

Routes to and Experiences of a Diagnosis of Head and Neck Cancer

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Abstract

Head and neck cancer (HNC) is currently the 6th most diagnosed cancer worldwide and is a growing problem. Many HNC are diagnosed at a late stage and patients are generally diagnosed due to the presence of symptoms. However, symptoms can be vague and easily mistaken for benign conditions. There is little understanding of the HNC pathway and there are many different elements that can impact negatively in terms of experiences and outcomes. This thesis will explore the routes to diagnosis for HNC patients to understand what impacts experiences.

A multi-method approach was utilised. Study 1 is an analysis of routine data from Public Health England, in which all HNC patients diagnosed between 2006-2014 (68,752 patients) had been assigned a "route to diagnosis". Studies 2-5 involve qualitative interviews with HNC patients (n=19), General Practitioners (n=8), Dentists (n=12), and HNC surgeons (n=8), which are analysed using thematic analysis.

Analysis of the routine data highlights the inequalities within the route to diagnosis, in particular the socio-demographic differences of those presenting through each route. The qualitative interviews highlight a lack of knowledge around symptoms, difficulty in understanding and accessing healthcare services, non-explicit communication around potential cancer diagnoses and fragmented communication within primary care and between primary and secondary care.

This thesis provides new insights into the routes to diagnosis of HNC, giving a deeper understanding of the experience of progressing towards diagnosis. Placing the work within the context of the Model of Total Patient Delay, adaptations to the model (e.g., consideration of health literacy) are suggested to enable future studies to better understand patient delays. Suggestions are made on elements of the findings which could be incorporated into clinical practice.

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I believe, that in the same way it takes a village to raise a child, it also takes a village to raise a PhD student. My village has been, and still is, very important to me.

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Dedication

For Mum...

Mary Cornall

1957-2021

"Tá sí mar chuid de na scéalta a inseoidh mé go deo."

"She is part of the stories I will tell forever"

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Chapter 1: Introduction

The Problem

Despite significant effort in last 10-20 years, UK cancer outcomes are far poorer than in some European and other high human development countries. This is despite having universal healthcare free at the point of access, dedicated pathways and targets for early diagnosis and treatment.

Head and neck cancer (HNC) is the name for the group of cancers arising in the oral cavity, pharynx, and larynx. It is currently the 6th most commonly diagnosed cancer worldwide and is a growing problem with numbers of cancers diagnosed increasing over time. Incidence rates have increased overall by around 34%, with female rates rising by almost 45% and male rates by around 22% (Cancer Research UK, 2022).

In contrast to other cancers, improvements in survival for HNC over the past two decades have been modest and most of the advances in treatment have focused on early-stage disease.

How and when HNC patients present with symptoms affects the length of the diagnostic pathway and timing of investigations. A delay in diagnosis may impact upon disease staging and subsequent treatment. At least half of all HNCs are diagnosed at a late stage, which is associated with poorer survival and reduced quality of life outcomes.

Improved understanding of the HNC diagnostic pathway, and patient experiences of this, would be valuable to inform the development of strategies to promote earlier presentation and diagnosis. This is the focus of this thesis.

This chapter introduces the thesis. It will give background on what HNCs are and data around known risk factors and epidemiology. It will then look at the current route to diagnosis in the UK, considering the role and history of the “Two Week Wait” urgent cancer referral pathway, “standard” GP referrals and diagnosis after emergency admissions. Next it will consider the roles and responsibilities of the health care professionals involved in the route to diagnosis; General Practitioners (GPs), Dentists (General Dental Practitioners, Community Dentists and Hospital Dentists), and Head and Neck Surgeons. There will then be a review of current understanding of the routes to diagnosis, considering what is currently understood, models of patient delay and the role of communication in delay and being given a cancer diagnosis. Finally, the thesis aims and objectives will be discussed.

1.1 Head and Neck Cancer

1.1.1 Definition

HNC is an umbrella term for malignant tumours arising in the mouth (oral cavity), throat (oropharynx and hypopharynx), voice box (larynx), nose (paranasal sinuses, nasal cavity, and nasopharynx) and the salivary glands (as seen in image 1). They are predominantly (over 90%) squamous cell carcinomas (SCC), which means they develop within the cells which line the mucosal surfaces. (DAHNO, 2011). Cancers of the thyroid are sometimes included in the definition of HNCs, however for this piece of work the definition excluding these cancers will be used. This is due to them having a different profile and distinctly different diagnostic pathway and treatment.

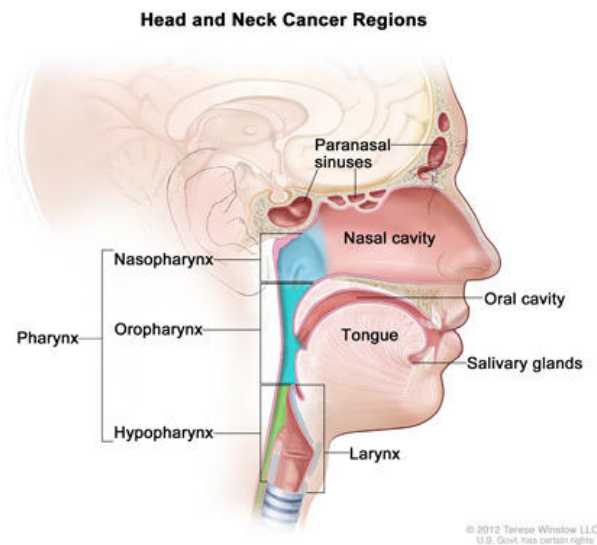


Figure 1: Head and Neck Cancer Regions (Winslow, 2012)

1.1.2 Descriptive Epidemiology

HNC is the sixth most common cancer worldwide (Ferlay et al, 2019) and the eighth most common in the UK, accounting for 3% of all new cases (Cancer Research UK, 2022). Currently, there are on average 12,422 (2016-2018) new cases of HNC each year in the UK (Cancer Research UK, 2022). The overall incidence is continuing to rise with a predicted 30% increase, worldwide, annually by 2030 (Sung et al, 2021; Johnson et al, 2020).

This disease is more frequently diagnosed in males, with men accounting for 69% of cases. When split by sex, in the UK, HNC becomes the 4th most common cancer in men and the 13th most common in women. (Cancer Research UK, 2022). There are two main aetiologies of HNC with some related to the human papilloma virus (HPV) and others not (see section 1.1.3). The median age of diagnosis for non-HPV related cancer is 66 years and for HPV related cancer is 53 years (Windon et al, 2018).

Since the 1990's incidence rates have increased overall by around 34%, with female rates rising by almost 45% and male rates by around 22% (Cancer Research UK, 2022). Most tumours occur within the oral cavity (gum, palate, tonsil, tongue, floor of mouth, oral cavity) and account for around 58% of all HNCs. The larynx accounts for over 18% and the oropharynx (hypopharynx, nasopharynx, and oropharynx) accounts for just under 8% (Cancer Research UK, 2023). However, it is predicted that over the

next 20 years the majority of HNCs will be HPV positive and, as a consequence, in the UK oropharyngeal cancer incidence may overtake oral cavity cancers (Conway, Purkayastha and Chestnutt, 2018).

In the UK approximately 4100 people die every year (2017-2019) from a HNC, accounting for 2% of all cancer deaths. It is the 17th most common cause of cancer death for females and the 10th for males (Cancer Research UK, 2023). Survival rates in HNC have shown modest improvements over time; survival rates increased from 55% during 1992-1999 to 66% in the period 2002-2006 (Johnson et al, 2021). Three-year survival rates vary by tumour sub-group, ranging from 75.2% in the salivary glands to only 33.6% in the hypopharynx (National Cancer Intelligence Network, 2011).

1.1.3 Risk Factors

The main risk factors for cancers of the head and neck are alcohol, tobacco, smokeless tobacco, exposure to environmental pollutants, infection (Human Papillomavirus (HPV) and Epstein – Barr virus (EBV)) and, particularly in Asian-pacific populations, chewing of areca nut/betel quid products (Johnson, 2021).

People who smoke are almost 10 times more likely than those who have never smoked to develop a HNC (Jethwa & Khariwala, 2017). Pooled data from European and American studies showed that there is a population attributable risk of 72%, which included 33% for smoking, 4% for alcohol and 35% for alcohol and tobacco together (Hashibe et al, 2009; Dal Maso et al, 2016).

The HPV16 and HPV18 strains of the virus have been linked with oropharyngeal (Torrente et al, 2011; Mehanna et al, 2013; Rietbergen et al, 2013) and oral cavity cancer (Warnakulasuriya, 2009), and account for more than 50% of all cases of oropharyngeal cancer (Lewis, 2015), although it is worth noting that routine testing for HPV is only a recent change to diagnostic procedures. The main route of HPV transmission is believed to be through sexual contact. Those who have had six or more sexual partners, four or more oral sex partners or those who were younger when they first had sexual intercourse are considered higher risk for an HPV-related cancer (Heck et al, 2010; D'Souza et al, 2016; D'Souza et al 2009; Chaturvedi et al,

2015). Those with a HPV positive HNC tend, more often, to be white, male, young (under 50 years), married, educated, and employed when compared to HPV negative patients (Dodd, 2016).

Areca nut products are several different mixtures which contain areca along with betel leaf, slaked lime, spices and/or tobacco, and are generally chewed as a stimulant. Use of these products is linked to high rates of oral cavity cancer, particularly in India, Taiwan, and China. In India oral cavity cancer is the most common cancer in men and 4th most common cancer in women (Johnson et al, 2021).

HNC is associated with lower socio-economic status, (Cancer Research UK, 2022) with age-standardised incidence rates around 2-4 times higher in those with lower levels of socio-economic status compared with those in higher groups. Sex can also be considered a risk factor as HNC are more than twice as common among men than women (Siegel et al, 2021).

1.1.4 Presentation, Diagnosis and Treatment

Unlike some other cancers, there is no test suitable for screening for HNC. Therefore, patients are generally diagnosed due to presence of symptoms. The symptoms of HNCs are quite vague and can easily be mistaken for benign conditions. The main symptoms include an un-healing mouth ulcer, a red or white patch inside the mouth, a neck lump, sore tongue, throat pain, persistent hoarseness, or difficulty swallowing. Due to the vagueness and location of these symptoms' patients could present at their GP or their dentist. Oral symptoms could be picked up at routine dental check-ups.

After consultation, patients with "red-flag" symptoms are normally referred onto specialist care. NICE guidelines (NICE, 2021) state that patients should be referred on the suspected cancer pathway (often known as "Two Week Wait" urgent cancer referral pathway¹) for specialist input with regards a potential laryngeal cancer if

¹ In section 1.2.2 I will discuss the Two Week Wait Pathway within the wider process of cancer diagnosis in England.

they are over 45 years and have persistent and unexplained hoarseness or an unexplained neck lump. For a potential oral cancer, patients should be referred if they have had an unexplained ulcer for longer than 3 weeks, a persistent and unexplained neck lump, or a lump on the lip or in the oral cavity, or a red or red and white patch consistent with erythroplakia or erythroleukoplakia. In the case of the dentist assessing these symptoms, then a direct referral into the suspected cancer pathway is recommended. These guidelines change over time and the last significant change was in 2015.

Once referred into secondary care patients will be seen by a member of the specialist team: they will triage them and conduct an initial clinical examination. If further investigations are required these will be arranged, including scans. A biopsy may also be required, and this may need to be conducted via surgical means; the sample will be sent to pathology to confirm the cancer diagnosis. If cancer is confirmed, then the biopsy will be staged, and this will determine the treatment recommendation. Staging considers the tumour size, spread and growth rate. Patients are given a numbered TNM stage from 0 to 4; the TNM staging system considers the size of the tumour (T), whether the cancer has spread to the lymph nodes (N), and whether the cancer has spread to other, distant parts of the body (M). Stage 0 is when there are abnormal cells, but they are contained and have not spread, and this is not technically considered an invasive cancer. Stage 1 and 2 cancers are considered early stage but are usually small and have not spread. Stage 3 and 4 cancers are larger cancers that have spread into nearby lymph nodes, surrounding tissue or both. Occasionally there has been spread to other parts of the body (e.g.: liver or lungs) which becomes metastatic/secondary cancer, but in HNCs it is more common for the spread to only be in the area where the tumour started, with potentially spread to the lymph nodes (Macmillan, 2023). A treatment plan will then be discussed with the patient and their carer/family, involving members of the multi-disciplinary HNC team.

Curative treatment for HNCs can include surgery, chemotherapy, radiotherapy and, in recent years, targeted therapies and immunotherapy (NICE, 2021). Or in the case of a non-curative diagnosis or when treatment has failed, patients are provided with best supportive care or palliative treatment.

In many cases a combination of different treatments is required, although in early-stage disease, single modality treatment (surgery or radiotherapy generally) may be sufficient. HPV-positive cancers (at least those in the oropharynx) generally have a better prognosis and may not need such extensive or aggressive treatment as HPV-negative tumours (Economopoulou, Kotsantis and Psyri, 2020).

1.2 The Current Route to Cancer Diagnosis in the UK

For a few cancers, there are organised screening programmes, but these only diagnose a minority of patients. The majority of the remainder of cancer patients are diagnosed through presentation with symptoms and onward referral (usually from the GP) to secondary care. There are two pathways for such referral – standard and urgent. A proportion of patients present directly to secondary care as emergencies.

This section will describe the different routes that patients most commonly use to enter the healthcare system, the Urgent Cancer Pathway, Standard GP, and Emergency routes. It will also describe the history behind the Urgent Cancer Pathway and its introduction.

1.2.1 History of the Urgent Cancer Referral Pathway

The urgent cancer pathway was introduced by the Department of Health in 2000 as part of The Cancer Plan (Department for Health, 2000) to address the UK's comparatively poor survival outcomes and variation in care quality and treatment across the country (Sant et al, 2009). It was intended to provide reassurance to patients that their symptoms were being investigated quickly and to provide a framework for primary care for their referral decisions. This was the first time the UK government had produced a strategy considering prevention, diagnosis, treatment, care, and research for improving cancer outcomes.

1.2.2 Urgent Cancer Pathway “2 Week Wait”

The urgent cancer pathway, also known as the 2 week wait (TWW)², requires that all patients presenting in primary care with symptoms which could be indicative of cancer are referred and seen by an appropriate specialist within two weeks. The cancer waiting times report for 2020-21 reported that 94.8% of suspected head and neck cancer patients are seen within the 2-week target (Coward, Moon, & McDonnell, 2021). TWW referrals are usually completed on pro-forma which is produced at Trust level.

The National Institute for Health and Care Excellence, NICE, have created a set of signs and symptoms criteria for each suspected cancer, NG12 (NICE, 2022). Patients who fulfil these criteria are eligible for this urgent referral pathway. Decisions regarding which symptoms should be included in this list are based on positive predictive value (PPV). The PPV for cancer symptoms is 3%; this means that the proportion of people investigated for the symptom or sign listed who turn out to have cancer should be at least 3%. This guideline development is an iterative process based on the best available evidence. However, much of the research this is based on is retrospective studies of cancer patients. There is little prospective (or contemporary) evidence on the symptoms patients present to a GP with (Mulka, 2005).

A lack of clarity over signs and symptoms within HNC has led to some Cancer Alliances adding additional requirements to the NG12 criteria. Within the HNC guidance, of the 18 Cancer Alliances in England, only 5 use the NG12 criteria alone; within the remaining alliances there have been an additional 15 signs and symptoms added, with each Alliance selecting to add between one and 10 of these to the NG12 criteria (Bradley, 2021).

² Targets for the pathway changed in Oct 2023, however, these changes won't be discussed further in this thesis as the work undertaken was conducted when the TWW target was in place. It is worth noting that whilst this pathway has changed this most likely has not impacted how clinicians work on a daily basis.

There has been controversy over the effectiveness of the TWW pathway; although limited, there have been audits conducted on HNC referrals which have shown that most cancers are diagnosed outside of this route. One study reported 71% of HNC were diagnosed outside of the TWW route (Lyons et al, 2004). In addition, those cancers that are diagnosed through the TWW are often diagnosed at a late stage (Rovia et al, 2023) meaning there is no improvement in survival associated with TWW referral and diagnosis. A systematic review of all cancers referred through the TWW highlighted a limited number of papers focussing on HNCs but concluded from those papers that the TWW pathway might actually *increase* time to diagnosis for these patients (Hanna, Muneer & Khalil, 2005). Across all cancers there is a wide variation in the proportion of referrals with an eventual cancer diagnosis with the highest rates in leukaemia (61% of those referred subsequently diagnosed with cancer) and some of the lowest rates in laryngeal, where only 7.8% of those referred are diagnosed with cancer. When these referrals were assessed for compliance against guidelines, the highest level of compliance (94%) was within laryngeal cancer, compared to the lowest compliance level (75%) seen in suspected leukaemia (Baughan, Keatings, & Neill, 2011). This would suggest that there is something more difficult for GPs to assess in suspected HNCs; for example, GP may be more willing to refer outside guidelines for leukaemia and are picking up more cancers, but this is not happening in potential HNCs.

In the first few years following the introduction of the TWW pathway, there were concerns around an increase in inappropriate referrals due in part to a strict adherence to the referral guidelines (Hanna, Muneer & Khalil, 2005), with some suggestions that these may result in a high level of patient pressure on GPs to refer urgently despite there not being a need. It was suggested that clinical judgement may be overridden to comply with the TWW guidelines, and that guidelines are less discerning than clinical judgement and therefore the need to use such guidelines means that GP skills would be undermined (Hanna, Muneer & Khalil, 2005). Removing the need for the clinician's clinical judgement could also mean that the referrals become more of a box-ticking exercise, potentially reducing the quality of the referrals. However, TWW referral forms should be used as an adjunct to clinical suspicion rather than as the only decision-making aid (Kumar et al, 2012). The low

positive predictive value of TWW referrals (6.3%-14.6%) indicates that most referrals are either made inappropriately or the criteria listed has low specificity (Kumar et al, 2012). A more general paper on TWW suggests that in primary care the predictive value of symptoms suggestive of cancer are poorly defined. The authors reported that patients can meet the criteria for a referral, but it still be considered an “inappropriate” referral by the consultant whilst the opposite is also true with some people not meeting the criteria but there being a high suspicion of cancer (Jones et al, 2001).

With finite resources and a time restriction on TWW referrals (i.e. patients referred on this pathway must be offered an appointment within two weeks), there may be impact on the experiences of patients who follow the standard referral pathway (see 1.2.4). It is often the case that the TWW standard is being met at the expense of a significant increase in waiting time for standard referrals (Jones et al, 2001). This is especially important when we consider the large numbers who are ultimately diagnosed with cancer after being referred through the standard referral rather than the TWW pathway (Lyons et al, 2004; Kumar et al, 2012).

1.2.3 Standard GP referral

A standard GP referral to secondary care is used when it is felt that further investigation is required but the criteria for a TWW referral is not met. The current government guidelines are that these referrals should take place within 18 weeks of the hospital receiving the request (National Health Service, 2022). However, in reality the waiting time is often much longer, depending on the demands on that service; for example, in 2022 average waiting times for ENT referrals ranged from around 18 weeks to over 56 weeks (National Health Service, 2022).

1.2.4 Emergency Presentation

An emergency presentation of cancer is defined as a patient being diagnosed after attending an Accident and Emergency department (this may have been after consulting a primary care clinician, referral from another hospital ward, contact with the 111 triage service, or self-presentation). Unlike other cancer areas, where the percentage of cases diagnosed as an emergency is high (for example, 50% of all

pancreatic, 39% of lung and 26% of colorectal cancers) (Ellis-Brookes et al, 2012), emergency presentation for HNCs is considered to be relatively rare (Bannister, Vallamkondu, & Ah-See, 2016).

The most common reason for an emergency presentation in HNC is an obstruction of the airway resulting in dysphagia and/or stridor (Bannister, Vallamkondu, & Ah-See, 2016). For cancers in general, the majority of those who present as an emergency have late-stage disease and are less likely to survive their cancer (McPhail et al., 2013).

1.3 Clinicians Roles and Responsibilities in the UK

In this section I will cover the roles of the healthcare professionals whom a patient with a HNC may meet during their route to diagnosis from assessing symptoms and referring into secondary care (GPs, General Dental Practitioners, and Community Dentists) to those within secondary care who a patient may meet during investigative tests (hospital dentists and head and neck surgeons).

1.3.1 General Practitioners (GPs)

GPs are the first point of contact for individuals accessing healthcare in the UK. They are trained in general medicine and are responsible for “cradle to grave” healthcare. They assess, diagnose, treat, and manage illness, as well as referring on to other services when appropriate. They are also involved in health and wellbeing promotion and work with other services such as social care. GPs play an important role within cancer care and are crucial to the early diagnosis of cancer. They are involved in cancer screening programmes (e.g., provision of HPV tests for cervical screening), as well as the promotion of healthy behaviours to reduce cancer risk. They also are responsible for referring patients with suspected cancer to the appropriate services. They have a significant role to play in HNCs with regards to promotion of healthy behaviours (reducing smoking, drinking, betel nut chewing, and HPV vaccine uptake) and the identification and onward referral to secondary care. Their role with regards to oral cancers has changed in recent years with the difficulties many patients now have in accessing NHS dental care (Healthwatch, 2022).

1.3.2 Dentists

Dentists work within different areas in primary and secondary care and play a role within the diagnosis of those with HNC and in preparation for treatment.

General Dental Practitioners (GDPs)

GDPs work within primary care, providing dental care to the public. They are usually based in a “high street” practice and provide a wide range of services from check-ups to fillings and extractions. GDPs can work as an NHS provider, in only private practice or both. They tend to be viewed in the same way as a General Practitioner (GP) providing dental treatment and services for all ages. The role of a GDP in the HNC diagnostic pathway covers several areas.

1. **Primary Prevention** – through lifestyle advice and behaviour change: for example, encouraging a reduction in alcohol intake, smoking cessation, and improving dietary intake.
2. **Secondary Prevention** – catching cancers early through the early detection of malignant and potentially malignant lesions through soft tissue checks (mucosa, tongue, floor of mouth, edentulous areas, salivary glands, pharynx, and neck) during check-ups (College of General Dentistry, n.d).
3. **Tertiary Prevention** – Working with patients with a HNC diagnosis to keep them dentally fit during and after their treatment and to “screen” for any cancer recurrences (British Dental Association, 2000).

If a patient has symptoms that require further investigation, then the GDP can refer patients into secondary care using a standard referral or the urgent cancer referral (“Two Week Wait”; see section 1.2.2). What proportion of HNC nationally are diagnosed following a referral from a GDP is not well documented (see section 1.4).

Community Dentists

Community dentists are a specialist service who work in a similar role to GDPs although patients are normally referred to this service if the GDP does not suit their needs. This service is made available in several different venues (such as health centres, mobile clinics and hospitals) with the aim of increasing accessibility. Community dentists are normally accessed by people with complex needs such as

learning and physical disabilities, mental health problems or dental anxiety. They also care for people with medical conditions who may require additional dental care.

The role for community dentists in the pathway to a diagnosis of a HNC is similar to the GDP, through primary and secondary prevention. Some community dentists are involved in making a patient dentally fit before treatment is started if the patient would prefer being seen in the community or if the hospital does not provide this service. They also will continue working with HNC patients following treatment if they would prefer to be seen in the community or if they are unable to find a GDP to register with.

Hospital Dentists

Hospital Dentists are specialised dentists based within a hospital and patients are normally referred into this service, although some hospitals also run an emergency dental clinic where patients can turn up on the day; these are often run by dental students overseen by a clinical tutor. Hospital dentists normally see patients who have been referred for advice or treatment by a GDP or GP, and/or who have medical conditions that means hospital treatment is preferred. They will also see hospital in-patients who require dental treatment as part of their general treatment or for pain relief. It is usual for the HNC Multi-disciplinary team (MDT) to have a hospital dentist involved and all patients will see a hospital dentist as part of their preparation for treatment.

Hospital Dentists can be involved in all aspects of the HNC patient pathway from primary prevention through to tertiary prevention. They may speak to patients about risk factors if appropriate and may spot signs of potentially malignant lesions whilst seeing the patient for other reasons and refer into the appropriate service. They will also be involved in the dental management of a patient prior to treatment by making sure a patient is dentally fit before treatment starts. Hospital dentists will also see these patients post treatment for restorative work and during this time they may spot potential recurrences of disease.

1.3.3 Head and Neck Surgeons

Patients with a potential cancer of the head and neck area may be seen by a Head and Neck specialist, ENT specialist or an Oral and Maxillofacial surgeon. When a patient is referred into secondary care for a suspected cancer, a surgeon will generally take responsibility for the patient from this point, arranging tests and investigations as appropriate. If no cancer is found, they are either discharged from their care or given an onward referral is necessary. As with many cancer sites, the surgeons work as part of a larger multi-disciplinary team and treatment decisions are made within an MDT meeting, which is standard practice now within the NHS and complies with HNC guidelines (NICE, 2004).

1.4 Current understanding of routes to diagnosis undertaken by HNC patients.

Current knowledge on the routes patients take to a HNC diagnosis is limited. The National Cancer Registration Dataset (NCRD) collects data on all patients in England newly diagnosed with cancer (Henson et al, 2020). Around a decade ago, colleagues working with the NCRD investigated the feasibility of using this data (alongside linked hospital episode statistics (HES), cancer waiting times data, and cancer screening programmes data) to define the routes to diagnosis of cancer patients nationally. They also considered whether these varied by factors such as age, sex, ethnicity, deprivation and geographical area of residence (National Cancer Intelligence Network, 2015). Using the combined data they categorized each individual into one of eight potential routes to diagnosis; GP Referral, Two Week Wait, Emergency Presentation, Other Outpatient, Screen Detected, Inpatient Elective, Diagnosis by death certificate or unknown (Ellis-Brookes, 2012; National Cancer Intelligence Network, 2015).

Their analysis of cancers diagnosed in 2006-2008 showed that patients who are diagnosed with a HNC are more often diagnosed through GP referral (42% of larynx and 40% nasopharynx cancers compared with 27% for all cancers combined) and they were less likely to present through the emergency route (7% for oropharynx compared with 23% overall). There hasn't been any further analysis on the head and neck cancers; data for more recent years is lacking as is any information on how presentation through different routes may vary by patient characteristics. For example, such a fuller exploration of variations in cancer route to diagnosis has been conducted for sarcoma patients (Gerrand et al, 2015). In that analysis,

patients were more likely to be diagnosed through GP referral or emergency presentation than through the TWW referral system and those under 10 and over 80 years of age were most at risk of emergency presentations. Those arriving through the emergency route had lower 1 year survival and more metastases. There was also an impact of deprivation with those from the more deprived quintiles being more likely to present through emergency routes. This research shows the importance of conducting cancer site-specific analyses of RTD; the authors were able to identify patients and tumours with particular routes and outcomes enabling a starting point on which to improve the route for those most likely to be adversely affected. Similar analyses may be of value in HNC. Moreover, further investigation of the “other outpatient” route could also be illuminating as it includes self-referrals as well as referrals from Dentists and other outpatient providers.

The 2010 National Cancer Patient Experience Survey in England (CPES) (Lyratzopoulos et al, 2012) with 41,299 respondents, found large variation in the number of visits made to a GP for cancer symptoms before a referral for cancer investigations was made. Those with rarer cancers (which included laryngeal cancer) were likely to visit three or more times before a referral was made. The number of pre-referral visits was used as a surrogate of diagnostic quality. The study had limitations, such as lacking the information on the time period these appointments covered and the knowledge of whether these appointments were repeated because the cancer was not recognised and symptoms persisted, or due to the patient returning for clinically appropriate investigations. However, these limitations alone would be unlikely to account for the large effects noted. When considering the results for laryngeal³ cancer patients only, a clear pattern emerged on the effect of age. Younger patients were more likely to have a higher number of pre-referral visits. It is important to note the implications of age here in relation to the rise in HPV-related HNCs, particularly given its impact on a younger demographic; the data raise the possibility that individuals diagnosed with HPV-positive cancers may experience delays in both diagnosis and subsequent treatment, potentially influencing their post-treatment outcomes. Certain ethnic minorities are more at risk of HNC; for example, there is a link between mouth cancer and the chewing of betel quid, which is common in those from the Indian sub-continent (Chen et al, 2017). The analysis of the CPES also suggested that ethnic minorities are at increased risk of more

³This piece of work only analysed laryngeal cancer, no other HNCs were included.

pre-referral appointments across a range of cancers, including larynx. Being able to recognise the increased risk of HNCs for certain populations is important in general practice to reduce delay and improve patient care.

These two studies (NCRD analysis, CPES analysis) allow an insight into the route patients are (or were, in the first decade of this millennium) taking to a HNC diagnosis. Whilst this data is quantitative, so depth and detail are lacking, it gives a good starting point for understanding the current diagnostic routes. Further investigation using qualitative methods may allow for a deeper understanding of how patients are accessing, using, and experiencing these routes to diagnosis.

1.4.1 Delays in Cancer Diagnosis

The diagnostic process for any condition starts when a patient experiences something that they perceive as needing further investigation; they then engage with the healthcare system, which could involve information gathering, integration and interpretation (a working diagnosis); finally, they receive a communication of the diagnosis (Balogh, 2015). This process is often interrupted with delays at various time points which may impact on the outcomes for the patient. An investigation of the diagnostic route should consider all these time points, as well as what happens to trigger the start of the process, where patients and healthcare professionals experience problems, and what helps the flow through to diagnosis.

The most widely cited theoretical framework for patient delay was initially proposed in 1979 (Safer et al, 1979) as a three stage model which accounted for the total time from a patient noticing symptoms to seeking treatment. The three stages were: Appraisal delay (Am I ill?), Illness Delay (Do I need to see a healthcare professional?) and Utilization Delay (Is it worth the costs?). During each stage an individual must make a decision that could either delay or hasten the potential diagnosis. This model was extended by Anderson et al (1995), who added Behavioural Delay (what actions do I need to take to deal with what I am experiencing?), Scheduling Delay (when is there and can I fit in an appointment?) and Treatment Delay (how long will I wait for treatment?). Each of these delays are what occurs between decisions. Behavioural delay occurs between the decisions to seek medical attention and to act on that

decision. Scheduling delay is the delay that occurs between deciding to make an appointment and making the appointment and treatment delays is the time between the decision to treat and when treatment is started.

A 2012 systematic review (which included two studies with laryngeal, and oral and pharyngeal cancers and one study which included HNCs alongside others) found evidence to support the majority of the models stages in cancer (Walter et al, 2012). There was limited evidence for behavioural delay, conflicting evidence for scheduling delay and illness delay was difficult to distinguish from appraisal delay (though the authors judged that there was considerable evidence for appraisal delay despite this), and strong evidence for treatment delay. Overall, the review commented on the difficulty in interpreting published findings due to the lack of theory, different definitions of delay and different methods of data collection, making direct comparisons between studies problematic. The resulting model is shown in figure 2. It is worth noting that the model recognises that a range of patient, healthcare system/provider and disease factors may also contribute to delays.

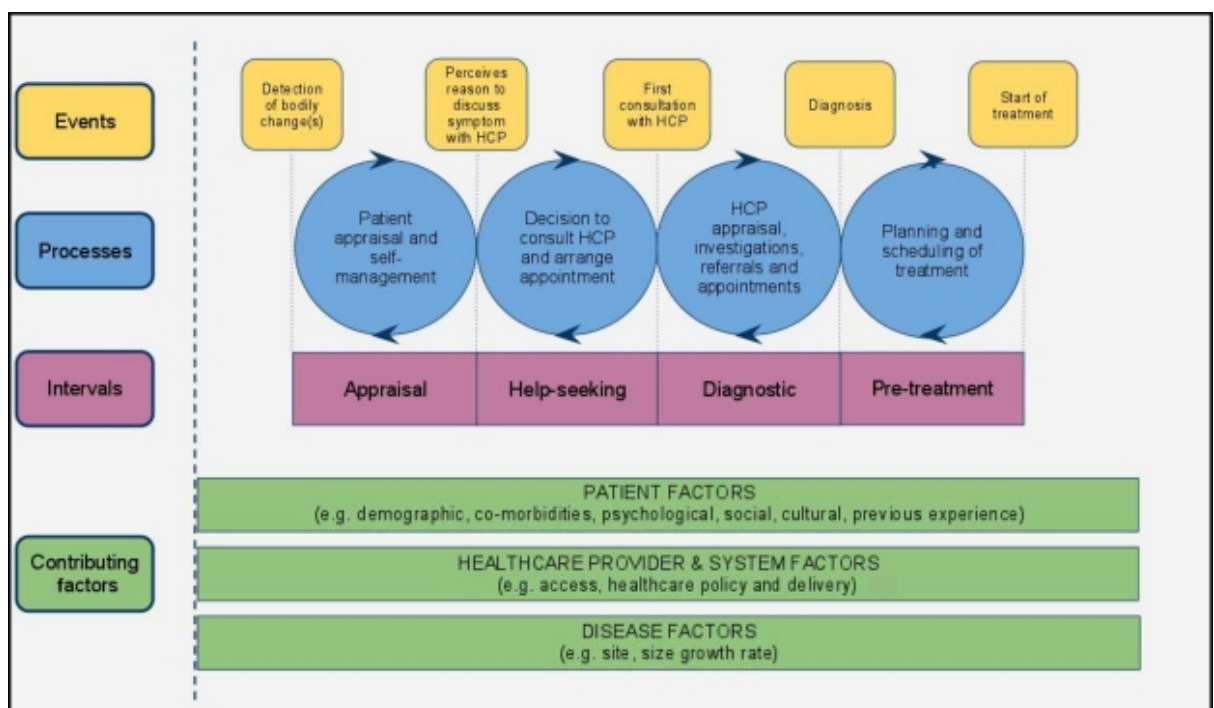


Figure 2: Model of pathways to treatment (Walters et al, 2012)

1.4.2 Patient Delay

A worldwide systematic review, published 2009, of quantitative and qualitative studies on delay and common cancers found that appraisal delay (i.e. the lack of interpretation of symptoms as serious by patients) was the main patient factor associated with delay (Macleod et al, 2009). This review excluded HNCs although it did note that the more vague or atypical a symptom is, the higher the risk of delay – “vague” symptoms are a common issue for HNC. The presence of a lump in the breast or more alarming symptoms such as pain in gastrointestinal and gynaecological cancers, and bleeding in upper gastrointestinal cancers, reduced the risk of delay. These authors also noted how time to referral for colorectal cancer was increased for those patients who saw their GP more frequently. It was also interesting that the risk factors for delay drawn out of the review were not universal across all cancers investigated. The main risk factors associated with delay in some, but not all cancers, were older age, male sex, lower socioeconomic status (SES) and lower education level. Non-white ethnicity was related to both increased delay and reduced delay depending on the cancer type. The findings suggest that investigation of delay by cancer type is important as certain risk factors may be more important in different cancers or may have the opposite effect of reducing delay.

A qualitative systematic review on cancer delay, published in 2005, revealed that factors contributing to delay include symptom recognition, interpretation, fear (e.g.: being seen as a time waster, of the cancer itself), and gender (men viewed it as easier for women to seek help, women reported competing priorities as a reason for delay) (Smith, Pope, and Botha, 2005), aligning with Macleod et al., 2009. Additionally, sanctioning (support from family or friends in recognizing the need for help-seeking) emerged as a key factor in reducing delay (Smith, Pope, and Botha, 2005.) While not specified to cancer type, these findings are consistently supported across the literature (Tromp et al., 2005; Grant et al., 2010)

In terms of HNC, evidence on patient delays in diagnosis is limited. One of the significant risk factors for developing a HNC is alcohol, and this also appears to be a risk factor in prolonged delay (Hollows, McAndrew and Perini, 2000; Pitiphat et al., 2002; Brouha et al., 2011). It is also known from previous research in other cancers

that older age and lower SES are risk factors for delay - both are also risk factors for developing HNC. HPV negative cancers have a worse prognosis than HPV positive cancers (Ang et al, 2010); these cancers are more commonly diagnosed in those who are older and live in a more deprived area (a marker of lower SES) (Dahlstrom et al 2015) This suggests that it may be more important to be able to reduce delay among this cohort and acknowledging that they may be more at risk of delay is important for implementing change.

The data on the impact of delay on disease progression in HNC presents contradictory findings. Some studies suggest a link between delay and increased tumour size (Kowalski and Carvalho, 2001; Jensen et al, 2007), while others show no correlation (Wildt, Bundgaard and Bentzen, 1995; Allison, Locker and Feine, 1998). A UK cohort study found 50% of patients delayed seeking help (median delay of three months), with no indication of advanced disease in both 1960s and 1990s cohorts (McGurk et al., 2005). The authors attributed the consistent delay to the disease's "silent" early stages, but this definition remains unclear. They argued against using this finding to reduce patient education, given potential poor public knowledge of HNCs and their symptoms, especially around HPV link (Milbury et al., 2013; Luryi et al., 2014; Dodd et al., 2016). Questionnaire studies (Amir et al., 1999) found delay was not associated with tumour size but stressed the importance of health promotion on early symptoms. Further research suggests a complex relationship between diagnostic delay and disease stage (Scott, Grunfeld and McGurk, 2005), with some experiencing delay yet remaining in early stages, while others without delay being diagnosed with advanced cancer. Besides disease progression, evidence indicates perceived delay impacts patient well-being (Miles et al, 2016), although in this case this is a perceived by practitioners and/or the healthcare system rather than a patient delay.

1.4.3 Practitioner Delay

Alongside patient delays there may also be delays at the healthcare professional/healthcare system level. The literature in this area is often limited to descriptions of delay happening, or being possible, at this stage (diagnostic interval, and listed as contributing factors in Walters et al, 2012 model; section 1.4.1).

Suggested reasons for this are practitioner lack of knowledge of cancer symptoms, particularly around rarer cancers with vague or less specific symptoms. HNCs are rare in primary care; a Finnish study found that a primary care physician (PCP) would encounter on average only two patients with HNC during their entire career (Alho et al, 2006). However, 11% of the patients they see during their clinics were experiencing the same symptoms as patients ultimately diagnosed with HNCs. As cancer is such a rare explanation for symptoms seen reasonably frequently, it may not be the PCP's initial thought (Alho et al., 2006). A study with colorectal cancer patients also reported a delay when the symptoms were not recognised as serious by the healthcare professional (HCP) (Siminoff, Rogers and Harris-Haywood, 2015). Interestingly, analysis of the National Survey of NHS Patients: Cancer data (Allgar and Neal, 2005) found that patients who visited their GP were more likely to experience delays than those who did not. This finding was unexpected but the authors suggested it may be explained by the fact that patients are more likely to present at the GP with earlier stage, and less symptomatic, disease whereas those who did not go to the GP were most likely those presenting as an emergency in secondary care with a more advanced disease; secondary care "entry" with symptoms usually means faster diagnostic testing, reducing diagnosis delay compared to primary care entry.

Other studies which undertook closer examination of the professional aspect of the pathway underscored the challenges in diagnosing early-stage disease or smaller tumours (Wildt, Bundgaard and Bentzen, 1995; Allison, Locker and Feine, 1998; Brouha et al., 2007). Larger tumours and those in the oral cavity, which are visually easier to detect, tended to be diagnosed earlier.

1.4.4 Communication

This section will discuss the role that communication; both between a patient and healthcare professional and between professionals, has in the route to and experience of a diagnosis of HNC, and how previous research has discussed the role of communication within cancer.

The ability to communicate well within a consultation around cancer is important for both the HCP and the patient. Communication is a vital process used to gather

information which can then be interpreted to make a diagnosis (Kreps and Massimilla, 2002; Arora, 2003). Therefore, it is important to consider how communication can impact on the route a patient takes to diagnosis.

Much of the research in relation to cancer (in general, rather than in relation to HNC) focuses on general communication skills within primary care and the imparting of a diagnosis and treatment decisions. Many studies promote the value of good communication, e.g. the use of open-ended questions, verbal encouragement, allowing the patient to speak and reducing interruptions, showing warmth and empathy, and providing patient education (Cegala & Lenzmeier, 2002; Beck, Daughtridge and Sloane, 2002; Rocque & Leanza, 2015). This type of good communication may improve relationships, patient satisfaction, and autonomy. Poor communication can lower quality of care, and result in the under or overuse of resources and dissatisfaction and non-adherence to treatment and drug regimens.

In HNC specifically, several studies have highlighted how communication impacts early diagnosis. For example, GPs' making urgent referrals often communicate the referral in practical terms but often don't provide any supportive or explanatory information meaning patients may not fully understand that cancer is suspected (Russell et al. 2025). When considering the communication between professionals' poor communication between dentists, GPs' and specialists was identified as a key barrier to timely diagnosis with patients reporting confusion and anxiety over referral pathways (Birkeland et al, 2024).

When considering the broader cancer literature there is evidence that communication issues during early consultations (vague reassurance, limited discussion on symptom seriousness, or no safety netting advice) can delay referrals (Lyrtzopoulos et al, 2015). This is also seen during analysis of the English National Cancer Patient Experience Survey where it was shown that many patients had multiple GP consultations before onward referral, highlighting the importance of communication around symptoms and escalation in the route to diagnosis (Lyrtzopoulos et al, 2012).

One important area is the impact of gender on communication during primary care interactions. There is some evidence that females present with more symptoms and give a more detailed response to questions around their medical history which may provide the HCP with more information to make a potential diagnosis in a timely fashion (Elderkin-Thompson and Waitzkin, 1999).

This evidence highlights that communication has a role to play and can shape a patient's route to diagnosis.

1.4.5 The Experience of a Cancer Diagnosis

The evidence on the patient experience of being diagnosed with a HNC is largely limited to the grey literature published by charities (see, for example, <https://theswallows.org.uk/support/resources/patient-stories/>). In terms of published studies, these generally cover all types of cancer.

Two English Cancer Patient Experience surveys linked patients' reported care experiences with the number of pre-referral GP appointments patients attended. The greater the number of appointments, the worse the reported care experience (Mendonca et al., 2016). This study included laryngeal patients but they only accounted for 0.7% (521) of the participants; however, they reported worse care experiences than those patients with other cancers (Lyratzopoulos, 2012).

Further survey data analysis conducted in Canada (Coronado et al., 2017) found that although 92% of respondents (with mixed cancers) felt they were informed of their cancer diagnosis in a sensitive way, 56% felt they had emotional concerns following from the diagnosis for which they were not appropriately referred on. When considering their treatment, 18% felt they were not able to discuss their treatment plan with the clinician.

Emotional concerns that are not dealt with early on can intensify over the course of treatment and potentially have lasting negative effects for the patient and their families.

A US qualitative study (Schaepe, 2011) explored patient and caregiver perspectives on cancer diagnosis, focusing on pre-diagnosis interactions. Patients often recounted detailed pre-diagnosis interactions, while descriptions of the actual diagnosis were brief. This study highlighted that the type of news received was less important to the patient than the way the news was communicated. When the way it was reported was seen as poor the patient felt alienated from the medical team; this then influenced how the individuals coped with their diagnosis. This research shows the importance of considering the multiple interactions a patient may have leading to their diagnosis not just the point of diagnosis. This is supported by further work on melanoma (Schofield, 2003) who found sub-optimal communication had long lasting effects on the patient.

1.5 Conclusion

Gaining a diagnosis of cancer in general, and HNC in particular, can be a complicated and difficult journey. There are many different elements of the journey that can impact negatively both in terms of experiences and outcomes. It is important to obtain a full picture from those who have been through the pathway to diagnosis (and the health professionals involved) to understand what is happening and where the barriers are. It is also important to understand what improves the experience and enables earlier diagnosis with the least negative impact on the patient as possible and, ultimately, provides the greatest chance of survival. HNC patients have been underrepresented in research to date, therefore it is important to conduct research with this population to understand what their specific experiences of a diagnosis are and the impact of these experiences. This is the focus of this thesis.

1.6 Thesis Aims and Objectives

In this thesis I aim to examine the pathways patients take to a diagnosis of HNC and their experience of their diagnosis. My objectives are:

Objective 1: To examine national routine data to understand the pathways (“route to diagnosis”) HNC patients follow to their diagnosis with a HNC and how these vary across different patient subgroups (e.g., cancer site, age, sex).

Objective 2: To understand how HNC patients experienced symptoms, navigated the healthcare system, and received a diagnosis, and to elicit patients views on this experience.

Objective 3: To understand the experiences of HCPs working within primary care and secondary care when dealing with patients who may potentially have a HNC and to elicit their views of the current diagnostic pathway, and how this can be improved.

It was decided not to include as systematic review as part of the thesis as this was an exploratory topic area, so it was unclear how to focus a systematic review.

The remainder of this thesis is organised as follows. Chapter 2 includes a description of the methodology and methods. Chapter 3 is the routine data results and chapters 4-7 are the qualitative results (Patients, GPs, Dentists and HNC Surgeons). Chapter 8 is the discussion and Chapter 9 considers the implications and conclusions of this piece of work.

Chapter 2: Methodology and Methods

The aim of this chapter is to describe the methodology and methods of this study in detail. This chapter contains, firstly a description of the type of research conducted, along with a discussion on the approach. There is a description of the public patient involvement (PPI) and how the research questions were designed following this. This is followed by a description of the two methodological approaches used:

1. Registry Data Analysis
 - a. Description of population
 - b. Method of data collation
 - c. Explanation of the approaches to statistical analysis
2. Qualitative Data Analysis
 - a. Description of population
 - b. Recruitment strategies for each population
 - c. Data collection methods
 - d. Analysis methods

2.1 Introduction

Health services research has many different working definitions, but ultimately is centred on identifying a problem, conducting a study with appropriate design and implementing the findings accordingly. Its focus is on population health and is the study of healthcare quality, access and costs to contribute to making health services more effective, equitable or efficient (Phillips, 2006). This project aims to understand how patients with a diagnosis of a HNC access health services and their associated experiences. It also aims to understand the perspective of those working within this system. Therefore, this study is best considered as an example of health services research. The aim is for the project to produce evidence or highlight potential areas of improvement which could be used to improve services for those seeking help for potential HNC symptoms and as they move along the route to diagnosis.

I decided that this work would require more than one method to answer my research questions. Analysis of routinely collected health service data with epidemiological methods would allow me to understand the topic from a population level while an in-depth analysis using qualitative methods would allow me to obtain the rich in-depth data required to fully

explore the experiences of both patients and clinicians who have experienced or worked within the route to a diagnosis of HNC. Mixed method research allows multiple methods, integrating findings at the analysis and discussion stage, and I initially considered this to be the best option. However on further investigation and reflection I felt that there were difficulties with data integration, a vital part of this methodological approach (Creswell, 2003). Routine data is limited in what is collected and restricted in what can be made available to researchers and this can make the integration with other data difficult. For example, you could not examine an individual's route to diagnosis then contact that individual to unpick this further. Whilst I felt that the qualitative data might be able to illustrate certain parts of the routine data and the routine data would be potentially able to inform the recruitment of the qualitative part of the study, I did not feel that there would be enough integration for it to be a mixed methods study.

A multi-method approach recognises that health services research is complex and using one method alone may not provide a full understanding of the area of interest. This approach also accepts that there is equal value in both quantitative and qualitative research methods, both contributing to an understanding of a health services research problem (Hunter, 2015). Consequently, this study uses a multi-method approach whereby both qualitative and quantitative (epidemiological) methods were used.

2.2 Philosophical Stance

I believe that all methods of data collection have a place in research and that the combination of more than one method can further enhance the data produced and the ability to interpret and understand findings. Qualitative data is important to represent the patients' voice in the research and because the richness of data cannot be provided through quantitative methods. The epidemiological data is important to be able to place the research in the context of the wider population and to be able to understand the research questions from a population level.

One consideration when using two methods is the potential for a clash of philosophies. With qualitative research it is usual for a researcher to make their philosophical position clear, whereas with quantitative research this is not standard practice. As I have used both methods, I have had to consider if my stance as a qualitative researcher clashes with the

assumed stance of a quantitative researcher. I consider myself to take a pragmatic approach, so my interest is in the outcome of the research with the importance being placed on the research question (Tashakkori, 1998), therefore I picked the best method to answer the research question. The pragmatic approach is often associated with a multi-method approach (Teddlie, 2009) due to this flexibility. It allows the researcher to embrace the two extremes of research; the postpositive, deductive approach linked to quantitative data and the constructivist, inductive approach normally associated with qualitative methods (Feilzer, 2010). This approach believes that everybody has different experiences but that there is also a shared social experience leading to shared social beliefs. It also considers that there is a set of shared beliefs among the research community around the topic area, around the importance of the topic being studied, and the most appropriate methods for investigating the research question (Kaushik and Walsh, 2019).

In planning the study, I explored the beliefs and priorities of research active clinicians and researchers in the field about important questions and appropriate methods. I also consulted with patients (see section 2.3.1). This confirmed that there were shared beliefs around the importance of this topic area.

The decisions about study design and methodological approaches were also influenced by my personal history and belief system. I have worked in several non-clinical healthcare roles for over 15 years. Over this time, I developed an interest in how individuals interact with the medical system and healthcare services. This led me to studying Health Psychology at Master level and, subsequently, to a first research role within cancer survivorship and designing an intervention to improve outcomes. This work included patients who were living with and beyond a diagnosis of HNC. I decided that this was an area I wanted to investigate further and applied for a PhD position at Newcastle University. I am a strong proponent of patient involvement in research which is why, as I will detail in section 2.3.1, my research question was directly informed by conversations with cancer patients and more specifically with patients living with and beyond a diagnosis of a HNC.

2.3 Background to the study set-up

This study was undertaken as part of an internally funded PhD, provided by the Institute of Health and Society (now known as Population Health Sciences Institute) within the Faculty of

Medicine, to Professor Linda Sharp. The precise topic of the PhD – other than it had to be in applied cancer research - was not defined at the outset. As the topic evolved, the supervisory team was extended to ensure that it contained both topic expertise and appropriate methodological expertise. The final supervisory team consisted of Prof Linda Sharp, Professor of Cancer Epidemiology, and who has particular interest and expertise in research using routine health service data and Prof Joanne Patterson, Professor of Speech and Language Therapy, a clinical academic specialising in HNC and qualitative methods.

2.3.1 Public Patient Involvement

Public Patient Involvement (PPI) has been integral throughout this study to ensure quality and relevance. In the initial stages of developing my research question, I visited HNC units in Newcastle and Sunderland and consulted with patients as I wanted the research to be designed with the patients rather than for them. I presented some potential ideas at a HNC support group, which had been considered after initial background reading, particularly in the areas of survivorship, where my initial investigation had started. The following discussion showed a frustration and insistence that there was a lack of focus on how they had been diagnosed. Many reported difficult and complicated routes and whilst they recognised that there was also work to be done on the survivorship stage, this initial route to diagnosis was considerably difficult for some members. They felt that it wasn't being investigated and that they were not being listened to when raising these concerns. The stories they shared on their experiences were incredibly powerful and they recognised that there had been a significant impact on their lives which may have been down to this journey. There was also a discussion on the experience of being told they had cancer. Many spoke about a lack of understanding around the diagnosis and of confusion, at the point of diagnosis. They spoke about how they often were alone and that this was a very confusing point for them. It was felt that this was a topic area which was worth further exploration, and review of the literature confirmed that there was very little on this topic within HNC research. Following this, I organised a formal PPI group meeting, to collaborate on the proposed design and processes. I invited people living with and beyond cancer, regardless of cancer type, for a broad perspective. Six people attended the meeting, (two people who were living with and beyond HNC). We discussed the interview studies and the analysis of the routine data, and drafts of

paperwork associated with the study (patient information sheets, interview schedule, debrief form) were shown to the members for feedback. During this meeting there was a consensus that the project was going in the right direction. When discussed whether the point of diagnosis was an area worth investigation there was a similar response to the initial meeting with many recounting similar feelings of confusion at this point. I also followed up on a discussion which had been started during the initial meeting with the support group around the experience of being diagnosed with cancer. One point which was raised by the PPI group was that they felt carers had a role to play and should also be interviewed as they may have a perspective on the route participants took to a diagnosis. This was discussed in some depth during the meeting, and it was agreed that they would provide another perspective on the route. However, within the scope of this PhD it was felt that adding on carers would potentially be too much. It was agreed that this was an area that could be considered after this research was completed. Following this meeting I was contacted by one of the members who was living with and beyond a HNC as she felt that it was important her views were heard separately. This was mainly as she felt that the experience of those with HNC was significantly different to those living with and beyond other cancers and wanted to make it clear how important it was to recognise the difficulty of symptom recognition within this cancer group.

Alongside this formal PPI group consultation, I also spoke about the research idea at three patient conferences (Newcastle, Sunderland and Blackpool) and asked for further feedback from the attendees. I felt this was important to seek further views of those who had lived experience of a HNC diagnosis, rather than from another group of those with mixed cancer diagnoses. This was after the conversation with one of the members of the PPI group, as there was a feeling that those with HNC had very different experiences than those with other types of cancer. When I discussed this topic, this often caused people to tell me their "diagnosis story". This confirmed that there was a need to find a space for patients to discuss their route to diagnosis and the importance of this element of their cancer journey.

2.4 Methods of data collection

As noted above, the pragmatic philosophical approach is about recognising where there is a problem and then picking the most appropriate method to address it. The problem of navigating the route to diagnosis and receiving the diagnosis was highlighted through PPI and then I broke it down into the elements that I felt could be investigated. Due to previous experience of qualitative research, I knew that it could be a very useful tool and was something I felt comfortable using. I also felt that the topic, in particular investigating the experiences of the route and diagnosis, was suited to a qualitative investigation. However, I also wanted to incorporate a quantitative element to enable me to gain valuable experience with this type of data and because I felt the whole project would benefit from more than one type of method. My supervisor (Prof Linda Sharp) highlighted a dataset that Public Health England had developed which tracked the routes patients took to their cancer diagnoses. When we investigated current work using this dataset, nothing had been conducted on routes to diagnosis and HNCs specifically with only a small mention in one paper which didn't include HNC in the reporting (Elliss-Brookes, 2012). Initial discussions with Public Health England confirmed that there was data available for HNCs and that it covered more years than originally documented. This was felt to be ideal to investigate the routes taken at a population level. The initial plan was to conduct a mixed methods study, however as described later the types of data I collected were not suitable for a mixed methods study, so it was changed to a multi-method study.

In terms of the qualitative element of the PhD, I wanted to a) fully understand people's experiences of these routes and ultimately receiving a cancer diagnosis and b) the perceptions of clinicians involved in these routes. Therefore, I selected semi-structured interviews as the best method. Interviews allow an in-depth discussion with flexibility to change question wording and order and to explore related topics generated by the participant (Robson, 2002). I considered focus groups as an option, however wanted to investigate the individual experience rather than the collective. It is also worth noting that a diagnosis of cancer can be a traumatic experience and being asked to recall that experience could potentially bring up powerful or upsetting memories, whilst this can be managed in a one-to-one interview in a group this may make the participant less likely to share. Group dynamics can have a significant impact of the data generated, and whilst I would have sought a homogeneous sample there was a strong potential for there to be significant power

imbalances which may have silenced some members. Communication difficulties are a common side effect of the treatment for HNC, and this again may make groups more difficult. Meeting one-to-one would allow me to plan for any potential difficulties and would hopefully provide a more comfortable experience for the participant(s). I was unsure how successful recruitment would be for this group, and attempting to co-ordinate a group may have meant that I lost potential participants due to difficulties with recruitment and access for the participants with regards potentially travelling long distances to take part⁴.

I discounted focus groups for healthcare professionals due to a) practical difficulties (co-ordinating a suitable time and place), and b) participants would be known to each other, perhaps restricting topics they would be comfortable exploring. Therefore, one-to-one semi structured interviews were deemed the most suitable approach based on the research question and practical issues.

I then considered whether to offer telephone or only face-to-face interviews. An important aspect of interviewing is the ability to build rapport with the participant so that they feel comfortable talking about sensitive topics. Often visual cues are an important element of rapport building and understanding what is being said and telephone interviews remove this element. There is limited research to suggest that one method is better than another (Novick, 2008) however it should be noted that phones are increasingly part of everyday life and therefore not something that is seen as unusual by participants. Some participants may prefer the apparent anonymity of a telephone interview and be more comfortable speaking on the phone than they would be in person. (Novick, 2008). Offering interviews on the telephone also removes the pressure of the individual having a stranger in their home or having to travel to attend somewhere locally. However as mentioned previously there are often communication difficulties associated with HNCs, and this can make telephones difficult for some individuals. Therefore, I decided that as there was little evidence to support one method of interviewing over another that I would offer interviews as either face-to-face or by telephone to all participants and allow them to select the option they felt most comfortable with.

⁴ Please note this work was undertaken pre-COVID where it was more usual to conduct focus groups in person.

2.5 Study Populations and Recruitment

The recruitment sites for the qualitative aspect were selected to enable access to patients from as many different backgrounds and potential routes as possible. Newcastle Upon Tyne Hospitals NHS Trust was the main site and sponsor of the study and covered a range of urban areas, and areas of high and low deprivation. The head and neck team also took responsibility for patients within Cumbria which covers a large mainly rural area and has areas of deprivation. City Hospitals Sunderland Trust was selected due to its high levels of social deprivation and Leeds Teaching Hospital NHS Foundation Trust was selected as it covered a range of urban and rural sites and had a mixture of very wealthy areas along with the more deprived areas. I was able to access these sites through contacts my supervisors had; one of my supervisors, Prof Jo Patterson, worked clinically within Sunderland at the time of data collection.

NHS Ethics was sought for the routine data analysis and qualitative interviews through the Integrated Research Application System and the Health Research Authority. Although the routine data I received would be pseudonymised it was a requirement of the PHE Office of Data Release (ODR; to whom applications for data access had to be made at the time) that NHS ethical approval is obtained for the study protocol.

Approvals were received for both applications.

1. Qualitative Interviews (207201), North East – Tyne and Wear South Research Ethics Committee (appendix A)
2. Analysis of Routine Data (206040), Yorkshire & The Humber - South Yorkshire Research Ethics Committee (appendix B)

There were requested amendments to both applications which I have listed below along with my response to the request.

Qualitative Interviews

1. The Committee requested that appropriate professionals were informed about potential referrals for participants who may be distressed or needed support following participation in the study. I felt that although there was the potential that someone may need further support as recalling a cancer diagnosis could be distressing, I did not think it was appropriate to inform professionals (in most cases this would be the patient's GP) in advance. Participants in the study may have had difficulties with their GP or may not want any of the medical

professionals they are involved with knowing they were taking part in this study. I had already compiled a document with a list of appropriate support services and their contact details to give to every participant who took part and agreed that if a patient became distressed, I would ask if they would like me to contact their GP or, if they were still under hospital care, their clinical nurse specialist for further support. This was approved by the Committee.

2. There was a request that the patient information sheet was updated with more clarity on the reasons for the study and that sensitive topics would be discussed. This was added and approved by the Committee.
3. Finally, they required clarity on whether data would be moved between the NHS and the University, and whether Trust employees would be involved as investigators. I confirmed that there would be no confidential data removed from the Trust to the university and that only Prof Jo Patterson (who was employed by Sunderland NHS Trust at the time) was an investigator but would not have access to any patient identifiable data.

Analysis of Routine Data.

1. There was only one request and that was for the study details to be published on the university website. This was agreed and the details were added.

For the qualitative interviews each Trust (Newcastle Upon Tyne Hospitals NHS Trust, City Hospitals Sunderland Trust, and Leeds Teaching Hospital NHS Foundation Trust) involved in recruitment was assigned as a Patient Identifier Site (PIC) in the IRAS application and Research and Development approvals were also sought.

The entire study was sponsored by Newcastle University. To fulfil the information governance requirements of ODR, the routine dataset was registered on the Newcastle University Information Governance Toolkit. It was stored on a secure section of the University network, had to be analysed only via specific computers (and could not be copied onto portable devices, including laptops), and access was restricted to named individuals.

2.6 Routine Data

The “core” dataset for this element of the study was the English National Cancer Registration Database (NCRD), which was held by PHE. The NCRD is a population-based cancer registry – that is, it seeks to systematically identify and record information on all newly diagnosed tumours in people resident in England. These records include personal data on the patient (name, age, address, and gender), the type of cancer (location, staging details etc.) and clinical details (e.g., date of diagnosis, hospitals of diagnosis and treatment, cancer-directed treatment(s) received). This data is compiled from numerous sources involved in the care and treatment of the patient (GP Practices, Hospitals, Screening services etc.) (Public Health England., 2019).

The Routes to Diagnosis data set was created by the National Cancer Registration and Analysis Service (NCRAS), the cancer team within PHE, using records from the Cancer Analysis System (CAS)(an series of databases including the National Cancer Registry Database (NCRD) and other relevant health service data sources) and applying an algorithm which then classifies the “Route to Diagnosis” for each registered cancer on the NCRD, using the various sources of available data. NCRAS defined a route to diagnosis as “a sequence of interactions between the patient and the healthcare system which lead to a diagnosis of cancer” (National Cancer Intelligence Network, 2015 page 24). The datasets that were used included the following.

1. The Hospital Episode Statistics (HES)
 - a. The Admitted Patient Care HES for 2003/2004 and 2013/2014
 - b. Outpatient HES for outpatient appointments for the same dates.
2. National Cancer Waiting Time (NCWT)
3. Three screening programmes data was also included; Breast, Cervical and Colorectal (However as this recorded cancer diagnosis discovered through a national screening programme this was not relevant for HNC cases).

The algorithm assigned each tumour a three-part code, broken down as; route endpoint, pathway group and route start-point. The route end-point was the inpatient or outpatient event closest to the date of diagnosis (Inpatient, Outpatient, Special cases; where the cancer diagnosis is the same day as the inpatient or outpatient date, Unknown and Death Certificate only). The Pathway Group codes were assigned based on the HES data, so reflect

the type of admissions they had in the time before the diagnosis. These were coded A-E. Finally, the route start-point was assigned, this was the last part of the three-point code as the start-point is assigned after working backwards from the endpoint. These were split into routes starting from an outpatient attendance (OP) or an inpatient attendance (IP). This resulted in 70 different routes, and these were further aggregated into eight broader defined categories.

Standard GP Referral: Any referral from a GP which was not sent under a two week wait referral.

Two Week Wait: Urgent referrals where there is a suspicion of cancer.

Emergency Presentation: Emergency route via Accident and Emergency, Emergency GP referral, emergency transfer emergency admission or attendance.

Other Outpatient: Those which have started as an outpatient referral that is either a self-referral, consultant to consultant referral, other or unknown referral.

Screen Detected: Those which were detected through the cervical or breast screening programmes.

Inpatient Elective: Those where no earlier information can be found prior to admission.

Death Certificate Only: Cancer diagnosis by death certificate only.

Unknown: No data is available from any registry.

The full process, described in detail, can be found in the Routes to Diagnosis Technical Document (National Cancer Intelligence Network, 2015) (Elliss-Brookes, 2012). This dataset summarises a patient's path through the healthcare system during the months preceding their diagnosis (Elliss-Brookes, 2012). As I only required data on HNCs I applied to the ODR for a section of this dataset. I requested pseudonymised data on all malignant HNCs diagnosed 2006-2014 (ICD-10 Codes grouped as follows; hypopharynx (C12, C13), larynx (C32), nasopharynx (C11), oral cavity (C02-C04, C06), oropharynx (C01, C09, C10), palate (C05), salivary glands (C07, C08), other sites (C05, C07, C08, C11, C12, C13), and non-specific sites (C14, C31). 2014 was the most recent year for which the RTD data was available at the time of the data request. The data was requested at the tumour-level i.e., in the format of one record per cancer.

For those cancers with an eligible ICD-10 code (oral cavity (C02-C06; includes palate), oropharynx (C01, C09, C10), larynx (C32) and other HNC (nasopharynx C11; hypopharynx C12, C13; salivary glands C07, C08; other sites C05, C07-C08, C11-C13; and non-specific sites C14, C31) I requested variables related to the demographics of the patient:

1. Age at diagnosis (available in 5-year groups to reduce possibility of data being identifiable)
2. Sex
3. Ethnic Group (This was a free text category).
4. Deprivation which was an area-based measure of the income domain of the Index of Multiple Deprivation (IMD) (Dept for Communities and Local Government, 2015). Quintile 1 includes the least deprived and quintile 5 the most deprived residents; these refer to quintiles of the general population. Deprivation was used as a SES proxy measure.
5. Urban/rural category of area of residence at time of diagnosis (categorised according to RUC2011, which had 4 rural categories and 6 urban categories (Office of National Statistics, 2016).
6. Co-morbidities. A weighted comorbidity score based on the Charlson Comorbidity Index (Charlson, 1987) reported the number of relevant in-patient hospital admission comorbidities recorded in the period 3 – 27 months before diagnosis. Comorbidities were classified as none, 1 and 2+, with the index cancer disregarded.

I also requested variables related to the cancer diagnosis.

1. Cancer network
2. Year of diagnosis⁵
3. Cancer site
4. Morphology
5. Summary stage (TNM and REF)
6. Grade
7. HPV status (positive and negative). This is an inferred field and was assigned to each case through an algorithm based on location of the cancer and patient

⁵ Precise date of diagnosis was not available to researchers to keep confidentiality.

demographics as HPV status has not, in the past, been routinely tested for and recorded.

Finally, variables related to the route (route start-point and route end-point) were also requested. A number of cases (n=10) were removed to maintain the confidentiality of the data.

2.6.1 Data Analysis

The three research questions I was aiming to answer were as follows:

1. Is there a difference in those who present through the emergency route compared with all other routes to diagnosis?
2. Is there a difference in those who present through the Urgent Cancer Pathway (“2 Week Wait”) compared with those who come through other primary care routes?
3. Is there a difference in those who are referred by a dentist compared with those referred through other primary care routes?

2.6.2 Data cleaning

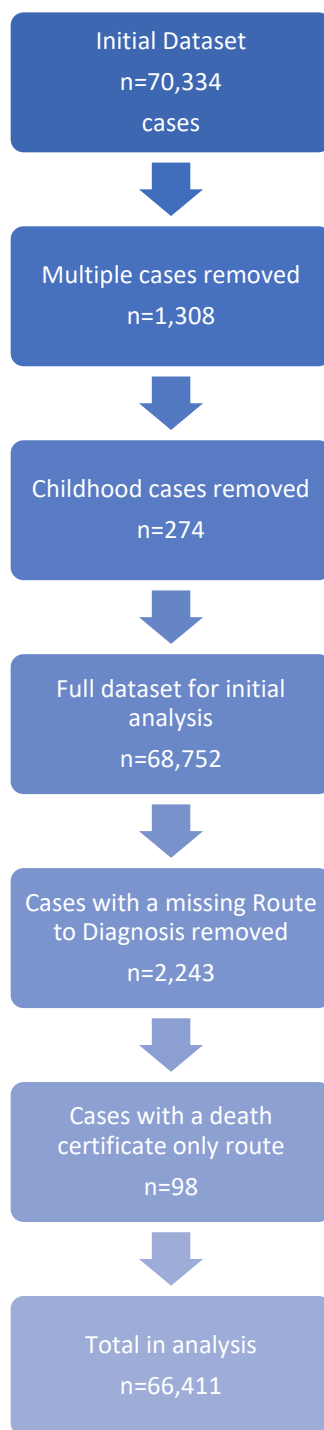


Figure 3: Data Cleaning Process

The data from Public Health England was transferred to STATA 15 (StataCorp, 2017) and cleaned. The process is shown in figure 3. Any tumour with a missing route to diagnosis was removed from the analysis (table in appendix C), (2243 cases). There were multiple entries for some patients, i.e., where there had been multiple records of HNC diagnoses within the time period to which the data pertained. While it is

theoretically possible that an individual might have two distinct primary HNC diagnosed in the study period, this would be uncommon. Although the NCRD only seeks to record primary cancers, as with any cancer registry, it is possible that recurrences or metastatic cancers are recorded in error as a new diagnosis (especially if, for example, a patient moved to another part of the country and was seen in a different hospital). It was impossible to know whether these second and subsequent cancers were true new primaries or erroneously recorded recurrences. Either way, the route to diagnosis might be expected to be different to that for the initial primary cancer. Therefore, where patients had multiple cancers recorded, only the case with the earliest date was kept. If there were multiple entries with the same date, then this was assumed to be a potential inputting error where there had been a spread of the cancer to multiple sites, but it was entered as different primary cancers. In this case the case with the earliest referral date was kept. If there was no difference in dates, then the case marked as HPV positive was kept. Finally in the case of no other information the case kept was selected at random and the others were removed from the analysis. This resulted in 1308 tumours being removed from the dataset, which now contained one record per patient.

I then removed the Death Certificate Only cases (n=98) i.e., where the cancer had been diagnosed after death, therefore there was no “active” route to diagnosis for these cases. All cases in any 5-year age bracket which fell under 20 years of age were also removed from the dataset as this was an analysis on adults only (n=274). Due to only having 5-year age bands the decision was between removing those aged under 15 years or under 20 years. As this is predominately a disease seen within older adults and due to the small numbers within these age groups this was felt to be an acceptable choice.

2.6.3 Statistical analysis

My first step was to create the variables that I would be using for the analysis; these are listed below.

Demographic Variables

1. **5-year age bands** – The ages were grouped into 5-year age bands. This variable was created by NCRAS.
2. **Sex** – Male and Female categories for each case. This variable was created by NCRAS.
3. **Ethnicity** – This was originally a free text box which resulted in a large list. The list was aggregated into 7 categories initially and then further aggregated down to 3 categories (White, non-white, and Unknown). This was due to the very small numbers in each category other than White.
4. **Urban/Rural Category** – This category was split into the 10 categories: 6 urban and 4 rural. This was reduced into two codes: Urban and Rural. This was felt to be suitable for the level of analysis I was conducting.
5. **Deprivation Category** – Each case was assigned a deprivation code 1-5 with 1 being the least deprived and 5 being the most deprived. This variable was created by NCRAS.

Route Variables

1. **Final Route** – This variable was created by NCRAS and assigns each case with one of the 8 aggregated routes defined by the final part of the individual's pathway code.
2. **Start Code** – This again was created by NCRAS and related to the first part of an individual's pathway code, this gave more details as to who the initial referral came from. I used this variable to create the new extended route variable.
3. **Extended Route** – I used the Final route and start Codes to create a new variable whereby I was able to identify those cases referred by a Dentist on a standard referral and a 2 week wait referral. This gave me an extended route variable.

Cancer related Variables

1. **Diagnosis Year** – A new variable was created with the year of diagnosis being grouped into three groups of three years: 2006-2008, 2009-2011, 2012-2014
2. **Stage** – this variable was created by NCRAS and reports the stage of disease at point of diagnosis (Stage 1 – 4, or unknown/missing)
3. **Grade** – this variable was created by NCRAS and reports the grade of cancer at point of diagnosis (Grade 1 – 4 or missing/unknown).
4. **Site** – A new variable was created grouping the ICD-10 codes into cancers of the Oral Cavity (C02, C03, C04, C05, C06), cancers of the Oropharynx (C01, C09, C10), cancers of the Larynx (C32) and other HNCs (C07, C08, C11, C12, C13, C14, C31). The

categories were based on the National Cancer Intelligence Network (NCIN) grouping (Oxford Cancer Intelligence Unit, 2011) and have been used in previous analysis of routine data of HNCs (Louie;Mehanna and Sasieni, 2015). Although the NCIN recognise Thyroid cancer as being part of the HNC grouping, it was decided that this would not be included in my analysis; previous research has also removed this from their analysis (Louie, Mehanna and Sasieni, 2015) due to the different aetiology to other HNCs, and it was felt this could impact the results when considering routes to diagnosis.

After initial cleaning and creation of variables I then looked descriptively at the routes to diagnosis in detail. A descriptive analysis on the data was conducted (table 3) using the eight defined route to diagnosis categories. The extended route to diagnosis (where I had split the routes into 10 defined categories) allowed a descriptive analysis of the dental referrals separately from the 2WW category and the Other Outpatient Category. Dental referrals were separated as patients with head and neck symptoms can present in primary care at their GP or Dentist. Therefore, separating this data from the general Outpatients referrals and 2WW referrals was important to fully understand the routes patients were undertaking.

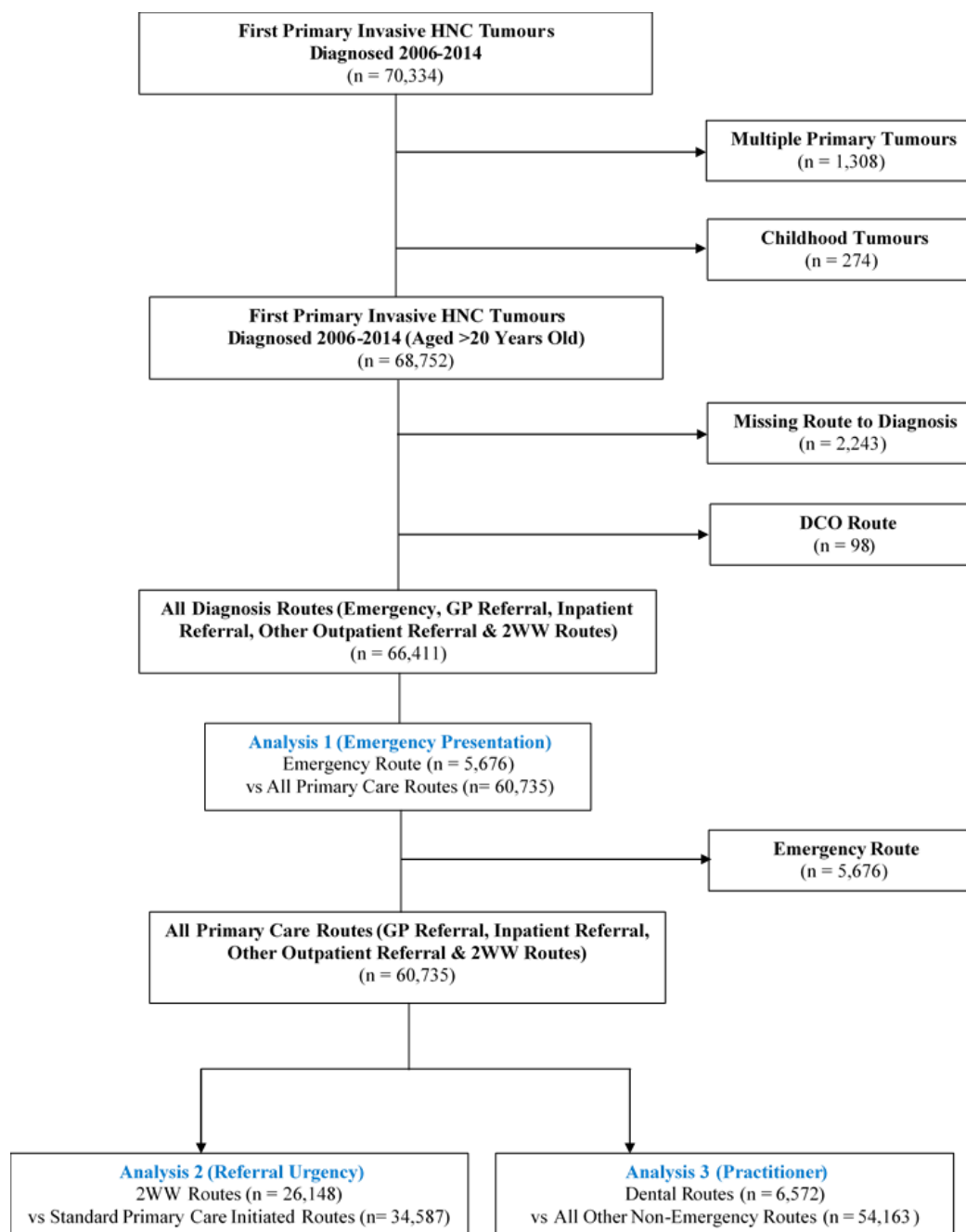


Figure 4: Flow diagram of the analytical cohorts for Routine Data Analyses 1-3.

Abbreviations: DCO: Death certificate only; GP: General practitioner; HNC: Head and neck cancer; 2WW: Two week wait.

The outcome variables (and comparisons) for each research question are listed below;

1. Those who were coded as an Emergency were compared with all other routes where the diagnosis had been made when the patient was alive.
2. I then considered the difference within primary care, comparing Two Week Wait (TWW) coded cases with all other Primary Care Initiated referrals (GP, Other

Outpatient, In-patient elective). It was decided to include all of these coded cases as in England you cannot access secondary care without coming through primary care or as an emergency so to just compare TWW with GP referrals would have underestimated the number of cases which were primary care initiated (Elliss-Brookes, 2012)

3. I then wanted to investigate if there was a difference in those who attended a dentist over another primary care referrer. For this option I was able to conduct a sub-group analysis by finding all the cases referred by a dentist from within the Other Outpatient group and comparing them to all other primary care initiated referrals

For the modelling for each research question, I first conducted a descriptive analysis using chi square tests of association. I then ran univariate logistic regressions and identified variables statistically significant on likelihood ratio tests; $p \leq 0.05$ was considered to be statistically significant throughout. I then fitted these simultaneously and checked each variable remained statistically significant. I then reduced the models by dropping any variables that were no longer significant and checked again for any variables which then became non-significant. When I had a model where all the variables were significant, I checked for goodness of fit. I also used AIC and BIC to choose between the “competing models”.

2.7 Qualitative Interviews

The interviews were conducted as semi-structured interviews which would highlight specific areas of interest using open ended questions, with follow up probing questions. This style also allows the participants to bring in other topics which they feel are related to their route to diagnosis. I decided to conduct these interviews simultaneously (i.e. recruiting to all participant groups at once), rather than sequentially. This was to allow for topics raised by the different groups to be included in subsequent interviews of other interview groups, which may not have been considered in the original interview schedule. For example, the initial dentist interviews raised the topic of discussions around teeth removal prior to treatment starting; this was then included as in subsequent patient interviews, so the topic was able to be explored from both perspectives.

The qualitative interviews were split into two groups; Patients and healthcare professionals (this included GPs, Dentists and Surgeons). Within the healthcare professionals' group, I wanted to pick those who would be involved in the route to diagnosis with HNC. Within the UK primary care is the gatekeeper for secondary care unless a patient comes through an emergency admission. Therefore, it was decided that GPs and dentists would be the best groups to include. Both these groups can refer patients into secondary care. As I was also considering the experience of a diagnosis of a HNC I also included surgeons. There was initial discussion on including nurses, however after speaking to staff within the relevant departments it was felt that they became involved more fully after the diagnosis, and although were often attending the diagnosis appointment were rarely the ones who gave the official diagnosis.

At the end of the interview, participants were given a debrief form which explained the aims of the study and provided them with contact details for the research team and supervisory staff in case they wanted to contact the team later. They were reassured that if they wanted to discuss anything but did not feel comfortable contacting me, they could contact a member of the supervisory team directly. This also included a list of support services in case they felt they needed further support after the interview; for patients there were general support services such as The Samaritans listed alongside specific HNC charities contact details (appendix D). For healthcare professionals there were contact numbers for The Samaritans and Mind Blue Light line which is a specific service for healthcare and the emergency services (appendix E).

2.7.1 Eligibility and Recruitment

Recruitment methods and interview processes differed for the patients and for each HCP group and will be described separately.

2.7.2 Patient Interview Recruitment

The patient participant inclusion criteria were:

1. Medically stable
2. Aged 18 years and over
3. Had received a diagnosis of HNC (hypopharynx, larynx, nasopharynx, oral cavity, oropharynx, palate, salivary glands but not including thyroid cancer,

which is sometimes included within HNCs but is a significantly different cancer; this matches the criteria for ICD-10 codes within the Routine Data)

4. Received their cancer diagnosis a maximum of three years prior to the interview date.
5. Must speak and understand English to a level that they can understand the interview questions and communicate their responses.

With regards the time period since diagnosis, this had originally been decided on as a minimum of two months post diagnosis as it was felt that the patient may potentially be upset discussing the diagnosis so close to the event. It was assumed that patients beyond three years may have difficulties recalling the diagnostic pathway and experiences in detail. This changed early into the study as participants who were less than two months post-diagnosis requested interviews. They had heard of the study through initial information sessions at patient conferences and through social media about the study. After discussing the criteria with them, it was determined that they were not overly upset and, in fact, were eager to talk about their experiences and participate in the study. Therefore, an amendment was sought from the NHS ethics committee to recruit any patient from the point of diagnosis; this was approved.

I used purposive sampling to recruit patients with a range of diagnoses, stage of disease at diagnosis and HPV status and different referral routes. I also sought diversity of socio-economic backgrounds, ages and both males and females. I chose these as I wanted to ensure I captured a range of experiences. Different tumour sub-groups, and HPV status could potentially present in different ways, and I wanted to explore how that may have impacted an individual's journey. I also felt it was important to hear from people who presented through different routes to explore these experiences. With regards stage of disease, those who are diagnosed at a lower stage generally have better prognosis than those diagnosed later (Gatta et al, 2015). Therefore, it was important to obtain interviews from people at these different stages to understand what if anything was helping or hindering earlier presentation. It was important that those with communication problems were not excluded as this is a common side effect associated with HNC and its treatment. A decision was taken to address this on an individual basis using the expertise in my supervisory team; Prof

Patterson was available to provide advice on how to make the participant comfortable and facilitate communication. I also offered the option of shorter interviews if that was preferable for the participant. Patients were not excluded if they were receiving, or planned to receive, palliative care. This group was considered crucial to understand delays for those presenting with non-curative disease, although they were not approached if the clinical team regarded them to be within the last few months of life.

There were two streams of recruitment for the patients; one was through the NHS Trusts involved in the study and the other was through social media and charities. The process of recruitment within the NHS Trusts was that the head and neck surgeons would identify and approach potentially eligible patients about the study. During the initial planning stages I spoke to the teams at each site about how their clinics ran and the best approach to recruitment. The care pathways within HNC can be very complex and involve many different staff members. It was felt that the consultants would be the best staff member to approach the patients as they tended to be the main clinician who saw all the patients and could explain the study to the participant at the end of their consultation. They also had details on the patient so were able to help with recruiting a diverse sample. The clinicians gave a copy of the study information sheet (appendix F) to interested patients when they attended follow-up clinics. They would ask the patients to contact me by telephone, email or using the contact sheet attached to the study information sheet if they were interested in taking part. On contact, I briefly described the study, answered any immediate questions, and sent them a consent form (see appendix). I suggested they read over the information again, making notes of any questions and agreed to contact them a minimum of 24 hours later. At this point, I asked if they were willing to take part and if agreeable, we arranged either a face-to-face or telephone interview, at a convenient time. Options for location of a face-to-face included a home visit, a local public venue such as a coffee shop or library or Newcastle University offices.

The recruitment through social media (Twitter and Facebook) and through relevant charities aimed to broaden my pool of patients who may be appropriate for the

interviews but may not be attending follow-up clinics at the hospital in the timeframe needed for the study. It also provided me with a contingency plan in case I was not able to recruit the patient numbers I required through the NHS Trusts. While I emphasized to the collaborating clinical sites that I was interested in speaking to patients from all kinds of backgrounds and social circumstances, and who had had varied experiences of diagnosis, it is always possible that clinical colleagues may be overly thoughtful and/or somewhat selective in who they approach about research studies (van den Brink et al 2020). This additional recruitment stream was therefore intended to provide the possibility of recruiting patients who had not been pre-selected by clinical colleagues. Two HNC charities - The Swallows and Northern HANC - were approached to share my study details through their networks. I also attended patient conferences run by both charities to pass on information about the study to potentially interested patients.

2.7.3 Patient Interview Process

At the start of the interview, I took the participant through the consent form (appendix G). If this was a telephone interview the consent form had been emailed in advance and verbal consent was taken over the phone; they were also asked to sign the consent form at home and either scan/photograph and return via email or put in the post. If it was an in person interview then the participant was asked to read and sign the consent form at the beginning of the interview. I offered to read out the consent form to anyone who may need additional support, around reading (i.e. eyesight or literacy problems). I also answered any further questions and checked that they were still willing to participate. All interviews were audio-recorded and transcribed with the agreement with the participant. If any participant requested that they were not audio recorded, then the interview would still go ahead with the requirement that I could make notes during the interview. Participants were also asked if were happy for their GP or Dentist to be contacted as a potential participant within the study. This was entirely voluntary, and the participant had the option of providing the clinic details and I would approach the clinic without discussing the link with the patient or I could contact the clinician and explain their patient had given me their details as they had been involved in their route to diagnosis. All participants were offered a £10 Love2shop voucher as a thank you for their time and for taking

part in the research. Participant travel expenses were reimbursed and were provided with the study debrief document.

2.7.4 Patient Reliability and Validity

There was an option for the participant to receive a copy of their transcript after their interview for consensus agreement. It is possible that discussions and topics can become misunderstood, and this extra level of checking was to allow for these to be corrected before analysis. If a participant requested this option, they were given two weeks to do this and if no contact was made after this time the assumption was that the transcript was accepted as an accurate record of the interview

They were also asked if they would like a report on the study once it was completed. The purpose of this was member checking (Braun and Clarke, 2013) i.e. the practice where some or all participants are sent a report once analysis has been conducted for them to comment on the results and whether they feel this an authentic or trustworthy analysis. I chose to do this as not only is it good practice but I felt it was important that those who had taken part in the research had the opportunity to comment on it before it was in the public domain. It was important to me that the participants felt that these findings matched their own understanding of the experience they went through. There are limitations with using this approach; it is possible that participants may feel uncomfortable informing the researcher that they disagree with their findings. To minimise this, I planned to make it clear in the report that the participants are the experts in their experiences and that it is important for me to know if what I have found/concluded matched their experience. There is also the potential for contradictory feedback. If that had occurred, I intended to record this and discuss further with the participant to see where the discrepancies lay. Feedback would be requested either by email or post within two weeks from the report being sent out. This would allow participants time to read the report and reflect on it and allow me enough time to incorporate this feedback into the analysis and discussion.

2.7.5 Transcription

All recordings were transcribed using a third-party company (Type It Write) or by myself and then anonymised. Unfortunately, one recording (with a surgeon; further details of recruitment of HCPs provided in section 2.7.9) failed, however I took detailed notes immediately following the interview. Each participant was given a pseudonym which matched their sex, alongside their participant number as I felt this was more appropriate than just using their study ID number, which felt impersonal.

2.7.6 Patient Interview Schedule

The aim of the interview was to study the route to diagnosis up till the point of diagnosis only, not the period beyond. Therefore, the aim was to design an interview schedule to reflect this time period.

Interview schedules were designed around an adaptation of Anderson's model of patient delay (Anderson, 1995). This model was originally based on the Safar et al (1979) stages of delay in seeking medical help. Anderson's model looked at delay in a general context of seeking medical help and was further refined, by Walter et al., in the light of new evidence from a systematic review on potential mechanisms for this delay specifically around cancer (Walter et al., 2012). The updated model (figure 2) is shown in section 1.4.1. All three models consider the points in a patient's journey where there could be delay to a potential diagnosis of a health condition. The updated model (Walter et al., 2012), has four intervals - periods of time between two events where a delay could occur;

1. Appraisal Delay – This is the time period between detecting a change or potential symptom and perceiving a reason to speak to a health care professional.
2. Help Seeking Delay – The time between perceiving the reason to speak to a healthcare professional and the first consultation.
3. Diagnostic Delay – The time between the first consultation and the diagnosis.
4. Pre-Treatment Delay – The time between diagnosis and the start of treatment.

As an initial ice breaker my first question was to ask the participant to talk me through what they had been diagnosed with. Then I asked the following questions linked with the intervals noted in figure 2.

1. Appraisal Delay - For "Appraisal" I asked an opening question about their experience of a health problem. "When did you realise something wasn't right?"
2. Help Seeking Delay - The opening question was around engaging with the healthcare system -. "Can you tell me what first led you to seek medical advice?"
3. Diagnostic Delay - I opened with a question about the communication of the diagnosis. "Can you tell me about how you were told you had cancer?"

As stated earlier as my study was only considering the period up to diagnosis, I did not investigate anything around the Pre-Treatment Delay. However, I did ask questions on the patient's knowledge and understanding of their diagnosis and cancer in general ("What did you know about HNC before you were diagnosed?"). After I had started interviewing the dentists there were many comments by the hospital dentists about the difficulty of explaining the impact the cancer treatment can have on patients' teeth and how often they had to pre-emptively remove teeth. Based on this a question was added to ask patients about the impact of the dental visit which was often during the same diagnosis appointment. Finally, I asked if there was anything further they wanted to say that had not been covered in the interview, to ensure that all topics the patient considered important to their route to diagnosis were covered. I included question prompts should clarification be required. The schedule development was iterative and responsive to new areas of enquiry derived from previous interviews. Question order was flexible according to the flow of the interview. The schedule allowed for additional probes to enable me to explore topics raised by patients in more detail. A copy of the interview schedule is included in the appendix H.

2.7.7 Dentists Eligibility and Recruitment

For the interviews with dentists, I sought to recruit a range of dentists to cover each sub discipline involved in HNC pathways; General Dental Practitioners, Community Dentists and Hospital based dentists. The inclusion criteria for the dental participants were.

1. Had previously been involved in the care of a patient who was subsequently diagnosed with a HNC.
2. Be a fully qualified dentist (i.e. not a student)

I wanted the dentists to speak about their actual experience rather than what they thought they would (or ought to) do. I excluded student dentists as their work and referrals would often be checked by other qualified staff and I was interested in the decisions made by those who were fully qualified rather than those still in a training position.

They were recruited from the catchment areas of the three NHS trusts the patients were recruited from; Newcastle, Sunderland, and Leeds. Various recruitment strategies were used to cover the wide range of potential participants.

1. Targeted Recruitment

An email was sent out through the Newcastle University dental school to all their contact lists and the clinicians who worked with the university.

The email explained the study and asked any interested parties to contact me via email or phone.

2. Snowball sampling

During initial planning of the study, I had made contact with some of the hospital dentists working within Newcastle Hospitals NHS Foundation Trust. I contacted these people and asked them to pass on an email with a description of the study and my contact details. The email also asked for respondents to forward the email on through their own networks. I also asked any participant who agreed to take part in the study if they would be willing to pass on the information to anyone who they felt may be interested in taking part. Community Dentists were also recruited through snowball sampling using contacts I had within Sunderland; this was via

emails which were sent to contacts and asked to forward onto anybody else who might be suitable.

3. **Social media (Twitter)**

I contacted various communities of dentists on Twitter; some of these were formal organisations to retweet a request for participants.

4. **Through Patient Participants**

I also asked the patient participants if they were happy to pass on the details of their dentists so that I could contact them with regards this study. If they agreed this could be conducted one of two ways; 1) Anonymously where I would contact the dental practice and explain the study but not that one of their patients was taking part 2) With agreement from the patient explicitly stating to the practice/dentist that I had been given their details by one of their patients who had been diagnosed with a HNC

2.7.8 General Practitioners Eligibility and Recruitment

The inclusion criteria for GPs were.

1. Have experience of assessing a patient who was ultimately diagnosed with a HNC
2. Be a fully qualified GP (i.e. not a student)

They were recruited through various methods. Initially recruitment was from the same areas the patients were recruited from; Newcastle, Sunderland and Leeds using Newcastle University contacts. GPs were also identified by the patient participants. Social media (Twitter) was also used; my tweets asked to be retweeted by relevant organisations or GPs with work-based accounts. However, recruitment was very difficult in the initial stages. I was unable to get any GP identified by a patient participant to take part in the study and although I managed to gain a large interest with around eight GPs contacting me through Twitter, none of these initial contacts ended in an interview. My next step was to widen the geographical area to include all GPs working in England. I also adopted the following methods based on advice I sought from other researchers working within primary care research⁶;

⁶ All changes went through ethical approval.

1. A presentation at a GP Masterclass on Routes to Diagnosis in Cancer held at Sunderland Hospital
2. A notice in the NHS North of England Commissioning Support newsletter (multiple times)
3. Direct emails to Practice Managers of surgeries located in the initial recruitment areas.
4. Direct phone calls to Practice Managers of surgeries located in the initial recruitment areas.
5. Distributing study recruitment information at surgeries located in the initial recruitment areas.
6. Email sent out to the Macmillan GP network.

2.7.9 Surgeon Eligibility and Recruitment

The inclusion criteria for the surgeons were:

1. Head and Neck, ENT, Maxillo-Facial and Oral Surgeons who had been involved in the diagnosis of a patient with HNC.
2. Not medical students (i.e. needed to be on the specialist ENT, Oral or Maxillo-Facial Trainee route or above).

Recruitment was through the three participating NHS Trusts. I had already been in contact with the lead clinician for the multi-disciplinary HNC team in each Trust during the study set up. Therefore, I asked them to forward an email to the head and neck surgeons in their team asking those interested to contact me directly, if they were interested in the study.

2.7.10 Healthcare Professionals (HCP) Interview Process

This process was the same as the patient participants. Interested parties were sent the HCP study information sheet (appendix I) and were then contacted to see if they had any further questions. If they were happy to participate, then an interview was booked in at a time and place convenient to the participant. At the time of the interview full consent was taken as well as consent for the interview to be audio recorded. If this was a telephone interview than the consent form would have been sent to the participant in advance and they were asked to give verbal consent over the phone and then sign the form at home and either scan/photograph and email

back or put in the post. There was no financial reimbursement for the HCPs. This was due to insufficient funds, and it was decided that the priority should be the patient participants. Once the interview was completed, recording stopped, and clinicians were given a debrief form which explained the aims of the study again and gave contact details of the team in case of any questions or comments later. It also included the contact details for The Samaritans and Mind (Blue Light Line) which is a support line specifically for those working within healthcare, in case the interview had raised any issues that the interviewee wanted to speak to someone about. They were also recommended to make use of their occupational health services if they felt they needed any further support.

2.7.11 Healthcare Professional interviews Reliability and Validity

Again, as with the patient participants there was a process of consensus agreement, where the interview transcripts were sent to the participants and they were asked if they would like to check the transcript was a fair representation of the interview, and if they felt anything had been misunderstood. They were also asked if they would like a copy of the final study report.

2.7.12 Healthcare Professional Interview Schedule

Unlike the patient interviews there was no theoretical framework that I felt was suitable to base the interview schedule on. However I tried to link it with the updated Anderson Model (Walter *et al.*, 2012) as much as possible. The questions were designed to be very open with the ability to focus on any topics which were raised by the HCP. The same interview schedule was used for all HCP groups (appendix J). The opening question was designed to be an ice breaker and to allow me to understand what the HCP's current roles and responsibilities were; "Would you mind giving me some information on your current position?" The next question was designed to obtain information on their level of experience with HNC; "What has been your experience of HNC in your current position?"

The focus on the healthcare professional questions was from the section of the model which comes under contributing factors, particularly those related to healthcare and systems. This covers; Access, Healthcare Policy, and Delivery.

With regards delivery I wanted to investigate how they felt about communicating with patients and how prepared they felt patients were to hear the word cancer; “Do you feel that you are able to have discussions with patients about suspected cancer?” I also wanted to understand what they felt their role was in the route to diagnosis and what training needs they have in this area. I felt that these questions would give me some insight into the delivery of healthcare within HNC and relating to the route and diagnosis and their view of how patients access the healthcare system. To try and understand the HCP’s view of healthcare policy in this area and asked a question on their views of the current routes to diagnosis; what worked well and where there were potential problems.

Finally, as with the patient interviews I asked if there was anything they felt they hadn’t had chance to discuss that they would like to say now. This was an iterative process therefore I was open to change or adapt the interview schedule as the interviews progressed. After some initial GP interviews the influence of funding on referral decisions was raised so I decided to add this to the interview schedule for all the healthcare professionals.

2.8 Analysis of Qualitative Interviews

My analysis was primarily informed by the thematic analysis approach now termed reflexive thematic analysis described by Braun and Clarke (Braun and Clarke, 2013; Braun and Clarke, 2019a). Whilst it could have been possible to approach the data with a framework analysis based around the Model of Pathways to Treatment (Walter *et al.*, 2012) I felt that this would not allow a full analysis of the rich data that the interviews provided. I felt that framework analysis would have restricted the analysis of the data as it would have only considered what the Model of Pathways to Treatment considered part of the route to diagnosis; it may be that this model has not considered all the potential impacts on the route to diagnosis and conducting a reflexive thematic analysis enabled me to look at the data without the restrictions of the model.

2.8.1 Reflexive Thematic Analysis (RTA)

RTA is one method of analysis for capturing themes and patterns of meaning across a qualitative dataset. This is an inductive approach, where the analysis is data driven rather than shaped by existing theory or hypotheses (Braun and Clarke, 2013). RTA puts the researcher's role in knowledge production as central to the approach: there is a need to actively engage with the data and to make decisions. This means that it is not assumed that there are themes within the data that "appear" to the researcher; rather that the researcher must work to decide on what themes they believe represent the data. This approach considers the importance of full data immersion and reflection by the researcher conducting the analysis. This does not mean that a researcher must work alone; collaboration can be useful if used to obtain deeper understanding of the data rather than consensus. This is not a straightforward process and requires the researcher to question themselves and their assumptions during interpretation, going back to the data when needed. I kept a handwritten diary which I wrote notes in after each interview and when reading the transcripts. I was able to go back over these notes during the analysis stage and found it helpful to read what my initial thoughts were and how they may have changed or stayed the same during the analysis.

In the RTA approach, themes are developed and generated and are a representation of the researcher's engagement with the data. They are stories about patterns of shared meaning across the data (Braun and Clarke, 2019a). Whilst some thematic analysis approaches value the importance of coding reliability (Boyatzis, 1998) RTA does not. Coding reliability assumes that there are codes in the data waiting to be discovered which takes away the context of the researcher conducting the analysis.

I initially conducted the data analysis according to the groups; patients, GPs, Dentists and HNC clinicians as on preliminary immersion, very different stories being told by each group, and I did not want to lose this diversity. However, I did compare and contrast across groups after analysis was completed in each individual group. The results for each group are presented in the relevant chapter for each group and the discussion of how these compare and contrast is in chapter 8.

The process of analysis is outlined below, as recommended by Braun and Clarke (Braun and Clarke, 2013);

1. **Familiarisation with data** – Familiarisation was achieved through the reading and re-reading of the transcripts alongside listening to the audio recordings. The audio recordings were very important as I felt that this allowed me to fully immerse myself in the data. As I had conducted all the interviews it also worked as a reminder of my own thought process during the interviews. During this stage I made notes of any items of interest as I came across them at both the individual level and whole level. I also referred to my notebook, where I kept field notes from each interview and added to these notes during this familiarisation stage.
2. **Coding** – After I felt that I was fully immersed in the data, I then went through each transcript individually. Inevitably people talked about other things beyond route to diagnosis, so there were sections of the transcript which were not fully coded. However, for the remaining transcript I went through it line by line and any sections which were of interest, and I felt were important were highlighted in the text. I then copied and pasted these sections into an Excel spreadsheet where I gave them a descriptive, explanatory label. If I came across more data which I felt fit in with that code I added that to the same row. After each transcript I went through the excel document and considered the label given to each code to make sure it fit what I felt the quote was describing. It is worth noting that the familiarisation and coding happened simultaneously with data collection; this was an iterative process, whereby the decision to seek more data was decided during analysis.
3. **Theme Generation** – I printed out all the initial codes, and using large pieces of paper grouped them together into sections which appeared to be telling the same story, attributing preliminary ‘candidate’ themes. At this point I discussed this grouping with my supervisory team, explaining “the story” behind the themes. These discussions involved a lot of questioning, going back to the original data and repositioning codes until all themes had a clear definition. There were some codes during this time which were not considered big enough to be a theme, on reflection, and others which were felt to be a subtheme. During this stage I also considered how the themes interacted with each other within each

participant subset. It was during this analysis stage that it was clear that many of the themes interacted with each other. To fully explain this relationship, I drew diagrams of the themes and how I felt they were related. This is fully described in the relevant results chapters. I also felt that there were sub-themes, and these were described under each theme at this point as well.

4. **Defining and Naming Themes** – Once I felt that the themes were telling the story from the data I then defined and named them. Names were selected to capture the essence of the theme and the significance in relation to the data.
5. **Writing up the results** –For the final stage of analysis I wrote up the results including appropriate quotes from participants. The quotes were selected based on how well they encapsulated the theme. It was during this stage that I also looked at divergent cases, to see where and who highlighted something that was the opposite to the themes found. I also triangulated the results from the different subgroups, at this stage.

2.8.2 Data Saturation

The analysis was conducted iteratively; therefore, data collection and the initial stages of analysis were conducted alongside each other. This meant that the analysis informed the decision to stop data collection. The decision to stop data collection relies upon data saturation, defined as the point at which any further data does not result in new codes or themes (Lincoln and Guba, 1985). This concept has recently received criticism (Braun and Clarke, 2019b) particularly when used with reflexive analysis, where there is no inevitable fixed end point. ‘Pragmatic saturation’ is an alternative tool (Low, 2019). This is where the researcher decides, based on the aims of the analysis, that there is enough data. With regards this analysis I made the decision that I had reached pragmatic saturation during the process of data collection by reviewing the story the data was telling. Once I felt that the stories were being repeated without anything new being added then that was the point I decided to stop data collection within that group of participants. This also took into account the pragmatic constraints of the project (timelines and recruitment potential) (Braun and Clarke, 2019b).

2.9 Reflexivity

As a researcher, it is important to reflect on my own impact on the study. Reflexivity enables researchers to examine how they may have shaped their work, from topic, design, data collection, and analysis, by their own prior assumptions and experiences (Mays and Pope, 2000). It is difficult to fully account for the impact I may have had on my work, as some influences may operate at a deeper, unconscious level.

Nonetheless, acknowledging those I am aware of helps to clarify my potential impact. I described my positionality as a researcher in section 2.2 within this chapter. This section will focus on my personal experiences and values, and how they have shaped this piece of work.

My interest in this topic as a researcher developed following a research role post master's degree on a cancer survivorship project. I became interested in patients' experiences of cancer through that piece of work and was especially drawn to head and neck, as that had been an area within that role. Before that project, I had no prior knowledge of this cancer, but I enjoyed working with this patient group as I felt that this was an under-researched area, and one where there was the potential to have a significant positive impact on patients' lives. This interest led me to apply for this PhD in head and neck cancer.

My prior experience as an actress influenced my interest in communication and how communication happens, alongside stories, which is what led me to qualitative research as a method. This has been an interest for many years and led me to work with medical students preparing for their OSCE exams during my undergraduate degree and teaching communication skills at Queen Mary Medical School in my research job post masters. This interest has shaped my focus on communication within this study and the emphasis I place upon it.

As a researcher, I have a background in health psychology, and this training will have shaped how I approach questions about patient experiences, healthcare decision-making, and health service pathways. I bring a perspective influenced by psychological theory, which will have influenced my interpretation of the participants' accounts.

I was aware that I had outsider status with all the participants; I am not a clinician, although I have previous experience with hospital administration, so I am aware of the structure of health services, and have worked within a medical school, so I was aware of the training structure and topics. However, working in these positions gave me a different perspective on how this aspect of the health system functioned. I have also not been a cancer patient or gone through the process of being investigated for cancer, so I am an outsider to this process. Before commencing this PhD, my mum was diagnosed with breast cancer, and during the PhD, she was diagnosed with a recurrence; later, my uncle was also diagnosed with pancreatic cancer. With both members of my family, I was involved in helping them navigate the healthcare system. Both journeys were difficult, and both died. I am aware that this time was difficult, and that this personal connection may have introduced an emotional response to descriptions of delays in presentation and descriptions of interactions with healthcare providers, potentially impacting how I then analysed these aspects. I also had to consider how much of myself to reveal to the participants.

Part of interviewing is creating a situation where the participant feels safe to share their story. I was aware that as the researcher, I held more power in the interview, as I set the questions, asked for their time, and controlled the recording. Keeping this imbalance in mind during the data collection period was important. I tried to reduce this by using open questions, allowing participants to guide the direction of the conversation, and giving them space to pause or go back to topics if they wished. I also gave participants a choice over when and where the interview took place, so they had some control over the process. These steps helped create a more equal dynamic and encouraged participants to feel comfortable and in charge of their own story. One of the challenges I reflected on was how much of my own experience to share with participants. While limited disclosure about my family's experience of cancer sometimes helped participants feel comfortable, I was aware that it could also influence how they spoke about their own situation.

To reflect on how my background and experiences may have influenced my work, I kept a reflexive journal during data collection and analysis, recording thoughts,

emotional responses, and challenges to expectations. I also made use of peer debriefing and supervision to discuss my diary reflections and to actively question my assumptions.

I aim to remain transparent about how my background and experiences may have shaped my research process, whilst striving for interpretations that faithfully represent my participants.

2.10 Conclusion

This chapter has outlined the methodological and practical decisions underpinning this research. A pragmatic, multi-method approach was adopted, combining epidemiological analysis of registry data with in-depth qualitative interviews, to capture both the population-level patterns and the lived experiences of patients and healthcare professionals involved in the diagnostic pathways for head and neck cancer. The study design was shaped by public and patient involvement, ensuring that the research questions addressed issues of direct relevance to those affected. Careful attention was given to recruitment strategies, ethical considerations, and the rigour of both quantitative and qualitative analysis. The chosen methods provide a robust foundation for exploring variations in routes to diagnosis and the factors shaping these experiences.

The following chapters present the findings from these two strands of work, beginning with the analysis of registry data, before moving on to the perspectives of patients and clinicians.

Chapter 3: Understanding routes to diagnosis through routine data

This chapter will contain the results of the routine data analysis including: demographics, route analysis, a comparison of the emergency route, urgent cancer referral route and the dental route.

3.1 The Head and Neck Cancer Patient Population

Between 2006 and 2014, 68,752 patients were diagnosed with a first, invasive head and neck cancer (HNC). After excluding those with missing route to diagnosis (n=2,243) or death certificate only (n=98), 66,411 patients were included in the analysis.

The number of diagnoses increased over time, 29.5% were diagnosed in 2006–2008, 33.4% in 2009–2011, and 37.0% in 2012–2014. Most patients (64.1%) were aged 55–79 years at diagnosis, and nearly 70% (46,421) were male. The population was predominantly White (81.2%), although completeness of ethnicity recording improved substantially over time (the level of missing data for this variable decreased from 20.8% in 2006-2008 to 2.8% in 2012-2014). The majority (73.1%) had no recorded comorbidities, but over one-quarter had one or more (26.9%).

Clear socio-economic and geographic gradients were evident: patients from the most deprived quintile accounted for 24.5% of diagnoses compared to 15.7% from the least deprived, and over 80% resided in urban areas, although this is most likely to reflect the larger population in urban areas. Oral cavity cancers were most common (34.1%), followed by laryngeal (23.9%) and oropharyngeal cancers (22.8%), a full list of all cancers included with C codes is in appendix K. The most common summary stage at diagnosis was IV (19.6%), though staging was incomplete in 62% of cases due to missing or unstageable data.

These findings establish the overall profile of the HNC population: predominantly older, male, White, urban-dwelling, and increasingly diagnosed with advanced disease, with strong social inequalities by deprivation.

3.2 Distribution over time

Patient characteristics changed significantly across the three time periods (Table 1). The proportion of patients aged 65–79 years rose from 33.5% in 2006–2008 to 36.3% in 2012–2014 ($p<0.001$), while other age groups remained stable. Although the most deprived quintile (IMD5) consistently represented the largest share of cases, its proportion fell slightly over time (25.4% to 23.9%; $p=0.002$).

Ethnicity recording improved, with missing/unknown data decreasing from 19.7% to 2.3%. Correspondingly, the proportion of patients coded as White increased from 76.6% to 91.5%, while those in non-White groups also rose modestly (3.6% to 6.2%). Comorbidity burden grew: the proportion with two or more comorbidities increased from 12.1% to 15.3% ($p<0.001$).

Cancer site distributions also shifted. Oropharyngeal cancers increased substantially from 19.3% to 26.1% ($p<0.001$), while laryngeal cancers declined from 26.1% to 21.9%. Reporting of stage improved: missing stage data fell from 89.3% in 2006–2008 to 28.6% in 2012–2014, revealing more cancers diagnosed at advanced stages, particularly stage IV (rising from 4.8% to 37.4%).

Overall, the HNC population became older, more comorbid, and more likely to be diagnosed with oropharyngeal cancers and advanced disease. Data quality also improved substantially, especially for ethnicity and stage.

	2006-2008	2009-2011	2012-2014	Total	p
Age at Diagnosis					0.000
20-54 years	4690 (23.9)	5067 (22.8)	5502 (22.4)	15259 (22.9)	
55-64 years	5738 (29.2)	6661 (30.0)	7060 (28.7)	19459 (29.3)	
65-79 years	6575 (33.5)	7594 (34.2)	8923 (36.3)	23092 (34.8)	
80+ years	2620 (13.4)	2884 (12.9)	3097 (12.6)	8601 (12.9)	
Sex					0.743
Male	13677 (69.7)	15419 (69.4)	17145 (69.7)	46241 (69.6)	
Female	5946 (30.3)	6787 (30.5)	7437 (30.2)	20170 (30.4)	
Cancer Site					0.000
Oral Cavity ¹	6651 (33.9)	7561 (34.1)	8408 (34.2)	22620 (34.1)	
Oropharynx	3787 (19.3)	4921 (22.2)	6420 (26.1)	15128 (22.8)	
Larynx	5120 (26.1)	5359 (24.1)	5406 (21.9)	15885 (23.9)	
Other ²	4065 (20.7)	4365 (19.7)	4348 (17.7)	12778 (19.2)	
Deprivation Category					0.002
IMD 1 (Least Deprived)	3003 (15.3)	3469 (15.6)	3945 (16.1)	10417 (15.7)	
IMD 2	3477 (17.7)	4175 (18.8)	4608 (18.8)	12260 (18.5)	
IMD 3	3897 (19.9)	4461 (20.1)	4887 (19.9)	13245 (19.9)	
IMD 4	4268 (21.7)	4681 (21.1)	5268 (21.4)	14217 (21.4)	
IMD 5 (Most Deprived)	4978 (25.4)	5420 (24.4)	5874 (23.9)	16272 (24.5)	
Ethnicity					0.000
White	15037 (76.6)	16381 (73.8)	22501 (91.5)	53919 (81.2)	
Non-White ³	712 (3.6)	792 (3.6)	1528 (6.2)	3032 (4.6)	
Unknown ⁴	3874 (19.7)	5033 (22.7)	553 (2.3)	9460 (14.2)	
Urban/Rural Category					0.011
Urban	16296 (83.1)	18250 (82.2)	20158 (82.0)	54704 (82.3)	
Rural	3327 (16.9)	3956 (17.8)	4424 (18.0)	11707 (17.6)	
Stage					0.000
I	516 (2.6)	1164 (5.2)	3621 (14.7)	5301 (7.9)	
II	317 (1.6)	689 (3.1)	2270 (9.2)	3276 (4.9)	
III	338 (1.7)	731 (3.3)	2457 (10.0)	3526 (5.3)	
IV	934 (4.8)	2908 (13.1)	9201 (37.4)	13043 (19.6)	
Other ⁵	17518 (89.3)	16714 (75.3)	7033 (28.6)	41265 (62.1)	
Grade					
1 (Low)	1814 (9.2)	1937 (8.7)	1838 (7.5)	5589 (8.4)	
2	6832 (34.8)	8499 (38.3)	9743 (39.6)	25074 (37.8)	
3	4620 (23.5)	5790 (26.1)	7441 (30.3)	17851 (16.9)	
4 (High)	211 (1.1)	184 (0.8)	208 (0.9)	603 (0.9)	
Unknown ⁶	6146 (31.3)	5796 (26.1)	5352 (21.8)	17294 (26.0)	
Comorbidities⁷					0.000
None	14925 (76.1)	16308 (73.4)	17339 (70.5)	48572 (73.1)	
1	2319 (11.8)	2877 (12.9)	3494 (14.2)	8690 (13.1)	
2+	2379 (12.1)	3021 (13.6)	3749 (15.3)	9149 (13.8)	

¹Includes palate; ²Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites and non-specific sites; ³Non-white refers to other ethnic groups; ⁴Unknown ethnicity refers to missing and unknown ethnicity; ⁵Other stage refers to missing and unstageable tumours; ⁶Unknown grade refers to unknown and missing tumour grades; ⁷Measured using the Charlson Comorbidity Index;

1. Table 1: Demographic and Clinical Characteristics of HNC over Time (3 Year Groups)

3.3 Distribution by sex

Sex distribution remained stable across time, with men consistently representing around 70% of cases (Table 2). This male predominance was evident across most age groups, particularly at ages 55–64 (74% male), though it narrowed in the oldest group (80+ years: 56% male).

Socioeconomic gradients differed by sex: the proportion of men increased with deprivation (from 67% in IMD1 to 71% in IMD5), while the proportion of women decreased correspondingly (33% to 28%). Ethnicity distribution also varied, with women comprising 29% of White patients but 35% of those in non-White groups.

Sex differences were observed by cancer site and stage. Men accounted for 58% of oral cavity cancers, 75% of oropharyngeal cancers, and 83% of laryngeal cancers. At stage I, men comprised 67% of cases, rising to 73% at stage IV.

These findings highlight persistent male predominance across most HNC groups, with particularly strong differences for oropharyngeal and laryngeal cancers and for advanced stages. The deprivation gradient also differed by sex.

	Male	Female	Total	p
Period of Diagnosis				0.905
2006-2008	12,353 (69.9)	5395 (30.4)	17,748	
2009-2011	14,126 (69.4)	6230 (30.6)	20,356	
2012-2014	15,734 (69.5)	6897 (30.5)	22,631	
Age at Diagnosis				0.00
20-54 years	9822 (69.2)	4376 (30.8)	14,198	
55-64 years	13,372 (73.9)	4704 (26.0)	18,076	
65-79 years	14,835 (70.4)	6251 (26.6)	21,086	
80+ years	4184 (56.7)	3191 (43.2)	7375	
Cancer Site				0.00
Oral Cavity ¹	12,482 (58.6)	8822 (41.4)	21,304	
Oropharynx	10,634 (75.4)	3470 (24.6)	14,104	
Larynx	11,814 (83.2)	2385 (16.8)	14,199	
Other ²	7283 (65.5)	3845 (34.5)	11,128	
Deprivation Category				0.00
IMD 1 (Least Deprived)	6546 (67.1)	3215 (32.9)	9761	
IMD 2	7889 (68.9)	3563 (31.1)	11,452	
IMD 3	8406 (69)	3777 (31.0)	12,183	
IMD 4	9058 (70.2)	3840 (29.8)	12,898	
IMD 5 (Most Deprived)	10,314 (71.4)	4127 (28.5)	14,441	
Ethnicity				0.00
White	34,820 (70.2)	14,774 (29.8)	49,594	
Non-White ³	1755 (64.7)	956 (35.3)	2714	
Unknown ⁴	5638 (66.9)	2789 (33.1)	8427	
Urban/Rural Category				0.185
Urban	34,681 (69.6)	15,134 (30.4)	49,815	
Rural	7532 (68.9)	3388 (31.0)	10,920	
Stage				0.00
I	3480 (66.9)	1716 (33.0)	5,196	
II	2119 (67.0)	1042 (32.9)	3161	
III	2291 (69.2)	1021 (30.1)	3312	
IV	8627 (73.1)	3181 (26.9)	11808	
Other ⁵	25,696 (68.9)	11,562 (31.0)	37,258	
Grade				0.00
1 (Low)	3299 (62.7)	1967 (37.4)	5266	
2	16468 (70.7)	6836 (29.3)	23,304	
3	12073 (73.5)	4354 (26.5)	16,427	
4 (High)	363 (67.6)	174 (32.4)	537	
Unknown ⁶	10010 (65.9)	5191 (34.2)	15,201	
Comorbidities⁷				0.210
None	31,207 (69.4)	13,779 (30.6)	44,986	
1	5422 (69.4)	2390 (30.6)	7812	
2+	5584 (70.4)	2353 (29.6)	7937	

¹ Dentist refers to outpatient (dentist) and 2WW (dentist); ² All other non-emergency routes refers to GP referral, inpatient referral, outpatient (other referral), 2WW (GP) and 2WW (other); ³ p values in bold are from

LRT of the contribution of the variable to the model. Unbolded *p* values are from a test of whether the OR is different from 1; 4 Includes palate; 5 Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites, and non-specific sites; 6 Non-White refers to other ethnic groups; 7 Unknown ethnicity refers to missing and unknown ethnicity; 8 Other stage refers to missing and unstageable tumours; 9 Unknown grade refers to unknown and missing tumour grades; 10 Measured using the Charlson Comorbidity Index. Abbreviations: CI: Confidence interval; IMD: Index of multiple deprivation; GP: General practitioner; LRT: Likelihood ratio tests; OR: Odds ratio: Model adjusted for age at diagnosis, sex, cancer site, deprivation category, period of diagnosis, ethnicity, stage, and grade.

Table 2: Demographics and Clinical Characteristics of HNC by sex

3.4 Routes to Diagnosis

The dataset defined eight routes to diagnosis with regards HNC. These routes were GP Referral, Two Week Wait, Emergency Presentation, Other outpatient, Screen detected⁷, Inpatient Elective, as well as Death Certificate Only (DCO) and Unknown routes (as described in section 2.5.1)

Initial analysis was on the whole population including those with a missing/unknown route and those who were diagnosed by death certificate only. Then further analysis on factors associated with route to diagnosis excluded those with a missing /unknown route or death certificate only route. An explanation of the outcome variables used at each stage of analysis is shown in the figure below (figure 5).

⁷ There were no screen detected cases included in this analysis as there is currently no screening programme for HNCs.

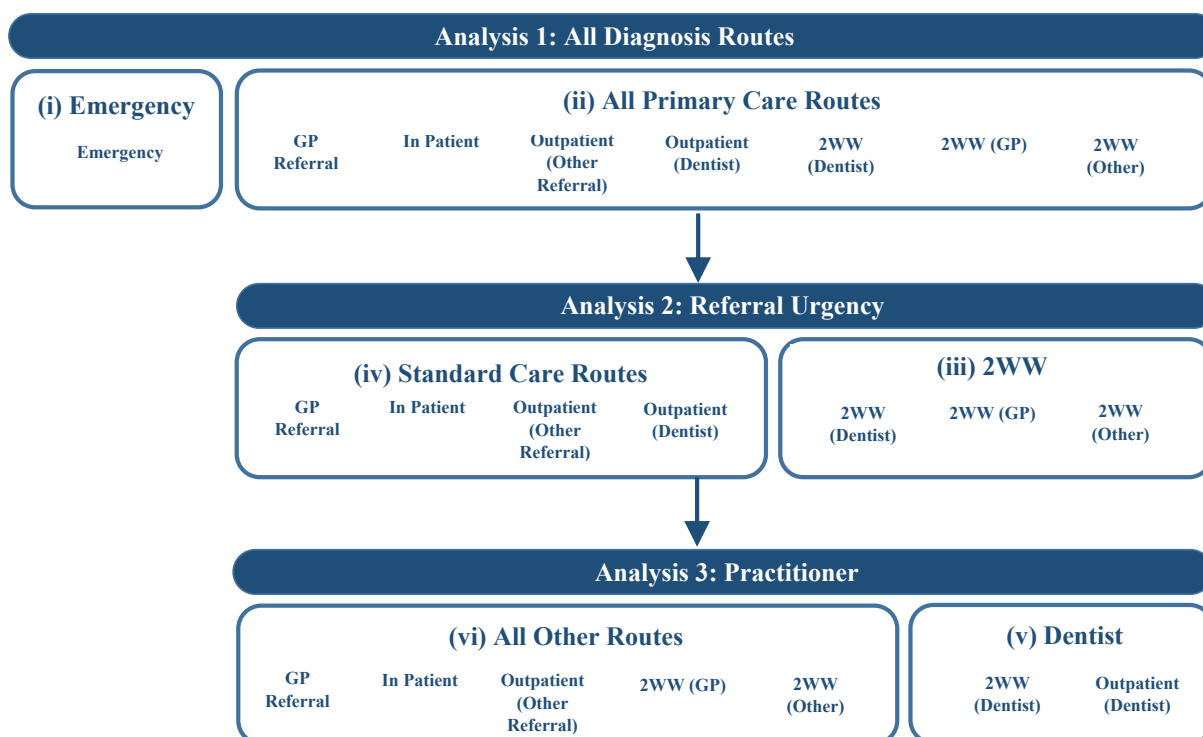


Figure 5: Route to diagnosis categorisation by each analysis

When the full dataset of all HNCs (after removal of missing/unknown route and DCO) was considered (66,411), The most common route to diagnosis was GP referral, there were slightly more referred along the urgent cancer pathway (34.2%) than a standard referral (32.8%). The emergency route accounted for 8.5% of the cases. Standard dental referrals accounted for 8% and urgent cancer pathway referrals from a dentist accounted for 19% of the cases (Table 3)

Other routes shown in this analysis were inpatient routes which referred to any referral initiated from an in-patient setting, other outpatient referral which covered any other referrals made by healthcare professionals working within an outpatient setting and 2WW Other which was an urgent cancer referral which was initiated by someone other than a GP or Dentist.

These findings highlight the diversity of diagnostic pathways in HNC. While GP referrals remain the dominant route, the urgent 2WW pathway has become increasingly important, accounting for nearly 40% of all diagnoses.

Analysis 1: All Diagnosis Routes	Emergency	All Primary Care Routes							
Analysis 2: Referral Urgency		Standard Care Routes					2WW		
Analysis 3: Practitioner		All Other Routes			Dentist		All Other Routes		
Overall	Emergency	GP Referral	Inpatient	Outpatient Other Referral	Outpatient (Dentist)	2WW (Dentist)	2WW (GP)	2WW (Other)	
(n=66,411; 100%)	(n=5,676; 8.5%)	(n=21,803; 32.8%)	(n=746; 1.1%)	(n=6,733; 10.1%)	(n=5,305; 8.0%)	(n=1,267; 1.9%)	(n=22,741; 34.2%)	(n=2,140; 3.2%)	
Age at Diagnosis									
20-54 years	15,259 (23.0)	1,061 (18.7)	5,288 (24.3)	178 (23.9)	1,543 (22.9)	1,206 (22.7)	270 (21.3)	5,234 (23.0)	479 (22.4)
55-64 years	19,459 (29.3)	1,383 (24.4)	6,137 (28.1)	237 (31.8)	1,847 (27.4)	1,440 (27.1)	344 (27.1)	7,378 (32.4)	693 (32.4)
65-79 years	23,092 (34.8)	2,006 (35.3)	7,586 (34.8)	243 (32.6)	2,460 (36.5)	1,909 (36.0)	439 (34.6)	7,711 (33.9)	738 (34.5)
80+ years	8,601 (13.0)	1,226 (21.6)	2,792 (12.8)	88 (11.8)	883 (13.1)	750 (14.1)	214 (16.9)	2,418 (10.6)	230 (10.7)
Sex									
Male	46,241 (69.6)	4,028 (71.0)	15,050 (69.0)	526 (70.5)	4,568 (67.8)	2,863 (54.0)	773 (61.0)	16,860 (74.1)	1,573 (73.5)
Female	20,170 (30.4)	1,648 (29.0)	6,753 (31.0)	220 (29.5)	2,165 (32.2)	2,442 (46.0)	494 (39.0)	5,881 (25.9)	567 (26.5)
Cancer Site									
Oral Cavity ¹	22,620 (34.1)	1,316 (23.2)	5,831 (26.7)	204 (27.3)	2,284 (33.9)	4,523 (85.3)	1,106 (87.3)	6,802 (29.9)	554 (25.9)
Oropharynx	15,128 (22.8)	1,024 (18.0)	4,613 (21.2)	177 (23.7)	1,310 (19.5)	351 (6.6)	105 (8.3)	6,917 (30.4)	631 (29.5)
Larynx	15,885 (23.9)	1,686 (29.7)	6,228 (28.6)	189 (25.3)	1,593 (23.7)	37 (0.7)	6 (0.5)	5,631 (24.8)	515 (24.1)
Other ²	12,778 (19.2)	1,650 (29.1)	5,131 (23.5)	176 (23.6)	1,546 (23.0)	394 (7.4)	50 (3.9)	3,391 (14.9)	440 (20.6)
Deprivation Category									
IMD 1 (Least Deprived)	10,417 (15.7)	656 (11.6)	3,438 (15.8)	187 (25.1)	1,294 (19.2)	1,030 (19.4)	239 (18.9)	3,279 (14.4)	294 (13.7)
IMD 2	12,260 (18.4)	808 (14.2)	4,147 (19.0)	158 (21.2)	1,292 (19.2)	1,117 (21.1)	234 (18.5)	4,137 (18.2)	367 (17.1)
IMD 3	13,245 (19.9)	1,062 (18.7)	4,431 (20.3)	156 (20.9)	1,260 (18.7)	1,094 (20.6)	260 (20.5)	4,537 (20.0)	445 (20.8)
IMD 4	14,217 (21.4)	1,319 (23.2)	4,731 (21.7)	129 (17.3)	1,343 (19.9)	1,046 (19.7)	251 (19.8)	4,934 (21.7)	464 (21.7)
IMD 5 (Most Deprived)	16,272 (24.5)	1,831 (32.3)	5,056 (23.2)	116 (15.5)	1,544 (22.9)	1,018 (19.2)	283 (22.3)	5,854 (25.7)	570 (26.6)
Period of Diagnosis									
2006-2008	19,623 (29.5)	1,875 (33.0)	7,193 (33.0)	384 (51.5)	2,312 (34.3)	1,467 (27.7)	240 (18.9)	5,588 (24.6)	564 (26.4)
2009-2011	22,206 (33.4)	1,850 (32.6)	7,452 (28.1)	175 (23.5)	2,399 (35.6)	1,836 (34.6)	366 (28.9)	7,447 (32.7)	681 (31.8)
2012-2014	24,582 (37.0)	1,951 (34.4)	7,158 (34.8)	187 (25.1)	2,022 (30.0)	2,002 (37.7)	661 (52.2)	9,706 (42.7)	895 (41.8)

Table 3. Demographic and Clinical Characteristics of all Individual HNC Diagnosis Routes During 2006-2014.

Analysis 1: All Diagnosis Routes	Emergency	All Primary Care Routes							
Analysis 2: Referral Urgency		Standard Care Routes					2WW		
Analysis 3: Practitioner		All Other Routes			Dentist		All Other Routes		
Overall (n=66,411; 100%)	Emergency (n=5,676; 8.5%)	GP Referral (n=21,803; 32.8%)	Inpatient (n=746; 1.1%)	Outpatient Other Referral (n=6,733; 10.1%)	Outpatient (Dentist) (n=5,305; 8.0%)	2WW (Dentist) (n=1,267; 1.9%)	2WW (GP) (n=22,741; 34.2%)	2WW (Other) (n=2,140; 3.2%)	
Ethnicity									
White	53,919 (81.2)	4,325 (76.0)	17,267 (79.2)	577 (77.3)	5,407 (80.3)	4,151 (78.2)	1,034 (81.6)	19,338 (85.0)	1,820 (85.0)
Non-White ³	3,032 (4.6)	318 (5.6)	1,130 (5.2)	30 (4.0)	375 (5.6)	336 (6.3)	71 (5.6)	694 (3.1)	78 (3.6)
Unknown ⁴	9,460 (14.2)	1,033 (18.2)	3,406 (15.6)	139 (18.6)	951 (14.1)	818 (15.4)	162 (12.8)	2,709 (11.9)	242 (11.3)
Urban/Rural Category									
Urban	54,704 (82.4)	4,889 (86.1)	17,913 (82.2)	593 (79.5)	5,569 (82.7)	4,262 (80.3)	1,023 (80.7)	18,628 (81.9)	1,827 (85.4)
Rural	11,707 (17.6)	787 (14.0)	3,890 (17.8)	153 (20.5)	1,164 (17.3)	1,043 (19.7)	244 (19.3)	4,113 (18.1)	313 (14.6)
Stage									
I	5,301 (8.0)	105 (1.8)	1,918 (8.8)	25 (3.4)	480 (7.1)	738 (13.9)	166 (13.1)	1,757 (7.7)	112 (5.2)
II	3,276 (4.9)	115 (2.0)	1,063 (4.9)	37 (5.0)	298 (4.4)	268 (5.1)	93 (7.3)	1,300 (5.7)	102 (4.8)
III	3,526 (5.3)	214 (3.8)	1,087 (5.0)	19 (2.5)	271 (4.0)	202 (3.8)	71 (5.6)	1,537 (6.8)	125 (5.8)
IV	13,043 (19.6)	1,235 (21.8)	3,312 (15.2)	96 (12.9)	1,008 (15.0)	925 (17.4)	350 (27.6)	5,600 (24.6)	517 (24.2)
Other ⁵	41,265 (62.1)	4,007 (70.6)	14,423 (66.2)	569 (76.3)	4,676 (69.4)	3,172 (59.8)	587 (46.3)	12,547 (55.2)	1,284 (60.0)
Grade									
1 (Low)	5,589 (8.4)	323 (5.7)	1,926 (8.8)	49 (6.6)	568 (8.4)	802 (15.1)	136 (10.7)	1,649 (7.3)	136 (6.4)
2	25,074 (37.8)	1,770 (31.2)	7,728 (35.4)	265 (35.5)	2,175 (32.3)	2,382 (44.9)	663 (52.3)	9,281 (40.8)	810 (37.9)
3	17,851 (26.9)	1,424 (25.1)	5,551 (25.5)	207 (27.7)	1,708 (25.3)	854 (16.1)	289 (22.8)	7,101 (31.2)	717 (33.5)
4 (High)	603 (0.9)	66 (1.2)	237 (1.1)	8 (1.1)	69 (1.0)	14 (0.3)	5 (0.4)	175 (0.8)	29 (1.4)
Unknown ⁶	17,294 (26.0)	2,093 (36.9)	6,361 (29.2)	217 (29.1)	2,213 (32.9)	1,253 (23.6)	174 (13.7)	4,535 (19.9)	448 (20.9)
Comorbidities⁷									
None	48,572 (73.1)	3,586 (63.2)	16,074 (73.7)	599 (80.3)	4,649 (69.0)	3,976 (74.9)	915 (72.2)	17,175 (75.5)	1,598 (74.7)
1	8,690 (13.1)	878 (15.5)	2,887 (13.2)	70 (9.4)	895 (13.3)	618 (11.6)	184 (14.5)	2,885 (12.7)	273 (12.8)
2+	9,149 (13.8)	1,212 (21.4)	2,842 (13.0)	77 (10.3)	1,189 (17.7)	711 (13.4)	168 (13.3)	2,681 (11.8)	269 (12.6)

¹Includes palate; ²Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites and non-specific sites; ³Non-White refers to other ethnic groups; ⁴Unknown ethnicity refers to missing and unknown ethnicity; ⁵Other stage refers to missing and unstageable tumours; ⁶Unknown grade refers to unknown and missing tumour grades; ⁷Measured using the Charlson Comorbidity Index; Abbreviations: GP: General practitioner; HNC: Head and neck cancer; IMD: Index of multiple deprivation; 2WW: Two week wait.

Table 3. Demographic and clinical characteristics of all individual HNC diagnosis routes during 2006-2014 (Cont.)

3.5 Analysis 1: Emergency route versus all other primary care initiated routes

3.5.1 Characteristics of cases presenting through the Emergency Route

In total, 8.5% of patients (n = 5676) were diagnosed through emergency presentation, compared to 91.5% diagnosed through a route which commenced in primary care (n = 60,735).

Emergency presentation accounted for 8.5% of diagnoses (n=5,676), compared with 91.5% diagnosed through primary care-initiated routes (n=60,735). Patients diagnosed through emergencies were disproportionately older (56% aged 65+), male (71%), and White (76%). Over one-third (36%) had at least one comorbidity, and more than half (55%) came from the most deprived areas (IMD4–5). Most resided in urban areas (86%).

Nearly 30% of emergency diagnoses were laryngeal cancers and 29% were “other” (e.g.: nasopharynx, hypopharynx, salivary glands etc) rarer HNCs. More than one in five emergency cases were diagnosed at stage IV, although staging information was missing for over 70% of cases.

3.5.2 Univariable regression results: Emergency route compared with all other primary care initiated routes to diagnosis

In univariate analyses, several variables were associated with diagnosis through the emergency route. These were older age, being male, living in a more deprived area, having two or more comorbidities, non-white ethnic group, stage IV disease and higher-grade cancer (Table 4). Compared with oral cancers, cancers of the larynx and other HNCs were more likely to present through emergency routes.

Those aged over 80 years were more than twice as likely to be diagnosed through the emergency route when compared with those aged 20-54 (Odds Ratio (OR) 80+ v 20-54 = 2.22, 95% Confidence Interval (CI) 2.04-2.43). When compared with males, females had a slightly lower likelihood of being diagnosed through the emergency route (OR 0.93, 95% CI 0.88-0.99). With regards ethnicity those in the “other”

category were 1.3 times more likely to be diagnosed through the emergency route compared to those whose ethnicity is White.

As level of deprivation increased so did the chance of being diagnosed through the emergency route. Those in the most deprived areas were almost 1.9 times more likely to come through an emergency route (OR 1.89, 95% CI 1.72-2.07) when compared with those in the least deprived areas. Those living in rural areas were significantly less likely to be diagnosed through the emergency route (OR 0.73, 95% CI 0.68-0.79).

Compared with those diagnosed with stage 4 disease, those with a lower stage of disease were less likely to have come through the emergency route (Stage 1= OR 0.19, 95% CI 0.16-0.24, Stage 2 = OR 0.35, 95% CI 0.29-0.42, Stage 3 = OR 0.62, 95% CI 0.53-0.72). Those diagnosed with higher grade cancers were twice as likely to have been diagnosed through the emergency route when compared with those diagnosed with the lowest grade cancers (Grade 4 v Grade 1 OR 2.00, 95% CI 1.52-2.65).

When compared with oral cancers, those diagnosed with cancer of the larynx were almost two times more likely to have come through the emergency route (OR 1.92, 95% CI 1.78-2.07) and cancers of the Oropharynx almost 1.2 times more likely (OR 1.18, 95% CI 1.08-1.28). Those within the “other” group which covered some of the rarer HNCs were almost 2.5 times more likely to come through the emergency route (OR 2.40, 95% CI 2.22-2.59). Overall, there appeared to be a decrease in those being diagnosed through the emergency route over time; when compared with 2006-2008 those diagnosed in the later periods were less likely to have come through the emergency route (2009-2011 OR 0.86, 95% CI 0.80-0.92, 2012-2014 OR 0.82 95% CI 0.76-0.87).

3.5.3 Multivariate Analysis results: Emergency route compared with all other primary care initiated routes to diagnosis

Socio-demographic associations (apart from with sex) persisted in multivariable analyses and were statistically significant ($p \leq 0.05$ was considered statistically significant). Those aged 80 and over were almost twice as likely to be diagnosed through emergency presentation (80+ years old vs. 20–54 years old; multivariable odds ratio (mvOR) 2.00, 95% CI 1.82, 2.19) and those aged 65-79 were 1.17 times

more likely to be diagnosed through this route (mvOR 1.17 95% CI 1.08-1.27. There was also a consistent trend of increased likelihood of emergency diagnosis as the level of deprivation increased. Deprivation remained strongly predictive, patients from the most deprived quintile were nearly twice as likely as those from the least deprived to present as emergencies (IMD5 vs. IMD1; mvOR 1.82, 95% CI 1.65, 2.00). Non-white patients were 1.28 times more likely to be diagnosed via emergency presentation than white patients (non-whites vs. white; mvOR 1.28, 95% CI 1.13, 1.45). Patients residing in rural areas were significantly less likely to be referred through an emergency route (rural vs. urban mvOR; 0.91, 95% CI 0.84, 0.99). In terms of clinical variables, patients diagnosed with a higher-grade cancer were 1.45 times more likely to present through emergency routes (high vs. low grade; mvOR 1.45, 95% CI 1.09, 1.93). Stage I cancers were 82% less likely than stage IV cancers to be diagnosed via emergency presentation (I vs. IV; mvOR 0.18, 95% CI 0.15, 0.23).

The impact on year of diagnosis reduced slightly for the years 2009-2011 still showed a decline in the likelihood of being diagnosed through the emergency route, but the years 2012-2014 showed a slight increase in likelihood although this was non-significant (OR 1.05, 95% CI 0.97-1.13), indicating some improvements in timely referral.

Emergency presentation is strongly patterned by age, deprivation, comorbidity, and cancer site. These inequalities highlight persistent barriers to early diagnosis, with deprived groups particularly disadvantaged.

	Emergency ¹ n=5,676 (8.5%)	All Primary Care Routes ² n=60,735 (91.5%)	Analysis 1: Emergency Presentation Emergency ¹ vs All Primary Care Routes ²					
			Unadjusted			Adjusted		
			OR	95% CI	P Values ³	OR	95% CI	P Values ³
Age at Diagnosis			<0.001			<0.001		
20-54 years	1,061 (7.0)	14,198 (93.0)	1.00	-	-	1.00	-	-
55-64 years	1,383 (7.1)	18,076 (92.9)	1.02	0.94 - 1.11	0.578	1.01	0.92 - 1.09	0.908
65-79 years	2,006 (8.7)	21,086 (91.3)	1.27	1.18 - 1.38	<0.001	1.17	1.08 - 1.27	<0.001
80+ years	1,226 (14.3)	7,375 (85.7)	2.22	2.04 - 2.43	<0.001	2.00	1.82 - 2.19	<0.001
Sex			0.0215					
Male	4,028 (8.7)	42,213 (91.3)	1.00	-	-	-	-	-
Female	1,648 (8.2)	18,522 (91.8)	0.93	0.88 - 0.99	0.022	-	-	-
Cancer Site			<0.001			<0.001		
Oral Cavity ⁴	1,316 (5.8)	21,304 (94.2)	1.00	-	-	1.00	-	-
Oropharynx	1,024 (6.8)	14,104 (93.2)	1.18	1.08 - 1.28	<0.001	1.17	1.07 - 1.28	0.001
Larynx	1,686 (10.6)	14,199 (89.4)	1.92	1.78 - 2.07	<0.001	1.92	1.78 - 2.07	<0.001
Other ⁵	1,650 (12.9)	11,128 (87.1)	2.40	2.22 - 2.59	<0.001	1.98	1.83 - 2.14	<0.001
Deprivation Category			<0.001			<0.001		
IMD 1 (Least Deprived)	656 (6.3)	9,761 (93.7)	1.00	-	-	1.00	-	-
IMD 2	808 (6.6)	11,452 (93.4)	1.05	0.94 - 1.17	0.371	1.06	0.96 - 1.19	0.254
IMD 3	1,062 (8.0)	12,183 (92.0)	1.30	1.17 - 1.43	<0.001	1.28	1.15 - 1.42	<0.001

IMD 4	1,319 (9.3)	12,898 (90.7)	1.52	1.38 – 1.68	<0.001	1.46	1.32 – 1.61	<0.001
IMD 5 (Most Deprived)	1,831 (11.3)	14,441 (88.7)	1.89	1.72 – 2.07	<0.001	1.82	1.65 – 2.00	<0.001
Period of Diagnosis					<0.001			0.0001
2006-2008	1,875 (9.6)	17,748 (90.4)	1.00	-	-	1.00	-	-
2009-2011	1,850 (8.3)	20,356 (91.7)	0.86	0.80 – 0.92	<0.001	0.90	0.84 – 0.96	0.003
2012-2014	1,951 (7.9)	22,631 (92.1)	0.82	0.76 – 0.87	<0.001	1.05	0.97 – 1.14	0.203
Ethnicity					<0.001			<0.001
White	4,325 (8.0)	49,594 (92.0)	1.00	-	-	1.00	-	-
Non-White ⁶	318 (10.5)	2,714 (89.5)	1.34	1.19 – 1.52	<0.001	1.28	1.13 – 1.45	<0.001
Unknown ⁷	1,033 (10.9)	8,427 (89.1)	1.41	1.31 – 1.51	<0.001	1.32	1.22 – 1.43	<0.001
Urban/Rural Category					<0.001			0.0286
Urban	4,889 (8.9)	49,815 (91.1)	1.00			1.00		
Rural	787 (6.7)	10,920 (93.3)	0.73	0.68 – 0.79	<0.001	0.91	0.84 – 0.99	0.030
Stage					<0.001			<0.001
I	105 (2.0)	5,196 (98.0)	0.19	0.16 – 0.24	<0.001	0.18	0.15 – 0.23	<0.001
II	115 (3.5)	3,161 (96.5)	0.35	0.29 – 0.42	<0.001	0.30	0.25 – 0.37	<0.001
III	214 (6.1)	3,312 (93.9)	0.62	0.53 – 0.72	<0.001	0.55	0.47 – 0.64	<0.001
IV	1,235 (9.5)	11,808 (90.5)	1.00	-	-	1.00	-	-
Other ⁸	4,007 (9.7)	37,258 (90.3)	1.03	0.96 – 1.10	0.415	0.87	0.80 – 0.94	0.001
Grade					<0.001			<0.001
1 (Low)	323 (5.8)	5,266 (94.2)	1.00	-	-	1.00	-	-
2	1,770 (7.1)	23,304 (92.9)	1.24	1.10 – 1.40	0.001	1.18	1.04 – 1.33	0.010
3	1,424 (8.0)	16,427 (92.0)	1.41	1.25 – 1.60	<0.001	1.24	1.09 – 1.41	0.001

4 (High)	66 (10.9)	537 (89.1)	2.00	1.52 – 2.65	<0.001	1.45	1.09 – 1.93	0.012
Unknown ⁹	2,093 (12.1)	15,201 (87.9)	2.24	1.99 – 2.53	<0.001	1.74	1.54 – 1.98	<0.001
Comorbidities¹⁰					<0.001			<0.001
None	3,586 (7.4)	44,986 (92.6)	1.00	-	-	1.00	-	-
1	878 (10.1)	7,812 (89.9)	1.41	1.30 – 1.52	<0.001	1.29	1.19 – 1.40	<0.001
2+	1,212 (13.2)	7,937 (86.8)	1.92	1.79 – 2.05	<0.001	1.68	1.56 – 1.81	<0.001

¹Emergency refers to: A&E, emergency GP referral, emergency transfer, emergency admission or attendance; ²All primary care routes refers to: GP referral, inpatient referral, outpatient (dentist), outpatient (other referral), 2WW (dentist), 2WW (GP) and 2WW (other); ³P values in bold are from LRT of the contribution of the variable to the model. Unbolded p values are from a test of whether the OR is different from 1; ⁴Includes palate; ⁵Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites and non-specific sites; ⁶Non-white refers to other ethnic groups; ⁷Unknown refers to missing and unknown ethnicity; ⁸Other stage refers to missing and unstageable tumours; ⁹Unknown grade refers to unknown and missing tumour grades; ¹⁰Measured using the Charlson Comorbidity Index. Abbreviations: A&E: Accident and emergency; CI: Confidence interval; IMD: Index of multiple deprivation; GP: General practitioner; LRT: likelihood ratio test; OR: Odds ratio: 2WW; Two week wait. Model adjusted for: age at diagnosis, cancer site, deprivation category, period of diagnosis, ethnicity, urban/rural categorisation, stage, grade, and comorbidities.

Table 4: Likelihood (OR, 95% CI and p values) from Logistic Regression of Emergency versus all Primary Care Routes by Socio-Demographic and Clinical Characteristics

3.6 Analysis 2: Referral Urgency; “The 2 Week Wait” (2WW) compared with all other primary care initiated routes.

3.6.1 Characteristics of cases presenting through the Urgent Cancer Referral “The 2 Week Wait”

Overall, 39.3% of patients (n=26,148) were diagnosed via the urgent 2WW pathway, this referral either came from a GP (34.2%), Dentist (1.9%) or through “other” (3.2%) which refers to any other healthcare professional 2WW referral, rising significantly from 36.0% in 2006–2008 to 49.8% in 2012–2014 ($p < 0.001$). The majority were aged 55–79 years (65%), and over 80 years (10%) and males accounted for nearly three-quarters of referrals. Approximately 40% came from the most deprived areas (IMD4–5).

Oral cavity cancers and cancers of the Oropharynx accounted for the majority of those diagnosed through this route, unsurprisingly, within the dental 2WW over 80% of the cancers diagnosed were oral cavity cancers. Cancer stage was around 25% diagnosed at stage 4.

3.6.2 Univariable regression results; 2WW compared with all other primary care-initiated routes.

Of HNC patients who were diagnosed through a route initiated in primary care, just over 40% came through the urgent 2WW pathway (n = 26,148; 43.1%). This proportion rose over time from 36.0% in 2006–2008 to 49.8% in 2012–2014. When comparing patients referred via 2WW rather than via other standard care routes, the variables associated with an increased likelihood of urgent referral in univariate analyses were as follows: being aged 55–64 years old, male, and of white ethnicity; having a cancer of the oropharynx, stage III and IV disease, grade 3 tumours, no comorbidities and residing in an area of higher deprivation. There was no observed variation by urban/rural residence.

Those aged 80+ (OR 0.87, 95% CI 0.82-0.92) were less likely to be referred on the 2 Week Wait when compared to those in the 20-54 year old age group there was a higher likelihood in a 2WW referral in those aged 55-64 years (OR 1.20, 95% CI 1.14-1.25). Females were less likely to be referred on the 2WW when compared with males (OR 0.72, 95% CI 0.69-0.74). Those who were categorised as “other” for ethnicity were almost 50% less likely to be diagnosed through the 2WW (OR 0.56, 95% CI 0.51-0.60). Two or more (but not 1) co-morbidities reduced the likelihood of a 2WW referral; 2+ co-morbidities (OR 0.83, 95% CI 0.79-0.87).

The chances of being diagnosed through the 2WW increased as the level of deprivation increased, with those in the most deprived areas having the most increased chance when compared to the least deprived group (Most deprived (5) =OR 1.35, 95% CI 1.28-1.43). The likelihood of being diagnosed through TWW reduced with reducing cancer stage (Stage 3=OR 0.91, 95% CI 0.84-0.98, Stage 2=OR 0.74, 95% CI 0.69-0.80, Stage 1=OR 0.53, 95% CI 0.50-0.57). Compared to those with oral cancers, those with a cancer of the oropharynx (OR 1.80, 95% CI 1.72-1.88) were 1.8 times more likely to come through the 2WW, and those with cancers of the Larynx (OR 1.16, 95% CI 1.11-1.21) were 1.16 times more likely to come through the 2WW. However, those whose cancer was at another site in the head and neck were less likely to come through the 2WW route (OR 0.81, 95% CI 0.77-0.85).

3.6.3 Multivariate Analysis results; 2WW compared with all other primary care-initiated routes.

In multivariable analysis, associations with stage and grade did not persist. Patients aged 55–64 years were more likely to be referred via the urgent 2WW pathway than younger patients (55–64 years vs. 20–54 years; mvOR 1.18, 95% CI 1.13, 01.24); more modest increased risks were seen for the two older age-groups. Compared to cancers of the oral cavity, cancers of the oropharynx were more likely to be referred via 2WW (mvOR 1.64, 95% CI 1.57, 1.71). Patients were more than 40% more likely to be referred by 2WW pathways if they resided in the most deprived areas (IMD5 vs. IMD1; mvOR 1.43, 95% CI 1.35, 1.50). Being female was associated with a reduced likelihood of 2WW referral (mvOR 0.76, 95% CI 0.73, 0.79) as was being from a non-

white ethnic group (non-white ethnic group vs. white; mvOR 0.57, 95%CI 0.52, 0.62) (Table 5).

Deprivation showed a distinct pattern across diagnostic routes. Patients from the most deprived areas were nearly twice as likely as those from the least deprived to present via an emergency route (IMD5 vs IMD1; mvOR 1.82, 95% CI 1.65–2.00). However, within primary care referrals, deprivation was also associated with higher likelihood of urgent 2WW referral compared with standard referral (IMD5 vs IMD1; mvOR 1.43, 95% CI 1.35–1.50). These findings reflect different comparison groups: deprivation is linked both to increased emergency presentations overall and to greater use of urgent referral once patients engage with primary care.

The expansion of 2WW referrals over time particularly benefited deprived patients and those with oropharyngeal cancers. However, persistent inequalities remained for women, non-White patients, and the very elderly.

	2WW ¹ n=26,148 (43.1%)	Standard PrimaryCare Initiated Routes ² n=34,587 (56.9%)	Analysis 2: Primary Care					
			2WW ¹ vs Standard Primary Care Initiated Routes ²					
			Unadjusted			Adjusted		
			OR	95% CI	P Values ³	OR	95% CI	P Values ³
Age at Diagnosis					<0.001			<0.001
20-54 years	5,983 (42.1)	8,215 (57.9)	1.00	-	-	1.00	-	-
55-64 years	8,415 (46.6)	9,661 (53.4)	1.20	1.14 – 1.25	<0.001	1.18	1.13 – 1.24	<0.001
65-79 years	8,888 (42.2)	12,198 (57.8)	1.00	0.96 – 1.04	0.983	1.07	1.02 – 1.12	0.005
80+ years	2,862 (38.8)	4,513 (61.2)	0.87	0.82 – 0.92	<0.001	1.06	1.00 – 1.13	0.062
Sex					<0.001			<0.001
Male	19,206 (45.5)	23,007 (54.5)	1.00	-	-	1.00	-	-
Female	6,942 (37.5)	11,580 (62.5)	0.72	0.69 – 0.74	<0.001	0.76	0.73 – 0.79	<0.001
Cancer Site					<0.001			<0.001
Oral Cavity ⁴	8,462 (39.7)	12,842 (60.3)	1.00	-	-	1.00	-	-
Oropharynx	7,653 (54.3)	6,451 (45.7)	1.80	1.72 – 1.88	<0.001	1.64	1.57 – 1.71	<0.001
Larynx	6,152 (43.3)	8,047 (56.7)	1.16	1.11 – 1.21	<0.001	1.07	1.02 – 1.12	0.005
Other ⁵	3,881 (34.9)	7,247 (65.1)	0.81	0.77 – 0.85	<0.001	0.81	0.77 – 0.85	<0.001
Deprivation Category					<0.001			<0.001
IMD 1 (Least Deprived)	3,812 (39.1)	5,949 (60.9)	1.00	-	-	1.00	-	-
IMD 2	4,738 (41.4)	6,714 (58.6)	1.10	1.04 – 1.16	0.001	1.11	1.05 – 1.17	<0.001
IMD 3	5,242 (43.0)	6,941 (57.0)	1.18	1.12 – 1.24	<0.001	1.21	1.14 – 1.28	<0.001
IMD 4	5,649 (43.8)	7,249 (56.2)	1.22	1.15 – 1.28	<0.001	1.26	1.19 – 1.33	<0.001

IMD 5 (Most Deprived)	6,707 (46.4)	7,734 (53.6)	1.35	1.28 – 1.43	<0.001	1.43	1.35 – 1.50	<0.001
Period of Diagnosis					<0.001			<0.001
2006-2008	6,392 (36.0)	11,356 (64.0)	1.00	-	-	1.00	-	-
2009-2011	8,494 (41.7)	11,862 (58.3)	1.27	1.22 – 1.33	<0.001	1.27	1.22 – 1.33	<0.001
2012-2014	11,262 (49.8)	11,369 (50.2)	1.76	1.69 – 1.83	<0.001	1.71	1.64 – 1.79	<0.001
Ethnicity					<0.001			<0.001
White	22,192 (44.7)	27,402 (55.3)	1.00	-	-	1.00	-	-
Non-White ⁶	843 (31.1)	1,871 (68.9)	0.56	0.51 – 0.60	<0.001	0.57	0.52 – 0.62	<0.001
Unknown ⁷	3,113 (36.9)	5,314 (63.1)	0.72	0.69 – 0.76	<0.001	0.84	0.80 – 0.88	<0.001
Urban/Rural Category					0.504			-
Urban	21,478 (43.1)	28,337 (56.9)	1.00	-	-	-	-	-
Rural	4,670 (42.8)	6,250 (57.2)	0.99	0.95 – 1.03	0.504	-	-	-
Stage					<0.001			-
I	2,035 (39.2)	3,161 (60.8)	0.53	0.50 – 0.57	<0.001	-	-	-
II	1,495 (47.3)	1,666 (52.7)	0.74	0.69 – 0.80	<0.001	-	-	-
III	1,733 (52.3)	1,579 (47.7)	0.91	0.84 – 0.98	0.013	-	-	-
IV	6,467 (54.8)	5,341 (45.2)	1.00	-	-	-	-	-
Other ⁸	14,418 (38.7)	22,840 (61.3)	0.52	0.50 – 0.54	<0.001	-	-	-
Grade					<0.001			-
1 (Low)	1,921 (36.5)	3,345 (63.5)	1.00	-	-	-	-	-
2	10,754 (46.1)	12,550 (53.9)	1.49	1.40 – 1.59	<0.001	-	-	-

3	8,107 (49.4)	8,320 (50.6)	1.70	1.59 – 1.81	<0.001	-	-	-
4	209 (38.9)	328 (61.1)	1.11	0.92 – 1.33	0.264	-	-	-
Unknown ⁹	5,157 (33.9)	10,044 (66.1)	0.89	0.84 – 0.95	0.001	-	-	-
Comorbidities¹⁰					<0.001			<0.001
None	19,688 (43.8)	25,298 (56.2)	1.00	-	-	1.00	-	-
1	3,342 (42.8)	4,470 (57.2)	0.96	0.92 – 1.01	0.105	0.93	0.88 – 0.98	0.004
2+	3,118 (39.3)	4,819 (60.7)	0.83	0.79 – 0.87	<0.001	0.80	0.76 – 0.85	<0.001

¹2WW refers to: 2WW (dentist), 2WW (GP) and 2WW (other); ²Standard primary care initiated routes refers to: GP referral, inpatient referral, outpatient (other referral) and outpatient (dentist); ³P values in bold are from LRT of the contribution of the variable to the model. Unbolded p values are from a test of whether the OR is different from 1; ⁴Includes palate; ⁵Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites and non-specific sites; ⁶Non-White refers to other ethnic groups; ⁷Unknown ethnicity refers to missing and unknown ethnicity; ⁸Other stage refers to missing and unstageable tumours; ⁹Unknown grade refers to unknown and missing tumour grades; ¹⁰Measured using the Charlson Comorbidity Index. Abbreviations: CI: Confidence interval; IMD: Index of multiple deprivation; GP: General practitioner; LRT: Likelihood ratio tests; OR: Odds ratio: 2WW; Two week wait. Model adjusted for: age at diagnosis, sex, cancer site, deprivation category, period of diagnosis, ethnicity, and comorbidities.

Table 5: Likelihood (OR, 95% CI and p values) from Logistic Regression of 2WW versus Standard Primary Care Initiated routes by Socio-Demographic and Clinical Characteristics

3.7 Analysis 3: Practitioner referral; Dental referral versus all other primary care initiated routes

3.7.1 Characteristics of cases presenting through a dental referral

Overall, 9.9% (n = 6572) of all HNC patients who followed a non-emergency route were referred via a dentist. This was split between those referred via a standard referral (8%) and those referred through the “2 Week Wait” (1.9%). Within the standard pathway 54% were male, and within both routes almost 50% were aged 20-64 years old. Within the standard referral the deprivation pattern was more evenly spread than seen within other routes, with each deprivation category accounting for around 20% of the referrals.

Unsurprisingly, the main cancer site diagnosed was oral cavity cancers (around 85%), however other cancers were also diagnosed through this route. There was a split in stage, with around 13% diagnosed at stage 1 and within the standard route 17% diagnosed at stage 4 and within the “2 Week Wait” route 27% diagnosed at stage 4.

3.7.2 Univariable regression results; Dental referral versus all other primary care initiated routes

In the univariable analysis, when compared with referral via all other routes, dental referral was associated with older age, female gender, residence in a less deprived area and having an oral cancer.

Older age was related to a higher likelihood of being referred by a dentist (80+ = OR 1.30, 95% CI 1.19-1.41, 65-79 = OR 1.08, 95% CI 1.01-1.16). Females were 2 times more likely to be diagnosed by a dentist (OR 2.00, 95% CI 1.90-2.11) and those who were categorised as “other” for ethnicity were 1.5 times more likely to be diagnosed by a dentist (OR 1.51, 95% CI 1.35-1.69).

The likelihood of being diagnosed through a dentist reduced as the level of deprivation increased, with those in the most deprived areas 34% less likely, when compared to the least deprived, to be referred by a dentist (Most Deprived (5) = OR

0.66, 95% CI 0.61-0.72,. Those living in rural areas were more likely be diagnosed through a dentist (OR 1.13, 95% CI 1.06-1.20).

When compared to oral cancers, other cancers of the head and neck were far less likely to be diagnosed through a dentist; the risk estimates for cancers of the oropharynx and larynx were 0.09 (95% CI 0.08-0.10) and 0.01 (95% CI 0.01-0.13) respectively and cancers which were grouped in the “other” category were 88% less likely to come through the dentist (OR 0.12, 95% CI 0.10-0.13). The cancer was more likely to be an earlier stage (stage 1) in those diagnosed through the dentist (OR 1.74, 95% CI 1.59-1.91).

3.7.3 Multivariate Analysis results; Dental referral versus all other primary care initiated routes

All variables apart from urban/rural category and comorbidities were statistically significant in the final model. In multivariable analyses, patients aged 65–79 years old were most likely to be referred via the dentist (65–79 vs. 20–54 years; mvOR 1.13, 95%CI 1.05, 1.22) as were female patients (mvOR 1.27, 95% CI 1.20, 1.34) and those from a non-white ethnic group (non-white vs. white; mvOR 1.26, 95%CI 1.12, 1.43). Residence in an area of increasing deprivation was associated with a reduced chance of dental referral when compared to all other routes (IMD 5 vs. IMD1; mvOR 0.71, 95%CI 0.65, 0.78). Patients with stage I cancer (stage I vs. stage IV; mvOR 1.19, 95%CI 1.07, 1.32) were more likely to be referred via dental routes. Diagnoses via dental referral when compared to all other routes also increased over time (2012–2014 vs. 2006–2008; mvOR 1.22, 95% CI 1.12, 1.32) (Table 6).

There was a change to the stage of cancer, stage 2 cancers went from having a positive influence of the likelihood of a dental referral to a negative influence, although in both cases this was non-significant (OR 0.88, 95% CI 0.77-1.01). Stage 1 cancers were still associated with a higher likelihood of being diagnosed through the dental route when compared with stage 4 cancers, but the impact was slightly reduced (OR 1.19, 95% CI 1.07-1.32). Stage 3 cancers were also less likely to be diagnosed through a dentist (OR 0.83, 95% CI 0.72-0.96). This split with the higher

likelihood of those with very early and very late-stage disease coming through a dentist can still be seen in this model.

Dental referrals made up about one in ten diagnoses, with a more even sex distribution, younger age profile, and a strong concentration in oral cavity cancers. Stage information indicated both early and late diagnoses within this pathway.

	Dentist ¹ n=6,572 (10.8%)	All Other Non-Emergency Routes ² n=54,163 (89.2%)	Analysis 3: Practitioner Dentist ¹ vs All Other Non-Emergency Routes ²					
			Unadjusted			Adjusted		
			OR	95% CI	P Values ³	OR	95% CI	P Values ³
Age at Diagnosis			<0.001			0.0106		
20-54 years	1,476 (10.4)	12,722 (89.6)	1.00	-	-	1.00	-	-
55-64 years	1,784 (9.9)	16,292 (90.1)	0.94	0.88 – 1.02	0.119	1.04	0.97 - 1.13	0.283
65-79 years	2,348 (11.1)	18,738 (88.9)	1.08	1.01 – 1.16	0.028	1.13	1.05 - 1.22	0.001
80+ years	964 (13.1)	6,411 (86.9)	1.30	1.19 – 1.41	<0.001	1.06	0.96 – 1.16	0.256
Sex			<0.001			<0.001		
Male	3,636 (8.6)	38,577 (91.4)	1.00	-	-	1.00	-	-
Female	2,936 (15.9)	15,586 (84.1)	2.00	1.90 – 2.11	<0.001	1.27	1.20 – 1.34	<0.001
Cancer Site			<0.001			<0.001		
Oral Cavity ⁴	5,629 (26.4)	15,675 (73.6)	1.00	-	-	1.00	-	-
Oropharynx	456 (3.2)	13,648 (96.8)	0.09	0.08 – 0.10	<0.001	0.11	0.10 – 0.12	<0.001
Larynx	43 (0.3)	14,156 (99.7)	0.01	0.01 – 0.01	<0.001	0.01	0.01 – 0.01	<0.001
Other ⁵	444 (4.0)	10,684 (96.0)	0.12	0.10 – 0.13	<0.001	0.13	0.11 – 0.14	<0.001
Deprivation Category			<0.001			<0.001		
IMD 1 (Least Deprived)	1,269 (13.0)	8,492 (87.0)	1.00	-	-	1.00	-	-
IMD 2	1,351 (11.8)	10,101 (88.2)	0.90	0.82 – 0.97	0.008	0.92	0.84 – 1.01	0.075
IMD 3	1,354 (11.1)	10,829 (88.9)	0.84	0.77 – 0.91	<0.001	0.88	0.80 – 0.96	0.004

IMD 4	1,297 (10.1)	11,601 (89.9)	0.75	0.69 – 0.81	<0.001	0.80	0.73 – 0.88	<0.001
IMD 5 (Most Deprived)	1,301 (9.0)	13,140 (91.0)	0.66	0.61 – 0.72	<0.001	0.71	0.65 – 0.78	<0.001
Period of Diagnosis					<0.001			<0.001
2006-2008	1,707 (9.6)	16,041 (90.4)	1.00	-	-	1.00	-	-
2009-2011	2,202 (10.8)	18,154 (89.2)	1.14	1.07 – 1.22	<0.001	1.14	1.06 – 1.22	<0.001
2012-2014	2,663 (11.8)	19,968 (88.2)	1.25	1.18 – 1.34	<0.001	1.22	1.12 – 1.32	<0.001
Ethnicity					<0.001			<0.001
White	5,185 (10.5)	44,409 (89.5)	1.00	-	-	1.00	-	-
Non-White ⁶	407 (15.0)	2,307 (85.0)	1.51	1.35 – 1.69	<0.001	1.26	1.12 – 1.43	<0.001
Unknown ⁷	980 (11.6)	7,447 (88.4)	1.13	1.05 – 1.21	0.001	1.14	1.05 – 1.23	0.002
Urban/Rural Category					0.0004			
Urban	5,285 (10.6)	44,530 (89.4)	1.00	-	-	-	-	-
Rural	1,287 (11.8)	9,633 (88.2)	1.13	1.06 – 1.20	<0.001	-	-	-
Stage					<0.001			<0.001
I	904 (17.4)	4,292 (82.6)	1.74	1.59 – 1.91	<0.001	1.19	1.07 – 1.32	0.001
II	361 (11.4)	2,800 (88.6)	1.07	0.94 – 1.21	0.319	0.88	0.77 – 1.01	0.073
III	273 (8.2)	3,039 (91.8)	0.74	0.65 – 0.85	<0.001	0.83	0.72 – 0.96	0.013
IV	1,275 (10.8)	10,533 (89.2)	1.00	-	-	1.00	-	-
Other ⁸	3,759 (10.1)	33,499 (89.9)	0.93	0.87 – 0.99	0.027	0.89	0.82 – 0.96	0.005
Grade					<0.001			<0.001
1 (Low)	938 (17.8)	4,328 (82.2)	1.00	-	-	1.00	-	-
2	3,045 (13.1)	20,259 (86.9)	0.69	0.64 – 0.75	<0.001	0.86	0.79 – 0.94	0.001

3	1,143 (7.0)	15,284 (93.0)	0.35	0.31 – 0.38	<0.001	0.62	0.56 – 0.68	<0.001
4 (High)	19 (3.5)	518 (96.5)	0.17	0.11 – 0.27	<0.001	0.54	0.33 – 0.87	0.011
Unknown ⁹	1,427 (9.4)	13,774 (90.6)	0.48	0.44 – 0.52	<0.001	0.88	0.79 – 0.97	0.009
Comorbidities¹⁰					0.204			
None	4,891 (10.9)	40,095 (89.1)	1.00	-	-	-	-	-
1	802 (10.3)	7,010 (89.7)	0.94	0.87 – 1.01	0.111	-	-	-
2+	879 (11.1)	7,058 (88.9)	1.02	0.95 – 1.10	0.594	-	-	-

¹Dentist refers to outpatient (dentist) and 2WW (dentist); ²All other non-emergency routes refers to: GP referral, inpatient referral, outpatient (other referral), 2WW (GP) and 2WW (other); ³P values in bold are from LRT of the contribution of the variable to the model. Unbolded p values are from a test of whether the OR is different from 1; ⁴Includes palate; ⁵Other cancer site refers to nasopharynx, hypopharynx, salivary glands, other sites, and non-specific sites; ⁶Non-White refers to other ethnic groups; ⁷Unknown ethnicity refers to missing and unknown ethnicity; ⁸Other stage refers to missing and unstageable tumours; ⁹Unknown grade refers to unknown and missing tumour grades; ¹⁰Measured using the Charlson Comorbidity Index. Abbreviations: CI: Confidence interval; IMD: Index of multiple deprivation; GP: General practitioner; LRT: Likelihood ratio tests; OR: Odds ratio; Model adjusted for: age at diagnosis, sex, cancer site, deprivation category, period of diagnosis, ethnicity, stage, and grade.

Table 6: Likelihood (OR, 95% CI and p values) from Logistic Regression of Dentist versus all other Non-Emergency Routes by Socio-Demographic and Clinical Characteristics

3.8 Closing Remarks

This chapter has presented the quantitative analysis of registry data, examining routes to diagnosis for patients with head and neck cancer. Differences were identified across sociodemographic and clinical groups, highlighting variation in how patients entered the healthcare system.

Emergency presentations accounted for a minority of diagnoses but were more common among older patients, men, and those from deprived areas, with higher levels of comorbidity and more advanced disease. Urgent 2WW referrals increased over time and were more frequent among patients aged 55–79, men, those from deprived areas, and those with oropharyngeal cancers. Women, non-White patients, older adults, and those with multiple comorbidities were less likely to be diagnosed through this route. Dental referrals accounted for around one in ten diagnoses, most commonly for oral cavity cancers, with patients generally younger and a more even sex distribution. Deprivation was associated with both emergency and 2WW pathways, but in different contexts. At the population level, patients from the most deprived areas were more likely than those from the least deprived to be diagnosed through emergency presentation. Among patients entering through primary care, those from deprived areas were more often diagnosed via 2WW referral compared with standard referral.

By outlining how patient and tumour characteristics are associated with different diagnostic routes, this chapter provides a population-level overview of variations in access to diagnosis. The following chapter builds on this by presenting qualitative perspectives from patients and healthcare professionals, adding further insight into the experiences that underpin these pathways.

Chapter 4: Qualitative interview results; Understanding the patient's journey

4.1 Chapter Overview

In this chapter I will present the participant demographics for the patient interviews. I will also provide a description of some of the participants' routes to diagnosis to give an overall impression of the varied and different routes undertaken by the participants. I will then discuss the themes and subthemes resulting from analysis of the patient interviews. Finally, I will note some comments and suggestions which came from the participant interviews which did not fit within the thematic analysis but I felt important to record.

Within this chapter "participants" refers to the patient participants only, "clinicians" refer to all healthcare professionals (primary and secondary care), and "primary care clinicians" refers to GPs and dentists, unless otherwise stated.

4.2 Participant Overview and Interview Context

In total 19 patients were interviewed. They had all received a diagnosis of a HNC, and all interviews were post diagnosis. The age range covered 40's through to 76 years. There was a mixture of stage and diagnosis types with the majority (n=10) of interviewees having a tonsil cancer. Most participants were male (n=13) reflecting the sex difference seen in HNC diagnoses. The demographics of the participants can be seen in Table 7 and recruitment numbers for each site on Table 8.

Interviews lasted for an average of 44 minutes and took place either in person (n=18) or on the phone (n=1). Those interviews which took place in person were conducted in the participant's own home (n=13), a local coffee shop (n=2), the university (n=1), in the speech and language department at Sunderland (n=2) and in a private room on a ward (n=1) as they had been admitted as an inpatient but still wanted to participate in the interview. Some participants had requested a partner be present during the interview (n=3) and this was felt to be appropriate, however any comments that were made by the partners were not analysed or included in these results as they had not consented to be included in the study and were ineligible. Two of the participants (Anna and Ben) were a couple and although were interviewed separately there was some interaction in parts of the interviews.

Pseudonym	Diagnosis	Stage at diagnosis	Gender	Age at Diagnosis	Route to Diagnosis
Anna^	Oropharyngeal (Tonsil)	T2	Female	70	GP
Ben^	Oropharyngeal (Tonsil)	T2	Male	70	GP
Charlie	<i>details unknown⁸</i>	<i>unknown</i>	Male	64	GP
Derek	Oropharyngeal (Tonsil)	T4	Male	47	Emergency
Elaine	Salivary gland Oropharyngeal (Base of tongue)	T4	Female	50-60*	GP Dentist
Freddie		T1	Male	62	
Gordon	Oropharyngeal (Tonsil) Oropharyngeal (Base of tongue)	<i>unknown</i>	Male	50-60*	GP GP
Harry		<i>unknown</i>	Male	58	
Isabel	Hypopharynx	T2	Female	60-70*	GP
Jerry	Mandible Oropharyngeal (Base of tongue)	T4	Male	49	Dentist GP
Kevin		T1	Male	65	
Larry	Oropharyngeal (Tonsil) Oropharyngeal (Base of tongue)	<i>unknown</i>	Male	65	GP GP
Martin		T4	Male	59	
Noreen	Oropharyngeal (Base of tongue)	<i>unknown</i>	Female	76	GP
Peter	Oropharyngeal (Tonsil)	T2	Male	58	GP
Richard	Oropharyngeal (Tonsil)	T2	Male	60	GP
Sarah	Oropharyngeal (Tonsil)	T2	Female	40-50*	GP
Teresa	Oropharyngeal (Tonsil)	T2	Female	60	GP
Vincent	Oropharyngeal (Tonsil)	T2	Male	61	GP
^Married Participants				*No exact age provided by the participant	

Table 7: Patient Participants Demographics

⁸ Diagnosis details were provided by the participant, I did not have approval to access their medical records.

Recruitment Site/Source	
Sunderland NHS Trust	4
Newcastle Upon Tyne NHS Trust	4
Leeds NHS Trust	6
Charity Recruitment	4
Social Media	1

Table 8: Recruitment Numbers via site/Source

4.3 Overview of participants' routes to diagnosis

The participants described complex and varied pathways to diagnosis. Some reported a smooth route they recognised symptoms; they booked an appointment, then the GP referred them. However, at the other end of the spectrum, some participants spoke about multiple visits to primary care, with referrals to inappropriate services, and in some cases, hospitalisation. To give an idea of the range of routes the following patient “stories” (based on what patients described in interviews) give examples of GP delay, Patient Delay, Patients delay through a dentist and an example of an “ideal route”.

Anna's Route to Diagnosis: An example of GP delay

Anna is retired and lives with her husband. Her husband had been diagnosed with cancer 5 years previously. She felt what appeared to be a swollen gland in her neck, and whilst she was concerned it may be cancer initially, she felt that it most likely wasn't so didn't seek help straight away. Around 4 weeks later the symptoms started to get worse, and she started to experience pain. It was at this point she decided to see her GP. Her GP asked her to return in 2 weeks if she was still experiencing symptoms. She returned 2 weeks later where she reported that the GP considered the swelling to have reduced and she was sent home. Although she felt this wasn't right, she didn't question this decision.

The symptoms continued and the pain increased and spread to her ear. She returned to the GP (this was 12 weeks since symptoms were first noticed) and was diagnosed with impacted ear wax and an appointment was made with the practice nurse for syringing. She attended the nurse appointment 2 weeks later but was told it wasn't possible to remove the wax so to

return in another 2 weeks. At this appointment she was told it wasn't possible to perform the procedure and she needed to see the doctor again. She saw the GP for a 4th time and was referred into secondary care for impacted ear wax (she later received an appointment for 3 months' time but did not attend this appointment, as she had already been referred through a different route). It was at this point that the pain became a lot worse, and she went along to a walk-in clinic at a local hospital. The GP at the walk-in centre said he would email her GP to refer her into secondary care. She already had a GP appointment booked for a few days later so attended this appointment. She felt that the GP didn't want to refer her, but she asked to be referred to see someone in ENT. Two weeks later she attended a hospital follow up appointment with her husband, which was with the clinician she had an appointment with later in the week. She spoke to the clinician then about her concerns and the clinician confirmed she would be seeing her at the end of the week.

In summary, she had her first appointment with secondary care 22 weeks after she had first noticed the symptoms. Between the first secondary care appointment and her next booked appointment she found the pain increasingly difficult to manage. She contacted her GP and received a home visit from a locum GP. He admitted her to hospital for pain control and it was in hospital 2 days later she received her confirmed cancer diagnosis of oropharyngeal cancer.

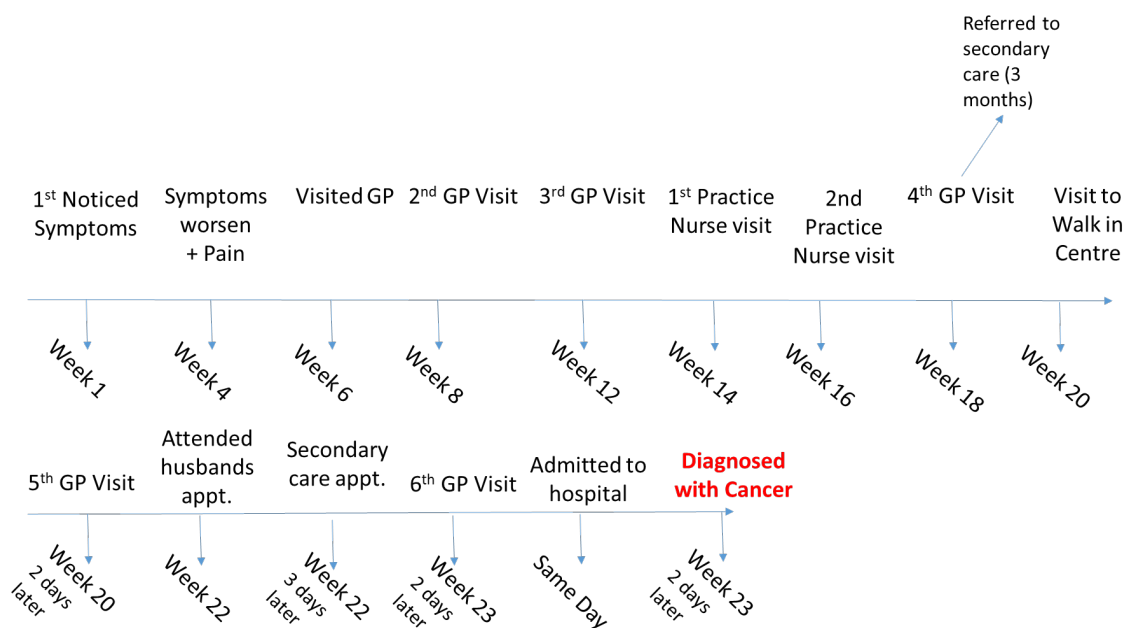


Figure 6: Anna's route to diagnosis

Charlie's route to diagnosis: An example of patient delay

Charlie was working full time in a job that required he work away from home during the week. He lived with his wife and the first time he realised something wasn't right was when he noticed problems with his voice around January. He sometimes lost his voice completely; other times his voice became high and squeaky whilst speaking. He wasn't initially concerned although his wife felt he should seek help after this had been going on for a few weeks. He found it difficult to make an appointment with his GP at a time he could make due to working away from home Monday to Friday. He still wasn't concerned but after comments from work colleagues about his voice he began to have some concerns it was more serious. His contract with work ended in June and he then made an appointment with his GP. He was prescribed antibiotics and asked to return in 3 weeks if nothing improved. He returned in 3 weeks and was then referred into ENT on a standard referral to investigate his hoarseness. His first appointment was 34 weeks after he initially experienced symptoms and he was diagnosed with cancer a week later.

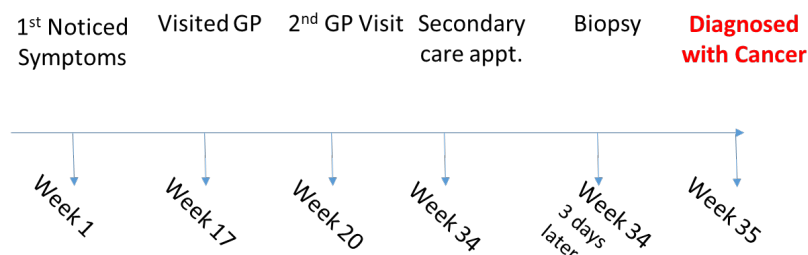


Figure 7: Charlie's route to diagnosis

Jerry's route to diagnosis: An example of patient delay through the dentist

Jerry (49 years old) works full time and lives with his partner. He had previously had a pre-cancerous lesion removed from his mouth 12 years ago but only remembered this after his cancer diagnosis. He first noticed something wasn't quite right in January but thought it was an abscess, related to his teeth. He explained he was the sort of person to put off going to get help so ignored it. Eventually he thought that he should do something about it but was due to go on holiday and didn't want to ruin his holiday by potentially having a tooth removed beforehand. There was no major pain, just a small amount of pain that he could manage. So, he went away on holiday and when he returned, he went back to work.

However, the symptoms changed, and one half of the lower side of his face went numb. This concerned him so he decided to see a dentist. He hadn't been to the dentist for several years so wasn't currently registered with one. He looked online and found a dentist who had good reviews and made an appointment; this was in November. The dentist explained that he needed to see someone in maxillofacial and would refer him. He was seen in the maxillofacial unit 2 weeks later, where he had a biopsy and was diagnosed with a stage 4 mandible cancer.

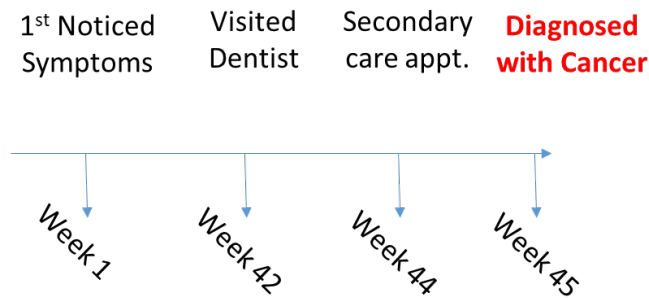


Figure 8: Jerry's route to diagnosis

Noreen's route to diagnosis: An example of an idealised route to diagnosis

Noreen (76 years old) is retired and lives with her husband. She noticed a lump when she swallowed and was instantly concerned although wasn't in any pain. She made an appointment to see her GP within a few days and was given antibiotics and asked to return if it didn't improve. She went away on holiday for a couple of weeks and when she returned still had symptoms. She went back to the GP and was referred on the urgent cancer pathway. She attended a secondary care appointment 2 weeks later and 2 weeks after that was diagnosed with oropharyngeal cancer.

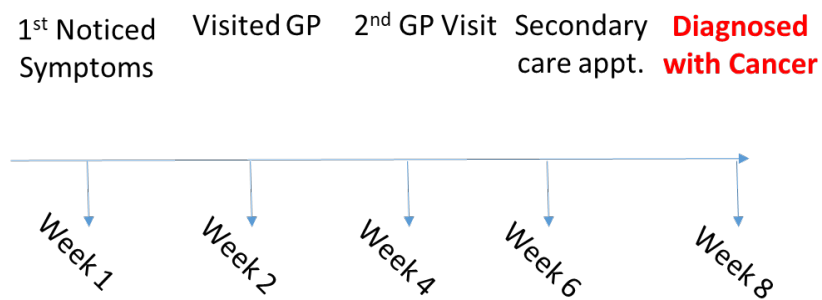


Figure 9: Noreen's route to diagnosis

4.4 Thematic Analysis of Patient Interviews



Figure 10: Interaction of Patient Themes

In total 7 themes were interpreted from the data. All the themes interacted in some way with (an)other theme(s) and the interaction can be seen in figure 10. Six themes are embedded in the theme of *Knowledge*. This theme lay under everything within the patient participant interviews. *Emotional labour* was also a major theme and interacted with five of the themes (including *Knowledge*). Only one theme interacted with *Knowledge* alone and that was *Symptoms*. Within all themes (except *2 Week Wilderness*) there are also subthemes, and these are all described below.

Themes and Subthemes

Knowledge	The C word	Control	Two Week Wilderness	Negotiation and Navigation	Symptoms	Emotional Labour
Cancer	Use of the word Cancer	Pass the Control	-	Trust	Self	Doing emotional labour of others
The System	Communicat ion Context	Decision Making	-	Confidence	Others	Coping (Self) Blame
-	-	-	-	-	-	-

Table 9: Themes and Sub Themes from Patient Analysis

4.4.1 Knowledge

This theme underpinned all the other themes and was something which came out in every interview. It has two subthemes: (1) Cancer, which is about knowledge around cancer and their specific diagnosis, and (2) The System, which is around the participants' knowledge of the health system and their route through it.

Subtheme 1: Cancer

Many participants did not fully understand what cancer was or how it developed.

*"I just had in my head I've got cancer, I've got cancer. I didn't know, I didn't know, didn't understand that you had different, like strains or names for it, just cancers, cancer" **Derek***

The participants spoke about how initially they felt that a cancer diagnosis meant they would die. The concept of cancer spread was also very concerning and was equated with death for the participants. Many spoke about their fear of the cancer spreading during the time they had to wait for results. They were concerned the cancer could develop significantly or spread to other organs during this wait.

*You know, when you're saying that word, you know, it's just, it's hard to explain how it impacts you when you've got cancer, because I don't know how everyone feels but I just thought, "Well that's it. I'm dying. How long have I got?" **Peter***

Most participants felt they did not have enough knowledge of their condition to make informed decisions and wanted to leave treatment decisions with the clinicians who would know more about it. This directly links with the sub theme of decision making in the Control theme (discussed later in this chapter; section 4.4.3).

Interestingly one of the participants (Elaine) was employed in a cancer-related NHS role and often felt that the clinical team treating their cancer overestimated how much she understood of what was happening to her.

“When I see doctors in hospital with my husband I always ask them to talk to my husband, I find that if you work in a hospital people tend to assume you know more than you do and we are all very specialised and I find that if they talk to my husband, a) it means I understand everything and b) it means I don’t have to interpret what they have said to my husband” Elaine

Prior knowledge of others with cancer did not necessarily increase a participant’s knowledge. Whilst some reported prior knowledge of throat and mouth cancers through friends or relatives, they also reported being unaware of the other areas in the head and neck in which cancer could develop. When discussing their understanding of throat and “mouth” cancers the majority were unclear about risk factors for throat cancer but many linked “mouth” cancer with smoking.

“I didn't even know you could have it, never, never heard of it. So I've heard of bowel cancer, breast cancer, brain cancer, skin cancer, bone cancer. I had no idea you could even get it...I knew people who smoked could get it in their mouth...But, you know, I had no idea you could get throat cancer.” Sarah

Many participants were also unaware of the specifics of their own diagnosis; they were often not able to say what they had been diagnosed with, with regards site or whether their cancer was HPV+ or the stage the cancer was at diagnosis. Those that were told the stage, were not always sure what this meant at the time of the diagnosis, and some were still unsure of the meaning at the time of the interview.

“...so we don’t know how bad a T2 is we have no idea...” Ben

“They never really, they never mentioned HPV till a while....till later on in the journey, I kept saying how have I got it, how have I got cancer, I don’t smoke, you know everyone tells you, you know smoking gives you cancer and I said I’ve never smoked, I

never smoked, so how have I got cancer? And they were just saying it was one of them things, it wasn't until later on that they, I can't remember if it was (Macmillan nurse name) or one of them had said do you not know what it is? And I went no I've just been told I have cancer and that's when I was told it was HPV and I still didn't know what that was,..." **Derek**

There was also some discussion over where the cancer came from, and risk factors. Many participants were confused by their cancer diagnosis and what could have been the cause. This lack of knowledge meant some developed their own backstory for the cancer.

"So it's, you know, I don't know what's caused it, stress, certainly wasn't over drinking" **Harry**

Subtheme 2: The System

The System subtheme encompasses the knowledge participants have of the healthcare system; accessing healthcare, what the different clinician's roles and responsibilities are, and what onward referrals meant.

Some participants were unsure when to access the healthcare system; this relates to the theme on symptoms (section 4.4.6) and knowledge around what symptoms to seek help for and when. Participants spoke about how they were unsure of which health professional dealt with different symptoms, particularity for symptoms in the mouth, and were unsure who to seek help from.

"Quite a big lump, uh, in October. And I went and got a GP's appointment [inhales] because I thought it would be quicker than a [stutters] dentist... "Go and see the GP. If it's going to be an antibiotic job, I'll get one from the GP instead of the dentist."..." **Freddie**

Although there is a requirement to make patients aware that they are on an urgent referral for a potential cancer when referring on the "TWW"⁹ many participants reported being unaware of the reason for the referral. Some were unsure if they had been referred along this pathway but recognised that they had been seen at the hospital very quickly.

⁹ <https://www.nice.org.uk/guidance/ng12>

“No, no, I don't think, I don't think they did. Um, whether they thought there was any urgency or not, I'm not sure. Obviously the, the appointment for them happened pretty quickly.” Vincent

4.4.2 The C Word (Cancer, Communication, Context)

This theme, fully embedded within knowledge, also linked with Emotional Labour (section 4.4.7), 2 Week Wilderness and Control. It includes three subthemes; subtheme one is in relation to the *use of the word cancer* within both primary and secondary care. Subtheme two is about the *communication* participants experienced throughout their route to diagnosis. The final subtheme within the theme is on *context* which covers where the diagnosis took place, who delivered the diagnosis and the participant's preparedness for it.

Subtheme 1: Use of the word “Cancer”

Part of the diagnosis of cancer is the use of the word “cancer”. All the participants reported feeling comfortable using the word cancer when talking about their experiences and all but one was happy to use the word when discussing their diagnosis with other people. However most participants spoke about how the clinicians they interacted with across the route to diagnosis rarely used the word and this led to them feeling confused over their diagnosis.

Within primary care interactions, cancer was rarely mentioned as a potential explanation for the symptoms they presented with and the majority of those referred on the urgent cancer pathway (Two Week Wait) could not remember the possibility of “cancer” being mentioned as a reason for the referral. Within the paperwork for this type of referral there is usually a tick box the referring clinician marks to say that the patient has been made aware that this is a referral for a potential cancer. However, most participants referred along this route reported not hearing the word.

“They didn't mention the big C word yet...” Ben

Within secondary care interactions the participants often found that more complicated terminology was used rather than the word “cancer”. This often resulted in confusion with some participants being unsure as to their diagnosis; some concluded they had cancer based on the departments they visited (Radiotherapy and

Chemotherapy ward) which were felt to be associated with cancer, or the types of staff they saw (e.g.: Oncology nurses).

*“It is cancer, because you were in a cancer place so you knew it was cancer. ” **Martin***

*“...I don't know whether it sound picky or foolish – the fact that I am bringing it up that nobody ever told me. I knew pretty much, I kind of think it would have helped on the initial journey, it would have been... Yeah, okay, it would have been hard to deal with, but in one sense easier. Strangely enough I knew what metastatic was, but I think for somebody to say okay, you have got cancer and there are these stages of cancer.” 301-325 **Jerry***

It also impacted their relationships with family and friends as they felt embarrassed to say they had cancer in case they were wrong.

*“I didn't ever tell anyone that I had cancer, because I didn't actually – it sound strange – know for sure myself. The way that I knew was when I started getting appointment letters and letters that consultants were writing to my doctor. And the heading – if you like – was (participants name) T4 Squamous Cell Carcinoma. ” **Jerry***

*“Um, but he... he never said ‘cancer’. And, to be honest with you... but, I mean, at the same time, that day, I had, uh, an MRI organised, lymph nodes, uh, an aspiration organised – which all happened, like, within a week. I had to wait, like, two weeks for the actual results. Um, a bi... he did a biopsy, ... it got into a week and I thought, “Have I got this wrong?” And I went... I even said to my husband... because I went in to see Mr (consultant name) on my own.” **Teresa***

In both primary and secondary care, the participants reported that they felt the potential cancer diagnosis was almost hidden from them until it was confirmed through testing. They reported a feeling of cancer being the elephant in the room. They were sure they had cancer and they felt that the consultant was sure they had cancer, but nobody was communicating it verbally. This impacts on the theme “2 Week Wilderness” discussed later.

Subtheme 2: Communication

The level and type of communication across the diagnostic route was discussed by participants. Participants felt that communication improved as they went through the service. There were more negative comments around communication within primary care and more positive comments about communication within secondary care. Those participants that had presented with less obvious symptoms or who had

experienced a more difficult journey in terms of their diagnosis (e.g. multiple GP visits, being diagnosed with other conditions first) often spoke about their interactions with primary care clinicians involving friction and leaving them feeling irritated. They felt that they were not believed and that their concerns were ignored and dismissed. These participants often felt that the primary care clinician had misunderstood them, weren't really listening during consultations, and actively did not want to see them or speak to them about these symptoms. In contrast, those that had an easier/simpler route rarely mentioned any communication issues within primary care.

Participants also spoke about doubt in their own knowledge (an example of how this subtheme is nested within the overarching theme of *Knowledge*). This was often about initial symptoms in the pre diagnosis stage that they felt were something serious; if the response from the primary care clinician was not as expected (e.g.: the GP did not appear to be concerned about the symptom) then they would doubt their own knowledge or understanding of themselves that something was wrong.

"...yeah and they say yeah we can see the swelling now when I look at you and yet still the doctor is saying impacted earwax...it canna be, earwax wouldn't do that, I wouldn't have thought, but what do I know?" **Anna**

Once the participants entered secondary care most reported that communication improved. Many spoke about their diagnosis being given to them in a positive way, which increased their confidence that this was something they would survive.

"...he said, "Yes, it's cancer." And they told me in such a nice, jolly way, you know, like a positive way? I thought 'oh, well, I'm fine. I'm going to beat this,' you know..." **Isabel**

However, they often reported that the amount of information provided was not always right for them. Some participants felt overwhelmed and bombarded and others felt they were not given enough, so used internet searches to top up their knowledge. Many did not want a lot of information around their diagnosis and treatment, with a couple wanting no information at all. These tended to be older participants and they spoke about just wanting to get through it and being told as little as possible was the best way they felt they could handle the situation. Linked with the sub theme on the use of the word "cancer" (section 4.4.2) many felt that

they didn't always understand the medical terminology used in consultations and in their copies of follow up clinical letters

"I never asked a lot of questions...Never, and I never Googled anything on the internet...Never. Nothing. I think, I think all I wanted to be told was, "We'll get you through it." That's all I wanted to know...No. I didn't want loads of information. I definitely didn't want to start, you know, I didn't even try and analyse, analyse why. I thought, "Well, it's happened to me. I've just got to get through it."..." Peter

Participants also spoke about the information they received about the treatments they were about to undergo. They felt that they were always given worst case scenarios. However, they didn't state whether this was something they felt negative or positive about. They felt that the healthcare professionals were very clear about what the worst outcomes could be for the various treatment options.

"You just can't imagine it. And I have to say, it... that is all they used to talk about – how bad it was...constantly saying, and giving you... and, uh, you know, I had loads of stuff about side effects and..."Teresa

There was a little bit of discussion, with some of the participants, on the way a diagnosis of a HPV positive associated cancer was communicated, although not a huge amount was said on this topic by clinicians. What was discussed was usually around how HPV is a virus and how being HPV positive meant that they had a very treatable cancer. Only two of the participants spoke about the relationship between HPV and oral sex and many did not want to know anything further about the virus than it being a potential cause of their cancer.

"Ben: not really no, they just said it's a virus that's all. Anna: I mean really let's face it you've got it and that's it, I: so it's not something that you wanted to know more about? Anna: I didn't think it was necessary really. Ben: no we had it and that was it" Anna and Ben

Subtheme 3: Context

One of the main points discussed within this sub-theme was the number of people in the consultations. Some participants reported that they felt there were too many people involved at times where it did not feel appropriate, and they spoke about how it added an element of stress to a situation that was already stressful. There was

confusion as to who the people were and what their role was or would be and why they were present at that moment.

“And we felt it was almost like, um, crowd control and not voyeurism, that would be the wrong word to, to use 'cause that would be absolutely unfair but it was almost as though some people involved in those meetings who didn't need to be involved in the meetings because in the early stages, particularly when we were looking at the big facts and figures if you like of what decision to make, I don't think the, some of the aspects of the multidisciplinary team could be any assistance, certainly not to me, at that stage. And (partner) very strongly felt the same in that we just really needed to talk to, whether it was (surgeon) or (oncologist) and get that information.And it was almost like putting extra pressure on you because you were clearly the centre of attention, you're the poor guy who's getting this bad news and we're all there to witness it. Well why are you there to witness it, you know, if you know what I mean.”

Sarah

Many felt that with so many people in the room they were unable to ask questions about their diagnosis. They spoke about how they felt it was important to meet these people and understand their role within their care in the future, but they couldn't understand why they all needed to be there at the point of diagnosis; the sheer number in the room was felt to be a little intimidating.

“...I could well imagine that it could be intimidating, it could well be because clearly you have, um, experts in their own fields and your master of none and so to ask any questions, you could, you know, I could well imagine a lot of people might take the view that, "I daren't ask a question because it will sound foolish," and, you know, maybe a lot of the questions are foolish but if that's what people wanna ask, that's what they wanna ask. And, um, so I, I think it could have been intimidating, it could have been, yeah.” **Vincent**

When asked about how prepared they had felt for a diagnosis of cancer, none of the participants felt that they were prepared; this included those who were referred on the urgent cancer pathway (2 Week Wait) where, as discussed earlier, the referrer is expected to discuss this possibility at the point of referral. For some this discussion hadn't taken place or it was framed as being a very rare occurrence.

“No, no, I didn't. it didn't enter my head.” **Isabel**

“I had the leaflet saying, you know, urgent cancer referral but you read the bit at the bottom that says does this mean you've got cancer and she said, "No. 90% of people don't but it's, it's a precaution." So I even went down to the hospital on my own, um, saw (clinician name)” **Richard**

Whilst some of the participants reported that they had researched their symptoms prior to entering secondary care and read about the possibility of a cancer diagnosis they still felt that they were not prepared for it. Some participants described themselves as positive people so the thought of potentially having cancer went against their positive nature; others felt that their lifestyle meant they “*didn’t fit the category*” for this type of cancer.

4.4.3 Control

This theme, as with all themes, was embedded within *Knowledge* but also crossed over with *The C Word* (section 4.4.2), *Emotional labour* and *Negotiation and Navigation*. There are two subthemes; 1.) *Pass the Control* which relates to how participants felt they had to take control whilst within primary care but once their care moved to secondary care, they were able to pass control over to the clinicians and they would take a step back and “*go with the flow*” and 2.) *Decision Making* which covers the experience of making a decision within secondary care around their cancer treatment.

Subtheme 1: Pass the Control

Participants often spoke about how they felt they had to make more of an effort to get through primary care; this was through repeated visits or through questioning or challenging what they were told by the GP (this is where it links with the *communication* subtheme of *The C Word* theme).

“I was quite insistent and I said, “Look there’s something, I can feel something.” Sarah

“You go and all he ever says is take some time off work and that’s it. And I, I just don’t feel like he listens, and I don’t feel like he acts upon things like he should. And, I’ve said this for years. Not just with this, with a lot of things. It’s a waste of time going to see him. He can say what he’s going to say to you before you even get in the room.”

Anna

“I’m very pleased that I personally pushed it with my GP because we could have waited six months to just, kind of, keep it under review and I think it could have cost me, a lot more, erm, in treatment terms, because I think it could have obviously may have spread.” Harry

However, once they were in the secondary care system, they reported that they didn't need to put in as much effort. They described a feeling of relief at being under the care of a specialist. They reported a relaxation and handing over responsibility for their care to the clinicians.

"I didn't feel the need to have – at that point [once at the hospital] – any control."

Jerry

"I just wasn't that bothered really. You know, what, you know, the treatment. You're in the hand of the experts. They're going to provide the treatment. They have analysed it to give you the best treatment possible. I felt comfortable so let them, when I say, let them get on with it based on their judgement –" **Kevin**

Subtheme 2: Decision making

This subtheme is mainly focussed on the experiences of the participants whilst in secondary care, and around treatment decisions. When discussing their treatment decisions many spoke about cancer as something that needed to be cut out of their body as soon as possible. They felt that surgery was better as that guaranteed that the cancer was cut out.

"You know, so I was never worried about the operation...Yeah, just wanted to get on with it and get it out, yeah. Yeah. Yeah.....But um, yeah, the, they obviously they discussed the risks and everything but um, I didn't really worry about anything at that... just get the cancer out. Just get the cancer out whatever, yeah." **Peter**

"it was also so that I wanted to, in some ways, cut the disease out" **Vincent**

At the point the participants attended secondary care they spoke about how everything "kicked into gear and started to happen". There was little time to process what was happening to them, but the majority were happy with this.

"Well, I kept saying, "This has been a rollercoaster," because it had. It was... it felt really fast. But I don't think more time would have been useful. [Inhales] I don't think more info... I don't you could have taken in more information" **Freddie**

Participants spoke about feeling that treatment had to start as soon as possible to stop the cancer from spreading. However, it was unclear in their accounts where this perception had come from and appeared to be a generally held view that cancer needs to be treated quickly.

"Erm, I don't think, I don't think I did have time, but only because it had - ... - to be done straight away" **Jerry**

However, participants said they found this pace too quick to process information about treatment choices, and that this affected their ability to make an informed decision. They were also uncertain about whether they were qualified to make decisions about their care as they had less knowledge than healthcare professionals. Some described understanding that their decision was between doing as the HCP said and dying.

“Oh, yeah. But if you want this treatment and you want to live, you do what they tell you, don’t you?” Noreen

4.4.4 2 Week Wilderness

This was a smaller theme but highlights a specific part of the route to diagnosis and the impact this part had on the participant. Again, it is imbedded within *knowledge* (section 4.4.1) but crosses over with *The C Word* and *Emotional Labour*.

“That was the worst time ever, erm, there were a lot of dark spots during that two-week period” Harry

Many of the participants spoke about the period between initial biopsies/tests and the actual cancer diagnosis. They spoke about this as a very difficult and stressful time. They understood they were under investigation for cancer, and some felt that that they understood at this stage that it was likely they were going to be diagnosed with cancer, but they didn’t know for certain. As they were unsure of their diagnosis many reported how they didn’t talk to or meet with friends or family during this time. They did however feel like they had to continue with normal life; going to work etc. with this potential diagnosis.

“– sent, sent for tests and that must have been, maybe it was two weeks, and it could have been up, up to a month and all that... that’s a... that’s the... the hardest thing is waiting for, waiting for tests and then waiting for results. And not knowing exactly what you’ve got and where you stand, really. So, mentally, all the way through it, the mental side of things is a lot – more difficult than any of the um, than any of the treatment, really.” Peter

“I think one of the things I found harder was as I said, it’s a bit like a slow car crash. In some respects, I can see that might have been good in terms of it gave you time to get your head around it. But that period of waiting to find out, I suppose it’s easier when somebody just comes and tells you, you’ve got cancer. Like with a breast lump it’s going to be cancer and you move on.....I knew it was cancer. I didn’t want to go

back to work when I couldn't tell people I knew it was cancer. I couldn't do the smiley face thing, either. So I'm sort of in that torn thing.” Elaine

4.4.5 Negotiation and Navigation

This theme once again is nested within *Knowledge*; it also links with *Emotional Labour* and *Control*. There are two subthemes: 1.) *Trust* covers the participants' trust of healthcare professionals as they move through their route to diagnosis. 2.) *Confidence* is around the participants' feeling of confidence in their interactions with healthcare professionals but also their confidence in the healthcare professionals and the system they are in.

Subtheme 1: Trust

“Oh yeah, I didn't trust them [GPs]. I trusted the people at the (hospital name) but to a degree” Sarah

Trust was a theme that came through in all of the participant interviews. The level of trust increased as a participant moved through the pathway to diagnosis, with trust of primary care clinicians being much lower than that in secondary care clinicians. Trust was spoken about in two different ways; the level of trust participants had for the clinicians and how this trust was impacted by their experiences from first noting symptoms to the diagnosis. Trust was described as being able to talk to the clinicians and feeling comfortable in their presence.

“What is it about the surgery that makes you trust them?” “They're nice, they talk to you, you can have a laugh, do you know what I mean? Er, and basically you have a bit of a joke... it's just, you know, normal banter. Yeah.” Martin

Some reported a lack of trust in GPs due to how overworked they perceived GPs to be and because they are generalists rather than specialists. Those who had a long-term relationship with their primary care clinician were far more likely to speak about trusting their GP. This trust continued through the diagnosis and beyond treatment, with some participants using their GP to “translate” the clinical letters they received from secondary care.

“No...That's why... well, that's why they're GPs isn't it? They're really like, jack-of-all trades, aren't they, a little bit? That's why... obviously he, he referred me straightaway. I mean, he said, “I'm not sure what this is.” ...No, I've not got a lot of

faith in GPs and I think they're um, obviously they're um, they're over, overwhelmed with work load, aren't they? And I feel like all they want to do is write, write you um, a prescription and give you some tablets, so..." Peter

Those who had a longer or more difficult route (e.g.: multiple trips to primary care, difficulties in communication with primary care and/or a feeling of not being believed) felt their trust of primary care was greatly reduced. Some reported that they would not return to the same GP or even changed GP surgeries. There was often a lot of anger about difficult routes, even years after the event.

"No. I would never go back there." Sarah

"I was just angry, I was pretty angry to know that all these medical professionals had missed it and yeah sometimes I understand like a GP because they are general practitioner but when you've got 5 different GPs, looking and checking and just now I think could one of them not have thought this is, you know this is more sinister"

Derek

When discussing their experiences within secondary care, consultants were almost viewed as being "like gods". Despite discussing some instances where things had not gone right (e.g. confusion over their diagnosis etc.) participants only viewed these secondary care clinicians in a positive light and felt that they had saved their lives.

"...and they are like gods to me know these people, because these are the ones who helped us..." Derek

Some participants spoke about needing to trust these clinicians as they were the people who were going to help them get through the cancer diagnosis.

"...just his manner...I think, you know, really experienced and he was really confident...But I had to trust him, I guess, didn't I? And I did, 100% trusted him." Peter

Subtheme 2: Confidence

Many participants spoke about how they felt there was a correct way to behave in the medical environment. They equated this with being someone who was an infrequent GP attender and was uncomplaining, and not too outspoken.

"yeah and I don't tend to go in saying, I've got cancer I think I'm dying, I tend to go in and say, I've got a problem, it's probably nothing erm but I'd like it being checked out, erm in my experience that seems to have a better out than somebody coming in and telling you what they think it is and expecting the doctor to do what you think, does that make sense...?" Elaine

“...not one of these, kind of, you know, habitual people who go a lot, I tend not to, because I tend to be quite fit, active, erm, still felt fit and active” Harry

However, some participants (particularly those who had a more difficult route) described feeling that they needed to ‘push’ their GP to believe them and/or do something such as refer them for tests or to see a specialist. This required a level of confidence to break out of the mould of being a “good patient” and it also meant the participants had less confidence in primary care more generally.

“And by then I was past caring what anybody thought of me” Anna

“erm, I didn’t feel I needed to have stamped my feet like that and it always worries me that if someone like me has to stamp my feet, other people who are not as assertive as me will get treated badly and this is normally what I tend to say, this isn’t acceptable. It’s alright for me to stamp my feet and get my own way but if you are treating other people that way, they won’t” Elaine

Those participants who went to see a dentist with their symptoms often made an initial check of the dentist’s expertise through online sites and recommendations from friends and family (no-one spoke about this with regards their GP). This process increased the participants’ confidence that they were going to see someone who would be able to help them.

“And again, everything is done online nowadays and you research. And everybody is so knowledgeable about this that and the other, so I did look. Because there is a dentist within a minutes’ walk from my front door and I looked at that and looked at the reviews – the dentists trip advisor, kind of thing.” Jerry

4.4.6 Symptoms

Although it is embedded within knowledge, this is the only theme which does not overlap with any other theme. It covers how the participants viewed the symptoms they were experiencing (subtheme 1.) *Self*) and the impact of others view of their symptoms (subtheme 2.) *Others*).

Subtheme 1: Self

Most participants interpreted their lack of pain alongside symptoms as a sign that there was nothing to be concerned about, and therefore that the symptoms were not a serious problem. In contrast, those participants who did have pain or discomfort

were far more likely to see their symptoms as a sign of something serious and sought help quickly.

“It was a big lump but there was no pain with it or anything like that whatsoever, that’s the thing, you see. I would’ve thought there would’ve been pain but there wasn’t” **Larry**

“...so I went to the GP and said I’ve got the lump I know it’s possibly nothing erm but I’m just conscious that it’s there and its painful and it doesn’t seem to be going, so I hadn’t noticed it growing or anything it is uncomfortable and I’d just like to get it checked out.” **Elaine**

Lumps were not automatically equated with cancer in this group, and therefore did not raise a cause for alarm. Participants spoke about how minor colds and infections often caused their glands to swell so they viewed neck lumps as not serious.

“I’d had a bit of a bad cold and, er, I just noticed that I thought me glands were a bit swollen” **Richard**

Swellings in the oral cavity were assumed to be due to teeth and again, were not viewed as serious.

“And I had, uh... I had had an infected salivary gland in more or less the same place, so I thought, “It’s a recurrence of that. I’ll go and see the dentist.” And it kept going down and coming up again, and it seemed to be corresponding to the sore tooth...So, I thought, “Yeah, that’s what it is” – self-diagnosis, of course...” **Freddie**

Many participants reported feeling fit and well whilst having these symptoms which confirmed their feeling that the symptoms were nothing serious.

“...because I tend to be quite fit, active, erm, still felt fit and active....” **Harry**
“Well I felt fit, I had no pain...” **Anna**

Symptoms were often rationalised away mainly due to them being so like ones experienced previously by themselves or others which had not been serious or were explained as being linked to their working environments.

“I was on a dirty job and I’d just been moved to a new job and it was a dirty job with dust and... just all really horrible stuff and everything, you know? So, it wasn’t ‘til I started to get like sort of... well, my adenoids had swelled up, which just was a symptom I thought of where I was working. I didn’t know it was a symptom of this...” **Gordon**

“I was stopping smoking and I was coughing more than normal but I thought it was just stopping the smoking.” **Isabel**

However, it is worth noting that two of the participants felt that although their symptoms did not feel serious, they had a feeling that something was not right with their body.

“Erm, I was concerned, as an individual, because I know my own body and, erm, it didn’t feel, it didn’t fit quite right with me.” Harry

Whilst experiencing symptoms some participants attended routine appointments with their dentist but did not mention symptoms they had as they did not feel it was something to discuss with them. Many participants said that it had not occurred to them that a dentist may be someone they could/should discuss oral/neck symptoms with.

“I went to the dentist and she examined the ulcer and she was very particular and she did examine my neck presumably checking for lymph nodes under my neck and this was just before Christmas so I was aware of something and I thought no..no whether she has always checked my neck or I was just more aware, I was beginning to be niggled by the fact that I had a lump in my neck but I didn’t mention it. I don’t think it would have made any difference as it was only a matter of weeks before I went to my GP but I was very conscious that she was checking for lymph nodes in the neck... I presumed if she was checking for lymph nodes she was checking in terms of dental infections rather than... she probably was looking for lymph nodes with malignant causes” Elaine

Subtheme 2: Others

There was some discussion of the influence of other people, although this element was far less extensive than the participant’s discussions of their own symptom appraisal. Four participants spoke about how they discussed their symptoms with family members or friends and listened to their appraisal of the symptoms; however, they did not describe these appraisals as being something which delayed or encouraged their help seeking. In addition, a small number of male participants felt they would have delayed seeking help if their female partners had not told them they needed to go to their GP.

“My wife....there’s always a woman right.....get to the GP, get yourself sorted out you know, especially after it had been going on for 1 or 2 weeks because sometimes it was completely disappearing you know” Charlie

4.4.7 Emotional Labour

Emotional Labour was embedded within Knowledge but also had a cross over with all the other themes (*2 Week Wilderness, The C Word, Control, Negotiation and Navigation*) except *symptoms*. Most participants spoke about the difficulty of dealing with the emotional labour of a diagnosis, and how it impacted most areas of their lives. This could be split into three sub-themes: 1. *Doing emotional labour of other people*; 2. *Coping with the cancer diagnosis*; and 3. *(Self) Blame* around the diagnosis.

Subtheme 1: Doing emotional labour of others

Many participants spoke about their family and friends wanting to be involved in the process of the diagnosis: e.g., attending appointments, tests, being in the consultation room and having questions of their own. However, for some patients this was difficult as it meant they had to deal with other people's emotions at the same time as their own.

"Yeah. Um, I think one, uh, thing I do wish is not telling everybody before I went, [pause] or not saying after I'd been. I... you know, because I think that two weeks while you're waiting for your results is [pause]... you know, I don't think I was worried, in away. I... all you were more worried about is going somewhere else, because I had an MRI, sort of, for my chest and that....Um, but then, uh, you have everybody else worrying with you, which I wish I hadn't have done. I wish I'd have..." **Teresa**

They described the difficulty that resulted from close friends and family wanting to know what was happening to them and wanting to be involved. They spoke about how this was at a time when they were trying to manage a distressing process themselves, and this family/friend interest was an added burden for them.

*"My brother's missus went with me...She wanted to, do you know what I mean?...I think she was more interested to see what.. do you know what I mean? (I: **Was it useful having someone there with you?**)[Pause]. For me? No, not really."* **Martin**

Many described how they would have liked to have gone through the process alone, or with just one close family member as that would have reduced the pressure they felt to deal with someone else's emotional response to their diagnosis.

"I felt like I didn't want to... apart from wife, I didn't really want to um, talk about it too much to anyone else" **Peter**

There was also an element of protecting loved ones from the emotional burden of cancer. Some described delaying telling partners that they were being investigated for cancer until further along the process.

"I did tell my husband that I had a lump but I didn't think it was anything and I would go to the GP, erm my husband travels internationally so he's probably out of the country 2 to 3 weeks out of 4 so I'm quite independent from that point of view and I don't tend to worry him about things he can't do anything about... (Laughter) If that makes sense" Elaine

Subtheme 2: Coping

Whilst many participants described the impact of doing the emotional labour for others, they also spoke about the benefits of having social support to enable them to cope with the journey. These benefits tended to be practical and often related to having someone else there who could try to take in the vast amount of information they were given at each appointment. They could then ask that person to relate information as and when it was needed or wanted.

"...my son in particular's taken a big interest. So he, he read up everything. He had a big awareness of it. Sometimes when I, when I had gone I felt so tired and fatigued that I just couldn't take it all in. I said, "Look, just speak to (son's name). He'll tell me later when I feel a bit better"..." Kevin

Two of the participants had very limited support networks and they felt that there was an expectation from the clinicians that everybody had a support network. They felt that lack of social support wasn't taken account of, and they were not offered any additional support. Again, they mainly spoke about this through the practical disadvantages – for example lack of support in getting to appointments or in collecting prescriptions and lack of assistance with the practicalities of negotiating their diagnosis and treatment as a single parent. Some comfort aspects were discussed too.

"I really wanted a cuddle off my mum and a chat with my dad, but they are long gone, so there was nobody to, um [pause]... [Inhales] I've nobody to fall back on for that, you know...And, uh, nobody else will do [pause], you know, so..." Freddie

"It was horrendous the whole system setup, just the expectation that you've got a massive support network doing everything for you and all you have to do, well in fact you don't even have to do it, there's someone bringing you. I drove myself to the hospital every single day. I was on morphine. I was off my head. I shouldn't even have

been in the car. It was the only way to get there. So the whole system, everything is set up for expectation that people are doing a million and one things. It doesn't work like that. And everyone just disappears into the woodwork.” Sarah

Normalizing their diagnosis helped many participants. They spoke about how their own diagnosis made them more aware of others who had a similar diagnosis. They described how this helped them cope as they were able to see others who had completed treatment. They were also able to compare themselves to others who they felt were worse off than they were.

“Yeah, it was something... it was, like... when I... when I got it, there were so many people going, “Oh, so-and-so and so-and-so had that. “And I thought, “Hang on. It’s, like, so common.”...” Teresa

Positivity was an important coping strategy for many participants, and many spoke about how they had to stay positive to get through this process. There was a feeling that staying positive would help with survival, whereas negative feelings were considered a sign of giving up. This added another level of emotional labour as the participants felt it was less accepted to share any negative thoughts about their diagnosis and treatment, positivity was viewed as vital to get through the diagnosis and treatment.

“I found that a positive mind set half the battle” Charlie

Several participants - particularly those with a HPV+ diagnosis - spoke about how they coped with their diagnosis by restricting the amount of information they were exposed to. They were happy with the basic facts and did not want to know anything about the aetiology of the cancer.

“so finding out more about it wasn't going to help me. And, um, it might just do the opposite, it might just do the opposite. And so I genuinely didn't go and look it up, didn't research it, you know. I think I got enough information for what I wanted there and as I say, I could have got more I'm sure had I wanted but..... you know... All I had to do was, from my point of view, was get my head down and see my way through the battering that I was going to get, you know, and that was the reality, yeah.”

Vincent

Subtheme 3: (Self) Blame

During the interviews many participants felt that they needed to justify their health behaviours prior to their diagnosis, when discussing the cancer diagnosis with other people (friends, work colleagues etc.) and during the interview with me. They

explained in the interview that they had never smoked or emphasised their level of fitness/healthiness. Many described previous fitness related achievements.

Some reported that they were often questioned about their smoking history when explaining their diagnosis to friends. Those who had smoked felt that they were to blame for their diagnosis, and they felt embarrassed when informing people of their cancer.

*"I remember everyone saying when I said I've got cancer in my throat, everyone, every... 100% apart from people who know me said, "Oh, do you smoke?" And I... I've never smoked in my life. Like it, almost like it's, like you've brought it on yourself. Maybe people think, "Oh, well, he must be the smoking... it's, um, the result of smoking. It can't be anything else," you know? **Peter***

*"So, probably because I smoked, I got cancer. I sort of deserved it [laughter]...And... and it... it's like [pause]... they don't... I mean, I always had that at... at the... you know, if I got a bad cough or I had a cold, it was because I smoked...If anybody else gets a cough or a cold, it's because they've got a cold or a cough. It's not [laughter]... [Laughter] yeah. And it, uh... that annoys me a bit, you know... No, nobody has ever said that – "You deserve it." But, in a way, I sort of feel like I do a bit deserve it."
Teresa*

When trying to make sense of where the cancer may have come from, many felt there was a lot of uncertainty and confusion in society's "knowledge" on how cancers develop in general. This was seen particularly with those who identified as being "fit and healthy".

*"I just... you automatically everywhere tells you smoking causes cancer, you can't smoke, now they are saying alcohol causes cancer, now they are saying obesity, but in my head all I remember saying was but I've never smoked, I've never, I've kept myself fit and active and I just couldn't deal with it, I've just... something hit us which I've had no control over and that's how I, that's how it affected us I think."
Derek*

Some spoke about how they felt previous stress may have been the catalyst for the cancer, whereas others spoke about a family history of cancer (although generally not HNC specifically) implicating a genetic component. Overall, there was a lot of uncertainty on this topic.

Sometimes participants ruminated on whether they would have had better outcomes if they had sought help earlier.

"Because even that, in waiting a month to go, maybe... I don't know how much that affected my, my treatment and the outcome. If I'd gone straightaway and been in a

month earlier for the operation, would that... I guess it would have been less for him to, to remove. I don't know." Peter

4.4.8 Participant suggestions for changes to the healthcare system

During the interviews some participants wanted to discuss changes they would like to see within the system. Whilst these cannot be put within the themes, I felt it was important to record them;

1. Introduction of a neck lump clinic. One participant felt that they would have had more confidence attending a specialist clinic at the hospital that specialised in lumps that they could access directly, rather than going through their GP. Part of this was due to difficulties accessing and obtaining an appointment with the GP and part was their feeling that they would be seen by specialists who could have made decisions regarding the lump quicker.
2. Another idea discussed was more centralised care, so patients do not have to move across various sites. The participant who made this suggestion had had to go to various sites for different aspects of their treatment and felt it would have been easier to have one place to attend for everything.
3. The final suggestion was laminated sheets with the names of everybody in the team, what they do and how and when to contact them. The participant who suggested this spoke about being introduced to a lot of people in the initial stages and not feeling able to keep track of who they all were, what their roles were and when, and in what circumstances, to contact them.

4.5 Closing Remarks

As can be seen from these results whilst there were clearly defined themes they did interact and influence each other. Everything was embedded in knowledge; the participant's knowledge and understanding of cancer, their diagnosis, and the healthcare system. A patient's route to diagnosis was not a simple process as was seen by the example routes at the beginning of the chapter. There were many different elements which could make the journey smoother or more difficult. The findings, strength and imitations of this work will be discussed in the discussion chapter 8.5.

Chapter 5: Qualitative Interview Results; Understanding the GPs view and experience.

5.1 Chapter Overview

In this chapter I will present the participant demographics for the General Practitioner (GP) interviews. I will then discuss the themes and subthemes resulting from analysis of the interviews.

5.2 Participant Overview and Interview Context

In total eight GPs were interviewed, 12 GPs agreed to take part initially but three were then uncontactable and the fourth changed her mind about being interviewed. Four GPs were recruited through the Macmillan network and the remaining eight were recruited through a snowball recruitment. They had all referred at least one patient who was ultimately diagnosed with a HNC. Interviews lasted for an average of 36 minutes and took place either on the phone (n=3) or in person (n=5). All in person interviews took place at the participant's place of work. All interviews were conducted one to one. The participant demographics can be seen in table 10.

Participant ID Number	Sex	Location	Number of years as a GP
G18	Male	Essex	18 years
Dr Alpha			
G19	Male	West Devon	Unknown
Dr Beta			
G20	Female	South Tyneside	11 years
Dr Charlie			
G22	Male	Gateshead	24 years
Dr Delta			
G23	Male	Newcastle	32 years
Dr Echo			
G40	Male	Unknown	21 years
Dr Foxtrot			
G42	Male	Durham	17 years
Dr Golf			
G47	Male	Bradford	20 years
Dr Hotel			

Table 10: GP Participant Characteristics

5.3 Thematic Analysis of GP Interviews

Five themes were interpreted from the data; 4 of the themes (*Roles and Responsibilities, Working (within) the system, Patient relationships and Communicating a potential diagnosis of cancer*) were embedded in the 5th theme (*Fear*), shown in figure 11.

Two of the themes (*Working (within) the system, Patient relationships*) had subthemes and these are shown in table 11.



Figure 11: Interaction of GP Themes

Themes and Subthemes				
Roles and Responsibilities	Working (Within) the system	Patient Relationships	Communicating a potential diagnosis of Cancer	Fear
-	“Guidelines are good but...”	Impacts on Relationships	-	-
-	Clinical Communication	The Head and Neck Cancer Patient	-	-

Table 11: Themes and Subthemes from GP Analysis

5.3.1 Roles and Responsibilities

There was large variation in what GPs felt their roles and responsibilities were with regards the route to diagnosis for HNC patients. At one end of the spectrum, some GPs considered that their role is solely functional – that is, to suspect cancer and then refer on to appropriate secondary care services, thereby handing over responsibility of the patient to someone else. At that point their responsibilities stop until the end of the patient’s treatment and the patient is handed back into their care.

“...to suspect possible cancer and refer promptly and, and institute get tests done that the hospital might appreciate the result of.” Dr Foxtrot

However, there were other GPs who felt their role was more of a lynchpin - they were the centre of the patient’s care, and held ultimate responsibility for them throughout. These GPs felt their role was to signpost patients to whatever support they may require (emotional, financial etc.) and to be an “interpreter” for the information they were receiving in secondary care. They were concerned that patients can get lost and scared in secondary care and so it was their role to support the patient to navigate their care.

“lots of patients will come back. Because I think when you actually get one thing confirmed, I think often patients just, you know, don’t hear anything more after that. They’ve heard it and then it’s a shock and all the rest of the stuff at the time and they’ll come back and say, well, based on their condition, I think he said they can’t do anything, or they’ll say, oh, they’re going to treatment for this. And so, I think I see that as a GP’s role actually to do that. Whether you do it as a part of cancer care review, um, or just because you think, because I think your patients remain your patients no matter what happens, you know, what happens in secondary care... I think we are the only constant in the whole journey.... That’s a journey because they will see so many different people at the hospital that it’s, I think it’s scary for them, and I think it’s, um, um, er, I think, you know, I think some people get lost in, you know, in the whole process.” Dr Echo

Handing over responsibility to secondary care was difficult for GPs as they weren’t sure what their role should be at this point. There was some internal conflict on how they should progress with the patient as they felt the responsibility was now in someone else’s hands but were aware that the patient may still need their input and support. Once the patient entered the secondary care system, the GP felt distanced from them; they described how they didn’t know what was happening and how the

patient was coping. Some felt that the onus was on them, as the patient's GP, to contact the patient to keep up to date with what was happening.

"...there is a feeling that, you know, you've done your bit, that's the end of it. But if someone's diagnosed with cancer then they're going to need some kind of support and it may be that you're not the right person exactly all the time but it may be that you're in a good position to act as sign posting patients that practical health..." **Dr Foxtrot**

"It's then really an onus on the GP to try and maintain contact with the patient...as they make their way through the pathway." **Dr Golf**

"More often than not, people just get subsumed by the consultant, the CNS, the oncologist, the you know, and they, sort of, and you know, probably mostly rightly so but yes, that then leads to that feeling of disconnect and then really, as a GP, you're sort of, you're waiting for, you know, the end of treatment" **Dr Golf**

Most of the GPs viewed the roles and responsibilities they took on in relation to patients with suspected HNC as very different to those of dentists. They considered that dentists lacked the same sense of urgency in dealing with these patients and had less of a relationship with their patients. This view appeared to be influenced by their view of financial arrangements for dental care. They spoke about how dentists had less incentive to spend time with patients as they were paid based on the number of patients they saw. Although they recognised that dentists' knowledge around oral cancer was greater than their own, some GPs thought that dentists didn't share the same sense of responsibility for the patient as they felt themselves.

"it's a very odd situation really, that, that in a sense a GP is, has got all these urgent appointments but doesn't seem to be quite the case that with, um, with, with a dentist or that's the impression I get from patients that if they say, "Well I've got an ulcer." They say, "Yes, wait two weeks." Or whatever it is. When I think, when, that's, the expectation would be that this is an urgent problem, needs to be seen quickly. Um, and certainly that's what I'll be telling patients" **Dr Echo**

"The thing is they've got a larger number of patients that they cover and they, they rattle through lots and lots and lots of patients every morning, you know, because that's how they get paid. They get paid to see lots of people. So somebody comes along with something out of the ordinary, you know, again, benign things like, you know, if somebody needs, you know, suddenly a filling or extraction and they, they don't have the time to do it, so... Anything out of the ordinary, that throws them off their routine... You know, you don't see them doing anything out of hours and you see them driving much nicer cars than we do." **Dr Foxtrot**

Many GPs also felt that patients were far less willing to go to a dentist about a dental or mouth problem due to difficulties accessing dental care, which they felt was due to a lack of NHS dentists and patients not being able to afford to pay for a dental visit. GPs also felt that people commonly associated attending the dentist with fear, and that this was not the case for appointments with them. This resulted in some GPs feeling that they were taking on things that should be the responsibility of a dentist, and there was concern that they did not have the adequate knowledge to deal with some of these dental problems. When it came to a clear potential cancer, however, then they felt more comfortable and would refer on to make sure nothing was missed.

"...and then I suppose, I'm happy to speak to you about her concerns and she'd [the patient] say, "Well, if I see you, it's free." She said, "Even though I'm on the NHS, if I see the dentist, I get a bill" and um, you know, particularly where I work, some of the areas quite deprived that, that puts people off, you know, even the, the, the NHS costs put them off, a needle phobia, dental phobia, you know, puts patients off the dentist as well. Often they say, and this really makes me sigh. I think we go too far for our patients in our practice, which is a nice problem to have, but not for them. It was easier to get an appointment with you than it is the dentist. I'm like, well this is a joke, you know, we're doing something wrong here. Um, so yeah" **Dr Charlie**

Some GPs felt concerned that their patients may not get the care they needed within secondary care and felt a pressure to monitor the situation so that patients were not lost in the system and understood what was happening to them. There was a feeling among these GPs that many secondary care doctors weren't effective communicators with their patients.

"Often we say...anyway during the referral, so, erm, "Usually if you haven't heard from the, from the department within seven or ten days please let me or my secretaries know. If there's anything... if anything goes wrong or you're concerned see me please after, afterwards." So often they come back and want to discuss letters or... And then we usually ask, "So how was it? Did you think you got good care? Were they friendly? Could you talk to them? Are there any questions?"..." **Dr Alpha**

Many GPs felt that there was a lack of communication between primary and secondary care (described in further detail in section 5.3.3, subtheme 2: *Clinical Communication*) and this meant it was difficult for them to understand what their

responsibility in relation to cancer patients should be. It also impacted their ability to talk with the patient about what to expect at the hospital and then after they had been to the hospital about the potential outcomes.

“So, I think the sticking point about, personally, not just head and neck but everything is correspondence, correspondence, correspondence without that information, we've got no idea what's gone on and we have to rely on the patient. And nine times out of ten the patient's fine and is very reliable, but one time out of ten it is, they are poor communication, or they've got dementia, or they can't remember. Or they didn't understand and then we're left not having the information. And as GPs, we've got, uh, cradle to grave notes. We've got a huge amount of information. We pass on that information as readily as we can to the hospital team, but when it doesn't come back – We're then left with the patient coming back to us going "So what was the outcome doc?" and you're like, "I don't know." ...” Dr Beta

They also considered that secondary care clinicians worked in siloes and were unable to consider the bigger picture, beyond their speciality. They felt that secondary care was so focussed down on in narrow specialities, that if their area was ruled out then the patient was often left without being moved onto the next investigation or speciality.

“...GPs are expected to be masters or know everything but at the hospital, you can get very siloed experience and they only care about their bit of medicine and they're not always very good at looking after the bits which isn't their speciality and there isn't very good systems in place, in hospital, for sharing that kind of thing. So yes, I've seen that, not just with cancer but with other things as well, if they get in the wrong place to get the test, they happen in an ad hoc, slow way, not for the benefit of the patient. I don't know whether I should say that or not but I'm just going to say it anyway [laugh].” Dr Delta

5.3.2 Working (within) the system

This second theme includes two subthemes; 1. *“Guidelines are good but...”* and 2. *Clinical communication*. Overall, this theme was about the ways in which the GPs had to work within the system and the ways they found to make the system work for their needs.

Subtheme 1: “Guidelines are good but...”

The majority of GPs spoke about the importance of guidelines and the need to follow them. There was a general consensus that the time before these guidelines was like the “wild west” with outcomes for patients being unpredictable.

“Er, looking back to the time when, er, the system, the pathways were introduced for two week wait referrals, er, before that time, you know, going back maybe more than ten years when it was introduced – it was very kind of hit and miss, er, both in the surgery about thinking, specifically certain things the guidelines weren’t so clear – and also, about what happened to a referral, you know. Sometimes it would be like where they had a relationship with a consultant er, you know, like your senior partner seemed to get people referred and seen quicker than you did even though your patients were maybe not... were not worthy, you know. They hadn’t got... So going back, you know, to a time when I started here, it was kind of difficult really but now we’ve got some specific guidelines and pathways it’s much more clear.” Dr Foxtrot

They considered that, before the guidelines, outcomes for patients were very dependent on the experience and knowledge of the referring clinician, and that this wasn’t always the best approach. However, although GPs spoke about the importance and need for urgent referral guidelines, they also described many ways in which they felt they needed to override or ignore them. Examples included a “*gut feeling*” that something more sinister was wrong with the patient; when they needed to convince the patient that nothing more serious was going on; and to bypass long waiting lists. They felt the choice was for the patient to be seen in two weeks or waiting potentially over 4 months.

“You, you... Well, yeah, now, confident... I mean with experience and seeing cases over the years you get more confident about, you know, contravening what’s in black and white, in guidelines, blah blah, and you know, it’s well known that, you know, the gut feeling of the clinician is worth a lot. You know, you might... the patient might... My form might say a patient’s had to have had these symptoms for more than three weeks and if they’ve had them for two weeks and you’re really worried about them because there’s lots of other things going on then you just refer them and you explain why you’ve done what you’ve done. You know. And quite often the form tells you to do one thing and then at the other end they say, well why didn’t you do this, and you say, well the form says that, you know.” Dr Foxtrot

In these cases, the GPs spoke about exaggerating the length of time the patient had experienced symptoms to enable them to put a referral through the TWW pathway. Some GPs wrote a referral letter rather than using the TWW proforma¹⁰ so that they were able to describe their concerns in more detail. The GPs spoke about how they

¹⁰ Unlike routine referrals, which may go through triage or referral management services, urgent cancer referrals are sent directly to the hospital’s cancer referral team. Each NHS Trust has a dedicated 2WW office or team that prioritises these referrals. So by not completing this proforma the referral may be delayed reaching the hospital’s cancer referral team.

made these decisions and “worked” the system to aim for the best care for their patients.

*“Yeah. Yeah. I mean I think now I’m at the stage in my career where I’m experienced enough that I can kind of ignore what the proforma says or **make the proforma say what I want it to say**. Even if it doesn’t quite meet the rules, I’ll just tick the box..” Dr Charlie*

There was also a level of fear linked with potential medico-legal complaints if a cancer was missed. This didn’t appear to be a major fear but one which underlay a lot of the GPs’ decisions (see theme *Fear*, section 5.3.5).

Subtheme 2: Clinical Communication

GPs described very clear routes of communication within their own practices and within their peer groups. They spoke about sharing of information and referral decisions, auditing their cancer referrals, and providing support and training to junior staff.

“we are and generally we’ve always been an auditing practice, we’ve always like to share things, we’ve always liked to learn from each other, erm, from that point of view and some characters have got a very, erm, good system for doing that.” Dr Delta

However, most GPs felt that communication between different primary care specialities (i.e.: GPs and Dentists) was almost non-existent. They felt that they both work independently from each other with no incentives for communication nor was communication required.

“...but why they would need to communicate with us to tell us what they’ve done... Maybe getting a copy of their referral form er, would be helpful but I don’t honestly think... Or maybe I’m missing something obvious, but I can’t see why they would need to communicate with us.” Dr Foxtrot

“I mean I suppose the relationships between primary care, general practice primary care and, erm, dentists and local dentists, really throughout my time, they’ve been fairly tenuous to be honest. I mean obviously, sort of, contract changes and things, there aren’t really any imperatives in the systems for us to have very much to do with them. You know, so we tend to work in, you know, we tend to work, very much, sort of, independently of each other.” Dr Golf

Some GPs reported having worked in locations where they shared space with dental surgeries and in other locations where the dental surgeries were a considerable

distance away; they observed that this did not affect the level of communication.

There was one divergent case; this GP reported that their practice had shared space with a dental surgery and that in this instance there was open communication with advice being sought on patients in both directions; unfortunately, this stopped when the dental surgery had to move out of the shared space.

“And the other thing to say is we used to, they've pulled it now, but we used to have a dentist upstairs in the same building who if we wanted to would see, see patients the same day. So sometimes if there's things inside the mouth we weren't quite sure I could always just write a letter. They take it to the receptionist at the dentist and the dentist would have a look. And that was quite nice for me in terms of oral lesions because if, obviously they're much more trained in head and neck anatomy and particularly in the oral cavity then we, than we ever have.” **Dr Charlie**

When considering communication between primary and secondary care, the GPs felt that this had changed over time; specifically, they said that there used to be a good level (in terms of quality and quantity) of communication and that this communication was personal, but that this is now lacking. Some GPs reported that they receive an appropriate amount but that it comes too late to be of use to them.

“I think they do their best, er, but often things take a while getting to us. You know, often the consultant might dictate a letter there and then but, you know, his secretary's off sick and, you know, there's no cover for three weeks and we get a letter too late, you know, to be, you know, it's obviously then filed away for reference but it's all a little bit late...” **Dr Foxtrot**

Others reported that they felt the communication from secondary care was “impersonal”; they spoke about how they no longer had a personal relationship with the secondary care clinicians. A small number of GPs felt that lack of communication from secondary care (and, hence, patient level information) impacted their feeling of connectedness with the patient.

“...you haven't got that same relationship where you can just ring up somebody and ask a question, because it's impersonal, I think the patients do suffer because of that.” **Dr Delta**

“The information that we get back, the feeling of connectedness to that, erm, to individual patients, erm, progress, I would say is limited and then the other thing, which complicates ENT is, often how the services provide ... obviously quite a lot of services are provided on this, sort of, hub and spoke model, erm, so you have that, you know, that, sort of, increased complexity of distance and assessment at, erm, sort of, tertiary units, erm, for instance, that, you know, for detailed investigation, which

then, you know, physically obviously takes patients further away. It increases our disconnect” Dr Golf

They reported that they generally do not know who the consultants working within HNC care are and had not met them. They described how the main route of communication used by both primary and secondary care is letters to the hospital, and from the consultant, with the occasional use of email direct to the secondary care team. GPs felt that this impersonal communication disadvantaged the patient as they were no longer aware of who may be the best clinician for a certain patient.

They also reported being unaware of what would happen once the referral was made and if the patient was diagnosed with a cancer what their journey would be like. They were concerned that this impacted on their relationships with their patients as they were unable to talk their patients through the expected diagnostic process or deal with any potential side effects or problems raised during their journey. This overlaps with the earlier theme *Roles and Responsibilities*.

“...Trying, trying to get a specialist on the phone is a nightmare. (Okay.) Especially somebody who knows the patient. So if, if it’s... especially if it’s something around something as specific as ENT cancer, head and neck cancer...It’s tricky to get somebody on the phone in a secondary or tertiary hospital...” Dr Alpha

5.3.3 Patient Relationships

This theme considers how the GPs view their relationships with patients with subthemes of 1. *Impacts on relationships* and 2. *The Head and Neck Cancer Patient*.

Subtheme 1: Impacts on relationships

The GPs spoke about how trust was an essential part of the relationship with the patient, but this required time to build up. Some of the GPs had been working within their practices for many years and had a good knowledge of local families, often being the GP for two or three generations of the same family.

“I mean, I could, it’s certainly the patient, you know, some of the patients will say, “Well I know you very well.” And I think that, I think that makes a difference because you have a relationship with them and a certain, a certain amount of trust. And, um, er, and I think if I did say to them, “Look, I think you’ve got to see a dentist.” I think they would. I don’t think it’s that they wouldn’t, but I think that probably does relate from your, that, to a doctor patient relation that you’ve got and as the quantitative care you’ve had over the years. I’ve been here a long time and some of my patients

I've known for, well, two generations really. So, I see children of their children, if you see what I mean." **Dr Echo**

They considered that this helped build a good level of trust. The main barrier that they felt impacted trust, and thereby inhibited them in developing good relationships, was GP accessibility. They spoke about how, if a patient couldn't get an appointment or lived in an area with a GP shortage, then they had less trust in primary care generally.

"...we're not, we're not in as high esteem as we used to be. Erm, mainly due to access issues. Erm, but I think when I comes to, comes to actual, erm, decisions around their health I think they do" **Dr Alpha**

They also described trust as being a personal thing: they felt that patients trusted them as an individual (and they backed up this belief based on feedback from practice questionnaires) but they felt that overall GPs as a group were less trusted than in the past.

"...the feedback we get across the medical profession as a whole is usually very good compared to other people in other, you know, other professionals, and certainly usually within general practice, it's high. So, yes, I think, I'm not saying all patients trust doctors or clinicians or their GP, but I think a majority, I think a majority do value our opinion." **Dr Hotel**

"No, I think we are, I think we are locally. Um, I think that, um, uh, within our surgery, we're trusted ...I think there's a lack of trust of GPs because there aren't the GPs for patients to build that, to build that relationship up with." **Dr Beta**

Having an ongoing relationship with a patient was considered important: GPs felt that this meant that the patient would be more open with them and that they (the GP) would be more likely to spot behaviours that may indicate something was wrong.

"it's much easier if you know the patient from previous contact but if you've never met them before it can be kind of hard to, to get the balance right, you know." **Dr Foxtrot**

The GPs also reported that they did not feel that patients deliberately delayed seeking help from them. They stated that, in their opinion, most patients were reasonably knowledgeable about cancer; in particular those who were smokers seemed more aware of the potential for oral cancers. They did however feel that they saw more "worried well", for all issues, than patients who were sick.

“Um, now, the ‘worried well’ who come regularly, I mean, the problem as, as, certainly as a GP is that these patients do get ill, they do serious illnesses, and unfortunately, you have to take, every time they come, seriously. Um, but obviously, what the same time, we also try to do, is to teach them some health-seeking behaviour, like saying that if this happens again, you might be better off trying a bit of some sort of, some gel or something or taking paracetamol for a couple of weeks to see if it goes away. But then if it doesn’t go away or gets bigger then you know you must come back or the sort throat doesn’t go away, you know. So, you’re doing that, and I think that’s probably part of, um, you know, part of, I think that’s part of our role really as a GP to, to, to inform and educate’s the wrong word but to let them have the information so they can make better choices next time, and, um, but also, just to inform them what things are potentially serious.” Dr Echo

Subtheme 2: The Head and Neck Cancer Patient

Some GPs spoke about there being a typical “Head and Neck Cancer” patient who could be easily identified. This was based on GPs’ judgements about who they viewed as being more likely to be diagnosed with HNC; they spoke about how the disease is strongly related to lifestyle factors, specifically mentioning smoking and drinking alcohol.

“I think it’s related to their lifestyle and they know they’re going to be told and they, kind of, almost say, it’s my fault, so I know what you’re going to say, doctor, you know, and it’s all my fault.” Dr Delta

“Uh, compared to, um, colorectal cancers or otherwise, partly probably because our population base has been quite affluent one. Alcohol is a high risk, I think smoking, our smoking numbers are quite small. Um, so I think compared to..... deprived patients. We don’t have a large number of smokers at our practice, or they quit many, many years ago. So, I mean, the factors have reduced that too” Dr Beta

There was less discussion of HPV related cancer, and the “type” of person who may be more likely to have this type of cancer. This archetype could be altered; for example, if the GP had experienced an unexpected case, this then raised their index of suspicion overall.

“Well the, it’s changed. I now have no set, set of, sort of expectation, uh, because I’ve had two young patients, one with none of the classical risk factors that you’d associate with head and neck cancer, um, but in, in general smokers, um, excess alcohol, age over 50, um, you know, would be the sort of like classical high-risk group. Um, however, as I say, I’ve had two, um, quite young patients who’ve then been diagnosed with head and neck cancer, so I think it’s just, you know, you have that thing of, you know, in general which patients are going to be more at risk, but always anything unusual, anything not healing, anything not behaving as expected. Even if they’re young to, to, you know, consider a referral or, or, or signpost them or get a second opinion, you know, around that.” Dr Charlie

GPs also considered that those who were smokers or drinkers were less likely to engage with healthcare and were more likely to delay presenting at the GP due to their lifestyle.

“...the other interesting problem we have with the group, the head and neck cancers, they’re often drinkers and smokers and sometimes they miss their appointments through their ill health, i.e. they’re still sleeping it off and therefore it’s not purposeful, erm, well yes, you know what I mean [laugh]. But yes, I think the fact, if they come to see you, nine times out of ten, they want to get sorted out, erm, yes there’s a few that are incidental, they don’t really want to find things out but then they will often say I don’t want a referral” Dr Delta

5.3.4 Communicating a potential diagnosis of cancer

This theme covered GPs’ experiences of communicating a potential diagnosis of cancer and the difficulties in balancing the need to prepare a patient without causing undue distress.

GPs recognised that the majority of patients referred for a suspected HNC were ultimately found to not have a cancer. They spoke about having to balance this knowledge with emphasising the importance of attending further appointments whilst also trying not to cause undue anxiety over the (small) possibility that the symptoms may be due to cancer.

“Well, we... I think, I think every GP has probably, probably has its own way, but, erm, I usually, erm, say... have to have... a stern line that if it’s, if it’s hoarseness then it needs to be checked out. Erm, so that there’s none... and I would say that so there’s nothing serious going on. I think that’s, erm, that’s an okay, erm, okay description. Because that’s the last thing you want to do is overly scare the patient, but, erm, but I think that you’re taking their concerns seriously, that you’re responding, responding to their concerns and that you’re, that you’re concerned that anything not, erm, not particularly cautious going on, erm, I think is probably appropriate.” Dr Alpha

The majority of GPs felt that using the word “cancer” was very important but that it had to be done in the right way, framing the risk so that patients were aware that the chance of the symptoms being cancer was very low. They said that the term “cancer” was always used by them in context of “this is what we are trying to rule out” and against a background of the low level of risk; they described letting patients know it was a possibility but a rare one.

“you have to always give people hope, erm, and sometimes you’re 99.9% certain it’s cancer but you will still say that it needs to be excluded, yes, let’s be blunt...It’s a warning so they take it seriously and a warning .” Dr Delta

Some GPs felt that the word “cancer” should only be used after the patient had broached the subject, whereas others felt it was important to be very clear that this was a potential diagnosis that would be explored further.

“...I tell all mine very clearly, I may upset some of my patients by doing that but as I say to my patients, I say it’s best to be honest about what’s going on, because, you know, if they’re going to have cancer, they’re going to have cancer and if they’re not, at least they know they’ve been taken seriously, erm, and a lot of patients say to me, not knowing is worse than knowing I’ve got cancer. Knowing something is wrong but people not doing anything about it, that’s more frustrating for people. So people are used to me being blunt or to the point, hopefully in a caring way but, you still mention the word cancer, rather than pussyfooting around and I will mention it, yes.” Dr Delta

They described that being confident to use the word “cancer” was something which developed over time and over their career; those who had been in the profession longer felt that they had developed in confidence and skills over time.

“I don’t think I used to, but I think using, I think it’s come over the years, I’ve certainly, I think when I was younger and less confident and less experienced, but if you’re not careful, you talk using euphemisms like growths and abnormalities, and I don’t think that’s particularly helpful. U-u-usually patients are worried about cancer, and I think if you bring it up and articulate that clearly with them, I-I’ve never had a particular issue with it.” Dr Hotel

Most GPs felt that patients were worried that cancer was a potential outcome and that it was their underlying fear even if they didn’t say this to the GP during their appointment. GPs felt that cancer was the “*elephant in the room*” and getting that worry out in the open helped progress the consultation.

“Oh yes, I’ve been doing [it] so long I don’t mind. And I think often it, it can be, if, if you don’t, it’s often just the elephant in the room, you know, the patients very rarely just come at the first sign of anything and have often thought about it, discussed it with other family members, had the pharmacist have a to look at it, read up online, you know, it’s, it’s a different sort of world now. So you know, if, if they’ve already read up their symptoms and signs and y-y-you might know it’s a possibility but didn’t want to bring it up and then you don’t bring it up but say, “Oh, I’m sort of maybe going to refer you.” And it, it it’s just better to be, in general, uh, just upfront and you know, have it out in the open as a possibility.” Dr Charlie

The GPs felt that the majority of patients were prepared for a potential cancer diagnosis; they described that, for some patients, this appeared to be an acceptance

that cancer was always a possibility due to their lifestyle while for others cancer seemed to be something they often feared when seeking help for their symptoms.

“Yes and I think a lot of them, I think it’s related to their lifestyle and they know they’re going to be told and they, kind of, almost say, it’s my fault, so I know what you’re going to say, doctor, you know, and it’s all my fault. So speaking about head and neck, that’s the majority that I would see...” **Dr Delta**

“Er, it all depends. There is some very well informed patients, some that worry about cancer when, when you, you kind of laugh that it’s something, you know, how could they possibly think that was cancer, you know. It’s a huge variation, really” **Dr Foxtrot**

Most GPs observed that there was an increase in patients using the internet for information prior to an appointment and this helped frame the discussion and their concerns. They felt that the majority of patients were able to discern reliable sources of information.

“No. I quite like it when my patients have an, have an idea of what, what might be wrong with them. I think expectation is a good thing, because you can have a better discussion with them...I don’t mind. If they bring it up that’s fine and if they say, “Listen, I’ve Googled it,” and they always usually say, “I’m sorry about that, but I Googled it.” I say, “No, that’s absolutely fine.” And then you can actually have... they have a spread of potential diagnosis they want to make sure that are being addressed. And if those are being addressed that’s, that’s helpful for them.” **Dr Alpha**

All the GPs mentioned the importance of safety netting, in the context of making sure potential cancers were not missed or symptoms were ignored but said that this looked different for different patients. This might involve phoning the patient to check on symptoms or checking-in to make sure onward referrals were attended.

“safety netting is one of the most important things that a GP can do...So to make sure that before you leave you have a negotiated agreement of what’s happening next...So if it continues for, I don’t know, another four weeks, come back. If it gets worse, come back earlier. If you start having additional symptoms definitely come back very soon. If everything goes away and everything happy and nothing else changes, wonderful. If things come back, come back. So it’s important that you have a negotiated agreement around how to take things forward for me, even if you’re not concerned...It’s, it’s one of the most important pillars of General Practice” **Dr Alpha**

Some patients required very little; the GP was confident the patients would return for a follow-up appointment if they needed to. In contrast, GPs felt that other patients were at a higher risk of not returning so various safety nets were available and could be put in place, including following up with the patient by phone or email

or making sure follow up appointments were booked in advance of the patient leaving the surgery.

“...and some patients, I would tell them to come back in two weeks anyway because I really cannot trust them. In a sense, where I can trust them, I don’t, I don’t know them well enough or there’s something about their previous behaviour or because, just because I know them, I feel that the only way I can be absolutely sure is that, or I will say to them, “In two weeks’ time, I will ring you and check you.” To say, “Look, has it gone? Or is your throat better?” Or whatever it happens to be. I mean, those are few and far between. I’m not saying those are the majority but they will be some patients where you have to do that...” **Dr Echo**

GPs said that having an ongoing relationship with the patient enabled them to make appropriate safety netting plans and to understand how best to communicate with the patient. When the patient was new to a GP, the GP was often more cautious as they had no understanding of the patient’s needs and how best to communicate with them.

“I mean, I could, it’s certainly the patient, you know, some of the patients will say, “Well I know you very well.” And I think that, I think that makes a difference because you have a relationship with them and a certain, a certain amount of trust. And, um, er, and I think if I did say to them, “Look, I think you’ve got to see a dentist.” I think they would. I don’t think it’s that they wouldn’t, but I think that probably does relate from your, that, to a doctor patient relation that you’ve got and as the quantitative care you’ve had over the years. I’ve been here a long time and some of my patients I’ve known for, well, two generations really. So, I see children of their children, if you see what I mean. So, yes, I think, um, so I think there’s probably that.” **Dr Echo**

Most GPs reported that their patient communication skills had improved with time, experience and practice.

“I think I’ve got better with it, better at it over the years, and I think it’s surely something that experience helps with.” **Dr Hotel**

5.3.5 Fear

This theme lay under all the other themes and influenced them. There was a feeling of fear which ran through all of the GP interviews and whilst it was not all encompassing it was always there and affected behaviour, thoughts and decisions, and was expressed either directly or indirectly through how they spoke about their experience with HNC patients.

GPs spoke about how the fear of potentially missing a cancer influenced many of their decisions. Some mentioned cases where they had missed a cancer diagnosis and this single case stayed with them and often raised their index of suspicion for future patients. GPs described uncertainty and difficulties in spotting symptoms of potential HNCs. In the “Roles and Responsibilities” theme (section 5.3.1), this fear affected what the GPs perceived these to be. In the “Working (Within) the System” theme (section 5.3.2), fear of missing a cancer was evident in how GPs spoke about their use of guidelines and overriding the guidelines to refer patients who did not meet the criteria.

“I mean I suppose when I say a fear, erm, it’s sort of managing the uncertainty of general practice...the fear is not, erm, not identifying, not acting on and not making a referral that, erm, makes, erm, of a patient that is seem to me, two-week wait guidance, that’s probably a much deeper and much more powerful fear” **Dr Golf**

Linked with this was a fear of litigation. Some GPs described the way they worked as “defensive”, meaning they made sure they fulfilled all the requirements for a potential red-flag symptom. This is alongside the behaviour described earlier where GP’s spoke about being willing to “make the proforma say what I want it to say” and was another element of making sure a cancer wasn’t missed. However, whilst the previous behaviour was motivated by a need to get the patient into secondary care quickly this behaviour appeared to be motivated by a fear of missing a cancer.

“We, we, we apply, you know, defensive medicine as well and if it says there in the guidelines and you’ve not followed the guidelines you, you’ve got to have, you know, a lot of confidence not to sometimes.” **Dr Foxtrot**

Litigation was something which was felt to be more common in general practice nowadays and whilst the GPs themselves did not suffer financially, they spoke about how any litigation resulted in very stressful situations and was destructive to long-established patient relationships. Some spoke about how this fear added an extra pressure to how they perceived their roles and responsibilities (section 5.3.1). GPs felt that they had to make sure that they had practiced in a way which would not result in a potential lawsuit, and this sometimes meant that they took on more roles than required. An example of this was seeing patients with dental problems rather than turning them away and facing the potential risk that the patient won’t attend a dental appointment and their condition may worsen.

“in the present day obfuscation and things, I think it’s what you write down in your notes is also very, very important because if you don’t say that the patient, told the patient to come back in two weeks, you know, risk of serious problem or something like that, then I think you are leaving yourself open to the charge that, because unfortunately what you say is hearsay, what you write down is evidence.” **Dr Echo**

The fear of litigation was also evident in relation to the “Clinical Communication” subtheme (section 5.3.2) and related to GP surgeries undertaking internal audits on cancer diagnoses. They spoke about conducting audits so they could identify anything they could have done to identify the cancer more quickly or to improve the experience for the patient.

“There is and the other thing that we do, is that, erm, before I took the cancer job up a few years ago, we’ve always ordered our cancers and looked at how do we diagnose them, could anything have gone better, what was unusual, what could do better and then we share that, as a group and sometimes we find, as a group, we don’t follow the referral criteria and by raising it and discussing it, then we’ll hopefully educate everybody for the next year, that they’re a bit better” **Dr Delta**

In relation to “Communication of a Potential Diagnosis of Cancer” (section 5.3.4), GPs described how fear of litigation could adversely affect patient communication. The fear of facing litigation for missing a cancer meant that they felt a need to document every decision and how going against the guidelines and using their own judgement took a huge amount of confidence.

“We, we, we apply, you know, defensive medicine as well and if it says there in the guidelines and you’ve not followed the guidelines you, you’ve got to have, you know, a lot of confidence not to sometimes.” **Dr Foxtrot**

GPs also expressed a fear of upsetting patients. This fear lay under all their patient communications and impacted how a potential diagnosis of cancer was communicated to a patient and how relationships were built (as can be seen in the “Communicating a potential diagnosis of Cancer” theme; section 5.3.4).

“Because that’s the last thing you want to do is overly scare the patient, but, erm, but I think that you’re taking their concerns seriously, that you’re responding, responding to their concerns” **Dr Alpha**

Within the “Working (within) the system” subtheme “Clinical communication” (section 5.3.2), GPs spoke about the fear of looking stupid. This was more of a concern for more junior GPs and the more senior or experienced GPs reported

feeling this concern in their early days of working. This concern related to sending an inappropriate referral to secondary care and their clinical expertise being judged on this basis. They spoke about how this fear could impact some (although not many) referrals.

“...because when you have clear guidelines, I think it’s always easier to, um, to have something to base your referrals on because what you do is look silly and by referring things which are, which are, which are very benign or which the history isn’t quite right.” Dr Echo

Finally, there was some more limited discussion, by one GP, about the fear of negative press, whether this was the result of legal action or a patient speaking to the press about a missed cancer diagnosis. It is worth noting at this point that another GP declined to take part in the study as they were concerned that I may be a journalist after a story on missed cancer diagnoses.

“I think, you know, it would be very good for the press, you know, especially, certainly certain papers, probably be the Daily Mail [laughter], to sort of recognise that the GP, they’re dealing with uncertainty all the time...” Dr Echo

5.4 Closing Remarks

These results show five clearly defined themes which interact with at least one other. Four were fully embedded in the fifth theme *Fear*. The GPs role is not clearly defined and they are required to find ways to work within the current system to achieve the required next steps for their patients. They describe the importance of relationships with patients and other healthcare providers and balancing clear communication without creating anxiety. This is all impacted by an underlying feeling of fear around missing a cancer, litigation, upsetting a patient and looking stupid in front of secondary HCPs. The findings, strength and limitations of this work will be discussed in the discussion chapter (Chapter 8).

Chapter 6: Qualitative Interview Results; Understanding the Dentists view and experience

6.1 Chapter Overview

In this chapter I will present the participant demographics for the dental participants. I will then describe the themes and subthemes resulting from analysis of the interviews.

6.2 Participant Overview and Interview Context

In total 12 dentists were interviewed; 3 were community dentists, 3 General Dental Practitioners, 4 Hospital dentists and 2 worked as Hospital dentists and General Dental Practitioners. They had all referred at least one patient who was later diagnosed with a HNC. All the dentists were fully qualified as per the inclusion criteria. Interviews lasted for an average of 36 minutes and took place in person, either on the university premises or within their clinical practice. All interviews took place one to one, except participant D37 (Dr White) who had a student dentist with him, and he requested they stay for the interview. The student did not answer any questions, and any comments made were removed from the transcripts and were not included in the analysis. The participant demographics can be seen in table 12.

Participant ID Number	Sex	Location	Position
D03 Dr Red	Female	Sunderland	Community Dentist
D04 Dr Green	Female	Sunderland	Community Dentist
D05 Dr Yellow	Male	Sunderland	Community Dentist
D08 Dr Blue	Female	Newcastle	General Dental Practitioner
D10 Dr Purple	Female	Newcastle	Hospital Dentist
D11 Dr Indigo	Male	Newcastle	Hospital Dentist
D12 Dr Violet	Female	Newcastle	Hospital Dentist
D13 Dr Orange	Female	Newcastle	General Dental Practitioner
D14 Dr Turquoise	Male	Newcastle	Hospital and General Dental Practitioner
D16 Dr Pink	Female	Newcastle	Hospital and General Dental Practitioner
D17 Dr Black	Female	Newcastle	Hospital Dentist
D37 Dr White	Male	Northumberland	General Dental Practitioner

Table 12: Dental Participant Demographics

6.3 Thematic Analysis of Dentist Results

Six themes were interpreted from the data (*Knowledge, Professional Role, Reputation and Responsibility, Trust, Relationship with Patient, Clinician-Patients Communication and Co-ordination of care*). Each theme interacted with at least two others, with *Trust* being the

theme which interacted with all but *Knowledge*. One theme *Relationship with Patient* was fully embedded within the *Trust* theme. The theme interactions are shown below in figure 12. Each theme had subthemes, and these are shown in table 13.

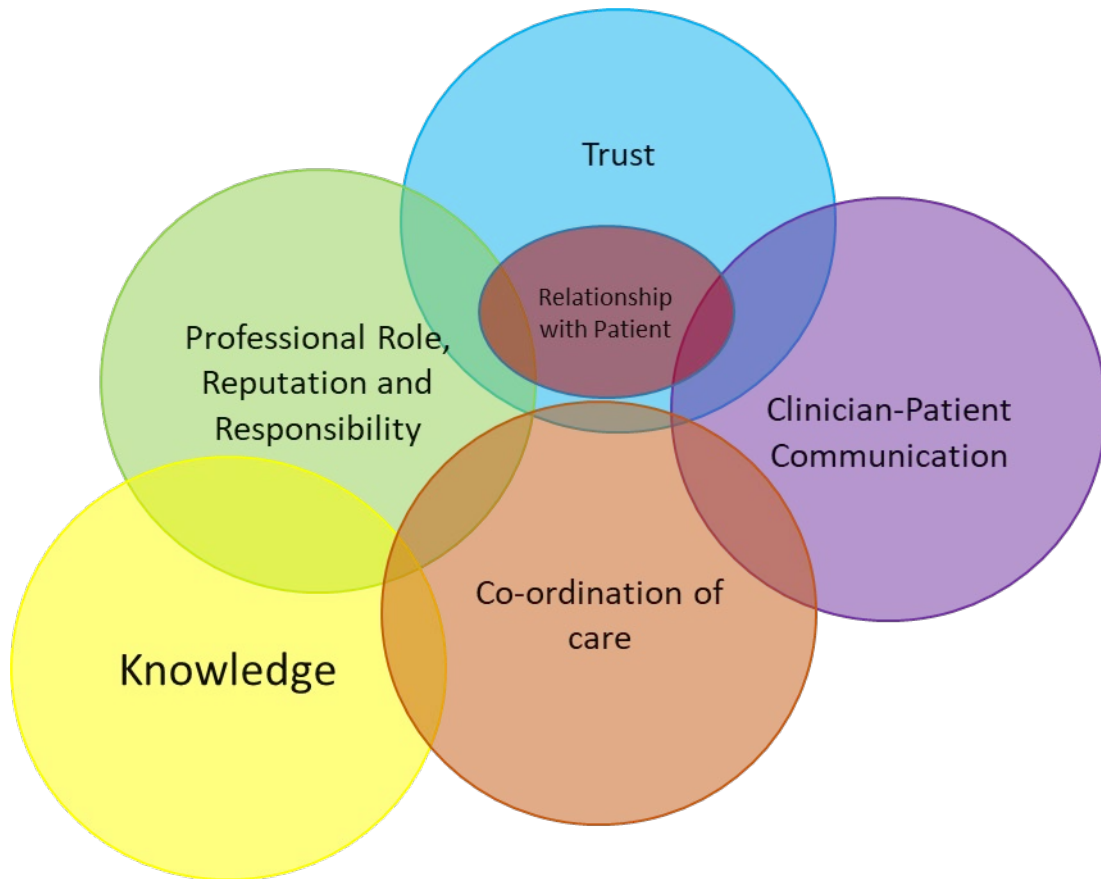


Figure 12: Interaction of the Dental Themes

Themes and Subthemes					
Knowledge	Professional Role, Reputation and Responsibility	Clinician-Patient Communication	Co-ordination of Care	Trust	Relationship with Patient
Clinical Knowledge	Perceived Patient Understanding of dentists' role and barriers to accessing help (Role)	Communication about a potential cancer	The Primary Care working relationship	Perceived patient trust of dentist	Cancer diagnosis as pivotal point in relationship
Perceived Patient Knowledge	Fear and Confidence (Reputation)	Use of the word "Cancer"	Communication between Primary and Secondary Care providers	Trust in the referral pathway	Continued relationship/loss of control
Pathway Knowledge	Different roles dentists undertake within the pathway and Training (Responsibility)	Conversations on HPV	Informal Routes to Diagnosis		
		Time			
		Communication about the pathway			

Table 13: Themes and Subthemes from Dental Analysis

6.3.1 Knowledge

The *knowledge* theme covers the dentist's clinical knowledge around HNCs, their perceived view of patients' knowledge of HNC and the dentists' role and their knowledge and understanding of the pathway to diagnosis.

Subtheme 1: Clinical Knowledge

Dentists reported that they felt very knowledgeable about HNCs and that they kept up to date with compulsory CPD on oral cancers.

"I've always been very keen to make sure that I've kept up on my CPD, making sure I'm up to date with diagnosing early signs of oral cancer, so that's something that I feel is a huge part of the responsibility of being a clinician erm so that you are keeping people healthy as opposed to not just looking after their teeth" **Dr Blue**

However, most of the dentists reported that they felt it was rare for them to see an oral cancer, with many reporting only seeing one or two in their career to date.

"...in terms of actual primary diagnosis erm, I think in my career of, I've been qualified now, nearly 17 years, I think actually confirmed diagnosis, I've actually only picked up 1 where I spotted the primary. Where I was the person who picked up the primary." **Dr Yellow**

It was felt that at times it was "*obvious*" that something wasn't right, and they felt they knew that they were looking at a cancer or something which they were highly suspected to be cancerous. Although there was some discussion on the difficulty in spotting HNCs. They reported that they felt some cancers are small, could be mistaken for benign pathology or could be hidden, this meant they were difficult to see in the mouth and throat area due to many areas within the mouth that are difficult to view. They felt it was important that patients described other symptoms they were experiencing so the dentist was able to make a full assessment of the situation. So whilst clinical knowledge was very important they reported being reliant on patients reporting of symptoms.

"So, things that are just simple white patches that are very easy to, erm, miss. Hidden amongst folds in the mouth, even if the patient does attend a dentist. It is easy to miss them." **Dr Indigo**

“...symptoms and maybe a lump in the neck or persistent sore throat or you know some kind of unusual presenting factor that isn’t disappearing and I think our role as a dentist we should be more alert to those if a patient comes in and you know you ask about their general health and they say I’m fine but I’ve had this hoarse throat for 6 weeks and it’s not disappearing you should be able to ask a few more questions and maybe advise them that they go and get that checked by their GP because you know I think it’s worth saying to patients, I’ll be honest I hope it isn’t something nasty but a persistent cough or something etc. you know a sore throat can be signs of something more sinister erm...” **Dr Yellow**

They also felt that their knowledge increased with time and experience, both with regards to their knowledge and understanding of HNCs but also understanding the oral cavity and being able to find the more hidden cancers.

“But, there are so many different presentations that don’t necessarily do what the text books tell you, and there are so many nooks and crannies in the mouth that aren’t, um, immediately visible unless you go looking.” **Dr Purple**

When speaking about known risk factors the majority of dentists interviewed were aware of current known risk factors (smoking, alcohol, HPV virus), and were aware of the symptoms linked to a potential cancer. There was one divergent case who felt that there was no link between smoking, alcohol and HNCs and that these cancers are caused by another unknown trigger.

“Well traditional profile ...used to be male, probably in their 60’s, with a history of being a heavy smoker and heavy drinker, that is changing erm with the increase in HPV virus we are starting to see patients who have never smoked, don’t really drink much alcohol and are younger, even female, kind of not that traditional stereotype. There is still a fair number of patients who fulfil that, you know, criteria that I mentioned at the beginning but I think the demographic is changing and talking to colleagues the HPV virus is a huge increasing problem with oropharyngeal and nasopharyngeal cancers.” **Dr Yellow**

“...no I wouldn’t say necessarily related to smoking and alcohol, don’t what they’re related to, um, I wouldn’t say necessarily smoking and alcohol are related.” **Dr Pink**

The dentists spoke about how they understood that there was a link between HPV and HNCs. However, some reported that they didn’t fully understand the mechanisms by which the infection occurred, and some spoke about how they were uncertain about whether HPV could be considered a sexually transmitted disease. They felt that there were more unknowns in this area, and it was difficult to get clear answers on this topic when they have attempted further reading.

"I was aware in, in the early days because, um, Professor Crispin Scully was one of the first people to kind of pick up on the idea of, um, the potential for oral cancer to be sexually transmitted, although I don't personally believe that it is truly sexually transmitted. Um, and I know when he started to talk about that, quite a lot of people in the sort of mainstream thought that he was off his rocker. And I kind of decided that I'd do a little bit of background reading. So I, from the early days I had done some, er, reading about it and I was obviously aware of the growing link between HPV and cervical cancer. And, and, um, and there are a great many links between cervical, um, embryology in terms of the sources of cells and that in the oral cavity. So it's not a great leap to think that there might be some link between the two." **Dr Turquoise**

"... I didn't really know anything about it until I came to work with this team really. Erm so I don't recall having much teaching or anything about it.." **Dr Red**

"[HPV] it's not really something I've thought about because to be honest, other than our oral medicine lectures at Uni, it's not something I've really discussed or come across since. It's not ... it's not something that's been in the papers much in dentistry." **Dr Indigo**

Subtheme 2: Perceived Patient Knowledge

This subtheme covered the dentists' perceived understanding of patient's knowledge on HNC, the role of HPV and on the dentist's role within HNC.

The dentists interviewed spoke about how they felt that overall patient's knowledge of HNCs was low. They spoke about how they felt there was a lack of knowledge around the possibility of getting cancer in that area. They also felt that patients lacked understanding and knowledge of their own mouths, and that this was not an area that people would look at on a regular basis in the same way as a women may check her breasts for signs of a potential cancer.

"I think people think of cancer as breast cancer, prostate cancer, you know, all the cancers that you hear about in the media. You don't hear about head and neck cancer. Um, so I don't think people are. People come to the dentist to have their teeth checked. And in fact, they even, you know, even if you say something about their gums or, you know, their mouth's very dry, or they're a bit, you know, they see a dentist as looking after your teeth. They don't see a dentist as looking after anything else. So, I think they are quite surprised." **Dr Indigo**

When discussing what they felt their patients understood about HPV most of the dentists explained that they had never been asked about HPV by patients whether

that was in conversations about it as a potential risk factor, around advice over the vaccination or because a patient had an interest in the topic. They felt that this was due to patient knowledge of this area being very low.

“Erm, but I can’t think of an episode where a patient has really mentioned HPV. Erm, I just don’t think it’s very much in the public understanding. Erm, I think they see the jab that they’re getting now ... the girls they get the jab in their arm and they won’t relate that to their mouth. So, I don’t think there’s enough press coverage or national media type attention on it.” Dr Green

They felt patients were far more likely to attempt to deal with problems in this area themselves before seeking help and were less concerned by symptoms that would have raised alarm if it was in another area of their body;

“Um, I think, as I’ve said before, there’s a little bit of a, a lack of public awareness about the possibility of mouth cancer and they’re more likely to put off doing something about it for longer than they would say with, with something that was going on elsewhere, you know. If you got bleeding from, from your gums you tend to put up with it. If you had bleeding from your rectum, you’d probably do something about it.” Dr Turquoise

It was noted however that they perceived those patients who attended the dentist for check-ups and exhibited more of the traditional risky behaviours (such as drinking and smoking) as more aware of oral cancers due to previous discussions on the potential risks of their behaviour. So, they believed that these patients were more aware of the signs and symptoms of oral cancers.

“Erm, but I’ve got plenty of patients who are long-term smokers or high alcohol, erm, or the occasional people who are chewing tobacco or various things. I will specifically, erm, use a bit of the appointment to explain. I usually show them, me typing it into the computer to make it quite official. Erm, something along the lines of, ‘The patient is a smoker.’ Explain that this involves various risks to health including – and I’ll show them the word on the screen – oral cancer. I’m like, “That’s what we look out for when you come in for a check-up.” I put, today I can’t see any problems but the longer you are a smoker for, the greater that risk increases. So, I think I’ll sort of pave the way a little bit for them and lay it out, kind of, you know, because you are a smoker I’m having to write in my medical notes that you are at risk of oral cancer. So, I’ll try and make it a bit more clear for them. Almost, as if in ten years’ time, if they were to receive a diagnosis they would think, ‘Well, (own name) did sort of say.’ Which is think is sort of fair enough.” Dr Indigo

Subtheme 3: Pathway Knowledge

The final area of knowledge was the dentists' knowledge of the current pathway to diagnosis.

The dentists expressed concern that they did not know what would happen to patients after a referral was made. So, they were unable to explain the process and felt that this impacted the trust patients had of them and impacted on their relationship with the patient as they were unable to assist them through this part of the process. This in turn affected the dentist's confidence in helping a patient navigate the next steps.

".....but then it's hard if they've got questions that you don't know how to answer because I don't have the right knowledge, I don't know what is the next procedure for them that's something when it gets a difficult conversation and then you don't want them to loose trust in you, thinking you don't know what I'm talking about but I think, I do have, it's quite a limited knowledge of more diagnosis but you don't often get told what the next step..." Dr Green

There was also a fundamental misunderstanding of the urgent cancer referral system, where many dentists would not use the required proforma and instead would choose to write a clinic letter to secondary care or use their own in-house designed template. There was an assumption that if it was marked urgent it would be treated in the same way as referrals sent in on the proforma. The majority of GDPs referred in this way and although they were aware of, and the majority had access to the urgent cancer referral document, they chose not to use it. The main reason for this appeared to be a lack of trust that the proforma was the most appropriate tool for this job; not asking for the correct level of information or giving an appropriate amount of space to complete a full explanation of the patient and their symptoms that they felt was required for this type of referral.

"Proforma? No, I tended not to. I tended to write a bespoke letter. Um, partly because initially when I began working in practice, there were no, there was no two week, um, pathway and also, um, the proformas that became available are, um, I don't find them particularly useful actually. Um, I think you can be much more concise and much more accurate in writing your own letter. And again that, you know, maybe it's that the proforma is there to guide perhaps those people who are a little bit less experienced...Well there's no standardised proforma so depending on trusts, you will find that there's some variation between them. Um, and, um, I just a natural suspicious, suspiciousness about that kind of, you know, document that's mass

produced like that. I just don't know whether they're... one of the, one experience I did have was someone said to me that they, they, they tended to not pick them out, which I found rather strange. I would have thought surely to goodness you would pick them out even more 'cause they're designed to be picked out...It did make, did make me a little bit wary of, um, of using them as well...I mean I would put, I would put it on it and make it absolutely clear that it was, um, an urgent referral, suspected, um, cancer, um, under the two week pathway.” Dr Turquoise

There was also no space for their details. The referrer information asked for the patients GP details rather than referrer details.

“the last one I did had GP details and obviously I think it was more tailored just to GP referring so I filled in the GP details and then realised at the end I hadn't put my details anywhere so I think that was meant to be for the referrer rather than the GP so that was the only thing that I sort of picked up on with the new form I was using that time but the form itself is quite good and patients seem to get booked in quite quickly.” Dr Green

6.3.2 Professional Role, Reputation and Responsibility

This was one of the largest themes encompassing the subthemes on 1. *Perceived patient understanding of dentist's role and barriers to accessing help (Role)*, 2. *Fear and confidence (Reputation)* and the 3. *Different roles dentists undertake within the pathway (responsibility)*.

Subtheme 1: Perceived patient understanding of dentist's role and barriers to accessing help (Role)

As previously discussed, (in section 6.3.1 – perceived patient knowledge), the dentists felt there to be a lack of understanding among patients as to what a dentist's role is. It was felt that patients perceived a dentists' role to be looking after their teeth, and even when gums were mentioned they felt that was something unexpected by some patients who, they believed, perceived this to be outside of the dentist's role.

“I think people think of cancer as breast cancer, prostate cancer, you know, all the cancers that you hear about in the media. You don't hear about head and neck cancer. Um, so I don't think people are. People come to the dentist to have their teeth checked. And in fact, they even, you know, even if you say something about their gums or, you know, their mouth's very dry, or they're a bit, you know, they see a dentist as looking after your teeth. They don't see a dentist as looking after anything else. So, I think they are quite surprised.” Dr Indigo

Dentists often reported that patients would pick to go to their GP with some issues that would normally be a dentist's responsibility, which they felt was due to a lack of understanding of their role. They also felt that many patients did not expect dentists to be involved in identifying and referring on for potential cancers.

"I don't think they really understand that we are looking for, um, cancer, in the main."

Dr Pink

They also discussed what they felt the barriers were to patients seeking help from them. The main barrier which was raised by many of the dentists was the concern around paying for treatment. They felt that this stopped patients seeking help earlier as the cost was difficult for many people. Many spoke about how some patients may be exempt from paying for dental treatment but that this didn't appear to be widely known.

"I think partly having charges for dental care as well, obviously a lot of patients are exempt but a lot of exempt patients still worry because they haven't been for so long since the system changed and they perhaps don't know their rights to free treatment so I think erm...cost puts people off sometimes from coming in." **Dr Red**

"...the fact that they have to fork out some cash at the desk, I think just does jar it. It just offsets it and makes it just seem a bit, a bit grimy. Everywhere else medicine is free. Yet us dentists ... I don't know whether they think we just like taking money and charge them. Erm, it ... we don't fit into that same sort of friendly box as a nice doctor or a nice medicine hospital doctor or something like that." **Dr Indigo**

Subtheme 2: Fear and confidence (Reputation)

They also felt that there was a general fear and anxiety around their profession with many patients appearing very anxious about attending appointments and it was felt that they were picking to see a GP instead because of this anxiety. There was also discussion around patients being potentially embarrassed due to neglected teeth. They felt this may make them fearful to see a dentist about (for example) a suspicious lump as they may be made to have treatment that they didn't want or were scared to have.

"I think the barrier for a lot of people is probably coming to the dentist as well because it is associated with other anxieties, they probably put off coming erm

because they don't want to come to the dentist and then perhaps those people present to the doctor and then the doctor doesn't know what they are looking at because they are not a dentist (laughter). Ermm so that's probably a bit of a barrier for some people as well." Dr Red

A strong topic within this theme was the concern by many dentists of "looking stupid". They were concerned that their professional integrity/skills would be considered poor if they referred patients into secondary care who did not have cancer. There appeared to be a concern that if all their referrals didn't result in a cancer diagnosis, then that would be deemed as them lacking knowledge or skills in their job role.

"...So, I don't want to be seen as the clinician who, like, they'll get a referral, and they'll think, "Oh, no not her again, what's she referring in for?" Um, I don't want to be the person who's wasting time. Um, it is also hard, because now, where I work, I would be referring to the dental hospital, where I work, [laughter] and I just ... and I just don't want the oral surgery department to think, "Oh, gosh, who've we got working in this hospital making these silly referrals?" That's just another pressure which I haven't had before because, normally, it was just the district hospital, and you didn't meet the people there who ... who you referred to" Dr Orange

However, they did report that this would not prevent them referring patients although it did appear to have an impact on their confidence. An element of this relates to the lack of communication between primary care and secondary care. Some reported that a lack of feedback from secondary care enhanced this feeling of uncertainty around their referral decisions and if they received some relevant feedback that would help increase their confidence in their decisions.

"... either to affirm that you are doing the right thing about making referrals onwards, or for somebody to say, "Why did you refer that, it was a complete and utter waste of time." Or, "Actually, we understand why you were concerned. As it happened it was such-and-such, and there wasn't a problem, but please don't hesitate to refer." And, it goes back to this, sort of, "Are you prepared to make yourself look a little bit foolish by getting somebody else to look at something if you are not 100% certain? And, is it okay to do that? Or, would you rather be certain before you made the referral, in which case it ..." So, I think it just depends on how you ... how you operate, really, yeah, yeah, if that makes sense?" Dr Purple

Those dentists who were more experienced with HNC referrals discussed how they felt that they had worked to get to a trusted position and were confident that their

referrals would be seen within this context. They had built up a reputation as a “good referrer”.

“If, I mean I think I made enough referrals that were a), a) positive or b) you know, reasonable referrals that I probably had sufficient of a reputation where I could have rung up one of the consultants as a primary care dentist and spoke to them and said, “Look, I’ve got this in, in the chair, what do you think?” and usually they would say, “Do a letter. Send it, er, by fax and we’ll see the patient as soon as possible.”

Dr Turquoise

Fear and rumination over referrals was common among the dentists. They appeared to be trying to balance their fear of their professional integrity being viewed negatively with their fear of not making a referral that later turned out to be something more serious than they had anticipated. For example, they spoke about ruminating over a referral overnight and then changing it to a more urgent referral the next day.

“If I’m worried. I can’t remember, no I can remember when I last did that, and I hadn’t referred under the two-week rule, and then I went home, and started thinking about it, and I thought, “Right, I’m going to change that letter to the two-week rule.” And it was nothing.”

Dr Pink

There was also fear that when they did spot something that they felt needed further investigation that this was something they had missed at a previous appointment. They referred patients initially because they were afraid that if the patient came back in 6 months’ time it would be something more serious that they should have referred on at that initial stage.

“It’s not a fear that I’ll miss something, it’s a fear that I’ll just think oh that’ll be fine and to be too blasé about it, and just think that’s going to be absolutely fine and I’m going to see the patient again in 6 months and then they come back and you think, I should have done something about that to start with.”

Dr Blue

Subtheme 3: Different roles dentists undertake within the pathway (responsibility)

The dentists also spoke about the different roles they were required to fill when one of their patients had been diagnosed or was going through the diagnosis stages; they

believed that when they were the initial referrer, they became a central point of support, advice and information for the patient.

“you’re there as, as part of their support. You’re there for them to talk to. You need to be a good listener. You need to be empathetic. You need to be able to advise them. Because if there’s something that they’ve been advised to do by the multidisciplinary team, and they’re not sure, they might ask you. So, you need to have a little bit of, of knowledge about that sort of side of things, and sort of prevention and, but more a listening, more to be there to listen, and to support. Because they often want to talk. They often find it easier or maybe less threatening to talk to me than the team because there might be things that the team have said that they’re not sure about it, and they want to just chat it over, or they may talk to me about, you know, how they find the whole process. So, yes, I think you’re there as a support really, and you need to be able to be a good listener, and be sort of responsive, and empathetic, I suppose, with them.” **Dr Violet**

Some described how patients would come back to them to talk through their options, or “translate” the medical language in communications from the hospital.

“I have found on a number of occasions that people have actually come to me and they are wanting me to explain more fully about what’s happening and I have said to people has this been explained to you before and.... I think sometimes when people are in the middle of treatment it’s difficult for them to retain information so if they are coming to see someone who they know is a more familiar person it is perhaps easier and also out of that environment where everything is fairly terrifying” **Dr Blue**

They also described how they were providing informal counselling for some patients, although this was not something they took on in a professional role (for example undergoing training) but something that they did to support their patient through the system.

“I think counselling them, how well they are doing in the early stages is actually quite a good thing and I just do that off the top of my head, I don’t really, no-one’s ever said oh it’s important to counsel these patients, in fact no one has ever really done any training with us as a dental team it’s just right I’ve started work in this job, by the way you’re going to have to look after some cancer patients. I’ve never had any formal training on how to counsel or manage these patients from a psychological point of view, erm you know I kind of look after these patients how I’d hope that someone would look after me or my family or that kind of friends and family approach to things really,” **Dr Yellow**

It appeared that there was no clearly defined role for the dentists to play within the pathway to diagnosis, which meant that different dentists took on different roles based on their own view of their abilities.

When discussing the skills required for these different roles, there was some discussion over whether these skills could be taught or whether they were non-teachable/personality traits.

“I think you can teach it to a degree, and I think there’s a lot, and I think it’s the same in all aspects of health care. I think a lot of it is somebody’s personality, somebody’s general background, you know, where you’re coming from, what your interests are, um, but I think there is an element where we can teach, um, sort of medical, dental professionals, at undergraduate and post-graduate level, more about the whole process, albeit, it might be a little bit more didactic rather than, you know, I can’t teach you to be empathetic about something because that kind of comes through experience. Um, but you can nurture that, and you can nurture that certainly at an undergraduate level” **Dr Violet**

“it’s just being human, really. To, you know, just to kind of give that feeling to patients that they are being cared for. I don’t think you can get trained for that, it’s just who you are and how you are.” **Dr Orange**

Most reported that their education around what a cancer is and what it looks like was good, but it was the training around communication skills which they felt they required more of, although some felt that only so much of this could be taught as this was seen as something to do with a dentist’s personality; some people were just better at communicating than others.

“the type of thing that I think really helps with communication about it would be like the role play type training thing that everybody hates doing (laughter) but is really useful....yeah... so I think probably generally most dentists aren’t confident enough and err...only more training or experience or both is going to help with that and they aren’t going to get experience of it because it is still pretty few and far between, err... so perhaps more like practical experience type training instead.” **Dr Red**

6.3.3 Clinician-Patient Communication

This theme on *Clinician-Patient communication* covered 1. *Communication about a potential cancer*, 2. *Use of the word “cancer”*, 3. *Conversations on HPV*, 4. *Time* and 5. *Communications about the pathway*.

Subtheme 1: Communication about a potential cancer

The communication of a potential cancer was described as a fine balance between making sure the patient was aware that it was important to attend an onward referral and not scaring the patient.

“because you don’t...obviously you want to kind of make them aware that its serious you want them to go and attend their assessment appointment erm but at the same time you don’t want to overly cause concern and worry if you’re not sure” Dr Red

There was a nervousness around talking to patients about a potential cancer, although some dentists reported feeling more confident than others, especially those who had undergone training or felt themselves to be more experienced.

“I think people just don’t want to upset people and you don’t want to, you know you don’t want to worry people unnecessarily but at the same time you have got that obligation to tell people, you know I think it’s that really fine line, people just don’t know what the right thing to say is and erm... if they had a bit more training in that it might help.” Dr Red

Some dentists spoke about the importance of being honest with the patient and explaining that they thought there was a potential cancer whilst others felt that they shouldn’t make the situation sound too serious as the potential of it being cancer is not high. Those that felt there needed to be more honest felt happy fully explaining to the patient what their differential diagnoses were, and they felt strongly that this was an important part of their job role. Those who were less confident with this aspect tended to worry more about the potential upset and anxiety they could cause a patient and attempted to avoid this at all costs.

“So I.....I guess I don’t feel confident going into full detail, about exactly what it is I’m worried about, erm, unless maybe they ask me, are you thinking this is cancer, I tend to talk more around that it...(sigh)....it’s just routine in that when we see something like this its best to get it checked out, just for peace of mind so we know exactly what it is, because I find I don’t want to panic them and worry them too much when it, it has come back that sometimes it’s nothing to worry about that it just sort of ticks by boxes that it needs following up. So I so often find that I, maybe don’t tell then enough, that I think it’s something sinister, and we do go down the route that it’s just something I’d like to get checked I don’t always feel confident to tell them, I think its....Yeah, Uh hu....that they are going to go home and have sleepless nights

and worry about things when....it's not....it's not confirmed and it's not a field I'm an expert in, I would feel.....until it's all properly diagnosed." **Dr Green**

Subtheme 2: Use of the word "cancer"

When talking to patients about potential cancers or risk factors associated with cancer there was a wariness of using the word "cancer". Some dentists spoke about this wariness from the initial stages with many not explaining to patients that part of their regular check-up is a cancer check; they felt that their time was limited and that mentioning the word "cancer" was likely to cause the patient to want more information which is unsustainable with the current time and workload.

"...so I think to describe that simply, if I've got twenty minutes to do all the bits I need to do, and I spend eighteen minutes explaining that as a dentist I do look out for cancer and that I've checked, and I've got no worries. But the patient has then been switched onto this idea that the word cancer has been used. It's not sustainable to do that for every patient all day. You'd just get exhausted. So, I specifically try and avoid the word cancer, unless the patient uses it, then I'll have to use it." **Dr Indigo**

"Um, I find it very challenging, and, um, I think I am able to do it, but I often think afterwards, "Oh, did I handle that as well as I ... as well as I could?" Because, sometimes you can be ... one can be reluctant to use the cancer word, because that's the thing that I think a lot of patients would just leave thinking, "Cancer, cancer, cancer," not everything else that you've said where, um, you know, "There might be low risk for it," or, "It doesn't..." you know, "It could be lots of other things." Um, I just worry that I could say something that going to make them really, really, focus on, and the chances are it wouldn't be cancerous. Um, so, yes, it is ... it's hard. I think I can balance it, but, it's hard." **Dr Orange**

There was often no information given to the patients that this check had taken place. Some dentists did state that they may comment on the fact that they had "healthy tissue" but that wasn't put in the context of checking for cancer, for fear that this would be upsetting to the patient. Some dentists' felt more confident mentioning the word cancer when there were obvious risky behaviours that they wanted to address such as smoking or drinking.

"I don't specifically say that, er, I always say to them, "Your soft tissues are nice and healthy." And, no, I don't specifically say that. I ask them about smoking and alcohol, um, and if they smoke, I will then go on to talk about oral cancer more, at risk of all cancers. But, no, I don't say; having a check for cancer." **Dr Pink**

When communicating with a patient about a potential cancer diagnosis, the dentists split into two groups, one group felt it was very important to be honest with patients and that meant using the word cancer so patients were clear about potential diagnoses. They felt using other words was wrong as this often led to misunderstanding.

“But I think the confidence to deal with it comes from perhaps one's core beliefs in terms of how much you should tell a patient about any aspect of treatment, irrespective of whether it's cancer or, or just a simple filling. Um, and I suppose I'm one of those people who would rather, er, try and give a true picture without using euphemisms to describe something, um, 'cause I believe that if you leave the patient hanging in the air, the danger with that is that they, they go and Google it and possibly find out something that they may not understand or they misinterpret. Whereas at least with you there, there is the possible, possibility of having a dialogue and you being able to couch it and frame, um, in terms of reference that they can understand” **Dr Turquoise**

The second group were not happy using the word “cancer” and there was concern using this as the diagnosis would not be definitively known at that point, and it was felt to be unfair to panic or concern the patient.

“I'm trying not to send them into panic mode. Because I think if you mention the word oral cancer, then they're going to think, oh god, you know, something's, you know, really wrong here, erm, and as I say, nine times out of ten, you know, the diagnosis will come back with something completely different. So yes, don't put them into panic mode, as such” **Dr White**

Often language such as “lumps and bumps” something “suspicious” or “sinister” was used instead of cancer.

“Now, what I probably don't do overtly is say, “This area in your mouth could be oral cancer,” I will use phrases such as ‘suspicious’, or ‘it doesn't look normal, it doesn't look healthy’. But, I don't think I consciously have ever said to the patient, “This could be a cancerous lesion,” or “It could be a cancer.” But, I'm not afraid of using the word ‘cancer’ in the broader discussion, if that makes sense?” **Dr Purple**

The fear of using the word cancer could also be linked with the dentists' confidence around their communication skills with “cancer” being seen as a trigger word that they didn't feel they had the skills to cope with the aftermath of.

“I specifically try and avoid the word cancer, unless the patient uses it, then I’ll have to use it. But I found if I bring that up out of the blue, it’s almost like, erm, an alarm bell goes off and they just ... they twitch then and they can’t get away from it.” **Dr Indigo**

Subtheme 3: Conversations on HPV

Discussions around HPV as a risk factor or when speaking to a patient about a HPV related cancer caused the dentists’ a great deal of awkwardness and embarrassment.

“Um, I just ... I find ... it’s hard enough talking to people about smoking and alcohol, let alone the risk factors for HPV. I just think it’s something I feel it’s uncomfortable, because I know it is a risk, and I feel that I should be discussing it, but, it’s um, yeah. It’s hard” **Dr Orange**

As with talking about cancer, if the topic was raised by the patient, they were happier to have a conversation. However, this was an area that none of the dentists felt comfortable opening a discussion in regard to a possible cancer diagnosis or as a potential risk factor. They felt that by talking about HPV they would be making assumptions about the patient’s life that they weren’t comfortable making.

(“Do you, um, ever bring up any of the risk factors around HPV at all with patients?) No, that would be very tricky to do in the surgery. Well, we would be talking about oral sex, wouldn’t we really? [Laughter]. That’s sort of what you’d be saying. We’re talking to somebody who was of an age, you are making an assumption. No, I wouldn’t be talking about that.” **Dr Pink**

There was also a lack of understanding on the transmission of HPV which meant they were often uncomfortable talking to patients about this aspect. Some felt that the emphasis was too much on the transmission through sexual contact and that this made discussions more difficult for them to have as they felt they didn’t have the skills required for this. Many also felt that discussions that may involve talking about a patient’s sexual history were inappropriate in their situation. There was a considerable amount of difficulty discussing these thoughts with the interviewer (as evident in several quotes in this section) which indicated that this was a significant problem for many dentists. The dentists reported that they would only know the details of the patient’s disease if they were part of the hospital team or if the patient informed them at a later point.

*“I’ve never had that conversation with a patient, ermm and ermm I have to admit yes I have some knowledge of the HPV but if they said well how have I got HPV virus and what route was the transmission is it safe to do things with my partner or.... I...I... I have to admit I probably wouldn’t be...feel completely confident in answering those questions....it’s almost a bit easier to say to a patient your cancer is because you smoked 60 a day or you’ve drunk 4 litres of cider every day for the past 20 years, it’s probably an easier conversation than you’ve gotwell a Sexually transmitted virus that’s caused this...as far as I’m aware...” **Dr Yellow***

Subtheme 4: Time

Time to have a conversation with a patient was rare, particularly for those working in general dental practice and in community dentistry, who were working to short appointment times. However, many said, if required, they would take extra time to speak to a patient, although this was patient led rather than the dentist taking extra time to explain about cancer risks etc. Many gave examples of time spent talking to patients who were going through the process of diagnosis and how they generally got good feedback from the patient on how this helped them with the process of being diagnosed and having someone, especially in the case of GDP, separate from the process to talk to.

*“I feel it’s important to take the time so I may have other patients waiting, I think in this service we do get the time a little bit more we are not a pressured as maybe a practice seeing a larger number of patients a day, but no I think I’m always happy to take the time because it’s often just a few more minutes to help reassure that patient or guide them through so I might then not have time the rest of the day or for lunch but I think, no I think I do have the time. Yeah....I wouldn’t want to cut it short if they were wanting to speak about it, but if they were getting themselves worked up unnecessarily and it wasn’t doing them any good then yeah...but uh huh... I don’t feel there is a sort of time pressure myself, no.... I’ve always took that approach even in practice that just spending that little more time, saves me time down the line because they might end up just being back tomorrow so.....” **Dr Green***

Subtheme 5: Communication about the pathway

Communication about the pathway was another area that was often tricky for the GDPs. They noted that they knew very little about this process and what it would involve for the patient, so they often felt that they were unable to help prepare the patient for the next steps in the diagnostic pathway.

“.....but then it’s hard if they’ve got questions that you don’t know how to answer because I don’t have the right knowledge, I don’t know what is the next procedure for them that’s something when it gets a difficult conversation and then you don’t want them to loose trust in you, thinking you don’t know what I’m talking about but I think, I do have, it’s quite a limited knowledge of more diagnosis but you don’t often get told what the next step...” **Dr Green**

6.3.4 Co-ordination of Care

This theme included subthemes around 1. *The primary care working relationship*, 2. *Communication between primary and secondary care providers* and 3. *Informal routes to diagnosis*.

Subtheme 1: Primary care working relationship

The majority of dentists described the working relationship between dentists and GPs as non-existent with limited communication between the two parties.

“I think that’s one of our failings between the medical profession and the dental profession is that we don’t work close enough in lots of areas. And I know there’s a lot of GPs think the same thing. So, it’s not a criticism of our GP colleagues, it’s more a criticism of the system. Um, and I think there could be more joint networking, and I don’t think there’s enough really” **Dr Violet**

Dentists described how they were unlikely to contact GPs as they felt that they were too busy and had little time to communicate with them; they also therefore didn’t expect any contact from GPs either.

“...the GPs are so busy and they have got so much workload and so much pressure just from other areas, I don’t think they get time to communicate with us as dentists” **Dr Yellow**

“personally I don’t at all because it’s kind of a difficult group to get hold of and get them all in one place to speak to people and you never even meet them, whereas the sort of dentist community it’s like a relatively small community and people tend to know each other and you know what certain practices are like over others and ermm... whereas the GP’s I have all these names of GP’s that have sent people in but I haven’t got the foggiest what they are like or who they are...” **Dr Red**

They described practical difficulties with communication due to non-linking computer systems and patient records. Dentists do not have access to the patients' health record and described being unlikely to have a full understanding of a patient's clinical history, other than what is shared by a patient during consultations. They described working in very separate silos with little or no opportunities for meeting and or shared learning. Dentists reported that they would not contact a patient's GP if they were referring a patient for a suspected cancer and that they would not expect to hear from a GP if they were referring a patient for anything in the head and neck area either.

"Um, I would say, in my experience, there's no, well, very, very little communication between a GP and a ... and a dentist about, um, where patients go. Because, I will have seen patients who would go to their GP about a lesion on their lip, or their tongue. The GP would make a referral to the services, and then the first I'd hear of it would be a patient saying, "Oh, well, I went to my doctor, and said that..." So, the GP wouldn't ... GPs in my experience don't copy you into referrals, or let you know that they've made a referral. Um, I suppose, equally well, I wouldn't necessarily copy in ... a GP to an oral ... to an oral cancer, um, potential referral. So, I'm equally guilty. Um, I think there is better communication with things like ulceration and diabetes, because you can ask for blood tests, and recommend going to see, um, a GP for a diabetes test, but there's less communication, I think, about oral cancer, and head and neck. Um, I think it's just ... it's almost tradition, I don't know, because you just work in our slightly ... in our unique streams, and it's possibly because dental practices are their own business, they are not like a ... they are not part ... well, they are part of the NHS, but they are not within that, kind of, system, where a GP could refer to a thoracic person, or a cardio person, and it's all, kind of, centralised, and streamlined, isn't it? In their own little system, we're not ... our computers don't link, you know, it's very separate, so..." **Dr Orange**

"No. I don't think so. It's something that bugs me a bit because there's this idea we would have a patient who maybe wanted to just check her medication. And the teaching we give to students and you read in textbooks is you give the GP a quick ring and, you know, you can just have a little chat with the GP. Of course, they've got a list of 50 people and they've got stuff to do and they're busy. So, it just doesn't really work. Erm, again email wise I've got this NHS.net account now. Which I meant to be able to use because it's meant to be a secure platform, were they know I'm a dentist and you're not a patient and they can talk to me. But I'm not ... we've hadn't really had any training on how to use it and it's a bit clunky. Erm, so that might improve things, I think. Because there's less of a confidentiality risk and they know who they're emailing back. Erm, but I must say, most of my experiences doing that, I've rung and then they've said, "Right, we'll ring back." Then, of course, I'm busy. Then I try and speak to them, then they need to check who I am. Then ring back once they've got consent from the patient to discuss things with me. It all just ... it is a bit clunky." **Dr Indigo**

Dentists felt that there should not be an expectation on the GPs to have the same level of knowledge on oral cancers as they have and that they had different roles to play but that the way the system was set up makes this a difficult task.

“...the kind of training they (GPs) got as undergraduates in terms of head and neck or kind of mouth care was an optional 2 hour lecture that they didn't have to turn up to in their 5 years..., so I think in terms of what is normal anatomy and what is cancerous I think most GP's will admit they don't have a huge knowledge erm... obviously they have a basic knowledge of a persistent ulcer that's not disappearing or persistent sore throat or a big lump in the neck, I think they would, if they weren't sure about it, or a white patch in the mouth, the GP's you know generally go, say go and see your dentist I'm not sure, so they would probably feel that they might be referring patients inappropriately on the two week rule, so they would rather maybe let the dentist who has probably got, you know understandably, more experience in looking at what is normal and what's not.” Dr Yellow

Subtheme 2: Communication between primary and secondary care

The level of communication between dentists and secondary care was also raised in the interviews, with dentists feeling that they had very little contact and feedback from the clinicians working with HNC.

“In terms of detection and diagnosis, I suspect what, what, what isn't good is the taking up the opportunity to then feedback outcomes of diagnoses which could then inform future learning and future practice...Now, I'm not sure what comes back then to the primary care practitioner in terms of feedback about the diagnostics, and whether or not everything was done that could be done, or the lessons that could be learned from that. Um, that, if anything, is... but I don't really know, I don't really know for certain. I just know from my own perspective, I get some feedback, but the, sort of ... the patient disappears out into the ... in the yonder, and they sometimes, they sometimes come back to you, they sometimes don't.” Dr Purple

They often felt like they were not kept up to date with referral procedures and they had no links with secondary care. This lack of communication with secondary care meant they reported feeling confused about where to refer patients and, practically, how (Fax machines were a problem for some dentists as they no longer used them and were told that referrals had to be faxed).

“Um, where I used to work, it was awkward, because the referrals had to be faxed and we didn’t have a fax machine [laughter]. Um, and the forms kept changing, and you weren’t necessarily updated as to which form to use. And, sometimes, if you have patients who live on a postcode boundary, you have to ... it’s awkward to know which hospitals that they have to be referred to. So, that kind of logistic is tricky” Dr Orange

There was a lack of knowledge among the dentists (as mentioned earlier in section 6.3.1, subtheme 3; Pathway knowledge) on the procedure of diagnosing someone with a HNC and this meant they were unable to pass on the information to their patients. There was also little feedback from referrals meaning that often they didn’t know what happened to a patient after the initial diagnosis unless the patient themselves came to see the dentist. This lack of communication manifested itself in a feeling of isolation and complete separation from the rest of the NHS, with dentists appearing to work completely independently.

Many of the dentists felt that they were unable to affect change within the system that they did not feel part of.

“Oh its completely out of our hands....oh management and commissioning and stuff is just like an impenetrable barrier of legislation and red tape and rubbish....yeah.... Im....yeah....one of the reasons I’ve left....when I did leave my surgery aspect...erm... one of the reasons was just frustration with the lack of control with how to change processes that were clearly inefficient and erm... a waste of everybody’s time but actually making any changes in the NHS structure in those ways is...is ridiculously impossible... so unless you are kind of the head of the department or of the hospital then I feel like very little is taken on board from what the other staff actually say... yeah cause it’s kind of written into the framework elsewhere” Dr Red

Subtheme 3: Informal routes to diagnosis

Hospital dentists also discussed the informal routes to diagnosis that their patients often took, which was something only raised by this group. Working within the hospital meant that they often had access to the clinicians working within HNC purely based on geography. This enabled them to call on these people for a quick second opinion whilst in clinic. The patients who were seen this way often bypassed the standard and urgent cancer pathways with some patients being seen the same day as symptoms were noticed by a dentist. These patients may then be able to be seen and discharged or referred on for further investigation very quickly. Hospital dentists

described this informal route as something they learned on the job. It developed naturally through workplace relationships, allowing them to take advantage of it when needed. They identified clinicians who could be approached in this way and often used them without thinking about it too much.

“I know that there are certain members of the oral surgery team that, if I go and knock on their door, they won't be receptive, because that's not how they operate. There are others that I know if I go and knock on the door, they'll go, “Yeah fine, okay, we'll do that.” So, I've sort of learned those. Coming in as a newcomer, I think the formal processes would be fine, but having that, um, that institutional knowledge, and institutional memory is very difficult to give to somebody, yeah, yeah. But I think there's ... I think again, here, because we are quite a small team, and because we have a lot of the all surgery team members, and all medicine members in the building, [cough] it's relatively easy in ... even in comparison to, um, set-ups where you might have a dental school, or a dental hospital, but separate to that, you have the oral maxillofacial surgery unit, but they are not in the same building. Um, I ... at one time, I did do a year working as an SHO – and this is going back 28 years – working in (place name), and (place name) unit, although it was a general hospital unit, had the dental unit, and the oral maxillofacial surgery unit, were all one and the same. Um, and that enabled a very quick communication and referral where necessary. So, it works well where physically, you are in the same place, but I think, when you're not, and you don't perhaps know each other as well, you have to do that formal route, you have to go through the two-week letters, and what have you, yeah.” **Dr Purple**

Referral letters would always follow, and this route meant that patients entered the system very quickly or were never referred into the system as a quick check to rule out any problems was able to be completed whilst the patient was still attending their initial appointment.

6.3.5 Trust

This theme came through very strongly and impacted on many of the other themes. There were two subthemes with this, 1. *Perceived patient trust of dentist* and 2. *Trust in the referral pathway*.

Dentists perceived that there were difficulties with the general public trusting them overall. They felt that one reason was financial and that they were seen as less trustworthy than GPs because they had to ask for payment. They also felt the general public didn't always trust their opinion on work that needed doing as it was a way for them to get more money out of the patient.

*“I think they trust dentists, some dentists less, yes if they, if there isn’t a good relationship there, I think the very fact that money changes hands over the dentists reception desk means that there is a different relationship there and yeah, I think probably yes there is an assumption that the GP is always on your side and the dentist might be out to make a bit more money out of you. Which is a shame... I think it certainly changes the relationship that it’s not seen as purely benevolent perhaps in quite the same way as the GP is, even though the GP is being remunerated, in a different way but it is just because it’s not actually seen by the patients I do think that changes things quite a lot.” **Dr Blue***

They also felt that the relationship they had with the general public was very different to that of a GP because of the, often, “operative” nature of the job. This was compared to GPs who it was felt rarely did anything to a patient other than examine them and then refer on if necessary, this meant the relationship was different.

*“I think people have more trust for doctors than they do for dentists, I think part of it is because of the operative nature of coming to the dentist, you might need to get something done, whereas the GP very rarely does anything more than just examine you, erm and its probably a friendlier environment going into the GP surgery as well, because you sit in a nice chair next to the desk whereas we are asking patients to come and sit in the dental chair and recline and I think the personal space issue, with them lying back, there’s a control thing erm... so that upsets people a little bit more, erm” **Dr Red***

There was a feeling that those patients who became regular attenders did trust them but that this was a long process and that some patients may have gone to many other dentists until they found one they felt comfortable with. Those patients who were less regular attenders or who only came in an emergency were seen as less trusting of the profession.

*“Yes, I do. I do very much, particularly those who see their dentist regularly, they form a very close, trusting bond with those, er, professionals. However, I think if you're one of those people who attends sporadically and in symptoms, it's much more difficult to gain that trust. And it's almost more difficult in a sense 'cause those are the very people who are suspicious about a dental interaction.” **Dr Turquoise***

There was also some discussion on how a lack of knowledge by the dentists, particularly on what would happen next to a patient referred on for further investigations was felt to negatively impact the level of trust (as seen in section 6.3,

subtheme 3; Pathway knowledge). The dentists felt that their lack of knowledge made them less trustworthy to the patients.

“it’s hard if they’ve got questions that you don’t know how to answer because I don’t have the right knowledge, I don’t know what is the next procedure for them that’s something when it gets a difficult conversation and then you don’t want them to lose trust in you, thinking you don’t know what I’m talking about but I think, I do have, it’s quite a limited knowledge of more diagnosis but you don’t often get told what the next step...” **Dr Green**

Trust was also considered in respect of the pathway. Many dentists reported a lack of trust within the pathway. They reported feeling that they had to follow-up on referrals and make sure that they had been received and were being dealt with. Some dentists reported a previous urgent referral going missing or the patient not being seen within the two week timeframe and this had triggered a change in how they dealt with onward referrals. There was often a system implemented within the surgeries/teams whereby referrals would be followed up to check that that had been received.

“So what we do now is, we email in but then if it’s an urgent referral, we’ll chase it and make sure they’ve received it. I mean, I think in the past, there has been an incidence where somebody has been referred under the two-week rule, erm, and then it got lost in, you know, correspondence somewhere and that patient wasn’t followed up, erm, so we’ve learnt from that and, you know, I think they contacted us after three weeks to say I haven’t heard anything yet, you know, and we chased it up. So we’ve learnt from that, to ensure that actually it has been received.” **Dr White**

There was little knowledge of what happened to the referrals once they reached the hospital and that urgent cancer referrals were dealt with separately than letters (as seen in section 6.3.1, subtheme 3; Pathway knowledge). This lack of knowledge appeared to impact their trust of the system.

“...there has been times when I know that people have got lost in the process and people that I’ve wanted to be seen quickly haven’t been seen quickly so that, that worries me and part of my referral is to say to the patient you should have been seen within a certain amount of time and if you haven’t tell me and I’ll chase it up and that worries me sometimes that they, I don’t know whether it’s an organisational thing or a triage thing erm that does worry me sometimes.” **Dr Blue**

6.3.6 Relationship with Patient

Whilst the majority of building up a relationship with a patient was seen as being about trust (see section 6.3.5) there was also some discussion on how the cancer diagnosis impacted this relationship. There are two subthemes within this theme 1. *Cancer diagnosis as a pivotal point in relationship* and 2. *Continued relationship/Loss of control*.

Subtheme 1: Cancer diagnosis as a pivotal point in relationship

The dentists felt that spotting a potential cancer and referring appropriately often created a lifelong trusting relationship with the patient. They spoke about how these patients would have a bond with them and sometimes would only be seen by that dentist for as long as they were able to.

“I think if you made a referral and the patient turns out to have a cancer and you made an appropriate referral that probably builds the trust up. That's certainly been my experience. Er, there have been a couple of occasions where I have, knew patients who've come to me who have attended with, er, with lesions that I've referred that turned out to be, er, cancers, um, one of whom became a lifelong patient over probably a twenty year period and the other of whom was a patient for as long as she lived.” Dr Turquoise

Subtheme 2: Continued relationship/loss of control

The dentists also spoke about their relationship with the patient whilst they were going through the diagnosis process and during treatment. As spoken about in the professional, role, reputation and responsibility (Section 6.4, Subtheme 3: *Different roles dentists undertake within the pathway and training*) this was something they felt was part of their role as a dentist, although to what extent differed between dentists. There was felt to be a lack of communication from secondary care about what was happening with the patient; and the dentists spoke about how this impacted their relationship with the patient as they felt they didn't have the level of knowledge needed to be able to help their patients through the process.

“It is very important to me, because this was a patient, albeit he was referred to me for treatment, but it’s important to me because I am interested to know the outcome for that person. Um, and also, I was doing some follow up treatment for him, so I wanted to be aware of where we were at with things so that when I saw the patient, I was aware of how his treatment was going or what was happening. So, yes, it is very important” Dr Violet

6.4 Closing Remarks

It could be seen clearly in the interviews that trust was something that was thought about and felt in many different areas, as well as in its own right. Trust impacted the dentists’ view of their reputation and responsibilities. They viewed the role as being impacted by how much a patient trusted them and how much they trusted themselves to perform all the duties that they believed were part of their job role. The way a dentist and patient communicated with each other was impacted by the level of trust they each had for each other and again for how much the dentist trusted themselves to communicate effectively to the patient about their risk factors associated with HNCs or potential diagnosis. Trust was an integral part of the dentists’ relationship with their patient and lack of trust significantly harmed this relationship. When considering the co-ordination of care, it was clear that this could be significantly impacted by a lack of trust in the system, and this lack of trust affected how GPs and Dentists worked together and how the dentists worked with secondary care. Co-ordination of care was also impacted by knowledge, a dentist’s knowledge of the route to a diagnosis was important to enable an effective co-ordination of care for the patient and enabled them to understand what their role and responsibility should be within this route. Having a clear understanding of this helped them feel more confident in their role and improved their communication with the patient. The dentists also felt that those patients who had good knowledge of the system were able to seek help from the correct source at an appropriate time. The six themes are clearly different from each other but each impact other themes so cannot purely be understood alone.

Chapter 7: Qualitative interview results; Understanding the Surgeons view and experience

7.1 Chapter Overview

In this chapter I will present the participant demographics for the surgeon participants. I will then describe the themes and subthemes resulting from analysis of the interviews.

7.2 Participant overview and Interview Context

In total eight surgeons were interviewed; four were oral and maxillofacial surgeons and four were ear, nose, and throat (ENT) surgeons. Some detail about the surgeons has been suppressed to protect participants' identities as the pool of possible participants within the recruitment areas was small and therefore it may be possible that they could be identified.

All surgeons conducted HNC related surgery and were qualified as per the inclusion criteria. The interviews were on average 37 minutes and were all conducted one to one, in person, within the hospital they were based at. The participant demographics can be seen in table 14

Participant Pseudonym	Sex	Position
Mr Aire	Male	Consultant oral and maxillofacial surgeon
Mr Bann	Male	SHO oral and maxillofacial surgeon
Mr Clyde	Male	Consultant ENT surgeon
Mr Dee	Male	Consultant oral and maxillofacial surgeon
Ms Eden	Female	Consultant ENT surgeon
Mr Forth	Male	Registrar ENT surgeon
Mr Hull	Male	Consultant oral and maxillofacial surgeon
Mr Irwell	Male	Consultant ENT surgeon

Table 14: Surgeon participant demographics

7.3 Thematic Analysis of Surgeon Interviews

Five distinct themes were seen within the analysis of this group (1. *Professional Responsibility*, 2. *Communication*, 3. *Social Influences*, 4. *Coping Mechanisms* and 5. *Being at the mercy of the system*). Three of the themes (*Communication*, *Social Influences* and *Coping*

Mechanisms) were embedded within *(Professional) Responsibility*. The fifth theme *Being at the mercy of the system* was linked to *(Professional) Responsibility* but not fully encompassed within it; some “system” issues (described in section 7.3.5) were not related to the theme. The theme interactions can be seen in figure 13. All themes, except *Social influences* had sub-themes and these are presented in table 15.

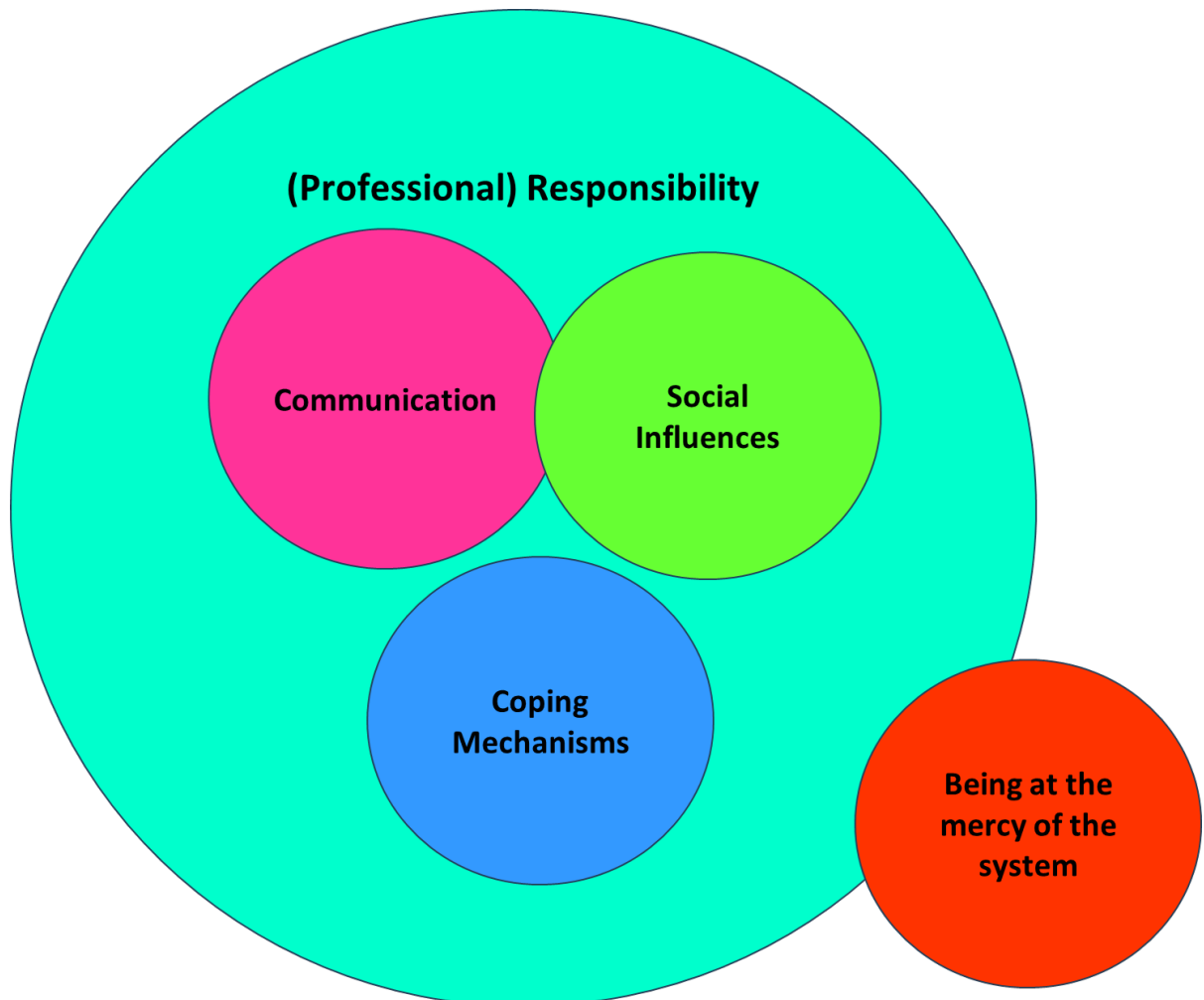


Figure 13: Interaction of Surgeon Themes

Professional Responsibility	Communication	Social Influences	Coping Mechanisms	Being at the mercy of the system
Self	With the patient	-	Enjoyment	Control
Others	With Primary Care	-	Self-care	Balancing time and targets
		-	-	Affecting change

Table 15: Themes and Subthemes from Surgeon Analysis

7.3.1 (Professional) Responsibility

The *(Professional) Responsibility* theme covered the surgeons' knowledge and view of what their responsibilities are and what they believed other healthcare professionals and patients' responsibilities are.

This theme was split into two subthemes;

Subtheme 1: Self

This subtheme focussed on the surgeons' knowledge and how they perceive their role in the patients' route to diagnosis. When considering what they felt their role was (in relation to those patients attending with a suspected cancer) they spoke about how it was to diagnose and prepare patients for treatment, as quickly as possible.

"Erm, and so it's all about information gathering, information giving, arranging tests, biopsies and treatments, as necessary." **Mr Irwell**

They described their role as dealing with those who had cancer and how those who were referred through the Two Week Wait referral system but who did not have cancer were discharged from their care and their responsibility ended at that point.

"...most patients I tend to see already have a good understanding. They are coming to see a head and neck cancer specialist to deal with a cancer related problem." **Mr Dee**

Some discussed the difficulties around this and how they felt that they should be able to further investigate the patient's symptoms and refer them on if needed but that this wasn't always possible, mainly due to time restraints.

“And that...that’s it. That’s where it starts and stops and the difficulty is nobody is...nobody has got the real-time on the ward to actually invest in reviewing the patient’s notes and to look through the...look through the...through the letter again to actually change their practice.” **Mr Dee**

The defining characteristic of their role was a lack of time, and this is where this theme interacts with the theme; *Being at the mercy of the system*. This presented itself in many ways. They spoke about how they felt they had limited time with each patient, meaning there was difficulty in giving the patients the time they felt they needed to understand their diagnosis and make decisions about next steps.

“And, the quicker you rush a patient through, in my general feeling...again, you need to see it from a patient’s perspective, if you push for time, push for targets, my feeling is the patient actually doesn’t appreciate what they are letting themselves in for. So, treatment related mobility, treatment related changes aren’t actually fully appreciated. How much ever you explain something to somebody, ‘til you experience it it’s a different balance of situation. So, you can explain things really well, perhaps with, erm, with IT, with physical patients talking to each other but actually ‘til it happens to the person it’s very difficult to appreciate and the quicker you rush patients through, if they don’t have the knowledge of that work-up then they find it more difficult to, to, to accept and manage the situation they are in at a later date. It can be detrimental. Yes. It can be detrimental. I wouldn’t say it is always but it can be detrimental in some patients because, what takes me a day to process, may take my son two weeks to process, may take my grandfather four, four months to process. And, we are treating everybody at the same speed.” **Mr Dee**

“...you know when you're expected to see, you know, fifteen patients in a, in a clinic, so you’ve got twelve minutes for each patient then.....No. It’s not really that long. And I, I, like I said, I try to not worry about that too much and just er, spend enough time with the patients er, but, but you know the bottom line is, you can't completely divorce from your mind the fact you’ve got a waiting room full of patients.” **Mr Hull**

Another area impacted by lack of time was interactions with primary care. Most of the surgeons spoke about was how they would like to interact more with primary care, to enable more knowledge exchange, but that wasn’t possible due to their current workload.

“So at present, my role is purely secondary care orientated but I think we should probably try and have a broader role but at the moment, I just don’t have the time or the resource to get involved with it and, erm, yes.” **Mr Irwell**

Within this subtheme there was also a discussion on the surgeons' knowledge of HNC and in particular the changing demographic of patients. The surgeons spoke about how HNC patient demographics have changed and that there was an increase in "non-traditional" patients; younger, non-drinkers/smokers.

"...but you know we're getting more people who would be thought to be someone who was looking after themselves. Eating healthily and with a relatively healthy lifestyle" **Mr Hull**

However, there appeared to be a rejection that this was solely due to the increase in HPV related cancers.

"I think, I think my, my, my understanding of the last, the last serious look at the data was that all head and neck cancers were on the increase, except maybe larynx. But, but oral cavity and oral pharynx and it's not just the HPV positive ones, –er, and it, I don't know if it's true 'cos we'd have to audit our data, but I, I think, I just get the feeling we've seen quite a few younger patients recently – with, with, with mouth cancers. Er...(And that's regardless of status? HPV status.) Yeah. Yeah. So in, in... for mouth cancer it's only about 4% of the population, we think, based on the sort of best available data. Er, doesn't seem to be obviously linked, although something's causing people to get cancers that don't smoke. So, we just haven't necessarily nailed down what that is yet." **Mr Hull**

Many reported that they felt very little is known about HPV and the means of transmission.

"Er, a little bit. Erm, it's... the HPV status is complicated, and it's not something you can easily run past somebody and say, you know... patients will ask now, and they tend to be younger and better educated. If they ask, I'll tell them. But actually, we don't know that much about HPV, why it affects some people and not others, is it sexually transmitted? Maybe, but that's only because Michael Douglas says. We don't really know. I mean, HPV is endemic. Erm, you know, it causes warts, er, and certainly, I see lots of people, kids, who have laryngeal papillomatosis. Well, they obviously haven't got it sexually transmitted. Some people used to think it was from their mothers but it isn't. So that's not, that's not a straight forward conversation. But if they ask, I'll say, "Well, some people say that," but frankly, I don't think it's worth getting into some involved conversation about their sexual practices because it's not known" **Mr Clyde**

In particular there was a resistance to accepting the reported association between higher numbers of oral sex partners and increased risk of HPV related cancers.

Yeah, because I think that the traditional information that has been given in terms of the, you know, the number of sexual partners increasing your chance of HPV, I don't

think the evidence is good enough. They did it, effectively, from a, um... a...a questionnaire study of less than 50% responders, um, looking at that. And actually, if you take kids who have had a tonsillectomy, um, and have had their tonsils tested for high-risk HPV, um, up to 25% have had reported high-risk HPV within them. So, I think that some of those conversations around that don't have to be as awkward as perhaps they have, because I don't think it is clear cut. As clear cut in that, sort of, um... that sort of manner. And to... I don't think it's easy for us to say, "This is the reason why you've got it." But I think it's [pause]—many different reasons as to why you might have a HPV infection rather than just having lots of oral sex partners." **Mr Forth**

Subtheme 2: Others

Most surgeons spoke about feeling very comfortable working as part of a multidisciplinary team within secondary care and there was a recognition that different team members had different roles to play in the patient's journey. There was often a feeling that they didn't have time to do everything they wanted to in clinic (as noted earlier) but there were other members of the team who could take on those tasks or there were others who were more knowledgeable, so it was more appropriate for them to take on that task.

"I think that's why the MDT is so important, – and part-, particularly the, you know, the role of the Nurse Specialist that advocate on behalf of the patient. I find that they do a lot of that in my experience which is mainly at (hospital name). But, they're, they're great for, for advocating for the patient and, and helping the patient understand. Because there's only so much you can get across in a short clinic appointment. You know, when you've got a room full of other patients to see. And, that's why the, the nurses are so vital to, you know, give them time to get that across...Yeah, I mean, I, I certainly have thought of them as kind of the hub to the wheel and, and all the other kind of professionals were the spokes really, you know. Speech and Language Therapists, Dieticians, Surgeons, Oncologists and tying it together with the patient in the middle would, would be the Nurse Specialists." **Mr Bann**

Surgeons felt that GPs had poor HNC knowledge,

"Erm...the difficulty is there is not enough education around...the...so, GPs get a week or two weeks of head and neck experience – through five years of training. So, that's all they get looking into a patient's mouth, oral cavity and things like that. So, the difficulty is they don't have that experience to actually call something a cancer or call something benign...give something a diagnosis in the oral cavity. Erm...that's where the difficulty lies so they are using the two week wait...the cynical view to take is that

they are using the two week wait to more allay their anxiety - of missing a cancer – rather than actually do a service for the patient, if you know what I mean” Mr Dee

They acknowledged that GPs were working in the best interest of patients but considered that they were not working in the best interest of the service which they felt was “clogged” with inappropriate referrals from GPs.

“So, [they are] their patient’s best advocate. But, the problem is when they are channelling they are not in the best position to make a, a decision on that patient so there just escalate it and create...send it to another system - where it clogs up a separate pathway. So, actually...actually my feeling is if GPs are educated about oral conditions, about making a, a general diagnosis – and the GP should refer it to the dentist if they think it’s benign – or if they think nothing needs doing, they just need reassurance, and send only the specialist work into the hospital sector.” Mr Dee

They felt that GPs were in a difficult position as they had to manage patients who would have been better served attending a dentist but who may have been unable to due to the current payment system.

“Um, I think with oral stuff you have to pay to go and see a dentist. You don't have to pay to see a GP. So I think GPs, they haven't had any training in oral pathology. This isn't a criticism of them. Um, but if, if patients are choosing to see their GP about stuff that they should really be paying to go and see the dentist about, then the GPs are gonna have a lower threshold for sending in something that he's not sure about, you know. And the criteria, a lump or swelling for greater than three weeks, is ulceration greater than three weeks? And there's lots of things that can cause you know ulceration greater than three weeks that it will be wrong for them to not send him.” Mr Aire

With regards to preparing a patient for a potential cancer diagnosis, surgeons expressed some uncertainty as to who should take on this role; as they were unsure as to who should be the first person to mention cancer as a possibility.

“So for every one patient referred in, there’s 19 patients who don’t ever get a cancer diagnosis. So, erm, I can totally understand, erm, GPs are, erm, referring lots of patients in, with a very low threshold for referral and the vast majority of those aren’t going to have a cancer diagnosis. So therefore is there really a lot of point in spending time with them, explaining about cancer preparedness, because I don’t think it’s a really valuable use of a GPs time.” Mr Irwell

There were concerns around the large number of patients who ultimately were not diagnosed with cancer and whether the GP talking about a potential cancer would cause unnecessary worry. However, they did feel that cancer needed to be mentioned at some point but were unsure if it should be the surgeons who should be the first people to mention it. Some felt that the possibility of cancer should be mentioned at the point that patients were referred for further tests if required, but there may not be a need for it to be mentioned before this point.

“But, clearly that anxiety element is there for the patient when they turn up for an urgent appointment which is done within two weeks... So, that in itself primes the patient as much that there is something suspicious....most patients I tend to see already have a good understanding. They are coming to see a head and neck cancer specialist to deal with a cancer related problem.” Mr Dee

The dental pathway was considered more trustworthy and established compared to GP referrals.

“I think with dentists it’s a lot better...The thing with dentists is it’s...it’s a well-established, erm, pathway for them because they’ve, they’ve trained for five years looking into patient’s mouths. They are much more confident. They are much more...they can make a decision as to whether they are worried about something or not and they can make a, a...at least a provisional diagnosis before they refer a patient across.” Mr Dee

The surgeons felt more confident over dental referrals; they spoke about how the dental training meant that dentists were far more knowledgeable about the mouth than GPs and therefore had more confidence that if dentists were referring someone it was because they had genuine concerns regarding a possible cancer. They also felt they obtained better information from dentists. They spoke about how dentists would often write a full referral letter which would include far more clinical information than the referrals from GPs which were usually on the TWW referral document, where there are tick boxes and limited space for additional clinical information.

“I think if, if a dentist sends me a letter that, where they've taken the time to write down the features of symptoms... I'm thinking that's, that sounds sinister. I would say dentists are better at picking up, you know, the benign, spotting mucocoeles, fibro-epithelial polyps, um, smokers keratosis, um, than a GP will be, you know, a dentist looks in people's mouths all day every day and it's only, and they get more oral

pathology as part of their syllabus. So I think if, if a, if a dentist sends someone in thinking it's cancer, I would expect their diagnostic rate to be far higher than 3%. You know, they'll, they'll send patients in on a, "Please see this patient urgently, um, I don't know what's going on," but if a dentist, if it's, if it's a dentist calling out cancer, which I suppose we have to assume if a GP is, is sending someone in on a cancer referral pathway, you know, they're, they're concerned it could possibly be cancer. If they're not, then they should be sending them, they should be calling it as benign and sending them on the benign path. So if a GP is calling it on a urgent pathway, um, I think if we extrapolate that, if a dentist is sending something in for an urgent query cancer diagnosis, they tend to be much better at, at picking it up. Um, but I've got no data to support that. That's just my anecdotal opinion." Mr Aire

Interrelationship with other themes

The overall theme of *(Professional) Responsibility* underpinned the other themes. It strongly influenced how the surgeon interacted with the pathway and with their patients. How the surgeons viewed their role and responsibilities impacted how they communicated with patients, what they communicated based on what they felt other people's responsibilities were within this area, and how that communication was impacted by social influences. Surgeons' own coping skills were also linked with their view on their professional responsibility; if they felt they were unable to meet their responsibilities then this impacted how they coped and what skills were required for them to cope. Finally there was some impact on the theme of *Being at the mercy of the system* as there was a tension between what the surgeons felt their roles and responsibilities were and what they were able to achieve within the confines of the current system.

7.3.2 Communication

This theme had three sub-themes which considered the communication 1. *With the patient*, communication 2. *With primary care* and communication involved with 3. *Shared decision making*. Communication is very much placed within the theme of *(Professional) Responsibility* and is also linked to *social influences*.

Subtheme 1: With the Patient

Surgeons considered that using the word cancer with patients was very important for the patients' understanding of what was happening to them. However, some felt it

was not always appropriate to use the word, particularly in the initial stages of investigation, as it may increase distress unnecessarily, as many had benign disease.

“They usually have, but they don’t say it, um. And so, um, I’ll often just start by saying, “You’ve come in under the urgent wait, uh... urgent two-week wait to talk about your symptoms.” And then, at the end, we’ll say, “Well, I can’t find any evidence of anything concerning, like, cancer.” Um, so at least they go away with a clear mind that that’s been looked at, and they’re happy that they haven’t got it. [Inhales] um, but [pause], often, even if they have got, um, some symptoms, you might not know for certain that... well, you won’t until you’ve got the biopsies, though you have a high suspicion. And we, sort of, just discuss the options of, um... you know, from [inhales] one end, you’ve got, sort of, early cancerous changes, but on the other end, you’ve got definite cancer, and I can’t say where you fall within that spectrum, but I want to investigate further. So they... they will know, if they are going for further investigation, that the reason we are doing it is because I’m concerned that there may be some form of cancer there.” **Mr Forth**

However, the surgeons did feel it was important to give “warning shots”, especially to those patients they felt were at high risk of a cancer diagnosis. They said that, if they felt that the likelihood was the test results would come back with a cancer diagnosis, they would speak to the patients about this possibility in advance as they felt it was important that the diagnosis didn’t come out of the blue. They described the process, for the patient, as being a slow realisation rather than a “lightbulb moment”.

“it rarely happens that somebody comes in without that cancer diagnosis and then they leave, with new information, that they had no idea that they were getting and that, sort of, lightbulb moment is very uncommon, I think...So, I’m, kind of, drip-feeding it into the consultation at an earlier stage and that, kind of, links back to what I was saying about preparedness for cancer, because often they are prepared because they, kind of, know and, erm, and if you don’t ... and I personally think that if you don’t, erm, address it early, then you end up dancing around this, sort of, cancer diagnosis thing that both of you can see but neither of you want to talk about, erm, and I don’t think that’s necessarily the right thing to do.” **Mr Irwell**

However, it was felt that the word spoken out loud was a ‘full stop’ on the consultation as after that point the patient and any significant others present were unable to take anything else in.

“...because there is very little information they will take in. Erm, once you use the word ‘cancer’. Be it family members, be it friends, be it the patient. Whoever is along with them, my general feeling is everything just goes over their head and I’ve been in that situation of receiving that news for a family member and that’s what happens.

You, you're not focussed. You, you have lost everything at that point, all hope." **Mr Dee**

Surgeons were highly confident in their own communication skills and felt that their skills had improved with experience and age. They were more confident mentioning the possibility of a cancer earlier in the process as they became more experienced and felt an increased confidence in their diagnostic skills.

"Yeah. I think it's something... there's a lot of, um [pause]... nowadays, there's certainly a lot of simulation training and things along those things, so I felt prepared for that anyway. I had done an oncology job, um, previously, so I'm used to being around these patients anyway, um, and so it has always been something that I've not really struggled with, that part of, uh... that part of it. I quite enjoying having the... those conversations. Or at least I enjoy... um, the relationship that you get with a patient with cancer is very different to the relationship that you have with other patients. I've found that quite interesting." **Mr Forth**

There was a little discussion on feeling less comfortable with how to communicate where there was no clear pathway for treatment. In addition, they described how the MDT meetings could involve long and complicated debate over the best way forward for a patient and this could be difficult to then try and communicate to a patient afterwards.

"And there's quite an awful lot of... you know, it's [pause]... there's often quite complex discussions that are had at an MDT, whereas [pause] we don't always know exactly the best way to manage that. And then to be able to portray that in a conversation with a patient and then expect them to be able to come up with a decision or [pause] to at least have, um [pause], think about... it's actually really quite challenging, um. The clinic always overruns, um [pause], you know...And... and it is what it is, and you try and give them as much information as you can, as possible." **Mr Forth**

Surgeons described the information needs of cancer patients as being polarised with some patients wanting to know everything and some nothing. They described the patients who wanted to know more as being younger and healthier than those who didn't want as much information.

"Yeah. I think, I certainly felt and, you know, this was seeing patients occasionally in a clinic, but mostly further down the line of treatment when they, they actually come into hospital to have any treatment. But, you would tend to find patients either wanted to know everything about it: – what caused it; what their risk factors were that precipitated it; what treatment they could do; what their prognosis was in minute detail. Or patients that were the other side of the spectrum – and, you know,

were passive to it and didn't necessarily want to discuss prognosis or treatment and would just, – you know, take the, the team's advice, the Consultant's advice about what was best for them. And people tended, I felt, to be a bit more polarised rather than something in that common ground." **Mr Bann**

There was very little spoken about in terms of HPV, it was felt that (as with general information needs) there was a difference in what people wanted to know; some patients had knowledge through the media whilst some had no knowledge at all. Some surgeons reported a feeling of discomfort and a lack of training on how to deal with this topic, and some reported that they had developed strategies to make it an easier topic to discuss; these were normally around trying to talk about HPV in terms of a virus with less focus on the sexually transmitted element.

"So I wasn't trained to talk about people's sexual health with them.... So, in terms of HPV, yeah it took a bit of getting used to and then I just, kind of, I, I thought it through a bit er, so, er, there's er, there was a... My philosophy's been borrowed from a Catholic priest who was working in a leper colony, er, so his approach to looking after his congregation was he would always say, "We lepers" and he would just count himself as one of them, so I kind of was reflecting on that and I thought, actually the way to talk about it is to say, "We all get exposed to the HPV virus, er, some of us, most of us, most of us just either live with or get rid of the infection. It doesn't cause us any long term problems but some of us end up developing either pre-cancerous or cancerous lesions because of the HPV virus," and when I started doing that I felt a lot more comfortable after that." **Mr Hull**

Some surgeons said they spoke about it in a way to highlight how common a virus it was, that the majority of the population has been exposed to it and that the patient (if HPV positive) was just "unlucky". The diagnosis of HPV positive cancer also tended to be framed in a positive way, with surgeons highlighting that this made it a more treatable disease.

"Um, but if, if I was having a chat with the patient about their HPV status, I would, um, explain to them actually that this is, you know, a positive thing, you know. It's, it's, it's a positive prognostic marker, you know, in their terms, you know. These patients tend to do better. There's no guarantees but, you know, across a big group of patients, you know, this is, this is something that would confer a good outcome on you. Um, I can't remember if I... it's a conversation I have very infrequently, um, so, um, yeah, I don't think I tend to volunteer how they've caught it, um, how, how it's, how they've come about to be a carrier, um." **Mr Aire**

Most reported that they felt the current idea that HPV was transmitted through oral sex was not the whole story (see section 7.4) and this altered what they would communicate to the patient about their condition.

“Yeah, because I think that the traditional information that has been given in terms of the, you know, the number of sexual partners increasing your chance of HPV, I don’t think the evidence is good enough. They did it, effectively, from a, um... a [stutters]... a questionnaire study of less than 50% responders, um, looking at that. And actually, if you take kids who have had a tonsillectomy, um, and have had their tonsils tested for high-risk HPV, um, up to 25% have had reported high-risk HPV within them...So, I think that some of those conversations around that don’t have to be as awkward as perhaps they have, because I don’t think it is clear cut. As clear cut in that, sort of, um... that sort of manner. And to... I don’t think it’s easy for us to say, “This is the reason why you’ve got it.” But I think it’s [pause]—many different reasons as to why you might have—a HPV infection rather than just having lots of oral sex partners.” **Mr Forth**

Subtheme 2: With Primary Care

Surgeons described a “*disconnection*” between primary and secondary care. They noted that this relationship had changed over time; most surgeons reported that earlier in their career they felt they had had had a good working relationship with GPs. Some described a change in the way communication happens. They felt that GPs no longer speak to them on the phone and appointments are made in secondary care by the administrative staff. As a consequence, they are no longer known personally to the local GPs (and vice versa).

“I think there is a disconnection between GPs and hospitals which used to exist and doesn’t anymore. So if you had a good GP, he would know which consultants would suit you best and which ones to send them to. That’s been beaten out of the GPs so they now...but it’s because, I think, er, GPs are not really... Apart from referring themselves and their family, they don’t pick where they send patients anymore, and they used to. It used to be an important part of a consultant’s, er, sort of, work plan, that they had good connections with certain GPs...It’s gone completely...they’ve been made to refer anonymously on block. If GPs could be bothered, they could send things to individuals, but it’s essentially been, over the last 20 years, I think they’ve been told not to, I think they’ve been told “Don’t do that.” I think the patients... And part of it’s this ‘Choose and Book’ thing...” **Mr Clyde**

Whilst it was felt that a good relationship with GPs was important, most of the surgeons considered it was the GPs’ responsibility to improve this relationship.

“But I know there are still GPs around who know me, but they don’t communicate like they used to. And there’s no reason for me to be ringing up GPs – they have to call me.” **Mr Clyde**

Surgeons considered that there was (too) limited information on GP referral letters and this increased the feeling of disconnection. They compared GP referral letters with those from Dentists who they felt gave them far more thorough referral letters (as discussed in the *(Professional) Responsibility* theme, section 7.4) They described how GPs and surgeons nowadays communicated mainly through clinic letters; they also described how this was the main method they used for feedback after referrals. It was through this method that surgeons provided any “education” or confirmation of “appropriate referrals”

“The more times I’ve given feedback would be for somebody who came in on a routine pathway who should have been a two-week wait rule. And they’ll often say... They’ll sometimes say, “This doesn’t meet the two-week wait criteria,” when actually it does. And those... and I’d be much more concerned about that referral than I would be from some of the two-week wait referrals who have got a lump in their throat. And I have written that ‘I know that you’ve written that this hasn’t met the two-week wait criteria, but I am more than happy to see these under the two-week wait rule.’” **Mr Forth**

Most surgeons felt uncomfortable feeding back on perceived incorrect procedures or when they felt the primary care clinicians’ referral had been inappropriate (i.e. they felt it was “obviously” not a potential cancer). They felt that this was important but were uncertain of how this was best achieved.

“... if a patient, erm, was saying, oh I went to my doctor six months ago with this and they didn’t believe me, they didn’t believe me, they didn’t believe me, they didn’t believe me. Then I think, erm, in those situations, I would probably, erm, communicate that back to the GP, sort of, separately, either with a letter that doesn’t go in the patient’s notes, as a, sort of, personal communication, erm, to say, look this is the situation, erm, the patient is worried that, you know, I can’t comment on the GP’s management, because I’m not there, I can’t see but I think it ... so for those groups of patients, then I would feed that back to the practice, if they felt there was something wrong or something had been managed incorrectly.” **Mr Irwell**

Some surgeons reported difficulties when talking with patients who felt that their route had been delayed by primary care; this was mainly around maintaining their professionalism and not commenting on a situation they do not fully understand.

“The real tricky one is the patients who have been going backwards and forwards, you know, not happy, not happy. Um, they, they, that’s a real issue for them. Their faith and their trust is, is devastated. Now for a guy who’s got a massive tumour, um,

that's clinically obvious to me, I can't really help them deal with that, you know, without being unprofessional and saying, "Yeah, your dentist was shit and he's a muppet," um, you know. And I just have to say, "Well I can't, I don't know what, I can't pass any comment If it, if it's, if it's a patient who has clearly, um, had, you know, been difficult to diagnose, if, if the, if the bits don't fit then I, I'll be quite upfront and say, "Well actually I can, you know, once that..." you know, if, if, if, if I'm in a position of trust then actually I think I can help those patients. If, if I agree that this was, this was a sequitous route to getting the diagnosis and it wasn't obvious and even as a, as specialist I can see, I can understand how that's happened, sometimes that can help them get over that, that, that hurdle of, um, it's not very often but, you know, if, it can in some ways, you know, change their perception, they're not in this situation because that doctor or dentist was incompetent and I'm gonna direct all my anger at them, you know, it introduced that kind of well actually that's life and it's difficult and sometimes things aren't... I'm having to put up with this now but, um, if, if you can spare them that sense of being let down then, then I think I will, provided I believe it, you know, um, you know, I will try." Mr Aire

7.3.3 Social Influences

Surgeons described their perception of a patient diagnosed with a HNC. For most surgeons, it was evident in the discussion how they viewed those with a HPV+ related cancer as different to those diagnosed with a HPV- cancer. Almost all spoke about how there should be no stigma attached to a HPV+ diagnosis; as noted in the communication results (section 7.5) would often explain that these patients had just been “*unlucky*”. In contrast they described those with a HPV- cancer, traditionally seen as being linked to tobacco and alcohol use, as being uninterested in their healthcare. They described them as unwilling to change their behaviours and more likely to have delayed help seeking.

Most rejected assumptions that a HPV+ cancer was more likely in those who had more sexual partners and spoke about how this didn't sit well with them (see section 7.4). They said they were likely to talk to patients about how everybody has been exposed to HPV at some point and deliberately spoke in a way that included themselves in that group. Whilst those interviewed felt that there was no stigma attached to HPV+ cancers they did report instances where assumptions were made about a patients' sexual history based on a diagnosis, although this was reported as being in a stereotypical way, congratulating the male on having had a lot of sex.

“—and it felt a lot more comfortable talking about it in that way. ‘Cos you're not saying... You, you... it's much less judgemental, isn't it? You just sigh and think, we've

all been, we've all been exposed to this. Er, and I think that's the, for me anyway, that, that, that's helped." **Mr Hull**

"... there was a picture of a well-known consultant whose nationally known and, erm, he didn't have HPV related cancer but there was a link made between this consultant whose quite a character and him developing an HPV related head and neck cancer. I really took dislike to that actually because, erm, you know, he was being played as a, sort of jack the lad, you know, multiple sexual partners type character, erm, and, erm, you know, it was all due to his, erm, testosterone fuelled lifestyle that led to him developing head and neck cancer. Which I really dislike because I didn't think it helped the audience understanding of what HPV related cancer is, at all." **Mr Irwell**

Some reported feeling that cancers related to smoking and drinking were more "lifestyle choices" and therefore they assigned more of the blame to the patient. They also spoke about how these patients were more likely to present late and were less engaged with healthcare. In comparison those with a HPV+ cancer were often described as being better educated and more likely to engage with healthcare systems.

"And I think that, er, the new group of Head and Neck patients that are the HPV positive ones, who are younger, better-educated, tend to turn up early because they're aware of it and they also tend to be worried about symptoms, which makes them come along a bit earlier. I have not yet thought of – unless you go trawling the pubs and clubs and the gutters at night, you're not going to find guys with head and neck cancer until it's a late stage and they come along with something serious. And I just can't think of any real public educational programme that would change that. Unless you change people's lifestyles completely, then... and you can try that, I'm not against initiatives to stop smoking and stop drinking, and clean your teeth and go to the dentist but there's still going to be plenty of people who just don't and never will do that." **Mr Clyde**

"And, I think one of the big problems is the population that are at risk of these cancers...So, patients who sort of don't look after themselves: they're smokers and they're drinkers who ignore the symptoms and present late. And, I think the reason that maybe survival in these cancers lags behind some other areas, is that they present late – and they present late for those reasons. Because, they're quiet sometimes if they're in hidden places –or they're in patients who don't listen to, to the symptoms until it's unignorable." **Mr Bann**

7.3.4 Coping Mechanisms

There were two subthemes within this theme: 1. *Enjoyment of role* and 2. *Self-care*. This theme was fully immersed within (Professional) Responsibility as their

enjoyment and self-care practices were impacted by what they felt their role should be and their view of others and the patients they were responsible for.

Subtheme 1: Enjoyment of role

Most surgeons spoke about how they picked their job because it was something they enjoyed. They stated that they wanted to work in cancer and despite the negatives of their job (e.g.: lack of time with patients and lack of control in job, (discussed in detail later in the “*Being at the mercy of the system*” theme, section 7.8) it was one they wanted to continue in. Some surgeons noted that their skills were in this area, and they enjoyed being able to help a patient through this time, so they should be the ones who did this job. This enjoyment enabled them to cope with the perceived negatives.

“But cancer is something very different, you know. There is a... there is much more of a, um [pause]... uh, they... they seem a... a lot more [pause] dependent, if you like, in a way of... because we are doing something that’s more, um, [pause] life-changing, in a way, for all of them. It’s probably the worst thing that’s... the worst news that they’ve ever had in their life, and embarking on probably the most difficult time in their life that they’ve ever had, and I quite like helping them through that.” Mr Forth

Subtheme 2: Self-Care

Self-care was an important part of the how the surgeons coped with their job. Most described how their colleagues, friends and family were their main support system. They spoke about how they needed to ensure their own personal feelings and needs were dealt with outside of patient consultations. They spoke about how the patient consultation should only be about the patients’ needs and emotions and by sharing too many of their own emotions it was felt that would make the consultation less about the patient and would be inappropriate.

“I think, and this applies to lots of other things in my life as well, you just, kind of realise that there are things that you need to do in life and it, and you may be scared, maybe getting on a plane to travel somewhere, er, leaving home and, and it... And, and, and er, anything that’s perceived, I guess... I think anyway, anything that’s perceived as being something brave or someone is being brave, in actual fact they have all that emotion, all that fear, all those anxieties, but they just learn that they just need to push those to one side and do whatever it is they need to do. And I think, when I say I’m comfortable with it, I, I don’t mean I like doing it,... – I just mean that I have learned to push those thoughts aside –...– because there’s a job that needs to be done and it needs to be done in a, in a way that doesn’t indulge my emotional

problems, it... 'Cos it's not about me, it's, it's... I need to park, you know... And I have sat through consultations where I've wanted to cry and I've just thought, it's not my place to cry in this consultation. It's... That's... It's, it's the patients time." **Mr Hull**

A few surgeons spoke (in a limited way) about the need to keep an emotional distance from patients, not allowing the patients to become too friendly and of making sure there was a clear boundary in their relationship. This was described as a feeling that they didn't want or need the patients' "friendship", but did not discuss this in any more detail.

"Er, some patients kind of er... I don't get too involved in the rest of.. I mean, quite often, some patients will try to draw you into their life. They think I'm their friend but I'm not. I don't go to their funerals, I don't go to their weddings, don't go to their christenings. I get invited but I er, I keep a fairly... not obvious but clear line between getting too involved with them and not. I think that... I know some doctors get very... and the nurses particularly, actually, get kind of.. I don't know if it's part of their personalities that draw them into this work, but they get involved with patients. But you cannot be getting involved with the patients, really. I'm happy to be nice to them, and I'm glad if they're doing well, but I don't want to get involved, really. I've got my own friends." **Mr Clyde**

When discussing self-care the majority of the surgeons spoke about their use of an informal system as and when needed: talking to partners, friends and colleagues, and strategies they used to de-stress such as sport.

*"Er, yeah. Er, there's been a couple of times I have er... I did, I did on one occasion er, er, I have burst into tears in front of a colleague before now in, in this room in actual fact er, and I've, you know, been upset, with, er, er, my partner or, or, or, or close family members but, you know... And, and, and we do informally, you know, talk as, as colleagues. So my current er, so like you've met Mr.(consultant name), haven't you? So, so we generally socialise about at least once a fortnight, sometimes once a week. And er, we go for a drink or we'll have a game of tennis or have something to eat and, and er, and er, and, and, and in a, part of that is actually a very informal debrief and we talk about things. And that, that's, that's really helpful...Because there is an emotional burden with the job. I, I, I, I, I do quite a lot of sport just to keep myself... because I think that's very good way of just de-stressing, I guess. **Mr Hull***

There was no mention of a formal support system being used by those interviewed but most reported that they were satisfied with this. However, one surgeon highlighted that they considered that a formal support system was lacking in this area of medicine, and contrasted it with other areas, including psychiatry. This

interviewee felt that this was only something which was starting to be discussed in recent times but was needed.

“Er... I'm not sure if I've just gone off topic there, but er, but I think, I think, I think it's an under looked at or under [pause]... So surgeons self... people or... Surgeon as it is, just clinicians self-caring. It's not really, it's only just starting to get into the... er, attention of, of, of, well the healthcare community, I guess. I think the mental health care community have been doing this for a long time, 'cos er, and you know they have peer review groups and they have support er, and so forth and that's not really come through into the rest of the health care.” Mr Hull

7.3.5 Being at the mercy of the system

There were three subthemes within this theme; 1. *Control*, 2. *Balancing time and targets*, and 3. *Affecting change*. This theme only overlapped with one other theme (*Professional*) *Responsibility*, due to the impact the system had on the surgeons' view of their professional responsibility.

Subtheme 1: Control

Most surgeons reported that they felt they could improve their working practices in a number of ways but were unable to do this because they did not have *control* over their time, their diaries, and how and when they interacted with their patients and with primary care. This can be seen across the subthemes.

All the surgeons reported a feeling of lack of control within their clinical environment. They spoke about how they did not have the responsibility for looking after their own diaries; this was frustrating because they felt having this control would have helped improve the service as they knew which patients may need more time and which would only require a short appointment.

“Erm, and those are the difficulties really when it comes to, to cancers. It can be frustrating because you've got fifteen patients waiting outside but equally you know this patient needs an hour. So, there's no, there's no personalised appointment basis... it's very difficult to actually facilitate that because you don't have a slot where you can give somebody half an hour or an hour pre-programmed into your week.” Mr Dee

They did however understand that this would be a further time commitment from them to manage diaries and time was something they felt they lacked.

“You're not clicking that appointment slot. Somebody else is clicking that behind the scenes and, to be honest, I'll be honest, I can't micro-manage every little bit. I won't

go back and say, "Oh, have they made a 30 minute slot for this patient?" Maybe that's what I should be doing but... [laughter]. It's quite time consuming." **Mr Dee**

They spoke about how, when they passed on requests for longer appointment times for specific patients to the booking service, they were not listened to.

Subtheme 2: Balancing time and targets

Surgeons felt strongly about the need to give patients the time they needed to think through decisions. However, they spoke about the pressures imposed by government targets (discussed in section 1.2.2) and concerns over patients breaching these targets (which could result in a financial impact on their hospital). Those newer to the profession felt this pressure but felt less burdened by it than those with more managerial responsibility.

"And, the quicker you rush a patient through, in my general feeling...again, you need to see it from a patient's perspective, if you push for time, push for targets, my feeling is the patient actually doesn't appreciate what they are letting themselves in for. So, treatment related mobility, treatment related changes aren't actually fully appreciated. How much ever you explain something to somebody, 'til you experience it it's a different balance of situation. So, you can explain things really well, perhaps with, erm, with IT, with physical patients talking to each other but actually 'til it happens to the person it's very difficult to appreciate and the quicker you rush patients through, if they don't have the knowledge of that work-up then they find it more difficult to, to, to accept and manage the situation they are in at a later date. It can be detrimental. Yes. It can be detrimental. I wouldn't say it is always but it can be detrimental in some patients because, what takes me a day to process, may take my son two weeks to process, may take my grandfather four, four months to process. And, we are treating everybody at the same speed." **Mr Dee**

One area of particular interest to the surgeons was the rapid cancer referral pathway (2 Week Wait). There were many difficulties seen within this service, and surgeons viewed the 2 week wait process and targets as inappropriate for this type of cancer.

"So I'm not happy about 2-week waits. I was around when it didn't exist and GPs used to just send a letter or give you a ring, and if ever a GP gives me a ring, I'll see the patient that day or that week. If they can be bothered to do that, they'll get seen quickly. The letters from GPs are clear and there are certain keywords in GP letters that will say, "There might be a neck cancer, and they have hoarseness and a neck lump, and anything else they come along with: a bit of a pain in the back of the head, a bit of a feeling of a lump in the throat – it's all nonsense. So I don't think it's got any better than it was, and I think that it's overburdened with inexpert opinion about how

the best way to refer head and neck cancers is to us. I think it's not very good." **Mr Clyde**

The surgeons spoke about how the 2 Week Wait referrals overloaded the system with inappropriate referrals and had repercussions for patients who were admitted through a standard referral (e.g. longer waiting lists and potentially missed cancers).

"So, it...it does impact the service significantly really. So, all the routine referrals get pushed back and if there are more two week waits waiting then, then the routines take a hit and then all the two week waits are bumped into those slots to meet targets. So, clearly, the routine patients wait a lot, lot, lot longer" **Mr Dee**

There was also a feeling that the level of experience the clinicians had was being used inappropriately within this system. They spoke about how everyone referred was seen by a consultant and it might be a better use of resources to have another level of triage to filter out those patients that do not need to be seen by a consultant.

"So, there should be a better screening system, better use of resources rather than a specialist seeing 90% of patients that are not going to need any form of active treatment in terms of cancer. They should be seen by a...a well...a well-trained junior or a...or a specialist nurse for that matter. So, there should be an intermediate screening system to screen these referrals and feedback needs to be given to the clinicians that are sending these patients. At the moment there is no feedback going back to the clinicians." **Mr Dee**

Subtheme 3: Affecting change

The surgeons spoke about difficulties they felt around *affecting change*. Combined with the feeling of a lack of control and a lack of time meant that surgeons spoke about feeling unable to affect change. They said there was little time in their days to allow them to consider other ways of working. Some spoke about working in a *"reactive service rather than a proactive service."* They described how they wanted to expand their roles (e.g.: working more with primary care on head and neck referrals) but were unable to do so within current limited time and resources.

"So at present, my role is purely secondary care orientated but I think we should probably try and have a broader role but at the moment, I just don't have the time or the resource to get involved with it..." **Mr Irwell**

7.4 Closing Remarks

Surgeons described their role as diagnosing and preparing cancer patients for treatment. They acknowledged the evolving demographics of HNC patients but expressed scepticism over reported HPV transmission routes. Multidisciplinary teamwork was valued, though they perceived GP referrals as often inappropriate compared to more detailed dental referrals. Communication with patients was nuanced, with surgeons gradually introducing the possibility of cancer while balancing clarity and distress. Relationships with primary care had weakened over time. Shared decision-making is challenging, particularly when treatment plans differ from patient expectations or when balancing survival with quality of life. Social perceptions of HNC patients influence attitudes, with HPV-positive cases seen as "unlucky" and HPV-negative cases often linked to lifestyle choices. Surgeons found fulfilment in their work despite systemic pressures, relying on informal coping mechanisms rather than structured support. They felt constrained by a lack of control over their time, inefficient referral pathways, and government targets, making meaningful change difficult within the current system.

Chapter 8: Discussion

This chapter will contain a short summary of the studies undertaken, highlighting the novelty and contribution of the studies. It will then discuss the routine data results, giving an overview of the varying routes to diagnosis and the inequalities within these routes. This will be followed by a discussion of the qualitative interview results with a focus on the role of communication and relationships, symptom knowledge and recognition, and the concept of the “Good Patient”. It will then go on to discuss the diagnosis experience, communicating a HPV diagnosis and health literacy. Finally, this chapter will close with a discussion on the strengths and limitations of this body of work.

8.1 Summary of Main Findings

8.1.1 Study 1: Routine Data Analysis

This was an analysis of the route to diagnosis data from PHE where all patients diagnosed with a HNC in 2006-2014 had a route to diagnosis assigned to them. I was then able to analyse the different routes, considering who presented through each route and then comparing the routes using patient demographics.

This analysis showed that those who were diagnosed with cancer through the emergency route were more likely to be non-white men over the age of 65 years who live in urban areas and had no co-morbidities. The majority of them had a cancer of the larynx or a rarer HNC. Those coming through this route were also more likely to have higher stage disease. Referrals through this route reduced over time.

Those coming through the urgent cancer referral route (Two Week Wait) were more likely to be male, white, and aged 55+ years. Those diagnosed with cancer via this route were more likely to have a cancer of the oropharynx. Diagnoses through this route have been increasing over time. Both groups showed higher referrals in those living in more deprived areas.

Those who presented through the dentist prior to their cancer diagnosis were more likely to be female, and non-white and as expected were more likely to have an oral cancer and an earlier stage disease. As deprivation increases the chance of being referred by a dentist reduces, although this difference was not apparent in the most deprived group.

8.1.2 Study 2: Patient Interviews

Interviews were conducted with 19 patients who had received a diagnosis of HNC. They were analysed using reflexive thematic analysis. Seven themes explained the findings from these interviews.

1. **Knowledge**; this covered the participants' knowledge of cancer in general, HNC specifically and of the healthcare system and how and when to access help.
2. **The C Word**; considered the use of the word cancer, the level and type of communication along the pathway to diagnosis and the context of the communication at the point of the diagnosis.
3. **Control**; this covered the participants' decision making processes during the pathway to diagnosis and how control was shouldered during the pathway, ie perceived to be by the patient whilst in primary care and then passed over to the clinicians within secondary care.
4. **2 Week Wilderness**; this was a difficult stage for many participants and was the point after cancer as a potential diagnosis had been discussed and biopsies had been taken but no "official" diagnosis had been given.
5. **Negotiation and Navigation**; covered the participants' trust and confidence of the system and their ability to navigate through it.
6. **Symptoms**; covered how the participants viewed the symptoms they were experiencing and the impact of others' view of their symptoms.
7. **Emotional Labour**; covered the participants' coping and self-blame alongside their need to shoulder their families'/significant others' emotional needs.

8.1.3 Study 3: GP Interviews

Interviews were conducted with eight fully qualified GPs who had experience of a patient with HNC. Five themes were developed from these interviews.

1. **Roles and Responsibilities**; explained how GPs' understood their role within the route to diagnosis. Views varied with some considering that their role was to suspect cancer and to refer appropriately, whereas others felt their role was as the lynchpin for the patient, being the centre of their care as they moved through to diagnosis and beyond.

2. **Working (within) the system;** covered how the GPs had to “work the system” to fit their approach to care and how they had to work *within* an imperfect system. Guidelines were welcomed and prevented a “*Wild West*” approach, but GPs considered their own clinical opinion as better than the guidelines. This theme also covered communication and how this worked well between GPs but was less successful between primary care (Dentists and GPs) and primary and secondary care.
3. **Patient Relationships;** the importance of trust within the relationship and how this impacts the route to diagnosis was covered in this theme along with the GPs’ understanding of who a HNC patient is.
4. **Communicating a Potential Diagnosis of Cancer;** this encompassed the difficulty in balancing the need for patients to attend follow on appointments without causing undue anxiety. The majority of referred patients would not have cancer so it was important that the risk was framed in an appropriate way.
5. **Fear;** all the above themes were embedded within the theme of fear. This was a level of fear which was present all the time but was not all consuming. There was a fear of missing a cancer, litigation, upsetting patients, looking stupid and of negative press.

8.1.4 Study 4: Dentist Interviews

Interviews were conducted with a range of dentists; community, hospital and general dental practitioners (n=12). All had experience of referring a patient who ultimately had a diagnosis of HNC. Six themes explained this data.

1. **Knowledge;** there was a high level of knowledge around HNCs, but dentists felt that patients’ knowledge was very low. There was a lack of knowledge of what happens to a patient once they are referred into secondary care.
2. **Professional Role, Reputation and Responsibility;** dentists felt that their role was not easily understood, and that having to pay at point of care disrupted their relationship with patients causing distrust, as well as the operative nature of their job role caused patients fear and anxiety. There was a fear of “looking stupid” if referrals were perceived as inappropriate by secondary care clinicians. Dentists also expressed a lack of confidence in these referrals. They played a role in many different aspects of a patients journey and in particular discussed the difficulties

around discussions on making a patient dentally fit post diagnosis and prior to treatment.

3. **Trust;** this was split into two elements, the perceived lack of trust patients had for them and the trust the dentists had in the referral pathway. They felt that they were not seen as very trustworthy by patients. They reported a lack of trust in the referral pathway due to a lack of understanding and knowledge. They felt excluded from the process, lacking any follow-up to referrals.
4. **Clinician-Patient Communication;** this covered difficulties around having discussions with patients over potential cancers and HPV as there was a lot of fear that they were not trained to have these conversations. The use of the word “cancer” was particularly difficult as they felt this would open up conversations, they would not feel comfortable taking part in and would take a considerable amount of time, time which they did not feel they had in their day.
5. **Co-ordination of Care;** dentists felt that healthcare was split into different silos with a lack of communication and shared knowledge, this was between primary care clinicians and between themselves and secondary care. There was a feeling that they were unable to effect change in this process. Dentists were involved in different aspects of the process and those employed within the hospital who were part of the multi-disciplinary team felt that the diagnostic process was very intense. These dentists also reported being able to make use of informal routes to diagnosis which meant that often their patients had a very quick route to diagnosis.
6. **Relationship with Patient;** many dentists who had referred a patient who then turned out to have a cancer diagnosis felt that this was a pivotal point in their relationship, and those patients often created a long lasting bond with them. The role of the dentist whilst the patient was going through the diagnosis process was seen to be impacted by a lack of knowledge and understanding of the process and what the patient would be going through.

8.1.5 Study 5: Head and Neck Surgeon Interviews

Interviews were conducted with eight surgeons, with a range of career level and ENT and Maxillofacial specialities. All had experience working with HNC patients. Five themes explained this data.

1. **Professional Responsibility;** this theme underpinned all the other themes. This was split into 3 subthemes around their perception of their own role which was defined by a feeling of lack of time and ability to affect change. Their view of other healthcare professionals' roles within the route, which covered positive views of secondary care multidisciplinary working. The view that GPs whilst working for the best interest of their patients were not working in the best interest of the system. Finally, they considered that patients were often prepared for a cancer diagnosis, due to a feeling of urgency around their symptoms.
2. **Communication;** the communication theme had 2 subthemes. The first was communication between the surgeon and the patient, with the importance of using the word cancer but how the use ended communication at that point. The second - communication between the surgeon and primary care - was described as disconnected with a significant negative change in their relationship, which has meant a loss in previously good working relationships.
3. **Social Influences;** this was a smaller theme focussed around how the surgeon perceived HPV+ and HPV- patients differently.
4. **Coping Mechanisms;** self-care was an important aspect of how the surgeons coped with their job role, using informal support systems, and keeping an emotional distance from their patients. They also spoke about the importance of enjoying their work.
5. **Being at the mercy of the system;** this covered the perceived lack of control to effect change within their clinical environment. There was also a difficulty in balancing time and targets; to meet targets, patients were not given the time they needed. Finally, there was a particular interest in the Two Week Wait referrals and how it was felt that this system was not working as efficiently as it should do.

8.2 Novelty and contribution of the studies

This work has investigated, for the first time, the route to diagnosis for HNC patients. It has attempted to unpick the complexity of this route using multiple methods taken from a number of different perspectives focussing on shedding light on the issue of delays in the route to diagnosis. This is the first time route to diagnosis national data in HNC has been

examined and the first time where both qualitative and quantitative data has been used to try and fully understand what impacts a patient's journey to diagnosis.

The picture that emerges from the analyses included in this thesis is one of many different interactions impacting on the route to diagnosis, and how there are many inequalities inherent within the system. There are impacts not only on the patient, but also the healthcare professionals working within the route. Previous research on routes to diagnosis has focussed on delay to diagnosis and the impact that delay has on patient outcomes. What is striking is that despite many years devoted to this area there has been little change in the percentage of those presenting with late stage cancer, including HNC. The contribution of the current work is that it focussed on the overall route to diagnosis which has given insight into not only delays but facilitators and other factors which may have an impact on the route to diagnosis.

My quantitative and qualitative findings indicate that delays are influenced by socio-demographic background, knowledge and understanding of HNC and interactions with the healthcare system. The main results found multiple points of potential delay and misunderstanding.

1. Inequalities within the route to diagnosis
2. Lack of knowledge around symptoms of HNC
3. Difficulty understanding and accessing healthcare services
4. Non-explicit communication around potential cancer diagnosis
5. Fragmented communication within primary care and between primary and secondary care

I will discuss these findings in this chapter, considering how they fit with current theory.

8.3 Discussion of Routine Data Analysis (Study 1)

In this population-based study, significant socio-demographic inequalities were observed and were shown to vary across diagnosis routes.

There were some indications in the results of positive changes over time, most notably the increase in those picked up through the urgent cancer referral route (2WW). However, there are several areas of concern. The analysis showed that there has been an increase over time

in the number of HNCs diagnosed, although the distribution of HNC cancer sub-sites has changed with the predominant tumour site being the oropharynx in 2012-14, rather than larynx which was most common in 2006-08. This echoes trends reported elsewhere (Jakobsen et al, 2018) and likely reflects changes in risk factors such as a reduction in smoking prevalence and an increase in HPV-related cancers (Sturgis & Cinciripini, 2007).

Although overall the number of patients diagnosed through the emergency route is relatively small compared to some other cancers (Tsang et al, 2013; McPhail et al, 2013), there was a small increase in the number (albeit not the percentage) of emergency presentations over time. This is concerning as emergency cancer presentations may be considered, in some ways, as a “failure” of the system, and indicative of significant delays or barriers to presentation.

8.3.1 Emergency Route

Those diagnosed through the emergency route were more likely to present with advanced disease, which is consistent with patterns of other cancers in the UK and internationally (McPhail et al, 2022). In terms of socio-demographic characteristics, emergency presentations were more often patients from urban areas and areas of greater deprivation, from non-white ethnic groups, and over the age of 65.

The association between older age and emergency presentation is supported by previous research in all cancers in England where likelihood of emergency presentation rose significantly in those over 70 years (Kmietowicz, 2012). Whilst it is known that advanced age is a risk factor for HNC, the vague or non-specific nature of some HNC symptoms may mean that symptoms are not recognised as being of concern or are perceived as “normal” aging (as is reflected in the Patient interviews, *symptoms* theme, section 4.4.6). Previous research has shown that cancer awareness is lower in this age group than among younger people (Forbes et al, 2013). It has also shown that people, and in particular older adults, can be more reticent to seek help in primary care due to a fear of wasting clinicians’ time, particularly when symptoms are vague (Cromme et al, 2016). This fear may then reduce the chances of a person seeking help from primary care, resulting in a delay to diagnosis and an increased likelihood of an emergency presentation.

There are a growing number of reports on healthcare experiences of ethnic minority groups in the UK and internationally; people from ethnic minorities more often experience significant barriers to accessing healthcare, and once within the system, more often report poor experiences (For example: Pinder et al, 2016; Sze et al, 2015; Smedley et al, 2003). Much of the recent work has focused on the experience with COVID-19; however, it seems plausible that barriers such as lack of trust, inappropriate services and discrimination impacted help-seeking prior to COVID-19 too (Public Health England, 2022). The finding here that patients from non-white ethnic groups are more likely to be diagnosed after an emergency presentation adds further to this accumulating evidence base (Razai et al, 2021).

Older age, deprivation and being from an ethnic minority have all been associated with suboptimal health literacy (Rowlands et al, 2015; NHS Scotland, 2022). Health literacy is the extent to which an individual has the capacity, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services (Public Health Literacy, 2022). It includes the capacity to communicate, assert and enact health decisions (NHS England, 2022). It has been associated - in other clinical areas - with less use of preventive health services and greater use of emergency services (Public Health Literacy, 2022). Given the socio-demographic patterns observed here, future research exploring the role of health literacy in emergency cancer presentation (and, more generally, across the entire cancer diagnosis pathway) would be of value. Health literacy is discussed further later in this chapter (section 8.4.8).

8.3.2 Urgent Cancer Referral (2WW)

Those patients diagnosed through the urgent cancer referral route, compared to other routes which commenced in primary care, were more likely to be white, male, aged 55 years and older, resident in areas of greater deprivation and to have a cancer of the oropharynx.

The 2WW pathway requires that a patient meets a list of referral criteria for urgent investigation of a suspected cancer. Compared to other HNC tumours, oropharyngeal

cancer more often presents with a neck lump/swelling (Macmillan Cancer Support, 2022). This may mean that it is more likely to be recognised as potentially concerning by patients and primary care clinicians than vague, less specific (and perhaps more benign-seeming) symptoms, thus triggering a 2WW referral far quicker. Previous research on multiple different cancers has shown that those with vague symptoms delay attending primary care take a median of 34 days longer to diagnosis than those with alarm symptoms (Neal et al, 2014). Moreover, the stereotypical “traditional” HNC patient is an older deprived male (likely with tobacco and alcohol addiction problems) (Doximity Network, 2022). It is therefore possible that primary care staff may be more likely to have a higher index of suspicion of a potentially serious underlying condition around individuals who match this profile, and therefore refer them for urgent investigation.

Some research in Denmark suggests that GPs suspect cancer in more patients than they refer onto cancer specific pathways, and that those patients who reported vague symptoms are less likely to be referred (Jensen et al, 2014). This suggests the possibility that those who do not display what the GP considers to be clear symptoms of a potential HNC, despite a suspicion of cancer, may not be being referred through the 2WW pathway.

8.3.3 Dental Referral Route

Patients from ethnic minorities, women, and those from less deprived areas, were more likely to have been referred through a dentist than through other primary care routes. As might be expected, oral cavity cancers were more often diagnosed through this route, but it is noteworthy that dentists also referred patients who were diagnosed with cancers elsewhere in the head and neck.

The dental system in the UK involves payment at the point of treatment, in contrast to the rest of primary care which is free at point of treatment; moreover, not all dental costs are subsidised by the State. There are significant barriers to accessing NHS dental services, including financial difficulties, lack of availability of services (i.e., no appointments being available), or lack of services being offered in the local area (UK Government, 2022). The finding that people from more deprived areas were less

likely to be diagnosed through the dental route may be explained by the cost of accessing dental check-ups and treatment (echoing issues raised in the dentist interviews; see section 6.4). While some of those on the lowest incomes are entitled to free dental care, this involves the completion of lengthy forms (Marshman et al, 2013). Research has shown that areas of deprivation have far fewer NHS dentists (so called “dental deserts”) (Local Government Association, 2022), suggesting that those who may be entitled to free dental care may not be able to access a dentist. This is concerning given that dentists provide a potential route for early diagnosis of some HNC.

The finding that women are more likely to have been diagnosed from a dentist referral is supported by previous research which has shown women are more likely to have made an NHS dental appointment (Hill et al, 2009). The association between being from an ethnic minority and diagnosed through a dentist is more striking. It has been reported that people from all minority ethnicity groups have greater mistrust of dentists, are less likely to have visited a dentist and, of those who have visited, are more likely to have done so because of a specific issue rather than a routine checkup (Marshman et al, 2013). Often research which focusses on ethnicity and health outcomes is confounded by SES, which may not be controlled for in the analysis. However, this finding was apparent after adjusting for the effects of deprivation. It is consistent with results from a small study in London, which found that once SES had been considered, Asian people were far more likely, than white people, to have visited the dentist (Al-Haboubi et al, 2013).

8.4 Discussion of Qualitative Interviews (Studies 2-5)

In these qualitative interview studies, patients and healthcare professionals were interviewed. It was clear that the route to diagnosis was often difficult for both the patients and the healthcare professionals to navigate. However, there were clear examples of when the route (essentially the health care system) worked well.

The patient interviewees themselves were diagnosed through a number of different routes; 2WW, standard GP referral, dental referral and A&E. Those coming through a standard or 2WW referral, whether via a GP or dentist, reported positive and negative experiences. The

individuals who had experiences involving A&E, whilst being happy that they had reached a stage where help was being administered, had very difficult journeys and reported highly negative experiences. However, it is worth noting that those coming through A&E did not necessarily have a longer route to diagnosis than those coming through other routes.

8.4.1 Experiences of Two Week Wait Referrals: a system with unintended consequences?

The TWW system was created with the concept of improving patient survival. A study using routine data before and after the introduction of the TWW system showed a reduced diagnostic interval (time between patient presenting in primary care and specialist referral), of 5.4 days, although the authors did note a large variation across the cancer groups (Neal et al, 2014). Similar results were seen in a Danish study after a standardised cancer pathway was developed (Jensen et al, 2015); indeed, the authors reported an even larger reduction. Diagnostic interval has been linked to survival, and in another Danish prospective study mortality decreased with shorter diagnostic intervals (Tørring et al, 2013). However, this may not be the case for all cancers. A survival analysis of patients diagnosed with breast, prostate, lung, and colorectal cancer found that the association between diagnostic intervals and survival is complex and doesn't appear to have a simple, direct relationship (Redaniel et al, 2015). For example, in colorectal and lung cancer patients with non-alarm symptoms, longer diagnostic intervals were associated with lower mortality and the risk of excess mortality in prostate cancer reduced with longer diagnostic intervals (known as the waiting time paradox).

Research focussing on specific cancers also shows a less clear picture on the impact of the TWW system and survival. Research within colorectal cancer suggests the TWW referral pathway does not improve survival (Aslam et al, 2017; Currie et al, 2011), and research within oesophagogastric cancer has also not seen a relationship with increased survival (Sharpe et al, 2010). An analysis of TWW referrals for all cancers between 2009-2019 reported that whilst TWW referrals have doubled in those 10 years there has been a decrease in conversion rates (conversion rate is the percentage of urgent suspected cancer referrals which result in a diagnosis of

cancer), suggesting that the system is becoming less efficient and more patients are being referred who do not have cancer (Round et al, 2021).

There are many critiques of the referral system, with a view that it does not increase the early diagnosis of cancer but does in fact flood secondary care with inappropriate referrals causing a significant impact on the waiting time for general referrals. Whilst there has only been limited work within HNC, a 2012 systematic review on the efficacy of HNC TWW referrals concluded that GP clinical skills were being undermined by the tick boxes of the TWW form, and that this pathway does not expedite diagnosis. The low conversion rate was considered an indicator of inappropriate referrals, or poor TWW criteria (Kumar et al, 2012).

In my qualitative work, the TWW pathway was viewed as a contentious system and not easily accessible by all clinicians. Whilst it was felt to be "*better than nothing*" at getting patients into the healthcare system quickly, it was described as less than perfect. Dentists, although having access to a paper referral system, were unable to use it within an integrated system as easily as GPs. There were numerous local issues such as the referral form only having space for GP details, but not for dentist details. This further emphasised the dentists' feelings of separateness from the rest of the healthcare system. There have, more recently, been attempts to improve the TWW system for dentists with the development of a referral pathway guide for General Dental Practitioners in Cheshire and Merseyside (Metcalf et al, 2019). When TWW referrals were analysed following the introduction of this guide, an increase in dental referrals were seen but the conversion rate for dentists reduced significantly, so less cancers were being diagnosed. Whilst this is a small single centre study it does show that there is a need for some type of intervention around this topic, to improve both referrals and specificity of referrals.

GPs also expressed feeling separate from secondary care in the TWW process. This was in part due to a lack of communication back from the hospital following referrals and, for some, a lack of understanding on what processes the patients would go through once they entered secondary care. For many there was only a brief letter which they may not receive for many weeks after the patient had been seen. Strict

referral requirements denied GPs an opportunity to use clinical judgement. This resulted in some GPs changing clinical details to ensure access to the TWW referral pathway. There was also a lack of informal communication; they felt the decision was often to refer or not refer whereas an opportunity to discuss the patient briefly with a specialist before making a decision regarding referral was something that was felt to be helpful. The lack of avenues for informal communication was felt to be a detriment to their primary care work. Those who had been working for many years felt that this was a change that had been happening over time; in their earlier working life they felt there was a relationship between primary care and secondary care with the ability to build up relationships so that phone calls for advice was normalised and they knew who to call. However, they felt that this was no longer the case. Much of these findings are supported by a large interview study with 55 GPs across England (Green, Atkin & Macleod, 2015). This study (which did not focus on HNC) also reported that, for many GPs, the TWW referral system could act as a barrier to early presentation if the patient didn't meet all the criteria. GPs, in this study, reported that this could be more easily dealt with when there were opportunities to discuss a patient in a less formal way with secondary care. However, they felt that these opportunities were reducing. These authors also reported that GPs had systems for bypassing the TWW requirements. A small questionnaire study conducted more than a decade ago with GPs and HNC surgeons to understand their views of the TWW match many of these findings; this study reported a need for more scope to report clinical suspicion when this doesn't fully meet the TWW criteria, a lack of communication and interaction between primary and secondary care and that the TWW system needs improving (Bethell & Leftwick, 2015). The current work, as it involves in-depth interviews, has managed to expand on these findings providing greater depth of understanding of GPs' experiences of the systems.

From the secondary care clinicians' perspective, many reported the TWW referral system resulted in overcrowded clinics and inappropriate referrals. It seems possible that this referral system may be causing problems which may inadvertently be impacting patient care. The increased workload within secondary care may be delaying those who have come through standard referral routes (Rovira et al, 2023).

It is also worth considering that these strict guidelines may be causing unnecessary referrals due to their perceived inflexibility. There is also the potential that these guidelines could change how GPs work. There is less reliance on using their own clinical judgment and more reliance on the TWW criteria. However as reported earlier, this criteria differs depending on locality. This referral system also appears to emphasise an idea of siloed working. Each clinical group reports working in a siloed way, and the TWW referrals remove the need to communicate across the groups and this in turn erodes relationships which have the potential to build across specialities and could potentially improve knowledge, understanding and ultimately patient care. In conclusion, it is possible that the TWW system has created unintended consequences that were not considered when first developed – namely (as shown here) increase in waiting lists, siloed working and unnecessary referrals. These unintended outcomes reflect deeper systemic tensions. Clinicians described pressure to make only “good referrals” yet feared both missing cancers and overburdening secondary care. Patients meanwhile often felt their concerns were dismissed or not fully explained, linking back to wider communication gaps. This highlights the need to balance two competing imperatives; protecting the system from overload while ensuring that patients (particularly those with vague symptoms) are still taken seriously.

8.4.2 Communication and relationships with patients along the Route to Diagnosis

One of the striking findings within the qualitative element of the work was the importance of communication. This was a consistent finding although very different groups were interviewed, and they all experienced communication in very different ways. It was perhaps the element which most impacted experience of the route to diagnosis whether this was as a patient or as a clinician working within the routes. The importance of this issue was evident from the amount of time interviewees spent focussing on this topic, and the level of emotion with which both clinicians and patients spoke about communication. This section will cover: patients’ and GPs’ views of the relationship within primary care; patients’ and dentists’ views of the role of dentists and barriers to effective communication; patients’ awareness of the TWW

referral system; dealing with patient anxiety; communication difficulties; and the impact of cognitive bias.

Communication between Primary care and the Patient

A major part of communication in the early stages is around the relationship between a primary care clinician and patient. Those patients who had a good relationship with their GP reported that they felt listened to, so were more likely to go and seek help for symptoms. However, those patients who reported long and difficult journeys often put this down to poor communication between themselves and the clinicians. This contrasts with GPs' accounts, where caution in raising cancer explicitly was often framed as a way to protect patients from unnecessary worry. What GPs saw as reassurance, many patients experienced as dismissal, reinforcing their sense of not being listened to. This illustrates how the "good patient" ideal (avoiding inappropriate use of health services) can unintentionally reinforce communication breakdowns. This supports previous findings from a review of both qualitative and quantitative studies on the impact of non-cancer diagnoses on subsequent help seeking (Renzi, Whitaker & Wardle, 2015). This study reported that patients who were "undersupported" (for example didn't feel like they were taken seriously, or their symptoms were dismissed) were vulnerable to delays to diagnoses; these patients reported poor communication between themselves and their clinicians. A 2005 qualitative synthesis (Smith, Pope & Botha, 2005) on help-seeking and delay in cancer presentation also reported delays related to fears of being seen as a time waster, perhaps indicating that there was not a perceived good relationship in place already. Within this current analysis patients often reported not feeling listened to by GPs whereas with dentists the difficulties were more around not feeling they had an existing level of trust that had been built up through a relationship. This was often due to patients not seeing a dentist frequently and also not fully understanding the dentist's role, many patients hadn't felt that a dentist would have a role to play in recognising potential cancers, and some patients did not realise that they were able to refer for cancer symptoms.

From the dentist's viewpoint, they reported a feeling that the financial side of dentistry, whereby a patient had to pay for care, was the main reason for a poor

relationship. However, patients did not report the same feelings. This topic rarely came up in the patient interviews. Other work has also shown that lack of trust in dentists is a barrier to seeking help and whilst there are additional barriers to going to a dentist even when the financial barriers are removed (found after providing people with vouchers for a free dental screening) this doesn't always result in an increase in attendance. One study in the UK (Zohoori et al, 2012) reported no participants used their free screening voucher. Of course it is difficult to know what barriers may have influenced redeeming vouchers, but it is notable that they reported that there was a lack of trust in dentists.

Routine data suggested a preference for patients to seek an opinion from GPs over dentists, although this may be due to the nature of the symptoms (for example hoarseness would not be something patients would tend to speak to a dentist about). Cancers diagnosed following dentist referrals only accounted for a very small percentage overall (8%), including oral cancers. Patient interviewees in this study reported that they would often go for routine dental check-ups but not mention symptoms that they would later go and see a GP about. Some studies have reported as many as 70% of people being more likely to seek help from a GP than a dentist for oral symptoms (Eadie et al, 2009). The analysis of the GP interviews supported this with many reporting that they were seeing patients for oral symptoms on a regular basis. This suggests that there appears to be a lack of understanding on a dentist's role, or potential barriers to accessing and visiting a dentist.

Many patients in the current study were unaware that at regular check-up visits they are being screened for oral cancer. This supports the findings that dentists had a fear of upsetting patients by mentioning cancer. Dentists were worried that they didn't have the time and experience to have these conversations and that they would lead to upset and concern by patients. Previous research (Awojobi et al, 2015) on dentist-perceived barriers to screening is a concern that patients will respond negatively to the word "cancer". Despite interventions to improve patient communication, dentists remain anxious around this topic (Awojobi et al, 2016). However, my findings suggest that clear communication that dentists are conducting a cancer screening assessment provided patients with a sense of security. The patients reported feeling positive

about knowing a check had taken place. There is good evidence to show that extending patients' knowledge and awareness of oral cancer and access to information does not increase fear and anxiety. An intervention to encourage early presentation of oral cancer using a leaflet on signs of oral cancer decreased delay, increased understanding and did not increase anxiety (Scott et al, 2012; Humphris, Ireland and Field, 2001).

Conversely, GPs reported feeling confident discussing potential cancers and referring patients on for further tests via the TWW. However, this wasn't always seen within the patient interviews. Many patients reported that they had no understanding or knowledge of what a TWW referral meant and that they often hadn't realised it was a referral for suspected cancer. There is limited research in this area, however there is some evidence from patient experience survey data (Cummings & Vincent, 2010). This suggests that almost half of the cancer patients surveyed were unaware that their GPs were concerned that their symptoms may be indicative of cancer. A study on non-attendance at TWW appointments found that GPs described difficulties similar to the dentists (Jefferson et al, 2019). In the current study, GPs reported a fear about upsetting patients and handling their anxiety. This fear wasn't something they discussed as a major concern, nor was it overwhelming, but it was something which appeared to be underneath every decision they made. It was not often outwardly expressed but was felt to be the emotion underlying the discussion with the patient. When it was outwardly expressed it was in context of a fear of missing a cancer.

Much of a GPs career is dealing with the worried well, so responding to a patient's anxiety is important, and this importance is reflected in their medical school training (Von Fragstein et al, 2008) There is a need to balance out the knowledge that most won't have cancer but also preparing the patient for this potential diagnosis and making sure they see the importance in attending further appointments within primary or secondary care. All the GPs within this study were well established within their career and some were Macmillan GPs, so were more closely involved with cancer care. Many doctors find interactions stressful and emotional, and it is often perceived to be due to lack of ongoing training; there can be difficulty in handling their own emotions and there is some evidence that this gets easier with experience

(Hardavella et al, 2017). This was also seen in this analysis with those doctors who were more experienced reporting more confidence in dealing with the emotional impact of the job.

Another element of protecting oneself from the emotional aspect of the job is the censoring of information, not discussing a potential cancer with a patient in advance of their referral for example. It has been suggested that the reason many doctors do not disclose more information is about *their* ability to cope, rather than concern for the patient (Fallowfield and Jenkins, 2004). However, sharing information about the suspicion of cancer as early as possible is valued by patients resulting in greater patient satisfaction with care (Tran et al, 2019). Again, the patient analysis found that they valued being told that there was a potential that they may have cancer as often it was an underlying fear they had and knowing it was being investigated gave them a feeling of being taken seriously.

My patient interviews also afforded a different perspective; those patients who reported difficulties communicating with their GP often felt that they were not being heard and that they were viewed as “difficult” patients. They felt that they had to fight to be seen and taken seriously and that if they hadn’t have done this then they may not have survived their cancer (the concept of the Good Patient is discussed further in section 8.4.6). This feeling that they had to “fight” impacted their relationship and the way they communicated with their GP. There was a feeling this ruined any relationship that may have existed prior to this experience. This initial difficult relationship had a long-term impact on the patient, with a feeling of reduced trust. Patients who lost trust in their GP felt that they couldn’t talk to them about other problems with arose following their cancer. A further concern is that the consequences may be even more long term. Patients will most likely need to return to their GP later in life, for potential on going effects of the cancer and its treatment, a potential recurrence, or for other unrelated reasons. When you consider the survivorship literature you can see that patients often report a lack of trust of their GP with cancer follow-up and, in part, this is due to perceived bad experiences around the cancer diagnosis. A systematic review on views of cancer follow up (Lewis et al, 2009) reported that patient-GP relationships could be undermined by

difficulties that occurred during the diagnosis and initial referral period, and that this meant patients were reluctant to use their GP for support following a cancer diagnosis.

Interestingly the majority of the patients interviewed reported that this lack of communication ended when they entered secondary care although this perhaps did not match their descriptions of this part of their route to diagnosis. This will be discussed in more depth in the section on “The Diagnosis Experience” (section 8.4.5). There is the potential that cognitive factors may be playing a role in communications issues around HNC in primary care. In the UK a GP working full time may only see 5-10 new cases of any type of cancer a year, meaning that even the larger practices are unlikely to see a new HNC once a year. Optimism bias (Lyratzopoulos, Versted and Singh, 2015) could be impacting their decisions. When cancer is rarely seen then it is less expected. This bias means that, particularly in cases where patients appear to be in a low risk group, it is harder for GPs to believe that it could be a potential cancer (Lyratzopoulos et al, 2012; Lyratzopoulos et al, 2013; Nicholson et al, 2014). This is even in cases where the patient themselves report that they believe the symptoms are due to cancer. It is easy to see how this bias can not only delay a diagnosis of cancer but can cause communication difficulties between the patients and the clinical staff.

These findings are consistent with a systematic review conducted to explore patients’ perspectives of the medical primary–secondary care interface (Sampson et al, 2015). Although this review was not on cancer specifically it supports the findings of the current work and shows that similar issues occur for other conditions. This review found that patients perceived communication to be a vital part of their journey through the healthcare system. Good communication was linked to trust and an appropriate amount of time spent with the patient alongside the clinicians interpersonal skills. Poor communication was linked to inadequate information and a perception of not being listened to. However, this systematic review did highlight that patients reported that poor communication was also related to their own lack of knowledge, feelings of lower comparative social status (compared with clinician) and physical condition. The impact of lack of knowledge and a feeling of low status on

communication can be seen within this data and can be related to health literacy; this is discussed further in section 8.4.8.

8.4.3 Communication and relationships within the clinical community

Communication between Primary and Secondary Care

The relationship between primary and secondary care has been investigated previously in regard to cancer more generally. A focus group in Ireland (Daly & Collins, 2007) reported that one of the barriers towards earlier diagnosis of cancer in general was poor communication between primary and secondary care. A survey study conducted in Canada (Scott, Wong & Sowerby, 2015) with primary care providers referring specifically to Otolaryngology also reported the importance of a pre-existing relationship with secondary care providers when considering onward referrals, and the difficulties seen in knowing who the most appropriate person to refer to was.

In my studies, there were different expectations from all parties about the level of information that should be shared when referring a patient or when passing on information about a patient who had been referred. Dentists felt excluded due to the nature of the referral system and the priority given to the patient's GP for contact over the dentist. This perhaps feeds into a lack of confidence that many dentists reported with regards their diagnostic skills; this may be compounded by the fact that they are not recognised by the TWW system as being potential referrers or are recorded as being a referrer so do not receive communication back from secondary care. Many felt concerned about referrals and were worried that they may have made an "incorrect" referral; they viewed a non-cancer diagnosis as an incorrect referral. This lack of feedback made it difficult to increase their knowledge and to know if their suspicions around a potential cancer were confirmed. It also reduced their confidence talking to patients about what would happen at the hospital as they had very limited information. They were unable to describe the diagnostic process and felt that they should be able to do this for patients. GPs felt that the level of information they received was acceptable but was often sent too late to be of use, delays in receiving letters often meant they received diagnosis details after a patient had already progressed significantly through the pathway. They found this difficult as

they felt they were not up to date with what was happening to their patients. Some patients would report back to their GP but often they did not have the full information on their diagnosis. This was another impact on the patient/GP relationship, as discussed earlier.

Both GPs and dentists felt excluded from the secondary care experience, with the exception of the dentists who worked across primary and secondary care. There is some evidence in other cancers that the information sent back to GPs often missed important details. In particular a study undertaken to analyse correspondence between primary and secondary care found that specialist letters to GPs rarely stated the treatment intent, discussions around treatment and how the patient felt about the diagnosis and treatment plan (Stegmann et al, 2019). This appears to support the feeling of exclusion from secondary care, as the information being returned doesn't allow GPs to fully understand what is happening for the patient within secondary care. Those dentists who worked across primary and secondary care were very familiar with the secondary care environment as they worked within hospital departments where they communicated with the secondary care clinicians daily, some were part of the HNC multi-disciplinary team (MDT). They understood the secondary care systems and felt very confident talking to patients about this part of the diagnostic process. There has been research looking at the impact of social networks on healthcare delivery (Hu et al, 2021; Cunningham et al, 2012), although nothing specifically within cancer. However, this work highlighted that where there were effective social networks this improved healthcare quality and safety. Although it was vulnerable to over reliance on specific individuals and cliques.

Surgeons also felt discontent with primary care, although they were more positive about Dentists than GPs. They described having more trust in a dentist's diagnostic ability. Although many dentists did not use the TWW proforma it was felt that they provided appropriate and relevant information allowing the patient to be prioritised correctly. Surgeons reported a level of distrust with many GPs as they felt that they were just passing on problems to them (e.g.: patients who were perhaps more difficult, or who they didn't know what to do with). There was a general feeling that the GPs did not use the TWW pathway correctly. While surgeons and dentists often

positioned GPs as central to these communication gaps, it is important not to interpret these accounts as individual failings. Rather, they reflect structural and organisational features of the system that limit opportunities for dialogue and shared learning. Framing the issue in this way avoids scapegoating and instead highlights the need for systemic solutions.

This segregation further enhanced the feeling of working within a silo (discussed in the section on TWW 8.4.1). It restricted the ability to enhance knowledge; there was no shared learning across the primary and secondary care clinicians, and it appeared to enhance a feeling that the others were not doing the best job they could be. All clinical groups felt like their job role was not understood and that they were having to make up the shortfall of others. Practical issues impacted everybody's ability to improve communication, the main one being time. There is no time in which to undertake training or networking events which may remove some of these perceived feelings of under appreciation and overwork. The majority of previous research has focused on the potential to improve patient experience of healthcare when there is more of a primary and secondary interface enabled. However, it is worth noting that there could be considerable benefits to the clinicians' working environments and relationships. Not only would interaction enable increased knowledge of HNCs it would potentially remove stress and misunderstandings of how others work, and the different barriers each group face. The impact on patient care is also incredibly important and as can be seen when there is a closer working relationship between primary and secondary care there is an improved patient experience (Sampson et al, 2015).

In the same way as there needs to be a level of trust for the patient-clinician relationship to work effectively there also needs to be a level of trust between the different clinicians. A lack of trust in this area not only impacts the patient but also the clinicians, causing stress and anxiety. This can be seen in the GP interviews where there is a level of fear underpinning many of their decisions and in the dentist interviews by their concern for their professional integrity and worry over decisions to refer.

These findings support previous research within other areas of health which has shown the importance of good communication between healthcare professionals and the impact this has on patient care overall (Baxter & Brumfitt, 2008). The patients' perspective of this element has also been seen in previous research (Sampson et al, 2015); when patients perceive tensions between different groups of clinicians then they report higher levels of stress and anxiety and lose trust in the system. The impact of this cannot be underestimated within patient care and alongside a detrimental impact to patient care there is also a detrimental impact on the clinicians' working relationships and environments. This negatively impacts knowledge, learning and professional relationships.

Communication between Primary Care Specialities

As is clear in the findings of the current work, our current NHS set up emphasises siloed working, or what has been described as "professional tribes" (Weller, Boyd, and Cumin, 2014) where there is very little interaction. This was even evident *within* primary care. One GP explained the difficulties well when describing how they had worked within a large health centre with an onsite dentist. The ease of proximity meant that they were able to share advice, knowledge and expertise and the patient experience was improved. However once the dentist moved out of the health centre this relationship disappeared as there were no other means of communicating. The lack of communication between the GPs and Dentists was something which was accepted by many, in particular the GPs who felt that there was little reason to change this. There was a difference in how communication was viewed between GPs and dentists and how it was viewed between primary and secondary care. The former was viewed as less of a priority for GPs whilst the latter was seen as a significant shortfall. Dentists viewed the need to communicate with both GPs and secondary care as equally important.

Dentists reported that they would like to have access to patient records in the same way as GPs. They felt that this would improve the experience for patients so they could be aware of relevant risk factors or social issues. Dentists were reliant on the patient informing them of relevant health history, and often patients were not aware of what was relevant to a dentist. They also felt a shared IT system would allow

easier communication as they would be able to discuss patients from a level of shared understanding. The inability to easily communicate due to not working within the same IT systems meant that opportunities for shared learning were also lost.

Whilst many of the dentists welcomed the opportunity to have more contact with their GP colleagues this was not reciprocated by the majority of the GPs interviewed. These results were supported by previous research undertaken in Germany, which also has a system where GPs and Dentists work separately. That study also reported that whilst dentists were interested in extending collaboration, most GPs were not (Sippli, Rieger & Huettig, 2017). Dental care and medical care crosses over in many other conditions so this is not a unique issue related to only HNCs. Work on dental issues within a diabetic population in the UK found that there were organisational and professional divisions which had the potential to negatively affect patient care (Bissett et al, 2013). This is similar to what is seen in this study.

In the current work, both groups spoke about how they felt like very different communities. This is something which was reinforced through the majority of their careers starting with training, where there is often no shared learning or time together between medical and dental students. There was a lack of understanding of each other's workload. The "morality" of the dental work was questioned by the GPs interviewed. This appeared to be linked to the different way GPs and dentists are funded.

There was often a feeling among GPs that dentists didn't want to deal with issues relating to cancer and that they were happy for GPs to take on this responsibility. GPs felt they were forced into taking on more oral concerns, despite a recognised lack of knowledge in this area because dentists were not willing to take on this aspect of their job role. However contrary to this, the GPs did not feel that information needed to be shared with dentists, so would not inform a dentist if they referred a patient for a potential oral cancer. Dentists were further left out by rarely getting information returned to them after a referral. This had the follow on impact of leaving the dentist out of further discussions which reduced the learning opportunities for the dentist as they did not know whether or not the patient went on to be diagnosed with a cancer.

There is a very small body of research considering the relationships between GPs and Dentists, which supports the findings from this research, namely poor and limited communication and a lack of understanding of the others role (Huettig et al, 2018; Sippli, Rieger & Huettig, 2017; Boyes, 2015; Bissett et al, 2013; Holzinger, Dahlendorf and Heintze, 2016). This work shows that there are difficulties within the GP/dentist relationship and that there is work to be done to try and improve this relationship, and potentially have a positive impact on patients' experience and the working life of the clinicians.

These professional divisions not only limit opportunities for shared learning but also intensify patients' perceptions of a fragmented system potentially compounding delays within the cancer pathway.

8.4.4 Knowledge and Recognition of symptoms

Knowledge and understanding of HNCs arose as a key theme within this work. Both the clinicians and patients spoke about their levels of knowledge. This impacted the patient's journey and who they sought help from and also impacted the way referrals were made.

Patients

Patients reported having very little knowledge of HNC, and its potential symptoms. For many this was the first time they had heard of cancers in this area. This matches the findings from the International Cancer Benchmarking Partnership (ICBP)(Forbes et al, 2013) which showed that those in the UK had the lowest levels of awareness around age-related cancer risk. The majority of patients had experience of other cancers, some having a previous cancer or a friend or relative who had been diagnosed. However, there was little understanding of what cancer actually was, just that it would require treatment such as surgery, chemotherapy or radiotherapy. Further analysis on the ICBP data has shown that when you take into account socio-economic status then there is a significant difference in negative beliefs around cancer. Those with the lowest levels of education attainment were more likely to have negative beliefs around cancer and its treatment and more likely to view cancer

as a death sentence, with treatment that is significantly worse than the cancer itself (Forbes et al, 2013) This suggests that cancer beliefs are nuanced and the influence of socio-economic status cannot be ignored. This is especially important when you consider HNCs due to the high incidence rates in those living in more deprived areas. This is also, of course, pertinent to the findings (from the routine data analysis, discussed in section 8.3).

A lump in the head and neck area did not trigger an urgent need to seek help among the patients in the study. This is in contrast to other cancers where a lump is far more likely to trigger earlier help-seeking and to be linked with a potential cancer (McCutchan et al, 2015; Forbes et al, 2014). Patients within this study described lumps within the head and neck area as normal, and not something to be concerned about; there was a feeling that lumps in this area were most likely indicative of a mild infection and/or a cold. The most significant trigger for help-seeking was pain. Unexplained pain is often spoken about as a potential cancer red flag symptom, and previous research has shown a relationship between unexplained pain and earlier help-seeking (Whitaker et al, 2016). However it is not often related to a potential HNC. Pain is not a red flag symptom in the NICE guidance (NG12 criteria), and whilst some Cancer Alliances have additional symptoms only two have “severe facial pain or numbness” as one of them (Bradley, 2020). Whilst much of the research around symptom recognition happens after the point of diagnosis there has been work asking the general public about potential cancer symptoms (Quaife et al, 2014). This work showed that when a symptom isn’t recognised as being a potential marker of cancer then help seeking would potentially be delayed. This work was conducted on symptoms which are perceived to be well known, breast changes, rectal bleeding and persistent coughs. So, it can easily be seen how those symptoms related to HNCs would not trigger an urgent response and lead to a delay in presentation.

However, another option which should be considered is that the nature of HNC symptoms mean that they are not experienced as serious problems which require an urgent consultation. As can be seen in the results of the routine data analysis very few people are diagnosed through an emergency route for HNCs, despite this being a significant issue within some other cancer types. This perhaps suggests that HNCs

could be silent for some people for a significant amount of time. All the patients were able to describe symptoms that they had experienced prior to a diagnosis, but these symptoms were generally seen as minor. When considering the impact of silent symptoms, the most important element is if this delay impacts on the stage of disease at presentation, which is more closely associated with survival rates. Do the silent symptoms mean the patient is more at risk of late stage disease? A cohort study conducted compared the stage of disease and level of delay in two cohorts diagnosed with a HNC between 1960 and 1999. The study concluded that there was no relationship between patient delay and stage of disease. Some patients diagnosed with high stage cancer had not delayed at all whilst others who had delayed had a low stage disease (McGurk et al, 2005). This would suggest that in HNCs, when symptoms start is not indicative of the stage of disease (Vernham et al, 1994).

Traditionally HNCs have been seen as an illness which disproportionately impacts those within lower socio-economic groups. The results from the routine data analysis supports this as well. There is evidence that poorer cancer symptom knowledge is associated with lower socio-economic status (Brain et al, 2014; Quaife et al, 2014; Waller et al, 2009; Robb et al, 2009; Rauscher et al, 2010). Whilst this was not data collected from all the interview participants (postcode was collected from those who were interviewed at home for the purposes of finding the venue, but not from those who chose to be interviewed elsewhere) this suggests that the impact of socio-economic status on cancer symptom knowledge may be a contributory factor in delayed help-seeking.

Clinicians

When considering the level of clinician knowledge around HNC, the dentists reported high levels of knowledge, which is confirmed by research in other settings (Nazar et al, 2019; Coppola et al, 2021) but low levels of confidence, whereas GP's reported low levels of overall knowledge around oral cancers in particular but high levels of confidence in dealing with cancers.

One element discussed within the GP participants was the use of "gut feelings", particularly among the more experienced GPs. They described how, with some

patients, they had a gut feeling that something wasn't quite right, even in the absence of obvious red flag symptoms. This supports previous research in other cancers (Donker et al, 2016) which has suggested that GPs use something they call "cancer gut feelings", with an average positive predictive value of 35%; this figure increased with patient age and more years of practice for GPs. There is normally a trigger to the gut feeling and often these triggers are red flag cancer symptoms (e.g.: weight loss). A more recent study (Smith et al, 2021) on cancer gut feelings reported that GPs felt that this was a manifestation of their knowledge and experience. It is worth noting that those interviewed within the current study were asked about experiences they had with patients who were ultimately diagnosed with a cancer, therefore confirming their gut feeling. It is entirely possible that they may have experienced this gut feeling with other patients who were not later diagnosed with cancer (and whom they would have been less likely to recall).

The mismatch between patients' limited awareness and clinicians' variable confidence shows how both groups operate under uncertainty, which contributes to diagnostic delay.

8.4.5 The Diagnosis Experience

The overall aim of this work was to understand the route to diagnosis, and an important element of that is the actual diagnosis itself. The current study has shown that the diagnosis experience was varied across the participants but was an impactful event for all, which could alter their experiences considerably.

Many of those interviewed reported that they had multiple encounters within secondary care and felt that there was a build up to the diagnosis. There were points where they reported being told that there was a potential that the symptoms were indicative of cancer, but tests were required for confirmation. Whilst there was an understanding from many that there needed to be tests before the diagnosis was confirmed this was a difficult time for them. Those that had been made aware of the potential cancer from very early on in their route to diagnosis had had longer to process the potential diagnosis, however all felt that the actual diagnosis was a very upsetting time, as beforehand there was always hope it wasn't cancer. A longitudinal

ethnographic paper with patients diagnosed with a haematological cancer and their care givers showed the importance of all the communications leading up to the diagnosis. The experiences prior to the point of diagnosis played an important role in the way the diagnosis was internalised. Those initial encounters and the time between them were used to contextualise the actual episode of hearing the diagnosis (Schaepe, 2011).

There is a lot of emphasis placed on the one person who communicates bad news in medical training, whereas in cancer care this is often delivered in a multidisciplinary approach (Kim and Alvi, 1999). The patients mostly reported a large group being present at the point of diagnosis with many specialities that they did not realise would be part of their care. It was, often, described as an overwhelming experience, and they would have preferred to be one-to-one with the person explaining the diagnosis. One patient powerfully described how this felt like a theatre performance; she felt she was expected to act in a certain way when diagnosed and questioned herself later for not crying, feeling she may have been judged for this.

An interesting finding within this study was the difficulty often experienced by patients when they had a partner or relative attend the diagnosis appointment with them. It is common practice to encourage a patient to bring someone to support them to appointments, to help advocate for the patient, perhaps asking questions they are not able to ask at that point or providing support. The Macmillan website, for example, encourages patients to take along someone to support them (Macmillan Cancer Support, 2018). However, a proportion of people found this difficult as they felt that they then had to deal with the emotional needs of this person in addition to taking in the diagnosis themselves. This finding is similar to a very small US questionnaire study (n=16), reported in 1999, which found that 81% of HNC survivors did not want anyone else with them at the point of diagnosis (Kim and Alvi, 1999). These results suggest that this can potentially put a patient under more stress. This recommendation should be individualised, perhaps making a suggestion that some people like to have someone attend an appointment with them whilst others do not, and it is up to the patient to pick what they believe would work best for them.

The majority of patients felt more positive and had a feeling of relief once they were in the secondary care system. However, some had poor experiences around the way their diagnosis was communicated, and a lack of understanding and knowledge around their condition. This was illustrated by one interviewee not being aware he had cancer until the point his treatment started. This has also been seen in a project on upper GI cancer in England, where patients diagnosed through 2WW reported never hearing the word cancer on their journeys to diagnosis (Haste et al, 2020). Ambiguity is common in cancer consults; this is often due to the language used which tends to be used to reduce the impact of the diagnosis (Chou et al, 2017). Ambiguity appears to start early in the process, with qualitative work in lung and colorectal cancer describing how GPs often explain the reason for referral in non-specific terms rather than explaining it is for cancer investigation, even in those who are being referred on a cancer specific pathway (Banks et al, 2014). This misunderstanding is common in cancer care (Chapman et al, 2003). As described earlier in “Communication and relationships with patients” (section 8.4.2) and “The Good Patient” (section 8.4.6) many patients found it difficult to go back to the clinicians when they didn’t understand something, and this included when there was confusion over their diagnosis.

The surgeons who were interviewed reported that they felt confident and able to communicate a cancer diagnosis. Whilst it could sometimes be distressing (for both themselves and, more commonly, the patient), this was viewed as one of the core elements of their job. However, it was evident from the interviews that there was a disconnect between what the description of how the diagnosis was dealt with and how it was received by the patient, yet neither party felt that there was anything “wrong” with the interactions when expressly asked. Patients were often not able to express any displeasure or concern about any of the surgeon’s actions or ways of communicating despite on reflection there being a distinct lack of information given and/or understood. This showed that despite positive reports from both sides there were still communication difficulties. This may have in part been due to a feeling that reporting anything negative about someone who they felt had saved their life was wrong. There may have also been a difficulty in seeing any negatives in someone who was perceived as saving their life. There appeared to be a difficulty in patients

viewing their surgeon in a critical way, although there is limited research in this area this was supported by a study with patients with upper gastrointestinal cancer who reported being reluctant to complain about their care (Haste et al, 2020). This is developed further in the following section on The Good Patient.

8.4.6 The “Good Patient”

The findings from the interviews suggested the concept of the “good patient”. This was not only from the patients themselves but also from the clinicians. Patients positioned themselves as a “good patient” as they did not seek appointments with the GP all the time and the time, they did seek help was due to a genuine need. In particular this was around not wasting a GP’s time. They positioned themselves as not being someone who wasted time unlike other people who would go to the doctor over minor issues. This is a common finding within cancer early diagnosis research (Hvidberg et al, 2015; Forbes et al, 2014; Cromme et al, 2016; Smith et al, 2005). In particular these studies showed that the worry associated with wasting GPs time was seen to increase when symptoms appeared vague or minor. This is an important aspect with regards HNCs as, discussed earlier (section 8.4.4), symptoms often appear vague or “minor”. It is worth noting that this is the first time this has been shown within HNC specifically.

Another aspect of being a good patient was the need to be positive throughout diagnosis and treatment. Positivity was an important coping strategy for many participants, and many spoke about how they had to stay positive to get through this process. There was a feeling that staying positive would help with survival, whereas negative feelings were considered a sign of giving up. The importance of positivity was discussed from the point of being referred into the TWW; many spoke about how they had to maintain a positive outlook during this time. Positivity is seen behind many cancer campaigns and the need to “fight” cancer. The majority of research on positivity tends to focus on its role at the treatment stage and beyond (Menger et al, 2022; Larsson, Hedelin and Athlin, 2007; Llewellyn et al, 2013). It appears that the concept that being positive is important starts, for many people, quite early in their route to diagnosis. However, this is not always a helpful idea for patients and can impact on the psychological distress caused by a cancer diagnosis. Previous work,

conducted in Australia, which considered coping strategies for people affected by different cancers (including HNC) reported that positivity was not often seen as a helpful coping strategy (Knott et al, 2012). It is interesting that the patients in this piece of work were clear that this positivity was unhelpful whereas the patients in my analysis felt it was important.

Asking questions of the clinicians was another aspect whereby the concept of being a good patient could interfere with the patients care. Once participants were in secondary care the majority reported that they felt confident in asking questions of the clinicians but said that they didn't have any questions to ask. However, there was often a feeling of embarrassment at asking something they may have already been told or at not understanding something that had previously been explained to them. This stopped many patients from clarifying points they hadn't understood or obtaining more information.

One interesting area in this study was that none of the patients spoke about the nurse specialists. There was some discussion around the role of Speech and Language Therapists and how they may occasionally seek additional help and support around their diagnosis; however, the nurse specialists (CNS) were not mentioned. It may be that the nurse specialists were not considered to have a role this early in their route to diagnosis or that they were less present with this cancer than they are in other cancer areas. Previous work highlights the importance and pivotal role head and neck clinical nurse specialists play in this cancer area (Greedy, 2022; Semple, 2001) and recommendations are that a CNS is part of the complete patients' journey (Dempsey et al, 2016). This was not an area which was probed further, it is notable for the lack of discussion and may perhaps be an area of future research.

The concept of the "god patient" mirrors clinicians' emphasis on the "good referral", with both groups navigating expectations of restraint. While intended to protect relationships and resources, these ideals risk silencing concerns and discouraging timely help-seeking, reinforcing the communication gaps seen elsewhere.

8.4.7 Communicating a HPV diagnosis

The topic of HPV was not raised by many of the patient participants during the interviews. Those who did raise it mainly spoke about it in terms of it being a more “optimistic” diagnosis. This was matched by the secondary care clinicians who spoke about how discussions on HPV were framed around the more positive outcomes linked with this diagnosis. This is supported by previous work which found that part of communicating a diagnosis of HPV+ cancer was emphasising the positive prognosis (O'Connor et al, 2020a; O'Connor et al, 2020b; O'Conner et al, 2020c; Baxi et al, 2013). There was very little discussion around the nature of HPV. Some clinicians felt that the route of transmission (sexual contact) was not clear, so it was best to not engage in those discussions around HPV. Again, this feeling of a lack of knowledge around the topic was seen in other work which focussed just on communicating a diagnosis of HPV (Dodd, Marlow and Waller, 2016; Connor et al, 2020c). However, some clinicians did express some discomfort with some topics around HPV, in particular transmission. Perhaps interestingly, and in contrast to previous work (Milbury et al, 2013) HPV+ participants in this study did not express a need for any further information on their HPV diagnosis. It is worth noting that the Milbury et al study (2013) was conducted in the US where there are different cultural norms around health information seeking.

In discussing patients some clinicians subtly revealed implicit biases. Those patients with a HPV+ diagnosis were viewed in a more sympathetic light, and were seen as being more like themselves (the clinicians). Their diagnosis was described in terms of normalising the HPV infection (explaining how the majority of adults have been exposed to HPV at some point or another and they were just unlucky). In contrast, those patients who were diagnosed with a cancer which could more clearly be linked to smoking and alcohol behaviour were seen as very different from the clinician, and as people who had made lifestyle choices which had resulted in their cancer. Although, HPV related cancers are linked to a higher number of sexual partners and more unprotected sex (Heck et al, 2010; D'Souza et al, 2016; D'Souza et al, 2009; Chaturvedi et al, 2015) this was viewed very differently to alcohol and smoking. This was not a level of bias which was obvious but showed itself in more subtle ways. Those whose cancer was more likely to be related to alcohol and smoking were also

often viewed as being less likely to understand their diagnosis and would be less likely to engage with and understand the healthcare system. It is possible that this is related to socio-economic status, and health literacy which will be discussed later in this chapter.

8.4.8 Health Literacy

When considering the findings of this body of work it is possible to view them within a “frame” of health literacy. Health literacy refers to the extent to which an individual has the skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services (Public Health, n.d). It includes the capacity to communicate, assert and enact health decisions (NHS England, 2023). Further to this, the concept of distributed health literacy has been identified (Edwards et al, 2015), whereby people can draw on the health literacy of others in their social network.

Suboptimal health literacy is associated with unhealthy lifestyle behaviours, such as smoking (Fawns-Ritchie et al, 2018). There is also a link between health literacy and socio-economic group, with lower levels of health literacy in those within a more deprived socio-economic group. A systematic review reported that in both Europe and the US people who are more socio-economic deprived are more likely to have low health literacy (Sørensen et al, 2015). It concluded that health literacy mediates the relationships between socio-economic status and health status, quality-of-life, specific health-related outcomes, health behaviours and use of preventive services. As noted earlier, HNC disproportionately impacts those from more deprived backgrounds, therefore the question of whether health literacy is impacting on the patients’ route to diagnosis is particularly pertinent.

Health literacy can be seen as an overarching concept to explain many of the findings within this research. There are delays seen when patients have difficulty accessing healthcare, facing barriers around making appointments. There is also a lack of knowledge around symptoms and accessing healthcare (patients are not always aware of who the best clinician is to see for different symptoms) alongside a difficulty in evaluating symptoms and when to seek help. Difficulties are also seen when

patients have difficulties navigating the healthcare system and having the confidence and skills to communicate with healthcare providers.

Health literacy differs from many other elements of a patient's life as it is considered potentially modifiable. This means that, unlike socio-economic status which we cannot easily impact, we could potentially use health literacy as a basis for an intervention to promote earlier diagnosis by encouraging the development of health literate skills, knowledge, understanding and confidence. This is an area which warrants further investigation and development.

Health literacy therefore acts as the backdrop against which fears, communication gaps, and expectations of "good patients" and "good referrals" are played out, reinforcing inequalities across the route to diagnosis.

8.5 Strengths and Limitations

This is the first study which has considered the route patients take to a diagnosis of HNC from different perspectives. It was a multi-methods study that used both routine data and qualitative interviews which allowed a view from the population and individual level. It was clear from the outset of the study that the two methods were complimentary; there were places where the qualitative work shed light on the quantitative analysis. Moreover, the qualitative element was novel in its approach in that it allowed for multiple perspectives to be considered all in one study (GP, Dentists, Secondary Care and Patients). This qualitative approach also allowed a significant amount of rich data to be analysed.

With regards the routine data, the strengths lie in the access and analysis of population level data. Completeness of cancer registration in England is considered to be very high, meaning that the cancer registry dataset used here likely included almost all (if not all) HNC diagnosed in the population during the years of the study. This means that bias is minimised. This enabled me to understand who the patients are and how they entered secondary care. I have also been able to show some of the significant inequalities which are part of the route to diagnosis, giving a starting point to consider where future research should be focussed. However, no study is without its limitations and the main limitations with this study are discussed below.

There are several known limitations associated with analyses of routine cancer registry data. Routine data sometimes has a significant amount of missing information and in this dataset, levels of missingness for summary stage and ethnicity were high. For the latter, this meant I could not explore whether there were differences between different ethnic minority groups, and further research on this topic would be of value. This is important as there is some evidence that non-whites have poorer survival than whites (Russo et al, 2020), and they may have different risk factors such as betel nut which is more prevalent within Asia. We also know that non-whites experience more health inequities, but that the picture is complicated with differences showing across different conditions and between different ethnic groups. This data did not allow an in-depth exploration of ethnicity. For the former, care is needed in making inferences from my findings. Completeness of stage details has improved over time in registry data, so subsequent studies would be of value to confirm the findings here. I took the decision not to exclude patients with missing information as the data was unlikely to be missing completely at random and exclusion may have introduced bias. In addition, information was not available on risk factors for HNC, such as HPV status, (which was not routinely tested for during the study period), and tobacco and alcohol use; these could be associated with patient diagnostic route. The registry provided a proxy variable for inferred HPV status based on tumour site and morphology, but this was not used in the final analysis as it was not more informative than cancer site alone. It is also likely that analyses are subject to residual confounding from comorbidities; the Charlson Comorbidity Index is a crude measure of the number of comorbidities that a patient has and only includes particular conditions documented during hospital admissions in a specified time period (Schneeweis and Maclure, 2000), so likely underestimates true levels of comorbidity. However, as comorbidities increase with age, and age was also included in the models, any residual confounding is likely somewhat mitigated.

Another important factor is that this data is from 2006-2014. While cancer pathways in England have not changed in the intervening years, it is possible that the frequency with which different routes are followed, or variations between socio-demographic groups, may have changed in the intervening years. In particular, the impact of the COVID-19 pandemic had a significant impact on cancer services; in England, urgent referrals decreased dramatically, and it is estimated that there will be substantial increases in cancer deaths due

to delays in diagnosis and treatment (Lai et al, 2020; Maringe et al, 2020). Research investigating whether the inequalities in route to cancer diagnosis reported here have persisted since 2014, leading up to, during, and following the pandemic should be a priority. The current analysis could usefully serve as a baseline for such future work. Finally, these results may not be generalisable to all healthcare systems outside of England which may differ in terms of processing of diagnosis routes.

It is also worth noting that the data only included those who were diagnosed with HNC. For example, I didn't have data on those who were referred through TWW but did not have cancer, and how that varied by socio-demographic factors. A paper reporting this study has been published in International Journal of Environmental Research and Public Health and can be found in Appendix L (Deane et al, 2022).

There was a lack of diversity within the qualitative data: all patients interviewed were white and only one clinician interviewed was of a non-white ethnicity. Recruitment of non-white participants was difficult, and I was unable to get a good ethnic mix within this data. This is in part due to fact the study took place in the least diverse region on England (Office for National Statistics, 2022). Therefore, the findings need to be placed within this context. I also did not collect deprivation data from the patients. As differences were shown in the routine data it would have been interesting to have this additional data and consider the qualitative findings within this context. With regards patient recruitment, this was open to any individual who was post cancer treatment and was a mix of healthcare professional led recruitment and social media/advertisements. It is possible that I was not recruiting in the right areas or that I had not made the information culturally relevant enough. All participants were required to speak English to a level so that they could easily participate in an interview. I do not speak another language and was unable to fund an interpreter so this may have also limited those who volunteered for the study. It is possible that that there may have been some selection bias with regards those patients recruited through the healthcare professionals. Although I worked closely with them to emphasise the importance of not being selective it is possible that they made specific selections with whom they approached. Future work exploring experiences of HNC diagnosis among people of non-white ethnic groups would be of value, particularly in light of recent data from England on ethnic

variation in cancer incidence (Delon et al, 2022) and results from the National Cancer Patient Experience Survey (Pinder, Ferguson and Møller, 2016)

This study only looks at patients who ultimately had a diagnosis of HNC. Many people present with symptoms and face similar barriers and facilitators in their help seeking decisions irrespective of whether they were ultimately diagnosed with cancer or another benign condition. However, the focus of this study was on those who did receive a diagnosis of cancer, and it is possible that the experiences of those who did not get a cancer diagnosis might be different.

This was a retrospective study, and a person's framing of events and decisions in retrospect may be different from how they felt at the time. Memory recall can be difficult after an event. However, a cancer diagnosis is a significant life event for many people and all the patient interviewees could recall parts of their journey clearly. Whilst a prospective study may have allowed me to speak to patients at the point of symptom recognition and or seeking help, this would have been incredibly challenging to undertake.

Finally, there were some difficulties within the recruitment of the clinical staff, in particular GPs. This is not an unusual experience and others have reported significant difficulties (Patel et al, 2017) I tried various methods of recruitment (Individualised letters to GP practices, advertisements in GP networks, advertisements through Macmillan GP's, email through Northern Cancer Alliance, targeted the GPs of patients who had taken part in the study and agreed to share GP details, social media advertisements, academic GPs within the university, emails through RCGP). The most success was through the Macmillan GP network, who are GPs with a specific interest in cancer. There is the potential that their experience may have been different to those GP's who did not have this interest.

Most of the difficulties appeared to be time restraints and I was unable to provide recompense for time. Moreover, the study was not on the portfolio, so sites could not avail of Service Support Costs or obtain recompense for health professional time. However, training sessions were offered which could be incorporated into their CPD requirements. Unfortunately, this failed to attract participants. Although this study was prior to COVID and the associated issues which GPs have been facing, there was also a level of distrust from

some GPs who felt that this may be around placing blame on GPs for missed cancer diagnoses.

Overall, the numbers within the clinical groups were small, however the initial plan was not to consider each group individually, or to recruit to a level of data saturation or sufficiency within each group as that would have been unfeasible within a PhD; instead, the plan had been to analyse the clinical staff in one single group. However, during the interviews and initial analyses it became clear that each group had specific issues and experiences which could potentially be lost if they were considered as one group, Therefore, it was decided that they should be viewed within their own separate groups. This did mean however that the numbers within each group were relatively small. The impact of this might be that there are other themes which may have come through with additional interviews. However, that those which did come through were supported by previous research and came through strongly. It may be that more interviews would not have brought about any new themes but may have strengthened the current findings.

8.6 Closing Remarks

Taken together, these findings highlight that delays and difficulties in the route to diagnosis for head and neck cancer are not the product of single failings, but of systemic tensions that shape the behaviours of both patients and clinicians. Communication gaps emerged at every level—between patients and GPs, between dentists and secondary care, and even within primary care specialties—undermining trust and leaving patients feeling unheard. Fear was also a consistent thread: patients feared wasting time, GPs feared missing cancer, dentists feared professional embarrassment, and surgeons feared system overload. These fears were intensified by the structural pressures of the healthcare system, where the need to avoid “flooding the system” with inappropriate referrals sits in direct tension with the imperative for early diagnosis. The concepts of the “good patient” and the “good referral” capture how both patients and professionals internalise these expectations, often reinforcing silence and delay. Understanding the route to diagnosis through this lens suggests that solutions must go beyond technical fixes or pathway reforms, and instead address the competing values of efficiency, reassurance, and equity that underpin the system itself.

Chapter 9: Implications and Adoptions

9.1 Implications and Conclusions

This chapter contains a proposal to adapt the Model of Patient Delay with the inclusion of clinician/patient relationships and health literacy. Clinical implications will highlight clear areas which can be incorporated into clinical work. This will then be followed by a discussion on how this work has impacted current practice and specific points where future research would be of value. Finally, it ends with a conclusion of this piece of work.

9.2 The Model of Patient Delay

As discussed in the introduction (section, 1.4.1) the main theory by which the majority of routes to diagnosis research is based on is the Anderson model of patient delay (Anderson, 1995). Further work has developed this to produce the Model of Pathways to Treatment (Walter et al, 2012). This model is informed by the Common Sense Model of Illness Self-Regulation (Leventhal, 1970) (which feeds into the Appraisal and Help-seeking intervals) and Social Cognitive Theory (Bandura, 1986; Bandura, 1997).

The results of this body of work support much of this model and underpinning theories. However, the findings of the studies included in this thesis suggest that this model could usefully be expanded to take into account other impacts on HNC patient delays and routes to diagnosis, and a proposed adapted model will be presented below.

9.2.1 Adapting the Model of Patient Delay

When considering these findings in context with the current model I felt that there should be two additions to the model;

1. Clinician/Patient Relationship
2. Health Literacy

These additions were felt to be important as the current model did not emphasise the importance of them. The results from this work show how these are vital components along the route to diagnosis.

Clinician/Patient Relationship

The findings from the qualitative aspect of this study show the importance of the clinician/patient relationship (and, indeed, relationships) and how it (they) can impact the patients' journey. This/these relationship(s) underpinned the different processes that the patient underwent as they moved through the pathway. In the model, processes are defined as "the cognitive, emotional, behavioural, organisational, or structural actions that occur within intervals, the outcome of which may lead to the next event". Thus, this relationship could be seen as defined by emotional actions, behavioural actions and be impacted by structural and organisational actions – for instance the decline in GPs knowing their patients due to organisational changes in how primary care is actioned has a clear impact on the patient's relationship with their clinician; it could impact a patient's decision to consult or arrange an appointment and how the health care professional appraises the patient's symptoms and conducts onward referrals. A patient's own appraisal of symptoms may be impacted by their relationship with their healthcare providers. The results from this work show that those with a good relationship may be more likely to appraise their symptoms as something to seek help for, whilst those with a more difficult relationship were more likely to try and avoid seeking help and to self-manage (perhaps inappropriately). Therefore, the Clinician/Patient relationship impacts every stage of the process.

By adding this into the model as an additional process it highlights the importance of this relationship and allows consideration that these processes are taking part within a context. However, it is worth noting that a relationship like this is not static and may change based on different circumstances. This relationship and potential impacts upon it, is an area which could be considered a target for future interventions, or a measure which could be taken to attempt to understand a patient's behaviour in different circumstances.

Health Literacy

As discussed, (in section 8.4.8) the results from this work indicate that health literacy may have an important role to play within the route to diagnosis and can clearly be seen to influence many different aspects of this route.

Health literacy was clearly a factor which contributed to a patient's journey and therefore fits within the model. I judged that this should be added as a contributing factor. There was the potential to think of this as a patient factor, described as representing both the individual and the social and cultural context in which they exist (e.g.: demographics, previous experience, co-morbidities, cognitions and emotions); however, that does not fully cover what health literacy is. Health literacy is not just in the patients' realm. It also considers the health care system and how accessible that is to people with different levels of health literacy. For example, a patient may see a clinician who has a good understanding of health literacy so that impacts the patients' journey. This may not be something that impacts on every process – potentially if a patient's health literacy is around accessing health information, then it may impact the patient appraisal process but it may not impact planning and scheduling treatment (e.g.: they may not have a problem with understanding what is happening next in the process or the health professional they encounter that that stage may have better skills to support engagement of those with limited health literacy).

It is important to consider this as a separate contributing factor as unlike many other patient factors (co-morbidities, demographics etc.) this is modifiable. It is possible to increase someone's health literacy, and potentially make services more accessible to those with low levels of health literacy. This is an area which could then be identified as a potential target for future interventions.

The hope would be that others would test this adapted model with other cancers to see if this adaption is valid in other cancer areas.

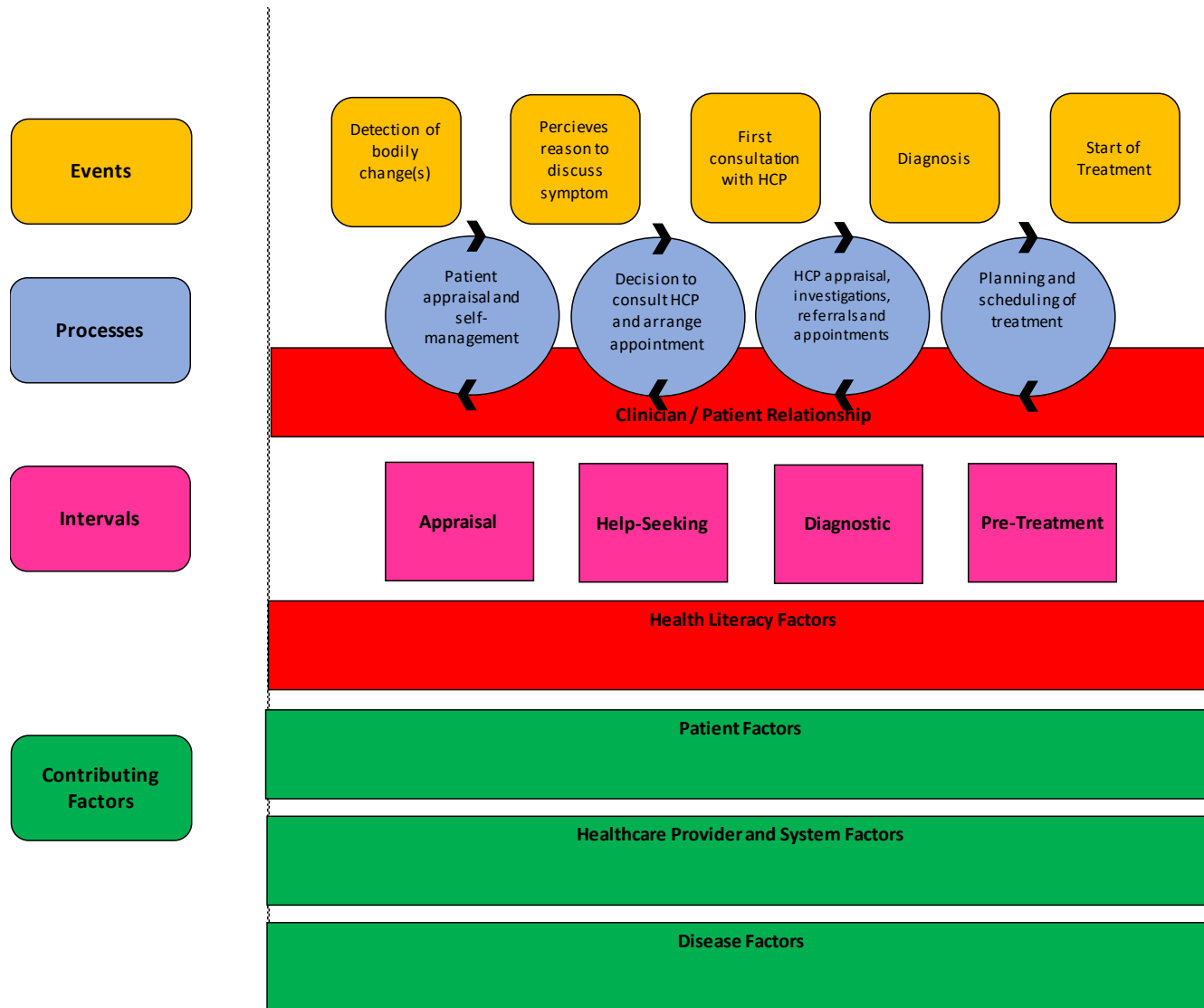


Figure 14: Updated Pathways to Treatment Model, with proposed additions shown in red.

9.3 Clinical Implications

Within this piece of work, there are some clear areas for improvement within the clinical environment. The recommendations below have been separated into the bigger ideas, which require significant change to practice, policy, or funding, and those that could easily be implemented now with relative ease and limited disruption.

The Big Ideas

1. Rethinking the Urgent Cancer Referral System

This work has revealed that the urgent cancer referral system creates significant anxiety across the clinical pathway. Primary care practitioners experience pressure to make “good referrals,” concern about missing cancer diagnoses, and challenges in managing patients’ expectations. Secondary care clinicians report that suspected cancer clinics are increasingly overwhelmed with patients who do not have cancer, creating delays for those referred via routine pathways. Moreover, patients who are ruled out of cancer are often left without resolution of the original symptoms that prompted referral.

The system’s reliance on rigid performance targets compounds these issues. NHS trusts are penalised when targets are not met, yet compliance remains low, suggesting the model is no longer fit for purpose. The inflexibility of the criteria also leads to “gaming,” with some GPs amending referral details to ensure patients meet pathway thresholds. This undermines equity and contributes to the inequalities demonstrated in this research.

A potential alternative would be to remove Urgent Cancer Referrals and have a robust triage system in secondary care, where all referrals are assessed by senior clinicians. Such a model would improve accountability, reduce inappropriate referrals, and potentially lower costs. It could also strengthen trust between primary and secondary care by providing clear communication about referral reasons and outcomes. Implementing this approach would require a dedicated workforce and appropriate resourcing, but it offers a sustainable route towards a more responsive and equitable system.

2. Creating New Health Spaces

This thesis has also demonstrated the problem of siloed working in healthcare delivery. The NHS has long promoted multidisciplinary health centres to consolidate services, yet dentistry

is frequently excluded due to its separate funding model. Workforce challenges and the migration of dentists to private practice have reinforced this divide.

I propose that dental funding be brought into alignment with primary care funding, and that GP and dental practices be structurally integrated. Integration should also include shared electronic health records, enabling reciprocal access between GPs and dentists. This is crucial not only for cancer detection but also for managing a wide range of health conditions.

International and UK-based examples highlight the benefits of such integration. Studies in Scotland and the United States show improvements in attendance, care quality, communication, and reductions in unnecessary secondary care referrals (Haughney, Devennie, Macpherson & Mason, 1998; Pourat, Martinez & Crall, 2015; Pawloski, Hilgert, Senturia, Davis, Koday & Cunha-Cruz, 2021). However, these findings also emphasise the need for cultural change among professionals and early emphasis on collaboration during training.

Implementing reforms of this scale will require commitment from dentists, GPs, and patients, alongside support from NHS management and policy makers. Yet the potential benefits in terms of efficiency, patient experience, and equity are substantial.

3. Transforming Medical and Dental Education

A further barrier to integration is the educational divide between medicine and dentistry. This research has shown how limited training on oral health in medical school restricts understanding of dentists' diagnostic roles. Recent evidence indicates that only 7% of final-year medical students can identify oral cancer, and just 22% feel confident conducting a dental assessment (Glossop et al., 2024).

There is robust evidence that interprofessional collaboration (IPC) improves care and reduces costs (Schmitz, Atzeni & Berchtold, 2017; Wei et al., 2022). However, IPC depends on interprofessional education (IPE), opportunities for students and professionals to learn "with, from and about each other" (CAIPE, 2017, p.14). Current provision of IPE in medical schools remains limited and fragmented.

I propose the development of joint medical–dental training programmes, where students learn together throughout pre-clinical and clinical stages, including shared placements. Embedding IPE from the outset would foster a culture of collaboration and shared responsibility.

Looking further ahead, there may be scope to train dual-skilled primary care clinicians, able to work across both medicine and dentistry. This would mirror existing dual registration requirements in Oral and Maxillofacial Surgery and reframe primary care as a whole-body discipline, rather than separating the mouth. While such reform would require significant curricular, regulatory, and financial change, it offers a transformative opportunity to redesign care pathways around patients rather than institutional boundaries.

Short Term and Immediate Recommendations

One element has already been incorporated into practice within the Northern Cancer Alliance; this is described below.

1. Recognition of Symptoms

It is clear from this work that there is a need to promote the recognition of symptoms. Whilst many charities (The Swallows, Oracle etc.) produce documents, these are not always evidence based. In terms of knowledge translation, there perhaps needs to be more collaborative working between researchers and charities to generate greater impact. Alongside the recognition of symptoms there needs to be a promotion of what to do once you realise you have symptoms. Many people have difficulty accessing care and may need to have clear steps that make this easier. I am currently working with Oracle on ways to promote symptom knowledge using findings from this PhD.

2. Reduction in inequalities within the Route to Diagnosis

It can be seen from this work that there are significant inequalities with the route to diagnosis. It is important to make clinicians aware of these inequalities and the impact they can have on a patient. Awareness would be the first step in being able to overcome these inequalities. Raising awareness may challenge a GP or Dentists pre-existing ideas on who a HNC patient is.

3. Recognition of the role of health literacy

It is important for clinicians to understand the impact that low health literacy can play in the route to diagnosis and to consider how their service can be made more accessible for those with lower levels of health literacy. The findings from this piece of work were used as the basis for a successful, NIHR Research for Patient Benefit Grant application to explore the role of health literacy in the early diagnosis of head and neck cancer (NIHR201966; <https://fundingawards.nihr.ac.uk/award/NIHR201966>).

4. Two Week Wait Referral Paperwork

Allowing space for dentists to be able to write their referral details would allow them to be contacted by secondary care clinicians more easily and to be included in follow up correspondence. This has already been actioned by the Northern Cancer Alliance and all new TWW documents allow space for both the GP and the Dentist.

5. Communication between Primary and Secondary Care

There is a very clear need for there to be more communication between primary and secondary care. This could be using letters, opportunities to meet in person, shared learning events or CPD events. It is important that this is not seen as secondary care “teaching” primary care how to do something “better” but as an event where there could be shared learning and co-creation of solutions. This element has recently been used to form the basis of a piece of work which looked at how communication between primary and secondary care could be improved for the purpose of early diagnosis in head and neck cancer and various listening workshops were undertaken with the different stakeholders to consider future directions for research conducted with Dr Paula Bradley and funded by North of England Care System Support (NECS).

6. Communication between the clinician and the patient

There are areas where communication could be made easier for both parties. Using clear language when talking about diagnosis would allow the patient to have a clearer understanding of what is happening to them. Using the word cancer is important, and giving patient’s space, permission, and time to ask questions.

Consideration needs to be given to the service delivery setup. When clinicians have restricted time, it does not allow them the space to hold open honest conversations. Within secondary care some clinicians spoke about how they had no access to their diaries to manage the time they spent with patients. Allowing them the autonomy and access to decide on how long a patient needs with them may help open the space to allow for these conversations.

9.4 Dissemination and Impact

Work from this PhD has already had an impact on current practice; it has been shared widely, and collaborations have been created to continue work in this area.

1. As stated above the Northern Cancer Alliance has changed the TWW referral form to include Dental Practitioners, with the hope that this will allow easier communication between primary care and secondary care.
2. I have worked with the Swallows Charity to promote the findings of my research. I was invited to speak at their annual patient conference to patients and healthcare professionals with an interest in HNC.
3. I am currently working with Oracle (a HNC Charity Alliance) to turn my findings from the routine data into short communications which can be sent out to patients and professionals to start conversations on how we can tackle these inequalities. This work has also formed the basis of a project with communities in Leicester. A pilot project on the use of forum theatre for improving patient communication skills in the route to diagnosis; funded through Gilead Sciences.
4. I was invited to talk to Queen Mary University London's Squamous Cancer Research Group at their annual symposium on the Routine Data findings.
5. I was invited to talk to the Dental School researchers and students at Newcastle University on the role of dentists within the route to diagnosis.
6. The findings from this research formed the basis for a grant proposal to NIHR Research for Patient Benefit to consider the role of health literacy in the route to diagnosis of HNCs. This was successful and the study is currently ongoing.
7. Finally, the analysis of routine data has underpinned a further project focussing specifically on routes to diagnosis in hypopharyngeal cancer (with which I am

involved) and a successful funding application to Oracle/North West Cancer Research to investigate inequalities across the entire HNC pathway.

Academic dissemination, through conference presentations and papers, is summarised in appendix L

Future Directions for Research

A number of specific points where future research would be of value have been highlighted within the Discussion. In terms of more overarching issues, I would make three research suggestions:

1. As stated above I am currently undertaking research to further understand the role of health literacy in the route to diagnosis, and it is hoped that this may lead to the development of an intervention to increase health literacy to increase earlier diagnosis of HNCs
2. It would be worth considering the adapted model of patient delay within other cancer areas to see if the findings are similar or if some of these findings are unique to HNCs.
3. A final consideration would be to try and understand how to engage primary care in this type of research and to try and understand where the fear of taking part comes from.

9.5 Conclusion

This body of work has provided new insights into the routes to diagnosis of HNCs. It has highlighted the many inequalities within the pathway, giving areas on which to focus further work. It has also allowed a deeper understanding of the experience of progressing through this route as a patient or working within this route, allowing many different voices to be heard. The findings also extend theoretical models of patient delay, offering an adapted framework that incorporates these new perspectives.

Some recommendations are readily transferable into current practice, while others call for systemic change in referral systems, professional education, and service integration. Collectively, these findings offer a foundation for building a more equitable, efficient, and patient-centred diagnostic pathway.

References

- Al-Haboubi, M., Klass, C., Jones, K., Bernabé, E. and Gallagher, J. E. (2013) 'Inequalities in the use of dental services among adults in inner South East London', *European Journal of Oral Sciences*, 121(3 Pt 1), pp. 176–181. doi: 10.1111/eos.12043.
- Alho, O.-P. *et al.* (2006) 'Head and neck cancer in primary care: presenting symptoms and the effect of delayed diagnosis of cancer cases', *CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne*, 174(6), pp. 779–784. Available at: <https://doi.org/10.1503/cmaj.050623>.
- Allgar, V.L. and Neal, R.D. (2005) 'Delays in the diagnosis of six cancers: analysis of data from the National Survey of NHS Patients: Cancer', *British Journal of Cancer*, 92(11), pp. 1959–1970. Available at: <https://doi.org/10.1038/sj.bjc.6602587>.
- Allison, P., Locker, D., Feine, J.S. (1998) 'The role of diagnostic delays in the prognosis of oral cancer: a review of the literature.' *Oral Oncology*. 34(3) pp. 161-70. doi: 10.1016/s1368-8375(97)00071-7.
- Amir, Z., Kwan, S. Y., Landes, T., Feber, S. and Williams, A. (1999). Diagnostic delays in head and neck cancers. *European Journal of Cancer Care*, 8(4), pp.198–203. doi:<https://doi.org/10.1046/j.1365-2354.1999.00165.x>.
- Anderson, B. L., Cacioppo, J. T. and Roberts, D. C. (1995) 'Delay in seeking a cancer diagnosis: Delay stages and psychophysiological comparison processes', *British Journal of Social Psychology*, 34, pp. 33–52.
- Arora, N.K. (2003) 'Interacting with cancer patients: the significance of physicians' communication behavior', *Social Science & Medicine*, 57(5), pp. 791–806. Available at: [https://doi.org/10.1016/s0277-9536\(02\)00449-5](https://doi.org/10.1016/s0277-9536(02)00449-5).

- Aslam, M.I., Chaudhri, S., Singh, B. and Jameson, J.S. (2017) 'The "two-week wait" referral pathway is not associated with improved survival for patients with colorectal cancer', *International Journal of Surgery*, 43, pp. 181-185. <https://doi.org/10.1016/j.ijsu.2017.05.046>.
- Awojobi, O., Newton, J.T. and Scott, S.E. (2015) 'Why don't dentists talk to patients about oral cancer?', *British Dental Journal*, 218(9), pp. 537-541. Available at: <https://doi.org/10.1038/sj.bdj.2015.343>.
- Awojobi, O., Newton, J.T. and Scott, S.E. (2016) 'Pilot study to train dentists to communicate about oral cancer: the impact on dentists' self-reported behaviour, confidence and beliefs', *British Dental Journal*, 220(2), pp. 71-76. Available at: <https://doi.org/10.1038/sj.bdj.2016.57>.
- Ball, J., Balogh, E. and Miller, B.T. (2015). *Improving diagnosis in health care*. Washington, Dc: The National Academies Press.
- Bandura, A. (1997). *Self-efficacy: the Exercise of Control*. New York: W. H. Freeman.
- Banks, J., Walter, F.M., Hall, N., Mills, K., Hamilton, W. and Turner, K.M. (2014) 'Decision making and referral from primary care for possible lung and colorectal cancer: a qualitative study of patients' experiences', *British Journal of General Practice*, 64(629), pp. e775-e782. doi:10.3399/bjgp14X682849.
- Bannister, M., Vallamkondu, V. and Ah-See, K. W. (2016) 'Emergency presentations of head and neck cancer: a modern perspective', *The Journal of Laryngology & Otology*, 130(6), pp. 571-574. doi: 10.1017/S0022215116001043.
- Baughan, P., Keatings, J. and O'Neill, B. (2011) 'Urgent suspected cancer referrals from general practice: audit of compliance with guidelines and referral outcomes', *British Journal of General Practice*, 61(592), pp. e700-e706. doi: 10.3399/bjgp11X606591.

- Baxi, S. S., Shuman, A. G., Corner, G. W., Shuk, E., Sherman, E. J., Elkin, E. B., Hay, J. L. and Pfister, D. G. (2013) 'Sharing a diagnosis of HPV-related head and neck cancer: the emotions, the confusion and what patients want to know', *Head Neck*, 35(11), pp. 1659–1667. doi: 10.1002/hed.23182.
- Baxter, S.K. and Brumfitt, S.M., 2008. Professional differences in interprofessional working. *Journal of Interprofessional Care*, 22(3), pp.239-251. DOI: 10.1080/13561820802054655.
- Beck, R. S., Daughtridge, R. and Sloane, P. D. (2002) 'Physician-patient communication in the primary care office: a systematic review', *The Journal of the American Board of Family Practice*, 15(1), pp. 25–38.
- Bethell, G. and Leftwick, P. (2015) 'Views of general practitioners and head and neck surgeons on the referral system for suspected cancer: A survey', *The Journal of Laryngology & Otology*, 129(9), pp. 893-897. <https://doi.org/10.1017/S0022215115001723>.
- Birkeland, A.C., Kulkarni, A., Parker, N., Saleh, A., Lee, J.S., Shuman, A.G., Rozek, L.S. and Newman, J.G., 2024. Perspectives on referral pathways for timely head and neck cancer care. *JAMA Otolaryngology–Head & Neck Surgery*, 150(6), pp.535–543. doi:10.1001/jamaoto.2024.0917
- Bissett, S.M., Stone, K.M., Rapley, T. and Preshaw, P.M. (2013). 'An exploratory qualitative interview study about collaboration between medicine and dentistry in relation to diabetes management.' *BMJ Open*, [online] 3(2), p.e002192. doi:<https://doi.org/10.1136/bmjopen-2012-002192>.
- Boyatzis, R. R. (1998) *Transforming Qualitative Information: Thematic Analysis and Code Development*, Thousand Oaks, CA: Sage.

- Boyes, H. (2015) 'Increasing collaboration between GPs and dental practitioners', *British Journal of General Practice*, 65(638), p. 451. <https://doi.org/10.3399/bjgp15X686725>.
- Bradley, P. (2020) A qualitative exploration of the prospective implementation of a primary care clinical referral decision tool for patients with suspected head and neck cancer. Doctoral thesis, University of Sunderland. Available at: <http://sure.sunderland.ac.uk/id/eprint/15552> [Accessed 6 February 2025].
- Brain, K. E., Smits, S., Simon, A. E., Forbes, L. J., Roberts, C., Robbe, I. J., et al. (2014) 'Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample', *BMC Cancer*, 14, pp. 171–181. doi: 10.1186/1471-2407-14-17.
- Brain, K. E., Smits, S., Simon, A. E., Forbes, L. J., Roberts, C., Robbe, I. J., et al. (2014) 'Ovarian cancer symptom awareness and anticipated delayed presentation in a population sample', *BMC Cancer*, 14, pp. 171–181. doi: 10.1186/1471-2407-14-17.
- Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*, London: Sage Publications Ltd.
- Braun, V. and Clarke, V. (2019a) 'Reflecting on reflexive thematic analysis', *Qualitative Research in Sport, Exercise and Health*, 11, pp. 589–597.
- Braun, V. and Clarke, V. (2019b) 'To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales', *Qualitative Research in Sport, Exercise and Health*, pp. 1–16.

Brouha, X. Tromp, D., Hordijk, G.-J., Winnubst, J., and De Leeuw, R. (2005) 'Role of alcohol and smoking in diagnostic delay of head and neck cancer patients', *Acta Oto-Laryngologica*, 125(5), pp. 552–556. doi: 10.1080/00016480510028456.

Brouha, X.D.R. *et al.* (2007) 'Professional delay in head and neck cancer patients: Analysis of the diagnostic pathway', *Oral Oncology*, 43(6), pp. 551–556. Available at: <https://doi.org/10.1016/j.oraloncology.2006.06.002>.

CAIPE, Center for the advancement of interprofessional education. (2017). *Interprofessional Education Guidelines*. <https://www.caipe.org/download/caipe-2017-interprofessional-education-guidelines-2/>

Cancer Research UK (2023) Head and Neck Cancer Incidence Statistics. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/head-and-neck-cancers> (Accessed: 6 February 2025).

Cegala, D. J. and Lenzmeier Broz, S. (2002) 'Physician communication skills training: a review of theoretical backgrounds, objectives and skills', *Medical Education*, 36, pp. 1004–1016. [PMID: 12406260].

Chapman, K., Abraham, C., Jenkins, V. and Fallowfield, L. (2003) 'Lay understanding of terms used in cancer consultations', *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 12(6), pp. 557-566.

Charlson, M. E., Pompei, P., Ales, K. L. and MacKenzie, C. R. (1987) 'A new method of classifying prognostic comorbidity in longitudinal studies: development and validation', *Journal of Chronic Diseases*, 40(5), pp. 373-383. doi: 10.1016/0021-9681(87)90171-8.

- Chaturvedi, A. K., Graubard, B. I., Broutian, T., Pickard, R. K., Tong, Z. Y., Xiao, W., Kahle, L. and Gillison, M. L. (2015) 'NHANES 2009-2012 Findings: Association of sexual behaviors with higher prevalence of oral oncogenic human papillomavirus infections in U.S. men', *Cancer Research*, 75, pp. 2468–2477. doi: 10.1158/0008-5472.CAN-14-2843.
- Chen, P.-H. *et al.* (2017) 'Adverse Health Effects of Betel Quid and the Risk of Oral and Pharyngeal Cancers', *BioMed Research International*, 2017, pp. 1–25. Available at: <https://doi.org/10.1155/2017/3904098>.
- Chou, W. S., Hamel, L. M., Thai, C. L., *et al.* (2017) 'Discussing prognosis and treatment goals with patients with advanced cancer: A qualitative analysis of oncologists' language', *Health Expectations*, 20, pp. 1073–1080. doi: 10.1111/hex.12549.
- Conway, D.I., Purkayastha, M. and Chestnutt, I.G. (2018) 'The changing epidemiology of oral cancer: definitions, trends, and risk factors', *British Dental Journal*, 225, pp. 867-873.
- Coppola, N., Mignogna, M.D., Riviaccio, I., Blasi, A., Bizzoca, M.E., Sorrentino, R., Lo Muzio, L., Spagnuolo, G. and Leuci, S. (2021) 'Current knowledge, attitudes, and practice among healthcare providers in OSCC awareness: Systematic review and meta-analysis', *International Journal of Environmental Research and Public Health*, 18(9), p. 4506. doi:10.3390/ijerph18094506.
- Coronado, A.C. *et al.* (2017) 'The experience of patients with cancer during diagnosis and treatment planning: a descriptive study of Canadian survey results', *Current Oncology*, 24(5), pp. 332–337. Available at: <https://doi.org/10.3747/co.24.3782>.
- Coward, A., Moon, K. and McDonnell, P. (2021) Waiting Times for Suspected and Diagnosed Cancer Patients. 2020-21 *Annual Report*, NHS.

Creswell, J. W. (2003) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, US: Sage Publications.

Cromme, S. K., Whitaker, K. L., Winstanley, K., Renzi, C., Smith, C. F. and Wardle, J. (2016) 'Worrying about wasting GP time as a barrier to help-seeking: a community-based, qualitative study', *The British Journal of General Practice*, 66(648), e474–e482. doi: 10.3399/bjgp16X685621.

Cromme, S. K., Whitaker, K. L., Winstanley, K., Renzi, C., Smith, C. F., et al. (2016) 'Worrying about wasting GP time as a barrier to help-seeking: a community-based, qualitative study', *British Journal of General Practice*, 66(648), e474–e482. doi: 10.3399/bjgp16X685621.

Cummings, R. and Vincent, M. (2010) 'Two-week cancer referrals: what do you tell the patient?', *British Journal of General Practice*, 60(578), pp. 689–690.
<https://doi.org/10.3399/bjgp10X515430>.

Cunningham, F.C., Ranmuthugala, G., Plumb, J., Georgiou, A., Westbrook, J.I. and Braithwaite, J. (2012) 'Health professional networks as a vector for improving healthcare quality and safety: a systematic review', *BMJ Quality & Safety*, 21(3), pp. 239-249.
<https://doi.org/10.1136/bmjqs-2011-000187>.

Currie, A.C., Evans, J., Smith, N.J., Brown, G., Abulafi, A.M. and Swift, R.I. (2011) 'The impact of the two-week wait referral pathway on rectal cancer survival', *Colorectal Disease*, 14(7), pp. 848-853. <https://doi.org/10.1111/j.1463-1318.2011.02829.x>.

D'Souza, G., Agrawal, Y., Halpern, J., Bodison, S. and Gillison, M. L. (2009) 'Oral sexual behaviors associated with prevalent oral human papillomavirus infection', *Journal of Infectious Diseases*, 199, pp. 1263–1269. doi: 10.1086/597755.

D'Souza, G., Wentz, A., Kluz, N., Zhang, Y., Sugar, E., Youngfellow, R. M., Guo, Y., Xiao, W. and Gillison, M. L. (2016) 'Sex differences in risk factors and natural history of oral human papillomavirus infection', *Journal of Infectious Diseases*, 213, pp. 1893–1896. doi: 10.1093/infdis/jiw063.

Dahlstrom, K. R., Bell, D., Hanby, D., Li, G., Wang, L. E., Wei, Q., Williams, M. D. and Sturgis, E. M. (2015) 'Socioeconomic characteristics of patients with oropharyngeal carcinoma according to tumor HPV status, patient smoking status, and sexual behavior', *Oral Oncology*, 51(9), pp. 832-838. doi: 10.1016/j.oraloncology.2015.06.005.

DAHNO (2011) National Head and Neck Cancer Audit 2011. Leeds: Health and Social Care Information Centre.

Daly, H., Collins, C. (2007) 'Barriers to early diagnosis of cancer in primary care: a needs assessment of GPs'. *Irish Medical Journal*, 100(10), pp 624–26.

Dal Maso, L. et al. (2016) 'Combined effect of tobacco smoking and alcohol drinking in the risk of head and neck cancers: a re-analysis of case-control studies using bi-dimensional spline models', *European Journal of Epidemiology*, 31(4), pp. 385-393. doi: 10.1007/s10654-015-0028-3.

Deane, J., Norris, R., O'Hara, J., Patterson, J. and Sharp, L. (2022) 'Who Presents Where? A Population-Based Analysis of Socio-Demographic Inequalities in Head and Neck Cancer Patients' Referral Routes', *International Journal of Environmental Research and Public Health*, 19(16723). doi: 10.3390/ijerph192416723.

Delon, C., Brown, K. F., Payne, N. W. S., et al. (2022) 'Differences in cancer incidence by broad ethnic group in England, 2013–2017', *British Journal of Cancer*, 126, pp. 1765–1773. doi: 10.1038/s41416-022-01718-5.

Dempsey, L., Orr, S., Lane, S. and Scott, A. (2016) 'The clinical nurse specialist's role in head and neck cancer care: United Kingdom National Multidisciplinary Guidelines', *Journal of Laryngology & Otology*, 130(S2), pp. S212-S215. doi:10.1017/S0022215116000657.

Department for Communities and Local Government (2021) The English index of multiple deprivation (IMD) 2015 – guidance. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/464430/English_Index_of_Multiple_Deprivation_2015_-_Guidance.pdf [Accessed 28 August 2021].

Department of Health (2000) The NHS Cancer Plan 2000. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4014513.pdf (Accessed: 1 March 2022).

Dodd, R. H., Marlow, L. A. and Waller, J. (2016) 'Discussing a diagnosis of human papillomavirus oropharyngeal cancer with patients: An exploratory qualitative study of health professionals', *Head Neck*, 38(3), pp. 394–401. doi: 10.1002/hed.23916.

Donker, G. A., Wiersma, E., van der Hoek, L., et al. (2016) 'Determinants of general practitioner's cancer-related gut feelings—a prospective cohort study', *BMJ Open*, 6, e012511. doi: 10.1136/bmjopen-2016-012511.

Eadie, D., MacKintosh, A., MacAskill, S. (2009) 'Development and evaluation of an early detection intervention for mouth cancer using a mass media approach', *British Journal of Cancer*, 101(Suppl 2), pp. S73–S79. Available at: <https://doi.org/10.1038/sj.bjc.6605395>.

Economopoulou, P., Kotsantis, I. and Psyrris, A. (2020) 'Special Issue about Head and Neck Cancers: HPV Positive Cancers', *International Journal of Molecular Sciences*, 21(9), p. 3388. doi: 10.3390/ijms21093388.

Edwards, M., et al. (2015) 'Distributed health literacy: longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition', *Health Expectations*, 18, pp. 1180–1193.

Elderkin-Thompson, V. and Waitzkin, H. (1999) 'Differences in Clinical Communication by Gender', *Journal of General Internal Medicine*, 14(2), pp. 112–121. Available at: <https://doi.org/10.1111/j.1525-1497.1999.tb00006.x>.

Elliss-Brookes, L., McPhail, S., Ives, A., Greenslade, M., Shelton, J., Hiom, S. and Richards, M. (2012) 'Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets', *British Journal of Cancer*, 107(8), pp. 1220–1226. doi: 10.1038/bjc.2012.408.

Elliss-Brookes, L., McPhail, S., Ives, A., Greenslade, M., Shelton, J., Hiom, S. and Richards, M. (2012) 'Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets', *British Journal of Cancer*, 107, pp. 1220–1226.

Elliss-Brookes, L., McPhail, S., Ives, A., Greenslade, M., Shelton, J., Hiom, S. and Richards, M. (2012) 'Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets', *British Journal of Cancer*, 107, pp. 1220–1226.

Entwistle, V.A. (2000) 'Supporting and resourcing treatment decision-making: some policy considerations', *Health Expectations*, 3(1), pp. 77-85.

- Fallowfield, L. and Jenkins, V. (2004) 'Communicating sad, bad, and difficult news in medicine', *Lancet (London, England)*, 363(9405), pp. 312–9. Available at: [https://doi.org/10.1016/S0140-6736\(03\)15392-5](https://doi.org/10.1016/S0140-6736(03)15392-5).
- Fawns-Ritchie, C., et al. (2018) 'Health literacy, cognitive ability and smoking: a cross-sectional analysis of the English Longitudinal Study of Ageing', *BMJ Open*, 8, e023929.
- Feilzer, M. Y. (2010) 'Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm', *Journal of Mixed Methods Research*, 4, pp. 6–16.
- Ferlay, J., Colombet, M., Soerjomataram, I., Mathers, C., Parkin, D. M., Piñeros, M., Znaor, A. and Bray, F. (2019) 'Estimating the global cancer incidence and mortality in 2018: GLOBOCAN sources and methods', *International Journal of Cancer*, 144(8), pp. 1941–1953. doi: 10.1002/ijc.31937.
- Forbes, L. J. et al (2013) 'International Cancer Benchmarking Partnership Module 2 Working Group. Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival?', *British Journal of Cancer*, 108(2), pp. 292–300. doi: 10.1038/bjc.2012.542.
- Forbes, L. J., Warburton, F., Richards, M. A. and Ramirez, A. J. (2014) 'Risk factors for delay in symptomatic presentation: a survey of cancer patients', *British Journal of Cancer*, 111(3), pp. 581–588.
- Forbes, L.J.L. et al (2013) 'Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival?', *British Journal of Cancer*, 108(2), pp. 292-300. <https://doi.org/10.1038/bjc.2012.542>.

- Gatta, G., et al (2015) 'Prognoses and improvement for head and neck cancers diagnosed in Europe in early 2000s: The EURO CARE-5 population-based study', *European Journal of Cancer*, 51(15), pp. 2130–2143. doi: 10.1016/j.ejca.2015.07.043.
- Gerrand, C. *et al.* (2015) 'Routes to diagnosis for sarcoma – Describing the sarcoma patient journey', *European Journal of Surgical Oncology (EJSO)*, 41(10), pp. 1393–1399. Available at: <https://doi.org/10.1016/j.ejso.2015.07.009>.
- Glossop S, et al. (2024) Oral and maxillofacial surgery and dental health education in undergraduate medicine: a systematic review. *Br J Oral Maxillofac Surg*. 62(10):882-888. doi: 10.1016/j.bjoms.2024.07.014.
- Grant, E. *et al.* (2010) 'The experiences of young oral cancer patients in Scotland: symptom recognition and delays in seeking professional help', *British Dental Journal*, 208(10), pp. 465–471. Available at: <https://doi.org/10.1038/sj.bdj.2010.450>.
- Greedy, J. (2022). 'The role of the clinical nurse specialist in head and neck cancer care.' *British Dental Journal*, 233(9), pp.806–811. doi:<https://doi.org/10.1038/s41415-022-5143-4>.
- Green, T., Atkin, K. and Macleod, U. (2015) 'GPs' perceptions and experiences of public awareness campaigns for cancer: a qualitative enquiry', *Health Expectations*, 19(2), pp. 377–387. Available at: <https://doi.org/10.1111/hex.12362>.
- Hamilton, D.W., Heaven, B., Thomson, R., Wilson, J. and Exley, C. (2022) 'How do patients make decisions in the context of a multidisciplinary team: An ethnographic study of four head and neck cancer centres in the north of England', *BMJ Open*, 12(8), p. e061654. doi:10.1136/bmjopen-2022-061654.

Hanna, S. J., Muneer, A. and Khalil, K. H. (2005) 'The 2-week wait for suspected cancer: time for a rethink?', *International Journal of Clinical Practice*, 59(11), pp. 1334–1339. doi: 10.1111/j.1368-5031.2005.00687.x.

Hardavella, G., Aamli-Gagnat, A., Frille, A., Saad, N., Niculescu, A. and Powell, P. (2017) 'Top tips to deal with challenging situations: doctor-patient interactions', *Breathe (Sheffield)*, 13(2), pp. 129–135. doi: 10.1183/20734735.006616.

Hashibe, M. et al. (2009) 'Interaction between tobacco and alcohol use and the risk of head and neck cancer: pooled analysis in the International Head and Neck Cancer Epidemiology Consortium', *Cancer Epidemiology, Biomarkers & Prevention*, 18(2), pp. 541-550. doi: 10.1158/1055-9965.epi-08-0347.

Haste, A., Lambert, M., Sharp, L., Thomson, R. and Sowden, S. (2020) 'Patient experiences of the urgent cancer referral pathway—Can the NHS do better? Semi-structured interviews with patients with upper gastrointestinal cancer', *Health Expectations*, 23(6), pp. 1512-1522. doi:10.1111/hex.13136.

Haughney, M.G., Devennie, J.C., Macpherson, L.M., Mason, D.K. (1998) Integration of primary care dental and medical services: a three-year study. *Br Dent J.* 184(7):343-7. doi: 10.1038/sj.bdj.4809620.

Haste, A., Lambert, M., Sharp, L., Thomson, R. and Sowden, S. (2020) 'Patient experiences of the urgent cancer referral pathway—Can the NHS do better? Semi-structured interviews with patients with upper gastrointestinal cancer', *Health Expectations*, 23(6), pp. 1512–1522. doi: 10.1111/hex.13136. Published online 28 September 2020. PMID: PMC7752202; PMID: 32989907.

- Heck, J.E. et al. (2010) 'Sexual behaviours and the risk of head and neck cancers: a pooled analysis in the International Head and Neck Cancer Epidemiology (INHANCE) consortium', *International Journal of Epidemiology*, 39(1), pp. 166-181. doi: 10.1093/ije/dyp350.
- Henson, K. E., Elliss-Brookes, L., Coupland, V. H., Payne, E., Vernon, S., Rous, B., Rashbass, J. (2020) 'Data Resource Profile: National Cancer Registration Dataset in England', *International Journal of Epidemiology*, 49(1), p. 16h. doi: 10.1093/ije/dyz076.
- Hill, K. B., Chadwick, B., Freeman, R., O'Sullivan, I. and Murray, J. J. (2013) 'Adult Dental Health Survey 2009: relationships between dental attendance patterns, oral health behaviour and the current barriers to dental care', *British Dental Journal*, 214, pp. 25–32.
- Hollows, P., McAndrew, P. and Perini, M. (2000) 'Delays in the referral and treatment of oral squamous cell carcinoma', *British Dental Journal*, 188(05), pp. 262–265. Available at: <https://doi.org/10.1038/sj.bdj.4800449a>.
- Holzinger, F., Dahrendorf, L. and Heintze, C. (2016) "'Parallel universes"? The interface between GPs and dentists in primary care: a qualitative study', *Family Practice*, 33(5), pp. 557–561. <https://doi.org/10.1093/fampra/cmw058>.
- Hu, H., Yang, Y., Zhang, C., Huang, C., Guan, X. and Shi, L. (2021) 'Review of social networks of professionals in healthcare settings – where are we and what else is needed?', *Global Health*, 17(1), p. 139. <https://doi.org/10.1186/s12992-021-00772-7>.
- Humphris, G.M., Ireland, R.S. and Field, E.A. (2001) 'Immediate knowledge increase from an oral cancer information leaflet in patients attending a primary health care facility: a randomised controlled trial', *Oral Oncology*, 37(1), pp. 99–102. Available at: [https://doi.org/10.1016/s1368-8375\(00\)00069-5](https://doi.org/10.1016/s1368-8375(00)00069-5).

- Hunter, A. and Brewer, J. D. (2015) 'Designing multimethod research', in Hesse-Biber, S. N. and Johnson, R. B. (eds.) *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*, Oxford, UK: Oxford University Press.
- Huettig, F., Said, F.M., Sippli, K., Preiser, C., Rieger, M.A. (2018) 'Was berichten Hausärzte und Zahnärzte über ihre Zusammenarbeit? Ergebnisse aus einer qualitativen Exploration' [What do General Practitioners and Dentists Report about their Cooperation? A Qualitative Exploration]. *Gesundheitswesen*. 80(3), pp.262-265. German. doi: 10.1055/s-0042-108645.
- Hvidberg, L., Wulff, C. N., Pedersen, A. F. and Vedsted, P. (2015) 'Barriers to healthcare seeking, beliefs about cancer and the role of socio-economic position. A Danish population-based study', *Preventive Medicine*, 71, pp. 107–113.
- Jakobsen, K. K., Grønhøj, C., Jensen, D. H., Schmidt Karnov, K. K., Klitmøller Agander, T., Specht, L. and von Buchwald, C. (2018) 'Increasing incidence and survival of head and neck cancers in Denmark: a nation-wide study from 1980 to 2014', *Acta Oncologica*, 57(9), pp. 1143–1151. doi: 10.1080/0284186X.2018.1438657.
- Jefferson, L., Atkin, K., Sheridan, R., Oliver, S., Macleod, U., Hall, G., Forbes, S., Green, T., Allgar, V. and Knapp, P. (2019) 'Non-attendance at urgent referral appointments for suspected cancer: A qualitative study to gain understanding from patients and GPs', *British Journal of General Practice*, 69(689), pp. e850–e859. doi: 10.3399/bjgp19X706625. PMID: 31748378; PMCID: PMC6863680.
- Jensen, H., Nellesmann, H.M. and Overgaard, J. (2007) 'Tumor progression in waiting time for radiotherapy in head and neck cancer', *Radiotherapy and Oncology*, 84(1), pp. 5–10. Available at: <https://doi.org/10.1016/j.radonc.2007.04.001>.

- Jensen, H., Tørring, M. L., Olesen, F., Overgaard, J. and Vedsted, P. (2014) 'Cancer suspicion in general practice, urgent referral and time to diagnosis: a population-based GP survey and registry study', *BMC Cancer*, 14, 636. doi: 10.1186/1471-2407-14-636.
- Jensen, H., Tørring, M.L., Olesen, F., Overgaard, J., Fengergron, M. and Vedsted, P. (2015) 'Diagnostic intervals before and after implementation of cancer patient pathways – a GP survey and registry-based comparison of three cohorts of cancer patients', *BMC Cancer*, 15, p. 308.
- Jethwa, A.R. and Khariwala, S.S. (2017) 'Tobacco-related carcinogenesis in head and neck cancer', *Cancer Metastasis Reviews*, 36(3), pp. 411-423.
- Johnson, D. E., Burtneess, B., Leemans, C. R., Lui, V. W. Y., Bauman, J. E. and Grandis, J. R. (2020) 'Head and neck squamous cell carcinoma', *Nature Reviews Disease Primers*, 6, p. 92.
- Johnson, D. E., Burtneess, B., Leemans, C. R., Lui, V. W. Y., Bauman, J. E., and Grandis, J. R. (2021) 'Head and neck squamous cell carcinoma', *Nature Reviews Disease Primers*, 6(1), p. 92. doi: 10.1038/s41572-020-00224-3
- Jones, R., Rubin, G. and Hungin, P. (2001) 'Is the two week rule for cancer referrals working?', *BMJ* (Clinical research ed.), 322(7302), pp. 1555–1556. doi: 10.1136/bmj.322.7302.1555.
- Kaushik, V. and Walsh, C. A. (2019) 'Pragmatism as a research paradigm and its implications for social work research', *Social Sciences*, 8.
- Kian Ang, K. et al. (2010) 'Human Papillomavirus and survival of patients with oropharyngeal cancer', *New England Journal of Medicine*, 363, pp. 24-35. doi: 10.1056/NEJMoa0912217.

- Kim, M. K. and Alvi, A. (1999) 'Breaking the bad news of cancer: the patient's perspective', *Laryngoscope*, 109(7), pp. 1064–1067. doi: 10.1097/00005537-199907000-00010.
- Kmietowicz, Z. (2012) 'One in three cases of cancer in patients over 70 are diagnosed at emergency admission', *BMJ*, 345, e6402. doi: 10.1136/bmj.e6402.
- Knott, V., Turnbull, D., Olver, I. and Winefield, A. (2012) 'A grounded theory approach to understand the cancer-coping process', *British Journal of Health Psychology*, 17, pp. 551-564. doi:10.1111/j.2044-8287.2011.02054.
- Kostopoulou, O., Russo, J. E., Keenan, G., Delaney, B. C. and Douiri, A. (2012) 'Information distortion in physicians' diagnostic judgments', *Medical Decision Making*, 32, pp. 831–839.
- Kowalski, L.P. and Carvalho, A.L. (2001) 'Influence of time delay and clinical upstaging in the prognosis of head and neck cancer', *Oral Oncology*, 37(1), pp. 94–98. Available at: [https://doi.org/10.1016/s1368-8375\(00\)00066-x](https://doi.org/10.1016/s1368-8375(00)00066-x).
- Kreps, G.L. and Massimilla, D.C. (2002) 'Cancer communications research and health outcomes: Review and challenge', *Communication Studies*, 53(4), pp. 318–336. Available at: <https://doi.org/10.1080/10510970209388596>.
- Kumar, R., Drinnan, M., Mehanna, H. and Paleri, V. (2012) 'Efficacy of the two-week wait referral system for head and neck cancer: A systematic review', *Annals of the Royal College of Surgeons of England (Suppl.)*, 94, pp. 102–106. doi: 10.1308/147363512X13189526439917.
- Kumar, R., Drinnan, M., Mehanna, H. and Paleria, V. (2012) 'Efficacy of the Two-Week Wait Referral System for Head and Neck Cancer: A systematic Review', *Annals of the Royal College of*

Surgeons of England (Suppl), 94, pp. 102-106.

<https://doi.org/10.1308/147363512X13189526439917>.

Lai, A. G. et al (2020) 'Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study', *BMJ Open*, 10, e043828. doi: 10.1136/bmjopen-2020-043828.

Lai, A. G., Pasea, L., Banerjee, A., Hall, G., Denaxas, S., Chang, W. H., Katsoulis, M., Williams, B., Pillay, D., Noursadeghi, M., et al. (2020) 'Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: Near real-time data on cancer care, cancer deaths and a population-based cohort study', *BMJ Open*, 10, e043828.

Larsson, M.M.N., Hedelin, B. and Athlin, E. (2007) 'Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy', *Cancer Nursing*, 30(4), pp. 324-334. doi:10.1097/01.NCC.0000281722.56996.07.

Leventhal, H. (1970). 'Findings and theory in the study of fear communications'. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 5, pp. 120–186). New York: Academic.

Lewis, J.S. Jr. (2015). "Morphologic diversity in human papillomavirus-related oropharyngeal squamous cell carcinoma." *Modern Pathology*, 28(8), 989–997.

Lewis, R.A., et al.(2009) 'Patients' and healthcare professionals' views of cancer follow-up: systematic review', *British Journal of General Practice*, 59(564), pp. e248-59. <https://doi.org/10.3399/bjgp09X453576>.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry*, Newbury Park, CA: Sage.

- Llewellyn, C.D., Horney, D.J., McGurk, M., Weinman, J., Herold, J., Altman, K. and Smith, H.E. (2011). 'Assessing the psychological predictors of benefit finding in patients with head and neck cancer.' *Psycho-Oncology*, 22(1), pp.97–105. doi:<https://doi.org/10.1002/pon.2065>.
- Local Government Association. NHS Dental Deserts Persist in Rural and Deprived Communities: LGA Analysis. Available at: <http://pas.gov.uk/about/news/nhs-dental-deserts-persist-rural-and-deprived-communities-lga-analysis#:~:text=Analysis%20of%20data%2C%20collected%20by%20the%20Care%20Quality,proportion%20of%20residents%20in%20rural%20areas.%20More%20items> [Accessed 20 October 2022].
- Louie, K. S., Mehenna, H. and Sasieni, P. (2015) 'Trends in head and neck cancers in England from 1995 to 2011 and projections up to 2025', *Oral Oncology*, 51, pp. 341–348.
- Louie, K. S., Mehenna, H. and Sasieni, P. (2015) 'Trends in head and neck cancers in England from 1995 to 2011 and projections up to 2025', *Oral Oncology*, 51, pp. 341–348.
- Low, J. (2019) 'A pragmatic definition of the concept of theoretical saturation', *Sociological Focus*, 52, pp. 131–139.
- Lyons, M. *et al.* (2004) 'Audit of referrals for head and neck cancer - the effect of the 2-week, fast track referral system', *Clinical Otolaryngology and Allied Sciences*, 29(2), pp. 143–145. Available at: <https://doi.org/10.1111/j.0307-7772.2004.00744.x>.
- Lyratzopoulos, G., Abel, G. A., McPhail, S., Neal, R. D. and Rubin, G. P. (2013b) 'Gender inequalities in the promptness of diagnosis of bladder and renal cancer after symptomatic presentation: evidence from secondary analysis of an English primary care audit survey', *BMJ Open*, 3, e002861.

Luryi, A. L., et al. (2014) 'Public awareness of head and neck cancers: a cross-sectional survey' *JAMA Otolaryngol Head Neck Surg*, 140(7) pp.639-46. DOI: 10.1001/jamaoto.2014.867

Lyratzopoulos, G. *et al.* (2012) 'Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England', *The Lancet Oncology*, 13(4), pp. 353–365. Available at: [https://doi.org/10.1016/s1470-2045\(12\)70041-4](https://doi.org/10.1016/s1470-2045(12)70041-4).

Lyratzopoulos, G., Vedsted, P. and Singh, H. (2015) 'Understanding missed opportunities for more timely diagnosis of cancer in symptomatic patients after presentation', *British Journal of Cancer*, 112, pp. S84–S91. doi: 10.1038/bjc.2015.47.

Macleod, U., Mitchell, E.D., Burgess, C., Macdonald, S. and Ramirez, A.J. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British Journal of Cancer*, [online] 101(Suppl 2), pp.S92–S101. doi:<https://doi.org/10.1038/sj.bjc.6605398>.

Macmillan Cancer Support (2018) Ask about your cancer treatment. 7th edn. MAC12159_E07_N.

Macmillan Cancer Support (2023) Staging and grading of head and neck cancer. Available at: <https://www.macmillan.org.uk/cancer-information-and-support/head-and-neck-cancer/staging-and-grading-of-head-and-neck-cancer>.

Macmillan Cancer Support. Signs and Symptoms of Oropharyngeal Cancer. Available at: <https://www.macmillan.org.uk/cancer-information-and-support/head-and-neck-cancer/signs-and-symptoms-of-oropharyngeal-cancer> [Accessed 29 September 2022].

Maringe, C., Spicer, J., Morris, M., Purushotham, A., Nolte, E., Sullivan, R., Rachet, B. and Aggarwal, A. (2020) 'The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis

in England, UK: A national, population-based, modelling study', *Lancet Oncology*, 21, pp. 1023–1034.

Maringe, C., Spicer, J., Morris, M., Purushotham, A., Nolte, E., Sullivan, R., Rachet, B., Aggarwal, A. (2020) 'The impact of the COVID-19 pandemic on cancer deaths due to delays in diagnosis in England, UK: a national, population-based, modelling study', *Lancet Oncology*, 21(8), pp. 1023–1034. doi: 10.1016/S1470-2045(20)30388-0.

Marshman, Z., Nower, K. and Wright, D. (2013) Oral health and access to dental services from people from black and minority ethnic groups. A Race Equality Foundation Briefing Paper 29. *Better Health Briefing*.

Mays, N. and Pope, C. (2000) 'Qualitative research in health care: Assessing quality in qualitative research', *British Medical Journal*, 320(50). doi:10.1136/bmj.320.7226.50

McCutchan, G. M., Wood, F., Edwards, A. et al. (2015) 'Influences of cancer symptom knowledge, beliefs and barriers on cancer symptom presentation in relation to socioeconomic deprivation: a systematic review', *BMC Cancer*, 15, p. 1000. doi: 10.1186/s12885-015-1972-8.

McGurk, M., Chan, C., Jones, J., O'Regan, E. and Sherriff, M. (2005) 'Delay in diagnosis and its effect on outcome in head and neck cancer', *British Journal of Oral and Maxillofacial Surgery*, 43(4), pp. 281–284. doi: 10.1016/j.bjoms.2004.01.016.

McKie, C., Ahmad, U.A., Fellows, S., Meikle, D., Stafford, F.W., Thomson, P.J., Welch, A.R. and Paleri, V. (2008) 'The 2-week rule for suspected head and neck cancer in the United Kingdom: Referral patterns, diagnostic efficacy of the guidelines and compliance', *Oral Oncology*, 44(9), pp. 851-856. doi: 10.1016/j.oraloncology.2007.10.010.

McPhail, S., Elliss-Brookes, L., Shelton, J., Ives, A., Greenslade, M., Vernon, S., Morris, E. J. and Richards, M. (2013) 'Emergency presentation of cancer and short-term mortality', *British Journal of Cancer*, 109(8), pp. 2027–2034. doi: 10.1038/bjc.2013.569. Epub 2013 Sep 17. PMID: 24045658; PMCID: PMC3798965.

McPhail, S., Elliss-Brookes, L., Shelton, J., Ives, A., Greenslade, M., Vernon, S., Morris, E. J., Richards, M. (2013) 'Emergency presentation of cancer and short-term mortality', *British Journal of Cancer*, 109(8), pp. 2027–2034. doi: 10.1038/bjc.2013.569.

McPhail, S., Swann, R., Johnson, S. A., Barclay, M. E., Elkader, H., Alvi, R. (2022) 'Risk factors and prognostic implications of diagnosis of cancer within 30 days after an emergency hospital admission (emergency presentation): an International Cancer Benchmarking Partnership (ICBP) population-based study', *Lancet Oncology*, 23(5), pp. 587–600. doi: 10.1016/S1470-2045(22)00127-9.

Mehanna, H. *et al.* (2012) 'Prevalence of human papillomavirus in oropharyngeal and nonoropharyngeal head and neck cancer-systematic review and meta-analysis of trends by time and region', *Head & Neck*. Edited by D.W. Eisele, 35(5), pp. 747–755. Available at: <https://doi.org/10.1002/hed.22015>

Mendonca, S.C. *et al.* (2016) 'Pre-referral general practitioner consultations and subsequent experience of cancer care: evidence from the English Cancer Patient Experience Survey', *European Journal of Cancer Care*, 25(3), pp. 478–490. Available at: <https://doi.org/10.1111/ecc.12353>

Menger, F., Deane, J., Patterson, J.M., Fisher, P., O'Hara, J. and Sharp, L. (2022) 'The nature and content of rumination for head and neck cancer survivors', *Frontiers in Psychology*, 13, 995187. doi:10.3389/fpsyg.2022.995187.

Metcalfe, C., Dailey, Y., Lowe, D. and Rogers, S.N. (2019) 'Introduction of a referral pathway guide for general dental practitioners in Cheshire & Merseyside: the effect on two-week suspected cancer referrals', *British Dental Journal*, 227, pp. 1058–1062.
<https://doi.org/10.1038/s41415-019-1003-2>.

Milbury, K., Rosenthal, D. I., El-Naggar, A. and Badr, H. (2013) 'An exploratory study of the informational and psychosocial needs of patients with human papillomavirus-associated oropharyngeal cancer', *Oral Oncology*, 49(11), pp. 1067–1071. doi:
10.1016/j.oraloncology.2013.07.010.

Miles, A., McClements, P. L., Steele, R. J. C., Redeker, C., Sevdalis, N. and Wardle, J. (2016) 'Perceived diagnostic delay and cancer-related distress: a cross-sectional study of patients with colorectal cancer', *Psycho-Oncology*, 26(1), pp. 29–36. doi: 10.1002/pon.4093.

Mulka, O. (2005) 'NICE Suspected Guidelines', *British Journal of General Practice*, 55(517), pp. 580–581.

Murray, E., et al (2010) 'Normalisation process theory: A framework for developing, evaluating and implementing complex interventions', *BMC Medicine*, 8, p. 63. doi:10.1186/1741-7015-8-63.

National Cancer Intelligence Network (2015) Routes to Diagnosis 2006 to 2013: Technical Document, Public Health England.

National Cancer Patient Experience Survey 2021 National Report (Quantitative). Available at:
https://www.ncpes.co.uk/wp-content/uploads/2022/07/CPES21_Standard-National-Report_JK-PF-NG_RM_BA_SH_280622_FINAL.pdf [Accessed 10 October 2022].

National Health Service (2022) My Planned Care. Available at: <https://www.myplannedcare.nhs.uk/>
(Accessed: 8 March 2022).

National Health Service (2023). *Health Literacy Toolkit 2nd Edition, 2023*. [online] Available at:
<https://library.nhs.uk/wp-content/uploads/sites/4/2023/06/Health-Literacy-Toolkit.pdf>.
Accessed: 3rd March 2023

National Health Service (n.d.) Guide to NHS waiting times in England. Available at:
<https://www.nhs.uk/nhs-services/hospitals/guide-to-nhs-waiting-times-in-england/>
(Accessed: 10 March 2022).

Nazar, H., Shyama, M., Ariga, J., El-Salhy, M., Soparkar, P. and Alsumait, A. (2019) 'Oral Cancer Knowledge, Attitudes and Practices among Primary Oral Health Care Dentists in Kuwait', *Asian Pacific Journal of Cancer Prevention*, 20(5), pp. 1531-1536.
<https://doi.org/10.31557/APJCP.2019.20.5.1531>.

Neal, R. D., Din, N. U., Hamilton, W., Ukoumunne, O. C., Carter, B., Stapley, S. and Rubin, G. (2014) 'Comparison of cancer diagnostic intervals before and after implementation of NICE guidelines: analysis of data from the UK General Practice Research Database', *British Journal of Cancer*, 110(3), pp. 584–592. doi: 10.1038/bjc.2013.791.

Neal, R.D., Din, N.U., Hamilton, W., Ukoumunne, O.C., Carter, B., Stapley, S. and Rubin, G. (2014) 'Comparison of cancer diagnostic intervals before and after implementation of NICE guidelines: Analysis of data from the UK General Practice Research Database', *British Journal of Cancer*, 110, pp. S84–S92.

NHS England. National Health Literacy Toolkit. Available at:
<https://www.england.nhs.uk/ltphimenu/personalisedcare/national-health-literacy-toolkit/>

NHS England. National Health Literacy Toolkit. Available at:

<https://www.england.nhs.uk/personalisedcare/health-literacy/> [Accessed 10 October 2022].

NHS Scotland. The Health Literacy Place. Available at: <http://www.healthliteracyplace.org.uk/>

[Accessed 15 October 2022].

NICE (2004) Improving Outcomes in Head and Neck Cancer - the Manual. London.

NICE (2021) Suspected Cancer Guidelines. Available at: <https://www.nice.org.uk/guidance/ng12>

(Accessed: 1 March 2022).

NICE Guidance (accessed February 2024) Available at: [https://cks.nice.org.uk/topics/head-neck-](https://cks.nice.org.uk/topics/head-neck-cancers-recognition-referral/diagnosis/symptoms-suggestive-of-head-neck-cancers/)

[cancers-recognition-referral/diagnosis/symptoms-suggestive-of-head-neck-cancers/](https://cks.nice.org.uk/topics/head-neck-cancers-recognition-referral/diagnosis/symptoms-suggestive-of-head-neck-cancers/)

[Accessed 1 February 2024].

Nicholson, B. D., McGrath, J. S. and Hamilton, W. (2014) 'Bladder cancer in women', *BMJ*, 348, g2171.

Novick, G. (2008) 'Is there a bias against telephone interviews in qualitative research?', *Research in Nursing & Health*, 31, pp. 391–398.

Okasako-Schmucker, D. L. et al (2023). Community Health Workers to Increase Cancer Screening: 3 Community Guide Systematic Reviews. *American journal of preventive medicine*, 64(4), 579–594. <https://doi.org/10.1016/j.amepre.2022.10.016>

O'Connor, M., O'Donovan, B., Waller, J., Céilleachair, A.Ó., Gallagher, P., Martin, C., O'Leary, J. and Sharp, L. (2020a) 'The role of healthcare professionals in HPV communication with head and

neck cancer patients: A narrative synthesis of qualitative studies', *European Journal of Cancer Care*, 29(4), e13241. doi:10.1111/ecc.13241.

O'Connor, M., O'Donovan, B., Waller, J., Ó Céilleachair, A., Gallagher, P., Martin, C.M., O'Leary, J. and Sharp, L. (2020b) 'Communicating about HPV in the context of head and neck cancer: A systematic review of quantitative studies', *Patient Education and Counseling*, 103(3), pp. 462–472. doi:10.1016/j.pec.2019.09.017.

O'Connor, M., Waller, J., Gallagher, P., O'Donovan, B., Clarke, N., Keogh, I., MacCarthy, D., O'Sullivan, E., Timon, C., Martin, C., O'Leary, J. and Sharp, L. (2020c) 'Barriers and facilitators to discussing HPV with head and neck cancer patients: A qualitative study using the theoretical domains framework', *Patient Education and Counseling*. doi:10.1016/j.pec.2020.05.032.

Office for National Statistics (2022) Regional ethnic diversity in England and Wales. Available at: <https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/regional-ethnic-diversity/latest> (Accessed: 6 January 2025).

Office for National Statistics (2022) The 2011 rural-urban classification for small area geographies: A user guide and frequently asked questions (v1.0). Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/239478/RUC11user_guide_28_Aug.pdf [Accessed 26 October 2022].

Office of National Statistics (2016) 2011 Rural/Urban Classification [online]. Available at: <https://www.ons.gov.uk/methodology/geography/geographicalproducts/ruralurbanclassifications/2011ruralurbanclassification> (Accessed: 19 November 2020).

Oral cancer – College of General Dentistry (no date). Available at: <https://cgdent.uk/oral-cancer/>. (Accessed 5th March 2024)

Oral Cavity Cancer: Time to Re-Think Stereotypes. (2022) Doximity Network OP-ED. Available at: <https://opmed.doximity.com/articles/oral-cavity-cancer-time-to-re-think-stereotypes> [Accessed 20 October 2022].

Oxford Cancer Intelligence Unit (2011) Profile of Head and Neck Cancers in England: Incidence, Mortality and Survival.

Patel, S., Cain, R., Neailey, K. and Hooberman, L. (2017) 'Recruiting General Practitioners in England to Participate in Qualitative Research: Challenges, Strategies, and Solutions', *London: Sage Publications, Inc.* Available at: <https://doi.org/10.4135/9781473994003> [Accessed 18 July 2023].

Pawloski, C., Hilgert, J., Senturia, K., Davis, S., Koday, M., Cunha-Cruz, J. (2022) Medical-Dental Integration in a Rural Community Health Center: A Qualitative Program Evaluation. *Health Promot Pract.* 23(3):416-424. doi: 10.1177/15248399211002832.

Pham, T.M., Gomez-Cano, M., Salika, T., Jardel, D., Abel, G.A. and Lyratzopoulos, G. (2019) 'Diagnostic route is associated with care satisfaction independently of tumour stage: Evidence from linked English Cancer Patient Experience Survey and cancer registration data', *Cancer Epidemiology*, 61, pp. 70-78. <https://doi.org/10.1016/j.canep.2019.04.011>.

Phillips, C. D. (2006) 'What do you do for a living? Toward a more succinct definition of health services research', *BMC Health Services Research*, 6, p. 117.

Pinder, R. J., Ferguson, J. and Møller, H. (2016) 'Minority ethnicity patient satisfaction and experience: results of the National Cancer Patient Experience Survey in England', *BMJ Open*, 6, e011938. doi: 10.1136/bmjopen-2016-011938.

Pitiphat, W. *et al.* (2002) 'Factors Associated with Delay in the Diagnosis of Oral Cancer', *Journal of Dental Research*, 81(3), pp. 192–197. Available at:
<https://doi.org/10.1177/154405910208100310>.

Pourat, N., Martinez, A.E., Crall, J.J. (2015) Better Together: Co-Location of Dental and Primary Care Provides Opportunities to Improve Oral Health. *Policy Brief UCLA Cent Health Policy Res.* (PB2015-4):1-8. PMID: 26591904.

Public Health England (2019) Guidance: National Cancer Registration and Analysis Service (NCRAS) [online]. Available at: <https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras> (Accessed: 10 February 2020).

Public Health England. (2022) Beyond the data: understanding the impact of covid-19 on BAME groups. Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf
[Accessed 15 October 2022].

Public Health Literacy. (2015) Improving health literacy to reduce health inequalities. Available at:
<https://www.gov.uk/government/publications/local-action-on-health-inequalities-improving-health-literacy> [Accessed 15 October 2022].

Quaife, S., Forbes, L., Ramirez, A. Brain, K. E., Donnelly, C., Simon, A.E., and Wardle, J. (2014) 'Recognition of cancer warning signs and anticipated delay in help-seeking in a population sample of adults in the UK', *British Journal of Cancer*, 110, pp. 12–18.
<https://doi.org/10.1038/bjc.2013.684>.

- Quaife, S., Forbes, L., Ramirez, A., Brain, K., Donnelly, C., Simon, A., et al. (2014) 'Recognition of cancer warning signs and anticipated delay in help-seeking in a population sample of adults in the UK', *British Journal of Cancer*, 110(1), pp. 12–18.
- Quaife, S.L., Winstanley, K., Robb, K.A., Simon, A.E., Ramirez, A.J., Forbes, L.J.L., Brain, K.E., Gavin, A. and Wardle, J. (2015) 'Socioeconomic inequalities in attitudes towards cancer: an international cancer benchmarking partnership study', *European Journal of Cancer Prevention*, 24(3), pp. 253-260. <https://doi.org/10.1097/CEJ.0000000000000140>.
- Rapley, T. (2008) 'Distributed decision making: The anatomy of decisions-in-action', *Sociology of Health and Illness*, 30(3).
- Rauscher, G. H., Ferrans, C. E., Kaiser, K., Campbell, R. T., Calhoun, E. E. and Warnecke, R. B. (2010) 'Misconceptions about breast lumps and delayed medical presentation in urban breast cancer patients', *Cancer Epidemiology, Biomarkers & Prevention*, 19(3), pp. 640–647. doi: 10.1158/1055-9965.EPI-09-0997.
- Razai, M. S., Kankam, H. K. N., Majeed, A., Esmail, A. and Williams, D. R. (2021) 'Mitigating ethnic disparities in covid-19 and beyond', *BMJ*, 372, m4921. doi: 10.1136/bmj.m4921.
- Redaniel, M. T., Martin, R. M., Ridd, M. J., Wade, J. and Jeffreys, M. (2015) 'Diagnostic intervals and its association with breast, prostate, lung and colorectal cancer survival in England: Historical cohort study using the Clinical Practice Research Datalink', *PLoS ONE*, 10(5), e0126608. doi: 10.1371/journal.pone.0126608.
- Renzi, C., Whitaker, K.L. and Wardle, J. (2015) 'Over-reassurance and under-support after a “false alarm”: a systematic review of the impact on subsequent cancer symptom attribution and help seeking', *BMJ Open*, 5, p. e007002. <https://doi.org/10.1136/bmjopen-2014-007002>.

- Rietbergen, M.M. *et al.* (2013) 'Increasing prevalence rates of HPV attributable oropharyngeal squamous cell carcinomas in the Netherlands as assessed by a validated test algorithm', *International Journal of Cancer*, 132(7), pp. 1565–1571. Available at: <https://doi.org/10.1002/ijc.27821>.
- Robb, K., Stubbings, S., Ramirez, A., Macleod, U., Austoker, J., Waller, J., et al. (2009) 'Public awareness of cancer in Britain: a population-based survey of adults', *British Journal of Cancer*, 101, S18–S23.
- Robson, C. (2002) *Real World Research*, Oxford: Blackwell Publishing Ltd.
- Rocque, R. and Leanza, Y. (2015) 'A systematic review of patients' experiences in communicating with primary care physicians: intercultural encounters and a balance between vulnerability and integrity', *PLOS ONE*, 10(10), p. e0139577. doi: 10.1371/journal.pone.0139577.
- Rogers, S.N., Staunton, A., Girach, R., Langton, S. and Lowe, D. (2019) 'Audit of the two-week pathway for patients with suspected cancer of the head and neck and the influence of socioeconomic status', *British Journal of Oral and Maxillofacial Surgery*, 57(5), pp. 419-424. doi: 10.1016/j.bjoms.2018.09.016.
- Round, T. *et al.* (2021) 'Cancer detection via primary care urgent referral and association with practice characteristics: a retrospective cross-sectional study in England from 2009/2010 to 2018/2019', *British Journal of General Practice*, 71(712), pp. e826–e835. Available at: <https://doi.org/10.3399/bjgp.2020.1030>.
- Rovira, A., Russell, B., Trivedi, P., Ojo, O., Oakley, R., Byrne, E., Daryanani, A., Van Hemelrijck, M. and Simo, R. (2023) 'The impact of 2-week wait referral on survival of head and neck cancer patients', *European Archives of Otorhinolaryngology*, 280(12), pp. 5557–5564. doi: 10.1007/s00405-023-08152-0. Published online 1 August 2023. PMID: 37526700; PMCID: PMC10620249.

- Rowlands, G., Protheroe, J., Winkley, J., Richardson, M., Seed, P. T. and Rudd, R. (2015) 'A mismatch between population health literacy and the complexity of health information: an observational study', *British Journal of General Practice*, 65(635), e379–e386. doi: 10.3399/bjgp15X685285.
- Russell, J., Boswell, L., Ip, A., Harris, J., Singh, H., Meyer, A.N., Giardina, T.D., Bhuiya, A., Whitaker, K.L., Black, G.B. (2025) How GPs communicate the urgent suspected cancer referral pathway to patients: a qualitative study of GP-patient consultations. *British Journal of General Practice Open*, 9(2) doi: 10.3399/BJGPO.2024.0115.
- Russo, D.P., Tham, T., Bardash, Y. and Kraus, D. (2020). 'The effect of race in head and neck cancer: A meta-analysis controlling for socioeconomic status'. *American Journal of Otolaryngology*, 41(6), p.102624. doi:<https://doi.org/10.1016/j.amjoto.2020.102624>.
- Safer, M. A., Tharps, Q. J., Jackson, T. C. and Leventhal, H. (1979) 'Determinants of three stages of delay in seeking care at a medical clinic', *Medical Care*, 17, pp. 11–29.
- Sampson, R., Cooper, J., Barbour, R. et al. (2015) 'Patients' perspectives on the medical primary–secondary care interface: systematic review and synthesis of qualitative research', *BMJ Open*, 5, e008708. doi: 10.1136/bmjopen-2015-008708.
- Sant, M., Allemani, C., Santaquilani, M., Knijn, A., Marchesi, F. and Capocaccia, R. (2009) 'EUROCORE-4. Survival of cancer patients diagnosed in 1995–1999. Results and commentary', *European Journal of Cancer*, 45(6), pp. 931–991. doi: 10.1016/j.ejca.2008.11.018.
- Schaepe, K.S. (2011) 'Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis', *Social Science & Medicine*, 73(6), pp. 912–921. Available at: <https://doi.org/10.1016/j.socscimed.2011.06.038>.

- Schmitz, C., Atzeni, G., & Berchtold, P. (2017). Challenges in interprofessionalism in Swiss health care: the practice of successful interprofessional collaboration as experienced by professionals. *Swiss medical weekly*, 147, 4344
- Schneeweiss, S. and Maclure, M. (2000) 'Use of comorbidity scores for control of confounding in studies using administrative databases', *International Journal of Epidemiology*, 29(5), pp. 891–898.
- Schnelle, C., Whiteman, D. C., Porceddu, S. V., Panizza, B. J. and Antonsson, A. (2017) 'Past sexual behaviors and risks of oropharyngeal squamous cell carcinoma: A case-case comparison', *International Journal of Cancer*, 140, pp. 1027–1034. doi: 10.1002/ijc.30519.
- Schofield, P.E. (2003) 'Psychological responses of patients receiving a diagnosis of cancer', *Annals of Oncology*, 14(1), pp. 48–56. Available at: <https://doi.org/10.1093/annonc/mdg010>.
- Scott, S. E., Grunfeld, E. A., and McGurk, M. (2005) 'The idiosyncratic relationship between diagnostic delay and stage of oral squamous cell carcinoma' *Oral Oncology*, 41, pp. 396-403 DOI: 10.1016/j.oraloncology.2004.10.010
- Scott, S.E. Khwaja, M., Low, E.L., Weinman, J., Grunfeld, E.A. (2012) 'A randomised controlled trial of a pilot intervention to encourage early presentation of oral cancer in high risk groups', *Patient Education and Counseling*, 88(2), pp. 241–248. Available at: <https://doi.org/10.1016/j.pec.2012.03.015>.
- Scott, J.R., Wong, E., Sowerby, L.J. (2015) 'Evaluating the referral preferences and consultation requests of primary care physicians with otolaryngology - head and neck surgery'. *J Otolaryngol Head Neck Surgery* 44(57). doi: 10.1186/s40463-015-0114-2.

- Semple, C. (2001) 'The role of the CNS in head and neck oncology', *Nursing Standard*, 15(23), p. 39. doi:10.7748/ns2001.02.15.23.39.c2987.
- Sharpe, D. *et al.* (2010) 'The "two-week wait" referral pathway allows prompt treatment but does not improve outcome for patients with oesophago-gastric cancer', *European Journal of Surgical Oncology*, 36(10), pp. 977–981. Available at: <https://doi.org/10.1016/j.ejso.2010.07.002>.
- Siegel, R.L., Miller, K.D., Fuchs, H.E. and Jemal, A. (2021) 'Cancer statistics, 2021', *CA: A Cancer Journal for Clinicians*, 71(1), pp. 7-33.
- Siminoff, L.A., Rogers, H.L. and Harris-Haywood, S. (2015) 'Missed Opportunities for the Diagnosis of Colorectal Cancer', *BioMed Research International*, 2015, pp. 1–9. Available at: <https://doi.org/10.1155/2015/285096>.
- Sippli, K., Rieger, M. A. and Huettig, F. (2017) 'GPs' and dentists' experiences and expectations of interprofessional collaboration: findings from a qualitative study in Germany', *BMC Health Services Research*, 17(1), p. 179. doi: 10.1186/s12913-017-2116-4.
- Smedley, B. D., Stith, A. Y. and Nelson, A. R. (2003) 'Unequal treatment: Confronting racial and ethnic disparities in health care', *New England Journal of Medicine*, 349(13), 1296. doi: 10.17226/12875.
- Smith, C. F., Kristensen, B. M., Andersen, R. S., Hobbs, F. R., Ziebland, S. and Nicholson, B. D. (2021) 'GPs' use of gut feelings when assessing cancer risk: a qualitative study in UK primary care', *British Journal of General Practice*, 71(706), e356–e363. doi: 10.3399/bjgp21X714269.

- Smith, L. K., Pope, C. and Botha, J. L. (2005) 'Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis', *The Lancet*, 366(9488), pp. 825–831. doi: 10.1016/S0140-6736(05)67030-4.
- Sørensen, K., *et al* (2015). 'Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU)'. *The European Journal of Public Health*, [online] 25(6), pp.1053–1058. doi:<https://doi.org/10.1093/eurpub/ckv043>.
- Statacorp (2017) *STATA 15*, College Station, TX: StataCorp LLC.
- Stegmann, M. E., Meijer, J. M., Nuver, J., *et al.* (2019) 'Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis', *European Journal of Cancer Care*, 28, e12903. Available at: <https://doi.org/10.1111/ecc.12903>.
- Sturgis, E. and Cinciripini, P. M. (2007) 'Trends in head and neck cancer incidence in relation to smoking prevalence. An emerging epidemic of human papillomavirus-associated cancers?', *Cancer*, 110(7), pp. 1429–1435. doi: 10.1002/cncr.22963.
- Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A. and Bray, F. (2021) 'Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries', *CA: A Cancer Journal for Clinicians*, 71(3), pp. 209–249.
- Sze, M., Butow, P., Bell, M., Vaccaro, L., Dong, S., Eisenbruch, M., Jefford, M., Girgis, A., King, M., McGrane, J., Ng, W., Asghari, R., Parente, P., Liauw, W. and Goldstein, D. (2015) 'Migrant health in cancer: outcome disparities and the determinant role of migrant specific variables', *The Oncologist*, 20(5), pp. 523–531. doi: 10.1634/theoncologist.2014-0274.

Tashakkori, A. and Teddlie, C. (1998) *Mixed Methodology: Combining Qualitative and Quantitative Approaches*, Thousand Oaks: Sage Publications, Inc.

Teddlie, C. and Tashakkori, A. (2009) *Foundations of Mixed Methods Research*, Thousand Oaks: Sage Publications.

The Healthwatch Website (2024) Our position on NHS dentistry. Available at:

<https://www.healthwatch.co.uk/news/2024-02-01/our-position-nhs-dentistry> [Accessed 6 February 2025].

Torrente, M.C. *et al.* (2011) 'Human papillomavirus infections in laryngeal cancer', *Head & Neck*.

Edited by D.W. Eisele, 33(4), pp. 581–586. Available at: <https://doi.org/10.1002/hed.21421>.

Tørring, M. L., Frydenberg, M., Hansen, R. P., Olesen, F. and Vedsted, P. (2013) 'Evidence of increasing mortality with longer diagnostic intervals for five common cancers: A cohort study in primary care', *European Journal of Cancer*, 49(9), pp. 2187–2198.

Tran Y, Lamprell K, Nic Giolla Easpaig B, Arnolda G, Braithwaite J. (2019) 'What information do patients want across their cancer journeys? A network analysis of cancer patients' information needs.' *Cancer Med.* 8(1), pp. 155-164. Available at: doi: 10.1002/cam4.1915.

Tromp, D.M. *et al.* (2005) 'Patient factors associated with delay in primary care among patients with head and neck carcinoma: a case-series analysis', *Family practice*, 22(5), pp. 554–559. Available at: <https://doi.org/10.1093/fampra/cmi058>.

Tsang, C., Bottle, A., Majeed, A. and Aylin, P. (2013) 'Cancer diagnosed by emergency admission in England: an observational study using the general practice research database', *BMC Health Services Research*, 14(13), 308. doi: 10.1186/1472-6963-13-308.

UK Government, 2022. Inequalities in oral health in England. Available at:
<https://www.gov.uk/government/publications/inequalities-in-oral-health-in-england/inequalities-in-oral-health-in-england-summary> [Accessed 17 Oct. 2022].

van den Brink, M. J., Hummel, M., Lemstra, M., Berger, M. Y., Dekker, J. H. and Blanker, M. H. (2020) 'Factors affecting patient recruitment to trials: qualitative research in general practice', *BJGP Open*, 4(3), pp. bjpgopen20X101056. doi: 10.3399/bjpgopen20X101056.

Vernham, G. A. and Crowther, J. A. (1994) 'Head and neck carcinoma—stage at presentation', *Clinical Otolaryngology*, 19, pp. 120–124.

Von Fragstein, M., Silverman, J., Cushing, A., Quilligan, S., Salisbury, H., Wiskin, C. and UK Council for Clinical Communication Skills Teaching in Undergraduate Medical Education. (2008) 'UK consensus statement on the content of communication curricula in undergraduate medical education', *Medical Education*, 42(11), pp. 1100–1107.

Wale, A. et al (2024) The Effectiveness and Cost-Effectiveness of Community Diagnostic Centres: A Rapid Review. *Int J Public Health*. 23;69:1606243. doi: 10.3389/ijph.2024.1606243.

Waller, J., Robb, K., Stubbings, S., Ramirez, A., Macleod, U., Austoker, J., et al. (2009) 'Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England', *British Journal of Cancer*, 101, S24–S30.

Walter, F., Webster, A., Scott, S. and Emery, J. (2012) 'The Andersen model of total patient delay: a systematic review of its application in cancer diagnosis', *Journal of Health Services Research & Policy*, 17(2), pp. 110–118. doi: 10.1258/jhsrp.2011.010113.

- Warnakulasuriya, S. (2009) 'Global epidemiology of oral and oropharyngeal cancer', *Oral Oncology*, 45(4-5), pp. 309–316. Available at: <https://doi.org/10.1016/j.oraloncology.2008.06.002>.
- Wei, H., Horns, P., Sears, S. F., Huang, K., Smith, C. M., & Wei, T. L. (2022). A systematic meta-review of systematic reviews about interprofessional collaboration: facilitators, barriers, and outcomes. *Journal of Interprofessional Care*, 36(5), 735–749.
10.1080/13561820.2021.1973975
- Weller, J., Boyd, M. and Cumin, D. (2014) 'Teams, tribes and patient safety: overcoming barriers to effective teamwork in healthcare', *Postgraduate Medical Journal*, 90, pp. 149–154.
- Whitaker, K. L., Smith, C. F., Winstanley, K. and Wardle, J. (2016) 'What prompts help-seeking for cancer 'alarm' symptoms? A primary care based survey', *British Journal of Cancer*, 114(3), pp. 334–339. doi: 10.1038/bjc.2015.445.
- Wildt, J., Bundgaard, T. and Bentzen, S.M. (1995) 'Delay in the diagnosis of oral squamous cell carcinoma', *Clinical Otolaryngology*, 20(1), pp. 21–25. Available at: <https://doi.org/10.1111/j.1365-2273.1995.tb00006.x>.
- Windon, M.J. et al. (2018) 'Increasing prevalence of human papillomavirus-positive oropharyngeal cancers among older adults', *Cancer*, 124(14), pp. 2993-2999. doi: 10.1002/cncr.31385.
- Winslow, T. (2012) Head and Neck Cancer Regions (Image). National Institute for Health; National Cancer Institute. Available at: <https://www.cancer.gov/types/head-and-neck/head-neck-fact-sheet>
- Wright, D., Foster, R., Miles, P., Duffield, N., Rickard, S., Frankland, J., Calman, L., & Foster, C. (2025). Communities against cancer: a qualitative study assessing the effectiveness of a community

engagement initiative in improving cancer awareness for marginalised communities. *BMC public health*, 25(1), 2011. <https://doi.org/10.1186/s12889-025-23179-0>

Zohoori, F.V. Shah, K., Mason, J., Shucksmith, J. (2012) 'Identifying Factors to Improve Oral Cancer Screening Uptake: A Qualitative Study', *PLoS ONE*. Edited by R. Fielding, 7(10), p. e47410. Available at: <https://doi.org/10.1371/journal.pone.0047410>.

Appendix A: Qualitative Interviews Research Ethics Approval



Health Research Authority

North East - Tyne & Wear South Research Ethics Committee

HRA Jarrow Jarrow Business Centre
Room 001 Rolling Mill Road
Jarrow NE32 3DT Telephone: 0207 104 8084

6 February 2018

Professor Linda
Sharp Professor of
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Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Dear Professor Sharp

Study title:	The Routes to Diagnosis - A qualitative investigation on the experience of being diagnosed with head and neck cancer.
REC reference:	17/NE/0368
IRAS project ID:	207201

Thank you for your letter of 5 February 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment Poster - Patients]	1.1	26 September 2017

Copies of advertisement materials for research participants [Social Media Recruitment]	1.0	26 September 2017
Copies of advertisement materials for research participants [Recruitment Poster - HCP]	1.1	26 September 2017
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)		
Interview schedules or topic guides for participants [Topic Guide - HCP]	2.2	27 September 2017
Interview schedules or topic guides for participants [Topic Guide - Patient]	2.2	11 December 2017
IRAS Application Form [IRAS_Form_02112017]		02 November 2017
Letter from sponsor [Sponsor Letter]	1	05 September 2016
Letters of invitation to participant [Letter of Invitation - HCP]	1.0	26 September 2017
Letters of invitation to participant [Letter of Invitation - Patient Identified]	1.0	26 September 2017
Other [Patient Debrief]	1.1	04 January 2018
Other [Response to ethics letter]		08 January 2018
Other [Second Response to Ethics Feb 2018]		05 February 2018
Participant consent form [Consent Form - HCP]	V1.0	20 May 2016
Participant consent form [Consent Form - Patients]	1.3	05 February 2018
Participant information sheet (PIS) [PIS - HCP]	V1.1	20 May 2016
Participant information sheet (PIS) [PIS - Patients]	1.4	04 January 2018
Research protocol or project proposal [Research Protocol]	1.2	25 September 2017
Summary CV for Chief Investigator (CI) [CV for CI /Academic Supervisor]		18 August 2016
Summary CV for student [CV - Student]		13 September 2017
Summary CV for supervisor (student research) [CV_Academic Supervisor]		18 April 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/NE/0368

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp



**Mr Paddy
Stevenson Chair**

Email: nrescommittee.northeast-tyneandwearsouth@nhs.net

Enclosures: 'After ethical review – guidance for researchers' SL-AR2

Copy to: Mrs Jennifer Deane - Institute of Health and Society, Baddiley-Clark Building, Newcastle University

Karen Howe – Research Dept, Newcastle University

Mr Aaron Jackson – Joint Research Office, Newcastle Hospitals NHS Foundation Trust

Appendix B: Analysis of Routine Data Research Ethics Approval



Health Research
Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Room 001 Jarrow Business Centre Rolling Mill Road
Jarrow Tyne & Wear NE32 3DT

Tel: 0207 104 8082

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

16 November 2017

Professor Linda

Sharp
Institute of Health and Society
Newcastle University
Baddily-Clark
Building
Richardson
Road
Newcastle-
Upon-Tyne
NE2 4AX

Dear Professor Sharp

Study title: Routes to Diagnosis in Head and Neck Cancer in England, using secondary data.
REC reference: 17/YH/0399
IRAS project ID: 206040

The Proportionate Review Sub-committee of the Yorkshire & The Humber - South Yorkshire Research Ethics Committee reviewed the above application on 13 November 2017.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months

from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point,

wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

- Register the study on the following link:
<http://www.ncl.ac.uk/ihs/research/themes/care/#projects>

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

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

Summary of discussion at the meeting

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

Members asked for clarification about whether exploring other outpatients require access to additional data not discussed in the proposal.

Ms Jennifer Deane replied that no additional data on top of what had been discussed in the protocol would be required.

Members asked for justification for answering "No" for Question A50 of the IRAS form. The Study should be registered on a publicly accessible database, i.e. Charity, Trust or University.

Ms Deane replied that as stated in response to the question, there was no suitable register to record the research on. The study would be listed on the Newcastle University staff page for the supervisors and effort had been made to advertise the research with attendance at survivorship and head and neck cancer specific charity conferences (Sunderland head and neck cancer Survivors Day, Newcastle head and neck cancer survivors day, Northern Head and Neck Cancer Conference, The Swallows Head and Neck Cancer Conference).

The Committee were not satisfied with this response and agreed that this needed to be registered on the following webpage: <http://www.ncl.ac.uk/ihs/research/themes/care/#projects>

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]		02 October 2017
IRAS Application Form [IRAS_Form_01112017]		01 November 2017
IRAS Checklist XML [Checklist_01112017]		01 November 2017
Letter from sponsor [Sponsor Letter]		05 September 2016
Research protocol or project proposal [Project Protocol]	V1.4	25 September 2017
Summary CV for Chief Investigator (CI) [CI CV]		
Summary CV for student [Student CV]	1.1 - Sept 2017	
Summary CV for supervisor (student research) [Supervisor CV]		
Summary CV for supervisor (student research) [CV for Supervisor (Jo Patterson)]	1.1	18 April 2011

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

17/YH/0399

Please quote this number on all correspondence

Yours sincerely

pp



Dr David Broomhead Chair

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: List of names and professions of members who took part in the review

"After ethical review – guidance for researchers"

Copy to: Ms Kay Howes

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting on 13 November 2017 via correspondence.

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>	
Dr David Broomhead (Chair)	Therapy Consultant	Yes		
Mr Martin Edmunds	Editor	Yes		
Mrs Carole Taylor	Deputy Chief Pharmacist	Yes		

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>	
Miss Kerry Dunbar	REC Manager	

Appendix C: Missing Route to Diagnosis

		Unknown RTD	Known RTD	Total
Age	20-54 years	781 (34.8)	15263 (22.9)	16044
	55-64 years	656 (29.3)	19472 (29.3)	20128
	65-79 years	602 (26.8)	23125 (34.8)	23727
	80+	204 (9.1)	8649 (13.0)	8853
Gender	Male	1552 (69.2)	46295 (69.6)	47847
	Female	691 (30.8)	20214 (30.4)	20905
Deprivation Score	1 - Least Deprived	728 (32.5)	10439 (15.7)	11167
	2	538 (24.0)	12274 (18.5)	12812
	3	409 (18.2)	13266 (19.9)	13675
	4	313 (13.9)	14237 (21.4)	14550
	5 - Most Deprived	255 (11.4)	16293 (24.5)	16548
Urban Rural Classification	Urban	1737 (77.4)	54787 (82.4)	56524
	Rural	506 (22.6)	11722 (17.6)	12228
Referral Year	2006-2008	891 (39.7)	19646 (29.5)	20537
	2009-2011	702 (31.3)	22243 (33.4)	22945
	2012-2014	650 (28.9)	24620 (37.0)	25270
Ethnicity	White	1349 (60.1)	53946 (81.1)	55295
	Other	109 (4.9)	3033 (4.6)	3142
	Missing/Unknown	785 (35.0)	9530 (14.3)	10315
Stage at Diagnosis	Stage 1	120 (5.4)	5301 (7.9)	5421
	Stage 2	60 (2.7)	3276 (4.9)	3336
	Stage 3	91 (4.1)	3526 (5.3)	3617
	Stage 4	296 (13.2)	13043 (19.6)	13339
	Missing/Unknown	1676 (74.7)	41363 (62.2)	43039
Cancer Grade	Grade 1	164 (7.3)	5589 (8.4)	5753

	Grade 2	652 (29.1)	25074 (37.7)	25726
	Grade 3	559 (24.9)	17851 (26.8)	18410
	Grade 4	32 (1.4)	603 (0.9)	635
	Missing/Not Known	836 (37.3)	17392 (26.2)	18228
Site of Cancer	Oral Cavity (Inc Palate)	770 (34.3)	22652 (34.1)	23422
	Oropharynx	610 (27.2)	15137 (22.8)	15747
	Larynx	378 (16.9)	15910 (23.9)	16288
	Other	485 (21.6)	12810 (19.3)	13295
Charlson Comorbidity Index	None	1946 (86.8)	48633 (73.1)	50579
	1 Comorbidities	118 (5.3)	8708 (13.1)	8826
	2+ Comorbidities	179 (7.9)	9168 (13.8)	9347
Total		2243	66509	68752

		Odds Ratio	P>z	95% Confidence Intervals		
Age	20-54	1				P<0.0001
	55-64	0.66	0.000	0.59	0.73	
	65-79	0.51	0.000	0.46	0.57	
	80+	0.46	0.000	0.39	0.54	
Gender	Male	1	0.675			
	Female	1.02	0.675	0.93	1.12	
Deprivation Category	Least Deprived (1)	1				P<0.0001
	2	0.63	0.000	0.56	0.70	
	3	0.44	0.000	0.39	0.50	
	4	0.32	0.000	0.28	0.36	
	Most Deprived (5)	0.22	0.000	0.19	0.26	
Urban/Rural	Urban	1				P<0.0001
	Rural	1.36	0.000	1.23	1.51	

Referral Year (3 yr bands)	2006-2008	1				P<0.0001
	2009-2011	0.70	0.000	0.63	0.77	
	2012-2014	0.58	0.000	0.53	0.65	
Ethnicity	White	1				P<0.0001
	Other	1.44	0.000	1.18	1.75	
	Unknown	3.29	0.000	3.01	3.61	
Cancer Stage	1	1.00	0.982	0.80	1.24	P<0.0001
	2	0.81	0.134	0.61	1.07	
	3	1.14	0.289	0.90	1.44	
	4	1				
	Unknown	1.79	0.000	1.58	2.02	
Cancer Grade	1	1				P<0.0001
	2	0.89	0.173	0.74	1.05	
	3	1.07	0.471	0.89	1.27	
	4	1.81	0.003	1.23	2.67	
	Unknown	1.64	0.000	1.38	1.94	
Cancer Site	Oral Cavity	1				P<0.0001
	Oropharynx	1.19	0.002	1.06	1.32	
	Larynx	0.70	0.000	0.62	0.79	
	Other	1.11	0.068	0.99	1.25	
Charlson Comorbidity Index	None	1				P<0.0001
	1 Comorbidities	2.95	0.000	2.45	3.56	
	2+ Comorbidities	2.05	0.000	1.76	2.39	

Appendix D: Patient Debrief Form

Participant Debrief

Study: The Route to and Experience of a Diagnosis of Head and Neck Cancer through Qualitative Interviews

Thank you for taking part in this research, your participation has been very valuable and we appreciate your time.

The aim of this study is to gain a greater understanding of the routes individuals take to a diagnosis of head and neck cancer and their experiences of this process. A better understanding of this may allow us to pinpoint areas or episodes which may cause someone to delay seeking help, or prompt them to seek help, for a particular symptom. We hope this information may help to improve services for future patients.

If you would like to discuss any topics which may have been raised during the interview further then these charities may be of assistance to you:

Samaritans 116 123 jo@samaritans.org 24 Hours a day
Phone and email support line, for anyone in need of emotional support
www.samaritans.org

Macmillan 0808 808 00 00 9am – 8pm every day
Cancer specific helpline
www.macmillan.org.uk

The Swallows 07504 725059 24 Hours a day
Head and Neck Cancer specific helpline
www.theswallows.org.uk

HANC 07743 226312
Head and Neck Cancer charity which provides links to in person support groups, and online support
www.hanc.org.uk

If you feel distressed about any of the issues raised in the interview, or need further help, we would recommend making an appointment with your GP. If you are still under the care of the hospital, you could contact our Clinical Nurse Specialist.

If you would like to contact the research team then the details are below:

Jennifer Deane (Researcher)
J.deane2@newcastle.ac.uk

Prof Linda Sharp (Supervisor)
Linda.sharp@newcastle.ac.uk

Dr Joanne Patterson (Supervisor)
Joanne.patterson@newcastle.ac.uk

Appendix F: Patient Information Sheet

Participant Information Sheet

Study: The Route to and Experience of a Diagnosis of Head and Neck Cancer through Qualitative Interviews

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully. Please ask us if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

This is part of a PhD study being run through Newcastle University in conjunction with Newcastle Hospitals NHS Foundation Trust, City Hospitals Sunderland NHS Trust and Leeds Teaching Hospitals NHS Trust. Its aim is to investigate the route people take to a diagnosis of head and neck cancer and what their experience of this route is. I would like to discuss what symptoms led you to seek medical help, whether there was anything that encouraged you or stopped you from seeking help, and what your overall experience was of the route you took to diagnosis. A better understanding of what prompts people to seek help, or discourages them from seeking help, will help us to identify any problems with how patients are diagnosed at the moment and where any improvements in services might be needed. We hope that this information will help improve experiences of diagnosis for future head and neck cancer patients.

2. Why have I been chosen?

You have been chosen because you have had a diagnosis of a head and neck cancer

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

4. What do I have to do if I take part?

I shall visit you at a place of your choosing to conduct an interview, it is anticipated this will last between 60-90 minutes, however it is possible that it may take slightly less or more time depending on what you want to say. With your consent, the interview will be audio recorded and transcribed. You will be asked about how you got your diagnosis of cancer, which healthcare professionals you saw along your route and whether there was anything that encouraged or stopped you from seeking help.

5. What are any possible disadvantages and risks of taking part?

It will take time out of your day, but every effort will be made to minimise inconvenience and to ensure your comfort in the interview process. Many people value the opportunity to talk about their experiences. Because the interview covers your experience of being diagnosed with cancer, it may bring up some difficult memories or experiences. However, you will not be asked to discuss anything you find too sensitive and it will be possible to take a break or stop at any point during the interview. If, at the end of the interview, it has brought up issues you wish to discuss further, we shall be able to signpost you to more expert sources of support.

6. What are the possible benefits of taking part?

Although this research is unlikely to be of direct benefit to you, it will give you the opportunity to talk about your experiences with an interested, non-judgemental listener who is not involved in your medical care.

7. What will happen if I don't want to carry on with the study?

If you agree to be interviewed, you can withdraw at any time during or after the interview. You can withdraw your transcript prior to it being analysed, after it has been analysed it will be anonymised therefore it will not be possible to remove any data at that point.

8. Complaints

We do not anticipate any problems arising during this study. If you do have a concern, however, about any aspect of this study or the conduct of the researcher, please feel free to contact the research supervisor Professor Linda Sharp (contact details below).

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Every step will also be taken to assure your anonymity. However, in reporting the data we would like permission to refer to your age, gender and cancer site.

10. What will happen to the data?

The data recorded from the interview will be analysed for a final written project. It will be held on a secure computer database following the universities security guidelines and will be destroyed after 10 years.

11. What will happen to the results of the research study?

The results of the research study will be written up and form part of a PhD thesis. Parts of the study will also be submitted for publication in peer reviewed journals. A report of the research findings will be provided for any participants who would like a copy.

12. Who is organising and funding the research?

The research is a PhD project funded by the Institute of Health and Society, Newcastle University. The supervisory team are all based within the Institute.

13. Who has reviewed the study?

This study has been reviewed internally by the project supervisors (listed below), internal assessors and has undergone NHS ethical approval (IRAS Reference Number 207201, REC reference Number 17/NE/0368), and HRA Approval. It has also been assessed by the Research and Development office at each NHS site.

14. Contact Details:

Jennifer Deane (Researcher)
J.deane2@newcastle.ac.uk
Tel: 07970846460

Dr Joanne Patterson
(Supervisor)
Joanne.patterson@newcastle
.ac.uk

Prof Linda Sharp (Supervisor)
Linda.sharp@newcastle.ac.uk

Reply Slip

If you are interested in taking part in this study or would like some more information then please complete the details below and send this form back in the post to the following address:

**Jennifer Deane
Institute of Health and Society
Newcastle University
Baddiley Clark Building
Richardson Road
Newcastle upon Tyne
NE2 4AX**

Alternatively you can contact me via email on; j.deane2@newcastle.ac.uk or by phone on: 07970 846 460

Name: _____

Contact details:

Daytime: _____

Evening: _____

Email: _____

Do you have a preferred contact time?

Morning (9am-12noon)

Afternoon (12noon-3pm)

Late Afternoon (3pm-6pm)

Early Evening (6pm-8pm)

Location: _____

Just a general location is required

Please note you are under no obligation to take part by replying and if you just want some further information then please feel free to get in touch.

Office Use Only:

Please tick the correct NHS Trust:

Newcastle Foundation Trust

Sunderland Foundation Trust

Leeds Teaching Foundation Trust

Charity Referral

ID Number: _____

Appendix G: Consent Form (Patients and HCP)

Participant Consent Form

Study: The Route to and Experience of a Diagnosis of Head and Neck Cancer through Qualitative Interviews

I agree to participate in this interview being carried out by Newcastle University.

I can confirm that (Please initial each box):

I have read and understood the information sheet about taking part

I understand I can ask questions at any point during the interview about any aspect of the research

I understand that the interview will be audio recorded

I understand that the recording will only be listened to by the research team on this project

I understand that the audio will be transcribed (typed up) and all potentially identifying information will be removed

I understand that the data collected for this study will be stored in the Institute of Health and Society at Newcastle University

I understand that the information collected for this study will be used only for research purposes.

I understand that my name will not be used on any documents or in any presentations about the research.

I understand that I can leave the study at any time without needing to say why.

Signature of participant.....

Name (in capitals) Date.....

Signature of researcher.....

Name (in capitals) Date.....

If you have any questions about this research please feel free to contact:

Jennifer Deane (Researcher) **j.deane2@newcastle.ac.uk**

Linda Sharp (Supervisor) **linda.sharp@newcastle.ac.uk**

Joanne Patterson (Supervisor) **Joanne.patterson@newcastle.ac.uk**

I would like a copy of my interview transcript (a typed up copy of the interview) to be sent to me for my approval before it is included in the research.

Yes: No:

If you answered yes to this please can you provide contact details to send the transcript to below:

Email: _____

OR

Address: _____

Postcode: _____

I would like a summary of the research once the project is completed.

Yes: No:

If you answered yes to this please can you provide contact details to send the summary to below:

Email: _____

OR

Address: _____

Postcode: _____

Appendix H: Patient Interview Schedule

Participant Interview Schedule / Topic Guide

Qualitative Interviews

1. Introduction

Introduce self and study

Purpose of the interview

This is a study on “The Route to Diagnosis in Head and Neck cancer”. We want to explore how people come to be diagnosed with head and neck cancer, and your experience of this route.

Length of interview

60 – 90 minutes

Type of Interview

Please talk freely, there are no right or wrong answers.

Voluntary Participation

If there are any questions you don't want to answer then you don't have to, and you can stop the interview at any point. You don't have to give a reason for stopping.

Confidentiality

Everything you say will be confidential, you won't be named in any report and we would only share anything you said if there was a strong risk of very serious harm to you or others and if we had to do that we would discuss it with you first. Nothing said in this interview will impact any ongoing or future care you receive from the NHS.

Dissemination

This interview is part of my PhD and will form part of the final thesis. It is also expected that there will be publications in academic journals and I can provide copies of these to you if required.

Recording

With your permission I will be recording this interview, only I and members of the research team will have access to the tape recording.

TURN TAPE RECORDER ON

Any Questions

Verbal Consent

Signed written consent from received yes/no
Go through verbal consent process

2. Experience of a health problem

When did you first realise that something wasn't right?

Probes

How did you make the decision to seek help?

Did anything stop you seeking help earlier?

Did anything help you decide to seek help?

Is there anything that would have helped you seek help?

How did you feel seeking help?

How did you decide who to see?

3. Engaging with the health care system

Can you tell me what first led you to seek medical advice?

Probes

Who did you speak to about your symptoms?

Which medical professionals did you speak to?

Why did you choose that person?

How did you feel speaking to (Healthcare Professional(s) spoke to)?

4. Communication of the diagnosis

Can you tell me about how you were told you had cancer?

Probes

Who told you your diagnosis?

Who was with you at the time?

How did you feel when you got the diagnosis?

Did you understand what you were being told?

When did you first hear the word "Cancer" about your diagnosis?

5. Knowledge and Understanding of Cancer

What did you know about Head and Neck Cancer before you were diagnosed?

Probes

Were you aware of the risk factors of head and neck cancer? (HPV, Smoking, Alcohol)

Did you know how cancer is diagnosed before your diagnosis?

6. Any Further Questions?

Is there anything that you haven't had a chance to say that you would like to say now?

7. Conclusion of Interview

Explain what will happen to the recorded interview now and what results will be used for Give debrief sheet, explain that researchers contact details are on the sheet and that they can contact anyone if they have any further questions, also explain the list of support services should they need any further support.

Thank participant for their time and help

TURN TAPE RECORDER OFF

Appendix I: HCP Information Sheet

Participant Information Sheet

Study: The Route to and Experience of a Diagnosis of Head and Neck Cancer through Qualitative Interviews

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully. Please ask us if there is anything that is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

This is part of a PhD study being run through Newcastle University in conjunction with Newcastle Hospitals NHS Foundation Trust, City Hospitals Sunderland NHS Trust and Leeds Teaching Hospitals NHS Trust. Its aim is to investigate the route people take to a diagnosis of head and neck cancer and what their experience of this route is. I would like to discuss your experience of diagnosing patients with head and neck cancer, the route they take to reach you and how prepared you feel patients are to hear a diagnosis of cancer.

2. Why have I been chosen?

You have been chosen because you are a healthcare professional who has seen a patient who has been diagnosed with head and neck cancer.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

4. What do I have to do if I take part?

I shall visit you at a place of your choosing to conduct an interview, it is anticipated this will last between 60-90 minutes, however it is possible that it may take slightly less or more time depending on what you want to say. With your consent, the interview will audio recorded and transcribed.

5. What are any possible disadvantages and risks of taking part?

It will take time out of your day, but every effort will be made to minimise inconvenience and to ensure your comfort in the interview process. Many people value the opportunity to talk about their experiences, but it will be possible to take a break or stop at any point during the interview. If, at the end of the interview, it has brought up issues you wish to discuss further, we shall be able to refer you to more expert sources of support.

6. What are the possible benefits of taking part?

Although this research is unlikely to be of direct benefit to you, it will give you the opportunity to talk about your experiences with an interested, non-judgemental listener.

7. What will happen if I don't want to carry on with the study?

If you agree to be interviewed, you can withdraw at any time during or after the interview. You can withdraw your transcript prior to it being analysed, after it has been analysed it will be anonymised therefore it will not be possible to remove any data at that point.

8. Complaints

We do not anticipate any problems arising during this study. If you do have a concern, however, about any aspect of this study or the conduct of the researcher, please feel free to contact my research supervisor Professor Linda Sharp (contact details below).

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Every step will also be taken to assure your anonymity. However, in reporting the data we would like permission to refer to your age, gender and profession.

10. What will happen to the data?

The data recorded from the interview will be analysed for a final written project. It will be held on a secure computer database following the universities security guidelines and will be destroyed after 10 years.

11. What will happen to the results of the research study?

The results of the research study will be written up and form part of my PhD thesis. Parts of the study will also be submitted for publication in peer reviewed journals. A report of the research findings will be provided for any participants who would like a copy.

12. Who is organising and funding the research?

The research is a PhD project funded by the Institute of Health and Society, Newcastle University. The supervisory team are all based within the Institute.

13. Who has reviewed the study?

This study has been reviewed internally by the project supervisors (listed below), internal assessors and has undergone NHS ethical approval (IRAS Reference Number 207201, REC reference Number 17/NE/0368), and HRA Approval. It has also been assessed by the Research and Development office at each NHS site.

14. Contact Details:

Jennifer Deane (Researcher)
J.deane2@newcastle.ac.uk
Tel: 07970 846 460

Prof Linda Sharp (Supervisor)
Linda.sharp@newcastle.ac.uk

Dr Joanne Patterson (Supervisor)
Joanne.patterson@newcastle.ac.uk

Appendix J: HCP Interview Schedule

Participant Interview Schedule – Healthcare Professionals

Qualitative Interviews

1. Introduction

Introduce self and study

Purpose of the interview

This is a study on “The Route to Diagnosis in Head and Neck cancer”. We want to explore how people come to be diagnosed with head and neck cancer, and your experience as a healthcare professional involved in this route.

Length of interview

60 – 90 minutes

Type of Interview

Please feel free to talk freely, there are no right or wrong answers.

Voluntary Participation

If there are any questions you don't want to answer then you don't have to, and you can stop the interview at any point. You don't have to give a reason for stopping.

Confidentiality

Everything you say will be confidential, you won't be named in any report and we would only share anything you said if there was a strong risk of very serious harm to you or others and if we had to do that we would discuss it with you first.

Dissemination

This interview is part of my PhD and will form part of the final thesis. It is also expected that there will be publications in academic journals and I can provide copies of these to you if required.

Recording

With your permission I will be recording this interview, only I and members of the research team will have access to the tape recording.

TURN TAPE RECORDER ON

Any Questions

Verbal Consent

Signed written consent from received yes/no
Go through verbal consent process

2. Background Information

Would you mind giving me some information on your current position?

Probes

How long have you been a HCP?
How long have you been in your current role?

3. Knowledge of Head and Neck cancer

What has been your experience of head and neck cancer in your current position?

Probes

How many patients do you normally see with suspected HNC?

What would you say the patient profile of someone with HNC is?

Are you aware of changes in patient profile (HPV)?

What symptoms do you normally associate with a suspicion of HNC?

4. Communication and Patient Preparedness

Do you feel that you are able to have discussions with patients about suspected cancer?

Probes

Is there a difference in the way you speak to those who have their own suspicions of cancer compared to those where it's an incidental finding?

How prepared do you think patients are when they reach you to hear the word cancer?

5. Current role and potential training needs

What do you perceive your role to be in the route to diagnosis?

Probes

Do you think this is a more difficult cancer group to detect? In comparison to other more common cancers?

Do you think you have any training needs around this cancer type, diagnosis and communicating that diagnosis?

6. Current Route

What do you think of the current pathways?

Probes

Two Week Wait, Diagnostic Pathway, specifically?

What works well in the current route?

What needs more work?

Is it easy for you as a medical professional to negotiate the route?

7. Does funding ever influence your decision to refer?

8. Any Further Questions?

Is there anything that you haven't had a chance to say that you would like to say now?

9. Conclusion of Interview

Explain what will happen to the recorded interview now and what results will be used for Give debrief sheet, explain that researchers contact details are on the sheet and that they can contact anyone if they have any further questions, also explain the list of support services should they need any further support. Thank participant for their time and help

TURN TAPE RECORDER OFF

Appendix K: ICD-10 Codes

C00 – Malignant neoplasm of the lip

- C00.0 – External upper lip**
- C00.1 – External lower lip**
- C00.2 – External lip, unspecified**
- C00.3 – Upper lip, inner aspect**
- C00.4 – Lower lip, inner aspect**
- C00.5 – Lip, unspecified, inner aspect**
- C00.6 – Commissure of lip**
- C00.8 – Overlapping lesion of lip**
- C00.9 – Lip, unspecified**

C01 – Malignant neoplasm of base of tongue

C02 – Malignant neoplasm of other and unspecified parts of tongue

- C02.0 – Dorsal surface of tongue**
- C02.1 – Border of tongue**
- C02.2 – Ventral surface of tongue**
- C02.3 – Anterior two-thirds of tongue, NOS**
- C02.4 – Lingual tonsil**
- C02.8 – Overlapping lesion of tongue**
- C02.9 – Tongue, unspecified**

C03 – Malignant neoplasm of gum

- C03.0 – Upper gum**
- C03.1 – Lower gum**
- C03.9 – Gum, unspecified**

C04 – Malignant neoplasm of floor of mouth

- C04.0 – Anterior floor of mouth**

- C04.1 – Lateral floor of mouth**
- C04.8 – Overlapping lesion of floor of mouth**
- C04.9 – Floor of mouth, unspecified**

C05 – Malignant neoplasm of palate

- C05.0 – Hard palate**
- C05.1 – Soft palate**
- C05.2 – Uvula**
- C05.8 – Overlapping lesion of palate**
- C05.9 – Palate, unspecified**

C06 – Malignant neoplasm of other and unspecified parts of mouth

- C06.0 – Cheek mucosa**
- C06.1 – Vestibule of mouth**
- C06.2 – Retromolar area**
- C06.8 – Overlapping lesion of other and unspecified parts of mouth**
- C06.9 – Mouth, unspecified**
- C07 – Malignant neoplasm of parotid gland**

C08 – Malignant neoplasm of other and unspecified major salivary glands

- C08.0 – Submandibular gland**
- C08.1 – Sublingual gland**
- C08.9 – Major salivary gland, unspecified**
- C09 – Malignant neoplasm of tonsil**

C09.0 – Tonsillar fossa

- C09.1 – Tonsillar pillar**
- C09.8 – Overlapping lesion of tonsil**
- C09.9 – Tonsil, unspecified**

C10 – Malignant neoplasm of oropharynx

- C10.0 – Vallecula**
- C10.1 – Anterior surface of epiglottis**

- C10.2 – Lateral wall of oropharynx**
- C10.3 – Posterior wall of oropharynx**
- C10.4 – Branchial cleft**
- C10.8 – Overlapping lesion of oropharynx**
- C10.9 – Oropharynx, unspecified**

C11 – Malignant neoplasm of nasopharynx

- C11.0 – Superior wall of nasopharynx**
- C11.1 – Posterior wall of nasopharynx**
- C11.2 – Lateral wall of nasopharynx**
- C11.3 – Anterior wall of nasopharynx**
- C11.8 – Overlapping lesion of nasopharynx**
- C11.9 – Nasopharynx, unspecified**

C12 – Malignant neoplasm of piriform sinus

C13 – Malignant neoplasm of hypopharynx

- C13.0 – Postcricoid region**
- C13.1 – Aryepiglottic fold, hypopharyngeal aspect**
- C13.2 – Posterior wall of hypopharynx**
- C13.8 – Overlapping lesion of hypopharynx**
- C13.9 – Hypopharynx, unspecified**

C14 – Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx

- C14.0 – Pharynx, unspecified**
- C14.2 – Waldeyer's ring**
- C14.8 – Overlapping lesion of lip, oral cavity and pharynx**

C32 – Malignant neoplasm of larynx

- C32.0 – Glottis**
- C32.1 – Supraglottis**
- C32.2 – Subglottis**
- C32.3 – Laryngeal cartilage**

C32.8 – Overlapping lesion of larynx

C32.9 – Larynx, unspecified

Appendix L: Conference Presentations and Papers

Publications

Deane, J., Norris, R., O'Hara, J., Patterson, J., & Sharp, L. (2022). Who Presents Where? A Population-Based Analysis of Socio-demographic Inequalities in Head and Neck Cancer Patients' Referral Routes. *Int. J. Environ. Res. Public Health* 2022, 19(24), 16723; <https://doi.org/10.3390/ijerph192416723>

Conference Presentations

Deane, J., Patterson, J., & Sharp, L. (May, 2021) "The Elephant in the Room" Communicating a Diagnosis of Head and Neck Cancer; Results from a Qualitative Study of Patients and Clinicians. IPOS, Kyoto, Japan (Online)

Deane, J., Patterson, J., & Sharp, L. (Aug 2019). Socio-demographic variation in routes to diagnosis in head and neck cancer: a population-based analysis, NCRI, Glasgow, UK (Best Abstract Award)

Deane, J., Patterson, J., & Sharp, L. (May, 2019). The Route to and Experience of a Diagnosis of Head and Neck Cancer: a qualitative study with patients and health professionals. Ca-PRI, Toronto, Canada

Deane, J., Patterson, J., & Sharp, L. (Nov 2018). What are Dentists Experiences of the Head and Neck Cancer Pathway? 11th QoL in Head and Neck Cancer Conference, Leeds, UK

Conference Posters

Deane, J., Patterson, J., & Sharp, L. (May, 2020). Understanding who presents where: A population-based analysis of the socio-demographic variation in patients presenting as an emergency or urgent cancer referral. BAHNO, UK (Online)

Deane, J., Patterson, J., & Sharp, L. (May, 2020). "Fear and Loathing in the NHS"; Clinicians' views of the pathway to diagnosis for head and neck cancer in the UK. BAHNO, UK (Online)

Deane, J., Patterson, J., & Sharp, L. (Aug 2019). "I thought there would have been pain"; A Qualitative investigation of the patients experience of the route to and diagnosis of head and neck cancer. NCRI, Glasgow, UK

Deane, J., Patterson, J., & Sharp, L. (Feb 2019). The Role of Dentists in the Head and Neck Cancer Route to Diagnosis. Cancer Research UK, Birmingham, UK

Invited Talks

Deane, J., Patterson, J., & Sharp, L. (April, 2023). Inequalities in the pathway to a diagnosis of head and neck cancer. Invited speaker at the Barts Centre for Squamous Cancer annual symposium 2023.

Deane, J. Patterson, J., & Sharp, L., (May, 2023). Understanding the role of dentists within the route to diagnosis in Head and Neck Cancer. Invited speaker at the Newcastle University Dental Sciences Summer Seminar Series.

Awards

Insights Public Lecture Doctoral Thesis Prize Winner (2019), Newcastle University

Best Abstract Award (2019), NCRI Conference, Glasgow: Deane, J., Patterson, J., & Sharp, L. (Aug, 2019). Socio-demographic variation in routes to diagnosis in head and neck cancer: a population-based analysis. NCRI, Glasgow, UK