    d. What support did individuals receive and access?

4. METHODS AND METHODOLOGY

The Chapter starts by outlining a justification for the research approach used and the study design. As outlined in the previous Chapter, there is a clear gap in the research, which articulates the patient voice, therefore choosing a narrative and observational approach is the most appropriate and effective way to unpick this perspective. The Chapter will then outline the data collection methods, the exclusion and inclusion criteria, recruitment and consent procedures and data collection. This is followed by a detailed account of how the different types of data were analysed using each method. Finally, a reflection on ethical issues, security of data and reflexivity is presented. The next section justifies the use of ethnography as a study design. It describes how this enables a holistic view of the experiences of people living with HNC.

4.1 METHODOLOGY

4.1.1 ETHNOGRAPHY

As highlighted in Chapter Two, there currently exists a large volume of clinical and quantitative study in the area of HNC. However, the body of qualitative work that currently exists in this area is relatively small and involves small cohorts of patients or is focused on targeted areas of investigation. Therefore, in using qualitative methods this study sought to bolster the existing work and address the imbalance with the current quantitative studies. Providing triangulation and complementation to this extensive clinical analysis. It should be noted that in this context triangulation refers to methodological triangulation, which captures the concept of multi method approaches to data collection to minimise bias, ratify findings and identify gaps. Other forms of triangulation can also be taken including, but not limited to, multiple investigators or researchers (investigator triangulation), multiple theoretical concepts (theoretical triangulation), or using data from different sources, times, locations etc., (data triangulation).

In a health services research context this approach allows for the study of how healthcare is carried out on a daily basis and how actors and their practices constitute the patient care pathway. This approach provides a narrative representation of treatment and rehabilitation experiences that is currently lacking in the associated dental, clinical and health psychology literature, as was shown in the previous Chapter.

The approach used is novel, compared to the existing literature and this Chapter begins by unpicking the reasons for using the methods chosen and an outline of the analytical lens used to guide the research. This section therefore begins by understanding why a qualitative approach aims to address a gap in knowledge and literature around HNC experiences (as identified in the Chapter Two).

Ethnography explores the cultural contexts in which people experience a given issue. Used in healthcare, it can offer a richly nuanced account of the ways people live with a condition. Ethnography explores experiences, day-to-day practices and perspectives. It has many benefits including offering a rich and granular understanding of experiences and local practices which can provide illumination and greater depth than qualitative studies that only rely on structured interviewing. It can uncover experiences, unintended consequences and perspectives that other methods miss out because of its real-world focus and flexible approach or because studies do not have the time for immersion process that happens with ethnographic methods. In this particular study, it also gives a voice to a group of patients that are seldom heard due to the practical nature of being hindered in communication and mobility and also for being marginalised and stigmatised for the associations of lifestyles that can come with HNC. Ethnography allow the researcher to embed in their world rather than the research subject coming to theirs.

As discussed above, the policy document analysis (Chapter Five) provides the wider political, strategic and national socio-economic healthcare view. The localised view is captured through observations, which is an ethnographic process that allows us to understand the conditions in which HNC patient’s transverse and the spheres they frequent, understanding how they intersect with multidisciplinary health professionals and services. This ethnographic fieldwork is crucial to providing an effective analysis routed in grounded theory. Tacit and unsaid elements are captured through this ethnographic process and the ethnographic researcher can uniquely embed and immerse themselves in the world of the HNC patient (Featherstone and Northcott, 2020a). Whilst we can acknowledge that the ethnographic exploration is specific to the spatial-temporal setting it can inform and inspire reflections on how these individuals may experience care in other places in the future, as the ambitions at a national level continue to progress.

Ethnography provides the *"ability to make visible the 'real world' sociality of a setting producing detailed descriptions of the 'workaday' activities of social actors within specific contexts. It is a naturalistic method that seeks to present a portrait of life as seen and understood by those who live and work within the domain concerned"* (Rouncefield, 2011 p.45). Designing and evaluating systems and services is therefore ideal for this method which can explore interactional phenomenon in their natural environment and creates a more informed researcher through experiencing the settings and surroundings of the participant or research subject (Rouncefield, 2011).

Ethnomethodology, coined by Garfinkel (Seale, 2004) is the process of understanding the how actors negotiate and navigate their environment through everyday practices. With ethnomethodologically informed ethnographic research the study involves more than just the research subject but also the wider setting and structures, processes and organisations that are part of their world. An ethnomethodological process is unique as a research approach in that it enables the understanding of a particular phenomenon through the production of *"a deep wonder about what is often regarded as obvious, given or natural. Whether it be the interpretation of documents, the utterance "uh-huh" or the flow of everyday interaction, ethnomethodology has provided a way of questioning which begins to reveal the richly layered skills, assumptions and practices through which the most commonplace (and not so commonplace activities and experiences are constructed."* (Seale, 2004 p.384).

This emphasises the philosophy around ethnomethodology whereby everyday life and routine are observed to understand the meanings and intricacies of behaviours. Findings are positioned and orientated in the environment, seeking to ascertain the experience and meaning behind the actions, decisions or negations that take place. With an emphasis on witnessing phenomenon in a naturalistic way, seeing the raw, complex and actual practice which sits in juxtaposition to the process models, policy documents and institutional mandates that are analysed in the document analysis.

4.1.2 RATIONALE FOR STUDY DESIGN

Adopting ethnography, this study draws on document analysis, observations and interviews, with each providing detail on the context and experience of patients being treated, from a different perspective and aims to provide a holistic view of the patient experience. *"It is important to recognise that HNC patients face a complicated journey through various treatments which all impact on one another."* (Fitchett *et al.*, 2018 p.2048) This patient experience account is required to understand the entwinement and interdependencies and this forms the justification for this study and its methodological approach.

The study is presented in the order below, which captures the flow of the enquiry from an initial document analysis, followed by the ethnographic observations, finishing with the analysis of the in-depth interviews.

- The impact of integration principles for HNC care in the UK: a policy and document analysis.
- Participant observation of a community-based multidisciplinary approach to rehabilitation.
- Understanding patient experience to optimise collaborative care: Listening to the experience of HNC patients in Community Head and Neck Cancer Team (CHANT) services.

The results start with a document analysis of the policy backdrop that informed the model of care that participants are being treated within (CHANT services). In many methodologies document analysis serves research enquiry best when it is used alongside other methods (Dixon-Woods *et al.*, 2014; Angers and Machtmes, 2015) and it is used in this way in this study, as a means of triangulation that compliments the ethnographic method adopted. It is this combination of methods that enable a deeper and more holistic picture to emerge (the experience of HNC) (Denzin, 1970, p. 291).

Whilst this multimethod approach is used in other disciplines it is still somewhat underutilised in healthcare settings (Darbyshire, MacDougall and Schiller, 2005). The educational arena provides many examples of such approaches. Sogunro (1997), for example, used questionnaires combined with interviews, document analyses, and direct observations to study that sought to explore the effect of training on leadership evolution. The study was strengthened on the findings of a document analysis reporting that a review of a 19-year-old leadership training program's records provided information on historical elements such as goals, programme objectives and key competencies (Sogunro, 1997) demonstrating the potential strengths of this approach.

There are some interesting studies emerging in health services research that utilise this multilayered approach to study a given phenomenon in situ, ((Russ *et al.*, 2012; Dixon-Woods *et al.*, 2014; Johnson *et al.*, 2017), rooting their work in ethnographic methodologies such as, Dixon Woods *et al.,* (2014) research on *"Culture and behaviour in the English National Health Service"*, which provided an overview of lessons from a large multimethod study. This study involved collection and triangulation of data from multiple sources, including interviews, surveys, ethnographic case studies and publicly available datasets along-side document analysis of board minutes, with the study highlighting that it was the synthesis of data across these methods that produced a holistic picture (Dixon-Woods *et al.*, 2014). This thesis takes its inspiration from this type of research and other such work. Multimethod studies work as each method is not analysed in isolation. Observations are *"valuable in understanding broader organisational needs but observations must be supplemented by other techniques such as interviewing and document analysis to understand the 'organisational' requirements and constraints on systems design"* (Rouncefield, 2011 p.48). The strength of this study therefore lies in its triangulation of methods to provide a holistic view.

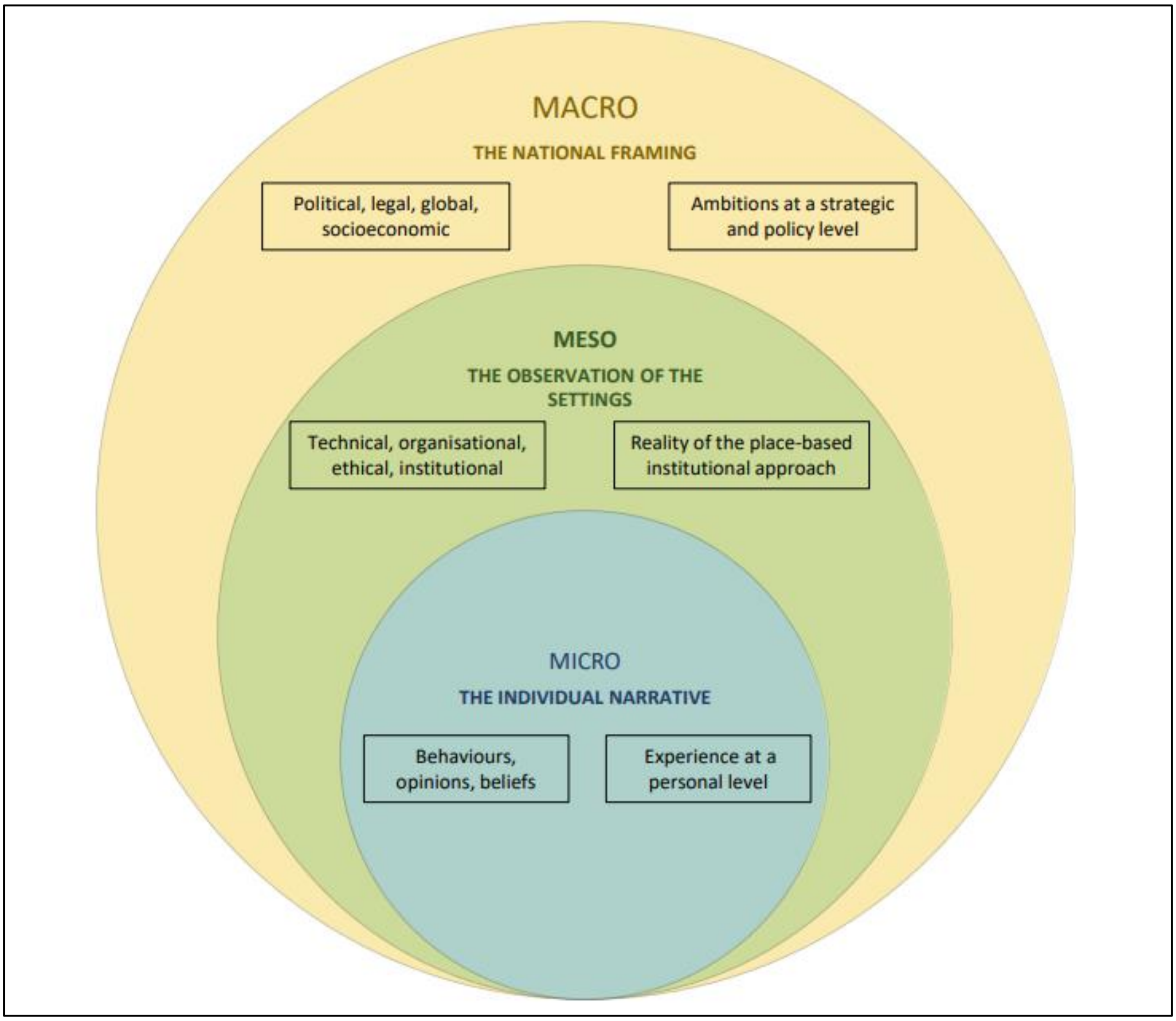
Document analysis (Chapter 5) provides an insight into the policy context in which individuals using HNC services are based and provides the framework for mapping the network of interactions in which the personal patient stories (detailed in Chapters Six and Seven) take place. Data collected through these methods will illuminate the complexities involved in experiences of HNC including the resources that people are able to draw on while accessing HNC care. In this Chapter, the healthcare settings and services that people with HNC find themselves within is outlined.

4.1.3 MACRO, MESO AND MICRO SOCIAL ANALYSIS

The concept of micro, meso and macro are routed as conceptualisation used to capture the complexity of a given phenomenon and has been used in health services research (Richter and Dragano, 2018). It captures the layers of a reality, from the smallest (micro) components to the largest (macro). At the macro level in healthcare and in this thesis, we are capturing the structural factors, which shape the broad social space that is examined in this study and in which this provision of cancer care in the UK health system sits. It provides the conceptualisation of how that cancer care is organised at the community level and what that means for patients who are using these services (meso), looking at those interactions that individuals have within that service, which is the micro level, capturing the smallest levels of interaction, with the self, or other individuals.

The meso level exploration involves investigating groups, studying how norms of behaviour vary. At the macro level, this involves understanding the wider context of the micro and meso, with social structures and institutions, exploring large-scale patterns. The broader framing of the macro level is important, as power imbalances may exist not only within the interaction between patient and CHANT team/health professionals, holding the expertise. This is also situated within the physical community setting and clinic. Within the local setting, power dynamics and valued resources (e.g., medical expertise or extensive social network) are weighted across the system between actors (those within the studied phenomenon). This conceptualisation is summarised in Figure 4.

Figure 4: The mapping of micro, meso and macro to the methodological approach



An example of how viewing a health pathway in this holistic way may be helpfully demonstrated in Scambler *et al.,* (2014). The study discusses the context of empowerment and self-care within the field of diabetes highlighting the importance of empowerment as a way of encouraging people to take control of and responsibility for the successful management of their disease. This work looks at the meso and macro view in which participants are situated, as *"a bounded social space in which actors conduct their lives day-to-day, to explore the context within which issues of empowerment are addressed and negotiated"* (Scambler, Newton and Asimakopoulou, 2014). Without this lens unpicking the juxtaposition of encouraging self'-management and empowerment within the field of diabetes and the privileged medical arena is challenging.

4.2 METHODS

4.2.1 OUTLINE OF METHODS

This section outlines some of the fundamental principles that govern each method. Each section aims to articulate the key features and principles behind the chosen method. This is then followed by details of each method, data collection, sampling and data analysis.

Document analysis

Document analysis can use a variety of resources as part of a study including, advertisements; agendas, attendance registers, and minutes of meetings; manuals; background papers; books and brochures; diaries and journals; event programs (i.e., printed outlines); letters and memoranda; maps and charts; newspapers (clippings/articles); press releases; program proposals, application forms, and summaries; radio and television program scripts; organisational or institutional reports; survey data; and various public records. Like other analytical methods in qualitative research *"document analysis requires that data be examined and interpreted in order to elicit meaning, gain understanding, and develop empirical knowledge"* (Bowen, 2009 p.27).

The purpose of this thesis is not to understand specifically the impact of the MTD community approach on the experience of HNC, but in seeking to elucidate the experience of HNC patients it is important to build a picture of the social context in which these experiences occur and to acknowledge the impact the service approach may have and, it may be that this examination begins to shine a light on questions about comparisons of health service delivery approaches for these patients. As a research method, document analysis is particularly applicable to qualitative case studies where intensive studies produce rich, granular descriptions of a phenomenon (Yin, 1994; Stake, 1995).

Non-technical literature, such as reports and internal correspondence, is a potential source of empirical data for case studies; for example, data on the context within which the participant operates (Mills, Bonner and Francis, 2006). Furthermore, as Merriam (1988) points out, *"Documents of all types can help the researcher uncover meaning, develop understanding, and discover insights relevant to the research problem"* (Merriam, 1988 p. 118). As highlighted previously the document analysis serves to bolster and triangulate observational and interview data collected as part of this thesis. By triangulating data, the researcher attempts to provide *"a confluence of evidence that breeds credibility*" (Eisner, 2017 p.110).

Observations

All of the observations carried out in this research took place in closed settings (Caulfield, 2022). These are settings where gatekeepers are required for access, and observations were undertaken, initially with the intent to gain access to, and help with recruitment to interviews. A closed or private setting is harder to access than an open setting and as the research took place in a healthcare setting it is therefore considered to be closed. Similar to a business or a school, where boundaries are clearly defined and where the observer can become fully emersed. This type of setting required gatekeepers. In these types of settings negotiating a way in or acquiring trust and a role within the organisation was key to facilitating a holistic picture of the experience of HNC patients.

In addition, as with most ethnography, the observations carried out were overt. In an overt approach, it is decided that the researcher should be clear about their role and do this upfront, clearly defining their purpose and role in the group (Caulfield, 2022). In this study overt ethnography was ethically preferable, to ensure participants could give verbal informed consent and it was understood that the research played no professional role in their care. It is, however, important to be reflexive about this approach as people may behave differently with the awareness that they are being studied.

I took a passive approach (Robson, 1999 p.115) to the observations and did not take an active role in any of the interactions that I observed. A passive approach relates to the level of immersion taken in the context of the research. A passive stance was chosen due to this being a health care setting and professional knowledge being required to be an active member of the settings. Therefore, a *"stands back from the activities of others"* approach was taken, behaving as a more distant observer and not participating in discussions or activities. This allowed a more detailed and careful observational assessment and allowed for notetaking but, as with being overt in the nature of the research the passive approach does mean that those observed may act differently with the awareness of being observed (Robson, 1999).

Observations were carried out as an initial feasibility/explorative phase and involved the conduct of mini focused ethnographies, which incorporate key clinical encounters but also the day-to-day clinical environment in which patients step into. Patients consented at the beginning of each consultation, where the healthcare professional asked permission for the researcher to observe the appointment. This phase aimed to inform the topic guide for the next interview stage and allowed for familiarisation with the environment in which the patient was situated. The observations also aimed to provide a naturalistic observational account routed in the rationale put forward by Malinowski that *"only through living with and experiencing 'native' life in their own environment could a researcher really understand that culture and way of life*" (Rouncefield, 2011 p.45)

In-depth interviews

Interviews were carried out to uncover the accounts of participants, with the aim of understanding the day-to-day impact of living with a diagnosis of HNC through detailed exploration of their experience of the care pathway and rehabilitation journey and unpicked the long-term impacts of a diagnosis of HNC and its effect on daily life as well how people have received treatment and rehabilitation for HNC feel their experiences could be improved. This method provides a rich, granular, direct account of the experience of HNC patients and gives an insight into if services, aspired to at national level, suit the needs of the patient, from their perspective.

The interviews took place in a number of settings. Clinic A was embedded within an existing hospice, although the Community Head and Neck Caner Team (CHANT) services were not part of this palliative provision, with a number of other clinics, some of which aligned with the work of the CHANT team e.g., lymphatic massage services. The second clinic is the larger and busier of the two clinics. This is where the CHANT team are based and where most interviews and observations were taken. Participants were invited into a private room next door to the MDT consultation space and any reasonable adjustments were made with the help of the CHANT team, so participants were comfortable to speak for an extended period of time. Where breaks or second or third sessions were required, this was also facilitated.

Ethnography uses interviews with the aim of providing a naturalistic lens (Seale, 2004). Interviews are probably the best way to capture participant's voices. Being in the field as a participant observer enables the researcher to familiarise themselves with the context, introduce the study to potential participants and facilitate, or negotiate, gatekeeping relationships. In-depth interviews require active listening on the part of the researcher to understand what has been said and react, develop and assess in relation to the research inquiry, with a focus on the context, aligned with ethnography.

4.2.2 SAMPLES

This section outlines the sample data used for each type of method. First, the criteria set for the document analysis are described, then the settings and scope of the observations are set out. Finally, the features of the patient group selected for interview are detailed.

Document analysis

The aim of this process was to identify policy, guidance and information documents in particular that include reference to multidisciplinary integrated care for people diagnosed with HNC. Documents published about the healthcare provision in the UK, from 2000 onwards were eligible for review and the selected documents were critically appraised to elicit meaning and provide empirical knowledge based on interpretation and a deeper understanding through examination. (Seale, 2004). The documents that were eligible for analysis as listed Table 2 (sourced from Bowen, 2009).

Table 2: Types of documents eligible for review

TYPES OF DOCUMENTS ELIGIBLE FOR REVIEW	
advertisements/leaflets;	Programme proposals
Agendas, minutes of meetings; manuals;	Application forms and summaries
background papers;	Radio and television records
books and brochures;	Program scripts
diaries and journals;	Organisational and institutional reports
event programs	Survey data and other public records
letters and memoranda;	Society offices and organisational or institutional files
maps and charts;	press releases; newspapers (clippings)

Observations

Observations spanned a number of years and took place in two phases, the initial observations in the hospital setting were taken during early scoping in 2013 and community-based observations took place from 2018-March 2020. The settings are outlined in detail in the results Chapter but included Multidisciplinary team consultations and other elements of the healthcare pathway for the HNC patients.

Research took place in a number of hospital and community-based settings within the focused geography of the CHANT team as discussed earlier. Chapter Six details the settings and Table 6 provides descriptive detail of each type of setting where observations were collected. In total approximately 50 hours of *observations* were taken (excluding hours spent interviewing) in a variety of settings with approximately 40 patients (including interview participants). The observations can be grouped into two key environments.

- Observations in group settings including MDT reviews and patient groups
- Observations of individual patient consultations with MDT members

Observations were recorded as field notes which were written up during the observations and immediately after each observation took place. Participants were recruited through their participation in the setting (i.e., I approached participants at observed events and invited them to be part of the study). Where practicable participants were asked for verbal consent for the observation to occur and verbal consent was obtained for all observations that took place within patient consultations.

Observations were undertaken over 6-year period which enabled the researcher to become fully immersed in the health services culture of the CHANT service, providing an *'experientially-rooted insight'* into HNC rehabilitation. Observations were undertaken and written up prior to analysis. Analysis was undertaken following an iterative and reflexive process. This involved field notes being read and re-read and questioned to develop insights, with leads emerging from the analysis informing the questions and lines of enquiry for the interview study and guiding further data collection and analysis.

In-depth interviews

Face-to-face interviews were conducted with a purposive sample of HNC patients attending the Southeast London Community HNC Team at Clinic A and B. Patients were invited to participate in the study.

A maximum of 20 participants was set. This was set with the aim of providing information power. This is where conclusions and recommendations can be made, informed by the data that has been collected or analysed, rendering further data collection unnecessary. The concept of information power aims to provide a different and more useful approach than the alternative, more historically pervasive saturation point. Saturation point, whilst still cited in sample size justification for many qualitative studies, is now being critiqued and even questioned as potentially impossible to do.

Information power *"indicates that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed"* (Malterud et al., 2016). Sufficient information power is assessed on a number of qualities which include, aligning with the aim of the study, the specificity associated with the sample, accounting for the use of a theoretical frameworks, the detail and quality of data, and the method of analysis taken.

Information power, in contrast to saturation point does not suggest an objective point of saturation where no further new data can be discovered, but rather sufficiency of data is embedded in the processes, nuances and level of detailed analysis applied to the data. In this thesis, the evidentiary value of this depends on the methodological triangulation, the micro, macro and meso conceptualisation. Furthermore, the detailed, in-depth interviews and the specifically defined cohort of patients (an often-unheard cohort of cancer patients) embedded in a unique phenomenon (CHANT community based health team) all coalesce to create a position of information power equating to sufficient evidence.

There are a number of approaches that can be taken when conducting qualitative research, such as simple random sampling, systematic sampling, purposive sampling, theoretical sampling, cluster sampling and snowball sampling (Seale, 2004). The purpose of this study was to capture a specific, prescribed group of hard-to-reach patients, with a diagnosis of HNC. As this was a specific population, and not necessarily representative of the whole population, a non-probability sampling approach was taken. This study used a purposive sampling strategy i.e., to sample a group of people with particular characteristics, where respondents were selected because they have knowledge that has significant relation to the research topic and questions

During the course of the study, demographic information about the patients was collected where shared with the researcher. However, participants were not directly asked for this information and the researcher gleaned this through observation or natural dialogue. It is key to note this, as the chosen approach, of semi-structured interviews, focuses around allowing the participant to tell their story in their own words and therefore not to ask closed questions relating to sociodemographic information, in a questionnaire style. Given this was not the key focus of this study, any information collected relating to demographics served to frame the thematic analysis but not inform or colour conclusions. The results section details the demographic information of the sample taken when available. This includes age, gender, ethnicity and type of treatment undergone.

4.4.2.1 Inclusion and exclusion criteria for interview participants

The inclusion criteria identified for this study are:

- Participants are diagnosed with HNC (including the oropharynx, throat and larynx).
- Participants must be undergoing rehabilitation (approx. 3 months to 1 year post treatment for initial interviews)
- Participants should be undergoing rehabilitation with curative intent including those having radiotherapy, chemotherapy, surgery or any combination of the three.

The exclusion criteria identified for this study involve:

- Participants that are not able to speak and understand English.
- Participants who cannot give consent.

Participants were recruited 3 months to 1 year after initial treatment. Participants were interviewed to gain an in-depth insight into their treatment and rehabilitation. This may cause distress and a feeling of intrusion. In order to minimise distress, the interviewer strived to nurture an atmosphere of openness and trust. This was further managed by ensuring that participants are informed that they can leave the study and terminate an interview at any point.

Furthermore, a protocol was put in place to ensure that should a participant feel distressed or expresses any concern that may be detrimental to the participant’s well-being; this concern will be quickly and adequately escalated. This involved informing the chief investigator who was able to contact the allocated psychologist. This reporting was conducted immediately on the researcher logging in and out of an interview (see Appendix Four for the risk flowchart).

The research was focused on those who are further along in the rehabilitation journey, rather than those who are just starting out in treatment or follow up, to ensure that we gain a full picture of the journey. They were interviewed at varying stages in their rehabilitation journey in order to uncover nuanced experiences of living with HNC and identify salient features relating to diagnosis and management and rehabilitation.

4.4.2.2 Recruitment for observation and interview participants

Potential participants were approached via the Southeast London Community HNC Team at Clinic A and B, by their treating health professional (members of the Community Team), who acted as gatekeepers at this clinical intersection point). It is important to note that this may have introduced a bias in terms of creating a selected sample, identified through the lens of the CHANT team. This a part of ethnographic research that one needs to be reflexive about but is necessary to ensure the safeguarding, safety and wellbeing of the participants.

Consent to observations were taken at the point of consultation and it was not possible to allow an extended period of reflection for consent to observational work. Time was allowed at the beginning of every consultation to ensure that any patient could opt out of being observed and to clarify that the observations were not part of the clinical treatment. Written information leaflets around the purpose of the study were also supplied. Ensuring effective consent also relied on creating an informed treatment team, who understood the intricacies of the study and may have previously informally discussed this with the patient where possible, before the consultation, to ensure that questions could be asked, and an understanding was established. A strong reiteration by the researcher, that this was not mandated, and was voluntary was communicated at numerous opportunities reinforcing that they could withdraw via the team should they wish, at any point.

If an interest was expressed around participation in the interview stage, further information could be supplied via an email or letter of invitation or broached during an appointment observation. This was accompanied by the information sheet (as Appendix 1). This could then be followed up with a further email to introduce themselves and ask about the details of carrying out an initial interview and provide them with further details about consent and participation or separate conversation about this after their appointment. Suitable participants were identified, via the team, through reviewing their medical records and at consultation visits through daily contact with potential participants, as part of their clinical treatment.

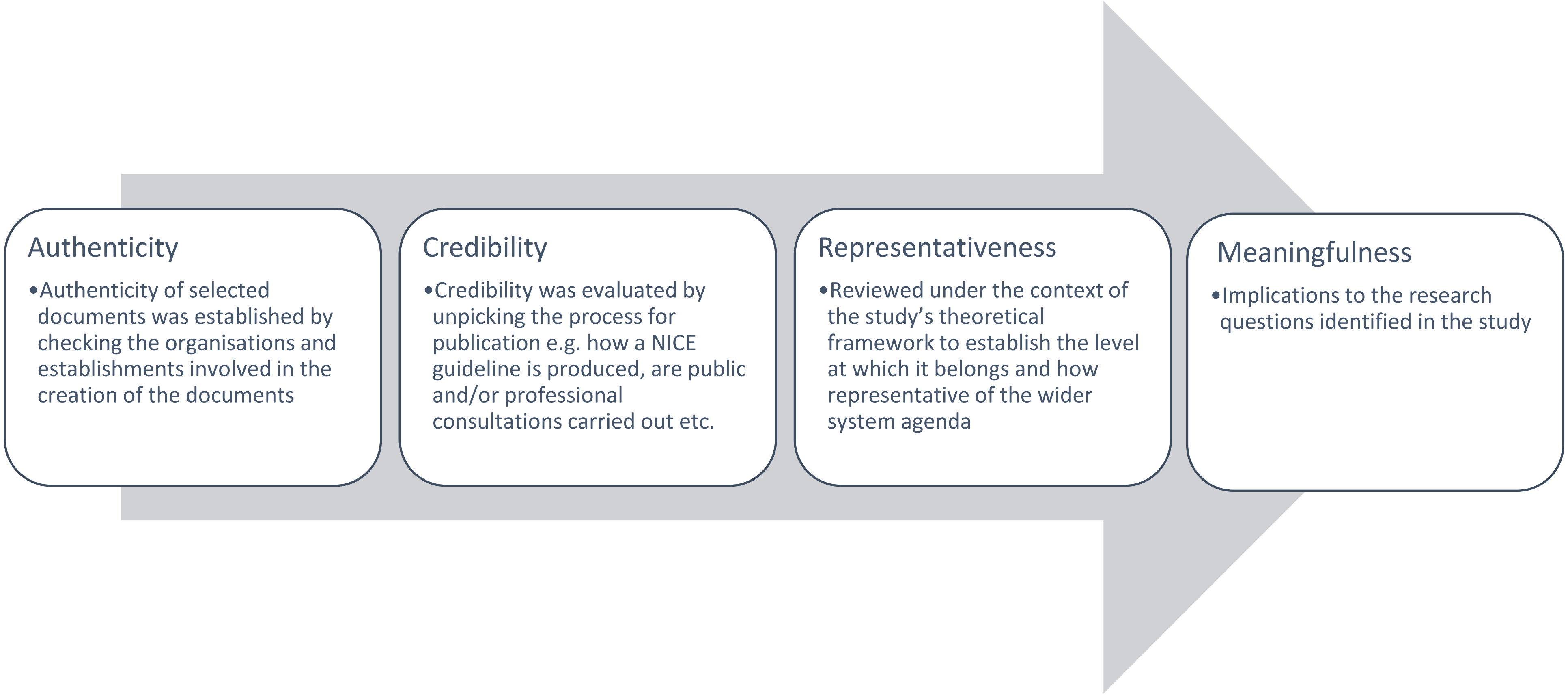
4.2.3 DATA COLLECTION

Document analysis

The analytic process entailed a phased approach. There was an initial finding and selecting process followed by an appraisal phase, which involves synthesis and critique in order to make sense of the data in the documents. There were two main routes for identifying the documents. The first involved undertaking a keyword search for documents containing *"National", "Disease", "Regional", "London", "HNC", "community care", "cancer" "community-based services/rehabilitation", "policy" and "CHANT".* Secondly documents were also included if they were provided or directed to by members of the CHANT Team during the period of ethnographic research, In total 15 documents were chosen through this process for further thematic analysis. These documents were chosen because they are specifically related to policy or process of relevant services and are seminal in representing the intentions, practices and aspirations at a national, disease, regional and local levels.

For the purposes of this study, documents are defined as an artifact that *"contain text (words) and images that have been recorded without a researcher's intervention"* (Bowen, 2009 p.27). Atkinson and Coffey (1997) coined documents as 'social facts'. Their definition outlined that they are produced, shared, and used in socially organised ways (Bowen, 2009 p.47). Once identified, the documents were read several times in order to reach a general comprehension. To assess the document a process detailed in the Figure 5 was carried out. Each document was assessed for authenticity, credibility, representativeness, and meaningfulness.

Figure 5: The 4 step Scott method for document analysis



Authenticity

- Authenticity of selected documents was established by checking the organisations and establishments involved in the creation of the documents

Credibility

- Credibility was evaluated by unpicking the process for publication e.g. how a NICE guideline is produced, are public and/or professional consultations carried out etc.

Representativeness

- Reviewed under the context of the study’s theoretical framework to establish the level at which it belongs and how representative of the wider system agenda

Meaningfulness

- Implications to the research questions identified in the study

Observations

For both settings, detailed field notes were taken. This involved a combination of taking reflective notes (a record of how ideas are formed and shaped during the research process – this may be about the research topic, the context, myself and my relation to the settings and the research subjects) and more formalised field notes (these include descriptive details of the location, team present, medical information etc.,).

However, as the individual consultations took a predictable format it was helpful to take a more structured note taking process, which meant the accounts lent themselves to a thematic analysis. As individual consultations were carried out in over 20 patients (from a total of over 40 patients included in the study) there was an opportunity to carry out a thematic review on a significant sample. There was a greater volume of consultations and the information between accounts were comparable with the opportunity to therefore identify themes across the accounts. Field notes were translated into fuller patient stories. The stories were then analysed using iterative thematic analysis to identify key themes. Interviews (presented in Chapter Seven) were reflected upon concurrently where possible. During repeated rounds of coding, re-coding, and memo-writing, frequent comparisons across codes and the interviews and the field note data were made and this cohesion and triangulation is drawn together further in the Discussion Chapter.

However, the group settings were often less predictable and were part of the immersion process and context gathering phase so relied on a more opportunistic approach. Therefore, in these circumstances field notes were taken with a different framing, more open and reflective in approach. They provide a more descriptive account and are therefore the findings are written up as descriptive narratives with relevant reflective musings and highlights from patients and staff.

In all observations however, it is important to say that the aim was to gather enough information to develop vignettes forming evocative accounts of patient experiences that shine a light on pertinent features of the patient journey. All field notes were taken mindful of practicing good, rigorous note taking as well as ethical observational notes. This involved not generalising ideas, being aware of positioning and biases, writing down observations that show something rather than just my thoughts, keeping a tally of questions and critiques, always being aware of the privacy and respect of the research subjects through using pseudonyms and ensuring they are informed, content and willing.

In this study, no structured framework was used. Unstructured observations allowed for discursive and descriptive notes, recording naturally occurring phenomena as and when they occurred. This therefore did not limit the data to predefined concepts and fields (Jackson 2016). However, 4 areas of focus were used to frame collecting data and provide consistency between accounts. These served as a reminder of the purpose of the study on commencing each observation. The 4 conceptual areas were:

1. Ensuring that a brief medical history of the patient was documented.
2. Understanding the family dynamics, social context and supportive networks were captured
3. Documenting key challenges, concerns and successes that were articulated by the patient.
4. Observing the dynamic between the patient and the setting and MDT.

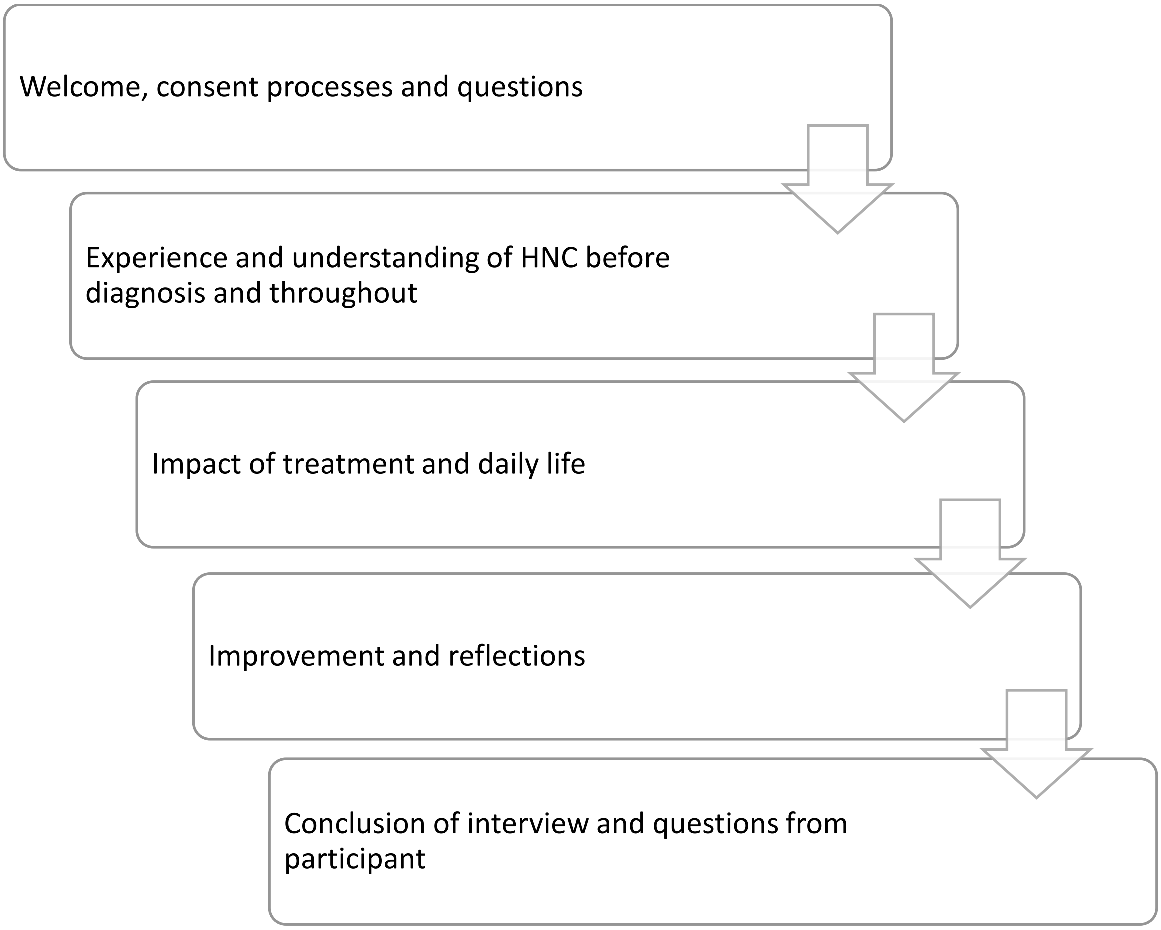
In-depth interviews

Interviews were recorded alongside the collection of field notes which were written up during the interview and immediately after each interview took place. Participants were recruited through their participation in the health setting (i.e., we approached participants at observed events and invited them to be part of the study). Each participant was provided with the information sheet in advance of the interview and prior to recording were given the opportunity to ask questions and clarify anything. The consent forms were filled out and where the participant wanted a partner or third person present, they were included in the interview. Guided by the literature review and observational data a broad topic guide was designed (see Appendix Three) to help shape the interview, however these were used only as a guide to allow an open platform and not create a prescriptive process, allowing narratives to be guided by the participants.

As with the observations, interviews were undertaken over 6-year period which enabled full immersion in the health services culture of the CHANT service. Interviews were often prefaced with observational findings from witnessing consultations between interview participants and with the multidisciplinary team. Where this is the case, it is identified in Table 10 which shows the demographics and summary of the participant's story. Again, aligning with the observational analysis approach the analysis was undertaken following an iterative and reflexive process. All participants communicated verbally, but some had less clear communication (3 interviews) and therefore notes were also taken to support transcription. The details of the participants are listed and outline the detail of how the participant pseudonym, gender, and their story and whether the participant was observed and interviewed more than once (aligning to Table 11 in the Interview results Chapter).

Through the use of a topic guide, to help steer discussion, the interviews explored the impact on the wider family and the outside world, health uncertainty, fear of reoccurrence (Rogers, Ahad and Murphy, 2007) and biographical disruption. The impact on appearance, speech, information and decision-making processes during treatment were also explored. This study sought to explore some common themes that are associated with patient's experience of cancer, as discussed in the literature review, drawing on a micro, macro, meso conceptualisation allowing for both an enquiry into the effects of cultural, social, biological and political arenas on HNC patients' experiences of health systems and an exploration into participants' opinions and experiences including the power dynamics that are in play during treatment between different actors. The topic guide (see Appendix three) was divided into the following key areas (see Figure 6).

Figure 6: Structure of interviews



4.2.4 DATA ANALYSIS

Document analysis

A thematic analysis was undertaken as part of a document analysis. Analysis was used to explore patterns and differences in how HNC patients experience treatment and rehabilitation. This was carried out through a directed content analysis technique as described by Hsieh and Shannon (2005). *"According to Hsieh and Shannon, the directed content analysis is guided by a structured process where the predetermined key concepts and initial coding categories are formulated based on existing theory"* ((Eklund Karlsson *et al.*, 2020) p.4). In this study the structure of policy from national, regional to place based models and the concepts of integration and multidisciplinary team working pre-existed. The data extraction and analysis were informed by addressing the key research questions that were formulated in accordance with the main aims of this study. Through asking these questions, which pick out key words and predefined codes relevant strategies, measures, key features, principles, themes and sub-themes are identified (these are detailed in the results Chapter).

The data extraction and analysis process *entailed "identifying, selecting, making sense of, coding, and narratively synthesising data contained in the included documents"* (Eklund Karlsson *et al.*, 2020) The document texts were saved in pdf formats to allow coding with colour highlighting. During the coding process, the texts were first read several times before words, sentences and areas of text were identified and highlighted to be included in the predetermined codes which were "National, Disease, Regional or CHANT". The over-arching themes of *Integration of services, regional infrastructure aligning to national ambition, Integrated ways of working* were also defined and are identified in Table 3 of Chapter Five and each document is analysed with the core research question and three sub questions identified as the key aim for the document analysis.

Observations

As described in the data collection process, observations were taken in two ways. The consultations were more formulaic for key reoccurring themes and therefore information could be directly compared, and stories formed. However, the group, professional and other settings involved taking a more immersive approach and the notes taken were analysed for important salient points rather than themes and codes. The combination of discursive descriptive group setting analysis vs more structured thematic analysis of the individual observations intends to provide that spectrum of information for the reader to be immersed in. These are split into separate group and consultation sections in Chapter Five.

For the group settings, field notes, recorded reflections, literature taken and discussions with staff and patients were all included and were re-written as an account of the experience. As is typical of ethnographic studies, findings are written using a storytelling technique capturing evocative and sensory elements that give the reader an immersive experience, written alongside objective descriptions and factual information. This is an approach *"that examines work as it is practised in a naturalistic setting and ethnomethodology is an approach to* *analysis that gives precedence to the actors their ways of structuring work rather than attempting to analyse this using some theoretical framework."* (Rouncefield, 2011). As discussed in section 4.1.1 and 4.1.2, the rationale for using ethnographic observational methods is to experience *"the environment in the same way as the people in that environment and observes their activities and interactions."* (Rouncefield, 2011). However, it is an important reflexive consideration to acknowledge that we can never experience the environment in the same way as another. Interpretation of experience is coloured by our perceptions, past experiences and frames of reference. Part of the premise of this thesis is to capture the sheer complexity and nuance that can inform this.

However, observations of consultations with the MDT were analysed differently as there was a more standard format so notes were taken, then read and reread. As codes and repeated ideas were apparent, they suited a thematic analysis approach. Hence, the notes and memos were then coded into categories providing descriptive grouping, related to the roles of patients and professionals at an individual and system level, guided by issues related to values, knowledge, practices, structures and beliefs. The core themes were identified. To present the thematic findings in an ethnographic style that provided the immersive and descriptive impact that the observations provide they were written as vignettes or stories and the codes highlighted.

In-depth interviews

Interviews were transcribed and notes taken on transcription. Transcripts were read and re-read and then coded under three overarching themes. Each transcript was then re-read to develop the short patient story, and which helps to provide background on the social, psychological and biological context and develop theoretical insights, with leads emerging from the analysis informing the questions and lines of enquiry for the interview study and guiding further data collection and analysis.

Analysis is routed in an ethnomethodological perspective (Sharrock and Anderson, 2012). This means taking what people say and exploring elements of the conversation that may be looked at as a social action rather than a neutral statement. E.g., Understanding the implication of someone saying, “I don’t feel myself” or “I don’t remember them telling me that”. Therefore, whilst interviews were transcribed using simplified transcription symbols (Seale, 2004 p.387), this was not the sole contribution to the analysis. As described by Seale (2011) “*they can help you remember what was going on the recordings. The subsequent benefit of making transcripts is that you can use them in the presentation of your findings”* (Seale, 2004 p315) Interviews were transcribed, notes written up and recordings repeatedly listened to provide that in depth thoughtful account of each individual. Interview transcripts were coded through the development of coding scheme and highlighted on the transcript. This was then transferred into a coding framework in Excel with notes and attributes aligned to each quote to help guide the development of themes. Themes were then grouped and organised within the framework. They were analysed using a thematic framework developed through the literature and further through the analysis process.

4.2.5 CONSENT PROCEDURES AND ETHICAL APPROVAL

This section summarises the approaches taken to security and confidentiality of the data produced in the study, the ethical approvals required to conduct the research and the importance of taking a reflexive approach. All observed and interviewed participants were given information sheets. Observations were consented verbally, and all participants were given the option for the researcher to not sit in on the consultation. Those that participated who raised an interest in being interviewed were also asked to complete consent form (see Appendix Two). Prior to this, they were given time to read the information sheet and take some time to confirm if they would like to participate. At this stage, arrangements to discuss this further with the researcher were made an interview. There was no maximum period of time between initial interest and consenting and participating in the research. The informed consent and information sheet were written in accordance with plain language guidance, to ensure they were accessible, and sensitive to the audience it is designed to be read by. If a participant required a more detailed explanation the researcher offered the patient an initial consultation to further guide them through the details of the project.

A protocol was completed, with review by educational supervisors (Appendix Five). The protocol was then peer reviewed by the wider research team and key academic members of staff and used as basis for ethical approval. Authorisation for this study has been granted by NHS Research Ethics Committee (project reference 14/LO/0011). Further to this NHS Research and Development at Guy's and St Thomas' NHS Trust, as a KCL student have finalised approval to conduct the project with R&D Reference: RJ114/N204.

A break in the study occurred (due to an extended maternity leave). This resulted in a change of site, identified in 4.2.4 which required a review of the approval granted by the Health Research Authority. Re-approving a cross site, community-based service as part of the study caused a delay as a number or Research and Development departments required documentation, the REC required a review and the HRA requested further a suite of more detailed documents that were not required as part of the original IRAS approval and all appropriate approvals were received in consultation with the Health Research Authority.

4.2.6 SECURITY AND CONFIDENTIALITY

All data were stored on a university one-drive server and interview transcripts kept separate from personal details. Appropriate measures (password protected digital spaced and anonymised transcriptions and writing) were taken to store research data in a secure manner, with personal information kept in separate, secure files. Electronic data was stored on password-protected devices and if there is transfer of this data files will be sent securely (through encryption techniques or password protection).

Throughout all data has been anonymised, including the removal of identifiers, the use of pseudonyms, and other technical means for breaking the link between data and identifiable individuals. Redaction also took place, where appropriate, for all data collected. In accordance with King's College London data governance, data will be stored for 4-8 years (archiving). If participants wish to view the reports, they can view a copy of a short report summary.

4.3 **REFLEXIVITY**

During the course of the study, it was important to understand the impact of how one's own position may influence the data obtained and its interpretation (Seale *et al.,* 2004). It is fundamental to good quality rigorous research, that the researcher is reflexive of how their own view of the world may colour the process of interpretation and how this may affect the way they interpret the data and draw conclusions.

An important reflexive point to note in this particular course of enquiry, is that I do not have a clinical background in dentistry, medicine or an allied health profession and therefore I am able to view the patient journey through this lens of non-familiarity with the clinical arena with which the patient engages as part of their treatment journey. This approach is informed by my background as a health policy professional and therefore understanding this in the political, governmental and social context.

Whilst this offers many strengths, in terms of being able to view the journey in a comparable way to the patient, this patient pathway is highly clinically and technically complex and layered. In recognition of this, the preliminary observational work was also used as an opportunity to be immersed in this speciality and learn about the key clinical terms and junctions, so as to allow interviews to focus on more detailed, nuanced elements. It is also this non-clinical background that will help to elicit a more open and honest exchange with the patient during their in-depth interviews, with technical language being avoided and a focus of the personal experience being maintained. The process of reflexivity requires the consideration of other characteristics such as age, gender social class and ethnicity and how the researcher's demographics interact with the profile of the patient group requiring introspection and bias checking throughout.

4.4 SUMMARY

This Chapter summarised the rationale and justification of the methodology and highlighted the novel methods used to illicit the voice of this hard-to-reach group of patients. The theoretical lens used to guide this research was discussed and a summary of the methods, data handling and challenges around ethical approval to the study were presented. The next Chapter presents an overview of how the results will be presented including an outline of the clinical pathway, and the flow of the policy document analysis, observations, and interview, followed by a presentation of the document analysis.

5.THE IMPACT OF INTEGRATION PRINCIPLES FOR HNC CARE IN THE UK: A POLICY AND DOCUMENT ANALYSIS

This Chapter is the first of three results Chapters as outlined in the overview of findings. As with Chapter Six and Seven this Chapter will begin by outlining the detailed process of the document analysis, followed by outlining the documents identified and the categorisation process which frames the thematic analysis (table 3 and 4). Then each overarching theme is examined in turn. Finally, the Chapter will close with a summary of key findings. First, however, an overview of the results Chapters is set out.

5.1 SUMMARY OF RESULTS CHAPTERS

This study aims to answer the overall research questions (outlined in Chapter Three) through three different methods, providing different angles and therefore illuminating a more holistic picture, answering the research questions from multiple dimensions.

5.1.1 DOCUMENT ANALYSIS

This strand aims to explore the macro view, or policy around HNC.

1. **What is the national ambition for services designed and provisioned for HNC services and what are the core principles behind this?**

The document analysis aims to capture the governing principles and infrastructures of the services involved in the provision of care for people with HNC. They are explored through a range of systematically identified and chosen documents. This addresses the study's wider research aim of *"understanding what facilitators and barriers exist in creating the care pathway for HNC".*

It is important to understand the evolution of this service from a political and policy perspective and this document analysis therefore unpicks the evolution of services aimed at the treatment and rehabilitation of those with HNC by first looking at the policy ambitions of wider cancer services and even more generally, healthcare in the UK. In doing this, the aim is to understand the following specific questions:

a. What is the national ambition for wider cancer services and HNC services specifically and what are the principles behind this?
b. What are the regional infrastructures that have been created to support these national ambitions?
c. How have the regional infrastructures been used in reality at a local placed based level?

An evaluation or review of how these national ambitions have been realised in daily practice and by local systems is currently lacking in the published literature and therefore this element of the study aims to articulate the ambitions of integration, and then provide an account of the reality of services on the front line. CHANT is the unique example of where this service has come to be in reality (in line with national ambitions) and this thesis then goes onto explore how patients experience this service through observations and interviews.

5.1.2 OBSERVATIONS

Chapter Seven presents a series of focused observations that resulted from the researcher being embedded in the CHANT team setting. The use of ethnographic methods in health settings as a research tool is still relatively novel (Greenhalgh, T., and Swinglehurst D., 2011; Featherstone and Northcott, 2021) and can provide a unique insight into the patient journey.

This Chapter will first present how these observations evolved as part of the process of seeking to foster the most intimate and detailed narratives from patients with HNC through one-to-one interviews. In order to carry out in-depth interviews it became necessary to first understand the patient's situation and gain trust through being embedded within the CHANT team. In doing this research, it became apparent that being an observer was part of the research process and built understanding of the interactional dynamics at play within the HNC context and particularly within the environment in which participants were accessing care. This enabled the contextualising of individual experiences to map power relations and the interplay of resources within the social space they exist, as relational concepts to unpick the patient journey in more detail. This Chapter will therefore focus on presenting the rich ethnographic data, gleaned from observation of a range of clinical interactions. The specific questions that aimed to unpick the broad research questions were:

2. **What are people's experiences of the care pathway for HNC, in relation to the settings and clinical interactions?** *(Chapter SIX: results, Chapter Six:8.2.2 discussion and key findings)*

a. Is the community integrated care model set up as the national and regional policy outlines?
b. How do participants experience these settings and traverse a pathway designed in this way?

5.2.3 IN-DEPTH INTERVIEWS

The final results Chapter (Chapter Eight), presents the narrative accounts of participants, with the aim of understanding the day-to-day impact of living with a diagnosis of HNC through detailed exploration of their experience of the care pathway and rehabilitation journey. The key research questions were:

3. **What are peoples understanding and experiences of HNC?** *(Chapter Seven: results, Chapter Six:8.2.3 discussion and key findings)*

    a. What are people's expectation, experiences and understanding of the treatment and rehabilitation options available to them once a diagnosis of HNC has been received?
    b. What are the short and long-term impacts and consequences of receiving a diagnosis, and treatment of HNC?

c. What elements of the journey were most challenging and what were the drivers to surviving and thriving?
d. What support did individuals receive and access?

5.2 SCOPE OF ANALYSIS AND DOCUMENT IDENTIFICATION

The rationale for carrying out this document analysis is detailed above and in Chapter 5 – methodology Chapter. Furthermore, the rationale behind the chosen method for the process of the document analysis is explained. In summary the method for analysis involves a conventional document analysis informed by the 4-step Scott method for document selection and data validity alongside Kripendorff's (Krippendorff, 2018) five-step approach "*including access to documents, validity of documents, comprehending the documents, analyzing the data and applying the information*" (Barasteh, 2021). The process of identifying documents and how they were appraised is detailed in the methodology section on sampling (section 4.2.1).

This a process of mapping to the micro meso and macro contexts that were outlined in Chapter Four (methodology) and provide the lens through which this enquiry is framed. The micro aligns to the documents that elucidate detail on individuals, which occurs at the disease and service levels. The local context documentation provides the meso level exploration around how different localities do things and the macro explore larger scale patterns at the national level. The documents were examined using thematic analysis, which involved coding the data and organizing into themes. Documents were categorised into groups and coded in batches to unpick overarching themes and sub-themes. As mentioned previously, in total 15 documents were identified as eligible for the document analysis. The key documents analysed are identified below in Table 1 and are grouped into four levels that capture the national ambitions to place-based cascades.

1. **National level**-Integration and community-based approaches in UK Policy and National guidance
2. **Disease level** – These are national documents that relate specifically to HNC.

3. **Regional and level**–documents relating to guidance around setting up regional support and specifically around treating HNC
4. **CHANT level** - CHANT systems and service delivery information.

These documents are listed in the following table, in the levels identified above, and then by order of reference, in the discussion.

Table 3: Document Analysis: Data sources identified

	Document	Type/Audience	Date	Group
1	The NHS Long Term Plan	NHS Policy Planning	2019	National Level
2	BSRM Rehabilitation Medicine - The National Position in 2007	Professional group recommendation report	2007	National Level
3.	Independent Cancer Taskforce, Achieving World-class Cancer Outcomes: A Strategy for England. 2015-2020	NHS Policy Planning	2015	National Level
4	Implementing the cancer taskforce recommendations: commissioning person centered care for people affected by cancer.	NHS Policy Planning	2016	National Level
5	BSRM Cancer Rehabilitation: Position Paper	Professional group recommendation report	2019	National Level
6	Improving outcomes in HNCs: The National Institute for Clinical Excellence guidance	NICE Guidelines	2004	Disease Level
7	The National Institute for Clinical Excellence "Healthcare services for HNCs" - Understanding NICE guidance	NICE Guidelines	2004	Disease Level
8	Ear, Nose and Throat surgery GIRFT Programme National Specialty Report	GIRFT report NHS Policy Planning	2019	Disease Level

9	Your guide to personalised cancer care	Patient guidance cancer alliance document	2021	Regional Level
10	Delivering World-Class Cancer Outcomes: Guidance for Cancer Alliances and the National Cancer Vanguard	NHS Guidance document for regions	2016	Regional Level
11	Article – OPINION REVIEW - CHANT: In tune with clinical outcome guidelines (- Ming Wei Tang, Samantha Tordesillas, Joanne Jefford and Jenny Gallagher)	Review/Editorial/News article	2016	CHANT Level
12	CHANT Staff structure	Internal document	2017	CHANT Level
13	Trust Presentation to Thames Valley CCG outlining process for setting CHANT service	Internal document	2016	CHANT Level
14	Blog Article - A Day in the life of the Community HNC Team (CHANT)	Review/Editorial/News article	2016	CHANT Level
15	CHANT - Head & Neck Cancer Rehabilitation Pathway – flowchart	Internal document	2014	CHANT Level

5.3 KEY THEMES

Chapter Three, methods and methodology outlines the data analysis process and how the subthemes and themes were identified. The remainder of this Chapter takes each level of documentation in turn. The rational for structuring the review in this way is to capture the cascade of National, Disease, Regional to local and individual place-based scenarios that is currently the direction of healthcare infrastructure development. Furthermore, this mirrors the theoretical frameworks articulated in earlier Chapters, capturing the meso, macro and micro views that are part of these spheres.

Table 4: Themes identified in document analysis (coded in levels of national, disease, regional and local level)

Group	Over-arching theme	Theme	Sub-themes
National Level	1. INTEGRATION OF SERVICES	1.1 Place based models	• Integrated care systems • Health professionals preferred method of working • Improving patient experience
		1.2 Community-based cancer models	• Multidisciplinary working • Patient centered care • Long term support
Disease Level	2. THE NATIONAL HNC GUIDANCE	2.1 Multidisciplinary working	• Merging of historically separate specialties • Local support
Regional Level	3. INFRASTRUCTURE ALIGNING WITH NATIONAL AMBITIONS	3.1 Evolution of community-based cancer services	• Creation of Cancer Alliances
		3.2 A personalised care approach	• Function of Cancer Alliances
CHANT Level	4. IMPLEMENTED INTEGRATED WAYS OF WORKING	4.1 Unique multidisciplinary team	• The care pathway • Daily activity • Team structure

In the section below each group or level of documents will be presented according to overarching themes. The sub themes will be discussed, and the relevant documents will be identifiable in the text via the number assigned in Table 4.

5.3.1 OVERARCHING THEME 1: NATIONAL LEVEL - INTEGRATION OF SERVICES

This section will start with examining the key findings from the National level documents setting out the themes and sub-themes in turn. Five documents were identified at a National level from government issued documents to professional group advisory reports. The overarching theme was the concept of integration within health services as the progressive model of healthcare. This is illustrated with a focus on integration of care through place based or regional/area models and the community-based models. The core ethos in many contemporary service design models is the integration of services, which is capable of addressing complex needs, care pathways and eliminates fragmentation.

5.3.1.1 THEME 1.1: Place-based models

Integration through a place-based model is the first theme identified at a broad level, and for cancer this is also community based which is the second theme. Therefore, this over-arching theme first unpicks the rational for place-based models and then explores community-based cancer services.

Integrated care systems

The document analysis identified the **NHS Long Term Plan [1]** as the key national level document that set out the intention for integration in England. The introduction of integrated care systems (ICSs), first introduced in 2018 with an aim to roll out new infrastructure that supports this agenda by April 2021 was set out in this Plan. This new model would be enshrined in law providing legislation aiming to remove barriers for strategic partners to work together. ICSs are defined as:

> “new partnerships between the organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups (NHS England – ***NHS England » What are integrated care systems*?”**

It is clear from review of this document that one of the fundamental tenants for ICSs is that services are arranged as closely as possible to those who use them with a key strength of the system being that “arrangements can be adapted to reflect what makes sense locally.” Evidence suggests that integrated care has been proven to improve services for patients. It provides a better quality of care, that is less fragmented, more cost-effective and is routed in a place-based ethos (Kodner and Spreeuwenbury 2002). This move to place-based models very much aligns to the philosophy of community based, multidisciplinary team approaches that are the basis of services such as CHANT. Many areas of healthcare are moving towards integrated models of care and the recent Long-Term Plan for the NHS [1] has a strong emphasis on integration of services.

The commitment to this is reflected in the creation of this new infrastructure in England around integrated Care Systems, signalling a conscious trend to creating fewer barriers between physical and mental health; secondary, tertiary, primary and community-based settings, as well as managing points of transition and entry-level access to services. Integrated Care Systems are now making progress and are embedded at every locality around England. This feeds into a supra regional footprint that sits below the national programme and government structures. Their success, based on evidence gathered from studies such as this, will need to be evaluated over the coming years.

> *“…the NHS and our partners will be moving to create Integrated Care Systems everywhere by April 2021, building on the progress already made. ICSs bring together local organisations in a pragmatic and practical way to deliver the ‘triple integration’ of primary and specialist care, physical and mental health services, and health with social care. They will have a key role in working with Local Authorities at ‘place’ level,*

> *and through ICSs, commissioners will make shared decisions with providers on population health, service redesign and Long-Term Plan implementation."* **(NHS Long Term Plan [1]**)

Health professionals preferred method of working

This a shift in historical paradigms that has previously delineated care into specialisms that often plays heavily into the how individuals navigate healthcare services and thus how they experience the patient journey. This creates notions of what healthcare is, and how professionals should work together, and with patients. To illustrate this **The NHS Long Term Plan [1]** details a survey conducted by the British Medical Association in 2018 showing the views from doctors on integration demonstrating a desire for integrated services between primary and secondary care.

Table 5: Doctors' views on the need for integration of primary and secondary care. Percentage of doctors agreeing with the following statements

Collaboration between primary and secondary care doctors will improve the quality of patient services and experience	94%
GPs and hospital doctors should work together more directly in a collaborated and coordinated manner	93%
There should be shared pathways across primary and secondary care, with resources fairly directed to where care is delivered	92%

Source: Taken from* The NHS Long Term Plan [1] *British Medical Association. Caring, supportive, collaborative? Doctors views on working in the NHS. November 2018.

This is a theme that is reflected across all of the national level documents included in this analysis [1-5]. There is an emphasis on professionals working most effectively in an integrated way. There is a will in the system to align with the expectation that this will ease the burden on staff and improve services.

Improving patient experience

The NHS 'Long Term Plan' and the other national documents showed a recurrent theme around integration being a way of working that aims to achieve system change and improve patient care. However, what this looks like will vary depending on the context and locality and therefore understanding how this might be applied to health services and cancer specifically has been an ongoing challenge for policy and service design in the healthcare. Articulating its strengths and weaknesses in the rehabilitation phase is key to understanding the efficacy of these models and is the main focus of all the national documents identified.

All national level documents reference improving patient experience as a primary driver **[1,2, 3, 4,5]**. There is a growing body of evidence in academic literature to suggest that it is not only more pragmatic and collaborative for staff, but patients have a better more supported experience through integration, particularly with community-based rehabilitation services. Research cited in all national level documents [**1,2, 3, 4,5]** suggests that the most effective models for many conditions (e.g. Mental illness, cancer, long term conditions) are reached through coalescing a number of key integration features including having a clear infrastructure and long term impact, looking at biosocial model of care and treating the patient holistically, where they are based, through a supportive team with different skill sets.

5.3.1.2 THEME 1.2: Community-based cancer models

The analysis of national level cancer specific documents highlighted a trend towards favouring community-based cancer models and is therefore highlighted as a theme. Community based cancer care was seen as central to the provision of integrated cancer care **[1,2,3,].** Three features of community-based care are seen as fundamental and therefore discussed as subthemes - multidisciplinary working, patient centered care and long-term support.

Multidisciplinary working

Within England a new area of medicine is emerging, this is rehabilitation medicine. Clinicians working in this area are represented by the **British Society of Rehabilitation Medicine** and in **2007 [2]** a report was published outlining the key issues and features of successful rehabilitation medicine. Whilst the document focused on the role of the consultant and community matron and primary care settings it highlighted the ethos of good rehabilitation as:

> *"Multidisciplinary working is integral to RM both in specialist inpatient rehabilitation units and in the community. Rehabilitation Medicine consultants constantly interact with professionals in primary healthcare teams, social services and other agencies. Home-based assessments are often required and in some centres consultants are members of community teams"*

This highlights that community-based multidisciplinary working is seen as an approach that can be relevant and optimal in many areas of healthcare. The backdrop of this drive towards integrated services nationally is relevant to this thesis because it is possible that cancer patients in particular could benefit significantly from such policy changes due to the complexity and multidisciplinary nature of their patient journey, also considering the impact of cancer on wider elements of an individual's life that reach further than the treatment of their malignancies. As shown in the literature review in Chapter Two, care for HNC may involve the oncology team, maxillofacial surgeons, the dental team, psychologists, nurse specialists, physiotherapists, speech and language therapists, dieticians and nutritionists and occupational health. The benefits of having as many of these specialisms as possible in close proximity, working as a team and in the community, is clear.

Integration can take place on horizontal and vertical levels and often-horizontal approaches are favoured rather than vertical. There are some useful examples of cancer services taking an integrated approach that is, in particular community based. Vertical integration takes place across the patient pathway for a particular condition, which might traverse organisational layers e.g. acute, secondary, or primary care. Therefore, CHANT connects community-based services with hospital-sited specialists, whereas horizontal integration captures the idea of more social or cross sector services (this could include mental health services), which may be seen to contribute to improving overall health and well-being at the same service level. Integrating these methods ensures that an over medicalised view of care is not the focus and that holistic care is provided acknowledging elements of wellbeing and care that may not be traditionally considered from a service design perspective. Successful integration relies on effectively combining vertical and horizontal approaches and this is particularly key for community-based models.

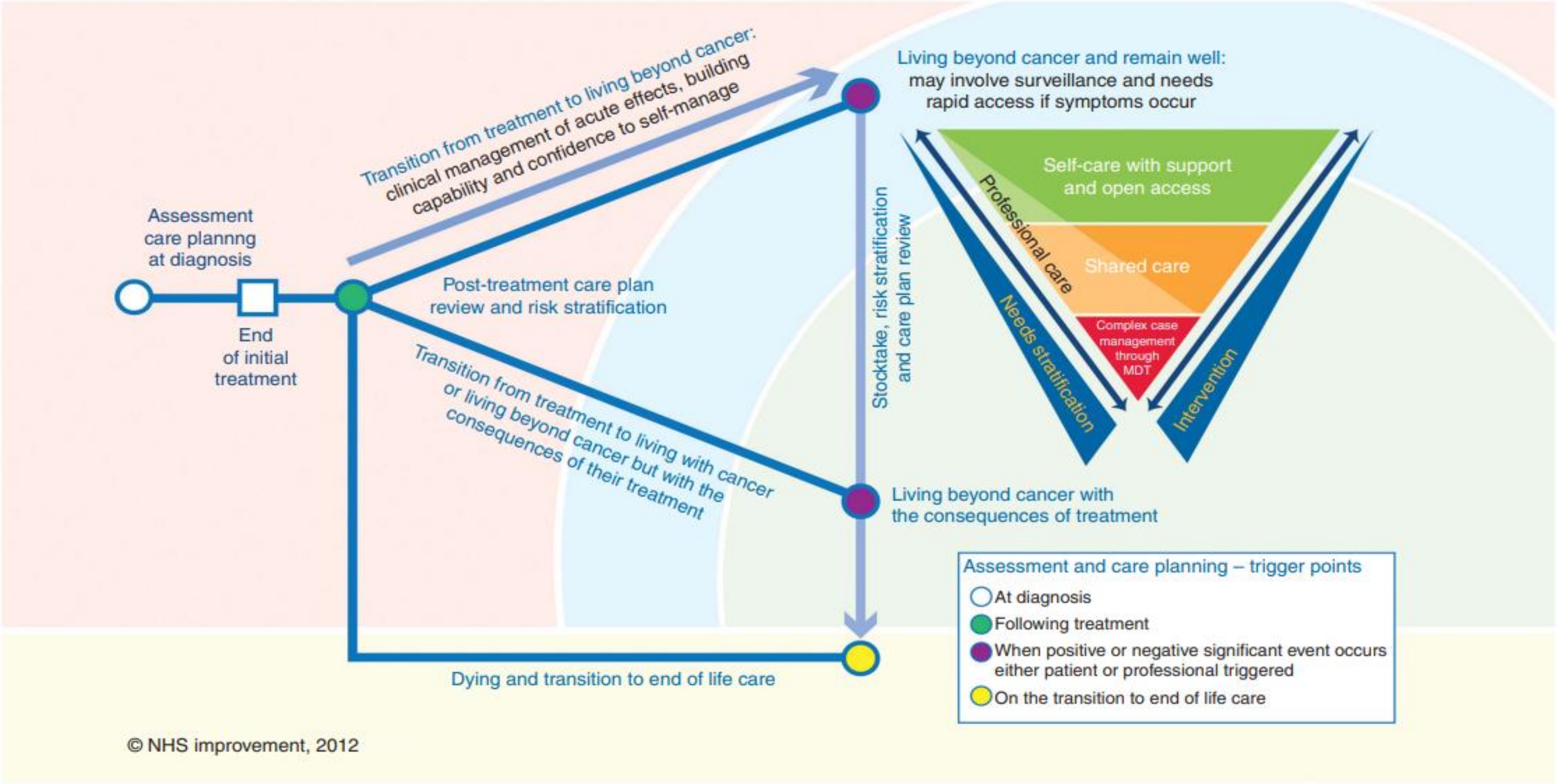
Patient-centred

The NHS Cancer Taskforce (**Independent Cancer Taskforce, Achieving World-class Cancer Outcomes: A Strategy for England. 2015-2020 [3]**) provided recommendations that highlighted the need for a holistic rehabilitative model that was patient centred. In 2016 the NHS published a report on **Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer [4]** which reiterated the themes identified in all national level documents around patient centered care and unpick the fundamental role the MDT plays in creating this approach. So community based services need to be not just integrated, but centred around the needs of patients.

Long-term support

The importance of meeting the needs of an increasing number of cancer survivors through integrated care approaches has led to the development of the National Cancer Survivorship Initiative (NCSI), a partnership between the Department of Health and Macmillan Cancer Support, and supported by the NHS. Their aim was *"to ensure that those living with (and beyond) cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. (***OPINION REVIEW - CHANT: In tune with clinical outcome guidelines [11]***)".* This focus on rehabilitation as part of the pathway is a purposeful shift and move toward a model of care that reflects the needs of the patient to transition from treatment to the next phase. The key principles are captured in the diagram below which was taken from the **a position paper by BSRM on cancer rehabilitation (2019) [5]** (Figure 7)

Figure 7: Model of care for living with and Beyond Cancer



© NHS improvement, 2012

This is supported further in the final document identified through the analysis –**BSRM on cancer rehabilitation (2019) [5].** This document identified this key theme around supporting patients through rehabilitation, specifically for cancer patients with long-term functional and cognitive impairments. The document provides a strong evidence-based recommendation for:

> “Patients who develop functional or cognitive impairments or symptoms (including issues around communication, continence, swallowing and fatigue) as a consequence of cancer or the treatment of cancer should have access to a specialist in rehabilitation medicine who can initiate or refer for appropriate ongoing treatment strategies”

Documents **2, 3, 4 and 5** all identified the theme of specialist roles for rehabilitation physicians that may complement role of the MDT and form a lynchpin. This area of medicine is growing and the aforementioned position paper **[5]**

> *“We would suggest that the training and experience of rehabilitation physicians working with the wider multidisciplinary team working with the wider multidisciplinary team places them in an ideal position to take on this role as they currently do for patients with currently do for patients with neurologic neurological problems, musculo--skeletal disease and limb loss.”.*

It is a biopsychosocial model of care, which is patient-centered in focus and strives to deliver an integrated, holistic approach to care. The aim of this approach in rehabilitative medicine, is to empower patients. To further understand this approach the next section focusses on specific guidance in creating such a model for HNC.

5.3.2 OVERARCHING THEME 2: DISEASE LEVEL – THE NATIONAL HNC GUIDANCE

The document analysis highlighted that there are some key national guidelines relating specifically to HNC cancer and these documents provide a steer for how to manage services.

In 2004, The National Institute for Clinical Excellence published a document on **“Healthcare services for HNCs” [6].** The document describes the direction envisaged for HNC services following the publication of the NICE guidelines. The guidance recommends “which healthcare professionals should be involved in treatment and care, and the types of hospital or cancer centre that are best suited to provide that healthcare” – this type of guidance is called ‘service guidance’.

5.3.2.1 THEME 2.1: Multidisciplinary working

The supporting document (entitled **The National Institute for Clinical Excellence “Healthcare services for HNCs” - Understanding NICE guidance [7]**) highlights that service change can involve large-scale changes and therefore implementing these new models can be ambitious and challenging. This document analysis suggests that the NHS is working towards putting the guidance recommendations into practice. Most notably there is a recommendation that Local support teams should provide long-term support in the community that is multidisciplinary (including dieticians, dental services, speech and language and clinical nurse specialists). These Allied Health Professionals are not typically collocated and identifying at a national level that these services as need to coalesce demonstrates the nationally agreed impetus for designing services such as CHANT. Finally, it is pertinent to note that this document highlights that more research is urgently needed on the management of HNC to improve the care of patients and that “multidisciplinary teams should be involved in relevant studies, and where appropriate patients will be invited to take part…” The recommendations suggest that:

> *“Coordinated local support teams should be established to provide long-term support and rehabilitation for patients in the community. These teams will work closely with every level of the service, from primary care teams to the specialist MDT.”*

It is of note that despite the PCC approach identified above, patients are only involved 'where appropriate' suggesting that a service could be designed around the assumed needs of the patients without consultation with the actual patients themselves. This sits in contradiction to the idealised patient-centered approach and could be construed as a very un-patient centred way to look at a patient centred service. Creating an evidence base, which documents the voice of the patient would serve to inform service design, where appropriate is perhaps detailed to caveat situations where patients are not easy to talk to. However, the challenge to this is that underheard groups would benefit most of resource time spent on understanding whether services work for them.

This is an incredibly important document in terms of setting the direction of travel for how this cohort of patients should be treated and the key steer from this thematic review is the importance of this multidisciplinary approach. In November 2019 NHS England published a report through its programme of work *"Getting it Right First Time* "(GIRFT). This was an **Ear, Nose and Throat surgery GIRFT Programme National Specialty Report [8].** A review of this report was conducted and it is important to note that HNC was acknowledged as not being the main focus of the report, nor is there a dedicated programme of improvement work due to a lack of good quality national data. It is cited in other GIRFT programmes and the National Clinical Improvement programme. The report noted that "There is a significant opportunity to use consultant out-patient time more effectively by making a more appropriate use of skill mix. There are opportunities for the wider multidisciplinary team, including specialist nurses and allied health professionals, to play a significant role in the delivery of ENT services." (p8).

The report highlights that Patient Reported Outcomes Measures (PROMS) should be collected for HNC surgery cases engaging the wider multidisciplinary team and feeding into the national PROMS programme as a useful indication of the outcomes or quality of care. Currently, PROMS calculates the health gains after surgical treatment using pre- and post-operative surveys in some elective surgeries (knee and hip operations). Patient completed questionnaires are collected from patients, which are then analysed alongside Hospital Episode Statistics Data (HES). Data provide an indication of a patient's health status or health-related quality of life.

5.3.3 OVERARCHING THEME 3: REGIONAL LEVEL - INFRASTRUCTURE ALIGNING WITH NATIONAL AIMS

5.3.3.1 THEME 3.1: Evolution of community-based cancer services

The National level documents analysed demonstrated that in order to achieve the national goals regional infrastructure is required and a key document for outlining how this is done was selected - **"Delivering World-Class Cancer Outcomes: Guidance for Cancer Alliances and the National Cancer Vanguard" [9]** outlines the ask of regions to facilitate the ambitions set out by an independent Cancer Task Force:

> *"for improving services, care and outcomes for everyone with cancer: fewer people getting cancer, more people surviving cancer, more people having a good experience of their treatment and care, whoever they are and wherever they live, and more people being supported to live as well as possible after treatment has finished."*
> *(Guidance for Cancer Alliances, 2016)*

This quote communicates the key theme around supporting more than just treatment and diagnosis but also to provide the patient with wider social and practical support and to ensure they are monitored and engaged with following treatment, during rehabilitation. The policy and process documents identified in this analysis demonstrate a will to evolve services into this whole pathway approach.

Creation of Cancer Alliances

A network called Cancer Alliances were set up to embed and cascade these ambitions. "*Cancer Alliances bring together clinical and managerial leaders from different hospital trusts and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. These partnerships enable care to be more effectively planned across local cancer pathways".* **(NHS England website)**

The guidance identified practical recommendations for addressing the core ambitions of the Cancer Task Force around prevention, early diagnosis, treatment, and care and living with and beyond cancer. This is governed by a number of key principles:

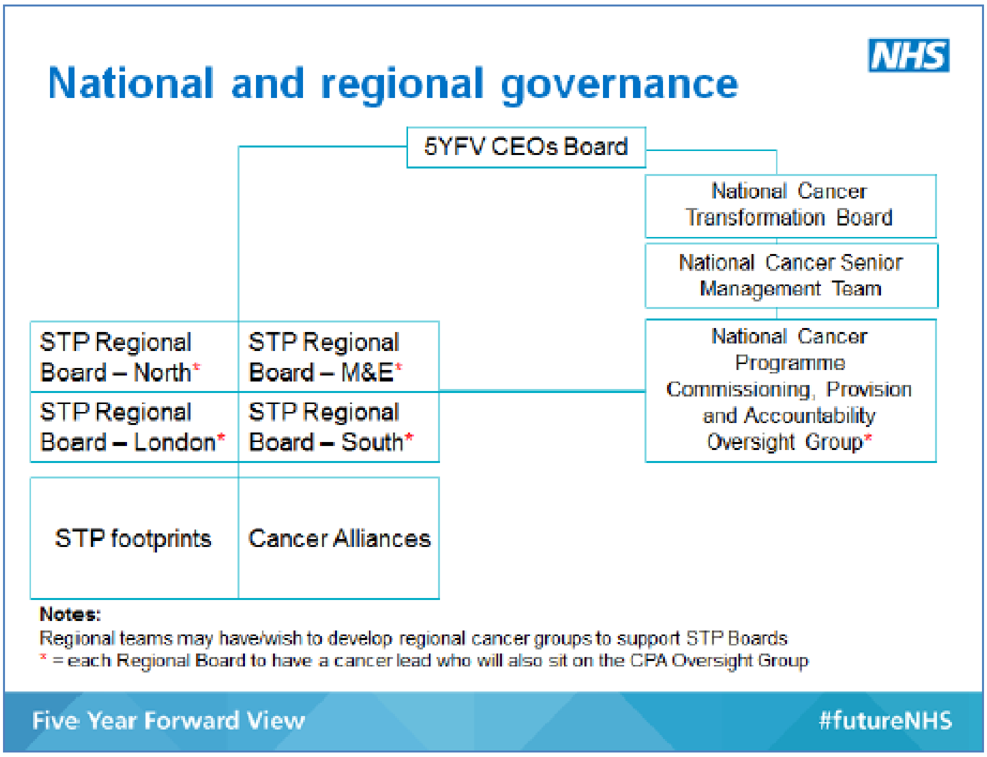
1. "Coordinating a new way of **collaborative working** across their locality. This will be aligned with STPs (see below) and focused on whole population and place-based

approaches to maximise the benefits from CCGs' and providers' baseline investments in improving cancer outcomes.

2. Managing and directing a proportion of additional funding in a small number of priority areas. The Taskforce found that funding was necessary over and above baselines, specifically: **earlier diagnosis, the Recovery Package and stratified follow up pathways.**
3. Aligning with **new service models for cancer**, for example radiotherapy provider networks as they are developed.
4. Working with the National Cancer Programme team on particular **national initiatives**, such as development of a national framework on roll out of the 28 day faster diagnosis standard; helping to coordinate targeted support to CCGs, in particular on improving performance against the 62 day standard and engaging with the 100,000 Genomes Project." **(Guidance for Cancer Alliances and the National Cancer Vanguard 2016 [9])**

Cancer Alliances were designed to *"provide a focus for improvement and leadership on cancer locally, but they were not expected to exist in isolation and need to work within a supported governance structures to address both geographical and population variation".* The proposed governance is captured in this guidance and summarized in the diagram below. The guidance emphasises alignment between the governance structures for other regional structures such as Sustainability and Transformation Plans (STP). The current priorities of the Cancer Alliances focus around prostate, lung, colorectal and breast cancers which may meant that actualizing the ambitions for wider cancer services may be challenging with constrained funding envelopes.

Figure 8: National and regional governance model



National and regional governance

5YFV CEOs Board

National Cancer Transformation Board

National Cancer Senior Management Team

STP Regional Board – North*

STP Regional Board – M&E*

STP Regional Board – London*

STP Regional Board – South*

National Cancer Programme Commissioning, Provision and Accountability Oversight Group*

STP footprints

Cancer Alliances

Notes:
Regional teams may have/wish to develop regional cancer groups to support STP Boards
* = each Regional Board to have a cancer lead who will also sit on the CPA Oversight Group

Five Year Forward View

#futureNHS

5.3.3.2 THEME 3.2: A personalised care approach

In a resource developed by the Southeast London Cancer Alliance entitled **"Your guide to personalised care [10]**, the intended regional approach in Southeast London is outlined. It is clear from this document that the intention is to provide regional guidance that takes a 4 step approach:

1. Personalised care and support planning.
2. A treatment summary.
3. Health and wellbeing information and support.
4. Cancer Care Review

The document highlights the importance of a support worker, often the clinical nurse specialist role and the importance of Holistic Needs Assessment and there is consistent reference to the patient working with the clinical team to ensure what matters to the patient is addressed.

Figure 9: Demonstration of patient centered approach and what matters to a patient

This document is a useful example of the approaches of regional teams and the intent of the Cancer Alliances to promote this way of working. The way they are expected to function is outlined in the next section.

Functions of Cancer Alliances

A Cancer Alliance board should be established with the following functions.

- “The Cancer Alliance board will bring together senior clinical leaders from across the whole pathway, along with appropriate senior commissioning and management representation.
- Members of the Cancer Alliance board will be senior local leaders who are able to make decisions on behalf of their organisation and are able to lead the transformation required locally to improve cancer outcomes.
- It is expected that members of the Cancer Alliance board will represent partner organisations in addition to their own. For example, an individual from a CCG would represent a number of CCGs on a Cancer Alliance board.

- Alongside the Cancer Alliance board, a robust mechanism for engaging systematically with wider stakeholders, such as patients, the public and patient organisations should be established. Other groups, such as task and finish groups on specific issues, may also be established." (Guidance for Cancer Alliances and the National Cancer Vanguard 2016)

"CHANT was initiated through the work of the former Southeast London Tumour Working Group. The working group, having been established in line with NICE guidance, to bring together clinicians, managers, commissioners and public health to shape services in support of the local population and patients" (**OPINION REVIEW - CHANT: In tune with clinical outcome guidelines [11]**) and therefore has been an exemplar in cascading the national, regional vision for such services. The next section of this document analysis therefore focuses on the CHANT level documents that were identified in this process to understand how this looks at local, place-based level.

5.3.4 OVERARCHING THEME 4: IMPLEMENTED INTEGRATED WAYS OF WORKING

Five documents were identified as relating directly to the local Southeast London Community HNC Team (CHANT) level of services. These were acquired during the period of ethnographic and interview-based research and inform the mapping of the service and its structure. On review a number of key subthemes focusing on the care pathway, daily activity and team structure. The website and a number of other key documents including the care pathway, a blog article and staff structure were reviewed. The Southeast London Community HNC Team (CHANT) provides support, advice and specialist rehabilitation for patients who have undergone treatment for HNC. CHANT is the only service of its kind in the UK, bringing specialist care and rehabilitation closer to the patients' home and therefore serves as a unique example of theory, policy aims and infrastructure discussed above.

5.3.4.1 THEME 4.1: Unique multidisciplinary community-based working

The CHANT team was established in 2010 and works hand in hand with the affiliated NHS Foundation Trust, which is a large city-based university teaching hospital, which is the regional

Cancer Treatment Centre for HNC. The Southeast London Community HNC Team, known as CHANT, is the first funded and dedicated community team in England. This provides a further bridge between settings of care and creates a more integrative approach to moving from hospital to home following a patient's cancer treatment. This was witnessed on numerous occasions, as will be seen in the next Chapter, with members of the CHANT Team able to communicate directly with the treating consultants, with the addition of the clinical nurse specialist who is based at NHS Foundation Trust but also participates in the multidisciplinary CHANT Team.

The care pathway

Services offered by CHANT include:

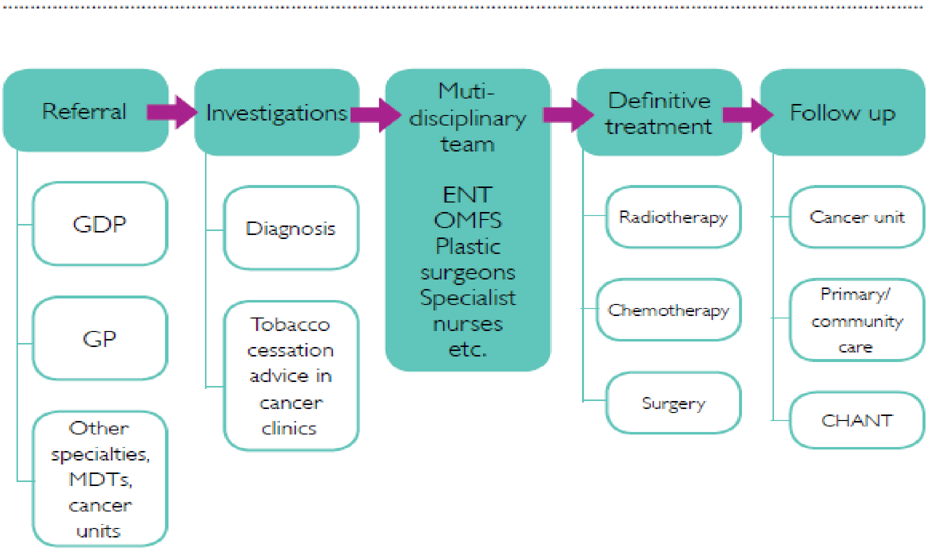
- Holistic needs assessment and care planning
- Advice, support and exercises for speech and swallowing problems
- Exercises for shoulder and neck problems following treatment
- Support and advice for patients with a tracheostomy, laryngectomy or feeding tube
- Help to increase independence
- Advice and support for breathing problems
- Emotional support for patients and carers.

CHANT is located across a number of sites but has one base site (clinic 1). However, the team covers the whole of SE London, and has clinics in each of the six boroughs of Lambeth, Southwark, Lewisham, Bromley, Bexley and Greenwich with the team moving from site to site organized by weekly clinical rotas. The team often visit patients in their own homes if there is a clinical need. The **CHANT Team structure [12]** is therefore a complex, multidisciplinary and mobile in approach (see Figure 12) comprising dietitians, speech and language therapists, clinical nurse specialists and physiotherapists, who are all specialists in HNC. Figure 11 outlines the process of referral that happens in the cancer care pathway and how the acute settings links to the Community based CHANT Team. The figure demonstrates how they reporting to primary care, palliative care are part of the pathway and that there are mechanisms that feed back into acute settings where needed. At a system level, effective design of the pathway is crucial to the embedding and success of a Community based intervention. CHANT serves 6 CCG's in South East London now within the London Cancer Alliance with a population of 1.8 million and the aim of the service is governed by the 6 key parameters (**Document [13] "Trust Presentation to Thames Valley CCG outlining process for setting CHANT service")**.

- 1. Reduced length of stay in the hospital
- 2. Avoidance of emergency hospital readmissions and A& E attendances
- 3. Planned and coordinated handover if hospital admission required
- 4. Reduced demand on consultant time
- Individually tailored support plan
- Seamless service delivery

In accordance with the NICE guidelines the service pathway is as below **(Article – OPINION REVIEW - Ming Wei Tang, et al. - CHANT: In tune with clinical outcome guidelines [11])**

Figure 10: NICE guidelines service pathway demonstrating key milestones and intersections



Approximately 570 new patients with Head &Neck cancer (including cancer of the larynx) are seen each year at Guy's and St Thomas' NHS Foundation Trust. The cancer treatment, patient management and subsequent rehabilitation is planned with a multidisciplinary team (MDT) and organised around NICE 2004 guidelines. Between 170-180 people require irradiation.

Those with teeth are seen after their H&N cancer diagnosis by a consultant in special care dentistry and Oral Surgery/Maxillo facial surgeons in multidisciplinary team (MDT) clinics. In these clinics decisions are made about the treatment needed (including dental treatment and tooth extraction) prior to surgery and irradiation. As radiotherapy promotes cellular and vascular change resulting in a low response rate in healing, simple extractions and surgical procedures in irradiated tissues can present high rates of complication such as Osteoradionecrosis (ONJ).

Daily activity

Some key statistics taken from document 12 highlight the following and set the scene for daily activity

- Referrals increasing year on year (40% increase since 2010)
- 275 new referrals last year
- Rolling caseload of around 200 patients
- 70:30 split between local clinics and domiciliary visits depending on clinical need
- Local clinics in each of the 6 boroughs
- Joint sessions where possible
- Visit to patients with altered airways within 24-48 hours of d/c
- Strong emphasis on training and support of community staff
- Referrals expected to continue to rise due to HPV, increase in late effects and demographic growth

A typical schedule involves (**Blog Article - A Day in the life of the Community HNC Team (CHANT) [14]**) the involves a Multidisciplinary Team caseload meeting where the current caseload and new patient referrals are discussed in detail as a group. An example of such discussions is detailed below:

> "Last week we were made aware of a patient called James when we attended the ward discharge meeting at the hospital. James was discharged home yesterday following a 3 week stay in hospital. As a result of his head and neck surgery James now breathes via tracheostomy tube in his neck; he has swallowing difficulties and requires supplementary

feeding via a tube in his stomach. Our physio and speech and language therapist agree to visit James en route to one of the 9 CHANT community clinics, to ensure he has all the appropriate airway management equipment and he is confident and competent in using them and thus safe in his own home. The phsyio texts James to let him know of our arrival time (he is unable to speak because of his tracheostomy).

……

The meeting highlighted 2 new patients completing six weeks of chemoradiation on Friday. They are booked into next week's post treatment clinic at the hospital to see our Dietitian and a Clinical Nurse Specialist (CNS), to provide early intervention of acute treatment related toxicities thus preventing admission to hospital."

The blog also highlighted that the team are able to respond to ad-hoc queries from their patient caseload, if a patient has an issue they may ring the team before going to direct point of contact services such as A and E or their GP. The team may discuss and then agree an action/management plan or refer immediately and call the relevant department or specialist base on their expertise and familiarity with the networks.

Members of the team will often visit patients at home if they are unable to attend a clinic or unwell. They may engage with wider community services to solve issues or support patient care at home. They may also attend a GP to allow closer to home care. The team may also spend a proportion of their day together as a team based in the clinic, seeing patients. This model is summarised in document **Article – OPINION REVIEW - CHANT: In tune with clinical outcome guidelines [11]**

> *"…the service has developed a local clinic model of delivery in each borough across South East London, in which all different specialties are able to work together in a multidisciplinary setting within one centre. Patients are now seen at home (accounting for approximately 30% of clinical activity) or in a local clinic (approximately 70% of clinical activity), based on the patient's individual clinical need, thus providing a more flexible, personalised and cost-effective approach."*

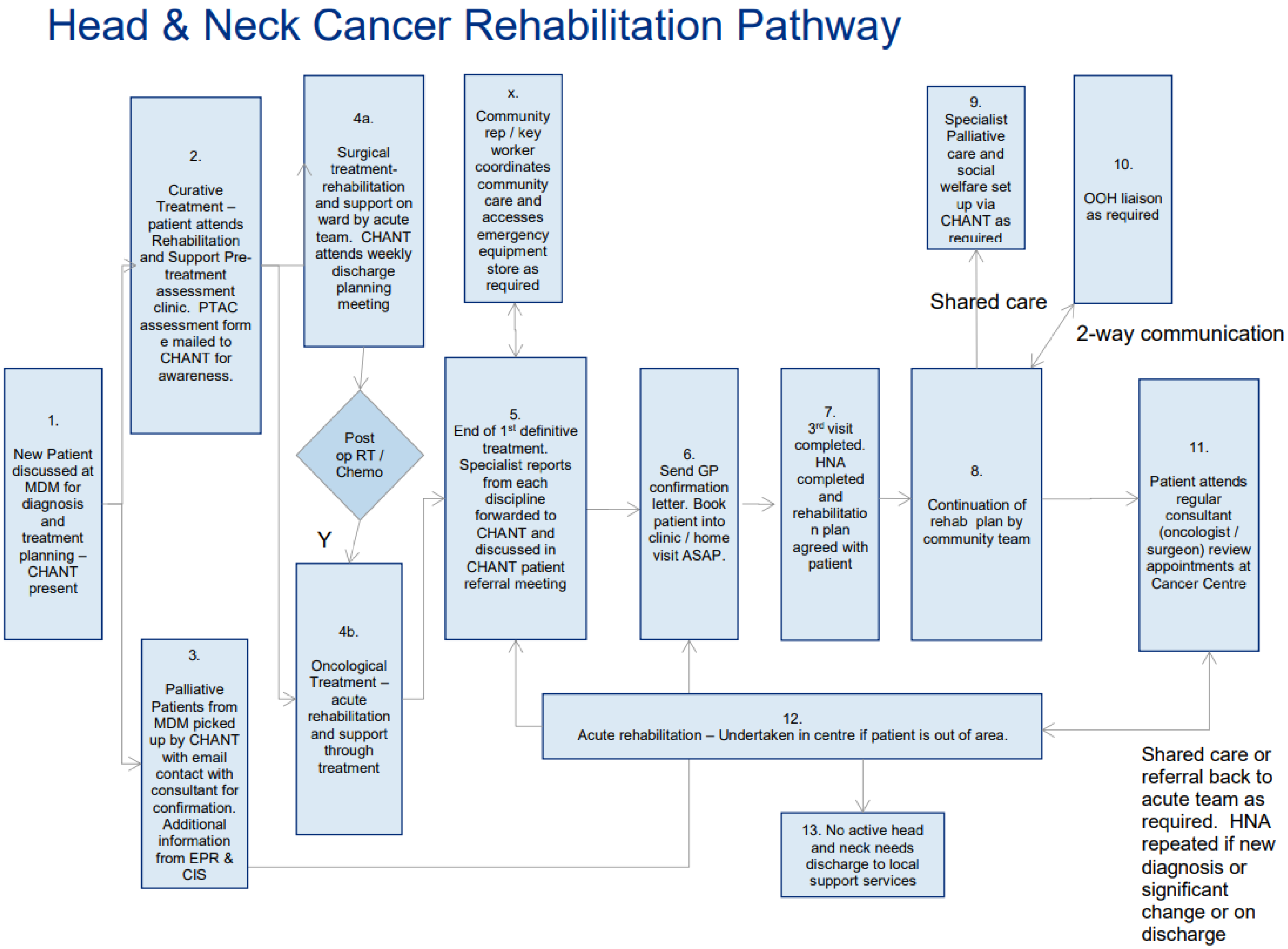
The team may also refer to other supportive frameworks such as the Dimbley psychological services, Food Groups (focusing on food choice, restaurant menu choices and social interaction around food and other patients) or the Living with and Beyond Cancer Day, which "promotes a healthy lifestyle, self-management and early identification/prevention of further disease to empower the patient." In between patients, the team will take phone calls, emails, case discussion, with regular communication between the admin team back to base and between the members.

Team structure

A detailed the patient pathway **(CHANT - Head & Neck Cancer Rehabilitation Pathway – flowchart [15])** can be seen in Figure 11 where acute treatment takes place followed by a referral to the CHANT team at stage 5 in the flow chart with a feedback loop into hospital/acute/consultant led service.

What this shows is both the vertical and the horizontal integration that was highlighted in the .policy paper and demonstrated by the CHANT team linking back to secondary care as and when needed, or through to primary care , and also consisting of a multidisciplinary team in their own right across a whole range of different, complementary, specialisms.

Figure 11: Head & Neck Cancer Rehabilitation Pathway



Head & Neck Cancer Rehabilitation Pathway

1. New Patient discussed at MDM for diagnosis and treatment planning – CHANT present

2. Curative Treatment – patient attends Rehabilitation and Support Pre-treatment assessment clinic. PTAC assessment form e mailed to CHANT for awareness.

3. Palliative Patients from MDM picked up by CHANT with email contact with consultant for confirmation. Additional information from EPR & CIS

4a. Surgical treatment-rehabilitation and support on ward by acute team. CHANT attends weekly discharge planning meeting

Post op RT / Chemo

Y

4b. Oncological Treatment – acute rehabilitation and support through treatment

x. Community rep / key worker coordinates community care and accesses emergency equipment store as required

5. End of 1st definitive treatment. Specialist reports from each discipline forwarded to CHANT and discussed in CHANT patient referral meeting

6. Send GP confirmation letter. Book patient into clinic / home visit ASAP.

7. 3rd visit completed. HNA completed and rehabilitation plan agreed with patient

8. Continuation of rehab plan by community team

9. Specialist Palliative care and social welfare set up via CHANT as required

Shared care

10. OOH liaison as required

2-way communication

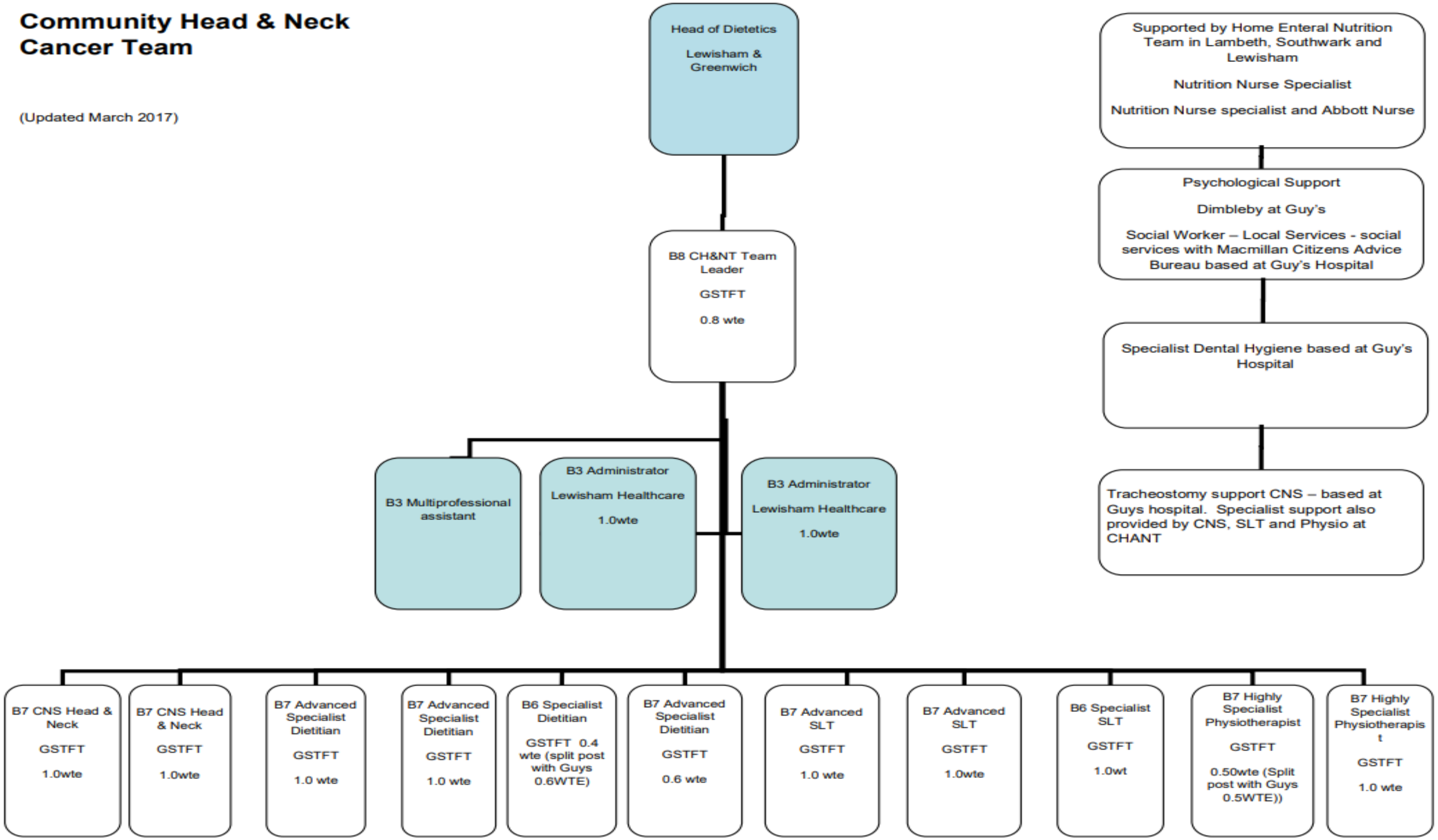
11. Patient attends regular consultant (oncologist / surgeon) review appointments at Cancer Centre

12. Acute rehabilitation – Undertaken in centre if patient is out of area.

13. No active head and neck needs discharge to local support services

Shared care or referral back to acute team as required. HNA repeated if new diagnosis or significant change or on discharge

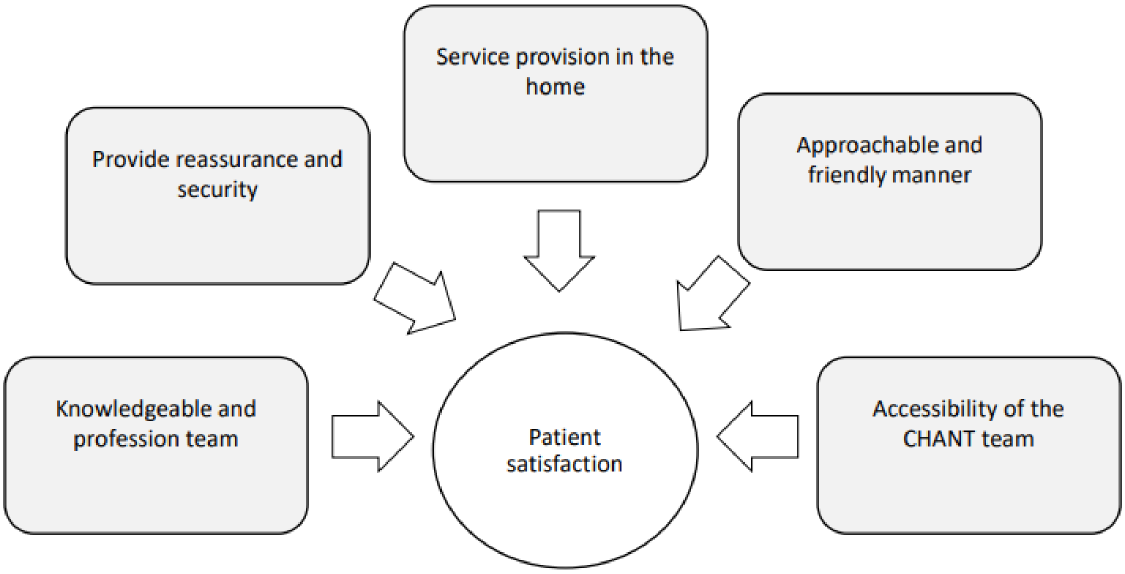
Figure 12 – CHANT team structure showing the diverse specialists that work as part of the chant team



In the opinion piece (document [11] of the analysis), the feedback of patients is summarised below. This diagram shows the areas evaluated as contributing to patient satisfaction and summaries some of the core elements of the service that are described above. This thesis will explore this in more detail and will start with the next results Chapter which summaries the observations taken over a number of years.

Figure 13: Reported reasons for high patient satisfaction with CHANT services

(colour modified from Figure 7 in Tang et al. 2016)



Document [12] "Trust Presentation to Thames Valley CCG outlining process for setting CHANT service" further highlights that lessons learned from this model can only be improved by focusing on a number of areas including "*A true understanding of how our patients live*" have clear baseline data prior to service start and to "*Build in research element from the outset*". This thesis therefore aims to produce this narrative and form part of the research rigour that may inform the development of CHANT and other similar services. This thesis seeks to unpick, through the lens of observations of patients and the CHANT Team and through the patient narrative directly, the effectiveness and impact of a service that purports to be based in realizing the integrated, community based multidisciplinary, person-centered approach to cancer treatment in the NHS.

5.4 SUMMARY

Within the context of the documentary analysis presented in this Chapter the second and third stage of this research took place in community-based settings where HNC rehabilitation was provided by a local team of experts. This Chapter enabled the mapping of the social space in which cancer care is provided within the UK NHS system. Drawing on the analysis presented above we can start to map HNC rehabilitation and CHANT services sitting within a healthcare system (the NHS) which has National guidelines on the provision of care (NICE) which Health Care Professionals are required to follow.

The health care system is currently divided into primary, secondary and tertiary care settings but looking to integrate care that is place based with community teams overseen by Integrated Care Systems (ICS). The document analysis highlighted that within national regional and local policy there is a clear direction of travel for multidisciplinary community-based care. This is seen as the more patient-centered and most suited to the complex needs of the patient. However, this is potentially more resource intensive and requires joined up team working that is often difficult to implement at the beginning – moving away from silo working and specialist settings being located in separate areas. Therefore, there is a need to reflect on whether this truly improves the patient and treatment experience and therefore requires more work such as this thesis to solidify and justify this approach. Furthermore, these aspirational ideas are not yet realized widely, and it is therefore crucial to understand if there is an intention to support cancer alliances in the future and if this is supported by an evidence base of successfully implemented services.

The results in this Chapter therefore demonstrate that whilst there is national and regional intent create integrative models of care with multidisciplinary approaches, in reality these models are few at a local level. CHANT is a vanguard example of a community-based approach, meaning that they are innovating, developing, and testing new ideas in models of care. CHANT has evolved out of the necessity to work in this way with the population it serves, placing all phases of care in a co-located space with team interaction. It is an unusual example of a realised national ambition.

This document analysis reveals a gap in knowledge about why these national, regional mechanisms have not facilitated wider local adoption and prompts questions about understanding the successes and challenges of the CHANT service. Both a patient and a professional view of this would be illuminating and this in-depth assessment of the policy measures now provides the context that influences the experience for patients. The remainder of this study therefore focusses on capturing the experiences of patients who participate in this service.

The analysis of these documents suggests that patients accessing rehabilitative care following treatment for HNC should be able to access a community based local multidisciplinary team who are able to meet their varied health and allied health needs. The local system should be supported but regional and national level systems, which enable this type of localised integrated systems of care. The analysis further suggests that CHANT is a service, which has been designed purposely to function in this kind of way and can therefore be potentially emulated with the right infrastructure. However, the experiences of patients' need to be understood further to solidify if this model is successful and CHANT is a successful vanguard. The CHANT level documents themselves highlight that to understand the impact of this service further research is vital **[12]**. Therefore, interactions between patients and healthcare professionals within the CHANT service are the focus of the next chapter where the clinical observations are presented.

What is interesting about the policy documents identified here is that the majority of them, certainly at national and regional levels are aspirational rather than plans that have actually been out in to place. This is what makes the CHANT services so interesting as an exemplar, because it is actually in place and providing care for patients that meets many of the aspirations set out in the policy documents analysed here.

6. PARTICIPANT OBSERVATION OF A COMMUNITY-BASED MULTIDISCIPLINARY APPROACH TO REHABILITATION

This Chapter details the observations that were collected in a number of locations linked to the community based HNC team services. The aim of the observation phase of the study was to glean an understanding of the complexities and physical reality of the service and pathway. Observations allow a unique insight into the experience of a patient and facilitates a view of the service that provides a third perspective that is outside of the professional and patient accounts of the process. This layer of research also provides a type of triangulation in the research that strengthens the account of the experience of those navigating this service through an understanding of the physical environments in which the services are provided. This ethnography allowed acknowledgement of the nuanced, social implications of diagnosis with HNC and undergoing treatment and rehabilitation.

As explained in Chapter Six, in order to uncover insights into how patients navigated this often-arduous journey, the observations sought to focus on two key questions which align with the overarching research questions (2-4) in chapter Three:

What are people's experiences of the care pathway for HNC, in relation to the settings and clinical interactions? *(Chapter Six: results, Chapter Six:8.2.2 discussion and key findings)*

a. Is the community integrated care model set up as the national and regional policy outlines?
b. How do participants experience these settings and traverse a pathway designed in this way?

This approach enabled a unique and detailed exploration of the full narrative of a patients' journey, looking at the processes and practical aspects. This study sought to identify common themes that are associated with patient's experiences of living with HNC. Acknowledging the power dynamics that are in play during treatment, between different actors. The setting of this ethnographic work can be considered to have taken a closed setting (vs open), overt (vs covert) active (vs passive) approach, and the rationale and outline of this approach is detailed in the Methodology and Methods Chapter, section 4.2.1. Furthermore, the data collection processes are outlined in chapter Four.

6.1 PARTICIPANT OBSERVATION

The observations took place in a number of settings. The Table below (Table 6) shows the variety of settings within which the observations were undertaken. The group settings were two very different environments for the patient. In one, the patient is not present and is discussed by a range of clinical professionals as a ‘case’. In the other, patients take an active role in the sessions learning about different aspects of rehabilitation. This group is led by members of the CHANT team so is also professional led. The individual consultations take place across four clinics with a range of healthcare professionals involved in each setting and these settings occur at different times in the patient journey. The initial group settings were observed within the hospital setting and taken very soon after diagnosis and during the treatment phase.

The individual consultations were all post treatment and during rehabilitation. This is identified, as it is clear from the observations that are described in the next section, that rehabilitation consultations are very different to the early treatment phase. However, often the staff work across settings (rehabilitation and treatment). The rehabilitation team do not change in composition or rotate, providing consistency for the patient. This ensures the patient is not repeating their issues, concerns or history to many different health professionals. This strength is compounded by the overlap in the staff between treatment and rehabilitation, which adds another layer of understanding and consistency for the patient. Specialists have seen the patient throughout the journey of treatment into recovery. This contrast is useful to see in understanding the significance and effectiveness of how rehabilitation is designed.

Table 6: Research settings

	Type of setting	Function of setting and actors involved	Timeline in patient pathway
MDT Reviews and patient groups	Hospital Recall visits – Morning follow up clinic	This clinic sees referrals from the oncology team who identifies patients who may require dental work following a diagnosis of HNC. Patients range from having a good prognosis of complete recovery to extensive cancerous tumours and complications.	Immediately following diagnosis (within days of receiving confirmation of diagnosis)
	Multidisciplinary Team Meeting	This meeting contains only clinical professions and incorporates all the points of contact a patient will have already experienced and may see in the future. Each patient is presented as an individual case study with a presentation led by the treating consultant.	Carried out during early diagnosis period whilst in early to late treatment phase
	Living with, and Beyond HNC support group	This is a support group run by members of the CHANT team to support those who are in less active treatment and are in the process of rehabilitation, learning to adopt new ways of communicating and eating. The group runs periodically and meets at the Waldron centre. The groups are a small cohort of patients who can interact and garner peer support.	This is attended after treatment phase and during rehabilitation and beyond or during rehabilitative treatment phase.

Individual consultation	Friday morning oncology clinic with Consultant Oncologist and Dental Consultant	This is often the patient's first experience of a discussion about HNC. It is at this meeting that consultants offer a first diagnosis of cancer and explain the future pathway of the treatment of cancer. At this stage a dental assessment is made and they are also introduced to their personal, clinical specialist nurse. This the point of contact the patient is provided with should they have any problems. A "holistic patient questionnaire" is conducted in order to understand the wider patient's needs. It may be useful to further analyse what this particular questionnaire covers.	This is attended after treatment phase and during rehabilitation and beyond or during rehabilitative treatment phase.
	Tuesday AM - Recall visit – HNC	This clinic is based in the same location as the Monday Dental clinic however the patients here are seen after their treatment (radiotherapy, surgery, extractions and/or chemoradiation). The patients are seen by a consultant and they are asked about the healing of any extractions they may have had.	This is attended after treatment phase and during rehabilitation and beyond or during rehabilitative treatment phase.
	Clinic A – CHANT Team	The Clinic A provides a wide range of community services available to anyone living in the surrounding area or registered with any local practice. These services include reproductive and sexual health (family planning), rapid HIV testing, antenatal care, phlebotomy (blood samples), district nursing and health visiting, leg ulcer clinic, sickle cell care, enuresis (bed wetting) clinic, community dentistry, podiatry (foot health care), smoking	This is attended after treatment phase and during rehabilitative treatment phase.

		cessation groups, speech and language therapy, community diabetes team and school nursing. The CHANT team are based here alongside the other teams	
	Clinic B – CHANT Team	This clinic is based in a Hospice and exists to promote and provide skilled and compassionate palliative care of the highest quality. Whilst running as a hospice this building is also a central point for those seeking rehabilitation with CHANT being one of a small number of community outreach teams.	This is attended after treatment phase and during rehabilitation and beyond or during rehabilitative treatment phase.

6.2 OBSERVATION ANALYSIS

The details of the analysis process are provided in the Methodology and Methods Chapter, however as highlighted earlier, observations spanned a number of years and took place in two phases, the initial observations in the hospital setting were taken during early scoping in 2013 and community-based observations took place from 2018-March 2020. In total approximately 40 hours of observation (over 60 including interview sessions) were carried out across the various settings, with most observations conducted in sessions of approx. 2-3 hours (observing an afternoon or morning clinic) that started with sitting with the CHANT team (in their staff room) preparing to move to the clinical rooms.

The participants in the research were involved in different ways too, weaving themselves through the study through different pathways. Some participants in the observations were later interviewed and re-interviewed, some were only observed, others were recruited via the team who discussed the project with them beforehand. It is therefore helpful to understand this diversity of participation approaches and we begin this by mapping the patient journey. The following Table 8 demonstrates the possible pathways that those participating in the study took. Later, in the interviews the participant type 1 will be discussed so that we can view them in the context of the whole study and the unique and extra-layered narrative that comes with this.

Table 7: Participant journeys

Participant type	Activities conducted
1	Observed with MDT In-depth interview Follow up Interview
2	Observed with MDT

	In-depth interview
3	Interviewed but not observed in consultation with MDT Interviewed with recruitment via MDT team
4	Observed with MDT No interview

The next section sets out the findings of group settings and individual consultations. They are presented in two different formats as data gathering and analysis of these settings were carried out in slightly different ways and therefore it is helpful to consider the anthropological approach that was taken for data gathering followed by analysis in these two settings. For details about how the data was collected and therefore analysed, see the methods and methodology Chapter. In the next section we will begin with the group settings to mirror the order of the process taken during research.

6.3 FINDINGS IN GROUP SETTINGS

As described in Table 6 observations were split into two different types. These were group settings and individual consultations. The findings are presented in this order. First, the findings outline the early experience of patients in the form of the morning recall visits, and then the multidisciplinary team briefing, which captures staff decision-making, occurring early on in the experience. Finally, the findings present a thematic analysis of the individual observations.

6.3.1 MORNING RECALL CLINIC

On commencing this research project, early observations involved immersion into the hospital setting from which this cohort of patients are referred. This involved observing a recall visit and then a multidisciplinary team briefing led by treating consultants and healthcare profession teams. The recall visit is one of the first encounters that patients have with the cancer team having received their diagnosis. This often happens very early in the patient's journey, prior to the start of active treatment.

These observations enabled an understanding of the settings in the hospital where patients undergo treatment, and as the first part of the ethnography serves as a way of *"attuning with the cultures and the wider institution"* (Featherstone and Northcott, 2020b p.21) in which patients experiences are embedded. These hospital settings were notably clinical, neutral and intimidating in their non-familiarity.

The recall clinic is set up as a series of pods (approx. 15), which resemble a dental consultation room in an open plan style. The lighting is fluorescent, and the area feels sparse with patients looking visibly uncomfortable and apprehensive. There is very little privacy. Health professionals are milling and busy but attentive and clearly aware that putting the patients at ease is key to ensuring that they are calm. An example of a similar clinic is shown below:

Figure 14: Example of dental extraction clinic (dental extraction clinics - Bing images)

Patients in this environment were often struggling to deal with the diagnosis and some of the key elements noted from observations were:

1. The environment is very clinical and potentially intimidating if not familiar with that setting.
2. There are a large number of health professionals although the team were very adept at spotting the fragility of the patient and therefore slightly changing their approach.
3. There is a large volume of information supplied at these consultations
4. This is an invasive and life-changing juncture for the patient where teeth are removed which happens very quickly.

Josh attended this clinic during observations. His observed consultation really highlighted the large volume of information supplied and the speed at which diagnosis moved to life changing treatment. Josh had no previous radiotherapy but was scheduled to undergo chemotherapy. He was slightly dentally anxious and had only very recently been given a diagnosis of cancer (approx. four days).

He had previously smoked but had quit 16 years ago so was emotional about the development of HNC. He started by telling the dentist "it's not me imagining it…feels like something falling through a hole" and felt that their teeth needed some attention. The Dentist confirmed that this was a filling that has been removed and that he would require a further extraction. Josh was told that radiation treatment can sometimes affect the back molars and result in the development of infection. The recommendation is that such teeth should therefore be removed as precaution. Josh was informed that chewing may be a problem if the back molars are removed and that they can try local or general anaesthetic.

Josh expressed a lot of concern about eating and what the aftercare would involve and was clearly vulnerable, taking advice from the dentist. There were a lot of people involved in the consultation, but the patient seemed comfortable with this. It was noteworthy how quickly a large amount of information needed to be assimilated by a patient in a very short period of time within the context of the consultation and on the back of a life changing and very scary diagnosis. The patient may go from not realizing they will have teeth removed at all to having up to 8 removed during that consultation.

Another consultation demonstrated how traumatic and invasive it is for individuals. Marilena had cancer of the sub-mandibular gland and had just undergone radiotherapy for cancer of the kidney. She was very upset and quiet and for this reason the dentist decided that they would not undergo any tooth extractions that day. The consultant identified that 8 teeth would need to be removed and that this needs to be conducted before chemotherapy. Marilena asked *"does it all have to be done in one day",* clearly struggling with the extent and impact of treatment.

These examples highlight the intensity and experience of patients entering this environment. The speed at which potentially life-altering decisions are made, treatment received following the diagnosis and the environment in which this occurs, give context for this early part of the patient journey. Both of these examples raise questions about the nature and possibility of fully informed consent in this context. How aware were these patients that having teeth removed was optimal and therefore did they understand the consequences and impact? This issue has been explored (Clough *et al.*, 2018) and is examined from the patient perspective in the next Chapter. The next section moves onto the multidisciplinary team meeting that happens in conjunction with this clinic. In this meeting, no patients are present, but the MDT decide the treatment plan for patients.

6.3.2 MULTIDISCIPLINARY TEAM BRIEFING

The Multidisciplinary Team briefing took place in a meeting room in the clinic and was very well organized with key images being displayed and annotated by the consultant radiologist as the remaining members of the multidisciplinary team listen. The group are then asked for further comments and the treating consultant asks for advice on any issues they are not sure of. There is a real feeling of multidisciplinary working here with everyone free and able to contribute their perspective having had different experiences of the patient and being able to contribute their past knowledge to help best treat each individual. Whilst representatives of the MDT team are present, the cases were often discussed by a few individuals and often seemed to be medic led.

The meeting consisted of 15 cases which does mean it felt like the team were having to get through each case very quickly. As an observer it was apparent that incredibly serious and nuanced, subjective decisions were made in these contexts and had to be made rapidly with no input from the patient, reiterating the feeling in the recall clinic described above. This emphasised the urgency of treatment and the intensity faced by the patients who are part of this treatment. Observing these early treatment settings and discussions provides insightful context into what patients undergo before active treatment and rehabilitation.

The first two group observations took place prior to treatment and within a hospital environment. The key aspects observed were the relative anonymity and detachment of the encounters and the sense of urgency and speed. The third group observation took place in a very different environment, during the rehabilitative phase of care, with active personalised involvement of the patients and at a speed designed to facilitate the active participation of everyone.

6.2.3 PEER SUPPORT GROUP

As part of CHANT services, supportive elements are provided for patients such as psychological services and peer support groups. As part of the observational work in this study, the CHANT led peer support group was observed. This group was named *"Living with and Beyond HNC"*. The meeting lasted approximately 3 hours (10:30-14:15) and was held at the community-based site.

The observed meeting was attended by a number of members of the multidisciplinary team (5 members who shared leading focussed agenda items). The group was small, approx. 6-8 patients at different stages of their treatment and recovery. The meeting was held in a small room and tea and coffee was provided. Most of the attendees did not or were not able to participate in the refreshments. Attendees were able to come with partners or support workers. The meeting agendas were patient centred and an example is provided below:

Table 8: Agenda for Peer Support Group

• Welcome with tea and coffee (Dietician)
• Self-management (CNS)
• Dental (Specialist dentist in special care)
• Living with the Emotional impact of Head & Neck Cancer (CNS)
• Physical Activity (Physiotherapist)
• Dietary changes/Communications and swallowing (Dietician and SLT)
• Finish and closing comments • Evaluation (Team Dietician)

The meeting highlighted some elements of care that are very tailored to supporting this cohort in a multidisciplinary way and that each patient has a slightly different journey. Each patient is assigned a Clinical Nurse Specialist who can advise on physical, psychological, and practical elements of rehabilitation. The meeting focuses on supporting patients into their “new normal” highlighting that the impacts can range from skin changes, mouth and throat changes, pain management, peripheral neuropathy to hearing loss. In this session, a specialist dentist was also addressing an often-traumatic component of treatment for HNC patients and letting patients know that they would all have reviews at dental clinics during rehabilitation. This group notably signposts to other supportive services such as Dimbleby (psychologist support), Men with Cancer group, Fear of recurrence and other HNC support groups. Some of the interview participants mentioned this peer support group in their interviews and talked about how this combatted the isolation that came with the treatment and rehabilitation process.

What stood out most in this session was the groups clear need for emotional support. Those attending discussed how the HNC pathway was “brutal” and “toxic”, with treatment quickly compounding this feeling. The brutality felt by patients at the dental stage, was perhaps extenuated by the fact that this was the first invasive treatment a patient faces and therefore perhaps is overly perceived as the most painful, and a shock to the system. Later treatments are set against a backdrop of more familiar context and understanding of the road ahead. Many of the patients don’t necessarily feel relief when they get to the rehabilitation stage of their treatment because of the complex issues that they are dealing with, and they are still reeling from the intense treatment and the side effects.

Themes in discussion really focussed on fear of reoccurrence, processing the treatment period, and how to find your old self as well as acknowledging the impact on families and partners, and the impact of the dental element feeling the most brutal. As a researcher, observing this group provided an incredibly raw and real perspective of the immediate aftermath of treatment, setting the scene for the challenges faced by patients, which would then be witnessed in the individual consultations and articulated the patient narratives during the in-depth interviews.

6.4 FINDINGS FROM INDIVIDUAL CONSULTATIONS

In this section, observations are written up as short patient stories. Participants’ accounts were characterised by a number of recurrent themes. Seven stories have been selected to demonstrate these themes. They are chosen as they reflect themes and pertinent issues that were seen across many of the individual consultations. They are presented as examples of a wider data set that has been coded. These stories are presented next.

The stories of Barbara, Daniel, Sangita, Angus, William, Roger, and Claude are presented, who are a mixture of ages, and the majority are male which matches the profile of HNC patients attending this service. The demographic information of the patients involved in the stories are not listed unless this information was elicited by the patient during the consultation. Aside from introductions, consent, answering questions by the participant and outlining details of the study, there was no conversation between the researcher and the participant. Whilst some ethnographic work may involve informal interviews as part of the observation process, this was considered beforehand and was excluded so as not to disrupt the process of consultation.

The Table below identifies the themes that reoccurred. This is then followed by the patient stories. Each theme is highlighted in a different colour and then the relevant sections of each of the seven case studies are highlighted in the corresponding colour to illustrate how the themes merge and interact within the consultations that were observed. The themes are then discussed in more detail in turn, with reference to the patient stories.

Table 9: Reoccurring themes identified in the observational data

Theme	Summary description
Networks	The importance of trusted support networks which included friends, family, and connected medical teams. These networks helped them create alternative coping mechanisms when food and communication were unavailable
Changes to routine	Often capturing drastic changes to individuals routines and disrupts work, family and social routines dramatically. They may also have difficulty in adhering or settling into new routines and adhering to recommendations from healthcare professionals
Complexity of symptoms and care needed	The sheer number of symptoms and variety of symptoms that come with rehabilitation in this area is a consistent theme in the observations and the breadth of symptoms is also striking. The observations highlight the need for the MDT approach and the benefits of situating the specialists together in the same consultation.
Difficulty eating and speaking	This is something that is very pronounced in HNC and in contrast to other cancer sufferers who they may be able to utilise talking therapies. Furthermore, eating is often a key part of recover for other cancer suffers whether it be about

	maintaining a good recovery through consistent nutrition or whether it is engaging in the social element. Therefore, talking and eating is often a coping strategy for those suffering from cancer or chronic disease.
Loneliness and mental health issues	Individuals engage with the team about all aspects of their life and it is clear that many are grappling with the mental impact of the hugely invasive treatment and drastic changes. There are often expressions of isolation and loneliness and struggling to accept their new self.

BARBARA

Barbara came to visit the team, she was clearly keen to engage and catch up, cheery and positive as she sat down with the Dietitian and the Nurse. Her demeanour did not initially give away any signs of the turbulent journey she had recently been on. She sat and took off an elegant silky scarf, revealing the first signs of having recently had her feeding tube removed and the site was healing.

The scarf had seemed so innocuous but was purposeful and meaningful, a cover of the wound of her recent surgery. The Nurse noted that she would monitor the area to make sure it didn't get infected. In order to heal the wound, skin was removed from her legs to be transferred to her throat, which she now covered with the scarf. The Nurse initiated a discussion around the option of a plastic surgery consultation.

In meeting Barbara at this point in her journey, I was able to see a window into how Barbara wanted to present herself to the world. The scarf and plastic surgery captured her resilience and desire to be who she had always been. There was a self-consciousness of her scars and improving this was as important as any other part of the rehabilitation process for her.

As she relaxed into the session, Barbara talked of the pains in the arm every day, incessant, since surgery and the Nurse suggested that she should see the Physio within the CHANT team. There was a fragility in her account of her symptoms, at points speech verged on tears. It felt that whilst she talked of the physical pain, it reflected the emotional pain she also experienced. The Nurse said a referral for physio could be made quickly, as the pain Barbara was experiencing could be a result of the neck surgery she had recently had. Her reaction was muted, but there was a grateful, resigned nod of acknowledgment. The nurse suggested that Barbara takes Ibuprofen and gel for the site of the pain, and this was likely to be something she would need for everyday life in the near future.

As was the case with many consultations, regaining eating habits was a focus. Barbara explained that she felt she was slowly getting back to eating normally but was just blending her normal meals. She seemed motivated and wanting to return to her former life. She had a calmness and control in her exchange at this point. The Dietician suggested that she attend a food group run through CHANT, which she was keen to attend appearing willing to reach out for support and share her feelings.

Barbara reflected that she felt some foods tasted different since treatment and that she was rediscovering what she liked to eat. As her diet was mostly blended, she felt it was low in fibre and that she needed extra fibre to prevent constipation. The Dietician also suggested that she could take fortisip fibre for additional intake.

There was a sense that she was informed and motivated to do everything she could in terms of her treatment to try and get back to who she was before the diagnosis. She described a busy schedule and spoke of a network of friends and family that supported her. She was interviewed as part of the study but had to leave and return to finish the interview as her daughter had arrived to pick her up

DANIEL

Daniel was a quiet, retired man with a close family and supportive wife, who accompanied him to his appointment. He came in, seemingly a little reticent and shy but with a stoic, matter of fact, almost ambivalent, manner in his exchanges. This sense of ambivalence, perhaps more of a numbness, or a reaction to finding himself in this situation.

His wife did most of the talking through the consultation, meaning Daniel didn't need to advocate for himself, he sat back letting her take the lead. Although Daniel's speech was understandable it had been significantly affected by his treatment and he seemed a little self-conscious, stuttering, pausing and stumbling as he tried to speak. The consultation was with the Dietician, Speech and Language Therapist and Nurse. Like some of the other patients I observed there was a sense of isolation and struggle in his silence and he was unable to talk fluently without effort.

The dynamic between him and his wife was affectionate, but she came across as very much the mitigating force behind his recovery. She was stern but caring in her tone, describing Daniel's behaviours and correcting his recall at times. Daniel and his wife exchanged many disagreements during the consultation, and it was notable they were disagreeing on how quick his recovery should be and what was the best way to approach gaining weight and eating.

It was interesting to note that their perceptions didn't always align, there was a sense that his wife didn't feel like he was trying hard enough sometimes. Daniel was composed in his delivery when asked if there was any pain or other issues, he said that he'd been taking paracetamol for some pains around the surgery site and experiencing bouts of dizziness. These potentially distressing symptoms were conveyed factually and without drama. Daniel and his wife seemed to mirror different approaches to the recovery, the conflict between striving and pushing for recovery, (his wife), and acceptance of new limitations and identities (Daniel). Whilst appearing in conflict the two approaches worked in parallel.

The Speech and Language Therapist discussed doing daily exercises to strengthen his swallow. He was told that this would involve setting aside time at least 5 times a day to complete the exercises and Daniel quietly agreed to do this before the next visit.

Daniel was finding eating difficult and at this point he showed a more emotional reaction in the consultation, speaking to the dietician and saying that "things don't seem to be going down" gesturing to his throat. He described the food burning when going down his throat and this was discouraging him from trying to eat more. Speaking about food was where Daniel became most distressed, physically and emotionally, trying to express how he was feeling and the difficulty he faced eating enough to remain healthy. Daily, he ate a lot of custard and cake and complan shakes as well as porridge. He currently drank 5 fortisips a day and confirmed opening his bowels normally. He appeared physically weak and his weight was decreasing. It had gone down by 3kg since his last appointment which was a physical indication of his struggle to eat.

His wife highlighted that she was encouraging him to eat normal meals with the aid of painkillers and the team agreed that this would be a useful strategy until the pain eased. Daniel didn't seem keen on doing this but agreed that he would try to eat with painkillers. There was a sense that his struggle was being downplayed.

SANGITA

Sangita was a small lady in her 70s who came to her appointment accompanied by her daughter and grandson. Her daughter translated for her into Hindi. They both came in smiling and with the small boy standing quietly next them, he settled himself on the floor playing with a toy. Sangita's daughter started by mentioning she had always accompanied her mother to appointments and for procedures, addressing this point to me directly. The team knew the daughter and grandchild and so it was apparent that Sangita was surrounded by close family who had been with her throughout. They were clearly pivotal to her accessing this treatment, given potential language and cultural barriers. The consultation was with the dietician, Speech and Language Therapist and the Nurse, filling the small room with people.

Sangita had just finished her chemotherapy and she still had a central catheter line from her treatment. The consultant was due to remove this the next day. She didn't have any pain in that area and was not taking any painkillers, although she was on anti-sickness medication. Sangita communicated symptoms she was experiencing through her daughter, including having thrush in the mouth and feeling constantly cold but said she felt like things were improving.

She had a clear optimism about her. Communicating through her daughter, every difficulty was matched with a "but she feels ok". The Nurse reassured her that problems regulating body temperature and thrush were symptoms many patients struggled with following chemotherapy and would subside. She had had 6 rounds of chemotherapy and was waiting to see whether she would require radiotherapy). Sangita was relaxed and I observed her willingness to be guided and cared for by the team, being reassured by their advice. Although she spoke through her daughter, in the first half of the consultation, Sangita's facial expressions showed no signs of any obvious distress, pain or anguish. She was not, however without discomfort following chemotherapy, having pain and obstruction when eating. She did communicate this through her daughter, raising initially that there was a tickling when she tried to eat and the tube was sliding about but that she was able to swallow.

She was currently nil by mouth. Her daughter mentioned she was keen to start to eat again. Sangita had put on 2kg since their last appointment with the CHANT team and was happy with this progress (45kg to 47kg). The team agreed she would need steroid cream for the site of the tube and would need to be careful to prevent infection. At this stage of the consultation Sangita did became a little agitated, tapping her daughters arm to communicate through her, that she wanted the feeding tube removed as soon as possible and asking "when". Showing her enthusiasm to return to eating properly.

The team explained that another X-ray would be required first. I observed from her reaction, in comparison to the other issues she discussed that this was clearly a priority. The fortitude and endurance, observed earlier in the consultation was replaced with a sense of urgency and frustration. This was a must for her.

ANGUS

Angus arrived at the clinic appearing out of breath and a little flustered. On settling into his chair, he exchanged pleasantries with the team, who were the speech and language therapist and physiotherapist. However, it was apparent his speech was notably affected by his treatment as he gagged throughout the consultation.

As part of his treatment Angus had some of his tongue removed and a tissue transplant from hi arm, to replace the section of his tongue. It left him having to learn how to make sounds and adjust to a new tongue, that felt different and alien. He was visiting the team early in his journey to discuss how his transplant had settled. He needed his tongue to acclimatise to the new tissue, transplanted from his arm. His speech was very good but the transplant site was making him gag and he could feel the loss, he was clearly in discomfort and it was all very new. This was the beginning of a journey of hard work to retrain his tongue.

The Speech and Language Therapist highlighted that the Consultant could recommend laser surgery and further reconstruction if it shrinks or remains uncomfortable. There was also the potential of liposuction. Angus needed to heal some more before considering these options though. His teeth and left side were feeling more normal. He took some paracetamol which got stuck. The team suggested they could do an x-ray of the swallow to see what was happening. He was to see the surgeon for advice on how to manage the bulky feeling of his transplant site as this was making his tongue feel odd in his mouth. His arm was healing but the area was still sensitive, and he was keen to find out what the monitoring plan would be.

Angus explained he had struggled previously to make sounds and he could not say ee vowel sounds or "high vowels". He said in the consultation that he felt "It sounds like someone talking on the radio, it doesn't sound like me", these words highlighted the shift in his self perception and the struggle post treatment. Angus said phrasing was hard work and was upset and visibly frustrated at this point. He was gagging during the consultation, which was distressing for him and he seemed fed up. The team were calm and supportive, there was a feeling of it being a safe and nurturing space, in a time of extreme vulnerability.

The SLT suggested pauses if he is struggling with other sounds, gently and caringly finding ways for him to manage as much as he can without pushing him too hard. He suggested he'd pick out articles he was interested in and read them aloud every day to practice his speech. This consultation was very much focussed on Angus's communication, and he was at a stage where eating was now feeling more normal, but reconstruction and retraining himself to speak was going to be a mammoth task and his clear priority.

WILLIAM

William, a grey haired, thinly framed, good natured man came to the CHANT clinic to see the Speech and Language Therapist, Dietician and Physiotherapist. He entered the room looking very visibly drained and exhausted but notably, open and genial in his manner, keen, almost urgently so, to speak to the team. He began by sharing readily, that he was not sleeping and was feeling exhausted and unwell over the last two weeks. He was in acute need. He'd been using his nebuliser and was having chest pains. He was clearly weak and frustrated. He had tried to contact the team stating he "couldn't get past reception", feeling thwarted in his attempts to get support when he needed it. The team Physiotherapist was consoling and told him that he could and should call 111 if he was experiencing any chest pain.

William was using his nebuliser at least 3 times a day but it worried him because he felt it was invasive and loud and was waking the neighbours. He also used mouth wash 3 times a day. William was concerned because when he coughed he was bringing up phlegm which was green. He stated that "he can't hang on" until his next consultant appointment, clearly upset by this situation, feeling vulnerable. He had said that the GP "won't give him an appointment", but the team encouraged him to seek medical advice for his chest, even if it meant accessing 111 or another service. William's needs were acute and distressing and the team were a vital access point for him.

He was taking food through a feeding tube and his mouth was very sore. William was taking 2-3 bottles of fortisip but was feeling weak. He had bottles via his feeding tube and he felt he was tolerating the feeds well with no nausea or vomiting but he was taking painkillers 4 times a day (paracetamol), and had remained the same weight. He recently had his tube replaced and it really hurt. In his previous consultation he mentioned he had mouth ulcers but this time they have gone. His mouth was still dry though and the dietitian told him that he is not getting enough fluid.

In the consultation William was honest and open about his struggles, frustrations and feelings. He was upset that he was struggling with walking and daily tasks. He said he had not been moving much and spent a lot of his time in his bed or in a chair. He also had a bed sore and he took a laxative every other day so that he opened his bowels.

The Speech and Language Therapist checked William's swallow. He didn't cough when he swallowed but she recommended he turn his head to the right when drinking to make it more comfortable. She suggested it may be worth carrying out another X-RAY. They could also look at his throat through a camera up the nose, but William wasn't keen to do this again, he was his usual affable self but it was clear he was fed-up and starting to question whether the treatment side effects were worth it. The Speech and Language Therapist suggested that she would prefer he had an X-RAY, gently trying to encourage him to stay positive and see what could be done.

The dietitian then suggested that he should have a litre bottle of water and that should be his target for a day. The physio, Speech and Language Therapist and Dietitian all agreed that he should go to the GP and the Physiotherapist suggested that they have a follow up appointment and that she would ring in between, rallying as a team to ensure William received the support he needed. He said "he seems to go forward and then go back" and was feeling unwell. William was in a place of frustration and feeling despondent, managing multiple different issues and feeling generally weak and unwell.

ROGER

Roger was a stout healthy-looking man in his early 60's. Roger had thyroid cancer and was post-surgery attending clinic with his partner. He was recovering from treatment but was still using a feeding tube and so was fairly early on his rehabilitation journey. The consultation included a dietician and Speech and Language Therapist, and later the Nurse came in to see him, greeting him and his partner with familiarity. He had been taking co-codamol as he was having pains at the back of the ears. He was also on slow release oral morphine and was querying why the pain was still bad. Pain management was a priority for him and the team talked about this and how he should approach it. It was clear he was suffering daily. The Nurse looked at scars from surgery and suggested it was the scar tissue causing pain and that this is something that would need to settle, so the pain had to be managed in the meantime.

Roger ran through what he had eaten that day which started with an omelette in the morning and sipping from bottled water. The account of his food intake highlighting how restricted his food was, but that he was trying to regain some elements of variety. He said that as a treat he drinks a cold hot chocolate once a day and can eat a bit at a time but cannot eat full meals as it starts to hurt. He was upset that since treatment he "never felt hungry" and therefore tube feeding suited him. To eat he used a numbing spray but said he felt it wasn't working. At this point his partner said that she felt he had been very depressed and couldn't swallow own saliva. This was a bleak and distressing reminder of the stark reality of surgery. His wife was clearly a vital support to him and she stated that she always includes him in meals to encourage him to try to eat

It was noted that his chest was noisy, and the team discussed that perhaps one of his vocal chords was paralysed. Roger said that he felt there was a "mental block" with eating but he was exercising every day and going for long walks and gardening. This was a big contrast as he used to be active and talked about being a builder before diagnosis. His wife noted that he was pushing himself physically and getting tired after walks or gardening. He was hopeful and optimistic at times, and this was mirrored in his wife. However, He felt he was struggling with rehabilitation and was having symptoms that were preventing him from being as physical as he would like He explained that he had not been sleeping well but after exercise he slept better and would need to sleep in the day. He described the nights as "feeling long" with the ongoing pain. The Physiotherapist commented that he should pace himself throughout rehabilitation, pushing himself too much could tire him out when he was weak.

He was tired after a 3 mile walk and also noticed that his hands were "stuck sometimes" and found it difficult to release from some positions, for him this was a dramatic physical difference to his previous capabilities in a very physical job. However, he explained that some symptoms had improved and even gone, for example the range of movement in his neck and shoulders was normal. He noted that when he napped his neck fell forward and that could cause pain.

The team prescribed steroids as the top of his food pipe was mostly scarred and the swelling needed to be reduced. They discussed tilting his head to the left to ease the pain but this wasn't helping much. The team also encouraged Roger to try lumpy foods to stop further deterioration of the top of his food pipe but he said he was in too much pain to try this. Pain was now a huge part of Rogers life, and he was finding it difficult to cope with.

CLAUDE

Claude was a bespectacled, well-spoken, smartly dressed, middle aged man. He attended his appointment on his own carrying a large shoulder bag across his body. At first glance you would not know the extent of his treatment but for the disc nestled in his neck. He walked in, to be seen by the Speech and Language Therapist, confident and composed.

Claude was diagnosed in 2012 and at the time of diagnosis, he only had a hoarse voice and his tumour was slow growing. Several years after his initial diagnosis he had a further 2 operations, with a tracheotomy tube inserted which remains in place. There was 6 years between his first operation and the second one and so his HNC journey had been a long one. Claude's tumour had now started to grow aggressively and had not been formally identified. He was a positive person but he talked about expecting to keep going forward and keep making progress.

Claude talked about how he was so pro-active in his recovery and staying as healthy as he could. He clearly took pride in taking care of himself and spoke about how he didn't lose any teeth at the time of treatment. What had impacted him most, following a laryngectomy, was that he now needed to communicate through an electrolarynx which is a battery-operated machine that produces sound for you to create a voice. It required carrying apparatus that worked with the disc positioned in his throat. The voice he was left with after treatment took time to develop and, he had to learn how to make sounds. The voice he could create sounded robotic and was sometimes difficult to understand. He persevered and, reflecting his general outlook, he was determined to improve and use his voice more and more. He had a clear desire to communicate and push through difficulties, despite sounding very different to how he once was and the effort speaking took.

The team discussed that a review would take place soon. The Speech and Language Therapist suggested following up every six months but Claude talked to the Therapist about speeding up his recovery through a positive approach. He said routine had been key and he was strong minded and consistent, he was unflinching in his resilience and composure throughout his consultation.

He told the team that it really helped him to see other patients. Claude was clearly someone who had handled a devastating diagnosis with strength, almost defiance. But he made subtle reference to sometimes feeling isolated. In his previous career as a high profile butler, he travelled a lot alone, leaving him with a sparce network of friends now. He talked about his flatmate helping, but Claude had said he needed to navigate some of this at his own pace and alone.

He discussed how his life had changed a lot and how he gets tired often. He had been a busy career focused person. Now, he had to carry machinery that helped him to speak mechanically and spare parts, around with him everywhere. It was very different, but he was very organised and carried what he needed in a carefully organised bag that he showed the team. Claude came across as well presented and put together and even his bag with medical equipment was smart and polished. He spoke about having a positive and self-reliant attitude throughout which helped him with his mental health. He said, you "cannot allow yourself to have any restrictions" routine has kept him going and maintaining some normality.

6.4.1 NETWORKS

Many participants highlighted the importance of strong networks and relationships in their daily routine, some highlighted the importance of a supportive clinical team that provided them with clear information and directed them to supportive services. Others focused on how close relationships, supportive friendships or family networks got them through treatment and how it helped to know that there were people with whom to share the burdens of rehabilitation. The importance of trusted support networks was identified in each of the consultations that were observed although this took different forms. For some, social relations were at the front and centre of the consultation whilst for others they were in the background but no less important. Many of those who attended clinics came accompanied by a partner or family member and in some cases more than one person.

Recognising this as a recurrent pattern in the observations highlights the importance of networks and families in a very practical sense (as seen in the need to navigate and attend the appointments or prepare food or manage medical equipment) and in an emotional sense. Rachel for example attended the consultation with her daughter and grandson who attended to provide support. Barbara’s daughter, conversely, wasn’t present in the consultation but arrived to pick her up afterwards. Whilst her daughter played no part in the consultation, therefore, and was not mentioned at all, her role became apparent in her presence at the end in facilitating Barbara’s consultation visit.

For Sangita, her daughter was central to the consultation, not just as a support for her but also as the translator that made it possible for her to communicate with the clinical team. Both her daughter and her granddaughter were present at this consultation and her daughter attended every consultation with her. Similarly, Daniel’s wife also attended every consultation with him. But what was apparent from observing their consultation was that she often talked for him and that they frequently disagreed either with each other either on what had happened or what should happen going forward. Roger’s wife offered insight into his rehabilitation experience by talking about including him in meals to keep him included and talking about his mental health issues.

The importance of social networks could also be seen for those who did not mention family at all. William attended the consultation on his own and described a series of health concerns. There was no mention of a partner or family member in his consultation. In his account, however, one of the reasons that he is concerned about his cough is that he is worried about disturbing his neighbours. This illustrates the indirect importance of social networks for people living with a health condition within a community. Whilst this is just a snapshot of the references to social networks apparent in the observed consultations, almost every consultation observed had either a family member present or some reference to friends or families in relation to recovery and rehabilitation.

6.4.2 CHANGING ROUTINES

A consistently mapped theme across the patient stories is around changing routines. Many patients articulate that they have a disrupted routine and are keen to get back to their old habits and regain function. Often, there are discussions about expectations and what patients can realistically expect to see in terms of improvements. This theme captures that many patients struggle with accepting that functionality around eating, speaking and even walking may not return to previous states. The team therefore serve to provide optimism in balance with realism to ensure the patient can find a new routine that allows them to have a sense of returning as close to normality as possible or to support them to adapt to a new reality.

I noted here that these consultations take time, and care, consistency and history are key. The team spend time with the patient talking through their daily habits and the impact of treatment, each from their respective speciality viewpoints without the patient necessarily feeling like they have to isolate their symptoms and explain them separately for each professional. This is a particular benefit of the multidisciplinary team and this theme highlights that this setting requires this approach to really understand the impact on daily routine in a holistic way that puts the patient first and sees medical symptoms and issues in the context of their daily lives.

Again, William’s story resonates with this theme. He has had many issues and therefore his routine is very different now, impacting on mealtimes, hobbies, socialising, how he feels in himself and many different aspects of his life. Roger talked about struggling to eat but that he was changing his daily routine doing things he is still able to do such as long walks and gardening. Daniel's story also showed that changes to routine can be very challenging. In the context of gaining weight and eating, his account documents that he and his wife "were disagreeing on how quick his recovery should be". This misalignment of expectation could cause conflict and stress to both the partner and patient. If there was a difference in how recovery should look this created an additional burden of expectation to the patient undergoing rehabilitation.

6.4.3 COMPLEXITY OF SYMPTOMS

Another theme that was striking and pervasive throughout all the observations was that of the complexity of recovery and rehabilitation. Almost all patients came to the appointments needing to discuss more than one ailment and complication and many intersected. This was perhaps the most powerful element of witnessing the MDT working together. William, for example, came to the clinic feeling very low and the team slowly unpicked each element of concern, ranging from mouth sores from feeding tubes, to using his nebuliser, coughing up phlegm, difficulty walking, struggling with his diet, and daily tasks, bedsores and use of laxatives to improve his bowel movement patterns.

In a service with sequential appointments with specialists, it is difficult to see how such a holistic account would be fully understood. This is particularly pertinent in William's situation where he describes a number of ailments, each quite different and requiring input from different specialists. What could be seen in the consultations was that different members of the team picked up on what the patient was saying and responded from their perspectives. Often different members of the team would comment on the same statement highlighting different areas of concern.

6.4.4 DIFFICULTY EATING AND SPEAKING

What was apparent from these observations was that many participants had impaired speech and/or difficulty eating the same diet as before diagnosis as well as symptoms of fatigue and often physical changes in their bodies (teeth removal, muscle wastage and changes to the face) relating to their faces and the functionality of their mouths and necks. This huge change to their anatomy was often very challenging and many observations included reference to this. Patients also highlighted the emotional impact of these changes as well as the functional impacts. All accounts discussed the huge impact of struggling to eat during rehabilitation. In observations with Daniel, for example, he talked about finding difficulty eating and complained that swallowing was challenging.

Sangita, who attended with her daughter and communicated through her, was anxious about her feeding tube and wanted it removed as soon as possible. Her agitation was very clear and whilst she had put on weight, she wanted to make progress saying that the feeding tube was causing discomfort and soreness at the site of entry, which required steroid cream. This is something with which all patients struggled. There is consistent desire across most patients to return to eating. A smaller minority of patients found the change manageable but most complained that there was no pleasure in eating and the pain was demoralising and saddening. This highlights the social importance of eating and the pleasure associated with food prior to treatment and is something that is revisited in the interviews.

The impact of HNC and its treatment on speech was also marked. Those that were still getting used to losing their ability to speak would often get frustrated with not being able to make themselves understood in consultations or with others. They also stated that their voices were unrecognisable to them, which illustrates both the social and the very personal impacts of the loss of speech or of speech intelligibility. Angus, for example, had had a tongue transplant which felt alien to him in his mouth. He was very uncomfortable and gagged throughout the consultation. He talked about the tongue now being covered in hair and feeling odd in his mouth. He also talked about his voice saying "*It sounds like someone talking on the radio, it doesn't sound like me*". Angus explained that phrasing is effortful and was upset and visibly frustrated. This was a clear example of the curative treatment he received, creating new problems to overcome.

6.4.5 LONELINESS AND MENTAL HEALTH ISSUES

The final theme that recurred throughout the consultations was related to the emotional and mental health impacts of HNC and the side effects of HNC treatment. A number of consultations touched on the patients' experiences of loneliness, isolation, depression or other mental health issues. Often patients would describe feeling low, isolated, fed-up or distressed and this tended to be the result of a complex combination and culmination of all the above themes alongside the undoubted impact of the diagnosis itself.

Roger's partner, for example, highlighted that Roger felt *"very depressed and couldn't swallow his own saliva"*. Roger himself referred to other indications of feeling low or struggling with psychological issues where "he felt there was a mental block with eating" and that "he also was upset that since treatment he had "never felt hungry" and therefore "tube feeding suited him". Finally, he spoke about his sleep struggles saying that he had *"not been sleeping well*" but after exercise, he *"slept better"* and would need to *"sleep in the day."* He described the nights as *"feeling long*". These references show how many of the physical symptoms during rehabilitation and living beyond that, can cause mental distress, isolation and other mental health issues, such as depression. Again, it also shows that these feelings and responses stem from the complex interaction of symptom impacts on daily life.

Claude talked about his mental health and wellbeing during his consultation – he seemed to be in a different place to some of the other stories after having reoccurring bouts of cancer, going back a number of years. He spoke candidly with the team about his mindset and how he lives with it now. Claude had had a fulfilling career as a butler and he discussed how his life had changed since he received his tracheotomy as he now has to take machinery and spare ports around with him everywhere, but he was very organised and carried what he needed in a carefully organised bag. He spoke about having a positive and self-reliant attitude, which helped him with his mental health. He said, "*you cannot allow yourself to have any restrictions"* and routine has kept him going and maintaining some order.

This emerging theme was noted in a small number of consultations where patients talked about focussing on treatment and recovery and framing this as optimistically as they could, seeing the cancer as something to challenge them and that they could get through it. The observations captured the beginnings of this theme of how the mental wellbeing of the patient can frame the experience of treatment and in Chapter Eight this is explored even further, looking at what helps patients cope best and therefore what support can be effective.

6.5 SUMMARY

Having healthcare professionals with different expertise (multidisciplinary team - MDT) allowed multiple issues to be addressed in a single consultation. This was particularly important where symptoms cut across specialisms, or where patients had multiple issues that needed addressing at one time. There were multiple clinical symptoms discussed in the consultations, but little directly related to the effects of those symptoms except in the case of William who was quite candid about the impact his symptoms were having on his daily life.

We see the importance of networks and how they come in many different forms including partners, family, friends, flatmates and wider more formal networks. Two prominent features of HNC specifically centre around the varying symptoms and needs of a single patient, which necessitates person centred integrated, MDT working for effective treatment that is highlighted in the document analysis as a benchmark for well-designed services at national level and facilitated by the Cancer Alliances regional structures at regional level. CHANT is a unique example of this, with these observations really highlighting the effectiveness of this approach and demonstrates the poignancy and value in carrying out this research. The discussion section will elaborate further on why this model is not prevalent across England and whether the national and regional aspirations are being realised and best facilitated through these structures.

The second is demonstrated in the early observations of initial diagnosis and the dental extractions where patients undergo fast-paced changes that form part of the treatment. This initial fast, invasive traumatic treatment leaves a huge impact that is often only beginning to be processed during rehabilitation.

Challenges to recovery are particularly unique with HNC patients. I observed that all patients struggled with the enormity of the impact it had on their ability to eat and speak, two areas of human function that are key to how we navigate the world and survive, bound to our identity and sense of self, as well as how we connect with other people. With these changes to self comes huge changes to routine and what an individual can do, and this change in routine is felt deeply by all those going through rehabilitation with patients coping in different ways. There were also key themes around eating, swallowing and pain, which came up repeatedly. These will be addressed in more detail in the one-to-one interviews, which took place with a sub-sample of patients following the observation. It is therefore relevant here to discuss the limitations of the observations and why in-depth interviews are necessary as the next step.

In summary, these observations show the different environments in which integrated, community based, care is practiced and contextualises the policy recommendations and practical guidelines that were explored in some detail in the previous Chapter. The next Chapter takes the personal stories and journeys that we began to see in this Chapter and looks in far more detail at the experiences of people living through HNC and HNC care and accessing these services. The aim of these interviews is to explore the experiences of patients from their perspective in their own voice, and through providing time, space, and a comfortable setting they are able to tell their stories. Layering the narratives of patients with the findings already elucidated through understanding the field via the document analysis and understanding the habitus through the observational work provides a unique and holistic picture of the journey for HNC patients.

7. THE EXPERIENCES OF HNC PATIENTS IN CHANT SERVICES

In the previous Chapter, I introduced some of the environments in which people diagnosed with HNC find themselves and the people that they encounter within those environments. The Chapter introduced some of the people whose stories are told here in the form of in-depth interviews and, in some cases, multiple interviews. As explained in Chapter Six, to uncover more detail following the observations, the in-depth interviews sought to unpick and explore the narratives from the patient's perspective. The interviews focus on three pivotal questions, which align with the overarching questions in chapter Three.

What are people's understanding and experiences of HNC?

a. What are people's expectation, experiences and understanding of the treatment and rehabilitation options available to them once a diagnosis of HNC has been received?
b. What are the short and long-term impacts and consequences of receiving a diagnosis, and treatment of HNC?
c. What elements of the journey were most challenging and what were the drivers to surviving and thriving?
d. What support did individuals receive and access?

These research questions focus on unearthing the detail of the experience of having a diagnosis of HNC and how an individual lives with HNC from treatment through the rehabilitation phase. By speaking to participants at the rehabilitation phase a narrative of recent historical events can be captured. The treatment phase is rapid, and it is at this rehabilitation phase that individuals often get a period of reflection. They are also readjusting, acclimatising, or striving to recover at this stage. They are still accessing regular ongoing support from the multidisciplinary team and therefore the team provide an ideal gatekeeper to speaking to patients who have had this experience.

Chapter Five provided us with a documentary analysis to build a picture of the healthcare rehabilitation setting in which the participants receive care for and learn to live with the longer-term impacts of HNC. Chapter Six provided observational data that helps to build a picture of the healthcare structures that patients find themselves within, through the eyes of the researcher embedded in the settings. Chapter Seven now explores the individual stories of how patients have navigated the field and the impact of this, articulating the challenges/strengths and barriers routed in understanding their own resources and agency. In order to understand the narratives of the patients it has been helpful to map the common touchpoints that each participant underwent, mapping the clinical pathway and seminal milestones for each individual. This can be visualised as being in three phases and is described below. Each phase in this clinical pathway maps to an overarching theme in the in-depth interviews, underpinned by the fourth theme of supportive networks who track all three phases (see Figure 2). Figure 2 aims to set out the core elements of the patient's experience of HNC and details the activities that happen in phased sequence (!-3). The timelines are also detailed on this figure to provide an idea of timescales and milestones for each phase.

As described in the methodology participants stories are taken at a particular spatial-temporal part of their rehabilitation journey which may be palliative, still undergoing reconstructive surgery, intense therapeutic support, or phasing down of active rehabilitation. Due to the nature of a multidisciplinary team, they are able to work with this broad range of patients and therefore it is important that that variety of narratives is captured in this study.

Overall, over 40 were involved in this study as part of consultation events, group events and interviews. Group settings included support patients, staff, carers and family moving in and out of the room during the session. Therefore, headcounts could not be accurately recorded. Of these patients, 12 participants were interviewed, some more than once (crossover is shown in Table 9). A wider number were included in group observations and dental clinics. Difficulties in recruitment were experienced in continuing past March 2020 due to the pandemic restrictions when all non-COVID data collection was halted across the University. Gender representation is not equal and mirrors the wider cohort of HNC patients in this area, nationally and globally. There were four female participants and eight male participants which accurately reflects the gender split in the wider HNC population. Interviews were conducted to create a story to build on observation snapshots in time. The interview approach is outlined in the Methodology and Methods Chapter where some important practical steps that were taken during the conduct of the interviews was outlined.

Table 10: Outline of patient details and summary of their story

Participant No	Gender	Participant pathway	Participant short story
1 (Helena)	Female	Helena was observed in consultation with the multidisciplinary team in Clinic A on three occasions and interviewed twice as she was keen for the study to follow her progress in further, rehabilitative surgery. (story not featured in observations chapter)	Helena is an outgoing, articulate person who is 41. She is successful in her career in the financial industry and articulated that she was blindsided by the diagnosis of HNC. Her career is a big part of her life and she was keen to get back to work. Her ability to communicate verbally is a fundamental part of her professional identity and she is striving to get back to her old self and back to work. She made an effort to inform herself about treatments and ask questions and felt supported by the team approach at CHANT. She was keen to utilise all the support available to her and make a full recovery, feeling that she was not part of the traditional cohort of patients with this diagnosis.

			In the later observations Helena was keen to undergo reconstructive surgery that might restore some function to her tongue, which she hoped would improve the clarity of her speech.
2 (Aga)	Female	Aga was observed twice in consultation with the multidisciplinary team in clinic B and was interviewed once (story not featured in observations chapter)	Aga experienced breast cancer earlier in her life, remaining cancer free for 20 years. She was diagnosed after noticing an ulcer on her tongue. The diagnosis was delayed as it was initially thought it would heal and resolve itself. Aga had a supportive network with her husband and daughter accompanying her to many of her treatments and appointments, and she spoke fondly of her Clinical Nurse Specialist and teams that treated her. The surgery removed the cancer from her tongue initially and a sample was taken from her lymph nodes. This sample later proved to be cancerous and she very quickly had further surgery to remove this node. This was followed by radiotherapy, which she found tough. She spoke about her struggles with food as this was more affected than her speech, which was good. She came across as having a very positive and resilient outlook on her treatment. She spoke of being active and trying to maintain this by carrying on with her Pilates and staying positive and focussing on eating to maintain her strength and get back to normal.

3 (Gerald)	Male	Gerald was observed once in Clinic B with the team and was then interviewed a number of weeks later. (story not featured in observations chapter)	Gerald was working with the multidisciplinary team on his rehabilitation post treatment most notably with the SLT for feeding and swallowing and with the physio for improving his strength. He is currently taking oxygen and it is hard for him to move his lower jaw which affects feeding. A few months ago, he could speak much better, but the jaw now feels its pulled back and tight. Gerald is doing neck stretches and massage and it is not painful to move or exercise the jaw. He was awaiting seeing the dental team to look at this. The jaw is used to help push fluid down so there is also less movement for him to drink. The removal of parts of the tongue has meant he’s struggled to control fluid intake and cannot have any solids and he is working to progress to soup. At the time of interview, he was also suffering from thrush in the mouth and cannot rinse so has to apply with a swab. Using a soft toothbrush to apply it. He was working with the SLT to consider the risks of the intake going down the airway pipes which is dangerous. His Epiglottis has a gap which means swallowing is more

precarious. There is risk of a chest infection, so he needs to be vigilant of this and look for any signs of complication, calling the team immediately if so.

Gerald wanted to go back to work as a gardener and that he changes his own balloon (a balloon retained gastrostomy tube (BGT) which is a feeding tube through the skin into the stomach) water now so feels much more independent. They are taking fibre feeds and bowel movements are ok. However, his weight has gone down and he now works 4 hours a day of his physical job. His grip strength has also gone up and he is focussing on his feeding, but his weight was not increasing.

Pertoxyphiline and vitamin E were recommended as they said that skin had lost its elasticity. Radiotherapy can cause loss of elasticity and fibrosis can come on slowly. Gerald is keen to progress, but the team want him to acknowledge the pain and respect it, so not to stretch if it hurts. With the physio Gerald needs to ensure lip and mouth flexibility is maintained and therefore asked to do some more exercises to ensure mouth is wide enough. Even 1 time a day to prevent further issues. With these exercises false teeth is a realistic goal. Gerald had gained in strength after going back to work. Speech has made him less sociable. He doesn’t like going to new places where he cannot know how he will

			accommodate for his new needs. He would remain under ongoing monitoring with the team until his fatigue, feeding and strength had improved.
4 (Alex)	Male	Marcus was observed by the team in Clinic A and interviewed following this consultation	Alex's treatment involved surgery and radiotherapy. He was diagnosed in November 2018 after a diagnosis of lichen planus and a stomach infection. He has a current ear infection. At this point in his rehabilitation Alex is also experiencing very low energy levels and had been napping a lot during the day getting very easily fatigued. He was waking several times a night and was low in energy, which was under further exploration through blood tests. Alex also has Lymphedema pains which could be compounding low energy and sleeplessness. For him, the pain subsides with exercise and was positive stating that the aches could be as a result of exercising. His speech was still under rehabilitation as it was sounding impaired and he was doing exercises of a minimum of 5 times a day and the team were working with him on how to implement these exercises into his daily routine as Alex felt it was all quite time consuming. His physio in the CHANT Team and has been giving him daily exercises and he was being referred to begin an exercise class.

			At the time of the study, Alex is due to be reviewed for his swallowing and follow this with a potential camera swallow test. This shows the anatomy can see where the swelling is from the inside. They can also review secretions. This may also need to be accompanied by an x-ray and this would happen in a month. He was currently under the care of a dietician asked about his weight and current feeding tube, which had been in place for the last 6 months as patient is he is only consuming liquids orally. However, he was not worried about his weight.
5 (Brandon)	Male	Observed once in consultation with the multidisciplinary team and interviewed following this consultation. (story not featured in observations chapter)	Brandon was accompanied by his wife, who often attended appointments with him, and participated in the interview. He was a slight man and his mobility seemed to have suffered following treatment. He was a year into his rehabilitation following a diagnosis of HNC, which had involved surgical intervention. Since his last appointment, the previous month Brandon had been eating more food and was happy to tell the team about his progress stating that he had started eating cornflakes and lamb stew but was still having 5 fortisips a day and caligen. He had had annual review the week before and they were happy that he had gone up by 2 kilos from 47-49kg.

			He has more flexibility now and can use public transport, giving him more independence and has improved from having no food or drink. The team consultation covered all aspects of his health and he was updating them on progress with opening his bowels much more frequently, potentially as a result of eating more. He talked about his pain management and the dilemma as the morphine makes him constipated so he is afraid to take it. He was positive and to the point in his consultation which reflected his attitude, being at times very matter a fact about the process and his troubles.
6 (Barbara)	Female	Barbara was observed twice in clinic A during consultation with the team and interviewed following these consultations in two parts **(featured in observations chapter)**	Barbara's story featured in Chapter x.
7 (Marcus)	Male	Marcus was observed by the team in Clinic A and interviewed	Marcus is 61 and is one-year post diagnosis. He is now looking to phase out support from the CHANT Team. His diagnosis journey was circuitous as he had a sore mouth and went to the dentist who didn't suspect anything serious. He sought a second opinion, which

		following this consultation	triggered further investigation and from there treatment was rapid. His key support figure was his brother who he moved in with once receiving his diagnosis to avoid stresses he was having with his neighbours at the time and provide him with support. Marcus didn’t have radiotherapy or chemotherapy. He attended peer support groups but did not access Dimbleby psychology services. Marcus had a surgical intervention, which meant he required a transplant to replace the removed cancerous area in his tongue. His transplant came from his arm so he required Physio, speech therapy and dietetic support for this. He highlighted the initial Intensive care episode as a particularly traumatic element of his treatment.
8	Male (Jame)	James was observed by the team in Clinic A and interviewed following this consultation	James described his diagnosis as a shock as it was initially diagnosed as recurrent bouts of tonsillitis. James underwent dental clearance, chemotherapy and radiotherapy as part of his treatment. He described the dental clearance (removal of 20 teeth) as the most traumatic period and consequence of treatment. He spoke about not fully understanding that with the dental removals he may never gain functionality back and therefore James’ narrative reflects a key theme around

			acclimatising to a new normal and reconciling one's sense of self post treatment and during rehabilitation.
9	Female (Santi)	Santi was observed by the team in Clinic A and interviewed following this consultation	Santi had two surgeries within the space of 6 days. She also had many teeth removed and talked about the part of her treatment as challenging. Santi had no chemotherapy but had radiotherapy which she described as very tough. She talked about the mental impact on her from not being able to speak or eat and how she had to find other outlets for managing the stress and socialising. She talked about the all-encompassing nature of treatment and rehabilitation and coming to terms with the uncertainty of who she would become. She talked about loving her job but accepting she may not return and how she focussed her time now on rehabilitation, fitness and pursuits she was able to do such as tending to her allotment.
10	Male (Claude)	Gerald was observed by the team in Clinic x and interviewed following this consultation **(featured in observations story)**	Claude's story featured in Chapter x

11	Male (Ian)	Ian was observed by the team in Clinic A and interviewed following this consultation	Ian is 71 had previously had polyps removed from his nose so when similar symptoms returned, he assumed that it wasn't serious. His symptoms were first flagged as suspicious by his dentist and treatment moved quickly after this. He had a successful career which he felt passionately about and informed his outlook on his cancer diagnosis. He worked as a mentor and believed in the power of the mind so much of his story is framed with how he approached treatment and rehabilitation with positive thinking, hypnosis and supporting his mental health throughout his journey. He spoke positively about staff and the CHANT team and there was a sense that this personal approach, with a team of professionals who supported him really nurtured his positive mental attitude and belief that he could return to his previous self. He talked extensively about his coping mechanisms of journaling, supportive networks and the power of positive thinking. There was a strong sense of empowerment and ownership of his recovery that resonated throughout his narrative.
12	Male (Owen)	Ian was observed by the team in Clinic A and interviewed	Owen attended the interview with his partner. He had an active job but was nearing retirement age but was agile and a non-smoker. He described working 24/7 and how all he had known was hard physical work being in the building trade. He had a persistent cough that he ignored and that didn't flag as suspicious to healthcare professionals.

following this consultation	His narrative was particularly poignant when he talked about his experience of radiotherapy in his treatment, which he found extremely traumatic. He vividly outlined the reality of a mask placed on the face and the claustrophobia and raw reaction to this part of treatment. His account of this process paints the harrowing reality of the process for HNC patients and how this can have a lasting traumatic impact on the patient. He really felt the social element of not being able to eat with his family and how his children felt for him with this challenge. He spoke about really pushing himself to get a little stronger each day and focus on eating a bit more, speaking a bit more and moving a bit more each day without pressure or expectation.

7.1 FINDINGS OVERVIEW

It is clear that the themes from the observational findings are mirrored from the patient perspective too and are embedded in the themes and subthemes that have been elucidated in the interview process. The Table below starts to explore these themes in more depth and from the patient narrative directly but where relevant they are also discussed with a mind to:

- The observational data findings will be discussed to highlight the triangulation of the researcher and participant experiences.
- The policy document analysis to unpick if the aspirations and ambitions of the service are being met and played out in the patient's own experience.
- Finally, the themes are considered with a theoretical lens (set out in chapter x) to understand the "why" and "how "of the described narratives, unpicking the habitus and capital contexts in which accounts are situated.

The themes are explained in more detail to unpick the remaining research questions of the consequences of their diagnosis, the impact of the treatment, and the experience of rehabilitation. The findings and discussion are presented together and findings from the interviews are presented as verbatim text and as either short quotes or vignettes showing full dialogue. This is to capture the impact of the narrative story described by the participant. The following nomenclature is used when presenting the quotes:

- ... words/ sentences I removed from quotes for continuity or clarity, e.g., the interviewer saying yes, mmm, ok etc.
- (...) pause of participant
- [..] words I inserted into quotes for clarity or explanation
- (inaudible) is used where the recording didn't pick up speech or speech was difficult to understand

The themes matrix is presented next, in Table 11. There are 3 overarching themes which formed the basic structure of the in-depth interviews around (1) "*Experience and Understanding of HNC",* (2) "*The Impact of treatment and rehabilitation*", (3) *"The rehabilitation and beyond"*. and (4) *Supportive Networks*. There were 10 themes identified and 26 subthemes.

Table 11: Summary of over-arching themes, themes and sub-themes

Over-arching theme	Theme	Sub-themes
7.2 (1.) EXPERIENCE AND UNDERSTANDING OF HNC	7.2.1 DIAGNOSIS OF HNC	7.2.1.1 Stories ignored symptoms and delayed diagnosis *Symptoms identified through dental consultations* 7.2.1.2 Experience of the urgency to seek treatment *Good initial experiences* *Missed or badly communicated information* *Struggles with early consultations*
	7.2.2 PERCEPTIONS OF HEALTH PROFESSIONALS IN DIAGNOSIS AND EARLY TREATMENT	7.2.2.1 The impact of receiving information on treatment alongside difficult news 7.2.2.2 Struggles with early consultations
7.3 (2.) THE IMPACT OF TREATMENT	7.3.1 HIGHLY INVASIVE AND COMPLEX TREATMENT	7.3.1.1 Unexpected dental consequences 7.3.1.2 Surgical interventions 7.3.1.3 Chemotherapy and radiotherapy experiences *Chemotherapy* *Radiotherapy*

	7.3.2	THE IMPLICATIONS OF HAVING TREATMENT	7.3.2.1 Swallowing and breathing 7.3.2.2 Food, mood and the social power of eating together for wellbeing 7.3.2.3 Hearing oneself: Identity, voice and communication 7.3.2.4 The all-encompassing impact of treatment
	7.3.3	IMPACT ON DAILY ROUTINE	*7.3.3.1* Becoming a *“professional patient”* 7.3.3.2 Hampering careers and passions
	7.3.4	CHANGING SENSE OF SELF	7.3.4.1 Feeling profoundly changed 7.3.4.2 Strong fear of reoccurrence
7.4 (3.) THE REHABILITATION AND BEYOND	7.4.1	RECONCILING SENSE OF SELF POST TREATMENT	7.4.1.1 The role of the grieving process 7.4.1.2 Goal setting and objectives
	7.4.2	ATTITUDES TO RECOVERY	7.4.2.1 The power of movement on rehabilitation 7.4.2.2 The role of hope, optimism and gratitude 7.4.2.3 Post-traumatic growth following a diagnosis of HNC
7.5 (4.) SUPPORTIVE NETWORKS	7.5.1	INFORMAL SUPPORT	7.5.1.1 Families, partners and friends 7.5.1.2 Peer support 7.5.1.3 Implications of not having support
	7.5.2	CHANT MULTIDISCIPLINARY APPROACH	7.5.2.1 Supporting personalised patient centred care 7.5.2.2 Supporting decision making 7.5.2.3 An integrated approach to care

Table 10 presents short summaries of the participant’s journey through treatment and into rehabilitation. However, discussion in the interviews started with the recognition of symptoms and the diagnosis itself. This sets the scene for the treatment and rehabilitations journeys that will follow. Whilst experiences and timeframes were different, there were shared experiences around delayed diagnosis, a lack of symptom recognition and the impact of the sense of urgency and rapidity in receiving treatment.

This leads to a discussion about the early treatment, which often started with dental extraction in the early phases. This section ends with this description of initial treatment, which begins with dental extractions and leads into the next section detailing the impact of surgery, chemotherapy and radiotherapy treatments, followed by rehabilitation.

7.2 OVERARCHING THEME 1: EXPERIENCE AND UNDERSTANDING OF HNC

7.2.1 DIAGNOSIS OF HNC

This section will explore these key three phases of treatment in turn. Starting with phase one the experience and understanding of HNC. As demonstrated and outlined in the diagram x. this phase starts at early symptoms and maps through to a health professional having a suspicion of cancer and then being referred to cancer specialists (which should take two weeks), decisions around treatment (which can happen immediately) and then preparing for cancer treatment with prophylactic dental extractions (which can happen within days of deciding to treat).

Section two and three on the individual accounts in the early phases of treatment moving into rehabilitation their experience of health professionals, and it should be noted that whilst this section focuses on the individual section 3 then unpicks the individual account embedded in their own social context and reflecting on the support of the professional team.

7.2.1.1 Stories of trivialised ailments, ignored symptoms and delayed diagnosis

The symptoms that pre-empt a suspicion of the diagnosis of HNC can be varied and appear minor or chronic which lends them to being either untreated, ignored or trivialised by patients and healthcare professionals. For this reason, a patient may delay visiting a health professional, or once they do it may be treated without further exploration or be taken seriously by health professionals. This was seen throughout the participants' narratives when describing how they were diagnosed with HNC. For example, James discusses that he attributed his symptoms to recurrent bouts of tonsillitis stating:

> *"Erm, it was quite a shock to get the diagnosis really, erm, it sort of came about when I thought I was having recurrent bouts of tonsillitis, which I'd had sort of on and off through quite a bit of my adult life and I just assumed it was ongoing of that. Erm, and it was only really when I, I was getting extra time off work because I was having recurrent infections that I pushed for*

> *surgery, which they don’t really like to do in adults if they can avoid it and, and it was, that’s how we got, got the diagnosis really. It was pure fluke, I guess if I hadn’t have pushed for, er, surgery to try and clear up the tonsils…”* **(James, Participant 8)**

James had recurrent bouts of tonsillitis that doctors had not identified as anything more serious. He requested a tonsillectomy, which uncovered the cancer. James described being grateful that actually what he thought was an everyday bout of tonsillitis was actively investigated by health professionals and a diagnosis received. Some individuals accounted that they had to push for further investigation for symptoms that were persistent or didn’t feel quite right. In the case of Aga, who was an individual who had experience of previously being diagnosed with breast cancer, she talked about not thinking her symptoms were serious and that she saw two GPs before for minor symptoms which she attributed to an ongoing condition, she then developed ear issues and it was then that the nurse flagged that further exploration was needed.

> *“Last April yeah, yeah. Erm, I can't remember whether I actually went for something else and just mentioned the ulcer on my tongue or whether, because it wasn’t really of a prime concern to me then…. But anyway, I did mention it and he looked at it and he said oh yes, I can see where you mean but that’s healing so don’t worry about it, anyway I felt that it didn’t heal so I went back and I actually saw another GP and he looked at it and he said well I don’t think it's anything and we wouldn't do anything for four weeks anyway. So I said well I did see the other doctor erm, sort of maybe I don’t know, five weeks ago, so he said oh no I think this is in, that one has cleared and this is in a different place. Now I can't, I don’t know whether that's right or not erm, because I couldn’t see it anyway erm, so anyway I went on holiday erm and I said I've been getting this feeling in my ear and he said we’ll get the nurse to syringe your ears. When I saw the nurse I told her and she said well I don’t like the sound of that, she said I think you ought to see the GP again. So anyway, after four weeks I went back and saw him and immediately he said I need to refer you, he said do you understand, he said I don’t, I don’t think it's anything but you know fair enough. Erm, he said but I'm sending you and you will be seen within a fortnight which I was and erm, the consultant wasn’t there at the time so I saw, I don’t know, a registrar something like that but anyway he was fine and he said erm, we need to a biopsy done which was arranged, I had to wait about ten days for that”* **(Aga, Participant 2)**

Like Aga, Alex, also attributed his symptoms to an existing condition. He had a historical diagnosis of lichen planus (which is an autoimmune condition that causes a rash inside the mouth). He felt pain and soreness so sought advice.

> *"I wasn't aware of it. It hadn't really crossed my radar…[Interviewer: Yeah what happened with your diagnosis] It came about because I was having some burning in my mouth and there a soreness in my tongue. They thought it was an ear infection but it was bad pain in my tongue….I thought maybe erm (inaudible) it was something else because I had a diagnosis three years ago of lichen planus so I had sort of had some issues in that area…* ***(Alex, Participant 4)***

Gerald, who has had intense treatment (removal of parts of the tongue) and a difficult rehabilitation started his account by saying that his HNC experience began as what he thought was a straightforward ulcer that he treated with Bonjella.

> *"Oh yeah well to tell you the truth, in 2018 probably about February I had, well it was like a mouth ulcer, and it did cause a lot of a pain sort of I thought hang on….then a typical man thought I will just put some bonjella on and so I put that on I thought the pain side was so bad that I had a look in the mirror and oh….then the day before I saw the doctor I had a look in pain in my tongue was…(inaudible)….They put me straight in to see the Dr x….and it all happened very erm…very…very quick erm*." ***(Gerald, Participant 3)***

Helena had a similar story initially thinking it was just an ulcer and that because it wasn't consistently sore it was nothing to be concerned about. Helena described noticing it around Christmas and not seeing the GP until around March when she began to think it was something needing treatment. Furthermore, she had to wait another month before seeing a consultant and at that point, as she was not in a high-risk category, (a woman aged 41) the doctor was not concerned. She returned for a follow up appointment two further months later so her story starts with a minor symptom and a delayed diagnosis.

> *"…it was there and it was coming back, and because it wasn't there all the time I presumed it was minor…and then maybe end of February/March I realised it was still there so more for the piece of my mind than anything else I went to see my GP (…)Then they sent my referral to the X hospital and I saw a consultant a month after I saw my GP about it.(…) The consultant*

> *checked my throat and checked my mouth and he said it's probably just your immune system and it's affecting the healing process and because of my age I wasn't kind of in the risk category for anything more serious."* **(Helena, Participant 1)**

Aga describes the toing and froing that often takes place pre-diagnosis. She had to return to the GP and saw a number of health professionals before being referred to the stage of a biopsy. Here she describes the waiting in between each step of 5 weeks between the first GP appointment and the next, and then a further 4 weeks after symptoms in her ear. It was then that the cancer "Two week wait" referral request was triggered. This is in line with the Cancer waiting times set nationally. For patients with cancer there is a "target for treatment within 31 days from Decision To Treat to First Definitive Treatment of cancer and 62 days from receipt of urgent GP referral for suspected cancer to First Definite Treatment of cancer are included for each organisation" (https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/).

Like Aga, Barbara's early symptom was a small lump/ulcer under her tongue and she describes that the initial diagnosis was a blocked salivary gland which was then operated on but came back 6 months later and was reluctant to have further surgery.

> *"Um, it started off with really having a little lump under my tongue, and I went to my doctor's and they said ... they referred me to Lewisham Hospital alone [ph], and they said it was my salivary glands that were blocked. And I had an operation, at home the same day, um, I think a few months later, it came back, six months later it came back, and they said that my salivary glands are blocked again. I went in, to have another operation, I woke up in the recovery room, and the surgeon was sitting on my bed ... no, he came over when I woke up, and he said it's been a nuisance [ph] have we explained to you, that we cannot do your operation? And I said no. He said that they couldn't get the tube down my throat, which I found um ... but my throat I could just about talk, I thought that I had had the operation, but I hadn't. So they sent me home, um, that evening…Um, I was meant to go back in, to have the salivary duct removed again, I did not want to go through the experience of that anaesthetist forcing that tube down my throat. Um, so yeah, the anaesthetist phoned me, and ... to say could I come into his office, so we can talk. It got to the point where I had a panic attack at the thought of the anaesthetist even speaking to me.…* **(Barbara, Participant 6)**

Barbara’s cancer was diagnosed only after the second procedure sparked suspicion and a biopsy was taken of a lymph node. The biopsy itself can be a traumatic process due to the location of the possible cancer. Santi describes the process of biopsy as being a particularly painful part of the treatment and will be the first medical procedure in an often-arduous journey. I painful first experience can therefore set the tone for the trauma of further treatment:

> *“…the biopsy was very, very painful, um, Um I can’t remember if I asked him on that occasion what would happen if it was, I might have done, I don’t know, because…”* ***(Santi, Participant 9)***

Ian describes minor symptoms that he initially wanted to deal with on his own. It was his girlfriend who flagged that he should go to the doctor. However, he didn’t go to the doctor until it was recommended by his dentist, and his account highlights something particular to HNC, which is that symptoms can be discovered by dentists as well as doctors. Ian, as mentioned in his story had a very positive outlook on his ability to recover and felt he could recover on his own having suffered from polyps before which were not identified as serious. His symptoms were escalated due to bleeding in his throat.

> *“I wasn’t clever enough to connect the dots. It started very slowly with my nose getting blocked. Fifteen years ago, I had polyps removed from my nose, to help me breathe better, and I just assumed that it was coming back so it didn’t really worry me. It just went on and on and on. My girlfriend said to me, “Blimey, I’d see a doctor.” I said, “No, no.” I said, “I’m … I’ll get rid of this with mind power.”* ***(Ian, participant 11)***

In the case of Owen, he experienced a tickly cough, which he had dismissed as a minor symptom and trivialised it. It was again his partner who felt there was something more serious as he had a persistent cough and was not a smoker.

> *“He kept saying it's just a cough, I said it's not a cough now, that has gone on, I think it was about April, before I got him to the doctors, and I actually rang up the receptionist, and said*

> *he's got a cough, but it's not a cough any more. He won't come near. She said I think we'll just make him an appointment, and that's when it …"* ***(Owen's partner, participant 12)***

This reflection from Owen's partner also reflects the intersectionality between ignored symptoms and seeking medical advice with having a supportive network around you. His partner was key to his diagnosis and later we will discuss how he articulates the importance of his family and wife in his rehabilitation and recovery. Owen describes extensive investigations triggered by what he felt was a minor symptom of a tickly cough. This led to exploration of his lungs and CT scans. However, nothing was found in those particular investigations and so they did more tests, which he described as "from head to toe". This uncovered a mark on his throat, prompting referral to an ENT specialist. Owen's story of diagnosis also captures something that reoccurs in other accounts around delays. He begins his journey in May and is not seen by an ENT consultant until September of the same year.

> *"It started off with a tickly cough (….). A tickly cough, but I've never smoked, which was unusual to have a tickly cough, which was about March '18. It went on and on, (…) And I couldn't just talk to you about this tickly cough coming in you know So I went to the doctors, explained everything. So, she said you need to go and have an x-ray, which I went up and had an x-ray. They rang up one day when I was at work, you know, and just said, we think you've got a shadow on your lung, can you come into the surgery? So, I said I can't get there now, I'm working, but if that's what it is, that's what it is. Went back to the doctors, and they said you need to go and have a CT scan (...). Fair enough, the bloke who I was going to go and see had enough savvy to ring up and say look, you're booked in for a CT scan tomorrow. (…). So obviously very timely, had the scan, went and found the consultant, and he said I've checked you from head to foot, he said you've got nothing in your lungs or anything. He said you've got a little mark in your throat. He said I'm going to get you to see an ENT specialist. The only issue I've ever had is that was May, I didn't get to see anyone until September. (…)… I can't do anything about it, but I think at that point there, if I'd gone to Guy's, but like who can say? So it's May until September, so I said, I had a scan in this hospital, the guy, if you look on your thing, he's shown me, I've seen there's something on the left hand side of my throat."* ***(Owen, participant 12)***

Owen's partner attributes delay not only to this referral to ENT but also to Owen not realising that his symptoms could be a sign of something more serious.

> *"I think maybe in hindsight now, if you'd taken heed, you might have not had… not saying it wouldn't have happened but might have got it caught a little bit earlier. Whereas you ignored it for so long. People would say oh, you're healthy, you've a cough and the tickles, and it went on for a long … from January, and I never got him to the doctors, until April, so all that wasted time, where I knew it wasn't just a cough."* ***(Owen's partner, participant 12)***

We can see that HNC cancers, like many other cancers start with what appear to be minor symptoms that become chronic and therefore are not always flagged early to GPs**.** This is a theme that is common to many cancer diagnosis stories. However, as mentioned in Ian's story, a number of other participants in this study had initial symptoms that presented in a way that guided them to see a dentist rather than a GP and we look at these accounts of diagnosis next.

Symptoms identified through dental consultations

What is unique to HNC diagnosis, over other cancers, is that initial symptoms often centre on the mouth, neck, teeth or face. For this reason, patient diagnosis tended to follow one of two healthcare pathways that are distinct and accessed in different ways by patients, through visits to doctors (as described above) or dentists. Marcus in particular, detailed a process of diagnosis that saw him visit a dentist initially with soreness in the mouth that was not referred to secondary care. It was his own instinct of not feeling his first diagnosis was accurate that led him to a second dental opinion. Marcus stated:

> *"I have um, err, a dental check-up every year and that slips a bit, but by the end of the summer I was due to go for um my annual check-up and um…And my dentist, every time you go there, you see somebody different, which is not ideal.(…) And this fella I saw, I said "I've got this", I said "I had this pain in my tongue", and I thought what it was, because they told me years before that the amalgam was leaking out of my tooth, so I thought this was irritating my tongue, so let's block off this tooth you know. And um, so I said this to him, I said "I've got this pain, it's like, pain at the back of my tongue", and um, well quite frankly I wasn't really happy,*

> *I couldn't complain about it formally, but I wasn't happy with what he did. He got one of these metal sort of hooks and put it into this and when I come off the seat, he said "Did that hurt?", and I said "Yeah it did hurt actually yeah", he said "Oh I'll keep an eye on that", fair enough, but as I walked away from the dentist, I thought I'm not happy with that. You know, I couldn't say every single thing, but I, I just wasn't happy with, with that. So I thought I'll change dentists.(…)So I made an appointment for a check-up there and thankfully the lady I saw was pretty with it, really quite sharp, nice but with it, you know, as soon as she saw it, she sort of referred me. She didn't say what she thought it was, but she knew. She knew. And she referred me to King's* ***(Marcus, participant 7)***

This really highlights the importance of dentists in the diagnosis stories of HNC patients and the impact of the dental intersection with medical spheres and how a swift referral can make a difference to early diagnosis and therefore better chances of recovery from HNC.

> *"...I mean I sometimes, my blood runs cold, when I think if I hadn't, if I, let's say I said "That dentist was rubbish, oh I'll leave that, he don't know what he's talking about", and walked off for a year and some people would have done that."* ***(Marcus, Participant 7)***

The role of the dentist is a crucial element of the care pathway, which when carried out effectively and consistently, has the potential to ease the burden on medical routes of diagnosis as well as potentially providing an earlier touchpoint for patients and therefore having an impact on finding cancers. Hence, when this pathway works well patients articulate a gratitude to the triage dentists perform. Vigilant dentists are described in the narratives of the individuals who participated in this study. Santi, who had multiple surgeries and radiotherapy, was initially red flagged by a dentist and then she went on to have teeth removed.

> *"I had some pain, by King's, and I'd been referred by another dentist, who thought I had um bone and tongue syndrome, but King's said, the dental department said "No...And then it got particularly bad and so I went to my, well I was due to go to my dentist anyway, I went to my dentist, because I'd been told that at King's, they just told me when I first came in, that if it got worse, I could possibly use steroids, so that was in my mind, that I could go back to King's and so I used steroids and um, in fact it was only six months after my first."* ***(Santi, Participant 9)***

Another vivid account of symptoms flagged by a dentist occurred with Ian. He describes his dentist fervently suggesting he needed to see a doctor following an appointment and this needed to happen quickly. This was during what Ian had felt was a routine dentist appointment, so it came as a shock to him that his dentist flagged the need for further exploration which he describes as happening at unbelievable speed.

> *"I'm telling you," he says, "I'm insisting you see a doctor today cos there's something wrong with you." At that moment in time I hadn't got a clue, right?...Treatment followed "Ever so quickly….Can't believe how quick it was. Obviously, I had to, at Guys, I had to go through loads and loads of tests and scans and bloods and all sorts. But still it was quick...really quick" (**Ian, Participant 11)***

Dentists may play a role in the initial diagnosis but as we will see, they also play a significant role in the initial stage of treatment of patients. Dental extractions often form part of their initial treatment as a pre-radiotherapy (pre-RT) process, which can be incredibly invasive, and this part of treatment is discussed specifically in section 7.3.

7.2.1.2 Experience of the urgency to seek treatment

Something that is common for many those diagnosed with cancer is the speed and urgency that surrounds diagnosis once there is a suspicion of cancer and the first phase of treatment and the feeling of rapid escalation. The minor symptoms may have been persistent and trivialised for some time and then suddenly they equate to a much more serious and impactful illness. What compounds this feeling in the particular case of HNC, is that often the treatment involves initial dental extraction or invasive surgery and they are in areas that immediately impact on one's ability to function as normal, in terms of communication and eating.

The speed at which someone's functionality and identity is changed is often dramatic, traumatic, blindsiding, and unexpected. To fully understand the process and impact of this, hearing the narrative of patients can also help to inform how we guide them through this initial ordeal. This section focuses on demonstrating this whirlwind phase following the escalation of treatment. Diagnosis is precipitated by a biopsy and potentially scans, examinations and blood tests. The patient often has to undergo a number of appointments in a busy hospital and speak to a number of consultants and health professionals. As they move from biopsy and diagnostic testing to agreeing a treatment plan, this is compounded further. Many professionals in busy, open and unfamiliar spaces rapidly provide them with information. Aga describes her experience of biopsy and tests below and vividly remembers the date and the fact that scans happened within a few days.

> *"I had the biopsy done and then I saw the consultant at Beckenham and he said you know, it was cancerous, so they needed to get erm, an MRI scan done and a CT scan. I had the MRI scan done within a few days actually and I remember the date of that because it was my birthday [laughter], so that was the 8th August we had to go there."* ***(Aga, Participant 2)***

Marcus also describes the speed at which diagnosis happens and his shock at diagnosis and the rapid biopsy, with confirmation that it was cancer two weeks later. Following the confirmation, he was then told to await a phone call and it struck him that he didn't even have time to shave before being called in to commence treatment.

> *"I went to King's, still quite relaxed by it all on the twenty first of November and asked them, and he said "Well can you come back for a biopsy tomorrow?", I nearly fell of my chair you know. I said "What are you're saying it's malignant?" He said "Well I don't know", he was very, very nice, he said "It could lead to that". And there's phone calls going from departments, I thought this is serious, you know. So, I had the biopsy the next day and then two weeks later on December the fifth, he told me that it was cancer. So, you know, I, I was fearing and that, and um, my fears were realised…. They can't study the niceties of it, like how are you? They just want to get you in there and sort of sort this out for you, that's what it, they're just trying to save your life basically."* ***(Marcus, Participant 7)***

James also reflected on the speed at which decisions are made early on in the journey, often in the moment or at great speed. Early choices are made about teeth extraction or removal of parts of the mouth, tongue and throat which, even once cancer, free have a drastic long-lasting impact on a person. Many accounts, including James, as below, described making very pragmatic decisions and choices about their treatment that are based on survival rather than quality of life, which focussed them on making the immediate next decision and not necessarily thinking about the future or impact of losing speech, communication or being able to eat.

> *"I think I was allowed to make the choices, it's just the situation doesn't always give you time to actually think too long about the choices, you've got choices to make and they have to be made."* ***(James, participant 8)***

7.2.2 PERCEPTIONS OF HEALTH PROFESSIONALS IN DIAGNOSIS AND EARLY TREATMENT

The experience an individual has with health professionals early in their journey with HNC is can often shape their perspective of approaching treatment, allay their fears, provide comfort for their families and friends and help manage how they cope with the early days of diagnosis and treatment.

In all interview's participants spoke of the formative nature of these interactions early on. Whether this be around early symptoms being taken seriously (as discussed in the section around diagnosis and trivialised symptoms) or around information provision and caring guidance through their treatment journey. At the referral to a consultant stage an individual may receive a diagnosis and alongside a plan for treatment. Therefore, this milestone can often be profoundly upsetting and overwhelming for patients. A theme arose from this study around the impact of this particular moment and the elements related to provision of information and communication around diagnosis, which we explore further in this section.

7.2.2.1 The impact of receiving information on treatment alongside difficult news

Although wider studies have highlighted the importance of communication with care providers in how patients experience their cancer (Thorne *et al.*, 2008; Baile, 2015), the importance of this In relation to the individuals resilience, happiness and direct health outcomes is not easy to quantify or articulate and therefore is somewhat lacking in the literature.

The in-depth interviews uncovered a mixture of experiences when receiving diagnosis and their initial treatment plan. Many spoke with gratitude and praise for the teams that supported them in those initial stages. These individuals were often those whose accounts of treatment and rehabilitation were most optimistic, and therefore this positive affirming experience with care providers supported a resilient, optimistic outlook that meant coping with the process helped and reduced some of the distress. This is reflected in the examples below.

Good initial experiences

The descriptions of a good experience often captured communication with the team that was tactful, empathetic and sensitively delivered. For what is a profoundly devastating diagnosis clarity, sincerity and fostering a positive communication strategy builds trust and creates the beginnings of a relationship that can serve to help patients successfully navigate treatment and rehabilitation. Receiving a life-threatening diagnosis such as HNC is therefore a pivotal moment for an individual. To draw on work looking at another life-threatening diagnosis, Pavey *et al.,* 2013 describes this phenomenon for those receiving a diagnosis of motor neuron disease (MND) (Pavey, Allen-Collinson and Pavey, 2013). Owen reflects back on his perception of the staff and team who have supported him through his journey and how they guided him through his treatment. He conveyed how he valued the delivery and soft skills they employed in his care:

> *"I'll tell you what. Obviously, I've met lots of doctors, lots of nurses and I have to tell you … what's your name again? Your first name? one hundred per cent. Everybody, a hundred per cent. Not a negative word … well, you've seen the support there today. Fantastic.(…) Such a special team…The cancer wards don't stop, they're just lovely….Lovely, you can't fault any of the staff….We couldn't be in a better place…..All the staff, I never had any problems with them, they're all so sincere"* ***(Owen, Participant 12)***

Health professionals providing detailed information empowers the individual to make decisions with their treating clinicians and this often affirms the patient's positive experience of treatment. Disclosing information comprehensively with the patient that is factual and clear was described as important but what individuals accounts demonstrate. Further to this, is that provision of clear and accurate information is only one part, how it is disseminated is pivotal to the success of a patient receiving this and building a treatment plan that is patient-centered can only be created with fostering these types of relationships. Helena talked about her consultant and the CNS as pivotal relationships in her decision-making.

> *"I was in control of my responses, er so I went to an MRI scan I went to a CT scan. Everyone was very supportive, Jane [CNS] was there for me."* ***(Helena, Participant 1)***

Therefore, creating a joint decision-making space, which is non-patronising and empathic is something that should not be overlooked or underestimated as a bedrock to a successful care pathway.

> *"I mean they were very, er, clear about, erm, what they'd found which I fou-found really helpful. I, I've always said I found it, it's the not knowing that makes things seem a lot worse, I'd always rather somebody sit down and go through things clearly(…)… then I can make my decisions. If I've got the, the information there, erm, I can say right, well we need to do this now, we might need to do that later but we'll, we'll cross that bridge when we come to it because it, it's wasted effort focusing on that."* ***(James, Participant 8)***

Studies have shown that providing information on diagnosis, throughout treatment and rehabilitation, can contribute to a better experience of such a diagnosis. Thorne *et al.,* (2007) carried out a study with cancer patients and described that the communication with their care providers has a meaningful part to play in shaping their disease outcomes. Through a qualitative exploration, they *"generated an interpretive description of patterns and themes within their accounts of a relationship between communication and cancer survivorship."* (Thorne *et al.*, 2008 p34).

Marcus, who came across as resilient and strong during his treatment and rehabilitation described the team as reassuring and described his consultant as attentive and going into detail to provide comfort about upcoming procedures.

> *Um and he really sort of um I mean, I mean, what a man you know, he's sort of, he, he …, I don't know how much detail to go into, but you know, but he was very, very sort of like, three days before the surgery, so he pulled out his mobile phone and said "He's going to film the operation" Oh he was very, very, I mean very nice, the first time I saw him, I think he was running a bit late, but subsequent times, I, I mean what a man, you know, he's very, very sort of reassuring.(…)and I couldn't speak highly enough of the people in there really, it sort of reaffirmed my, in that part of it.* ***(Marcus, Participant 7)***

Again, this demonstrates the value of sincere, empathetic but realistic communication. He was left with a lasting good impression of his consultant and a trust was nurtured as a result. The reassuring and informed consultant was a pivotal gatekeeper of information for Marcus and was a fundamental part of his initial good experience.

Missed or badly communicated information

For individuals receiving a diagnosis of HNC it can be highly stressful, distressing and numbing and ineffectual or problematic dissemination of information or communication can create a negative environment in these initial stages, which may affect them later. As highlighted above, the strategies used by health professionals to impart information are therefore crucial. Many participants note that they were not able to process information fully whilst they are receiving their diagnosis. As mirrored in the relaying of dental extraction information participants communicated that sometimes when in the state of upset and panic about receiving a diagnosis they missed information. Santi captures this feeling well by describing herself as not feeling in "a listening state of mind".

> *Um I think, um I think that I had to breath in the information over and over again…I was and that was sensible, because um I could only absorb um, well yeah, I mean I think to some extent stuff was drip-fed to me in a way that I completely understand, um, because um, I wasn't in a very listening state of mind maybe.* ***(Santi, Participant 9)***

Another example of this state of numbness and not being able to absorb information comes from Marcus, who talked about how he was told radiotherapy might be on his treatment plan but had not computed this to be the case. Luckily, the surgical intervention had been successful, so it wasn't required but this captures the idea of overwhelm when receiving information that relates to treatment and prognosis, which in turn means individuals struggle to absorb key information.

> *I, I wasn't aware that that could have led to radiotherapy, maybe I was told and I didn't hear, but all's well, well at that time, you know, when I went back about four days after coming out of hospital, they said "We've got some good news, it's all, it was clear".(…) So it's good news but um, it was all sort of hitting me at a hundred miles an hour, but I must be honest, they told me what was going to happen, I mean it was the eleventh hour, but I knew what was happening, we're going to put a thing in your throat, I can't say I wasn't told.* ***(Marcus, Participant 7)***

Not being able to absorb information about treatment plans and consequent long-term impacts may contribute to patients reflecting back on their experiences and feel that they were not clearly informed, as described by Barbara.

> *yeah, everything was explained yeah, they were brilliant, absolutely brilliant. But with this operation, I didn't think it'd be this traumatic(..)not a lot was explained to me about the after effects of your operation.* ***(Barbara, Participant 6)***

Santi also describes not fully understanding a second surgery she underwent, expressing some regret at this being carried out and the impact it had on her rehabilitation.

> *I suppose one example is that um, I think the first surgery was explained to me quite clearly and then the second surgery wasn't explained to me, in fact how I found out about the second surgery was, an Anesthetist came into my room and said "I'm doing this test for tomorrow" and I had no idea that I was having anymore surgery and they then became very worried, and wouldn't tell me what it was about and it took quite a long time to...Well a couple of hours, when I didn't know what this was, before eventually someone came down and explained what was going to happen. So um, and then it took me many months exactly what had been done in the second surgery and that's been important to me, because um, because my, the rehabilitation has been limited, and that, no one knows what I would have been like if I'd only had the first surgery* ***(Santi, Participant 9)***

Santi goes on to say:

> *"I found the Consultant appointments very difficult, um, you know, you go in with your questions, if, if you don't ask the question in exactly the right way, you don't get an answer, um or not an answer, um that is helpful."* ***(Santi, Participant 9)***

It is clear that it is difficult to comprehend what the future would hold for a patient embarking on the treatment for HNC. Whether it would involve surgery, radiotherapy or chemotherapy, dental extractions and what the impact would be on a person. James talked about needing time to process the information and how the clinical team gave him some time to understand and take stock.

> *…I, I think, erm, I was quite lucky in that the people that I saw initially were willing to let me take some time out and think about things. Erm, it didn't stop it being a very busy time, 'cause obviously there were a lot of other investigations and steps you have to take while you're waiting for the treatment to start.* ***(James, Participant 8)***

Therefore, a number of seemingly contradicting concepts are at play and create a difficult juxtaposition needing navigation for both clinical teams and those diagnosed. There is a need to be clear, objective and accurate whilst being sensitive, empathic and supportive. Furthermore, there is a need to treat quickly but provide time for patients to absorb diagnosis and treatment plans. The factors that need to coexist to create a personalised approach can be conceptualised into three important elements.

- **Accuracy** - Clear, concise accurate understandable information
- **Delivery** - Empathetic, sincere, and supportive staff build a relationship that is essential to a successful and positive experience of diagnosis, treatment and rehabilitation.
- **Feedback and processing** – an iterative consistent check-in process that allow time for processing information within a heightened intensive and condensed period of time but does not compromise rapid and swift treatment.

It is delicate balance around how much information to provide and how to deliver it and this depends on the patient. Ian captures when an individual receives information in a way that suits him and allowed him to feel empowered, informed and comfortable with each stage.

> *Yeah, but you have to be a bit savvy about how you take the pieces of information …Only one doctor came in and it was perfect timing and I did find that all the doctors who parlayed information to me, the timing was always perfect…it was communicated beautifully well...It really was. I can't fault any of them but it was piecemeal. I'd get a little bit of the jigsaw puzzle here, a little bit of the jigsaw puzzle there, and maybe that was the way to do it because they could've overwhelmed me.* ***(Ian, Participant 11)***

Knowing how to impart information and what decisions can be made at that time is something that needs to be carefully considered if a service is to be patient-centered. This is the ambition nationally and reinforces the importance of communication skills training for all staff involved in treating these individuals so they are able to navigate these types of complex patient scenarios. When these factors do not coalesce, it can lead to struggles with early consultations and these are described in more detail in the next section.

7.2.2.2 Struggles with early consultations

Some participants spoke of struggles with early consultation and some difficult experiences they had initially. This shaped their treatment and their perception of how they were coping with treatment. Santi talked about how she felt sometimes gaining information felt hard.

> *"I had, I had understood, um I mean I had sometimes felt I've had to work incredibly hard to get information, um, and I have sometimes wanted more information than I've got um (…) as I say I'm not, I don't know what, I think the point at which I was told that I almost certainly had cancer, I don't, if someone had been able to sit with me for a little bit immediately after that, that would have been, it wouldn't have made it better obviously, but um, that was quite a hard moment. "* ***(Santi, Participant 9)***

Santi describes an example of feeling unsupported and not effectively communicated with and not having a clear idea of her upcoming treatment and second surgery and felt she wasn't told what the consequences might be. It was a couple of months before she actually knew the details of her surgery and now feels that this second surgery has impacted on her post treatment self.

> *Well then he said, not him but one of his colleagues did the biopsy which was horrible, and then they said "Oh you can go home now", um and that was so hard, because um I was on my motorbike, I was supposed to be travelling into work, and you know, and I don't know what might have helped, but I did feel very, that's probably the one point where I thought um, I felt very sort of unsupported.* ***(Santi, Participant 9)***

Much has been written about the psychosocial impact of poor communication in cancer care. It is increasingly documented in research that poor communication can contribute to patients having elevated levels of anxiety, fear, apprehension, and distress. *(*Ziegler *et al.*, 2022). Santi's example illustrates this and highlights the importance of clear, understandable information that is imparted with thoughtfulness and with care can make a huge impact on how a patient feels and empowers them to manage their treatment. Information giving is a crucial part of ensuring that a patient feels some sense of control and can help to appease the sense of unpredictability and the unknown.

Clinicians play a vital role in providing a service that creates a team atmosphere and a sense of a common goal. There is emerging literature (Thorne *et al.,* 2007, Ellis *at al.,* 1999) suggesting that *"the perception that communication may influence clinical outcomes seems sufficiently pervasive and persistent that it warrants serious attention within care systems and by the psychosocial cancer research community."* (Thorne *et al.*, 2008 p34. What makes this even more pertinent is that it is clear that patients have a perception that good communication with care providers affects their experience and successes in this journey and therefore, it is important to highlight this element in the HNC pathway. Creating a supportive framework with clear and beneficial communication mechanisms is an ethos that is at the centre of the CHANT philosophy and is at the core of the policy ambitions for a community-based team.

Understanding the challenges staff may have in providing this information must start with identifying the needs of patients and, in parallel the challenges perceived by staff. A study by Banerjee *et al.,* (2016) identified that oncology nurses felt the fundamental challenges were around *"communicating empathically: dialectic tensions, burden of carrying bad news, lack of skills for providing empathy, perceived institutional barriers, challenging situations, and perceived dissimilarities between the nurse and the patient."* (Banerjee *et al.*, 2016 p.1). Whilst, exploring this further is beyond the scope of this study, it is useful to be aware of the staff challenges to set the context for the feedback that patients provided in this study.

7.3 OVERARCHING THEME 2: THE IMPACT OF TREATMENT

In the first section, we have heard from individuals about pre-diagnosis symptoms, the dual point of intersection with healthcare professionals, the urgency around diagnosis and treatment planning and the dissemination of information between staff and patients. In this section, I turn to the next phase, as set out in Figure 2, the active treatment phase, which can take a number of routes and include initial dental extractions (pre-radiotherapy), surgery, chemotherapy and/or radiotherapy.

7.3.1 HIGHLY INVASIVE AND COMPLEX TREATMENT

The narratives from patients detailed harrowing and difficult experiences of treatment. It is extremely invasive and complex and in order to understand the experience it is important to reflect on the accounts and reflections of the treatment phase from participants. Treatment, for many begins with dental extractions with teeth removed to avoid complications following active cancer treatment, specifically the aftereffects of radiotherapy. This is a voluntary risk mitigation process as radiotherapy can cause Osteoradionecrosis (ORN) in the teeth. The radiated bone becomes necrotic and exposed and can lead to further complications involving infection. Therefore, this section starts by hearing the experiences of dental extractions, then the accounts of surgical interventions and finally the experience of chemotherapy and radiotherapy.

7.3.1.1 Unexpected dental consequences

The decision around dental extraction is something that happens within days of diagnosis and is often the first active treatment (although prophylactic) that an individual undergoes. It is an example of a rapid decision, but the later consequences can be profound and not well understood by the patient, at the time of making the decision.

In Chapter Six, observational work described the intimidating setting and process of early treatment for HNC patients. The accounts of this phase of treatment were often harrowing for participants. Many went into dental treatment unaware of the implications or consequences of the removal of teeth. All participants who described dental extraction reflected on finding the process incredibly hard and feeling vulnerable, powerless and in many cases uninformed about the number of extractions, implications of extractions and the pain and discomfort that happens during the process itself. James captures this in describing his dental extraction as the most traumatic part of his treatment.

> *"That was, that was actually a little bit more traumatic than the actual diagnosis really, I think. It was quite strange. You sort of sit there and then you're faced with it, the fact you've got cancer…(…) … and you're going to need to have chem-chemo, chemotherapy or radiotherapy or whatever, but you don't really think about the other things that you potentially might have to (…) and it was, I, I sort of confronted with it, I thought right, well it, it needs to be done (…) I understand the reasons why it needs to be done and I'm happy to proceed with it, but it's only after you've actually had it done that you realise how much impact it has (…) I have no teeth here at the back, they've all gone (…) They took 20."* ***(James, Participant 8)***

He reflects on not really considering the long-term impact on his quality of life and how, in the moment of treatment extractions happened, and he felt he would return to some normality afterwards. However, dentures were later not advised, to give him the best of chance of recovery and there was a mourning of this loss much later down the treatment journey that was impactful on his sense of self, and his quality of life.

> *"... when all you've got is your front teeth and you have to, you have to use those for chewing and for everything…(…)… erm, it becomes, things you didn't think about are things like food and, erm, eating, you don't really think about it most of the time 'cause you just do it (…) But once you've had something like that where the teeth have gone and it's changed how you eat…and also for quite a while of what you can eat… (…) it has a bigger impact and you don't always think about that when you're… I certainly, I mean I sort of said, yes okay, I understand the reason why we need to do the dental clearance, I'm happy for it to go ahead, make the days, make the plans whatever, er, but you don't really get a chance to sit down and talk to somebody perhaps about how it's going to affect you after the surgery's been done… and that "…was, it wasn't a, a complete shock, 'cause obviously you know you're going to be without teeth so it's going to make a difference. It perhaps might be nice to maybe speak to somebody*

> *who has had it done and then you'll get a clearer picture of what's, what the reality is of it…And I guess that, even just that part where they told you, right…"* **(James, Participant 8)**

Marcus also captures this sense of eliminating the cancer above all things and not processing the impact, assuming and hoping his teeth could be restored in some way later down the line. Marcus also interestingly reflects on the environment stating, *"But after I went up to, well what a dental place at Guy's, I've never seen anything like it."* His recount of broaching the subject of teeth removal captures the feeling that this part of treatment is an incidental precursor to surgery and chemoradiation.

> *"As soon as we're back from Christmas, it all took off again, so it was all explained to me and beforehand, I must be honest, that the thing was going to my neck, the trach [ph] was sort of going into my neck and then they sort of turned round and said um, a few days before, "We've got to check your teeth as well (…) "I'd like to take some teeth out", I mean just like that, [chuckling]….Well and then they were doing surgery, I mean to them, I suppose, I'm not laughing, but if they're taking away a bit of your tongue, I suppose a few teeth, while you're there….I said "Well what, can these teeth be capped?" he said "Oh later on they can be, but it'll be at the back anyway, it won't be your front ones, it'll be your back ones".* **(Marcus, Participant 7)**

Finally, Santi describes her experience of dental treatment prior to her surgery and that she had more teeth removed than expected.

> *"…I didn't get the referral and then they said I needed to come in, so I went up the day before, and then they removed the teeth during the main surgery which was better, for me…they didn't plan to have a tracheotomy, so I didn't, they actually removed more teeth than they said they will, but it took them quite a long time to realise."* **(Santi, Participant 9)**

There is little research available to determine the impact of this approach on patients. However, Clough *et al.,* (2018) carried out a qualitative study based on semi-structured interviews conducted with 18 HNC patients who experienced pre-RT extractions. Participants described the experience as being made *"worse by the fact that teeth were often healthy, asymptomatic and were not the actual site of cancer."* (Clough *et al.,* 2018, p28) and they had a deeply negative impact on quality of life. Many participants just did not understand the consequence of teeth being removed. James had not fully appreciated the impact of having so many teeth removed and the weakness in his jaw area that would happen after an extended period of recovery. For him restoring strength in the jaw was a race against time so that his muscle strength did not erode and make dental work unfeasible.

> *I think, I think I was, again maybe I was holding onto, focussing on the fact that right, well after all this is over and done I can have dentures and it'll be fine.(…)Erm, but I did-…(…) Yeah, but, erm, the fact that I, they sort of said no we don't really feel it's appropriate that you use them and because of that they then didn't offer to provide them, if I wanted them I had to source them myself, erm, but I felt a little angry about that. Erm, but I think that perhaps they missed an opportunity to say well this is what we'd like to happen, but there is always a chance that you won't be able to. I think that perhaps might matter, it wouldn't, I, I would have felt better if that had been stressed a bit more. (Sense of self) ….. Erm, 'cause I wouldn't have sort of held onto the fact that I, this is all, it's awkward eating at the moment but, er, eventually I'm going to get back to a reasonable diet and…* ***(James, Participant 8)***

This reflects the whirlwind that surrounds dental extractions which can often lead to decisions being made without fully comprehending the consequences of this. Clough *et al.,* (2018) findings showed this too, highlighting that patients *"felt that their information needs about pre-RT extraction were not addressed and choices were limited."* (Clough *et al.,* 2018 p28) Extractions had a profound negative impact. Therefore, there is growing evidence that carrying out pre-RT extraction is not beneficial to the patient and should be considered more carefully. For many patients, the next step is swiftly moving onto surgical interventions and the next section looks at what this entails for participants.

7.3.1.2 Surgical interventions

At the point of surgery, the patient's main interactions are with hospital settings, however they will begin to meet the multidisciplinary professionals who will go on to support post treatment review, follow up and their rehabilitation. This may include speech and language therapists, dieticians, clinical nurse specialists, consultants, psychologists, and physiotherapists. The individuals follow up is decided on the basis of the success or effectiveness of the surgery and their medical history. Individuals described their surgical experiences and there were a variety of timings depending on complexity, progression of the problem or availability. Barbara describes waiting two weeks for her first operation.

> *think it was um, two weeks after that, I was in. Because the hospital phoned mum, I was at home, but it was the first operation there*, ***(Barbara, Participant 6)***

Aga describes surgery happening much quicker due to a cancellation. Health professionals will take the opportunity to progress individuals who are waiting if cancellations come in but this can be quite a turbo boost in the timescales for individuals and therefore be quite trauma inducing if treatment moves at a pace they were not expecting or ready for.

> *"the secretary rang me and they'd had erm, a very big operation cancelled a person had pulled out. So, they asked me if I could go in the next day which I did erm, and so then they took the lymph nodes away and that turned out."* ***(Aga, Participant 2)***

Marcus discusses the potential invasiveness of surgery in the mouth, face or neck area. He underlines the extent and complexity of the recovery period sometimes required. Marcus had part of his tongue removed and as part of rebuilding function he had a transplant of skin from his arm.

> *"And I was still, [chuckling], I was still hoping they might, might pop it off in day surgery or something, but that was um not going to happen. So I saw the um the Consultant and he, he gave it to me and he said um, "We're going to rebuild the tongue" and all this, "And you'll be in hospital for two weeks". I thought oh right, I've never been in hospital in all my life…"* ***(Marcus, Participant 7)***

Marcus faced an extremely intrusive transplant process that involved being in hospital for two weeks. In the further quote below, he describes the shock and that hearing the positive prognosis from his surgeon was reassuring and affirming. The surgeon had described him as fit and therefore likely to recover well.

> *"I was really shocked about that, but I think he was running a bit late that day and he was a bit sort of, he was a bit sort of, um, rushed, but once he saw it, he said "Oh that's not too bad", he saw it and said "That's not too bad" and um, then subsequently to that he was, he was very, very positive about it and I saw him several times, and I had to have all the um, CT scans and MRI scans, all this, and he was, and he was um, really very, very positive, very reassuring, he just, he just spoke about it, as if oh you'll be alright, because I was going in their like wreck.(…) And he was very sort of, um confident isn't the word, um, [chuckling], he just said "Oh it'll be right, you'll young", well I'm sixty one, well yeah I'm fit."* ***(Marcus, Participant 7)***

Santi spoke about her surgeries which followed each other closely and that she found this extremely traumatic, not being able to really process what was happening and having to realign her expectations as she needed more treatment.

> *"when I saw him again the next week, um, so he told me, that, that there would be surgery and it would be fairly soon(…)that was all in a space of weeks from that very first diagnosis?....I don't think your head can get round it in a way so um I don't know, um, um.(…) was still in hospital and um and it was six days after the first one...Yeah I mean basically the fake tongue began to die, um so yeah."* ***(Santi, Participant 8)***

Owen highlighted a complexity in the surgical elements that isn't always assumed with HNC diagnosis. This relates to removing cancers in other areas that may have spread or coexist. He talks of going into surgery expecting one thing and coming out feeling a pain somewhere he didn't expect. This is something that is a consistent theme across cancer treatment as surgeons cannot be certain about what they will remove beforehand and this can lead to difficult conversations with the patient being left feeling like they are not aware or in control of what their treatment will entail.

> *"No, not the chemo, that's the radiotherapy, yeah, so when I'd finished the chemo, they didn't want to leave it too long, in case it started again, so it wasn't long after the chemo, that they done the second bit of surgery, and this was in April. They took it all out, I think they took a bit of my tongue away as well, just the edge of it, because it was really painful there, they didn't tell me they'd done that. When I saw Mr Steen, I said I've really got the pain, but not where you've done it, but over here. He said well, we had to take a little bit off the lung,*

> *because there was a bit of a question in it, it wasn't in your lung, but you know, obviously where it had been attached to it, so got it out."* **(Owen, Participant 12)**

Surgery and dental extractions are extremely invasive and distressing for individuals but what follows or accompanies these surgeries, (chemotherapy and radiotherapy) is also very trying and profoundly life changing for many. Elements of this are compounded in terms of intensity due the locations of the cancer being around the head, neck, face and mouth area. In the next section, accounts of this phase are examined further.

7.3.1.3 Chemotherapy and radiotherapy experiences

Chemotherapy

Chemotherapy is a cancer treatment, which uses anti-cancer (cytotoxic) drugs to destroy cancer cells. These drugs halt cancer cells reproducing, preventing them from proliferating, however they also affect the other normal cells in someone's body, which cause the individual to have illnesses. Chemotherapy is usually a number of sessions, with some rest periods factored in which make up a cycle of treatment and a course may involve a number of cycles. The chemotherapy might be given over a number of days and is most commonly given in a hospital setting via a pump. The pump is connected to a tube that leads to a patient's veins, either in the arm (PICC line) or the chest (central line) so the drugs travel through the blood to reach the cancerous cells.

Chemotherapy protocols vary in terms of the drugs used from patient to patient and can affect an individual in different ways. Side effects can include a variety of symptoms including hair loss, hearing loss, changes to taste, loss of appetite, bruising and bleeding, sore mouth and most commonly nausea and sickness. Most individuals in this study experienced sickness as described by Owen below:

> *"Then I met my consultant, Dr Khan, and he says, "I'm recommending three massive hits of chemo and thirty days of radiation (…). The chemotherapy really made me sick, and it really hurt. I couldn't eat anything. The pain was so bad. And obviously I was getting sick as well. (…)*

> *The first one I thought that's not too bad, but you could get a reaction halfway through it, any time, you know. Of course, I'm sitting there, all the voices are going, and the thing, I thought this is my lot, you know what I mean? But that's what I had to do isn’t it, slow it down. And then anyway, so I had the course of the chemotherapy, and another scan, and it had shrunk by two thirds, because this thing only, thank god, it originated from my thyroid. So it wasn't here, there and everywhere. So that's what Mr Steen [ph] mostly you know, so he could contain it, he can't just keep cutting bits off you know. So it had shrunk by two thirds, so then they booked a surgery in, and obviously took all my thyroid out. But after the … I've got to have it out, because they've had to do the thoracic surgery, so now we've gone from my throat into my chest. I think there was three surgeons, and it was like eight- or nine-hour operation, so they opened my rib cage up.”* ***(Owen, Participant 12)***

For HNC chemotherapy is often used in combination with radiotherapy (chemoradiation) and is usually given before radiotherapy to shrink tumours. Some patients may only have chemotherapy and it can be used palliatively, with targeted drug therapy. Whilst sickness and nausea can be severe and traumatic other symptoms like taste and hearing loss can be surprising to patients as described by Owen who mentions the impact on taste.

> *“So yeah, my taste is okay. Because that was the awful thing with the chemo, taste the metal, no matter what you tasted, it's like metallic, awful taste wasn't it? So yeah, I've got my taste.”* ***(Owen, Participant 12)***

Brandon, who had attended with his supportive partner talked about chemotherapy happening quickly and feeling it was well managed, however both him and his partner spoke in contrast about radiotherapy.

> “*It was constant treatment…it was hard, but they treated you well…(…) after chemo it was radiotherapy. It was like the next day [partner: “no a week after”], a week after. That treatment was really hard that really hurt me.”* ***(Brandon, participant 5)***

This reflects a common theme amongst participants, who felt radiotherapy was a marked contrast, in terms of experiences vs. surgery or chemotherapy and this is explored next.

Radiotherapy

As outlined previously, radiotherapy is the next stage of treatment for many who have undergone chemotherapy or as a sole treatment. It uses radiation to kill cancer cells. As with chemotherapy it can be used as adjunct to other treatments and can make them more effective. It can also be used to prevent cancer returning or to relieve symptoms palliatively. It can be given in a hospital setting via injectables, implants, or as is the case for most HNC patients, via a machine, which directs beams of radiation at the cancer. This phase is therefore more intrusive for HNC patients over other cancer patients as it often involves wearing a mask covering the neck, face and mouth area. Ian describes the process of the mask fitting which captures the reality and intensity of the process.

> *"..this is my mask and they put that on you and they have to put that on you because they strap you on to the bed and your head can't even move like half a millimetre. Then they raid the radiation at you at just the right places, okay? So that's the mask they give you. Well it's between seventy minutes, and the longest I was under there for was an hour because the machine wasn't working too good. That's the machine. Right? So, it's a massive, massive machine. Nearly fills up the whole room. This is the bed that you lie on. Obviously, the bed's tucked in at the moment, but the bed comes out and you lay on the bed, right? That bed comes out and you lay on it and they strap you to the bed with your mask and then the machine comes down and..."* ***(Ian, Participant 11)***

Aga, further reinforces the unique distress that comes with HNC as she had previously received breast cancer treatment and therefore had the comparison, she described this below.

> *"Now as I understand it from the oncologist, she said erm, she said I'm sorry we've got to put you through this, the radiotherapy but she said you know, there is nothing that we can see in there but we're not sure what's floating around… I mean I don't know if you know how they do it but I lay on the bed and had the mask fitted and screwed down, which I mean it wasn't pleasant. I mean it didn't hurt, there was no pain ever and the radiologists were brilliant, absolutely you know, all the medical staff have been fine."* ***(Aga, Participant 2)***

Owen describes a vivid account of the visceral discomfort and distress that an individual has to undergo for radiotherapy with HNC. He felt it was the worst part of his HNC treatment and felt trauma that has stayed with him.

> *"So as soon as I got over the surgery, the worst thing I think has been the radiotherapy, that has been an absolute nightmare. I've never been the same since that have I? (…) I coped with, every day a little bit stronger, and you know it's healing. But this is going backwards, with the radiotherapy…It's been the worst thing."* ***(Owen, Participant 12)***

Hearing Owen's description of radiotherapy highlights the ordeal and the claustrophobia that occurs with treating HNC this way. The face, mouth and neck area is where one routes their communication, breath and essence of who they are. Having this area covered can lead to the patient feeling very out of control, scared and distressed.

> *"I couldn't get my breath. Couldn't breathe, next thing I get rushed to St. Thomas A&E. I could not get my breath. And they're saying oh, you've got plenty of oxygen in your thing, but I couldn't physically get it in, so I'm getting worse. Anyway, all the doctors had disappeared, so he said, we'll have to call an ambulance, take you to St. Thomas'. So, I think I was there until about I don't know, 11, 12 o'clock at night. But it was more panic, I think."* ***(Owen, Participant 12)***

Owen captures the panic that the method of delivering this radiotherapy elicits. A person's face is held in place by mask screwed to a bed. This treatment takes time and an individual has to keep returning to complete the course and therefore it is an ordeal that has to be endured and persevered with.

> *"But I did say to them it's too tight, but obviously that fluid's gone somewhere, but that's the worst thing I've ever been through. 28 consecutive days, including the bank holiday. They gave me that pill once, was that the first time? Something got cancelled or something went offline, there I was waiting, I'd been waiting a long time, not their fault. I said I can't wait here anymore; I'm getting too freaked out. So they said the only thing we can do is … because they didn't want to miss a day, come back Friday, but you have to do one at one 30, and it's got to be a six hour gap, which I did two Fridays. I can't think when the other one was. Oh yeah,*

> *when I had the … St. Thomas' for example, missed that … I've missed that thing, so two Fridays, so I just came up here, one at like half eight I think it was, yeah, and three or four o'clock in the afternoon. But 28 consecutive days and there wasn't one easy day. I couldn't get used to it at all.”* ***(Owen, Participant 12)***

Radiotherapy can leave psychological scars as well as physical symptoms, which can be impactful on a person’s quality of life and wellness. Some patients keep their facemasks after treatment as it reminds them of the experience they went through. This mask becomes a symbol of a trauma that they have endured, survived and come out the other end. It is a physical visceral reminder of the treatment endured and their ability to get through it. Santi described the pain and the potential for her to have to nasal feed following this treatment.

> *“I hadn’t, what the radiotherapy would be like, and I’ve been told that it would be tough, but I’ve also been given lots of information about that. Yeah it got, it got incredibly painful, and I couldn’t speak, um, that, the first, the first couple of weeks were fine. (…) Um and then the next two weeks were, yeah so I had, I didn’t, they’d said that I would need to go back to being nasal fed.”* ***(Santi, Participant 9)***

Ian spoke of his relief when the treatment was over and the lasting impact on his skin, he also alludes to the powerful strength of such a treatment on the body.

> *“When it was the last one, I was absolutely relieved because I was expecting it to be much, much worse, and obviously all the skin from the outside of my neck [unclear-34:17] up in a huge hump. It was terrible but that only lasted about a week, and I had been putting cream on religiously, twice a day. But that cleared up ever so quickly and obviously they were saying, “Well, think what that has done to the inside of your mouth and throat.” And obviously I couldn’t see in there, but you can imagine those radiation rays going in there, so that was all, not good. “* ***(Ian, Participant 11)***

Owen describes how he felt coping with radiotherapy was partly due to his level of fitness. It is clear that coping strategies is a crucial part of navigating the journey of HNC treatment and rehabilitation.

> *“You see some of the elderly people, I don't know how they cope with it. There's nothing of them. They need to get fit before they put you on a course of chemotherapy, not … you know, build you up and …Just so you've got something you can afford to lose. Yeah, positive thing, because you don't know what … it hits you like a rocket doesn't it?... The only thing like I say, now I know about radiotherapy, would have been to get you really fit and make you eat, and the stronger you are …You can afford to cope with it.… the more you've got to fight with it, don't you?” (Owen, Participant 12)*

However, what is most cruel to HNC patients is that talking, eating, and moving can all be seriously compromised because of treatment. In the next section an examination of the experience following treatment is captured and explored in more detail, looking at consequences of losing functionality and being physical impaired. Once treatment had finished people found that they were left with bodies, that didn’t look or feel how they did previously and therefore the next section explores this in more detail.

7.3.2 TREATMENT IMPLICATIONS

As reiterated throughout this thesis, HNC is unique in that it affects areas of the body that are so pivotal to how one functions and the core needs of a person. The narrative accounts capture that the implications of treatment can be devastating and profound and that there is a gradation of affects. From basic needs such as breathing, walking and swallowing to communicating and eating and then to socialising, exercising or working. This section seeks to understand these elements by first understanding the extreme impacts around swallowing and breathing, and then looking at how this impacts on food and eating and socialising around food. This section then goes on to look at how speaking, communication and voice are affected by the treatment.

7.3.2.1 Swallowing and breathing

The impact on HNC can have a huge impact on basic needs and often swallowing and hence breathing can be obstructed. Patients may find they have excretions and they are not used to dysfunction in this area, with impairments in the larynx, throat and mouth. Probably the most invasive aid would be the insertion of a tracheostomy following a laryngectomy, which had happened to Claude and therefore he needed aids to breathe and talk after surgery. Claude has since had to learn how to function with this and how to speak and communicate.

> *"…and it was dangerous so the only option was a laryngectomy (…) it was a process that culminated in a laryngectomy"* ***(Claude, Participant 10)***

Owen describes how he couldn't swallow even his own saliva and had to carry around a Tupperware box which is very common for patients with HNC, this issue was incredibly frustrating for Owen who wanted to gain his swallowing back as soon as possible.

> *It was about three weeks into it, then it started, I couldn't eat, couldn't swallow, couldn't swallow my own saliva, so I'm going round indoors with a Tupperware thing, awful. Go out, get on a train, mouthful of like phlegm. It wasn't so bad as when it's all gooey, but it's like foam. (…)You clear your mouth, you put it in a bag, within minutes you're like this again. I was like that for a long time. But every time I went to the treatment room, wasn't it, I was … you know, I can understand you say I will get better, but every time I come up here, I'm not getting better with swallowing, it's getting worse. That was peeing me off because I kept saying to you, [inaudible - 20:33] for time, you know, I know I said that we should start to feel the benefits, and just ease off a bit, but it was like consistently bad.* ***(Owen, Participant 12)***

Santi describes this how it also affected her breathing and how having a tube inserted into her neck (the trachea) can be very traumatic:

> *Um the tracheotomy was much, much more um, so breathing was far more problematic than the feeding, the main problem I remember with the feeding, was because it would be, it would take about ten or twelve hours to trickle through, so for all that time you were quite immobilised, um. As I became better, I was able to disconnect it and wheel myself to the bathroom and things but um...To start with, that felt a real, the hours would go so slowly, so I was away from that, yeah.* ***(Santi, Participant 9)***

This is a pre-requisite to life and a basic physical need. Often the severity is unexpected and can cause great distress to the patient. It is all consuming and if they begin to find a routine where they can swallow and breath, the next challenge they face is eating and consuming food.

7.3.2.2 Food, mood and the social power of eating together

Patients are often fed through a tube from the early days of surgery and Marcus describes the tube going in when he was in hospital.

> *"So I had a tube going in, so it just winds you up at night for that, that was fine, because you could get up and go and pee and ring a bell and somebody took it, fine, not a great problem for them, so no problem for me, and at the end of the day, you wasn't being fed, so you could walk about, go out and walk down the corridor." (**Marcus, Participant 7)***

If they are feeding via tubes, this usually involves a specific regimen, which may be used for a long period to eat and feed. Each feed may take time to complete, and this was another element that immobilised patients and made them feel frustrated and at the mercy of their diagnosis.

Barbara also describes the disconcerting nature of having a device that feeds you inserted through your throat or in your stomach. The site of the feeding tube can cause pain and have complications to the change in how their body works and the level of discomfort they are undergoing.

> *But um, [inaudible - 08:46] and having a tube through your throat and [inaudible - 08:51] and being fed through your nose, you know, it's quite daunting, yeah. Yeah, it was either up my nose or through my stomach, last one was through my hip [ph], but it was meant to be [inaudible - 13:34] three months, and the nurse came to the house and [inaudible - 13:44]. So I had to go down to Lewisham hospital, and they had me on light sedatives, to pull it out, they pulled it out. But obviously they tried to put it back in, it wouldn't go in. So I had to be sent down a surgeon's room, and [inaudible - 14:16] Lewisham hospital. And I went through everything, I was in agony, when they were putting this tube in for half an hour. Oh yeah, I'm very happy that the tube's out, because*

> *it was a problem there. I was further on antibiotics, it infects them, so I am pleased that's out. And I'm pleased that I haven't got to get a new one.* ***(Barbara, Participant 6)***

Eating can be impaired for a number of reasons with HNC. It may be that surgery on the tongue, mouth or neck has impaired mastication. Transplanted tissues in this area may not function in the same way. They may have apparatus that supports breathing which compromises feeding and finally, dental extractions may mean that they have difficulties with eating in the short and longer term. The physical process of eating can therefore be arduous, painful, tiring and even precariously dangerous for the patient due to choking or food not going down the right pathway. Feeding issues can start approximately 3 weeks into the pathway and this is therefore a short period for many patients.

What must also be considered, and is less focused, on with a medical model approach is the impact that not eating has on a person's psyche and wellbeing. In practical terms, patients may require tube feeding initially after treatment and it will vary, depending on the cancer, and rehabilitation process. Whether this will be long term or not depends on the extent of reconstruction required and the success of rebuilding functionality through rehabilitation. Food can have an intrinsically emotional element and therefore can be very complex for a person's recovery. Helena, who was in her 40s felt that there was element of recovery that perhaps didn't quite address the emotional element and gaining confidence around eating, socialising etc. The health professionals approach was very pragmatic around calories and nutritional intake and there wasn't an emphasis on the quality of calories.

> *"Quite often I would see the dietician and she'd take my weight and she'd ask what are you eating? what are you drinking? and once she was satisfied, I had enough calories, then you know, she's "I'm happy, you can go". I felt it was about monitoring how much I was eating and nothing else."* ***(Helena, Participant 1)***

Owen's partner talks about his struggles with food, the role she played in helping him to eat and encouraging him. She also spoke of Owen making sure he took care of himself and was honest about his progress and how much he was eating so that he could be supported effectively by the team and improve. Owen's partner came across as supportive and often advocated for Owen when he was a little reluctant to either complain or push himself. This type of support appeared to be key to his recovery and this will be reflected on in section x when we explore mechanisms for support.

> *"Yeah, but a lot of the time, yeah, I'm eating fine, I'm fine, and then he gets cross with me, I'll say you haven't been fine, you haven't been eating. Whereas you've got to be honest, because you're not going to get better if everyone in that team …"* ***(Owen's Partner, Participant 12)***

Many have liquid supplements or pureed food in the immediate aftermath of treatment as described by Marcus again below.

> *"so I was due back to Guy's on the Friday and they said, and they had told me this to be honest, but it goes in one ear and out the other, puree the food, puree the food, so it's like baby food basically. So if you get the sign saying, soft food, even then you puree it down, so you get a cheap blender, which fortunately we had, blend it down…. And then they give you these um, [unclear 00:46:43], the sort of nutritious things, which I was on them in the, in the ward anyway, so they were quite good. But in the early days, it was pureed and then they said to me, here they said "Well look that's fine, you've got to now start trying to eat more normally" (****Marcus, Participant 7)***

Owen describes the quantity that is required to maintain strength during treatment and rehabilitation. He describes how daunting it is to feed in this way and have to consume the right amount to survive and have the strength for rehabilitation.

> *Then you see all the crates of stuff in the room, thinking this is so depressing, look at that, it's got to go in me. But that eating, it's definitely you feel like you're doing the right thing, so when I was in the hospital, I said, forget the drinks, now the most important things going in here, and if I need one of them, I'll have one, but that's priority, you know.* ***(Owen, Participant 12)***

Ian describes the importance of a strong mindset in approaching cancer treatment. He has been strongly embedded in a spiritual framework since before his treatment, which crossed his social and professional spheres and was a base for his identity.

> *I'm not joking, Anna. I was saying to my guy the other day I said, "I'm glad I did the mind power route as well because," I said, "not having all those food things and all the medications and all of that has really helped me."* **(Ian, Participant 11)**

Owen describes how this has a psychological impact and that progressing with his food has brought him to a better place in his recovery, as he makes tentative steps to cook for himself and others.

> *"Yeah, well it's like what are we going to eat isn't it? That's the highlight of the day. Yeah, that's what life is, what are you having for dinner today. It's like what shall we have then, you know, or do you want a little nibble or something? Out of the question.(…) Now I can eat, even if it's a bowl of stuff, I feel better in my head.(…) I've done …I like cooking, I like doing pasta and rice and things, and fresh mushrooms, all in the wok. (…) I've tried all the different things, I know what's … what I can swallow easy and what I can't, so I just avoid them things you know. Like even a lump of cheese, it gets stuck, but if you melt it, it's fine. Just to get to know and…"* **(Owen, Participant 12)**

Many other participants talked about the mental and wellbeing impact, and the absence of joy around eating now that they were unable to swallow, chew and taste in the same way. This social element is a reoccurring factor in the impact on wellbeing of patients and when discussed in in-depth interviews brought sadness to participants and their caregivers and families. Marcus talked about how it has impacted his life and ability to socialise and taste food.

> *"Well you know, obviously there's two things that I love to do most, eating and drinking, are the two things that've been affected(…) I think I'm fortunate, I have got taste, I mean this, this, err it's not um, I think it's about a third has been taken away, maybe less, so I'm, I'm no expert, but I think there are still the taste on the other side of the tongue, yes I have got the taste but um, by the sounds of it, some of these poor souls, well poor, generally been through radiotherapy or something, haven't got any taste, but I, I think, touch wood, I still have.* **(Marcus, Participant 7)**

Santi describes how the pleasure of eating is taken away and that going out for meals or sharing food is really hard and embarrassing for her. She feels she has to look ahead and see if there are soups or options for her and it has taken the joy of socialising away from her.

> *a bit depressed about that, um I still have, I mean the majority of my nutrition comes from um supplements, um, I have very little taste, so there's no really any pleasure in food, I can't eat anything that isn't mashed up, um, and it's such hard work, it's so slow, that um, that you know, I have small portions um. (…) And it's such a social, I mean as a solitary pleasure, you know, oh I've got the house to myself, I'm going to have you know, some, it was oh I'll suffer, because I can, no one else is here. Um but also like going out for meals or sharing food, um. Um I mean I do now um, I don't like going out for meals particularly but I mean I will if it's a special occasion, I mean sometimes we have to trail around so many different places to find somewhere that's got soup or um, um. (…) And I do, I, like my family are used to it, but other people find it very embarrassing eating in front of me, um, which I don't mind, you know, because that's, I'm used to that, but it's very awkward for them, when they're eating and I'm, I'm not really* ***. (Santi, Participant 9)***

Aga too, talks of difficulties with socialising after and during rehabilitation and that she can no longer eat what she would like, she also talks about the longer-term impact on her taste and feels things do not taste the same and describes burnt flavours, neither can she drink alcohol as she used too.

> *"Erm, I mean you know socialising, like meals and that is obviously much harder erm, but I do do it. But you know, obviously eating out, but you know there's certain things I absolutely have no problem, things like fish and pastas but I mean things like erm, a roast dinner, vegetables are fine obviously but the meat is difficult still.(…) And drinking, I can't drink alcohol. Erm, but erm things like chocolate is, some things, chocolate, I find but other things are really, they really are testing. Well they do taste a little bit different but they really make tongue, well they make my tongue erm, a bit, I mean it's not pain it's just erm, it feels as though it's been burnt [laughter]." (****Aga, Participant*** *2)*

Aga goes on to say:

> *I mean it's slow erm, and the tongue reacts to different things I might eat you know and because I think my mouth has changed, so I am catching my tongue on the sides of my mouth…it takes me longer to eat erm a decent meal, so erm yeah so that takes up a bit of time. (…) you know to be able to erm, you know just say yeah let's, where it was a pleasure to go out and eat, now erm, you know it's not got quite the same appeal [laughter].* ***(Aga, Participant 2)***

Owen’s describes the raw reality of the challenges he faces, which has an impact on his family life and mealtimes and it is important to note that how this impacts on the wider networks demonstrates the complex and far-reaching impacts of HNC.

> *“Yeah, but they're there to help you, it's no good saying I'm fine, I'm feeling good, at home he wasn't good, and he wasn't eating great, but especially with the eating, what I tried to do, even when he couldn't eat, I'd even give him a little bowl with a few scoops of ice cream, so psychologically he's still eating enough. Because we're eating, we all … our children felt bad saying oh Dad, we feel bad, we can't eat. They've got to stay, if they're eating, I go out and tidy the kitchen up and do the dishwasher or I'll do something (…) Yeah, because it makes you feel bad not being able to eat. Yeah, I didn't want to eat because of pain, I couldn't get anything, down could I? But it's psychological as well, he … that's all part of …I went for months and months, getting drinks in syringe yeah. That's the only way I could get enough stuff to keep the rest of my body working.”*
> ***(Owen, Participant 12)***

Swallowing and breathing are so intrinsic to a person’s functioning and life preserving, furthermore eating and feeding is a core element of socialising and a person’s wellbeing that it must be considered as a key pillar of the narrative of a person’s experience of HNC. The next impact relates to another core pillars of what contributes to one’s sense of self. This is speaking and communicating.

7.3.2.3 Hearing oneself: Identity, voice and communication

A consequence of HNC that has often marginalised the view of HNC patients and prevented the amplification of their voice is the impact that the treatment has on communication. Silencing them on a day-to-day basis but also making communication about their troubles, experiences, and challenges even harder than other patients. Furthermore, not being able to speak as they used to may inhibit emotions, prevent them from engaging with peer support or one to one therapies as readily and it inhibits individuals' adjustment to illness and formulation of adequate coping mechanisms. Some participants have temporary impairment and return to more or less their former function in weeks or months. Such as Ian who had a short period of not being able to speak but made progress quickly.

> *"A week or two ago I could hardly talk. A lot of it was to do with the ulcer under my tongue so I was really struggling. I'm definitely making progress with my talking, with my eating, and although this hurt it's not stopping me eating."* ***(Ian, Participant 11)***

The changes in speech aren't often associated with pain relating to muscular tightness and creates a different sound to that which the patient would have been previously used to. Marcus described it as:

> *"…well you see I was, I was worried about how I would talk and how I would be, and because it feels different, you think it sounds different. (…) people seem to understand me, but I'm sure it's not quite the same as it was."* ***(Marcus, Participant 7)***

SLTs will play a big role in progressing speech alongside swallowing, eating and strength during rehabilitation. They work closely with the dietician, physio and clinical nurse specialist to do this. This may involve using a series of exercise to improve function.

> *"I made a point of trying to do them, she said "These ones you should concentrate on". There's little tricks you know like I couldn't say "Ashes", I still can't say "Ashes", but if you say "Ash is in the grate, Ash is", that's a trick you know, these little techniques. So she taught me that and she um, yeah she sent me these sort of sheets now and um, but in the end she said "Well it is what it is, it's getting better" and she signed me off, so it's how I am."* ***(Marcus Participant 7)***

For others it can be a more up and down journey with functionality returning or varying during the course of treatment and rehabilitation, which can make the journey of rehabilitation more arduous. Sometimes recovery requires strict regimens of exercises or feeding patterns. If they are uncomfortable for patients or too taxing. This can set individuals back and periods of regression can be difficult to manage. Owen describes these fluctuations stating:

> *"It's okay, but it wasn't husky like that. It's definitely got worse the last couple of weeks. Whether that's coming off the steroids and having to help in that, I don't know. But it was definitely clearer."* ***(Owen, Participant 12)***

The impact of functional impairments around eating and speaking not only impacts on one's ability to cope but also on the daily routine and structures that make up a person's everyday life. Santi describes that her voice and communication is crucial to her job and now she was self-conscious of this.

> *"I felt very self-conscious about my voice, um but um, then something happened at work, well, um, my um, my other Manager got in touch to say that the job I was, I'd been sort of um, there was a sort of general census that if a certain job became available, I would apply for it."* ***(Santi, Participant 9)***

At the more transformative end are those whose voices need mechanical support, as is the case with Claude who was featured in the observations. Claude talked about maintaining a positive outlook.

7.3.2.4 The all-encompassing impact of treatment

The treatment is so all encompassing, their work life, social life, family life, and financial status may all change. The social capital that they may possess shifts and they have to re-acclimatise to a new version of themselves, involving physical and sometimes psychological changes. Their resources and skills therefore change in all areas of their lives. Santi describes how she didn't quite believe the outcomes of treatment could have such a traumatic and devastating impact on her. She describes feeling it would not be the worst-case scenario but that actually it transpired that the doctor was being realistic. She describes it as a course of events that have impacted every element of her life. She now feels aged and physically weaker. She is no longer the active person she once was.

> *"I thought then I would recover and I didn't have any expectation about the long term impact, um, and I remember that the, the guy, the Consultant, when he explained the surgery, he said to me "We hope to maintain the speech and swallow function", but I just thought that was funny, I didn't laugh then, but I went, afterwards, I met a friend and I said "Guess what he said? How ridiculous!", you know, and that never, I suppose you know if you take a Paracetamol and they take the leaflet out of the box, and it explains all the terrible things that might happen if you have a Paracetamol, you just think, you know, you understand why they*

> *have to explain this, but you don't, I had no expectation, that any of that is relevant to me and so I suppose I thought in the same way, that, when that risk was explained it was just the worse possible scenario, not the likely course of events.(…) "um I feel a lot older than I did before, um, um, I was very physically active before"* ***(Santi, Participant 9)***

Aga describes the all-encompassing nature in the context of how she communicates and having to think twice before she answers the phone. Something that is so instinctive is now a challenge. She also touches on something that is an interesting and subtle, little discussed impact. The outside world sees an individual in their current state, but due to the rapid changes after treatment, the individual may not have quite accepted the physical change. They are self-conscious, paranoid, and nervous about the new version of themselves that they are presenting to the world and can feel trapped and frustrated in a version of themselves, they do not recognise but others react in an unfamiliar way.

> *"I am getting better. I feel sometimes, I mean sometimes, I mean I'll answer the phone now where at one time I wouldn't, I'd say to my husband you answer it but I will answer the phone now. Erm, and most of the time now erm, yeah I'm, I mean with strangers then obviously they didn't know what I spoke like before but where people maybe that I haven't seen for some time, erm who knew me sometimes I think oh, I wonder what they're going to think [laughter]. They don't think anything I know but erm, I mean I'd rather it wasn't like this but on the other hand you know, if all this hadn't been done I wouldn't be here now. So I've got to you know, make the most of erm, you know."* ***(Aga, participant 2)***

The impact of treatment for HNC is unique and frequently visible, or it affects communication to the extent that patients struggle with the multiple impacts. This is highlighted in the dramatic diagnosis and initial treatment accounts. Once the patients reach rehabilitation stage every area of their lives are affected, including social, financial, physical, and mental health. Some describe very powerful journeys that have light and shade, darkness and light and strength and weakness. Owen mirrors several other patients' narratives that there can be a feeling of both extremes. Owen describes his daily practices of mind power, how this is supported and how he feels in a more powerful place following this journey.

> *"And I'm sure I have. And I'm sure I feel really vibrant and everything because of … nothing to take away from the treatment I've had cos it's a hundred per cent, but the bonus has been the mind power stuff that I've done, and I'm still continuing to do on a daily basis.* **(Owen, Participant 12)**

It is important to understand the impact of treatment on their daily routine and their sense of self. These themes bridge the time between treatment and moving into rehabilitation phases and the above demonstrates that breathing, swallowing, feeding, eating and communicating all have biological, psychological and social impacts (these biopsychosocial elements are discussed further in Chapter Eight). The iatrogenic effects of treatment coalesce to having a wider impact on the daily routine of an individual and this is what we reflect on this next.

7.3.3 IMPACT ON DAILY ROUTINE

HNC patients' lives are put on pause and biological, social and psychological areas of their lives are all affected, as they traverse the care pathway. Understanding this is essential to designing a service that supports their everyday needs and consequently how they engage and intersect with the care pathway. The life that goes on around treatment, it is therefore discussed in this section, looking first at how their lives change in terms of their day-to-day schedule.

7.3.3.1 Becoming a *"professional patient"*

A theme around the process of pursuing active treatment is the consuming nature of the day to day. The participants described appointments, letters, admin, synthesizing information and attending meetings that often mirrored the level of intensity of a job in its daily activity. Marcus describes the intensity of urgency and intricacies of navigating treatment and needing to be in different places at different times e.g. from a chemo appointment, to a consultant review, to seeing a psychologist or dentist.

> *“Everything, I mean it’s like um, yeah, yeah, it’s all, you’ve got to be here, you’ve got to be there, and then after it, yeah, that, once they’ve done it though, the urgency’s gone, they’re, they’re still seeing you.”* ***(Marcus, Participant 7)***

Every day is filled with something that involves either treating the cancer or supporting the treatment and the patient to do this. It becomes a 5 day a week or even 24/7 job. Aga captured this in the quote below.

> *“I mean to be honest, because we’re up there five days a week you don’t really have time to do much else erm, because that’s your day really.”* ***(Aga, Participant 2)***

Many participants talked about the daunting nature of this and that it was quite overwhelming to navigate and to get through it you have to take it one step at a time. Owen captures this in the quote below:

> *“It's always the next appointment, isn't it? That was a bit daunting, not today, but you know when we first came down here, I think oh well, that was the day you were in here, but they're all lined up, it's like question time. It's hard to remember, I remember, and then you start thinking, so who was that one there, too many, that was fine today wasn't it?”* ***(Owen, Participant 12)***

As does Santi who describes taking things day-by-day and the all-encompassing nature of treatment.

> *“Um and it’s, it’s all encompassing, once you’ve got radiotherapy you have to, that, that’s it, that’s everything you’re doing all day every day, um….Just plodding on really, just ticking off the day’s um, that’s so much percent, now I’ve done that much percent um (…)I think the other thing was that while I was off, I could look after myself….Whereas now um, I, yeah, it’s much more of a struggle for, to look after myself um.”* ***(Santi, participant 9)***

Marcus captures the information synthesis that is required of a patient with all the letters, leaflets, times and medical details that are provided for each patient undergoing treatment.

> *"I've had so many letters; I can't say I've scrutinised them all. Everything, I mean it's like um, yeah, yeah, it's all, you've got to be here, you've got to be there, and then after it, yeah, that, once they've done it though, the urgency's gone, they're, they're still seeing you."* ***(Marcus, Participant 7)***

Owen described switching off as essential when there were so many traumatic and tiring activities.

> *"But we tried, just things like the weather, we'd go for a little walk round the corner, these are little light jobs, just doing the dishwasher, that was good for him, getting up and …Just doing things, wasn't it? And the lawn, I kept … I'd been doing all the heavy work since then, so the lawn was just like easy, with the light thing. That was great exercise for him. Just gentle things like that wasn't it?"* ***(Owen, Participant 12)***

The accounts from participants provides a consistent and strong sense of this duty to be on top of their treatment and competency around completing all their treatments and appointments. Even those with less compliance articulated that they felt that their treatment was all consuming and a daily commitment. With all of this in mind they take on the role of 'professional patient' but this can mean dropping other roles and is not always in the interest of the wellbeing of the patient, but will be discussed further in Chapter Eight.

By necessity, the patient is therefore steered to self-manage their care. This happens in many long-term condition scenarios and has led to the coining of the term "expert patient". This is the notion that the patient is the most expert in their own indications and therefore their care. This has been fostered into a policy approach that is seen as empowering the patient and providing further building blocks to a personalised care approach.

7.3.3.2 Hampering your careers and passions

Many of the participants talked about the impact of an HNC journey on their careers. The time off during treatment rendered them unable to work with a new focus on their medical treatments. There daily life revolved around medical appointments, recovery, convalescence and supporting activity. Therefore, during this active treatment phase a patient is focused on activity that is fundamental to their survival and wellbeing. Following treatment, they then have to make a decision about when and how they return to work as their new selves, post-treatment.

> *"…mean obviously before the kind of, if you like, illness, or whatever, yes. For the last five months I have not been anything like as productive as what I normally would be."* ***(Ian, participant 11)***

This could have an impact not just on how people lived on a day-to-day basis but also on the practicalities of earning the money needed to live. Their very livelihoods are put on pause and often the roles they play in their lives are undermined by an HNC diagnosis. How they are as professional, a parent or friend is changed. These roles are often what an individual defines their sense of self from and therefore exploring this impact holistically is key.

Many participants talked about the impact that the long road of rehabilitation had on their career and the impact the changes to their physicality had on their ability to return to their former work routines and passions. They may need to take months off work and it can be very traumatic and disconcerting to know this at the outset. There were participants with physical jobs who had to grapple with knowing they did not have the strength to do what they used. Owen who works in a physical job describes this physical change on returning to work. He was having to adjust to his new capabilities. He was in the building industry and ran his own business working 24/7 and he had to put this on hold for a year and therefore not working was a huge pressure.

> *"It's hard to think, because I've got my van, and one of the van's parked in the front, you know, like tipper thing, my toolbox is bolted in the back, but one day I remember when I was just about to leap up on the back of it, I went to get something out of my toolbox, and I couldn't physically get up there. I couldn't believe that was me, because your head says you can do it, but your body can't."* ***(Owen, Participant 12)***

Gerald too had a physical job as a gardener, which was a big part of his identity. He loved his job and found stepping back difficult, but he had suffered considerably, resulting from his treatment. Not only was his speech and tongue very impaired but he was struggling with swallowing and week and had setbacks with his jaw function. This all meant he found it very hard.

> *"And yeah yeah so I was a gardener and yeah I found that hard, very hard, mentally too you know"* ***(Gerald, Participant 3)***

Finally, Brandon also alluded to having to abruptly stop a physically demanding job as a car mechanic, and how he'd worked right up to the point of treatment. Brandon had not yet returned to work and had been in rehabilitation for just under a year, he was slowly building up his nutrition and working on his speech with the SLT.

> "I was a car mechanic, I worked here there, everywhere. I worked hard all my life."
> (***Brandon, participant 5)***

Others had to think about the impact of their ability to communicate rather than their physical strength. Helena was young for someone with a diagnosis of HNC and had just started a new job.

> *"Erm I wasn't in a hurry to make an appointment as the ulcer had gone, the white patch had not but the ulcer had gone. I was in this new job so it was a stressful time, physically and mentally."* ***(Helena, Participant 1)***

For some the impact was so severe that they could no longer talk or breathe unaided and Claude is an example of this. He had to take machinery around with him to maintain his tracheostomy and practice how to speak with this equipment. He had previously worked as a butler and travelled a lot but was no longer able to work in a long-standing career he had enjoyed.

> *"…It involved a tracheostomy and the things to do with it and it had a big impact on my travelling"* ***(Claude, Participant 10)***

Ian describes his realisation that he would need to step back from his work life.

> *"It really was and it was Doctor Imran that told me. He says you do need to be thinking about taking three months off of work. That was six months ago. I'm 70. I'm 71 this year. So, in seventy years I haven't had a day off work ever. To have six months off is like unbelievable." **(Ian, Participant 11)***

Ian was in a position where he did have to step back from his work, but he is still able to do his career and mentoring. This has proven to be a great support during his treatment and career. He used his expertise in hypnosis to support his mindset and resilience to treatment and rehabilitation.

> *"I am a business mentor, but helping people in business I always do hypnosis on them as well because it really helps them get their confidence up and get their minds around things and all of that.(…)"* ***(Ian, Participant 11)***

This has come with a need to adapt but his drive to keep working has pushed him to acclimatise to his new capacity. He discusses how he now has to email where he would have been most comfortable talking.

> *"… funnily enough, with existing clients obviously I'm a very verbal and articulate person, but I've had to deal with all of their queries and questions just with email….And I've carried that on throughout. I've never missed a beat with a single client or a single whatever, and some of them have had serious, serious problems, and I've just had to handle that through email. They're all pleased that I could talk again because obviously that's a huge difference between articulating something rather than giving them advice over the email."* ***(Ian, participant 11)***

Santi describes feeling fortunate that her workplace were supportive and how she maintained contact with work and colleagues throughout her treatment.

> *"I mean I'm very fortunate that I work for a Trade Union, and they were very supportive, um…. And then I was in touch with, I've worked there for a long time, so I was in touch with sort of friends at work throughout, um, and so while I was still off, um someone was covering my job as well as their own job, which was not great, but you know.*
>
> *"I was so passionate about my job and I just wasn't interested at all, people said "You must miss it", I was like no, but I was interested in the people. I sort of hoped that someone would say "On such and such a day you will be ready to go back to work", and I kept sort of waiting for someone to say that, and of course, I realised no one was going to, and I would have to decide when I was going to go back to work. and then, I knew that I didn't want to give up work, um yet, I had, I decided, I wasn't planning to retire um yet and um, I felt very strongly that I wanted to manage my retirement, that was quite hard, yeah, because I, I think that, I mean everyone was pleased to see me but um everyone said "Oh", um you know, "It must feel like you were never away". You know, as if I'd been off on a sabbatical, um and um, you know, you don't want to um, I didn't want to sort of get into a heavy conversation with people, um."* ***(Santi, Participant 9)***

Santi did not want to give up work and it is clear this was a passion and a big part of her life. Many felt the same and were rocked by the inability to return to their work lives, as for many they were either unable to communicate in the same way, had feeding needs that didn't fit in with the requirements of a daily job or they were still physically weak and fatigued from the treatment and requirements of rehabilitation. Santi also talks about having to re-acclimatise to work following treatment and rehabilitation and struggling with the pressures of work, long days and discomfort of her physical symptoms.

> *"I feel like I don't handle the work pressure as well as I did before, um, and I almost resent it more, um…and I was thinking the other day that I mean I'm, I'm not as confident at work as I was, so I do worry about, a lot more about work than I wish I did, um, I mean I am in a different role, I did apply for that job and I'm doing it now, so maybe that's part of it, that I'm not, yeah it's a more demanding role…and sometimes they're very long days and so like um, I've had days here, um, and so I have more discomfort when I'm at home, than when I'm off of work, um and that's partly tension in my jaw, the muscles…"* ***(Santi, Participant 9)***

Santi's job was integral to her sense of wellbeing as she describes loving her work, when participants are passionate about their day-to-day jobs it can have a more pronounced impact. This theme around work and returning to work captures a significant issue for all HNC patients. The invasiveness of such a life changing cancer means that individuals are changed in so many ways. Their whole physicality, functionality and what many define themselves by, is compromised with many talking about the impact of compromising or losing their livelihood. But there is a much wider impact looking at the biopsychosocial spheres, discussed further in Chapter Eight. Every area of their lives is impacted and dealing with this changing sense of self can be hugely overwhelming, compounded by the rapid nature of the treatment, many talks about the significant impact on their physical and mental health.

7.3.4 CHANGING SENSE OF SELF

This disease has such a profound impact on an individual's self-esteem, confidence and sense of identity. It often rocks a person's sense of meaning and purpose in life (Nund *et al.*, 2014; Bickford *et al.*, 2019). The aesthetics of a person's face and body can all change within the space of weeks. They may have areas of transplant and will likely have lost teeth. They will also likely be generally physically weakened in terms of their fitness or ability to move. Therefore, it can be extremely traumatic as they face this change in appearance alongside a huge change in the ability to eat and speak.

7.3.4.1 Feeling profoundly changed

These changes are incredibly profound and impact on the physical, social and psychological. Barbara alludes to this when she says talks about her looks.

> *"…how I looked, um, and not being able to speak, and can't move my tongue, you know, and completely different yes."* ***(Barbara, Participant 6)***

Gerald who was dealing with a terminal diagnosis described his change in the starkest terms conveying the raw reality of the loss a person feels with such a devastating diagnosis and the lack of having a choice about the severe consequences.

> *"Well because it's stage 4 cancer….they had to cut my tongue away, part of my face, I can't remember some stuff at the back…[---] I didn't have any choice, you have to remember I will never be able to eat properly again…I will never be able to speak properly again…".(**Gerald, Participant 3)***

Marcus talked about the feeling of a voice that has changed and that he was self-conscious. He describes how these changes made him change his behaviours and avoid talking to people.

> *"I was very conscious of that actually, I was, I was avoiding talking to people, and um, in the end I just had to sort of, I think I had to sort of phone the Gas Board up about something, so you have to do it, and then the bloke on the other end seemed to understand me, so you think well maybe, maybe it's alright, but then there's a certain thing you have to do, you can avoid it as much as you like, you avoid friends, you avoid talking to people on the phone, but there comes a time when you know, you've got to do a certain thing, or try and do a, certainly you had to try." **(Marcus, Participant 7)***

Santi captures this idea of having a changed sense of self that happens so rapidly that one can forget that they no longer have the capacity to do what they used, they find themselves in familiar situations with unfamiliar capabilities and functionalities.

> *"um I think the other thing with Pilates, I do, I do it again, um I've been, I've got lovely pictures for [ph] both, who I know very well, so um, so they've modified for me, um but I think one of the things I find the hardest, um and it's always another first that surprises me, is being in a situation I'm very familiar with, but my body's not the same, that's when it hits me, um so I can't do certain things in Pilates, or Yoga or things I used to do, movements, that used to be a lovely stretch, are now very uncomfortable and yeah, so that's, I do feel quite grumpy." about it." **(Santi, Participant 9)***

It is almost an inevitability with this type of cancer that a person will have some long-term impacts of treatment. For many it is physical and functional and impactful on their day -to-day existence, for others it may affect their mental health, as a traumatic event, even if they are fully recovered. The treatment is all-encompassing, and many are changed profoundly as a result of it. They may be left with a fear of re-occurrence or sense of having to find a new identity. The next two sections therefore reflect on this. Starting first with fears around re-occurrence, which touched all the participants in this study.

7.3.4.2 Strong fear of reoccurrence

Part of the changes that happen with individuals is a cognitive change of mind-set. Some elements may be around the physical, aesthetic shifts that happen, but a final element is the change that happens mentally and part of this is a new sense of uncertainty in the future and whether the cancer would reoccur. Marcus talks about this fear of reoccurrence. Marcus states:

> *"…cautiously optimistic I suppose, you're forever checking, feeling round here you know. Not obsessively but you aware of what's happened, now you've got to.[That fear.] So I'm, I'm um I'm not pessimistic, but I'm not blasé about it, I'm not sort of, well everything's going to be alright, I'm cautiously optimistic, but one's aware of what's happened and um how serious it was, and um. That's' always with you. (…) Oh yeah always, I mean always you know. You're different. "* ***(Marcus, Participant 7)***

There is a great sense of your own mortality. It is a stark and traumatic life-threatening event and can leave a patient feeling vulnerable as Marcus goes onto say.

> *"um, I think it, it reminds you of your sort of mortality really, don't want to be too pompous about it, but we all know, but this brings it really home to you, that you know, yeah you're sort of, yeah you're, you're more, you feel more vulnerable I think.* ***(Marcus, Participant 7)***

The fear of reoccurrence can be such a visceral feeling for someone who has already just undergone a hugely traumatic event that it can be difficult for participants to even talk about within these highly sensitive narratives.

> *"I think that's the best advice I could [give] anyone, don't look three months ahead, or how much longer have you got, if you can just get through each … because if you look too far ahead, it's just a muddle, and the equipment and the hospital, take each day, and that's the only way … that's the way I dealt with this, and I … it made me talk about everything, because I think*

> *well, I'm your Mum, no one's going to tell you things…So if anything, like my youngest, she's very genned up on life, and everything, because you think I'm going to tell the like the way, because I might not have been here."* **(Owen, Participant 12)**

This fear of re-occurrence is something that exists for all but how an individual approaches this lingering fear is something that varies. For Aga and Ian, there is a self-preservation mechanism around not thinking of the worst-case scenario and trying to remain in an optimistic place to face the future. Aga talks about the fear of it returning given she had already had breast cancer and that it could all return in 5 years.

> *"No, because I think, I never really want to know what the worse scenario could be, when things happen I'll face it but I don't really want that in the back of my mind saying well yes, but in five years you know this could all backfire and you might have something else. Because, I can remember once erm, having a scan, it was, and that was actually at erm, for the breast cancer that was and I used to hate having the CT scans because I knew what they were looking for."* **(Aga, Participant 2)**

Ian states that his whole perspective is central to getting through it. He talks about facing the future of more chemotherapy and that he might require more treatment even as he goes through parts of rehabilitation. This acknowledgement that he is forever changed and may face these ongoing battles, speaks to the idea that reoccurrence fear is an inevitable part of the process.

> *"My whole perspective is I'm very, very optimistic about everything, you know, and even if this tumour that is, was at the top of my mouth stopping the two nasal passages working, if that's still there, and I suspect it might be, or whether it's just [unclear-37:47] because I'm not breathing through my nose still, you know. Like I say, the chemo cleared that up for a week or two. I don't know whether that's back or whether … So even if it's still there they'll have to do more chemo, or whatever, but I'm still highly optimistic, you know, about everything."* **(Ian, Participant 11)**

The fear of reoccurrence is an element that has lasting impact in the HNC experience. HNC patients are drastically and profoundly impacted by the diagnosis and process of treatment and in the next section, I consider how patients cope and move from early rehabilitation to the next stages.

7.4 OVERARCHING THEME 3: THE REHABILITATION AND BEYOND

7.4.1 RECONCILING SENSE OF SELF POST TREATMENT

Leading on from the previous theme around sense of self and identity, as treatment forces an individual to take stock of their existing lives, they have to begin to acclimatise during rehabilitation, to who they are after treatment. Many aspire to be back to their original self, and this can motivate them to recover so they can return to their previous lives. Owen talked of not being able to believe the version of himself after and during treatment, *compared* to who he was now, as he had become so much weaker. He stated:

> *"The pin thing fell off in the kitchen the other day, and I thought I … we changed the dishwasher and it was just catching it a little bit, and I just tried to show Marian, you just need to adjust the legs, to lift it up anyway. I had a go the other day, didn't I? Because I get down on my knees I can't get up….I kept thinking I'll pull myself … I did get up though eventually, but with the falling doors, and I thought I'd broken something, but like I couldn't get up off the floor, so my son's 26, and my wife, it's like dead weight, I'm thinking I've lost all this weight, I could fly up there. But you struggled, didn't you?"* ***(Owen, Participant 12)***

This is the reality for most HNC patients, and often their lives never return to what they were before. For those that are cancer free they may find themselves living with the aftereffects of the impact of cancer on their bodies such as reduced mobility. For others they may have bouts of reoccurrence or complications and everyone in this study talked about feeling profoundly changed and different resulting from their HNC experience. Aga who had previously experienced and recovered from breast cancer decades before, had felt that she was weaker because of HNC.

> *"I mean I can't do things like I used to, I haven't the strength, I feel weaker in myself…"* ***(Aga, Participant 2)***

Aga describes a process that seems to take place for a number of the participants. There are phases of acclimatising to new functions and physical changes. This may take longer for those more severely affected. The next time-period is where the team will support the patient to adapt to their new self. With this rehabilitation, patients begin a process of accepting and reconciling their sense of self. However, there are many barriers and facilitators to this happening in patients undergoing such traumatic disease pathways.

The evidence base recognises that for a variety of long-term conditions or cancers the well-being of the patient and their ability to rehabilitate and recover well goes beyond the disease process and functional impairments. Research suggests that psychological factors are key (Ruf, et al. 2009; Roing et al., 2009). These include illness perceptions and coping strategies which will be explored later in this Chapter, but psychological flexibility and emotional self-regulation is also posited as a vital element looks at mindset from the perspective of the patient in more detail.

The adaptive phase practically looks like adhering to medications and exercise regimes, attending appointments with health professionals, changing diets and eating habits or changing the daily routine. In parallel a psychological adjustment may also occur. This involves *"evaluation of the condition (for example on social and occupational functioning) and the regulation of any resultant distress"* (Graham *et al.*, 2016 p46). Reconciling sense of self is therefore a process of psychological rehabilitation alongside physical. CHANT offers psychological support during rehabilitation aiding reconciliation of self. Aga was very determined to strive for a better version of herself and spoke with a sense of aiming for the next step in her recovery with conviction.

> *"Well I just thought this will get better, so I've just got to, I've got to just you know, live with it really until it does get better. I know it will never actually be back to … your speech will change, he said now other people might not notice it but you will you know, so they were, they were very, very honest. I am getting better."* ***(Aga, Participant 2)***

It is important to note, the notion of acceptance within the discourse around long-term conditions has been somewhat problematised in that it perhaps does not capture the messiness and reality of rehabilitation and the iatrogenic effects of HNC. It is not simply a process of waiting for an individual to get used to their surroundings (acclimatise), finding ways of working around their impairments (adapting) and then embracing the changes they must live with (acceptance). These changes are profound and, in many ways, not recoverable and to suggest that it is driven by an individual's own mindset and acceptance suggesting it as a faculty of agency, which in critique can be seen as part of the jigsaw, but not necessarily seeing the wider context. This can trivialise the extreme impact and devastating changes as well as not acknowledge the effects of immutable circumstances and future challenges. Therefore, rehabilitation support must take a broad and empathetic approach.

Furthermore, these stages happen repeatedly on a micro level and the cycle may happen for some elements and not others. It should be noted that the changes that happen are profound and all-encompassing and acceptance of the trauma they have undergone is not something that happens for everyone. Recovery and rehabilitation is much more about surviving the day-to-day and piecing back together elements of normality or finding new ways to live rather than acceptance in the traditional sense. The process of acclimatisation, adaptation and acceptance are therefore not linear or achievable for everyone and it is so intrinsically linked to a person's positioning and capital.

7.4.1.1 The role of the grieving process

With illnesses that have better recovery prognoses a person can aspire to return to their previous self, and their process of rehabilitation can be much more linear. However, with HNC and cancers or diseases that affect mobility, speech and eating in such a dramatic way there is often a process of grieving that has to take place and a better model therefore, is akin to that of a grieving process, as they are often a very different version of themselves during rehabilitation and are mourning the loss of that version of themselves. Therefore, a more appropriate conceptualisation of stages in rehabilitation is captured by Worden's four tasks of grieving as show below.

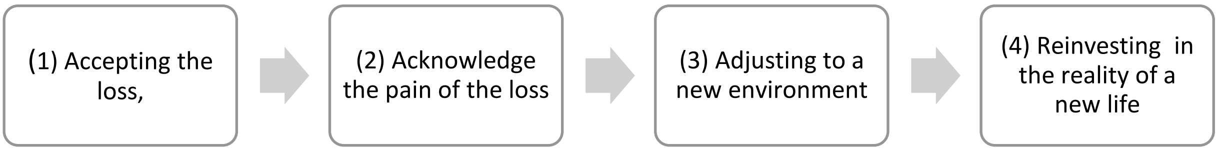


Figure 15: Worden's four tasks of grieving - Adapted from Matthews, 2019

This model captures that stages are a fluctuating process with the aim of accommodating a new normal lifestyle, which, in the context of HNC is accepting the loss of functions that were a fundamental part of a person's identity. Santi talks of her allotment as an example of how she cannot be who she once was and how she can't tend to it and eat from it. She is accepting that this might be something she has to give up as a result of the new version of herself post diagnosis and treatment and this articulates what many go through in their first phase of *"accepting the loss"*.

> *"Um not very satisfactorily, um I'm very, I've been very much wondering whether to give it up, because it's become a real difficulty, I got a letter from the Society, um, um, but I decided, I thought this probably wasn't the time to make a decision about that, because I managed to, we went through the summer, was one effort [ph], and now it's the sort of quiet period [ph] and then see what next year brings, but um, there's no point in doing things like that if they're not appealing [ph]. Also, I can't eat anything from the allotment."* ***(Santi, Participant 9)***

Aga captures the next phase in her account, where she reflects this idea of *"acknowledging the pain of the loss"*, in the way she talks about her speech, wishing it wasn't as it was, but knowing that she is now changed. She says:

> *"I feel sometimes, I mean sometimes, I mean I'll answer the phone now where at one time I wouldn't, I'd say to my husband you answer it but I will answer the phone now. Erm, and most of the time now erm, yeah, I'm, I mean with strangers then obviously they didn't know what I spoke like before but where people maybe that I haven't seen for some time, erm who knew me sometimes I think oh, I wonder what they're going to think [laughter]. They don't think anything I know but erm, I mean I'd rather it wasn't like this but on the other hand you know,*

> *if all this hadn't been done, I wouldn't be here now. So, I've got to you know, make the most of erm, you know."* ***(Aga, Participant 2)***

This also captures the next stage which is beginning to reshape your life and adjust and aclimatise, *"adjusting to a new environment"*. This is a feeling of needing to move on and make the most of the functionality and life they have after the shock of treatment and the potential for something else to happen.

Marcus also captures this phase, where he talked about being very active before his diagnosis and having to rethink how he moves physically. He can no longer do what he used to do but through going through the phases of acclimiatisation, adaptation and reconciliation he has found a form of movement that he can maintain.

> *"I'm quite active, I mean I've given up sort of running and all that and football years, and years ago.(…)So I'm more active, I mean what, I've got back to what I used to do, but I never did, I, I, I didn't do anything really, didn't sort of do any sport anymore, but I did a lot of walking."* ***(Marcus, Participant 7)***

There were some patients who talked about a change that realigned their priorities or started a change process, as described by Ian. This captures the "reinvesting" stages of grief and that there is a time when some participants begin to regain strength and resolve to progress, with the understanding that some things may never quite be the same again. Section 3 discusses patient's experiences of surprising turns when living with HNC.

> *"I'm invigorated. I'm inspired and the only thing really holding me back … I mean the dry mouth is a problem but it's the pain from the ulcer that's really holding me back. I've got meetings in the City next week with various people and I'll just push forward with them. They all know what I've been through and obviously I don't look the same because before, like, before I lost all my hair and everything … I had a full head of hair and a full beard."* ***(Ian, Participant 11)***

Santi talks about feeling changed but seeing improvement has helped her to strive to become the best she can, even if it is not who she used to be. She talks about feeling positive that she can walk a walk that used to be difficult. Even though she cannot do Pilates and Yoga the way she used to, but achieving a goal has motivated her.

> *"…and that's, that's been important and I, I can, I can see such a change in that, I can remember, this time last year, a particular walk that would be so difficult. And now I can do it yeah, so that's been very positive,"* ***(Santi, Participant 9)***

Participants, who were conservative about the process of progress and fluctuations, recognised the importance of disciplined self-preservation coping strategies, to maintain some attempt at regaining control and working towards what were sometimes marginal gains. Conversely, some patients who had relentless, ambitious, optimism also thrived in the process, this mindset challenging them to keep pushing the ceilings of recovery they have been prescribed.

This is an attribute of resilience which is "*a dynamic process of positive adaptation to adversity"* (Tan, Beatty and Koczwara, 2019 p43). Tan and colleagues (2019) sought to unpick definitions of resilience from a patient perspective and the themes relating to attributes of resilience as identified by patients. Interestingly, this systematic review had no definition of resilience but *"instead identifying coping strategies, social support, growth, and spirituality as attributes associated with resilience."* (Tan, Beatty and Koczwara, 2019 p43).

Resilience can sometimes be used as a term to victimise or denigrate those unable to cope, as discussed later. This narrow definition can therefore attribute surviving and thriving to an attribute that is rooted in the agency of a person. However, this does not take into account the macro and meso contexts and the history and challenges that differ from person to person. Patients often do not think of resilience or mention this term, rather they talk of their own personal resource but instead, in terms of attributes like creating support networks, leaning on hobbies, positive/spiritual mindsets and setting goals and objectives that lead to growth. This takes us to the next theme.

Setting goals is something that often helps patients navigate their rehabilitation in an incremental way and helps them to not get overwhelmed or phased by the long journey that rehabilitation can be. Goals for an individual with HNC are not dramatic or transform someone back to their previous self. They are poignantly mundane and sometimes frustratingly incremental or fluctuating and it is important to note that patients are not able to aspire to full recovery. They are painfully clawing back basic skills around eating, speaking and moving. Regaining function, as highlighted by the Worden tasks of grief, are not about a state of achievement but about finding a new normal and this is the context in which goals are set.

7.4.1.2 Goal setting and objectives to manage rehabilitation

One of the ways participants managed the mismatch and how they now see themselves, how they were before and what they want to be, is through setting small goals and objectives during rehabilitation. It is through an approach of incremental change that facilitate maintaining everyday practices (e.g., leisure activities, cultural practices) supported by people to live as well as they can with their condition, that sees patients progress and thrive during rehabilitation. (Franklin *et al.,* 2019; Entwistle *et al.,* 2018; McQuoid, 2017; Morgan *et al.,* 2017).

> *"If I can get a bit more strength back in my legs because I've never thought about what I do before, I just get on and do it, you know, never think of anything. That's why it's hard to accept, it's my strength bit, it's what I just do all day, every day. Think nothing of anything, even merely thinking about how I am going to get that, I just do it."* ***(Owen, Participant 12)***

The impact of the wider context and the supportive framework is key to understanding how patients navigate rehabilitation and how successful they are in acclimatising to their new sense of self and setting objectives and targets for recovery. Hence, their ability to live with having had cancer and this can relate to their supportive networks (which we will discuss next but also to that individual's own resources). When navigating treatment and rehabilitation spheres, an individual uses agency to participate dynamically within the macro and meso arenas. It is with this combination of social and structural factors aligning with the individual's sense of agency and "patient hood" that a narrative can be defined. Franklin *et al.,* (2019) concluded "that goal negotiations need to extend beyond the incorporation of patients' social context, to accounting for (and addressing) the broader structural constraints shaping people's experience of living with a chronic condition." (Franklin et al., 2019 p.14).

Understanding this is intrinsic to embedding the concept that intervention success depend on the circumstances and individual's access to resources that is spatial-temporal in nature (Ong *et al.,* 2014) i.e. they are not measurable or specific to a point in time, they are not discrete or fixed in nature. We can further purport that, understanding the needs of patients is most effectively facilitated by a place-based, multidisciplinary approach and this is reflected in many of the interviews conducted. This is discussed further in this Chapter.

Alex is a good example of the nature of the goals being incremental; starkly functional milestones he had to put in place to help recovery. He was keen to get some function back into his jaw and improve his speech. To do this he needed SLT and physio exercises which required repeating up to 5 times a day, so he had the muscle tone and strength to improve his communication. His recovery was up and down due to the phases in the treatment. He had setbacks as once he saw initial improvement after surgery the radiotherapy set him back again.

> *Well it's been up and down. So after surgery erm, there was very little improvement but, and then after the radiotherapy it started to get worse again and it's been a slow improvement from then, but it's very, its quite difficult and erm since then with the physiotherapy it's with the experience of swallowing, very very slow…**(Alex, Participant 4)***

Helena articulates goals as incremental and by necessity, practical first, and emotional second saying:

> "*And you just do the next step, you kind of, you focus on the physical side, and you do what was needed so the emotional side is pushed to the back to deal with this later." **(Helena, Participant 1)***

Marcus also spoke in language of goal setting through the course of his in-depth interview. He talks about how he struggled to eat breakfast and the discomfort around eating scrambled eggs. For him an important milestone was to go out somewhere and order a breakfast that he could sit down and eat. Setting these incremental goals helps to map the path back to as much functionality as they can achieve following treatment.

> *"maybe a, six weeks or something, eight weeks and then I went and ordered a breakfast somewhere, and I felt like, if I ate this breakfast, I felt like doing a lap of honour really, so. It's very strange, you know, it's like, because it's so swollen, because what they're doing is, they're, it's your tongue, your tongue, so it's all swollen here. I mean it is very strange, you can't, how can you not, imagine not being able to eat scrambled eggs, just put it in your mouth and it just lays on the back of your tongue, swallowing, it was a bit difficult."* ***(Marcus, participant 7)***

Goal setting is often supported by the multidisciplinary team to make sure they are feasible. Furthermore, the goal setting may be supported by individual practices such a mindset work, journaling, or determination within the individual. The behaviours and attitudes that underpin this is described next.

7.4.2 ATTITUDES TO RECOVERY

There are number of themes that arose relating to facilitators or barriers to recovery and effective rehabilitation. This section therefore explores alternative coping mechanisms, which seem to underpin a better rehabilitation journey. This may involve finding new physical outlets or mental stimulation that allows them to express themselves in ways that do not rely on their voice. This may be around focussing on mindset and resilience.

In section 2 of this Chapter, the impact on eating and speaking was explored, and this highlighted the need for patients to find a way of managing their stress, communicating, and channelling their energy in new ways, not being able to lean on talking and eating. Many participants talked about finding outlets and activities that allowed them to socialise or feel productive which didn't require the need to speak or eat. Participants talked about spending time gardening, writing, yoga, Pilates, and other exercise regimes.

7.4.2.1 The power of movement on rehabilitation

Exercise played a biopsychosocial role in many HNC patients recovery journey. They were all physically impaired by their treatment but through the process of reconciling their new sense of self many found ways to exercise that fit with the new functionality they had. Marcus talked about walking after he had transplanted tissue from his arm rendering both his mouth/tongue and hands restricted. He continued to walk to maintain movement.

> *"When I went down Lewisham Hospital, one visit there, and that's it, so I was a bit restricted with my right hand, for the tape, my right hand and here, they say you shouldn't carry too much after a major, my neck hurt, so I had to be careful what I carried, but I did what I could. I mean there's nothing wrong with my legs, I could walk about." (Marcus, Participant 7)*

Santi too reflects on her physical strength beforehand from tending to her allotment, whilst she was at a stage in her recovery where she wasn't sure if she would be able to meet the demands of maintaining it but found it to be a release. To maintain that sense of movement and feeling the strength in her body she also did Yoga, Pilates, and walking which she has maintained during recovery and rehabilitation.

> *"I think that um, I would, because I was quite fit, I think that my recovery was, or easier, than um if I'd been unfit, um….I'm not that massive aerobics stuff, but I was, with my allotment and things, there's quite a lot of physical, heavy sort of physical work there, and then I do Yoga and Pilates and um and walking a lot." (Santi, Participant 9)*

Santi goes on to say:

> *"But I've, I mean I worked very hard, that was my main sort of motivator, like through the recovery was to try and build up my stamina, my physical stamina, so I am walking a lot again now." (Santi, Participant 9)*

Aga also spoke about Pilates as a practice she used before treatment and the use of it post treatment. She has pushed herself to keep trying to move in this phase of her life and self-reported that it helped with her recovery, reiterating that she did this as part of conscious positive approach to treatment and rehabilitation.

> *"Pilates classes are difficult, but I do try to do some at home…I used to really, I know I used to really enjoy it and did it for a long time. I think what they told you before, I mean the operations I think I've recovered from quite well and I felt really well before….. I didn't feel ill as such, I think I've always been quite a positive person…." **(Aga, Participant 2)***

It is clear from the narrative accounts that those who prioritised exercise and movement gained great benefits from the mental and physical strength it brought and, particularly in the absence of being able to express themselves verbally. It was a form of release that evidently and consistently supported rehabilitation. Helena says:

> "…*when I was going for radiotherapy around lunchtime, I would always do my exercises in the morning. I would always eat and have my smoothie and porridge before radiotherapy. I would come home and exercise before going to have a rest and I would exercise before going to sleep so I managed, do ask me how but I decided to somehow my, my brain, as part of a coping mechanism." **(Helena, Participant 1)***

The CHANT team have signposted to exercise classes and this was also mentioned in the narratives. This is another example of the holistic approach that is taken by the team and that is tailored to the personalised approach and multidisciplinary ethic that contributes to a better standard of care for the HNC patients. However, getting to a point of moving more and accepting your boundaries whilst not limiting your recovery requires the support and framing of the right mindset for the patient. This is a theme that oscillates and weaves throughout the narratives. For some it isn't a conscious thing but is apparent in their articulation of their recovery, for others it is a nurtured and cultivated mindset that supports them in rehabilitation.

7.4.2.2 The role of hope, optimism and gratitude

Hope, optimism and goal setting therefore seemed to be integral to progressive rehabilitation and was mentioned repeatedly, as stated above, either implicitly or explicitly by the participants, for those who appeared to be managing recovery well and progressing with their rehabilitation. Aga talks about it in the context of fuelling her body with the right food to be strong. She talks about "trying to be positive".

> *"I think that's my, so trying to be so positive with the food side because I know that I have to eat decently to be able to build the rest of my body you know. Erm, so…"* ***(Aga, Participant 2)***

Ian has taken a very conscious approach to developing a mindset that will get him through the hardships and ordeals of this journey. He leans on his networks, his journaling and his beliefs around mindset and positive programming.

> *"Just tons of positive programming. I knew that sooner or later it would come back and obviously I kept trying (…). You mustn't say if you've got cancer, or, how are you? I think talking about it, I'm very … especially like I've had it, and I talk about it, and people say what's wrong with your arm, they'd be saying, and I just say well I'm grateful to be here. You know, I'd sooner have this, than not be here. Yeah, so I'm very grateful for life..."* ***(Ian, Participant 11)***

Barbara states that she consciously nurtured a positive attitude, knowing that this was crucial to surviving the journey of cancer and rehabilitation. In the face of extreme adversity, she had to keep positive to keep going. The process of positive thinking can feel like a trivialisation or unrealistic option when the prognosis is so stark and bleak for many. It is important to acknowledge that the situation of positivity occurs within the context of a person being up and down. Setting expectations may have felt trivial before, but in the wake of the profound loss of function, it becomes a reorientation of their frames of reference.

> *"I had to stay positive, yeah, I had to"* ***(Barbara, Participant 6)***

Marcus captures this in the realignment of small goals and celebrating things that were once taken for granted. He references shopping, but walking, having a coffee with a friend, feeling thirty and being able to drink water to quench it, speaking on the phone or receiving a delivery and not being able to speak are all incredibly practical things that now require a huge shift in mindset to just get by.

> *"I had to, I had things to do you see, I had to sort of, you have to sort of get shopping and stuff, and you know."* ***(Marcus, Participant 7)***

Ian was unique in his account, having regained communication to a level that he could carry on his work meant that he felt unfazed at times, by his treatment. This came with fluctuations but in recounting his journey, he felt he had to focus on how to recover. Ian is an example of someone whose spiritual capital provided an incredible pillar of strength. This was linked to his employment and he finances and all this coalesced to create a support that saw him feel this way about his treatment.

> *"To be honest with you it didn't faze me one little bit and I know a lot of people fall off the chair when they hear the Big C and all. It didn't do that to me. I said, "Thank you very much for telling me. Now I know what I've got to deal with," and that was it...What can I do? You know? And I put any negativities out of my mind."* ***(Ian, Participant 11)***

Ian had support from others that bolstered his mindset and, it is important to note that positivity from others in your network seems to have an impact on the experience of an individual. Owen's partner, for example talks about this.

> *"Good eating, positive thoughts, anything herbal, music, I believe in all of that, whereas my husband is very negative. This isn't going to get better, and … but each day I think the best way we coped is every day, do the best you can, like she's at college, some days she didn't want to go. She said I want to stay here. And I said but that's not achieving anything. I said go to college, do your best that day, if there's anything you need to know, or we had to go to hospital, I would message her, so she knew exactly every day what was happening. When he was in hospital, she'd come up of an evening or her brother would take her, and I think that's the way we've coped, rather than not talk about it, and then sudden" (****Owen's Partner, Participant 12)***

7.4.2.3 Post-traumatic growth following a diagnosis of HNC

As discussed in the two previous sections, many participants framed alternative coping mechanisms and strategies of positive thinking, hope and optimism as being crucial elements in their recovery as well as leaning on things that didn't revolve around talking or eating and kept them challenged, stimulated and positive. Going through a cancer diagnosis can differ depending on mindset and "*the suffering of cancer may turn on the psychological process of demoralization, post-traumatic growth, and meaning-making in patients.*" (Li *et al.*, 2015) p1449).

In this thesis I found that some patients postulated that they felt they had revaluated priorities, found peace or discovered resilience in a way that they do not feel they could have achieved without going through such a traumatic and life changing event. This is sometimes termed post-traumatic growth. It refers to a process of positive personal growth and/or transformation. It occurs when someone recovers from something traumatic or some sort of intense life challenge.

There are few studies that provide a narrative or qualitative insight into post-traumatic growth experiences in those recovering from cancer. However, there is a small body of literature exploring post-traumatic growth using a tool called the Post-traumatic Growth Inventory (PTGI), which allows psychologists to measure the impact of such transformation. This tool has been used to assess PTGI in cancer survivors in a small number of studies (Ho *et al.*, 2011; Leong Abdullah *et al.*, 2015; Li *et al.*, 2015) but the experience of this is not captured in published literature. This study therefore uniquely provides an insight into to the experience for those who feel they have found some learning or growth through the traumatic treatment and the process of rehabilitation

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Ho *et al.,* (2011) used the PTGI to investigate the association of the positive coping strategies, hope and optimism, on post-traumatic growth (PTG) in oral cavity (OC) cancer patients. The PGTI tool was used alongside the hope scale (HS) and the life orientation scale-revised (LOT-R) questionnaire. The study postulated that "*Hope and optimism correlated significantly positive with PTG and accounting together for a 25% variance of post-traumatic growth*" (Ho *et al.*, 2011 p.121). This demonstrates the importance of hope and optimism in the assessment of post-traumatic growth and this study demonstrates that these factors can contribute to positive rehabilitation experiences.

> *"When I went down Lewisham Hospital, one visit there, and that's it, so I was a bit restricted with my right hand, for the tape, my right hand and here, they say you shouldn't carry too much after a major, my neck hurt, so I had to be careful what I carried, but I did what I could. I mean there's nothing wrong with my legs, I could walk about.(…) In fact I feel probably more active now because I was, before, I was feeling a bit tired, you know, I'm feeling better now, stairs were difficult, but after they done this, I felt much, much better."* ***(Marcus, Participant 7)***

This is supported by the work of Li *et al.,* 2015 who found, using the PGTI that *"cancer patients who evidenced higher post-traumatic growth experienced less demoralisation*" (Li *et al.*, 2015 p.121). The study concluded that trying to identify positive changes in the experience of cancer may be a powerful way to increase post-traumatic growth. As seen in this thesis patients who described positive outlets, coping mechanisms, supportive networks or positive thinking processes allowed them to go through a process of sense-making, surviving and even thriving. Li *et al.,* 2015 showed that *"patients with less benefit-finding experience higher demoralization, but sense-making buffers this effect."* (Li *et al.,* 2015 p.121)

Whilst there is a dominant cancer discourse of optimism and individual transformation through adversity. It is however important to note that why there are differences between patients and what meanings are aligned to this. The research in this area of psycho-oncology (Wilkinson and Kitzinger, 2000), supports this idea of positive attitudes supporting and improving the chances of effective rehabilitation and recovery from cancer. However, it is important to take heed of a more discursive exploration of what *"thinking positively"* and *"growing from adversity*" really means to a person, and how these mindsets come to be. The patient cohort differs in many ways, including ethnicities, social networks, economic situations, religious groups or mental health/addiction backdrops and these factors all frame the capacity for an individual to *"cope well"* with a diagnosis of HNC.

Therefore, it is important to recognise that to enable the best support for those navigating this journey, the individual must be surrounded by networks. This is the final factor that is discussed in the over-arching theme 4. This is often crucial to achieving and setting a goal driven pathway during rehabilitation. This is from the support of networks and this can look very different to different people and is dependent on a person's access to resource described earlier. Therefore, in the next section we move from the onus on the individual, to the individual embedded in their own social context, to a focus on the social network that surround that individual.

7.5 OVER-ARCHING THEME 4. SUPPORTIVE NETWORKS

Through the entire journey, through the 3 different phases from diagnosis to treatment to rehabilitation, complex networks of support are available to, or used by patients going through this process and these can be split into informal networks. This section therefore begins with setting out the informal friends and families or communities' networks. This section then finishes with discussing the more formal chant networks. In between these spheres lies peer support which can be structured and formal in the shape of support groups or can happen to an individual because of meeting individuals on their treatment journey.

All participants identified networks as a hugely important part of their experiences of treatment and as contributing to surviving rehabilitation. Therefore, this theme explores the various types of support that participants spoke of, including families, partners, friends, and peers. Networks are nuanced support in that they depend on existing resources and structures held by the individuals. This were identified in the observations and it was clear that the staff team felt that making sure that individuals had support in some guise was an implicitly felt key step to recovery. One says implicit as this is not something that is clearly defined at a policy level although it is identified that living with cancer peer support is important – familial and friendship networks seem to play a crucial part too.

7.5.1 INFORMAL SUPPORT

7.5.1.1 Families, partners and friends

Many participants discuss the importance of support from family, friends, partners and friends. They are emotionally, tearfully, and reverently spoken of, as intrinsic to surviving the trauma and distress of HNC treatment. Owen talks about his partner stating:

> *"Well, I couldn't … I couldn't have done it without my other half as well. Because Marie's always positive, whereas I look at the worst of everything you know."* **(Owen, Participant 12)**

It is acknowledged that in the surrounding literature that *"an intact dyad relationship seems to be important for hope and consecutive higher levels of Post-Traumatic Growth when* *compared to unmarried patients."* (Ho *et al.*, 2011)p.121). Owen's partner, who was present at his interview and in his consultation provided immense support to Owen and helped him to stay positive.

> *"It makes me sad if they're on their own, without just someone even popping in, especially elderly people. And you think how are getting home on their own, and it's very sad isn't it? Knocks you right back doesn't it?"* ***(Owen's Partner, Participant 12)***

The day-to-day role of the partner is much wider than being there to support them at treatment. Their own lives are forever changed, and they will become carers, driving them to appointments, blending their foods, speaking on their behalf, socialising less, and compromising to make time and space for the care of their partner. Aga talked about how supportive her husband was but that she felt he needed to maintain normality for himself and keep his networks alive. She mentioned that he played golf and she encouraged him to keep going.

The practical reality of supporting someone undergoing this type of treatment and rehabilitation is that they are not able to take the leisure time they may have had beforehand. They are supporting with driving them to and from appointments, moving them in and out of care settings, helping them in and out of bed, making sure they are eating and exercising and sometimes they may also have to advocate for the patient, not only in the health care setting but also in everyday life, at the shops, in the bank or travelling around.

> *"I said you know, I mean obviously he wanted to be perceptive, but he plays golf and I said you have to keep going, you have to keep playing golf."* ***(Aga, Participant 2)***

Marcus talked the importance of having his brother's support and that he felt he wouldn't have got through it without him. Other stresses in life compounded his distress and therefore having his brother there to unconditionally support him throughout this journey was vital.

> *"Who's got his {brother} own house, and I still go back to mine, but fundamentally I'm still with him, because I've had problems and the last thing, I needed was this bloke next door, sort of you know, trouble, I didn't need that (…). That's all I've got, if it wasn't for him, I don't think I'd have got through it really, I really don't."* ***(Marcus, Participant 7)***

James referred to just knowing his family were around to support if he needed anything or just to talk provided great comfort. Family and friends provide pastoral support outside of the health setting, they are the people who patients turn to when they are upset, distressed and scared. Patients talked at length about how they would not have gotten through their cancer journeys without key individuals.

> *"…that they're there if I ever need them and if I want to talk"* ***(James, Participant 8)***

Barbara talked about the importance of her family and children in surviving the cancer. She also alludes to the loneliness she experienced too by not having some of the friends she had before treatment, and this is discussed further in section x. Barbara talked about really leaning on her family. During her interview she actually stopped to speak to her daughter on the phone who was waiting to pick her up and it was clear that she had a strong network that was around her and enabling her to even get to the appointments. It was clear that she was well-supported and her day-to-day existence could only happen with her family managing logistics and the practicalities of everyday life.

> *"Yeah, supported, it's very ... a lot of people ... I thought I had friends, I thought I had a lot of ... you know, a wide range of friends, but when you have cancer, everyone is gone. I'm glad I've got my family and my children,"* ***(Barbara, Participant 6)***

There is much work exploring the perceptions and needs of partners/carers but that is beyond the scope of this study and therefore they were not specifically interviewed. If a partner had accompanied a participant to the consultation or interview, then they were included in and therefore their roles are considered as part of the narrative of the patient.

7.5.1.2 Peer support

Peers sometimes have experience of living with HNC and can offer support, useful tips and advice. Peer support gives individuals support, they can share advice around self-management and can also provide a friendship base which tackles isolation and loneliness. As part of the observations a "Living with and Beyond Cancer" peer support group was observed.

It is clear that there is much support, learning and strength to be found in being with others who are going through, or have been through the experience.

The NHS is committed to supporting peer support and community capacity via an Integrated Personal Commissioning programme (IPC). Whilst it is not mandatory or directly funded, there is guidance in place that outlines what the baseline should be to provide good peer support and community capacity. The reality is that these services aim to bridge a long-standing gap between social care and health services, and this can often be challenging and therefore accessing formal peer support can be difficult.

Those that had access to someone else who had been through similar journeys spoke of the positive impact it has had on them, in being emotional and empathetic support. Peer support has great potential to provide a cost-effective support mechanism as part of a wider patient centered approach to care and is widely cited in the literature (Campbell, Phaneuf and Deane, 2004; Zhang, Li and Hu, 2022; Ziegler *et al.*, 2022). It can offer an insight into the future for many and helps to reassure them that there are others who have found a way to cope with the impact of diagnosis.

> *"What we've always wanted to help with the programme, that someone in the future comes in with your cancer … You're going tell them more how to deal with it because it's such an aggressive cancer."* ***(Owen, Participant 12)***

For some, however peer support can be quite de-moralising and doesn't help as there is such variability in the severity with HNC patients. Although this is a perspective that is not represented in the wider literature it is an interesting element of the impact or a barrier to accessing peer support. Seeing patients who have not had a smooth recovery (which is often the case) can draw an individual to the stark reality and make them lose hope that they can return to normal. Therefore, some are reluctant to engage with peers. Marcus talks about his experience and feeling this way.

> *"I went to the support group a few weeks ago. Um I'm very pleased that I went, but obviously what's happened to me has happened, but I got the impression that they'd been through a probably worse experience, what's happened to me is not a walk in the park. But what, what*

> *they said, some of the things they were saying, so I'm quite glad I went, I joined in the discussion."* ***(Marcus, Participant 7)***

Owen talks about finding peer support through discussing treatment. Owen talked about meeting a man who was having treatment and they developed a supportive relationship, and this is often termed informal peer support. Owen described that this person understood how he felt.

> *"Yeah, because he was going through it, and of course, he rings me up, when he'd just come out of hospital, we were having the same symptoms, you know, where he couldn't eat, because it was all swollen and he was having to have them drinks, but it did help speaking to someone, because some of them don't want to speak to you, and … but you know, I've got a good rapport with him, don't I? … Because you think you're the only one, really don't you?"* ***(Owen, Participant 12)***

Owen also talked about not being able to share food with those on chemotherapy who were fellow patients at the time of his treatment, so he bought magazines instead. This quote captures the idea that support can be tacit and, in the circumstances, where talking is a struggle that subtle support such as buying magazines for fellow suffers is an important gesture.

> *"You can't offer them even drinks, they couldn't … that's all you could go like, I could only go and get magazines and papers. At least some of them loved it, didn't they, because they can't get out."* ***(Owen, participant 12)***

This illustrates the importance of informal peer support and not just the formal groups organised by CHANT or other organisations. This informal peer support is documented in the literature as having a positive impact on the experiences of individuals undergoing a cancer journey.

7.5.1.3 Implications of not having support

For some, undergoing treatment it can be lonely process and this was clear in both the narratives and the observations. As Santi described earlier, friends can find it difficult to see such trauma and also cannot be as present as a partner. Treatment is intense and sometimes daily so to have a consistent presence can be very affirming and supportive but can leave some feeling lonely if they do not have this.

> *"I felt sorry for people on their own, you know, when you think they're on their own, and some people are very private, don't want anyone. Because you were literally there for eight, nine hours, and you don't like to intrude on people, but there's some people would I'd say, I'm only here, you want a cup of tea, or drink or anything, I'm just here. And then there's other people don't want any help. So it was nice helping some people who were on their own, saying would you mind just getting me something, a drink of water, or … it was just nice, and then they just didn't feel so on their own, did they?"* ***(Owen, Participant 12)***

Furthermore, as Marcus highlights, friends may also not really understand the experience and impact of HNC and find it difficult to empathise or spend time with someone as it is emotionally taxing and distressing.

> *"I mean, the trouble is, I mean when you talk to friends and things, you don't want to become bored with them do you, you don't want to sort of keep going on about it, you know, it's big to, to me, but err, change the record maybe some person might think you know."* ***(Marcus, Participant 7)***

It is here that formal and accessible peer support may come into its own, as being peers, means they are going through the same issues and can empathise with each other and share similar treatment experiences. They also understand the daily impact and can be there more consistently to advise on practical activities of daily living such as who to contact for queries, how to manage finances, what benefits can be accessed, what technologies and treatments might help rehabilitation and how to use transport, travel and other services with their new functionality.

All participants highlighted the importance of strong networks and relationships in their daily routine, some also highlighted the importance of a supportive clinical team that provided them with clear information and directed them to supportive services. This was a key theme in the observations and noted that others supporting the individual and how these impacts on them is fundamental to capturing the journey of the experience for HNC patients. Others focused on how close relationships, supportive friendships or family networks got them through treatment and how it helped to know they were there. This section has described how, through goal setting and support from networks an individual can begin to accept their journey and reconcile their sense of self and how crucial the wider networks are. For those that do not have support or lack a social network, the additional support of the right professional team is crucial.

A personalised care approach is therefore vital. Understanding a person's own resources and coping strategies (Walshe *et al.,* 2017) is crucial to creating professional intervention that is community based, and multidisciplinary provides a platform for a model of care that strengthens the ability to take this approach providing support when other networks are lacking. Therefore, next we reflect on this approach and the CHANT model to unpick the patient experience of this type of service provision.

7.5.2 CHANT MULTIDISCIPLINARY APPROACH

CHANT has the opportunity to tailor services to the patient and provide structured support for individuals that aim to make realistic and achievable goals for living with the impacts of HNC similarly to those who live with chronic conditions. (Entwistle *et al.,* 2018; Morgan *et al.,* 2017). In the study conducted by Franklin *et al.,* (2019) they suggest that *"extending these insights by examining different illness populations and settings will further develop understandings on goal options, the process of goal-setting, the intersectionality of different structures, and the support required both inside and outside of health encounters for people to achieve meaningful goals for living well"* (Franklin *et al.,* 2019, p.19). This study contributes further to this work by examining how goal setting is articulated in many patient's recovery and rehabilitation journey in a HNC context, with supportive structures. The next section reflects on the supportive elements of CHANT from the perspectives of patients living with HNC.

On what feels like a very practical and logistical level, these services are located in such a way that the patient is often familiar with the area and it is not too far for them to travel. This is practical with their impaired movement but also supports them on an emotional level. For many the hospital setting is unfamiliar and distressing and to be in the vicinity of where they live is much more comforting and practical, as Marcus states:

> *"it's more practical for them isn't it, I mean more practical for me, it's only one visit and then they all sort of see, see what they say, it might be more practical things, but it's certainly more practical for me." **(Marcus, Participant 7)***

An example of this personalised, place-based support is shown below in interview with Owen. This participant discussed struggling with radiotherapy and anxiety during treatment. The team were able to direct them to support that was local and the proximity is mentioned, acting as a driver to facilitate them attending.

> *"I did, well I have got … because one of the ones that do the treatment really, one of the nurses, she said have you thought about the relaxation thing? But I booked it twice and then something come up, so I actually …He had to go into hospital, so we had to cancel it. So, I actually booked … because they've got it in Sidcup, you know, where we are, so I think it's next month. (…) It's like a relaxation, they tell you how to relax. Yeah, a wellness clinic. Yeah, but some of the staff said well, we've been on it. It's worth going, just try and get in to relax. Yeah, that's on 6 February, and the following …*Yeah, three hours at a time, that's what it will be."
> ***(Owen, Participant 12)***

Many participants provided feedback on the CHANT Team and expressed immense gratitude. Aga stated:

> *"they've been really good, really good. Erm, I mean I think they've all you know, I mean they've all been lovely people I have to say erm." **(Aga, Participant 2)***

Barbara also felt supported and felt the team were an important part of that. She spoke of them fondly and with praise. They were the backbone to her recovery and the way that all participants referred to them as a collective also highlights the importance of them being a single entity that worked together to support the patient.

> *"The team have been absolutely brilliant, absolutely brilliant."* ***(Barbara, Participant 6)***

Owen too captures the impact that the whole team had on him and highlights the empowering impact of informing patients and keeping them up to date with clarity and empathy. The team presenting as a group helps the patient to understand the information in its wider contexts and see how the therapy and treatments suggested work together to create a more effective rehabilitation regime.

> *"Every single one of them, you know, I had a good rapport with them. Even the cancer nurses have come round, they're all you know, there's no thing, well why didn't you say that? But they've all been excellent haven't they, can't fault them at all. (…) Every one of them explained everything, there's nothing you come away and say what did she mean? Everything's been clearly explained and everything. (…)"* ***(Owen, Participant 12)***

Marcus alludes to the wider community-based set up, which includes the receptionist, the pharmacy downstairs, the café, and other people in this setting who are experiencing the same thing as them. The team feels like a nurturing place to be and they feel supported.

> *"once again the people there couldn't be nicer, the bloke on the desk, the people upstairs, and when you got in there, you saw patients who are in there, nobody doesn't want to be in there anyway, no one wants to be there, so it's sort of very, very nice… Oh they've been very good, very good, because yeah, yeah, I wouldn't say a word against, I saw the um, Physio, Dietician, and a Speech Therapist."* ***(Marcus, Participant 7)***

Santi articulates what it means to her to have the holistic view and the team approach. She compares it to her knowledge of how other cancers can be treated and that having the Dietician, SLT and Physiotherapist in the same space can help when asking questions and gives the impression that this team really understand the specific needs of HNC patients.

> *"Um, um I mean I have to say I think that the, the all-round support has been pretty fantastic, um, and if I compare, you know, I've got other friends who've had different cancers and um for some of them, it sort of hospital treatment, out, you know, come back in six months sort of thing, and, so because of the, the physical rehabilitation, um,*

> *that has provided so much psychological support. Um because I mean with both the, with the Dietician, the Speech Therapist and the Physio, probably fifty per cent of the questions I ask them, are related to their specialism and the other fifty per cent are related to their knowledge about people living with HNC."* ***(Santi, Participant 9)***

In summary, the CHANT approach clearly seems to have benefits and perceived as improving the experience of care from the patient perspective. There is a very clearly articulated sense that the team are able to cater to the needs of the patient, support them wholly and provide a nurturing environment. In the next section the personalised nature of this community based, integrated, supported decision making environment is discussed.

7.5.2.1 Supporting personalised patient centred care

In recent history, personalised care has formed the basis of policy and service reformation of cancer treatment in the UK and described as one of the five major practical changes to the NHS that will take place over the next five years. This is set out in the NHS 'Long Term Plan,' which was examined in this thesis as part of the policy review. There is a strong and growing evidence base to make these service changes for people to have a more positive experience of care. As already discussed, there are some key features to good, personalised care and the next two sections will outline the fundamental components.

- **Joint/supported and shared decision making** is crucial, so individuals and expectations matches clinicians
- **Integrated** approaches which aligns systems and sectors
- **Community** and team-based setting

What is also particularly pertinent is that a personalised care enables services to suit varying needs and therefore aims to have a*" positive impact on health inequalities, taking account of different backgrounds and preferences, with people from lower socioeconomic groups able to benefit the most from personalised care."* (NHS England - NHS England » What is personalised care?). The CHANT team are set up to be able to provide services in a community-based setting, sign post to other areas of support, meet the patient where they are in terms of their needs and often provide care that is easily accessible for the individual.

An example is described by Owen who required a replacement tube on Christmas eve, he would have had to be admitted in other circumstances but knowing that this was not something that Owen would have liked and being able to do this as community-based team, they were able to do this for Owen.

> *"And I said yeah, it's not going in, because I have to turn it once a week, and deflate the balloon, you know. And I went up to the dietician, in fact it was [inaudible - 58:18], I've got an issue with this, it comes out of the hole, and within five minutes, you heal up, so I kept it in there, and said there's something not right, it's got numbers on the tube. Because when I fell over indoors, I must have dislodged it, pulled it into this track. So, they turned round and said, you get yourself up to Guy's, and this was about 20 to 5 at night, I said I can't physically get up there at this time."*

The team were able to get hold of someone who could reposition the tube in the community setting on Christmas Eve. They provided painkillers instead of local anaesthetic and this suited Owen, who was then able to be with his family at Christmas.

> *"Christmas Eve, she said she'd be here at 12, and she'll have a go. So fair play to her, she turns up, said I can't thank you enough. She said well, we'll give it a shot, it was about 40, 45 minutes wasn't it? Went in there, two blokes, and the woman that came to do it, and tried all sorts of things. And it turned out she's got … they've got it open, and then kept putting bigger ones in to see … she said I've got some painkiller stuff, she said, that I can pour it around it. Oh, that would be better than doing you know, the local anaesthetic."* ***(Owen, Participant 12)***

CHANT provide a patient centred, personalised approach that is suited to the HNC patient cohort (as highlighted as a key feature at national, regional and place based service design through document analysis and further supported through the varying stories taken from the ethnographies). Some key elements that contribute to a supportive facilitative rehabilitation are consistent throughout many of the narratives and observations taken in this study. One of these elements is around supportive and joint decision-making. Marcus talked about the practicality of having all specialities that support rehabilitation as being coterminous. He talks about *"seeing what they say"* so feels more involved and at the centre of his care.

> *"it's more practical for them isn't it, I mean more practical for me, it's only one visit and then they all sort of see, see what they say, it might be more practical things, but it's certainly more practical for me."* ***(Marcus, Participant 7)***

Next, therefore, we turn to discussing these and how the CHANT service supported this or where opportunities might be to create support structures.

7.5.2.2 Supporting decision making

An area that is also pivotal to the personalised care approach is that of joint decision-making. This is facilitated by the CHANT team model, as it creates an environment where the team can not only talk to the patient as a team but can also talk to each other. In an approach where the specialities are not located within a coterminous set up, the patient often becomes the conduit through which information is passed and this can be a burden for a patient. This also creates a scenario where specialists are communicating to each other when the patient is not there and therefore does not put the patient at the centre of their care. The team, therefore, literally, and figuratively put the patient at the centre of their care in this community-based set up.

Marcus also captures another element of the MDT approach. The MDT team are not only physically at the community-based location. They first see the patient in the hospital setting, perhaps early on in their treatment. They then track with the patient into the rehabilitation phase and this can provide tremendous comfort. They are visible not only 9-5 but also at other times and in other settings. There is a demarcation between perception of staff in the hospital setting (with associated traumas) and the team in the community setting often. Some staff may overlap but the community-based settings were definitely more favourably reminisced about. This suggests that associated traumas, high intensity treatment and the intimidating setting may contribute to the perception of the staff held by the individual.

> *"whatever ward it was, they were very, very good, and they, and they had sort of things like Physios coming in and Dieticians and the whole, you know, what it's like in hospitals, in the week it's sort of um, like a working place, isn't it, the weekends, it's just holding really, just keeping people ticking over."* ***(Marcus, Participant 7)***

Marcus also talked about how the team approach phasing out the support. There is a sense that they are there for the patient as and when they need them. No one is left to feel like they are on their own after recovery and rehabilitation, acknowledging that the process can take a long time for any individual. This sense of team support appears important to participants.

> *"I will phone them up, if anything's worrying me, I think the um, well I see them every six weeks, but I think they, they said now, they're, we've both decided they're happy and I'm happy that I've got their number, and they've sent me all the contact numbers and everything. They've been very helpful, actually the service, seeing these um people down here*." ***(Marcus, Participant 7)***

It is useful to have a safe space to talk through the concerns and impact of the treatment together and to have that group of experts that they can talk to about concerns. Santi highlights this community-based approach

> *"Certainly I mean, um there's all, them all being in the same room is one thing, but the other thing is that having one appointment as opposed to having to come, you know, because there's so many appointments at some point."* ***(Santi, Participant 9)***

Marcus talks about a time where he needed advice and he was reassured by his Clinical Nurse Specialist (CNS). The CNS is a role that aims to provide the patient with a place to go with any health concern and in less coordinated cancer treating teams they often play a strong coordination function. Within CHANT they are often the first port of call for a patient and they create a bond with the patient that makes them feel that they have a person to come to rather than a system.

> *"Oh yeah, definitely coming down here, as I said to your colleague (…) Because there had been times when I had been worried about something or nothing, I bit my tongue once and I was*

> *really quite worried. I was sitting in that park over there, thinking oh God. And as soon as Claire saw it, she said "Oh that's alright", so yeah very much so yeah. (…). I will phone them up, if anything's worrying me, I think the um, well I see them every six weeks, but I think they, they said now, they're, we've both decided they're happy and I'm happy that I've got their number, and they've sent me all the contact numbers and everything. They've been very helpful, actually the service, seeing these um people down here." (Marcus, Participant 7)*

Ian talks about feeling empowered to make his own decisions about his care. But talks about it in the context of his positive attitude and mindset.

> *"all through the process I've made my own decisions and day one when I heard that word 'cancer' immediately he said it, it was positive thinking, I'll get through this, and I'll do with the cancer what I've done with the diabetes. Yes, I'll take the chemo. There was no argument because I thought, well, blimey, I've missed … haven't connected the dots myself. I didn't even know I had cancer. So, they've told me I've got cancer. They know how to treat it. I'll have my chemo. I'll have the radiation and all the way through the process I will make my own decisions as I go." (Ian, Participant 11)*

Owen is another example of a participant that felt decisions were made jointly and he mentioned the example of understanding exactly where is tube would be located and how the SLT explained the consequences and the positioning using a diagram. Whilst this sounds like an incidental practice, it is something that was illuminated in the observational work. The team spend a lot of time working together to provide a practical focus on what the patient will face and puts them at the centre of deciding about how they want to proceed. As discussed earlier there is a delicate balance of paternalism and providing a strong professional steer in balance with allowing the patient to make a choice and helping them to be informed.

> *"Yeah, she was very good, she had a diagram and made a little model, so I had visions of this big tube sticking out."* ***(Owen, Participant 12)***

Supported decision-making is something that can only effectively work within the context of an integrated care system. As described in the policy review (Chapter Five) there is a national ambition to create a more holistic environment of care by linking together local authority activity with the NHS and trying to ensure that social, psychological and physical needs are met in tandem. The CHANT team is a model that facilitates and complements this approach and we can see that this is a burgeoning example of integrated care that really benefits the patient.

In section 7.3.3.1 the expert patient was referenced, and the negatives of the expert patient model is that it can result in the patient feeling unsupported or too “in charge”. This is where the CHANT model provides great strength, whilst the HNC patient is expected to manage their appointments, home rehabilitation activity is guided and nurtured by a team that are community based and feel present, this is covered in section 8.2.1.1. First, however, morphing to the professional patient” comes at the expense of an HNCP having to give up passions or careers and so the next theme uncovers how this impact on the patient.

7.5.2.3 An integrated approach to care

A component of integration that is part of the MDT approach is linking mental and physical services. This is key to the integrated care approach and provides patients with the opportunity to access therapy services alongside or after their treatment. Marcus talks about being offered this service and whilst he didn’t use it, he was offered the opportunity to do this alongside the treatment itself.

> *“Um, I, to be fair, they did, they did offer me um a six week course, now at fairly early days, and it’s the only thing that I didn’t do, because I had so many things going on there, that I thought another six weeks, I couldn’t, and I didn’t really want to come in myself, another six weeks, where I had lots of appointments, so it was offered.”* ***(Marcus, Participant 7)***

Ian talks about the mental health support that is integrated into the cycle of rehabilitation approaches and treatment episodes, should the patient need it. He describes how he needed it and how he brought up financial issues, which were compounding how felt. This captures the reality of the overlapping spheres.

> *“I did go into that Dimbleby thing. I didn’t really get any joy from them because they offered me all sorts of things. I said, “Well sort some benefits out for me.” But they … like, five months*

> *ago and still haven't been able to move that forward but I think you filled something in for me today…But it's been horrendous and other people get benefits just like that…That side of things, I guess, the practicalities of like, managing your house, managing day-to-day, managing finances when you're this sick is another element of it, I guess. We haven't really touched on that. It sort of adds to the stress of the treatment."* **(Ian, Participant 11)**

7.6 SUMMARY

Section one captures the urgency of treatment and the impact this rapid process has on a patient. The salient points are around the beginnings of the cancer, which often show as innocuous or minor symptoms which may not initially be recognised by the patient. Furthermore, due to the location of the cancer it is sometimes flagged by dental professionals as well as general practitioners, which makes the path to diagnosis more complex. The urgency that follows often minor symptoms is huge shock to patients and the information overload is of note. There is a need for those providing this information to walk a delicate balance of providing enough information but not overloading the patient. The key factors are outlined as being around accuracy, delivery, and feedback. Pinpointing patient needs is a key finding in this study. This section also discusses pre-treatment dental extractions that take place and highlights the negative impact this has on patients, adding to the existing evidence that, fewer extractions under the rationale of pre-RT dental treatment planning should be considered.

Section two unpicks the experience of the treatment phase of HNC, by first exploring the unexpected impacts of dental treatment that takes place pre-radiotherapy. Participants talk of this stage as not fully understood, in terms of the implications and impact to their looks and eating. Surgery is next explored and this phase was accounted as happening rapidly and being very invasive, but what comes across as the most unexpectedly invasive element is radiotherapy, due to the fact that it involves a mask on the face and being secured to a bed. The harrowing accounts of treatment demonstrate that patients with this cancer need support in terms of the information they are provided with and decision making. The next part of this section looks at the impact of these treatments in terms of not being able to eat, speak and move in the same way as before. This has a profound impact on the individual. This study demonstrates that HNC often deprives individuals with traditional coping mechanisms and this causes trauma to the individual that is unique to this cohort of patients.

Section three explores how patients recover and rehabilitate. There are clear themes around finding the right support and coping mechanisms that suit the patients' needs and this is supported by existing literature and the model of care that CHANT provides. What is less documented is the factors that create these traits that dispose an individual to rehabilitate well and how a service such as CHANT can deliver personalised, integrated care, which supports the flexibility required to treat the individual as they are, within their own spheres, with the access to capital they have.

This research has been able to identify barriers and facilitators to creating effective, patient sensitive, healthcare pathways and provides a novel conceptualisation of the key actors and processes involved in this journey, through the use of methodological triangulation. In the next section the key findings from each research method are set out and the overarching findings are discussed. Furthermore, in conducting the project it is hoped that participants will benefit from feeding back their opinions of the care pathway as this data will be used to inform the clinical team, and in the next section, make recommendations for improving outcomes for patients and potentially lead to training and development within the team.

8. DISCUSSION, RECOMMENDATIONS AND CONCLUSION

This Chapter first outlines the research questions and then provides a summary answer, linking to parts of the study that are relevant to them and the views the questions aim to capture, see table 12. How this study answers each of the three research questions is then considered in more detail in the discussion. To do this I first consider the key findings from each methodological strand, aligning to each research question (section 8.2), and finally reflect on the overall findings (summary section 8.3). This Chapter then reflect on the limitations and strengths associated with the study (section 8.4). The implications for policy and practice are outlined (8.5), followed by future research potential (section 8.6). I close with final reflections highlighting the contribution of this research to furthering the understanding of the experience of HNC (section 8.7).

8.1 OVERVIEW

The aim of this ethnographic study was to explore the HNC care pathway from different perspectives. One focus is patient experiences to provide in-depth accounts of living with HNC. As outlined in Chapter three the study sought to address three research aims, (highlighted in table 12). Each method sought to draw out the answers to these questions and therefore this section will summarise the findings for each question, followed by more detailed discussion. Framing these research questions is a vital element of carrying out an effective research study. The methodology and philosophical approaches taken are fundamental to demonstrating the rigour and validity of the process undertaken to answer these questions and to unpick the findings.

Furthermore, the research process was governed by guiding ethical principles. This was research conducted with vulnerable patients at a turbulent time in their lives. Therefore, it was vital to ensure informed and voluntary consent and that information was shared confidentially and anonymously. Participants were therefore able to be involved with no harm to themselves and to ensure their welfare (and that of the researcher) was paramount. This was facilitated by constant contact with the treating team and regular check ins with the participant during the process, ensuring they are treated with dignity, openness, and honesty, with the aim, and guiding principle, of telling their life-changing stories earnestly and compassionately.

Table 12: Outline of research questions showing research method, research purpose and summarized answers

NO.	**RESEARCH QUESTION**	**RESEARCH METHOD**	**RESEARCH PURPOSE**
1	**What is the national picture for services designed and provided for people with HNC and what are the core principles behind this?** *(Chapter 5: results, Chapter 8:8.2.1 discussion and key findings)* ***a.*** **What is the national ambition for wider Cancer services and HNC services specifically and what are the principles behind this?** *The NHS Long Term plan set out plans for the integration of services, aiming to support this through a regional infrastructure that enables transformation of disparate services and creates an opportunity for more patient centered care.* ***b.*** **What are the regional infrastructures that have been created to support these national ambitions?** *National ambitions centre around a personalised care approach for cancer and hinges around the integration ethos whereby services and specialties do not work in silos. The national policy guides services to organise themselves regionally via Cancer Alliances who support the framing and implementation of these strategies in local areas at a system level.*	DOCUMENT ANALYSIS	MACRO VIEW: THE NATIONAL FRAMING

	c. **How have the regional infrastructures been used in reality at a local placed based level?** *The CHANT Model is based on the ambitions of the national policy and is embedded in its regional infrastructure. The model is routed in an ethos of providing patient centered, personalised, community-based multidisciplinary care which aims to break down obstacles related to silo working, tribalism and other barriers to integrative ways of working. CHANT is a unique service in the English NHS. Its multidisciplinary approach, together with its coterminous community-based setting is not reflected across services for HNC in other regions.*		
2	**What are people's experiences of the care pathway for HNC, in relation to the settings and clinical interactions?** *(Chapter 6: results, Chapter 8:8.2.2 discussion and key findings)* **a. Is the community integrated care model set up as the national and regional policy outlines?** *Observing the different settings helped to contextualise the words and thoughts of the individual narratives and allows us to see how the theoretical ideas and ambitions of policy play out in real life. CHANT does mirror the model of care outlined at a national level and aligns with the Cancer Alliance ambitions.* b. **How do participants experience these settings and traverse pathway designed in this way.**	OBSERVATIONS	MESO VIEW: THE OBSERVATION OF THE SETTINGS

	There is a marked contrast between early treatment settings and the community-based MDT settings. The team settings fosters a less intimidating environment for the patient and is markedly quieter and more relaxed.		
3	**What are peoples understanding and experiences of HNC?** *(Chapter 7: results, Chapter 8:8.2.3 discussion and key findings)* **a. What are people's expectation, experiences and understanding of the treatment and rehabilitation options available to them once a diagnosis of HNC has been received?** *Participants unanimously felt underinformed and underprepared for their treatment and the impact it had. They had little to no understanding of what impairment would feel like or what treatment might entail. They were often shocked and traumatised and profoundly changed. The rapid nature of their treatment was also startling and hard to process.* **b. What are the short and long-term impacts and consequences of receiving a diagnosis, and treatment of HNC?** *Impacts are first felt with dental extractions. Teeth being removed pre-RT can have a big impact on function and form. They are left feeling changed even before direct cancer treatment. Treatment can then leave impacts ranging from basic functions around breathing, swallowing and walking to issues around speech impairments, communication issues and difficulties eating.*	INTERVIEWS	MICRO VIEW: THE INDIVIDUAL NARRATIVE

c. **What elements of the journey were most challenging and what were the drivers to surviving and thriving?**

Many described the radiotherapy as being the most traumatic element of treatment due to the target areas being around the face, mouth and neck. Post-treatment the impact of not being able to continue with socialising, eating, hobbies and work was enormous and ongoing.

d. **What support did individuals receive and access?**

Support networks were pivotal to the cancer journey, and they were recorded as such in the observations and interviews. Both informal and formal networks play a vital role in supporting treatment and effective rehabilitation.

8.2 DISCUSSION

In addressing the research questions, findings were constructed from the data through the analysis process, and these are outlined in the next section alongside discussion around these findings. Therefore, each section maps to a research question. It begins with discussion around research question one and the findings of the document analysis, summarising the key findings followed by discussion around the strengths of community-based approaches that was highlighted through carrying out the document analysis.

8.2.1 THE NATIONAL PICTURE FOR SERVICES DESIGNED FOR PEOPLE WITH HNC

(Research question one)

The document analysis set out to understand the impact of integration principles for HNC care in the UK through a policy lens. The aims of this work were to identify policy, guidance, and information documents that include reference to multidisciplinary integrated care for people diagnosed with HNC. Therefore, a document analysis of policy documents at a national, disease, regional and local level were examined. This grouping allowed the aspirational national and disease level picture to be mapped, and then the demonstrated regional infrastructure designed to facilitate this, as well as the real-world place-based actualisation of the national aspirations and regional infrastructure. This provides the macro level framework within which to understand the community-based (meso) service described in the observations and the personal stories (micro) of people undergoing care for HNC.

In summary, the analysis demonstrates the following key findings:

- The national aspiration is that health services as a whole move to a model of care that is integrated vertically and horizontally with a focus on patient centred care.
- The regional infrastructure is set up to govern and support a move to community based MTD models of care for cancer services.
- Aspirations are not yet played out in reality. CHANT is a unique example of the national aspirations for integrated place-based MDT care.

8.2.1.1 Strengths of community-based models

Enderby and Wade (2001) carried out a study focused on teams who identified themselves as a community rehabilitation service that worked primarily with adults with physical disability within the UK (Enderby and Wade, 2001). This study showed that *community* rehabilitation in the UK currently bears some key common characteristics. In that they are often small, short-term teams lacking in identity and clarity about their function (Wykes and Holloway, 2000). Therefore, the term requires a clear and consistent meaning in order to provide a strong rehabilitation process that can be translated across localities and regions. This is achieved by identifying; direct behavioural goals; aims to produce specific effects on relevant outcomes; tailored and evidence-based interventions; and long-term tracking. Furthermore, it should be geographically close to clients' natural environments and have the multi-disciplinary team approach (MDT) which combines skills training with a broad range of social and environmental support mechanisms. (Wykes and Holloway, 2000). What is clear, is that the macro level policy documents outline the need for the community based meso provision.

As stated in Chapter Five the document analysis demonstrated that within national regional and local policy, there is a clear direction of travel for MDT community-based care. This document analysis provides the macro view that informs the meso and micro narratives and contextualises the experiences and accounts. This was part of the study design as it provides cultural, political, economic explanations of habits, reactions and feelings of individuals. Illness experiences do not occur in a vacuum but are situated within arenas of social values and stigmas, cultural capital, socioeconomic influences and holistic mental and physical components.

Treating this cohort of patients, who have varied and complex needs, lends itself to a patient centered, MDT approach. In an HNC study by Parker *et al.,* (2014) the authors conclude that a *"critical examination of current practices, together with efforts toward coordinated care tailored to individual needs, is required, along with outreach services for patients in rural areas."* (Parker *et al.,* 2014 p.263). This is however, challenging financially and logistically, on an infrastructure level, relocating services so they are coterminous and joined up.

Furthermore, there are workforce resource and cultural issues of silo working in specialisms. This is an issue that crosses many NHS and non-NHS services.

The national and regional support is therefore crucial, however, buy-in at a local level is also essential, (as evidenced in the document analysis) so that areas are empowered and able to embed services as well as believe in the ethos behind the service design. This part of the study demonstrates that whilst there is national and regional intent these models are few at a local level. CHANT is a vanguard example. This document analysis reveals a gap in knowledge about why these national and regional mechanisms have not facilitated wider local adoption and prompts questions about understanding the successes and challenges of the CHANT service. This study seeks to answer the latter part of this question but as stated in the future research section, understanding why implementation and adoption is not far reaching across other areas would involve further work.

There are, however, unintended, and likely specific, de-implementation challenges (Rapport, Clay-Williams and Braithwaite, 2022) that come with trying to standardise and introduce new models of care across all areas. It would be a helpful to explore further what may be holding other areas back from taking a CHANT approach, including understanding financial, cultural and practice-based elements, which may contribute to the de-implementation of current ways of working. This is separate but interconnected issue to what would encourage implementation and adoption (see section 8.2.1.2). Understanding why one model of care is easily adopted in one locality over another is crucial to forming personalised care that is integrated to provide a supportive regional and national infrastructure.

As stated in the summary of Chapter Five, it is pertinent to note that the policy documents identified at national and regional levels are aspirational rather than plans that have actually been put in place. This is what makes the CHANT services so interesting as an exemplar because the community based local care model is actually in practice and embedded, providing care for patients that meets many of the aspirations set out in the policy documents analysed here. CHANT is a service, which has been designed purposefully to function in this kind of way and can therefore be potentially emulated with the right infrastructure. Understanding the experiences of patients’ is crucial to furthering the success of tailored models of care that suit the needs of this cohort of patients. The CHANT level documents themselves highlight that to understand the impact of this service further research is vital (Tang *et al.*, 2016a).

This is underpinned by the NICE guidance (Improving outcomes in head and neck cancers | Guidance | NICE) and through partnership working between the National Cancer Survivorship Initiative (NCSI) and the Department of Health. Macmillan Cancer Support, and supported by the NHS, (Richards, Corner and Maher, 2011) there is a priority to meet the needs of an increasing number of cancer survivors. Therefore, there are two important elements to consider. If knowing the evidence base favours, a CHANT approach then the following questions should be asked. 1) what is preventing adoption? 2) more generally how does the patient experience inform the way we develop services in the NHS? (Section 8.5.2.3)

8.2.1.2 Challenges to good practice: adoption and implementation

The challenge of spreading good practice and vanguards is an issue that runs through many models of care within the NHS. Understanding the barriers to spreading and adopting change is therefore key to taking this work further and benefiting from the findings of this study and the work of CHANT. However, understanding spread, adoption and how to get the maximum reach on innovative or effective models of care is much understudied (Côté-Boileau *et al.*, 2019). Many evidence-based, seemingly effective interventions fail to translate to national and standardised practice (Damschroder *et al.*, 2009a). It is this issue of scaling and sustaining change that can be difficult to operationalise.

Implementation science seeks to take a systematic and rigorous approach to effectively adopting innovation (Bauer and Kirchner, 2020). Implementation science is the field of study coined to capture methods to encourage the systematic application of research findings and is used move theoretical ideas to practice. It sits alongside quality improvement and other dissemination studies to improve the quality and effectiveness of health services. From this discipline several frameworks or principles have come to be (Stetler, 2001; Gustafson *et al.*, 2003; Perrin *et al.*, 2006; Carroll *et al.*, 2007), that aim to assess the *"implementatbility"* of a particular intervention (Damschroder *et al.*, 2009b) and form part of the toolkit for policy professionals to consider how to increase spread of vanguard/exemplar interventions.

However, what is more applicable to the hectic, complex and varied needs of a model of care such as community-based HNC pathways, is the approach termed “complexity science” which takes a flexible and adaptive approach to change in a dynamic, self-organising system. This approach should seek to understand why someone acts in the way they do, especially the wider influencing factors and organisational/institutional forces that shape, inform and constrain an individual’s actions and beliefs (Greenhalgh and Papoutsi, 2019). Greenhalgh and Papousti (2019) suggest that a combination of these perspectives is needed for effect adoption and spread.

From the document analysis the rationale from national policies is to operationalise through regional hubs (NHS Long Term Plan). However, this has not be actualised across England. In this highly institutionalised setting innovation uptake can be unpredictable and context specific, however this thesis bolsters the rationale for adoption as it captures the effectiveness of this approach in meeting the needs of this cohort, and this can be transferred to similar localities who have similar cohorts of patients.

8.2.2 SETTINGS AND CLINICAL INTERACTION *(Research question two)*

The participant observations set out to explore peoples’ experience of the care pathway though the eye of the researcher, being embedded in the world in which the patient interacts, seeing interactions with the health settings and practitioners. Doing this enables contextualisation of the experiences and perceptions of patients living with HNC, through the researcher constructing a descriptive narrative of the milieu in which the patient finds themselves. It captures the health and social environment and therefore helps to illuminate the theoretical, political and national ambitions at a local level, the meso level, as well as the individual experiences captured in research questions 1 and 2. Through narratives and observations this study provides a descriptive immersive account of the different environments in which CHANT’s integrated, community based, care is practiced and contextualises the policy recommendations and practical guidelines that were explored further in the previous Chapter.

8.2.1.3 Traumatic, hectic and profound experiences of HNC

Immediately following diagnosis, patients undergo fast-paced clinical interactions that form the initial part of the treatment journey for patients diagnosed with HNC. This fast, invasive and traumatic process leaves a huge impact that is often only beginning to be processed during rehabilitation. Observations were also taken during the dental extractions phase, where patients undergo rapid changes that form part of the treatment, in a very intimidating, open, busy environment. The dental extractions element is explored further in section 8.2.2.3 but has been the focus of some existing research (Clough *et al.*, 2018; Parahoo *et al.*, 2019) and often has a lasting impact on patients.

The observations also included sessions of the 'Living with and Beyond' peer support group. This observation again highlighted the profoundly changing sense of self that each individual engaged with. This peer support demonstrated that sharing experiences with a network was a seminal part of surviving and going on to build a life after Cancer. This is supported in the literature review (Hodges and Humphris, 2009; Schaller, Liedberg and Larsson, 2014; Balfe, Butow, *et al.*, 2016; Badr *et al.*, 2018). Observations of the MDT consultations within the rehabilitation phase of care, demonstrated consistent themes across observations. Many patients struggled with the enormity of the impact the condition and its treatment had on their ability to eat and speak, two areas of human function that are central to how we navigate the world and survive, bound to our identity and sense of self, as well as how we connect with other people.

8.2.1.4 Functional impairments following treatment

In the multi-disciplinary consultations that were observed during rehabilitation there were key themes around eating, swallowing and pain which came up repeatedly. These themes were also explored in more detail in the one-to-one interviews. The severity of these impairments varied greatly in the observations of consultations, and everyone had slightly different issues and support needs which is already documented in a small body of research identified in Chapter Two (Literature Review). This demonstrates the importance of providing person centred care.

The existing literature looks at the impact of treatment but this often looks at the loss of eating or speaking in very functional, physiological terms (Einarsson, Laurell and Tiblom Ehrsson, 2019; Granström *et al.*, 2022). This study sought to understand how the biological change affects the wider social and psychological elements of a person's life and this is discussed further in section 8.2.3.5. What was particularly apparent in the observations was the importance of enabling patients to access multiple HCPs within one consultation. Many of the issues patients wanted to discuss crossed disciplinary boundaries and patients were able to get expert input on nutrition, speech and language, and physiotherapy within the one consultation without the need to repeat themselves or attend further appointments. This is explored further in section 8.2.2.4.

8.2.1.5 Informal Networks

Observations also began to highlight the importance of networks and how they come in many different forms incorporating partners, family, friends, flatmates, and wider more formal networks. This is further supported by the individual narratives (Chapter Seven, section 4). We see the crucial role informal networks play and how they come in many different forms. A study by Guidry *et al.,* (1997) explored the impact of social networks showing that such networks are important in helping cancer patients to cope with their diagnosis and treatment. These networks form part of their wider contextualised experience and therefore it is wise for professionals to understand the value and influence they play in treatment, care and rehabilitation. This area of study is growing with a number of research papers exploring the role of social networks (Hodges and Humphris, 2009; Schaller, Liedberg and Larsson, 2014; Balfe, Butow, *et al.*, 2016; Badr *et al.*, 2018). Research focused on the impact caregiving has on the carers themselves, the fear of reoccurrence, the helplessness they feel and the potential to support them with better support systems. The importance was clearly demonstrated in the observations, with the majority of patients either accompanied by, or supported to attend by partners, families and friends. HNC patients need daily support and this often comes in the form of caregivers in their existing pre HNC networks.

Another type of network support is peer support. Peer support modalities are varied, and the effectiveness is systematically under evaluated. However, a peer support approach is advocated in many spheres including the national regional policy context. A study by Dunn *et al.,* (2008) looked at peer support interventions for people with cancer. The studies found that peer support programs helped by bringing emotional and informational support to patients from the perspective of a peer who has that shared personal experience (Dunn *et al.*, 2003). However, as identified by this review, there are key factors that help shape effective peer support. These include supervision style, for peer support (whether it is informal connections or supported by MDT teams or other health professionals), the interpersonal context (the way in which the support is delivered), and the mode of delivery (e.g., in person vs virtual). It is the importance of these factors that needs to be explored further to optimise the facilitated support in cancer services.

Observations highlighted the importance of peer support in the HNC, CHANT environment, as it was clear that all individuals sought some comfort in the mutual sharing of experiences. This was particularly pertinent in the observation of the *"Living with and Beyond HNC*" peer support group. Attendees came, shared experiences and discussed problems, in an accessible and friendly community-based location, with the MDT in attendance, and left feeling uplifted, more informed and feeling supported. Peer support groups bridge the gap between the informal networks and the healthcare professional. The observation of such a peer group captured the raw experiences that are shared and the value of focusing on learning and supporting each other, with the presence of the wider health professional teams there to provide support as needed.

8.2.1.6 Formal Networks – The CHANT model

CHANT is a unique example of community-based MDT care in practice. The observations highlighted the effectiveness of this approach in meeting the complex needs of patients. Having healthcare professionals with different expertise (multidisciplinary team - MDT) allowed multiple issues to be addressed in a single consultation is important where symptoms cut across specialisms, or where patients had multiple issues that needed addressing at one time. A single consultation can look at the issue or concern from several different angles. A patient does not feel as much burden to recite accounts of treatments, history, or advice to a sequence of different health professionals and a team bond nurtured. The patient is made to feel supported and surrounded by a team who is able to address many needs. The strengths of an MDT in the treatment of patients is well documented in the literature (Ellis, 2012; Bergamini *et al.*, 2016; Blackwood and Deb, 2020). However, the strengths of the MDT focus on ways of working as professional teams and discussing cases, and less around the benefits of MDT consultations themselves, and the benefits it brings to the patient experience.

There is wider acceptance of the importance and strength of a patient-centred approach to decision-making around treatment. Multidisciplinary case conferencing is becoming an integral part of care (Ellis, 2012). This MDT supportive approach takes a holistic approach seeking to provide the patient with wider psychosocial support to meet their daily needs. However Ellis (2012) states that the institutional commitment and backing is required to support the implementation of multidisciplinary care and integrative ways of working (Ellis, 2012). This feeds back into the previous research question and the rationale for providing community based multi-disciplinary care for patients with this type of disease diagnosis and is supported by the intent set out in the document analysis, the observed consultation approaches, and defined clinical pathways. The strengths of this approach are also articulated by the patients themselves who unanimously fed back favourably on the MDT, community-based approach and the benefits of CHANT, which supports the early exploration set out by Tang *et al.,* (2016).

Bergamini *et al.,* (2016) carried out a case review to explore the impact of MDT approaches during the treatment phase for patients with HNC in an Italian setting. The study highlights that this approach has been under evaluated in HNC contexts and demonstrated that where MDTs were involved 60% of treatment plans were modified, following initial assessment. This demonstrates the impact that this evaluation can have. To date, Tang *et al.,* (2016) is the only early evaluation of such approaches in England for HNC and a more detailed account of experience does not exist for any English setting, therefore highlighting the potential of the research presented in this thesis to inform future models and approaches for treating HNC in England.

HNC patients have varied and complex needs, which necessitates a person-centred integrated, MDT working for effective treatment that is supported by the national and regional intentions set out in the document analysis. CHANT is a vanguard and exemplar for well-designed services, facilitated by the Cancer Alliances regional structures at regional level. This form of care organisation is not yet replicated across England. Even if the national framing is evidence based, adoption and implementation is far more complex and spreading change and uptake of implementation of vanguard models is a constant challenge, as discussed in section 8.2.1.2.

8.2.3 EXPECTATIONS AND UNDERSTANDING OF HNC *(Research question three)*

The interviews set out to capture patient experiences of living with HNC. This process sought to provide a vivid, in-depth account of the patient's HNC journey. This element aimed to provide the rich and sometimes difficult to hear, elements of the stories of these patients.

Interviewees took time to go through difficult elements of their journey, generously opening up about their experiences of trauma and chaos at the beginning through to the turbulence and hardships of treatment, into the difficult rehabilitation phase, moving to living with the impact of the diagnosis and treatment in the longer term. The interviews set out to build on the work of the policy review, to see if the ambitions had been met for a personalised integrated, community-based model of care, from the experience of those using such services. The interviews provide a first-hand account of the experience of diagnosis, treatment, and rehabilitation, which compliment, triangulate and bolster the ethnographic observational work. The key findings from this process are listed and discussed in turn below.

8.2.3.1 Urgency and rapidity causes trauma

There is, unsurprisingly, a huge shock to patients on receiving their diagnosis and the information overload is of note. There is a rapid escalation from diagnosis to the first phase of treatment. The minor symptoms may have been persistent and trivialised for some time and then suddenly they equate to a much more serious and impactful illness. This is something that is documented in the wider literature around cancer diagnosis and is often talked of in terms of the post-traumatic stress experienced after such a trauma (Güner, 2017; Gieseler *et al.*, 2018). What compounds this feeling in the particular case of HNC, is that often this initial, rapid treatment phase includes multiple dental extractions and/or invasive surgery, both of which have an immediate impact on one's functional ability, in terms of communication and eating. The speed at which someone's functionality and identity is challenged is often traumatic and unexpected. In all interviews, participants spoke of the formative nature of these early interactions with the healthcare team, whether this is around early symptoms being taken seriously or around information provision and caring guidance through the treatment journey.

What is clear from the accounts is that whilst participants attribute some of the confusion encountered to communication problems with the professional, they actually attribute much confusion to the urgency of the first part of the process. Some of them say everything was explained very honestly but most have suggested they did not really understand what the information they were given meant, until they found themselves unable to eat or swallow. This is echoed in similar feedback around dental extractions particularly (Clough *et al.*, 2018). So, whilst it is not the sole contributor, optimising information giving is a crucial part of the process of providing quality care.

8.2.3.2 Importance of information giving

From a patient perspective information giving is a critical part of managing expectations, fears, and trauma before and during treatment. The literature review highlighted that this is something that is pervasive across Long Term Conditions where individuals have to absorb extensive biomedical information (May *et al.*, 2004). The fundamental factors are outlined as being around accuracy, delivery, and feedback. Even with clear information giving practices, HNC and its' treatment can be so transformative to a persons' identity and ability to function it is often difficult for people to comprehend the impact that this may have. However, providing staff with clear approaches to joint decision-making could aid HNC patients in making informed decisions about the treatment following a traumatic and profound diagnosis. As stated in the previous Chapter (Seven), it is a delicate balance around how much information to provide and how to deliver it and this can depend on the patient.

A study by Parker et al (2020) highlighted the paucity of good clear information around surgery for HNC patients. Of particular concern is the problem related to information provision and comprehension. The study recommended that the *"development and evaluation of targeted resources in a variety of forms such as DVD, Internet, and pamphlets are needed. Robust assessment strategies are required to inform supportive interventions matched to stages and significant events in patients' journeys."* (Parker *et al.*, 2014 p.263).

The importance of information giving was a key theme in the patient stories. The stories outlined key gaps and that there is a need to be clear, objective and accurate whilst being sensitive, empathetic and supportive. Furthermore, there is a need to treat quickly but provide time for patients to absorb diagnosis and treatment plans. The factors that need to coexist to create a personalised approach, can be conceptualised into three key elements.

- **Accuracy** – Clear, concise, accurate and understandable information
- **Delivery** - Empathetic, sincere, and supportive staff who build a relationship is essential to a successful and positive experience of diagnosis, treatment and rehabilitation.
- **Feedback and processing** – an iterative consistent check-in process that allows time for processing information within a heightened intensive and condensed period of time but does not compromise rapid and swift treatment.

This ties in with the body of work that emphasises the importance of clear information giving at challenging times (references), discussed in the results Chapter Seven. Healthcare professionals require guidance and support to deliver appropriate and relevant information in a timely and compassionate manner and patients require access to a variety of information mediums, accessible in a various ways (Parker *et al.*, 2014).

8.2.3.3 Dental extractions

Implications of early pre-RT extractions are often not processed, as this pre-treatment procedure tends to happen at the intersection of diagnosis and commencement of active treatment where there is considerable information overload for the patient. This creates a perfect storm of emotions that contribute to the participant not being present or fully understanding the decisions around dental extraction. Participants were profoundly affected by dental implications and fewer extractions under the rationale of pre-RT dental treatment planning should be considered (Clough *et al.*, 2018; Parahoo *et al.*, 2019). Clough *et al.,* (2018) first highlighted this issue demonstrating that two key elements contributed to a disruption in carrying out this procedure. As highlighted in the previous section, this was around information giving and not being aware of the options available to them, and the consequences in terms of their functionality.

In a study by Moore *et al.,* (2020) a Delphi process was carried to understand the expert opinion around dental extractions. This work builds on the concerns expressed by early qualitative studies that dental extractions should take a more discerning approach. Pre-radiotherapy dental assessments for HNC patients are considered mandatory. However, the study by Moore *et al.,* (2020) suggests that different criteria should be considered for pre-radiotherapy extractions, in accordance with the *"collective consensus opinion of participated consultants in restorative dentistry in the UK and Ireland*". The study showed that consensus was reached through a Delphi process on 89 consensus statements around *"the decision-making process for the pre-radiotherapy extraction of molar, premolar, and anterior teeth with periodontal pocketing, furcation disease, mobility, caries, tooth-wear, apical disease, or other pathology",* (Moore *et al.*, 2020 p.1) that dental extractions can be reduced and assessed more critically. This thesis further supports this approach from the personal perspective and opinion of the patient.

8.2.3.4 Trauma relating to radiotherapy that is unique to HNC

Participants identified the most invasive element of the HNC experience as being radiotherapy. The harrowing accounts of treatment demonstrate that patients with this cancer need support both practically in relation to managing this aspect of treatment but also in terms of the information, they are provided with and decision-making.

Each participant talked about their experience of active treatment. Across all accounts, there was a clear emphasis on finding the radiotherapy elements distressing. This was due to the process of having to wear a facemask and being secured to a bed. This left a lasting impact on many who found it incredibly challenging. This is perhaps an element of treatment that is inevitably traumatic, but it is helpful to have the vivid patient account so that health professionals can begin to understand how better to support patients during this particular phase of treatment. There is some current literature exploring the impact of radiotherapy, as an experience of care and the consequences in rehabilitation (Epstein *et al.*, 2001; Zackrisson *et al.*, 2003; Lang *et al.*, 2013; Álvarez-Camacho *et al.*, 2017).

However, much of this research does not differentiate between the different treatment options. i.e., no comparison of treatment pathways such as surgery versus radiotherapy or chemotherapy and therefore more research should be carried out focusing on the experience of radiotherapy specifically. Research that does focus on this element shows that radiotherapy causes distress, trauma and disruption in patients' lives. Radiotherapy causes many unpleasant side effects as well as being an intensely claustrophobic experience (Fitchett *et al.*, 2018). The findings highlight that patients feel isolated and often withdraw from their social networks, but need guidance, information, and expertise to help them through the treatment (Fitchett 2018). Radiotherapy disrupts their daily lives and is very intense. However, the impact of radiation and the cancer overall is difficult to dis-entangle and is therefore often not a focus of research.

HNC patients undergoing radiotherapy have many unmet needs which, Fitchett (2018) highlights as requiring further study. This thesis has shown that there is great anxiety and uncertainty patients feel around this phase of treatment. Interventions could take place at this juncture around how the radiographers can support patients (this could be fundamental relationship in the HNC journey), how different kinds of information provision could be approached, how policy makers and health professionals should consider the impact when designing clinical pathways and supporting the development of coping strategies to get through treatment.

8.2.3.5 Loss of eating and speaking

Implications of treatment side effects relating to their appearance, speaking, and eating were traumatic and not fully expected, by the patient, on commencing treatment. This study demonstrates that HNC often deprives individuals of traditional coping mechanisms, due to their loss of function in communicating and eating. *"HNC patients feel isolated, uncertain, and in need of coping strategies."* (Fitchett *et al.*, 2018 p.4). This causes trauma to the individual that is unique to this cohort of patients. Finding the right support and coping mechanisms that do **not** revolve around speaking, moving, and eating can support the rehabilitation.

The Interviews Chapter detailed the losses experienced and how some of the participants coped with treatment and its invasiveness. What is particularly pronounced in this type of cancer is how impaired eating, drinking and speaking, swallowing and even breathing becomes and how these underly many core coping mechanisms for navigating cancer journeys. Individuals may lean on speaking therapies, talking to their networks, socialising over food to lift spirits and feel supported, maintaining strength through eating well and, yoga and breathing relaxation and other mechanisms that may help anyone get through difficult times or ill health. These are not possible for HNC patients.

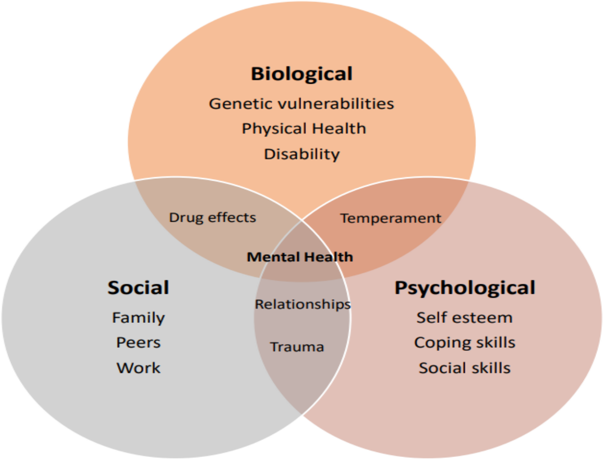
Coping mechanisms for cancer patients has been a research focus for many years now (Chittem, 2014; Roberts *et al.*, 2018) as it impacts on how a patients processes their journey and the psychological effects on a person. However, most studies focus on quantitative analysis (Chittem, 2014) and other cancers (Kunkel *et al.*, 2000; Ellis, 2012; Gaton-Johansson *et al.*, 2015; Roberts *et al.*, 2018; Blackwood and Deb, 2020). One recent study does focus on HNC in particular and discusses coping strategies employed by the patients to deal with their emotions (Jagannathan and Juvva, 2016). This study details that HNC patients are highly likely to experience severe emotional distress after treatment and that understanding how they cope is best elucidated through qualitative methods but highlight that research has not focused on the emotions and feelings experienced and the coping mechanisms used by HNC patients. (Jagannathan and Juvva, 2016, p143). This study took a qualitative content analysis of in-depth interviews and demonstrated that patients with HNC in India coped through three core approaches. They coped with their emotions by either:

> *"1) inculcating a positive attitude and faith in the doctor/treatment,*
>
> *2) ventilating their emotions with family and friends, or*
>
> *3) indulging in activities to divert attention.* (Jagannathan and Juvva, 2016 p143) *"*

The results showed that an in-depth nuanced understanding of the emotions, their root cause, coping strategies, and spiritual and cultural orientations is absolutely essential to develop any effective intervention program (Jagannathan and Juvva, 2016). What Jagannathan and Juvva (2016) do not explore is the direct impact the treatment has on the ability to enact these coping mechanisms.

Whilst treatment may have eradicated the cancer, the side effects of the treatments can have a wider impact on patients that is social, biological and psychological. It highlights the importance of considering patient's needs in the context of the biopsychosocial model (Engel, 1977) where a patient's wider needs are understood and addressed. Understanding the intrinsic importance of this in the pathway of rehabilitation helps to shape services in the future. Understanding a patient's social and psychological needs, alongside their more obvious biological needs, is paramount, therefore, to their successful rehabilitation.

Figure 16: The Biopsychosocial model - adapted from Biopsychosocial-model-of-health.PNG - Physiopedia (physio-pedia.com)



Whilst this model helps to articulate a complex array of factors it is important to note that this is one framing of the reality of the account of the patients experiences. It has been widely used in the context of health policy and the redevelopment of services within the NHS to foster the integration agenda and encourage more cross system working but it is important to note that within health psychology this model has been critiqued (Hatala, 2012) as being restrictive and failing to fully define the concept of culture amongst other things. Therefore, a more integrative multilevel or holistic perspective strengthens the Biopsychosocial Model, and this study seeks to do that through understanding the micro, meso and macro context, using an ethnographic approach.

8.2.3.6 Attitudes to recovery and incremental goal setting

In the literature review, it was helpful to reflect on the parallels with chronic disease management and cancer. The barriers and facilitators to living well with a chronic condition and rehabilitating following cancer treatment can often have similar hallmarks. In particular, the interview narratives highlighted an important parallel in terms of setting aspirations and goals for recovery and how this is different for different people and is impacted by their situation, frames of reference and historical contexts. There are some common themes around chronic illness and long-term conditions (LTC) that useful comparisons can be drawn with (Nettleton, 1995; Scambler, Newton and Asimakopoulou, 2014).

The sense of self is dramatically altered in both HNC experience and other LTCs and with this disruption in their sense of self comes other factors around the stigma it brings from outside influences in their daily lives. In the social, political and economic fields they may have once traversed with a different version of themselves, many are grappling with the new fear of stigmatisation and marginalisation (Grattan *et al.*, 2018; Reynolds and Harris, 2021; Tseng *et al.*, 2022) , feeling trapped in an unfamiliar body following extreme treatment. To navigate rehabilitation within this context therefore takes time, patience and a strong, versatile formal and informal network of support. These networks enable and facilitate goal setting at a very rudimentary level, around essential life supporting functions.

In a study by Franklin *et al.,* (2019) the impact of goal-setting and self-management was explored. The ability for an individual suffering from a chronic condition were created in a space that is influenced over time and guided by past experiences playing out in present situations and finally facilitated by the access to resources available to that individual. Therefore, an effective management strategy must be tailored and centred around the expectations and reflections of the patient. A personalised, patient centered framing to goal setting, involves collaboration between patients and healthcare professionals, and is a guiding principle in service and policy development relating to managing long-term illness and chronic conditions. Analysis by Franklin *et al.,* (2019) highlighted three distinct interactional styles. In controlled interactions, goals are set in the context of specific medical and physical references, by the health professionals and directed at patients', in a paternal way. In constrained interactions, patients are invited to present goals, but this is countered again with the authoritarian approach form health professionals with language orientated toward biomedical issues when discussing goals.

The third and most facilitative style (flexible style) is presented by Franklin *et al.*, (2019). Highlighting that the interactional style of any healthcare professional is fundamental to the success of effective goal-setting in this multidisciplinary environment. These interactions need to be flexible with focussed directive language, used alongside an approach that creates open spaces for contribution by everyone, allowing the input of the patient to contribute to the formulation of goals (Franklin *et al.*, 2019) and is a model that seems to reflect the aspirations of CHANT's approach best. Another example highlighted in the literature review is the Danish intervention explored by Kristensen *et al* 2019 where a residential rehabilitation focuses on nutritional intake in an intense period, but with flexible interactions for goal setting. This is a safe and supportive environment where patients can intensively practice functional skills around eating and do this with others going through similar challenges. This format provides information and knowledge gathering that may not have been carefully disseminated during or immediately after treatment. (Kristensen *et al.*, 2019). This MDT focussed and goal setting environment enabled patients to thrive and could be used as an extension to existing community-based outpatient settings, further harnessing the principles of the CHANT model.

By opening up goal-setting at the level of a patient-professional intersection, it allows for goals to be realistic and can broaden the range of legitimised and achievable targets, plus professional input can legitimatise the goal to the patient and can help them to map the benefits of small incremental change. With psychological flexibility and support from the MDT team, patients can optimise the chances of a successful rehabilitation.

8.2.3.7 Informal and formal network supports as key to supporting HNC patients

As outlined in previous sections of the discussion and in the literature review, the role of partners, families and friends is crucial to surviving, enduring and thriving in rehabilitation. An understanding of the importance of how these networks support the individual and where they sit in the context of the journey, provides a map of the micro toward a macro view. The layering of experiences enables the shift at micro level to meso and macro level and provides a description of the networks that surround the individual. The context helps to inform the social, political, economic and cultural influences. The individual story is told through the patient accounts; and whilst much of this thesis focuses on the individual's journey, collectively and alongside other forms of data, a holistic picture emerges. What is clear from the policy document analysis, is that a focus on peer support and the MDT formal support networks is crucial. The observations also showed that patients needed physical and emotional support to attend appointments and to support their rehabilitation activities on a very practical but also emotional level. CHANT can complement existing networks and sometimes fill a gap in those who are lacking in networks, by delivering personalised, integrated care which supports the flexibility required to treat the individual as they are, within their own spheres at place-based level (Tang *et al.*, 2016a)

Finally, the individual narratives really emphasised the impact that support from more informal networks had on their recovery. They talked often about how fundamental their families, partners and friends were to them and how they could not imagine how someone without support could manage. It was clear that without the support for practical and emotional elements this journey would prove too arduous and engulfing. All these themes begin to form the bigger picture of the experience and the next section explores the overall findings, the reason for carrying out this research and why these findings matter. The next section aims to summarise the findings, demonstrating why doing this furthers the existing research and provides a unique view of the experience for HNC patients (micro, meso and marco perspective).

8.3 SUMMARY OF FINDINGS

The three strands of work triangulate to provide a holistic picture of the experiences of patients undergoing the journey of HNC diagnosis, treatment and rehabilitation. It contextualises the personal individual narratives (micro levels) through documentary analysis (macro) and observational methods (meso). This meso to micro approach is an important lens through which to convey the nuanced, complex and multi- layering of experiences; capturing the political, cultural, social and biological. Health services research is slowly moving towards this approach through visualising care through a more biopsychosocial lens. This study has added an understanding of how policy shapes service provision and shows that the framework and recommended approach is one that suits the needs of this cohort, even though this approach is not spreading across the NHS in a way that national ambitions had planned.

What it shows in policy terms is that HNC is a particular type of condition that is ideally suited to being treated at a local community level within a model of integrated care. At an individual level, however, it is a catastrophic diagnosis, which turns people's lives upside down. Once they have gone through the treatment and rehabilitation, they are never quite the same as they were when they started. This is demonstrated in observations where the reality of the environment and interactions that patients are involved in can be seen. The impact is then reinforced through the individual stories that came out of the interviews.

This thesis is strengthened by this multimethod layered approach, with each phase being informed by the last and with the nexus of seeking to shed light on the contextualised experience of people through HNC diagnosis, treatment and beyond. Therefore, this thesis has effectively answered the research questions set out. This approach demonstrates that in order to understand the experience of HNC you cannot look at elements in isolation, e.g., the focus on functioning, on dental extractions, on swallowing or on nutritional intake. All of these are parts of a bigger picture and the whole cannot be fully understood through its constituent parts. This thesis shows the impact on a person as a whole, considering all the complexities together, to form a detailed ethnographic analysis of the experience for HNC patients. This is a holistic approach that has not previously been taken in research in HNC. This is important because it will help to shape the provision and design of services in the future.

Acknowledging that other quantitative or professional viewpoints are also fundamental to providing a full picture of the world experienced in the words of the HNC patient, with the observed outer structure, from the researcher's perspective. This study, therefore, provides an important evidence base for understanding the impact a service that realises the ambitions of nationally developed health policy to provide personalised care that is place-based and multidisciplinary.

8.4 STRENGTHS AND LIMITATIONS OF THE STUDY

Whilst the study demonstrates some seminal and useful findings, it is important to consider limitations that caveat these findings in order to understand how to bolster future research. This section explores three acknowledged limitations to this study.

8.4.1 ETHNOGRAPHIC METHODOLOGY

One potential critique of ethnography hinges around the lack of generalisability of the findings as the results are based on the cultural and situation specific responses and therefore the outcome of the study cannot necessarily be applied beyond where the study was conducted (Goodson and Vassar, 2011). However, this limitation does not ring true for this study as this was exploring a unique service in the NHS and therefore lends itself to this approach for initial open research. Furthermore, a combination of methods were used to provide a level of generalisability in the findings and to provide methodological triangulation.

Using observational methods over an extended period of time gave a feel for the experiences of those attending the CHANT service and the findings provides a window into some of the issues and challenges that patients undergo during rehabilitation. Observations were taken throughout a six-year period in which the service evolved and staff changed but the ethos and framework of the service remained, which is a rare opportunity and strength in this study. The document analysis was carried out as a pre-research phase, facilitating an assessment of the reality of the observational work. Furthermore, the observations facilitated the immersion process, nurturing familiarity with the team, which in turn supported the recruitment of the participants. The triangulation was pivotal to the study findings. It allowed for the mapping of the networks involved in the interplays between actors that participate in the journey of rehabilitation that the patient experiences. It also allowed for the physical environments in which people find themselves when receiving treatment for HNC. The nature of the physical environments affects care and people's experiences of it. However, when using participant observations as a tool for data collection, it comes with some limitations.

The limitations are associated with the person performing the observations. The observer brings their own bias, and the accounts may not be captured accurately or correctly due to it being taken in a snapshot of time. The observations could be biased by influences such as gender, sexuality, ethnicity, class and the values, beliefs or theoretical approach the researcher takes, thereby affecting the observations, written field notes, analysis and interpretation of data (Nielsen *et al.*, 2021). As referenced by Neilson et al., 2020 a helpful framework by which observational work was conducted using a recursive didactive approach (Wray, Markovic and Manderson, 2007; Spradley, 2016). This limitation was however combated by the use of other complimentary methods of research (document analysis and in-depth interviews) and consistent reflexive checking, alongside discussions with other members of the research team.

This ethnography seeks to represent the lives of the participants in the research and therefore it must be acknowledged that ethnographic accounts are representative and told from the researchers' perspective. Clifford Geertz produced a body of work that reflects on the complexity of ethnographic accounts and how it is an interpretive process that can be framed to acknowledge and articulate the authors' inevitable meaning and value on the studied phenomenon. The researcher cannot be embedded but sits as an outsider and oneself, cannot be transcended. There is always a conflict of personal narrative vs objective description, and this is inevitable with ethnographic work (Chiseri-Strater, 1996). To combat this, it is an integral part of the process to ensure there is due consideration throughout fieldwork and presentation of findings i.e., a demonstration that the account is balanced using triangulation and biases are acknowledged through consideration of reflexivity, positionality and subjectivity throughout.

8.4.2 SINGLE RESEARCHER CAPACITY

This study was completed as part of part-time PhD project and therefore research was conducted by a single researcher over an extended period of time. Having a single researcher lends itself to a subjective lens. The interpretation of the cultural phenomenon would be different depending on the researcher. *"The entire project is subject to the processes and* *interpretations developed by the researcher"* (Goodson and Vassar, 2011 p.4). A single researcher ruled out any possibilities of producing a greater volume of data. There are large studies that have explored health services across many sites in health spheres and these require extensive resource and funding. However, the strength of single researcher approach is that over an extended time-period, there was the possibility of embedding the researcher within the service, allowing them to build relationships with HCPs and patients within the HNC service and gain a more in depth understanding of the context in which care is received.

8.4.3 QUANTITATIVE ANALYSIS

Statistical research is often used in healthcare research and can provides a valuable function in quantifiable information on a large scale, in relation to variables and this is its fundamental strength. Within the context of HNC patient experience quantitative data can provide factual outcome data which may be seen to provide generalisable inferences on a wider scale. Quantitative analysis can identify specific elements that can provide insight into very specific questions on a large scale.

Whilst the limitations are acknowledged, they also form part of the strengths of this study. As highlighted in the methodology, there are strengths to employing ethnography. Furthermore, taking a qualitative multimethod approach further provides strength to the findings of this study, allowing different features of a given reality to be seen. Framing explorations in only quantitative terms can be a weakness and particularly not suited to early exploration of seeking to answer questions around patient experience of health services. With seeking to understand complex intersectionality and interdependencies, it can be more challenging using these statistical methods. Early exploration of services can benefit from open questions, which are not part of the process of statistical enquiry. There is potential in quantitative research to not capture the holistic view with an open mind due to the methodological approaches. Quantitative research can be critiqued as sometimes being reductive and not always reflective of true context and complexity of a given phenomenon.

8.4.4 QUALITATIVE DESIGN

A broad scope suits ethnography because it strives to use each phase of research to inform the last rather than framing with pre-determined unswerving questions throughout the research period. As outlined in the methodology section, this ethnographic approach suits early inquiry into a phenomenon, which can form the bedrock of other types of research. This method suits open broad research questions. Furthermore, ethnographic approaches can be ideally suited to exploring questions that surround a cultural experience or phenomenon that is not easily accessible. An ethnographer, as was the case in this study, is required to undergo an immersive process to build trust, understand the setting and foster gatekeeper/key informant relationships (Goodson and Vassar, 2011).

Furthermore, the ethnographer becomes familiar with a topic, with a lens of understanding unbiased by having a clinical or patient background in this area. This brings a perspective that may uncover nuanced and conclusions that lack certain pejorative assumptions. Although it should be noted, and this has been considered and documented throughout the study, it is impossible for a researcher to not bring with them a set of established values, views and interpretations (Liberati *et al.*, 2015) which would be absent in a double blinded randomised controlled trial. However, through a carefully designed multi methods approach, a rigorous analysis process and reflexive checking this can frame the findings and discussions. Bourdieu refers to reflexivity as "*mastering the subjective relation to the object at three levels – the overall social space, the field of specialists, and the scholastic view"* (Rae and Green, 2016 p.1543). This reflects the importance of objectivation (Deer, 2008) which is used in combination with Finlay's model of three stage research that is followed in this thesis (through a document analysis and observations before carrying out interviews) and is advocated as a rigorous approach to reflexivity in health research (Probst and Berenson, 2014; Rae and Green, 2016).

8.4.5 METHODOLOGICAL TRIANGULATION

As mentioned, another strength of this process of enquiry is the use of a number of methods to answer the research questions, seen in recent rigorous explorations of health services cited in the literature review (Russ *et al.*, 2012; Dixon-Woods *et al.*, 2014; Johnson *et al.*, 2017). This triangulation provides different views of the same phenomenon and therefore helps on two different levels and enables exploration of the whole system rather than individual influences and is growing as a preferred approach *to "identifying health care issues as they occur within the natural context"* (Johnson *et al.,* 2017 p.1).

It provides a meso, macro and micro view (Dopfer, Foster and Potts, 2004) of the lived experience, providing social, political, biological, psychological, and economic views that we have seen carried out for other cancers but used to approach the framing of the lived experience of HNC (Kunkel *et al.*, 2000; Raleigh, 2010). Carrying out these multiple methods is time consuming and whilst this limits the sample size, the granular detail gleaned from observations and long form interviews is invaluable. It is detailed and laborious data collection that requires immersion into the culture that surrounds the experience. The time spent doing this is not something that is often afforded to health services studies, which are often linked to wider political or funding constraints. Therefore, the time spent on this process is another important strength outlined next.

8.4.6 LONGITUDINAL STUDY

The opportunity to undertake repeated (longitudinal) data collection throughout the timelines, over the course of an extended period of time (6 years), meant that this research was able to collect a great deal of data to address the research questions and assess patients' experiences and different points in the rehabilitation journey. "It is much less expensive to conduct research with a survey than to immerse an investigator into a culture for a given period of time to extract extensive information" (Goodson and Vassar, 2011).

A qualitative, multiple method approach over time added depth, along with the diversity in patients' experiences, enabling a nuanced examination of people's goals, dispositions, resources, and sense of agency. It is acknowledged that locating the narrative through interview data only was limited in accounting for the complexities of the 'collective view'. However, repeat interviews over time, alongside observations over the period of 6 years assisted getting a sense of how dispositions were shaped by socially situated histories, within a given environment and alongside accounts of future imaginations related to an individual's social positioning (Seale, 2004; Johnson *et al.*, 2017).

8.5 RECOMMENDATIONS

The findings of this thesis provide important insight into the experiences of people who have navigated the HNC care pathway and from this insight a series of recommendations can be made. The previous section has shown that the bigger picture understanding is crucial to next steps for developing supportive services and the care for this group of patients. The recommendations are first presented below together, but then broken down into practice and policy. The first three recommendations focus on elaborating/corroborating the key findings in more detail to further elucidate the optimal support required in practical terms for HNC. The final three recommendations centre around wider policy recommendations which frame the infrastructure that facilitate these practical recommendations.

1. **The use of dental extractions as part of pre-RT treatment should be reconsidered and a more conservative approach to the number of removes should be taken, with a strong emphasis on clearly articulating the consequences to patients.**

2. **More widely, during the full course of the HNC experience, approaches to information giving should be clearly outlined to staff. Staff should be supported in the form of training and education.**

3. **Intense support is required around rehabilitation to ensure that HNC patients can improve speech and eating function, which is integral to a successful recovery and wellbeing.**

4. **Community based teams offer great strengths and place-based models are able to provide personalised and patient centred care.**

5. **Realising national and regional ambitions needs further support to be embedded at local/place-based level.**

8.5.1 IMPLICATIONS FOR PRACTICE

First, this thesis considers areas that relate to direct issues of practice in the care of HNC patients, looking at dental extraction and information giving/joint decision making.

- **Experiences of dental extractions in early treatment**
- **Approaches to information giving should be clearly outlined to staff**
- **Intense support around rehabilitation focusing on speech and eating function**

8.5.1.1 Experiences of dental extractions in early treatment

This study captures the urgency and rapid nature of the process of diagnosis with dental extractions often happening within days of diagnosis. Understanding this and setting it out in a research study helps to provide the backdrop in which dental extractions take place and hence why such an approach is not processing by the patient. Many patients were told that dental extractions were recommended. Often there were multiple removals, as recommended by the national guidelines (The Royal College of Surgeons of England / The British Society for Disability and Oral Health, 2012).

This builds on the work of Clough *et al.,* (2018) who explored dental extractions. This specific element of HNC treatment was examined in an interview-based study with those that had undergone pre-RT dental extractions. The extractions take place to prevent complications after radiotherapy and are often a conservative, prophylactic treatment to prevent osteonecrosis. This thesis further supports the work of Clough *et al.,* (2018) and demonstrates that patients found dental extractions to be traumatic (Muglali and Komerik, 2008). As highlighted by Clough *et al.,* (2018), the NCPES (NHS England, 2014) had recorded that 28.0% of patients with HNC felt that during any decision making their views were not considered at all enough or they had not been listened to as much as they would have liked. This is a risk mitigation process and it is essential that patients realise both what is proposed and that they have the option to refuse if they wish.

8.5.1.2 Information giving and joint decision making

Clarity around information giving (Fallowfield, Ford and Lewis, 1995; Pavey, Allen-Collinson and Pavey, 2013; Aunan, Wallgren and Hansen, 2021) and a focus on joint decision-making (Katz, Belkora and Elwyn, 2014) in their cancer treatment, is a clear finding of this study and can make an immediate and direct impact on the satisfaction felt by a patient in their treatment journey. It is also a well explored area in improving other cancer experiences (Josfeld *et al.*, 2021). There is a lack of an evidence base to form guidance that supports shared decision-making, in HNC, which this thesis addresses.

Josfeld *et al.,* (2021) demonstrated that patient decision aids (PDAs) were preferred by sampled cohort of 220 patients and therefore guidance on this could be important to improving information giving. This study identified a number of key attributes around information giving through the thematic analysis of the patient narratives and there are specific nuances related to the dental context with this cohort of patients, building on the National Cancer Information Pathways resources.

8.5.1.3 Intense support around rehabilitation for speech and eating function

As discussed in the literature review there are examples of providing care for this cohort of patients that is nuanced. MDT community-based support provides care that is more intensive and closer to the individuals settings. However, a potential area for improvement could be to provide intensive residential care for these patients immediately after treatment to provide the therapy that is needed to restore as much function as possible in terms of eating and speaking (Kristensen *et al.*, 2019)

8.5.2 IMPLICATIONS FOR POLICY

This section explores how expectations of practice can be embedded in wider managerial, policy level standards. This section therefore outlines crucial approaches that, if embedded can help to shape, inform, and evolve elements of practice, as well as guide more standardised approaches to care across the wider national and regional NHS. The key implications for policy are:

- **Importance of place-based models that are personalised and patient centred**
- **Realising national and regional ambitions needs further support to be embedded**

8.5.2.1 Importance of place-based models that are personalised and patient centred

As discussed earlier is the CHANT approach is unique in the HNC cohort. Taking a community-based MDT approach is recommended at a national level but is not played out in practice. Therefore, further policy recommendations need to address the barriers to implementation and report back to Cancer Alliances on the successes of vanguards such as CHANT. This study and the small but growing body of other work looking at CHANT and this approach can be used as the evidence base for disseminating the approach and encouraging further adoption across the county. Therefore, a fundamental recommendation of this study is that the importance and value of this approach is clearly articulated to the systems that are either still considering or beginning to move to this model of care. What is still not clear is how to further support areas who are struggling to achieve this, and this is discussed as the next policy recommendation. This section has highlighted that the focus on the why and the evidence base is important, but the other elements are discussed next.

8.5.2.2 Realising national and regional ambitions needs further support

This study shows that there are real, tangible and profound differences in the experience of those undergoing HNC treatment and rehabilitation. They have specific traumas relating to dental extractions (Clough *et al.*, 2018; Parahoo *et al.*, 2019), the intensity of the radiotherapy (Epstein *et al.*, 2001; Zackrisson *et al.*, 2003; Lang *et al.*, 2013; Álvarez-Camacho *et al.*, 2017), treatment being focused on their face, mouth and neck, facial disfigurements, the impact on eating and the effect on communication and speaking (Stanton, 2006; Threader and McCormack, 2016). These are all specific to this type of cancer and this therefore demands a tailored/nuanced approach to designing the model of care. When the care is modelled using the governing principles of national ambitions for integrated care, supported by the expectations of regional Cancer Alliances, and using a community-based approach this best suits the needs of this cohort. However, it is important to use the documented patient experience of this thesis to encourage uptake more widely across the country and also to ensure that reflections are made on potential improvements. This study confirmed that the core elements can be realised and therefore has great potential for transferability in similar cohorts, and regional, local settings.

As discussed in section 8.2.1.2 maximising the reach of innovative models of care is fundamental to spreading successful interventional approaches, and therefore understanding what barriers might exist to prevent the CHANT approach from having wider adoption is helpful. Côté-Boileau (2019) explored a number of innovations in healthcare to understand this. This study developed a framework of practical and actionable elements for health systems to consider and could help inform how to spread the adoption of the CHANT based approach for HNC patients. These elements are listed below:

> **"(1) focus on the why**
> **(2) focus on perceived-value and feasibility**
> **(3) focus on what people do, rather than what they should be doing -**
> **(4) focus on creating a dialogue between policy and delivery, and**
> **(5) focus on inclusivity and capacity building**
> (Côté-Boileau *et al.*, 2019).

Therefore, this framework not only helps to understand why something may not uptake but also practically helps to understand how to spread and adopt exemplar work. It is important to consider that this framework is set in the context of how to encourage implementation. Another pivotal facet of this issue is around de-implementation and there is growing exploration of this phenomenon (Roland *et al.*, 2022). This seeks to focus on understanding what weds professionals to their current practices and enables them to remove existing entrenched approaches. De-implementation has been defined as *"the process of identifying and removing harmful, non-cost-effective, or ineffective practices based on tradition and without adequate scientific support"* (Upvall and Bourgault, 2018 p.376) . What this definition does not capture is that sometimes, local ways of working may be preferable by a given set of requirements but may not be by a more standardised wider scale, sustainability or integrated framework.

8.6 CONSIDERATIONS FOR FUTURE RESEARCH

As discussed in the document analysis the CHANT service themselves identified a need to pursue detailed research exploring the experience for patients to better understand the effectiveness of the service, and further explore if more home-based care could further personalised care ethos established through integrative, community-based, MDT approaches. (Tang *et al.*, 2016b)

This thesis has sought to address this call for further research, but it is important to think about what other research could further elucidate pivotal ideas for improving the services offered to patients and the experience of those experiencing HNC. Six key recommendations for further research have been identified below starting with elaborating on the above recommendation (Tang *et al.*, 2016a). The service has developed a local clinic model of delivery in each borough across South East London, in which all different specialties are able to work together in a multidisciplinary setting within one centre. Patients are now seen at home (accounting for approximately 30% of clinical activity) or in a local clinic (approximately 70% of clinical activity), based on the patient's individual clinical need, thus providing a more flexible, personalised, and cost-effective approach.

- **Partners' experience of rehabilitation** – This study uncovered the pertinence of networks and partners in the rehabilitation process. It is not clear about the national, regional, or local support that exists for these supporters of patients and whilst there is a wealth of research around carer roles, a specific study exploring HNC carers would help to evolve services in this area.
- **Other models of integrated care for cancer** - Future researchers might consider a broader range of different care pathways other than the UK model to understand the strength and weaknesses of different care pathways, e.g., other community-based services.
- **Further exploration specifically into health centre-based vs home-based care –** Wei Tang *et al.,* suggests that *"there are also differences in opinion as to whether services*

should be provided in nearby health centres or in patients' homes. Provision of care in homes allows staff to better understand and evaluate patients' needs in their local environment. These services could be preferential for older patients and those with complex issues relating to mobility or comorbidities." (Tang *et al.*, 2016a) However, these services are cost and resource intensive, may mean less access to appropriate diagnostic or treatment equipment and may mean more complicated safeguarding considerations.

- **Different models of multidisciplinary care -** In the research there were several suggestions made about aspects of the care pathway that could be changed. For example, a qualitative study to explore participants' perspectives of two different styles of the multidisciplinary clinic could be undertaken and understanding how different cohorts of patients may benefit from different approaches.
- **Understanding the health professionals' perspective -** It would be both interesting and potentially useful to conduct a further qualitative study with healthcare professionals working within this area to compliment the patient exploration and to follow up on the issues raised in this study about the pathway and experiences of it and identify any ways in which current practices could be changed to better meet the needs of patients.
- **Further research into differences in experiences of patients who take different HNC care pathways –** this will shed light on the effect of varying rehabilitation programmes on patient health and wellbeing.
- **Comparative study of other patient experiences across England -** A study further understanding the fragmentation that other HNC patients face across England due to a lack of integrated care could provide an important comparison to this work

Finally, there are a number of quantitative approached analysis that will provide further context and information that will be fundamental to assessing the effectiveness of this service, the impact in improving patient outcomes and its wider applicability. These are cited in Tang *et al.,* (2016) and include:

- **Patient outcomes –** Further understanding of the impact of the CHANT service through specifically defined patient outcomes, including quality of life and mortality.
- **Regular and robust auditing at a hospital level** – For example specifically exploring readmissions would be a useful tool to evaluate the impact of CHANT support on emergency hospital readmissions (Tang *et al.*, 2016a)
- **Robust data on cancer diagnosis and treatment experiences -** Data integration and quality is an important part of this and should be integral to all further evaluation.
- **Observation around the changes in age and male-to-female ratio -** Continuing to understand the changing and evolving demographics in the HNC population exploring the context e.g., HPV positive HNC.
- **Discharge patterns should be monitored,** and surveys given on the exiting of patients to enable consistent monitoring and evaluation, measuring satisfaction in the service and any issues, concerns or suggested amendments.
- Wei Tang *et al.* 2016 highlight a need for **"a standardised integrated method, and robust system, for data collection on the type and site of cancer that was treated would aid future service provision analysis"** (Tang *et al.*, 2016a). It is also important to classify according to recognised codes (outlined in the Introduction) in order to be able to create bespoke responses depending on the subgroup.

Many of these data driven studies will evolve with the progression of the NHS digital shifts and a move towards standardised electronic patient records as well as more interoperable systems and better data integrity across pathways and settings. However, alongside these quantitative studies, there will be a need for this work to be complemented by rich, granular multidimensional and contextual qualitative research that can study the phenomenon from different angles, building on the work of this thesis, to shape and transform services to suit the needs of the patients they serve.

8.7 CONCLUSION

This research sought to bring together the micro, meso and macro picture around HNC care experiences of people diagnosed with and treated for HNC within the wider context of their lives and/or care provision. The document analysis showed that it is clear that the ambitions and aspirations for personalised place-based integrated care has been set at both national and regional level. Moreover, it is deemed particularly appropriate at a disease level where this approach most suits patients whose treatment and rehabilitative journey is complex and comes with an array of intersectional elements. However, since these ambitions were set within the last decade, recommended models have not been realised at a local level for HNC, with CHANT being the unique singular example.

Having discussed reflexivity in the Methodology and Methods Chapter, at the end of the study it was important to circle back to this framing of the ideas, themes and findings. Using ethnography where the ongoing findings have informed the next phase of work lends itself to a continuous reflexive approach whereby as a researcher, I am required to examine my own role in the work and how my own beliefs, judgements and practices during the research process impact and how they may have influenced the research at every stage.

As discussed in the methodology and methods section, I am a researcher with a background in health policy development and without a clinical background the lens through which this research was conducted was partly informed by this outlook. This steered me in the direction of understanding the experiences of patients in the context of a micro, meso and macro view of the world. This informed my methodology of conducting a policy analysis, followed by understanding the stories as an observer viewing the system passively. Finally, exploring the journey directly from the patient's perspective and understanding their lived lives, hearing these stories within the context of my system level understanding and observed environmental viewing.

Taking an ethnographic approach to this study provides the opportunity to study a social phenomenon, in an open way, without preconceived hypotheses. The core aim of an ethnographic process is to understand cultural insights and illuminate the practices, behaviours and social interactions that take place in a given context. This methodology allows for the collection of data that is rich, holistic and immersive. It aims to capture the multifaceted voices and experiences of a group of people who do not have their journeys documented in this way. By being embedded in an environment, there is an opportunity to gather information and observe interactions that create a more authentic narrative and account.

As discussed in the summary of findings, this study is important because it provides a voice for a group of patients, which is not captured holistically in existing literature. This piece of research affects policy and the way we go forward with service design for this group of patients and others who may have parallels. This is important because it helps us understand the sheer mess, noise, urgency and confusion of the process on an individual and it helps us understand that we need to be looking at the biological, social and psychological when providing care for such complex, life threatening, profoundly physically, mentally and socially impacting disease.

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10. APPENDICES

Appendix one: Information sheet

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON

IRAS NO. 131589 NHS REC NO. 14/LO/0011

INFORMATION SHEET FOR PARTICIPANTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

The experiences of people with a diagnosis of oral cancer

We would like to invite you to participate in this King's College London, Dental Institute research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Aims of the research

In this study we would like to interview you in order to understand the experience of patients who have had treatment for oral cancer. Our aim is to understand how you adapt to life post treatment and after rehabilitation including adjusting to any physical changes, changes in mouth function and what you would like to see change in the care you received.

We will do this by conducting one-to-one interviews with you either at the clinic you visit, at your home or at a location preferred by you.

Who would we like to include?

We would like to include patients who have undergone treatment for oral cancer, including those who have undergone radiotherapy, surgery or both forms of treatment and are currently in the rehabilitation phase of treatment.

Any risks?

Any personal views disclosed will not be identified with you. We understand that discussing your treatment and rehabilitation may be difficult and upsetting and we would like to reassure you that you can stop the interview at any stage and decide not to answer any questions you are not comfortable answering. If you would like further support following the interview we will refer you to a suitable contact to discuss this further.

Possible benefits

Participation in this research may help us to understand better the patient experience and the outcomes of care important to oral cancer patients. The insights derived from this study may be used to inform future professional training and practice and the development of patient care pathways. We will send you a copy of the final report once the research is complete if you wish to see it.

Arrangements for ensuring anonymity and confidentiality and withdrawal from the study

Interviews will be recorded, after to your permission and recordings of interviews will be deleted upon transcription. To ensure compliance with the Data Protection Act you will be informed of what information will be held about you and who will have access to it. Under certain circumstances, required by law, confidentiality may be broken. All information will be stored in an anonomised way so that individual anonymity is maintained. We do not need to see your medical records. We may use some small quotes from your interview, but you will not be identified in any reports we write or in any presentations we make.

You may withdraw any data/information you have already provided up until it is transcribed for use in January 2016). A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

If you have any questions or require more information about this study, please contact the researcher using the following contact details:

- **Researcher details**
  Name: Anna Rajakumar

  Email: anna.rajakumar@kcl.ac.uk

  Address: Dental Institute (2nd Floor)
  King's College London
  Denmark Hill
  London,

  SE5 9RS

  Tel No: tbc (university contact details)

- **Supervisor details**
  If this study has harmed you in any way you can contact King's College London using the details below for further advice and information:

  Name: Dr Sasha Scambler

  Email: sasha.scambler@kcl.ac.uk

  Address: Dental Institute (2nd Floor)
  King's College London
  Denmark Hill
  London,

  SE5 9RS

  Tel No: 0203 299 4455

Appendix two: Consent form

IRAS NO. 131589 NHS REC NO. 14/LO/0011

CONSENT FORM

Title of Project: The experiences of people with a diagnosis of oral cancer

Name of Researcher: Anna Rajakumar

Chief Investigator: Dr Sasha Scambler

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 24th January 2014 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. Furthermore, I understand that I will be able to withdraw my data up until the point stated on the Information Sheet.	☐
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from King's College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐

4. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be treated in accordance with the terms of the Data Protection Act 1998. ☐

5. I agree to the use of anonymous quotations, taken from interviews to be used in the report of the study and in publications ☐

6. I agree to take part in the above study and consent to my interview being audio recorded ☐

7. The information you have submitted will be published as a report; please tick the box if you would like to receive a copy. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent.	Date	Signature

Appendix Three: Topic Guide

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON

TOPIC GUIDE (INDICATIVE)

THE EXPERIENCES OF PEOPLE WITH A DIAGNOSIS OF ORAL CANCER

STUDY INFORMATION

Interviewer: This study is seeking to further exploring the entire journey from diagnosis through to life after restorative surgery through these one on one in depth interviews. The study will aim to understand how patients adapt to life post treatment and after rehabilitation exploring how they adjust to physical changes and oral function. We would like to explore how you have experienced the whole process.

We hope that participation in this research may help contribute to the further knowledge of the patient experience and serve to inform future professional practice and the development of patient care pathways.

PRIOR TO INTERVIEW CONSENT FORM AND PARTICIPATION DETAILS

Confidentiality

Interviewer: The results of this research will be presented in a final report. Individual responses are obtained and recorded anonymously and kept in the strictest confidence. No identifiable information or responses will be presented in the final form of this study. All data will be stored in a secure location accessible only to the researcher. At the end of the study, all records will be shredded and electronic data wiped.

Participation & Withdrawal

Interviewer: Your participation is voluntary and you are free to choose not to participate. Any personal views disclosed will not be identified with you or your work place/company. If at any point in the interview you find any topic of discussion too distressing to talk about we can move onto for terminate the interview.

Consent

Interviewer: Before commencing the interview we will take consent (with further reference to the information sheet).

KEY AREA FOR QUESTIONS:

Interviewer: At this point we would like to reiterate that whilst we have some key areas identified as questions we very much want to hear your personal account and therefore we will not stick to this format should you wish to discuss an area that you feel is important.

EXPERIENCE AND UNDERSTANDING

1. *Before diagnosis what was your understanding of oral cancer?*
2. *Upon diagnosis what were your expectations and experiences?*
3. *Did you feel you understood the processes involved in treatment and rehabilitation?*
4. *Were you aware of the options available to you for treatment and rehabilitation?*
5. *Did you find that making decisions about your treatment were supported?*

IMPACT

6. *What are the short and long term impacts and consequences of receiving a diagnosis of oral cancer?*
7. *What is the impact of the oral cancer diagnosis on your daily life?*
8. *What is the impact of the treatment on your daily life?*
9. *How does the rehabilitation impact on daily life?*

IMPROVEMENT

10. *How do you feel that your treatment and rehabilitation experiences could be improved?*
11. *What barriers and facilitators do you feel occur, relating to your care pathway, for H&N cancer?*

CONCLUSION OF INTERVIEW

Interviewer: Is there anything else you would like to discuss?

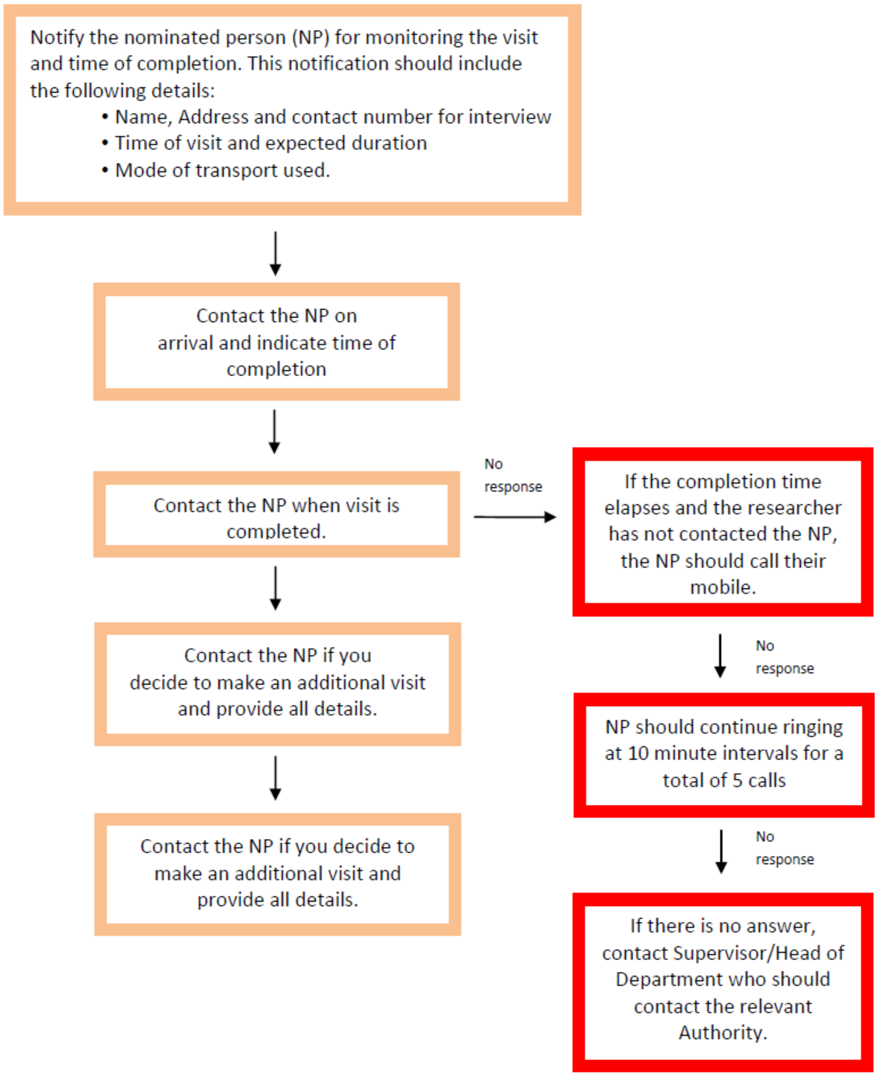
We will send you a copy of the final report once the research is complete if you wish to see it. Many thanks for your time.

Appendix Four: Risk flowchart

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON

Lone working – away from workplace Flowchart



Notify the nominated person (NP) for monitoring the visit and time of completion. This notification should include the following details:

- Name, Address and contact number for interview
- Time of visit and expected duration
- Mode of transport used.

Contact the NP on arrival and indicate time of completion

Contact the NP when visit is completed.

Contact the NP if you decide to make an additional visit and provide all details.

Contact the NP if you decide to make an additional visit and provide all details.

If the completion time elapses and the researcher has not contacted the NP, the NP should call their mobile.

NP should continue ringing at 10 minute intervals for a total of 5 calls

If there is no answer, contact Supervisor/Head of Department who should contact the relevant Authority.

Appendix Five: Protocol

PROTOCOL FORM

Title:	The experiences of people with a diagnosis of oral cancer
Author: (Please put in the order to appear on final papers etc.)	PhD Student: Anna Rajakumar Research Colloborators: Sasha Scambler*, Blanaid Daly* Mary Burke (MB), Mike Fenlon

Background and Rationale for Project

There were over 404,000 new cases of oral cancers worldwide in 2002 (Warnakulsuriya 2009). Oral cancers are the sixth most common cancer worldwide, accounting for 4 % of all cancers, though incidence and prevalence rates vary geographically. There is a higher incidence rate in men (attributed to greater exposure to risk factors) and amongst lower socio-economic groups (Warnakulsuriya 2009). The ratio of incidence rates between men and women has declined since the 1960s and is now at a rate of 2:1. The risk of developing oral cancer increases with age and in the UK the majority of cases (87%) occur in people aged 50 or over (Cancer Research UK 2011). Around one third (30%) of oral cancers are diagnosed in the mouth cavity and a similar proportion on the tongue. Cancers of the oropharynx, piriform sinus and hypopharynx together account for a further quarter (29%) of cases while lip, the least frequent type of oral cancer, accounts for 6%. More than 90% of oral malignancies are squamous cell carcinomas (Cancer Research UK 2011). Patients with oral cavity cancer generally present with early symptoms and early stage disease.

Approximately 570 new patients with Head &Neck (H&N) cancer (including cancer of the larynx) are seen each year at GSST. The cancer treatment, patient management and subsequent rehabilitation is planned with a multidisciplinary team (MDT) and organised around NICE 2004 guidelines. Between 170-180 of people require irradiation. Those with teeth are seen after their H&N cancer diagnosis by MB and Oral Surgery/Maxillo facial surgeons in multidisciplinary team (MDT) clinics. In these clinics decisions are made about the oral treatment needed prior to surgery and irradiation. As radiotherapy promotes cellular and vascular decrease resulting in a low response rate in healing, surgical procedures in irradiated tissues can present high rates of complication such as Osteoradionecrosis (ONJ).

The primary treatment (acute phase) involves surgery or radiotherapy or both. In contrast, oral pharyngeal cancers present at a later stage and primary treatment is likely to involve radiation or chemoradiation. The second phase involves rehabilitation following, what can be invasive acute treatment e.g. rehabilitation treatment may have involved the use of a palatal obturator or osteo-integrated implants.

While there is a wealth of literature exploring the perceived optimum clinical outcome for types of treatment (Yerit et al 2006), there is less known about the patient outcome (i.e. patient satisfaction and the impact on the quality of their lives) and longer term impact and consequences of living with a particular treatment pathway. It is important to note that these decisions are often decided upon in a relatively short (intensive and pressured) time frame. Patients are usually seen only a few days after receiving their cancer diagnosis and explanations about treatments have to be made quickly to avoid delay, with extractions often undertaken on the same day. The short timeframe means that patients have little time to reflect and think about the consequences and long term impact of treatment options on oral function as well as the changes to day to day living and the wider social impact.

Research problem: Currently little is known about the lived experience of people with a diagnosis of oral cancer; from the diagnosis process itself through the post treatment and rehabilitation phase to the longer term impacts of this process. Clinical literature suggests that more needs to be done to understand the long term needs of patients (Rogers et al 2010). The aim of this project is to understand and explore the experiences of people who have received a diagnosis and completed treatment for oral cancer and the long term consequences of this complex and invasive treatment pathway. An understanding of the patient's perspective (Edwards 1997) is essential for implementation of patient centred care and this work would therefore seek to inform and shape the design of future care pathways, acknowledging the nuanced, social implications of suffering from oral cancer, undergoing treatment and rehabilitation.

From a theoretical perspective we will explore the patient narrative using Bourdieu's theory of practice. To date, this framework has been underutilised in health research. Bourdieu's concepts hinges on the notion of habitus (the values and dispositions of an individual), capital (an individual's position in a particular sphere) and field (a structured social space). In this theory an action is produced as the outcome of a relationship between habitus, capital and field.

This will frame an exploration of the patient journey acknowledging power dynamics and social context. Through this theoretical lens we are able to engage with structures, agents and symbols of illness which may be part of the journey for those who have received a diagnosis of oral cancer. These complex and nuanced factors may be overlooked with a different approach. We will therefore use this theoretical positioning to guide a critical ethnomethodological approach drawing on both cancer literatures and wider work within the sociology of long term conditions to understand the lived experience of oral cancer.

On a practice and policy level the research would aim to identify barriers and facilitators to creating effective, patient sensitive, healthcare pathways and would provide a novel conceptualisation of the key actors and processes involved in this journey, through the use of qualitative methods.

Research Aims and Objectives

Aim:
The project will involve exploring the entire journey from diagnosis through to life after restorative surgery for oral cancer patients through qualitative methods. The study will aim to understand how patients adapt to life post treatment and after rehabilitation exploring how they adjust to their new looks and oral function. We will focus on cultural schemas, and attitudes about the mind and body.

Objectives:

1) What are people's understanding of oral cancer?
2) What are people's expectations, experiences and understanding of the treatment and rehabilitation options available to them once a diagnosis of oral cancer has been received?
3) What are the short and long term impacts and consequences of receiving a diagnosis of oral cancer?
4) What is the impact of oral cancer diagnosis, treatment and rehabilitation on daily life?
5) How do people who have received treatment and rehabilitation for oral cancer feel their experiences could be improved?
6) What barriers and facilitators occur, relating this to the care pathway, for H&N cancer?

Method

In this study it is proposed that a number of in-depth interviews with patients will be conducted in order to explore the expectations, experiences of those involved in the oral cancer treatment process.

An ethnomethodological (Garfinkel 1967) will be taken. In a health services research context this approach allows for the study of how healthcare is carried out on a daily basis and how many actors and their practice constitute the patient care pathway. This approach will provide a narrative representation of treatment and rehabilitation experiences that is currently lacking in the associated dental and health psychology literature.

Stage one would be an initial feasibility/explorative phase, involving the conduct of mini focused ethnographies, which would observe key clinical encounters but also observe the day-to-day clinical environment in which patients step into. This would aim to inform the topic guides for the next interview stage.

In the second, more detailed phase, face to face interviews will be conducted with a purposive sample of H&N patients attending for dental recall visits within the Dept of Sedation & Special Care Dentistry. All patients who have undergone treatment for oral cancer will be identified by the direct care team (MB). Patients attending for their dental recall visit i.e. three months after completion of radiotherapy will be invited to participate in the study. A maximum of 40 participants will be recruited (with a view to working to saturation point), all of which will have gone through the rehabilitation stage of treatment. We would like to focus the research on those who are further along in the rehabilitation journey, rather than those who are just starting out in treatment or follow up. They may be interviewed at varying stages in their rehabilitation journey in order to uncover more nuanced narratives of the lived experience and identify salient features relating to diagnosis and management and rehabilitation.

The study will explore the impact on the wider family and the outside world, health uncertainty, fear of reoccurrence (Rogers et al 2010), and biographical disruption. The impact on appearance, speech and information and decision making processes during treatment will also be explored. We will seek to explore some common themes that are associated with patient's lived experience of cancer drawing on Bourdieu's concepts allowing for both an enquiry into the effects of cultural capital on oral cancer patients' experiences of health systems and an exploration into participants' opinions and experiences and the power dynamics that are in play during treatment between different actors.

Data Analysis

All interviews will be recorded and transcribed verbatim. Data will be analysed using a thematic framework analysis developed through the literature and further through the analysis process. Analysis will take an ethnomethodological approach through a theoretical framework derived from the literature and influenced by the work of Bourdieu.

Ethics Permissions	NRES/IRAS system
Other Local Permissions required	R&D, other local approvals,

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Any suggested Reviewers	TBC