



Survivorship experiences of working-age adults previously treated for oropharyngeal cancer. Moving towards a post-treatment self, its hidden impact and an absence of recognition: An interpretative phenomenological analysis.

Submitted in accordance with the requirements for the  
degree of Doctor of Philosophy (PhD)

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## **Summary**

### **Background**

Incidence of oropharyngeal cancer continues to increase in many countries worldwide, largely due to human papilloma virus (HPV) 16 & 18. Treatment for oropharyngeal cancer can result in long-term side effects. There may be enduring societal costs associated with the long-term physical and psychological side effects of treatment. Current literature suggests HPV may negatively affect a person's lived post-treatment experience. However, there is little evidence to support this.

### **Aim**

The aim was to explore the participants' lived experience of survivorship following treatment for oropharyngeal cancer. From this, recommendations are made to inform future research.

### **Method**

Twelve participants were recruited through two oncology centres in England. Participants were of working age and had completed active treatment between six months and five years prior to interview. A single interview was conducted with each participant. Interpretative phenomenological analysis (IPA) was used to inform the design and analysis. Consistent with IPA, the participants' individual experiences were analysed descriptively, conceptually and linguistically.

### **Results**

All participants spoke about the physical side effects of treatment. Several described difficulties in coming to terms with a post-treatment self. These difficulties were exacerbated by the lack of visible outward change, thereby causing others to disregard the significance of their experience. There was a desire from some for external recognition of their experience. In attempting to establish a post-treatment self, those previously treated for oropharyngeal cancer may attempt to seek recognition for their experience. Gaining recognition can often be hampered due to the hidden nature of the experience to the outside world.

### **Recommendations**

Several areas are suggested for future research. These include experiential research involving oropharyngeal cancer patients and their relatives, and people's experiences of choice and informed consent. Auditing existing provision of supportive care post-treatment and exploring adaptation and recognition in a larger patient sample would also be beneficial for our understanding of this group.



## **Declaration**

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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## **Statement One**

This thesis is being submitted in partial fulfilment of the requirements for the degree of PhD

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This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references. The views expressed are my own.

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## **Glossary of terms**

### **Aetiology/Aetiological factors**

The study of causation, or origination of disease.

### **Allied health professions**

Health care professions distinct from nursing, medicine, and pharmacy. Allied health professionals include dental hygienists, diagnostic medical sonographers, dietitians, medical technologists, occupational therapists, paramedics, physiotherapists, radiographers, and speech and language therapists (SALTs).

### **Anogenital**

The region of the anus and the genitalia, especially the external genitalia.

### **Aspiration**

The entry of material (such as pharyngeal secretions, food or drink, or stomach contents) from the oropharynx or gastrointestinal tract into the larynx and lower respiratory tract.

### **Autonomic**

Involuntary or unconscious; relating to the autonomic nervous system.

### **Brachytherapy**

Cancer treatment. Radioactive seeds or sources are placed in or near the tumour itself, giving a high radiation dose to the tumour while reducing the radiation exposure in the surrounding healthy tissues. The term "brachy" is Greek for short distance.

### **Carcinogenic**

A carcinogen is any substance, radionuclide, or radiation that is an agent directly involved in causing cancer. This may be due to the ability to damage the genome or to the disruption of cellular metabolic processes.

### **Cell cycle regulation**

Any process that controls the series of events by which a cell goes through the cell cycle. During the cell cycle, a cell makes a copy of its DNA and other contents and divides in two. When cell cycle regulation doesn't happen correctly, cells may divide in an uncontrolled way, and diseases such as cancer can occur.

**Cellular differentiation**

The process by which a cell becomes specialised in order to perform a specific function, as in the case of a liver cell, a blood cell, or a neuron. There are more than 250 general types of cells in the human body.

**Cellular proliferation**

Cell proliferation is the process that results in an increase of the number of cells and is defined by the balance between cell divisions and cell loss through cell death or differentiation. Cell proliferation is increased in tumours.

**Chemo radiation**

Treatment that combines chemotherapy with radiotherapy.

**Chromosomal instability**

A type of genomic instability in which chromosomes are unstable, such that either whole chromosomes or parts of chromosomes are duplicated or deleted. Therefore, daughter cells do not have the same number of chromosomes as the cell they originated from.

**Cognitive mapping**

A type of mental representation which serves an individual to acquire, code, store, recall, and decode information about the relative locations and attributes of phenomena in their everyday or metaphorical spatial environment.

**Co-morbidities**

The presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder.

**Desquamation (dry/moist)**

The shedding of epithelial elements, chiefly of the skin, in scales or sheets.

**Dichotomy**

A contrast between two things that are, or are represented as being, opposed or entirely different.

**Dyad**

A group of two people, the smallest possible social group.

**Dysphagia**

Difficulty or discomfort in swallowing.

**E-health interventions**

The use of internet technology by the public, health workers, and others to access health and lifestyle information, services and support.

**Eidetic reduction**

A technique in the study of essences in phenomenology whose goal is to identify the basic components of phenomena.

**Epidemiology**

The study and analysis of the patterns, causes, and effects of health and disease conditions in defined populations.

**Epistemology**

The theory of knowledge, especially with regard to its methods, validity, and scope, and the distinction between justified belief and opinion.

**Epithelial tissue**

Membranous tissue covering internal organs and other internal surfaces of the body.

**Erythema**

Superficial reddening of the skin, usually in patches, as a result of injury or irritation causing dilatation of the blood capillaries.

**Grounded theory**

A systematic methodology in the social sciences involving the construction of theory through the analysis of data. Grounded theory is a research methodology which operates almost in a reverse fashion from social science research in the positivist tradition.

**Head and neck cancer (HNC)**

Used as a general term to describe all cancers of the head and neck region (excluding brain malignancies), rather than specific areas of the head and neck such as oropharynx or hypopharynx. Site-specific terms will be used where appropriate.

**Hermeneutics**

The theory and methodology of interpretation, especially the interpretation of biblical texts, wisdom literature, and philosophical texts.

## **Histology**

Dealing with the minute structure, composition, and function of tissues.

## **Histological grade**

The description of a tumour based on how abnormal the tumour cells and the tumour tissue look under a microscope. It is an indicator of how quickly a tumour is likely to grow and spread.

## **HIV (Human immunodeficiency virus)**

HIV is the cause of the spectrum of disease known as HIV/AIDS. HIV is a retrovirus that primarily infects components of the human immune system.

## **Homogeneity**

Being of a similar kind or of having a uniform structure or composition throughout.

## **HPV (Human papillomavirus)**

A virus with subtypes that cause diseases in humans ranging from common warts to cervical cancer. The mucosal HPV infections are classified further as latent (asymptomatic), subclinical, or clinical. Clinical lesions are grossly apparent, whereas latent infections are detected only with tests for viral DNA. Subclinical lesions are identified by application of 3-5% acetic acid and inspection under magnification. Most HPV infections are latent; clinically apparent infections usually result in warts rather than malignancies.

## **Hyperproliferation**

An abnormally high rate of proliferation (reproduction) of cells by rapid division.

## **Idiographic**

The effort to understand the meaning of unique and often cultural or subjective phenomena.

## **Immunosuppressed**

The inhibition of the normal immune response because of disease, the administration of drugs, or surgery.

## **Inductive**

Moving from specific observations to broader generalisations and theories.  
Inductive cycle starts with observation and moves through common themes to tentative hypothesis and finally, to theory.

### **Infectious aetiology**

Linking one disease or infection to another. These include peptic ulcer disease with Helicobacter pylori, Whipple's disease with Tropheryma whipplei, Lyme arthritis and neuroborreliosis with Borrelia burgdorferi, and cervical cancer with several strains of the human papillomavirus.

### **Intensity modulated radiotherapy (IMRT)**

A type of conformal radiotherapy. Conformal radiotherapy shapes the radiation beams to closely fit the area of the cancer, thereby reducing dose to healthy surrounding tissue.

### **Interpretative phenomenological analysis (IPA)**

IPA is concerned with trying to understand lived experience and with how participants themselves make sense of their experiences. IPA is phenomenological in that it wishes to explore an individual's personal perception or account of an event or state as opposed to attempting to produce an objective record of the event or state itself.

### **Iterative cycle**

The act of repeating a process, either to generate an unbounded sequence of outcomes, or with the aim of approaching a desired goal, target or result. Each repetition of the process is also called an "iteration", and the results of one iteration are used as the starting point for the next iteration.

### **Keratinisation**

The process in which the cytoplasm of the outermost cells of the epidermis is replaced by keratin.

### **Linear array assay**

Linear array is an HPV genotyping test trademarked by Roche. It is a qualitative test that detects thirty-seven high- and low-risk human papillomavirus genotypes.

### **Linguistically**

A way that relates to language or linguistics.

**Locoregional**

Limited to a localised area, as contrasted with systemic or metastatic.

**Longitudinal studies**

An observational research method in which data is gathered for the same subjects repeatedly over a period of time.

**Meta-analysis**

A subset of systematic reviews; a method for systematically combining pertinent qualitative and quantitative study data from several selected studies to develop a single conclusion that has greater statistical power.

**Meta-ethnography**

Meta-ethnography is a method for combining data from qualitative evaluation and research, especially ethnographic data, by translating concepts and metaphors across studies.

**Metastasis**

An active process by which tumour cells move from the primary location of a cancer by severing connections from the original cell group and establishing remote colonies.

**Methodology/methodological**

A system of methods used in a particular area of study or activity.

**Mucosa**

The thin skin that covers the inside surface of parts of the body such as the nose and mouth and produces mucus to protect them.

**Multidisciplinary**

Composed of or combining several usually separate branches of learning or fields of expertise.

**Mutagen**

An agent, such as radiation or a chemical substance, which causes genetic mutation.

**Nomothetics**

Nomothetic literally means "proposition of the law" (Greek derivation). Nomothetic approaches are most appropriate to the deductive approach to

social research in as much as they include the more highly structured research methodologies which can be replicated and controlled, and which focuses on generating quantitative data with a view to explaining causal relationships.

### **Oesophageal strictures**

A narrowing or tightening of the oesophagus that causes swallowing difficulties.

### **Oncogenic**

An agent, environment, process, or substance that causes tumours, or is known to have a direct causal link with their occurrence.

### **Oncoproteins**

A gene that has the potential to cause cancer. In tumour cells, they are often mutated or expressed at high levels.

### **Oropharynx/oropharyngeal**

The part of the pharynx between the soft palate and the upper edge of the epiglottis.

### **Orwellian**

An adjective describing a situation, idea, or societal condition that George Orwell identified as being destructive to the welfare of a free and open society.

### **Osteoradionecrosis**

Where bone does not heal from irradiation. Irradiation of bones causes damage to osteocytes and impairs the blood supply.

### **Palliative intent**

Treatment that is given to relieve symptoms and improve quality of life, rather than with the intention to cure disease.

### **Pharynx**

The soft part at the top of the throat that connects the mouth and nose to the oesophagus

### **Phenomenology**

Referring to a person's perception of the meaning of an event, as opposed to the event as it exists externally to (outside of) that person. The focus of phenomenological inquiry is what people experience in regard to some phenomenon or other and how they interpret those experiences.

**Polymerase**

A polymerase is an enzyme that synthesizes long chains or polymers of nucleic acids. DNA polymerase and RNA polymerase are used to assemble DNA and RNA molecules, respectively, by copying a DNA or RNA template strand.

**Prognosis**

A medical prediction of the future course of a disease and the chance for recovery.

**Psychosocial**

The combined influence that psychological factors and the surrounding social environment can have on a person's physical and mental wellness and their ability to function.

**Purposive sample**

Purposive sampling (also known as judgment, selective or subjective sampling) is a sampling technique in which researcher relies on his or her own judgment when choosing members of population to participate in the study.

**Self-efficacy**

A belief in one's ability to succeed in specific situations or accomplish a task.

**Snowballing**

Using citations in key studies to generate further reading/evidence.

**Socioeconomic status**

The social standing or class of an individual or group. It is often measured as a combination of education, income and occupation.

**Spontaneous mutations**

A mutation that arises naturally and not as a result of exposure to mutagens. Also called natural mutation.

**Squamous cell carcinomas**

The uncontrolled growth of abnormal cells in the skin outer squamous cells of the epidermis. It occurs as a result of keratinization of the epidermal cells.

**Survivorship**

Defined as the period of time a person is "living with or beyond cancer". This extends from diagnosis to the time of their death.

### **Symbolic interactionism**

A way of looking at the world that focuses on communication, meaning and symbols instead of large-scale social structures.

### **Synergistic**

The interaction or cooperation of two or more organisations, substances, or other agents to produce a combined effect greater than the sum of their separate effects.

### **Synthesis**

The combining of the constituent elements of separate material or abstract entities into a single or unified entity.

### **Therapeutic radiographer**

Healthcare professionals who specialise in the planning and administration of radiotherapy treatment for patients, most of whom have cancer.

### **Trismus**

Motor disturbance of the trigeminal nerve, especially spasm of the masticatory muscles, with difficulty in opening the mouth. Also referred to as lockjaw.

### **Tropism**

The turning or bending movement of an organism or a part of an organism in a particular direction in response to an external stimulus such as light or gravity.

### **Tumour suppressor proteins**

Proteins which inhibit cell proliferation and tumour development.

### **Undifferentiated (cells)**

A cell that has not yet acquired a special structure and function; pertaining to an immature cell or a primitive cell, often a sign of a poor prognosis.

### **Volumetric modulated arc therapy (VMAT or ARC)**

A radiation technique, which can achieve highly conformal dose distributions with improved target volume coverage and sparing of normal tissues compared with conventional radiotherapy techniques.

**Well-differentiated (cells)**

Well-differentiated cancer cells look more like specialised (normal) cells and tend to grow and spread more slowly than poorly differentiated or undifferentiated cancer cells.

**Xerostomia**

The subjective feeling of oral dryness, which is often, but not always, associated with hypofunction of the salivary glands. Can be a side effect of radiotherapy to the salivary glands.

## Chapter One – Introduction

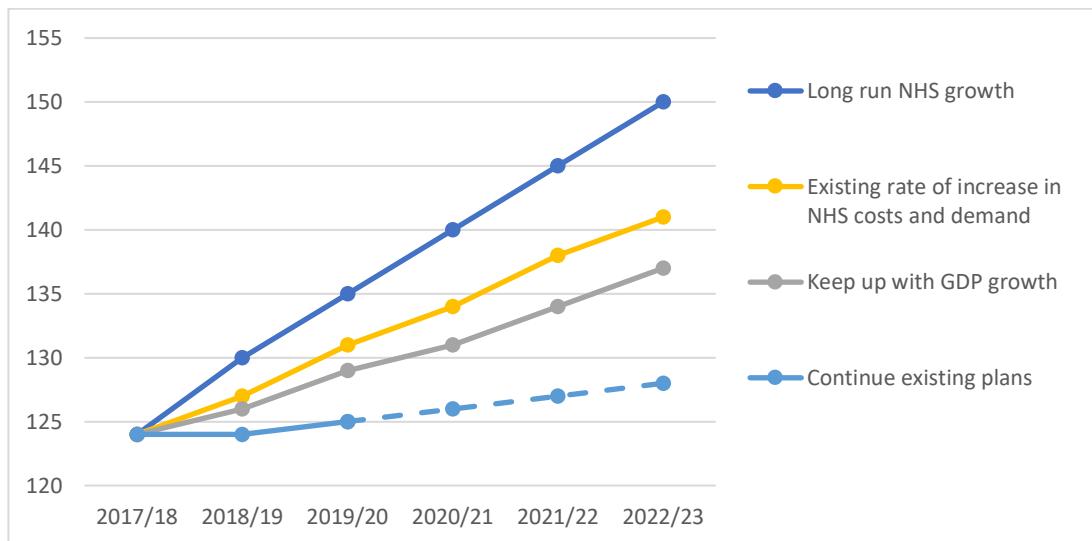
### 1.1 Introduction

This thesis is about the lived experience of a group of twelve people who have previously been diagnosed and treated for oropharyngeal cancer. It looks at their experience in light of existing literature, in the hope of exploring and understanding their life-world. Data from interviews will be presented to support interpretations, and these interpretations will be discussed against existing literature. Recommendations will be made for future research.

This chapter will briefly highlight why it is important to study and understand patient experience when healthcare funding is being scrutinised. It will go on to explain my own motivation to study head and neck cancer (HNC), as well as the particular changes in the population of oropharyngeal cancer patients. Following this, the aims of the study will be stated, and the participants will be introduced.

### 1.2 Demands on services

There is currently a great deal of pressure on the National Health Service (NHS) and the welfare system as a whole in the UK. Demands on services are high, so it is important to understand the needs of all service users in order to provide the most appropriate care. Figure 1 shows future projected annual NHS cost following several scenarios. Increasing demand is making, and will continue to make, the situation of appropriate spending and providing value-for-money evermore challenging for policy makers.



**Figure 1 - NHS spending scenarios set against current plans.**

Adapted from data from Nuffield Trust (2017). Figures on the left are in £ billions.

In 2015 the King's Fund wrote:

The NHS five-year forward view, published in October 2014, set out different scenarios to estimate how much funding the NHS would need by 2020/21. Based on current trends in demand, with just enough money to cover rising pay and prices and no productivity improvements, it estimated that a funding gap of £30 billion would emerge by the end of this period. Its most optimistic scenario estimated that productivity improvements of 2-3 per cent a year (significantly higher than the 0.8 per cent the NHS currently averages) could reduce this gap by £22 billion, leaving an additional funding requirement of £8 billion a year by 2020/21. (...) With deficit reduction still a high priority, finding this money will not be easy. However, unless it is found, patients will bear the cost as staff numbers are cut, waiting times rise and quality of care deteriorates.

(The King's Fund 2015a)

Given the demands on resources, it is often easier to look at short-term solutions, such as staff pay or reduction of service provision. However, better understanding of patient groups now may be the answer to future welfare savings. By gaining a better understanding of under-researched patient groups, policy makers can implement more appropriate care which, in turn, can lead to lower long term costs associated with chronic health conditions. This principle of prevention being cheaper than cure could encompass areas such as returning to work, thereby reducing out-of-work or long-term sickness costs.

### 1.3 The motivation to study head and neck cancer

I qualified as a therapeutic radiographer in 2012, but the idea of the study came much earlier whilst still training. In my second year of undergraduate training I attended a lecture given by a man who had been treated radically for laryngeal cancer some five years earlier. His vocal chords had been removed as part of the radical treatment, and he spoke with the aid of a valve which he depressed in order to manipulate his airway thereby mimicking his voice. He spoke for nearly an hour about the challenges he faced, both during and after his treatment. Despite the fact that it was often a struggle for him to talk, he spoke very eloquently about the impact of the diagnosis and how cancer had changed his life since. He talked about the claustrophobia he experienced during treatment due to the immobilisation mask, which is used for treatment accuracy. This was despite him being an experienced scuba diver and therefore accustomed to masks and restricted spaces. He also spoke about the changes to his life caused by the cancer and its treatment, such as taking early retirement. Most strikingly, he spoke about the emotional impact of the disease and how it had affected him and his relationships with those around him.

Radiotherapy is unusual in a lot of ways compared to other medical specialities, in that radiographers see their patients daily for six weeks (for most head and neck cancers). But then unless their cancer metastasises, they are unlikely to ever see them again. Follow-up clinics are led by oncologists, surgeons or clinical nurse specialists (CNSs). Therefore, therapeutic radiographers generally have no oversight as to the long-term impact of the treatment they give.

Hearing this man speak about how his life had changed so dramatically because of the treatment did not seem to match with what patients are being told clinically prior to treatment. This could include timeframes of when *normal* functional changes such as eating and fatigue would improve, or how long a skin reaction such as erythema or desquamation may last. Advice varies between hospitals, so patients can have access to conflicting advice. For instance, a brief internet search shows advice from a hospital in England (not used in this study) which states:

You may well find that your taste buds have been affected, and everything is bland or has a metallic taste to it. This is normal, and usually starts to subside between 2-4 weeks following completion of radiotherapy (...) most people have found it can take up to 6-8 weeks following radiotherapy before their swallowing and diet returns to normal, and for some people it may take longer.

(Torbay and South Devon HNS Foundation Trust 2016, pp. 6-7)

For some people such advice would be appropriate. However, for someone who relied on their sense of taste for their livelihood, such as a chef, the potentially false expectations and uncertainty around *normal* function may result in additional and unnecessary psychological and/or financial burden at a later date.

## 1.4 Oropharyngeal cancer – a changing population

The demographics of those diagnosed and treated for oropharyngeal cancer has changed in recent years (Chaturvedi et al. 2011). It is generally accepted that these changes are due to the impact of human papillomavirus (HPV) types 16 and 18 (Marur et al. 2010). People diagnosed with HPV+ve oropharyngeal cancer are generally younger than their HPV-ve counterparts (Chaturvedi 2012), which raises some interesting and novel issues. HPV+ve oropharyngeal cancer patients are more likely to be of working age, and as such, are more likely to be actively contributing to society, both in economic and social ways (Chaturvedi 2014). People of working age are also more likely to have dependent children and other financial commitments (Chaturvedi 2014). Therefore, in societal terms it is important to understand the experiences of this patient population, as these people will be potentially actively contributing to society for years or even decades to come. If the impact of treatment for oropharyngeal cancer is such that it hinders or prevents a person from returning to an actively contributing role, then to not consider the well-being of the patient beyond cure rates or other quantifiable measures would be short-sighted (Macmillan 2013). Not only do chronic conditions cost the NHS money to manage, but should someone require additional welfare support or be unable to work because of those conditions, the cost to the public purse through lost tax revenue and/or increased welfare payments may far exceed the initial cost of prioritising the patients' well-being during and following treatment (Jones et al. 2010).

Due, in part, to the rapid and recent emergence of HPV as a factor in HNC cases worldwide, there is a paucity of knowledge regarding this patient group, particularly in regard to the psychological and emotional effects of diagnosis

and treatment (Howren et al. 2013). A large amount of research on the psychosocial implications of an HPV+ve diagnosis up to this point has been drawn from other patient groups, such as those identified with HPV+ve cervical cancers (D’Souza et al. 2009; Kwan et al. 2011; Chu et al. 2013).

Regardless of HPV status, the options for treatment of oropharyngeal cancer would, on the whole, be the same. This is despite the fact that those with an HPV+ve tumour (and who do not smoke tobacco) generally have a better prognosis than their HPV-ve counterparts. In a systematic review and meta-analysis conducted by O'Rorke et al. (2012), patients with HPV+ve HNC had a 54% better overall survival compared to HPV-ve patients. There are currently trials, such as the De-ESCALaTE trial (Shaw 2012), which are aiming to reduce the impact of treatment related side effects in these patients while still maintaining the same therapeutic outcome. However, the vast majority of patients who have curative treatment are left with the long-term effects associated with surgery, radiotherapy and chemotherapy (Cousins et al. 2013; Berg et al. 2014). Swallowing difficulties (dysphagia), dry mouth due to reduced saliva production (xerostomia), damage to bone from radiation (osteoradionecrosis), spasm of the jaw and/or inability to open mouth fully (trismus), and oesophageal strictures are known late side effects in patients with head and neck cancer treated with chemoradiation (Rütten et al. 2011; Raber-Durlacher et al. 2012). Swallowing dysfunction and aspiration are seen in a high proportion in these patients after combined chemoradiotherapy with frequency estimates ranging from 30% to 100% (Nguyen et al. 2004; Frowen and Perry 2006; Rütten et al. 2011).

One of the largest challenges in researching an under-represented group such as those diagnosed with oropharyngeal cancer, regardless of HPV status, is understanding from direct accounts of their experience, what is of importance

to them. This may or may not be different to other HNC patients. HPV-ve HNC patients, sometimes referred to as *typical* or *traditional* HNC patients, may have a history of alcohol and tobacco dependency. This is due to the proven carcinogenic effect of each of these substances, and particularly the synergistic relationship they have on each other to amplify that carcinogenic effect (Andrews et al. 2009; Warnakulasuriya 2009). Previous research has tended to focus on quantifiable measures of quality of life (QoL) such as swallowing or skin reaction. What has not been fully explored is, for instance, what it means to someone if their ability to eat in a restaurant with friends is compromised in the long-term because of their diagnosis and treatment.

### 1.5 Aims of the study

This study will help to open the discussion around the experiences of this patient group thereby providing a platform for further research. The focus of this study is the experiences and life-world of the participants relating to their cancer. Questions and topics were purposefully made as open as possible and it was the participants' responses which guided the interviews. Any interpretations by me were reflected on and analysed against previously held knowledge or biases. Importantly, this study's data is a unique creation between me as the researcher and the participants at a specific point in time.

For the purposes of this study, survivorship is defined as "living with or beyond cancer" (2016), extending from the point of diagnosis throughout the remainder of that person's life.

The aims of the study were:

1. To better understand the lived experience of working-age people following diagnosis and treatment for oropharyngeal cancer.
2. Make recommendations from the information gained to inform future research.

## 1.6 Participant biographies

The group of participants comprised nine men and three women. All names have been changed to protect the anonymity of the individuals. As much personal information has been removed as possible, although some remains to give their stories meaning and context.

### 1.6.1 Joe

Joe is a fifty-five-year-old man who works in the electricity industry. He is married with no children. He was treated at Northtown three years ago and is back working full-time. He enjoys spending time with his wife and friends and vacationing abroad.

### 1.6.2 Bruce

Bruce is a fifty-nine-year-old IT manager. He lives in a town near Northtown with his wife. He has one grown up son and two grandchildren. He was diagnosed two and a half years ago and was treated at Northtown. Despite some uncertainty over his job security, he is working full-time and enjoys motorcycle racing.

### **1.6.3 Seth**

Seth is a forty-eight-year-old manufacturing engineer. He lives near Northtown with his wife and teenage daughter. He grew up in the area and has worked at the same company since leaving school. Seth is nearing the end of his five-year follow-up period.

### **1.6.4 Ernie**

Ernie is a forty-eight-year-old self-employed engineer. He lives in Northtown with his wife and two teenage children. Ernie was diagnosed two and a half years ago. He has a history of alcohol use and used to work with industrial solvents.

### **1.6.5 Sara**

Sara is a forty-six-year-old office worker. She lives in a large town near Northtown but works some distance away. She is the only participant who is not currently in a relationship. She was treated three years ago in Northtown. Sara comes from a small family and did not have a great deal of support from others during her treatment.

### **1.6.6 Casey**

Casey is a fifty-three-year-old catering manager/chef. He lives near Northtown with his partner. He has three children from a previous relationship, but they do not live nearby. His partner has two children from a previous relationship who both live nearby. All of the children are grown up. Casey and his partner do not have any children together. Casey was treated nearly a year ago and was in the process of returning to work at the time of the interview.

### **1.6.7 Sid**

Sid is a forty-five-year-old man who lives with his wife, two children and one grandchild. He works as a self-employed painter/decorator. Sid was treated one year ago and has just returned to work. He lives in a village some distance from Northtown, where he was treated. He enjoys playing sport and spending time with his family.

### **1.6.8 Terry**

Terry is a fifty-five-year-old retired company director. He lives with his wife near Northtown. He was treated just over one year ago. At diagnosis he was completely asymptomatic, but the tumour was picked up during an unrelated routine procedure. He has one daughter who is at university.

### **1.6.9 Grace**

Grace is a sixty-year-old woman who lives with her husband in a town close to Northtown. She has two adult children who do not live nearby. Grace works part-time for a charity. She was treated just under two years ago.

### **1.6.10 Michaela**

Michaela is a forty-eight-year-old full-time mother. She lives with her husband and young daughter near Southtown. She was treated two years ago in Southtown and had lots of support from family, including parents who live nearby.

### **1.6.11 Peter**

Peter is fifty-one years old and was living abroad when he was diagnosed a little over a year ago. He is married, although he is currently living in the UK without

his wife. Peter has three grown up children from a previous relationship, although he is not in regular contact with them. Peter's wife has one child from a previous relationship. Peter's last job was as a retail manager before he decided to take some time off to travel, where he met his current wife. His father had been treated for the same type of cancer some six years ago. Peter currently lives on his own in Southtown.

#### 1.6.12 Jack

Jack is a fifty-seven-year-old painter and decorator. He lives with his wife in Southtown. Jack had treatment just under four years ago. He has one grown up son who does not live nearby. Jack's wife was being treated for another form of cancer when he got his diagnosis.

Below is a table showing the details of the participants, including age, gender, occupation, treatment modality and approximate time since treatment.

Name	Date of interview	Age	Gender	Occupation	Treatment modality (S=surgery, R=radiotherapy, C=chemotherapy)	Time since treatment (approx.)
Joe	May 2014	55	Male	Electrical engineer	S, R & C	3 years
Bruce	May 2014	59	Male	IT manager	R & C	2.5 years
Seth	May 2014	48	Male	Manufacturing engineer	S, R & C	5 years
Ernie	June 2014	48	Male	Engineer	R	2.5 years
Sara	July 2014	46	Female	Office worker	S, R & C	3 years
Michaela	July 2014	48	Female	Stay at home mother	S, R & C	2 years
Casey	October 2014	53	Male	Chef	S & R	1 year
Terry	Nov 2014	45	Male	Retired company director	R	1 year
Peter	Dec 2014	51	Male	Unemployed	S, R & C	1 year

Sid	January 2015	45	Male	Painter and decorator	S, R & C	1 year
Grace	Feb 2015	60	Female	Charity worker	R &C	2 years
Jack	Feb 2015	57	Male	Painter and decorator	S, R & C	4 years

**Table 1 - Demographic table of participants.**

### 1.7 Chapter summary

In some areas of public health such as human immunodeficiency virus (HIV) prevention, decision makers within government and the NHS have been pushing for improvements now in order to ameliorate the long term costs of constant treatment and intervention through prevention (Jones et al. 2013). Each prevented HIV infection is estimated to save the state around £280,000 (Forde and Cook 2013). Similarly, with the introduction of the HPV vaccination programme in the UK in 2008 (Bowyer et al. 2013; Hibbitts et al. 2014), the aim was a long-term reduction in incidence and impact of cervical cancer. While the potential associated costs from HNC patients may not be of the same scale due to the number of people diagnosed each year, policy makers should be adopting the same forward-thinking strategy for all health conditions.

The following chapter will aim to gather and synthesise the existing literature surrounding various topics around HNC patients and associated areas. This synthesis will provide the justification for why the survivorship experiences of oropharyngeal cancer patients are worthy of study.

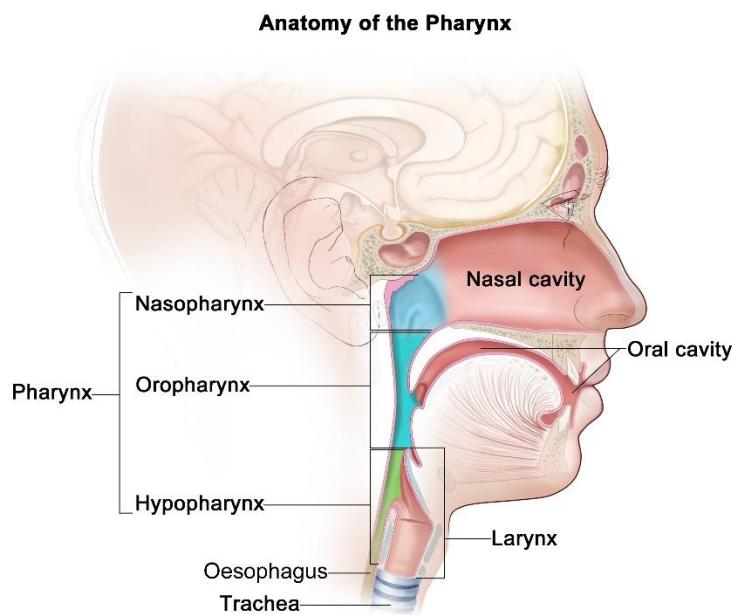
## Chapter Two – Setting the scene

### 2.1 Chapter introduction

This chapter will set out the evidence surrounding the scale and causes of HNC, and in particular oropharyngeal cancer. By the end of the chapter there will be justification as to why oropharyngeal cancer patients are particularly worthy of study.

### 2.2 Head and neck cancer

Cancers of the head and neck arise from mucosa lining the oral cavity, oropharynx, hypopharynx, larynx, sinonasal tract, and nasopharynx (Figure 2). The vast majority of these are squamous cell carcinomas, and histological grade can vary from well-differentiated keratinising to undifferentiated non-keratinising (Marur et al. 2010). HNC is the sixth most common cancer worldwide (Chin et al. 2006; Wise-Draper et al. 2012) and its incidence is increasing, particularly in younger age groups (Schantz and Yu 2002; Marur and Forastiere 2008). The main treatment modalities for HNC (surgery, radiotherapy and chemotherapy) often result in debilitating sequelae which can lead to enduring physical, social and psychological difficulties (Semple et al. 2008).



**Figure 2 - Diagram of the anatomical regions of the head and neck.**

Adapted from National Cancer Institute (2016)

### 2.3 Presentation

Due to the difficulty of early detection and the relatively small number of patients (in comparison to some cancer sites), there is currently no national screening programme for head and neck cancer. Patients with head and neck cancers may present with a variety of symptoms, depending on the site and function of the site where the tumour is located. Patients may even be asymptomatic at diagnosis (NICE 2004).

Any of the following lasting for more than three weeks	
Symptoms	
	Sore throat Hoarseness Stridor Difficulty in swallowing Lump in neck Unilateral ear pain

Signs	Red or white patch in the mouth Oral ulceration, swelling, or loose tooth Lateral neck mass Rapidly growing thyroid mass Cranial nerve palsy Orbital mass Unilateral ear effusion
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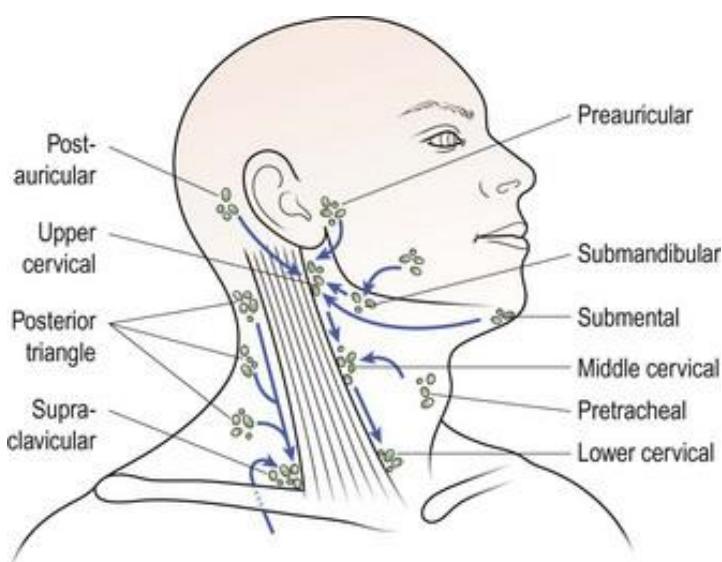
**Table 2 - Signs and symptoms of head and neck cancer.**

Adapted from Mehanna et al. (2010)

## 2.4 Routes of spread

The four main routes of spread in HNC are:

1. Local spread is achieved by direct invasion and infiltration of adjacent structures.
2. Perineural invasion (malignant cells spreading to the space surrounding a nerve).
3. Regional spread to the lymph neck nodes via lymphatic spread (see figure 3, below).



**Figure 3 - Lymph-node distribution in the neck, and the drainage pattern.**

**Arrows indicate direction of lymphatic drainage. Adapted from Entokey.com (2017)**

4. Infiltration of distant organs and structures via haematogenous spread.

## 2.5 Aetiology

### 2.5.1 Tobacco

The primary aetiological factors for HNC are tobacco and/or alcohol, with around 75% of cases being attributed to prolonged use of these substances (Hashibe et al. 2009). An estimated 65% (70% in males and 55% in females) of oral and pharyngeal cancers and 79% of laryngeal cancers in the UK are linked to tobacco smoking (Parkin 2011a). Tobacco is thought to result in a four to five-fold increase in risk of developing cancers of the oral cavity, oropharynx and hypopharynx (Hashibe et al. 2007). That rises to a ten-fold increased risk for developing laryngeal cancers (Vineis et al. 2004). The carcinogenic effect of tobacco is dose-dependent, with the risk of developing HNC closely related to the frequency, duration and intensity of cigarette smoking (Hashibe et al. 2007; Wyss et al. 2013). Results from a pooled analysis by Lubin et al. (2011) showed that oral cavity cancer risk in men is almost three times higher in those who have smoked the most cigarettes for the most years, compared with those who have smoked the least for the fewest years. The same study showed oral cavity cancer risk in women is more than four times higher in the heaviest and longest-smokers versus the lightest and shortest-smokers. Oropharyngeal cancer risk in men is almost twice as high in the heaviest and longest-smokers versus the lightest and shortest-smokers (Lubin et al. 2011). In women, the risk is more than three times higher in the heaviest and longest-smokers versus the lightest and shortest-smokers (Lubin et al. 2011).

Tobacco-associated laryngeal cancer risk may vary with specific site of cancer within the larynx, with a stronger association for supraglottic than glottic cancers (Muscat et al. 2012).

### 2.5.2 Smokeless tobacco

Smokeless tobacco, such as snuff or chewing tobacco, is also an important HNC risk factor, in particular for cancers of the oral cavity (Secretan et al. 2009).

Smokeless tobacco is classified by the International Agency for Research on Cancer (IARC) as a cause of oral cavity cancer (International Agency for Research on Cancer 2015). Betel quid with tobacco is classified by IARC as a cause of oral cavity and pharynx cancers, and betel quid without tobacco as a cause of oral cavity cancer (International Agency for Research on Cancer 2015).

There is an estimated 80% increase in risk of oral cavity cancer for individuals who have ever used smokeless tobacco (Boffetta et al. 2008; Lee and Hamling 2009), with a four-fold increase in odds of HNC among individuals who have used smokeless tobacco for at least ten years compared with never-users (Zhou et al. 2013). Although approximately 7% of oral cavity cancers in the United States are attributable to chewing tobacco, the attributable fraction is as high as 53% in India and 68% in Sudan, where the use of smokeless tobacco, including betel quid or areca nut with added tobacco, is popular (Boffetta et al. 2008).

Meta-analyses suggest that oropharyngeal cancer risk among South Asians (who comprise the majority of smokeless tobacco users globally) is between five and seven times higher in smokeless tobacco users versus non-users (Gupta and Johnson 2014; Khan et al. 2014). A meta-analysis by Wyss et al. (2016) suggests that gum and oral cavity cancer risk may be higher in never smokers who have ever used nasal snuff or chewing tobacco, compared with non-users.

### 2.5.3 Alcohol

Alcohol use independently increases the risk of HNC, with an estimated 1% to 4% of cases attributable to alcohol alone (Hashibe et al. 2007; Anantharaman et al. 2011), and a two-fold increase in odds of HNC for drinkers who have never used tobacco (Hashibe et al. 2007). In particular, alcohol use increases risk of hypopharyngeal cancer when compared with other sites (Rettig and D'Souza 2015). An estimated 30% (37% in males and 17% in females) of oral and pharyngeal cancers, and an estimated 25% (27% in males, 12% in females) of laryngeal cancers in the UK are linked to alcohol drinking (Parkin 2011b).

A meta-analysis by Bagnardi et al. (2015) showed that oral and pharyngeal cancer risk is 81% higher in people who consume between twelve and-a-half and fifty grams (one and-a-half to six units) of alcohol per day, and five times higher in those who consume fifty grams or more (six or more units) of alcohol per day, compared with non- or occasional drinkers. The same study showed that laryngeal cancer risk is 49% higher in people who consume between twelve and-a-half and fifty grams (one and-a-half to six units) of alcohol per day, and 2.4 times higher in those who consume fifty grams or more (six or more units) of alcohol per day, compared with non- or occasional drinkers. A meta-analysis by Turati et al. (2012) showed that oropharyngeal cancer risk is two and-a-half times higher in regular drinkers compared with non- and occasional drinkers.

Laryngeal cancer risk is not associated with drinking less than around 1.5 units of alcohol per day, but beyond this level, risk increases with higher alcohol intake (Islami et al. 2010; Bagnardi et al. 2015).

#### 2.5.4 Synergistic effect of tobacco and alcohol

While each substance is an independent risk factor for the development of HNC, combining them results in a multiplicative risk (Marur and Forastiere 2008). Estimates indicate that, compared with non-smokers/drinkers, users of tobacco and alcohol have between a thirty-five-fold (or greater) (Blot et al. 1988), to a fifty-fold (or greater) (Hashibe et al. 2007) increased risk of developing HNC. Oral and pharyngeal cancer risk is almost tripled in alcohol drinkers who currently smoke tobacco, while it is 32% higher in alcohol drinkers who do not currently smoke, both compared with never-drinkers (Hashibe et al. 2007). Oral cavity, oropharyngeal and hypopharyngeal cancer risk increases with amount of alcohol consumed among ever-smokers (Lubin et al. 2011), but among never-smokers the effect may be limited to oropharyngeal and hypopharyngeal cancer (Hashibe et al. 2007). Moreover, continued use of these substances beyond diagnosis increases treatment induced side-effects, risk of recurrence, and induction of additional primary malignancies (Dhooge et al. 1998).

#### 2.5.5 Human papilloma virus

More people without a significant alcohol or tobacco history are now being diagnosed at a younger age with oropharyngeal cancers due to the presence of HPV (Marur et al. 2010).

Over 120 types of HPV have been identified and fully sequenced thus far (Dufour et al. 2012). HPVs are small double-stranded DNA viruses with a specific tropism for squamous epithelia such as skin tissue as well as anogenital and oropharyngeal mucosa (Chen et al. 2005). While low-risk HPVs such as HPV-6 and 11 may lead to benign hyperproliferations of epithelial tissue such as warts, high-risk oncogenic types such as HPV-16 and 18 (and to a lesser extent 31, 33

and 35) are strongly linked with cervical cancer (Fakhry and Gillison 2006). The cellular transforming potential of HPV-16 and 18 is largely a result of two viral oncoproteins, E6 and E7, which functionally inactivate the tumour-suppressor proteins, p53 and pRb, respectively. Expression of high-risk HPV E6 and E7 results in cellular proliferation, loss of cell cycle regulation, impaired cellular differentiation, increased frequency of spontaneous and mutagen-induced mutations, and chromosomal instability (Münger and Howley 2002).

It was in 1907 that Dr Giuseppe Ciuffo demonstrated the infectious aetiology of the common wart (Chen et al. 2005). The carcinogenic potential of papilloma virus was first reported by Rous and Beard in 1934, but it was not until the 1970s that HPV was singled out to be the most likely causal factor of cervical cancer (Zur Hausen et al. 1974; Zur Hausen 1976). From 1983 to 1986, high risk HPV subtypes (16, 18, 31, and 33) were isolated from cervical cancer and its precursors (Dürst et al. 1983; Boshart et al. 1984; Beaudenon et al. 1986; Lorincz et al. 1987)). In 1995, the International Agency for Research on Cancer (IARC) concluded that sufficient evidence existed to categorise HPV subtypes 16 and 18 as human carcinogens (Herrero et al. 2003). During the 1980s several studies acknowledged a possible link between HPV and a subset of head and neck cancers (Syrjänen et al. 1982; Syrjänen et al. 1983; De Villiers et al. 1985; Löning et al. 1985). Since then evidence has continued to build.

In 2006 the American Food and Drug Administration approved the first vaccine against HPV (Markowitz et al. 2007). In 2009 the Food and Drug Administration subsequently licensed the quadrivalent HPV vaccine for use in boys and young men aged nine to twenty-six years (Pomfret et al. 2011). An HPV vaccination protecting against subtypes 16 and 18 was added to the UK childhood immunisation schedule in September 2008. The HPV vaccine is currently given to girls aged twelve to thirteen as a series of two injections within a six- to

twenty-four-month period. Girls who began their course of HPV vaccination before September 2014 receive three injections (Bowyer et al. 2013). From September 2012 the vaccine used in the UK was changed from Cervarix to Gardasil. Gardasil also protects against subtypes 6 and 11, which are responsible for approximately 90% of cases of genital warts (Hibbitts et al. 2014).

Although the vaccine was initially indicated for young women, HPV infection is highly prevalent in males, and according to Dietz and Nyberg (2011) is responsible for substantial disease in men, particularly men who have sex with men (MSM) (Palefsky 2007). Studies have suggested that the risk of developing anal cancer is seventeen times higher in gay or bisexual men than in heterosexual men (Weinstock et al. 2004; Palefsky 2007). A 2008 meta-analysis of the current literature found that HPV is associated with 85% of anal squamous cell carcinomas in men, 50% of penile cancers, and up to 72% of oropharyngeal cancers (Giuliano et al. 2008).

Infection by a high-risk subtype of HPV is known to be necessary for development of cervical cancer, although presence of HPV is not in itself enough to lead to cervical cancer. In contrast, HPV appears to play a part in only a subset of HNC, with most studies showing HPV+ve tumours are confined to the oropharynx. A number of studies using sensitive polymerase chain reaction (PCR) based methods to detect the presence of HPV have found that ≥ 50% of oropharyngeal tumours contained the HPV genome (Fakhry and Gillison 2006). Hobbs et al. (2006) suggest that inconsistencies in viral detection methods make comparisons between studies challenging.

### 2.5.6 Socioeconomic factors

People with a low socioeconomic status (SES) are not only more likely to be diagnosed with HNC, but they also tend to present with advanced disease and have considerably lower survival rates compared with people with higher socioeconomic status (Boing et al. 2011).

Indicators of low SES, such as low educational attainment and income, are strongly associated with increased risk of HNC globally. In a pooled analysis of 23,964 HNC cases and 31,954 controls across twenty-seven countries, the lowest socioeconomic stratum experienced more than a two-fold higher risk of HNC than the highest socioeconomic stratum (Conway et al. 2015). Although this risk was attenuated after adjustment for tobacco and alcohol use, which are associated with low SES (Cavelaars et al. 2000), approximately one-third of the risk associated with low SES remained unexplained by known risk behaviours. Even among never-users of tobacco and never-drinkers, individuals with low education had significantly increased risk of HNC (Conway et al. 2015). These associations vary by country, with greater effect of SES observed in South and Central America than in North America and Europe (Conway et al. 2015). Reasons for the increased risk of HNC associated with low SES are unclear, but may include occupational exposures (Menvielle et al. 2004; Boing et al. 2011), psychosocial variables, and other behavioural factors (Conway et al. 2015).

### 2.5.7 Other risk factors

The vast majority of HNC are caused by alcohol (65-79%), tobacco (25-30%) and HPV (8-14%) (Parkin 2011d). However, other factors have sufficient, convincing, limited or probable evidence to suggest a causal effect for HNC. Below is a table categorising certain factors and their effect on certain HNC. The scope of this

section does not allow in-depth exploration of all potential causes of HNC. Instead, a brief overview is provided of Epstein-Barr virus (EBV) due to its high prevalence among the general population (Jenson 2011), and wood dust and ionising radiation due to them being common occupational exposure risks for certain professions (Slack et al. 2012a).

	Increases risk	Decreases risk
'Sufficient' or 'Convincing' evidence	Alcoholic drinks (a,b,g) Betel quid with tobacco (a,b) Betel quid without tobacco (a) Human papillomavirus (HPV) type 16 (a,b,c) Tobacco smoking (a,b,g) Smokeless tobacco (a) X-radiation, gamma-radiation (d) Epstein-Barr virus (EBV) (e) Formaldehyde (e) Strong inorganic acid mists (g) Asbestos (g) Salted fish, Chinese-style (e,i) Wood dust (e)	
'Limited' or 'probable' evidence	HPV type 16 (g) HPV type 18 (a) Hydrochlorothiazide (f) Sulphur mustard (mustard gas) (g) Solar radiation (f) Radioiodines, including Iodine-131 (d) Asbestos (all forms) (b) Printing processes (b) Working in rubber production (g) Environmental tobacco smoke (b, g)	Non-starchy vegetables (h,j) Fruits (h,j) Foods containing carotenoids (g)

a Oral cavity; b Pharynx; c Tonsil; d Salivary gland; e Nasopharynx; f Lip; g Larynx; h WCRF/AICR classification is for mouth, pharynx and larynx; i IARC classifies evidence on Chinese-style salted fish as sufficient, WCRF/AICR classifies evidence on Cantonese-style salted fish as probable; j not salted or pickled

**Table 3 - Head and Neck Cancer Risk Factors Overview.**

**Adapted from Cancer Research UK (2017a)**

An estimated 10% of nasopharyngeal cancers in men in Great Britain, and around 2% in women, are linked to occupational exposure to wood dust (Slack et al. 2012b).

Older evidence from a pooled analysis (Demers et al. 1995) suggested that nasopharyngeal cancer death risk may be 2.4 times higher in furniture and plywood workers. However, more recent evidence suggests occupational exposure to wood dust may increase the risk of nasal cancer but not that of nasopharyngeal cancer (Siew et al. 2012).

An estimated 90% of nasopharyngeal cancer cases in the UK are EBV+ve (Parkin 2011c). However, it is thought that approximately 95% of the world's population sustains an asymptomatic, life-long infection with EBV. The oncogenic processes which involve EBV are poorly understood (Young and Dawson 2014).

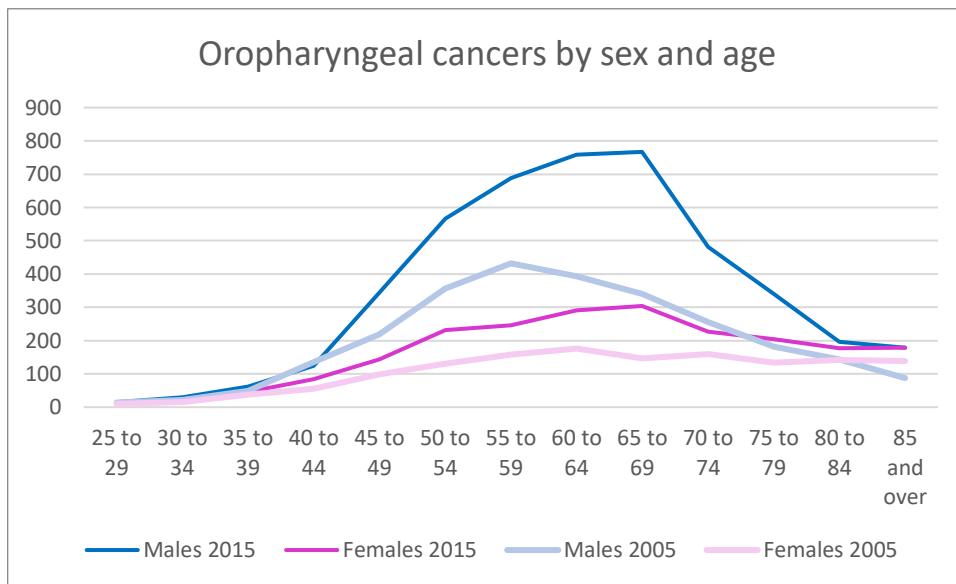
Cohort studies show that salivary gland cancer risk is higher in survivors of childhood cancer, Hodgkin's lymphoma, and thyroid cancer, compared with the general population. This is due to radiotherapy or radioactive iodine ablation to treat the primary tumour (Sandee et al. 2006; Boukheris et al. 2008; Iyer et al.

2011; Boukheris et al. 2013). Oropharyngeal cancer risk is also higher in atomic bomb survivors compared with the general population (Saku et al. 1997).

## 2.6 Epidemiology

### 2.6.1 Oropharyngeal cancer rates

Whereas the incidence of most HNC, including cancers of the larynx, is stable or decreasing in the UK, incidence levels of oropharyngeal cancer is continuing to increase (Cancer Research UK 2017b). As stated in the glossary, HNC will be the term used in this thesis for all non-site-specific forms of head and neck cancer (excluding brain malignancies). Where possible, the specific anatomical region will be specified. There were 7,680 new cases of oropharyngeal cancer in the UK in 2014, that's twenty-one cases diagnosed every day (Cancer Research UK 2017b). In 2014, oropharyngeal cancer accounted for 2% of all new cases in the UK (Cancer Research UK 2017b). For men in the UK, oropharyngeal cancer is the 11th most common cancer, with 5,124 cases diagnosed in 2014 (Cancer Research UK 2016b). For UK women, oropharyngeal cancer is the 16th most common cancer with 2,556 cases diagnosed in 2014 (Cancer Research UK 2016b). Since 1990, oropharyngeal cancer incidence rates have increased by over three quarters (84%) in the UK (Cancer Research UK 2016b). Although there are around double the number of cases in males (5,124 against 2,556), the increase was larger in females (87%), than in males (72%) (Cancer Research UK 2016b).



**Figure 4 - UK oropharyngeal cancer rates for men and women, 2005 vs 2015.**

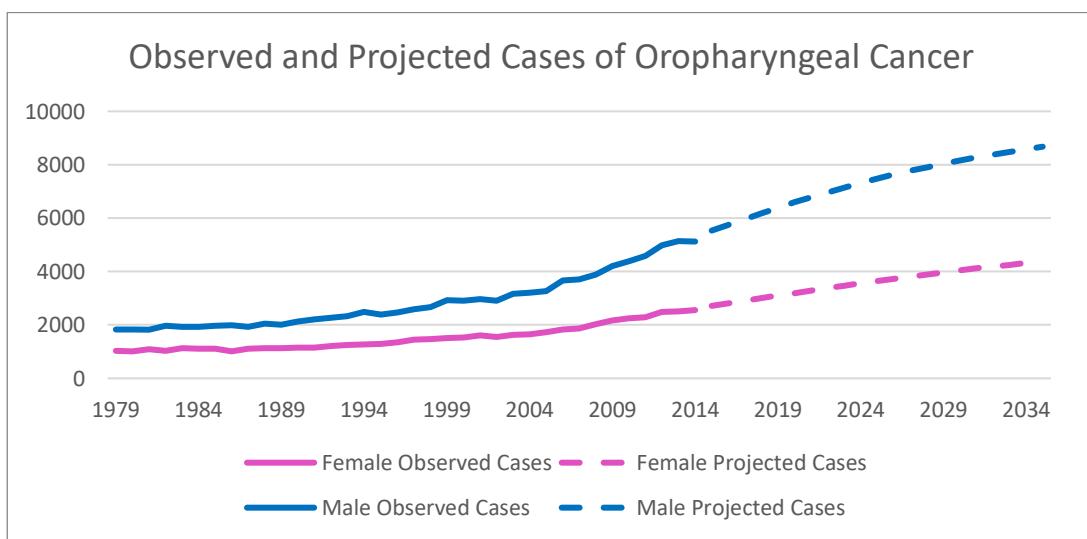
Data taken from The Office for National Statistics (2017).

Over the last decade in the UK, oropharyngeal cancer incidence rates have increased by over a third (39%), with a larger increase in females (39%) than in males (36%) (The Office for National Statistics 2017). Similar trends have been reported for the USA, Sweden and Greece, and several studies have attributed this increase in incidence to HPV infection (Kreimer et al. 2005; D'Souza et al. 2007; Romanian et al. 2008; Näsman et al. 2009). In Sweden, the incidence of tonsillar cancer (a subset of oropharyngeal cancer) almost doubled between 1970 and 2006 and the proportion of HPV+ve cases increased from 23% (1970-1979) to 79% (2000-2007) in the same time period. In 2006-2007, 93% of tonsillar cancers in Sweden were HPV+ve. However, the prevalence of HPV infection in oropharyngeal cancer varies widely between studies from 18% in a multinational study by the International Agency for Research on Cancer (Herrero et al. 2003) to 82% in an American study by Begum et al. (2005). This may in part be due to true geographical variations, but different HPV detection methods may also have influenced the prevalence rates reported by different

studies. The contribution of HPV to the development of oropharyngeal cancer in the UK is currently unclear (Evans and Powell 2010).

## 2.6.2 Predicted rise of cases of oropharyngeal cancer

Incidence rates for oropharyngeal cancer are projected to rise by 33% in the UK between 2014 and 2035 (Cancer Research UK 2017c).



**Figure 5 - Recorded and projected oropharyngeal cancer rates (UK).**

**Data taken from Cancer Research UK (2017c).**

One in seventy-five men and one in 150 women will be diagnosed with oropharyngeal cancer during their lifetime (Cancer Research UK 2016b). In 2015, over three quarters (79%) of males diagnosed with oropharyngeal cancer are aged between forty-five and seventy-five (Cancer Research UK 2017b). Women in the same age bracket account for two thirds (66%) of cases (Cancer Research UK 2017b). In 2015, 56% of oropharyngeal cancers in men were aged between thirty and sixty-four (Cancer Research UK 2017b). Women aged thirty

to sixty-four accounted for 49% of oropharyngeal cancer cases (Cancer Research UK 2017b).

Head and neck cancer in England is more common in people living in the most deprived areas (Cancer Research UK 2016b). Oropharyngeal cancer is more common in white males than in black or Asian males (Cancer Research UK 2016b).

In the UK, more than 38,600 people were still alive at the end of 2006, up to ten years after being diagnosed with head and neck cancer (Cancer Research UK 2016b). In Europe, around 61,400 new cases of lip and oropharyngeal cavity cancer were estimated to have been diagnosed in 2012 (Cancer Research UK 2016b). Worldwide, more than 300,000 new cases of lip and oropharyngeal cavity cancer were estimated to have been diagnosed in 2012, with incidence rates varying across the world (Cancer Research UK 2016b).

### 2.6.3 Conclusion

Dependent upon the primary cancer site, patients present with symptoms that may include dysphagia (difficulty swallowing), hoarseness, ear pain, enlarged cervical lymph nodes, nasal bleeding or blockage, and/or non-healing sores or ulcers in the mouth (Marur and Forastiere 2008). Given the importance one places on the appearance of the head and neck, coupled with the visibility of the disease and treatment sequelae, HNC is arguably the most psychologically traumatic cancer to experience (Björklund et al. 2010). This has led to an increasing focus in oncology research toward the assessment and consideration of (often subjective) patient-reported outcomes at all stages of treatment and recovery (Semple et al. 2008) as well as patient reported experience (PREMs) and patient reported outcomes (PROMs) (Black 2013).

The number of people being diagnosed with oropharyngeal cancer is predicted to increase for decades to come (Cancer Research UK 2017c). The average age at diagnosis of oropharyngeal cancer patients has declined, due mainly to the impact of HPV (Marur et al. 2010). Even now we are starting to see a younger, larger population of people living with the effects of HNC treatment. Treatment for oropharyngeal cancer can result in a number of short and long-term side effects. These can be both physical and emotional. In order to provide support for patients we need to first understand their experience and what is important to them.

Chapter three will provide an overview of the impact of HNC on peoples' lives. The following chapter will also detail how the literature review was conducted and highlight the gaps in the literature.



## Chapter Three - Literature review

### 3.1 Chapter introduction

The purpose of the literature review was to broadly sample the available HNC literature and to identify gaps which form the basis of the PhD study. The early stages of the review were started with as few preconceptions as possible. This chapter specifies the literature search and review process. It goes on to provide an overview of some of the important topics in HNC research. Finally, it highlights the gaps in the literature which are worthy of further study in this thesis.

### 3.2 Literature review method

The psychosocial impact of HPV in HNC is a largely under-researched area (Haisfield-Wolfe et al. 2009). In order to understand this impact, it was vital to develop a broad and thorough understanding of the existing literature in the field. However, there is a paucity of information or advice on how to conduct a thorough literature search in areas where little is written (Boote and Beile 2005). Following published advice (Feeak and Swales 2009; Aveyard 2010; Fink 2010) resulted in a large number of irrelevant results being returned, while relevant literature found through other methods (such as snowballing) was not returned by this searching approach. After discussing the problem with academic supervisors, it was decided that the best method of identifying pertinent literature would be to conduct three separate literature searches, each looking at a different aspect of the subject. This method has limitations, as it resulted in a large number of returned articles. For example, searching for literature on HPV yields a great deal of experimental biomedical research, which would not be applicable to this kind of study. Also, the volume of literature generated may increase the risk of relevant literature being overlooked. While this is less of an issue with multiple-researcher studies due to cross-researcher

scrutiny, a single-researcher study such as this does need to be mindful of such pitfalls. However, the method was deemed successful as subsequent examination of non-systematic sources (Google Scholar) and grey literature (Greylit, ProQuest) did not yield any additional relevant articles.

### 3.3 Reflections on the literature search process

As with many PhD studies, the initial proposal differed from the final study (Petre and Rugg 2010). What had started out as an exploration of spousal dyads in the context of HNC evolved into the study presented in this thesis. The focus of the study was not prescriptive, so as recommended by academic supervisors the first weeks of the study were spent immersing myself in the literature surrounding HNC. This was a non-systematic approach and purposefully included a great deal of freedom. In retrospect, this freedom may have caused some difficulty in returning to a more systematic method of literature searching once the topic was more defined. For instance, a lack of discipline in accurately recording all search terms and databases meant some work had to be repeated at a later date. Also, there was some difficulty in generating search terms that would provide a manageable number of returned articles across different databases. Literature searching workshops were organised by the School of Healthcare Sciences and by the university library services, which helped to refine the search terms used in the final literature searches (see Appendix B entitled Literature review tables of results and study summaries for a full list of search terms and databases used).

One strength of this study is that the literature searches did yield a large number of results. While this caused a great deal of work in evaluating them, other non-systematic methods unearthed no additional results. This suggests

that the process used was robust enough to encompass most, if not all, of the relevant literature.

### 3.4 Literature review update prior to submission

The literature searches were re-run prior to writing up the final version preceding submission of the thesis. There was consideration given as to how to best incorporate these new results into chapter three. The original literature review and analysis is representative of where I was, both intellectually and practically, at the start of the PhD studentship. Both Petre and Rugg (2010) and Phillips and Pugh (2010) suggest that a PhD is a developmental journey which should be reflected in the final thesis. To re-write the chapter would be to re-write history and would not reflect that developmental journey. The other option also considered was to add a separate update section to the chapter, thereby pooling all of the updated literature together. However, this would make it difficult to link the updated literature to what had been critiqued previously. After discussions with my academic supervisors, it was decided not to have a separate update section within the literature review. Instead, updated literature and analysis was woven into the existing review. While this change to a more developed and experienced critiquing style may result in a somewhat disjointed narrative, it is consistent with IPA's philosophy of demonstrating the development and growth of the researcher (Smith 2015).

### 3.5 Research questions, search strategies and findings

Figures in brackets are the number of results returned during pre-submission update; 2013-2017.

### 3.5.1 Search Strategy 1 and Results

<b>Research question:</b>	What is known about the experience of cancer survivorship?			
<b>Search Strategy 1 and Results</b>				
<ul style="list-style-type: none"> <li>• Neoplasm or malignan* or cancer (keyword)</li> <li>• Experien* or psychosoc* or psycho-social or psycho social or adjust* or adaptat* (keyword)</li> <li>• Survivorship (Title)</li> </ul>				
Limited to 2003-2013, English language only.				
<b>Database</b>	<b>No of returned results</b>	<b>No of articles selected</b>		
Ebsco - CINAHL	200 (233)	35 (6)		
Ovid - PsycINFO	88 (60)	34 (12)		
Ovid - Medline	185 (90)	26 (16)		
Ovid - Embase	307 (308)	32 (23)		
Ovid - PsycArticles	2 (2)	1 (1)		
<b>Total</b>	<b>782 (693)</b>	<b>128 (58)</b>		
<b>Total number of selected articles after removal of duplicates</b>	<b>88 (42)</b>			
<b>Total number of selected articles after analysis and review</b>	<b>18 (14)</b>			

### 3.5.2 Search Strategy 2 and Results

<b>Research question:</b>	What is known about the experience of head and neck cancer patients?			
<b>Search Strategy 2 and Results</b>				
<ul style="list-style-type: none"> <li>• Neoplasm or malignan* or cancer (keyword)</li> <li>• Experien* or psychosoc* or psycho-social or psycho social or adjust* or adaptat* (keyword)</li> <li>• Laryn* or pharyn* or oropharyn* or nasopharyn* or laryngopharyn* or hypopharyn* or oral or maxiofacial or glotti* or head and neck (keyword)</li> </ul>				
Limited to 2003-2013, English language only.				
<b>Database</b>	<b>No of returned results</b>	<b>No of articles selected</b>		
Ebsco - CINAHL	327 (456)	17 (15)		
Ovid - PsycINFO	34 (26)	3 (5)		
Ovid - Medline	181 (438)	29 (24)		
Ovid - Embase	268 (1180)	36 (13)		
Ovid - PsycArticles	26 (2)	1 (2)		
Ovid CU full text journals	256 (55)	5 (2)		
Scopus	80 (15)	13 (3)		
Web of Knowledge (Web of Science)	310 (1276)	19 (32)		
<b>Total</b>	<b>1482 (3448)</b>	<b>123 (96)</b>		
<b>Total number of selected articles after removal of duplicates</b>	<b>49 (42)</b>			

<b>Total number of selected articles after analysis and review</b>	<b>35 (21)</b>
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### 3.5.3 Search Strategy 3 and Results

<b>Research question:</b>	What is known about HPV in head and neck cancer?			
<b>Search Strategy Three and Results</b>				
<ul style="list-style-type: none"> <li>• Neoplasm or malignan* or cancer (keyword)</li> <li>• HPV or human papillomavirus or Human papilloma virus (Title)</li> <li>• Laryn* or pharyn* or oropharyn* or nasopharyn* or laryngopharyn* or hypopharyn* or oral or maxiofacial or glotti* or head and neck (Title)</li> <li>• (Excluding) Randomised or randomized or in-vitro or mice or mouse or expression or immun* (Title)</li> </ul>				
Limited to 2003-2013, English language only.				
<b>Database</b>	<b>No of returned results</b>	<b>No of articles selected</b>		
Ebsco - CINAHL	189 (287)	40 (13)		
Ovid - Medline	209 (134)	45 (12)		
Ovid - Embase	342 (338)	78 (15)		
<b>Total</b>	<b>740 (759)</b>	<b>163 (40)</b>		
<b>Total number of selected articles after removal of duplicates</b>	<b>109 (30)</b>			

<b>Total number of selected articles after analysis and review</b>	<b>27 (9)</b>
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### 3.5.4 Grey literature search strategies

The article by Mahood et al. (2014) strongly influenced the process of searching for, and including grey literature in the review. It would be difficult, if not impossible, to prescribe a method for searching grey literature which is sufficiently robust and reproducible enough to match systematic review standards (Mahood et al. 2014). As noted by Bates (2011), Google filters its results based on browser version, geographic location, and previously entered search strings. A search for “cancer experience” in Google.com will yield around 259,000,000 results (carried out 8/7/17). The same search in Google Scholar will yield around 3,280,000 results (carried out 8/7/17). Given the possible permutations of search terms and search engines, there will always be inherent limitations to any grey literature search. A subject specialist librarian from Cardiff University was consulted when creating the grey literature search strategy.

The same search terms were used when searching for grey literature as were used for other databases. The number of returned and selected articles was not recorded in the same way, but the results were cross-referenced with the studies already selected to see if any were duplicated or should be included. Search strings were adapted based on the particular search engine. E.g. search strategy 1 in Google Scholar was:

Neoplasm OR malignan\* OR cancer AND experien\* OR psychosoc\*  
OR psycho-social OR psycho social OR adjust\* OR adaptat\* AND  
intitle: survivorship.

Date range 2003 to present.

Returned results were often far fewer than more systematic databases but based on advice from university librarians it was deemed important to use the same search terms throughout.

### 3.6 Validation of the search strategy

Following feedback from examiners, a subject specialist librarian from Cardiff University was approached to test the validity of the search strategy and suggest any amendments to the search terms used. His revised search terms were as follows:

Head and neck cancer	HPV	Survivorship
(carcinoma* or adenocarcinoma* or tumor* or tumour* or submucosa* or cancer* or squamous cell carcinoma or neoplasm*) N3 (Esophag* or upper gastrointestinal tract or “upper GI” or upper digestive tract or Oesophag* or aerodigestive or laryn* or pharyn* or oropharyn* or nasopharynx* or laryngopharyn* or hypopharyn* or oral or throat or maxillofacial* or glotti or epiglott* or “head and neck” or nasal or paranasal)	Papillomaviruses (MeSH Heading)	Cancer survivors (MeSH Heading)
Head and neck neoplasms (MeSH)	HPV	Surviv*
HNC	Human papillomavirus*	Remission

	Papillomavirus*	Quality of life (MeSH Heading)
	Human papilloma virus*	Experience*
	Papillomavirus infections (MeSH)	Side effects
		Adverse effects

The subject specialist librarian re-ran the original search terms as listed in section 3.5 (starting on page 34) and examined the returned results. He then ran searches of the same databases using his search terms and compared the results. He recommended adding four studies, all of which were published after the initial searches were carried out, but before the update was conducted. These studies were subsequently added to the literature table (Appendix B) and incorporated into the literature review chapter.

### 3.7 Critical appraisal of the literature

The decision to conduct multiple literature searches within one review has led to a rich and plentiful source of information about the experience of head and neck cancer patients and HPV. However, the diverse topics and methodological approaches made synthesising the findings in a systematic way problematic.

Attempts were made to use Noblit and Hare's meta-ethnography (1988) and Paterson and Canam's meta-study approach (2001). Meta-ethnography is based on a seven-stage process: getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related,

translating the studies into one another, synthesising translations and expressing the synthesis. Noblit and Hare (1988) suggest that ethnographies themselves are interpretative acts. They propose that by translating metaphors and key concepts between ethnographic studies, it is possible to develop a broader interpretative synthesis. Meta-ethnography has been shown to be useful when critiquing small groups of papers (Britten et al. 2002; Campbell et al. 2003), but can become unworkable when dealing with non-ethnographic studies. Meta-study aims to look beyond individual findings, critically interpret variations and contradictions in the available research, and move towards knowledge synthesis. Paterson and Canam (2001) refer to this process of synthesis from multiple studies as “many individual pieces of the jigsaw puzzle” (p.4). While not universally suitable due to the wide variation in subject matter and methodological styles in the returned literature searches (Thorne et al. 2004; Bondas and Hall 2007), meta-study was chosen as the basis for literature analysis within this study.

The year 2003 was chosen as the starting point for the literature search as the search was initially conducted in 2013. Ten years was chosen as the cut-off for primary sources as this figure was often cited as a sensible cut-off for newer literature (Cronin et al. 2008). Older literature found through snowballing was included when deemed relevant.

Barbour (2001) suggests that due to the vast diversity of research methods employed in qualitative research, there is no one critical appraisal tool that would be suitable for all studies. All articles were assessed using the basic principles of the Critical Appraisal Skills Programme (CASP) checklist (CASP 2013). The CASP tool is considered to be one of the most accessible and commonly used critical appraisal tools in systematic reviews (Higgins et al. 2010). CASP approaches all research with three questions:

### **1. Is the study valid?**

The first step is to decide whether the study was unbiased by evaluating its methodological quality. Different criteria for validity of articles are used for different types of questions on: treatment, diagnosis, prognosis and economic evaluation. Depending on the validity of an article we can classify it within a scale of levels of evidence and degrees of recommendation.

### **2. What are the results?**

If we decide that the study is valid, we can go on to look at the results. At this step we consider whether the study's results are clinically important. For example, did the experimental group show a significantly better outcome compared with the control group? We also consider how much uncertainty there is about the results, as expressed in the form of p values, confidence intervals and sensitivity analysis.

### **3. Are the results useful?**

Once you have decided that your evidence is valid and important, you need to think about how it applies to your question. It is likely, for example, that your patient or population may have different characteristics to those in the study. Critical appraisal skills provide a framework within which to consider these issues in an explicit, transparent way.

(Adapted from CASP, 2017)

While all three questions may be viewed as subjective, keeping these questions in mind helped to add rigour to this literature review. There are eight CASP checklists. Each one is designed to address a particular type of research or methodology and are freely available to download (<http://www.casp->

[uk.net/casp-tools-checklists](http://uk.net/casp-tools-checklists)). See Appendix A for an example of the qualitative study CASP checklist.

The three searches focused on non-specific cancer survivorship, head and neck cancer specific survivorship, and HPV in head and neck cancer. The three searches were then brought together for the analysis.

The first literature search examining non-specific cancer survivorship was not conducted in a systematic way, as the subject area was deemed too broad to accurately incorporate all the relevant literature. Instead the aim was to build a thematic framework which would inform the two more specific literature searches. The remaining two literature searches were conducted following the same procedure as the first search, using the same methods and databases. Keywords were generated through background reading and refined over multiple drafts. Databases were selected based on relevance to the field and number of relevant articles returned in preliminary searches. Search strategies and databases used are detailed in Appendix A. Search strategies were saved in each of the databases used, and email alerts were added to keep up-to-date with newly published work.

While only two sources of grey literature have been included in the literature review, other sources of grey literature were used to develop the search strategy and areas of focus. The majority of the grey literature and blogs available online focus on the period between diagnosis and the end of active treatment. The main topics of conversation in such blogs tend to be side-effect related and do not focus on less quantifiable issues such as emotional and social wellbeing.

Other non-systematic sources of literature (Google Scholar and FreeFullPDF) were also searched once systematic searches were completed. However, in all instances these sources were not able to generate any new literature. Searches with the parameters detailed in section 3.5 were run in full in 2013 and again in 2016 and 2017.

Searches were completed on each database and articles were selected based on a brief examination of the abstract. Once all searches had been completed, results were entered into EndNote reference manager and cross referenced to remove duplicates. The remaining articles were then retrieved in full and examined in more detail to assess relevance, reliability and validity. The assessment of articles was done by myself. The assessment of each article was based around the CASP checklists and the evaluation tool created by Long and Godfrey (2004) (see Appendix A).

Snowballing was used to provide background information and inform the discussion.

### 3.8 Search strategy 1 - “What is known about the experience of cancer survivorship?”

#### 3.8.1 Survivorship in cancer research

Cancer survivorship research has seen a huge increase in output in recent years. To illustrate this, a search of Ebsco - CINAHL (accessed 12/1/18) for “cancer survivorship, 1987 (the earliest year retrievable) to 2007” returned 306 results. The same search from 2007 to present returned 2,195 results. In a seminal text, Dr Fitzhugh Mullan identified what he called the *seasons* of cancer survivorship: acute survivorship, extended survivorship, uncertainty and transition, and permanent survivorship (Mullan 1985). In 2005 “From Cancer Patient to Cancer

Survivor: Lost in Transition,” stated “psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitation in mobility, communication, and cognition are among the problems faced by some cancer patients.” (Hewitt et al. 2005, p.2) This is confirmed by Rowland et al. (2006) and Alfano and Rowland (2006), who suggest that a variety of difficulties (including fatigue, cognitive changes, sexual health and functioning, fear of recurrence, socioeconomic issues, distress, anxiety, and depression) may be experienced by the cancer survivor. Aziz and Rowland (2003) state that many cancer survivors are at risk of developing physiological and psychosocial late and long-term effects due to the cancer diagnosis and treatment. In 2013 Macmillan estimated that at least 500,000 people in the UK are facing poor health or disability after treatment for cancer. These figures are still being used in literature such as their statistics fact sheet published in March 2017. This equates to approximately 20% of those who have been diagnosed with cancer at some point in their lives. Around 350,000 are experiencing sexual difficulties, and approximately 240,000 are living with mental health problems. This can include moderate to severe anxiety or depression, and post-traumatic stress disorder (PTSD) (Macmillan 2013).

The term survivorship has a number of definitions and is not confined to the sphere of cancer. Peck (2008) points to existing definitions which suggest a survivor is someone who has survived a potentially life-threatening event; which may also include victims of natural disasters. However, some have suggested that the term may also be applicable for those who have experienced a life-altering event, which could apply to friends or relatives of cancer patients. However, Peck states that “Although a survivor has (...) become adapted to the new life circumstances, he or she continues to feel vulnerable to the past experience” (p.100). This theme of vulnerability permeates the survivorship literature, but can lead to a stagnation of development and personal growth.

Astrow (2012) suggests that simply by identifying oneself as a survivor, the person may be denying themselves the opportunity to forget the illness and emotional baggage that may still be attached to the memory of their experience.

### 3.8.2 Definitions in survivorship

Evidence from a literature review conducted by Aspinwall and MacNamara (2005) supports the commonly held belief that positivity among cancer survivors improves outcome and adaptation. However, they point to the belief in some medical staff that positivity among cancer patients may be an avoidance tactic and can indicate poor adjustment. The review has the limitation often shared by studies which examine poorly defined concepts, in that comparisons or conclusions are only as valid as the initial definition. This is a point raised by Bell and Ristovski-Slijepcevic (2013) and Doyle (2008) which suggests we can only hope to properly study constructs such as survivorship with clear and commonly accepted definitions. According to the US-based National Comprehensive Cancer Network, "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life" (Denlinger et al. 2014, p. 37). For the basis of this study, the Macmillan definition of survivorship will be used. Survivorship is therefore defined as "living with or beyond cancer" (2016), so from the point of diagnosis and for the rest of their lives.

The use of terms such as *fighting spirit* (p. 283) have recently been brought into question by authors including Ellis et al. (2015). They suggest that by using combative terms (fight, battle, win, lose), there is a danger of applying a negative value to those who do not recover from their cancer. The implications for practice are complex. If a patient does not show the perceived correct

amount of fighting spirit, should a psychological intervention be given to change their state of mind? There is also the possibility that if someone is perceived as not having fighting spirit, medical staff may disengage from them and give them a different level of care in comparison to a *fighter*.

In an overview summary of psychosocial and behavioural issues in cancer (non-site-specific) survivorship, Aaronson et al. (2014) identified four common themes important for future research. Firstly, that symptoms should not be viewed in isolation as symptom burden may have a cumulative effect on the patients' wellbeing. For HNC patients these could include swallowing, taste, low mood and returning to work (Ganzer et al. 2012; Isaksson et al. 2016b). Secondly, that psychosocial interventions should be evidence-based and where possible, individually tailored. Unfortunately, the authors do not offer any insight into the problem of identifying those patients who may benefit from psychosocial interventions or how to go about tailoring them. Thirdly, that interventions and their delivery should be a greater priority for health providers and decision makers. Finally, that more attention should be given to supporting vulnerable and high-risk populations of survivors. The authors suggest that the elderly and those who are socioeconomically disadvantaged may be at particular risk of psychosocial harm, such as isolation and depression, due to cancer treatment. However, the authors do not provide any quantitative data to support their claims about the increased risk to socioeconomically disadvantaged or elderly patients. Instead, they recommend that more work is needed in this area.

### 3.8.3 Identity in survivorship

Entwined with self-image, but distinct from it, is the concept of identity (Owens 2006). "Identities are the traits and characteristics, social relations, roles, and

social group memberships that define who one is (...) people also know themselves in other ways: They have self-images and self-feelings, as well as images drawn from the other senses - a sense of what they sound like, what they feel like tactically" (Leary and Tangney 2011, p. 69). In a study of thirty-five cancer patients and twenty-five partners, Miller (2015) suggests that cancer patients are put on a trajectory of changing identity by their diagnosis. She describes these identities broadly as the old (pre-cancer) identity, the patient (during treatment) identity, and the new (post-cancer) identity. While the study confirms other findings of altered identity, Miller goes on to describe the importance of identity-related conversations with friends, relatives and colleagues in assimilating each new identity. Inferred, but not discussed, is the potential threat to successful adoption of the altered identity should a cancer patient be unable to talk freely and openly for any reason with those around them. The study lacks focus regarding the sample population (thirteen breast, four colon, three prostate, two lymphoma, two cervical, two thyroid, two HNC, one lung, one bone marrow, one testicular, one ovarian, one kidney, one melanoma, and one vulva cancer). It could be argued that the experience, including diagnosis, prognosis, and recovery, of a HNC patient could bear little or no relation to that of a melanoma or kidney cancer patient. Factors such as acute and long-term side effects, and treatment modalities would be very different depending on the particular malignancy.

### 3.8.4 Survivorship and family

In an American cross-sectional study, Bowman et al. (2006) suggest that on average, family members view the cancer experience as more stressful and traumatic than their surviving relatives. The authors suggest that better information for relatives and more inclusion in the decision-making process may

make the experience less stressful, but they fail to address issues surrounding data protection and confidentiality.

### 3.8.5 Employment (all cancer patients)

Due to the relatively few cases of HNC when compared to other sites, more overarching themes within oncology research such as employment often include patients with a variety of diagnoses. In a telephone based American study of 1,433 cancer patients who were one to three years post-diagnosis, Short et al. (2005) found that 13% of all participants had reportedly given up working due to the cancer or its side effects within four years of diagnosis. Survivors of central nervous system, head and neck, and blood and lymphatic malignancies had the highest adjusted risk of disability or giving up work. However, given the social and welfare differences between the USA and the United Kingdom, these findings may not translate to a UK context.

A study by Grunfeld et al. (2010) examined the differing views on cancer (non-site-specific) and employment between patients (n=194, response rate 82%) and employers (n=252, response rate 31%), and found employers consistently reported more negative beliefs about the impact of cancer and treatment on work than patients. However, the study is limited both in design and by results. Patients were surveyed just four weeks after completing treatment which may not be enough time to recover from short-term treatment induced side effects and assess their longer-term capabilities. Secondly, a point recognised by the authors is that the study did not examine the beliefs of the employers of the cancer survivors included in the study and therefore pairwise comparisons were not possible. Also, employers' responses were only from medium and large organisations, with the majority of responses coming from large (1,000+ employees) organisations. Therefore, the study lacks representation from

smaller employers and does not address the challenges faced by patients who are self-employed.

In a study conducted for a UK based cancer charity, Pryce et al. (2007) administered a thirty-three-item questionnaire to 328 non-site-specific cancer survivors. Respondents were predominantly female (76.5%) and the respondents ranged from eighteen to sixty-eight years in age (average 50.37 years, standard deviation (SD)=10.08). Of the sample, 30% continued to work during their treatment and 42.3% of the sample returned to work following their treatment. Items measured in a patient's experience of returning to work included difficulties managing fatigue, managing the stress of cancer, managing physical changes associated with cancer, received advice from their doctor about work and return to work meeting with employer. The authors suggest that opportunities to work flexibly, disclosure to, and support from colleagues, difficulties managing fatigue, and paid time off to attend all medical appointments were associated with continuing to work during treatment. Items which may affect or influence a person's ability to return to work included difficulties managing fatigue, managing the stress of cancer, managing physical changes associated with cancer, received advice from their doctor about work and return to work meeting with employer. However, with the highest number of respondents identifying themselves as previously treated for breast cancer, the results may not be representative of other cancers such as HNC.

### 3.8.6 Gender bias in research

Some authors have raised concern about possible gender bias in cancer research, including insufficient inclusion of women or men, or studying women and men differently (Hoyt and Rubin (2012). Expecting to find women disproportionately represented in psychosocial cancer research, Hoyt and Rubin

(2012) suggest that gender disparities are less common in psychosocial research than previously suggested, showing a marked increase in male representation compared to previous years. Using only studies published in *Cancer* in 2007, their literature review showed representation of men increased to 47.9% (vs 30.4% [1983] and 29.9% [1992]). The proportion of men in studies of feelings/relationships increased to 47% (vs 22.9% in 1992); the proportion of women in studies assessing physical/functional ability increased to 58.3% (vs 45.4%). However, Meyerowitz and Hart (1995) highlight the danger of publication bias when data is gathered from a single journal.

### 3.8.7 Survivorship care plans

Survivorship care plans (SCPs) are an attempt to standardise long term care and also gain consensus on the best approach for a particular patient population. A systematic review and appraisal of the current literature conducted by Keesing et al. (2015) showed that, among other things, there was a lack of consensus on the format, content and who should develop the SCP, that cancer survivors do not consistently receive SCPs, and there was a lack of evidence to support the use of SCPs in practice. Given the breadth of variation in need and preference of intervention, it is little wonder that there is such a paucity of consensus as to the way forward of SCPs. What is most concerning is that given the potential lack of ongoing support for HNC patients (Wells et al. 2015), there is currently so little evidence to support the use of SCPs in practice. The ENHANCES study (Enhancing Head and Neck Cancer patients' Experiences of Survivorship) (Turner et al. 2014; Turner 2015), among others, will hopefully add to the debate on the design and implementation of SCPs.

### 3.9 Search strategy 2 – “What is known about the experience of head and neck cancer patients?”

#### 3.9.1 Impact of cancer and its treatment

There are a number of articles which, either through experimental design or literature review, identify themes among HNC patients which help to shape and inform future research. In a thematic analysis of semi-structured interviews conducted with ten HNC patients (six to twelve months post-treatment), Semple et al. (2008) tried to uncover areas or topics of importance for this patient group. Thematic analysis identified seven broad themes, five of which included areas of changes and challenges to participants' lifestyles post-treatment. These were physical changes, concerns about cancer, work and day-to-day tasks, interpersonal relationships and social functioning. The other two themes were personal attributes that facilitated and inhibited coping post-treatment and specific information needs relating to the post-treatment period. With regard to social functioning, the authors suggest that engaging in early exposure to social settings following treatment may improve self-confidence and, over time, lead to limited or no change in existing social patterns. Other notable strategies which helped in social situations was the use of fighting spirit, social support and openness with friends, active planning on how best to manage certain situations and, where possible, immediate reintegration in usual social activities after treatment. Factors that inhibited social functioning were mainly physical, such as modification in eating patterns, drooling, changes in speech, altered appearance, fatigue and shoulder dysfunction. When asked about concerns about their cancer, the majority of participants reported that they were living with uncertainty and fear of recurrence, and they were using a wide range of strategies to facilitate coping. Some looked for signs of progress, such as weight gain, as a sign that they were "free from cancer" (p.89). Others offered religious belief, fighting spirit, positive focus and professional support as helpful coping mechanisms. Concerns about cancer were often heightened prior

to follow-up appointments. While most participants reported positive changes or no change to interpersonal relationships, some reported less intimacy post-treatment. The authors do not explore these changes in intimacy in any depth, nor do they specify the number of participants affected. As well as informing future research, the authors hope it may also allow healthcare professionals to take a more holistic approach in caring for their patients, especially with regard to the post-treatment phase of survivorship. While the authors acknowledge the small sample size as a limitation of the study, it potentially gives the participants freedom to discuss topics which are of importance to them. Another limitation not acknowledged by the authors is the lack of patients treated with chemotherapy. A common treatment modality for HNC, chemotherapy could alter the experience of these patients in subtle or significant ways, and which is subsequently missing from the data.

Howren et al. (2012) suggest that due to the variety of subjective feelings HNC patients may experience in response to their illness, treatment, and subsequent long-term side effects, an expansion of the multi-disciplinary team may be required. This may include the addition of psychologists, psychiatrists and specialists in behavioural medicine. However, with the increasing recognition of survivorship research over recent years, HNC has played a limited part. An early overview by Anderson and Franke (2002) highlights many issues familiar in more recent research but recognises that a paucity of literature examining the psychosocial needs of HNC patients limits any conclusions or recommendations. Similarly, in a systematic literature review of forty-three primary research studies examining the psychosocial implications of long-term survival (five years or more) following a cancer diagnosis by Foster et al. (2009), only two focused on HNC. In the two studies that Foster identified (Bjordal and Kaasa 1995; Bjordal et al. 1995), several themes emerged. In the study by Bjordal et al. (1995), 9% of HNC survivors were dissatisfied with life and physical health

compared to 2% of control participants. In addition, 26% of survivors described themselves as worn out compared with 12% of control participants. In a study of the long term wellbeing of HNC patients (seven to eleven years post-treatment) 31% reported suffering from psychological distress (Bjordal and Kaasa 1995). These patients had completed their follow-up period and were receiving no further psychological support. Those with lower physical, social or cognitive function or higher pain fatigue or sickness also reported higher levels of psychological distress. Given the paucity of evidence around the long-term experiences of HNC patients, such studies are rare and give an insight into the patient experience at that time. However, any findings from older studies must be viewed in context. Radiotherapy equipment and technique has changed enormously in the past three decades. Conformal radiotherapy plans and advances such as parotid gland sparing may significantly change the long-term experience of this patient group. Also, there were significant differences in smoking status between HNC patients and control patients in both of these studies.

In a qualitative study of thirty-nine HNC patients who were between two and twenty-four months post-treatment at the time of interview, Swore Fletcher et al. (2012) suggest that while HNC patients face significant challenges post-treatment, the experience can also serve to allow time for reflection which may serve as a catalyst for deeper personal change. This study does not clarify whether the participants are describing their world at the time of interview or at some point during or post-treatment. Regardless, the impact of the “storm of symptoms” (p.128) HNC patients commonly face indicates that adaptation and subsequent challenges surrounding isolation, integration, and communication may be long-lasting and require more support than is currently available. The authors acknowledge the study’s limitations primarily due to a lack of ethnic and socioeconomic diversity in the sample population. However, the results

suggest there may be a positive aspect to experiencing such a traumatic life event. In critiquing this study, it is possible that the results may also be influenced by the process of participating in an interview-based study, which may itself be the cause of the observed self-reflection.

A Taiwanese study by Cheng et al. (2013) offers a rare phenomenological insight into the burgeoning middle-aged male oropharyngeal cancer experience.

Despite the cultural differences, the study discusses several themes which may be common to UK populations. The study's aim was to explore the *essence* of the cancer experience of nine men (aged forty-seven to sixty-four) who were previously treated surgically for oral cancer up to and including one year prior to interview. Specific sites of oral cancer were not specified. However, given the difficulty in isolating the exact location of the primary tumour, as well as the similar treatment-induced side effects between sites, the lack of differentiation does not impact the findings of the study. Using Colaizzi's phenomenological analysis, the in-depth interviews generated the following themes: the psychological journey in facing oropharyngeal cancer, the question of how patients can control their disease as well as the sequelae of cancer treatment, the continuous disturbance and turmoil resulting from the disease, the appreciation of the support from family and friends, and the ability to learn to actively face the future. Change and uncertainty are common factors to much of the experience of these cancer patients. The authors suggest that HNC patients' care should be holistic and multidimensional and should actively include medical staff and family members in the design and implementation of any ongoing supportive plans. They also suggest that while each patient's care plan should be individualised, medical professionals should develop a series of core plans which could then be refined with accumulating evidence-based knowledge.

Cheng et al. (2013) also point to cultural gender stereotypes ("in many cultures, men are expected to be strong and brave and to not admit to being beaten or weak. This expectation makes men reluctant to express their feelings or to ask for help when frustrated or upset"(p.3550)) to support the use of phenomenology in deciphering and explaining the essence of their cancer experience. They suggest that the experience of cancer for these men may be hidden, perhaps even from themselves, because of how they think they should respond to the illness. The authors also acknowledge that awareness of the perceived cause of the disease may have an impact on the experience of the cancer patient. With the chewing of betel nut/quid a major cause of oropharyngeal cancer in Taiwan, there may be less stigma attached to the disease compared to populations such as the UK where HPV is an increasingly prevalent causal factor. The authors also acknowledge the inherent challenges in translating findings from one language (Mandarin) to another (English). The authors used professional translation services which were checked to ensure the "translation was meaning-based rather than word-for-word" (p. 3552), thereby preserving local metaphors and the nuances of the native language. Inclusion of non-English speakers in a single-person study such as this PhD raises multiple questions regarding the validity of the data, regardless of cost implications.

In a recent Swedish study, Isaksson et al. (2016a) looked at the lived experience of HNC patients post diagnosis. The participants (n=56) were interviewed at six, twelve, and twenty-four months post diagnosis. The authors were able to categorise the participants into four distinct groups. The first group (n=15) viewed their illness experience as a past life experience, suggesting that they had psychologically left the illness behind. In the second group (n=9), the impact of the disease seemed to be mitigated by other life experiences and challenges. However, the patients in the second group were, to some extent, still hampered

by the treatment induced side effects. The third group (n=12) showed that while the cancer continued to impact on their lives, positive and negative aspects of the experience seemed to reflect a balance between such effects. In the largest of the four groups (n=20), there were ongoing physical and/or psychological problems which had changed the patients' lives for the worse. The authors do give details of the sub-site of HNC treated, which reduces the total number of participants with oropharyngeal cancer to twenty-four. Of those twenty-four, group one had seven participants, group two had five, group three had four, and group four was left with eight participants. The inclusion of patients diagnosed with cancer of the larynx may have been a mistake, given the potential long-term impact to speech which may not be as prevalent in other tumour sites.

In an Australian study of twenty-four radiotherapy patients (up to five years post-treatment), Nund et al. (2014) highlight the importance of ongoing support from health professionals, and in particular, speech and language therapists, in helping with the emotional and psychosocial impact of dysphagia, as well as the physical adaptation needed. This study highlights the long-term impact of one particular treatment-induced side effect in HNC patients. However, with participants having treatment as far back as 2007 when parotid sparing in radiotherapy was not as commonplace as it is today, it is difficult to suggest how these advances in treatment techniques have affected patients more recently. This is something the authors do not adequately address.

### 3.9.2 Self-image

There are inherent challenges when comparing studies over time involving HNC patients, in part due to the advances in surgical and radiotherapy planning and delivery techniques. In an older study of eighty-two non-laryngectomised

patients treated for HNC, Katz et al. (2003) suggests that female HNC patients who undergo face-disfiguring treatment and have minimal social support are at the greatest risk of psychosocial dysfunction. The mean Center for Epidemiologic Studies-Depression Scale (CES-D) score for the entire sample was 11.8 (SD, 11.69). A score of sixteen or greater suggests individuals are at risk for clinical depression. The mean CES-D score for men was 9.88 (SD 10.52) and 16.18 (SD 13.21) for women. Twenty-three percent of men and 40% of women had a CES-D score of at least sixteen. The mean score for the single-item Atkinson Life Happiness Rating was 7.78 (SD, 1.93) out of a possible range of one to eleven, with a higher score indicating a higher level of overall satisfaction with life. Men reported significantly higher mean life happiness (8.11; SD, 2.01) compared with women (7.04; SD, 1.54). However, while several studies support this view, Fingeret et al. (2012) suggest that men were just as likely as women to be affected by body image concerns. There are several explanations for this discrepancy including inconsistent definitions of body image across the literature, or cultural norms that presume physical appearance is more valued by women than by men. There is also the possibility that cultural norms may have changed in the nine years between the studies, indicating the changing meaning of self-image and masculinity in modern society. Fingeret et al. (2012) also suggest that measuring or predicting such dysfunction is inherently difficult due to the subjective nature of such concerns. In an earlier study, Penner (2009) states that while some of these patients are able to “cope” (p.232) well with their situation, others are prone to isolation and depression.

As mentioned previously, in a cross-sectional study of 280 surgically treated HNC patients, Fingeret et al. (2012) reported that 75% of participants acknowledged concerns or embarrassment about one or more types of bodily changes at some point post-treatment. While the authors hoped that by recruiting patients from three time-points across the care pathway (prior to

surgical treatment, less than one year from treatment, or greater than one year from treatment) there would be a greater understanding of the overall needs of these patients (14% of respondents were treated more than five years previously), the results fail to differentiate between these groups, thereby making any conclusions based on time since treatment difficult to interpret. However, the results do suggest that at least half of the sample experienced preoccupation with changes in physical appearance at some point following diagnosis, and approximately one-third of respondents reported behavioural difficulties and social avoidance because of concerns about changes in appearance, speech, or eating. In addition, the authors also noted younger patients were at greater risk of experiencing body image difficulties. The authors stress the importance of realistic and thorough preparation of these patients with regard to potential body image challenges *prior* to treatment in order to help them begin the adaptation process as quickly as possible.

In an attempt to explain the psychosocial processes that surgically treated HNC patients undergo, Konradsen et al. (2012) conducted a small-scale (fifteen nurse-patient dyads) qualitative study using grounded theory. The study consisted initially of fifteen patient-nurse dyads. Patients were admitted to either a surgical ear, nose, and throat department or an eye surgery department between 2007 and 2008. Nurses were assigned as the patients' primary caregivers on the day of data collection. The age of the patients ranged from twenty-five to seventy-eight. Nine of the patients were male, six were female. Some participants were experiencing facial disfigurement for the first time, whereas others had undergone previous surgical experience.

Initial data collection involved the nurses recording a conversation while the nurse spoke with the patient about discharge planning or while helping the patient with personal hygiene. The duration of the recordings was ten to forty

minutes. Separate interviews were subsequently conducted with the patients and the nurses. These separate interviews ranged from thirty to 100 minutes and took place in a private room within the hospital where participants could speak undisturbed with the researcher. A second interview was conducted six months after the surgery (either at an outpatient clinic or in the patient's home). The remaining twelve patients took part in the final interview, which occurred one year after surgery.

The question of whether the patients were disfigured after surgery is subjective, and the degree of disfigurement is difficult to measure. Disfigurement was deemed to be present when both the patient and others visually perceived a change. By interviewing the patients at three time-points, the authors were able to build a rapport with the participants and also tailor the interview structure to the individual participant. The authors concluded that patients move through three stages: becoming disfigured, being a disfigured person, and becoming a person with a disfigurement. They suggest that during the first stage (the operation) the hospital environment provides a safe-haven which is often shared by others experiencing the same thing. However, this safe environment may be threatened by visitors, especially young children, who act as a reminder of life before the operation. After leaving hospital the patients reported being met with silence and non-verbal changes in behaviour from those around them. Although acted out as a form of protection, the authors stress the importance of "breaking the silence" (p.1040) which will facilitate the patient moving into the second stage. The final stage is achieved through integration, which should occur at a natural pace. However, setbacks may result in the person moving back through the continuum as well as forward, and the process back and forth may be a lifelong one. Similar themes emerge from a small scale (five participants) Swedish study conducted by Röing et al. (2009). When analysing data collected from patients previously treated for oropharyngeal cancer and

using a hermeneutic research approach the authors were able to identify themes of existing as oneself, existing in the eyes of others, and existing with others.

The majority of studies examining the impact of disfigurement and body image in HNC have focused on patients who are treated surgically, and in some cases, used treatment by chemotherapy or radiotherapy as an exclusion criterion (Fingeret et al. 2012). However, it must be accepted that chemotherapy and radiotherapy can significantly impact on body image as well, potentially resulting in changes to skin and hair colour/texture, as well as more recognised functional changes such as dysphagia and xerostomia. After an average of eleven months post-treatment, Vickery et al. (2003) conducted a study comparing twenty-eight surgery and radiotherapy/ brachytherapy/chemo-radiation (S & R/B/C ) patients and twenty-five of their partners with twenty-three radiotherapy/brachytherapy (R/B) patients and nineteen partners. Participants completed several measures including the Hospital Anxiety and Depression Scale (HADS), Psychosocial Adaptation to Illness Scale, and the Dyadic Adjustment Scale. While the study looked at many measures of QoL rather than focusing on body image or disfigurement, their results suggest that HNC patients scored comparably with normal populations and other cancer patients. Vickery et al. (2003) also state that partners were more likely to report distress than patients, confirming the belief that the impact of HNC may be more prominently felt by spouses and family members, possibly due to a lack of control or involvement, than by the patient themselves. No differences were found between the surgical and non-surgical groups. The authors acknowledge that this dissonance in findings may be due to the use of a single time-point for data collection or the relatively high proportion of eligible participants that declined to take part (41%). On the HADS questionnaire, the S & R/B/C patients had median scores of 5.0 for anxiety and 3.0 for depression, compared with 9.0

and 4.0 for partners. R/B only patients had median scores of 5.0 for anxiety and 4.0 for depression, compared with 8.0 and 4.0 for partners. A commonly used cut-off point for anxiety or depression within the HADS is eight out of a maximum score of twenty-one (Bjelland et al. 2002). Vickery et al.'s findings are seemingly in opposition to subsequent findings (Chandu et al. 2006; Fingeret et al. 2012), which suggest QoL in surgically treated HNC patients is significantly affected.

More recently, Clarke et al. (2014) surveyed forty-nine HNC patients who were at least six months post-treatment. They found female participants reported higher levels of appearance-related distress than females in the general population or male HNC patients in the same cohort. Depression scores on the HADS were higher than UK norms, whilst anxiety was similar to UK norms. However, the study suffers from a large drop-out rate at the nine-month follow-up (only twenty remained in the study), and there is a lack of data regarding the cohort demographic such as treatment modality and anatomical subsite.

In an interpretative phenomenological study of fourteen Canadian HNC patients, Henry et al. (2014b) suggest that physical disfigurement caused by either the disease or its treatment can result in a “ruptured” (p.5) self-image and that people may struggle to adapt to their new post-treatment self. What the authors are less clear on is whether the outward disfigurement could act as a *story* or reminder for those around them that they are not the same people they were before diagnosis. Also, while not explicit in the study, it may be that their facial disfigurement acts as a reflection of their changed inner self, thereby acting as a catalyst for their adaptation to a new post-treatment self. For patients where there are few or no outward signs of change, there is a chance that they may find it more difficult to adopt a post-treatment self, or that they may continue to work towards regaining their pre-diagnosis identity.

### 3.9.3 Identity in HNC

In a small-scale study ( $n=16$ , 68% response rate) focused on intimacy, O'Brien et al. (2012) used multiple semi-structured interviews to highlight themes among HNC patients who were one year or more post treatment. The themes identified across the interviews were *personal identity*, *re-establishing social networks*, and *intimate relationships*. Of the respondents, 24% reported problems with intimacy following treatment, with losses within these themes categorised as either intermediate or ultimate. Personal identity meant different things for different people and stemmed either from physical changes caused by the treatment or from psychological changes caused by the treatment pathway itself, with one participant describing their personality as being “fragmented” (p.2504) by the treatment. Re-establishing social networks appeared to correlate on the severity of the treatment intervention (both actual and perceived) and subsequent ability to re-integrate into social or work settings. All participants stressed the importance of open communication in re-building intimate relationships, with those observing unwillingness by partners or loved ones to talk intimately and openly leading to feelings of resentment and rejection. Such findings support and build upon the work of Konradsen et al. (2012) and Anderson and Martin (2003). In contrast to the findings of Low et al. (2009), as discussed earlier, no gender differences were found in this particular study. However, such discrepancies may stem from a significantly smaller sample size.

In a study of 139 patient-spouse dyads involved in radical treatment for HNC or lung cancer, Manne et al. (2012) used a number of self-completed measures to assess spousal communication, intimacy and distress at three time points over a

period of six months. In all, ten different measurements were used. Table 4 (below) shows the measurements and scores.

Measurement	Patient		Partner	
	Scores	SD	Scores	SD
Self-disclosure	15.3-13.9	5.1-5.8	13.4-14.0	5.5-5.8
Perceived partner disclosure	13.2-14.8	5.4-5.9	13.8-14.2	5.4-5.9
Sharing concerns	2.5-3.0	0.1-1.3	2.5-2.8	1.0-1.3
Mutual avoidance	6.9-7.4	4.4-4.8	6.9-7.0	4.1-4.4
Patient demand-spouse withdraw	6.1-7.1	3.6-4.6	7.1-7.7	4.7-5.2
Spouse demand-patient withdraw	6.5-7.0	3.9-4.9	7.2-7.7	4.7-4.9
Spouse unsupportive behaviour	7.1-17.5	5.0-5.7	17.4-18.7	4.1-5.7
Cancer-specific relationship intimacy	6.0-6.1	1.3-1.4	5.4-5.6	1.7-1.8
Global relationship intimacy	4.1	0.8-0.9	3.7-3.9	0.9
Global relationship affection	9.0-9.3	2.1-2.4	8.8-9.0	2.4-2.9
Psychological distress	55.3-57.7	9.7-12.0	57.6-57.7	12.0-13.9
Psychological wellbeing	57.9-58.6	9.4-10.3	57.9-58.6	10.3-13.1

**Table 4 - Manne et al (2012) measurements and scores for patients and partners.**

From the data gathered, the authors were able to generate an over-time actor-partner interdependence model using multilevel modelling. The model

examined whether there were intimacy mediated associations between spouse-partner reports of communication at baseline and later distress. Patients and spouses who reported greater baseline distress also reported more negative baseline communication as well as lower levels of intimacy and greater distress across the subsequent time points. While the study draws some interesting conclusions, it is limited by several factors including a large number of drop-outs and a response rate of just 33.1%. The most common reason for declining was the view that the study would be too time consuming (10.4%). In total, 108 patients (77.6%) and ninety spouses (65%) completed the three-month follow-up and ninety-one patients (65.5%) and seventy-seven spouses (54%) completed the six-month follow-up. The most frequently cited reasons for drop-outs were that the patient died, felt too ill to continue, or felt the survey was too upsetting. The authors also acknowledge the relative homogeneity of the sample with regard to ethnicity and socioeconomic status which may limit how generalisable the results are.

The study by Manne et al. (2012) builds on earlier work involving the actor-partner interdependence model by Manne and Badr (2010). In this study 109 patient-spouse dyads undergoing active treatment for either HNC or lung cancer (average time since diagnosis was fifteen months) were asked to complete several questionnaires aimed at examining physical impairment, perceived self-disclosure, perceived partner disclosure, protective buffering, cancer-specific relationship intimacy, and distress. The results suggested overall, as well as cancer-specific, intimacy fully mediated links between self and perceived partner disclosure and distress. In addition, overall intimacy partially mediated the link between protective buffering and distress. Lower levels of distress were reported due to overall and cancer-specific intimacy, but these lower associations were stronger for partners than for patients. However, the validity of the conclusions is brought into question due to a response rate of just

29.4%. The authors suggest participation may be improved in similar studies when participants are compensated for their time in some way. However, compensating participants may raise additional ethical considerations such as validity of consent and reliability of data (Head 2009). Miller (2014a) suggests that the quality of dyadic communication can directly impact how well both the patient and their partner cope with, and adapt to, life after cancer.

An important aspect of cancer-specific psychosocial research is the impact of diagnosis and treatment as felt amongst the patients' friends and family. Those closest to the patient often play an important role in recovery and adaptation, but the impact of the illness and its treatment is often only viewed with regard to the patient. In a Dutch study examining forty-one patient-spouse dyads, Verdonck-de Leeuw et al. (2007) found that 27% of cancer patients and 20% of spouses were distressed, as defined by the HADS scale. The distress in spouses was reported as being due to the presence of a feeding tube in patients, passive coping styles, less vitality, and a disrupted daily routine due to caregiving. Distress in patients was related to the presence of a feeding tube, speech difficulties, swallowing problems, fewer social contacts, a passive style of coping, and non-expression of emotions. However, with an unspecified participant response rate, a relatively small sample size, and the use of just one measurement tool (HADS), any conclusions and subsequent recommendations must be viewed with these limitations in mind. Similarly, in a cross-sectional Swiss study of thirty-one patient-spouse dyads (male patients only), Jenewein et al. (2008) found that a lower QoL in patients was associated with more physical difficulties and higher levels of psychological distress, whereas in female partners QoL was found to be related to marital quality and levels of distress. According to a literature review conducted by Lewis (2006), family members' coping and adaptation style is crucial in the recovery of the cancer survivor.

In an American study by Ross et al. (2010), eighty-nine family caregivers (generated from eighty-one HNC patients) completed several QoL measures at six to twenty-four months post-treatment. Analyses showed that 38% of caregivers reported moderate to high distress and 61% reported that not all of their practical or informational needs were being met. Currently there is no definition of how long a person remains a *patient* or a *caregiver* or if they are able to revert to previous identities. By continuing with these terms, it is possible that the research literature is inhibiting patients' reversal to a previous identity or adaptation to a new identity by biasing the perceptions of healthcare professionals. Similarly, in an earlier German study of seventy-eight relatives of HNC patients (44.8% response rate), Baghi et al. (2007) extensively uses the terms *patient* and *carer* despite a median time since treatment of two years. The study also relies on concepts of the "nuclear family" (p.712) which may not be applicable for a great number of HNC patients.

In a UK-based cross-sectional survey of 386 disease-free HNC patients (response rate 50%), Precious et al. (2012) reported that 46% of respondents had one or more carers who were predominantly family members. Carers' roles were identified as providing emotional support (75%), taking them to healthcare appointments (67%), cleaning the home (62%), and shopping for food (59%). Thirty-four percent felt that their care was a considerable burden, and 32% felt that it was very hard for their carers. Given that patients were at least one-year post-treatment (160 were between one and two years post-treatment, ninety-three were between three and five years post-treatment, 123 were between six and sixteen years post-treatment) this study suggests that the impact of treatment may be much more long-lasting than previously thought. However, whether *providing emotional support* should be considered a carer's activity is questionable as this may be provided by family members and friends regardless of previous illness. These findings are in significant contrast to those of

Mehanna and Morton (2006) who in a two-year prospective QoL study on 200 HNC patients found that while long-term (ten years post-treatment) QoL was approximately 11% lower than pre-treatment levels, they point to previous studies which show QoL initially decreases during treatment, but then begins to improve three to six months after treatment to reach or exceed the pre-treatment levels by the end of the first year. In addition, they report that QoL appeared to continue to improve slightly for the following two to three years.

In an American cross-sectional study, Bowman et al. (2006) suggest that on average, family members view the cancer experience as more stressful and traumatic than their surviving relatives. The authors suggest that better information for relatives and more inclusion in the decision-making process may make the experience less stressful, but they fail to address issues surrounding data protection and confidentiality.

### 3.9.4 Intimacy and sexuality

An often neglected aspect of cancer care as a whole (Dasappa et al. 2014), and particularly HNC care, both clinically and within research, involves sexuality and/or intimacy (Penner 2009). Moreno et al. (2012) state that to date, the majority of attempts to assess sexual function and identity have used standard QoL questionnaires, rather than tools specifically aimed at such issues or at HNC patients. Their cross-sectional study using a modified sexual adjustment questionnaire ( $n=42$ ) found that all participants felt that the cancer and/or its treatment had negatively affected their sexual relationships. Moreover, with the patients assessed at a median time of one year after treatment (range four to thirty-three months), 31% were sexually unsatisfied. However, with no baseline data prior to diagnosis such statements must be viewed in context. The authors conclude that men who are sixty years of age or less have the highest

probability of sexual satisfaction during recovery. While the modified questionnaire used by Moreno et al. was specifically focused towards HNC patients, one concern is that by modifying the questionnaire, Moreno et al. may have affected the results or made comparison and transferability difficult. In a review of QoL tools in head and neck oncology, Heutte et al. (2014) could not find any evidence that the reliability of Moreno et al.'s modified questionnaire had subsequently been tested or verified.

Low et al. (2009) used a number of established QoL questionnaires (some modified) to 350 HNC patients who had previously been treated surgically (with or without chemoradiation). The study benefits from a high response rate (68%) and a largely representative gender split of HNC patients (Cancer Research UK 2016b) (67% male, 33% female). However, 110 of the 350 respondents did not answer the intimacy or sexuality questions despite answering other questions. Those who did not answer intimacy and/or sexuality questions tended to be female, older, and without a partner, which may suggest that such topics are still considered taboo, especially in older patients (mean age was sixty-four years). However, the gender disparity in response makes it difficult to compare the results to other studies such as Moreno et al. (2012). While men were more likely to respond to the intimacy and sexuality questions, they also appeared to be more likely to suffer from intimacy issues compared to women. The authors postulate that women may have more established social support mechanisms in place which could ameliorate difficulties with intimacy. They also noted that laryngeal and oropharyngeal groups tended to fair worse, which may be due to the taking of reconstructive flaps from elsewhere in the body causing additional body image issues. Low et al also stress the importance of differentiating between sexuality and intimacy in such studies and suggest the use of touch-screen technologies to enquire about sensitive topics and deliver interventions

may be a useful addition to clinical settings as a greater sense of perceived anonymity may encourage participation.

### 3.9.5 Food, and its personal and social importance

Eating difficulties are often one of the first treatment-induced side effects to present and can be one of the most long-lasting side effects in many HNC patients (Ottosson et al. 2013). McQuestion et al. (2011) suggest that food represents far more than a source of nutrition and can come to symbolise emotional and social loss. “Food represents not only a way to sustain life, but a vehicle to interact and socialize with others and to receive comfort.” (p.145) Using a qualitative descriptive analysis the authors examined interactions from seventeen HNC patients who had undergone radical radiotherapy (none of the participants had feeding tubes in place at the time of the interview). The authors found that participants felt distressed because of the disrupted expectations and changes in their daily routines, and these altered routines changed the meaning of food for them. These changed meanings, such as the social aspect of eating, presented in the physical and emotional aspects of the patients’ lives as well as highlighting and compounding perceived social losses. Presented as part of a larger study, the article lacks explicit detail regarding participants and methodology, but provides a powerful insight into a key aspect of life that many people take for granted.

The social and psychological value and importance of food was also captured in a qualitative study by Ottosson et al. (2013). Using in-depth semi-structured interviews with thirteen HNC patients, they found their experience of food, eating and meals up to nine months after radiotherapy was captured in six categories. These were the long journey – taking small steps to an uncertain future, a new way of eating, eating without satisfaction, challenging meals

outside the family, support and information – the key to a successful journey and the creation and acceptance of a new normal.

### 3.9.6 Employment (head and neck cancer patients)

Employment can have a myriad of meanings for HNC patients of working age. Not only may there be the negative financial impact of treatment and recovery in terms of lost income, but the return to work may be determined by long-term treatment-induced side effects. Added to this is the sense of identity and purpose that many people gain from their occupation, which may be undermined indefinitely. In a Dutch study of eighty-five HNC patients (less than 65 years of age, more than two years post-treatment; response rate 75%), Verdonck-de Leeuw et al. (2010) found that of the fifty-three patients who were employed at time of diagnosis, 83% eventually returned to work: twenty-eight to the same work, seven to adapted work and nine to other work. Of the fifty-three participants, 71% had returned to work within six months of treatment. Participants reported anxiety and oral dysfunction (xerostomia, trismus and problems with social eating) significantly affected employment after treatment.

Isaksson et al. (2016b) stress the importance and value to work and employment following HNC. They make several assertions about why work can play an important part in recovery and life in general. Returning to work is important for overall psychological and physical well-being in addition to the financial implications of working versus not working. Work is considered an important part of the healing process, but the meaning of work for the patients might vary before diagnosis and during and after sick leave. An inability to work may also interfere with daily life routines and subsequently lead to a lack of confidence and to social isolation. Of sixty-six participants, twenty-eight of

whom had been treated for oropharyngeal cancer, just 53% had returned to work at twenty-four months post treatment. They also noted that QoL measures were significantly worse for those who were not working at twenty-four months post treatment. The study does not explore the impact of the welfare system in place for Swedish cancer patients and how this may affect the impact on patients in other countries. Similarly, there is little acknowledgement of the impact on those who are self-employed versus those who are employed.

### 3.9.7 Patients as caregivers

While the majority of HNC patients are approaching or beyond retirement age, there are a significant and increasing percentage of patients who are younger, and therefore potentially have additional responsibilities such as caring for young children. Semple and McCance (2010) interviewed ten male and two female HNC patients from across Northern Ireland about their experiences of caring for children (under the age of sixteen) during and post-treatment. Using open-ended questions in a single interview, the results were analysed using cognitive mapping. The results suggested that caring for young children often added an additional level of complexity to their journey. Not only did the patient have to deal with their feelings about the illness and its potential impact on daily life, but they also had to take into account the reaction of their children, such as how and when to deliver the news of diagnosis. Several patients reported needing additional support from health professionals in delivering such news, but that this help was often lacking. All but one of the patients were employed at the time of diagnosis. The authors suggest that making the transition from “leaders in the home” (p.1285) to patient was often more challenging for male patients, as they were often viewed, either internally or externally, as head of their household. While many of the participants were able to eventually return to work, the illness caused many to re-evaluate their

priorities resulting in stronger emotional as well as family bonds, which was also reported in a later study by Swore Fletcher et al. (2012). While a larger sample size would clearly add strength to Semple and McCance's study, it is obvious that sample size must be sacrificed if a deeper level of detail and understanding is desired. The decision of whether to sacrifice larger participant numbers (greater breadth of data) for a smaller group of participants (greater depth of data) will be discussed in subsequent chapters. While these studies look at the dynamics of role and adaptation in cancer patients with caregiving responsibilities, it may be worthwhile to hear the thoughts of those closest to the patient, including children, to investigate where commonalities or differences lie in relation to interpretation of experience.

The likelihood of increased social and familial responsibilities among a younger HNC population, such as HPV+ve oropharyngeal cancer patients, would go on to be an influencing factor when deciding on the age limitations for this study.

### 3.9.8 Information needs

The informational needs of HNC patients can vary significantly before, during, and after treatment. Knowing what information to give as well as how and when to give it is a major challenge for healthcare professionals (Miller 2014b). Fang et al. (2012) attempted to examine the informational needs of American HNC patients using a convenience sample of sixty-five patients (mean age 56.3 years) at, or around, time of presentation. Despite a small sample size, the authors noted patients with early stage disease desired more information than those with advanced disease, with most patients wanting information at diagnosis or one to three months post-treatment. Younger patients (twenty-nine to forty-nine years of age) were more likely to desire information and advice regarding sexuality, and 32% of respondents desired information on

coping with emotional stress and anxiety. Relatively few patients indicated wanting information regarding communication with family members, coping with changes in appearance, managing social situations or intimacy/sexuality. Of female respondents, 62.5% desired information on coping with emotional stress and anxiety compared with 20.8% of men, and 25% of all respondents wanted information at more than one time-point, possibly to avoid information overload. The most popular formats for delivery of information were internet (43.1%), DVD (40%) and booklets or pamphlets (36.9%). However, the ethnic and racial homogeneity of the sample (92.3% Caucasian) may be generalisable to certain locales but makes transferability to other populations difficult.

### 3.9.9 Follow-up appointments and psychosocial needs

Ghazali et al. (2012) point out that oncology follow-up clinics are often the only source of healthcare professional-delivered information once treatment has concluded. However, in a study of 125 HNC post-treatment clinic appointments the average consultation lasted just seven minutes (range four to twenty-five minutes) and the most common topics discussed were function (92%) and rehabilitation (89%). The authors suggest that there is reluctance, possibly by both patient and healthcare professional, to discuss psychosocial issues. The authors fail to acknowledge the possibility that such concerns are already being addressed through other avenues such as GPs, third-sector organisations or support groups, or that such issues are of less importance to patients. However, Holloway et al. (2005) state that many treatment-induced psychosocial side effects will last indefinitely without appropriate intervention, and those psychosocial variables may be more important than physiological variables when predicting many aspects of QoL. The authors acknowledge that their conclusions are based on a cross-sectional study conducted at a single time point on 105 HNC patients (five years or more post treatment, three years or

more completely cancer free), and that further studies would benefit from a longitudinal approach in order to assess adaptation over time. There is also some evidence to suggest that the longer the cancer experience, from initial symptom to final treatment appointment, the more time is required to overcome the physical and emotional effects (CURE: Cancer Updates 2009b).

While Aaronson et al. (2014) support the development of e-health interventions as a way to improve engagement, there is some debate on how medical staff can identify patients in need of more specific interventions, and how to tailor them to the individual's needs. In a UK study, Scott et al. (2013) looked at whether an electronic touch screen version of the Patients Concerns Inventory (PCI) would illicit different or additional information in order to customise follow-up appointments. The idea that technology such as touch screens may give patients the perceived anonymity to divulge more challenging topics was suggested by earlier research such as Low et al. (2009). However, Scott et al. (2013) found no evidence that the electronic version of the PCI identified any additional information about the patients' needs when compared to the paper version. While not discussed in the paper, the electronic version may facilitate easier longitudinal data collection, thereby giving researchers more insight into the issues patients feel are of importance to them. The paper also does not address the issue of difficult or perceived taboo topics within a follow-up setting. The dominance of physical symptoms in early conversations may set the tone for future interactions, thereby precluding any psychosocial discussions (Scott et al. 2013).

### 3.9.10 Anxiety and depression

Depression amongst HNC cancer patients is common (Chen et al. 2013). Johansson et al. (2011) suggest patients using Helpless-Hopeless (when patients

are devoid of hope and see themselves as gravely ill) and Anxious Preoccupation (worrying about what the future may hold regarding the cancer) responses reported more anxiety and depression, as well as decreased health-related QoL. The authors based these conclusions on a longitudinal study of ninety-five patients with laryngeal cancer, measured by the Mini-Mental Adjustment to Cancer Scale (Mini-MAC), the European Organisation for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life core questionnaire (EORTC QLQ-C30) supplemented with the Head and Neck cancer module (QLQ-H&N35) and HADS at one and twelve months after commencement of treatment. While patients with laryngeal cancer may face different challenges to oropharyngeal cancer patients, such as speech difficulties, there are many commonalities. These include modalities of treatment, eating and swallowing difficulties and time spent following active treatment which may necessitate changes to employment and financial difficulties.

Elani and Allison's (2011) study links increased levels of anxiety and depression among patients with more negative coping strategies such as self-blame, wishful thinking and avoidance. While the data collected from 157 HNC patients did not indicate a temporal link between anxiety, depression and coping, the authors stress the importance of healthcare professionals recognising and reacting to different coping strategies amongst patients. Deno et al. (2012) suggests self-efficacy and social support from friends were found to ameliorate the negative effects of social and emotional distress, which is supported by Philip et al. (2013). These findings also support work done previously by Jenkins (2006). However, in their study of 225 HNC patients treated in Japan, Deno et al. (2012) did not find a similar buffering effect from social support from family members. Whether this Japanese study has implications for a UK population is questionable, due to differences in culture and family dynamics.

A small-scale qualitative study by Moore et al. (2014) looked at the support needs of HNC patients following the completion of active treatment. They found that coping was impaired following treatment due to the “loss of access to the supportive hospital environment” (p.192). A lack of support, or specifically a void of formal support which had been with them since diagnosis, led to feelings of isolation. Similar results were found in a Canadian study by Henry et al. (2014a). 127 HNC patients completed several standardised measures of QoL, including HADS. 68% of participants had experienced unmet needs, and 25% revealed a clinically significant distress level on the HADS. The highest unmet needs were psychological, with seven of top ten needs. Clearly there is a body of evidence to suggest that HNC patients are in need of additional support following the completion of active treatment. Additionally, in a study conducted in New Zealand with eighty-three HNC patients and seventy-three caregivers, Richardson et al. (2015) found similar unmet needs. In self-administered questionnaires, patients described *just being there*, empathy, maintaining normality and practical support as helpful from family and/or friends. They desired information, honesty, positivity and empathy from clinical staff. Formal psychological support was desired by approximately 40% of patients and caregivers, particularly soon after diagnosis and during treatment. Most participants desired face to face sessions, offering individualised information and coping strategies.

### 3.9.11 Stigma and guilt

Cancers with a commonly known causal factor such as tobacco use in lung cancer has led some researchers to believe the self-induced nature of the disease may lead to feelings of stigma and blame in both the patients and others who come into contact with them, including healthcare professionals.

Lebel et al. (2013) looked at the phenomenon of stigma amongst lung (n=107)

and HNC (n=99) patients. Overall the percentage of respondents who felt stigma around their illness was low, with more lung cancer patients possessing feelings of stigma than those with HNC. However, with a response rate of 55.5%, it may be that feelings of stigma in the non-respondents are a cause of non-participation. In contrast, a qualitative study of nine Australian HNC patients by Threader and McCormack (2016) suggested that stigma was a common theme following treatment. Importantly, this study only recruited people with some changes to their facial appearance caused by surgery. It could be inferred that the stigma they felt was linked in some way to the ongoing visibility of their experience. Those treated for oropharyngeal or lung cancer do not routinely have to cope with facial disfigurement as part of their symptom burden, and so may therefore be less susceptible to feelings of stigma.

In a large-scale Canadian study of 522 HNC patients, Devins et al. (2015) based their hypothesis on the assumption that HNC patients are stigmatised due to its potential causal lifestyle factors (alcohol, tobacco, HPV). While this assertion is a contentious one, the authors suggest that distancing (i.e. construing oneself as dissimilar to a negatively-stereotyped group) may preserve self-esteem. In addition, distancing may also benefit other domains of subjective well-being. The authors assert that distancing helped to preserve self-esteem in people with HNC. However, it is hard to imagine a scenario where the concept of the *cancer patient*, as used in Devins et al.'s study, could be introduced to HNC patients without some inference of value, either positive or negative, on what it means to be a cancer patient. A comparable example would be to ask someone what it means to be a company director or a homeless person. Each label may carry preconceptions, and the perception of inference regarding the attributes of the label may affect the validity of the participant data.

In a mixed-methods study, Perloff (2015) found that the majority of lung cancer patients who were in the survivorship phase following treatment experienced a sense of survivor guilt. Such results show that the experience of cancer is infinitely nuanced, and that themes such as stigma and guilt may be driven by a mixture of internal and external factors.

### 3.9.12 Age, race and ethnicity

There remains a question over why there are differences in incidence of oropharyngeal cancer with regard to ethnicity and race. In a case review of HNC statistics from 1995-2005, Cole et al. (2012) noted younger age groups, non-Hispanic whites and Hispanics experienced greater increases in incidence for HPV-associated sites, while HNC incidence declined for non-Hispanic Blacks independent of HPV-association. They proffer the suggestion that there are differences in sexual mores between different races and ethnicities, such as prevalence of oral sex, number of sexual partners and age at which people become sexually active, which may account for these differences. These findings are supported by findings from a retrospective cohort analysis by Weinberger et al. (2010) and from work done by Joseph and D'Souza (2012). Whether these findings translate to a multi-ethnicity society such as the UK population is unknown.

## 3.10 Search strategy 3 – “What is known about HPV in head and neck cancer?”

### 3.10.1 Human papilloma virus

There exists a stereotype which prevails amongst health care professionals of HNC stemming from a prolonged history of alcohol and tobacco consumption (Howren et al. 2012). However, with tobacco use declining in some parts of the world there is now a greater recognition of the part played by HPV (Heffernan

et al. 2010). While HPV+ve HNC generally respond more favourably to chemotherapy and radiotherapy treatments, the long-term care of these patients becomes even more important. According to Dufour et al. (2012), the clinical and biological profile of HPV+ve patients is distinct from that of other oropharyngeal carcinoma patients, with earlier onset, cystic cervical nodes and basaloid carcinoma histopathology (transitional malignancy containing areas that resemble basal cell carcinoma of the skin). Chaturvedi (2012) also states that HPV+ve oropharyngeal cancers are epidemiologically distinct from HPV-ve ones in that they are characterised by younger age at onset, male predominance, and strong association with sexual behaviours.

### 3.10.2 Increase of HPV+ve HNC cases

In a review of 802 oropharyngeal cancer cases taken from the UNC Pathology Archives (1995-2006), Andrews et al. (2009) were able to demonstrate that 25% were not linked to typical risk factors such as prolonged alcohol and tobacco use. In addition, they were able to show that 25% were 6.1 times more likely to test positive for HPV infection. Similarly, Chaturvedi et al. (2011) were able to determine a positive HPV status for all 271 oropharyngeal cancers (1984-2004) collected by the three population-based cancer registries in the Surveillance, Epidemiology, and End Results (SEER) Residual Tissue Repositories Program. The data showed HPV prevalence in oropharyngeal cancers increased significantly over time regardless of HPV detection assay. The authors conclude that if recent incidence trends continue, the annual number of HPV+ve oropharyngeal cancers in the United States is expected to surpass the annual number of cervical cancers by the year 2020. As indicated previously, there is often difficulty in accurately defining the location of a primary tumour site. Therefore, it is difficult to compare studies which mention, but do not precisely define, oropharyngeal cancer.

### 3.10.3 HPV risk factors

In an archive review of the National Cancer Institute Surveillance, Epidemiology and End Results databases for changes in the incidence of, and survival from, cancer of the oral cavity and pharynx, Bleyer (2009) looked specifically at HPV within women. Similar trends were found in incidence and the author concluded changing sexual mores and increasing oro-genital sexual practices in the United States were responsible for transmission of HPV and potentially other sexually transmitted carcinogenic vectors in younger populations. In a study of twenty-seven female US college students (taken from a larger sample of 1,010), Cook et al. (2014) used a linear array assay to detect a number of HPV genotypes. Oral HPV was significantly associated with number of lifetime penetrative sexual partners, number of lifetime and yearly oral sex partners, and hand and/or sex toy transfer from genitals to mouth. The authors also found that oral HPV was associated with greater use of alcohol, cigarettes, marijuana, and sharing of smoking devices, lipstick, or toothbrushes.

### 3.10.4 Transmission vectors

There is a great deal which is still unknown about HPV transmission vectors and proliferation patterns (Chen et al. 2005). HPV is thought to cause all cervical cancers, around 88% of anal cancers, 70% of vaginal cancers, 50% of penile cancers, and 43% of vulvar cancers (Chaturvedi 2014). Much of the literature surrounding HPV+ve malignancies mentions risky sexual behaviour (Bisht and Bist 2011) as a possible means of transmission. However, the term is poorly defined. In two population cross-sectional studies, D'Souza et al. (2009) found HPV infection was detected in 4.8% of 332 control patients from an outpatient

clinic and in 2.9% of 210 college-aged men (age range, eighteen to twenty-three years). Among control patients, the odds of infection developing independently increased with increases in the lifetime number of oral or vaginal sex partners. Among college-aged men, the odds of oral HPV infection developing increased with increases in the number of recent oral sex partners or open-mouthed kissing partners but not vaginal sex partners. Their conclusion was that oral sex and open-mouthed kissing are associated with the development of oral HPV infection. However, in a later paper D'Souza and Dempsey (2011) conclude that there is still not enough understanding about the vectors of HPV transmission from person to person.

One question common to some partners of HPV+ve HNC is whether they themselves are at risk of developing HNC (Osterweil 2013). In a study of 164 HPV+ve oropharyngeal cancer patients, of whom 90% were male, and ninety-three of their partners, D'Souza et al. (2014) set out to investigate the risk to the partners of people (90% men) who had been diagnosed with HPV+ve oropharyngeal cancer. Of the male cancer patients, 97% reported having performed oral sex on their partner. This study suggests that partners of HPV+ve oropharyngeal cancer patients are at no greater risk of developing an HPV-related malignancy than the rest of the general population. This confirms the findings of Osterweil (2013). D'Souza et al. (2014) also state that partners of patients did not demonstrate elevated oral HPV infection rates compared with the general population. There is still a lot of work to be done before definitive statements can be made regarding the success of diagnostic measures in pre-cancerous populations, as well as the progression from HPV infection to malignancy.

### 3.10.5 HIV and HPV

In a limited meta-analysis looking at HPV infection in HIV+ve individuals, Beachler et al. (2012) found that oral HPV infection is commonly detected in HIV-infected individuals and is elevated among those with a higher number of lifetime oral sexual partners, current tobacco use, and those who are immunosuppressed. While initial studies suggest that the majority of HPV infections clear within two years, HIV-infected individuals are at a much higher risk of most HPV-associated cancers than the general population due to their inherent immunosuppression. Studies suggest HIV-infected individuals have a more modest 1.5 to four fold greater risk for HPV-associated HNC (Gillison 2009), although data on the subject is limited.

### 3.10.6 HPV in men who have sex with men

Dietz and Nyberg (2011) in analysing data in current literature found that the incidence of HPV infection drops in women older than thirty years but remains high for men who have sex with men (MSM) in all age ranges. They state, "Physicians have an obligation to incorporate sexual health history and vaccinations into the routine care of their male patients." (p. s24). They also point to current UK vaccination programmes aimed at young females and suggest that this policy will leave a subset of the population at continued and increasing risk of HPV-related HNC. While the incidence of HPV+ve HNC is eventually likely to reduce among the female and heterosexual male populations due to the HPV vaccination programme (D'Souza and Dempsey 2011), MSM will continue to be negatively affected.

### 3.10.7 HPV+ve HNC outside of the oropharynx

Several studies have shown that HPV+ve HNC may not be confined to the oropharynx. While some of these discrepancies are accounted in misclassification of head and neck anatomy (Hobbs et al. 2006), other studies have found evidence pointing to HPV+ve cancer elsewhere in the head and neck. In a literature review, Isayeva et al. (2012) found the weighted prevalence (WP) of HPV DNA detection in 4,195 oral cavity cancer patients is 20.2%. The WP of HPV DNA in 1,712 laryngeal cancer patients is 23.6%. The WP of HPV DNA detection in 120 sinonasal cancer patients is 29.6%, and in 154 nasopharyngeal carcinoma patients is 31.1%. Prevalence is the proportion of a sample that have a specific characteristic, in this instance a positive indication of HPV within the tissue sample. Weighting the sample mathematically adjusts the sample characteristics to match with the target population. Only data generated from primary squamous cell carcinomas were extracted, and samples were excluded from reports if the detection methods were not well-detailed, and/or HPV data could not be extracted per anatomic site. The WP with 95 % confidence intervals (CI) was calculated using Comprehensive Meta-Analysis, version 2 (Meta-Analysis.com). Weights were based on the inverse variance from the random effects analysis (within-studies variance plus the between-studies variance). Preliminary data also suggested an association between HPV and certain salivary gland neoplasms. Similar results have been found by Li et al. (2013) in a meta-analysis of laryngeal cancer (of fifty-five eligible studies), HPV prevalence in laryngeal cancer tissues was 28.0%. In a systematic review of 5,046 HNC specimens from sixty studies, Kreimer et al. (2005) found HPV prevalence was 25.9%. HPV prevalence was significantly higher in oropharyngeal SCCs than oral SCCs or laryngeal SCCs.

### 3.10.8 The psychosocial impact of having HPV+ve HNC

Gold (2012) draws on evidence from cervical cancer screening studies (McCaffery et al. 2004) to suggest that patients diagnosed with HPV-related HNC are at an increased risk of experiencing emotional trauma throughout their care trajectory, including the long term survivorship phase, compared with patients diagnosed with non-HPV related HNC. Gold points out that at the time of diagnosis, the patient and their partner may be more focused on the implications of a life-changing, and potentially life-threatening illness. The impact of the knowledge that their cancer is caused by a sexually transmitted infection such as HPV may not be of importance at that point. However, when moving into recovery and long-term survivorship, feelings and thoughts regarding HPV transmission, which may have been suppressed, could potentially interfere with successful recovery and adaptation. This view is supported by Chu et al. (2013) who suggest patients with HPV+ve oropharyngeal cancer need education to optimally address concerns such as self-blame, guilt, intimacy, and interpersonal relationships. Such issues may have a long term negative impact on a patient's emotional and physical wellbeing, thereby compromising their ability to actively contribute towards society. Gold suggests that counselling and support should be offered at the end of treatment in order to help people address issues surrounding intimacy and sexuality and to provide information regarding oral transmission of HPV. However, with such a limited pool of literature to draw from, it is clear more research needs to be conducted into the psychosocial needs of HPV-related HNC patients and their families before any conclusions can be drawn.

### 3.10.9 Benefits of being an HPV+ve HNC patient

A benefit often emphasised by oncologists when discussing results with patients is that HPV+ve oropharyngeal cancer patients have substantially improved outcomes (28–80% reductions in the risk of death) compared with HPV-ve patients (Chaturvedi 2012), despite often presenting with advanced disease due to nodal involvement (Goon et al. 2009; Lassen 2010). In a meta-analysis of forty-two studies, O'Rorke et al. (2012) were able to show that patients with HPV+ve HNSCC had a 54% better overall survival compared to HPV-ve patients. Both progression-free survival and disease-free survival were significantly improved in HPV+ve HNCs. Currently patients are given the same treatment regimen regardless of HPV status. However, there is a great deal of work currently being done in assessing disease response according to HPV status. Marur et al. (2010) suggest that by reducing treatment dose to patients who are known to be at a reduced risk of locoregional recurrence, long term side effects may be reduced thereby improving quality of life. However, there is still debate over the influence of factors such as tobacco use and whether this is more of a prognostic factor than HPV status (Sinha et al. 2012).

### 3.10.10 Transparency in HPV screening

Shuman and Wolf (2010) raise the question about whether HPV status should be divulged to the patient or whether testing should be done at all. They query whether there is any benefit in knowing HPV status if the treatment is the same, as is currently the case, and that it would likely serve to increase psychological trauma to the patient. The authors do not offer any evidence to support this claim. In addition, this raises several moral and ethical issues around disclosure and transparency, as well as the duty of care to the patient's sexual partner(s). Since Shuman and Wolf's study, other authors have suggested a more

progressive approach to disclosure of HPV status (Baxi et al. 2013; Chu et al. 2013; Finnigan and Sikora 2014). They suggest that increased knowledge of the virus' transmission vectors, as well as the improved prognosis for those who are HPV+ve, can be incorporated into clinical conversations without any increased psychological risk to the patient.

Using data gathered from semi-structured interviews with ten survivors of HPV-related oropharyngeal cancer, Baxi et al. (2013) state that the approach of the oncologist and the way in which information regarding HPV status is delivered can have a significant impact on the patient. This impact can occur both at the time of diagnosis and throughout their cancer pathway and may include leaving the patient with feelings of confusion, stigma and anxiety. Finnigan and Sikora (2014) recommend a counselling process with newly diagnosed patients who may potentially be HPV+ve. Their rationale is to inform the patient about their disease and prognosis. Also, they suggest that counselling at this early stage would reduce possible harm through misinformation or later unsupported revelations. The authors also refer to possible feelings of guilt, fear, and/or confusion regarding an HPV+ve diagnosis, which they support with evidence from studies looking at cervical cancer patients (Daley et al. 2011; Kwan et al. 2011). Finnigan and Sikora (2014) go on to say that the counselling should also include information on transmission vectors and transmissibility. While this transparent approach may increase patient understanding of their disease, the authors largely ignore the huge amount of information and adjustment necessary in initial diagnosis and commencing treatment. Adding to these existing demands may prove unbeneficial or even harmful for some patients, as the trauma of the cancer diagnosis itself may impede their ability to rationally deal with the topic of HPV. The authors do acknowledge that data supporting any particular counselling structure would likely change rapidly over the coming years in response to new data and research recommendations. While less

prescriptive, the recommendations for patient-centred counselling are also supported by Chu et al. (2013).

### 3.11 Chapter summary

The findings of the literature review support the view that experiences of people treated for head and neck cancer are often complex and long lasting. How someone is affected by the diagnosis and treatment of cancer six months or more following treatment is still not well understood.

Unlike cancer sites where nearly all cases are treated (whole or in part) with surgery, such as breast cancer, people diagnosed with oropharyngeal cancer may or may not be offered surgery as part of their treatment pathway. This makes evaluating the impact on self-image and appearance in this population difficult. Looking at HNC patients as a whole, it is clear that surgical intervention can affect an individual's self-image in the short, medium, and long term. While Katz et al. (2003) and Fingeret et al. (2012) disagree as to the extent gender plays in coping and adaptation of surgical treatment of HNC, both agree that face-disfiguring treatment can lead to an increased risk of isolation, depression, and body image difficulties. The authors also reinforce the point that unlike many other surgically treated cancer patients, HNC patients are often unable to hide or disguise evidence of their illness. Fingeret et al. (2012) stress the importance of realistic and thorough preparation to aid with coping and adaptation. However, in clinical situations where time to treatment can impact on efficacy and where deadlines must be met in order to avoid health service provider fines (Dorning and Blunt 2015), it is often difficult to assess the optimal depth and breadth of information required without risking information overload for the patient (Kim et al. 2007). The three stages of adaptation as described by Konradsen et al. (2012) suggest that support and information giving should be

present and available throughout someone's cancer journey. Patients may feel deluged with information at the start of their treatment and then isolated once active treatment has ended. Their evidence suggests that a better understanding of patients' long-term information requirements is needed in order to improve physical and psychological wellbeing.

Intimacy and sexuality literature similarly looks at all HNC sites together rather than specific malignancies. However, Moreno et al. (2012) reported that of forty-two HNC patients questioned all described that their sexual relationships had been negatively affected by the disease or treatment. The difficulty faced by researchers of intimacy and sexuality is gathering data on topics which people may regard as taboo. Low et al. (2009) used a variety of established QoL questionnaires to investigate the experience of HNC patients but 110 of 350 respondents did not answer the intimacy/sexuality questions despite answering other questions.

Intimacy studies often suffer from low response rates (Manne et al, 2012 and Manne and Badr, 2010) of around 30%. Participants may be more open and forthcoming in an interview situation rather than responding to a questionnaire. However, the anonymity of a questionnaire may give respondents more freedom to honestly describe their experience. O'Brien et al. (2012) used semi-structured interviews ( $n=16$ ) to investigate intimacy among HNC patients. Of those patients, 24% reported problems with intimacy following treatment, and all participants stressed the importance of open communication in re-building intimate relationships. Currently, help with intimacy is not routinely offered to HNC patients following treatment, and resources for those seeking help or advice is often limited. Such open communication may be difficult in a situation where it is sometimes seen by all parties as positive to move on from the disease and its treatment rather than dwelling on past events. Skills that allow a

person to be emotionally articulate and self-aware may not be present and may need professional support or intervention.

There is increasing awareness in the media and among the general population of the role HPV can play in HNC, specifically oropharyngeal cancer. Chaturvedi (2012) states that HPV+ve oropharyngeal cancers are characterised by younger age at onset, male predominance, and strong association with certain sexual behaviours. In an interview with Michael Douglas in 2013, The Guardian newspaper asked whether he now regretted his years of smoking and drinking [causal factors of tongue cancer]. Douglas replied: "No. Because without wanting to get too specific, this particular cancer is caused by HPV [human papillomavirus], which actually comes about from cunnilingus." (The Guardian 2013). However, there is a great deal which is still unknown about transmission vectors and proliferation patterns (Joseph and D'Souza 2012). Much of the literature mentions risky sexual behaviour (Bisht and Bist 2011) as a possible means of transmission, but the term is poorly defined. D'Souza et al. (2009) concluded that open-mouthed kissing as well as oral sex is associated with the development of oral HPV infection. However, in a later paper D'Souza and Dempsey (2011) state that there is still not enough understanding about the vectors of HPV transmission to change current clinical practice. What is undeniable is the increase in younger people over the past decade presenting with oropharyngeal cancer who have no significant history of alcohol or tobacco use, but yet have a better prognosis than their HPV-ve counterparts. All evidence suggests this trend is likely to continue for decades to come, and our understanding of this population needs to improve if we are to ameliorate against the long term negative effects of HNC treatment. A failure to do so may result in increased financial and societal burden for future generations due to the increased costs of long-term co-morbidities and lack of societal engagement.

Gold (2012) relates HPV-related HNC to the impact that a positive HPV diagnosis can have on women during cervical screening. Patients who are told, or who may suspect that their cancer is caused by HPV may experience feelings of self-blame and worries about intimacy and transmission. While Chu et al. (2013) support this view, there is currently a paucity of empirical work which looks at whether an HPV diagnosis affects HNC patients' long term psychosocial health. This suggests the largest gap in the literature at time of review. The oropharyngeal cancer population is growing in number, whilst the average age of a patient at diagnosis is reducing. The size of this patient group is set to continue increasing. HPV+ve head and neck tumours generally have a better prognosis than their HPV-ve counterparts. This will result in a greater number of people living for longer post-treatment. The existing literature on the psychosocial impact of HPV in cervical cancer suggests that knowledge of living with HPV may act as a complicating factor in psychological wellbeing and interpersonal relationships for those people. What we do not currently know is what impact does knowledge of an HPV diagnosis have, if any, on oropharyngeal cancer patients in the post-treatment phase of their survivorship. Given the increase in diagnosis of oropharyngeal cancer in younger people due to the effects of HPV, it seems important to focus this study particularly on people of working age.

There was a great deal of media attention on the part played by HPV in HNC at the time of conducting the literature review (see appendix N). This impact on patients and the subsequent changing understanding of the disease amongst the general population was not reflected in the literature at that time. Therefore, the focus of this study was to explore the experience of this patient group and contribute to the understanding of their experience in the post-Michael Douglas era.

I acknowledge that, on reflection, carrying out three broad-ranging literature searches has led to difficulties in making sure the review is sufficiently robust. Returning a combined total of 3,004 results from the three searches meant inclusion and analysis was a major task for a single researcher. However, it enabled the study to be open to the gaps in the literature and meant that a topic of value and importance could come to the fore, whilst also exposing myself to a variety of methodologies and paradigms.

This literature review raises questions about people who are treated for oropharyngeal cancer that are the focus of this study, including how they cope in transitioning from patient to a new/post-treatment self, whether the knowledge of an HPV diagnosis affects their experience, and whether functional and/or psychological effects of treatment continue to impact their lives during survivorship. Failure to explore the experience of this patient population and identify problems that can be addressed may subsequently result in preventable long term societal and economic costs.

The following chapter will evidence the reasoning behind the choice of interpretative phenomenological analysis as the methodological paradigm for this study.



## Chapter Four – Methodology

### 4.1 Chapter introduction

This chapter will demonstrate what influenced the choice of interpretative phenomenological analysis (IPA) as the paradigm for this study, both for the successful completion of the thesis, and for my own personal development as a researcher. Historical context will be presented in order to demonstrate my understanding of the development of IPA and its theoretical underpinnings.

### 4.2 Research questions

The research questions which guided the study can be summarised as:

- What is the survivorship experience of working-age people who have been treated for oropharyngeal cancer?
- What impact does HPV have, if any, on the experience of this patient group?

### 4.3 Qualitative vs. quantitative methodologies

Quantitative research relies on universal languages of mathematics and statistics to support discoveries that are known to be true (Houser 2009). However, these *truths* are still only interpretations based on collected data. When dealing with the phenomena surrounding human experience, language and physical expression are made up of ineffable qualities which cannot be expressed by numbers. When Protagoras (490-420 BC) said “Man is the measure of all things” he effectively took a stand against the idea that one could ever know the truth, because the truth is only ever an interpretation of available data (Reale and Catan 1990). While many great scholars and philosophers disagreed with this view (including Socrates (470-399 BC) and

Plato (429-347 BC) (Abel 2010)), the foundations of all interpretative research are fixed in the concept that an individual's view of reality is based in interpretation of experience (Shinebourne 2011).

In the same way that statistical methods help to interpret quantitative data, qualitative researchers have developed a number of paradigms to help interpret qualitative data. However, it is only when these paradigms are viewed not as methods, but as philosophical approaches, or lenses, that they begin to seem compatible with the goals of qualitative research. "Qualitative research is not a method, it is a philosophical approach that overarches many different ways of collecting and analyzing data." (Dombro 2007, p. 99).

#### 4.4 Why IPA?

When choosing a method, the choice was guided largely by reading of the literature. Studies using quantitative methods, such as questionnaires, have the benefit of examining much larger sample groups, which the authors would argue meant their findings could be more easily be generalised to other population groups. However, the studies which used qualitative methods, such as unstructured or semi-structured interviews, seem to convey a great deal more of the personal experience of the participant. These interviews seem to carry the *voice* of the participant far more effectively than can be gained with a questionnaire. As Patricia Munhall wrote "we come to see that qualitative research *does not practice reductionism*, does not reduce human beings or experiences to parts that require separate investigation" (2007, p. 5).

#### **4.5 Generating knowledge within IPA**

The most common method of data collection in IPA is from semi-structured interviews (Brocki and Wearden 2006). While a number of studies have used other data collection methods such as focus groups (Flowers et al. 2000; Flowers et al. 2001; Flowers et al. 2003), Smith (2004) expresses concern regarding the use of group data collection. He argues that IPA is focused on the “detailed exploration of personal experience” (p. 50), and therefore is not ideally suited to a group dynamic. Flowers et al. (2000), Flowers et al. (2001) and Flowers et al. (2003) acknowledge the possibility that the use of focus groups may introduce differences in the data yielded. In contrast, Dunne and Quayle (2001) state that they are “convinced” (p. 682) that their participants generated essentially the same data as if they had been interviewed individually. The use of focus groups for this study was considered, but quickly dismissed, due to concerns over a lack of depth of data when compared to individual interviews.

#### **4.6 Methodological considerations - Rationale for qualitative methods**

Little is known about the experiences of people who have been treated for oropharyngeal cancer. Qualitative methods were deemed most appropriate given the exploratory nature of the study, thereby facilitating a deeper understanding of the participants’ experience (Biggerstaff and Thompson 2008; Pope and Mays 2013; Ritchie et al. 2013).

#### **4.7 Personal motivations for conducting the study**

Despite all of the altruistic motivations people often cite for choosing to undertake a PhD, internal factors can be the most important in actually

completing and submitting a finished thesis (Phillips and Pugh 2010). What drives someone to devote such a huge amount of time as well as physical and emotional energy to the process will vary. For this study, the internal motivation came from a desire to set a personal challenge and grow both professionally and personally.

The methodological approach selected for this research study is Interpretative Phenomenological Analysis (IPA). The reasons for choosing IPA are as much about the researcher as the participants. When justifying the use of IPA, it can be difficult to give a focused and concise answer. During the initial literature searching and protocol design, there was an overriding sense of IPA being *right* for this study; and *right* for me as a researcher. Through much thought and reflection, the conclusion drawn is that because IPA allows such a degree of collaboration between the researcher and participant(s), it can trigger and facilitate a huge amount of personal and professional growth for the researcher.

#### 4.8 Selecting a qualitative method

Interpretative phenomenological analysis (IPA) (Smith et al. 2009) was selected based on the following considerations: IPA is an inductive qualitative approach dedicated to examining how people make sense of their experiences (Smith et al. 2009). It typically involves using semi-structured interview data to develop a detailed understanding of how people view, experience, and make meaning of their world, reflecting its phenomenological underpinnings (Willig 2013). IPA adopts a critical realist epistemology which assumes a relationship between a person's words and their beliefs, experience and meanings. However, it also emphasises the researcher's role in making sense of participants' interpretations of their experience. This involves a double hermeneutic (Smith and Osborn 2007), where the participant is making sense of their experience

and the researcher is making sense of the participant's sense-making. After careful consideration, this method was considered appropriate because cancer is a major life experience and the way people make sense of this event will depend on their personal experiences, meaning-making, and emotional responses.

In addition, until recruitment began it was uncertain as to how many people could be successfully recruited into the study. With oropharyngeal cancer existing as a subset of a relatively uncommon cancer group, the concern was that recruitment numbers would be so small as to make the study unworkable. In 2013, there were 7,591 new cases of oropharyngeal cancer in the UK (up from 6,767 in 2011). Of these cases, 2,316 were oropharyngeal (oropharynx, tonsil and base of tongue) cancer (Cancer Research UK 2016b) (up from 1,340 in 2011). To put these numbers in perspective, in the same year there were 53,696 cases of breast cancer (Cancer Research UK 2016a) and 47,300 cases of prostate cancer (Cancer Research UK 2016c). Despite reassurances from Clinical Nurse Specialists (CNSs) as to their ability to recruit sufficient numbers, this concern was an additional factor which influenced the decision to use a paradigm that was suited to smaller numbers of participants valuing deeper exploration of their experiences.

#### 4.9 IPA and its value in this type of research

The phenomenological basis of IPA suggests that the world of experienced meaning is composed from acts of interpretation, so these acts relate equally to the researcher and the respondent. Something which was appealing about IPA was the possibility of creating a piece of research which is unique. The IPA researcher seeks a better understanding of respondents' experience, and a successful IPA study can give access to the true knowledge about the essence of

the studied phenomenon (Liamputtong 2009). However, it is necessary to keep in mind that at the heart of IPA, there is an idea that interpretations are subjective and informed by the researcher's life world. For this reason, this method cannot be used together with positivist approaches based on the principles of objectivity (Markula and Silk 2011). Similar opinions were voiced by Frost (2011) in regard to the subjective nature of IPA. Phenomenological research is almost solely based on the assumption that people's perceptions of the world in which they live, and meanings ascribed by them to these perceptions can be embraced by a researcher conducting IPA. However, they will nevertheless represent the blend of his/her subjective interpretation and respondents' subjective accounts of their experiences. To those seeking an absolute truth, this subjective influence may act as a reason to discount IPA. However, when seeking to illuminate subjective experiences, it seems only natural to use such an interpretative method.

The hermeneutic underpinnings of IPA suggest that successful interpretation requires a strong understanding of the context within which experience takes place. While I am experienced of certain parts of the cancer journey, everyone's environment in which the survivorship experience takes place will be different. As claimed by Smith and Osborn (2007), IPA's core commitment rests within the recognition of a link between people's talk, their thinking, and their emotional state. Such an assumption regards thoughts and feelings as mostly disguised, and respondents' talking to be the code that the researcher may decipher to uncover those hidden meanings. Hence, one of the drawbacks of IPA is that this method of analysis enables researchers to draw conclusions from the data received from respondents, which may not be in line with what the participant(s) had intended to communicate, or which may even be not in agreement with the respondents' position. However, even such a drawback of IPA may be used to advantage, if the explicit focus is made on the subjectivity of

interpretation and presentation of research conclusions through the prism of the researcher's self-world. This process can be viewed as a reflection of healthcare; providing cancer care is based on a series of interactions between the patient, those around them, and medical staff. How one group interprets the experience will affect their subsequent interactions with other groups, and vice versa.

#### 4.10 Practical aspects of IPA

IPA is a two-stage interpretative process that involves the use of double hermeneutic reasoning (Smith et al. 2009). At the first hermeneutic stage, participants are trying to make sense of their world and experience in regard to a common life-event. At the second stage of analysis, the researcher attempts to make sense of the participants' efforts to make sense of their world (Smith and Osborn 2007). From the phenomenological and hermeneutic perspective, my aim is to understand what it is like to experience a cancer diagnosis, treatment, and recovery. Subsequent deeper analysis should be done with proper regard to the fact that while the interviews are a snapshot of an interaction between a researcher and participant in time, interpretations are in a state of constant change because of the continuous, lifetime nature of the cancer experience and its re-conceptualisation (Kloss et al. 2011). The researcher's experience also changes and evolves with the course of time, and only due to the practicalities of PhD research, the IPA of respondents' experiences has to be presented as some finite interaction coming to an end with the end of the writing process (Koskinen et al. 2011). Furthermore, one should note that while this PhD thesis is complete, experiences of respondents, and the researcher's interpretation of those experiences, may change and evolve, and may not be congruent with the opinion presented in this work at some future point.

With regard to the structure and content of the second findings chapter, one may notice that interpretations presented in that section relate to a much smaller number of respondents than initially included in the study. The aim of the study was never to be able to make broad generalisable statements. Instead, the second findings chapter is much more fitting with recent IPA literature and the move towards smaller sample sizes in IPA studies (Pietkiewicz and Smith 2014). Of course the aim of using smaller samples is that it allows a narrower and deeper focus on production of a thick description of specific participant experiences (Cox et al. 2010; Hayes 2013).

#### 4.11 Phenomenological beginnings

Phenomenology may be defined initially as the study of structures of experience, or consciousness. Literally, phenomenology is the study of *phenomena*. Things become things as they appear in our experience, or the ways we experience things. Phenomenology studies conscious experience as viewed from the subjective. In recent philosophy, the term *phenomenology* may be restricted to the characterisation of sensory qualities such as seeing and hearing: what it is like to have sensations of various kinds. However, our experience is normally much richer in content than mere sensation. Accordingly, in the phenomenological tradition, phenomenology is given a much wider range, addressing the meaning things have in our experience, notably, the significance of objects, events, tools, the flow of time, the self, and others, as these things arise and are experienced in our “life-world”.

#### 4.12 Husserl

Edmund Husserl urged phenomenologists to go “back to the things themselves”, with the “things” being the experiential content of consciousness (Husserl and Moran 2012). He suggested that if a person could accurately know their own experience of a particular phenomenon, that with enough depth and rigour one may be able to identify the essential qualities of that experience. He went on to propose that by identifying these essential features, it may be possible to convey the experience to others with a depth and understanding that was previously unattainable.

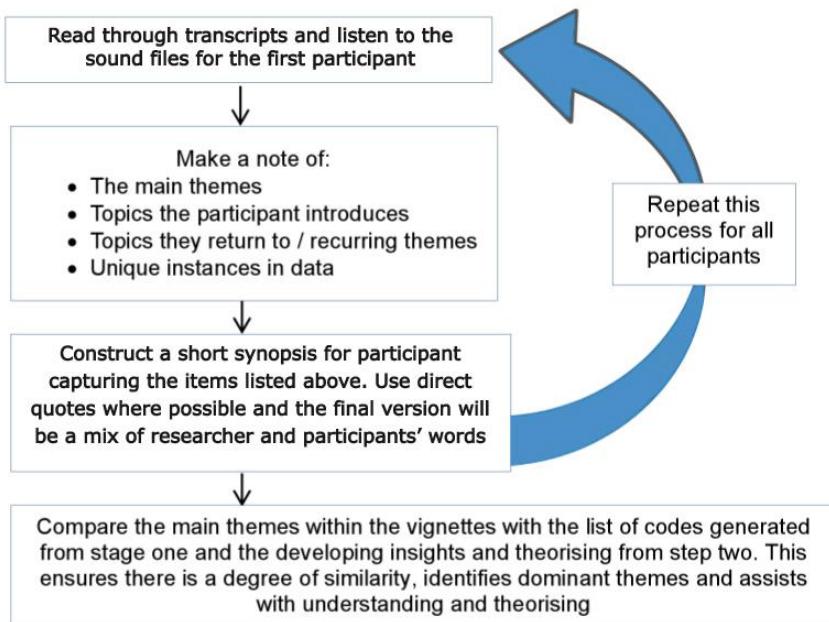
In attempting to transport phenomenology from a philosophical perspective to a practical scientific method, Husserl developed a phenomenological method which was intended to identify the core characteristics of human experience. Firstly, he suggested that the researcher should “consider the consequences of our taken-for-granted ways of living in the familiar, everyday world of objects”, and instead *brace*t these pre-conceptions in order to fully become part of the participant’s experience. Husserl also suggests that the method then proceed through a series of *reductions*, each offering a view through a different lens. It is suggested that this process of eidetic reduction leads the researcher away from the distraction and misdirection of their own assumptions, and towards the essence of the experience they are examining.

#### 4.13 Heidegger

Hermeneutics (from the Greek word *hermeneutice* meaning to interpret or translate) involves critical interpretation to uncover the meaning of a given text. Originally an approach used for the interpretation of ancient and biblical texts, *hermeneutics is the theory, rather than the practice, of interpretation*. Informed

by his reading of Schleiermacher, Droysen, and Dilthey, Martin Heidegger's *Sein und Zeit* (Being and Time) (1927) completely transformed the discipline of hermeneutics (Giorgi and Giorgi 2008). Heidegger, a student of Husserl, aimed to develop a more practical phenomenological approach in response to what he saw as Husserl's highly abstract approach. The aim of this more practical approach was to provide others with a method(ology) that would allow greater exploration and implementation of phenomenology. In *Sein und Zeit*, Heidegger is primarily concerned with the concept of Dasein (translated as 'there-being') and the ontological question of human existence. For Heidegger, Dasein is forever in a world of people, objects, language, and culture, and cannot be detached from it. One is part of the world and needs the world in order to interpret what it is to be a part of it, the *person-in-context* (Dowling 2007). In Heidegger's view, hermeneutics is not a matter of understanding linguistic communication, nor is it about providing a methodological basis for the human sciences. According to Heidegger, hermeneutics is ontology; it is about the most fundamental conditions of a person's being in the world. Hermeneutics recognises the historical basis of human understanding; ideas are nested in historical, linguistic, and cultural foundations of meaning. Therefore, a philosophical, theological, or literary problem can only be genuinely understood through a grasp of its origin (Giorgi and Giorgi 2008).

While there are many definitions of the hermeneutic circle, it has commonly come to mean a reflective exercise examining the interplay between our self-understanding and our understanding of the world, thereby uncovering a new interpretation of the world each time we view it.



**Figure 6 - Hermeneutic circle (example of how it can be applied to interview data).**

(Warner-Søderholm et al. 2015, p. 23) (adapted from).

#### 4.14 Development of IPA

Interpretative phenomenological analysis (IPA) was specifically developed by Jonathan Smith of Birkbeck University London, in order to allow rigorous exploration of idiographic subjective experiences and, more specifically, social cognitions. The term *idiography* is most often associated with the study of *individual* persons in psychology. However, it was originally used more widely, to distinguish the study of specifics from the study of things in general, also referred to as nomothetics (Larkin et al. 2006). Social cognition focuses on how people process, store, and apply information about other people and social situations. Social cognitions affect the way we think about others, and play a major role in how we think, feel, and interact with the world around us (Smith 1996). IPA's theoretical underpinnings stem from Husserl's attempts to

construct a philosophical science of consciousness with hermeneutics and symbolic-interactionism (Biggerstaff and Thompson 2008). The suggestion is that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process.

Consequently, IPA acknowledges that the researcher's engagement with the participant's text (such as a transcript of an interview) has an interpretative element, yet in contrast to some other methods such as discourse analysis, it assumes an epistemological stance whereby, through careful and explicit interpretative methodology, it becomes possible to access an individual's cognitive inner world. Because IPA explores how people ascribe meaning to their experiences in their interactions with the environment (Smith et al. 1999), it is especially suited to studies that aim to relate findings to bio-psycho-social theories that dominate current thinking within healthcare professions (Smith 1996; Willig 2001; Smith 2004). Gubrium and Holstein (2002) suggest that we are now members of an "interview society".

Within IPA, it is important to view experience within a hierarchy, and to differentiate *an experience* from *experience*. Dilthey (1976) refers to everyday occurrences as the *smallest unit* of experience, whereas IPA is more concerned with meaningful experience, what Dilthey refers to as a *comprehensive unit* of experience. Within head and neck cancer there are many components that may retain powerful meaning to the patient (diagnosis, surgery, radiotherapy, reactions from others) but they are all linked with a common meaning. The aim of the qualitative interview is to recall the individual parts and how they are connected and try to uncover the common meaning.

IPA in its simplest terms is made up of two parts; the first illustrated above is to identify a common meaning to an event or series of events to which the

participant attaches significance. The second axis is the subsequent interpretation of the experience. While this process of interpretation is strongly informed by hermeneutics, it can be said that when the qualitative researcher employs an IPA approach they are engaged in a double hermeneutic cycle; not only is the participant engaged in a process of interpretation through sharing the experience, but the researcher is then interpreting the experience again in an attempt to live the experience through the participant's eyes.

#### 4.15 Strengths and weaknesses of IPA

While smaller sample sizes may draw concerns over generalisability, another danger of interpretative analysis may be that the researcher is drawn away from the original meanings of the data (Pringle et al. 2011). This was a concern, particularly in the inclusion of researcher interpretation and metaphor placed alongside data extracts within the findings chapters. This decision is based upon the advice of Smith et al. (2009), when they encouraged researchers to "go beyond" immediately apparent content (p.186). The inclusion of this content aims to demonstrate the researcher's engagement with the double hermeneutic process, and the thought processes involved in understanding the participant's life-world. All of these thought processes and conclusions are firmly anchored in direct quotes from participant accounts (Smith et al 2009).

According to Smith and Osborn, "there is no single, definitive way to do IPA" (2015, p. 25). This can make the task of assessing the quality of an IPA study challenging. "IPA accounts should be both sufficiently interpreted and contextualised" (Brocki and Wearden 2006, p. 99). However, what is deemed as sufficient may also be subjective.

#### 4.16 Research questions in IPA research

While any theoretical framework carries with it a number of assumptions about the nature of the data (Braun and Clarke 2006), IPA-based studies should aim to minimise any assumptions which may influence the data (Larkin et al. 2006).

The study looked to explore themes, such as:

1. What are the experiences of working-age adults, previously treated radically for oropharyngeal cancer, who are between six months and five years post treatment?
2. How do these people view the emotional/psychological support which is available to them?
3. How does knowledge of any potential causes of the disease (HPV or lifestyle factors) impact on their experience and perceptions of HNC?

#### 4.17 My own life-world

“The researcher’s beliefs are not seen as biases to be eliminated but rather as being necessary for making sense of the experiences of other individuals.” (Fade 2004, p. 648). On this basis, an IPA study is as much about the researcher as it is the participants. But knowing how much of oneself to convey or reveal within a piece of research is challenging, especially for someone like myself who values and protects their privacy.

This section was not initially included in earlier versions of this thesis. However, one comment from the examiners was that they wanted to see more of me in the final thesis. While I find it uncomfortable to share myself like this in what will be a published piece of work, I acknowledge that by asking the participants to share their experiences, I must also be willing to share my own experiences in order to give the work context.

As I alluded to in the acknowledgments section of the thesis, a lot of what drives my professional interests comes from my father, who passed away from metastatic bowel cancer when I was aged ten. His death left a gap in my own life. As a boy, then as an adolescent, I was without a male role model to teach me many things. In essence, I was missing the guidance on what it is to be a man. Growing up, trying to understand the world and my place within it, I relied a lot on self-analysis and reflection. Many hours were spent alone, thinking about why I behave the way I do, or why others behave the way they do. Importantly, this process was a private one. I never enjoyed sharing these thoughts with others, and even recording them in a journal or diary seemed to leave me feeling exposed.

In section 1.3 (pages 3-4) I wrote about what initially made me interested in studying head and neck cancer patients. This was a man who was sharing his story of cancer, and his adaptation to life after it, with a group of strangers. In all likelihood, his account was selective, and it was his own interpretation of events. However, it gave me an insight into the impact of cancer to him as a person, beyond quantitative measurements of swallowing function and skin reaction.

Encouraged by first-person accounts of living with and beyond cancer, such as John Diamond's *C: Because Cowards Get Cancer Too* (2008), I found it fascinating that other people could identify with one person's story. It seemed from these accounts, that I didn't need a huge number of participants to learn something valuable about the experience of cancer.

Throughout my clinical career, I must have been involved in the treatment of many hundreds, if not thousands of people. Being honest, the number I

remember is actually very small indeed. Those I do remember, I remember because, in the main, they have shared something of themselves with me. Stories of fear, joy, family, friends, have made them important to me. They have helped to shape the way in which I treat and interact with patients and those close to them. Those few, individual stories have commonalities which can influence the care of countless others. For me, this is the power of small-scale, qualitative studies. It may be the smallest part of a fragment of a person's story, but that can resonate with something another patient may have said in passing. Or it may chime with a comment made by a family member.

#### 4.18 Method

This part of the chapter will look at the practical and ethical considerations involved in the design of this research study. This will include discussing the ethical issues, challenges faced in gaining ethical approval, and recruitment issues. By the end of the chapter, the reader should have a clear understanding of the process of carrying out the study and relevant literature which supported certain decisions.

#### 4.19 Design - User involvement and preliminary investigation

Before designing the study, I spoke with members of two head and neck cancer support groups (Northtownshire and an adjacent county). The aim was to discuss matters of importance with people who have been through treatment, including all malignancies of the head and neck region, rather than just those treated for oropharyngeal cancer. The support group members highlighted several long-term effects of treatment which continue to impact on their psychosocial wellbeing, such as eating, social and activity limitations. On the whole, they conformed to the findings of Ghazali et al. (2012), being far more at ease talking

about the practicalities of treatment such as transport, appointment times, or the physical side effects of treatment such as swallowing difficulties. It was only when asked probing open questions that they spoke about the less quantifiable effects. For instance, one man spoke about reduced saliva production and having to carry a bottle of water with him at all times. It was only when he was asked about what that meant to him that he spoke about not socialising as much, worrying about where he would be seated in a restaurant and would other people be staring at him, or still having to order from the children's menu even though it was nearly five years since treatment. These experiences led me to believe that an in-depth, qualitative approach would be necessary in order to uncover the meaning of these experiences.

Several support group members also gave feedback on draft versions of participant information materials. At the request of the REC for Wales, the participant information sheet was re-piloted with a different group of support group members before a favourable decision was given.

#### 4.20 Staff involvement

The level of involvement from clinical staff in the design of the study has varied enormously. Initially I had planned to use Northtown and an oncology centre in a much larger city (site B) as recruitment sites. At the time Northtown did not routinely test for HPV in their oropharyngeal cancer patients, whereas site B had been routinely screening their patients for over eighteen months. I hoped that by drawing participants from two different sites, a broader range of people and experiences could be recruited. However, despite several emails to the primary head and neck cancer oncologist at site B, he would not agree to a meeting or to support the study through ethical approval. He did not specify a

reason for this, although in one email he did mention concerns about patient burden from other studies already in progress.

Very early on in the design of the study, I met with the two head and neck cancer CNSs at Southtown. While I had not intended to use Southtown as a recruitment site (primarily due to distance and the impact it would have on resources when it came to collecting data), I wanted to get as broad a range of opinions on the design of the study as possible. They were very enthusiastic about the ideas and said they were getting more and more questions from younger patients about the emotional impact of cancer, including the implications of HPV. When it became clear that it would not be possible to use site B as a recruitment site, Southtown seemed like a logical choice. The CNSs there had been so engaged by the idea of the study that they had already spoken with an oncologist about the study and indicated that they would be more than happy to be involved. Within twenty minutes of emailing the oncologist at Southtown, I had received a reply giving her support.

At the time of designing the study, there were two oncologists at Northtown responsible for head and neck cancers who were approached for their opinion and support. One of them did not return phone calls or emails so had to be excluded from the study at an early stage. The other oncologist replied with concerns that there was too much overlap between the proposed study and the HN5000 study (Ness et al. 2015). Using a number of questionnaires at three time-points (diagnosis, four months post diagnosis and twelve months post diagnosis), the HN5000 study had several aims. These include comparing morbidity and mortality outcomes across different centres, comparing quality of life outcomes across different centres, and describing the individual economic cost of head and neck cancer care. During a meeting she also expressed reservations about the sample population considering Northtown did not, at

that time, test for HPV within any head and neck cancers. Thankfully, after explaining the purpose of the study and the fact that HPV was only one factor of interest, she was happy to lend her support.

The support received from CNSs across both sites was invaluable. CNSs are in a unique position in that they are often the main lasting contact for these patients throughout their care pathway. Loftus and McDowell (2000) state that patients are more likely to approach CNSs with questions or concerns about intimacy or emotional support compared to doctors. Therefore, it was vital that CNSs were involved in the recruitment of participants (Leathem et al. 2009). The CNSs also commented that they saw the need for studies like this to hopefully improve the overall care available to these patients, especially considering the changing demographic due to HPV.

#### 4.21 Participant identification

All participants were identified and approached through CNSs. While inclusion and exclusion criteria were made clear to the CNSs, it remained my responsibility as the principle investigator to assess or confirm eligibility prior to consent.

Prior to beginning recruitment, provision was made to identify potential participants through pathology records. However, this was not necessary due to the CNSs being able to identify and approach an adequate number of eligible patients.

#### 4.22 Inclusion/exclusion criteria

Inclusion criteria	Exclusion criteria
Treated with radical intent for a primary malignancy of the oropharynx.	Treated with palliative intent.
Completed treatment six months or more ago.	Treated for a secondary head and neck malignancy.
Completed treatment five years or less ago.	
No known distant metastatic spread (excluding nodal involvement at diagnosis).	
A positive prognosis at last follow-up clinic visit.	
Ability to speak, read, and understand the English language.	
Capacity to provide informed consent (as assessed by the consenting researcher).	
60 years of age or younger at diagnosis	
18 years of age or older at diagnosis.	

**Table 5 - Inclusion and exclusion criteria**

While an inclusion criterion was the absence of a poor prognosis at the last follow-up appointment, the study did not select participants based on T (referring to the size or extent of the neoplasm) or N (lymph node involvement) stages of disease. The protocol initially stated that these details would be recorded (if known) and used for analysis in order to identify any patterns

between stage of disease and psychosocial impact. However, with such a small number of participants this was abandoned due to concerns of validity and reliability. Metastatic status needed to be M0 or Mx (M0 refers to no known distant metastatic spread of the primary tumour. Mx refers to the status of distant metastatic spread being unknown. M1 would indicate known metastatic spread) in order to participate. The presence of distant metastatic disease would undoubtedly have changed not only the intent of the treatment but also the way in which the patient and their relatives viewed the disease and impact thereof.

It has been acknowledged that the day-to-day survivorship experience of this patient group may be very different depending on time since diagnosis. Those treated less than six months prior to the interview were purposefully excluded because the acute side effects of treatment may disproportionately impact their view of their survivorship experience. However, there was still a wide variation between the participants in terms of time since diagnosis.

Only English-speaking participants took part in the study. This was agreed initially due to resource limitations. With only myself as the principle investigator conducting the research, and with a very limited budget, there were no funds available for translation which would be needed during the interviews and for transcription. However, given the depth of data it was thought there would be too great a margin of error in the translation to evaluate the interviews to the same degree of depth as the English language ones.

Within this study, *working age* was defined as eighteen to sixty years of age. While this does not encompass all working people, it was deemed important to not differentiate between men and women with regard to retirement age. A

Department of Work and Pensions (2015) report states that while 58.7% of men aged sixty to sixty-four are employed, this figure drops to 40.7% for women. The figure for women aged fifty-five to fifty-nine is 68.7%. By choosing the upper age limit of sixty, it would therefore be more likely than not that female participants would be employed. This supports other studies where sixty has been chosen as the upper age limit, thereby mitigating potential gender disparity (Clegg et al. 2010). In addition, an upper age limit of sixty has several other potential advantages for a study of this type. Firstly, the age of people being diagnosed with oropharyngeal cancer is reducing (Warnakulasuriya 2009), which means more people are facing the disease and the consequences of treatment whilst managing employment, childcare and financial responsibilities. Secondly, those treated radically for cancer at a younger age potentially have a greater number of years ahead of them living with the long-term side effects of treatment. This makes their adaptation following treatment very important to their long term physical and psychological health (Chandu et al. 2006). Finally, little is known about younger people who have been treated for HNC. Many studies have a mean age of participants in their sixties (Marur et al. 2010) so it is important to know more about this growing population of younger oropharyngeal cancer patients.

#### 4.23 Sample size

In total, twelve people were interviewed for the study (from a total of twenty-nine who were approached by the CNSs). The aim of an IPA-based approach is to gather in-depth data focusing on meaning of experience. While there is no *perfect* sample size for an IPA-based study (Smith and Osborn 2007), it is important to aim for quality over quantity, with a small sample yielding detailed in-depth data being preferable to a larger sample yielding superficial data or data lacking in depth and meaning. Elliott et al. (1999) state that qualitative research should

strive to achieve “understanding represented in a way that achieves coherence and integration while preserving nuances” (p. 222–223). Smith et al. (2009) suggest that given the complexity of human phenomena, an IPA study should have a concentrated focus on a small number of cases, with between five and fifteen participants given as an example. The idiographic nature of IPA means that small sample sizes are both justified and necessary (Smith 2004; Reid et al. 2005; Mason 2010) as the analysis of large data sets may result in the loss of “potentially subtle inflections of meaning” (Collins and Nicolson 2002, p. 626). Achieving data saturation can be problematic in this context, as Smith et al. (1999) suggest that the cyclical nature of analysis could theoretically continue ad infinitum.

#### 4.24 Participant recruitment

CNSs were asked to approach potential participants in follow-up clinics. In each instance they gave the patient an information pack, which included a participant information sheet and an expression of interest form. Each envelope was coded in order to identify who would require a follow-up letter. The patient was given the option to return the expression of interest form in a pre-paid envelope or to hand the form back to the CNS who would then return the form to myself. A contact phone number and email address were also provided if they preferred not to use the form.

If an expression of interest form or phone call had not been received within two weeks from posting/distribution, a reminder letter was posted by the CNSs (also supplied in sealed, pre-paid envelopes) (Gravetter and Forzano 2009). In the event that no expression of interest had been made within two weeks from that postal date, it was assumed that the individual did not wish to take part and they would not be contacted again.

Contact with myself was minimised to avoid any potential influence in the person's decision to participate. However, the decision was made to accept expression of interests by phone or email with the assumption that take-up rates would be improved. This assumption proved false because all participants returned the forms by post.

<b>Task/action required</b>	<b>Person responsible</b>
Two recruitment folders compiled (one for each recruitment site), each with twenty initial patient information packs, and ten follow up packs (with more of each available on request).	Researcher
Recruitment folder given to CNSs at Northtown and Southtown, along with a separate list of inclusion/exclusion criteria and a record of who was approached and when.	Researcher
Eligible patients given an information pack.	CNSs
Name of patient, code number and date that the information given is recorded.	CNSs
CNSs notified of code number if patient responds with expression of interest.	Researcher
If expression of interest is not received within two weeks of the initial information pack being given, a follow-up pack is posted to the patient in a pre-paid envelope.	CNSs
Once an expression of interest is received, the potential participant is phoned to answer any questions about the study, confirm eligibility, and arrange a date and time to conduct the interview (if applicable).	Researcher
Three copies of the consent are obtained. One is kept by the participant, one is retained by the researcher, and one is sent to the relevant oncologist for inclusion in the patient's records.	Researcher
The interview is conducted and is audio recorded.	Researcher
Post-interview reflections are audio recorded within two hours of the interview ending.	Researcher

The audio recordings are transferred from the digital voice recorder to a secure data storage device.	Researcher
The audio recordings are deleted from the digital voice recorder.	Researcher
Recordings (including post-interview reflections) are transcribed verbatim	Researcher
Transcripts are read through several times whilst listening to the audio recording. Pauses, laughter and non-verbals are added. Names and identifiable information are removed/changed.	Researcher
Transcripts are imported into NVivo and coded.	Researcher
Codes are condensed into broader themes.	Researcher
Themes are exported as reports.	Researcher
Reports are used to identify commonalities and differences. These reports form the basis of the findings chapters.	Researcher

**Table 6 – Recruitment & data collection process and person(s) responsible for each task**

In total, nine men and three women were interviewed for this study. Several others returned expression of interest forms but did not choose to participate in the study. While the researcher did not directly ask any of these people why they chose not to take any further part in the study, some offered some explanation during initial telephone conversations. These reasons included the anticipated interview length being too long, although this was indicated on the information sheet, and no time due to work commitments.

The diagram on page 118 (figure 7) shows the process of data collection and analysis.

Twenty-nine patients approached by CNSs over a period of fourteen months



Two responded but could not make contact/did not return calls to arrange interview. One declined after clarifying time commitment by phone. One excluded as over upper age limit. Twelve participants agreed to take part.



Interviews took place between May 2014 and July 2015. Time between expression of interest being received and interview taking place ranged from one week to two months. Consent was always obtained immediately before the interview.



Reflection was an ongoing process, but time was taken after each interview (within twenty-four hours) to analyse and reflect on interview technique and interviewer bias.



Transcription took place as soon as possible after the interview. This ranged from one to three weeks depending on how close the interviews were to each other



At several points during data collection portions of interviews and transcripts were checked by supervisors for accuracy and feedback.



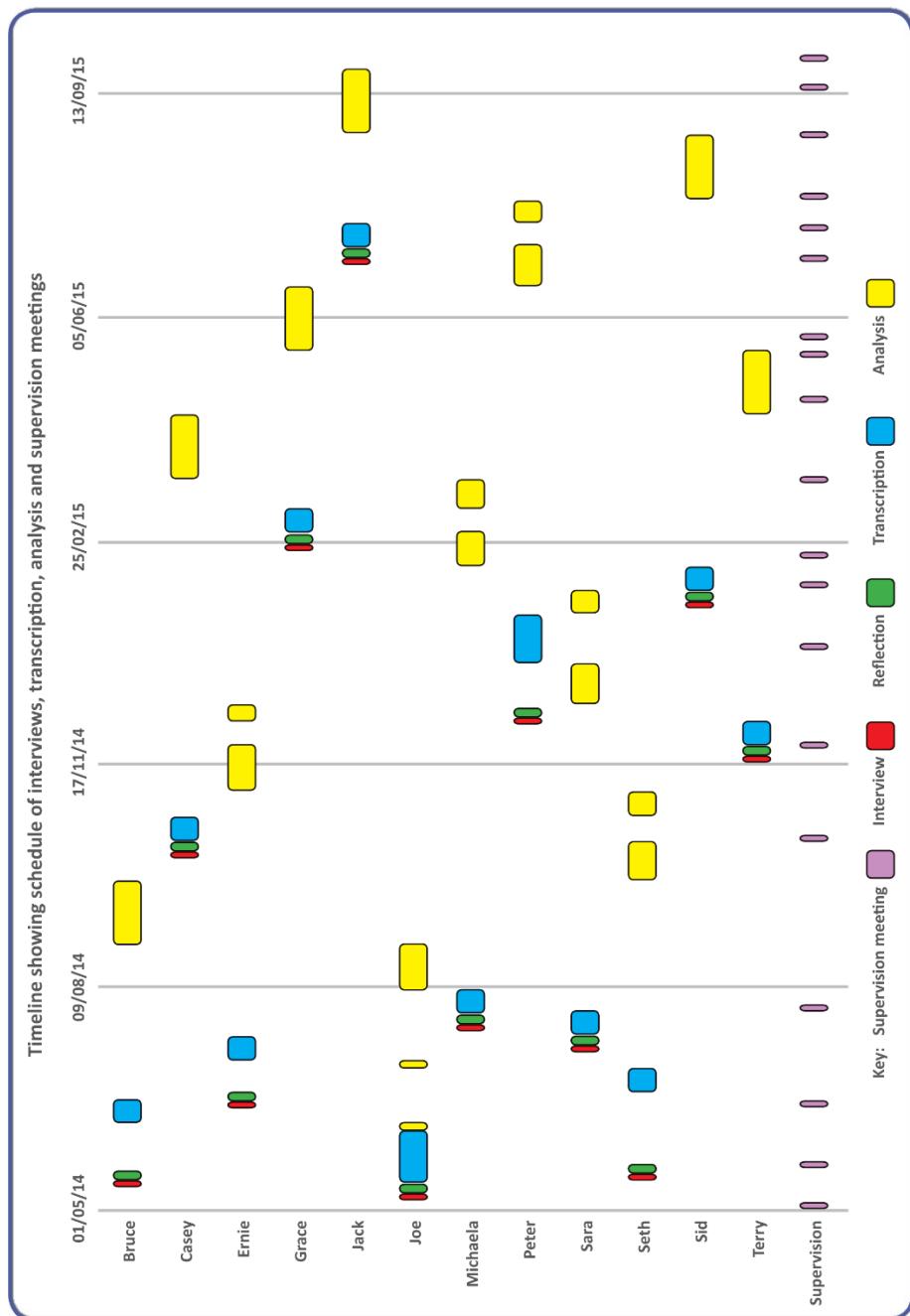
Analysis was an ongoing process and took several months.



Coding, themes, interpretations and reflection were all checked and discussed by supervisors at regular supervision meetings.

**Figure 7 - Diagram showing the process of participant recruitment, interviewing, transcription and analysis.**

Figure 8 (below) is a diagram showing when each interview was conducted, along with subsequent reflection, transcription and analysis. Supervision meetings are also recorded. Exact dates of transcription and analysis were not recorded and are approximated.



**Figure 8 - Graph showing when each interview was conducted, along with subsequent reflection, transcription and analysis.**

## 4.25 Data collection

### 4.25.1 Interview preparation

In my clinical role, I am accustomed to speaking to patients, often in a private setting similar to that of an interview. The training involved in becoming a therapeutic radiographer is very focused on meaningful communication.

However, with the pressures of clinical practice this communication is often very one-sided and focuses on information giving rather than exploration of psychological experiences. Moreover, personal experience shows that some radiographers are uncomfortable speaking about personal matters or sensitive issues such as sexual health and intimacy.

While I have had experience of recording and transcribing interviews prior to this study, these have been limited to training exercises of around twenty minutes in length. In preparation for the interviews, I and one of the academic supervisors conducted a mock interview. The aim of this was to assess my interviewing technique with regard to how well I use open probing questions, and to address other issues such as body language. This critique of interview technique and body language was invaluable and highlighted a number of mannerisms which I was not aware of previously, including the use of excessive hand gestures. This mock interview was transcribed in the same way that the real interviews would be.

There were times when I would use silences to gather my thoughts, but even then, I would sometimes struggle to use the correct language.

#### **4.25.1.1 Silence**

Silence was an important aspect of the mock interview as well as the real interviews. When looking at communication between two or more people, silence is simply the absence of speech (Van Servellen 2009) but its use and the importance of its use has been the focus of a great deal of research. Silence is usually described as a period within conversation devoid of speech lasting beyond three or four seconds, whereas a pause is shorter and is seen as a natural rest in the melody of speech (MacGregor et al. 2010). Silence in everyday social interaction can be uncomfortable and is often seen as a failing by either or both sides to engage with the other person (Faulkner 1998). The mock interview reaffirmed the value in using silence. Silence is a powerful tool in communicating empathy and eliciting emotions. Martyres (1995) suggests that because emotions are often complex and experiential, especially when coming to terms with a cancer diagnosis or thoughts of end of life (EOL) issues, in a clinical setting words are sometimes inadequate or fail to ring true with the patient. She goes on to say that silence helps to demonstrate active listening thereby suggesting an interest in the patient's well-being that goes beyond the need to do something or refer them to yet another person. Van Servellen (2009) states that there are three basic elements of conversational silence: interresponse time, the interruption response, and the over-talk response.

Interresponse time refers to the length of a period of silence, and these times are often less than a second in general informal conversation. However, while there seem to be common rules across languages and cultures such as turn-taking and not talking over the other person, interresponse times in normal conversation can vary according to social norms and values (Stivers et al. 2009). Interresponse times are usually extended in other groups where lethargy, pain, fatigue, or mental impairment (common in cancer patients) are present (Rojahn

et al. 2007). By extending interresponse times within an interview to more than three or four seconds a feeling of “interpersonal space” (Van Servellen 2009, p. 136) can be created, thereby allowing the participant space to think and form a comfortable and considered response.

Interruptions have the opposite effect of extended interresponse times and can reduce feeling of interpersonal space within a conversation. Sidnell and Stivers (2012) suggests verbal encouragements such *hmm*, *uh-huh* and *okay* are not classed in the same way as complete responses or interruptions and therefore can be used without fear of breaking the silence. However, overuse of such encouragements may seem somewhat clumsy. Personal experience suggests that the limited use of non-verbal encouragements such as open hand gestures and nods may be more effective in allowing the patient to express themselves.

Over-talk (where there is no interresponse time and one person speaks before the other has finished their sentence) may be seen as diametrically opposed to extended interresponse times in purpose or intent, as it can reduce interpersonal space to such an extent that free expression is diminished or conflict is encouraged (Markel 1975).

Each participant responded differently to silence during the interviews. For instance, Seth seemed slightly uncomfortable at times and would break any silences very quickly. These breaks were sometimes in the form of new information or sometimes turned into filled pauses such as “so...”. In comparison, Michaela seemed to need the silences in order to process her thoughts, so the silences would often go far beyond what someone else, including myself, would find comfortable. However, I was able to use visual cues to judge if this was suitable for her. Michaela would often look away from me during these silences and would not look back until she wanted to continue.

While it was only a personal interpretation, she appeared to use the silences as time to reflect on her experiences and make sense of them.

The use of silence in the interviews was invaluable, but it may not be something cancer patients are familiar with. Clare (1991) suggests that physicians often find such silences challenging as they seemingly go against the normal working pace of hospital life and interrupt the informative purpose of the conversation. Similarly, silences that are allowed to exist beyond what is useful (which can vary depending on the participants and the context) may allow the thoughts of the participants to wander, thereby resulting in a loss of the focus of the conversation (Browning et al. 2007).

#### *4.25.1.2 Phrasing*

Phrasing can be described as the way in which questions are asked or how topics are introduced (Patton 2014). Prior to starting the interviews, I felt a lot of pressure to get the phrasing ‘right’. Considerations of harm, credibility and usefulness were all driving factors to make sure the study was the best it could be. However, I was also aware that there would be a steep learning curve when deciding how to phrase questions in a real interview. Reading about how to conduct research interviews suggested that often the best way to approach it as a novice researcher is to be open and honest with the person you are interviewing. By stating that you are not very experienced at these kinds of interviews, it may actually help to allay possible concerns the interviewee may have about being interviewed and allow for a more meaningful exchange.

A good research partnership is more important to the quality of the interview than the phrasing of specific questions. If the respondent and I get along well, he or she will accept that the

detailed accounts I request are important for the study and will tolerate any fumbling or uncertainty in my questions.

(Weiss 2004) p.46

#### *4.25.1.3 Open vs. closed questioning*

This framing of questions can be tailored to finding specific information such as *what is your age in years* or *are you currently married*. These questions that seek definitive answers such as specific numbers or yes/no responses are referred to as closed questions (Patton 2014). As with many questionnaires that use Likert scales (disagree, somewhat disagree, somewhat agree, agree) (Allen and Seaman 2007), closed questions are more often used in quantitative research. What became apparent during the mock was that I often used closed questions where open questions would have been more suitable. Open questions are intended to be more open to interpretation and facilitate further conversation (Willig 2013). Examples of open questions would be, *tell me about your family* or *how did you feel when you were told of the diagnosis*. These questions have no specific answer, and therefore the interviewee is more likely to think about, and possibly interpret their experience (Pietkiewicz and Smith 2014), or they could ask for clarification if the question is too broad. What is desirable in IPA research is for the interviewee to think about their experience and interpret that in order to fit in with their life-world. This process forms one part of the double hermeneutic circle. The second part of the circle is then the interviewer, who tries to interpret the interviewee's interpretation in order to make sense of that experience (Smith 2015), as previously seen in Figure 6 (page 103). However, using open questions does not necessarily elicit reflective responses and in-depth detail.

#### ***4.25.1.4 Leading questions***

Leading questions are those which guide the participant towards a particular answer, or area of interest (Ritchie et al. 2013). Already presented in this study, there is a large amount of evidence linking HPV as an oncogenic factor in the development of oropharyngeal cancer, and particularly with the change in patient demographic. It was important for the credibility of the study, as well as the protection of the participants, that discussion around HPV not be artificially introduced by myself as the interviewer. Great care was taken during each interview to avoid this possibility. Questions were phrased such as, *what do you know about what may have caused your cancer?* It was acknowledged prior to ethical approval that even this kind of question may cause the participant to ask further questions about the possible causes of the cancer, or to seek out additional information after the interview. This was one of the reasons for the development of the supportive services leaflet (see Appendix L), so that questions could be directed appropriately.

#### ***4.25.1.5 Repeating and summarising***

A useful technique in demonstrating engagement with the interviewee is to summarise or to repeat their own words back to them (Patton 2014). This technique proved to be very beneficial in exploring the participants' survivorship experiences.

#### ***4.25.1.6 Probing and boundaries***

Probing, sometimes referred to as laddering, is a way to explore potentially sensitive topics whilst protecting the participant, or at least minimising the potential harm caused by being pressured to talk about difficult topics.

According to Price (2002), “the management of intrusive questions is key to successful interviewing” (p. 273). In practice, this means using verbal and non-verbal cues to assess the participant’s response and making the decision to either move forward with the line of questioning, or to retreat and move to topics that are more comfortable for the participant.

#### *4.25.1.7 Funnelling*

Funnelling builds on probing techniques, but is more focused at addressing particular topics of interest (Ashton 2014). The way in which funnelling was used has already been discussed in section 4.26.4 (page 131) and is also referred to in section 5.10 (page 188).

#### **4.25.2 Interviews**

A single, minimally-structured interview was conducted with each participant. Each interview was expected to last between forty-five minutes and two hours (Seidman 2012). Only two interviews extended to two hours, with most lasting between eighty and ninety minutes. With each interview, I had minimal written notes. I took a brief topic guide to help drive the interviews (Pope and Mays 2013), but the structure and flow of each interview was unique. Minimally or semi-structured interviews cannot be identical as they are led by the responses of the participant.

All but one of the interviews took place in the participant’s homes. On one occasion the participant did not wish to be interviewed in her home, so a private area in a cancer support centre was used. It was stipulated in the ethical submission that the interviews would not take place within an NHS Trust

building. Due to geographical constraints it was not practical to use Cardiff University property for any of the interviews.

After the interview, participants were asked to complete a short questionnaire intended to gather demographic information including age, gender, modality of treatment(s), time since diagnosis, tobacco history (both before and after diagnosis), alcohol history (both before and after diagnosis), marital status, household income, number of dependants and employment status (both before and after diagnosis). Due to the small sample size it would be impossible to draw any significant conclusions between thematic findings and such lifestyle factors. The questionnaire was intended to assist in comparing the sample with other studies and also to provide a detailed description of the participant demographic.

There were times when I could not complete the transcription of an interview before the next interview. This is not ideal as the transcribing process acts as a first stage of analysis and familiarisation, which helps to inform and shape the subsequent interview (Smith et al. 2009). However, the timing of each interview was, in most part, dictated by the interviewees' schedule. One interviewee wanted to bring the date of the interview forward to before the start of school holidays as she had a young daughter who was not aware of her diagnosis. Similarly, one respondent asked for the interview to be delayed by several weeks in order to fit in with her personal commitments.

#### 4.25.3 Post-interview reflection

Immediately after each interview, I would spend some time recording thoughts and reflections on an audio voice recorder. This allowed me to reflect on the interview and to record thoughts relating to aspects not apparent in the audio recording of the interview. These could include justification of prolonged

silences or body language cues which influenced the trajectory of the interview. These reflections were also transcribed as soon as possible after each interview.

#### 4.25.4 Interview questions

IPA-based studies are focused on the experience and subsequent perception of the participant. Therefore, interview questions were heavily influenced by the participant themselves. While these questions may appear lacking in purpose, they were intended to introduce topics which the participant and interviewer could then develop between themselves. Some examples of interview questions are:

- Tell me about your life.
- How would you describe your life now?
- Some people who have had cancer have said they have noticed changes in their relationship with their [partner, children, colleagues, parents]. Is this something you recognise in your own experience?
- What do you know about what may have caused your cancer?

#### 4.26 The reflective process/development as a researcher

It was important that some of the reflective work conducted throughout the PhD process was included within the finished thesis. The nature of the relationships that develop with the participants through their interviews is something which is difficult to capture. Reflective thinking and writing acted as a way to record these sometimes-fleeting thoughts. This chapter will demonstrate some of this work and acts as further proof as to the rigour of the study as well as my engagement with the hermeneutic process.

#### 4.26.1 Emotion

There were often displays of emotion which were difficult to convey in the transcripts. For instance, when Sara began to cry at one point in the interview, it felt very powerful and carried with it a lot of emotion. However, when transcribing the interview, just writing “starts to cry” did not convey the meaning or the impact. This reaffirmed the importance of me carrying out my own transcription. By doing this I would be able to reflect on the experience itself as well as analyse the data in the form of the transcript.

The difficulty of conveying meaning in the transcript was even more pronounced when the emotion was more subdued. When interviewing Bruce, he spoke very eloquently about his thoughts around ending his life during treatment, but his body language remained very static throughout, and his voice was almost monotone. In a strange way, this lack of emotion gave a greater impact to what he was saying as it appeared very calculated and thought-through. However, this was very difficult to convey in the transcript and so the use of post-interview recordings of my thoughts and impressions became vital in helping to include that emotion in the analysis.

#### 4.26.2 Difficulty talking

What was most difficult to address during the interviews was a reluctance to talk openly about their experience. This is somewhat common in clinical practice where the patient will engage in their treatment to the extent of attending appointments, but refuse all other support and advice, possibly as a way of maintaining control of a situation that they have very little control over (Semple et al. 2004). Previously I had assumed that if someone had taken the

time to respond for inclusion in the study that they would be willing to actively engage in the process.

While the motives for participating in research are often complex, it was surprising that someone like Ernie, and to a certain extent Seth, would take part when they did not seem comfortable talking about their experiences. While both men mentioned a desire to “give back”, they both seemed far more comfortable talking about the physical effects of treatment rather than the emotional or psychological impacts.

During these more challenging interviews it was often a consideration that it was my questioning style or interviewing technique that was at fault. Perhaps if I had found the right style or the right phrasing, the participant would open up in a similar way to some of the other participants. While my interviewing technique and style will continue to evolve throughout my career, it is inevitable that some people either do not want to talk as openly or they do not have the vocabulary to do so.

#### 4.26.3 Positioning

Something which was not thought about much before beginning the interviews, was how I should place myself in the room, other than for personal safety reasons. In clinical practice, I would not have to enter an unfamiliar room with a patient. This means that I am able to position myself between the patient and the door. Therefore, if the patient becomes aggressive, I would not be stopped from getting help. This is not the case in the majority of interview situations and was something that I was aware of when entering anyone’s home.

The seating position also had an impact on the interview itself, with an opposing position, as with Ernie, seeming confrontational and a side-by-side position, as with Joe, lacking the opportunity for eye contact.

#### 4.26.4 Protection

Given that the participants did not know the type of questions being asked or the areas of interest prior to the interview, I had to accept that there would be some areas that participants would not be comfortable talking about. This formed an important area of ethical approval and something I had to be aware of as much as possible, while still being able to collect valuable data.

Prior to beginning the interviews, I sought help from Dr Isabel White. Dr White is an expert in sexuality and intimacy research. She suggested funnelling as a way to approach traditionally sensitive subjects. Funnelling offers the participant an opportunity to acclimatise themselves to speaking about potentially sensitive issues as well as giving them an opportunity to give either implicit or explicit cues as to whether it is something they are willing to talk about.

While some participants seemed somewhat surprised at some of the questions asked, with one commenting that they expected more questions about physical side effects, nearly all seemed happy talking about intimacy, sexuality and body image. However, few went into detail and non-verbal cues often meant ending such lines of enquiry short.

#### 4.26.5 Post-interview reflections

After all-but-one of the interviews, I would drive a short distance away from the participant's house (or other location if the interview was conducted elsewhere) and spend around twenty minutes recording my thoughts and reflections of the interview using the digital voice recorder. There was no set format for these reflections. The aim was to get all of the initial thoughts out, so I could refer back to them later, in conjunction with the transcripts. For the first interview I did not do this, and subsequently I found it difficult to think clearly about the interview, or to think about anything else for that matter. By recording the thoughts immediately after each interview, I found that I was able to clear my head and think about each encounter more objectively.

#### 4.27 HPV diagnosis

With each participant their HPV status was not known prior to the interview, as this may have influenced the data. It was a matter of concern when conducting the interviews, that the subject of HPV should not be a primary focus. Questions were phrased as to be deliberately ambiguous, such as *what do you know about what may have caused your cancer?* Only if the participant raised the issue of HPV or *a virus* would the topic be explored more fully.

It was considered prior to beginning the study, that by highlighting a potential viral cause to the participants' illness that had not previously been discussed by their cancer care team, they may be worried or distressed by new information.

At no point had this study been given permission, through ethical approval or by the participants, for medical records to be accessed. Therefore, any information regarding the participants' medical history, such as HPV diagnosis, had to be proffered by the participants themselves.

#### 4.28 Transcription

Transcription has been one of the most important steps in understanding the data. While extremely time consuming, by spending approximately two to three days (per interview) listening to and transcribing the interview recordings, I have been able to gain a connection with the data which would have been extremely difficult to do otherwise. Initially, this caused some problems when sharing the transcripts during supervision meetings, as I omitted from the transcript details such as silences, humour, and my own reflections at the time as I recalled them. This was a lengthy developmental process and seemingly improved with each transcript. However, the challenge was always to make the participants' voices heard through the data as if they were speaking directly to the reader (Larkin et al. 2006).

#### 4.29 IPA analysis

While there is no single prescribed method for working with data in an IPA study, it is important to demonstrate transparency and consistency between datasets. Regardless of approach, the focus should always centre on the "participants' attempts to make sense of their experiences" (Smith et al. 2009, p. 79). This focus can be typified by examining the journey from the particular to the shared, and from the descriptive to the interpretative (Smith 2004). The iterative and inductive cycle of IPA analysis commonly includes:

- Close line by line analysis of the experiential claims, concerns and understandings of each participant.
- The identification of emergent themes within the data, firstly within cases and then across multiple cases.

- Moving towards an interpretative account by developing a dialogue between the researcher and the experience of the participants.
- Development of a framework which illustrates the relationship between different themes.
- A clear and auditable structure which clearly shows the development of ideas and interpretations from initial comments through to themes.
- The use of supervision and/or collaboration to test the coherence and plausibility of the interpretation.
- The development of a full narrative evidenced by detailed transcript extracts, which takes the reader through this interpretation. This may be supported by a simple visual guide such as a diagram or table.
- Reflection on one's own perceptions and processes.

(adapted from Smith et al. 2009, pp. 79-80)

#### 4.29.1 Reading and re-reading

Each transcript was read and re-read multiple times. The first stage was to read the transcript whilst listening to the audio recording in order to ensure accuracy. This was also an opportunity to add additional comments, such as the use of humour. The aim at this stage was familiarisation rather than a conscious attempt at any sort of analysis. However, Smith et al. (2009) suggest that this stage is an opportunity to note down any initial observations in an attempt to bracket them off. In practice this was done in conjunction with the recordings made immediately after each interview, whereby I recorded my initial thoughts and preconceptions around the participant and the interview.

As a lot of academic reading can often be about speed and assimilating the most information in the shortest time, Smith et al. (2009) also suggest that this

stage is about slowing down. This ensures that the participant becomes the focus of the analysis and allows the researcher to begin to enter their world. This is something they describe as “active engagement with the data” (p.82).

#### 4.29.2 Initial noting

Potentially the most detailed and time-consuming stage of analysis, initial noting examined semantic content and the use of language on a very broad and descriptive level. There were no set rules at this stage. The aim was to continue the process of familiarisation with the data and produce a detailed and comprehensive set of notes for use in the next stage of analysis. It is at this stage where areas of importance to the participant will begin to develop, as well as the meaning to the participant of those areas.

This process changed and developed over time. Initially there was a colour-coded system used within the transcription, which could be amended and re-worked ad infinitum. This was adapted and amended from other IPA studies as highlighted in an IPA workshop. The colour coding used was:

**Yellow**: Areas of interest after initial reading

**Green**: Direct quotes taken from the transcript

**Blue**: Descriptive comments

**Red**: Linguistic comments

**Orange**: Conceptual and psychological comments

**Bold purple**: Emergent themes

After speaking to other experienced researchers, it was suggested that this method, while suitable for single data sets, may be more problematic for multiple data sets as themes or topics could not be easily linked or tracked.

After that advice, NVivo 10 (QSR 2016) was used as a way to bring all of the transcripts together. While this method is just as reliant on the researcher to analyse, evaluate and interpret the data, it does allow for a clearer and more transparent structure from initial ideas to emergent themes. See Appendix M for an example of how each transcript was coded. Codes and themes were developed over time from what best fitted the data as well as discussions with supervisors.

#### 4.29.3 Developing emergent themes

After initial noting, the data set had grown substantially. The aim of this stage was to reduce the volume of detail whilst maintaining complexity through mapping patterns and connections between the notes.

The process began by examining smaller chunks of the transcript, whilst bearing in mind all that was learnt about the participant through the earlier stages. This broke up the narrative but was necessary in order to come together as a “new whole” (Smith et al. 2009, p. 91) at a later point when writing up.

Themes are often expressed as phrases which sum up what is important in the extract or comment, and which are both tied to the particulars of the comment, yet also link to the conceptual or theoretical. These themes should unite the participant’s original words and also the analyst’s interpretation of what was said.

#### 4.29.4 Searching for connections across emergent themes

Once the themes have been collated, they need to be mapped as to how the analyst thinks the themes might fit together. Once again, this stage is not

prescriptive and relies heavily on individual interpretation. One way to do this is to group emergent themes under larger umbrella (super-ordinate) themes (Smith and Osborn 2007). For instance, emergent themes of giving up work, changes to relationships, and difficulty adapting to altered eating habits may all come under the super-ordinate theme of loss of control. Although interpretative, it was important to think about, and refer to what made this population worthy of study when looking at categorising emergent themes, as not all themes have to be linked and may be discarded at this stage.

For this study, searching for connections was done within NVivo. Initial stages of coding generated themes in response to the individual interviews and resulted in a large number of specific themes. For instance, Seth spoke a lot about going to the gym and took pride in his physical fitness, whereas Terry spoke about wanting to be fit enough to go on another skiing holiday with friends. Both were coded as *fitness*, but sub-categories were used to indicate the importance Terry put on fitness in order to facilitate previous social relationships rather than fitness for personal wellbeing or preventing future illness. This level of detail was important in the early stages of analysis as it helped to make each of the participants' stories unique and memorable. Subsequently, themes could be grouped to make the later stages of analysis more manageable. However, it is important to stress that those initial sub-categories were still of great value once I returned to the data at a later stage.

#### 4.29.5 Moving to the next case

One of the challenges faced with multiple participants and multiple data sets was the influence one data set can have on the analysis of each subsequent data set. While it is important to treat each data set individually and bracket all

others, every researcher must acknowledge the change in fore-structures caused by analysis of previous data sets (Brocki and Wearden 2006).

#### 4.29.6 Looking for patterns across cases

The final stage looked at the super-ordinate themes from each data set and compared them, taking a step back from the individual stories to give context and meaning to the data as a whole. This offered the opportunity for increased creativity and led to themes being re-labelled or re-examined (Smith et al. 1999).

A great deal of analysis was devoted to asking the question of why the participants described their experience in a particular way. In analysing each of the transcripts, specific questions were asked. What, if anything, did the participant want for themselves from taking part in the study? What, if anything, did the participants want from me as the researcher? When analysing the data as a whole, one specific question was asked: Do the participants' motives have wider implications (beyond the study)?

### 4.30 Quality and rigour

It was essential to maintain the quality of the research to ensure that the findings were robust enough to ultimately contribute to knowledge. However, unlike quantitative research, the quality of qualitative research cannot be measured by statistics such as confidence intervals or rigid reproducibility (Noble and Smith 2015). Instead, qualitative researchers aim to design and incorporate methodological strategies to ensure the *trustworthiness* of the findings (Noble and Smith 2015). *Trustworthiness* is a broad term but encompasses other concepts including *quality* and *rigour* (Nakkeeran and

Zodpey 2012). Although there are a number of different criteria used to assess the rigour of a piece of qualitative research (Houghton et al. 2013), the most commonly used are still those proposed by (Lincoln and Guba 1985); Credibility, Dependability, Confirmability and Transferability.

#### 4.30.1 Credibility

Credibility refers to whether or not findings of a study accurately reflect the life-world of the participant(s) (Lincoln and Guba 1985). Indeed, one of the most common issues with qualitative research is the subjective nature of data interpretation (Nakkeeran and Zodpey 2012). Consequently, qualitative researchers attempt to reduce this issue through various means including participant validation (Horsburgh 2003), external validation (Malterud 2001) and a mixture of peer and participant validation (Burnard et al. 2008).

Participant validation, or member checking, can be done during or after data collection, and involves asking participants to either affirm or reject summaries made by researchers on their views, feelings, and/or experiences (Mays and Pope 1995). External validation, on the other hand, involves an external qualitative researcher analysing the data independently and checking for consistencies between findings (Long and Johnson 2000). For my study, member checking was not used. This is in line with many IPA studies as it can be in conflict with the interpretative nature of the approach (McConnell-Henry et al. 2011).

"IPA is interpretative, so some validation strategies, such as 'member-checking,' may be less appropriate than others. Member-checking may be appropriate for single case designs, where the interpretation offered can be traced back to one person's account. For designs with multiple participants, the combined effects of amalgamation of

accounts, interpretation by the researcher and the passage of time, can make member-checking counter-productive." (Larkin and Thompson 2012) (p.112)

Instead, as a form of external validation, sections of transcripts were given to academic supervisors to read, and supervision meetings were held to discuss identified themes. Similar activities also took place between other PhD students at the university as a form of peer-checking.

Summaries of supervision meetings along with personal reflexive accounts were kept throughout the PhD process. These were kept in order to maintain self-awareness during the research process by describing and interpreting my experiences as I went along; a process often used by researchers to enhance credibility of findings (Guba and Lincoln 1989). An additional credibility strategy employed in my research was that of transparency of interpretation of data; ensuring that all findings and interpretations were discussed in relation to, and supported by, data extracts throughout.

#### 4.30.2 Dependability

The dependability of research is the extent to which the conduct of the study has been carried out according to accepted procedures (Lincoln and Guba 1985). During the design of the study protocol it was deemed necessary and prudent to seek expert advice regarding certain sensitive aspects of the data collection process. Isabel White is an expert in psychosexual research and has a great deal of experience in using interview to discuss issues surrounding intimacy and sexuality (White 2008). She suggested that it is extremely difficult, and potentially dangerous, to directly approach some topics without preparation and/or warning. Rather than asking a question such as, *how would*

*you describe you and your partner's sexual relationship since you were diagnosed?*, the topic needs several precursor questions which aim to funnel from the general to the specific (Ashton 2014). These additional questions allow the participant to acclimatise to discussing potentially sensitive subjects, as well as giving the interviewer the opportunity to assess if it is safe to proceed to the next level of questioning. When asked about determining what is a *safe* response, the recommendation was to use the same skills as in clinical practice. These include monitoring verbal cues (short responses, changes to tone and timbre of voice) and non-verbal cues (shifting in seat, avoiding eye contact, becoming flushed or defensive physical postures such as folded arms) to establish if it is acceptable to continue. Dr White also suggested that if the cues suggest it is not acceptable to proceed, that the topic may not be off limits for the entire duration of the interview. She suggested attempting to return to the topic at a later time, and perhaps re-phrasing the line of enquiry, and then re-assessing. As a rapport builds between participant and researcher, what may be uncomfortable to discuss part way into an interview, may become more acceptable later on. This is a view supported by Lee and Lee (2012) and Ashton (2014). This was shown in several of the interviews, including Michaela. When discussing partner intimacy, her non-verbal responses initially indicated that she was uncomfortable with this line of questioning. As the interview progressed, I returned to the topic, re-framing the questions, which elicited a much more open response.

#### 4.30.3 Confirmability

Confirmability considers whether the researcher has acted in good faith or demonstrated bias (Lincoln and Guba 1985). Both the dependability and the confirmability of the current study were enhanced by exposing the data, and my interpretation of it, to the scrutiny of other social scientists, namely my PhD

supervisors. Both supervisors reviewed excerpts of anonymised transcripts, along with the coding that I had done (see Appendix M for an example of the coding of Sara's interview). This was then analysed during supervision meetings and the validity and appropriateness of the coding discussed. An informal group of other PhD students undertook a similar task on several occasions; reading a number of extracts and reporting their interpretation of these data. Themes produced by my supervisors and the other PhD students matched my own interpretation of the data, therefore suggesting confirmability of results. Data interpretation continued to be discussed with my supervisors for the duration of the project, in order to maintain this rigour.

#### 4.30.4 Bracketing

Bracketing is used in qualitative research to mitigate the potentially damaging effects of preconceptions that may taint the research process (Tufford and Newman 2010). There is no one single definition of what bracketing is or how it can affect the outcome of the piece of research in question. Similarly, bracketing is not a one-time occurrence of removing or suspending preconceptions, but a process of self-discovery whereby buried emotions and experiences may surface (Drew 2004). In reality, pre-conceptions cannot be completely removed or bracketed (Koch 1995). Our pre-existing knowledge is vital for relating to people and contextualising situations. The aim is to become aware of these preconceptions and view our interpretations of the data alongside them. This view is supported by Smith et al. (2009), who suggest that the researcher must remain aware of and acknowledge the possibility of bias, but accept that one cannot completely ensure that it will not occur.

In practice, bracketing meant reflexive writing and discussion with supervisors both before and after interviews. For example, before each interview, I would

get directions using Google Maps (2016). To make sure I knew where I was going, I would sometimes look on Google Maps Street View (2016) as well. This meant that I was never late for an interview, and I could find alternative places to park if there was no parking in the immediate vicinity. However, I soon became aware after the first interview that I was also making some assumptions about the participants based upon socioeconomic factors. These included the area they lived in, the cars they and their neighbours drove, and the condition of the house they lived in. Even when I interviewed a participant at a cancer support centre rather than her home, I had unknowingly made assumptions before meeting her. On the phone prior to the interview, I had made sure that the participant met the inclusion criteria (including up to and including sixty years of age at time of diagnosis) but had not asked her actual age. On meeting her, there was some surprise to see that she was younger than had been imagined. Even on reflection, it was difficult to see why that assumption had been made. However, by being aware of such assumptions and recording them after each interview, I could minimise their impact on the interview and subsequent analysis. Such examples were also discussed with supervisors to investigate how these preconceptions could influence the analysis and subsequent interpretations.

#### 4.30.5 Transferability

Transferability refers to whether or not the findings of the research could be transferred to other contexts (Lincoln and Guba 1985). As transferability is dependent upon the degree of similarity between two contexts (Guba and Lincoln 1989), qualitative researchers propose that the original context of the study must be described adequately so that a judgement of transferability can be made by readers (Guba and Lincoln 1989; Semple et al. 2008). Chapter five has provided detailed demographics of participants. However, again due to the

highly interpretative nature of IPA, Pringle et al. (2011) suggest thinking in terms of theoretical transferability rather than transferability of results. The nature of IPA strives the researcher to bear witness to the life-world of the participant, through the lens of their own life-world. Taking both *that* participant and *that* researcher away would almost certainly result in different interpretations and insights.

#### 4.30.6 Participant freedom

Bruce's interview: This was the second interview, so while there was less uncertainty and awkwardness than the first, the experience of interviewing him in his own home was still a new and daunting experience. The fact that Bruce felt willing to share his thoughts of suicide gave me a sense of accomplishment because he had been given the space and implicit permission to discuss whatever he wanted to. However, there were mixed feelings around whether this was a safe situation for him to open up in this way and whether the support was in place if needed after the interview.

#### 4.30.7 Utility and relevance

Utility and relevance were important considerations when designing and conducting the study. The “so what” question was an important factor in choosing to explore the experience of oropharyngeal cancer patients. The literature suggested that HPV may be a major issue in their post-treatment experience, but yet little research had investigated the life-world of these patients after treatment had ended.

The timing of the study was important because of the increasing number of working-age people being diagnosed and treated for oropharyngeal cancer. More people means a greater need to understand their experience.

As previously mentioned, treatment techniques are continuously developing. Radiotherapy advancements such as parotid gland sparing will hopefully mean fewer side effects relating to reduced saliva production. However, the advancements may not improve the psychological impact of diagnosis and treatment.

Better understanding of the experience of this patient group will inform future research to provide opportunities for signposting or appropriately placed support where it is needed most. This will be explored further in later sections of the chapter.

### 4.31 Ethical issues

#### 4.31.1 Approval processes

In order to protect the identity of the study's participants, it was recommended during an annual university progress review that the locations of the hospitals and Trusts also be anonymised. Their names have been replaced with Northtown and Southtown.

A scientific review of the study was conducted by the School of Nursing and Midwifery Studies (now the School of Healthcare Sciences) Research Review and Screening Ethics Committee (RRESC) at Cardiff University. The purpose of the RRESC review was to assess the study's scientific merit; can it achieve what it sets out to do? This review is conducted by an experienced researcher and academic and forms an important part of the study's progression.

Ethical approval was obtained from the Research Ethics Committee (REC) for Wales (REC reference 14/WA/0013, see appendix C). NHS Research Ethics

Committees consist of up to eighteen members, roughly one-third of whom are lay members (non-researchers or registered healthcare professionals). The focus of the REC is to safeguard the rights, safety, dignity and well-being of research participants, independently of research sponsors (Health Research Authority 2016).

Local governance reviews were undertaken by the Northtownshire Research Support Service (part of the Northtownshire Hospitals NHS Foundation Trust) and the R&D Executive Group (on behalf of Southtown and Southtownshire NHS Foundation Trust). The focus of local governance is to manage the costs of any study within the Trust, to ensure that the study fits with the Trust's research goals, and to minimise risk (i.e. reputational risk).

Oncologists in both Trusts provided written consent for their patients to be approached for inclusion in the study.

#### **4.31.2 Delays in ethical approval**

There were several delays during the ethical approval process. The initial response from the scientific (RRESC) review was delayed by several weeks, partly because of the creation of the new School of Healthcare Sciences within Cardiff University, which led to a number of administrative errors. These delays added approximately three to four weeks before initial feedback was given.

The REC for Wales' decision (see Appendix C) was based on a meeting with the whole committee. The requested amendments to the study's participant information materials were to be reviewed and approved by the committee Chair only. Before the REC for Wales could give a favourable opinion, they requested that the patient information sheet (PIS) (Appendix H) be amended

and re-piloted. Unfortunately, the support groups used for the initial piloting met infrequently, leading to further delays before the PIS could be re-submitted to the committee's Chair. In addition, the original letter giving their favourable opinion did not arrive so there was a further delay in issuing a replacement. While these delays are frustrating, the safety of the participants should always be of paramount importance. Knowing that any study involving NHS patients is taken so seriously only adds to the rigour of the finished study.

Local governance review conducted by the Northtownshire Research Support Service (see Appendix D) was done on a case-by-case basis. This meant that despite some staffing issues they were able to approve the study within a reasonable timeframe. The R&D Executive Group at Southtown (see Appendix E) meets on a monthly basis, with a deadline for submission two weeks prior to each meeting. Unfortunately, due to the delay in receiving the favourable opinion letter from the REC for Wales, the first deadline for Southtown was missed by a matter of days. In addition, the study was not included in the next meeting (for reasons not made clear) meaning a total delay of nine weeks before they were able to approve the study.

#### 4.31.3 Harm and benefit

There was no suggestion of any direct benefit to the participant, other than the therapeutic benefit of participating in an interview (Hutchinson et al. 1994).

A great deal of consideration was made on how to explore the participants' experiences with sufficient depth and detail whilst still protecting them from harm. Harm could include psychological damage caused by discussion of topics which may be traumatic (for either the participant or the researcher), such as sexual history or bereavement. Clinical experience was pooled with expert

advice, including a clinical psychologist and psychosexual therapist, before beginning interviews. Their expert advice focused on issues that are less commonly discussed in a clinical setting, such as intimacy and sexuality. My clinical experience of discussing such issues had previously been confined to information giving. By seeking advice on how to approach and discuss these issues, the potential for making the interviewee feel embarrassed or distressed was minimised.

As some of the topics being discussed were personal in nature, provision was made for additional support, such as signposting to a counsellor or psychologist. These would be accessed through existing support channels such as the participant's CNS or GP. However, it was of utmost importance to deal with all topics with sensitivity thereby minimising the risk to the participant. A supportive services document (Appendix L) was provided in the initial information pack and further copies were available from myself at the time of interview.

The advice from the clinical psychologist differed on many counts from that of the psychosexual therapist. The psychosexual therapist also had a great deal of experience in research, so her advice was very much focused on phrasing, probing, and boundaries. The advice from the clinical psychologist was much more straightforward, most probably due to her own admission that when she sees people in clinical practice they are *ready* to talk about such issues and often have sought to discuss certain aspects of their life. As the interviewees were not aware of the potential topics for discussion prior to the interview, discussing sensitive issues such as body image, sexuality and partner intimacy without warning or reassurance of control and confidentiality may have been damaging to them and their view of the study. In each interview, the option to

decline to answer a question at any point was highlighted prior to the interview beginning, and again before such topics were broached.

#### 4.31.4 Data management

All personal identifiable data were, and are, kept in accordance with Cardiff University guidelines (2011). Participants were assigned identification numbers which were used on questionnaires and when labelling electronic files. Interviewees were allocated pseudonyms and identifiable information was removed from transcripts. All data, including consent forms, questionnaires, audio recordings and transcripts, were and are stored securely using a combination of locked cabinets and password protected computer networks. All data will be stored securely for fifteen years after completion of the study in accordance with University regulations.

There were times when data was not kept in a secure location out of necessity. These times were limited to travelling to and from interview locations and then returning to Cardiff University buildings. While this is not ideal, I did attend a data protection and confidentiality workshop, organised by Cardiff University's Graduate College, in order to clarify such issues. The advice from the workshop was that keeping data in non-secured locations are unavoidable in real life research situations. The advice from the University was that as long as these periods were kept to a minimum, and the data was in my personal possession at all times, then they would be seen as complying with all relevant data protection regulations.

Interviews were recorded using an Olympus VN-5500PC digital voice recorder. The files were transferred to a secure University drive as soon as possible after each interview and the recording was then deleted from the voice recorder.

It was explained to each participant that their expression of interest form would be destroyed after the interview. This was the only place where their full name, address and telephone number were recorded. This meant that I would not be able to contact them on completion of the study. However, they were each given the approximate completion date of the study and suggested that if they did wish to read the published results of the study, they could contact me or the university, where they could be signposted on where to find them.

Consideration was given to whether to contact the participants once the data had been analysed and/or when the study was complete.

#### 4.31.5 Informed consent

Written consent was obtained from each participant immediately prior to the interview (Miller et al. 2012). Three copies of the consent form (Appendix J) were signed by each participant (one to be retained by the researcher, one to be retained by the participant, and one to be returned to the appropriate oncologist's office for inclusion in the patient's medical records). The REC deemed it unnecessary to inform the participant's General Practitioner (GP) about their participation in the study. Capacity to provide informed consent was assessed upon meeting the participant prior to the interview.

No formal measure of capacity was used. In clinical practice, the person gaining consent will use their clinical judgement (making sure the person can summarise what they've been told, asking questions) to ascertain if someone is capable of giving informed consent. Guidelines for assessing capacity set out by the Department of Health (2009) were followed throughout the process. Guidance given by the Mental Capacity Act (2005) code of practice specifies a two-stage process for assessing capacity. Stage one asks, does the person have an

impairment of, or a disturbance in the functioning of, their mind or brain? Stage two asks, does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

In each instance, the only face-to-face encounter with each participant was to gain consent and conduct the interview. However, the option was given to all participants to have time to consider their inclusion in the study and to discuss their participation with someone else before beginning the interview.

On one occasion a person submitted a completed expression of interest form but did not take part in the study. During an initial telephone conversation (which would aim to answer any questions and to arrange for a suitable time and place to conduct the interview), he decided not to take any further part in the study due to the amount of time the interview would take. Although the time commitment was stated on the PIS, this demonstrates the importance of confirming essential details prior to meeting. His choice to decline to take part supports the assertion that people who chose to take part did so of their own free will and in an informed manner.

#### 4.31.6 Withdrawal from the study

Participants were informed that they were able to withdraw from the study at any time without reasons being given or asked, and that their medical care would not be affected in any way. Withdrawal from the study could be carried out by post, email or phone. The participant information sheet specified that no further correspondence would be entered into should they decide to withdraw.

#### **4.31.7 Complaint procedure**

Details regarding the complaints procedure were outlined on the PIS. In the first instance the participant will be encouraged to contact myself as the principle investigator. However, if any of the participants felt it necessary to complain formally regarding any aspect of the study, contact details of the Research Governance Officer at Cardiff University were also listed.

#### **4.31.8 Costs to subjects**

There would be no cost to the participant, assuming they chose to conduct the interview at their home, as was the case with all but one of the participants. In the one instance that the participant chose to be interviewed in an alternative location, they bore the cost of transport to and from that location.

#### **4.31.9 Remuneration**

No reward, financial or otherwise, was offered as an incentive to take part in the study. It was made clear in the PIS that the main benefit of taking part would be to people not yet diagnosed or treated for oropharyngeal cancer, although it was stated that “some people may feel that talking about their experiences actually helps them in making sense of what has happened.”

#### **4.31.10 Conflicts of interest**

There were no declared conflicts of interest. I have worked clinically at Northtown Oncology Centre since 2012, so it was possible that I would be interviewing people that I had treated. However, it was suggested by academic

supervisors, and confirmed by the REC, that this would not have any significant impact on the interviews or the data obtained.

#### 4.31.11 Personal safety

Consideration was made for safe lone working at all times. In accordance with the Cardiff University lone worker policy, it was suggested that another post-graduate researcher (PGR) student be given details of each interview and instructions on what to do in the event that I did not report in afterwards.

The setting for each interview was specified as *mutually agreed* in the PIS. This meant that I could suggest an alternative location if I thought my safety or the quality of the interview would be negatively affected by the choice of location (e.g. a pub or busy coffee shop where our conversation could be overheard).

The time and location of all interviews was arranged over the phone. I also told each participant that I would call them on the day of the interview as a matter of courtesy to make sure the time was still convenient for them. This phone call had another purpose which was to attempt to ascertain their mood and situation on the day. This could include background noises such as children or loud music, or if their tone of voice suggested any stress or anxiety. Whilst I could not gain a great deal of information from these phone calls, it did give me another opportunity to build up a picture of what I may encounter. This is in opposition to the principles of IPA interviewing, which should be entered into with as few preconceptions as possible. However, considerations of personal safety had to come first. In addition, the fact that I was aware of the possibility of creating pre-supposition meant that I could address it in other ways.

#### 4.32 Chapter summary

This chapter has presented how the study was conceived and executed. The reader should have a clear idea of the processes involved and would be able to carry out a similar study based on the evidence presented. Due to the interpretative and ideographic nature of the study, it may not be possible, or desirable, to reproduce the findings simply by following the same method. The findings of the study are a result of the unique interaction and interpretation of the researcher and participants. Instead, this chapter helps to support claims as to the study's rigour.

The following chapter will highlight and explore the findings of the study. After discussions with Virginia Eatough, an expert in the field of IPA research, it was decided that the findings chapter should be presented in two or more sections. In this way, the general themes can be presented in one section, while greater depth can be obtained in the remaining sections by focusing on particular aspects of the data.

## Chapter Five – Findings One: Overview of Participants

### 5.1 Chapter introduction

Chapter five of this thesis has been divided into three main sections: description of the participants and their experiences, reward through recognition, and oropharyngeal cancer as a hidden experience. After transcribing and collating the data, there was an unease that the depth of interpretation and understanding that is required from a successful IPA study (Smith et al. 1999; Larkin et al. 2006; Smith and Osborn 2007; Smith et al. 2009) would not be achievable with over 160,000 words of available data. Discussions took place with academic supervisors, as well as experts in IPA research such as Virginia Eatough. The example given was Eatough and Smith's (2006) paper *I feel like a scrambled egg in my head*, which looked at the experience of a single participant from a previous, larger study. This realisation that this study could focus on a subsection of the participants and not be detrimental to the product of IPA was a pivotal point in the study's developmental process.

This chapter will give an overview of the experiences of the participants. Themes presented in this chapter were present in all or almost all of the participants' stories. They are presented in order of appearance within the majority of transcripts, as many of the participants followed a similar order starting with diagnosis and moving through treatment, recovery and on to a post-treatment self. Below is a table of key themes within this chapter.

Shared experiences of all or most of the participants	
Key themes	Sub-categories
Diagnosis	<ul style="list-style-type: none"><li>• The shock of an asymptomatic diagnosis</li><li>• Breaking the news</li><li>• Information overload at diagnosis</li><li>• Waiting for results</li></ul>

Information and communication	<ul style="list-style-type: none"> <li>• Getting the right amount of information</li> <li>• Decision making</li> <li>• Shock</li> <li>• Not getting the right amount of information</li> </ul>
Control	<ul style="list-style-type: none"> <li>• Loss of control after diagnosis</li> <li>• Preparation for treatment (teeth extraction, radiotherapy immobilisation mask, feeding tubes)</li> <li>• Being 'done to'</li> <li>• Surgery</li> <li>• Loss of control during radiotherapy</li> <li>• Choosing to give control away</li> </ul>
Eating	<ul style="list-style-type: none"> <li>• Sudden loss of taste</li> <li>• Changed ability to eat certain foods</li> <li>• Food as a livelihood</li> <li>• Food seen as fuel</li> <li>• Social implications of a changed relationship with food</li> </ul>
Body image and weight	<ul style="list-style-type: none"> <li>• Negative body image after weight loss</li> <li>• Impact on physical/romantic relationships</li> <li>• Weight loss equals looking like a cancer patient</li> <li>• Concern and pressure from others to eat</li> </ul>
Physical and emotional support	<ul style="list-style-type: none"> <li>• Choosing to isolate oneself</li> <li>• Physical support more readily available than emotional support</li> <li>• Challenges within relationships</li> </ul>
Intimacy and sexuality	<ul style="list-style-type: none"> <li>• Communication and difficulties in communicating with loved ones</li> <li>• Changes to sexual relationships</li> <li>• Changes to relationships (intimacy levels, openness, shared goals)</li> </ul>
Isolation	<ul style="list-style-type: none"> <li>• Time spent alone during and after treatment</li> <li>• Isolation from friends or family</li> <li>• Other peoples' reactions</li> <li>• Uncertainty about what happens next (recovery, work, redundancy, money)</li> </ul>

Fear and worry	<ul style="list-style-type: none"> <li>• Efficacy of treatment (has it worked, will it come back, could I go through the treatment again)</li> <li>• Financial worries</li> <li>• What happens if I die?</li> <li>• Slow recovery, not being able to eat</li> </ul>
Employment	<ul style="list-style-type: none"> <li>• Uncertainty about support from employers</li> <li>• Money</li> <li>• Redundancy</li> <li>• Changes to routine</li> <li>• Ability to do the same job after treatment</li> <li>• Identity and challenge through work</li> <li>• How co-workers would react</li> </ul>
Comparison	<ul style="list-style-type: none"> <li>• Perceived schedule of recovery</li> <li>• Discovering a post-treatment self</li> <li>• Difficulties in seeing other people do what they can't (eating)</li> </ul>
Recovery and positivity	<ul style="list-style-type: none"> <li>• Cancer bringing people closer together</li> <li>• Changed outlook on life</li> </ul>

**Table 7 - Key themes and any sub-categories within chapter five.**

By the end of this chapter, the reader will have an insight into the varied and complex experience of a group of people who have previously been treated for oropharyngeal cancer, as well as the interpretative journey of myself as the researcher.

## 5.2 Demographic data

At the end of each interview, the participant was asked to complete a questionnaire (Appendix K) in order to gather information regarding age, marital status, modality of treatment and other demographic data. When designing the study, it was not known with any certainty if this data would be of relevance in the final analysis. As so few studies have looked at the survivorship

experience of this patient group, it was deemed better to include the questionnaire, should it generate any further insight.

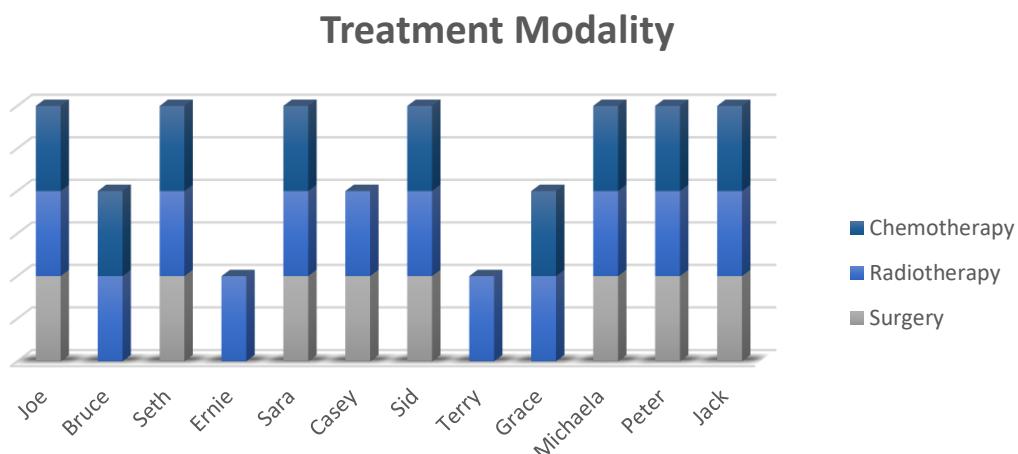
While ten of the twelve participants completed the questionnaires, Terry and Sid both asked if they could keep the questionnaire to complete at a later time. In each instance, a reason was not given. They were left with a blank questionnaire and a stamped addressed envelope and were asked to return it at their earliest convenience. Unfortunately, neither of these questionnaires were received. Also, as the information given prior to the interview stated that the participants would not be contacted following the interview, this could not be followed up.

The demographic and treatment data are based on the ten questionnaires that were completed. For Terry and Sid, information was taken from interview data where possible.

The mean age of the study's participants was 52.01 years, ranging from forty-five to sixty years of age.

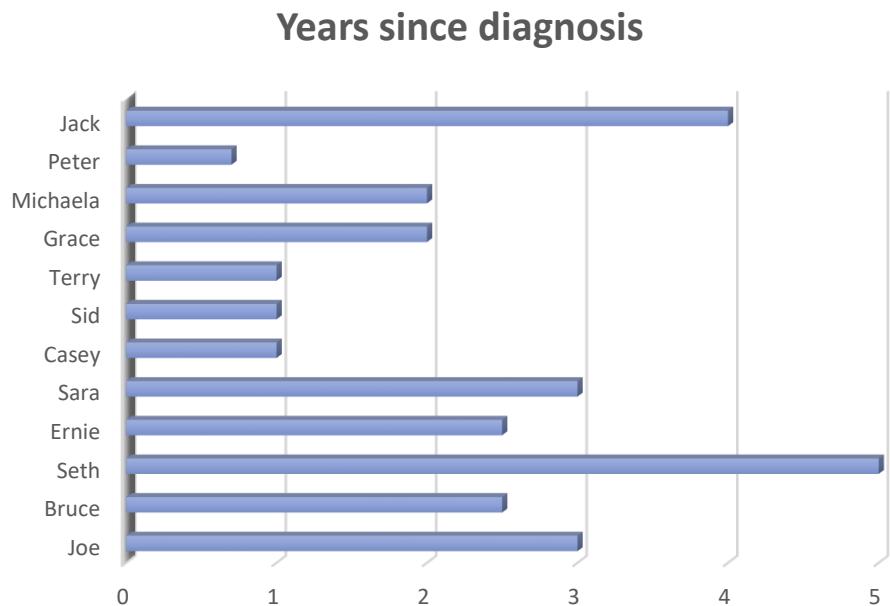
The location of the primary tumour was not included in the questionnaire (e.g. base of tongue or tonsil). While this would have been of interest, preliminary work with HNC support groups indicated that some people could not accurately identify the location of their primary tumour. Therefore, without accessing medical records, this information may not be known or reliable.

Participants were recruited based on diagnosis, so it was assumed that treatment pathways and modalities would vary. Figure **Error! Reference source not found.**<sup>9</sup> (page 159) shows the different treatment modalities used for each participant.



**Figure 9 – Graph showing combinations of treatment modalities for each participant.**

Figure **Error! Reference source not found.10** (below) the time since diagnosis of each participant (self-reported).



**Figure 10 - Graph showing self-reported time since diagnosis in years**

One of the inclusion criteria was to include people who were between six months and five years post diagnosis. It is both interesting and positive that this entire range is represented within the group.

### 5.3 Response rate

The response rate of the study (approximately 43%) is slightly better than was expected during the design of the protocol. Working from approximate figures supplied by CNSs during preliminary discussions, it was estimated that a 33% return rate would be enough to achieve the figures indicated by other IPA studies. Smith suggests that appropriate numbers for an IPA PhD thesis is between six and twelve (Smith et al. 2009). Although some IPA studies use far smaller study groups ( $n=$ fewer than 5) (Smith et al. 2009; Pietkiewicz and Smith 2014), advice from study supervisors was to aim for a larger number to account for any problems in data collection.

### 5.4 Diagnosis

Given that many of the participants were in their forties and fifties, and many were largely asymptomatic with few functional difficulties, the news of a cancer diagnosis came as a great shock. In the case of Sara, the only initial sign of there being anything wrong was a swollen gland. The diagnosis of a malignancy, as well as how the news was delivered, was difficult to deal with.

Um, when I went back for the results, this was probably about the only thing that was a little bit insensitive through the whole of my treatment, is that [pause], the person I saw who I can't remember his name, um, just said, are you on your own? And I said yes. And he said, right, we've got your

results back and it's cancer. [Pause]. And um, that was that really. And um, it took about five minutes for it to, sort of, sink in and I got a bit tearful, and I felt like I was being manoeuvred, you know, take her away to, you know, the room over there and discuss her options, you know. Just talk her though what's next. And I kind of felt like I was shunted out of the room. And now, everything that I went through, that was the only bit of where I felt a little bit, [pause], well, that was a bit insensitive really.

Sara

In many cases the participants indicated that they were taking part in the study to help or to give something back. Sara's account of the diagnosis suggested that she was reluctant to say anything negative about her experience of the hospital or its staff due to this perceived debt. Noted immediately after the interview was the emotion that was conveyed in this section. However, the use of phrases such as *only thing*, *little bit* and *kind of felt* suggest that she wanted to soften or excuse what appeared to be a very difficult experience.

It was a shock. I was expecting an all-clear, you know, yep, it's fine, off you go. And that was the very last thing I was expecting. It just hadn't even crossed my mind that could have been something like that. Um, I didn't tell anybody.

Sara

Michaela also found the way in which the diagnosis was delivered to have exacerbated the impact of the diagnosis.

Never occurred to me that I was, I was completely chilled and relaxed, I didn't, it didn't ever enter my head, you know, that it would be, and I think, [pause], even when I took the phone call to say, you know, we're sorry but we've found what looks like a primary tumour, I don't think you really

hear that, what you hear is you're going to die, you don't hear you've got cancer. But I remember putting the phone down and just carrying on ironing until it all sunk in. But no, I would never had suspected that it was there. And then I couldn't grasp why they couldn't just remove my tonsil, sort of, that be job done. So, um, it was a huge shock.

Michaela

Unfortunately, this perceived insensitivity in the delivery of the diagnosis appears elsewhere in the data. When arriving at the hospital to find out the results of a biopsy, Joe was given a letter marked *Oncology* which he was asked to take in to the meeting with him. While all the participants indicated differing expectations regarding the type and amount of information they wanted, failures in appropriate delivery of news of diagnosis seemed far too commonplace. Michaela's description of continuing to do the ironing, dazed, waiting for the realisation to hit her, is probably the most extreme example of this. Perhaps it is because of the mundanity of the task (of ironing) juxtaposed with the life-changing implications of the news which makes this description of the moment so identifiable and emotive.

Other participants described a lack of awareness or control once a diagnosis had been made. Sid felt so dazed by the diagnosis that he was unable to make any informed decisions regarding his treatment.

Once they initially found that there was summat there, they needed to find out everything they could. So, they, they sort of um, he was very um, he explained a lot to me that day, but trouble is you don't take it in. Because you've just been told, so you don't, it doesn't sink in or the technical stuff they're telling you and all the different things that they can do, it's like, it's not really, cause all you think of is, oh bloody hell I've got cancer, and that's all you can think of at the

time. It's not until afterwards when you start going and having all the tests like I was, I did that for two weeks, when they got me in, they did all these types of tests, body tests, scans and that.

Sid

It's clear from what Sid says that things were explained to him, but at a time when he was unable to process the information and actively engage with it. His description of the time between diagnosis and preparation for the treatment seemed quite frightening and gave the impression of *being done to*.

For Terry, there was no outward indication of anything being wrong. Diagnostic tests had been initially carried out because of difficulty in intubation during a routine hernia operation. This made the uncertainty waiting for the test results very challenging.

*What was going through your mind at that point [waiting for the biopsy results]?*

Everything. Everything and anything. You know. Is this the Big C, as you know, some people refer it to as, does it mean that um, I'm going to have to have my tongue taken out, does it mean surgery, does it mean, what does it mean. You just don't know. You know, you haven't got a clue what the future holds. Um, in relation to getting it sorted. And because I wasn't aware of any, anything being wrong, that's what made it even worse. Um, so very very difficult to cope with during that period. You know, because it was, what four weeks. Um, it's a long time to have to, something like that which is clearly serious and it's going to affect your health, is it benign, is it malignant, is it this, all those things. Very very difficult to cope with, yeah.

Terry

Terry seemed to find this lack of control challenging, repeating the phrase *very very difficult to cope with* on several occasions. While Terry came across as very intelligent and articulate, he did not seem especially emotional when describing his experience. Therefore, this repetition and focus on difficulty in coping with the unknown seemed to resonate particularly strongly when analysing the audio recording of the interview. Similarly, describing the prospect of having his tongue removed seems extremely visceral and far more emotive than mentioning having the tumour or even part of his tongue removed.

## 5.5 Information and communication

Even in such a small sample size, there were vastly differing expectations of the type and amount of information they felt was needed, as Joe describes.

And that's, I suppose I brought [spouse] along and that and she didn't need no, she wanted to do 100 percent for me, so we were heading for the sort of, we were heading to do everything what everybody said to give ourselves the best chance of getting through which we've done. So sometimes you can make too much of, of things can't you. Sometimes I look at the telly and they get all of the people and the kids in the schools, they get all the psychologists in to help them (...) So I didn't, well getting back to the point is I didn't want to really make, and that was me I can't [spouse] would, we just wanted to get on with it. We didn't want to go round in circles talking about what ifs cos what ifs don't help nobody and you are way you are.

Joe

On the surface it appears that Joe and his wife had been given a task to do and they saw no point in understanding it or discussing how the task should be

completed. Whether this was true for Joe's wife is unclear. He goes on to suggest that worry is linked to the amount of information one is aware of.

And [surgeon] said I'll tell you what you need to know, and I thought that was brilliant, so I don't think you need to know a great deal on the basis that you won't worry about it. The only things are the only things I worried about the things I knew. Does that make sense?

*Yes, I think.*

And now I got this bee in me bonnet that people come on telly saying, oh the hospitals didn't tell me anything and the surgeon didn't tell me anything, well you wanna think about that, some people ought to think about that statement before they start going on cos if you know too much even on the Internet you, you could have misinformation. And I do worry about things so if you've got all of that information you worry, you worrying about it that ain't going to help you, is it? And it's something else to worry about. You want your total focus on getting well and stress isn't, stress and anxiety can't be any good for especially in, so why add to it?

Joe

While Joe's views initially came across as rather old-fashioned in that *doctor knows best*, deeper analysis indicates his attitude may have more to do with self-protection than anything else. Reflecting on personal experience in instances where a number of important things have to be done at once, the mental strain and associated stress can reach a point where nothing can be achieved. Joe's lack of interest in anything other than what he was told by figures of authority may be a decision based on priorities. In stark contrast, Terry felt that the volume of information was far below what he required in order to better cope with the impact of treatment.

I don't feel the hospital and the staff at the hospital um, prepared, prepares you enough, for what to expect. Now whether that's intentional, or not I don't know. Whether they don't want to scare you or not, I don't know. But for me at least, I would've liked to have been prepared better, for what I was going to be going through. Because I would have thought that what I went through was not terribly dissimilar to what other people were likely to go through. Um, for my type of treatment. So, I do feel, not let down, but I do feel it would have been, it would have been very helpful and useful, because I think if you prepare yourself for things, nothing then comes as a surprise. And, um, you have less to worry about. (...) Because, you know, I would say to the um, staff at the hospital from time to time, um, oh I'm suffering with so and so, and they said, oh yes that's quite normal. Oh, is it? But I hadn't been prepared for anything. Does that make sense?

Terry

For Casey, the ability to absorb and comprehend the information that accompanied his diagnosis was severely compromised by the shock he felt.

*What kind of impact did the diagnosis have on you and [name of partner]?*

Um, I went um, (drinks water) we went to um, [hospital near Northtown] to, to go and see um, [surgeon]. And no, I mean it, it was a bit, I mean sort of thinking back on it now, I mean yes it, it, it was emotional, it took the wind out of my sail. Because we went to [town near Northtown], I mean [name of partner] took time off work, to go with me, um, basically we went into [hospital near Northtown]. Went into see um, [surgeon], and he sat there and I mean literally I mean we sat down, (laughs) and it was, I mean fair play to him, I mean

there was no bones about it, I mean I suppose there's no easy way of saying it, but, but basically it, it was the fact that, sorry to say, as soon as he said that I knew what was coming. Um, it was sent away for having a look at it and it's come back as cancerous. So, I mean basically then, it, anything after that he said, to be honest with you, I didn't really hear. I didn't really take on board. Um, he, then asked if we'd like to go into a side room and um, sort of discuss what, what it was we were going to do, and I must have said I haven't heard anything you said since you told me. (...) I mean the both of us were a bit, bit gobsmacked I mean [name of partner] was more upset on the tearful side than I was, I was a bit more sort of quiet and like I say, I think more pensive and the wind had been taken out me sails.

Casey

Describing how he felt the wind had been taken out of his sails again generates a very visual image. Reminiscent of The Rime of the Ancient Mariner (Coleridge 1857), Casey has lost his ability to either move forward (because of the shock of the cancer diagnosis) or return to a previous state of being. Peter highlights the need (certainly for him) for far more information and psychological support in coping with the cancer experience.

So, you know, um, yeah, it's weird that everything's changing and hopefully becoming better, but I think the psychological side of it [pause] is um [pause] it's not really spoken about. Do you know what I mean, I mean the doctors don't tell you [pause] you know, you could feel like this or you might feel like that or, you might have these type of swings. Your mood's going to change, or this is going to change, they just tell you all about the, you know, the medical side and you're given lots of books to read but [pause] I think maybe, I mean they're a team, they should have like psychologists or

something to talk you through about the possibilities of different types of behaviour that you could go through.

Peter

It is difficult to assess whether adequate psychological support was offered to Peter at specific timepoints throughout his treatment. He describes his experience of being told about the physical side-effects of the treatment but also mentions about being given lots of books to read. Whether he read those books and they did not contain enough information or books were not the best medium to convey the information about psychological side-effects is unclear.

## 5.6 Control

Several of the participants (often indirectly) raised the subject of control, or lack thereof, when talking about their experience of treatment. In the example of Seth, he seemed quite at ease complying with what was recommended by the surgeon or the oncologist. In his case, it was nearly five years since his diagnosis, so his interpretation of his experience may have been re-written several times over. This was something he implied in his interview as he mentioned mentally revisiting the experience prior to the interview. However, for others the subject of control was more complex.

Um, got over that, went back for the next appointment and then that's when I saw [oncologist] and she said, yeah, we're going to get you in for a course of radiotherapy and, um, a little bit of chemo as well, two sessions of chemotherapy. Um, and then that's when it all became a bit of a whirlwind and I was sort of shunted along. Right, you've got to do this, you've got to do this, you've got to go for that appointment, you've got to have this done, you've got to have teeth out which was, for me, before even knowing what was wrong

with me it was like, you're not taking my teeth out! I had to battle with the amount of teeth they took out. You're not taking my teeth! [laughs].

Sara

Sara's perceived battle around the removal of her teeth seems to suggest some sort of negotiation in how she wants to deal with her experience. She describes the *whirlwind* and *being shunted along*, as well as being told what treatment she was going to have. However, for her there was a breaking point where she wanted, or perhaps needed to regain control of this experience. In this example it appears that she realised she had to accept the recommendation of the treatment modality in order to give her the best chance of eradicating the tumour. However, the idea that she would permanently lose several teeth was a loss too far. It is unclear whether her teeth held a particularly strong importance regarding self-perception or body image, or whether she chose that point as a metaphorical line in the sand which she was not prepared to cross. When probed about this later in the interview, Sara became tearful and said she would prefer to move on to another question.

In his interview, Bruce was able to give an example of his loss of control.

There was problems with putting the feeding tube in. I went into have the normal way but for some reason they said they couldn't, they shine a light inside your stomach, but they couldn't find it. I can still remember that now, the actual op evolution was quite uncomfortable. For example, when they spray some anaesthetic in your mouth the chap doing it didn't actually explain to me what he was going to do, when he sprayed it in, you know, you lose all sensation in your mouth, and I just felt a bit forced into the situation actually.

Bruce

As was highlighted previously with Sara's description of diagnosis, there is a tendency for the participants to downplay difficult situations by their use of language. The idea of an unfamiliar person spraying an anaesthetic into one's mouth without explanation of the effects, with what seems to be a lack of informed consent seems very distressing. However, Bruce then qualifies that by saying that he felt *a bit* forced into the situation. With very little variation in the pitch of Bruce's voice, it was more difficult to ascertain the meaning of this section. Deeper interpretation using notes recorded after the interview suggested the use of the word *forced* was more important in this context. Similar to Sara, it was interpreted that the use of *a bit* was intended to soften any inferred criticism of the medical system. What is not known is whether this softening language would have been used had the participants had no knowledge of my own background and clinical experience.

With Bruce, as well as several others, there seemed to be a duplicity in what was said.

I didn't find the actual treatment itself, you know, too bad,  
you know, it only takes a few minutes while they bolt you  
down, get on with it.

Bruce

While he says he found the treatment not *too bad*, he describes being *bolted down*. This phrasing was interesting, as it gives the impression of something far darker and more menacing. Given that the immobilisation mask uses plastic clips, the phrase *bolted down* suggests a permanence or a harsh industrial-ness to the experience. The image generated at an early stage of analysis was that of Dr Frankenstein's laboratory and supports the concept of the patient *being done to* rather than taking an active part in their treatment.

Sara did not speak in such mechanistic terms, although she did elaborate on the perceived threats to her sense of control.

But you do feel like [pause], you've got no control in some ways. Which is good because everyone is looking after you but, right, okay, you've got to go for this, you've got to have these bloods done, and that, and you've got to have teeth taken out, you've got to have all these different scans and, you know, you're just going to a point, and this is even before treatment started so, it was just like, okay on to the next thing. I didn't really know what was going on, I did, it was happening so quickly, before I knew it I was starting radiotherapy. You know, and you didn't really, because there was so much going on with so many appointments to go to, sort of, prepping I suppose ready for the treatment you're having, that I never really had that much of a chance to sort of, sit down and think about what, what was actually happening.

Sara

Sara's description acknowledges a sense that she was aware that what was happening was best for her. Or at least best for her physical health. However, her tone seems almost mournful of the loss of control over her life. The impression Sara gave throughout her interview was that she valued her independence and took pride in not having to rely on anyone else. For her, probably more than any of the other participants, this loss of control seemed the most traumatic. This seems to have been made worse by the fact that what she really wanted during that period was time to reflect and to come to terms with what was happening to her.

For others, such as Sid, their description was more mechanistic but still strongly centred around *being done to*.

He was gonna, he was going to um, work in that area, on my head and my neck, and then um, he then said, [surgeon] said he would get me in, they would knock me out then and they would just go in and have an investigation in my throat and he did at the time we can do numerous things. He was saying, they could, some of it sounded quite not so nice and they could do neck dissections where they could cut tissue out the neck, cut and the part the neck away, all these things could be done on this day if it was needed to be. Um, so it, a lot of it didn't, some of it didn't sound very nice but I was, by then I was sort of like, sort of like, well they're gonna do what they're gonna do anyway, you know, so there's nothing I can do about it if they're gonna. And then I, and then when I was in the hospital that day recovering afterwards, I did see a guy, with all his neck had been and I thought, oh God, glad I didn't have that done, 'cause it didn't look, it looked awful, you know, but needs must.

Sid

Stating *there's nothing I can do about it* when describing such invasive and potentially life-altering operations certainly gives the impression of a complete loss of control. However, his complete capitulation to the medical recommendation given to him shows a great reverence for the authority the surgeon and the oncologist carry. Even afterwards, comparing himself to another patient, to what could have happened, his view was *needs must*. Unlike Sara and her teeth, it seems Sid never reached a point where the perceived cost was too high, or where he felt he needed to regain some control.

Sid speaks in similar terms regarding a perceived loss of control when talking about the insertion of his feeding tube and the removal of several teeth.

Oh yeah, yeah, [pause] again leading up to the treatment, you, it's not that I miss things out, it's just that you, you're having that much done, that many tests done to you and stuff that in preparation for the treatment, if you know what I mean, and, and I got to the, towards the end of January. This was, this was now getting towards the fortnight before the treatment, and the next thing there was, that they decided that they were gonna take my wisdom teeth out. (...) Then like, [oncologist] had spoke to me about having a PEG put in my stomach, because she said, cause you're having radiotherapy, it's going through your mouth, they explained to me how bad my mouth could get, um, you know, the fact the treatment would cause to that, so she advised I should have a PEG because she was worried I might not be able to eat. There'll come a point when eating become impossible, and all this. It sounded horrendous, but I had a go with it, so again, we got to the end of January, I'd had the teeth removed. They then stuck a PEG into my stomach, a feeding PEG, just in case, and I was pretty much been, ready to go then.

Sid

Peter described a similar loss of control when beginning treatment.

And then you know, after that, you've got to have a week before you start your treatment. And, er [long pause], and then when you go into this room and they tell you what's going to happen. And you feel, OK, you know, it's what's coming but when you actually get onto that table [pause] you're locked, and you just think of what's going to happen now. And yeah, because it's all new and you just don't know, I think, the uncertainty and you're in this huge machine, start to move and that, and er I think that's where the panic comes in. And er [pause] they had to stop, er the first couple of days, it was just, it was just too much. I just

wouldn't, er, yeah [pause]. I mean, they managed to do it, but it was, it wasn't easy. It was very, er, frightening.

Peter

Here Peter talks more about the loss of control at the beginning of treatment. It is not explicit from any of the participants when or if they felt any return of control. This may be due to the recovery being such a slow process, any gains go unnoticed in comparison to the sudden changes which occur at the start of treatment.

Peter does use very similar language to Bruce when he describes being *locked down* as well as being told what was going to happen, rather than it being a discussion. Peter describes the uncertainty of what was going to happen during treatment, despite already mentioning being told what was going to happen. This may suggest an inability or unwillingness to ask relevant questions because of deep-seated fears or phobias. However, it may also suggest that Peter does not trust what he is being told but feels unable to challenge the perceived authority of the radiographers or other medical professionals. Or, that however much explanation is given, it is only through experience that someone really comes to know.

For Ernie, control was not as challenging as for some of the other participants.

My assumption is that they knew what they were doing. They, I did, I Googled [oncologist], [surgeon], so I knew what they were specialists at, I knew what they were doing. They knew what they were doing, they knew the best things to do, I didn't, there's no point me questioning what they're going to do because [pause], I'm assuming that they're only going to do the best things for me. I can't second guess them.

Ernie

This statement seems similar to his comments of business dealings, in that he found someone who could do a good job and then handed that responsibility over to them. This can be seen as a way of staying in control by relinquishing control; by handing over responsibility for those choices Ernie is removing the possibility of control being taken from him. What is not clear is whether how or when the information is delivered prior to any procedure would change their perception of this loss of control.

## 5.7 Eating

The impact of treatment varied for all of the participants, but a treatment induced side effect they all had in common was the inability to eat and drink normally (compared to before treatment). Rather than reporting the impact of eating for all participants at length, which may reduce the depth of the study, a decision was made to use data from five of the participants which seemed representative of the group as a whole. The data presented in this section illustrates the far-reaching impact of a changing relationship with food, and its potential social consequences. For Casey, it even threatened his ability to continue with his job as a chef.

I've got very little taste buds, um I've got very little saliva, so it's, it's difficult for me to eat certain things, um I can't eat sort of like rice, I can't swallow bread I'm not too good with, obviously because I've lost the weight that I had they put me on um, high calorie milkshakes. I suppose where, also where over a period of time my stomach shrunk so much me appetite would, is, is nothing like what it was then. Plus, the fact takes me so long to eat anything it gets cold, I get fed up and about a third of it normally ends up in the bin. Where it probably takes a normal person about twenty minutes to eat

through their evening meal, I'm probably having about forty to forty-five until I get fed up with, but so say my, I should explain it won't go back to normal or not to how it was before, um not the saliva glands, my taste buds should come back but I mean that, that could take as long as another sort of five to six months.

Casey

Contemplating the prospect of returning to work as a professional chef at the time of the interview, the changes to his palate and his ability to eat have affected something he used to be passionate about.

So in [town near Northtown] then, (...) they got a Burger King, so we decided well go down and have a Burger King then we're going to the pictures. And I love Burger King, then out of all of them that's my favourite Burger King. So we went to Burger King and I didn't think anything of it. So we ordered, um, ordered our burgers and I was heartbroken because I remember sat down and I'd been really looking forward to this burger and started eating it and thinking, something strange about this burger, what's the matter with it. I said: 'Is your burger alright?' She said: 'Yeah, why?' I said: 'Something wrong with this.' She goes: 'What?' I says: 'It's got no flavour. Think I've no taste. I'm telling ya, don't taste of nothing.' Of course, it then twigged, they sort of said to me prior to me having radiotherapy, so, so that was it, to be honest with the food, I think partly became very boring, especially being a chef, that it had basically really only become a fuel and not, not something that I was enjoying. Um, and as radiotherapy progressed it got more difficult to eat certain things as, as this sort of scar tissue was going up inside my throat.

Casey

Aside from the physical difficulty of eating that Casey mentions, what is striking is that he can pinpoint the moment that food stopped being a source of enjoyment. There is a definite sense of loss which he is able to expand upon.

*What about in terms of your own relationship with food? In terms of enjoyment.*

Oh, it's really difficult, um but because I don't enjoy it. Um, it, it is basically a fuel. I know I-I've got to eat otherwise I'm gonna lose more weight um get m'self in a bad situation and so I mean yes, it is a fact now, I can't say that there's anything, it's like [name of partner] will come in what you want for tea, I don't know, what you fancy, I say, what's the point? (Laughs) You know what I mean, so I don't fancy anything because I can't taste anything, I mean I would dearly love, I cannot wait, touch wood that in some form my taste buds do come up because I am desperate for a crispy bacon sandwich with toast. I can't wait, you know what I mean. Um, but at the moment it, it is not a joy it should be. (Laughs) So, I don't know I mean, like I say touch wood, I hope to god that the taste buds do come back to some degree, because I don't, I don't think I'd wanna go through the rest of my life like, you know, not, not enjoying your food.

Casey

For many of the participants they simply did not want to eat. This can be because of the altered taste of food, or pain associated with chewing and swallowing.

I definitely lost appetite. I can remember not feeling hungry for five, maybe six months.

Bruce

And funny enough, the very first time I tried to eat anything, having not eaten anything for five months now, um, it was surprising how alien it felt. Even putting a spoon, a teaspoon in my mouth. Unbelievable. To think I'd been eating fifty-four years, fifty years whatever, you know, without giving it a moment's thought, suddenly you put a spoon with something on it in your mouth and it just feels wrong. Totally alien. Most peculiar. And to then try and swallow, was just impossible, the pain was just too much.

Terry

For others, there was a perceived inability to eat, despite acknowledgment of the negative physical impact of weight loss.

I met lots of people in there. And I could see them eating, and that was a bit frustrating because I would, I could watch my family eat, and I could see other people eating and, and, the, the thing that I, that made you sort of, was, any, I don't, I-I'm not gonna be big, touch wood, but I was happy with my weight, but it just frustrated me to see me go so thin.

Sid

For others, the changes in their relationship with food has far more to do with the social implications of eating than with the food itself.

I think it's, I think it's you don't actually realise how much you take food for granted, how much of a big thing it is, you know, just looking at, you know, how many amazing restaurants there are in the world, you know. How many food programmes are on TV? Everything revolves around food in one way or another. And um, when you suddenly can't, you know, do the simplest thing like eat a sandwich [pause], it's like at work we were having a team meeting, or we were planning a team meeting and they decided that,

because we'd, you know, we'd had a good month the month before we'd go for a picnic and have our meeting as a picnic. Everybody, what do you want to eat? Well, straight away it's like, wow! I mean I never get, I never get, I do get down about it with myself, but I would never be like "well I can't come!" [gruff voice], you know. It's just like, look, don't worry about me, I'll still come but don't worry about sorting anything out for me. And they get, the people at work are a little bit, well you've got to have something, you've got to have something. But I would rather not go through the, you know, have to worry about trying to find something that I can eat. It comes down to the fact that if they're having picnic food I can't eat it [laughs]. Um, I just can't do it. The only thing I could probably do is like, um, carrot sticks with a dip or something like that. That's what it would come down to, something like that I can do. A dip or something like that but I wouldn't be able to eat sausage rolls or, you know, anything like that. They're just too dry. Um, but yeah, [pause], it is a big thing, the food thing I think. Not that I would, you know, used to eat massively before but, you do realise you miss it when you can't have it.

Sara

Sara spoke at length about the loss caused by the changes in what she can and cannot eat. When talking about food, Sara seemed to focus largely on the loss and what she couldn't eat rather than what she could. In this extract she recognises that there was an option for her to join in with the group picnic, albeit very limited in scope, but she keeps returning to what she cannot eat. There seems to be an element of conspicuousness in her story which she finds uncomfortable and which is less apparent when the other participants discuss food. Sara seems very shy and private, making references to not wanting to be *the girl with cancer*. It appears that one of her difficulties with food is the lack of anonymity that comes with adapting to changes in lifestyle.

## 5.8 Body image and weight

While body image and weight issues were not featured in all of the interviews, those where it did feature seemed to have a significant impact.

*Can you tell me more about the confidence issues you mentioned?*

Um, I just don't like how I look and I just lost so much weight that I just [pause], don't like how I look. So, I'm just so skinny now. Um, um, [pause], so, [pause], I guess dating or anything like that is sort of out the window. You know, because I don't feel confident enough. And even if I did, [pause], I wouldn't want it to go anywhere because I don't like [pause], me [laughs]. [Pause].

*Looking back to before you had the diagnosis, was that, were you dating then? Was that a part of your life?*

Um, yeah. I would have, you know, I'd go out, I would have go out on dates and look forward to them. Um, feel confident in how I looked. Um, and yeah, never really had, I've always had a bit of a confidence issue but, that wouldn't have been a problem then beforehand. But now it is. So, [pause], yeah. [Pause].

*Is that something you can see yourself getting past or getting over?*

No. [Laughs]. I don't think so. I just, hmm, um, [pause], I can't imagine that anyone would be interested anyway but, [pause], no. They'd have, they'd have to, um, be quite understanding and, you know, even things like if you date

someone and you can't go out for a meal. You know, it's, it's little things like that, it's um.

Sara

For Sara the issues around food, weight loss and body image appear to have exacerbated pre-existing negative emotions. As with her thoughts about food, Sara focuses on the parts of a relationship which may be more challenging than she had previously experienced such as a first-date dinner. The impression Sara gave was of a kind and thoughtful person. What seems tragic is that she is self-aware enough to admit that it is herself she doesn't like, yet so far she has been unable to devise a strategy to address that. It also seems that Sara is accustomed to using laughter as a way to soften the impact of what she says when she reveals particularly personal thoughts.

For some others, including Sid, body image and preconceptions about cancer became a self-fulfilling prophecy.

I remember saying to [CNS], even though at that point still after knowing everything, I still didn't feel ill. You know, in January, I didn't feel like, I didn't feel like a cancer patient, I remember saying to [CNS], you're now gonna make me a, into a cancer patient. She sort of looked at me and I said, you're gonna make me look like a cancer patient now, and she sort of said yeah, you know, that image you get of somebody, pale and gaunt and just frail. And that's what I had in my head. (...) And within no time at all, by the time I got to the end of the treatment then, four more weeks had passed, I was down to, God, I don't know, 10½ stone? So, and that's when I realised then, that's, that's when I looked in the mirror then, and I looked at myself and that's when I could say, now you look like a cancer patient. That's when I felt I looked like one. Because I was gaunt, pale, lost so much weight, and then to me, I just, I wasn't being, I wasn't trying

to, I don't know what the right word is, I wasn't trying to, to, to, to, you know, make out that there was anything wrong with that or that, that, there was anything wrong with how I looked. It was just how it made me feel looking at myself. I couldn't express it any other way than saying to me I felt like a cancer patient, because of, whether it's right or wrong, that what you think you're gonna look like, because you, I-I, from pictures or from what you mentally think you're gonna look like.

Sid

In Sid's recollection of events he managed to predict the effect the treatment would have on him physically and mentally. With little direct experience of cancer, Sid had an association with cancer patients using words like *pale*, *gaunt* and *frail*. Despite his very positive outlook, conceptualising what it means to be a *cancer patient*, may have become something to aspire to. Because he did not feel ill, by looking like a cancer patient he may have allowed himself, or even pursued an outward physical representation of what he was told was happening within him.

Grace described a situation which seemed beyond her control.

But certainly my husband was very worried, about my weight, extremely. Um, about how much weight I was losing and what, what I was eating, well by mouth was very little and my weight was just plummeting at that time. He was extremely worried. Um, I was probably out of it most of the time with drugs and um, tiredness. Um, I guess that was late January-February.

*How did he show that he was worried?*

He would tell me, you got to try and eat a bit more. Um, and um, [pause], yeah very reassuring and um, I guess a couple

of times not quite as much as got cross, but he knew I could tell he was worried. And that would upset me. That he was worried. But I don't think I realised you know, he said I don't think you've realised how much weight you've lost. Although every, every hospital appointment you have, you're weighed. But I suppose it's actually looking at somebody who you know, you know, I'd lost certain features and I went very, very bony. Putting it on again now but went from sort of size fourteen clothes to size six, so it was quite a drop. Hmm. (long pause) I suppose you don't really um, realise your appearance, how much you've changed then. Yourself. Yeah.

Grace

Using words like *very*, *extremely*, *plummeting* and *bony* all suggest that weight loss was a major issue for Grace and her husband. However, unlike Sid, Grace was not able to see the dramatic changes which were all-too visible to her husband.

### 5.9 Physical and emotional support

While some of the participants were able or willing to openly discuss their experience with those around them, others including Joe, Seth and Ernie seemed to exclude those around them in one way or another. During analysis it seemed that while this may be a valid coping mechanism for them, it may cause additional difficulties for those closest to them.

Yeah, but in answer to your question is yes, she coped but she coped with my cancer by, by being so useful and, you know, every appointment, you know, you need this, you need your tablets here. Do you want your nebuliser? Spot on, couldn't fault it, she got a hundred percent of the time

and there ain't many people I think that'd do that without sort of forgetting once or. But she was on the case everything, so and I think that's the way she coped with it, she wanted to help, she felt useful (...) But she had to put her life on hold for six months to look after me basically, cos it does take, your life is completely changed and that's why you want to get back to normal because your life is completely changed for six months. And then you spend another eighteen months then trying to get back to normal I think.

Joe

From how Joe described the dynamic of their relationship it seemed as though Joe's wife may have realised that Joe was emotionally unavailable during this experience. While acknowledging that she could not support Joe emotionally, she could support him physically. For Ernie's wife, the substitution of physical support for emotional support may not have been adequate.

She [spouse] wasn't too happy about it. So. [Pause]. It's [pause], I'm, I can put things into boxes so [pause] it actually didn't worry me because there's nothing I can do about it. She, she was more upset about it. So. [Pause].

*Upset?*

Yeah. People assume that you're going to die when you've got cancer. I think that's still what people expect nowadays [pause] so [pause].

*How did she deal with that?*

Um, took the dogs for a lot of walks. [Pause]. She's got some good friends and uh, yeah, how can you deal with it? [Pause].

*Did you talk about it?*

Yeah. Yeah. It really didn't worry me so, I'm quite happy to talk about it. It wasn't something that concerned me or upset me, So, yeah, if it helps somebody else to talk about it then I was quite happy to do so. [Pause]. Um, told the boys [teenage sons]. But obviously, softened it a bit so it didn't sound so bad. They were happy. They were not upset, not happy.

Ernie

Ernie's description of the experience seems very cold and mechanistic both towards his wife and his children. He gave the impression that there was very little affection in the home. Seemingly because he was able to *box* certain thoughts and emotions he assumed that the rest of his family could do the same. Taking the dogs for lots of walks and seeking support from friends suggests that Ernie's wife experienced more difficulty than him in coping with the situation.

While not as obviously distant as Ernie, Seth also highlighted a lack of communication around the cancer experience.

*How did [wife] and [daughter] deal with it [the diagnosis]?*

Um, [pause], quite well really I think. If they didn't they didn't show it to me. You know, they didn't deal with it, but from the outset they were quite positive as well. But they never, seemed to get down about it. Whether that was just to help me or not, I don't know. I don't know, but they seemed quite positive about it, so. And when you say to them, cos [wife] came with me when I was diagnosed look. And, um, when he said like, you know, you've got good prospects and all that, you know, good recovery rate and all

that, I think that helped her as well. But, if it did affect them they didn't show it.

*Is it something you've talked about since?*

No, we don't really, [pause], no, not really asked about it, no. Just don't sort of mention it now. Just part of life. Just move on really I suppose. [Pause]. No, never really asked her. [Pause]. Sometimes you don't want to get her upset. At first she did get upset, you know, diagnosed. But I just said, you know, be positive, I'm young, fit, but, you know, so [pause].

Seth

While firstly indicating a lack of awareness of any emotional difficulty experienced by his wife or child, Seth then admits that his wife was upset at one stage. Certainly, his response implies a lack of willingness to discuss things to the point where the subject is almost forbidden. This lack of openness is something that was incredibly difficult to identify or empathise with, and which led to a sense of impenetrability during the analytical process.

Sid spoke of being aware of the emotional support that is available for families of cancer patients, but also of not seeking out that support.

I'm sure lots of people and families then, maybe did, they took the help out there. But we didn't you see. So, you know, we didn't take, grasp that, for somebody to come and sit with us and talk, and I know, I know, I know, I do, tend, sometimes I think that we should have maybe. I think again, naively, I think, maybe for them.

Sid

Others including Michaela were more articulate about the degree of support they wanted during active treatment.

And I quite, um, I am quite a loner and I also quite like being ill on my own. But I physically didn't, I just didn't have it in me, you know, physically, to kind of do it all on my own. Um, and emotionally we completely, on the days that I was wobbly, he was very strong and on the days that he was wobbly I was very strong. And that's kind of how it worked really, the whole, you know, four months, you know, from diagnosis to the end of treatment.

*Wobbly?*

Wobbly. Yeah. Well I think there were just some days where you couldn't kind of get your head around it all and, I just wanted to hole up and cry all day. [Pause].

Michaela

The use of the word wobbly seems incredibly powerful in this context, as again it provides a strong visual image of Michaela's experience to the point where one may actually feel a physical imbalance while reading it. It also strengthens the image of someone going through HNC treatment needing someone there to support them both physically and mentally.

In stark contrast to the viewpoints of Seth and Ernie, Michaela also acknowledges the value of open communication in helping her during her experience.

I have got friends that have had cancer and don't want to talk about it, was very important to me to talk about it and it was something that I found quite healing. Um, but I very much underestimated the impact that it had on the whole family really. [Pause].

Michaela

## 5.10 Intimacy and sexuality

When speaking to Seth, funnelling was used to try to open up lines of discussion around the relationship between him and his wife. When probed about the openness between them, and whether they communicated about his cancer experience he replied:

Not like a scare, a shock, suddenly think you turn up one day and they say you've got cancer and you suddenly think oh, you get it all sorted out and that's like I say, we don't talk about it much because, those nasty things from the past you don't want to be reliving it. Got better and, it's one of them things like, why rake up over old coals? And I don't, you know, I don't want to talk to her about it, I don't know how well she'd cope. She seemed to cope well that if she hadn't coped well and I talked to her she might get upset again. If she wants to talk about it she'd probably mentioned it to me.

*Is it something you feel comfortable talking about?*

Yeah, yeah. It's like I say, I beat it, so. I'm fine. [Long pause]. As I said, that's the only thing when I talk about it, I've got to drink plenty of fluids. My mouth gets dry and all that. No, I'm happy to talk about it. I've helped a few people since. As I said, that lady over the road, her brother-in-law, he had it. So he come over before the operation and I was telling them all about what I had and what happened to me and trying to tell him, you know, trying to tell him you might get down, positives and all that.

Seth

One of the difficulties faced when trying to funnel down to a particular topic is the potential for misunderstanding or miscommunication. It seemed important that Seth was reluctant to talk to his wife about the cancer because she may

become upset. During the analysis it appeared as though there were two possibilities for this reluctance. Firstly, Seth may have misinterpreted the question posed to him. *Is it something you feel comfortable talking about?* The *it* is ambiguous and open to interpretation and he may not have felt confident in asking for clarification on what was meant. Additionally, an open question such as *Upset?* may have been more appropriate in probing into the subject of his wife becoming upset when talking about his experience. However, given that throughout the interview Seth was far more comfortable talking about the pragmatic aspects of his experience (travel, work, side effects) than any emotional or psychological realisations, it may be that he was not prepared to talk about these issues in the context of the interview. Certainly, his use of the phrases *those nasty things from the past* and *why rake up over old coals?* suggests that there are things within their relationship which are uncomfortable for him to discuss, or perhaps even think about.

During the interview with Ernie it was difficult to get any sort of openness from him regarding his experience as most of his responses were very short and lacking in detail. It came as something of a surprise that Ernie was willing to talk about the intimate relationship with his wife.

For probably six to nine months after treatment finished, I wasn't particularly interested in sex. [Pause]. But now, pretty much back to normal, so, it was a short period of time.

*Pretty much back to normal?*

[Pause]. Back to normal. [Laughs].

*It sounds like I'm trying to catch you out, I'm not, I promise.*

No, it's, it's back to normal. It's, but probably six to nine months, it wasn't. I mean, we were still together, still happy, still in the same bed, just didn't have sex.

*Was that something you talked about?*

We talked about it [pause], a little, a little bit. Because it made her unhappy. [Pause].

*Do you mind talking more about that?*

If you ask the questions [laughs]. [Body language suggested this was an area he was uncomfortable with, but verbally he had given me permission to delve deeper, so I decided to proceed with caution].

*Okay, I'll lead it. Um, when, give me an idea of how that conversation went.*

[Pause]. Um, the assumption on her part was that I didn't fancy her anymore. [Pause]. And I was looking for somebody else. She wasn't happy with her, insecurity on her part.

*She hadn't linked it to the treatment?*

I'm sure she had but [long pause], it's [long pause], before she knew it was the treatment, but she wasn't happy so, I guess, she was blaming herself, wondering if there was something she could do or, you know, she was at fault. [Pause].

*What did you say?*

I explained that it wasn't her, it was the treatment. It's, yeah, it's [pause] it wasn't that I didn't love her, it's just that I

didn't want to have sex, I just wasn't interested. [Pause]. It wasn't important to me.

*And it became important again?*

Yeah. You know, eventually. I don't know why. Yeah, maybe a birthday or something [laughs] I don't know.

Ernie

During the analysis it appeared as though instead of increasing the use of open questioning in order to combat his very short answers, the questions had become increasingly closed. Reflection of the interview intimates a tendency to synchronise or mirror speech and language patterns in order to engage and identify with the participant. There was definitely an awareness on my part of anxiety during the interview at the perceived awkwardness of the encounter and lack of engagement from Ernie.

The repeated use of silence was important in this situation as it allowed time for Ernie to recall and reflect on the experience as well as indicating that he had the space or opportunity to talk about it in greater detail. Using reflective notes made immediately after the interview, this section appeared to hold a great deal of tension both for Ernie and myself. Given Ernie's body language it was unclear whether the line of questioning was appropriate for him, and this caution was noted during transcription. As the interviewer, there was a dichotomy of thought between protecting the participant and exploring what may have been a rich seam of data.

Other participants such as Casey were far more open about the impact of their experience on their sexuality and intimate relationships.

*I ask this of everyone I interview, um, in terms of your intimate relationship, your sexual relationship, has that changed?*

Yeah, massive. Um, (clears throat) but then I-I'll be honest, I-I don't know whether that's, that's due to my illness, I don't know whether that's due to our ages, time of life, um, I, I would say, it's a mixture of everything, um, it isn't, it isn't one specific thing. Um, I mean, [name of partner] has been going through menopause now for probably two three years, so I mean I think her, her sex drive is, has waned, um mine, yeah it's definitely, I mean obviously I mean from, from the beginning of the, the operations and the radiotherapy, it was probably the last thing on my mind then, um and yes I mean it, I won't say there is no sex life then, but yes I mean, it, it's not what it was. I mean I'm looking at the fact that the um, once we get back into something of a normal stride, or what's a normal stride for us then, that, that, that will come back into it a little bit more. Um, I suppose it's, yeah, the brain's willing but at the moment the body ain't, for me then.

Casey

The immediate response and the use of the word *massive* implies that this is a subject Casey had given at least some thought to. He demonstrates a great deal of analytical awareness in discussing not only his cancer experience but also the menopausal changes that have occurred with his partner during the same time period. It was also interesting to see him separate his sexual desire into the mental (*the brain's willing*) and the physical (*at the moment the body ain't*). There appears to be an element of disassociation in his description. By referring to both brain and body as *the* rather than *my*, Casey is able to remove any responsibility from himself about what he may view as a failure on his part to engage in a sexual relationship with his partner. Similarly, by referring to their

ages, his illness and the treatment, Casey is further able to distance the change in their relationship from who he perceives is the true Casey.

Thought	Evidence	Interpretation
Casey is trying to promote an idea of himself; a version of his own identity that he wishes to portray to others. He is concerned that his masculinity may be in question because of the changes in his sexual relationship with his partner.	Separating out the mind (the brain's willing) and the physical (at the moment the body ain't).  Shifting any perceived blame to external factors which are beyond his control (treatment, age, hormonal changes).	His view of himself and how he is viewed by others is important to him. Casey finds value in his identity. A change in his identity may be either beneficial or harmful, depending on how it is viewed by him or others.

**Table 8 - Thought process from evidence to interpretation.**

When talking about the change that he described within himself because of his experience with cancer, Terry was asked if such a life-change has affected the relationship between him and his wife.

*Has that changed the dynamic between you and your wife? If you've changed and she...*

Yeah it has. It has changed. Yeah.

*How so?*

Um, because you um, because, how has it changed? Because I feel now I want to get more out of life. Um, and my wife is, is, I mean don't get me wrong, she's absolutely over the moon and delighted by the results of the, the treatment. Um, but she is still the same, still looks at life in the same way that she's always looked at it. And I'm now looking at

slightly differently. Um, it's a difficult one, too difficult really for me to explain. To be honest with you.

Terry

As with Casey, Terry did not pause or hesitate in confirming that a change had occurred. However, when probed Terry was unable to contextualise that change. His attempted description does give the impression of a divergence between them like a fork in the road. Describing it as too difficult to explain helps to propagate that analogy further by envisaging the two of them taking different paths in the road but the thought of them drifting apart is too difficult for Terry to contemplate. Michaela also highlighted this theme of divergence from her husband in her interview.

I just think it's changed my whole mind-set really. I'm very much, just kind of, live for today and, [pause], yeah. And it is a big wakeup call and I think that's his problem That he's suddenly realised how vulnerable we all are, and fragile life is and that's what he's started to struggle with. [Pause] Yeah. [Long pause]. (...) But at the moment whereas we've always run at a bit of a parallel he's kind of come through this, he's been on medication and stuff, and I'm very much want to do my, I want to feel, I kind of feel I want to do my own thing. Like there are still places in the world I want to see and now I'm determined, right I'm going to see them, and if I can't go with an eight-year-old then so be it, I'll go on my own. And he's taken up a couple of new hobbies because, I think, he's a bit like, we need to get on, you know, live life so we've gone a little bit like that [moves hands apart], it's a bit odd. [Long pause].

Michaela

Here Michaela displays a similar sense of positivity, but the tone is less marred by feelings of potential loss. Michaela seems to have at least partly accepted

that she and her husband are beginning to take different paths, as indicated by her hand gestures. However, Michaela seems far more at ease about how the new dynamic will work and her ability to not rely on someone else to fulfil her ambitions compared to Terry. Despite mentioning new hobbies, it is not clear if her husband is as accepting or welcoming of this new dynamic.

Peter was very forthcoming about all aspects of his experience, and the intimate relationship with his wife was no exception.

*When I've interviewed other people that have been in relationships, most of them have been in relationships of one sort or another, um, I've asked them if the, if the cancer, if the diagnosis and the treatment has changed things between them and their partner.*

Yes, yeah it does. Um, in terms of the sexual side of it, you know, we had a very healthy sex life, um, but, leading up to it, up to the treatment, it was OK. Once the treatment started, I just didn't want to know. Afterwards, you know, um, I haven't kissed my wife in over a year. You know, an intimate kiss, yeah a peck on the cheek but I'm paranoid now that I won't kiss anybody. You know, has it come from that, I don't know, but I haven't kissed her intimately in over a year. Um, you know, I mean I talk to my wife every day, every single day. If it's not by Skype I'll phone her, to make sure there's nothing wrong, you know, because obviously she's got now to deal with being there on her own.

Peter

While not fully recognising it at the time of the interview, Peter's description of the fear of kissing his wife does not support his response when asked about the possible causes of oropharyngeal cancer. While he was aware of a viral connection, he talked more about alcohol consumption when he was younger.

In this extract, it appears as though he may have more knowledge about HPV and the potential routes of transmission than he was willing to describe explicitly.

Peter also demonstrates a fear that is present throughout his interview. Rather than fear of the immobilisation mask or the treatment machine, here he describes his fear of transmission through kissing. What is not clear is whether he is fearful of passing on an infection to his wife or whether he is fearful of being (re-)infected. He certainly described having to move out of his father's house because he felt his father was a source of other infections such as chest infections. It is possible that he views his wife, or previous relationships, as the cause of his cancer and now he needs to protect himself from that type of exposure.

### 5.11 Isolation

Whether support was available from family and friends or not, all of the participants intimated a sense of isolation as a part of their experience. For some like Bruce it was the physical isolation of being away from work and feeling confined at home, while for others like Joe it was more of a sense that his wife did not empathise with what he was experiencing.

So that's whether seems a bit, of course I did get down. Did I get down? I remember once, I remember [spouse] saying to me, I think it was, you can ask her if you like but it was quite late in the treatment and we went for a walk. And I was doing the, um, you get the saliva and I was coughing and she said "come on" and I said "well I can't go I said if you had this you wouldn't be able to walk very fast", and that upset her. And at the time, I didn't say it as a joke. I felt a bit oh, you know, just leave me alone and [spouse] said she remembers

she was upset all day but she didn't talk to me about that at the time, and I wasn't so, I didn't think it was no big thing but obviously you're not aware of how much I was upsetting [spouse] but I don't think, but other than that, you know, we just got on with that. But that was, she told me that later, she said, oh, I was upset because I'd said, you know, I'd almost snapped at her saying well if you had this you couldn't walk very fast.

Joe

By not realising at the time that he had upset his wife, Joe seemed to have retreated into himself where he was only aware of his limitations caused by the treatment. The fact that Joe's wife did not communicate her feelings to him at the time also suggests that the normal lines of communication may have been disrupted by the cancer treatment or the change in roles from husband and wife to patient and carer.

Bruce's description of his isolation following treatment was far darker in tone and language.

*Tell me a little bit about what happened after you finish treatment.*

Well basically, I spent the next three months lurking in this room. At the mercy of daytime TV, reading books, I spent a lot of time asleep. [Spouse] managed to get me to go for a walk occasionally. I had lost a significant amount of weight by that time and a considerable amount of muscle as well. Even to just walk up the road back was quite, an event. Very short of breath, that sort of thing.

Bruce

The imagery used by Bruce is particularly powerful. His description, although not told in an emotive way, lends itself to thoughts of confinement and isolation. Use of the word *lurking* is most telling in this extract, as it is a very visually charged word. Other verbs such as sitting, recovering and recuperating would have all accurately described the situation. However, lurking encourages images of a prison cell or concealing oneself for a nefarious purpose. Also, being *at the mercy of daytime TV* suggests that he was powerless in that situation to do anything else. Again, this reinforces the concept of *being done to*. Bruce then goes into more detail about the experience.

I guess the overriding thing was, was, since I was, by then I had loads of problems with mucus in my throat and it was getting difficult to swallow and stuff so, as one day, sort of merged into the next and there was no visible improvement or no noticeable improvement, just really, thinking, you know, how long is this going to go on for. And the view, watching that transform into the winter landscape, raining, grey and horrible, dampened your spirits even more so to speak.

Bruce

With a large picture window dominating the main living space of the house it seemed fascinating, even during the interview, that Bruce saw so much of himself in the increasing bleakness of the winter landscape outside. Attempting to empathise with his experience, it was not clear whether had it been spring or summer during this period, if Bruce would have retreated further within himself. The thought was that the bleakness of the landscape acted as something identifiable for him. He may have seen the landscape as an extension of himself which meant he did not feel quite so isolated.

During treatment Bruce also had to deal with the possibility of redundancy.

Yeah. So that was actually quite I found that [redundancy] personally probably more traumatic than anything else. I think at the time I remember thinking when would be the best time to top myself if it came to it. You know, in terms of death in service benefits. Thinking, because at that time I had no idea whether the treatment was successful, whether I could go back to work in any capacity. And being ill and having a job is one thing but being ill and redundant and not having a job is a completely different kettle of fish really. Your financial cushion is completely gone. So yeah, that was quite worrying. And it was a relief to discover eventually you weren't going to be made redundant.

*Let me just go back a little way, to what you said then about the thoughts that went through your mind about, I think you said 'top' yourself?*

That's, yeah I did consider, you know whether it's more beneficial for [Spouse] if I would die as an employee or, you know, what the financial benefits for her would be if I died after I'd been made redundant. So that's the sort of thing I was dwelling on. Thinking of ways to do it as well. Without it being obvious. Looking back now it sounds pretty ludicrous but the thing was that, that's what I did think about. Several times.

*How far did you get in that thought process?*

I never got to the point of actually, you know, physically getting up with the intention of going somewhere and finding a bridge or, railway line. But, see, I've given it careful consideration for some time. But fortunately before it got any further word came back that I wasn't going to be made redundant. It never got beyond that. And I certainly haven't thought about it since.

*That's quite a powerful [pause] a powerful thing to admit so thank you for that.*

Bruce

Bruce's thoughts of despair to the extent of suicide wholly support his extreme feelings of isolation due to the treatment-induced side effects.

While Bruce's distancing himself from others was largely self-imposed, Seth experienced a different kind of isolation.

I've got a few friends that are not like, local, lives round the corner. They're not through work. So, we started going out with them quite a bit now. [Pause]. It was a shock for them, they was about the only ones who got quite shocked, she didn't like it. She never used to come and see me when I was ill because she didn't like it. She used to come round after I had my op when I had the staples in and that and that put her right off. She stayed away because it freaked her out.

*How did that make you feel?*

It didn't really worry me too much because he used to come round, and like I said, if it upsets her tell her not to come. It don't worry me none, I don't mind. You know, you don't want other people getting upset about it. She was always, happy and have a laugh like. And she didn't like it when you was all, like, wired up and that. But she was the only one that, like you know, that really knocked her for six.

Seth

While this person's reaction to Seth did not seem to adversely affect him, it does highlight the issues some people recovering from HNC face when interacting with others. Terry experienced isolation partly due to fatigue and

partly because of worries around the thought of interacting with people outside of his immediate family.

Didn't leave the front door. Didn't even go out of the back door. Or the front door.

*And in terms of, your interactions with your children, other people, maybe friends or family. How did that, um, how did people treat you during that time?*

Um, (clears throat) well the only people generally that I saw, were my family, really. Um, my friends, all would text me a lot, um, asking how I was coping, how I was getting on and all this sort of thing. Um, and I did put a number of friends off from coming round because I found it very tiring. And, I don't wanna talk about, I don't wanna talk about all this all the time, when I was going through it, um, and I know that they want to know how I'm doing, how I'm coping and if there's anything they can do and all this sort of thing. Um, so I gave them a bit of, not a wide berth, but I put them off from coming round. As much as they said you know, when can we come round see you and all this, which is lovely but the way I was feeling, um, physically, I just didn't feel up to visitors at all. Um, so it was only family, certainly for a good, probably month to six weeks after the treatment, um, it was only family really. Cause I just didn't want to, I was too tired, too, um, so lethargic and so um, suffering with fatigue, I just didn't have the energy, you know just talking for a half an hour would tire me out.

Terry

Here Terry echoes Bruce's experience of self-isolation and a near self-imprisonment in order to cope with the effects of the treatment. While not as dark in tone as Bruce's account, similar feelings are generated by the idea of Terry not even feeling able to go out into his private back garden. When

conducting the interview with Terry in his living room, notes were made of how dark the living area was during the day without any lights on. Assuming the ambience of the room was similar during this period, it strongly ties in with Bruce's description of *lurking* in a room.

Peter's description of his isolation is both mental and physical.

Um, after the third day, I managed to control my nerves [pause] and then on the fourth day it was the chemo. [Pause] again, never, not knowing what to expect and how to feel and how you're going to feel. Um [long pause] I was OK and then all of a sudden, bang! [Long pause] it was like lifelessness and [pause] just curled up in bed and slept all the next day. Didn't eat, didnn't drink. Couldn't eat, couldn't drink. It made me feel ill and, er, and then waking up at five or six in the morning and getting out of bed and feeling OK. And then, all of a sudden, back to the hospital for your next dose of radiotherapy and, um, two or three weeks into it, you're starting to feel the effect, you lose your energy, your er [long pause] patience goes, you start arguing with everybody. Yeah, and er [pause] it's like you become a different person.

Peter

Similar to Bruce, *lurking* becomes *curled up in bed*, but the sudden change is described as a *bang*. This description suggests a sudden explosion like a bomb being detonated. The curling up reminiscent of sheltering from something terrible. He describes himself as *a different person* because he is arguing with everyone. Seeing this kind of aggression is not unknown in a clinical setting and is often thought of as a release of anger against the disease. In this instance it may be the two extremes of an autonomic response to fear. The arguing is the fight response, while the lifelessness and curling up in bed is the flight response.

Because he cannot flee from the disease of the treatment in a literal sense, his flight is to mentally retreat from a situation he finds unable to reconcile.

Yeah, I still have good days and bad days. You know the last ten days are just emotional, burst into tears for no reason.

Yeah, and I'm not an easy man to make cry [laughs] but, yeah, just sitting here, talking with somebody – boom, floods of tears. Yeah, and then the other day I was just listening to some music, yeah, floods of tears. Why? [Pause] and that's the thing, because you have so much time on your own, you know um, not being able to work, not having enough energy to go to work. I think it's just, you're all what are you, it just takes a change and that plays on your mind, I think. [Pause] but, you know, I mean they told me I probably wouldn't work for maybe two years. I said, we'll see.

Peter

Even twelve months after treatment, it is clear Peter is still struggling to come to terms with what has happened to him. It is unclear who *they* are that told him he probably could not work for two years, and certainly other participants were able to return to work in a much shorter timeframe. The most challenging aspect of Peter's story from an analytical standpoint is that often his story is more reminiscent of someone experiencing depression. The cycle of inaction caused by a perception of not being able to do certain things such as work seems to have trapped Peter. While not recognised at the time, it may be that Peter's eagerness to take part in the study and openness during the interview may have been an attempt at asking for help in a situation he could not extricate himself from. Noted at the time was the feeling of unease that Peter may have been using the interview as a counselling situation. While at no time did he ask for advice, the interview felt somewhat rehearsed. The perceived unease with the interview was initially put down to a lack of control in guiding

the interview. Later reflection replaced that with a feeling of manipulation by Peter with the aim of gaining a reaction or response from me.

[Long pause] and it's like, you know, time stops. [Pause] and you know going through the treatment and everything, your immune system's killed, you pick up the slightest little bug, you go into hospital. [pause] yeah, and you know, I stayed in my bedroom and I still caught temperature, cold, rushed back into hospital for a week, you know, with the infection, after the treatment. You have to be so careful [pause] and er [pause] you know, I didn't go out because of my immune system after the chemo finished. You know, they told me I had to be very careful, and I was. I didn't go anywhere, I didn't mix with people, and yet, a week after finishing, I was back in the hospital for seven days, because I caught an infection. [Pause] so again, it just plays on your mind, you don't want to go nowhere, you don't want to mix with anybody, you don't want to talk to anybody, I haven't seen my grandchildren for almost a year because I didn't want to catch anything and I didn't want them to, you know, see me in the state I was in. Um, they're only two and five, er, seven, seven. You know, I haven't seen my three children for nearly a year, only spoke to them on the telephone. I mean, that's distance, but also again, you don't want to see your, because you don't want them to see you in that condition.

Peter

Peter seems to view himself as trapped. Initially in this extract he talks about his perceived lowered immunity during treatment. Yet he says that he has not seen his grandchildren in almost a year. Possibly advice given to him during or immediately after treatment has been misinterpreted meaning he now fears infections on a permanent basis. Similarly, Peter goes into great detail in order to present himself as different in many ways to the person he was at the time of interview.

Um [pause] for me as a person, you know, I became [pause] afraid, insecure, um, sort of retarded in myself in a sense, that, you know, I've always been [pause] in terms of, I've been a workaholic all my life. You know, age of eleven I started working. By the time I was sixteen I had four jobs. You know, never been out of work, I've always worked. You know, I'm going to give you an example. While I'm working nights at [company] as a manager, you know, on a very good salary, you know, er, I was earning close to £40,000 a year, um, you know, before tax. I'd still work [pause] on a Saturday and Sunday at [company] because I enjoyed talking with people, um [pause] and my love for cars and motorbikes, you know, I lived in [name of town] at the time so for me, it was another avenue to be talking with people, mixing with people, because that's, that I am, or I was a very sociable person. Um, and now, I'd be lucky if I see anybody or talk to anybody, er, other than my wife now.

Peter

There is something about his story that caused a sense of mis-trust in me when looking at it in detail. Initially I thought it was the number of contradictions such as the reasons his recovery is slower than many others. Despite much thought and analysis, it is still unclear as to whether there are other issues in Peter's life which he is either not aware of or is not willing to share in this situation.

Another interpretation is that Peter finds comfort in gaining empathy (or sympathy) from others. This will be discussed further in the second findings chapter. Yet another interpretation is that Peter's extended monologue was so different to all of the other interviews that it caused me, as a researcher, to feel out of control within the interview.

## 5.12 Fear and worry

The use of language has been a source of great interest during the analytical process. While the intention of certain language will be discussed in a later chapter, it was perhaps most evident when discussing fear and worry.

Well, pretty grim really, overall. I mean, I went in with the attitude after, well, actually it got grim even before the treatment started because on the first day I was told, I was in the room with all of the people and I was told, I had to see [Dentist] about my teeth, I needed my wisdom teeth out, because of the risk of damage to them from the radiotherapy. And she was quite blunt, you know? I find personally, looking at an x-ray of your mouth quite, um, scary anyway, you know? So my teeth had to come out and I remember she said the whole process would be pretty horrific, you know. As it turned out, she was quite right.

Bruce

In a similar way to how Bruce described his recovery, here he refers to the treatment as *grim*. Again, he uses a word with very visual associations (darkness, cold) which he then adds to with *blunt*, *scary* and *horrific*. All of these terms seem to add to a picture which is very bleak and almost Orwellian. When analysing Bruce's transcript, the image which kept coming to mind was that of the exterior of the Ministry of Love in Orwell's 1984. With no windows, steel doors and imposing barbed wire entanglements, the Ministry seems to be a perfect metaphor for Bruce's fear and isolation.

Terry described the time between diagnostic tests and diagnosis as the most fearful time of his experience.

So the last thing we wanted to do was to scare him [son], you know the way that I was scared. And I was scared, I

mean I've never been scared like that in my life before. Um, because it's not the sort of thing fortunately that you, something that you have to deal with. Um, and of course you never think it's gonna happen to you. These things always happen to other people. Never to you. And then you begin to question, well why has it happened to me. You know, why me. Why suddenly, what sparked it off. And of course no one really knows. (...) So you go from one extreme to the other. You know, making sure you've got your life insurance in place and your payments are up to date and all your affairs are in order. You know, but it's not easy. Very difficult. That was actually the hardest part mentally, to deal with. After you're diagnosed, and you're then told what the treatment's going to be, the mental side of it I found very easy to deal with. It was then the physical side that you had to relate to. As a result of the side effects of the, the um, treatment. So it, it for me anyhow, it very much came in two parts. The mental anxiety up until you know what, what it is. Cause once you know what it is and you're told well this is what we're going to do about it, then it settles your mind, to, to, to a level that you can very easily cope with it.

Terry

Unlike Peter, Terry found the treatment seemingly easy to cope with from a psychological perspective. While not being able to leave the confines of his house as mentioned earlier may contradict this, Terry asserts that confronting the unknown prior to diagnosis was far more challenging. With a lack of control, Terry's fear of the worst possible scenario forced him to address his own mortality to the point of confirming his life insurance status. This was a feeling shared by Grace.

But um, probably helped me, you know, at my lowest point I think was, yeah it was prior the treatment, with this awful wait. Um, yeah it was quite low at times. Um, yeah I was

thinking, thinking in terms of funerals and all sorts. Mm [pause]. Yeah, you know. Not knowing, um, well not knowing what the future brought really. Whether I'd be, like at Christmas, is my um my first treatment started on the 30th of December. So they said I could have a good feed-up. (Laughs) I could have put weight on 'cause I was going to lose it. Um, so have a good, have a good Christmas, the best you can, and um [pause] yeah. So that's what we did. Trying to get through Christmas the best we could. As I said at the lowest I didn't know [pause] whether I'd err, see the next Christmas really.

*Were these thoughts that you shared with anyone else?*

Um [long pause] most of them, but not what I've just said, the funeral and that. Yeah [pause] yeah. Those were the innocent really. (Long pause) So (very long pause).

*Yeah that seems [pause] that seems really difficult to try and keep inside I guess. Must be [pause]*

In a way it's protecting those around you. In a way, by not sharing those, or that thought and [pause]

Grace

For both Grace and Terry, they were unexpectedly forced to face their own mortality. What seems poignant is that while both being in seemingly supportive relationships, they felt they had to hide these thoughts and deal with them in a state of solitude. For others such as Michaela, the worry seemed to be less specific and more enduring.

But I do remember you'd wake up in the morning, and whereas before if you've had a worry when you go to bed, by the time you wake up in the morning that worry's kind of,

diminished or gone, and this was just a constant horrible black cloud that just didn't go away really. It just didn't leave you.

Michaela

Michaela's black cloud metaphor seems to fit perfectly with the inescapable nature of the cancer and the treatment. Knowing there is a collection of faulty cells inside your own body may cause feelings of ensnarement. Similarly, once the treatment induced side effects start to present (particularly from radiotherapy) there is no way out or around them. Like being forced onto a rollercoaster, once it starts there is no way to stop it even if you wanted to. Once the side effects from treatment start, even by stopping treatment the side effects will continue due to its cumulative nature. This may also be compounded by the knowledge that if treatment is stopped prematurely then the long-term prognosis could be negatively affected.

In Peter's interview he described the fear he has around regaining normal eating function.

Um [pause] you know it's very difficult and, er it's a massive effort, you know, and you start to get the pains in the neck from your jaw moving, and, you know, trying to eat. You just give up all the time, because it's a real, it's tiring, it's a real effort to eat something and er, and then the sensation of choking. Although you're not choking, you feel like you're choking, because you haven't eaten for so long you've forgotten what it feels like to eat and you panic. Yeah, um, I mean a few weeks ago it was so bad I choked on a poached egg. You wouldn't think an egg could choke you but, you know, choked on poached egg. Um, which puts you off, stops you from trying to eat, you know and er, [pause] and then the hospital they went and gave me a video. I forget what they call it, VF for short, but it's where they put a machine on

you and they give you some stuff to eat and they can see the food going down your throat. And it gives you some reassurance when you see it, I suppose, that proves it's not getting stuck, it's going down, it's just the sensation in your mind and what you're feeling, it's your perception that you're choking, because you haven't felt it for so long. (...)

So, you know, er, that really has been my last eleven months.

Peter

Here Peter described the psychological challenges of re-learning how to eat. While not commonly used for HNC patients in their recovery, the use of real-time imaging was used to demonstrate to Peter that his fear of choking was not based in reality. Interestingly here Peter switches to and from *you're*, *you* and *your* to *I*, *I'm*, *me* and *myself*. Although not exclusively, these changes seem to be around what he feels he can and cannot do, or perhaps where he thinks he fails and succeeds. For instance, *you feel like you're choking* becomes *I've managed to eat a little more and encouraged myself to eat*. It seems as though Peter is distancing himself from any perceived failure but recognising any perceived accomplishment.

### 5.13 Employment

Many of the participants faced a change in their employment status during and/or following treatment. This section contains quotes from five of the twelve participants. While most of the participants spoke about work, these quotes have been chosen as they reflect the group as a whole. Most of their experiences with employers were positive, but some faced financial difficulties as a result of taking time off work or were forced to work throughout their treatment due to financial concerns. At the time of interviewing Casey, he was about to begin the process of returning to work with a physical assessment.

However, given his work as a chef and the changes to his eating habits and ability to taste, he was apprehensive about returning to work.

I mean I, I got to be, I got to be sort of truthful to m'self, um, and to the company I work for. And I mean we take it from now, I mean, if it, if it is the fact that you know, I-I-it's not happening for me then, or I can't, I can't tweak things then to change it to, to how I am now then or to how I may be in, in six months' time. Um, with the taste buds and that side of things. Then, no, I mean, it will the fact I will still look for, like I say something in, in that trade because I know it's where double the wages-plus to anything I can get out. If, if it doesn't happen, then no, it will be the fact, like I say, I'm only fifty-three, fifty-four then, so I mean in that respect I've still got um, a good few years in front of me where, you know, I haven't got that type of money to fall back on, that, that I can afford not to work, I mean, something will have to happen then, I mean we've, we've been practical about it, in-in so much, as we both know without, without the wages I earn [at his job], we, we couldn't afford to do what we do and we probably couldn't afford to live here. So I mean, it, it would be the choice of alright then, we downsize, we, we go rent um whatever, I mean we're not impractical people then. I mean that, that sort of conversation has been, I mean no, I mean we haven't sort of, said right then, this is what's gonna happen, but, but yes we've obviously talked about the fact that um, it, it might not work out and what do we do in that instance.

Casey

For the majority of the participants, their experience with their employer during their treatment was a positive one. For most, in-work benefits meant they could take time off during their treatment without facing financial difficulty.

I naturally assumed that I was going to have the time off. I didn't even contemplate working through it because in a job you I started planning then, you meet people all the time, you're talking to people, they want their electrics you're under quite a bit of stress and I think when you're going through that you need to keep your head clear of problems really.

Joe

As with many of the participants, Joe viewed his job as a part of himself and his identity. More than the financial impact of not working, Joe wanted to get back to normal after treatment and normal meant working.

I could have took retirement instead of going back to work after the 6 months I had this I could have really, um, a bit later than that actually, it was 6 months and then a little bit longer and then I could have took early retirement but I thought to have gone through this and not gone back to normal, um, I thought I'd go back to work which I think was the right thing to do because I'm quite enjoying the job now and I felt if I'd have packed up then what with overcoming the cancer as well that that I'd have been altering my life too much from the norm. Does that make sense? So that's why I made the decision to go back to work (...) I felt that I wanted to get back to normal and normal at that time was work.

Joe

Several of the participants also saw work as a way to challenge themselves after an initial recovery period.

Work was fine with it. I was off for five months in the end. But I went back, when I went back I went back, like half days first just to build back into it. Because the only reason I went back early was, your brain turns to mush if

you're not using it so you want to go back and get different company. That's the thing when you're at home, just watching daytime telly, it's rubbish. But you're not, when you're first in the radiotherapy you're too tired to do any work anyway.

Seth

Three of the participants were self-employed. For two of those, the financial impact of not working full-time during treatment was not a major concern. Sid had a private insurance policy in place which meant he could take time off during treatment and for several months after. For Ernie, he could change his routine to mitigate any reduction in income.

*You were working all through the treatment?*

Yeah, but [pause] self-employed lighting engineer, it's not hard work. You know, it's working all through the treatment might mean half an hour's work in the day. So, you know, I can go to sleep when I want. [Pause]. The sleep patterns got disrupted massively obviously cos if you go to sleep in the afternoon you're awake at night.

Ernie

For many there was a lot of uncertainty about how long they could take off and how their employer would react.

I've never been really ill before or known anybody at work who'd been off for a long amount of time with such a serious illness. Um, and it's all those things, um, [pause], how they'd cope. You know, would they be understanding [pause]. How would I cope money wise? Um, didn't know how long I was going to be off work for. But it turned out that, you know, I got a full salary for a year, so they were very good [laughs].

Very understanding, um, they've got occupational health department. Um, before I could even come back to work I had to go and see them and then I was integrated back into work slowly so it was a couple of afternoons a week and then it sort of built up and, um, they were very, very good. I'm really lucky.

Sara

For Sara, one of her biggest concerns was how she would be treated by her co-workers upon her return.

Um, it's not something I wanted to tell anybody. It turns out by the time I got back to work everybody knew. But I didn't actually want to tell anybody because I didn't want people going [whispers] that's the girl that's got cancer, kind of thing. So, I didn't want people treating me any different or [pause], um, [pause], and also it was none of their business.

Sara

Although Jack managed to work throughout his treatment and recovery, he had few options due to the financial implications of taking time off.

And like, going to work helped. Always found that, yeah I don't like sit around and just think about it.

*Did you manage to work right the way through the treatment?*

Yeah. No, no, I, I couldn't have taken, and anyway you got the money stress side of it as well you know. You don't get paid, well personally I don't get paid a lot of money if I'm off, so you do, you try and work through it. That is sort of like real big one, when you sit there and think, right I've got cancer, how is it gonna affect me financially. Yeah, you just

don't know. You know, you're laid up for a couple of months, how you're gonna cope. It's just an added worry. But, the missus said don't worry about it, we'll get through it.

Jack

For Bruce, the concerns regarding work were even more immediate even while he was undergoing active treatment (see quote on pages 197-198).

#### 5.14 Comparison

This section looks at how several of the participants compared themselves and their recovery to others. For the participants who seemed more pragmatically minded, there was a desire to conform to a schedule of recovery. This was often of their own design and was sometimes informed by other HNC patients or even cancer patients with an unrelated malignancy. Sid described how he struggled with eating and drinking, and the implications that had for him and his self-perception.

Um, but because of the treatment I had, I met lots of people in there. And I could see them eating, and that was a bit frustrating because I would, I could watch my family eat, and I could see other people eating and, and, the, the thing that I, that made you sort of, was, any, I don't, I-I'm not gonna be big, touch wood, but I was happy with my weight, but it just frustrated me to see me go so thin. But I knew it had to be that way. But, when you see the other cancer patients eating, you think, blinking hell. But you realise, their treatments for whatever cancer they had, and they could have had a lot worse than me, it wasn't affecting other parts body then. Because mine was in my neck, it, you had to get your head round the fact that, you were going to be, they was gonna cause other problems then, to other, well to the, to the bits associate with your neck. Your mouth, and throat,

and all the bits, whereas I suppose if you, if you had, I don't know, if you say you was having treatment for bowel cancer or something, maybe, when you're having that treatment, it doesn't affect you from eating, drinking and doing the things that we take for granted. But, because my treatment, because of I had it in my throat, that's what the hardest thing was to get your head around the fact, that it stops you from doing everything that me and you take for granted.

Like, having a cup of tea, having your eat, sitting down and eating your food, it's just, you know. And I could see that, yeah you, you know, you could, you can get down about it. You could get down about, and, and, you know. So it was, it was just weird. Because it was, you go from being like, what you think, like I said to you, you think you're doing fine, and then, you get hit with this treatment and it's all that goes with it.

Sid

The advice given to patients regarding their recovery can often be quite ambiguous. This may be deliberate in order to avoid any distress if patients fail to fit predictions. For those such as Seth, who were able to recover their eating and drinking abilities relatively quickly, comparisons against other people or what was thought to be *normal* encouraged him.

But I seen the nurse and I was talking to one bloke one day, I said about it and they were saying, you know, you're doing well, you're keeping up, and it sort of gives you a boost, like.

Seth

For others like Sid, he saw his family as well as other cancer patients eating normally. This led to isolation and frustration. Interestingly he stops short of saying that it did negatively affect him, preferring to repeat the phrase *you*

*could/you can get down about it.* By avoiding an admission of difficulty, he seems to be protecting himself against a perceived failure in his ability to cope and recover.

Peter was in the unique position in the study group of having seen his father experience the cancer only a few years before his own diagnosis.

Like I said before, I'm a very positive person and at that time it didn't really worry me. Um [pause] you know, because, as I say, I had seen dad go through it [long pause]. I think going through the actual start of the treatment, that's where it really hit me. Um I had some panic attacks, um especially with the mask, um, so, um that was a very, um frightening thing. Um, have you seen the mask and how it all operates, yeah? It er, I mean when they made the mask, even then it was, you know, sort of hyperventilating and stuff. Because although they're there and they're holding your hand and, you know, because it's, er, not. Because it's new, I know my father had a mask, but it wasn't like mine. My father had a complete Perspex, um, one, which was as I say six years ago. It was obviously how they did it but this new one, how they did it, when they stick the thing over your face, um, and it moulds to your face and it's warm, well, it's hot [laughs]. Er, it's frightening and, er, then when they try and clip it down, you know, you feel [pause] trapped. I suppose is the word, you feel trapped. Um [pause] it's er, it's scary.

Peter

The changes in treatment technique and severity of side effects gave Peter difficulty in reconciling the comparison between him and his father. At several points, Peter suggests that his father's experience, or more specifically his treatment induced side effects, were more severe than his. However, his difficulty in coping with the immobilisation mask and treatment related side

effects appears to be compounded by comparisons with his father. Unlike Sid, Peter does not attempt to downplay these feelings. Moreover, Peter continues in this vein to emphasise and re-emphasise the difficulties he faced. This process of emphasis and presentation will be discussed in more detail in the second findings chapter.

### 5.15 Recovery and positivity

Despite many of the difficulties faced by the participants, several of them also highlighted positive changes as a result of their experience.

It's made me think differently. And it makes you value different things in a different way.

*Such as?*

Um, your home life, your personal life, your relationships, it makes you value those differently. Um, and it makes you realise, it makes you think about what's, what's more important. What is important to you and what isn't important. And what to worry about and what not to worry about. It-it's quite, quite odd. It really is quite odd. Um, and to value things more in terms of, or appreciate things more. You know, appreciate the wonderful things that we, we do have. Whatever that may be, and it will be different for different people. But um, to, to appreciate things more where things that we've taken for granted um, I'm now beginning to appreciate more.

Terry

While not a universal view, Terry's comments echo sentiments from Jack, Seth, Bruce and Grace that their experiences of cancer have enabled them to appreciate life a little more.

## Chapter Six – Findings Two: Recognition

### 6.1 Chapter introduction

The aim of this chapter is to present evidence of an original contribution to knowledge which is supported and evidenced by direct participant quotations, as well as in-depth researcher-led interpretations. While the first findings chapter aimed to capture the experience of all of the participants, albeit in a more superficial sense, this findings chapter will draw on evidence from just six of the twelve participants. The aim is to allow the freedom to explore certain aspects of their interviews in far more depth.

IPA is not a prescriptive approach. It provides a set of flexible guidelines which can be adapted by individual researchers in light of their research aims (Smith et al. 1999; Smith 2004; Smith and Osborn 2007). Similarly, themes are not selected only on the basis of prevalence. Other factors including the articulacy and immediacy with which passages exemplify themes and the manner in which the theme assists in the explanation of other aspects of the account are also important considerations (Smith et al. 1999).

There is no suggestion that any claim made in the thesis is representative or generalisable to the entire study group. The six participants were chosen because their interviews broadly represented the emotive use of language and the journey to a post-treatment self that was present, but perhaps not explicit, in many of the other interviews. The decision to focus on those six was done to ensure depth rather than breadth of analysis. To try and include all twelve participants at this stage would have stepped away from the principles of IPA. This exclusion of a proportion of the participants is not uncommon to IPA research (Eatough and Smith 2006) and will be considered in more detail in the

discussion chapter. The selection of the six participants was influenced during the latter analysis phases when ideas around reward began to surface.

## 6.2 Reward through recognition

The original contribution to knowledge generated by the data is the concept of desire for reward through recognition in people who have been treated for oropharyngeal cancer. Born of the question of why so many of the participants use such emotive language in the descriptions of their experience, it appears the need for empathy and the sharing of experience from a single person (me as the interviewer) can extend much further through the publication of the research. Clearly the perceived incompatibility of social recognition from an anonymised study must also be addressed.

## 6.3 Initial interpretations

During the initial stages of data collection and analysis there appeared to be a commonality to the participants' stories which was of triumph over adversity. Possibly with the exception of Peter, the other participants recounted very similar stories of difficulty and hardship (diagnosis and treatment) followed by a period of recovery, and finally returning to some sort of normality. The message seemed to be *it was tough, but I coped.*

## 6.4 Pre-existing ideas influencing outcomes

During post-interview reflections, it soon became apparent that there was a potential danger in looking for something that was not there. Advice from CNSs was that HPV was a relevant and important topic for many patients. HPV was not raised as an important issue during discussions with support group

members prior to the study's design. However, this was put down to the difficulty of discussing certain topics in a non-private and non-anonymised setting. Moreover, the first interview with Joe closely reflected the thoughts shared by some of the support group members: *it was tough, but I coped*. Even speaking to the wife of a former support group member who had passed away from cancer some time ago, she seemed to take solace from the fact that her husband had fought the cancer right to the end of his life. There was a general sense in the support group of taking pride in fighting the disease and wanting that achievement recognised. For the support group, the recognition of this fight seemed to come from each other but also from medical professionals who were invited to group meetings, as well as from the wider community through fund-raising activities.

## 6.5 Evidence of the desire for reward through social recognition

During analysis themes began to emerge around the idea of recognition for the participants' experience. My interpretation was that for many of the participants, there was a desire for their story to be heard, and their endeavours recognised. Below is a table outlining the thought processes involved in making some of the interpretations. IPA is influenced by the researcher and their life-world, but also grounded in the data. A concern was that interpretations would be more about my life-world than the data. Indeed, there are many different interpretations possible for each extract used. Supervision was an important part of making sure those interpretations were grounded in the data.

Data	Thoughts	Interpretation
Specific use of language (grim,	Would I use this language? If so, why would I use these words?	The participants want the impact

<p>bolted, lurking, forced – Bruce) (suffered – Ernie) (shunted, awful, stringy, horrible, agony – Sara) (suffering, petrified, trapped – Terry)</p>	<p>Does this language fit in with their normal speech patterns? Why have they chosen these words to describe their experience? What reaction are they expecting/wanting from me? Does it conjure up memories of other situations? (fear, pain, no control). Is this use of language common to all/most of the participants? How would I react/feel in their situation?</p>	<p>and difficulty of their experience to be heard and understood. Diagnosis and treatment can be difficult and traumatic. Not many people see or understand their experience.</p>
<p>Previously undisclosed information (Grace's letter to her family in case of her death or thoughts about her funeral) (Bruce's thoughts of suicide)</p>	<p>The participants must feel comfortable/safe enough to share this information. Are they in any emotional danger by revealing this to me? Would I do similar things in their situation? It frightens me that patients go through this and other people would not know. Do my patients experience similar or worse feelings? Why have they chosen to tell me? Are these participants representative of the whole study group, but not all are willing to share these thoughts?</p>	<p>These people want the wider world to know how difficult diagnosis and treatment for this cancer can be.</p>
<p>Emphasising inner change (Michaela and Terry's changed outlook on their relationships with their partners)</p>	<p>Satisfying that people are willing to share such personal details about themselves. What proportion of patients experience similar issues? Are their partners aware of these thoughts? Is there support to help people navigate these changes in their lives?</p>	<p>The cancer experience affects more than just the patient. The effects can be wide-ranging and long-lasting.</p>

Choosing to take part in the study	Would I take part in a similar study? If so, why? What would I want to get from the experience? Is it purely altruistic? Has the interview helped them in any way?	The participants want to help others as well as themselves understand their experience.
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**Table 9 - Path from data to interpretation.**

For several of the participants there was a conflict in some of their statements. Ernie's description of his experience was puzzling in that he repeatedly maintained his assertion that the treatment went *really smoothly*, yet he made repeated references to bouts of oral thrush.

I would have been fine but I just suffered massively through thrush, mouth, oral thrush. It still affects me even now. Um, and that's what stopped me from eating. You know, all the energy drinks and all the, you know, I couldn't drink any milk at all, cos that would just set me off immediately. Um, and as soon as that starts then [pause] it takes time to settle down and obviously radiotherapy is aggravating it all the time so, you know, I suffered, I suffered with oral thrush.

Ernie

What was most striking about this extract was his repeated use of the word *suffered*, which he goes on to repeat here.

Um, actually I suffered with and I continue to suffer with thrush. Right up until Christmas actually, um, um, another six weeks at least of thrush. Which is, I had to go back to the doctors with it as well as few times. But that was, the only problem I had [pause]. I still get it now, I had a throat infection two months ago which led on to thrush and [pause], but, I expect it, um [pause].

Ernie

If the treatment had indeed gone *smoothly* as Ernie initially said, this seems to be incompatible with *suffering* of any kind. So why would someone present the experience as simple and manageable and yet use words such as *suffered*?

While there are many different interpretations for this use of language, such as the practicalities and logistics of treatment went smoothly, it seemed that this kind of language adds a metaphorical weight to the experience. It can be likened to completing a marathon, where the challenge is perceived as greater for someone with a lower limb disability compared to someone who is able-bodied. Similarly, the achievement of completing cancer treatment may demonstrate more perseverance and character if the treatment causes a number of painful and challenging side effects than if no side effects are experienced at all. It is this perceived value related to the difficulty of the experience which leads to the theory that these participants choose their wording consciously so as to project an image of increased accomplishment. Possibly this is not thought through but employed as a device to prompt recognition.

Um, so, yeah, and then before I knew it, um, all the radiotherapy started, which is awful. Absolutely, within, um, because I thought that I would be able, I was, yeah, I'll carry on going to work. I'm sure it'll be fine for a while. Um, and, um, I think it was about two sessions in that I started to get this really horrible stringy, um, saliva that felt like it was hair around the back of your throat. It was, it's just awful. Um, and then that went on, it just got worse and worse as the radiotherapy went on. And, and then your mouth, your mouth constantly filling up with saliva every, like, ten seconds. And honestly, I must have got through bags and bags and bags of kitchen roll, where I was constantly spitting and, you know, I use to sit with a bag, a carrier bag next to me at home. I could fill one in a day. It was just awful. Couldn't lie down flat because obviously the saliva would

just keep building up, you know, every ten seconds or so. It was just awful.

Sara

Sara goes on to say:

I could cope with everything else, it was just this constant spitting and it was, it was just aw, horrible and it just, just like string, like hair round the back of your, you know, what would have been your tonsils, you know. Um, that's just what it felt like and, you know, literally it was just gross and it's just a horrible sensation in your mouth as well. That is what I, I think at the time if that would go then I would be hap.., I could cope with everything else. So, that was the biggest thing for me I think, during the whole treatment.

Sara

In this extract Sara uses very descriptive wording to create a highly immersive depiction of her experience during active treatment. She then counters this by describing how she was able to cope with the side effects of treatment with very little support from anyone else.

*How do you deal with it [the treatment induced side effects]?*

Do you know, strange, I, I actually think I coped okay. I didn't cope okay but um, considering I was on my own, I um, I just got on with it. Because it was a case of like, well, what else can I do? You know, everyone, there were, there were, um, a few occasions, not very many when you think of, you know, how long it all went on for, where I just sort of broke down and it was just like, I just couldn't cope and it was, I just, you know, cried and [pause], but then you've just got to, you know, it's not going to go away. So, you've just got to pick

yourself up and just carry on with it really. But I did all, I got myself to the hospital every day, I didn't take hospital transport. There was only, I mean there were days where I was throwing up in a bowl in my lap on the way here. Um, I don't know, I am one of those people that doesn't like to ask for help. [Laughs]. So it doesn't help.

Sara

In this extract, Sara demonstrates the value she places in being able to drive herself to the hospital most days rather than relying on hospital-provided transport. This is despite experiencing such severe nausea that she was sometimes vomiting during the journey. Even her admission of breaking down in tears is tempered by the suggestion that she picked herself up without help from anyone else. Sara also places additional value on appearing independent and self-reliant. For her, the sense of accomplishment of completing treatment despite the severe side effects is amplified by the knowledge that she remained largely self-reliant throughout the entire experience. By using such descriptive language Sara is ensuring that the magnitude of her side effects is fully communicated and understood. It also demonstrates that the side effects had a significant impact on her which proved challenging to overcome.

In the following extract Sara talks about the perception of cancer treatment and that not all cancer experience is equal.

I know that [laughs], I'm not trying to say that mine's better than yours but, um, I know that my treatment was a hell of a lot worse [laughs]. Um, but people probably don't realise that. Um, [pause], I don't, I don't think my friend from work needed to um, [pause], see I know that, you know, there are people with cancer that can carry on working throughout whereas because this is, you know, just basically half your throat, you know, is red raw and you can't swallow and

everything, it's basically, I know that the um, the symptoms are a lot, lot worse going through the treatment, than it probably is for something like breast cancer. Although the outcome could be worse with breast cancer.

Sara

In the same way that in the first findings chapter Sid talked about the frustration he experienced seeing other cancer patients and their ability to eat being unaffected by their treatment, Sara acknowledges feelings of frustration that people do not fully understand the complexity of her experience. In this extract she mentions breast cancer and how despite having not been through breast cancer treatment, Sara feels as though her treatment was far more gruelling. However, this desire for recognition is tempered by a desire for privacy and anonymity.

But I didn't actually want to tell anybody because I didn't want people going [whispers] that's the girl that's got cancer, kind of thing. So, I didn't want people treating me any different or [pause], um, [pause], and also it was none of their business.

Sara

In this sense, participating in a study with the guarantee of anonymity may provide the perfect opportunity to increase wider awareness of the true impact of head and neck cancer treatment whilst still maintaining a sense of personal privacy. Sara previously mentioned difficulties eating in public and particularly at work. Through increased awareness of the side effects of her treatment, Sara may be hoping for fewer questions and conversations or less perceived awkwardness around the subject.

Generally speaking, if a task or experience is challenging, the difficulty is made more acceptable by the offer of reward. Enduring the cost and self-application

needed to learn to drive a car results in a greater degree of independence. Renovating a house results in a visual reminder of the hard work as well as something other people may be envious or complimentary of. Even completing a PhD gives not only a personal sense of accomplishment, the possibility of greater career opportunities, but also societal acknowledgement by recognition of the title Doctor. The actual detail of the specific difficulties is perhaps less important in these examples because there is an end result which can be displayed and recognised by others. When comparing two similar achievements one may try to quantify the endeavour by the perceived difficulty. For example, in the realm of ultramarathons (foot races longer than 42.195 kilometres) the Hill Ultra held in the UK is four miles longer at 160 miles than the Marathon des Sables (156 miles) held in Morocco. However, the desert heat experienced in the latter means that it is commonly viewed as the greater challenge. Such an achievement cannot be quantified but it is the perception of the achievement which is important in this regard. In addition, a lot of examples of difficulty followed by reward are a matter of personal choice rather than the unexpectedness of a cancer diagnosis.

The frustration that many of the participants faced is that they have been through an extremely challenging experience, not of their own choice, but which leaves them with little or no outward signs of their accomplishment.

So um, so yeah, I mean yeah, I'll be honest, I suppose because um, where obviously during having surgery I looked like a bag of shit, um wasn't feeling too brilliant, so it was noticeable that there was something wrong with me. Whereas I suppose, over the past four or five months, physically, to, to anybody it doesn't look like there's anything wrong with me. So, it-it-it has sort of tended to fall to the background then that um, it's it's not so much in, in everybody's face because they see me as having got better

and I'm waiting to go back to work. I suppose, to say the first sort of six months, what with the surgery and looking a bit shit, losing the weight, and obviously looking a bit shit, and then sort of getting back into normal living, it-it was more, it-it was more in the forefront, whereas now it's more sort, not forgotten about but it'll be all Casey, can you do this, Casey, can you do that, blaadiblaadiblaa. It's a more normal, normal situation then I suppose. And, it's like I say, it's not that it's taboo to talk about it, it's not that we don't talk about it, but it's not that we do talk about it.

Casey

Casey talked about how he feels as opposed to how he looks. The impression he gives is that the experience of living with cancer is somehow made easier by other people acknowledging and accounting for the emotional and physical changes he is undergoing. Given his stage of recovery it may be that there is an apprehension about returning to a new normality. In this sense Casey's psychological recovery is taking longer than his physical recovery. However, everything from his return to work to how people interact with him is based upon his physical condition rather than a psychological one.

In addition, Casey talks about difficulties discussing aspects of his recovery, almost like there is a specific period of time where such discussions are acceptable. Now that he feels other people have moved past that point, indicated by his use of the phrase *normal situation*, he seems metaphorically left behind.

Also, using the phrase *not forgotten about but*, suggests that there is a sense of mourning over losing his identity as the cancer patient. In the same way that Michaela used non-verbal cues such as moving her hands apart to indicate the change in dynamic between her and her husband, Casey is describing a

perceived difference in himself from the normality of life before diagnosis. Again, this points to a desire to have his experience understood on a level other than the physical impact that is visible to others.

Similarly, Casey seems to want other people to overtly acknowledge the seriousness of his cancer diagnosis.

I mean, my brother, my brother turned around to me and said, 'You'll be alright.' I said 'What?' [shocked and negative tone] 'I knew you'll be alright. I knew it would turn alright at the end.' So, yeah, um, no, I can't say it was, I suppose I'm, I'm, on that score, I've been more, more reactive as to how people were seeing me, you know what, how were they going to, how were they going to deal with me knowing, that I had cancer, I, I have cancer, I've had cancer um, how, how they react, how they were going to deal with me.

Casey

In this passage Casey responds negatively to the assertion by his brother that he *knew it would turn alright at the end*. Casey has shown that he is clearly concerned about his future health, having already seen his father suffer what he perceives to be an undignified death due to bowel cancer. Therefore, what may have been a light-hearted quip perhaps aimed at Casey's determination or resilience, or an attempt at reassurance, is taken to be an affront to the difficulty of his experience.

What is also important to note is how Casey corrects himself after saying *I have cancer* to *I've had cancer*. The point of his transition from a *healthy person* to *cancer patient* was very specific and abrupt, as was the case for many of the participants. However, Casey's transition from cancer patient to healthy person, or perhaps more accurately to a person who once had cancer, is far more

indistinct. Many of the participants spoke about the transition back to some form of normality. However, the timing of the interview in relation to their treatment and recovery may mean this issue is more pertinent to Casey and Peter who were considering returning to work than for Seth or Bruce whose recovery was further evolved.

Other participants, such as Terry, also seemed to draw value from the views and opinions of others.

And funny enough, um, I'd seen a GP um, about something else which I'll tell you in a minute, and um, she had said that are a lot of people don't actually manage to stick the six weeks, because of the side effects. Um, they just find that they can't put up with it anymore. And they give up early. Um, which I can understand why people might want to do that. And especially if you haven't got that strength mentally, to see it through. You know, you think I can't take any more of this, you know, I have another week or two weeks of the treatment to go and already I'm suffering with this so much.

Terry

In this instance, Terry seems to gain a sense of pride and accomplishment from what his GP tells him. While there are no statistics to support the GPs assertion one way or the other in regard to oropharyngeal cancer patients specifically, Huang et al. (2011) suggests the percentage of people (treated radically with radiotherapy for all HNC) who are unable to complete treatment due to the side effects is around 4%. Clinical experience suggests this figure is much lower, particularly for younger oropharyngeal cancer patients. Combine this with the small likelihood of any one GP seeing more than a handful of people treated for oropharyngeal cancer in their working career, it seems to be more likely that the GP was attempting to provide emotional support and motivation in a time

of need. Terry is able to show the value he places on his mental strength in completing the treatment. He is buoyed by the idea that not everyone can do what he has done and draws strength from the recognition he receives from his GP.

While there were no questions in any of the interviews about the participants perceived reasons for taking part in the study, they all entered into it knowing that the results would be published at some point in time. Many of the participants offered comments regarding their reasons for taking part which were not necessarily recorded during the interview itself but were mentioned while gaining consent or when closing the encounter. The most common reasons given were to help other people going through the same treatment as them or to give something back. Whilst seemingly altruistic, there were some participants, such as Ernie and Jack, who used verbal and non-verbal cues to indicate that they were not at all comfortable in an interview situation (e.g. their use of very short responses and a reluctance to elaborate on their answers). The freedom not to take part in the study once an expression of interest had been given can be demonstrated by the several people who, for whatever reason, chose not to take part after more information was given to them. By taking part in a study aimed at shining a light on their experience it can be seen that a possible reason for them to take part would be greater understanding and acknowledgement for themselves as well as other people. Moreover, even the invitation to take part in a research study could be viewed as a form of recognition.

Direct comments from Casey such as to how he was affected by what his brother said, as well as interpreted comments from Terry, Sara and Peter suggests they are, in some way, impacted by how they and their cancer are viewed by others.

But um, I think, [pause], while I was told that I think head and neck cancer is one of the most complicated, you know, I'm not saying the worst type at all. But there's a lot of other issues that you never consider. If you knew somebody that had an oral cancer you wouldn't ever kind of consider what other things they might have, might have dealt with.

Michaela

By highlighting her previous lack of knowledge around the experiences of people treated for oral cancer, Michaela seems to be stressing the inherent value in the population as a whole having a better understanding of what she and others like her have been through.

### 6.5.1 A starting point

Even before any data was collected, it was suggested by a number of experienced researchers, including supervisors, that in order to successfully obtain rich data one must allow the participant to tell their story. For a purposive sample of people who have been treated for cancer it seemed obvious that a common and comfortable starting point would be their diagnosis. Unlike Peter who seemed to have his own narrative decided before beginning the interview, most of the participants requested a certain level of guidance as to what to talk about and where to begin. What was particularly interesting even in the very early stages of analysis was how people described their experience. In particular, it was their repeated use of visceral descriptive language which often contradicted the other content of what they said (see section 5.12, page 206 when Bruce talks about his experience between diagnosis and treatment.)

As already discussed in the first findings chapter, Bruce's use of the words *grim* (repeated) and *horrific* evoked images of darkness, fear and pain during the initial analysis. What came later was the question of why he chose those particular words and phrases.

Being only the second interview, it was unclear at any point whether Bruce's responses were rehearsed or scripted, either consciously or unconsciously. What came to mind was being in a social situation and hearing someone recount a story which is obviously familiar to others present. There is sometimes a familiarity which is hard to describe but is present nonetheless. This may be based on the confidence demonstrated in how the story is told or its fluidity. Regardless of whether the story has been embellished or re-interpreted, sometimes there is just a feeling that the story is being told in that particular way for a particular reason.

Here Sara describes the period after her surgery:

Um, and came back and, um, saw [surgeon], and he basically said that we're going to have to take your tonsils out and scrape, um, the nodes. Um, and at that point actually I thought that was the end, that would be it. I didn't realise that, maybe I wasn't listening properly or maybe that was the case at the time but I thought that once that had been done, that would be the end of it. Um, then I had that done which was the most [emphasising 'the most'] horrendous pain, and I've got quite a high pain threshold, I think, um, but, uh, it was awful. I think it was eleven to twelve days of absolutely the most excruciating pain in my throat.

Sara

What is particularly interesting in this example is that Sara describes *the most horrendous pain* and *eleven to twelve days of absolutely the most excruciating*

*pain* but also puts that pain in context by describing her *high pain threshold*. Sara's account is delivered with far more emphasis on certain phrases than Bruce uses, but the wording is very similar. With both participants it felt as though the use of language was aimed at sharing their experience. Their experience became a journey, with Bruce's *grim* experience with the dentist and Sara's *eleven to twelve days of (...) excruciating pain* becoming points where they feel people may be able to identify and subsequently empathise with their experience. By Sara describing her pain with the knowledge that she also has a high pain threshold she is able to amplify those feelings and assist in recalling periods of intense pain in my own past.

The difference between empathy and sympathy are important distinctions in this context and will be discussed later in the chapter.

### 6.5.2 A natural progression

As a logical progression from diagnosis, many of the participants went on to talk about their treatment. In the extract from Sara's interview in section 5.6 (page 168), she discusses her feeling about having teeth removed before radiotherapy.

What is particularly interesting is that Sara uses the words *whirlwind*, *shunted* and *battle*. Again, she appears to be using a particular type of language to increase empathy in the researcher. Reminiscent of facing a schoolyard bully, Sara portrays herself as dazed and disoriented by the whirlwind before being physically and forcibly pushed or manhandled. After being told *you've got to* several times Sara reaches a breaking point (the removal of her teeth) where she battles with her bully. In this account Sara is the victim and in reading the transcript, I am put in a place where I am encouraged to take sides. Given the

choice of the helpless victim trying to fight back or the faceless bully it is clear where most people would stand.

During the interview with Terry he was particularly open about some of the side effects of his treatment.

When I was at home here, I literally used to sit on the sofa with my feet up and I didn't even bother having the telly on, I was just felt mentally, I felt as if I was somewhere else, in another place. (...) You just felt as if you weren't all there, you felt as if you were on drugs. Um, and that just became worse and worse, only the highlight of the day was actually getting home after having had the treatment 'cause the treatment time varies from one day to the next. Um, which in some ways was, I prefer to have the same time every day, um because all you want to do is to get the treatment over and out the way so you can get home, put your feet up and try and sleep. Because that's all you felt like you wanted to do. I didn't bother having the television, didn't have any music on, you were just sort of in a, almost in another world, mentally.

Terry

Although Terry's description is about the effects of his treatment, he describes a scene which is familiar to most people. Whether through physical illness, depression or bereavement, most people would have experienced a degree of the numbness and isolation that Terry describes. Here he is taking an experience that very few people (as a percentage of the general population) have been through and putting it in a context which is so familiar and easy to empathise with. With an increased sense of empathy, Terry is then able to take the reader from the familiar to the specifics of his treatment and accompanying side effects.

But, um, after, certainly after three weeks, um, it got to the point where I couldn't lie down because I had too much mucus, and as soon as I laid down I was coughing the mucus etc. So I ended up sleeping down here on the sofa, sat up because it was only by staying sat up that I was able to keep the mucus to a level that would enable me to go to sleep for long enough, an hour, before the mucus would then wake me up and I was then sick because I was swallowing a lot of the mucus, um, so I was sick at night time. Mainly in the night, during the day it wasn't as bad but at night time, sickness was dreadful, and I'd be sick four or five or six times during the night. So, you weren't sleeping, so you were extra tired during the course of the day, um, and that's when it then became worse and worse when you came home, feet up, just want to go to sleep because you're so tired. You know, you have no energy cause you're not sleeping, your whole sleeping pattern disappears, you never sleep for more than an hour at the time, because of all the mucus and so on. Um, very little pain, if any at this stage.

Terry

Because Terry gave his initial description a sense of familiarity, it then becomes easier to imagine what it was like for him when he talks about less familiar experiences.

That's easy [the treatment], it's the being at home is the hard part. Dealing with the side effects. Um, cause by this time, I mean my, I had ulcers throughout the whole of my mouth, on my tongue, on the inside of my cheeks and everything, um which were all nasty and painful. Um, the inside of my cheeks were all swollen, um, it was just not very nice at all. Pretty horrid. Um, when I do think back to it, it's, it was ghastly. But, I knew that this was just something that I had to go through.

## Terry

Terry appeared to have a greater ability to articulate his experience compared to some other participants. While this increased the detail and complexity of his account, during analysis it seemed far more rehearsed. Whilst initially creating a sense of excitement about the richness of the data, there were also feelings of mis-trust surrounding the honesty of the account. It also felt as though sympathy would be more welcome to Terry than empathy.

The majority of participants reported feeling uncomfortable around certain people after the diagnosis because the other person didn't know what to say or the participant didn't know what they wanted to hear. Even in the context of an unstructured/minimally structured interview, Grace said "I actually find it quite difficult to, to suggest things so if you can help me out a bit." It is not surprising that people feel uneasy when they are out of their comfort zone, so it may be that Terry and others have become accustomed to people displaying sympathy for their diagnosis or their experience of treatment.

Peter presented the greatest challenge when it came to deciphering what he wanted from taking part in the study. Unlike Grace who asked for guidance within the first minute of the interview, Peter spoke for over fifty minutes after the opening question without prompting or encouragement. It appeared as though Peter had his own agenda, and despite meandering off point on a couple of occasions he seemed clear in what he wanted to say. What was less clear was what he wanted from the interview. Subsequently during the transcription and analysis of the interview there were feelings of loss of control and manipulation, which will be discussed later.

Despite being very positive about the care he had received, Peter was enormously detailed in his description of the psychological as well as the physical impact of the treatment. Throughout the interview he gave the impression of having thought through the interview many times before, and the experience allowed him to verbalise thoughts which he had not been able to share with anyone else.

### 6.5.3 What next?

Bruce was among several participants who were able to articulate the arduousness of the period after active treatment had finished. Like Peter, Bruce was generally very positive about the care he had received. However, as discussed in the previous chapter, Bruce describes a very bleak period recovering from the side effects of treatment (see section 5.11, page 197). In this moment Bruce seems to display a separation from who he normally is and who he was during this period of treatment. Similar to Peter describing himself as *a different person*, Bruce assigns blame for the thoughts of suicide to *the shadow of redundancy* and his *miserable existence*, almost as though he is describing someone else. What occurred during analysis was the thought that Bruce may find it difficult to reconcile such thoughts, as though they represent a part of him that he dislikes or does not wish to acknowledge. By disassociating himself from this other person it may be an attempt to share something important to him without the fear of being judged. Certainly, more than half of the participants describe the cancer as something to be fought and defeated. In this sense there may be a psychological value to the idea of having succeeded, and conversely a sense of failure in experiencing thoughts of suicide or developing cancer to begin with.

The impact and severity of the side effects of treatment were a source of complex descriptive language.

I do find that the first thing in the morning that the throat's quite um, like, full of crap and when I sleep I tend to, I tend to breathe through my mouth a lot um, so when I get up in the morning, I almost feels like somebody's put plastic inside my mouth, it's literally that dry and that thick but obviously I get up and I brush my teeth but, then the throat's quite, feels quite tight.

Casey

In this extract Casey describes how he feels each morning upon waking. While describing his throat as *full of crap* is a somewhat non-specific description, albeit a very unpleasant one, he elaborates on this when he says it feels as though *someone's put plastic inside [his] mouth*. Again, his description goes beyond what seems like recollection of facts to a sharing of the experience by using such emotive language. Terry uses similar language to describe the skin reaction from the radiotherapy around his neck.

Um, but where the skin all broke out, it was really very horrid. Very very painful and that's why the GP came round, um, because the district nurse came round first of all to have a look. And um, said I think I'd like to have the doctor come and have a look, and so the doctor came and they prescribed this, like a jelly, um and some special um, pads that had some sort of medication I think within the pad and that was placed on the neck and then bandages all the way round. And that took a fortnight, before that started to, to heal. So that was particularly nasty, on top of everything else, the ulcers, the mucus, the pain, um, the swelling inside the mouth and the fact that I couldn't swallow. And all this sort

of thing. Just added to everything and of course the lack of energy, the lack of sleeping, um just made it worse.

Terry

In Terry's description there seems to be a sense of accomplishment. While there is no suggestion that there is any embellishment on his part, the image that is generated is one of a fighter, victorious after a bout. Battered, bruised and bleeding, Terry describes visible signs of his ordeal and yet he is the one still standing. However, for many of the people who have experienced head and neck cancer there is very little long-term physical evidence of what they have been through, especially with recent advances in treatment modalities. It was at this point that an idea began to form based around the concepts of accomplishment and reward.

#### 6.5.4 The interview possibly fulfilling needs

There were occasions during the interview process where it felt as though the participants wanted something specific from the interview or from me. In particular, Peter seemed as though he wanted the interview to go beyond the catharsis of sharing his experience to a therapeutic or counselling relationship. A large amount of Peter's interview seemed rehearsed, as though he had mentally or verbally gone through the narrative before. His isolation may have given him a great deal of time to process and frame his experience, with the interview acting as an opportunity to share his thoughts and feelings.

[Pause] um, on my fourth one I was, I had to be taken in a wheelchair to the car, I couldn't walk. That's how it affected me. Um, couldn't walk and the fifth one I was reaching to vomit when I got home. The Red Cross bought me home on the last two occasions, um, because I couldn't drive. And, er, I literally got out of the car from the Red Cross, into the

house, into my room and vomited everywhere. It was awful. But that's an effect of the, you know, or one of the effects from the chemo. Um, but it's just the, not having the energy to lift your arm or your leg, you know and I just slept for fifteen hours afterwards to the next day. You know, your whole body just seems to shut down. Um [pause] and it's more worrying, because you don't really think about it, you just, because you're on another planet really, but I think it's more worrying for your family. Um, because they're checking on you all the time and you're, you don't know that they're there. They're talking to you and you haven't got a clue what they're saying because you're, you just have no consciousness and um [pause] it's three or four hours before you start to realise and you wake up.

Peter

This was a source of great personal anxiety when conducting the interview as well as during the analysis phase. A number of different factors led to this feeling of Peter having his own agenda. This included Peter's eagerness to take part in the study, his control of the interview agenda (or perhaps my loss of control over the direction of the interview) and his openness of the psychological impact of his experience comparative to other participants. During subsequent supervision meetings it became clear through discussion and deeper analysis that the interview did not become a counselling session due to the lack of information giving and advice from me. What I learnt from Peter's interview was to not be so concerned about controlling the interview if I want to get a true reflection of a person's experience. On reflection I now understand that there is value in allowing a person the freedom to explore their own experience and provide guidance if required.

What had occurred at an earlier point in time was the realisation that despite best efforts to enter each interview as near to *a stranger* as possible, there was

a hidden agenda in what was expected from the participants, namely discussion of the impact of HPV. While HPV formed an important pillar in the study protocol and ethical submission, no overt discussion around HPV could take place with any participant in order not to disclose information they may have been unaware of. Peter's interview acted as a catalyst for this realisation and a deeper realisation that the study was being conducted ethically and in line with IPA principles. Peter's interview demonstrated that the participants were being given the freedom to share their experience rather than what may have been expected of them.

Um, I couldn't dress myself. Um [pause] you know, my father, he has a shower, so I'd, you know, because he's gone through it, he had a chair in the shower from the, so I could sit in the shower and have a shower, but you know, my wife had to help me wash and things like that, so you do lose all, um, your independence, you know. And if you haven't got somebody with you, it's awful. [Long pause] yeah, but er, as I say the first three months was a massive [pause] whirlwind really. [Pause] and like I said, I'd seen some of it with my father, so some of it wasn't a shock, but I suppose for someone who hasn't seen it and hasn't gone through it personally, it must be horrendous and frightening, because some of the things that, you know, I, it did frighten me. You know, I was scared. You know, I never let my wife know but, you know, sometimes I'd just be in my room [pause] crying, er, especially when she went back. Yeah, my father and his partner tried to look after me [pause] but I spent most of the time inside the bedroom. I couldn't go anywhere, didn't feel like going anywhere, didn't want to go anywhere. To the hospital, back, back into my bedroom, sleep, watch TV, sleep, watch TV, have my food, go to sleep. [Pause] couldn't have a conversation with anybody because I'd end up arguing and losing my temper. Yeah, which is not me, because I'm a very placid person and a very positive person. So, I'd become somebody else really.

Peter

Peter is very open about the changes to his emotional self as well as his physical self. However, while he is aware of his altered post-treatment self, he seems particularly uneasy about many aspects of his new identity. Opening up like this regarding his difficulties towards others may act as a way to illicit reactions from them. If the outward signs of treatment are not enough to trigger recognition, then how he interacts with others may be a way to signal the impact of treatment and/or the move to an altered self.

In retrospect, Peter's interview has generated more confusion, deliberation and insight than any other interview during the analytical process. After initial feelings of excitement and success at the apparent detail and openness of Peter's interview, these were replaced with feelings of manipulation of the interview and me as the interviewer. As previously discussed, there are many possible interpretations of the points raised in Peter's interview. I cannot suggest that any interpretation made in this thesis is definitive of what the participant intended. In line with IPA, the interpretations are a product of the participants' sharing of their stories combined with personal reflection and influence from my own life-world. Peter's interview in particular may be a source of further investigation beyond this thesis.

Ernie was also someone who seemed to display a desire to present himself in a particular way. Here Ernie is asked about his preparation for the future of his business in the event of his death.

*Did you ever have that conversation with them?*

No. No, they don't know that I did it. [Long pause] [Sons] would have upset them. [Long pause]. If I'm telling people that it's radiotherapy, it's six weeks, it'll all be sorted and

then we can get on with things, to turn around to them and say, and by the way, if I die then this is going to happen then I'm showing some sort of perhaps everything's not going to be alright. [Pause].

Ernie

It seems as though Ernie is trying to project an image of how he wishes to appear to others. By controlling what his family are told he is able to be the strong patriarchal figure who can provide for their financial wellbeing. However, there is little acknowledgement of their psychological or emotional wellbeing. During a supervision meeting it was mentioned that his lack of awareness of his family's emotional wellbeing made him rather unlikeable. With nearly all the other participants there seemed to be an attempt to gain empathy, or perhaps sympathy, from me as the interviewer. Whether intentional or not, Ernie's description of his attempts to distance himself from those closest to him made empathy with his family far easier than it was to empathise with him. An idea mentioned in this supervision meeting was that Ernie does not particularly like himself. Therefore, it is more comfortable when people do dislike him as it reflects his own feelings about how he sees himself. Ernie wants to evidence that he is the strong patriarchal figure who has planned his family's financial security should he die. He seems to be seeking recognition for protecting his family from information that they may find distressing. Also, it is possible that he doesn't like the Ernie with cancer or the implications of being an Ernie who is dying. He does seem to find value in being the Ernie who protects his family from emotional distress and financial hardship. However, he cannot be open with his family regarding the ways in which he is protecting them without exposing the vulnerable Ernie that he doesn't like.

### 6.5.5 Contradictions

Another aspect of the interviews, which supports the idea of participants projecting how they wish to be seen, is apparent contradictions regarding certain things. Ernie goes on to describe how his family discussed the news of the diagnosis.

*Did you talk about it?*

Yeah. Yeah. It really didn't worry me so, I'm quite happy to talk about it. It wasn't something that concerned me or upset me. So, yeah, if it helps somebody else to talk about it then I was quite happy to do so. [Pause].

Ernie

Ernie seems very open about how his family dealt with the diagnosis. While it seemed difficult to understand from a personal perspective how someone could be so unconcerned about a head and neck cancer diagnosis, taken on face value he seemed to be happy to discuss his situation with his family and provide support if needed. However, after some probing it seemed Ernie was far more uncomfortable in discussing the situation than he had previously suggested.

They all knew about it. Um. My Dad was probably the worst, he weren't too happy. Cos he was working with me in the joinery shop. So. But, [pause] it's, they didn't talk about it. It don't make any difference to me so.

*When you say he wasn't happy about it?*

It's, [pause] we were working together and he's older than me. And I'm the one that got the cancer. [Long pause].

*Like he should have been looking after you?*

I guess, you know, protection and that sort of thing. If I were to guess, they assumed that I wasn't going to survive cos it was cancer, so. [Long pause]. Yeah, I think, uh, [pause] him it took probably about the worst. [Pause].

*Is that something you've talked about since?*

No. No. My Dad's very similar to me. We just don't talk. We don't tend to talk a great deal unless there's something to say [long pause].

Ernie

Despite an awareness that his father was not coping well with the news of the diagnosis, both men seemed unable or unwilling to discuss the subject. During the interview it seemed as though Ernie closed the topic down by re-iterating the fact that he doesn't talk, despite the contradiction that he is able to talk as long as there's something to say. The impression generated during analysis was of a person desperately trying to project the image of a strong and self-reliant man yet fearful of discussing anything which is remotely out of his control. The diagnosis of cancer and the impact of its treatment has challenged Ernie's self-perception of being a strong and self-reliant man. To talk about these concerns would expose a vulnerability that he does not like. But, in absence of talking, he has received little recognition of his cancer, and subsequently has become emotionally and physically isolated.

## 6.6 HPV – the missing data

Other reflective pieces included in this thesis discuss the difficulties in bracketing during this kind of purposive study. While every attempt was made to be *the stranger*, much of the reflective work done involved preconceptions and stereotypes. What made this patient group so interesting for me and others (supervisors, CNSs, oncologists) was the concept of a burgeoning patient group.

This new generation of HPV+ve cancer patients, according to the literature, are theoretically at risk of a range of psychological and emotional difficulties that so far have seemingly not been explored in qualitative research. There was little mention of HPV from the participants. Below is an extract from one interview where it is discussed.

I never actually knew you could get viral cancers. So, yeah, that was, [pause], that was the first thing that I learnt. [Long pause]. But it doesn't make me feel any better and actually, probably something that I'm glad my mum and dad have never questioned too much. You know, but that, I don't recall when I saw the Michael Douglas, it would have either been, it wasn't before treatment. It was either post-treatment I think. And I remember, you know, reading the lady's reply that had also had throat cancer who was of similar feeling as me really, that you kind of tarred us with not a very nice brush. Made us feel very [pause], dirty and, [pause], yeah I didn't like that.

Michaela

From comments made by Sid, it shows that HPV is being mentioned in clinical conversations. However, it is unclear how much detail is being offered or the context in which it is being presented.

It's what they, the name of what they call the type of cancer. Like bowel cancer or, or breast cancer, they referred to mine as like H-HP or HPV or something I think it is. HPV-virus. And that's what they, that is the technical word that they call for in the um, in my, in my, in my neck. And it, they don't really say so much, I can remember [oncologist] saying to me, could have

been there for years, and then all of a sudden, [clicks fingers] out it come, you know.

Sid

While I went to great lengths to design a study protocol which would limit focus towards any one particular topic, it came as a disappointment when so few of the participants had any awareness of HPV at all, let alone viewing it as an important factor in their cancer experience. It was not until the latter stages of analysis when the issue of HPV had been put to one side, that it again became relevant to the concept of seeking reward through social recognition. While only supposition, there does seem to be a discord between existing literature and the data collected in this study. Michaela's description of feeling *dirty* because of media coverage of HPV+ve HNC does suggest an incompatibility with seeking reward through social recognition. This incompatibility reflects existing work done on the effect of means of death (i.e. suicide) on the grieving process and will be discussed in more detail in the discussion chapter.

Preconception/reason	Evidence	Conclusion
HPV would be a factor in the experience of the majority of participants.  CNSs said HPV was a common topic of discussion amongst patients.  HPV was a popular topic in the media at the time after Michael Douglas' comments about the	Only two people mentioned a viral cause to their cancer, despite all being asked if they knew about the possible causes.	HPV is not a significant factor in the experience of these people.

viral/sexually transmitted causes of HNC.		
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**Table 10 - Thought process from preconception to conclusion**

## Chapter Seven – Findings Three: The Hidden Experience

### 7.1 Isolation

While the concept of a hidden experience will be discussed in more detail in the discussion chapter, the majority of the participants eluded to isolation from those around them at some point in their cancer journey. In some cases, the desire by the patient *to just get on with it* led them to withdraw both physically and emotionally. Those closest to them often responded by withdrawing emotionally, perhaps as an attempt to give them the space they perceived they needed. For both parties, this reinforced the idea that their cancer experience is private.

Some people were aware of their actions and used isolation as a coping mechanism. Michaela could be described as one of the more emotionally articulate participants in the study and spoke at length about her reflections on isolation.

But I think I also went to bed a lot because it was my way of, just blocking it all out and, sort of, getting through it. [Pause]. Which was never how I intended dealing with it, my intention always was to still see friends and, even if I didn't feel well, to sort of go for a drive and remain part of normal life.

Michaela

In this excerpt Michaela acknowledges that even before treatment began she was aware that she would, in some way, be removed from normality. Instead she describes wanting to go for a drive and remain *part of* normal life. She goes on to say how she felt so unwell she could not drive herself, so her husband would take her out in the car. In my experience, there would be a difference for me going for a drive as the driver versus as the passenger. As I driver I have, in the past gone

for a drive to escape my problems or surroundings and clear my head. However, I see going for a drive as a passenger differently, in that I am more of a passive participant. I may have a say over where we go, but ultimately, I am relying on someone else for the experience. It is not an escape, but more of a change of scenery surrounded by the same issues. The lack of independence in being driven made me think about seeing the world as an observer, but distinctly protected from it. The image created is of an outsider looking in or being a guest in someone else's home. While being protected behind glass and metal may provide a manageable bridge between isolation and everything else, it may also reinforce the idea that the cancer experience is a hidden one. In the same way as the car is the only solution Michaela could contemplate to going out, perhaps the only way some people know how to cope with cancer is to mentally and/or physically isolate themselves.

You know, if people came round I was happy to see them, but I was physically, I was physically washed out.  
And I just wanted to, kind of yeah, be on my own really.  
[Long pause].

Michaela

It is questionable whether we can separate the physical aspect of our life-world from the psychological aspect. While Michaela reinforces with repetition the image of her being physically washed out during this time, when trying to empathise with her experience it seems just as gruelling mentally as it would be physically. Perhaps there is a recognition by Michaela or those around her that it is easier to understand and account for a physical exhaustion rather than any psychological impact. Michaela seems to be describing the need for a period of isolation, to cocoon herself where she can metamorphose into a new/altered self. On emerging from this cocoon, she would display an outward representation of her changed inner self, thereby making recognition easier for her and those

around her. This linked relationship between body and mind and how people deal with it is something Michaela highlights.

As we got towards the end [spouse] got a bit tougher with it. He can cope with anything physically so when I was being sick and worse he was absolutely amazing. That weekend I had the complete emotional, breakdown, he had no idea how to deal with that. He was very, um, intolerant and, you know, very much pull yourself together. He couldn't understand that at all.

Michaela

Michaela's husband's reaction is something that is echoed by several other participants including Casey and Joe. They all eluded to times when those closest to them would be very supportive of the physical impact of the disease or of treatment but had difficulty in accommodating their partner's emotional needs. It may be that people are, in general, more accustomed to dealing with physical sickness as opposed to providing more acute mental or psychological support. While these cases do not suggest that partners or spouses are unwilling to provide emotional support, they may lack the skills to do so.

In part, focusing on the immediate matter of active treatment makes sense. Someone drowning cares more about where their next breath of oxygen is coming from than about pension plans or marital harmony. When presented with a life-threatening diagnosis, emotional wellbeing may not be an immediate priority. Moreover, a lack of awareness of an altered self is not included as a potential side effect of treatment, and therefore is something that may not be apparent until a later time. However, once either or both parties have moved beyond the immediate treatment, it may be difficult to move the focus back to discussions of emotional health. Seth appeared to be very at ease with his

experience but probing during the interview revealed a lack of awareness of his wife's emotional wellbeing (see section 5.9, pages 185-186).

By saying *be positive*, it appears as though Seth is setting out what can and cannot be discussed. It is no wonder that even at five years post diagnosis, the same rules implicitly apply. This makes aspects of the cancer experience private, for both Seth and his wife. Even assuming Seth's experience is as inconsequential as he appears to suggest, by making the subject taboo he is making some or all parts of his experience hidden.

## 7.2 Below the surface

As discussed previously, Ernie came across as a very complicated person, and cause of much analysis and thought. As an outsider, Ernie's approach to his illness as well as other aspects of his life, seemed cold to the point of callous. Any researcher conducting a qualitative piece of research, and particularly using a highly reflective paradigm such as IPA, would likely class themselves as at least somewhat emotionally aware. These clashing opposites were challenging both during the interview and as part of the analysis.

It doesn't worry me [long pause]. Honestly, it doesn't worry me. I didn't have any upset period of time. I didn't have thoughts of, I'm going to die. And [pause], it's [long pause], when people get upset and start crying about things, generally when you think about it they're actually crying for themselves, not for the thing that's just happened. And I don't do self-pity very well, so it, there isn't any case for getting upset. It's dealing with the facts. [Long pause].

Ernie

It seems highly improbable, if not impossible, for someone to receive a cancer diagnosis requiring such aggressive treatment and not to ever contemplate one's own mortality. Again, this was a source of much reflection as to how much of the researcher is put into IPA interpretations. The question was asked many times following the interview, is Ernie's reality and way of being so far removed from my own, that understanding his experience is simply not possible?

Ernie's bravado seemed so pronounced, it was hard not to look at other possible motives rather than accept his account as fact. After previously interviewing Joe and Seth, all three men seemed to want to play down the impact of their experience. Initially it was assumed this was perhaps due to a projection of masculinity. However, looking at Seth with the awareness of the experiences of the other eleven participants, it may be that his experience is the most hidden of all. Not only has he persevered in trying to hide his experience from his wife, children and parents, but also from himself.

It is difficult to conceive of any clinical strategy or intervention that would have helped Ernie share and/or explore his experience of cancer. An easy response to someone who shuts themselves off, or distances themselves as Ernie did during the interview, is to reciprocate in kind.

### 7.3 Interactions with others

How other people react to a person going through cancer treatment may be another reason that the real experience can become hidden. Just as Ernie spoke about the reason people cry as being for themselves rather than the other person, Sara described how her colleague reacted when learning of the diagnosis.

I used to car share with this girl and, um, she knew I was going for appointments and she, I think she guessed something was going on and when I, I did finally tell her [pause], and um, we were in the car and she cried all the way to work.

Sara

While crying or showing some other form of emotion may be a useful way to initiate a deeper dialogue between two people, some of the participants allude to this being inappropriate for them. The empathy that many people would want to demonstrate to their loved ones going through cancer treatment may be interpreted as superficial or patronising, however well intended it may be. If a gesture is not viewed sincerely then it may reinforce the feeling that their experience will not be understood by anyone else. Subsequently, feelings of isolation may reinforce the view that their experience will be something that is hidden and/or misunderstood.

The absence of a shared experience can be challenging for people who are in long term relationships. Both Terry and Michaela spoke about the distance they now felt between themselves and their spouse.

Um, and my wife is, is, I mean don't get me wrong, she's absolutely over the moon and delighted by the results of the, the treatment. Um, but she is still the same, still looks at life in the same way that she's always looked at it. And I'm now looking at slightly differently. Um, it's a difficult one, too difficult really for me to explain. To be honest with you.

Terry

While the personal growth Terry and Michaela described may be positive in demonstrating their progression towards a post-treatment self, such spiritual or

emotional distance that is placed between themselves and a partner may be a source of difficulty in the short and/or long term and act as a barrier to seeking recognition.

#### 7.4 Chapter summary

By this point, the reader should have a sense of the participants in relation to their experience of cancer survivorship. There should also be a developing understanding of the part played by me as the researcher in exploring and understanding their experience. One of the most challenging aspects of the research process was trying to encapsulate the vast amount of data generated, as well as the hermeneutic process that went on and continues to carry on, in a single piece of written work. In writing this chapter, the intention was to convey as much of this experience as possible.

The following chapter will start by discussing what social cognitive processing (SCP) theory is, and why it was chosen as the lens for interpreting this study. The chapter will go on to examine aspects of quality and rigour, before setting out the original contribution of the thesis. Namely, in attempting to establish a post-treatment self, those previously treated for oropharyngeal cancer may attempt to seek recognition for their experience. Gaining recognition can often be hampered due to the hidden nature of the experience to the outside world. These two positions of recognition for a hidden experience may appear contradictory. However, it is important to emphasise that the experience is not hidden from the person whose life-world has been changed by diagnosis and treatment. Rather, due to the outer-self remaining largely unchanged, it is this imbalance between a changed inner-self and the stable outer-self which causes the potential challenge for them in adjusting to their changed life-world.

Chapter eight will continue by exploring the findings in more detail and set them within and against the existing literature.

## Chapter Eight – Discussion

### 8.1 Chapter introduction

This discussion chapter will begin with exploring SCP theory as well as other theoretical lenses. Next, the chapter will consider how the topics of quality and rigour were addressed in the study. It will then explore the findings in more detail and in relation to the existing literature. It will support the findings and argue the case as to why this study, its participants, and its findings are of importance to future research. Finally, the chapter will go on to state the thesis' original contribution to knowledge.

### 8.2 Social cognitive processing (SCP) theory and other lenses

When setting out this chapter, several theories or lenses were considered in order to frame the findings. Similar experiential literature was reviewed in order to find a theory or model which may be suitable in supporting the understanding of the participants' experiences (Anderson and Martin 2003; Eatough and Smith 2006; Astrow 2012; Cheng et al. 2013; Miller 2015). SCP theory is consistent with the IPA framework and double hermeneutic as described by Smith et al. (2009). This section will examine some of the lenses which were considered for this study.

In Coping and Adjustment Theory, it is suggested that individuals diagnosed with cancer may have to adjust to meet demands of their illness and their new situation. Therefore, they may enact mechanisms of negative or positive adjustment – proactive coping or frustration, isolation, and even aggression. According to this theory, adjustment processes of cancer patients affect social health and well-being of all family members. Therefore, negative adjustment can result in heightened levels of family tension and conflict (Cohen and Lazarus

1983). Hence, this theory suggests the need to pay more attention to the process of role change in a family and emotions associated with the transition from the status of an active provider for the family (or for oneself), to a passive state of a cancer patient (Jenkins 2006; Semple and McCance 2010; Deno et al. 2012; Precious et al. 2012).

Stress is examined by Dimond (1983) and Coelho et al. (1974) as part of Adaptation Theory. They stated that adaptation to living with cancer is a dynamic, unending, and evolving process requiring huge resources from an individual, and involving vast behavioural changes. There is a body of research on application of adaptation theory to cancer experiences. For instance, Klimmek and Wenzel (2012) studied the adaptation of the illness trajectory framework in transitional cancer survivorship, while Foster (2012) applied the Adaptation Theory to explore adaptation to change and experiences of breast cancer survivors. Research in cancer survivorship involving HNC patients has also applied this theory (Christianson et al. 2013; Fingeret et al. 2014).

During the acute stage of treatment and rehabilitation, HNC patients can experience much physical and mental suffering, as seen from their accounts about eating with the help of the feeding tube, recovering the swallowing ability and hardship in family relations. (Pryce et al. 2007; Ganzer et al. 2012). Hence, many of them find meaning in suffering (which may be explained through the lens of the theory of meaning (Starck 1979), further validated by Fitzpatrick and McCarthy (2014)). With many challenges to overcome, cancer survivors develop a specific philosophy rooted in finding meaning and strength in their suffering. Therefore, after the outward signs of disease and treatment have abated, they again have to accommodate those changes into their worldview.

All of these theories could fit within this study. However, SCP theory was chosen to frame the findings. The origins of SCP theory come from Holt (1933) suggesting that all animal action is based on fulfilling the psychological needs of feeling, emotion, and desire, which relate closely to some of the participants' need for recognition following treatment. Evidence for this will be explored further in section 8.5 (page 268). In 1941, Miller and Dollard (1941) suggested there were four factors that contribute to learning: drives, cues, responses, and rewards. One driver is social motivation, which includes imitativeness, the process of matching an act to an appropriate cue of where and when to perform the act. A behaviour is imitated depending on whether the model receives a positive or negative response consequence. Miller and Dollard argued that if one were motivated to learn a particular behaviour, then that behaviour would be learned through clear observations. By imitating these observed actions, the observer would be rewarded with positive reinforcement.

The idea of social learning was expanded on by Canadian psychologist Albert Bandura. Bandura conducted a series of studies known as the Bobo doll experiments to find out why and when children display aggressive behaviours (Bandura 1969). Bandura's 1977 article claims that Social Learning Theory shows a direct correlation between a person's perceived self-efficacy and behavioural change (Bandura 1977). Self-efficacy comes from four sources; performance accomplishments, vicarious experience, verbal persuasion, and physiological states (Bandura 1977). In 1986, Bandura published his second book, which expanded and renamed his original theory (Bandura 1986). He called the new theory social cognitive theory. Bandura changed the name to emphasise the major role cognition plays in encoding and performing behaviours. In 2001, Bandura stated that the theory could be used to analyse how symbolic communication influences human thought, affect and action (Bandura 2001). The theory suggests how new behaviour diffuses through society by

psychosocial factors governing acquisition and adoption of the behaviour (Bandura 2001).

With regard to a stressful experience such as cancer, a supportive social environment encourages active cognitive processing of the stressful experience, thereby leading to resolution and integration of the trauma, and ultimately, positive psychological adjustment. In contrast, a socially constrained environment (for example, poor communication or limited emotional expression) may inhibit processing of traumatic events and can result in poor psychological adjustment, including higher levels of intrusive and avoidant cognitions (Harper et al. 2007). This is a highly popular theory, and it was substantiated by Manne and Ostroff (2008) and Holland et al. (2010) as appropriate for discussion of cancer-related experiences. In line with this theory, sharing and discussion help people to overcome a life-world change, and assist them in finding benefit and engagement in positive appraisal of cancer experience, which in turn leads to improved adjustment over time.

Critics of SCP theory suggest that not all patients experience diagnosis and treatment as traumatic (Kangas et al. 2002). However, the participants of this study all admitted to finding one or more parts of their cancer experience traumatic. This will be explored more fully in section 8.5 (page 268).

SCP theory highlights three key elements as related to positive psychological adjustment in cancer patients; experience of diagnosis and treatment as a stressful or traumatic event, the extent of intrusive and avoidant cognitions related to the cancer experience, and the role of the social environment in facilitating or restricting cognitive and emotional processing of the experience (Harper et al. 2007).

The principles of SCP theory are supported in the use of IPA studies (Smith et al. 1999; Smith 2004). The social cognitive paradigm is concerned with “a belief in, and concern with, the chain of connection between verbal report, cognition, and physical state” (Smith et al. 1999, p. 219).

### 8.3 Social cognitive processing theory within this study

As discussed earlier, SCP theory has two aspects; people perform and re-perform actions based on the feedback they receive, and people imitate actions based on what they see as positive (Bandura 1986, 2001). This section will look at both of these aspects in relation to this study’s participants.

#### 8.3.1 Participants performing actions

From the moment my participants were diagnosed with oropharyngeal cancer, they were put on a pathway which included tests, scans, treatment and follow-up appointments. For most, this was their first experience of any major disease or hospital treatment. For some such as Joe, Peter, Seth and Casey there was limited emotional or psychological support available at home. However, they acknowledged how their partners looked after their physical needs extremely well. But to do this, they had to be willing to let their partners provide that physical care. In order to include their partners, they had to take on the behaviours of a stereotypical patient, which could include a shift in the split of household chores, childcare responsibilities, time spent sleeping or resting or personal care needs. By changing their behaviour and judging the resulting feedback they could either assimilate and replicate those behaviours or modify them. Similarly, to engage with the doctors, radiographers and other people treating them, they would have to learn what was expected of them and their behaviour would be affected by the feedback received. This could include

challenging or capitulating to advice (such as Sara's experience with the number of teeth she had to have removed or Sid's experience with his surgery and his worries of facial disfigurement) or finding comfort and support from positive feedback (such as Seth with eating or Terry with his GP). Because the majority of the participants were unfamiliar with the experience of HNC treatment, there was little time or opportunity to learn these behaviours from others.

This is seemingly not the case for all of the participants. Sara was very focused on her own independence throughout treatment and found it difficult to spend time at her brother's house while she was experiencing the side-effects of treatment. She followed a similar pattern to Michaela in wanting to withdraw from those around her, which may be a pre-existing learned behaviour. In SCP theory terms, these behaviours may be viewed as avoidant, and not likely to encourage positive adaptation.

### 8.3.2 Participants imitating actions

Despite the majority of the participants having no close connection with anyone who had undergone treatment for HNC in the past, Peter was in a unique position to have seen his father go through the process some years earlier. Here Peter not only has the opportunity to affect his behaviour from those around him, but he also has the memory of what his father experienced, and the lessons learned from that. He can decide which of those behaviours were the most positive and try to replicate them for himself. Similarly, and tied in closely with the section on comparison earlier in the thesis (section 5.14, page 215), Sid saw someone about to go for a similar operation to him. He was able to view the behaviours and patterns of that man and choose what cognitions may work for him.

There is also the possibility that some of these people were imitating previous behaviours learnt in the acute treatment phase of their pathway for other purposes. Take Joe for example, and the way he *snapped* at his wife when walking (pages 196-197). This may have been a way to illicit behaviours in his wife he found comforting or favourable to address an emotional need. Alternatively, Joe's wife was so good at looking after his physical needs, Joe wanted to replicate those feelings regarding his emotional needs. He is imitating his learned behaviour. Similarly with Casey, he seems frustrated that people are treating him like they did before the diagnosis. He may have found comfort in how people treated him based on his physical illness, and during the interview is stressing the distance between his physical and emotional recovery. While only supposition, it seems that several of the participants (Joe, Sara, Casey, Terry, Peter) are stressing emotional or psychological changes as a way to illicit the same responses they had for their physical illness.

The majority of studies employing SCP theory come from applied health psychology, with most of those looking at behavioural change campaigns, as opposed to expanding on the theory itself. Campaign topics include increasing fruit and vegetable intake, increasing physical activity, HIV education and breastfeeding (Freigoun et al. 2017). However, there was always the question of why people chose to participate in the study in the first place. One possibility which does fit in with SCP theory and the original contribution of this study is the knowledge that the results will be published in one form or another. The desire for recognition can be fulfilled by wider understanding of the experience through publication. Their experience can be hidden from the outside world, but through wider understanding of that experience, their situation is more likely to be understood.

### 8.3.3 Limitations of SCP theory in this study

While Smith et al. (1999) support social cognition within IPA, there are obviously limitations and this study is by no means a perfect fit with SCP theory. However, it does fit with IPA's double hermeneutic in that participants' understanding of their experience helps me to understand that same experience. The relatively small population of oropharyngeal cancer patients in comparison to other sites such as breast or prostate means it is hard to draw any conclusions beyond suggesting possibilities which may inform future research. Also, the limited sample size used in this study makes any generalisations difficult.

The participants also had a limited pool of people to draw conclusions about their behaviour from. Added to that, they were on a pathway where there was a great deal of change in terms of the shock of diagnosis or onset of treatment related side effects. Therefore, there was limited time to learn or imitate behaviours which they may have found rewarding or unhelpful.

## 8.4 The importance of holistic care

Healthcare that is free at the point of need is something that many people across the globe are not able to benefit from. However, the NHS is facing a crisis. Demand is increasing and funding is close to stagnant or being cut (The King's Fund 2015b, a). If there is no more money available, then our priority as a nation should be on how we spend what money we have in the best possible way. All governments have a duty of care towards its citizens to educate, inform, and if needs be, care for them. Article eleven of the European Social Charter (Council of Europe 1996) specifies that the UK government, as a current member state of the European Union, must take steps to prevent disease, remove the causes of ill health, and educate its citizens regarding their own

health. There is also a growing consensus that each individual should take an active role in managing their health and wellbeing, not only for their own benefit, but also the benefit of the wider society (Brown 2013; Nunes et al. 2013; Leichter 2014). Eating well, not smoking and being active are all things we can do to reduce our risk of long-term co-morbidities. Co-morbidities such as diabetes, obesity, and heart disease may inhibit a person's ability to actively engage with, and contribute to, society (Jones et al. 2010). However, when people are diagnosed with diseases such as oropharyngeal cancer, it is the treatment itself which may cause or exacerbate co-morbidities such as difficulty eating, depression, or other negative phenomena such as social isolation. A lack of understanding about the survivorship experience of people treated for cancer may mean a much greater long-term cost both for the patient and for society.

#### 8.4.1 Self-care

One of the ways government is addressing the need for better value for money is through the use of self-management (or self-care) to encourage and enable people to recognise, treat and manage their own health (Batalden et al. 2015). They may do this independently or in partnership with the healthcare system. Initiatives such as Patient Activation (NHS England 2016) aim to encourage people to take ownership of their own health with the aim of improving outcomes. Tools such as diet and exercise have been shown by many studies to improve outcomes in a range of long-term conditions, not just in cancer patients (Chambers et al. 2015; Paterson et al. 2015; Shneerson et al. 2015). This long-term strategy may take many years to see real benefit but indicates a commitment to future public health improvements as well as budget considerations.

#### 8.4.2 Prudent healthcare

NHS Wales, informed by the work of the Bevan Commission, works on the principles of prudent healthcare. Any service or individual providing a service should:

- achieve health and wellbeing with the public, patients and professionals as equal partners through co-production.
- care for those with the greatest health need first, making the most effective use of all skills and resources.
- do only what is needed, no more, no less; and do no harm.
- reduce inappropriate variation using evidence-based practices consistently and transparently.

(NHS Wales 2016)

By adopting these principles, it is hoped that savings can be made by avoiding unnecessary care and/or expenditure whilst also improving outcomes.

#### 8.5 Cancer as a shared experience

Confidentiality in modern health care may also be reinforcing the hidden aspect of the cancer experience. By not actively including relatives or loved ones in the pathway, patients may feel isolated from the outset of their treatment. Greater involvement of people close to the patient may allow for a greater shared insight of the practicalities of treatment. This may, in turn, be a catalyst for the cancer pathway to be something that can be shared, albeit to a limited extent, thereby reducing the possibility of the cancer experience being a hidden one. Also, hiding the cancer experience and the possibility of evolving a new post-treatment self may not then be anticipated by the family members.

## 8.6 Looking outward

People treated for head and neck cancers used to often wear the story of their treatment for the whole world to see (Katz et al. 2003; Brada 2015). The facial disfigurement of the surgery or the changes to speech or skin tone from radiotherapy were much more pronounced than they are today, due to improvements in technology and technique (Yates et al. 2014). Surgeons are now more aware of the cosmetic impact of surgery (Vickery et al. 2003; Konradsen et al. 2012). While the cosmetic impact never outweighs the therapeutic intent, cosmesis is a factor in planning and carrying out surgical operations. Similarly, radiotherapy techniques such as intensity-modulated radiotherapy (IMRT) or arc radiotherapy have improved the conformity of the radiation dose to the tumour site (and areas of nodal spread) whilst minimising dose to surrounding tissues, including skin (Thariat et al. 2013; Brada 2015).

How we appear to others can influence how we are treated and how we interact with the world. While the effect of appearance and stereotypes are beyond the scope of this study, several of the participants referred to changes in appearance during their treatment and their later recovery. In Casey's experience, nearly a year after treatment, he was back to looking like the old Casey. His partner was starting to put the disease in the past and trying to return to their life together. However, inside he talked about still changing, adapting and coping. For Casey, there are likely to be two ways forward. He can either adapt to his altered post-treatment self (with or without assistance) and return to work, actively engage with his family and with society as a whole. Or he can move to an existence more akin to Peter's post-treatment life, where his day-to-day life is dominated by social isolation, fear, and a preoccupation of what he has lost and may continue to lose. While this type of behaviour may

have been studied previously, it has seemingly not been singled out from umbrella terms such as psychosocial or emotional needs (Harrison et al. 2009). For Sid, the changes he was experiencing were more of an immediate realisation. He commented to the CNS about how the treatment was going to make him *look like a cancer patient* (section 5.8, page 180). In addition to how he felt physically, he attached a meaning to his appearance that he associated with cancer. For several of the participants there seemed to be a value in their looks mirroring their inner physical and/or psychological state. This disconnect between the outer and inner self seems to be absent from the HNC survivorship literature and may be presented here for the first time. Other studies have looked at the psychological impact of HNC, but none seem to explicitly focus on the possible psychological or emotional strain that can manifest if a person views themselves as unwell but is treated as well. Exactly how manifest this is cannot be stated from such a small participant group, but this idea may be of value in influencing further research. For Bruce, Michaela, Sara and others, the period during active treatment and immediately after was a very physically demanding time. They were unable to work and do other routine activities, so their role as patient was reinforced by their appearance. For those such as Casey or Bruce, their psychological recovery did not keep pace with their physical recovery, and particularly with their outward appearance. They were facing yet another life-change; returning to work and to a version of normality. However, the disconnect between how they perceived themselves and how others viewed them was a source of difficulty. This was particularly prominent for Casey, whose ability to carry out his job cooking had been impacted by the treatment changing his sense of taste. Likewise, for Sara, who had ruled out the possibility of a romantic relationship because of her concerns over eating in public. It is this disconnect between the visible and non-visible self which underlies the need for recognition from other people.

## 8.7 The current focus of healthcare - disease or patient?

There is now a large move in healthcare towards holistic care, in both research and policy (Kelly et al. 2014; Wells et al. 2015). Certainly in training and education within allied health professions such as radiotherapy, there is a strong focus towards communication, empathy, and treating the patient rather than just the disease. Friends and family questionnaires ask about privacy, dignity, and being treated as an individual (Coulter et al. 2014). But what do these things have to do with treating cancer? The cancer mortality statistics are still the benchmark for assessing the success or failure of a particular cancer diagnosis (Denlinger et al. 2014). For the participants of this study, few were able to think past the possible prognosis of the disease prior to treatment. Sid was glad when he woke from surgery to find no facial disfigurement, but he consented to the procedure knowing that it was a possibility. Yet he went ahead with it anyway because he could not see past the life-threatening nature of the disease. So for him, at that point in time, the price of cure in terms of potential life-long side effects was acceptable. For Sara, this negotiation of cost versus benefit was not so clear cut. Even while preparing for treatment, the idea of the oncology dentist removing the number of teeth recommended was a price that was too high to pay. In that regard, Sara stood her ground and made her stance clear.

## 8.8 Survivorship: Making sense

Analysis of this study's findings revealed that respondents suffered from a wide range of existential changes and experiences. These included the initial shock and uncertainty about their illness, followed by a range of negative manifestations of illness reflected in the need to adapt to new lifestyles and ways of existence, both in physical and psychological terms. In many instances,

these challenges were exacerbated by the hidden nature of the physical and psychological adjustments. For example, Casey's changed relationship with food and the fear that his inability to eat and taste normally may endanger his career and level of income (Cox et al. 2014). No mention was made as to whether Casey had looked into financial support during his recovery. He and his partner had discussed the possibility of moving to a smaller house should the need arise, so it was clearly a real possibility for him that he may not be able to return to work. Financial help is available to cancer patients, but as Terry mentioned, he was only made aware of this support after he had completed active treatment. This may be another instance of information being delivered at the wrong time or in the wrong way for people to be able to actively engage with it (Fang et al. 2012). Moreover, respondents repeatedly highlighted the traumatic and challenging role-change they experienced because of them being of working age, providers for their family, and guarantors of family's well-being.

For most, financial security was not a pressing issue. Peter was struggling financially when we met, and Jack could not take time off work without losing money, but these were the exceptions. However, most did not know how the treatment or the change in their circumstances would affect their and their family's financial security. For my own circumstances, although I am not wealthy by any means, I am fortunate enough to not have to worry how the next bill is going to be paid and I do not generally worry about money. However, I do not know exactly how I would manage if my income were reduced by half or more for any significant period of time. This would cause me a great deal of anguish, regardless of how challenging it would be to face a cancer diagnosis. In every interview and in every interpretation, I have tried to think *how would I cope in the same situation?*

Respondents who participated in this research were mostly startled and unprepared for embracing their cancer diagnosis because of the quick and

asymptomatic progress of their disease. Hence, the diagnosis was a shock for participants (Gil et al. 2012). Moreover, soon after being healthy, they were forced to adopt the role of cancer patients (Mullan 1985; Miller et al. 2008; Pearson 2013) (see page 161 for comments from Sara).

Given this shock, it is understandable that there were feelings of loss of control, worries over entry into the healthcare system as a passive recipient of serious and life-altering treatment, and intense emotional challenges because of the fear of death (Gil et al. 2012) (see page 163 for comments from Terry). These respondents' reports are in line with prior findings of Howren et al. (2012) regarding a variety of subjective feelings in response to illness, treatment, and side effects experienced by cancer patients. Similarly, these also support the diversity of responses and depth of emotions resulting from cancer diagnosis reported by Semple et al. (2008) and Threader and McCormack (2016).

## 8.9 Making sense of sense-making

Analysis of the sense that participants make of their cancer survivorship is complex, since the very notion of survivorship is *seasonal*, as termed by Mullan (1985). The acute survivorship stage was characterised by all participants as a time of shock and urgent action to survive, which required treatment. This treatment was at times aggressive and disfiguring, but contributed to survival (Miller 2015). Hence, at the initial stage, as it comes from the interview transcripts, the core value of participants was to avoid death, while the next stages included a much wider spectrum of needs and concerns. Extended survivorship mostly took place between the hospital and their own homes, when survivors were protected from the wider external world by medical staff as well as family and friends (Egestad 2013). What followed was a lengthy process of rehabilitation and recovery of physical functions at home

representing the third stage – uncertainty and transition. No matter how much time passes after the transition period is over, cancer survivorship is neverending; it lasts for the entire lifetime of the cancer survivor, marking the fourth season – permanent survivorship (Miller et al. 2008; CURE: Cancer Updates 2009a; Pearson 2013). Hence, deriving argument about the essence of cancer survivorship based on Mullan's *seasons* (1985) and interviews with participants, the study has identified a considerable challenge faced by survivors when obvious physical symptoms subside and the physical rehabilitation process seems complete, or plateaued.

Cancer being a serious threat to every survivor's life, survivorship becomes a symbolically heroic deed that each patient overcoming cancer has accomplished (Ellis et al. 2015). However, time passes and (s)he lives largely symptom-free, returns to work, and again adopts the role of a healthy person after occupying the role of the sick person for some time (Goldstein et al. 2007). Along with other factors such as a fear of recurrence, psychological discomfort may arise because of the lack of perceived reward and recognition of the heroism, persistence, and endurance that the survivor demonstrated during the struggle with cancer. In line with the presented evidence, it is therefore vital to recognise that even after the visible physiological symptoms are over and the individual outwardly appears to have fully recovered, deeper emotional and psychological symptoms may still persist (Ganzer et al. 2012; Howren et al. 2013; Aaronson et al. 2014; Cox et al. 2014; Yates et al. 2014; Damaskos and Parry 2015; Miller 2015). This complicates the perception of cancer survivorship, and at times places a cancer survivor in a challenging psychological situation of diminishing an exacting endeavour. With only one participant close to five years post treatment (Seth), and therefore *cure*, it is hard to draw any conclusions about the development towards a post-cancer self in the long-term. One possibility, although only conjecture, is that social norms require people to

adapt to what is expected of them, thereby internalising any need for ongoing recognition.

## 8.10 A post-treatment self

### 8.10.1 Changes to identity

Cancer diagnosis can force a very abrupt role change, causing a devastating loss of status and perceived meaningfulness in one's family (Miller 2015). As a chef, Casey relied on his sense of taste to earn his living, and with that compromised by the treatment he faced an uncertain future as he began to prepare to return to work.

The observations made by Casey and Bruce regarding employment are consistent with the prior research findings of Semple and McCance (2010) about the more acute experience of negative feelings and changes associated with cancer diagnosis and treatment by those working and caring for the family. These experiences show how strongly the family and social status reflected most often through stable employment and ability to provide for one's family affect cancer experience (Pryce et al. 2007; Cox et al. 2014; Isaksson et al. 2016b). According to the researchers, men are most vulnerable to the abrupt transition from the status of a patriarchal family leader to the status of a sick person for whom his family cares. Thus, the present transition appears emotionally and psychologically challenging for many working-age adults, and exacerbates the overall negative experiences associated with cancer (Cheng et al. 2013).

Unfortunately, cancer diagnosis represents a feasible threat to employment, as was the case for Bruce (page 199-200). The concerns of this study's participants support prior research of Grunfeld et al. (2010). They suggest that cancer-

related side effects are viewed more negatively by employers than by the employees experiencing those side effects. Such findings suggest that there is still a considerable stigma surrounding the issue of cancer diagnosis with employers, particularly of smaller companies. There seems to be a reluctance to make adjustments for the working schedule and working environment for their employees to be able to continue working during and/or after active cancer treatment.

#### 8.10.2 Being 'done to'

Another aspect of concern may be seen in participants' worries about the absence of communication and consultation with them regarding their treatment, and the feeling of being *done to* (see supporting comments from Bruce page 169 and Sara page 171). These observations are consistent with the findings of Fang et al. (2012) about patients' requirements for more information about their disease, especially in the early stages around diagnosis. Hence, it is vital to improve the information provision and communication network for head and neck cancer patients to receive all necessary information, answers to their questions, and psychological consultation at all stages of undergoing treatment (Baxi et al. 2013; Miller 2014a). Decision-makers designing systems of communication and delivery of information to cancer patients should be aware that few patients may already have the tools to be able to calmly accept their diagnosis and process information relating to treatment needs (see pages 167 and 173 for comments from Peter). This section will look at the experiences of head and neck cancer patients only, as it is accepted that other cancer sites do already offer different decision-making tools where choices are more varied (prostate cancer, for example).

Service provision ideally aims to be sensitive to various psychological states, addressing the need for information, need for control, and need for participation in the decision-making process (Quillin et al. 2009; Van Servellen 2009; McGrory 2011; Thorne and Stajduhar 2012). For those participants who viewed the information given as inadequate, some of the distress and anxiety came about from their exclusion from the decision-making process. This was exacerbated by their lack of knowledge about cancer, as well as the unpredictability of treatment outcomes. This opinion was substantiated by Quillin et al. (2009) speaking about cancer patient communication as a complex and multi-dimensional system. When providing the system of communication to specifically address the needs and concerns of cancer patients, policymakers have to understand that a cancer patient becomes a health care recipient at multiple levels. These can include primary care, surgical oncology, radiation oncology, dietary, speech and language support. In addition, receiving high-quality and effective care requires cancer patients to actively engage with the healthcare system and communicate with many different professionals to make informed decisions about their treatment. Also, cancer patients' quality of life directly depends on the sufficiency of information they receive regarding treatment choices, management of possible side effects, specifics of their daily life activities, and considerations of continued survivorship or death (Quillin et al. 2009). Bottom-up thinking is therefore required for constructing an effective multi-dimensional network of cancer patient information and communication. The result is that all components become interdependent, intertwined, and readily available for cancer patients experiencing a crisis of self-identity, a psychological shock, and requiring various informational resources and support to *own* their diagnosis and make decisions which will impact the rest of their lives.

Many of the participants alluded to feelings of being done to, which for them had negative connotations. Sara, Bruce and Peter all described feelings of loss of control, which is in opposition to many recommendations and policy documents on the topic (Department of Health 2012). However, others such as Joe, Jack, Sid and Ernie found the level of information adequate. Choice is a challenging concept to integrate into healthcare. For several generations, we in the UK have had an ever-increasing level of choice in many aspects of our lives. Everything from what car we drive to how our food is produced and where our children go to school are all choices we can make, if we so choose. The idea of choosing our course of cancer treatment, or thinking about the long-term impact of treatment, may be too difficult when coming to terms with a cancer diagnosis (Browning et al. 2007; Davies et al. 2010). With these difficulties, health professionals face a problematic task. The success or failure of treating many malignancies can be affected by how quickly they are diagnosed and treated. Therefore, allowing time to engage with the process at a pace that is comfortable to the patient may be detrimental to their outcome and would therefore clearly not be acceptable to the majority of people. Similarly, there is often neither time nor capacity for a layperson to assimilate and evaluate all of the evidence required to make an informed decision regarding their options (Johansson et al. 2011). Similarly, Davies et al. (2010) suggest that head and neck cancer patients often have the ability to interpret information they receive during office visits, but have described making a treatment decision as “deciding to do something” (p.2434) rather than choosing a specific treatment. Their patient group also described trust in the physician as the most important factor in making a decision, rather than the type or amount of information received. It is therefore not surprising that newly diagnosed cancer patients often capitulate to the recommendation of care path given to them, despite a lifetime of choice and negotiation. Similarly, the task of adapting to a changed self during the survivorship period may be fraught with thoughts of whether the

price of treatment (e.g. long-lasting side effects which impact on function and psychological wellbeing) was truly worth it (Verdonck-de Leeuw et al. 2007; Röing et al. 2009; Johansson et al. 2011; Dasappa et al. 2014).

### 8.10.3 Food and its far-reaching impact

Virtually every participant spoke extensively about the range of negative and even painful experiences associated with feeding tube use and/or adjustments in eating habits (for comments see page 178-179 for Sara, page 178 for Sid and page 175-176 for Casey).

The accounts from Sara, Sid and Casey show that participants in this study attached much greater significance with their ability to eat *normally* than as a source of energy, nutrients and vitamins. These reports support prior research findings of McQuestion et al. (2011) reviewed earlier in this study, as well as those of Ottosson et al. (2013), suggesting that for HNC patients experiencing physical limitations with food intake, food symbolises much more than nutrition, and it often stands as an embodiment of emotional and social loss for those patients.

Many of the participants spoke about the wider social impact of a changed relationship with food. For Sara, there were multiple implications of being uncomfortable eating in public or being limited in what she could eat. She spoke at length about the perceived awkwardness of going on a company picnic, and how socially isolated she felt because she could not eat the same things as everyone else. She also spoke about the impact on her romantic life, and how she could not see herself going on a first-date again because a common first-date activity is to go for a meal. Casey mentioned socialising and meal times with family became difficult because he took so long to eat, and the food would

become cold. Michaela spoke about how her daughter would tease her for eating so slowly. All of these things are very relatable as they involve an activity which most of us have been doing without a great deal of thought for as long as we can remember. Eating is a daily activity necessary for a healthy life. But more than that, it can act as an opportunity for social bonding, maintaining links with family and as a pleasurable act.

From comments made by almost all of the participants, a difficulty came from the abruptness of change during their treatment. Casey's visit to Burger King was his realisation that his ability to taste had changed, but for others it could also be equally immediate. Their road to a post-treatment self where they could eat normally again was often very slow and filled with setbacks. There was also the possibility that they would not be able to eat what they would refer to as normally ever again. Even years after treatment had ended, Joe would often order from the children's menu at a restaurant because of his decreased appetite and speed at which he could eat. Peter spoke about his frustration with how slowly his ability to eat certain things was returning, as was the experience of many.

Terry is an excellent example of positive adaptation in a situation where eating function is compromised. He was able to continue eating with his family at regular meal times, albeit consuming food through his PEG, thereby maintaining familial bonds and enhancing understanding and support. In hindsight, Seth was quite philosophical about his recovery, and how he slowly managed to regain the ability to eat certain foods. Moreover, he found accomplishment in his recovery and the changes he saw on a weekly basis.

#### 8.10.4 Stress of uncertainty

A point of interest is also the feature of unpredictability associated with cancer diagnosis and treatment, causing intense uncertain feelings among patients and leading to chronic anxiety about treatment and disease outcomes (see page 204 for comments from Peter).

It is likely that all cancer patients experience a variety of emotions, feelings, and challenges following diagnosis. As claimed by Semple et al. (2008), cancer patients are commonly affected by negative physical changes, concerns about cancer, employment, ability to perform day-to-day tasks, quality of interpersonal relationships, and social functioning. Cancer can leave traces on functioning in all domains of the human life, at least during the initial stages of treatment and rehabilitation (Moore et al. 2014; Miller 2015; Isaksson et al. 2016a). Hence, such negative emotions related to these health experiences are reasonable, and in many cases, expected.

#### 8.10.5 Adaptation

Adaptation style and degree of acceptance of loss of control varied in the study from person to person. Looking to comments made by Sid (page 172-173), Ernie (page 174) and Sara (page 171), the concept of shared decision-making comes into play, and it is necessary to keep in mind that it contains advantages and challenges, both for the patient and the medical professional. Stacey et al. (2010) also concluded that cancer patients want to be involved in making treatment choices, to be given a choice, and want healthcare providers to listen to their needs more effectively. As clarified by Katz et al. (2014), patient-centred oncology requires allocation of time and effort to engage patients and their families into treatment-related decision-making. Cancer treatment is getting more and more complex, with many interconnected effective therapies, each

having its own benefits and risks. Hence, though a vital need of patients today, shared decision-making should be tailored to each patient, since decision quality may be affected by his or her ability to comprehend the options available. A universal requirement should be the provision of emotional participation to patients, and to demonstrate to them through example that their emotions and opinions are important. This may serve as reassurance and reinforce a sense of control which is important for many cancer patients.

#### 8.10.6 The journey to a post-treatment self

The change that seems to take place at the stage of *successful* rehabilitation is that of the loss of the sick role that cancer patients adopt, or are forced to adopt, as soon as they are diagnosed. One should also keep in mind that cancer survivorship is a lifetime issue. Therefore, recognition should be tailored to the patient's state of health and psychological condition. Nevertheless, it should not stop after the physical manifestations of cancer leave. Since for cancer survivors, their experience may be a lasting state of fear of recurrent disease, self-esteem related to their coping with the disease, changing life priorities and self-identity resulting from their traumatic experience (see page 194 for Michaela's comments).

While some cancer survivors find strength and meaning in their suffering, others develop and grow spiritually after the life-threatening encounter with cancer (Swore Fletcher et al. 2012), which was already discussed in the framework of the social-cognitive processing theory. However, there is one intricacy about this theory; it claims that people with a low level of hope and with a positive appraisal of their experience tend to resort to the practice of avoidance. In contrast, those with a high level of hope do not resort to avoidance and indeed integrate a positive appraisal into their cancer

experience. A similar conclusion was made by Elani and Allison (2011), stating that patients with poor coping styles are more likely to have increased anxiety and depression levels, while positivity among cancer patients is not a guarantee of proactive coping. Positivity may be a manifestation of normal adaptation, while at the same time it may be an external disguise for avoidance and poor adjustment. Therefore, a much more in-depth psychological evaluation would be needed to make a clear conclusion regarding the genuine state of a patient's coping and adjustment (Aspinwall and MacNamara 2005).

## 8.11 Recognition

### 8.11.1 Family: exclusion vs. inclusion

All but one of the participants had partners or spouses, with some also having dependent children. Therefore, the topic of familial and social support was one of the central issues of discussion in this study. Each of the participants experienced that support and assistance to a different degree, and the majority agreed that this support and understanding played one of the crucial roles in their recovery (see pages 183-184 for Joe's comments).

The role of family in recovery is also substantiated by prior research findings. Deno et al. (2012) and Jenkins (2006) look at the importance of self-efficacy and social support in terms of amelioration of social and emotional distress consequences associated with cancer experiences. However, the issue of social and family support is a well-researched theme, in contrast to the lesser-understood perspective of the caregiver which also emerged at several points as a topic of discussion. Thus, it has become evident from the present study that caregivers are often less involved in the treatment and decision-making process because cancer patients try to protect their spouses and families from perceived potential stressors (Cheng et al. 2013). Such practices are

understandable from an individual viewpoint. However, these practices have the potential to cause much greater distress regarding cancer caregiving in one's family, since caregivers may feel isolated and reluctant to discuss their partner's condition, thus causing deeper psychological and psychosocial problems within the family.

Such observations are not unique. Similar findings were indicated by Vickery et al. (2003) who reported that partners of cancer patients report greater levels of stress than those who actually experience cancer, since they experience a lack of involvement and control over the disease, treatment, and rehabilitation processes. Verdonck-de Leeuw et al. (2007) also concluded that stress of relatives and spouses of cancer patients is higher than that of cancer patients. Their major sources of discontent relate to intricacies of use of feeding tubes, passive coping styles and reduced vitality of their care recipients, as well as their own disrupted life routines because of caregiving. It is also important to note that the majority of respondents acknowledged the role of their caregivers' positive coping style and adaptation to the presence of cancer in their family as the core contribution to their recovery. Many of them confessed to being distressed and feeling helpless at the beginning of the rehabilitation process, when self-efficacy regarding recovery was extremely low. However, those whose family support was very optimistic, strong, and inducing towards pushing hard for recovery indeed managed to do that and were eventually grateful to their spouses and social surroundings for helping them out. These findings are also supported by Fletcher et al. (2010) who stressed the crucial impact of family members' coping and adaptation style on the cancer survivor's recovery. Such supportive psychological attitude gains even more importance in the context of recognising that caregivers generally regard caregiving and the overall experience of cancer treatment and recovery as more stressful than the actual cancer patients do (Precious et al. 2012).

Caregivers' fatigue is a special issue of concern, since many of the respondents touched upon the problems they experienced with their family and spouses during cancer treatment and rehabilitation. Even when they did not mention these problems directly, their appreciation of strength and endurance revealed by their partners suggest that it was indeed hard for them to provide care to people in crisis and shock because of the illness. Many would argue there is a need to incorporate family members and caregivers into the decision-making process, to share worries and feelings with them, and to include them in the adjustment process. Exclusion from these processes can lead to caregiver fatigue and a range of other negative psychological problems within familial or spousal relationships (Philip et al. 2013; Aaronson et al. 2014; Miller 2014b; Perloff 2015; Richardson et al. 2015).

#### 8.11.2 Better prognosis for HPV+ve patients

The success of treatment of certain malignancies has not significantly changed over the past ten years (O'Rorke et al. 2012). For instance, pancreatic and lung cancers still prove difficult to treat due to the late presentation of symptoms (Perloff 2015). Head and neck cancers, and in particular oropharyngeal cancer, are slightly more complicated due to the change in demographic over the last decade. Thought to be due to the effect of HPV-16 and 18, there is a greater percentage of people being diagnosed who are of working age and do not have a history of tobacco and alcohol dependence (Chaturvedi 2014). These people are more likely to be employed and have dependent children than many other types of cancer population (Andrews et al. 2009). Therefore, from a societal and financial perspective, it is even more important that the needs and experience of this population group are better understood. If a person is already out of the job market and in receipt of welfare support due to age, disability or alcohol

dependence then the financial impact on the economy will not be as noticeable as someone who was in work and paying taxes. The shift from actively contributing to society to relying on the state for support due to the physical or psychological effects of treatment may also lead to other health or social issues which could also require additional resources from the public purse (Foster et al. 2009; Cox et al. 2014). While oropharyngeal cancer patients make up a small percentage of all cancer patients, the message is the same; by looking after the long-term health of our population at an early stage, the demands placed on the state at a later date may be reduced (Chaturvedi 2014; D'Souza et al. 2014).

### 8.11.3 The wilderness following active treatment

Both Bruce and Sara experienced very low moments following the completion of active treatment. For Bruce, it was isolation and lethargy as well as fears of redundancy; his mood mirroring the bleakness of the changing landscape outside. Sara embraced the isolation but struggled with the constant stringy mucus caused by a reduction in saliva due to radiotherapy. Their isolation is similar to the isolation felt by those in the study by Konradsen et al. (2012) looking at the effects of facial disfigurement. There are few, if any interventions that could have helped Sara or Bruce during this period (Harr et al. 2014). However, due to the hidden nature of their experience there was little chance of that experience being acknowledged or recognised by those around them. In a clinical setting, some acknowledgement or advice delivered in the right way, at the right time during their treatment may have prepared them better or helped to mitigate feelings of isolation. Something as simple as saying 'it's all go during treatment but afterwards some people struggle with the differences in day-to-day life' may be all it would take to ameliorate some of those concerns (Aaronson et al. 2014; Miller 2014b).

#### 8.11.4 Comparisons

Support groups or online forums can provide much needed support both during and following completion of cancer treatment. However, there are dangers, especially in comparisons between patients (Holloway et al. 2005; Swore Fletcher et al. 2012). Seth spoke about how he had helped other people going through the same thing as him. However, there is rarely such a thing as the same thing. This is because everyone's treatment is bespoke, so the effects can vary. Similarly, no two cancer patients are identical, so everyone will respond and cope differently. It had not occurred to Seth that by telling others how well he had coped with treatment or what he was able to eat and when may hinder others' mental and/or physical recovery because they were at different stages. Sid discussed the fear he had when seeing another person who had been through the operation he was about to have. Similarly, he talked about the relief he felt after the operation and discovering that the cosmetic impact of the operation was not as noticeable as the other patient.

Jack spoke of the comfort he found in talking with another patient having a similar treatment at the same time as him (Deno et al. 2012; Cheng et al. 2013). That camaraderie and shared identity seemed to resonate with Jack which made it all the more difficult for Jack when the other man passed away. When asked about what they talked about, he seemed to be confused as to why they would talk about anything other than side effects and the physical impact of treatment. However, there may have been a hidden support in the relationship between the two men, in that they shared an experience which others close to them could not fully appreciate or understand. Similarly, they shared a common identity during and following treatment that precluded the awkwardness of social interactions that Terry mentioned in his interview. It may be that by engaging with patients in a more meaningful way, healthcare professionals are

able to address and normalise difficulties in a less formal way than specific interventions or specialist referrals.

## 8.12 The hidden experience

### 8.12.1 The suddenness of diagnosis

A common impression voiced by participants was that the diagnosis was a total shock for them, and they were unprepared to comprehend their quick transfer from a role of healthy person into a role of cancer patient (Gil et al. 2012). The aggravating contributor to such a shocked state was the perceived insensitivity of delivering the diagnosis that some participants experienced (see comments from Michaela page 161-162 and Sid pages 162-163). It should be recognised that a lot of work has been done on delivering bad news (Browning et al. 2007; Fang et al. 2012; Baxi et al. 2013; Brada 2015), and that the problems experienced by some of the participants may be down to local failings.

### 8.12.2 Relinquishing control

One of the most evident themes regarding shock about diagnosis and treatment is that of uncertainty and loss of control (Cheng et al. 2013). The majority of respondents claimed that they suffered most because of the loss of control over their lives, and the need to forgo certain fundamental freedoms and lifestyle choices, for the sake of recovering from cancer. Sid was able to talk about the loss of control with a strong sense of inevitability even with the prospect of disfiguring surgery (see page 171-172 for comments from Sid). This suggests that more work may need to be done during the period between diagnosis and the start of treatment employing tools used in teenage cancer cases, where loss of control is a common theme in the literature (Wicks and Mitchell 2010).

### **8.12.3 HPV: is its absence in the data important?**

A major focus of the latter stages of analysis was the challenge experienced in relation to acceptance and interpretation of HPV being a low-level priority for the study's participants. Moreover, such findings are in contrast to the majority of research findings available to date regarding HPV incidence and HPV-related perceptions among patients (Baxi et al. 2013; Chu et al. 2013; Finnigan and Sikora 2014). However, since the IPA interpretations are subjective and informed by my own life-world (Brocki and Wearden 2006; Smith et al. 2009), I assumed that presence of HPV, especially with regard to much interest and publicity around it, may taint the possible reward that cancer survivors derive from social recognition of their experience. Hence, the respondents might have a selective interpretation of their experience without an explicit focus on the cause and nature of disease, which may be possibly of a shameful nature (Devins et al. 2015). In this context, what was not said is perceived as possessing equal importance with what was said, since silence is a crucial element of interaction, important for creation of meaning (Santaemilia 2005).

Given the publicity surrounding Michael Douglas' admissions in 2013 regarding the part HPV played in his oropharyngeal cancer (The Guardian 2013) (Appendix N), it seemed odd that so few of the participants had any knowledge of HPV or its possible role in their own illness. After initially disregarding HPV as a proverbial 'red herring', it was only in the later analysis phases that it was recognised that the absence of HPV in the data may add further support to the idea that the participants are seeking some form of recognition for their experience.

The only participant to really comment on the publicity surrounding HPV in HNC was Michaela. Her comment about how she felt that her parents had not asked too many questions about the possible cause of the cancer (see page 248) is very illuminating.

Even the language Michaela used, such as *tarred*, suggests an unpleasant dirtiness that cannot simply wash off. While it is acknowledged that there may be a multitude of reasons as to why HPV is not more prominent in the data, Michaela's feelings about HPV are more in-keeping with the existing literature as well as anecdotal evidence taken from the recruiting CNSs prior to commencing the study.

The data does not support any conclusions involving the impact of HPV in this population group. Even for those who were aware of its existence such as Michaela and Joe, the associations did not match their experience or narrative, so they disregarded it. However, the location of the tumour site and the functional implications of treatment did lead to intimacy difficulties which were seemingly not addressed during or following their treatment (D'Souza et al. 2014). Peter spoke about not wishing to kiss his wife because of a fear of spreading any possible infection. He even went so far as to take his own eating and drinking utensils when visiting friends. He was not clear whether his intention was to protect himself or others, but clearly this continued to impact the ease and extent of his relationships with others.

#### 8.12.4 Health and the media

While many of the study's participants were actively encouraged by doctors or CNSs not to look for information on the internet, or from other sources, due to the risk of misinformation, there are some health stories which cannot be

avoided. Media coverage of HIV-AIDS in the 1980s, or the outbreak of Ebola in west Africa in 2015, was such that it would have been very difficult to avoid exposure to information in everyday life. Similarly, these stories came with a great deal of rumour and misinformation (e.g. routes of transmission of HIV or the extent of the Ebola outbreak within the African continent as a whole).

Before beginning data collection, there was a consideration of the impact the Michael Douglas story would have on the participants and their knowledge of HPV. Appendix N shows some of the media and popular culture coverage following the story published in the Guardian in 2013. With the exception of just two of the participants (Joe and Michaela), there was little or no awareness of HPV as a causal factor for their cancers. Given the broad media coverage of Michael Douglas' comments regarding his cancer, it is surprising that there is so little awareness of HPV in the data.

### 8.13 Improving outcomes through small changes

There are various ways in which minor changes could be incorporated into everyday clinical practice which may help the survivorship experience of this patient group. Continual professional development (CPD) is already a requirement of all allied health professions so reflective practice should be commonplace. However, existing literature and personal experience suggests there is still an inability and/or unwillingness to open up conversations around personal matters such as intimacy or sexuality (Low et al. 2009; Moreno et al. 2012; Dasappa et al. 2014). This may be due to such topics being seen as not relevant to the cancer treatment or there may be a comfort in focusing on information giving. While it may be damaging for AHPs to take on responsibilities associated with counselling or psychiatric care, both for the AHP or the patient, the focus should be on subtle changes which could benefit both

parties. Minor changes have the benefit of being easily incorporated into everyday practice and would therefore be more likely to become routine.

#### 8.14 Problems which should not exist

Undoubtedly there are some things which were experienced by the participants which should already not be taking place. For example, every health professional should be explaining procedures before they are carried out as this forms a critical part of informed consent (McGrory 2011; Egestad 2013). Bruce's recollection was that this did not take place correctly when attempting to fit his feeding tube. There is the possibility that Bruce was consented and dealt with correctly, but the stress of the situation prevented him from fully understanding it at the time. However, time constraints and other resource demands can mean losing sight of what really matters, which in every encounter should be the patient. Advice given to student radiographers is to always treat the patient as you would want your closest relatives to be treated. If the person delivering the cancer diagnosis to Michaela had considered this before picking up the phone to call her, Michaela's experience of the diagnosis may have been less traumatic.

#### 8.15 Continual improvement

There is no perfect encounter with a patient, but that should not discourage anyone from continuing to reflect and improve. For a patient like Ernie who presented himself as very self-reliant and coping well, there may have been little that health professionals could have done differently during his treatment. However, patients can be unaware that relatives or friends can be brought to appointments or shown the treatment equipment. Patients are often told and encouraged, either verbally or in written communication, to bring a friend or

loved one with them for consultations and appointments. However, clinical experience suggests that patients are sometimes unaware of this at their first radiotherapy treatment, possibly due to factors such as local deficiencies or information overload at previous appointments. Rather than isolating himself from his family, had his wife, parents or children been shown the treatment machine or immobilisation mask then they may have been better equipped to open up lines of communication about what he was experiencing (McGrory 2011; Miller 2014a). Some radiotherapy centres offer a non-compulsory trial or 'day-zero' appointment where patients can experience the practicalities of the treatment before any dose is delivered. This can also include using Virtual Environment for Radiotherapy Training (VERT) to talk a patient through their own radiotherapy plan, including the importance of any physical preparation or treatment immobilisation (Virtual 2018).

For Peter, gentle probing may have brought up difficulties such as loneliness or fear for which some therapeutic radiographers are not trained to deal with. However, a better understanding of his fragility may have meant an earlier psychological support referral or an adaptation to his treatment routine in order to abate his concerns (Egestad 2013).

## 8.16 Contribution

The experience of people previously treated for oropharyngeal cancer is infinitely complex and nuanced (McGrory 2011; Howren et al. 2013). While challenging, this study has been successful in many respects. By approaching the participants and the data they generated with openness, the result is a unique and worthwhile collaboration between myself and the participants. The original contribution of this study is: **in attempting to establish a post-treatment self, those previously treated for oropharyngeal cancer may**

**attempt to seek recognition for their experience. Gaining recognition can often be hampered due to the hidden nature of the experience to the outside world.**

This contribution comes from data from a small number of oropharyngeal cancer patients from two oncology centres in England. It focuses on a specific group of working-age adults at a particular time in their cancer experience, post-diagnosis and active treatment. It is not suggested that the findings in this study are representative of all oropharyngeal or head and neck cancer patients. This study aims to highlight possible areas for future research and suggest why those areas may be of importance. There is a large amount of literature which aims to examine the unmet needs of cancer patients (Soothill et al. 2001; Harrison et al. 2009; van Scheppingen et al. 2011; Carlson et al. 2012). Their rationale for doing so is to meet the holistic care needs of the patient. If a physical or psychological need is unmet then that could negatively affect their lifestyle, ability to work, ability to participate in family and social activities or fully engage with the world around them in other ways. Some people may cope and adapt without any outside intervention, but others may not. I believe this study has highlighted a possible psychosocial need of recognition within a number of participants which warrants further study.

Below is a table identifying some of the broad key aspects of the data which informed this interpretation.

Interpretation: in attempting to establish a post-treatment self, those previously treated for oropharyngeal cancer may attempt to seek recognition for their experience. Gaining recognition can often be hampered due to the hidden nature of the experience to the outside world.	
Evidence	Interpretation

Use of emotive language	Desire for a shared understanding of a traumatic experience. Having their voice heard.
Describing difficult experiences or physical challenges related to treatment	Stressing the difficulty of their experience to illicit a reaction or emotion. Gaining empathy and/or sympathy. Seeking validation.
Describing a difference between their inner and outward recovery	Showing there is a difference between physical and psychological recovery. Highlighting that their recovery is still ongoing. Showing that they are still going through changes which may not been seen.
Changed relationships post-treatment	Demonstrating that the impact of disease and treatment goes beyond the patient. Life-world changes are substantial and ongoing. There is a lack of understanding from those around them as to what they have experienced.
Hidden altered physical function (food)	Side effects can be hidden and long-lasting. Treatment impacts basic and everyday life. Treatment can limit or affect enjoyable aspects of life. Social bonds may be affected. Lack of understanding and/or sensitivity from others. Impatience from others for things to return to how they were before diagnosis.

**Table 11 - Thought processes which led to the original contribution to knowledge.**

This thesis provides evidence in three specific categories. Firstly, in relation to the literature gap as identified in chapter three, this study does not find any data to suggest that HPV is a significant factor for this group of oropharyngeal cancer patients. Secondly, this study does provide an insight into the experiences of working-age oropharyngeal cancer patients. Finally, this study

examines the experiences of people at a specific point in their survivorship experience of six months to five years post-treatment.

There is significance for this new knowledge in several key areas. Regarding clinical practice, healthcare providers will now have a better understanding of the complexities of experience in this group of cancer patients. This will allow for more reflexive and individualised care throughout the patient's care pathway. In regard to policy, this focus on the patient experience fits in with the NHS moving towards patient-centred care throughout all areas of healthcare provision (Health Education England 2018; NHS Wales 2018). This knowledge has also informed the recommendations for future research and improvements to clinical practice, which are outlined in chapter ten.

### **8.17 Implications of the theoretical framework**

As already acknowledged, while this IPA-based study is not a perfect fit for SCP theory, it does highlight the flexibility and adaptability of both IPA and SCP theory in relation to the experiences of cancer patients, adding to both and promoting their use in similar future research. To the best of my knowledge, this study is currently unique in using SCP theory so overtly in a piece of IPA research.

### **8.18 Chapter summary**

Many NHS trusts simply do not have the funding available to provide psychological support to all of their patients (The King's Fund 2015a). Similarly, not all patients need or would accept formal psychological support (Henry et al. 2014a). What the evidence shows is that the cancer experience is infinitely complex and nuanced and can be hidden from view.

The findings from this study show an understanding of a patient group which currently has a paucity of devoted research. These findings will allow other researchers to build and develop upon these ideas in order to better understand the needs of this patient group.

By making healthcare professionals more aware of the depth of experience of this patient group, the hope is that care can be given appropriately and adaptively based on the needs of the patient at that point in time. This study also highlights the healthcare professional's role in setting realistic expectations around recovery and the journey towards a new or altered post-treatment self.

The following chapter shows a small amount of the reflective work that went on as the research process evolved. An important part of the PhD process is the development of the researcher (Phillips and Pugh 2010). As such, a lot of reflection was done on my own personal journey as well as development of analytical skills.



## Chapter Nine – Conclusion

### 9.1 Chapter introduction

This chapter will re-state the original contribution of the study. It will also place this study within the existing literature and examine some of the study's successes and limitations in light of the original aims.

The aims of the study were:

1. To better understand the lived experience of working-age people following diagnosis and treatment for oropharyngeal cancer.
2. Make recommendations from the information gained to inform clinical practice and/or future research.

### 9.2 Contribution

The contribution of this study is: **in attempting to establish a post-treatment self, those previously treated for oropharyngeal cancer may attempt to seek recognition for their experience. Gaining recognition can often be hampered due to the hidden nature of the experience to the outside world.**

The conclusions of this study are of importance to the lives of its participants, and potentially to many more people who have been, and are yet to be diagnosed with cancer. This study questions the idea that people of working age can go back to *a normal life* following treatment with little or no support. This study's findings support the conclusion that people who are treated for oropharyngeal cancer desire some form of recognition for their experience. And with fewer obvious physical markers of treatment, their cancer experience may

be hidden from others, including loved ones. To the best of my knowledge, these findings have not been previously presented by any other study.

### 9.3 Providing evidence against the impact of an HPV+ve diagnosis

This study does not support previous research indicating an emotional or psychological effect of knowledge of HPV status (Shuman and Wolf 2010; Baxi et al. 2013; Chu et al. 2013; Finnigan and Sikora 2014). There are reasons why these people may not have reflected the findings of other research, which will be discussed later in the chapter.

Given the procedures at Northtown and Southtown at the time of treatment of most of the participants, there was a real possibility of causing harm by discussing HPV status with someone who was not aware of their own HPV status. This possibility was a consideration of the ethical submission of the study and had to be accounted for within the interviews. Broader questions such as “what do you know about the possible causes of your cancer?” were used, giving the participant the freedom to elaborate on their own experience without any outside influence.

The lack of evidence supporting previous findings adds to the rigour of this study. Participants were not led or coerced into discussing something which was not part of their own experience. For those who were aware of the possible involvement of HPV, most had developed their own narrative rather than looking for additional information regarding the virus.

## 9.4 Limitations of the study

While every effort has been made to make this study as robust as possible, there are limitations to the study which must be acknowledged. Some of these are inherent to a small-scale study, carried out with very little funding. Others, with hindsight, could be addressed if the study were to be repeated.

### 9.4.1 Size of study group

There are inherent limitations to any study with a small number of participants. The depth of data gained will always be at the cost of breadth and generalisability. The study has succeeded in gaining the depth of analysis it set out to achieve. It supports the value of obtaining rich data in helping healthcare professionals in their understanding of patient experience. However, further investigation must be done before clinical recommendations can be made.

### 9.4.2 Variation of time since diagnosis

The time since diagnosis did seem to have an effect on the recall of the participants during the interview. Many of the discussions during the interviews focused on adaptation towards a new or altered post-treatment self in the six to twenty-four months following treatment. For those like Seth, who was at the end of his five-year follow-up period, much of the detail was difficult to recall. Similarly, for someone like Peter who was still struggling with the day-to-day difficulties caused by his treatment, he may not have been able to show the perspective that many of the other participants did.

Given a larger pool of potential participants, it may have been advantageous to narrow down the time since diagnosis in order to achieve a more homogenous

sample. However, during the design of the study it was unknown as to how many people would be available to take part. Therefore, the design parameters had to take account of the potential for fewer participants than expected.

#### 9.4.3 Lack of demographic data from some participants

It is unfortunate that not all of the participants wanted to complete the questionnaire at the end of the interview. Two of the participants asked for the questionnaire to be left with them so that they could complete it at a more suitable time. Despite reassurances that the questionnaire did not need to contain a great amount of detail, the questionnaire was left along with a stamped addressed envelope for them to return the questionnaire at a later date. These two questionnaires were never received and so there is a gap in the background information of the participants. Despite this, the participants are broadly representative of the type of people described in the literature as more likely to be HPV+ve oropharyngeal cancer patients. Only Ernie described any form of alcohol dependency, and most did not use any tobacco products. Most were employed, or financially stable enough that they did not need to work (Michaela, Terry).

What motivates people to take part in research studies does vary, and the research on this subject is extensive. While it is beyond the scope of this study to comment on these factors, it is not surprising that those who decided to take part were, broadly speaking, of a similar socioeconomic background.

#### 9.4.4 Experience of the researcher

A “PhD is less like hacking through the jungle with a machete, and more like crawling around on the ground with a magnifying glass - less major discovery of

new lands, more painstakingly detailed investigation of familiar ones" (Petre and Rugg 2010, p. 2). As a therapeutic radiographer, there was, at the outset of the PhD, a quiet confidence that the interviews would be one of the more straightforward aspects of the research process. This was not the case. Experience included years of clinical practice talking to people being treated for a variety of malignancies, incorporating a range of HNC sites. In addition, there were practice interviews with supervisors as well as specialist advice from researchers whose primary focus is intimacy and sexuality. Despite all of this, the learning curve throughout the process was extreme, and is particularly evident when reviewing the first interview with Joe. Lots of closed questions and a lack of probing was gradually replaced with open questions, silences, and careful probing. While the large amount of data generated from the interviews (more than 160,000 words) led to challenges during the analysis, the number of interviews allowed much more development as a researcher.

As with the transcription and analysis, there was a sharp learning curve which would not necessarily be present in other studies. If repeating the study, it may be advisable to recruit fewer than five participants so that the depth of analysis can be more certain. Trying to achieve the depth of analysis recommended by Brocki and Wearden (2006) or other exponents of IPA would be challenging even to an experienced IPA researcher given such a large data set. However, with fewer participants there would not have been the opportunity to interview some of the most rewarding and challenging participants. For instance, when interviewing Peter, who was the tenth participant, the time between the first and second question was almost fifty-five minutes. As a novice researcher, the loss of control of the interview was extremely challenging, but also very rewarding.

In some ways, my lack of experience adds to the honesty and integrity of this study. It is not among the aims of an IPA study to produce something quantitative and repeatable. Instead, one of the aims of this study was to produce an honest representation of the experience of this group of people as interpreted through the lens of my own life-world. As a novice researcher, there is inevitably going to be a development of skills, ideas and understanding throughout the process. One of the strengths of this study is the transparency of this development and the reflection that has taken place throughout.

#### 9.4.5 Selection of the participants

While CNSs were instructed to approach potential participants based only on inclusion criteria, without visibility over the recruitment process it is impossible to say with any certainty that there was no selection bias. However, the CNSs who initially approached all of the potential participants are experienced professionals and have a great deal of experience in clinical trials. They are familiar with the problems of selection bias and would have been aware of this during recruitment.

The lack of direct involvement in the recruitment process removes any suggestion of coercion from me as the researcher. Moreover, having more than one person return the expression of interest form and then decide not to take part after learning more about the study demonstrates the freedom people had to voluntarily engage with, or decline in, the study.

Both Northtown and Southtown are located in the south-west of England. While catchment areas for oncology centres are large, recruiting from one part of the country that doesn't encompass any major cities (the largest town/city within either catchment area has a population of fewer than 150,000 (The Geographist

2013) may have effects on the racial or socioeconomic characteristics of the population.

#### 9.4.6 Survivorship experience relating to treatment modality

Figure **Error! Reference source not found.**9 (page 159) shows that all participants received radiotherapy and most had surgery. At no point was their survivorship experience linked or correlated to their treatment modality. While this may be seen as a limitation, the focus was emotional and social experiences post treatment, regardless of treatment modality.

### 9.5 Chapter summary

This chapter has re-iterated the study's original contribution to knowledge. One of the potential pitfalls of IPA research is having a wealth of data and the researcher becoming lost and unclear as to what the study has achieved.

Academic supervision has been important in this regard as it allowed fresh perspectives from experienced researchers who were not as immersed in the data as the researcher. The contribution of the study is of real and worthwhile importance in advancing our understanding of the experience of this patient group.

As part of the reflective process of IPA research, it was important that this chapter be open and honest about the study's limitations. These limitations include, at times, my own short-comings. These limitations do not distract from the validity of the findings, nor do they negatively impact the rigour of the study. Instead, they add to the evidence showing that this study is a real piece of research, and as such, there will be things that could have been done

differently. Stating these limitations will help to inform and improve similar future studies.

The first aim of the study was to better understand the lived experience of working-age people following diagnosis and treatment for oropharyngeal cancer. Through the generosity of the participants in giving their time and sharing their stories, I believe I have captured important aspects of their experience within this thesis. The following chapter is the final chapter of this thesis, and will address the second aim of the study; to suggest recommendations for future research.

## Chapter Ten - Future research

### 10.1 Chapter introduction

This chapter will set out suggestions for areas of future research. There is great variation and complexity in the survivorship experiences of oropharyngeal cancer patients. While all the patients spoke about the challenges of the physical treatment induced side effects, there was no real commonality in how these challenges were dealt with. It is not surprising that with such a large variation among the participants in time since completing treatment, the impact such side effects currently have on their individual life-world will vary greatly. What is clear is that *one size fits all* service provision is not suitable for this particular patient group.

This study was based on the experiences of twelve patients from two oncology centres in England. This work and its recommendations can suggest a direction for future research, which was an aim of the study, but without larger-scale quantitative studies it would not be possible to draw any definitive conclusions regarding this patient group. More evidence is needed before any specific clinical recommendations can be made. However, another aim of the study was to better understand the lived experience of working-age people following diagnosis and treatment for oropharyngeal cancer. At least with regard to these particular participants, this study has been successful in achieving its aims.

### 10.2 Adaptational needs

More work needs to be done in regard to the long-term adaptational needs of this patient group, beyond physical side-effects. At the time of writing, the head and neck 5000 study had collected data from their four and twelve-month questionnaires, and further follow-ups at three and five years post-consent

were underway (University of Bristol 2018). Once published, that long-term data should be compared with the conclusions of this study to look for commonalities or differences. Further larger-scale quantitative studies may be needed to look at perceived spousal harmony pre and post treatment (based on comments made by Michaela, Peter, Casey and Terry), or changes in sexual, romantic or social relationships (based on comments by Sara, Casey, Peter and Grace).

### 10.3 Further experiential research

Additional qualitative experiential research should take place into the experience of oropharyngeal cancer patients and particularly their relatives. Some of the topics highlighted in this thesis may be due, at least in part, to regional variations in care and service provision. While it would not be the aim of an IPA study to try to replicate the results of this study elsewhere, similar patient groups should be researched to investigate topics raised here and elaborate on their impact in the patients' life-worlds.

### 10.4 Audit of current practice and provision

While not research, a detailed audit should be conducted on the current provision of psychosocial care throughout the multidisciplinary care pathway, from diagnosis to the end of the follow-up period, across a number of oncology centres throughout the United Kingdom. Practices currently employed by some Trusts may be lacking elsewhere, and publication of these practices may encourage change in provision and cross-centre collaboration. The results of the audit may also suggest more research needs to be done into the effectiveness and appropriateness of existing support and interventions. While this kind of

support may not be taken up by people such as Seth or Ernie, it may be of great value to those like Sara, Michaela and Peter.

## 10.5 Patient empowerment

A common theme among many of the participants was the process of relinquishing control when it came to making treatment decisions. The trust that most of the participants put in their surgeon and/or oncologist is considerable. However, it is evident that patients are not necessarily equipped for, or do not want to play an active part in, making treatment decisions immediately following a cancer diagnosis. More work is needed to define and implement health policies such as *No Decision About Me, Without Me* (Department of Health 2012) which aim to empower patients in situations where control is often suddenly removed. A questionnaire looking at this issue administered years rather than months post-treatment would be useful in gauging peoples' views and well as suggestions for practical improvements.

## 10.6 Clinical practice

The study has highlighted a number of experiences of oropharyngeal cancer patients. This information can be used to adapt and improve care, specifically in the follow-up period after active treatment. This could include routinely incorporating psychological health interventions into follow-up appointments as well as routine and regular signposting for psychological support. Specific training should be available to all allied health professionals involved in the care of oropharyngeal cancer patients to identify and support those patients in need of additional psychological interventions.

## 10.7 Closing comments

This study has personally resulted in a much greater awareness of the value of small-scale studies in understanding the value and meaning of experience. The interpretative element of the study has led to a huge amount of personal and professional growth, which will continue for many years to come. The expectation is that this study will influence others through publication and through personal interaction, not only to reflect on their own practice, but also to encourage more healthcare professionals to engage in original research.

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## Appendix A - Evaluation tools of qualitative research

### CASP checklist for qualitative research



### 10 questions to help you make sense of qualitative research

**How to use this appraisal tool**

Three broad issues need to be considered when appraising a qualitative study:

Are the results of the study valid?	(Section A)
What are the results?	(Section B)
Will the results help locally?	(Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing: we recommend using the Harvard style citation, i.e.:**

Critical Appraisal Skills Programme (2017). CASP (insert name of checklist i.e. Qualitative Research) Checklist. [online] Available at: URL. Accessed: Date Accessed.

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## Screening Questions

### 1. Was there a clear statement of the aims of the research?

Yes     Can't tell     No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

### 2. Is a qualitative methodology appropriate?

Yes     Can't tell     No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

## Is it worth continuing?



### Detailed questions

### 3. Was the research design appropriate to address the aims of the research?

Yes     Can't tell     No

HINT: Consider

- If the researcher has justified the research design (E.g. have they discussed how they decided which method to use)?

**4. Was the recruitment strategy appropriate to the aims of the research?**

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Yes     Can't tell     No

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**5. Was the data collected in a way that addressed the research issue?**

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

Yes     Can't tell     No

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**6. Has the relationship between researcher and participants been adequately considered?**

Yes     Can't tell     No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  - (a) Formulation of the research questions
  - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

**7. Have ethical issues been taken into consideration?  Yes  Can't tell  No**

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

**8. Was the data analysis sufficiently rigorous?  Yes  Can't tell  No**

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

### 9. Is there a clear statement of findings?

Yes    Can't tell    No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

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### 10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Adapted from Long and Godfrey (2004)

### (1) PHENOMENON STUDIED AND CONTEXT

Phenomena under study	What is being studied?  Is sufficient detail given of the nature of the phenomena under study?
Context I: Theoretical	What theoretical framework guides or informs the study?  In what ways is the framework reflected in the way the study was done?
Framework	How do the authors locate the study within the existing knowledge base?
Context II: Setting	Within what geographical and care setting is the study carried out?  What is the rationale for choosing this setting?  Is the setting appropriate and/or sufficiently specific for examination of the research question?
Context III: Sample (events, persons, times and settings)	Is sufficient detail given about the setting?  Over what time period is the study conducted?  How is the sample (events, persons, times and settings) selected? (For example, theoretically informed, purposive, convenience, chosen to explore contrasts)  Is the sample (informants, settings and events) appropriate to the aims of the study?  Is the sample appropriate in terms of depth (intensity of data collection, individuals, settings and events) and width across time, settings and events? (For example, to capture key persons and events, and to explore the detail of inter-relationships)  What are the key characteristics of the sample (events, persons, times and settings)?

Context IV: Outcomes	What outcome criteria are used in the study?  Whose perspectives are addressed (professional, service, user, carer)?  Is there sufficient breadth (e.g. contrast of two or more perspective) and depth (e.g. insight into a single perspective)?
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## (2) ETHICS

Ethics	Was Ethical Committee approval obtained?  Was informed consent obtained from participants of the study?  Have ethical issues been adequately addressed?
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## (3) DATA COLLECTION, ANALYSIS AND POTENTIAL RESEARCHER BIAS

Data collection	What data collection methods are used to obtain and record the data? (For example, provide insight into: data collected, appropriateness and availability for independent analysis)  Is the information collected with sufficient detail and depth to provide insight into the meaning and perceptions of informants?  Is the process of fieldwork adequately described? (For example, account of how the data were elicited; type and range of questions; interview guide; length and timing of observation work; note taking)  What role does the researcher adopt within the setting?  Is there evidence of reflexivity, that is, providing insight into the relationship between the researcher, setting, data production and analysis? reader to quickly grasp the essential details of a study and its potential value.  This has considerable potential as a means of communicating key messages about the study in a reasonably succinct manner. It can provide one part of the information set, and knowledge base, for a policy
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maker. The reader retains the option of going inside the tool for a more detailed insight into a particular aspect of the study.

Data analysis

How are the data analysed?

How adequate is the description of the data analysis? (For example, to allow reproduction; steps taken to guard against selectivity)

Is adequate evidence provided to support the analysis? (For example, includes original/raw data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity—searching for negative evidence, use of multiple sources, data triangulation); reliability/consistency (over researchers, time and settings; checking back with informants over interpretation)

Are the findings interpreted within the context of other studies and theory?

Researcher's potential bias

Are the researcher's own position, assumptions and possible biases outlined? (Indicate how these could affect the study, in particular, the analysis and interpretation of the data)

#### (4) POLICY AND PRACTICE IMPLICATIONS

Implications

To what setting are the study findings generalisable? (For example, is the setting typical or representative of care settings and in what respects? If the setting is atypical, will this present a stronger or weaker test of the hypothesis?)

To what population are the study's findings generalisable?

Is the conclusion justified given the conduct of the study? (For example, sampling procedure; measures of outcome used, and results achieved)

What are the implications for policy? And for service practice?

## Appendix B – Literature review tables of results and study summaries

What is known about the experience of cancer survivorship?			
Author(s)	Year of publication	Title	Summary
Aaronson, N. K. et al.	2014	Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice.	<ul style="list-style-type: none"> <li>• Overview of psychological research.</li> <li>• No participants</li> <li>• 4 main topics: (1) Symptoms should not be viewed in isolation, but rather as part of a cluster of interrelated symptoms. This has implications for both understanding the aetiology of symptoms and for their treatment; (2) Psychosocial interventions need to be evidence-based, and where possible should be tailored to the needs of the individual cancer survivor. Relatively low cost interventions with self-management and e-Health elements may be appropriate for the majority of survivors, with resource intensive interventions being reserved for those most in need; (3) More effort should be devoted to disseminating and implementing interventions in practice, and to evaluating their cost-effectiveness; and (4) Greater attention should be paid to the needs of vulnerable and high-risk populations of survivors, including the socioeconomically disadvantaged and the elderly.</li> <li>• Good background piece.</li> </ul>
Alfano, C. M. and Rowland, J. H.	2006	Recovery issues in cancer survivorship: a new challenge for supportive care.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants</li> <li>• Common sequelae that disrupt the psychosocial aspects of life for adult cancer survivors after primary treatment include: fatigue; cognitive changes; body image; sexual health and</li> </ul>

			<p>functioning; infertility; fear of recurrence; PTSD and stress syndromes; family/caregiver distress; socioeconomic issues; and distress, anxiety, and depression.</p> <ul style="list-style-type: none"> <li>• Psychosocial interventions, particularly group-based interventions and physical activity programs, have shown great promise in improving these outcomes.</li> <li>• Lacking in depth but showing good understanding of the patient group.</li> </ul>
Anderson, J. O. and Martin, P. G.	2003	Narratives and healing: exploring one family's stories of cancer survivorship.	<ul style="list-style-type: none"> <li>• Single case study of a thyroid cancer patient.</li> <li>• Survivor over 8 months</li> <li>• Taken from a larger cohort of 20 (Ott, 1999).</li> <li>• In-depth interviews.</li> <li>• While not directly applicable to many HNC patients, really interesting to see the depth of data that can be gathered from minimally structured interviews.</li> </ul>
Aspinwall, L. G. and MacNamara, A.	2005	Taking positive changes seriously.	<ul style="list-style-type: none"> <li>• Overview article.</li> <li>• No participants</li> <li>• “positive emotions and beliefs seem not only to be associated with good outcomes among people experiencing adversity, but also to play a role in realizing them.”</li> <li>• Good gateway to other psychosocial articles.</li> </ul>
Astrow, A. B.	2012	A piece of my mind. Cancer survivorship and beyond.	<ul style="list-style-type: none"> <li>• Personal perspective of what it is to be a “survivor” written by a medical oncologist.</li> <li>• Two years post-surgery</li> <li>• Interesting insights.</li> <li>• What does the term survivor mean? Does it carry a sense of accomplishment? What happens if someone does not survive...are they losers/victims?</li> </ul>

Aziz, N. M. and Rowland, J. H.	2003	Trends and advances in cancer survivorship research: challenge and opportunity.	<ul style="list-style-type: none"> <li>• Early article – how much has changed?</li> <li>• Five years or more post diagnosis</li> <li>• Justification for my study: “Investigators conducting research among long-term cancer survivors (those 5 years or more beyond cancer diagnosis) are reporting that long-term adverse outcomes are more prevalent, serious, and persistent than expected in survivors of both paediatric and adult cancer. However, the long-term and late effects of cancer and its treatment remain poorly documented and understood among those diagnosed as adults.”</li> <li>• Aims to define survivor and survivorship.</li> <li>• Good background piece but old now.</li> </ul>
Bell, K. and Ristovski-Slijepcevic, S.	2013	Cancer survivorship: why labels matter.	<ul style="list-style-type: none"> <li>• Builds on work of Mullan.</li> <li>• No participants.</li> <li>• Labels can both help and hinder, depending on the person/situation.</li> <li>• Concise article but really important.</li> <li>• Do labels need to be visible?</li> <li>• What happens if the label doesn't match how someone feels?</li> </ul>
Bowman, K. F. et al.	2006	Appraisal of the cancer experience by family members and survivors in long-term survivorship.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants are not cancer survivors.</li> <li>• “family members appraised the cancer experience as more stressful than their surviving relatives.”</li> <li>• Effect of private healthcare in the US?</li> </ul>

CURE: Cancer Updates	2009	Transitional survivorship: finding the new normal.	<ul style="list-style-type: none"> <li>• Update on Mullan's work.</li> <li>• Supports the view that cancer has a psychosocial dimension.</li> </ul>
Dasappa, L. et al.	2014	Obstacles of cancer survivorship: Sexuality issues - Need to break communication barriers.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• Indian authors – social values and norms, does this translate to a UK population?</li> <li>• “Patients should be offered sexual counselling and informed about the availability of therapies for sexual dysfunctions.”</li> </ul>
Denlinger, C. S. et al.	2014	Survivorship: Introduction and definition: Clinical practice guidelines in oncology.	<ul style="list-style-type: none"> <li>• US review article.</li> <li>• No participants.</li> <li>• "Cancer survivors in the United States increased from approximately 3 million in 1971 to 13.7 million in 2012. These numbers are predicted to reach almost 18 million by 2022."</li> <li>• Definition of survivorship – "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted."</li> <li>• Useful in terms of defining survivorship and informing search strategies.</li> </ul>
Doyle, N.	2008	Cancer survivorship: evolutionary concept analysis.	<ul style="list-style-type: none"> <li>• "The concept of cancer survivorship appears frequently in cross-discipline literature but does not seem to have any precise definition or meaning." – Is this true? Other sources contradict this.</li> <li>• No participants.</li> </ul>
Ellis, L. M. et al.	2015	Losing “losing the battle with cancer”.	<ul style="list-style-type: none"> <li>• Comment article.</li> <li>• No participants.</li> <li>• Raises some very interesting questions about the language we use in cancer care.</li> </ul>

			<ul style="list-style-type: none"> <li>• Does “losing” make someone a failure? What are the judgments attached to “fighting” cancer?</li> <li>• Really useful when looking at language. Could be applied to interview data?</li> </ul>
Foster, C. et al.	2009	Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence.	<ul style="list-style-type: none"> <li>• Literature review of studies looking at psychosocial implications of cancer <math>\geq</math> 5yrs post diagnosis.</li> <li>• No participants.</li> <li>• 43 studies. Mixed methodologies and design types.</li> <li>• Only 2 studies looked at H+N. Most looked at breast ca.</li> <li>• “Psychosocial concerns may be neglected due to a tendency to raise physical problems with healthcare professionals and only discuss other matters when prompted (Ganz 1990).”</li> <li>• “Thirty-one per cent of head and neck cancer survivors treated with radiotherapy also reported high levels of distress when they were no longer receiving support (Bjordal &amp; Kaasa 1995).”</li> <li>• “To properly understand the experience of long-term survivorship, there is a need to enable long-term survivors to describe their own experiences of what it is like to live long term following a cancer diagnosis. Such an approach may generate new insights and suggest ways to support people experiencing difficulties.”</li> <li>• Supports the use of qualitative methods to allow people to elaborate on aspects important to them.</li> </ul>
Grunfeld, E. A. et al.	2010	Cancer survivors' and employers' perceptions of working	<ul style="list-style-type: none"> <li>• UK, questionnaire-based study.</li> <li>• Participants within 4 weeks of treatment completion.</li> <li>• 194 patients (response rate of 82%) and 252 employers</li> </ul>

		following cancer treatment.	<p>(response rate 31%). Employers and employees were not linked.</p> <ul style="list-style-type: none"> <li>• <u>Completed within 4 weeks of completing treatment. Does this inform longer term survivorship?</u></li> <li>• Organizational respondents consistently reported more negative beliefs about the impact of cancer and treatment on work and in general held more negative illness perceptions about cancer in relation to work.</li> <li>• Return to work rates of between 56 and 84% have been reported in the literature [6,7] although for many this can involve a change in job role or working hours [8,9].</li> <li>• Of the 815 questionnaires sent out to organizations, 252 were returned (a response rate of 31%). Non-responders cited lack of time or company policy as reasons for noncompletion.</li> <li>• The cancer survivor sample was overrepresented by participants who had undergone higher education and who worked in white collar occupations compared to the population of the UK as a whole. A further limitation of this study is that it did not examine the beliefs of the employers of the cancer survivors included in the study and therefore pairwise comparisons were not possible.</li> <li>• Only medium and large employers. Most responses were from large (1000+ employees) companies. Are the views of smaller companies or non-responders more negative?</li> <li>• What about the self-employed?</li> </ul>
Hewitt, M. et al.	2005	From Cancer Patient to Cancer	•

		Survivor: Lost in Transition.	
Hoyt, M. A. and Rubin, L. R.	2012	Gender representation of cancer patients in medical treatment and psychosocial survivorship research: Changes over three decades.	<ul style="list-style-type: none"> <li>• Meta-analysis.</li> <li>• No participants.</li> <li>• Limited to one journal.</li> <li>• Not HNC specific. Could be skewed by funding priorities and editorial bias.</li> <li>• Shows increase in psychosocial research involving male participants.</li> </ul>
Jenkins, J.	2006	Survivorship: finding a new balance.	<ul style="list-style-type: none"> <li>• Old article now.</li> <li>• No participants.</li> <li>• Nurse-centric and written as a personal comment piece.</li> <li>• Non-systematic but offers a personal insight into cancer care.</li> <li>• Not site specific.</li> <li>• Useful as background.</li> </ul>
Keesing, S. et al.	2015	Cancer survivors' experiences of using survivorship care plans: A systematic review of qualitative studies.	<ul style="list-style-type: none"> <li>• Found during update.</li> <li>• No participants.</li> <li>• Systematic and critical review article.</li> <li>• 2000-2014.</li> <li>• 11 studies.</li> <li>• Overall lack of evidence to support care plans, but authors suggest they may be of benefit.</li> </ul>
Kim, K. et al.	2007	Predictors of cancer information overload: findings from a national survey.	<ul style="list-style-type: none"> <li>• Unpublished research.</li> <li>• No participants.</li> <li>• Secondary analysis was performed of the 2003 Health Information National Trends Survey conducted by the U.S. National Cancer Institute with 6,369 randomly selected participants. A subset of this dataset, which includes the responses of 3,011 cancer information seekers.</li> <li>• Information can overload patients – must be appropriate and timely.</li> </ul>

Lewis, F. M.	2006	The effects of cancer survivorship on families and caregivers: more research is needed on long-term survivors.	<ul style="list-style-type: none"> <li>• Overview article.</li> <li>• No participants.</li> <li>• Survivorship from a nursing perspective.</li> <li>• Very accessible but lacking in detail.</li> <li>• More research is needed for long-term survivors – gap?</li> </ul>
Macmillan.	2013	Cured but at what cost? Long-term consequences of cancer and its treatment.	<ul style="list-style-type: none"> <li>• Long term financial, social, physical and psychological impact of cancer.</li> <li>• “There are more than two million people living with cancer in the UK today, but not all of them are living well. Cancer and its treatment often leaves a gruelling physical and mental legacy for many years afterwards. It begs the question – do we really understand the true cost of being cured?”</li> <li>• Really important document!</li> </ul>
Macmillan.	2016	Living with and beyond cancer	<ul style="list-style-type: none"> <li>• Great overview document, including statistics.</li> <li>• No participants.</li> <li>• Reliable resource.</li> </ul>
Meyerowitz, B. E. and Hart, S.	1995	Women and cancer: Have assumptions about women limited our research agenda? In: Stanton, A.L. and Gallant, S.J. eds. The Psychology of women's health: progress and challenges in research and application.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Useful in understanding gender biases in research.</li> <li>• Potentially important in sexual stigma research.</li> <li>• Now an old reference.</li> </ul>
Miller, L. E.	2014	Communication dilemmas in	<ul style="list-style-type: none"> <li>• US study.</li> </ul>

		the context of cancer: Survivors' and partners' strategies for communicating throughout survivorship.	<ul style="list-style-type: none"> <li>Participants completed treatment within last five years.</li> <li>Found on lit review update.</li> <li>In-depth interviews with 35 cancer survivors and 25 partners.</li> <li>Long term communication difficulties.</li> <li>Changes in outlook supports this study's findings.</li> </ul>
Miller, L. E.	2014	Uncertainty management and information seeking in cancer survivorship.	<ul style="list-style-type: none"> <li>Same data as previous study.</li> <li>Participants completed treatment within last five years.</li> <li>"Many of the participants in this study reported feeling uncertain about the challenges awaiting them in cancer survivorship and reported experiencing various information behaviours and challenges relating to their uncertainty management."</li> </ul>
Miller, L. E.	2015	"People don't understand that it is not easy being a cancer survivor": Communicating and negotiating identity throughout cancer survivorship.	<ul style="list-style-type: none"> <li>Same data as previous study.</li> <li>Participants completed treatment within last five years.</li> <li>"Participants reported having three potentially different identities that may shift throughout survivorship: old (precancer) identity, patient (during treatment) identity, and new (post cancer) identity. Survivors also described a number of challenges and strategies relating to their identity-related conversations with social network members."</li> <li>Very much in line with this study.</li> </ul>
Mullan, F.	1985	Seasons of survival: reflections of a physician with cancer.	<ul style="list-style-type: none"> <li>Personal account.</li> <li>No participants.</li> <li>Often cited article – famous phrase of seasons.</li> <li>Found through snowballing.</li> </ul>
Peck, S.	2008	Survivorship: a concept analysis.	<ul style="list-style-type: none"> <li>Literature review.</li> <li>No participants.</li> </ul>

			<ul style="list-style-type: none"> <li>• "The act of surviving a life-altering event can result in survivorship by altering continuity of identity. This paper analyses the concept of survivorship through the use of Walker and Avant's model of concept analysis."</li> <li>• No cancer specific.</li> <li>• Commonalities with people going through other life changing experiences such as natural disasters.</li> </ul>
Perloff, T.	2015	Survivor guilt: The secret burden of survivorship.	<ul style="list-style-type: none"> <li>• Conference presentation.</li> <li>• Patients at various stages of treatment pathway.</li> <li>• Found on lit review update – grey literature.</li> <li>• Focuses on lung ca but could be related to any disease with a known causal factor.</li> <li>• N=108</li> <li>• Online questionnaire.</li> <li>• Large gender bias (86% female). Age bias as online only?</li> </ul>
Philip, E. J. et al.	2013	Depression and cancer survivorship: importance of coping self-efficacy in post-treatment survivors.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Patients an average of 9.3 years post treatment.</li> <li>• N=124.</li> <li>• Questionnaires.</li> <li>• "A substantial minority of post-treatment survivors reported depression symptomatology. Coping self-efficacy may be an important component of patients' adjustment and possible target for intervention. These results highlight the ongoing mental health and support needs of cancer survivors."</li> </ul>
Pryce, J. et al.	2007	Cancer survivorship and work: symptoms, supervisor	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• Patients at various stages of treatment pathway.</li> <li>• n=328</li> </ul>

		response, co-worker disclosure and work adjustment.	<ul style="list-style-type: none"> <li>• 33 item questionnaire that assessed cancer-specific variables e.g. type and treatment, symptoms experienced during and following treatment, disclosure of cancer and adjustments and supports available at work.</li> <li>• “The findings indicate that opportunities to work flexibly, disclosure to colleagues, difficulties managing fatigue, and paid time off to attend all medical appointments were associated with continuing to work during treatment. Correlates of return to work included difficulties managing fatigue, managing the stress of cancer, managing physical changes associated with cancer, received advice from their doctor about work and return to work meeting with employer.”</li> </ul>
Rowland, J. H. et al.	2006	Cancer survivorship: a new challenge in delivering quality cancer care.	<ul style="list-style-type: none"> <li>• US overview article.</li> <li>• No participants.</li> <li>• Older, often cited article.</li> <li>• Found through snowballing.</li> </ul>
Short, P. F. et al.	2005	Employment pathways in a large cohort of adult cancer survivors.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Not HNC specific.</li> <li>• Telephone interviews 1-5 years post diagnosis.</li> <li>• 1433 participants.</li> <li>• “They were asked retrospectively about employment from the time of diagnosis to follow-up and about work-related disability at follow-up. They also were asked whether disabilities or reasons for quitting work were cancer-related.”</li> <li>• “A projected 13% of all survivors had quit working for cancer-related reasons within 4 years of</li> </ul>

			<p>diagnosis. More than half of survivors quit working after the first year, when three-quarters of those who stopped for treatment returned to work."</p> <ul style="list-style-type: none"> <li>• "Survivors of central nervous system, head and neck, and Stage IV blood and lymph malignancies had the highest adjusted risk of disability or quitting work."</li> <li>• Interesting study with a large cohort.</li> <li>• Question over generalisability to UK population.</li> </ul>
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What is known about the experience of head and neck cancer patients?			
Author(s)	Year of publication	Title	Summary
Anderson, R. C. and Franke, K. A.	2002	Psychological and Psychosocial Implications of Head and Neck Cancer.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Old study (2002) reporting little research done in the area.</li> <li>• No participants</li> <li>• A good overview of the topic at the time, although quite superficial and lacking in references.</li> <li>• Examines coping styles.</li> <li>• Focuses on treatment and shortly after.</li> <li>• Good section on rehabilitation.</li> <li>• "Lifelong adaptation."</li> <li>• Useful for selecting older references for background and context.</li> </ul>
Baghi, M. et al.	2007	Demands on caring relatives of head and neck cancer patients.	<ul style="list-style-type: none"> <li>• German study focusing on relatives of patients.</li> <li>• Questionnaire based study.</li> <li>• Patients free of active disease; median time since treatment was 24 (range, 6 –</li> </ul>

			<p>48) months.</p> <ul style="list-style-type: none"> <li>• Does not examine diversity of “family” – very focused on the “nuclear family”.</li> <li>• Median time since treatment was 24 months, but the study refers to <i>patient</i> and <i>carer</i>...when does a person stop being a patient or carer??</li> <li>• Over-simplistic conclusion that carers need more consideration in the treatment pathway.</li> </ul>
Bjordal, K. et al.	1995	Self-reported satisfaction with life and physical health in long-term cancer survivors and a matched control group.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Norwegian study.</li> <li>• Participants 7 – 11 years post treatment.</li> <li>• N=204 vs 766 match controls.</li> <li>• Concerns over long term psychosocial morbidity.</li> <li>• Still valid today? Treat with caution.</li> </ul>
Bjordal, K. and Kaasa, S.	1995	Psychological distress in head and neck cancer patients 7-11 years after curative treatment.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Norwegian study.</li> <li>• Participants 7 – 11years post treatment.</li> <li>• N=204.</li> <li>• Postal questionnaires.</li> <li>• Old study – affected by old treatment techniques?</li> <li>• Pre-dates the effect of HPV – still talks about tobacco and alcohol.</li> <li>• Study found pts were distressed many years after treatment – still valid today? Treat with caution.</li> </ul>
Björklund, M. et al.	2010	Living with head and neck cancer: a profile of captivity.	<ul style="list-style-type: none"> <li>• Swedish study.</li> <li>• N=6 (21 semi-structured interviews).</li> <li>• Participants &lt; 30 days post diagnosis at first interview; 1-year post diagnosis at final interview.</li> </ul>

			<ul style="list-style-type: none"> <li>“The participants were living ‘in captivity’ in the sense that their symptoms were constant reminders of the disease. Our findings also revealed existential loneliness and spiritual growth, as interpreted within six themes: altered sense of affiliation; hostage of health care; locked up in a broken body, but with a free spirit; confined in a rogue body, forced dependency on others, and caught up in a permanent illness trajectory. Living with head and neck cancer involves emotional and existential vulnerability.”</li> <li>Really valuable study in terms of design and result. Does this translate to late effects and a UK population?</li> </ul>
Chandu, A. et al.	2006	Health-related quality of life in oral cancer: a review.	<ul style="list-style-type: none"> <li>Literature review.</li> <li>No participants.</li> <li>Impact of surgery only.</li> <li>Site specific QoL should be measured, as subsites have a huge impact on QoL.</li> </ul>
Chen, A. M. et al.	2013	Depression among long-term survivors of head and neck cancer treated with radiation therapy.	<ul style="list-style-type: none"> <li>US study.</li> <li>Participants at least one-year post treatment.</li> <li>211 RT pts &gt;1-year post treatment, no previous history of depression.</li> <li>Cross sectional analysis.</li> <li>University of Washington Quality of Life instrument (UW-QOL).</li> <li>Patients who reported their mood as “somewhat depressed” or “extremely depressed” was 17%, 15%, and 13% at 1, 3, and 5 years, respectively.</li> <li>UW-QOL couldn’t be administered before</li> </ul>

			diagnosis, so are scores showing underlying conditions?
Cheng, C.-H. et al.	2013	The illness experience of middle-aged men with oral cancer.	<ul style="list-style-type: none"> <li>• “explore the essence of the illness experiences” – exactly what I would like to do.</li> <li>• Participants within one year of diagnosis.</li> <li>• Nine men diagnosed with oral cancer &gt; one-year post diagnosis.</li> <li>• In-depth interviews.</li> <li>• Analysed using Colaizzi’s phenomenological analysis procedures.</li> <li>• 5 themes: <ul style="list-style-type: none"> <li>◦ the psychological journey in facing oral cancer</li> <li>◦ the question of how patients can control their disease as well as the sequelae of cancer treatment</li> <li>◦ the continuous disturbance and turmoil resulting from the disease</li> <li>◦ the appreciation of the support from family and friends</li> <li>◦ the ability to learn to actively face the future.</li> </ul> </li> <li>• Taipei study – generalisability?</li> <li>• Useful for methodological validation – importance of qualitative studies.</li> </ul>
Clarke, S. et al.	2014	Appearance concerns and psychosocial adjustment following head and neck cancer: a cross-sectional	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• Participants at least six months post treatment.</li> <li>• HNC patients (non-site specific) completed baseline questionnaires (n=49). Participation dropped to 20</li> </ul>

		study and nine-month follow-up.	<p>for the nine-month follow-up questionnaire.</p> <ul style="list-style-type: none"> <li>• Part of the ARC study into visible differences following treatment.</li> <li>• DAS-24 questionnaire.</li> <li>• No significant differences between baseline and follow-up data.</li> <li>• Female participants reported higher levels of appearance-related distress than females in the general population and male HNC survivors.</li> <li>• Depression scores on the hospital anxiety and depression scale were higher than UK norms whilst anxiety was similar to UK norms.</li> <li>• Lacking in detail regarding population group demographic data.</li> </ul>
Deno, M. et al.	2012	The mediating effects of social support and self-efficacy on the relationship between social distress and emotional distress in head and neck cancer outpatients with facial disfigurement.	<ul style="list-style-type: none"> <li>• Japanese study.</li> <li>• Patient participants treatment pathway progress not specified.</li> <li>• 225 respondents completed questionnaires.</li> <li>• Self-efficacy strongly buffered the negative influence of social distress on emotional distress.</li> <li>• Social support from family members did not have a direct or indirect influence on emotional distress.</li> <li>• Social support from friends was related to lower social distress and higher emotional distress.</li> <li>• Preliminary study conducted to assess the questionnaires.</li> <li>• If patients are recruited by health professionals does this introduce bias?</li> <li>• Longitudinal research is needed to determine</li> </ul>

			causality.
Devins, G. M. et al.	2015	Distancing, self-esteem, and subjective well-being in head and neck cancer.	<ul style="list-style-type: none"> <li>• Canadian study.</li> <li>• Data used from 2 studies - <math>N_1 = 162</math>; <math>N_2 = 408</math>.</li> <li>• Center for Epidemiologic Studies Depression Scale, and the Illness Intrusiveness Ratings Scale.</li> <li>• Interpersonal stressors most common.</li> <li>• Data collected at follow up, but no time given – time may affect stress levels.</li> </ul>
Elani, H. W. and Allison, P. J.	2011	Coping and psychological distress among head and neck cancer patients.	<ul style="list-style-type: none"> <li>• Canadian study of 157 H+N pts</li> <li>• Participants 6-12 months post diagnosis.</li> <li>• Examines coping strategies.</li> <li>• Pts with higher levels of anxiety and depression used more <i>blamed self, wishful thinking and avoidance</i>.</li> <li>• Ways of coping checklist (WOCC) and Hospital anxiety and depression scale (HADS).</li> <li>• Questionnaires/checklists completed by researchers in interview.</li> <li>• Mean participant age was 62.6 yrs. 55% were homemakers or retired. 18.5% were employed.</li> <li>• No conclusion as to whether there was a temporal relationship between anxiety, depression and coping.</li> </ul>
Fang, C. Y. et al.	2012	Informational needs of head and neck cancer patients.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Patient participants treatment pathway progress not specified.</li> <li>• Convenience sample of 65 H+N pts. Mean age was 56.3 yrs.</li> <li>• Pts with early stage disease desired more information than those with advanced</li> </ul>

			<p>disease.</p> <ul style="list-style-type: none"> <li>• Younger pts (29-49) were more likely to desire info re sexuality.</li> <li>• Most pts wanted information at diagnosis or 1-3 months post-treatment.</li> <li>• Impact of Events scale (IES) to measure distress.</li> <li>• 32% desired information on coping with emotional stress and anxiety. Fewer pts wanted information regarding communication with family members, coping with changes in appearance, managing social situations or intimacy/sexuality.</li> <li>• 62.5% of female pts desired information on coping with emotional stress and anxiety compared with 20.8% of men.</li> <li>• 25% wanted information at more than one-time point (possibly to avoid information overload).</li> <li>• Preference for format of information: <ul style="list-style-type: none"> <li>○ Internet – 43.1%</li> <li>○ DVD – 40%</li> <li>○ Booklets or pamphlets – 36.9%</li> <li>○ One on one meetings – 15.4%</li> <li>○ Group meetings with health professional – 21.5%</li> </ul> </li> <li>• Higher educational attainment = greater desire for more information.</li> <li>• Small(ish) sample, ethnically and racially homogeneous. Transferability??</li> </ul>
Fingeret, M. C. et al.	2012	The nature and extent of body image concerns among surgically	<ul style="list-style-type: none"> <li>• US study. 280 pts.</li> <li>• Participants at three treatment stages: prior to</li> </ul>

		treated patients with head and neck cancer.	<p>surgical treatment; within one year of initial treatment; greater than one year of initial treatment.</p> <ul style="list-style-type: none"> <li>• Cross sectional design.</li> <li>• 75% of respondents acknowledging concerns or embarrassment about one or more types of bodily changes at some point.</li> <li>• Men were as likely as women to be affected by body image concerns.</li> <li>• Authors acknowledge inconsistent or simplistic definitions of body image.</li> <li>• Subjective nature of such concerns makes measuring or predicting difficult.</li> <li>• “preoperative expectations or anticipation of disfigurative surgery [affects] on overall distress, anxiety and coping effectiveness” p.837</li> <li>• Recommends health staff “directly inquire” p842</li> <li>• Respondents see benefit in setting realistic expectations for body image outcomes <u>prior to treatment</u>.</li> <li>• Younger pts were at greater risk of experiencing body image difficulties.</li> <li>• Authors recommend a prospective study rather than a cross sectional design.</li> </ul>
Ganzer, H. L. et al.	2012	Symptom Burden in Head and Neck Cancer: Survivorship Following Chemoradiotherapy.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants at continual stages of treatment pathway: early, mid and late recovery stages.</li> <li>• N=43.</li> <li>• Vanderbilt Head and Neck Symptom Survey 2.0.</li> </ul>

			<ul style="list-style-type: none"> <li>● Symptom burden improved over time but the following remained problematic:           <ul style="list-style-type: none"> <li>○ xerostomia making chewing/swallowing difficult</li> <li>○ taste alterations</li> <li>○ mucosal sensitivity to dryness</li> <li>○ mucosal sensitivity to spicy, hot, or acidic food.</li> </ul> </li> </ul>
Ganzer, H. L. et al.	2015	The eating experience in long-term survivors of head and neck cancer: a mixed-methods study	<ul style="list-style-type: none"> <li>● US study.</li> <li>● Participants more than 3 years post concurrent chemoradiation</li> <li>● 10 long-term survivors of non-site specific HNC.</li> <li>● Mixed-methods; exploratory qualitative research using content analysis and summary statistics was used to describe demographic and clinical characteristics and the Vanderbilt Head and Neck Symptom Survey version 2.0 scores.</li> <li>● Four categories associated with eating (psychological, social impact, functional status, and the current eating experience).</li> <li>● Psychological, functional, and social losses associated with eating were identified. Participants modify or avoid foods that are challenging yet report enjoyment with eating. Challenges with eating were downplayed. Possibly trying to return to their pre-treatment selves?</li> </ul>
Ghazali, N. et al.	2012	Items of concerns of head and neck cancer survivors in routine oncology follow up clinics.	<ul style="list-style-type: none"> <li>● UK study.</li> <li>● Participants are post treatment and in remission.</li> <li>● 125 post-treatment pts.</li> <li>● Mean length of consultation</li> </ul>

			<p>was 7 minutes (4-25 mins).</p> <ul style="list-style-type: none"> <li>• Items discussed per consultation: 3</li> <li>• Most common: function (92%), rehabilitation (89%)</li> <li>• Patients rarely ask about psychosocial issues.</li> <li>• Authors suggest this is due to a reluctance to discuss such issues. Could it be that these issues don't exist?</li> </ul>
Haisfield-Wolfe, M. E. et al. eds.	2009	Prevalence and correlates of depression among patients with head and neck cancer: a systematic review of implications for research.	<ul style="list-style-type: none"> <li>• N=21 (16 oropharyngeal, 5 laryngeal).</li> <li>• Participants interviewed at 4 time points during treatment: treatment initiation; treatment midpoint; end of treatment; one-month post-treatment.</li> <li>• Content analysis.</li> <li>• Interviews during treatment with open questions. Questions covered topics such as coping during treatment, treatment-related issues, and resources.</li> <li>• Analysis and conclusions seem superficial – use with caution.</li> </ul>
Henry, M. et al.	2014	Head and neck cancer patients want us to support them psychologically in the posttreatment period: Survey results.	<ul style="list-style-type: none"> <li>• Canadian study.</li> <li>• n=127.</li> <li>• 8% experienced unmet needs, and 25% revealed a clinically significant distress level on the HADS. The highest unmet needs were psychological (7 of top 10 needs). A multiple linear regression indicated a higher level of overall unmet needs when patients were divorced, had a high level of anxiety (HADS subscale), were in poor physical condition, or had a diminished emotional quality of life (FACT-G subscales).</li> </ul>

			<ul style="list-style-type: none"> <li>• Do UK patients experience similar distress?</li> <li>• Results lack depth, consistent with large scale studies.</li> </ul>
Henry, M. et al.	2014	Looking beyond disfigurement: the experience of patients with head and neck cancer	<ul style="list-style-type: none"> <li>• Recommended for inclusion as part of viva corrections. Not found through original literature search or update.</li> <li>• Canadian study</li> <li>• Participants at various points in treatment pathway.</li> <li>• N=14</li> <li>• Interpretative phenomenology.</li> <li>• In-depth semi structured interviews.</li> <li>• 64% advanced cancer (stage 3-4).</li> <li>• “Patients' experiences revolved around the concept of a ruptured self-image (a discontinuity in sense of self).”</li> <li>• Not site-specific.</li> <li>• Outward disfigurement could act as a “story” or reminder for those around them that they are not the same people they were before diagnosis.</li> </ul>
Heutte, N. et al.	2014	Quality of life tools in head and neck oncology.	<ul style="list-style-type: none"> <li>• Overview of QoL assessment tools – useful for study design.</li> <li>• No participants.</li> <li>• 492 French and English language studies examined.</li> <li>• 90 QoL scales organised by area and specifying psychometric quality and citation level: <ul style="list-style-type: none"> <li>○ ORL oncology</li> <li>○ voice</li> <li>○ swallowing and mastication</li> <li>○ mucositis</li> <li>○ xerostomia</li> </ul> </li> </ul>

Holloway, R. L. et al.	2005	Psychosocial effects in long-term head and neck cancer survivors.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants ≥5 years post treatment, ≥3 years completely cancer free.</li> <li>• 105 patients.</li> <li>• Cross-sectional study using a convenience sample.</li> <li>• Questionnaires (FACT and FACT-H&amp;N) administered to all, and physiologic tests administered to 86.</li> <li>• Premorbid pessimism (MBHI) was consistently the best predictor of QOL measures.</li> <li>• “most of the psychosocial side effects of treatment are enduring without appropriate intervention. In addition, predisposing psychologic factors may create variable responses to disabilities and/or treatment.”</li> <li>• “psychosocial variables may even be more important than physiologic variables when predicting many aspects of QOL in this group of long-term head and neck cancer survivors.”</li> <li>• Recommends a longitudinal design for future studies.</li> <li>• Seemingly strong study, although reliant on the strength of the questionnaires and definitions of QoL.</li> </ul>
Howren, M. et al.	2012	Psychological Factors Associated with Head and Neck Cancer Treatment and Survivorship: Evidence and Opportunities for Behavioral Medicine.	<ul style="list-style-type: none"> <li>• Very thorough overview of psychosocial issues in HNC.</li> <li>• No participants.</li> <li>• Reference regarding fear of recurrence from 1975 – How applicable?</li> <li>• Mentions “risky sexual behaviour” but does not attempt to define it.</li> <li>• Overview rather than literature review.</li> </ul>

			<ul style="list-style-type: none"> <li>• Topics covered:           <ul style="list-style-type: none"> <li>◦ Psychological distress</li> <li>◦ Body image-disfigurement</li> <li>◦ Personality-individual differences</li> <li>◦ Social support</li> <li>◦ Psychological interventions</li> </ul> </li> </ul>
Isaksson, J. et al.	2016	Living an everyday life with head and neck cancer 2-2.5 years post-diagnosis - A qualitative prospective study of 56 patients.	<ul style="list-style-type: none"> <li>• Found during update.</li> <li>• Swedish study.</li> <li>• n=56</li> <li>• Interviewed at 6, 12, and 24 months post-treatment about how they lived their lives.</li> <li>• “Four different trajectories and transitions emerged. The first group (n = 15) evaluated their illness experience as a past parenthesis in their life suggesting that they had psychologically left the illness behind. In the second group (n = 9), the impact of the disease seemed to be diluted by other strains in their life, and although these patients to some extent were still hampered by side effects, they regarded them as ‘no big deal’. The cancer really made a difference in the third group (n = 12) in both positive and negative ways and seemed to reflect a balance between such effects. In the fourth group (n = 20), the physical and/or psychological problems predominated and the patients’ lives had changed for the worse.”</li> <li>• “The narratives showed that being afflicted by HNC has different impacts depending on how the patients live their lives – it is a matter of individual transition in an</li> </ul>

			<p>everyday life context. This idiosyncrasy challenges the meaningfulness of screening efforts to identify vulnerable groups for psychosocial intervention.”</p> <ul style="list-style-type: none"> <li>• Broadly supports findings from my study.</li> </ul>
Isaksson, J. et al.	2016	Meaning of work and the process of returning after head and neck cancer.	<ul style="list-style-type: none"> <li>• Found during update.</li> <li>• Swedish study.</li> <li>• n=66.</li> <li>• Participants were aged 34–66 years. Repeatedly interviewed over a period of 24 months.</li> <li>• 53 % of the patients had returned to work at 24 months after treatment, and 17 % were deceased.</li> <li>• “Several quality of life parameters were significantly worse for patients not working at 24 months after treatment. Nine categories were found to describe the return-to-work process starting with symptoms causing sick leave, thoughts about the sick leave, and ending with the return to work and/or retirement.”</li> <li>• Does age of 66 invite gender differences?</li> </ul>
Jenewein, J. et al.	2008	Quality of life and dyadic adjustment in oral cancer patients and their female partners.	<ul style="list-style-type: none"> <li>• German language Swiss study.</li> <li>• Participants between four and 10 years post treatment.</li> <li>• Questionnaire based (HADS, Subjective QoL was measured with the WHOQOLBREF, an abbreviated version of the World Health Organization Quality of Life (WHOQOL-100) and The European Organization for Research and Treatment</li> </ul>

			<ul style="list-style-type: none"> <li>• of Cancer (EORTC) Quality of Life Questionnaire C-30.</li> <li>• 31 dyads.</li> <li>• Cross sectional study.</li> <li>• Mean time since diagnosis 3.7 years.</li> <li>• 52% response rate. Questions of engagement from this population. Non-respondents were significantly older than participants. [mean: 61.9 (SD 15.3) vs. 58.2 (SD 10.1) years.</li> <li>• Title specifies <i>female partners</i>, but the paper refers to them all as <i>wives</i>. Translation issue?</li> <li>• In patients, lower QoL was associated with more physical complaints and higher levels of psychological distress (HADS), whereas in wives, QoL was found to be related to marital quality (DAS) and levels of distress. In couples with highly discrepant ratings of marital satisfaction, wives reported more psychological distress.</li> <li>• **Really good section on equity theory**</li> </ul>
Johansson, M. et al.	2011	Mental adjustment to cancer and its relation to anxiety, depression, HRQL and survival in patients with laryngeal cancer - a longitudinal study.	<ul style="list-style-type: none"> <li>• Swedish longitudinal study.</li> <li>• Participants measured at 1 and 12 months after commencement of treatment.</li> <li>• 95 patients.</li> <li>• Self-administered questionnaires (Mini-Mental Adjustment to Cancer Scale (Mini-MAC), the European Organisation for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life core questionnaire (EORTC QLQ-C30) supplemented with the Head and Neck cancer</li> </ul>

			<p>module (QLQ-H&amp;N35) and the Hospital Anxiety and Depression (HAD) Scale.)</p> <ul style="list-style-type: none"> <li>• The most commonly used adjustment response at both occasions was Fighting Spirit.</li> <li>• Correlation analyses showed that patients using Helpless-Hopeless and Anxious Preoccupation responses reported more anxiety and depression, as well as decreased HRQL.</li> <li>• 2-year break in data collection – no explanation.</li> <li>• Patients with more advanced cancer were excluded which may affect results.</li> <li>• 63 eligible patients were excluded: participation in other studies (19), insufficient knowledge in Swedish language (10), second primary cancer tumour (9), psychiatric disorder (12), dementia (4) and alcohol addiction (9)</li> </ul>
Katz, M. R. et al.	2003	Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support.	<ul style="list-style-type: none"> <li>• Canadian study</li> <li>• Participants 6 months or more post treatment.</li> <li>• 82 participants (non-laryngectomised)</li> <li>• Cross-sectional, convenience sample.</li> <li>• “Patients with oral cavity and oropharyngeal cancer have been shown to have worsened psychosocial outcomes relative to laryngeal cancer patients.”</li> <li>• All surgically treated. 56% received radiotherapy.</li> <li>• Mean age 58.8 years. Age range 24-85.</li> <li>• 26% of sample reported a significant level of depression.</li> </ul>

			<ul style="list-style-type: none"> <li>• Women demonstrated higher levels of depression and lower life happiness; subjects with greater disfigurement were more depressed. Social support seemed to buffer the impact of greater levels of disfigurement on well-being for women but not for men.</li> <li>• These results suggest that women with head and neck cancer who experience low social support and face disfiguring treatment are at greatest risk for psychosocial dysfunction.</li> <li>• “Adverse psychosocial sequelae such as depression, anxiety, and reduced well-being have been well documented,<sup>3–7</sup> but persistent difficulties seem to occur in a minority of patients.”</li> </ul>
Konradsen, H. et al.	2012	Breaking the silence: integration of facial disfigurement after surgical treatment for cancer.	<ul style="list-style-type: none"> <li>• An excellent study, despite a small cohort.</li> <li>• Qualitative study. Denmark</li> <li>• Participants initially interviewed while still in hospital; second interview conducted 6 months post-surgery.</li> <li>• 15 patients surgically treated for head, neck, or eye cancer over the course of their first postoperative year.</li> <li>• Interviews were analysed using grounded theory method.</li> <li>• “The main concern of the patients was feeling isolated, which was resolved using a process of interactional integration. Interactional integration begins by breaking the silence to enable the progression from</li> </ul>

			<p>a disfigured person to a person with a disfigurement.”</p> <ul style="list-style-type: none"> <li>• “To discover possible links between concepts, we used diagramming as memos and as part of the constant comparison. Other researchers have also found diagramming helpful in the process of clarifying relationships between categories in forms other than a narrative description (Artinian, Giske, &amp; Cone, 2009).”</li> <li>• “The opportunity for patients to tell their story in an interview has been shown to be a helpful experience (Campbell, Adams, Wasco, Ahrens, &amp; Sefl, 2010; Holloway &amp; Freshwater, 2007).”</li> <li>• “People responded to the disfigurement with silence. Patients started noticing responses from others and were concerned that their own emotions caused these responses. As a result, patients began dissociating by avoiding, which enabled them to create a space where they felt protected or were able to temporarily forget.”</li> <li>• Hospital as a protective environment, which can be disturbed by visitors (especially children).</li> <li>• “Our study did not include interviews with the patients’ families or close friends, and the study might therefore lack important input.”</li> <li>• “Anderson and Franke (2002) stated that the process of accepting disfigurement</li> </ul>
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			<p>begins when the fear of death diminishes.”</p> <ul style="list-style-type: none"> <li>“In a psychosocial process called <i>transitional cancer survivorship</i> identified by Miller, Merry, and Miller (2008), the patients tried to adjust from acute survivors to extended or permanent survivors.”</li> </ul>
Lebel, S. et al.	2013	The psychosocial impact of stigma in people with head and neck or lung cancer.	<ul style="list-style-type: none"> <li>Canadian study.</li> <li>Participants less than three years post diagnosis.</li> <li>Questionnaires.</li> <li>Lung (n = 107) and head and neck cancer survivors (n = 99) ≤3 years post-diagnosis.</li> <li>Reported stigma was comparatively low.</li> <li>Reported stigma was higher in (i) men than women, (ii) lung as compared with head and neck cancer, and (iii) people who were highly disfigured by cancer and/or its treatment.</li> <li>Benefit finding buffered stigma’s deleterious effects, and illness intrusiveness was a partial mediator of its psychosocial impact.</li> <li>55.5% response rate.</li> <li>Are those who felt stigmatised among the 44.5% who did not respond? Something the authors acknowledge.</li> <li>Not a great study but does confirm the presence of stigma.</li> <li>“Members of the general public are largely unaware that tobacco and alcohol consumption place one at increased risk for head and neck cancer [56,57] and this is true of people with head</li> </ul>

			and neck cancer themselves [58]."
Low, C. et al.	2009	Issues of intimacy and sexual dysfunction following major head and neck cancer treatment.	<ul style="list-style-type: none"> <li>• UK study looking at intimacy and sexual function following H+N ca.</li> <li>• Patients between 3 months and 7 years post treatment.</li> <li>• Postal questionnaire with 68% response rate.</li> <li>• QoL is “best measured longitudinally”.</li> <li>• Mean age = 64.</li> <li>• 67% male, 33% female.</li> <li>• 110/350 respondents did not answer intimacy or sexuality questions, despite answering other questions.</li> <li>• Pts least likely to answer these questions were older and without a partner.</li> <li>• Is social support linked to feelings of isolations and vulnerability which may lead to lack of intimacy?</li> <li>• Intimacy is different to sexuality.</li> <li>• “Hammerlid et al. found that in 9 out of 11 tumour sites of the head and neck, less sexual interest emerged as one of the worst three HRQOL problems patients reported.<sup>30</sup>”</li> <li>• Possibility of using the questions in clinic via touch screen technology to reduce embarrassment.</li> </ul>
Manne, S. and Badr, H.	2010	Intimacy processes and psychological distress among couples coping with head and neck or lung cancers.	<ul style="list-style-type: none"> <li>• US study. Self-disclosure questionnaires.</li> <li>• 109 pts undergoing <u>active</u> treatment, and their partners.</li> <li>• Associations between 3 types of cancer-related support communication: <ul style="list-style-type: none"> <li>○ Self-disclosure.</li> <li>○ Perceived partner</li> </ul> </li> </ul>

			<p>disclosure.</p> <ul style="list-style-type: none"> <li>○ Protective buffering.</li> <li>● Actor-partner interdependence model.</li> <li>● Lower levels of distress were reported as a function of global and cancer-specific intimacy, but these associations were stronger for partners than for patients.</li> <li>● “Given the importance of the marital relationship in adaptation, a greater understanding of the process by which couples’ support-related communication affects psychological adjustment may aid in the development of interventions...” (p.942).</li> <li>● Relationship intimacy model of couples’ psychosocial adaptation to cancer - Manne and Badr (2008).</li> <li>● Incentives may increase participation especially amongst those with drug and alcohol issues.</li> </ul>
Manne, S. et al.	2012	A longitudinal analysis of intimacy processes and psychological distress among couples coping with head and neck or lung cancers.	<ul style="list-style-type: none"> <li>● US study.</li> <li>● Patients first approached during active treatment and again 3-6 months later.</li> <li>● 139 patient-spouse dyads completed measures of spousal communication, intimacy, and distress at three-time points over 6 months.</li> <li>● 33.1% response rate. The most common reasons for refusal were that the patient felt the study would take “too much time” (10.4%) or felt too ill (10.4%).</li> <li>● Multilevel modelling, an over-time actor-partner interdependence model was specified that examined</li> </ul>

			<p>whether intimacy mediated associations between one's own and one's partner's reports of communication at baseline and later distress.</p> <ul style="list-style-type: none"> <li>“one's own perceptions of relationship communication have a stronger association with one's own distress than a partner's perceptions (Manne et al., 2006). It is surprising that a partner's perceptions of negative communication predicted one's own intimacy, but one's own perception of negative communication did not.”</li> <li>“One-hundred eight patients (77.6%) and 90 spouses (65%) completed the 3-month follow-up and 91 patients (65.5%) and 77 spouses (54%) completed the 6-month follow-up. The most frequently cited reasons for drop-outs were: the patient died, felt too ill to continue, or <b>felt the survey was too upsetting.</b>”</li> <li>Limitations: “a low rate of study acceptance and a significant number of dropouts. Study refusals may have been more distressed which may have biased the results towards less distressed individuals and/or couples. Likewise, patients who completed the study had a higher income and their partners were more open with regard to sharing concerns.”</li> <li>Good study despite some limitations.</li> </ul>
McQuestion , M. et al.	2011	The changed meaning of food: Physical, social and	<ul style="list-style-type: none"> <li>This article describes research that is part of a larger study about patients'</li> </ul>

		<p>emotional loss for patients having received radiation treatment for head and neck cancer.</p>	<p>experiences of receiving radiation for head and neck cancer.</p> <ul style="list-style-type: none"> <li>● Participants three months post treatment.</li> <li>● 17 participants.</li> <li>● “Participants felt distressed because of the disrupted expectations and changes in their life routines. In particular, their altered routines changed the meaning of food for them. The changed meanings of food were evident in three parts of their lives: a) physical, b) emotional and c) social losses.”</li> <li>● “Difficulty with eating and regaining lost weight became a permanent part of the participants’ lives for many following treatment.”</li> <li>● “<a href="#">Larrson et al. (2005)</a> identified through a chart review that the majority of patients were still experiencing eating problems one year after treatment.”</li> <li>● “There are physical, emotional and social losses associated with a changed meaning of food for Head and Neck cancer patients. Acknowledging the significance of eating problems and the changed meaning of food is required in order to provide patients with the appropriate support, strategies and interventions to manage with the changes and losses. ”</li> <li>● “Qualitative descriptive analysis is an inductive rather than a deductive process. <a href="#">Giorgi’s (1985)</a> analytical technique was chosen as the</li> </ul>
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			<p>method of analysis for the study since it supported a repeated immersion into the data prior to coding, classifying, or creating linkages. <a href="#">Thorne (1997)</a> supports the use of <a href="#">Giorgi's (1985)</a> method of analysis since it capitalizes on synthesizing, theorizing, and recontextualizing rather than simply the sorting and coding of data."</p> <ul style="list-style-type: none"> <li>• Excellent article.</li> </ul>
Mehanna, H. M. and Morton, R. P.	2006	Deterioration in quality-of-life of late (10-year) survivors of head and neck cancer.	<ul style="list-style-type: none"> <li>• 200 patients recruited into a 2-year prospective QOL study from <b>1989 to 1992</b>. If published in 2006 that's 4 years to analyse data and write-up. Have things moved on?</li> <li>• Participants 10 years post diagnosis.</li> <li>• The Auckland Quality of Life Questionnaire was completed 10 years post-diagnosis.</li> <li>• "At 10 years, 136 (68%) patients were deceased, and 50 (25%) patients were confirmed alive, of whom 43 were successfully contacted." Small sample size.</li> <li>• "...patients' QOL decreases during treatment, but that it starts improving 3–6 months after treatment to reach or exceed the pre-treatment level by the end of the first year. Quality-of-life appears to continue to improve slightly for the following 2–3 years.<sup>4–11</sup>" If this is true then my study will discover nothing.</li> <li>• "Some cross-sectional QOL outcomes in long-term head and neck cancer survivors have been published,<sup>12–15</sup></li> </ul>

			<p>but these had no pre-treatment or early post-treatment measures for comparison – thereby considerably limiting the utility of the data."</p> <ul style="list-style-type: none"> <li>• Despite several limitations (which the authors acknowledge) it seems to be an interesting study but is hampered by definitions of QoL.</li> </ul>
Moore, K. A. et al.	2014	"I have quality of life...but...": Exploring support needs important to quality of life in head and neck cancer.	<ul style="list-style-type: none"> <li>• Australian study.</li> <li>• Patient participants treatment pathway progress not specified.</li> <li>• Qualitative, semi-structured interviews were held with 8 participants previously treated for HNC.</li> <li>• "Coping with psychological stressors (i.e. depression and anxiety) affected QoL in the first six to twelve months following treatment. Coping was influenced by loss of access to the supportive hospital environment after treatment and resulted in feelings of isolation post treatment."</li> <li>• Benefits from a smaller sample so more chance of getting depth of data.</li> <li>• Uses content analysis.</li> </ul>
Moreno, K. F. et al.	2012	Sexuality after treatment of head and neck cancer: findings based on modification of sexual adjustment questionnaire.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants time since treatment, median 12 months (range 4-33).</li> <li>• 42 participants (no mention of no. approached or response rate). 55.1 years mean age.</li> <li>• "All 42 patients rated that head and neck cancer negatively impacted their sexual relationships, including</li> </ul>

			<p>21 (50%) rating effects as negative or extremely negative. Men reported higher satisfaction scores with sexual function (mean ± standard deviation) than women (<math>19.9 \pm 5.0</math> vs. <math>16.3 \pm 6.5</math>, respectively; <math>P = .06</math>)."</p> <ul style="list-style-type: none"> <li>• An interesting study but the article focuses more on the questionnaire used than the results or the implications. More work in this area needs to be done.</li> </ul>
Nund, R. et al.	2014	Survivors' experiences of dysphagia-related services following head and neck cancer: Implications for clinical practice	<ul style="list-style-type: none"> <li>• Australian study.</li> <li>• Patient participants treatment pathway progress not specified.</li> <li>• N=24.</li> <li>• HNC non-site specific.</li> <li>• Non-surgical, RT only.</li> <li>• Single semi-structured interview.</li> <li>• Thematic analysis.</li> <li>• Speech and language therapists managing this caseload need to ensure post-treatment services are available and address not only the physical but also the emotional and psychosocial changes.</li> <li>• Overriding concern was the desire for ongoing access to dysphagia-related services in order to adequately manage dysphagia. <ul style="list-style-type: none"> <li>○ entering the unknown: life after treatment for HNC</li> <li>○ making practical adjustments to live with dysphagia</li> <li>○ making emotional adjustments to live with dysphagia</li> </ul> </li> </ul>

			<ul style="list-style-type: none"> <li>○ accessing support outside the hospital services</li> <li>○ perceptions of dysphagia-related services.</li> </ul>
Nund, R. et al.	2015	Communication changes following non-glottic head and neck cancer management: The perspectives of survivors and carers.	<ul style="list-style-type: none"> <li>● Australian study.</li> <li>● Participants are interviewed at a mean of 17.1 months post treatment (SD 15.1, range 1.5-46).</li> <li>● 14 survivors with non-glottic HNC and 9 of their carers.</li> <li>● Chemoradiotherapy only.</li> <li>● In-depth interviews.</li> <li>● Four themes emerged:</li> <li>● impairments in communication subsystems</li> <li>● the challenges of communicating in everyday life</li> <li>● broad ranging effects of communication changes</li> <li>● adaptations as a result of communication changes.</li> <li>● Focuses more on the physical ability to talk and its psychological impact rather than the quality or depth of communication.</li> </ul>
O'Brien, K. et al.	2012	An exploration of the perceived changes in intimacy of patients' relationships following head and neck cancer.	<ul style="list-style-type: none"> <li>● Focused on intimacy</li> <li>● 16 participants, ≥1 yr. post treatment (12 men, 4 women).</li> <li>● Interview with open ended questions.</li> <li>● 3 themes identified: 'personal identity', 're-establishing social networks' and 'intimate relationships'</li> <li>● 68% response rate. 24% of respondents reported problems with intimacy following treatment.</li> <li>● Losses either intermediate or ultimate.</li> </ul>

			<ul style="list-style-type: none"> <li>• Stratified quota sampling approach.</li> <li>• First interview using broad questions. Subsequent interviews more focused.</li> <li>• Colazzi's seven step framework to enhance the rigour of the analysis.</li> <li>• "Participants who observed an unwillingness by partners and loved ones to talk intimately and freely commented on a gradual build-up of feelings of resentment, frustration and anger."</li> </ul>
Ottosson, S. et al.	2013	The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study.	<ul style="list-style-type: none"> <li>• Swedish study.</li> <li>• n=13 in-depth semi-structured interviews.</li> <li>• Content analysis.</li> <li>• The experience of food, eating and meals up to nine months after radiotherapy was captured in six categories: <ul style="list-style-type: none"> <li>○ A long journey – taking small steps to an uncertain future</li> <li>○ A new way of eating</li> <li>○ Eating without satisfaction</li> <li>○ Challenging meals outside the family</li> <li>○ Support and information – the key to a successful journey</li> <li>○ The creation and acceptance of a new normal</li> </ul> </li> <li>• New normal - supportive of this study's findings.</li> <li>• Long term impact of quality of life and identity.</li> </ul>
Penner, J. L.	2009	Psychosocial Care of Patients with	<ul style="list-style-type: none"> <li>• Systematic literature review.</li> <li>• No participants.</li> <li>• Nurse-centric.</li> </ul>

		Head and Neck Cancer.	<ul style="list-style-type: none"> <li>• Decent literature review that provides an overview of the area. However, it does not specify whether the focus is during or post-treatment.</li> <li>• Areas covered are:           <ul style="list-style-type: none"> <li>○ Appearance</li> <li>○ Verbal communication</li> <li>○ Eating and drinking</li> <li>○ Employment</li> <li>○ Sexuality</li> <li>○ Psychological distress</li> <li>○ Psychosocial challenges</li> <li>○ Psychosocial challenges for family caregivers</li> <li>○ Future directions</li> </ul> </li> <li>• “Qualitative studies have begun to emerge that help us understand patients’ subjective experiences of daily life following treatment, but more work is needed to further explicate the psychosocial needs of both patients and their family members cross-sectionally and over time.”</li> </ul>
Precious, E. et al.	2012	Head and neck cancer patients' perspective of carer burden.	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• Patients between 1 and 16 years post treatment.</li> <li>• A cross-sectional survey of 751 patients with head and neck cancer who were alive and disease-free using two questionnaires: one combined study-specific questions about carers with questions from Khafif et al., and the other was the University of Washington Quality of Life questionnaire version 4 (UW-QoL).</li> <li>• 386 replies (50% response rate).</li> </ul>

			<ul style="list-style-type: none"> <li>• Nearly half (46%, 162/354) had carers who were mainly family members.</li> <li>• Patients identified their main roles as providing emotional support (75%), taking them to healthcare appointments (67%), cleaning the home (62%), and shopping for food (59%).</li> <li>• Around a third felt that their care was a considerable burden, and a similar proportion felt that it was very hard for their carers.”</li> <li>• Time from diagnosis/years: 1–2 = 160; 3–5 = 93; 6–16 = 123.</li> <li>• This study suggests that a large proportion of patients never manage to exit the <i>patient-carer</i> relationship. Is this due to need or perception of need??</li> <li>• Very interesting study.</li> </ul>
Richardson, A. E. et al.	2015	Psychological support needs of patients with head and neck cancer and their caregivers: A qualitative study.	<ul style="list-style-type: none"> <li>• New Zealand study.</li> <li>• Lit review update.</li> <li>• 83 patients and 73 caregivers completed questionnaires at diagnosis. Follow-up questionnaires were mailed to patients six months later.</li> <li>• “Patients described ‘just being there’, empathy, maintaining normality and practical support as helpful from family/friends. They desired information, honesty, positivity and empathy from clinical staff. Formal psychological support was desired by approximately 40% of patients and caregivers, particularly early after diagnosis and during treatment. Most participants desired face to face sessions, providing individualised</li> </ul>

			information and coping strategies.”
Röing, M. et al.	2009	Making new meanings of being in the world after treatment for oral cancer.	<ul style="list-style-type: none"> <li>• Swedish study.</li> <li>• Participants undergoing treatment.</li> <li>• Five patients (from an earlier study of seven (2 died)).</li> <li>• 2 women, 3 men. Median age 61 years.</li> <li>• Median time 4 years since starting treatment.</li> <li>• A “hermeneutic research approach was used to understand, explain, and interpret the transcribed interviews.” “Consequences of oral cancer affected the being-in-the-world of the participants in three ways: existing as oneself, existing in the eyes of others, and existing with others.”</li> <li>• “Against the background of the philosophy of Martin Heidegger, these findings illuminate how essential the mouth is to a human being’s identity and existence.”</li> <li>• This study required “a qualitative approach that focuses on human experience and subjectivity rather than objectivity.”</li> <li>• “Hermeneutics is both a way of being in the world and a method for interpretation of empirical data (Schuster, 2006).”</li> <li>• Very in-depth article but very open to interpretation by the interviewer.</li> </ul>
Ross, S. et al.	2010	Psychosocial adjustment of family caregivers of head and neck cancer survivors.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants were caregivers of patients who had completed treatment within 6-24 months.</li> <li>• 6-24 months post treatment.</li> </ul>

			<ul style="list-style-type: none"> <li>• 89 patients generated 174 family caregivers. Of these 59% (102) consented to participate (meaning 91% of patients were represented).</li> <li>• 65 female, 24 male.</li> <li>• 13 were excluded due to missing values.</li> <li>• 38% reported moderate to high distress.</li> <li>• Greater time spent caregiving was associated with worse psychological wellbeing, but more positive adaptation to caregiving.</li> <li>• 61% reported that not all of their practical and informational needs were being met.</li> <li>• Interesting study but should be used with caution due to limitations of sample.</li> </ul>
Scott, B. et al.	2013	The Patients Concerns Inventory in head and neck cancer: Comparison between self-completed paper and touch screen versions in the clinic setting.	<ul style="list-style-type: none"> <li>• N=105</li> <li>• No difference in whether people use paper or touchscreens.</li> <li>• Useful in study design and how people interact with healthcare.</li> </ul>
Semple, C. J. et al.	2008	Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer.	<ul style="list-style-type: none"> <li>• Northern Ireland based study.</li> <li>• Participants had completed treatment 6-12 months earlier.</li> <li>• "Semi structured interviews with a purposive sample of 10 participants who had completed treatment 6–12 months earlier for head and neck cancer."</li> <li>• "A thematic analysis was employed to interpret the findings."</li> <li>• "Seven broad themes were identified, five of which</li> </ul>

			<p>covered areas of changes and challenges to participants' lifestyles following treatment. These were: physical changes, concerns about cancer, work and day-to-day tasks, interpersonal relationships and social functioning."</p> <ul style="list-style-type: none"> <li>• "Specific posttreatment concerns and challenges cannot be viewed as unitary or discrete aspects of life, but should be considered within a biopsychosocial context, to address patients' needs holistically."</li> <li>• A very good article which identifies a number of important issues in the post-treatment phase.</li> </ul>
Semple, C. J. and McCance, T.	2010	Experience of parents with head and neck cancer who are caring for young children.	<ul style="list-style-type: none"> <li>• Northern Ireland based study looking at the experiences of patients caring for children during/post treatment.</li> <li>• Participants diagnosed in last 3 years.</li> <li>• 12 participants (10 male, 2 female)</li> <li>• Single interview with open ended questions</li> <li>• Data analysed with cognitive mapping</li> <li>• Importance of social networks</li> <li>• Changing roles: men felt less in control</li> <li>• Many were able to return to work, but priorities changed and many reported stronger emotional/family bonds as a result of the illness.</li> </ul>
Swore Fletcher, B. et al.	2012	A blessing and a curse: head and neck cancer survivors' experiences.	<ul style="list-style-type: none"> <li>• Looks at "survivors' experience of communication during and after treatment."</li> </ul>

			<ul style="list-style-type: none"> <li>• Participants between 2 and 24 months post primary treatment.</li> <li>• 39 participants (male/female split not identified)</li> <li>• Interview based with open ended questions.</li> <li>• Interviews analysed for thematic points.</li> <li>• “Two major themes were identified: “change in communication,” which included functional aspects of communication, and “going deeper into life,” which included the positive aspects of the process.”</li> <li>• USA, mainly white sample.</li> <li>• Themes identified based on personal experiences but little retrospective analysis of what may help others.</li> <li>• Authors possibly searching for positive aspects.</li> <li>• “Designing interventions that promote communication and emphasize positive connections in survivors’ lives will be a goal of future studies.”</li> </ul>
Threader, J. and McCormack , L.	2016	Cancer-related trauma, stigma and growth: the 'lived' experience of head and neck cancer.	<ul style="list-style-type: none"> <li>• Australian article.</li> <li>• Participants between 1-14 months post-surgery.</li> <li>• Found during lit review update.</li> <li>• N=9</li> <li>• IPA.</li> <li>• Not oropharyngeal ca specific – includes facial disfigurement.</li> <li>• Found stigma to be a factor which was not present in this study.</li> </ul>
Turner, J. ed.	2015	Engaging patients in survivorship care planning after completion of	<ul style="list-style-type: none"> <li>• Australian article.</li> <li>• Participants progress in treatment pathway is not specified.</li> </ul>

		treatment for head and neck cancer.	<ul style="list-style-type: none"> <li>• Found during lit review update.</li> <li>• Tied in to the ENHANCES study.</li> <li>• Advocates survivorship planning.</li> </ul>
Turner, J. et al.	2014	The ENHANCES study—Enhancing Head and Neck Cancer patients' Experiences of Survivorship: study protocol for a randomized controlled trial.	<ul style="list-style-type: none"> <li>• Preliminary study of 120 patients.</li> <li>• Participants progress in treatment pathway is not specified.</li> <li>• Stresses importance of managing adaptation in survivorship.</li> </ul>
Verdonck-de Leeuw, I. M. et al.	2007	Distress in spouses and patients after treatment for head and neck cancer.	<ul style="list-style-type: none"> <li>• Dutch study.</li> <li>• Participants had a mean interval to treatment of 29 months (range, 3-120)</li> <li>• 41 patient-spouse pairs completed the Hospital Anxiety and Depression Scale (HADS).</li> <li>• “A clinical level of distress was noted in 20% of the spouses and in 27% of the patients.”</li> <li>• “Distress in spouses was related to the presence of a feeding tube in patients, a passive coping style, less vitality, and a disrupted daily life schedule resulting from caregiving.”</li> <li>• “Distress in patients was related to the presence of a feeding tube, speech and swallowing problems, less social contacts, a passive style of coping, and nonexpression of emotions.”</li> <li>• “Distress is often present in spouses and patients treated for head and neck cancer. Routine screening for psychologic distress is recommended.”</li> </ul>

			<ul style="list-style-type: none"> <li>• Small scale study using only one questionnaire raises doubts of validity.</li> </ul>
Verdonck-de Leeuw, I. M. et al.	2010	Employment and return to work in head and neck cancer survivors.	<ul style="list-style-type: none"> <li>• Dutch study of 85 patients (response rate 75%).</li> <li>• Participants at least 2 years post treatment.</li> <li>• Patients younger than 65 years at time of diagnosis and at least 2 years after curative treatment for HNC were included.</li> <li>• Of the 53 patients who were employed at time of diagnosis, 44 patients returned to work (83%): 28 to the same work, 7 to adapted work and 9 to other work. Median time was 6 months to return to work (range 0–24 months) and 71% of the patient returned to work within 6 months after treatment.</li> <li>• Anxiety and oral dysfunction as xerostomia, trismus, sticky saliva, problems with teeth, and loss of appetite, problems with social eating and social contacts were significantly associated with employment after treatment.</li> <li>• Small study but valuable results.</li> </ul>
Vickery, L. E. et al.	2003	The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners.	<ul style="list-style-type: none"> <li>• UK study</li> <li>• Participants were 6-18 months post treatment (mean 11 months)</li> <li>• 28 surgery and radiotherapy/brachytherapy/chemoradiation patients and 25 of their partners were compared with 23 radiotherapy/brachytherapy patients and 19 partners. Participants completed the Hospital Anxiety and</li> </ul>

			<p>Depression Scale, Psychosocial Adaptation to Illness Scale, Dyadic Adjustment Scale, and European Organisation for Research and Treatment of Cancer Quality Of Life Scale, including the Head and Neck Cancer module. The Dropkin Disfigurement and Dysfunction scale classified surgical impairment.</p> <ul style="list-style-type: none"> <li>• Partners reported greater distress than patients on some scales.</li> <li>• Patients did not have a lower quality of life compared with normal populations and other cancer patients.</li> <li>• Average 11 months after treatment.</li> <li>• Interesting that their results disagree from the norm.</li> </ul>
Wells, M. et al.	2015	A national survey of healthcare professionals' views on models of follow-up, holistic needs assessment and survivorship care for patients with head and neck cancer.	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• Participants were between 3 months and 5 years post treatment.</li> <li>• Found during lit review update.</li> <li>• Online survey (43% response rate).</li> <li>• Nurses' and allied health professionals' views and practices in relation to follow-up, holistic needs assessment and survivorship care in this patient group.</li> <li>• Specialist staff were open to new models of care and to more responsibility, with adequate training and supervision.</li> <li>• Some specific areas of practice in which nurses lacked confidence, knowledge and skills, such as</li> </ul>

			managing medications and complex symptoms.
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What is known about HPV in head and neck cancer?			
Author(s)	Year of publication	Title	Summary
Andrews, E. et al.	2009	Oropharyngeal carcinoma in non-smokers and non-drinkers: a role for HPV.	<ul style="list-style-type: none"> <li>• Aetiological article on HPV.</li> <li>• 40 cases identified from 802 selected.</li> <li>• No participants – tissue samples only</li> <li>• Cases were 6.1 times more likely to have HPV infection in their tumours than controls.</li> <li>• High-risk HPV-DNA was readily detected in the tonsils</li> <li>• and base of tongue (oropharynx) of 14/18 cases and 6/22 controls. Of high-risk HPV containing lesions, 85% (17/20) originated in the oropharynx. High risk HPV was also detected in benign biopsies of the oropharynx in 30% (3/10) of individuals who had a previous oral cancer.</li> <li>• Good background material.</li> </ul>
Baxi, S. S. et al.	2013	Sharing a diagnosis of HPV-related head and neck cancer: The emotions, the confusion, and what patients want to know.	<ul style="list-style-type: none"> <li>• US study using semi-structured interviews.</li> <li>• Patients between 1 – 5 years post treatment.</li> <li>• Small sample n=10, generating depth of data.</li> <li>• “Physicians were a trusted source of</li> </ul>

			<p>information regarding HPV. Framing the diagnosis in terms of prognosis resonated with patients. The uncertainty about transmission, latency, and communicability coloured the dialogue about HPV. Despite some understanding of prevalence and transmission, patients worried about their partner's risk. Patients sought information about HPV on the internet, but it was not easily navigable. Emotional reactions to the diagnosis remained mostly cancer-centric rather than HPV-centric. A patient education handout was developed in response to patient questions."</p> <ul style="list-style-type: none"> <li>• Skewed by small pool of oncologists giving the information? Is this representative?</li> <li>• Useful based on information given by CNSs</li> </ul>
Beachler, D. C. and Dsouza, G.	2013	Oral human papillomavirus infection and head and neck cancers in HIV-infected individuals.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• Supports 2012 article and give more background detail.</li> <li>• Suggests that because HIV+ve pts are living longer due to advances in immunotherapy, they are at greater risk of HPV+ve HNC because</li> </ul>

			of the increased prevalence.
Beachler, D. C. et al.	2012	Risk factors for oral HPV infection among a high prevalence population of HIV-positive and at-risk HIV-negative adults.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Non-cancer participants.</li> <li>• Looks at possible links between HPV and HIV using oral rinses.</li> <li>• HPV elevated in HIV+ve pts. Cause or effect?</li> <li>• Common sexual risk factors?</li> <li>• HIV won't be a recruitment factor in this study so is it important? Useful for background discussion.</li> <li>• Does HPV carry a stigma of sexual transmission?</li> </ul>
Beaudenon, S. et al.	1986	A novel type of human papillomavirus associated with genital neoplasias.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Often cited article.</li> <li>• Provides background only due to the age of the article, but important nonetheless.</li> </ul>
Begum, S. et al.	2005	Tissue distribution of human papillomavirus 16 DNA integration in patients with tonsillar carcinoma.	<ul style="list-style-type: none"> <li>• N=176</li> <li>• HPV-16 was detected in 37 of 45 cancers arising from the oropharynx but in only 1 of 131 tumours arising from non-oropharyngeal sites.</li> <li>• Technical article.</li> <li>• Good evidence as to the aetiology and increases in incidence of HPV+ve HNC.</li> </ul>
Bisht, M. and Bist, S. S.	2011	Human papilloma virus: a new risk factor in a	<ul style="list-style-type: none"> <li>• Very important article – suggests that HPV status should help</li> </ul>

		subset of head and neck cancers.	<p>determine care pathway, as HPV+ve tumours respond to treatment better than HPV-ve ones.</p> <ul style="list-style-type: none"> <li>• Calls for all oropharyngeal cancers to be tested for HPV. This wasn't done in most centres at the start of the study!</li> </ul>
Bleyer, A.	2009	Cancer of the oral cavity and pharynx in young females: increasing incidence, role of human papilloma virus, and lack of survival improvement.	<ul style="list-style-type: none"> <li>• US data.</li> <li>• Questions changing sexual mores as a causative factor in HPV+ve HNC.</li> <li>• Does not relate findings to male population.</li> </ul>
Boing, A. F. et al.	2011	How much do smoking and alcohol consumption explain socioeconomic inequalities in head and neck cancer risk?	<ul style="list-style-type: none"> <li>• Brazilian case control study.</li> <li>• Participants are newly diagnosed.</li> <li>• N=1017 + 951 matched cases.</li> <li>• Fails to properly account for HPV factors. Does HPV have an impact in Brazil?</li> <li>• Caution over transferability to UK population.</li> </ul>
Boshart, M. et al.	1984	A new type of papillomavirus DNA, its presence in genital cancer biopsies and in cell lines derived from cervical cancer.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Seminal work.</li> <li>• Background article only due to age.</li> </ul>
Bowyer, H. L. et al.	2013	Knowledge and awareness of HPV and the HPV vaccine among young women in the first routinely vaccinated cohort in England.	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• Participants are not cancer survivors.</li> <li>• N=1033.</li> <li>• "About a fifth of the girls reported they were unaware of the</li> </ul>

			<p>HPV infection. Among those who reported being aware of HPV (<math>n = 759</math>) knowledge was relatively low. Approximately half of the participants knew that HPV infection causes cervical cancer, condoms can reduce the risk of transmission and that cervical screening is needed regardless of vaccination status.”</p> <ul style="list-style-type: none"> <li>• Important in establishing baseline knowledge.</li> </ul>
Chaturvedi, A. et al.	2011	Human papillomavirus (HPV) and rising oropharyngeal cancer incidence and survival in the United States.	<ul style="list-style-type: none"> <li>• US data.</li> <li>• No participants – tissue samples only.</li> <li>• Provides evidence to support the theory of HPV as the cause of increase in incidence.</li> <li>• Technical article.</li> </ul>
Chaturvedi, A. K.	2012	Epidemiology and clinical aspects of HPV in head and neck cancers.	<ul style="list-style-type: none"> <li>• “HPV-positive oropharyngeal cancer patients have substantially improved outcomes (28–80 % reductions in the risk of death) than HPV-negative patients. Given the superior survival, younger age, and good performance status of HPV-positive oropharyngeal cancer patients, de-intensified therapies are currently being considered for this group of patients.”</li> </ul>
Chaturvedi, A. K.	2014	Global burden of human papillomavirus-positive head and neck cancers.	<ul style="list-style-type: none"> <li>• Useful source of epidemiological data -</li> </ul>

			% of cases caused by HPV.
Chen, R. et al.	2005	Human papillomavirus type 16 in head and neck carcinogenesis.	<ul style="list-style-type: none"> <li>• PhD thesis – demonstrates access to grey literature.</li> <li>• No participants – tissue samples only.</li> <li>• Background on HPV – good supporting document.</li> </ul>
Chin, D. et al.	2006	Head and neck cancer: past, present and future.	<ul style="list-style-type: none"> <li>• Comprehensive overview of HPV+ve HNC, although now dated.</li> </ul>
Chu, A. et al.	2013	A patient-centred approach to counselling patients with head and neck cancer undergoing human papillomavirus testing: a clinician's guide.	<ul style="list-style-type: none"> <li>• Very relevant article – this is where the gap is!!</li> <li>• US authors.</li> <li>• No participants.</li> <li>• “Although there are currently few relevant studies focusing on this population, existing literature on HPV-infected women and patients with cervical cancer strongly supports the concept that patients with HPVOPC need education to optimally address concerns such as self-blame, guilt, intimacy, and interpersonal relationships. When HPV testing is done, it should be accompanied by evidence driven and patient-centred counselling to best minimize negative psychosocial outcomes and ensure optimum health promotion.”</li> </ul>

Cole, L. et al.	2012	Examining the incidence of human papillomavirus-associated head and neck cancers by race and ethnicity in the U.S., 1995-2005.	<ul style="list-style-type: none"> <li>Old data now but shows the increase in incidence of HPV – building the case.</li> </ul>
Cook, R. L. et al.	2014	Sexual behaviours and other risk factors for oral human papillomavirus infections in young women.	<ul style="list-style-type: none"> <li>US students.</li> <li>Participants not cancer patients.</li> <li>Supports the theory that HPV can be spread by sharing toothbrushes, smoking, as well as sexual activity.</li> <li>HPV can be difficult to detect – not definitive but supports other studies.</li> </ul>
D'Souza, G. and Dempsey, A.	2011	The role of HPV in head and neck cancer and review of the HPV vaccine.	<ul style="list-style-type: none"> <li>Overview of HPV and the case for vaccination.</li> <li>No participants.</li> <li>Useful data on epidemiology.</li> </ul>
D'Souza, G. et al.	2014	Oral Human Papillomavirus (HPV) Infection in HPV-Positive Patients with Oropharyngeal Cancer and Their Partners.	<ul style="list-style-type: none"> <li>US study.</li> <li>Patient participants treatment pathway progress not specified.</li> <li>Partner risk – something CNSs talked about. What to tell people?</li> <li>164 patients and 93 partners.</li> <li>Partners do not have elevated risk.</li> </ul>
D'Souza, G. et al.	2007	Case-control study of human papillomavirus and oropharyngeal cancer.	<ul style="list-style-type: none"> <li>Older study.</li> <li>Patient participants newly diagnosed.</li> <li>Evidence that oropharynx ca is strongly associated with HPV.</li> </ul>

D'Souza, G. et al.	2009	Oral Sexual Behaviours Associated with Prevalent Oral Human Papillomavirus Infection.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants not cancer survivors.</li> <li>• 332 control patients from an outpatient clinic and 210 male college students.</li> <li>• “Oral sex and open-mouthed kissing are associated with the development of oral HPV infection.”</li> <li>• Reinforces stigma that HPV is a sexually transmitted disease.</li> </ul>
Daley, E. et al.	2011	Exploring awareness, attitudes, and perceived role among oral health providers regarding HPV-related oral cancers.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants not cancer survivors.</li> <li>• 17 dentists and 21 hygienists.</li> <li>• Focus groups.</li> <li>• Supports opening up conversations about HPV with pts.</li> <li>• Caution over judgments and inaccurate information.</li> </ul>
De Villiers, E. M. et al.	1985	Papillomavirus DNA in human tongue carcinomas.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Seminal article – useful for background.</li> </ul>
Dhooge, I. J. et al.	1998	Multiple Primary Malignant Tumors in Patients With Head and Neck Cancer.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Old data but supports the “story” of HPV in HNC.</li> </ul>
Dietz, C. A. and Nyberg, C. R.	2011	Genital, oral, and anal human papillomavirus infection in men who have sex with men.	<ul style="list-style-type: none"> <li>• US review article.</li> <li>• No participants.</li> <li>• Interesting topic area, especially as boys are not offered the HPV vaccine in the UK.</li> </ul>

			<ul style="list-style-type: none"> <li>• Mixed messages about HPV being the cervical cancer cause.</li> <li>• Interesting and well written article.</li> </ul>
Dufour, X. et al.	2012	HPV and head and neck cancer.	<ul style="list-style-type: none"> <li>• French study (update).</li> <li>• Overview article.</li> <li>• No participants.</li> </ul>
Dürst, M. et al.	1983	A papillomavirus DNA from a cervical carcinoma and its prevalence in cancer biopsy samples from different geographic regions.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Early important article. Often cited.</li> <li>• Good for background and setting the scene.</li> </ul>
Evans, M. and Powell, N.	2010	The Changing Aetiology of Head and Neck Cancer: the Role of Human Papillomavirus.	<ul style="list-style-type: none"> <li>• Overview article.</li> <li>• No participants.</li> <li>• Supports the argument for more research into this patient population as it's set to continue growing for years to come.</li> </ul>
Fakhry, C. and Gillison, M. L.	2006	Clinical implications of human papillomavirus in head and neck cancers.	<ul style="list-style-type: none"> <li>• US review article.</li> <li>• No participants.</li> <li>• Better prognosis for HPV+ve HNC pts.</li> <li>• Different treatment regimens for these patients, resulting in fewer or less impactful side effects?</li> <li>• Does smoking change prognosis – evidence suggests the improved prognosis does not apply if someone smokes. Lacks some detail in this aspect.</li> </ul>
Finnigan, J. P., Jr. and Sikora, A. G.	2014	Counselling the patient with potentially HPV-related newly diagnosed head and neck cancer.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• “Maintain a balance between making recommendations</li> </ul>

			<p>based on the best available scientific evidence and acknowledgment of uncertainty for both patients and providers. We anticipate that both the standard-of-care diagnostic workup and treatment, and counselling guidelines for these patients will change rapidly in the years ahead, as data from ongoing and planned prospective clinical trials become available.”</p> <ul style="list-style-type: none"> <li>• Strong on clinical applications.</li> <li>• Does this reflect what is happening now in the UK?</li> <li>• This could make the difference between positive and negative adaptation post-treatment.</li> </ul>
Gillison, M. L.	2009	Oropharyngeal cancer: a potential consequence of concomitant HPV and HIV infection.	<ul style="list-style-type: none"> <li>• US meta-analysis.</li> <li>• No participants.</li> <li>• “Patients with HPV-positive oropharyngeal cancers were estimated to have a 28% (HR 0.72, 95% CI 0.5–1.0) reduced risk of death and a 49% (HR 0.51, 95% CI 0.4–0.7) reduced risk of disease failure when compared to patients with HPV-negative oropharyngeal cancers.”</li> <li>• <b>“In most of these studies, the 5-year overall survival for the</b></li> </ul>

			<p><b>HPV-positive patient is approximately 80–85% and for the HPV-negative patient between 30 and 35%.”</b></p> <ul style="list-style-type: none"> <li>• Older data but very interesting results and important clinical implications.</li> </ul>
Giuliano, A. R. et al.	2008	Epidemiology of human papillomavirus infection in men, cancers other than cervical and benign conditions.	<ul style="list-style-type: none"> <li>• Summary article.</li> <li>• No participants.</li> <li>• Background on HPV and clinical implications.</li> <li>• Supports vaccination for boys.</li> <li>• Useful as a supporting reference.</li> </ul>
Gold, D.	2012	The Psychosocial Care Needs of Patients with HPV-Related Head and Neck Cancer.	<ul style="list-style-type: none"> <li>• Overview of the field from diagnosis to survivorship and recurrence.</li> <li>• No participants.</li> <li>• HPV+ pts are more likely to suffer distress and anxiety compared with other H+N pts.</li> <li>• Issues around sexual history and future practices are more apparent. More relationship stressors?</li> <li>• Younger pts so more likely to be employed, have financial commitments and young families.</li> <li>• Stresses the importance of realistic preparation for recovery.</li> <li>• Oncology social workers may be ideally placed to provide support in the long-term.</li> </ul>

Goon, P. K. et al.	2009	HPV & head and neck cancer: a descriptive update.	<ul style="list-style-type: none"> <li>• UK-German overview article.</li> <li>• No participants.</li> <li>• Supports individualised treatment pathways.</li> <li>• Pros and cons of Cetuximab.</li> </ul>
Hashibe, M. et al.	2007	Alcohol drinking in never users of tobacco, cigarette smoking in never drinkers, and the risk of head and neck cancer: pooled analysis in the International Head and Neck Cancer Epidemiology Consortium.	<ul style="list-style-type: none"> <li>• “15 case-control studies that included 10244 head and neck cancer case subjects and 15227 control subjects, of whom 1072 case subjects and 5775 control subjects were never users of tobacco and 1598 case subjects and 4051 control subjects were never drinkers of alcohol.”</li> <li>• No participants.</li> <li>• “Among never drinkers, cigarette smoking was associated with an increased risk of head and neck cancer (OR for ever versus never smoking = 2.13, 95% CI = 1.52 to 2.98), and there was clear dose-response relationships for the frequency, duration, and number of pack-years of cigarette smoking. Approximately 24% (95% CI = 16% to 31%) of head and neck cancer cases among non-drinkers in this study would have been prevented if these individuals had not smoked cigarettes. Among never users of</li> </ul>

			<p>tobacco, alcohol consumption was associated with an increased risk of head and neck cancer only when alcohol was consumed at high frequency (OR for three or more drinks per day versus never drinking = 2.04, 95% CI = 1.29 to 3.21)."</p> <ul style="list-style-type: none"> <li>• Useful epidemiological data.</li> </ul>
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.	<ul style="list-style-type: none"> <li>• "Data from 17 European and American case-control studies (11,221 cases and 16,168 controls)."</li> <li>• No participants.</li> <li>• "A greater than multiplicative joint effect between ever tobacco and alcohol use was observed for head and neck cancer risk. The population attributable risk (PAR) for tobacco or alcohol was 72% (95% confidence interval, 61-79%) for head and neck cancer, of which 4% was due to alcohol alone, 33% was due to tobacco alone, and 35% was due to tobacco and alcohol combined. The total PAR differed by subsite (64% for oral cavity cancer, 72% for pharyngeal cancer, 89% for laryngeal cancer), by sex (74% for men, 57% for women), by age (33% for cases &lt;45 years,</li> </ul>

			<p>73% for cases &gt;60 years), and by region (84% in Europe, 51% in North America, 83% in Latin America)."</p> <ul style="list-style-type: none"> <li>• Useful statistical source involving large numbers of participants.</li> </ul>
Heffernan, C. B. et al.	2010	Oncogenic impact of human papilloma virus in head and neck cancer.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• Useful for supporting reference.</li> <li>• Lacking any new insights.</li> </ul>
Herrero, R. et al.	2003	Human papillomavirus and oral cancer: the International Agency for Research on Cancer multicenter study.	<ul style="list-style-type: none"> <li>• Old data.</li> <li>• Patient participants contacted before any cancer treatment.</li> <li>• Useful for scene setting.</li> <li>• 1670 case patients and 1732 control subjects.</li> <li>• Supports the case for HPV in HNC – early study.</li> </ul>
Hibbitts, S. et al.	2014	UK population based study to predict impact of HPV vaccination.	<ul style="list-style-type: none"> <li>• Prospective cohort study.</li> <li>• Participants contacted on their first call for cervical screening.</li> <li>• "13,306 samples tested, 3545 (26.6%) were confirmed positive for at least one hrHPV type and 1325 (10%) were positive for low risk HPV."</li> <li>• "Prior to the introduction of the HPV vaccine, approximately one-quarter of young women were positive for hrHPV and one-</li> </ul>

			<p>tenth positive for HPV16. Post-vaccination, we anticipate a substantial absolute risk reduction in high-grade cervical disease associated with both targeted and non-targeted hrHPV types. There is no significant difference between the two commercially available vaccines in terms of clinical impact."</p> <ul style="list-style-type: none"> <li>• Useful information on the 2 types of vaccine.</li> </ul>
Hobbs, C. G. L. et al.	2006	Human papillomavirus and head and neck cancer: a systematic review and meta-analysis.	<ul style="list-style-type: none"> <li>• Systematic review and meta-analysis.</li> <li>• No participants.</li> <li>• UK study.</li> <li>• The association between HPV16 and cancer was strongest for tonsil (often included in oropharynx), intermediate for oropharynx and weakest for oral and larynx.</li> <li>• Highlights problems in testing for HPV and anatomical delineation of sights.</li> </ul>
Isayeva, T. et al.	2012	Human papillomavirus in non-oropharyngeal head and neck cancers: a systematic literature review.	<ul style="list-style-type: none"> <li>• Systematic literature review.</li> <li>• No participants.</li> <li>• "The published data strongly support the need for studies on patients with oral and laryngeal carcinomas that will be powered to find any differences in clinical outcome</li> </ul>

			<p>with respect to HR-HPV and p16 overexpression."</p> <ul style="list-style-type: none"> <li>• Broadly supports other similar studies.</li> <li>• Ageing data.</li> </ul>
Joseph, A. W. and D'Souza, G.	2012	Epidemiology of Human Papillomavirus-Related Head and Neck Cancer.	<ul style="list-style-type: none"> <li>• Useful epidemiological data.</li> <li>• No participants.</li> <li>• Ageing data – seek newer references when writing up.</li> </ul>
Kreimer, A. R. et al.	2005	Human papillomavirus types in head and neck squamous cell carcinomas worldwide: A systemic review.	<ul style="list-style-type: none"> <li>• Systematic review.</li> <li>• No participants.</li> <li>• N=5046 from 60 studies.</li> <li>• Ageing data – scene setting.</li> </ul>
Kwan, T. T. et al.	2011	Psychological burden of testing positive for high-risk human papillomavirus on women with atypical cervical cytology: a prospective study.	<ul style="list-style-type: none"> <li>• Hong Kong study.</li> <li>• Chinese women n=299.</li> <li>• "HPV positivity may pose a prolonged psychosocial burden on women even after having had the necessary follow-up for their cervical abnormalities."</li> <li>• Cultural differences – can this be translated to UK population?</li> <li>• Authors acknowledged that anxiety decreases over time, regardless of HPV status.</li> </ul>
Lassen, P.	2010	The role of Human papillomavirus in head and neck cancer and the impact on radiotherapy outcome.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• "Despite having advanced disease due to nodal involvement, patients with HPV-positive tumours have markedly superior outcome compared to the HPV-negative</li> </ul>

			<p>patients, both in terms of tumour control and survival.”</p> <ul style="list-style-type: none"> <li>• Really important aspect of HPV is the positive prognosis – could this affect experience?</li> </ul>
Li, X. et al.	2013	Human papillomavirus infection and laryngeal cancer risk: a systematic review and meta-analysis.	<ul style="list-style-type: none"> <li>• Systematic review and meta-analysis.</li> <li>• No participants.</li> <li>• 55 eligible studies were included. The overall HPV prevalence in laryngeal cancer tissues was 28.0%.</li> <li>• The meta-analysis based on 12 eligible case-control studies suggests a strong association between HPV infection and laryngeal squamous cell carcinoma.</li> <li>• Most studies focus on HPV and oropharyngeal cancer, so this is interesting.</li> </ul>
Löning, T. et al.	1985	Analysis of oral papillomas, leukoplakias, and invasive carcinomas for human papillomavirus type related DNA.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• No participants.</li> <li>• Often cited article.</li> <li>• Useful for background.</li> </ul>
Lorincz, A. T. et al.	1987	Oncogenic association of specific human papillomavirus types with cervical neoplasia.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• No participants.</li> <li>• Often cited article.</li> <li>• Useful for background.</li> </ul>
Markowitz, L. E. et al.	2007	Quadrivalent human papillomavirus vaccine.	<ul style="list-style-type: none"> <li>• US article.</li> <li>• No participants.</li> <li>• Overview of Gardasil, and its clinical implications (USA only).</li> </ul>

Marur, S. et al.	2010	HPV-associated head and neck cancer: a virus-related cancer epidemic.	<ul style="list-style-type: none"> <li>• Review article.</li> <li>• No participants.</li> <li>• Good overview.</li> <li>• "Epidemic" – implications for research and clinicians for years to come.</li> <li>• Population group needs studying.</li> </ul>
Marur, S. and Forastiere, A. A. eds.	2008	Head and neck cancer: changing epidemiology, diagnosis, and treatment.	<ul style="list-style-type: none"> <li>• Literature review.</li> <li>• No participants.</li> <li>• Good overview.</li> <li>• Articles up to 2007 – ageing data.</li> </ul>
McCaffery, K. et al.	2004	Testing positive for human papillomavirus in routine cervical screening: examination of psychosocial impact.	<ul style="list-style-type: none"> <li>• UK study.</li> <li>• n=428 aged 20–64 years.</li> <li>• Postal questionnaire survey.</li> <li>• "The findings suggest that testing positive for HPV may have an adverse psychosocial impact, with increased anxiety, distress and concern about sexual relationships."</li> <li>• Suffers from the usual postal questionnaire problems.</li> </ul>
Münger, K. and Howley, P. M.	2002	Human papillomavirus immortalization and transformation functions.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• No participants.</li> <li>• Often cited technical article.</li> </ul>
Näsman, A. et al.	2009	Incidence of human papillomavirus (HPV) positive tonsillar carcinoma in Stockholm, Sweden: An epidemic of viral-induced carcinoma?	<ul style="list-style-type: none"> <li>• Rise of oropharyngeal cancer (HPV+ve) is not a country-specific phenomenon.</li> <li>• No participants, tissue samples only.</li> <li>• Worldwide implications.</li> </ul>
O'Rorke, M. A. et al.	2012	Human papillomavirus related head and neck	<ul style="list-style-type: none"> <li>• UK based authors.</li> <li>• No participants.</li> </ul>

		cancer survival: A systematic review and meta-analysis.	<ul style="list-style-type: none"> <li>• Meta-analysis.</li> <li>• 42 studies.</li> <li>• "Patients with HPV-positive HNSCC had a 54% better overall survival compared to HPV-negative patients"</li> </ul>
Osterweil, N.	2013	Partners not at higher risk for HPV-related head and neck cancers.	<ul style="list-style-type: none"> <li>• Supports findings of Marur.</li> </ul>
Palefsky, J. M	2007	HPV infection in men.	<ul style="list-style-type: none"> <li>• US overview article.</li> <li>• No participants.</li> <li>• Links between HPV and HIV infection in men.</li> <li>• Supports HPV vaccine for men and boys.</li> <li>• More investigation needed for how to test for HPV.</li> </ul>
Pomfret, T. C. et al.	2011	Quadrivalent human papillomavirus (HPV) vaccine: a review of safety, efficacy, and pharmacoeconomics.	<ul style="list-style-type: none"> <li>• Technical article.</li> <li>• No participants.</li> <li>• Background.</li> </ul>
Romanitan, M. et al.	2008	Human papillomavirus frequency in oral and oropharyngeal cancer in Greece.	<ul style="list-style-type: none"> <li>• Highlights the impact of HPV across countries and cultures.</li> <li>• No participants.</li> </ul>
Schantz, S. P. and Yu, G.-P.	2002	Head and neck cancer incidence trends in young Americans, 1973-1997, with a special analysis for tongue cancer.	<ul style="list-style-type: none"> <li>• Found using snowballing.</li> <li>• Background.</li> <li>• Pre-dates sudden increase in incidence due to HPV.</li> </ul>
Shuman, A. G. and Wolf, G. T.	2010	Human papillomavirus status in head and neck cancer: the ethics of disclosure.	<ul style="list-style-type: none"> <li>• Commentary article.</li> <li>• No participants.</li> <li>• HPV status indicates a better prognosis but with same treatment pathway what is the point of testing?</li> <li>• If you test for it, you need to be</li> </ul>

			<p>transparent about the results.</p> <ul style="list-style-type: none"> <li>• Very interesting article.</li> </ul>
Sinha, P. et al.	2012	Human papillomavirus, smoking, and head and neck cancer.	<ul style="list-style-type: none"> <li>• Literature review.</li> <li>• No participants.</li> <li>• "smoking tobacco posing an additional risk for development of head and neck cancer in the presence of HPV infection. This is consistent with available laboratory data that show evidence of biological plausibility for interaction between smoking and progression of HPV infection to carcinogenesis. It is therefore important that cessation of smoking is promoted in smokers with HPV infection."</li> </ul>
Syrjänen, K. et al.	1982	Squamous cell papilloma of the esophagus: a tumour probably caused by human papilloma virus (HPV).	<ul style="list-style-type: none"> <li>• Seminal and often cited article.</li> <li>• Supporting literature.</li> <li>• Found through snowballing.</li> </ul>
Syrjänen, K. et al.	1983	Morphological and immunohistochemical evidence suggesting human papillomavirus (HPV) involvement in oral squamous cell carcinogenesis.	<ul style="list-style-type: none"> <li>• Seminal and often cited article.</li> <li>• Supporting literature.</li> <li>• Found through snowballing.</li> </ul>
Weinberger, P. M. et al.	2010	Human papillomavirus-active head and neck cancer and ethnic health disparities.	<ul style="list-style-type: none"> <li>• US study.</li> <li>• Participants were at various stages of treatment pathway.</li> <li>• N=140.</li> </ul>

			<ul style="list-style-type: none"> <li>• HPV+ve tumours are less common in black participants with HNC.</li> <li>• Differences in sexual norms and alcohol/tobacco usage?</li> </ul>
Weinstock, H. et al.	2004	Sexually transmitted diseases among American youth: incidence and prevalence estimates, 2000.	<ul style="list-style-type: none"> <li>• Estimate of incidence, limited by ageing data.</li> <li>• No participants.</li> <li>• Highlights changing sexual mores.</li> </ul>
Wise-Draper, T. M. et al.	2012	Future directions and treatment strategies for head and neck squamous cell carcinomas.	<ul style="list-style-type: none"> <li>• Overview of possible future strategies including targeted treatments and reduced radiations doses.</li> <li>• No participants.</li> </ul>
ZurHausen, H.	1976	Condylomataacuminata and human genital cancer.	<ul style="list-style-type: none"> <li>• Seminal and often cited article.</li> <li>• Supporting literature.</li> <li>• Found through snowballing.</li> </ul>
ZurHausen, H. et al.	1974	Attempts to detect virus-specific DNA in human tumors. I. Nucleic acid hybridizations with complementary RNA of human wart virus.	<ul style="list-style-type: none"> <li>• Seminal and often cited article.</li> <li>• Supporting literature.</li> <li>• Found through snowballing.</li> </ul>



## Appendix C – REC for Wales confirmation of ethical approval

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.  
Yn rhwng o seilwaith ymchwil Cymru ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



**Research Ethics Committee for Wales**  
Sixth Floor, Churchill House  
17 Churchill Way  
Cardiff CF10 2TW

Telephone : 029 2037 6829  
Fax : 029 2037 6824  
E-mail : corinne.scott@wales.nhs.uk  
Website : www.nres.nhs.uk

18 February 2014

Mr David Evans  
PhD student/Therapeutic Radiographer  
Cardiff University  
Room 702a, 7th floor, Eastgate House  
35-43 Newport Road  
Cardiff CF24 0AB

Dear Mr Evans

**Study title:** The experiences of people who have been treated for oropharyngeal cancer.  
**REC reference:** 14/WA/0013  
**Protocol number:** SPON 1373-13  
**IRAS project ID:** 127176

Thank you for your letter of 12 February 2014, 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, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Dr. Corinne Scott, corinne.scott@wales.nhs.uk.

### Confirmation of ethical opinion

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

### Ethical review of research sites

#### NHS sites

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

#### Conditions of the favourable opinion

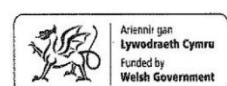
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys  
The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

**Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly 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 contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	IRAS covering letter v.1	11 December 2013
GP/Consultant Information Sheets	v1	01 July 2013
Interview Schedules/Topic Guides	v1	16 December 2013
Investigator CV	David Evans (short version)	11 December 2013
Investigator CV	Sally Anstey; no version or date	
Investigator CV	Jane Hopkinson; no version or date	
Letter from Sponsor	signed Dr KJ Pittard-Davies, Cardiff University	17 December 2013
Letter of invitation to participant	First contact v1	01 September 2013
Letter of invitation to participant	Second contact v1	01 September 2013
Other: Expression of interest form	v1	01 July 2013
Other: Emails supporting project	From Audrey Cook, Gloucester NHS; and Petra Jankowska, Taunton and Somerset NHS Foundation Trust	
Participant Consent Form	version no 2.0	15 January 2014
Participant Information Sheet	version no 2.0	15 January 2014
Protocol	1.0	07 November 2013
Questionnaire	v1	01 July 2013
REC application	signed electronically by Mr. Evans; electronically by Helen Falconer, sponsor's representative; electronically by Sally Anstey and Jane Hopkinson, academic supervisors	18 December 2013

Referees or other scientific critique report	SONMS Review and Ethics Screening Committee feedback; signed Liz Harmer Griebel	18 December 2013
Response to Request for Further Information	Letter from David Evans	12 February 2014

**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 NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

**Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**14/WA/0013**

**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

pp Dr. Pete Wall  
Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Helen Falconer  
Mr Thomas Llewellyn, Gloucestershire Hospitals NHS Foundation Trust



## Appendix D – Approval letter from Northtown R&D department

Our R&D ref: 14/028 [REDACTED]

Wednesday, 09 April 2014

Mr David Evans  
PhD Student  
School of Health Sciences  
Cardiff University  
7<sup>th</sup> Floor, Eastgate House  
35-43 Newport Road  
Cardiff  
CF24 0AB

Dear Mr Evans,

**Study title:** The experiences of people who have been treated for oropharyngeal cancer.  
**REC reference:** 14/WA/0013  
**IRAS reference:** 127176

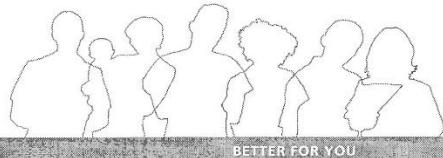
Thank you for forwarding information on the above study. I can confirm the approval of [REDACTED] for the above study to proceed.

Your project will now be added to the [REDACTED] Research Register which will identify the following:

- |                             |                    |
|-----------------------------|--------------------|
| • Chief Investigator(s)     | As above           |
| • Principal Investigator(s) | As above           |
| • Sponsoring Organisation:  | Cardiff University |
| • Host Organisation:        | [REDACTED]         |
| • Type of Study:            | PhD                |

It is important that all research conducted with NHS patients and/or staff complies with the Research Governance Framework. We would advise you to notify us at the above address, quoting our reference number for your study with regards to the following information.

- **Protocol Changes/Amendments to the study**



- Change of Principal Investigator/local Research Team at site
- Untimely closure of study
- Final study closure date
- Final recruitment figure of study

In relation to this I would like to take the opportunity to remind you of some of your responsibilities under this framework.

1. **Health and safety:** You are reminded of your responsibilities for health and safety at work under the Health and Safety at Work Act 1974. You have a legal responsibility to take care of your own and other people's Health and Safety at work under the Health and Safety at Work ACT 1974 as amended and associated legislation. These include the duty to take reasonable care to avoid injury to yourself and to others by your work activities or omissions, and to co-operate with your employer in the discharge of its statutory duties. You must adhere strictly to the policies and procedures on health and safety.
2. **Codes of confidentiality/Data Protection:** Anybody who records patient information (whether on paper or by electronic means) has a responsibility to take care to ensure that the data recorded is accurate, timely and as complete as possible. It is vital that you conduct your research in accordance with the principles of the Data Protection Act 1998 and codes of confidentiality.
3. **Liability and Indemnity:** Indemnity for your study will be as described in any applicable Clinical Trial Agreement or other Research Contract.  
Where such an agreement is not available, the Trust will indemnify its employees and researchers holding NHS Honorary Contracts for the purposes of Negligent Harm.  
NHS Trusts cannot provide cover for No Fault or Non-Negligent claims. Where this is required, it is expected that the Research Sponsor will provide such indemnity.
4. **Intellectual Property:** Intellectual Property is defined as the tangible output of any intellectual activity that is new or previously undescribed. It can include the following:
  - i. Inventions, such as new medical devices, software;
  - ii. Literary works, such as software, patient leaflets, journal articles;
  - iii. Designs and drawings, such as posters, leaflets;
  - iv. Brand names, such as logos and trademarks; and
  - v. Trade secrets, such as surgical techniques.

For projects originating from outside of the NHS Trust with which this agreement is made, Intellectual Property rights will remain with the Lead Site/Investigator unless developed from observations made outside of the scope and influence of the project. The rights to Intellectual Property generated in such a fashion will remain with the Host Trust unless an agreement to the contrary has been signed by both parties. Where a Clinical Trial Agreement or other Contract exists, this will take priority over this clause.

5. **Adverse Events/Incidents:** Any adverse events you witness or suspect to have happened *must* be reported to your supervisor or manager as soon as you know about them and dealt with as described in the research protocol.
6. **Fraud and Misconduct:** Any suspicions of active fraud or misconduct *must* be reported to your supervisor or manager immediately and will be treated in the strictest confidence. The monitoring of research will also seek to reduce incidents of research misconduct and fraud.
7. **Monitoring:** As part of the Research Governance Framework, during the course of your research you may be monitored to ensure that procedures in the protocol approved by the ethics committee are being adhered to. For locally sponsored studies this will be undertaken by the R&D Office. For externally sponsored studies this is likely to be arranged by the appropriate sponsor.

8. **Dissemination:** The Framework also requires the dissemination of research findings to the research subjects, NHS staff and the public. On completion of your research you will be expected to produce a summary of the project and an indication of how the results from the study will be disseminated. For studies where publication of research results is not the responsibility of the local Investigator, requests for such information will be made to the sponsor.
9. **Termination of Agreement:** The Trust also reserve the right to terminate the agreement for your research to proceed if, at any time, you are found to be in breach of the clauses in this Approval Letter or fail to adequately meet the requirements of the Research Governance Framework.

The documents we reviewed in relation to this study are listed on the REC Favourable Opinion letter(s):

- Original REC favourable Opinion Letter dated 18<sup>th</sup> February 2014

If you need any further support or information, please do not hesitate to contact us at the above address, quoting our reference number for your study.

I wish you every success with your project.

Yours sincerely,

Research & Development Manager

Cc: via email:

Dr Sally Anstey\_Cardiff University  
Professor Jane Hopkinson\_Cardiff University



## Appendix E – Approval letter from Southtown R&D department

COPY **NHS**

Mr D Evans  
PhD Student/Therapeutic Radiographer  
Cardiff University  
Room 702a, 7<sup>th</sup> Floor  
Eastgate House  
35-43 Newport Road  
CARDIFF CF24 0AB

14 May 2014

Dear Mr Evans

**RE: THE EXPERIENCES OF PEOPLE WHO HAVE BEEN TREATED FOR OROPHARYNGEAL CANCER (2364) [S]**

The R&D [REDACTED] considered this project at its meeting on 9 May 2014 and on behalf of [REDACTED] was happy to grant it approval.

Approval is given subject to the following standard conditions:

- a) Compliance with conditions specified by Ethics Committee(s)
- b) All amendments to the project to be notified to the R&D [REDACTED]
- c) Full co-operation with requests for information for monitoring purposes, including possible audit of the project to assess compliance with research governance standards
- d) There is an intention to publish, whatever the results
- e) Notification of local study specific SAEs (Serious Adverse Events) and SUSARs (Suspected Unexpected Serious Adverse Reactions) to the R&D Executive Group
- f) Compliance with the Research Governance Framework for Health and Social Care (For information and guidance on the Research Governance Framework for England, please see - [www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopment/123/ResearchGovernance/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopment/123/ResearchGovernance/fs/en))
- g) Uploading of recruitment information to the [REDACTED] management system is a condition of R&D approval. It is the PI's responsibility to ensure that recruitment to trials is entered directly onto [REDACTED] by a member of the research team at the time of participant recruitment. The Department of Clinical Research will provide access, training and monthly monitoring reports to help support this. Please ensure that you have provided the email addresses of all relevant team members who require access to the trial information on [REDACTED] and that you have identified the person responsible for recording this information.

Please note you must contact us for a letter of access prior to visiting this site ([REDACTED] NHS Foundation Trust) to conduct any face-to-face interviews.

[REDACTED]  
Page 1 of 2

Yours sincerely



cc. Professor J Hopkinson, Professor of Nursing, Cardiff University School of Healthcare Sciences,  
Room 501, 5<sup>th</sup> Floor, Eastgate House, 35-43 Newport Road, CARDIFF CF24 0AB  
A smaller black rectangular redaction box covering the address details.

## Appendix F - Participant invitation letter (first contact)

<p>School of Health Care Sciences Head of School and Dean Professor Sheila Hunt</p> <p><b>Ysgol Gwyddorau Gofal Iechyd</b> <i>Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt</i></p>		<p><b>CARDIFF</b> UNIVERSITY</p> <p><b>PRIFYSGOL</b> <b>CAERDYDD</b></p>
		<p>Cardiff University Eastgate House Room 702a, 7<sup>th</sup> Floor 35 – 43 Newport Road Cardiff CF24 0AB</p> <p>Tel Ffon: +44 (0)7443 505428 Email E-bost: evansdr1@cardiff.ac.uk</p>
		<p>Prifysgol Caerdydd 7<sup>th</sup> Llawn Ty Eastgate 35 – 43 Heol Casnewydd Caerdydd CF24 0AB</p>
<p>Date</p> <p><b>Study title:</b> The experiences of people who have been treated for oropharyngeal cancer. <b>REC reference number:</b> 14/WA/0013</p> <p>Dear [Redacted]</p> <p>I would like to invite you to take part in a PhD research project which will look at the experiences of people like you who have been treated for cancer of the oropharynx.</p> <p>Enclosed is an information sheet explaining more about the study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. I would be happy to meet with you to go through the information sheet and answer any questions you may have.</p> <p>Participation is completely voluntary. If you think you might be interested in taking part, or would like to chat to someone to explain more about the study, please return the <u>Expression of Interest</u> form in the prepaid envelope or phone 07443 505428.</p> <p>Kind regards,</p> <p>David Evans</p>		
<p><b>Participant invitation letter first contact date of issue:</b> 01/09/2013 <b>Participant invitation letter first contact version number:</b> v.1</p>		



## Appendix G - Participant invitation letter (second contact)

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt  
  
*Ysgol Gwyddorau Gofal Iechyd*  
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



Cardiff University  
Eastgate House  
Room 702a, 7<sup>th</sup> Floor  
35 – 43 Newport Road  
Cardiff CF24 0AB

Tel Ffur: +44 (0)7443 505428  
Email E-bost: evansdr1@cardiff.ac.uk

Prifysgol Caerdydd  
7<sup>th</sup> Llawn  
Ty Eastgate  
35 – 43 Heol Casnewydd  
Caerdydd CF24 0AB

Date

Study title: The experiences of people who have been treated for oropharyngeal cancer.

REC reference number: 14/WA/0013

Dear

Two weeks ago you were sent a letter inviting you to take part in a PhD research project which will look at the experiences of people who have been treated for cancer of the oropharynx.

This is a reminder letter that, should you wish to take part, you should complete and return the Expression of Interest form in the prepaid envelope enclosed, or phone 07443 505428. If I do not hear from you within two weeks it will be assumed that you do not wish to take part and you will not receive any further information.

Participation is completely voluntary. If you think you might be interested in taking part, or would like to chat to someone to explain more about the study, please return the Expression of Interest form in the prepaid envelope or phone 07443 505428.

Kind regards,

David Evans

Participant invitation letter second contact date of issue: 01/09/2013  
Participant invitation letter second contact version number: v.1



## Appendix H - Participant information sheet

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt*



REC for Wales reference number: 14/WA/0013

### Information Sheet

Study title: The experiences of people who have been treated for oropharyngeal cancer.

I would like to invite you to take part in a research study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. I would be happy to meet with you to go through the information sheet and answer any questions you may have.

Talk to others about the study if you wish. Ask me if there is anything that is not clear.

**What will the study involve?** I plan to interview people who have been treated for cancer of the oropharynx (the part that connects the mouth to the top of the throat). I will be doing this to gain a better understanding of how people experience cancer and life after treatment. The information I collect may help people who are diagnosed with oropharyngeal cancer in the future.

**What will happen to me if I take part?** If you decide to take part, I will meet with you to discuss your experience of cancer. With your permission I will record our conversation (audio only). We can meet in your home or another agreed location. Our conversation will not last longer than 2 hours.

**Why have I been asked to take part?** You have been asked because you have been treated for cancer of the oropharynx within the past five years.

**Do I have to take part?** You can choose whether or not you take part in the study. If you do decide to take part you are free to withdraw at any time and without giving a reason. Your decision will not affect the care or treatment that you receive in any way. You can withdraw from the study by contacting me by post, phone or email (see below for contact details).

**Will my participation in the study be kept confidential?** Yes. All information that is collected about you during the course of the research will be kept strictly confidential. Any information collected about you will have your name and address removed so that you cannot be recognised from it. It will not be possible to identify you in the research results or in any other publication of the study findings.

**What will happen to the information which I give?** The information you give will be kept confidential for the duration of the study. After the study is finished, Cardiff University will securely keep the data for a further fifteen years before it is destroyed.

**What will happen to the results?** The results will be presented in a PhD submission. The findings of the study may be published in journals or online.

**What are the possible advantages of taking part?** Some people may feel that talking about their experiences actually helps them in making sense of what has happened. The purpose of the study is to help people who will be diagnosed with cancer of the oropharynx in the future.

**What are the possible disadvantages of taking part?** There shouldn't be any disadvantages for you in taking part. It is possible that talking about your experience in this way may cause some distress. The Supportive Services document (enclosed with this information sheet) has advice on where to find additional support. Additional copies of the Supportive Services document can be obtained from me at any time.

**What if there is a problem?** If, after the interview you feel that you need additional support you can speak to me or your Clinical Nurse Specialist. Alternatively you can refer to the Supportive Services document.

**What if I have a complaint about the study?** If you have a concern about any aspect of this study, please contact me and I will try to answer your questions (phone 07443 505428). If you remain unhappy and wish to complain formally, you can do this by contacting the Research Governance Officer at Cardiff University, Helen Falconer, at Research, Innovation and Enterprise Services, Cardiff University, 7th Floor, 30-36 Newport Road, Cardiff, CF24 0DE. Email: [falconerhe@cardiff.ac.uk](mailto:falconerhe@cardiff.ac.uk). Telephone: 02920 879277.

**Who has reviewed this study?** The study has been examined by Cardiff University School of Healthcare Sciences Research Review and Ethics Screening Committee (RRESC), NHS National Research Ethics Committee (REC for Wales), and Research and Development Support Units at both Gloucestershire Hospitals NHS Foundation Trust and Taunton & Somerset NHS Foundation Trust.

**Any further queries?** If you need any further information, you can contact me: David Evans, 702a, 7th Floor, EastGate House, 35-43 Newport Road Cardiff. CF24 0AB. Email: [EvansDR1@cardiff.ac.uk](mailto:EvansDR1@cardiff.ac.uk). Phone: 07443 505428.

If you think you might be interested in taking part, or would like to chat to someone to explain more about the study, please return the Expression of Interest form in the prepaid envelope, or you can phone 07443 505428 or email [evansdr1@cardiff.ac.uk](mailto:evansdr1@cardiff.ac.uk).

## Appendix I - Expression of interest form

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt

*Ysgol Gwyddorau Gofal Iechyd*  
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



REC reference number: 14/WA/0013

### EXPRESSION OF INTEREST FORM

**Title of Project:** The experiences of people who have been treated for oropharyngeal cancer.

**Name of Researcher:** Mr David Evans

Please initial all boxes

1. I confirm that I have read the information sheet dated 15/01/2014 (version 2) for the above study.
2. I wish to know more about the study and agree to be contacted by the study's principle investigator.
3. I understand that I will be free to ask questions or refer to someone else before consenting to take part in the study.
4. I understand that I am not under any obligation to participate in the study and may decline to participate at any point.
5. I understand that my personal details will be kept confidential and will not be passed on to any person or agency outside of the study.

**Name:** .....

**Address:** .....

.....  
**Postcode:** .....

**Contact telephone number:** .....

**Preferred time to phone you:** .....

Please return this form in the prepaid envelope enclosed and the principle investigator of the study will be in touch shortly. Thank you.

Expression of Interest form date of issue: 15/01/2014  
Expression of Interest form version number: v.2

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## Appendix J - Consent form

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt

*Ysgol Gwyddorau Gofal Iechyd*  
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



REC for Wales reference number: 14/WA/0013

### CONSENT FORM

**Title of Project:** The experiences of people who have been treated for oropharyngeal cancer.

**Name of Researcher:** Mr David Evans

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 15/01/2014 (version number 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. I can withdraw by writing, emailing, or phoning using the details on the information sheet.
3. I give permission for my interview with David Evans to be audio-recorded
4. I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
5. I understand that all information collected about me during the course of the research will be kept strictly confidential. Direct quotations may be used in publication, but any information collected will have my name and address removed so that I cannot be recognised from it.
6. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Cardiff University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
7. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent.

Date

Signature

Consent form date of issue: 15/01/2014  
Consent form version number: v.2

Page 1 of 1



## Appendix K - Questionnaire

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt

*Ysgol Gwyddorau Gofal Iechyd*  
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



REC reference number: 14/WA/0013

Participant code number.....

### Questionnaire

Please answer all questions as honestly as possible. Answering all questions is *voluntary and optional* - the answers you give will only be used to provide more detail about the people taking part in the study.

All answers will be treated in the strictest confidence. To ensure anonymity, the questionnaire is coded so there's no need to include your name.

#### Q1. Gender

Male  Female

#### Q2. Age

- |                 |                          |
|-----------------|--------------------------|
| 18-24 years old | <input type="checkbox"/> |
| 25-34 years old | <input type="checkbox"/> |
| 35-44 years old | <input type="checkbox"/> |
| 45-54 years old | <input type="checkbox"/> |
| 55-60 years old | <input type="checkbox"/> |

#### Q3. Marital status (tick one that best describes you)

Married or in a registered same-sex civil partnership

Cohabiting

In a relationship but not living together

Single (never married or never registered a same-sex civil partnership)

Separated (but still legally married or still legally in a same-sex civil partnership)

Divorced or formerly in a same-sex civil partnership which is now legally dissolved

Widowed or surviving partner from a same-sex civil partnership

#### Q4. Employment status (tick one that best describes you)

Employed full-time (more than 30 hours per week)

Employed part-time (less than 30 hours per week)

Self-employed or freelance

Employed but on sick leave

Unemployed and looking for work

Not in work and receiving benefits

Retired

Research Study Questionnaire date of issue: 01/07/2013

Research Study Questionnaire version no: v.1

Page 1 of 4

**Q5. Annual household income**

- Less than £15,000
- £15,000 - £19,999
- £20,000 - £29,999
- £30,000 - £39,999
- £40,000 - £49,999
- £50,000 - £59,999
- £60,000 - £69,999
- £70,000 - £99,999
- £100,000 - £149,999
- £150,000 +
- Prefer not to say

**Q6. Qualifications**

Tick every box that applies if you have any of the qualifications listed. If your UK qualification is not listed, tick the box that contains its nearest equivalent

No Qualifications: *No academic or professional qualifications*

Level 1 qualifications: *1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma, NVQ level 1, Foundation GNVQ, Basic/Essential Skills*

Level 2 qualifications: *5+ O Level (Passes)/CSEs (Grade 1)/GCSEs (Grades A\*-C), School Certificate, 1 A Level/ 2-3 AS Levels/VCEs, Intermediate/Higher Diploma, Welsh Baccalaureate Intermediate Diploma, NVQ level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma*

Apprenticeship

Level 3 qualifications: *2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma, Welsh Baccalaureate Advanced Diploma, NVQ Level 3; Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma*

Level 4+ qualifications: *Degree (for example BA, BSc), Higher Degree (for example MA, PhD, PGCE), NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher level, Foundation degree (NI), Professional qualifications (for example teaching, nursing, accountancy)*

Other qualifications: *Vocational/Work-related Qualifications, Foreign Qualifications (Not stated/ level unknown)*

**Q7. Number of dependants (including children under 18).....**

**Q8. What type of treatment did you have for your cancer?  
(tick all that apply)**

- Surgery   
Radiotherapy   
Chemotherapy

**Q9. Time since diagnosis**

- Less than one year   
1-2 years   
2-3 years   
3-4 years   
4-5 years   
More than 5 years

**Q10. Lifestyle factors that increase risk of oropharyngeal cancer**

**Q10a. Do you currently smoke tobacco?**

Yes  No

If no, go to question 10b

If yes, do you smoke tobacco...

- less than before diagnosis   
the same as before diagnosis   
more than before diagnosis

**Q10b. Do you currently drink alcohol?**

Yes  No

If no, go to question 11

If yes, do you drink alcohol...

- less than before diagnosis   
the same as before diagnosis   
more than before diagnosis

**Q11. Sexual Health**

**Q11a. Are you currently sexually active with a partner?**

Yes  No

**Q11b. Do you have, or have you ever had, any risk factors for HIV? (List blood transfusions, needlestick injuries, intravenous drug use, STIs, partners who may have placed you at risk.)**

Yes  No  Would prefer not to say

**Q12. How would you describe your life now in comparison to before diagnosis?**

This is an opportunity to describe what is important to you. Think about what you enjoy to do in your spare time, how you feel, and how you think about yourself and your life.



A large rectangular box with a black border, designed for handwritten responses. Inside the box are ten horizontal dashed lines spaced evenly apart, intended for the respondent to write their answers.

**Thank you for taking the time to complete this questionnaire.**

## Appendix L - Supportive services document

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt



### Supportive Services

If you have any questions about the research study you should contact the principle investigator, David Evans, by writing to 702a, 7th Floor, EastGate House, 35-43 Newport Road Cardiff, CF24 0AB; Emailing [EvansDR1@cardiff.ac.uk](mailto:EvansDR1@cardiff.ac.uk); Phoning: 07443 505428.

If you feel that you would benefit from additional support, there are several options available to you. You may wish to contact your Clinical Nurse Specialist who could refer you on to someone who may be able to help.

The following organisations also provide advice and support in the South-West of England for people who have been treated for cancer.

Macmillan	Worcestershire Royal Hospital, Charles Hastings Way, Worcester, WR5 1DD. Phone: 01905 733837 Email: <a href="mailto:kay.tandy@worcsacute.nhs.uk">kay.tandy@worcsacute.nhs.uk</a> <a href="http://www.macmillan.org.uk/HowWeCanHelp/HowWeCanHelp.aspx">http://www.macmillan.org.uk/HowWeCanHelp/HowWeCanHelp.aspx</a>
Samaritans	Victoria House, Back Albert Place, Pittville, Cheltenham, GL52 2HN or 37 St Nicholas Street, Bristol, BS1 1TP. Phone: 08457 90 90 90 Email: <a href="mailto:io@samaritans.org">io@samaritans.org</a> <a href="http://www.samaritans.org/how-we-can-help-you">http://www.samaritans.org/how-we-can-help-you</a>
Cancer Network Group Support	Phone: 01242 604177 <a href="http://www.cancernetworkvoice.nhs.uk/counties344777.html">http://www.cancernetworkvoice.nhs.uk/counties344777.html</a>
RUH Cancer Information and Support Centre (Bath)	Royal United Hospital, Coombe Park, Bath, BA1 3NG. Phone: 01225 824049 <a href="http://www.ruh.nhs.uk/patients/services/clinical_depts/cancer_services/support_centre.asp?menu_id=3d">http://www.ruh.nhs.uk/patients/services/clinical_depts/cancer_services/support_centre.asp?menu_id=3d</a>
Maggie's (Cheltenham)	The Lodge, Cheltenham General Hospital, College Baths Road, Cheltenham, GL53 7QB. Phone: 01242 250611 Email: <a href="mailto:cheltenham@maggiescentres.org">cheltenham@maggiescentres.org</a> <a href="http://www.maggiescentres.org/cheltenham/introduction.html">http://www.maggiescentres.org/cheltenham/introduction.html</a>
Living Well with and Beyond Cancer (Bristol)	Bristol Haematology and Oncology Centre, Horfield Road, Bristol, BS2 8ED. <a href="http://www.uhbrisol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/support-for-patients/">http://www.uhbrisol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/support-for-patients/</a>

Supportive services document date of issue: 01/07/2013  
Supportive services document version number: v.1

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## Appendix M – Extract from Sara's transcription with examples of coding

at that point because I was feeling so poorly, but after a night in hospital it was like, I just want to go home again now. [Laughs].

R From what you've said it sounds like there was a certain amount of fighting going on. Is that fair?

P Um, I don't know whether I saw it as a fight. I think it was just one of those things that, like, you get swept along with it really. Certainly in the beginning, I mean everybody, everybody, through the course of my treatment have all been absolutely fantastic, but you do feel like [pause], you've got no control in some ways. Which is good because everyone is looking after you but, right, okay, you've got to go for this, you've got to have these bloods done, and that, and you've got to have teeth taken out, you've got to have all these different scans and, you know, you're just going to a point, and this is even before treatment started so, it was just like, okay on to the next thing, I didn't really know what was going on, I, it was happening so quickly, before I knew it I was starting radiotherapy. You know, and you didn't really, because there was so much going on with so many appointments to go to, sort of, preparing I suppose ready for the treatment you're having, that I never really had that much of a chance to sort of, sit down and think about what, what was actually happening. Which is good in some ways I guess. It means you're not, because you kept busy with all these other things you haven't really got time to dwell on anything. But, you know, everybody was, every appointment I went to, everybody explained everything, brilliantly. You know, there was no, apart from initially [pause], I thought I was just having my tonsils out, end of story. Um, apart from that where I probably just wasn't listening properly or it could have been something that was decided after, you know, I knew what was going on the whole time.

R You said about fighting the amount of teeth they took out. You obviously, there's a choice there and negotiation?

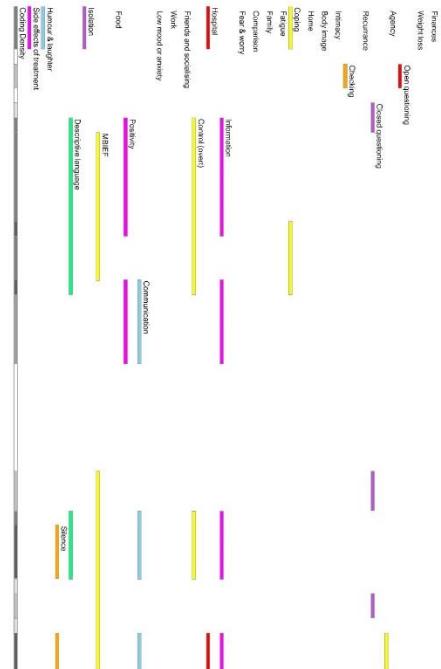
P Yeah, yeah.

R Did you feel there was a choice in the treatment you had or were you quite happy to go along with what you were told?

P To be honest I, [pause], I guess I just went along with what I was told to do, I guess. It was just like, right, we need to do this. And you need to go to this appointment, and that appointment, so I didn't even question it. [Long pause]. So.

R Would you have liked a choice?

P Um, [long pause], probably, [pause], well, I haven't really thought about that before. Um, no, because I think, um, well yes if there were other options, then, um, I suppose it would have been



4 / 20

4A

nice to know about them. But I mean, this was in my best interests. This was just to knock things on the head once and for all. You know, this was going to clear it up. So, yeah, I suppose hearing other options would probably have been a good thing but it's not something I would have really thought about before.

R I'm interested in the shock of being told that you've got cancer when that wasn't even in your mind.

P Yeah.

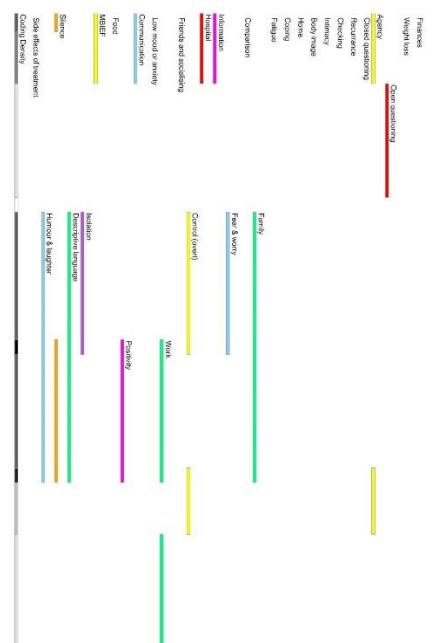
R Talk me through how that felt.

P Um, [pause], well, like I say, the first five minutes was like, oh, right. And then after that, I was driving home and I was starting to sink in. And then I started to get tearful. Um, and then it was like, what do I, cos I don't have, I really do, family wise I really do only have my brother, who is actually like my best friend even though I've slagged him off slightly [laughs]. Um, and the only thing, the main thing going through my head was, I can't tell him. Just, that was, I wasn't really so worried about me. It was more like, I just can't tell him cos he doesn't, my mum died, um, when he, I was 25, he was 19, and um, he didn't cope very well with that at all. And because we are so close I just didn't think he'd be able to cope with it really. And it was like I just, I really, I could have got away without telling him anything then I would have done. But it was, [pause], that was probably the main thing going through my head. Not so much me. Oh, and then it was like, god, what am I going to tell my wife? [Laughs]. Um, so all these things are going round in your head, I guess, not much of it was about me really. It was probably more about, how others were going to feel about it. Um, but then when I had to have this, um, no, I told my brother when I had to have my tonsils taken out cos I thought, on that's it, I can tell him now because it's not, I'm not going in and saying "I've got cancer". So, he could probably cope with that a bit better. But then I obviously did have to tell him and [pause], yeah he was pretty rubbish [laughs]. He coped in the best way he could which is normally swearing and joking with, um, probably helped me cos I kept me jazzy. So, but yes, it was [pause], it, yeah it was all sorts of, I, [pause], yeah, it was a bit of a shock after once it had sunk in a bit. Um, [pause], but app in it was just a case of um, [pause], well, it's happening, let's um, [pause], let's get on with it then. [Laughs]. You know, by that time it was like right, you need to go here and you need to go there so, and then that's when the sort of rollercoaster happened. But yeah, it wasn't, it wasn't the best of days. [Pause].

R You said you were worried about telling work as well.

P Yeah, who were absolutely amazing.

R Why were you worried about telling them?



5 / 20

5A



## Appendix N – Media reaction to Michael Douglas' cancer story

### Original Guardian article

#### Oral sex caused throat cancer that nearly killed me, says Douglas

Catherine Shoard

Michael Douglas - the star of *Basic Instinct* and *Fatal Attraction* - has revealed that his throat cancer was apparently caused by performing oral sex.

In a surprisingly frank interview with the *Guardian*, the actor, now winning plaudits in the Liberace biopic *Behind the Candelabra*, explained the background to a condition that was thought to be nearly fatal when diagnosed three years ago.

It has been a rough few years. But I am back. I feel fortunate that I am even alive.

**Michael Douglas talks to Xan Brooks about cancer, family troubles and getting the best reviews of his life as Liberace. In G2 »**



Asked whether he now regretted his years of smoking and drinking, usually thought to be the cause of the disease, Douglas replied: "No. Because without wanting to get too specific, this particular cancer is caused by HPV [human papillomavirus], which actually comes about from cunnilingus."

Douglas, the husband of Catherine Zeta Jones, continued: "I did worry if the stress caused by my son's incarceration didn't help trigger it. But yeah, it's a sexually transmitted disease

that causes cancer. And if you have it, cunnilingus is also the best cure for it."

The actor, now 68, was diagnosed with cancer in August 2010, following many months of oral discomfort. But a series of specialists missed the tumour and instead prescribed antibiotics.

Douglas then went to see a friend's doctor in Montreal who looked inside his mouth using a tongue depressor.

"I will always remember the look on

[continued on page 2 »](#)

### New York post front page

**NEW YORK POST** **Page Six**

MONDAY, JUNE 3, 2013 / T-storms, B1 / Weather: P. 47 • • • LATE CITY FINAL www.nypost.com • • • \$1.00

# MICHAEL DOUGLAS SHOCKER

# SEX GAVE ME CANCER

PAGE 7

Oscar-winner Michael Douglas has revealed that his life-threatening throat cancer was not the result of smoking or drinking — but of oral sex. "Without wanting to get too specific, this particular cancer is caused by HPV, which actually comes about from performing oral sex," the 68-year-old actor said, referring to the human papillomavirus.

## Radio show

Michael Savage radio show: Michael Douglas' throat cancer story is "humiliating, revolting, and disgusting" - <https://youtu.be/xLOmK6rOKoM>

## Lifestyle website

The grossest part of Michael Douglas' cancer brag -

[http://www.salon.com/2013/06/03/the\\_worst\\_part\\_of\\_michael\\_douglas\\_cancer\\_brag/](http://www.salon.com/2013/06/03/the_worst_part_of_michael_douglas_cancer_brag/)

## Appendix O – Thermoplastic mask used in radiotherapy



### Radiotherapy masks

If you are having radiotherapy to your head or neck, you will probably need to wear a plastic mask during your treatment. Some types of mask are see through and others aren't. The mould keeps your head completely still. So your treatment will be as accurate as possible.

A mould technician or radiographer makes the mask in the mould room of the radiotherapy department. The process can vary slightly between hospitals and usually takes around 30 minutes.

### Mesh plastic mask

This technique uses a special kind of plastic heated in warm water so that it becomes soft and pliable. The technician puts the plastic on to your face so that it moulds to fit your face exactly. It feels a little like having a warm flannel put onto your face. You can still breathe easily, as the plastic won't cover your nose or mouth.

Once the mesh has moulded and become hard (which takes around 10 minutes) the technician takes it off. The mask is then ready to be used when you have your treatment.

(Adapted from Cancer Research UK.org -  
<http://www.cancerresearchuk.org/cancer-help/about-cancer/treatment/radiotherapy/external/plan/radiotherapy-moulds#mesh>)