Health-related Quality of Life After Head and Neck Cancer:

Aboriginal Patientsô Experiences in South and Central Australia

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Thesis declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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Abstract

Purpose: To identify and address barriers to active and meaningful participation in self-reported health-related quality of life (HRQL) assessment for Aboriginal patients with experience of head and neck cancer (HNC).

Methodology: 18 semi-structured interviews based around two global-standard, HNC-specific, HRQL instruments, were conducted with 12 Aboriginal patients with experience of HNC in South and Central Australia. Interviews were transcribed and recurring HRQL issues were identified to form the basis of a novel HRQL assessment (UHRQL-HN). UHRQL-HN was refined through consultation with 30 key informants including healthcare professionals, family and others involved in the care of Aboriginal patients with HNC. UHRQL-HNôs face and content validity, cultural acceptability, utility and relevancy were assessed by 12 key informants and by trialling with five Aboriginal patients with experience of HNC.

Results: Cultural disparities and other pragmatic factors adversely affected the usability, reliability and validity of traditional tools and methods for assessing HRQL within this cohort population. UHRQL-HN shows promising face and content validity, cultural acceptability, utility and relevance for both Aboriginal patients with experience of HNC and healthcare professionals. Data yielded utilising UHRQL-HN was of good quality and depth, enabling patientsô HRQL concerns to be identified and addressed in a timely fashion and showed clinical correlation with ECOG status, TNM staging and clinical intervention.

Conclusions: Wider trialling and validation of this instrument is recommended as UHRQL-HN shows promise as a useful, clinically

relevant tool to assess the HRQL of Aboriginal people with experience of HNC.

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Definition of the use of terms Indigenous, Aboriginal and Torres Strait Islander

The term Indigenous is used to refer to first nation peoples or original inhabitants prior to colonisation, in different countries including Australia. In Australia, this term includes people of Aboriginal and/or Torres Strait Islander descent. Throughout this document the term Indigenous is used interchangeably with the terms Aboriginal and Torres Strait Islander people when referring to other studies or reports that involved both Aboriginal and Torres Strait Islander people. The terms Aboriginal and Torres Strait Islander are not abbreviated as to do so would be an offence to some people (1).

As this project was carried out in SA and the NT (where very few who identify as Torres Straight Islander people reside) no one involved in this study identified as a Torres Strait Islander person. Therefore, the terms Aboriginal and Aboriginal culture are often used to refer to participants and findings from this study.

It is acknowledged that the Aboriginal population in Australia is heterogenous in nature, with no one nation, language, beliefs or culture. However, there are commonalities in health disparities and experiences amongst Aboriginal people from different regions, language groups and backgrounds that warrant population-based investigations such as this one.

Aims and objectives of study

The primary objective of this project was to better healthcare professionalsô understanding of the impact that HNC and different treatments for HNC have on Aboriginal patients' symptoms, functioning and HRQL; to enhance the clinical decision making process and enable improved delivery of information and counselling for Aboriginal people with experience of HNC, primarily in relation to treatment options and predicted outcomes.

The initial aim of this project was to evaluate the reliability, relevancy and validity of commonly used, internationally recognised instruments for assessing the HRQL of patients with experience of HNC, within a cohort population of Aboriginal people with experience of HNC. Barriers to Aboriginal patientsô active and meaningful participation in standard HNC-specific HRQL assessment were subsequently explored. The final aim was to use these findings to develop a functional and useful way to assess the impact of HNC and HNC treatments on the HRQL of Aboriginal people with experience of HNC, considering the special needs of HNC patients and the cultural needs of Aboriginal people in South and Central Australia.

Abbreviations and acronyms

ABS = Australian Bureau of Statistics

ASGC = Australian Standard Geographical Classification

AIHW = Australian Institute of Health and Welfare

ALO = Aboriginal Liaison Officer

ASH = Alice Springs Hospital

AWCCC = Alan Walker Cancer Care Centre

CA = Central Australia

CXT = Chemotherapy

ECOG-PSR = European Cooperative Oncology Group Performance Status Rating

F = Female

FACT-HN = Functional assessment of cancer therapy quality of life assessment ï Head and Neck Version 4

HNC = Head and neck cancer

HNSCC = Head and neck squamous cell carcinoma

HPV = Human Papilloma Virus

HRQL = Health-related quality of life

M = Male

M stage = Metastases stage

MDT = Multidisciplinary team

N stage = Nodal stage

NET = Nasoenteric tube

NCHF = Northern Community Health Foundation

NPC = Nasopharyngeal carcinoma

NSW = New South Wales

NT = Northern Territory

PEG = Percutaneous gastrostomy

PROM = Patient-reported outcome measure

QoL = Quality of life

RAH = Royal Adelaide Hospital

RDH = Royal Darwin Hospital

RXT = Radiotherapy

SCC = Squamous cell carcinoma

SA = South Australia

SACR = South Australian Cancer Registry

T stage = Tumour stage

TNM = Tumour, node, metastases

UHRQL-HN = Universal health-related quality of life assessment ï Head and neck - version 1

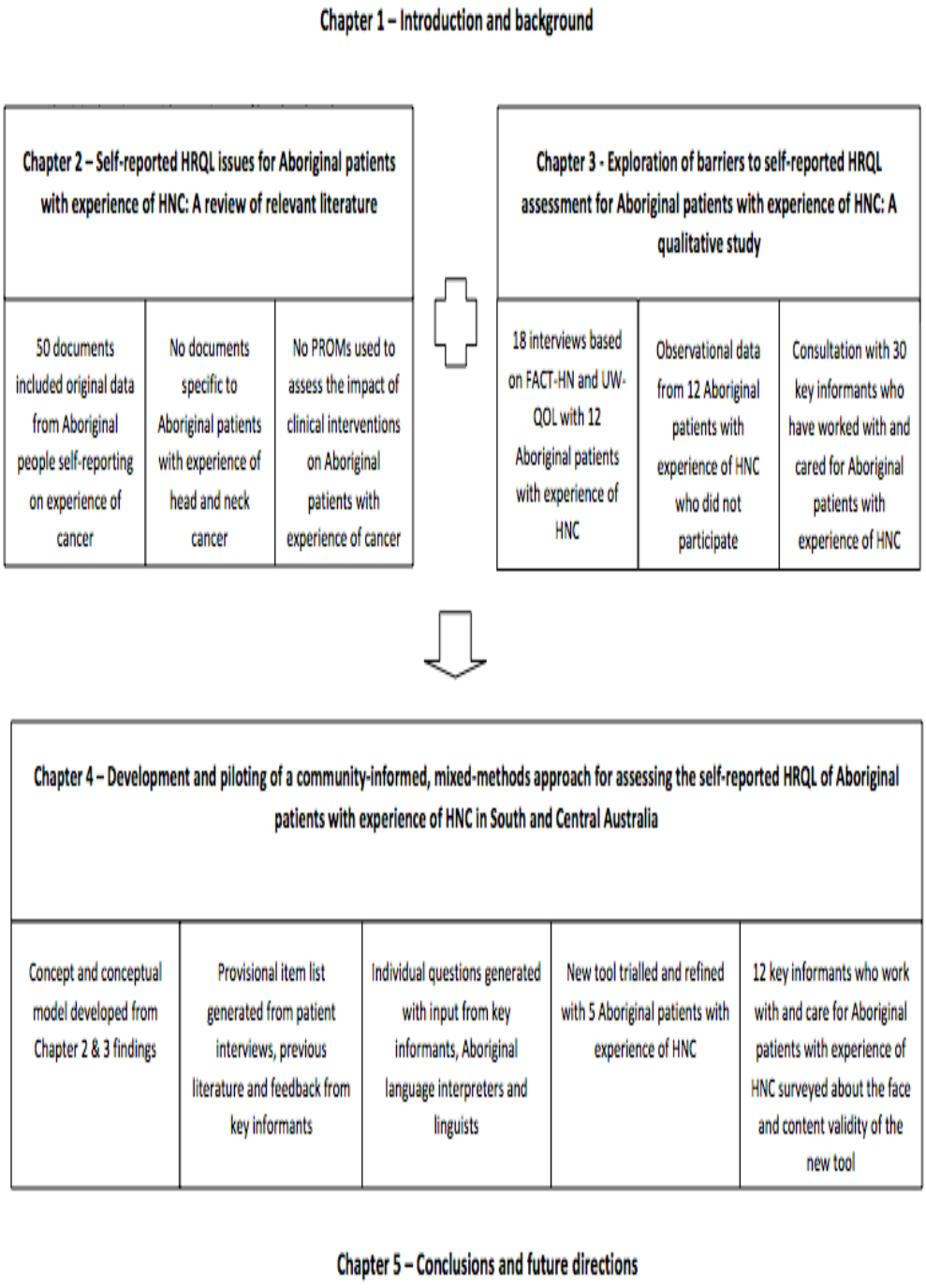
QLD = Queensland

WA = Western Australia

WQLQ = University of Washington quality of life assessment - version 4

YO = year old

Figure 1 – Flow chart of study protocol



CHAPTER ONE:

Introduction and background

Chapter 1. Introduction and background

The use of patient reported outcome measures (PROMs), such as health-related quality of life (HRQL) assessments, is becoming standard clinical practice in Australia. Collecting HRQL data ultimately informs decision-making about best practice for medical treatment and helps health care professionals to identify patient concerns, so they can offer appropriate and timely support. Collecting HRQL data from patients diagnosed with HNC is particularly important as the health-related needs of this patient group often exceed those of other patients. The effects of HNC and its treatment can have significant and often devastating effects on patientsô functioning, appearance, emotional wellbeing, socialisation and ultimately the quality of life (QoL) of patients. Physical functions which are often impaired during the course of HNC and its treatment include swallowing, chewing, saliva production, taste, speech, voice, breathing, shoulder function and facial expression. In addition, there is often impairment to self-esteem, confidence, energy and mood. These effects are typically ongoing and mainly arise in the post-treatment phase, so supportive care and monitoring is often necessary long after remission.

Compared with non-Indigenous populations in Australia, Aboriginal and Torres Strait Islander populations suffer a greater burden of many chronic illnesses including HNC. Yet to date, there has been very little published material examining the impacts of chronic illness and biomedical treatments on Aboriginal peopleôs QoL. This is the first published study examining the impact of HNC on Aboriginal peopleôs symptoms, functioning or HRQL.

1.1 Epidemiology of HNC in Australia

1.1.1 An overview of HNC and HNC treatment

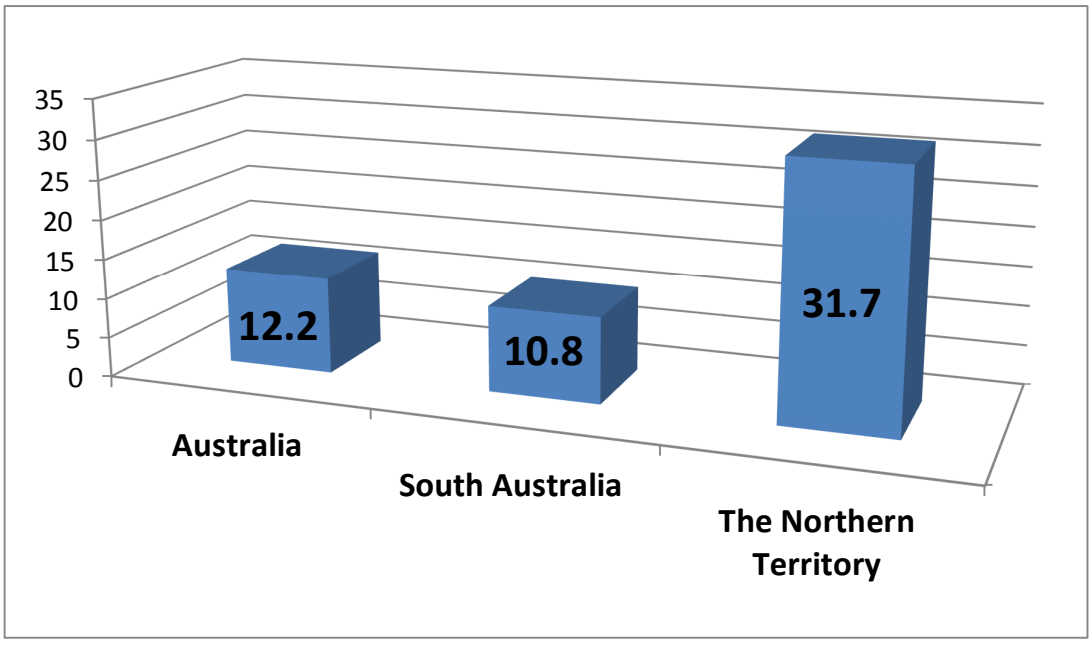
Cancers that begin in cells that are located in upper airway and digestive tract regions of the head and neck area (such as the nasal cavity, sinuses, lips, oral cavity, salivary glands, throat, larynx) are commonly referred to as head and neck cancers (HNC) (2, 3). These cancers often metastasize, spreading to the lymph nodes of the neck region and thus sometimes present in neck nodes before the primary site is identified. If the primary site is not identified, these cancers are commonly referred to as occult or unknown primaries (3).

The vast majority of HNCs are squamous cell carcinomas (HNSCCs) (2, 3). HNSCC is the most common pathological entity of the HNCs and is the 8th most common type of cancer, accounting for 6% of worldwide malignancies (4). Other cancers such as primary cancers of the salivary glands, lymphatic system, thyroid, brain, central nervous system, eyes, skin, muscles or bones of the head and neck may also be diagnosed and treated by head and neck clinicians (also known as Otorhinolaryngologists or Ear Nose and Throat specialists) in conjunction with multidisciplinary specialist teams from radiation oncology, medical oncology, oral-maxillofacial surgery, plastic surgery, pathology, radiology, haematology, endocrinology, dermatology, neurology, ophthalmology, and/or craniofacial surgery (3).

1.1.2 The incidence of HNC in Australia, SA and the NT

The incidence of HNC varies in different regions of the world. In Australia, approximately 2670 HNC cases are diagnosed each year, representing almost 3% of all the cancers diagnosed in Australia (5). From 2001 to 2005, HNC cases from South Australia (SA) represented an average of 7.36% of all registered HNC cases in Australia, while HNC cases from the Northern Territory (NT) represented an average of 1.6% of cases. As seen in Figure 2 below, during this time period, the age-standardised incidence of HNC was almost three times as high in the NT as in the overall Australian population or in SA (6).

Figure 2 - Average age-standardised incidence of HNC per 100,000 residents in Australia, SA and the NT, 2001 to 2005 (SACR)

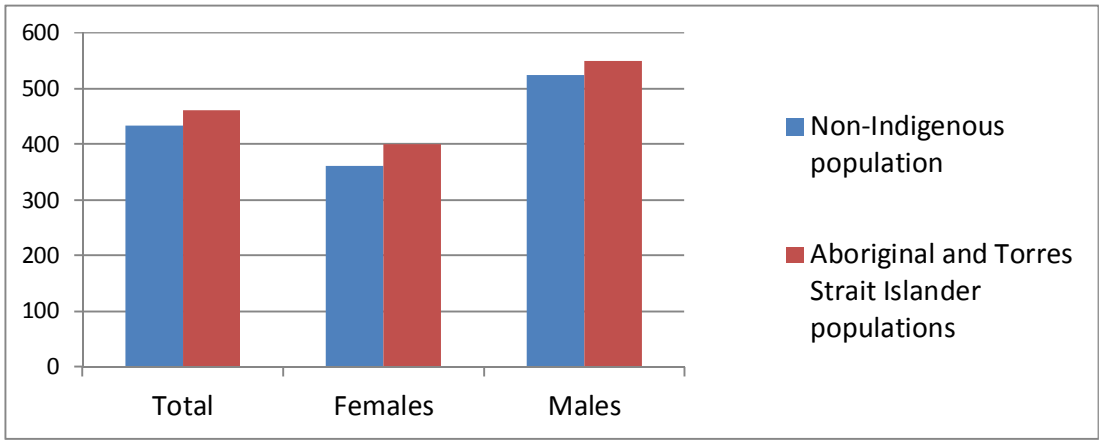


1.1.3 The incidence of HNC amongst Indigenous populations in Australia

Cancer has only recently been identified as a health priority for Aboriginal and Torres Strait Islander people. In recent years, Australian health organisations have been implementing improved data collection processes and systems for Aboriginal and Torres Strait Islander identification; allowing the incidence of cancer amongst Aboriginal and Torres Strait Islander people to be examined for the first time (7-16). In some regions of Australia, lower overall age-standardised incidence of cancer has been reported amongst Indigenous compared to non-Indigenous Australians, though it is possible that incidence may be under-reported due to Aboriginal and Torres Strait Islander status not always being recorded and some cancers remaining undiagnosed (8, 11, 16-20). The Australian Institute of Health and Welfare states that completeness of data for Aboriginal and Torres Strait Islander status is only sufficient from cancer registries in NSW, QLD, WA and the NT, with an overall level of missing data of 12%.

In the first amalgamation of national data (from NSW, QLD, WA and the NT only), from 2004 to 2008, higher recorded age-standardised incidence of overall cancer was recorded amongst the Indigenous population compared to the non-Indigenous population (see Figure 3 for details). Differences were statistically significant for women and the overall population but not for men (16).

Figure 3 - Age-standardised incidence of new primary cancer diagnoses per 100,000 people in the Indigenous populations compared to the non-Indigenous populations in NSW, QLD, WA and the NT, 2004 to 2008 (AIHW)



Interestingly, higher incidences are particularly noted with certain types of cancer that have particularly poor prognoses, such as lung, cervical, uterine, liver, pancreatic, HNC and occult primary cancer (16, 18, 21). Between 2004 and 2008, in NSW, QLD, WA and the NT collectively, 295 incidences of primary HNC diagnosis were recorded amongst the Indigenous population, accounting for 7.6% of primary cancer diagnoses recorded within these populations. Amongst the non-Indigenous population, primary HNC diagnoses accounted for only 2.9% of the overall cancer incidences recorded (16).

Between 2004 and 2008, occult primary site cancers were the fifth most common cancer site recorded in the Indigenous populations, with 167 cases collectively recorded in NSW, QLD, WA and the NT. Aboriginal and Torres Strait Islander people were 1.9 times as likely to be diagnosed with occult primary cancers and the age-specific incidence rate amongst those aged 45 to 74 was statistically significantly higher for Indigenous compared with non-Indigenous Australians (16). These findings may be meaningful for determining HNC incidence amongst Aboriginal and Torres Strait Islander people, as occult primaries often present as

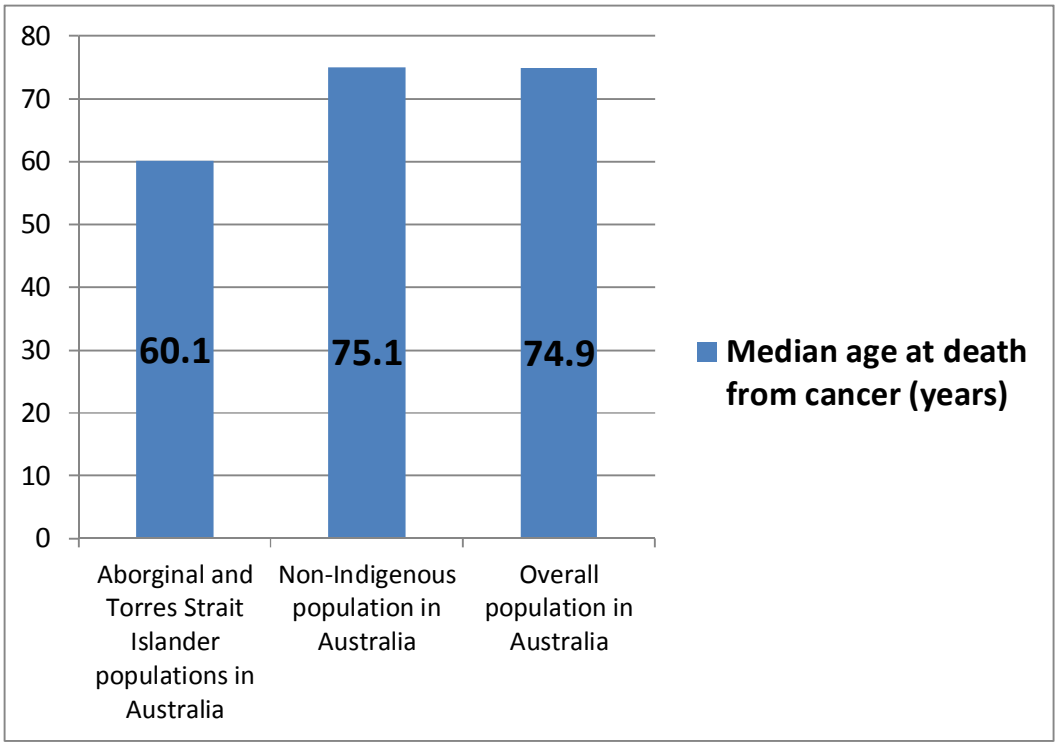
secondary metastases in the lymph nodes of the neck and represent approximately 2 to 6% of HNCs worldwide (16).

1.1.4 Average age at diagnosis and death for Aboriginal and Torres Strait Islander patients with cancer

It was previously assumed that cancer incidence and mortality rates amongst the Aboriginal and Torres Strait Islander populations were relatively low, as cancer is most prevalent in the 65 years and over age group (59.2% of cancers in SA) and those aged over 65 years comprise only 3% of Aboriginal and Torres Strait Islander populations compared with 18% of the non-Indigenous population in Australia (22, 23). However, compared with non-Indigenous people, Indigenous people are more likely to be diagnosed with and die from cancer at a younger age in Australia (16).

In 2004, despite the national average life expectancy at birth of Indigenous males being 59 years and Indigenous females being 65 years, cancer was the second leading cause of death recorded amongst the Aboriginal and Torres Strait Islander populations accounting for 17% of all deaths reported amongst the Aboriginal and Torres Strait Islander populations (20, 24). Figure 4 illustrates how cancer contributes to the significant gap in average life expectancies from birth between Indigenous and non-Indigenous people in Australia. Despite the overall median age of persons dying from malignant cancers in Australia continuing to rise from 72 years in 1997 to 74.9 years in 2006, the median age at death from cancer for Indigenous people in 2006 was 60.7 years compared to 75.1 years for other people in Australia (25).

Figure 4 - The median age at death from cancer in 2006 for Indigenous populations compared to the non-Indigenous population and the overall population in Australia (ABS)



HNC is most common in people over 40 years of age, with the median age at diagnosis being approximately 60 years (3). HNC in people under 30 years of age is rare, with this age group accounting for approximately 0.5% of all HNCs.

1.1.5 Gender distribution of Australian patients diagnosed with HNC

The incidence of HNC is higher amongst men than women in both Indigenous and non-Indigenous populations in Australia (16). From 2001 to 2005, men in SA were on average 2.8 times more likely to be diagnosed with HNC than women in SA and men in the NT were 5.6 times more likely to be diagnosed with HNC than women in the NT (26). See Table 1 - Age-standardised HNC diagnoses per 100,000 males and females in

South Australia by recorded primary site, 2008, for comparison of gender by primary site (27). In contrast to most other cancers of the head and neck region, thyroid cancers are more commonly diagnosed in females than males, with age-standardised rates of 10.3 diagnoses per 100,000 in females compared to 3.3 diagnoses per 100,000 in males amongst the South Australian population in 2008 (27). However, age-standardised incidence rates of thyroid cancer have been reported to be significantly higher amongst Indigenous compared to non-Indigenous men in Australia (4.8 vs. 3.4 per 100,000 between 2000 and 2004) and lower for Indigenous women compared to non-Indigenous women (6.4 vs. 9.8 per 100,000 between 2000 and 2004)(25).

Table 1 - Age-standardised HNC diagnoses per 100,000 males and females in South Australia by recorded primary site, 2008 (SACR)

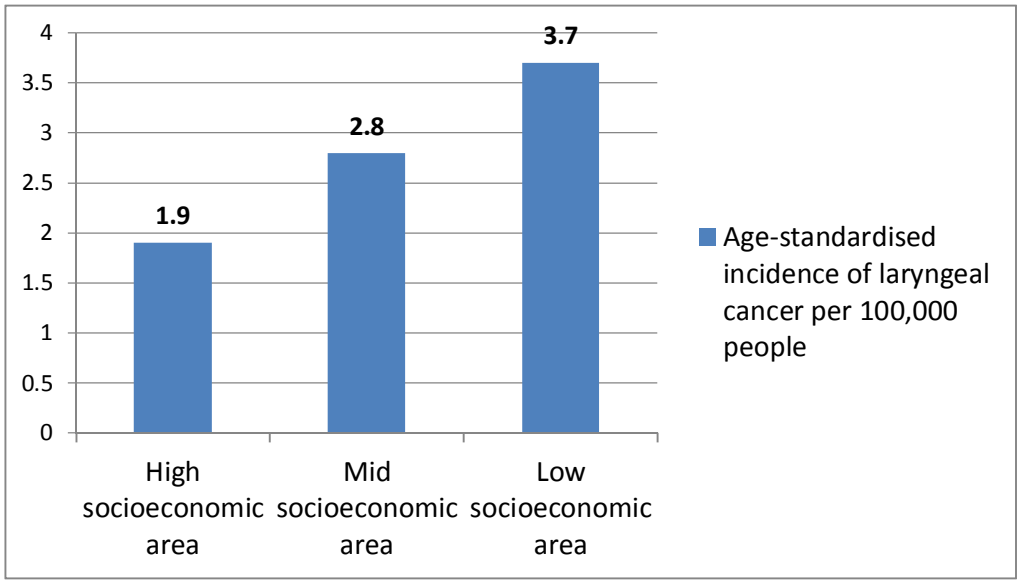
Primary Site	Male	Female
Larynx	3.1	0.6
Hypopharynx	0.8	0.1
Nasopharynx	0.6	0.3
Nasal cavities	0.7	0.3
Salivary Gland	2.4	1.1
Oropharynx	2.4	1
Tongue	2	1.9
Lip	8	2.6
Lip, and skin of lip	12	4.2
Gum	0	0.2
Buccal cavity	18	9.6
Oral cavity unspecified	0.5	0
Floor of mouth	0.4	1
Other parts of mouth	1.1	1.2

1.1.6 Socioeconomic status of patients diagnosed with HNC in Australia

It has long been established that low socioeconomic status is strongly associated with poor health and increased exposure to environmental health hazards (20, 28, 29). Today, Aboriginal and Torres Strait Islander populations are economically poorer than other Australians, they experience greater unemployment, have lower educational attainment, live in more overcrowded households and poorer housing with less access to basic facilities such as clean water, sewerage and waste disposal (20, 30). Further to this, they are more likely to be exposed to racism, domestic violence and other behavioural risk factors (20, 30). All these factors contribute to access to healthy lifestyles and health services, health-seeking behaviours and general health outcomes.

In SA Cancer Registry data from 1977 to 2000, the age-standardised incidence of primary laryngeal cancer was approximately four times higher among the unemployed and five times higher among labourers, cleaners and related workers compared with self-employed managers and related white-collar workers (6). Figure 5 illustrates there was a significant inverse relationship between the socioeconomic status of residential areas in SA and age-standardised incidences of primary laryngeal cancer, with residents of the lower socio-economic areas of Adelaide experiencing approximately twice the incidence of laryngeal cancers than that in the upper socio-economic areas (6).

Figure 5 - A comparison of age-standardised incidence of primary laryngeal cancer diagnoses per 100,000 people by socioeconomic status of residential areas in Adelaide, South Australia, 1977 to 1996 (SACR)



1.1.7 Aboriginal and Torres Strait Islander people treated for HNC at the RAH

As leaders in HNC treatment; the RAH HNC multidisciplinary team services the majority of public patients who are diagnosed with HNC. In addition, patients from Central Australia (CA) are referred from Alice Springs Hospital (ASH) to the RAH for HNC treatment. More than 34% of the CA population are Aboriginal and approximately 80% of ASHôs beds are occupied by Aboriginal people (31).

Aboriginal and Torres Strait Islander people with HNC are more likely to use Australian public hospital systems rather than private ones. A recent cohort study of Australians aged 45 and over (those at higher risk of developing HNC (32)) identified that predictive factors for not having private health insurance include being of Aboriginal or Torres Strait Islander origin, being a smoker, having a lower income, lower educational

attainment, holding a health care concession card, lower levels of self-rated health and functional capacity and high levels of psychological distress (33). Each year, approximately 52 Aboriginal people from SA and the NT are treated for cancer at the Royal Adelaide Hospital (RAH) (34). The most common types of cancer treated at the RAH are HNC and lung cancer in Aboriginal men and gynaecological cancer in Aboriginal women (34, 35). An analysis of the RAH HNC database suggests that Aboriginal patients represented approximately 10% of all HNC patients seen at the RAH between 1998 and 2008. It must be noted that during this time period, almost all patients from the NT who were diagnosed with HNC were sent to the RAH for treatment as there were no radiotherapy services available in the NT at that time (36). In March 2010, adjacent to the Royal Darwin Hospital, the Alan Walker Cancer Care Centre (AWCCC) commenced providing specialist radiotherapy and chemotherapy services for people in the NT. For the majority of cancer patients from the NT, this has reduced the need for lengthy interstate travel (37). However, before the AWCCC was commissioned, patients from Central Australia made it clear that they wished to retained their choice to travel to Adelaide for treatment and today many Aboriginal patients from Central Australia (particularly those diagnosed with HNC) and a lesser amount from Darwin and surrounds, still travel interstate to the RAH for specialist cancer treatment (36). At present, approximately five Aboriginal people are treated for a new primary diagnosis of HNC at the RAH each year.

1.2 Risk factors for the aetiology of HNC amongst Aboriginal and Torres Strait Islander populations

Although the precise biological mechanisms for HNC carcinogenesis are not yet fully understood, it is generally believed that the predominant cause is cumulative exposure to environmental carcinogens which lead to a series of genetic changes and consequent tumour progression (38). As this study includes patients diagnosed with HNSCC, nasopharyngeal carcinoma (NPC) and papillary thyroid carcinoma, commonly known risk factors for these three pathologies are discussed with particular reference to risks amonts Aboriginal and Torres Strait Islander populations.

1.2.1 Risk factors for HNSCC

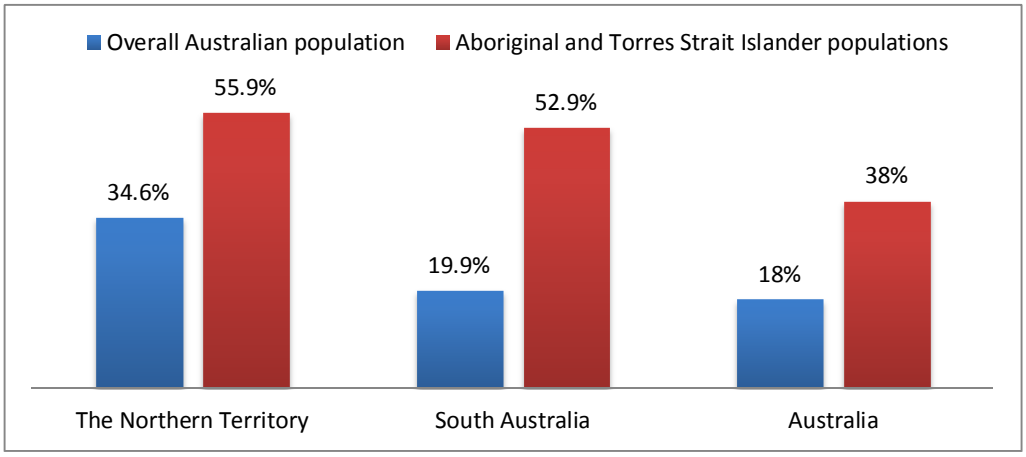
Tobacco, alcohol, certain strains of the Human Papilloma Virus (HPV) and excess exposure to ultraviolet radiation (UV) are well known risk factors that are most commonly attributed to the carcinogenesis of HNSCC. Other risk factors include immunosuppression, insufficient nutritional intake, poor oral hygiene, and possibly genetic factors (16).

1.2.1.1 Tobacco and alcohol

The two most important known risk factors for developing HNSCC are exposure to environmental carcinogens from tobacco (including active and passive inhalation as well as smokeless tobacco, sometimes called ñchewing tobaccoò or ñsnuffò) and the heavy use of alcohol (39-44). Approximately 85% of all HNSCCs are linked to tobacco use (40-43). Furthermore, people who use both tobacco and alcohol are at greater risk of developing these cancers than people who use either tobacco or alcohol alone (45).

More than 21% of all deaths from cancer in Australia are attributed to tobacco use and smoking-related cancers are the most common types of cancer that lead to deaths among Aboriginal and Torres Strait Islander people (16, 25). Recent figures report that around 38% of Aboriginal and Torres Strait Islander adults smoke compared to 18% of all other Australians and one in every five deaths in Aboriginal and Torres Strait Islander people is attributed to smoking (16, 46). Furthermore, itôs been reported that Aboriginal and Torres Strait Islander people generally commence smoking at a younger age, continue to smoke for longer and make fewer attempts to quit smoking than other Australians (47). See Figure 6 - Smoking rates amongst Aboriginal and Torres Strait Islander populations compared with the overall population in Australia, SA and the NT (48-51).

Figure 6 - Smoking rates amongst Aboriginal and Torres Strait Islander populations compared with the overall population in Australia, SA and the NT (compiled from data from the ABS, the AIHW, the NT Government Department of Health and Community Services and Drug and Alcohol Services South Australia)



Though evidence has not yet been scientifically validated, other suspected risk factors for HNSCC are inhalation of marijuana smoke and the consumption of smokeless native tobaccos which are commonly placed

around the lips or buccal mucosa areas so that nicotine can be absorbed via these membranes. It has been reported that some Aboriginal people use native tobacco for pain relief, sometimes in the post-operative period (52-55).

As mentioned, excess alcohol consumption is strongly associated with many HNSCCs (56). Though Aboriginal and Torres Strait Islander people are much more likely to abstain from alcohol than other Australians, Aboriginal and Torres Strait Islander people who do drink alcohol are more likely to drink it at high-risk levels (57, 58). Alcohol consumption is estimated to contribute to 6% of the total burden of disease for Aboriginal and Torres Strait Islander people in Australia (46).

1.2.1.2 Human Papilloma Virus (HPV)

The risk for developing oropharyngeal cancers arising from the tonsils and base of tongue is significantly increased with infection by certain strains of HPV (59). More than 320 different genotypes of HPV have been identified and though most are low-risk, they may induce benign hyper-proliferations of epithelium such as papillomas and warts. The two high-risk genotypes for HNSCC are HPV-16 and HPV-18, which are also implicated in cervical and anogenital cancers (38).

Compared with HPV-negative HNSCCs, better prognoses and response to therapy have been observed with HPV-positive HNSCCs, with cancer mortality reduced by up to 80%. As yet, no specific mechanism has been shown to explain higher rates of response to therapy, though HPV-positive HNSCC is genetically distinct from the HPV-negative HNSCC and inversely correlated with biomarkers for a poor prognosis in HNSCC (38, 60).

HPV acts independently to carcinogens from tobacco and alcohol and HNSCCs from patients with no significant history of tobacco or alcohol use are more likely to test positive for HPV than negative for HPV (38, 59). Despite this, the biological behaviour of HPV-positive HNSCCs may be altered by tobacco use, with reduction in responsiveness to therapy inversely correlated with increases in pack/year exposure (38).

In a national study of women aged 17 to 40 years, though Aboriginal and Torres Strait Islander women were more likely to have abnormal pap smear results than non-Indigenous women, no significant difference in HPV16 or 18 status was found (61). However, in some areas like East Arnhem Land in the NT, the age-standardised incidence rates of HPV infection are higher amongst Indigenous women than the National average rates. Lower uptake of the Gardasil vaccination has been reported amongst Indigenous school girls aged 12 to 17 compared with non-Indigenous girls of the same age in QLD and the NT. In the NT, the lower rates of uptake were partly attributable to difficulties gaining timely written consent from parents of children attending boarding schools. In QLD, lower school attendance rates amongst Aboriginal and Torres Strait Islander girls prevents many from completing the recommended three-dose course (62). As yet, estimates have not yet been published of how many HNCs amongst Aboriginal and Torres Strait Islander populations are HPV-related, though preliminary data for the NT indicated that alcohol and tobacco were much greater risk factors in the cohort studied (63).

1.2.1.3 Ultraviolet radiation (UV)

Melanoma and other malignant neoplasms of the skin represent just 1% of cancers amongst Aboriginal and Torres Strait Islander people compared with 4% amongst non-Indigenous Australians. Despite this, between 2005 to 2006 skin cancers were recorded as the second most common primary

site for which Aboriginal and Torres Strait Islander people were hospitalised (20).

1.2.2 Risk factors for thyroid carcinoma

Papillary thyroid carcinoma is the most common type of thyroid cancer, accounting for 60 to 70% of all thyroid cancers (64). Other types of thyroid carcinomas include follicular, medullary, anaplastic, hurthle cell, insular, lymphoma, metastatic and SCC (64). Though genetic disorders have been associated with a small number of thyroid malignancies, exposure to ionising radiation remains the only well-established known risk factor for thyroid cancers (6, 64, 65).

1.2.3 Risk factors for nasopharyngeal carcinoma (NPC)

NPCs have been associated with industrial exposure to chemical fumes and wood dust (66-68). There is also a strong link between Epstein-Barr virus (EBV) infection and the development of non-keratinising, undifferentiated, NPC. EBV (also known as Human Herpes Virus 4) is a one of the most common viruses, with the vast majority of the world having been exposed to it. Despite this, rarely does EBV lead to cancer, as other environmental factors and genetic susceptibility also play an etiological role in carcinogenesis (68-70). NPC has been strongly linked to genetic factors with increased risk in a first-degree family member reported to be as high as 20 times. Tobacco and alcohol consumption have not been associated as risk factors for NPC (68).

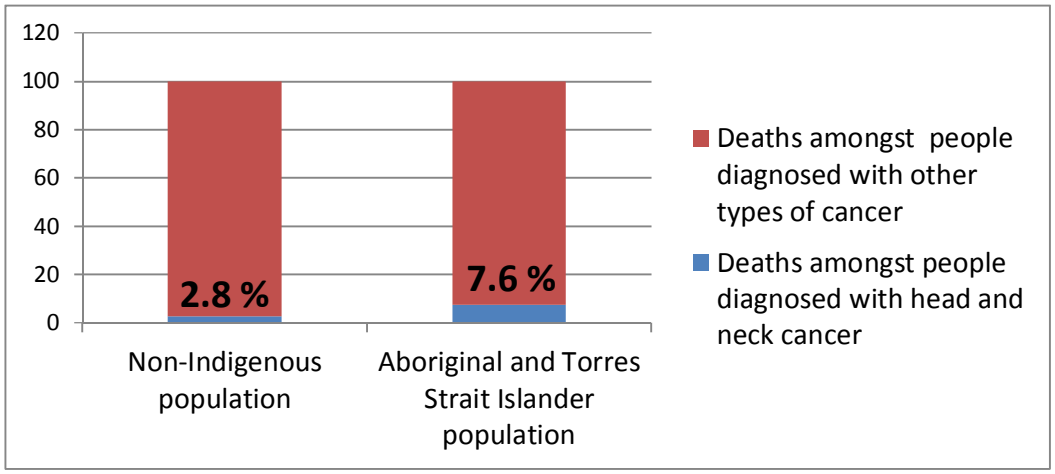
1.3 Outcomes for Aboriginal and Torres Strait Islander people with experience of HNC

1.3.1 Mortality rates amongst Aboriginal and Torres Strait Islander populations diagnosed with cancer

Markedly higher mortality rates have been observed amongst Aboriginal and Torres Strait Islander people diagnosed with cancer compared with others diagnosed with cancer in Australia (8, 16, 17, 71). Between 2004 and 2008, cancer remained the second highest recorded cause of death due to disease amongst Aboriginal and Torres Strait Islander people (18%), after circulatory diseases (27%) (72). Although the gap between Aboriginal and Torres Strait Islander people and other Australians for deaths due to circulatory diseases improved over this period, the overall life expectancy gap did not improve. This is partly due to the rate of improvement in cancer mortality being lesser for Aboriginal and Torres Strait Islander people than for other Australians; widening the gap between Aboriginal and Torres Strait Islander people and other people in Australia, in relation to deaths from cancer (72).

Between 2007 and 2011, there were 3,288 deaths recorded amongst non-Indigenous people diagnosed with HNC in NSW, QLD, WA and the NT, accounting for 2.8% of all deaths recorded amongst non-Indigenous people diagnosed with cancer in these regions. During that same time period, there were 197 deaths amongst Aboriginal and Torres Strait Islander people diagnosed with HNC in NSW, QLD, WA and the NT, accounting for 7.6% of all deaths amongst Aboriginal and Torres Strait Islander people diagnosed with cancer in these regions (16). See Figure 7 for a comparison of HNC-related deaths amongst Indigenous populations compared to non-Indigenous populations (16)

Figure 7 - The percentage of deaths amongst people diagnosed with HNC primaries amongst all deaths from cancer amongst Indigenous and non-Indigenous populations and in NSW, QLD, WA and the NT (AIHW)



1.3.2 Survival rates after diagnosis of cancer amongst Aboriginal and Torres Strait Islander populations

As well as higher cancer incidence and cancer-related mortality, Aboriginal and Torres Strait Islander populations are also experiencing poorer outcomes in terms of survival after cancer diagnosis. Aboriginal and Torres Strait Islander people diagnosed with cancer between 1999 and 2007 had a 40% chance of surviving five years after diagnosis compared to a 52% chance observed amongst other Australians (16).

South Australian Cancer Registry (SACR) data from 1977 to 2003 showed that Aboriginal and Torres Strait Islander patients had poorer expected 5- and 10-year survival after cancer diagnosis compared to other Australian patients, and even poorer actual five year and ten year survival after cancer diagnosis than expected (10). Cancer registry data analyses from QLD, NSW and the NT have also reported lower cancer survival rates for Aboriginal and Torres Strait Islander people compared to non-Indigenous Australians (11, 12, 73).

1.3.3 Factors contributing to poorer outcomes for Aboriginal and Torres Strait Islander patients diagnosed with HNC

Analyses of epidemiological data are beginning to reveal factors that contribute to higher mortality rates and lesser disease-free survival observed amongst Aboriginal and Torres Strait Islander populations diagnosed with HNC.

1.3.3.1 Advanced disease at diagnosis

In SA, the NT and QLD data, Aboriginal and Torres Strait Islander people were more likely than other Australians to have advanced disease at diagnosis for most types of cancers (11, 12, 15, 18, 71), with the exception of the opposite being found for lung cancers in the NT (71). The importance of detecting, diagnosing and treating HNC as early as possible cannot be stressed enough. SA hospital data from 1987 to 1998, showed the five year survival rate for patients diagnosed with cancers of the oropharynx and hypopharynx was 76% for early diagnosed cancers (TNM stages I & II), reducing to 48% for moderately advanced tumours without evidence of distant spread, and 28% for those with metastatic spread to distant organs (6). Patients who are diagnosed with HNC at a later stage tend to experience significantly reduced survival time after diagnosis and have a significantly increased risk of dying of the disease process. Even in the curative setting, patients are more likely to suffer from major symptoms of the disease progression alongside major side effects from the more aggressive treatment techniques necessary, which ultimately have major impacts on their HRQL.

1.3.3.2 Limited access to preventative, diagnostic and treatment facilities

The lower survival rates observed amongst Aboriginal and Torres Strait Islander patients with cancer compared to other Australian cancer patients may be partly attributed to advanced stage of disease at diagnosis and partly attributed to the higher incidence amongst Aboriginal and Torres Strait Islanders of some types of cancers that have poorer prognoses such as those of the lung and liver (10, 17). However, even after adjusting for cancer type and stage of cancer progression at diagnosis higher case fatalities still present in Aboriginal and Torres Strait Islander people than in other populations in Australia, suggesting poorer outcomes of treatment (10).

Despite higher cancer incidences and mortality, between July 2006 and November 2010, Aboriginal and Torres Strait Islander people were less likely to be hospitalised for a principal diagnosis of cancer, with 113 per 10,000 people admitted compared to 170 per 10,000 throughout the non-Indigenous population in Australia (16). People living in rural and remote areas tend to have more health issues, higher mortality rates and lower levels of education, income and employment than people living in city areas (74). While the vast majority of Aboriginal and Torres Strait Islander people live in urban or regional areas, in 2006, approximately 24% of Aboriginal and Torres Strait Islander people lived in remote or very remote locations (9% in remote areas and 15% in very remote areas), compared to just 2% of other Australians (20). Geographical barriers for people living in remote and very remote areas can cause issues with access to preventative, diagnostic and curative health-care services (75, 76). Poorer outcomes for HNC have been observed in Aboriginal and Torres Strait Islander populations living in rural and remote areas and research suggests that the further a personôs residential address is from major treatment centres, the poorer their cancer outcome (15, 17, 73).

1.3.3.3 Other factors contributing to poorer outcomes for Aboriginal and Torres Strait Islander patients

Co-morbidity is high amongst Aboriginal and Torres Strait Islander populations, with half the people aged over 15 years and over recorded as having a disability or long term health condition (72). Diabetes, cardiovascular disease, renal disease, respiratory organ disease, infectious diseases and injuries are more common in Aboriginal and Torres Strait Islanders than other Australians and this likely contributes to poorer treatment outcomes (20).

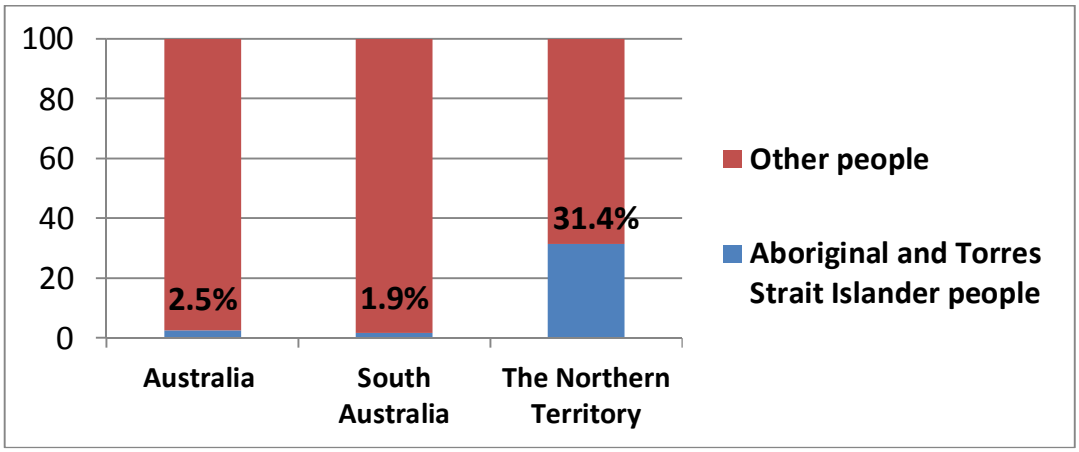
However, even after adjusting for stage at diagnosis, mode of treatment and presence of co-morbidities, a matched-cohort study of cancer patients in QLD observed higher mortality rates amongst the Aboriginal and Torres Strait Islander population compared to the non-Indigenous population (11). Socio-economic deprivation, cultural marginalisation, excess body weight and exposure to violence are other risk factors commonly encountered by Aboriginal and Torres Strait Islander people which impact negatively on health outcomes (20). Epidemiological data from the NT suggests that treatment outcomes for all cancers were consistently poorer for Aboriginal and Torres Strait Islander people whose first language was an Indigenous language; suggesting communication barriers and cultural differences may also contribute to poorer treatment outcomes for Aboriginal and Torres Strait Islander patients from rural or remote locations (77, 78).

1.4 Why is the experience of HNC different for Aboriginal and Torres Straight Islander people?

1.4.1 Aboriginal and Torres Strait Islander populations in Australia

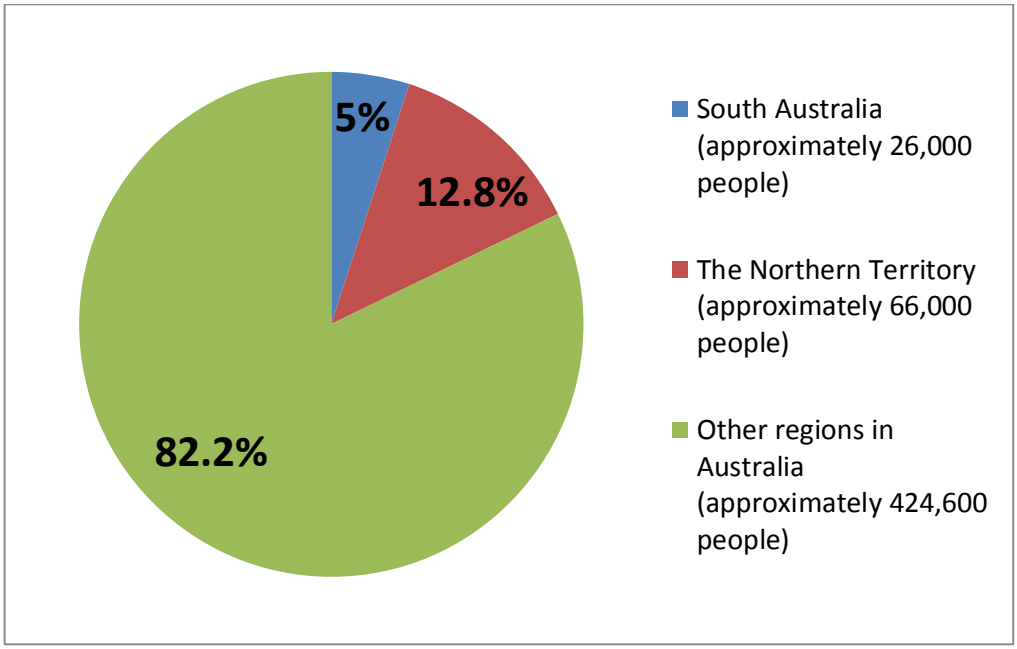
All population-based data reported in this study is based on Australian Bureau of Statistics (ABS) population estimates for Aboriginal and Torres Strait Islander people in Australia, SA and the NT in 2006. It was estimated that there were approximately 517,200 Aboriginal and Torres Strait Islander people residing in Australia, representing approximately 2.5% of the total Australian population (20). In SA, there were approximately 26,000 Aboriginal and Torres Strait Islander residents, representing 1.7% of the total SA population and 5% of all Aboriginal and Torres Strait Islander people in Australia. In the NT there were approximately 66,600 Aboriginal and Torres Strait Islander residents, representing 31.6% of the overall NT population and 12.8% of all Aboriginal and Torres Strait Islander residing in Australia, as illustrated below in Figure 8 (20).

Figure 8 - The estimated populations of Aboriginal and Torres Strait Islander people residing in Australia, SA and The NT in 2006 (ABS)



Below, Figure 9 illustrates that the combined populations of Aboriginal and Torres Strait Islander people residing in SA and the NT represent a significant proportion of these populations [37].

Figure 9 - Distribution of Aboriginal and Torres Strait Islander populations in SA, the NT and elsewhere in Australia based on 2006 estimates (ABS)



The Indigenous populations of Australia are now minority populations, marginalised within a foreign, dominant culture (30). A history of foreign oppression and segregation, disconnection from homelands, family, identity and culture, and ongoing racism, have all contributed to marginalization and subsequently poorer socioeconomic determinants of health are experienced within the Aboriginal and Torres Strait Islander populations compared with non-Indigenous Australian populations (28, 79-84).

1.4.2 A brief history of Aboriginal and Torres Strait Islander people's experiences of post-colonial Australia

Cultural and historical circumstances must be considered when approaching sensitive topics such as HRQL, with Aboriginal and Torres Strait Islander people (30). Post-colonial policies of oppression and segregation still influence the beliefs and behaviour of many Aboriginal and Torres Strait Islander people today. Whether well intended or not, colonial policies of annihilation, segregation and assimilation have systematically dispossessed Aboriginal and Torres Strait Islander people from their land, languages, family, culture and spirituality and this influences their health, behaviour around health and ultimately HRQL. Many Aboriginal and Torres Strait Islander people affected by past policies and actions continue to recount their personal and family histories to younger generations of their families. As a result, throughout all generations Aboriginal and Torres Strait Islander populations, there is ongoing, widespread mistrust of white Australians, government or other recognized bodies of authority. This is an important factor to consider when engaging with some Aboriginal and Torres Strait Islander people in a government hospital setting.

Aboriginal and Torres Strait Islander people were amongst the oldest, most sustainable and most isolated cultures on Earth with a population estimate of around 750,000 people and a presence in the land now known as Australia, dating back to at least 40,000 years prior to European colonization (85). The first British colony in Australia was established just over 200 years ago in Sydney in 1788 (80). However, foreign colonisation only reached some very remote parts of the country in the last 60 or so years (79). Therefore, diversity amongst Aboriginal and Torres Strait Islander populations in regard to individualôs experiences and exposure to the post-colonial contact and policies mentioned below should be noted.

In 1829, Australia was officially declared by the British to be under British óCrown Lawô, which meant all Australian inhabitants, including Aboriginal and Torres Strait Islander people, were British ósubjectsô (80). However, under this new rule Aboriginal and Torres Strait Islander people were not considered Australian ócitizensô. Such was the disregard for the rights of the traditional owners of the land, that in 1835 the official British Government position was óterra nulliusô - Latin for óland of no-oneô (28, 79, 80). Resistance fighting against the European settlers led to the deaths of at least 20,000 Aboriginal and Torres Strait Islander people between 1788 and the 1930s. Many individuals were shot and entire populations were wiped out through en masse massacres or having their waterholes poisoned (79, 81).

Throughout the process of European colonisation, newcomers cleared massive areas of land for agriculture and other purposes. This had obvious detrimental effects on the ecology of these regions and severely affected Aboriginal and Torres Strait Islander peopleôs livelihoods by reducing their access food, water, shelter and other essential resources necessary for their ways of living. This lack of resources progressively forced Aboriginal and Torres Strait Islander people into smaller areas and many died due to lack of resources and exposure to newly-introduced diseases (85). In the mid to late 1800s, many Aboriginal and Torres Strait Islander people were relocated, often against their will, from their homelands in the South Eastern regions of Australia to newly founded reserves and religious missions. Many of these institutions were soon closed as Aboriginal and Torres Strait Islander populations declined due to the rapid spread of diseases promoted by such close confines (85). Involuntary relocations continued into the next century for varying reasons including the testing of nuclear weapons by the British Government on Aboriginal homelands at Emu Field and Maralinga in the Great Victoria Desert areas in northern South Australia between 1953 and 1963 (86, 87). As a result of

relocations, many Aboriginal people today live in areas other than their traditional homelands, often having to share land and resources with other Aboriginal groups with different cultural and linguist backgrounds. This contributes to domestic tensions and instability for some Aboriginal and Torres Strait Islander people.

Between 1869 and the 1970s, many Aboriginal children were taken away from their parents and families by government and church bodies and placed in missions, boarding houses, orphanages and white foster homes (84). The óAborigines Actô gave the Government appointed óProtector of Aborginesô absolute power of legal guardianship over all Aboriginal people under the age of 16 years and he could remove children from their parents or family with police assistance as he saw fit (84). Parents were given no legal rights to dispute this. As a result, many Aboriginal children (particularly those of mixed descent) were forcibly taken away and often parents were not told where their children were, their childrenôs names were changed or the children were told that their parents were dead (84). Many children never found their way home and suffered immensely, both emotionally and physically, as a result of this removal policy and subsequent widespread abuse encountered at many places that they were sent (84). These children are now known in Australia as the óStolen Generationô (84). The majority of Aboriginal families today are still affected by the unfair laws and forced removal policies of the past and this likely contributes to their physical and mental health and HRQL.

Until 1967 (when the referendum was held and Aboriginal and Torres Strait Islander people were finally counted in the census giving them automatic citizenship rights), most Aboriginal and Torres Strait Islander people had no legal rights to paid work or to own land or property (82). Furthermore, many places had racial segregation laws in place, commonly known as óapartheidô (82). Laws pertaining to Aboriginal and Torres Strait

Islander people varied from state to state, but all states had laws in place that violated Aboriginal and Torres Strait Islander peoplesô basic human rights and freedoms; such as the right to move freely from reserves or missions and the right to marry who they chose without having to get permission from government representatives (83, 84). Gaining citizenship rights was significant in terms of Aboriginal and Torres Strait Islander people gaining rights to earn a fair working wage, to move about freely, and to own property and land, though these rights were not automatically forthcoming. Citizen rights should not be confused with the achievement of racial equity, as even almost half a century on this is far from achieved and racism towards Aboriginal and Torres Strait Islander people is widespread throughout Australia today.

1.5 The complex and challenging journey for a HNC patient

The journey to diagnosis, disease characterisation and treatment planning for HNC is complex and can be a stressful and daunting time for the patient and their support network. Patients are commonly referred to specialist consultants from general practitioners after presenting with signs or symptoms of disease. However, some patients present through hospital emergency departments with advanced disease progression requiring immediate attention due to acutely life threatening symptoms of disease such as airway obstructions, infection, major bleeding or severe malnutrition due to dysphagia. Patients with experience of HNC are at substantial risk for experiencing psychological distress including post-traumatic stress disorder, anxiety, depression, agoraphobia and/or suicidal ideation and therefore providing ongoing support and attention to HRQL issues is of utmost importance (38, 88, 89). Building social rapport, trust and mutual understanding with Aboriginal and Torres Strait Islander patients is particularly important, as invasive examination and investigative procedures, foreign biomedical environments, language barriers, historical contexts and other factors can compound the risk of psychological distress.

1.5.1 Common symptoms at presentation for patients diagnosed with HNC

Symptoms at presentation for patients diagnosed with HNC vary widely and are dependent on many factors including tumour stage, location and type. Symptoms vary from an incidental finding in an otherwise asymptomatic patient to severely debilitating functional impairments in later staged disease. Common symptoms in the head and neck regions

include pain, discomfort, lesions, ulceration, infection, lymphadenopathy, unusual lumps or masses, bleeding or nerve sensitivity, numbness or palsy, odynophagia, dysphagia, dysphonia, dysarthria, stridor, trismus, fatigue, weight loss, or altered taste or smell, tinnitus, otitis media or hearing loss. A persistent, non-healing sore throat is one of the most common symptoms of HNC. Inflammation and infection of the tonsils may cause the patient to feel a foreign body sensation in their throat and may also cause halitosis (90). Pain at the tumour site is a common symptom and may be the direct result of an ulcerative lesion or caused by the mass effect of the tumour putting pressure on other tissues and organs (91). Enlargement of the tonsils and base of tongue may contribute to upper airway obstruction, especially if the soft palate and uvula extend posteriorly (90).

1.5.2 Management of HNC at the RAH

Management of HNC is complex and depends on multiple individual factors including tumour type, location, stage and the patientôs age and general health (2, 3, 92). The RAH Department of Otolaryngology, Head & Neck Surgery is a recognized centre of excellence for the treatment of HNC and is the tertiary referral centre for HNC patients from urban and remote areas in and around SA and the NT (93). The Otorhinolaryngology and Head and Neck Unit works in partnership with the other South Australian Otorhinolaryngology Units in the Central Northern Health Service (at Lyell McEwin, Modbury and Queen Elizabeth Hospitals) and has an affiliation with the Head & Neck Unit from Flinders Medical Centre (93).

1.5.2.1 Multidisciplinary team decision making

Most centres that specialise in the treatment of HNC, hold multidisciplinary team (MDT) meetings where specialist medical and allied health care professionals meet to discuss the diagnosis, treatment and ongoing care of patients (94, 95). At the RAH, a MDT of HNC specialists (including radiation and medical oncologists, otolaryngologists, oral and maxillofacial surgeons, plastic surgeons, dentists, dieticians and speech pathologists) meet each week to discuss individual patientsô cases and decide on best practice treatment options. Apart from influencing treatment decisions, MDT meetings have been shown to improve the accuracy of cancer staging and subsequent treatment outcomes (96). In the last twenty years, data from PROMs, including HRQL data, have had an increasing influence on this decision making process. Guidelines for decision making around treatment options for HNC can be found in the National Comprehensive Cancer Networkôs óClinical Practice Guidelines in Oncology ï Head and Neck Cancersô (97). These guidelines and clinical decisions about best practice for the treatment of HNC are constantly evolving as new and better treatment techniques are developed and more knowledge is discovered and shared.

1.5.2.2 Curative vs. palliative treatment options

The primary goals for the treatment of HNC are to maximise cure and to maintain functional status through organ preservation (98). Usually dependent on multiple factors including tumour type, location, stage and the patientôs age and general health; curative treatment options for patients with HNC can include primary surgery, primary radiotherapy or surgery with adjuvant radiotherapy. Chemotherapy may also be given alongside radiotherapy as a radiosensitiser. For late stage HNC, therapy with curative intent is multimodal (38). For potentially resectable stage III or

IV HNC, surgery followed by postoperative radiotherapy is standard practice. Indications for postoperative radiotherapy include the tumour involving the surgical margins of excision, perineural involvement, bone or cartilage invasion, advanced primary tumour (T3 or T4) or nodal disease (N2 or N3). Research suggests that there is significant survival benefit for patients with extracapsular spread and/or microscopically involved margins, who undergo surgery with post-operative (chemo)-radiotherapy as opposed to those who undergo surgery and post-operative radiotherapy alone. However, there is a significant increase in acute severe mucosal toxicity and suggestion that the longer term toxic effects are also higher in the cohorts who undergo concomitant (chemo)-radiation (98-100).

Sometimes patients present with co-morbidities and/or complex disease progression, deeming the potential benefits of radical treatment with curative intent as outweighed by the potential risks of treatment-associated fatality or morbidity. In these cases, palliative treatment may be offered (in the form of modified surgery, radiotherapy or chemotherapy, or supportive care alone) with intent to slow disease progression or lessen disease-related symptoms, with a focus on HRQL (38).

Symptoms of HNC and side effects from HNC treatment vary greatly and depend on tumour site, pathology and staging, treatment modalities and regimes and individual patient characteristics such as age, co-morbidities and general health. Therefore it is difficult to concisely describe all possible adverse effects of HNC treatment in relation to individual contexts (38).

1.5.3 Surgical treatment for HNC, potential side-effects and complications

Since its inception, HNC surgery has continued to evolve with the aim of reducing treatment related morbidity and improving QoL whilst preserving positive oncological outcomes. Around 100 years ago, comprehensive radical neck dissection (including the removal of the internal jugular vein, sternocleidomastoid muscle and spinal accessory nerve) was considered the standard treatment for patients with neck node metastases and this resulted in significant functional and cosmetic morbidities for these patients. The introduction of the modified radical neck and later the selective neck dissection meant that the majority of HNC patients could avoid surgical sacrifice of these nerves, which greatly improved their functional outcomes without detriment to oncological outcomes (101).

Surgical intervention to remove or de-bulk HNC can cause major anatomical changes and result in short and long term side effects and impairments. Regardless of experience or technical skill, all HNC surgeons encounter surgical complications due to the complexities of the disease and individuals treated and the intricate anatomy of the head and neck region. These surgical complications have been associated with the patient having prior radiotherapy, medical co-morbidities, substance abuse, aero-digestive tract entry, prolonged anaesthesia times, the volume of intra-operative fluid administered and the need for microvascular free flap reconstruction (101).

Acute side effects or complications may include pain, discomfort, disfigured appearance, seroma, haematoma, wound dehiscence, flap necrosis, seroma, wound infection, salivary fistula, scar formation, chyle leak, pneumothorax, chylothorax, stridor, aspiration risk, oedema,

dysphagia, nutritional deficiency, weight loss or short-term dependence on a nasoenteric feeding tube (102).

Chronic, long term or permanent side effects related to surgical treatment of HNC may include dysphonia, dysarthria, dependency on a tracheo-stomal fistula for breathing, dysphagia and/or dependency on an enteral feeding tube, olfactory dysfunction, nerve paralysis or dysfunction, disfigured appearance and oedema (102).

1.5.4 Radiotherapy treatment for HNC, potential side effects and complications

Radiotherapy treatment (RXT) includes simulation, treatment planning, verification, dose delivery and quality assurance. RXT target areas include not only the gross volume of the tumour, but also areas at risk for spread (such as adjacent tissues or regions of lymphatic drainage) as well as a margin to correct for possible variability in daily positioning and patient motion during treatment (98).

Intensity-modulated RXT for advanced HNC can boost radiotherapy doses to tumour target areas whilst it may spare vital organs (including the major and minor salivary glands in the oral cavity, the mandible pharyngeal musculature, inner and middle ears, temporomandibular joints, temporal brain lobes and optic pathways) in an attempt to reduce treatment-associated morbidity (98).

Potential side effects of RXT treatment include pain, dermatitis, xerostomia, nausea and vomiting, oedema, dysphagia, trismus, weight loss, nutritional deficiencies, mucositis, radiation caries, orocutaneous fistula, osteoradionecrosis, hair loss, neurotoxicity, hearing loss or hypothyroidism (98). Acute side effects from RXT toxicities include

mucositis, odynophagia, dysphagia, hoarseness, xerostomia, dermatitis, and weight loss. Late toxicities may present months or even years later and include xerostomia, osteoradionecrosis, fibrosis, thyroid dysfunction, carotid artery rupture, and radiation-induced myelitis. Acute toxicity from radiotherapy treatment is a result of rapidly dividing epithelial, mucosal membrane, bone marrow and tumour cell tissues, while late toxicity is a result of late-responding tissues such as the spinal cord, brain cells and connective tissue (38, 98).

1.5.5 Chemotherapy treatment for HNC, potential side effects and complications

For treatment of HNC, chemotherapy is most often utilised in combined modality with radiotherapy, when avoiding surgery for organ preservation, post-surgery in the adjuvant setting, or neoadjuvantly before surgery or radiotherapy (103) . Cytotoxicity is increased with the addition of chemotherapy to the treatment regime and as chemotherapeutic agents are less targeted that surgery or radiotherapy, other organs such as the liver or audiosensory anatomy are also susceptible (104, 105). Chemotherapy is sometimes used as the sole treatment modality in the palliative setting when patients present with metastatic disease. HRQL data has become increasingly important for assessing potential benefit versus risk ratios in regard to the addition and dosing of chemotherapeutic agents in the treatment regime (103).

1.5.6 Ongoing monitoring and support for patients with experience of HNC in South and Central Australia

Many health care professionals are involved in the treatment, care and ongoing monitoring of HNC patients; including general practitioners, Aboriginal health workers and liaison officers, social workers, specialist

clinicians, specialist nurses, speech and swallowing pathologists, dieticians and nutritionists, special needs dentists, and palliative care professionals. Further to this, family, friends, carers and other cancer survivors play crucial roles in the monitoring and ongoing support of patients with experience of HNC.

1.5.7 Palliative and End of Life care

In 2007, there were 898 deaths recorded amongst people diagnosed with HNC in Australia, accounting for 2.3 % of all cancer-related deaths (106). Considering all types and stages of HNC, the five year survival rate for patients after diagnosis is 59% (38). The medical discipline of palliative care aims to reduce the suffering of patients and their families by providing care aimed at relieving acute and chronic symptoms of disease, considering the physical, social, emotional and spiritual impacts of disease rather than simply attempting to prolong life (38). Therefore, specific palliative care services aimed at end of life care are of utmost priority for the HRQL of patients with experience of HNC and their support networks.

In SA and the NT, primary service providers are involved in the delivery of general palliative care services to patients and their families throughout the course of a life-limiting illness. Palliation services may involve general practitioners, medical consultants and allied health professionals from a variety of disciplines, community care nurses, Indigenous health care providers, carers, public and private hospitals, residential aged care facilities, aged care assessment teams, remote health centres, non-government providers (such as Red Cross, home care services and private nursing agencies) and complementary therapists (107). Further to this general support, there are specialist palliative care teams in SA and the NT, to provide care to patients and their support networks aimed at improving patient QoL when cure is no longer possible (107). As

previously mentioned, patients with HNC experience complex symptom clusters and advanced care planning and decision-making is often complex requiring the involvement of specialist palliative care expertise.

In the NT, ŏTerritory Palliative Careô provides specialist palliative care with physicians, specialist nurses and Aboriginal health workers in two teams based in CA and the Top End. These teams support the work of primary medical providers and community nurses in providing care for patients at their place of residence, including residential care facilities. These teams also provide a consultancy service to ASH, RDH and Darwin Private Hospital, and run outpatient clinics at ASH and RDH (107). In the Top End, ŏTerritory Palliative Careô works as a multi-disciplinary team which includes a social worker, Aboriginal health workers, occupational therapist, dietician, physiotherapist and pastoral carer who provide services directly to palliative care patients, as well as consultancy services to other allied health professionals. There is also a 12-bed hospice on the grounds of RDH that accepts admissions for complex symptom management, including complex social and family issues, which may include transition from hospital to home, or for care in the final stages of illness. Respite care is limited to those patients and families who have particular complexities to their care and patients without complex issues who are not in a terminal phase may need to transition to a longer term care facility. In addition, a bereavement service is offered to family members and significant others who can access this service locally in Darwin (107). In CA and remote communities in the Top End, there is no provision of bereavement services through ŏTerritory Palliative Careô. In CA, ŏTerritory Palliative Careô provides a consultancy service to inpatients at ASH though they do not have access to specialist inpatient beds or hospice care (107).

In SA, the Palliative Care team at the RAH is part of the ócCentral and Western Palliative Care Serviceô, who provide specialised palliative care to patients in the acute hospital setting, hospice, and for patients at home (108). ócThe Central and Western Palliative Care Serviceôis provided by a multidisciplinary team; including specialist palliative care providers, a part-time pharmacist, a psychiatrist, social workers and an occupational therapist. Unfortunately, this service does not currently employ any Aboriginal health workers.

1.6 Assessing the health-related quality of life (HRQL) of patients with experience of HNC in Australia

1.6.1 What is HRQL and why do we clinically assess it?

Quality of life (QoL) is a subjective, multi-dimensional and complex concept which includes all things that can impact a personôs well-being and satisfaction with life (109). *Morton* defines QoL as:

> *ñThe perceived discrepancy between the reality of what one has, and the concept of what one expects or wantsò (110).*

Being subjective, QoL can mean many things to different people. As *Lowe and Rogers* state:

> *ñTo the patient it is an implicit state of being, something known that cannot be told. Whilst to the researcher it is a difficult measurement problem and to the clinician, just one of many other equally relevant inputs into a clinical judgement.ò(111)*

Health-related quality of life (HRQL) specifically examines the impact of illness, disease and health treatment to a personôs life and how they perceive this impact in relation to their general wellbeing and satisfaction with life (112-114).

A personôs HRQL is influenced by their lived experienced of illness across a broad range of domains. These domains commonly include physical symptoms and functional impairments from disease and side effects of treatment, along with other factors such as psychological, emotional and spiritual wellbeing, social functioning and wellbeing, the ability to fulfil the everyday roles they undertook before their health problems, sexual functioning and sexuality, cognitive functioning, financial capacity and unmet needs for information and support services (115).

1.6.2 Measuring the HRQL of patients with experience of HNC

In the past, clinicians treating patients for cancer focussed primarily on local regional control of tumours, with the aim of maximising patient survival. Less attention was given to important HRQL issues such as the psychosocial wellbeing of the patient or maximising the patientôs return to pre-illness functional status (89, 116, 117). The effects of HNC and its treatment can have significant and often devastating effects on the function, appearance, emotional wellbeing, socialisation and ultimately the quality of life of patients (116-121).

The health-related needs of people with HNC often exceed those of people diagnosed with other cancers and the ongoing care and monitoring of HNC patients is often necessary long after remission (122). Thus, to gain an adequate understanding of the HRQL of patients with experience of

HNC ongoing assessment with HNC-specific HRQL instruments is necessary.

1.6.2.1 Commonly used instruments for assessing the HRQL of patients with experience of HNC

10 different questionnaires have been specifically designed and validated (to varying degrees) for assessing the HRQL of patients with HNC (115). Of these, the most commonly used with HNC patients in Australia and throughout the world are "The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire 30" with "The European Organisation for Research and Treatment of Cancer - Head and Neck Cancer Quality of Life Questionnaire 30", "The Functional Assessment of Cancer Therapy – Head and Neck Scale" and "The University of Washington Head and Neck Cancer Quality of Life Questionnaire" (111)

The European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire 30 is a tool with 30 general QoL questions that are of importance for cancer patients in general. The European Organisation for Research and Treatment of Cancer - Head and Neck Cancer Quality of Life Questionnaire 35 has an additional 35 questions that are of specific importance to HNC patients. Both EORTC questionnaires primarily focus on physical and functional aspects of HRQL, with three additional questions about the impact of illness and treatment on family, social and financial wellbeing.

The original "Functional Assessment of Cancer Therapy QoL Questionnaire" (FACT-G Version 1) was developed in the United States of America (USA) for general use with patients with all types of cancer and consisted of 38 items scored using a five-point Likert scale. FACT-G

Version 2 was published in 1993 after validation with 316 to 545 cancer patients (109). The current version (FACT-G Version 4) consists of 28 items.

õThe Functional Assessment of Cancer Therapy ï Head and Neck Scaleô (FACT-HN) is a cancer-specific HRQL assessment tool (FACT-G) with additional questions specifically designed for use with patients with experience of HNC (109, 118). This instrument consists of the four cancer-specific domains from FACT-G (physical, social/family, emotional and functional wellbeing) as well as a domain containing 12 additional items addressing concerns specifically related to HNC (118, 123). FACT-HN was developed for general use with all patients with experience of HNC, including those treated with surgery, radiotherapy and/or chemotherapy. Of all the HNC-specific HRQL instruments, FACT-HN covers the broadest range of HRQL domains (124, 125). It was first published in 1996, after validation with 151 patients with HNC in the USA (126, 127).

õThe University of Washington Quality of Life Assessmentô (WQLQ) was also developed in the USA and was originally designed for measuring HRQL outcomes after HNC surgery. Since then, WQLQ has also identified effects in patients who have undergone (chemo)-radiotherapy (127, 128). The current WQLQ (version 4) has 12 domains covering the HNC-related issues of pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder function, taste, saliva, mood and anxiety. Each question is scored from worst (0) to best (100) according to the hierarchy of response (129). A multiple-choice question about the 3 most important issues during the past 7 days gives these domains some patient ranked order. In addition there are three questions that use a six-point Likert scale to ask patientsô about their HRQL and global QoL. Furthermore, WQLQ has a free text section for patientsô own annotations (111).

WQLQ was originally published in 1993 after validation with a range of patients with different HNCs (130). In 2001, after trial with over 500 Seattle-based HNC patients, a modified version of the instrument was published (WQLQ version 4). Two of the original questions were removed to improve internal consistency and additional mood and anxiety domains were included, along with questions about overall HRQL and global QoL (124). Since then, validity data have been reported in patients with HNC cancers of the oral cavity and/or oropharynx, nasopharynx, and larynx, patients undergoing neck dissection to remove lymph nodes and patients feeding via PEG (127, 128).

1.6.2.2 Benefits of assessing the HRQL of patients with experience of HNC

In addition to the research value of assessing clinical parameters like treatment techniques, evaluation of HRQL in individual patients has become an increasingly important clinical parameter (131). Many benefits of HRQL assessment have been reported for both HNC patients and HNC clinicians; including to assess new and existing treatments and techniques, to increase cliniciansô abilities to provide better information for patients, to help weigh up treatment options and help patient decision making, to improve clinical consultation and follow-up, and to help detect problems and implement timely clinical interventions to improve patient QoL and psychosocial well-being (132, 133). Despite these benefits, currently used HNC-specific, HRQL questionnaires were not developed with the intent of offering direct benefit to clinical interactions with patients.

It has long been established that patient and clinician aims and priorities for treatment can diverge considerably (132). Evaluating the HRQL of an individual can help clinicians to become more patient-focused and defer to their patientsô wishes (132). In the year 2000, a study by List *et al*, showed that HNC patient priorities primarily lie in achieving cure, then survival as

long as possible, then QoL issues (134). However, there was significant variability between patients, therefore it is important to seek individual patient views and not to make assumptions based on the majority (132, 134).

HRQL assessment is also important for comparing new treatment techniques to established ones and most research funding bodies require that HRQL assessment be an integral part of the clinical trial process (132). This is especially important when choosing between two different treatments with similar survival rates. For example, in oropharyngeal surgery, primary closures (when feasible) result in better swallowing outcomes for patients than free flap reconstruction. However, there is a distinct lack of high-quality prospective HRQL comparisons for some different treatments with equivalent cure rates; such as comparing primary radiotherapy to conservation laryngeal surgery for stage T1 or T2 laryngeal tumours and comparing surgery to chemo-radiotherapy for a stage T3 tonsillar tumour (132). Though cure and survival rates are equivalent, there are significant differences in side effects and functional outcomes from these different treatments and therefore HRQL outcomes and concerns are of utmost importance in determining which treatment is best for individuals.

1.6.2.3 Routine HRQL assessment of HNC patients in clinical practice

By assessing patient HRQL, clinicians gain valuable insights into the effects that their treatments have on individual patient lives, and this can help to improve clinical consultation and follow-up procedures (132). HRQL questionnaires have been shown to improve patient-clinician communication (111, 133, 135, 136) and the use of HRQL questionnaires in clinical practice can help clinicians and patients to identify issues of concern to the patient and trigger discussions of these issues (111).

Routine HRQL assessment during clinical practice can help clinicians to detect individual patientsô problems so that timely clinical interventions can be implemented (132). This can also help clinicians to identify ócriticalô periods and problems during the patient journey so these problems may be anticipated and clinical interventions implemented as early as possible (132). Previous studies have shown that the effect of HNC treatment is that the nadir of HRQL is reached at 3 to 6 months post-treatment and maximal improvement is reached at 1 to 2 years post-treatment (137). Following this, there may be a slow decline over a decade, as the issues relating to HRQL from the cancer recede and the impact of treatment on functionality increase (138). Long-term declines in the HRQL of HNC patients can be associated with factors such as the presence of a permanent or long-term tracheostomy and/or percutaneous gastrostomy (PEG) tube and have been linked to the presence of baseline (pre-treatment) co-morbidities (139).

In Australia, the practice of routinely assessing and collecting HRQL data in HNC clinics is relatively new and there is limited literature in this area (140). In 2013, the ósA HNC Pathwayô (the Statewide Cancer Clinical Networkôs guidelines for best practice in HNC management), recommended that HRQL assessment be included as part of routine clinical practice (141). The RAH Otorhinolaryngology Department has been collecting HRQL data for the last decade and since 2005 has employed a research assistant (the author of this manuscript) to routinely collect and analyse HRQL data from patients diagnosed with HNC.

1.6.2.4 The impact of cultural and ethnic identity on HRQL assessment

Culture and ethnicity can have significant impacts on patientsô HRQL priorities. HRQL assessment can help patients and clinicians to identify patient priorities so that this informs clinical practice. Elsewhere, there are

a growing number of studies examining HRQL in populations from differing cultural backgrounds and ethnicities. Ethnic and cultural differences can also have a significant impact on the validity and use of HRQL instruments (142). In Australia, particularly in a multicultural health care environment like the RAH, it is important to consider these differences when analysing population-based HRQL data. However, to date there have been no published studies examining the impact of HNC or treatment for HNC on the symptoms, wellbeing, functioning or HRQL of Aboriginal or Torres Strait Islander people.

To adequately address the health and well being of Indigenous people it is essential for health care professionals to adopt a culturally competent approach (143). Cultural competency in health care seeks to acknowledge and address disparities in cultural beliefs and practices that may prevent minority groups from accessing equitable healthcare and health outcomes (143). State and Federal guidelines on health practice with Indigenous people in Australia clearly state ñé the Australian health care system will not wittingly compromise the legitimate rights, practices, values and expectations of Indigenous peoplesé ò (144, 145). The privilege and power historically and contemporarily bestowed upon the dominant culture in Australia is imperceptible to the majority of Australians and the default positioning for health care practice is usually based on the ôunmarkedô cultural practices and standpoints of the dominant culture (146). In moving towards reconciliation and ôclosing the gapô in inequitable health outcomes and life expectancies for Indigenous people; we as health care professionals, researchers and policy makers have an obligation to rigorously examine our own racial and social positioning and how this impacts on health outcomes for Aboriginal and Torres Strait Islander people (143). Thus, investigation of current HNC-specific HRQL tools utilising a culturally competent approach to the cultural adaptation and translation of HRQL instruments is warranted.

CHAPTER 2:

Self-reported HRQL issues for Aboriginal patients with experience of HNC:

A review of relevant literature

Chapter 2. Self-reported HRQL issues for Aboriginal and Torres Strait Islander patients with experience of HNC: a review of literature

2.1 Methods for literature review

A search of peer-reviewed journal articles published prior to 2013 was undertaken using electronic databases Proquest, Medline, Science Direct, Informit, Indigenous Health Infonet, ISI Web of Knowledge and Google Scholar (see Articles were eligible for consideration if they reported original data from Indigenous people using patient-reported outcome measures or otherwise self-reporting on their experiences of cancer or cancer services in Australia. Additional articles including government and cancer council reports and other relevant grey literature were obtained through citation snowballing.

Content relating to self-reported HRQL outcomes was determined and categorised based around the Australian Psycho-Oncology Co-operative Research Groupôs definition of the term HRQL: ñé the impact of illness, disease and health treatment to a personôs life and their resulting ability to function physically, socially, mentally and emotionally.ò (115).

Table 2 - Key terms for literature search

self report OR patient report OR self reported OR self reports OR self reporting OR patient reports OR patient reporting OR self rated OR self rate OR self rating OR qualitative	cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*	australia* OR queensland OR new south wales OR victoria OR tasmania OR northern territory OR act	rural OR remote OR country OR aborigin* OR indigenous OR torres strait OR cultur*

Table 3 - Search engine phrases for literature search

Informit (Health and Indigenous)
(self report OR patient report OR self reported OR self reports OR self reporting OR patient reports OR patient reporting OR self rated OR self rate OR self rating OR qualitative) AND (cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) AND (australia* OR queensland OR new south wales OR victoria OR tasmania OR northern territory OR act) AND (rural OR remote OR country OR aborigin* OR indigenous OR torres strait)

Medline
(self report OR patient report OR self reported OR self reports OR self reporting OR patient reports OR patient reporting OR self rated OR self rate OR self rating OR qualitative) AND (cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) AND (australia* OR queensland OR new south wales OR victoria OR tasmania OR northern territory OR act) AND (rural OR remote OR country OR aborigin* OR indigenous OR torres strait)

Google Scholar
("self report*" OR "patient report*" OR "self rat*" OR qualitative) (palliat*) (australia* OR queensland OR "new south wales" OR victoria OR tasmania OR "northern territory" OR act) (aborigin* OR indigenous OR "torres strait")

("self report*" OR "patient report*" OR "self rat*" OR qualitative) (cancer* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) (aborigin* OR indigenous OR "torres strait")(australia* OR OR "northern territory" OR queensland OR "new south wales" OR victoria OR tasmania OR act)

("self report*" OR "patient report*" OR "self rat*" OR qualitative) (cancer* OR OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) (australia* OR queensland OR "new south wales" OR victoria OR tasmania OR "northern territory" OR act) (rural OR remote OR country)

Web of Knowledge
TS=("self report*" OR "patient report*" OR "self rate*" OR qualitative)AND(cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*)AND(australia* OR queensland OR "new south wales" OR victoria OR tasmania OR "northern territory" OR act)AND(rural OR remote OR country OR aborigin* OR indigenous OR "torres strait")

Science Direct
("self report" OR "patient report" OR "self reported" OR "self reports" OR "self reporting" OR "patient reports" OR "patient reporting" OR "self rated" OR "self rate" OR "self rating" OR qualitative) (cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) (australia* OR queensland OR "new south wales" OR victoria OR tasmania OR "northern territory" OR act) (rural OR remote OR country OR aborigin* OR indigenous OR "torres strait")

Embase

("self report" OR "patient report" OR "self reported" OR "self reports" OR "self reporting" OR "patient reports" OR "patient reporting" OR "self rated" OR "self rate" OR "self rating" OR qualitative) (cancer* OR neoplas* OR palliat* OR malignan* OR radiotherapy* OR surg* OR chemotherapy* OR onco*) (australia* OR queensland OR "new south wales" OR victoria OR tasmania OR "northern territory" OR act) (rural OR remote OR country OR aborigine OR indigenous OR "torres strait")

2.2 Findings from literature review

No publications reported Aboriginal or Torres Strait Islander people with experience of cancer using standard PROMs to assess the impact of clinical interventions. However, one study group has reported on the development and initial trialling of a novel PROM for assessing the unmet supportive needs of Aboriginal and Torres Strait Islander people with experience of cancer in QLD (147-151). As supportive care is aimed at improving QoL through activities that alleviate symptoms of disease or side effects of treatment, this data was considered quite relevant for the aims of this article. Initial development of the PROM involved interviews with 29 Aboriginal and Torres Strait Islander patients with experience of cancer. This tool was then trialled with 205 Aboriginal and Torres Strait Islander patients with experience of cancer, of which 16 % were HNC patients.

The most common supportive care need items where participants reported a moderate-to-high unmet need included: óworrying about the illness spreadingô (15.1%), ófeeling down or sadô (14.6%), óconcerns about the worries of those close to youô (14.6%), óanxietyô (12.7%), óworry about results of treatmentô (12.7%), ówork around homeô (12.3%), and ómoney worriesô (9.3%) (147).

Longitudinal data from three and six-months post-diagnosis was then reported for 158 patients, of whom 11% were HNC patients. Over each three-month period there were changes in priorities for unmet supportive needs and at six months post-diagnosis, more than half of participants continued to report at least one moderate-to-high unmet supportive need. At enrolment, the most common ómoderate to highô unmet needs reported were ómoney worriesô, óworrying about your illness spreadingô, and óconcerns and worries about those closest to youô. At three months post-diagnosis they were ómoney worriesô, óworries about illness spreadingô, óworries about the results of treatmentô. At six months post-diagnosis they were ómoney worriesô, óbeing told about things you can do to get yourself betterô and ódoing things you used to doô.

These results suggest that the use of culturally appropriate PROMs can help health professionals to gain insights into the health-related needs and priorities of Indigenous patients with experience of cancer in Australia. However, as there were substantial variations between each individual participantôs self-reported priorities and the priorities of each individual changed over time; ongoing, individualised assessment is likely to be necessary to gain an adequate understanding of the impact of clinical interventions on the HRQL of Aboriginal and Torres Strait Islander patients with experience of cancer.

Despite a growing number of studies examining HRQL in populations of cancer patients from differing cultural backgrounds and ethnicities (152), no published studies were found to examine the impact of HNC or treatment for HNC on the symptoms, functioning, well-being, or HRQL of Indigenous people in Australia. Despite a lack of reported data in this area, insights into how cancer and biomedical cancer treatments affect Aboriginal and Torres Strait Islander patientsô HRQL can be gleaned from previously published qualitative studies and other literature examining

patientsô self-reported experiences of cancer and cancer services. 37 articles and four abstracts from peer-reviewed journals were found to contain original data from Aboriginal and Torres Strait Islander patients self-reporting on their experiences of cancer or cancer treatment. Further relevant data was found in nine other documents, including reports from Government and Cancer Councils, academic theses and other literature (see Table 4 for details). Only one study mentioned the inclusion of self-reporting from Aboriginal and Torres Strait Islander people with experience of HNC (147-150, 153), though one unpublished thesis included qualitative data from one Aboriginal man undergoing biomedical treatment for HNC (154).

As this review is limited to printed material in English, it is possible that further relevant information may be available from other self-reporting mediums such as audio-visual material. Those with the greatest communication barriers and poorest health may be under-represented in this data, as it is likely that factors such as ill health or communication difficulties limited some patientsô abilities to participate in studies.

2.2.1 Physical symptoms, functional impairments from disease, side-effects from treatment

Some Indigenous women with experience of cancer report viewing health in relation to their ability to perform daily activities and fulfil familial roles rather than as an absence of disease (155). Within the first six months of treatment, tasks to do with everyday roles like ówork around the homeô and ódoing things you used to doô were among the most commonly reported unmet supportive care needs (147). Physical symptoms, functional impairments from disease and side-effects from treatment are largely dependent on multiple factors including specific cancer types, primary sites, tumor progression, stage and type of treatments, age, co-

morbidities and available supports. PROMS are often designed to measure symptoms, impairments and side-effects specific to the disease and are administered at specified stages of treatment. As there are no published studies specifically examining the physical symptoms, functional impairments and side effects of HNC and treatment experienced by Indigenous patients, data relevant to this topic is very limited. However, there are some general symptoms, impairments and sideeffects that can be common amongst people experiencing different cancers or treatment regimes.

Indigenous patients with experience of cancer report óphysical painô, ófeeling tiredô, ónot feeling well a lot of the timeô and óhaving hospital staff attending quickly to your physical needs (e.g., if you needed assistance getting out of bed)ô, as important supportive care needs (148). Some patients report a lack of understanding of clinical notions of pain relief including fears of the administration, side effects and outcomes of pain medications and fears that medications may speed up the dying process and inhibit the passing on of traditional knowledge and secrets that occurs during end-of-life. For some, cultural concerns about 'blame' and 'pay back' also impact clinical pain management. Important factors that can contribute to improving pain management include timely involvement of the doctor for administering pain medication, information giving to decrease fear, established trusting relationships, provision of the 'right' information to the 'right' person, provision of emotional support and generally strengthening health service provision (156).

Some patients report concern about side effects such as hair loss, whilst reporting the benefits of treatment outweigh the burden of side effects (157). Others report ceasing chemotherapy treatment early as side effects such as nausea, vomiting, fatigue, weight loss and hair loss made them feel sicker rather than healthier (155, 157). Some witnessed the suffering

and rapid death of family or community members from cancer diagnosed at an advanced stage, thus they considered biomedical cancer treatment as futile and associated pain and side effects as unjustified (158, 159). Some breast cancer patients report disfigurements caused by surgical intervention conflict with their beliefs about the importance and the sacredness of the human body and this alongside worries about interruptions to normal functioning prevented some from undergoing surgical intervention (155, 158, 160). In an unpublished thesis, McNamara reported witnessing the dilemma Indigenous people with cancer often face when trying to balance cultural values around health and wellbeing with biomedical ontology. Of particular interest is a report from an Aboriginal man, who after surgery for laryngeal cancer struggled to fulfil his cultural and spiritual need to be submerged in the water at a traditional healing place during due to the presence of a tracheostomy necessary to maintain his airway (34). Other cultural factors are likely to contribute to individualôs experiences of biomedical interventions, yet there is a dearth of published data about the physical symptoms, functional impairments and side effects of HNC and treatment experienced by Indigenous people in Australia.

Many patients report wanting more information about how to manage their cancer treatment and side-effects, such as ôbeing shown or given information (e.g., written, diagrams) about how to manage your treatment, illness and side-effects in hospital and at homeôand óunderstanding the good and bad effects of treatments before you chose to have them (e.g., having someone explain these to you)ô(147, 148, 157).

Some patients report óchanges in sexual feelingsôas an important unmet supportive care need, though some Indigenous people find questions about sex and sexuality culturally inappropriate, particularly when a female asks a male (or vice versa), or a younger person asks an older person (148).

2.2.2 Psychological, emotional and spiritual wellbeing

Patients report the notion of cancer commonly induces great fear and cancer diagnosis often causes shock. Fatalistic attitudes are reported as common, particularly amongst populations where stories of survivorship are rare or unheard of (155, 157, 158, 161, 162). The common belief amongst some populations that cancer is contagious can make cancer an even more frightening and alienating experience for those affected (158, 163). Some patient-reported emotional responses include, depression, anxiety, confusion, preoccupation with health changes and difficulty with usual functional roles (154). The clinical concept of depression is just beginning to be translated into traditional Indigenous languages and cultures. Thus, the understanding of the term may vary throughout populations (164). Feeling ódown or sadô, óanxietyô, óworrying about the illness spreadingô and óworries about results of treatmentô are amongst the most common moderate-to-high unmet needs reported (148). Patients who feel culturally compromised in foreign biomedical environments all reported feelings of discomfort, disempowerment, fear and shame (161, 165, 166). These feelings can contribute to individuals prolonging their initial presentation to biomedical services, and result in late diagnoses (155, 158, 165).

Many patients report spiritual well-being as a priority and some view the spiritual side of health and the importance of kinship as more important than the physical side of health (148, 157, 162, 165). óKeeping strong in your spirit (e.g., staying positive)ô is reported by patients as an important supportive care need (148). Some report that acceptance of cancer is important for spiritual wellbeing and healing, and others stress the importance of a positive attitude and using humour to ókeep peopleôs spirits upô (157, 162). Though, Indigenous populations in Australia comprise increasingly diverse people with differing and changing attitudes

and beliefs, traditional Indigenous spirituality and philosophy continue to form the basis of many Indigenous peopleôs personal identity and sense of well-being (167, 168). Personal identity in traditional Aboriginal philosophy is defined in terms of kinship, ritual, and spiritual relationships and responsibilities, all of which are viewed as synergistic and inseparable from each other and the land, or nature itself (168). This philosophy forms the basis of everything in life, including knowledge, attitudes, relationships, economics, spiritual, physical and emotional wellbeing (167). For some patients, being away from home or homelands for prolonged periods of time causes great distress and detriment to wellbeing (169, 170).

2.2.3 Social wellbeing

Patients report óconcerns about the worries of those close to youô, óensuring family members were able to be present when talking or seeing health professionalsô, óhaving one hospital person you can talk to about your condition, treatment and follow-upô, óbeing treated like a person not just another case or numberô and óhaving an Indigenous person to talk to and support you (someone who understands your culture)ôas important supportive care needs (148). Many patients are also the primary carers for others in their family, including others with chronic illnesses (149, 155, 157). Some report having concerns about how family members would be affected by their illness, and use this as a motivation to fight their illness (157). óConcerns about the worries of those close to youôis amongst the most common highly ranked unmet needs reported (150).

Family members are often in the primary supportive role for patients and many patients have stressed the importance of their family also receiving practical and emotional support (154, 157, 171). Some cancer treatments require patients to stay at or near hospital for six to eight weeks or more

and most support people canôt afford to stay away from home for that length of time due to both financial restrictions and commitments at home (154, 171). The Patient Travel Assistance Scheme (PATS) only provides funding for one companion to travel with each patient, so if that companion needs to return to their community, the patient is left alone and looses ongoing support (154, 172). Others report not receiving adequate support from their families early on because their families were afraid or didnôt understand what was happening (154, 157, 171). Being away from family and community can be particularly daunting in a foreign environment, separated from people who understand your culture and even more isolating for those whose primary language is not English (154, 155, 173). Many patients report feeling lonely and isolated whilst staying in hospital for cancer treatment and some have described the environment as cold, impersonal and intimidating (154, 155, 157, 165, 173). Some report cancer services not adequately catering for visits from large families and staff not understanding the importance of this, though others report some services to be understanding and accommodating of this (173).

Social relationships built on kinship, trust and respect for culture are of the utmost importance for many Indigenous people and literature highlights the importance of developing and maintaining a trusting relationship and the importance of the ñright personò being in the main supportive role, particularly in palliative care (157, 168, 173, 174). Patientsô considerations for who is the ñright personò can include many cultural and social factors that influence the nature of the interpersonal relationship including kinship, age, gender and trust. These factors can greatly influence Indigenous patientsô acceptance of biomedical treatments (156, 174, 175).

2.2.4 Unmet needs for information

Some patients report not having an adequate understanding of what is happening in relation to their cancer and treatment and some report being too scared to ask (154, 157, 166). Language barriers are common amongst Indigenous people, for whom English is often a second language. Interpreters are only available for some Indigenous languages, and are not always easily accessed. Most interpreting work is around gaining consent for treatment and there is often difficulty clearly communicating conditional phrases and the concepts of biomedical treatments such as radiotherapy and chemotherapy (154). Patients whose first language is English or Aboriginal English have also reported experiencing difficulties understanding the biomedical terminology used by health practitioners (155, 173).

In Australia, there is no traditional Indigenous word for ócancerô. Therefore, it is a foreign concept (162). Many Indigenous patients understand the concept of cancer through a combination of both traditional Indigenous beliefs and biomedical notions. Many share a view common to non-Indigenous patients that cancer is a frightening disease with serious life-threatening consequences. Though understandings and beliefs vary greatly amongst individuals, beliefs reported to be common amongst some populations are that a diagnosis of cancer is a death sentence, cancer is a single disease and therefore, all outcomes will be the same regardless of the primary site or stage of growth, cancer is contagious, and that sorcery and ópaybackô are the primary cause of many cancers (155, 158, 159, 162). These beliefs and associated shame may prevent some patients from accessing or continuing cancer treatment, though they can sometimes help patients to accept the disease and even death at the palliative stage (162, 176).

For many Indigenous people, death is a highly sensitive topic and end-of-life issues are often spoken of indirectly. In some places simply using the words ódeathô, ódyingô or ódeadô is highly offensive (177). McGrath *et al* noted some Indigenous Health Care workers avoid instigating direct discussions with cancer patients about their predicted life spans, for the primary purpose of preserving the patientôs spiritual well-being (162). Despite this, many patients and their families stress the importance of knowing in advance about the terminal nature of their illness so that they are prepared and can set their affairs in order (157). Furthermore, patients report ófeelings about death and dyingô as an important supportive care need issue, although a question about this was omitted from Garvey *et al*ôs supportive care needs assessment tool as it was deemed culturally inappropriate. In keeping with other findings, these authors found that an interviewer initiating discussions about death can bring about unnecessary negative thoughts for patients and omitting this question was about maintaining the patientôs cultural integrity and positive outlook towards healing (148). Cultural protocols around discussions about death and dying with Indigenous people are complex and warrant further consideration that is beyond the scope of this paper.

2.2.5 Unmet needs for support services

Patients report many factors that limit their access to resources and services for cancer treatment and support (178, 179). Many experience difficulties managing the practical and logistical aspects of cancer care, in particular isolation, transport, accommodation and financial burdens (154, 173, 180). Specialist cancer treatment is rarely available in rural areas and travelling for treatment can compound the anxiety and disorientation already induced by a cancer diagnosis (172, 173, 181). Patients report that an important supportive care need is óhaving access to care itemsô. Isolation from support services may also contribute to difficulties

accessing resources such as biomedical supplies (148). Indigenous patients with experience of cancer report that the use of traditional Indigenous healing practices is common and for many, access to traditional healers, medicines and healing places is also a major priority (148, 154, 157, 162, 179, 181-183).

ôMoney worriesô is amongst the most commonly prioritised moderate-to-high unmet supportive care needs reported (150). Patients report experiencing financial hardship during and after cancer treatment because of costs associated with treatment and not being able to work, which can be worsened by a lack of health insurance or income protection (154, 157, 165, 184). Patients report additional expenses associated with accessing cancer treatment to include transport, fees for hospital services, medicines, accommodation, food and childcare (165, 183). Though some patients may recover transport expenses through the PATS, the initial outlay and additional expenses make travel for treatment unaffordable for many patients (154, 172).

Some patients report difficulties finding culturally appropriate counselling services and support groups (155, 183, 185). In some Indigenous communities, there is little or no evidence of cancer survivorship, as survivor stories are discouraged due to a common belief that talking about cancer might tempt fate and make it happen. Widespread beliefs that cancer is a death sentence and that cancer is contagious can discourage people from discussing the disease. This can lead to social and emotional isolation for people diagnosed with cancer (157, 159, 181). Therefore, it is important to ensure that Indigenous people are given accurate and accessible information about survivorship and that survivors are supported to share their stories and encourage others in their journeys with cancer (157).

The literature points to the urgent need for cancer services in Australia to develop and practice more individualised and culture-centred approaches to cancer care (34, 159, 165, 181, 186). There is a need to investigate HRQL issues specific for Indigenous people with experience of HNC and to increase their participation in routine self-reported HRQL assessments so that issues adversely affecting their HRQL can be identified and addressed.

Table 4 – Published literature containing Indigenous people self-reporting on their experiences of cancer in Australia, 1993 to 2012

Study type	Region	Cancer sites	Aboriginal participants with experience of cancer	Published	Authors	Title of document	Document	Journal
Discussion paper	Queensland	Breast	1 *(Author)*	1993	Kirk M	An Aboriginal perspective on cancer	Article	Aboriginal and Islander Health Worker Journal
Qualitative study	Queensland	Gynaecological	Unspecified	1998	Kirk M, Hoban E, Dunne A & Manderson L	Barriers to and appropriate delivery systems for cervical cancer screening in Indigenous communities in Queensland - Final Report	Government Report	
Qualitative study	Queensland	Breast	Unspecified	2000	Kirk M, McMichael C, Potts H, Hoban E, Hill DC & Manderson L	Breast Cancer: Screening, diagnosis, treatment and care for Aboriginal and Torres Strait Islander women in Queensland - Final report	Government Report	
	Queensland	Breast		2000	McMichael C, Kirk M, Manderson L, Hoban E & Potts H	Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland	Article	ANZ J Public Health
Cancer Council Summit	National	Unspecified	Unspecified	2005	Lowenthal D, Grogan P & Kerrins E	The Cancer Council Australia's Darwin conference – summary of presentations	Cancer Council Report	Cancer Forum
				2005	Lowenthal D, Grogan P & Kerrins E	Reducing the impact of cancer in Indigenous communities: ways forward	Article	Medical Journal of Australia
Qualitative study	Queensland	Breast & gynaecological	13	2005	Prior D	Cultural strengths and social needs of Aboriginal women with cancer	Published PhD Thesis	University of Queensland
	Queensland			2005	Prior D	Don't mention the 'C' word: Aboriginal women's view of cancer	Article	Aboriginal and Islander Health Worker Journal
	Queensland			2006	Prior D	Aboriginal women's perception of cancer	Article	Australian Nursing Journal
	Queensland			2009	Prior D	The meaning of cancer for Australian Aboriginal women; changing the focus of cancer nursing	Article	European Journal of Oncological Nursing
Qualitative study	NSW, VIC, SA or NT	Gynaecological	3	2008	Willis EM, Dwyer J, Owada K, Couzner L, King D & Wainer J	Indigenous women's expectations of clinical care during treatment for a gynaecological cancer: rural and remote differences in expectations	Article	Australian Health Review
Qualitative study	South Australia	Unspecified (included 1 HNC)	>5 (patients and carers)	2008	McNamara C	Barriers to treatment for Aboriginal cancer patients; a qualitative study.	Unpublished Masters Thesis	

Study type	Region	Cancer sites	Aboriginal participants with experience of cancer	Published	Authors	Title of document	Document	Journal
Qualitative study	Western Australia	Unspecified	14	2009	Shahid S, Finn L & Thompson SC	Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting	Article	Medical Journal of Australia
	Western Australia			2009	Shahid S, Finn L, Bessarab D & Thompson SC	Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services	Article	BMC Health Serv Res
	Western Australia			2010	Shahid S, Bleam R, Bessarab D & Thompson SC	If you don't believe it, it won't help you: use of bush medicine in treating cancer among Aboriginal people in Western Australia	Article	J Ethnobiol Ethnomed
	Western Australia			2010	Shahid S, Finn L, Bessarab D & Thompson SC	'Nowhere to room ... nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment	Article	
	Western Australia			2011	Thompson SC, Shahid S, Bessarab D, Durey A & Davidson P	Not just bricks and mortar: planning hospital cancer services for Aboriginal people	Article	BMC Research Notes
	Western Australia			2011	Thompson SC, Shahid S, Greville HS & Bessarab D	A Whispered Sort of Stuff A Community Report on Research Around Aboriginal People's Beliefs about Cancer and Experiences of Cancer Care in Western Australia	Community Report	Cancer Council WA
Cancer Council Project	New South Wales	Testicular, lung, brain, breast, leg sarcoma, unknown		2010	Aboriginal Health & Medical Research Council of NSW	Aboriginal cancer journeys - Our stories of kinship, hope and survival	Cancer Council Resource	Cancer Council NSW
Cancer survivors forum	National	Unspecified	Unspecified	2010	M247 consulting	The Inaugural Australian Indigenous Cancer Forum	Community Report	M247 consulting
Cancer survivors forum	National	Unspecified	Unspecified	2011	Kanagasabapathy M & Jacka C	Australian Indigenous Cancer Survivors Forum	Article	Aboriginal and Islander Health Worker Journal
Qualitative/quantitative	Queensland	All cancers	29	2012	Garvey G, Beesley VL, Janda M, Jacka C, Green AC, O'Rourke P & Valery PC	The development of a supportive care needs assessment tool for Indigenous people with cancer	Article	BMC Cancer
		All cancers	205	2012	Garvey G	What are the supportive care needs of Indigenous cancer patients in Queensland?	Oral Abstract	Asia Pacific Journal of Clinical Oncology
		All cancers	158	2012	Valery PC, Beesley VL, Hawkes AL, Bernandes C, Elston J & Garvey G	Unmet supportive care needs of Indigenous cancer patients in Queensland: Preliminary results of a prospective, longitudinal study	Oral Abstract	Asia Pacific Journal of Clinical Oncology
		All cancers		2012	Bernandes C, Whop LJ, Valery PC & Garvey G	Health service utilization by indigenous cancer patients in Queensland: a descriptive study	Article	International Journal for Equity in Health
		All cancers		2012	Bernandes C, Valery PC & Garvey G	Are Indigenous Australians interested in family history and genetic predisposition to cancer? A report of cancer patients in Queensland	Oral Abstract	Asia Pacific Journal of Clinical Oncology
Qualitative	New South Wales	All cancers	22	2012	Treloar C, Newman C & Gray R	'I can't do this, it's too much': Building social inclusion in cancer diagnosis and treatment experiences of aboriginal people, their carers and health workers	Oral Abstract	Asia Pacific Journal of Clinical Oncology

Study type	Region	Cancer sites	Aboriginal participants with experience of cancer	Published	Authors	Title of document	Document	Journal
Qualitative	Northern Territory	Unspecified	>10 (palliative care patients including cancer patients)	2005	McGrath PD, Oglivie KF, Rayner R, Holewa H & Patton M	The "right story" to the "right person": communication issues in end-of-life care for Indigenous people	Article	Australian Health Review
				2005	McGrath PD, Holewa HA, Ogilvie KF, Patton MA, Rayner RD,	Insights on Aboriginal peoples' views of cancer in Australia	Article	Contempory Nurse
				2006	McGrath PD	The 'living model': a resource manual for Indigenous palliative care service delivery	Resource Manual	Researchman Publication
				2006	McGrath PD	Exploring Aboriginal people's experience of relocation for treatment during end-of-life care	Article	International Journal of Palliative Nursing
				2006	McGrath PD & Phillips EL	'The biggest worry..': research findings on pain management for Aboriginal peoples in Northern Territory, Australia	Article	Rural Remote Health
				2006	McGrath PD & Holewa H	Seven principles for Indigenous palliative care service delivery: research findings from Australia.	Article	Austral-Asian Journal of Cancer
				2006	McGrath P, Patton MA, McGrath Z, Olgivie K, Rayner R & Holewa H	'It's very difficult to get respite out here at the moment': Australian findings on end-of-life care for Indigenous people.	Article	Health Soc Care Community
				2006	McGrath PD, Patton MA, Holewa H & Rayner R	The importance of the 'family meeting' in health care communication with Indigenous people: findings from an Australian study.	Article	Australian Journal of Primary Health
				2007	McGrath PD	Indigenous understanding of hospice and palliative care: findings from an Australian study	Article	Hospice and Palliative Nursing
				2007	McGrath PD, Holewa H & McGrath Z	Practical problems for Aboriginal palliative care service provision in rural and remote areas: equipment, power and travel issues.	Article	Collegian
				2007	McGrath PD & Holewa H	End-of-life care for Aboriginal peoples in remote locations: language issues.	Article	Australian Journal of Primary Health
				2007	McGrath PD	Aboriginal cultural practices on caring for the deceased person: findings and recommendations	Article	International Journal of Palliative Nursing
				2007	McGrath PD	'I don't want to be in that big city; this is my country here': research findings on Aboriginal peoples' preference to die at home.	Article	Australian Journal of Rural Health
				2007	McGrath PD, Holewa H & Kail-Buckley S	"They should come out here ...": research findings on lack of local palliative care services for Australian aboriginal people.	Article	American Journal of Hospital Palliation
				2007	McGrath PD, Patton MA, Ogilvie KF, Rayner RD, McGrath ZM & Holewa HA	The case for Aboriginal Health Workers in palliative care.	Article	Australian Health Review
				2008	McGrath PD & Phillips EL	Aboriginal spiritual perspectives: research findings relevant to end-of-life care	Article	Illness, Crisis, & Loss
				2008	McGrath PD & Phillips EL	Insights on end-of-life ceremonial practices of Australian Aboriginal peoples	Article	Collegian
				2008	McGrath PD & Phillips EL	Australian findings on Aboriginal cultural practices associated with clothing, hair, possessions and use of name of deceased persons	Article	International Journal of Nursing Practice
				2008	McGrath PD & Phillips EL	Western notions of informed consent and indigenous culture: Australian findings at the interface.	Article	Journal of Bioethical Enquiry
				2008	McGrath PD	Family care giving for Aboriginal peoples during end-of-life: findings from the Northern Territory	Article	Journal of Rural and Tropical Health
				2009	McGrath P, Holewa H, Koilparampil T, Koshy C & George S	Learning from each other: cross-cultural insights on palliative care in Indian and Australian regions	Article	International Journal of Palliative Nursing
				2010	McGrath PD	The Living Model: An Australian model for Aboriginal palliative care service delivery with international implications	Article	Journal of Palliative Care

CHAPTER THREE:

Exploration of barriers to self-reported HRQL assessment for Aboriginal patients with experience of HNC:

A qualitative study

Chapter 3. Exploration of barriers to self-reported HRQL assessment for Aboriginal patients with experience of HNC: A qualitative study

3.1 Purpose of study

Compared to other Australians, Aboriginal populations are experiencing higher incidence rates for HNC and poorer outcomes after diagnosis. However, Aboriginal patients are under-represented in HRQL data that ultimately informs decision-making about best practice in HNC treatment. As yet there are no published reports about Aboriginal peopleôs experiences of HNC and treatment, or how this impacts HRQL. This study aimed to increase participation of Aboriginal patients in routine, clinical, HNC-specific, HRQL assessment, whilst identifying and addressing barriers to successful and meaningful participation.

3.2 Methods

3.2.1 Participants

This study received ethical approval from the óRoyal Adelaide Hospitalô, the óAboriginal Health Council of South Australiaô, the óCentral Australian Human Research Ethics Committeeô and the óNorthern Territory Department of Health and Menzies School of Health Researchô. Participation was on a voluntary basis. A cohort of 69 patients from SA (n = 29) and Central Australia (CA) (n = 40), who identified as Aboriginal and were treated for HNC at the RAH between 1997 and 2012, were identified through the RAH HNC database. 45 of these patients (65%) were confirmed deceased (SA = 18, CA = 27). The exclusion criteria were if an appropriate interpreter was not available in person or impaired

cognition at the time of recruitment. Barriers to participation were observed and recorded.

3.2.2 Data collection

The primary researcher maintained a regular dialogue with participants and their cancer care team when possible and conducted 1 to 3 in-depth semi-structured interviews with each participant at 2 to 7 month intervals (total number of interviews = 18). Interviews were based around two of the most globally accepted and commonly used HRQL assessments for HNC patients, the Functional Assessment of Cancer Therapy ï H&N v.4 (FACT-HN) and the University of Washington Quality of Life Assessment v.4 (WQLQ). The length of each interview ranged from approximately 20 to 170 minutes with a mean length of approximately 30 minutes (median 36 minutes) for each interview. When given consent from participants, interviews were digitally audio-recorded and transcribed. When permission was not granted to audio-record, hand-written notes were taken.

3.2.3 Key informants

30 key informants who have worked with or cared for Aboriginal people with experience of HNC in SA and the NT were consulted about the face and content validity, cultural acceptability, utility and relevance of the two HRQL instruments. Further opinions on language and cultural issues were sought from two independent Aboriginal language interpreters working in health care, two independent linguists working with Aboriginal languages, a hospital cultural competency advisor and Aboriginal community members from rural and remote areas.

3.2.4 Qualitative data analysis

This study utilised generic qualitative methodologies (187-192). Aboriginal referees were consulted for guidance and feedback throughout the processes of data collection and the subsequent analyses. Thematic analysis of data obtained was organised both manually and with the use of computer assisted qualitative data management software óQSR-N-vivo v.9.2ô (189, 193-195). Wherever possible, summaries of analyses were shown to participants for member checking, feedback and approval (189, 193, 196). Qualitative analysis of data was influenced by a critical theory paradigm and a decolonising research methodology approach (197).

Barriers to active and meaningful participation in standard HRQL assessment for Aboriginal patients with experience of HNC were identified and categorised utilising *Herdman et al's* universalist approach to the cultural adaptation of HRQL instruments as a framework for thematic analysis (198). This approach involves investigating six different properties of cultural equivalence, in relation to the use of each HRQL instrument within the populations in which they were developed and validated (patients with experience of HNC in the USA) and within the new population (Aboriginal patients with experience of HNC in SA and CA). These properties are conceptual equivalence, operational equivalence, item equivalence, semantic equivalence, measurement equivalence and functional equivalence.

3.3 Findings and discussion

3.3.1 Participant characteristics

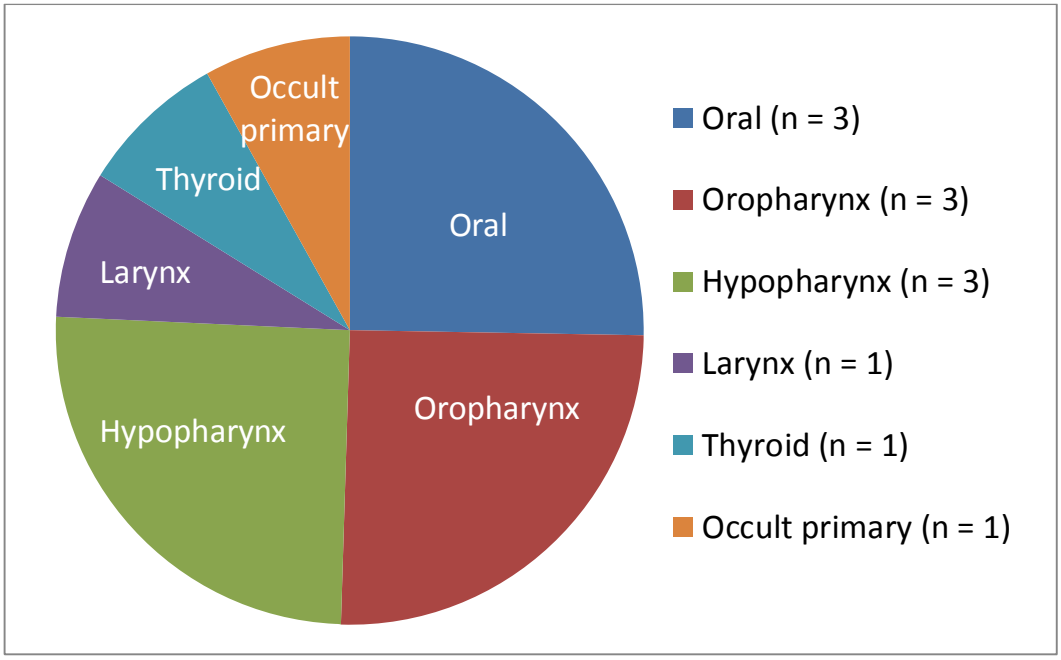
Of the 24 eligible patients (SA = 11, CA = 13), five were unable to participate due to cognitive issues or physical limitations from advanced stage disease (20%), two could not participate as an appropriate interpreter was not available at the time (8%), two declined to participate (8%), and three were unable to be contacted (12%). The remaining 12 patients (50%) consented to participate (SA = 7, CA = 5).

75% of participants were male (n = 9) aged 24 to 85 (median age 58, mean age 57) and 25% were female (n = 3) aged 47 to 64 (median age 53, mean age 55) at the time of recruitment. This is quite representative of the overall cohort of 69 patients in which 77% (n = 53) were male and 23% (n = 16) were female.

By Australian Standard Geographical Classification (ASGC), 39% of participants resided in very remote areas (n = 5), 31% in remote areas (n = 4), 15% in regional areas (n = 2) and 15% in major city areas (n = 2). This is also reasonably representative of the overall cohort of 69 patients in which 42% resided in very remote areas (n = 29), 33% in remote areas (n = 23), 10% in regional areas (n = 7) and 16% in major city areas (n = 11).

92% (n=11) of participantsô tumours were SCCs: three in the oral cavity, three in the oropharynx, three in the hypopharynx, one in the larynx, and one occult primary with neck node metastases. The other was a papillary carcinoma of the thyroid with neck metastases. Non-participants had a similar distribution of primary sites and pathologies.

Figure 10 - Participant's primary tumour site (n = 12)



The thyroid carcinoma was treated with primary surgery and radioactive iodine swallow. The SCC of the larynx was treated with primary radiotherapy. All other SCCs were treated with multimodal therapy, including all oral and oropharyngeal primaries treated with surgery plus post-operative radiotherapy (n = 6), surgery plus chemo-radiotherapy for the occult & post-cricoid primaries with neck metastases (n = 3) and primary chemo-radiotherapy for the advanced stage hypopharyngeal primaries with neck metastases (n = 2).

The majority of both participants and non-participants initially presented to the RAH with late stage tumours. 75% of participants (n = 9) presented with Stage IV tumours, 17% with Stage III (n = 2) and 15% with Stage II, whilst amongst the non-participants, 82% presented with Stage IV tumours, 9% with Stage III and 8% with Stage II (n=1). 83% (n = 10) of participants and 92% of non-participants (n=11) presented with metastatic spread of malignancy to lymph nodes in the neck.

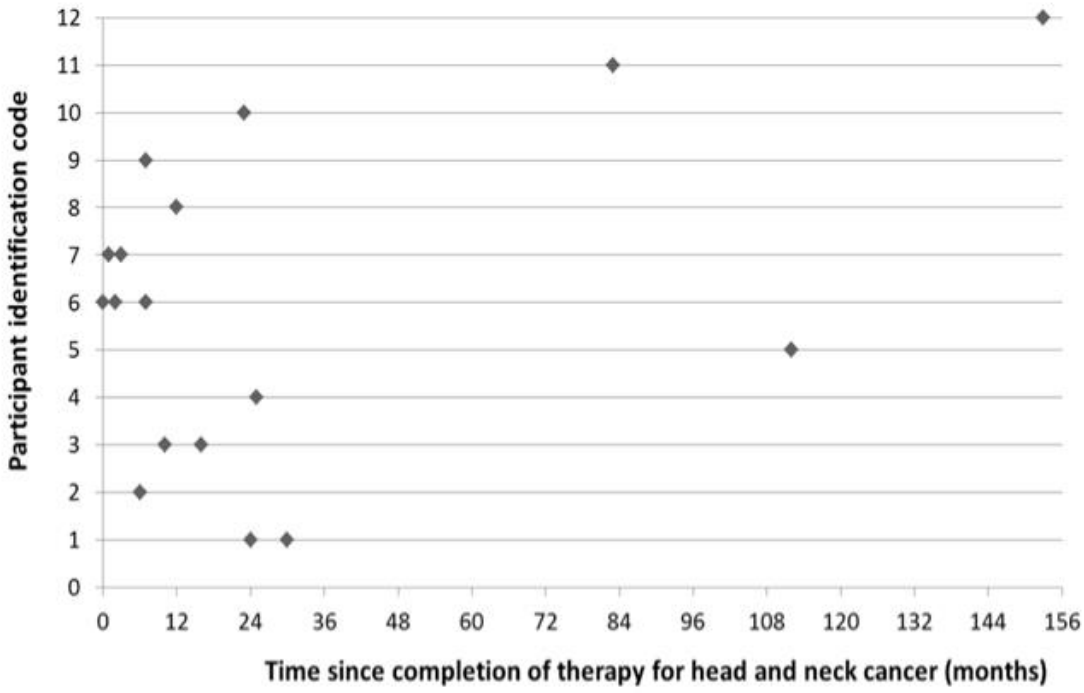
Table 5 – Participant demographics including tumour, node, metastases (TNM) and overall staging of HNC, primary site, pathology, treatment modality and ECOG performance status rating at recruitment

CODE	T STAGE	N STAGE	M STAGE	OVERALL STAGE	PRIMARY SITE	PATHOLOGY	TREATMENT	ECOG - PSR
1	T4a	N2b	M0	IVb	HYPOPHARYNX (PYRIFORM SINUS)	SCC	PRIMARY CHEMO-RADIOTHERAPY	1
2	T4a	N2b	M0	IVb	ORAL (FLOOR OF MOUTH)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	3
3	T3	N2b	M0	IVb	HYPOPHARYNX (LATERAL PHARNGEAL WALL)	SCC	PRIMARY CHEMO-RADIOTHERAPY	1
4	TX	N3	M0	IVb	NECK NODES (UNKNOWN PRIMARY)	SCC	PRIMARY SURGERY + ADJUVANT CHEMO-RADIOTHERAPY	1
5	T2	N1	M0	III	OROPHARYNX (TONSIL)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	0
6	T2	N0	M0	II	LARYNX (GLOTTIS)	SCC	PRIMARY RADIOTHERAPY	3
7	T2	N2b	M0	IVb	OROPHARYNX (SOFT PALATE)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	3
8	T3	N2b	M0	IVb	THYROID	PAPILLARY CARCINOMA	SURGERY + RADIOACTIVE IODINE SWALLOW	3
9	T4a	N1	M0	IVa	HYPOPHARYNX (POST-CRICOID/OESOPHAGUS)	SCC	INDUCTION CXT, SURGERY + RADIOTHERAPY	2
10	T4a	N2c	M0	IVb	OROPHARYNX (BASE OF TONGUE)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	3
11	T2	N2b	M0	IVb	ORAL (TONGUE)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	4
12	T3	N0	M0	III	ORAL (FLOOR OF MOUTH)	SCC	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	1

Participants were interviewed at various stages in their experience of HNC, from 12 days prior to commencing treatment to 13 years post-treatment.

Figure 11 below, shows the precise times at which individual participants were interviewed in relation to when their last treatment for HNC (surgery or (chemo)-radiotherapy) was completed. Individual participant identification numbers on this chart may be used to link this data to individual participant demographics in Table 5. Where the ótime since HNC treatment finishedô is presented as ó0ô months, this indicates that the patient also completed a pre-treatment interview.

Figure 11 – Scatterplot illustrating the varying times post-treatment at which participants were interviewed about their HRQL



3.3.2 Barriers to active and meaningful participation with traditional HRQL assessment

For many Aboriginal people, the concept of assessing and measuring HRQL is extremely foreign and far removed from traditional Aboriginal epistemologies (199). Biomedicine and biomedical concepts of HRQL are mostly concerned with the effect of disease or treatment on the patient as an individual, autonomous unit. In contrast to biomedical concepts of HRQL, a clear definition of what HRQL means for Aboriginal people is yet to be published. What is clear from previous literature and this research alike is that Indigenous concepts of HRQL are often collective and holistic, integrating physical, spiritual, relational and cultural factors. Indigenous concepts of HRQL recognise that the patient is part of a much greater system or collective and patients are often equally as concerned with the impact of disease and treatment on family, community and their relationships with land, culture and spirit, as they are with the impact on their person.

In biomedicine, it is commonly considered important to determine an overall ranking of importance for different HRQL issues and domains. The main reason for this is so that each issue can be quantified in relation to each other issue so that an overall score can be determined. This system of reductionism and hierarchy is counter-intuitive to Indigenous concepts of HRQL. Indigenous concepts of HRQL recognise that every issue and domain has a synergistic effect on each other and HRQL as a whole, having equal importance for the integrity of HRQL and wellbeing.

The Aboriginal population in Australia is heterogeneous and multi-lingual by nature, with no single dominant language used by all citizens. In Australia today, there are around 150 Indigenous languages and dialects in use, mostly in the most remote areas. Only about 10% of these languages

continue to be learned by children and all except about 20 are highly endangered (200). Those language groups with the largest populations, such as Walpiri and Tiwi, only have about 3000 fluent speakers (201, 202). As populations of each language group are small and mostly located in remote areas, there is a distinct lack of interpreters available for use in healthcare (34, 201, 202).

This study found that though many Aboriginal people speak and understand variations of formal English, the style of language and certain terminology used in the HRQL assessments was unfamiliar for some. In Australia, Aboriginal people are less likely to have received the same levels of formal English-based education as non-Aboriginal people and the ABS reports that at least 8% of Aboriginal people aged 55 years or over and 2% of those aged between 35 and 54, have never received any formal schooling. At least 38 % of those aged 55 and above, and 14% of those aged between 35 and 54 have completed less than the equivalent of year eight (20, 203). As a result, English literacy and numeracy skills can present significant barriers for many Aboriginal patients with experience of HNC successfully participating in HRQL assessment using standard instruments.

Referential meanings in traditional HRQL assessment tools were a key area of misinterpretation amongst participants. For example, the term ónauseaô often needed further explanation, as it is not commonly used amongst many Aboriginal populations.

Barriers for accurate and reliable HRQL assessment due to specific items in each standard instrument were identified by exploring whether or not each question was culturally appropriate and addressed the things that Aboriginal people with experience of HNC think are related to their concept of HRQL. Although most of the content in the standard HRQL

questionnaires was relevant and important to the concerns of participants, some of the content was not relevant or culturally appropriate and many other areas of importance for participants were identified. In the case of topics that may carry many cultural sensitivities or taboos, it is best to avoid mentioning the topic directly, leaving space for the patient to choose to discuss the topic as they see fit. Topics such as death, physical appearance and sexuality are all examples of potentially taboo topics amongst many Aboriginal populations and thus present a distinct barrier to collecting accurate HRQL data in this population.

The content of each item was assessed for relevance to the phenomena of the target groupôs culture. For example, dominant culture in Australia places significant emphasis on work and career and the word órecreationô is often used to clearly separate and describe activities undertaken for the primary purpose of increasing a personôs pleasure or enjoyment from other forms of activity that are concerned with the roles and responsibilities of everyday life such as taking caring of oneself and family, or working to earn money. Aboriginal peopleôs conceptions of roles and responsibilities can significantly vary from those in the dominant culture in Australia and the term órecreationôis a foreign concept for traditional Aboriginal people. Thus categorising activity and recreation as two separate concepts can create confusion.

Data was examined to see if each question covered all aspects the subject matter. A clear message throughout the data collection phase of this study was that different HRQL items have particular relevance to individual patients and the ability to expand on issues relevant to each individual patient is lacking in current HRQL tools. For example, simply asking about the presence of pain does not indicate where the pain is, whether or not the pain is related to the HNC, or if pain is being controlled by medication. Aboriginal patients are more likely to be experiencing

concurrent health issues or co-morbidities than non-Aboriginal patients, therefore it may be necessary to enquire further about where the pain is, whether it is pre-existing long term pain and about the use of pain medications.

Operational barriers were explored by examining the standard methods of HRQL assessment with respect to data yield. Most global-standard measures for assessing HRQL rely on patients self-reporting by way of standardised surveys. This method allows patients to self-report, whilst allowing clinicians to capture comparable data about how a patient feels at different points in time. A patientôs response to a question before an intervention can be directly compared to their response to the same question after the intervention, allowing the impact of the intervention to be assessed. Health research by survey within Aboriginal populations can pose significant challenges for both the researcher and the participants. Barriers to participation can be influenced by history and mistrust (particularly around research), differing cultural expectations and traditions and the nature of the relationship between the researcher and the participant. The asking of direct questions by strangers can be considered inappropriate or even highly offensive in traditional Aboriginal cultures (78, 204, 205). Though two participants did not mind filling in the questionnaires themselves by pen and paper, all 12 participants preferred oral dialogue based around the questionnaires.

Both health-care professionals and Aboriginal languages interpreters reported they had little confidence in the *Likert* scale used in FACT-HN or the two defined point scales used in the WQLQ assessment, for reliable use with many Aboriginal patients. Traditional Aboriginal language pronoun systems tend to be far more complex and precise than English, whilst mathematical terms appear less developed, reflecting the relative importance in each culture of human interactions on the one hand and

manipulation of abstract numbers on the other (205, 206). Thus, benchmark questioning and the quantitative nature of many HRQL assessment tools can be considerable barriers for many Aboriginal patients reporting on their HRQL in a meaningful way (207). Furthermore, using a *Likert* scale as a blunt measure without further narrative enquiry may pose problems for the overall psychometric properties of the tool. For example, the statement ñI am able to eat the foods that I likeò is intended as a measure of the impact of HNC treatment on patientsô functional ability to chew and swallow food. However, with further narrative enquiry, some participants who stated that they were not able to eat the foods that they like attributed this to other factors such as diabetes or sufficing on unfamiliar hospital food.

3.4 Conclusions

In order to ensure the usefulness, reliability and validity of HRQL assessments amongst different populations, these assessments must undergo scrupulous processes for cultural adaptation and translation. This paper explored barriers to accurate and culturally appropriate recording of HRQL data from Aboriginal patients with experience of HNC. Lack of ongoing relationships with medical staff and other trust issues, limited access to interpreters, limited English literacy and numeracy skills, lack of regular follow-up consultations and other cultural issues can prevent Aboriginal patients with experience of HNC from participating in routine clinical HRQL assessments in a meaningful and reliable way.

Barriers for Aboriginal patientsô active and meaningful participation in traditional HNC-specific HRQL assessment were present across a broad set of domains; including conceptual, semantic, thematic, referential, item, operational and functional parameters. Most current guidelines for the cultural adaptation and translation of HNC-specific HRQL measures

favour a theoretical approach of ‘foreignization’, whereby items, activities or ideas that pose a cultural problem are translated in their original form rather than being replaced by a similar notion that is familiar to the target culture (152). This approach favours the preservation of semantic equivalence to the detriment of experiential and conceptual equivalence (198, 208). Furthermore, the ‘foreignization’ approach poses a significant problem for health care professionals in Australia, where ethical guidelines emphasise cultural competency when working with Aboriginal patients (143, 145).

The substantial barriers encountered when attempting to utilise these tools using recommended administrative processes, alongside significant cultural divergences (with particular reference to the conceptualisation of the definition of HRQL), render current HNC-specific HRQL assessments inadequate for the unique needs of the Aboriginal patients who suffer this disease. If health care professionals do not embrace culturally competent approaches to HRQL assessment, then many Aboriginal patients will continue to decline to participate in HRQL assessments and patient-reported HRQL outcomes from Aboriginal patients will be misrepresented. Thus, there is a need for a novel, culturally safe, HNC-specific, HRQL assessment for use with Aboriginal patients with experience of HNC in SA and CA.

CHAPTER FOUR:

Developing a community-informed, mixed-methods approach for assessing the self-reported HRQL of Aboriginal patients with experience of HNC in South and Central Australia

Chapter 4. Developing and piloting of a community-informed, mixed-methods approach for assessing the self-reported HRQL of Aboriginal patients with experience of HNC in South and Central Australia

4.1 Purpose of study

Significant barriers to active and meaningful participation in traditional, HNC-specific, HRQL assessment have been identified for Aboriginal patients with experience of HNC in SA and CA. Thus, there is a need for a novel, culturally safe, HNC-specific PROM and pragmatic approach to HRQL assessment that encompasses Aboriginal conceptualisations of HRQL and addresses the concerns that are important to this group, in a culturally safe manner. The gold standard for developing valid, reliable and responsive disease-specific PROMs mandates that qualitative data from patient interviews be utilised to generate items and identify questions that are most meaningful for patients (131, 209). This study utilised data from previous literature, interviews with Aboriginal patients with experience of HNC and feedback from key informants who work with and care for Aboriginal people with experience of HNC, to develop a novel, community-informed PROM and pragmatic approach for assessing HRQL within this population. Through culturally sensitive HRQL assessment we aim to gain a better understanding of vital aspects that influence the health and wellbeing of Aboriginal patients with experience of HNC, with particular regard to the impact of biomedical treatments and interventions.

4.2 Methods

4.2.1 Data collection

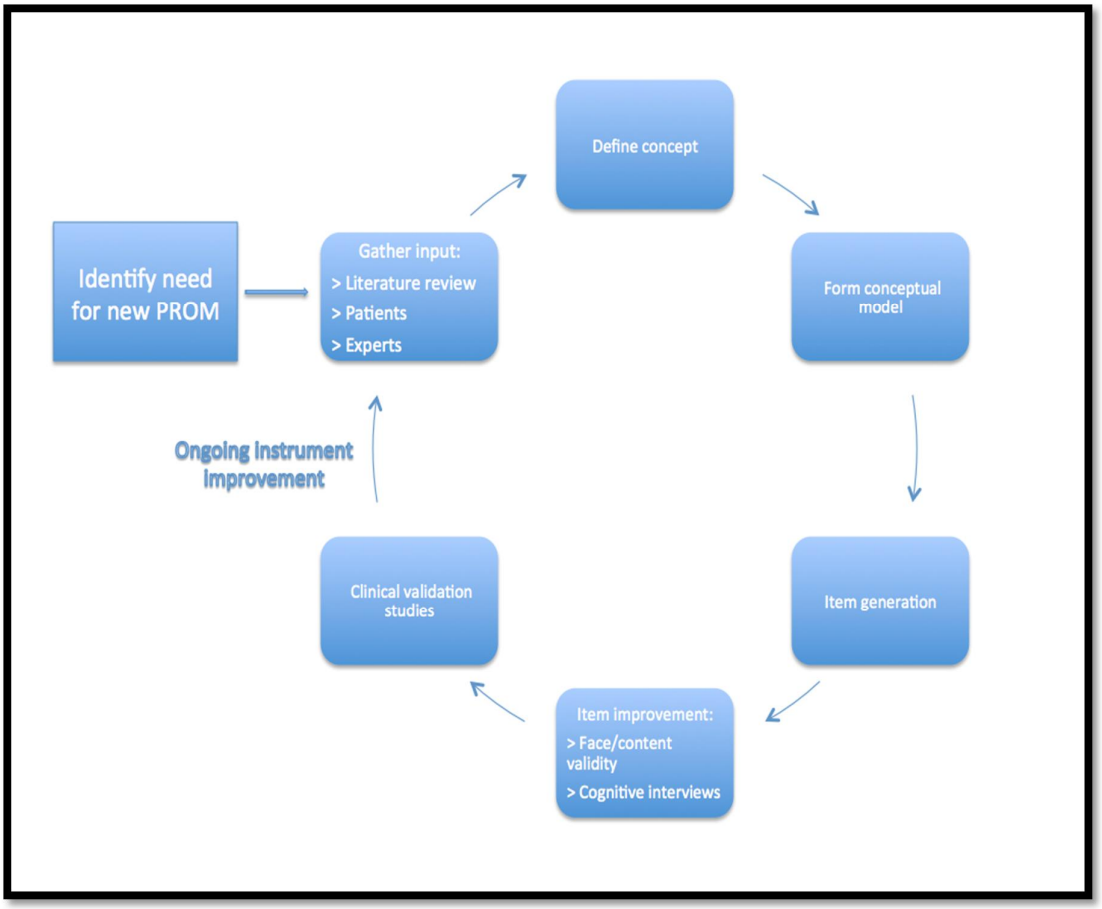
This study received ethical approval from the ôRoyal Adelaide Hospitalô, the ôAboriginal Health Council of South Australiaô, the ôCentral Australian Human Research Ethics Committeeô and the ôNorthern Territory Department of Health and Menzies School of Health Researchô. Participation was on a voluntary basis. A cohort of 69 patients from SA (n = 29) and Central Australia (CA) (n = 40), who identified as Aboriginal and were treated for HNC at the RAH between 1997 and 2012, were identified through the RAH HNC database. 45 of these patients (65%) were confirmed deceased (SA = 18, CA = 27). The participatory exclusion criteria were not having an appropriate interpreter available in person when required or impaired cognition at the time of recruitment.

The primary researcher maintained regular dialogue with participants and their cancer care team when possible and conducted one to three in-depth, semi-structured interviews with each participant at two- to seven- month intervals.

Figure 11 on page 72 has details of the time since treatment til each interview for individual participants. Interviews were based around two of the most globally accepted and commonly used HRQL assessments for HNC patients, the Functional Assessment of Cancer Therapy ï H&N v.4 (FACT-HN) and the University of Washington Quality of Life Assessment v.4 (WQLQ). The length of each interview ranged from approximately 20 to 170 minutes with a mean length of approximately 30 minutes (median 36 minutes) for each interview. When given consent from participants, interviews were digitally audio-recorded and

transcribed. When permission was not granted to audio-record, hand-written notes were taken. This study utilised generic qualitative methodologies (187-192). Aboriginal referees were consulted for guidance and feedback throughout the processes of data collection and the subsequent analyses. Thematic analysis of data obtained was organised both manually and with the use of computer assisted qualitative data management software óQSR-N-vivo v.9.2ô(189, 193). Wherever possible, summaries of analyses were shown to participants for member checking, feedback and approval (189, 193, 196). Qualitative analysis of data was influenced by a critical theory paradigm and a decolonising research methodology approach (197).

Figure 12 – Flow chart identifying the various stages for PROM instrument development



4.2.2 Development of the Universalist Health-Related Quality of Life Assessment – Head and Neck version 1 (UHRQL-HN)

Participant interviews were transcribed verbatim and recurring themes were identified and triangulated through consultation with key informants and a search of previous relevant literature. These themes formed the basis for generating the concept, conceptual model and provisional item list of concerns for Aboriginal patients with experience of HNC. Individual questions were refined with further input from key informants who have worked with or cared for Aboriginal people with experience of HNC in SA and the NT. Further opinions on language and cultural issues were sought from two independent Aboriginal language interpreters working in health care, two independent linguists working with Aboriginal languages, a hospital cultural competency advisor and Aboriginal community members from rural and remote areas.

4.2.3 Assessing the validity of UHRQL-HN

To evaluate this PROMôs overall functionality, face and content validity data was utilised to examine the instrument concept, items, semantics and operability, whilst criterion and construct validity data was utilised to investigate the instrumentôs psychometric properties. Face validity is an estimate of the degree to which a questionnaire is recognisably measuring the construct in which it purports to assess (210, 211). To assess face and content validity, UHRQL-HN was trialled and refined with five Aboriginal patients during various stages of their experiences with HNC in SA and CA. Face and content validity from the patient perspective was investigated in terms of functional usability, patient acceptance of the assessment methods and data yield. To assess UHRQL-HNôs face and content validity from the health care professional perspective, 12 health care professionals who regularly work with Aboriginal people with HNC,

completed a standardised survey with a five-point Likert scale and free text response options (see Table 7, Table 8 and Table 9 for details of this survey).

The criterion and construct validity of UHRQL-HN were assessed by examining the data yielded whilst trialling the assessment. To assess criterion validity, individualôs answers were compared with clinician assessed ôEastern Cooperative Oncology Group Performance Status Ratingô (ECOG-PSR) of each patient. Construct validity was investigated by examining the instrumentôs ability to detect clinical changes by comparing individualôs answers before and after clinical intervention.

4.3 Results and discussion

4.3.1 Defining the concept of UHRQL-HN

There is yet to be a clear published definition of Aboriginal conceptions of HRQL. As such, this concept of HRQL was explored in relation to the impacts of HNC and related biomedical treatment. Thematic analysis of qualitative data from interviews with participants revealed 11 key areas of importance for Aboriginal patients with experience of HNC in SA and the NT. Along with physical, functional, emotional and mental, social and family well-being; financial, environmental, spiritual and cultural well-being, tobacco, alcohol & other substance use, access to treatment and follow-up, access to information about illness and treatment and access to health supplies & resources were considered of equal importance and influence for Aboriginal peopleôs HRQL. Furthermore, all these areas are highly inter-related and influence each other, as they influence overall HRQL. Consideration of these domains can help to identify barriers to treatment and positive outcomes for Aboriginal patients with experience

of HNC, informing health professionals and the greater community about where additional support services may be needed.

Figure 13 - Simplified model illustrating 11 main areas of concern for the HRQL of Aboriginal people with experience of HNC in South and Central Australia



4.3.2 Forming the conceptual model for UHRQL-HN

UHRQL-HN (see Figure 14) consists of 54 items relating to HRQL issues affected by HNC and biomedical treatment. The first measure in this instrument is a simple óyesô or ónoô answer to indicate the presence of a HRQL issue. This information is useful in itself, though it only indicates the patientôs awareness of the presence of a phenomenon and does not indicate the effect that this phenomenon has on the individualôs QoL. A four-point response scale allows the patient to clarify how much each phenomenon affects their QoL and narrative/free text allows the patient to respond by placing the issue into their own individual context. There is strong recognition that HRQL data from HNC patients should be more accessible and relevant to clinical practice (131, 140, 212, 213). Incorporating narrative inquiry/free text comments to explore the experiences of cancer patients adds value to the use of standard surveys, adding insight and clinical relevance to the PRO data (214, 215). In addition to making PRO data more meaningful for clinical practice, incorporating narrative into HRQL research compliments Indigenous oral traditions that utilise story-telling or yarning as the primary form of transmitting and sharing knowledge (216). Prioritising Indigenous ways of communicating allows for reciprocity and mutual understanding of the research process, creating a culturally safe space where PRO data is more likely to be honest and insightful (216-219).

The Aboriginal population is heterogenous in nature and some advocating for Indigenous research methodologies will question why structured questions are necessary at all when direct questioning is deemed culturally inappropriate for some Aboriginal people (219). UHRQL-HN is designed for duel purposes. In clinical practice, it can be utilised as a patient concerns inventory to help detect, monitor and address individual patientsô HRQL concerns. It is also designed as a PROM to assess the impact of

clinical interventions on patientsô HRQL. Generic open-ended questions often lead to little response and/or confusion about the research topic and these questions help to clarify the concept of HRQL and what is considered by both patients and health care professionals to be of importance in relation to HNC treatment outcomes. Participants in this study were content to answer these questions in semi-structured interviews once these research objectives were clearly explained and understood. Though we can gain insight into HRQL issues from unstructured narrative analysis, it is difficult to assess the actual impact of clinical interventions without baseline questions, as patientsô accounts of their experiences change over time and how a person thinks they felt last month is usually different to how they actually felt at the time. To assess the impact of clinical interventions, it is necessary to establish the patientôs baseline status (pre-intervention) to compare to their post-intervention status. The change in response is most likely due to the intervention and complementing narrative can clarify this. It is acknowledged that for cultural reasons some patients may still prefer other data collection processes such as unstructured interviews and/or quiet phenomological observation (yarning, story-telling, Dadirri etc.) (219). It is hoped that despite the limitations that these alternate methods may place on this toolôs ability to detect clinically meaningful and statistically significant changes, useful HRQL data may still be gained and UHRQL-HN can act as an aid for subsequent thematic analyses of qualitative data.

The questions in UHRQL-HN are ordered to flow in the natural style of a conversation and feedback from Aboriginal healthcare professionals about the face and content validity supports this assertion. In addition to the questions mentioned above, throughout this assessment there are eleven questions to address patient supportive care needs such as pain management, unmet needs for health information, welfare assistance, social support, psychological support and quitting tobacco and/or alcohol.

These questions have been included as health care professionals have an ethical responsibility for their research to be of benefit to their patients when possible and it is most timely to try to address these needs as they are raised in discussion.

The last item in UHRQL-HN asks the patient what the three most important or biggest issues they discussed were. Though some patients say all issues are equally as important as each other, others have clear issues that want to prioritise and this is usual clinical information.

Figure 14 – The Universalist Health Related Quality of Life Questionnaire – Head and Neck version 1 (UHRQL-HN)

This past 'two weeks'…		**This past 'two weeks' how much did this upset you?** Not at all *Never*	A little bit *Sometimes*	A lot *Most the time*	Always *All the time*	**What upset you?** (and other comments)
Have you had any pain?	**Yes / No**	☐	☐	☐	☐	*Where is the pain?*
Have you taken any medicine for pain?	**Yes / No**	☐	☐	☐	☐	
Does this medicine work enough for your pain?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling cold?	**Yes / No**	☐	☐	☐	☐	
Have you been sleeping okay?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling tired?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling weak?	**Yes / No**	☐	☐	☐	☐	
Have you had to rest a lot?	**Yes/No**	☐	☐	☐	☐	
Have you been feeling sick in the stomach?	**Yes / No**	☐	☐	☐	☐	
Do you have a PEG/NET feeding tube?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling hungry?	**Yes / No**	☐	☐	☐	☐	
Have you been able to eat the foods you like?	**Yes / No**	☐	☐	☐	☐	
Have you been swallowing okay?	**Yes / No**	☐	☐	☐	☐	

This past 'two weeks'...		This past 'two weeks' how much did this upset you? Not at all *Never*	A little bit *Sometimes*	A lot *Most the time*	Always *All the time*	What upset you? (and other comments)
Have you been chewing okay?	**Yes / No**	☐	☐	☐	☐	
Has your mouth been dry?	**Yes / No**	☐	☐	☐	☐	
Have foods/drinks tasted okay?	**Yes / No**	☐	☐	☐	☐	
Have you been coughing?	**Yes / No**	☐	☐	☐	☐	
Have you been breathing okay?	**Yes / No**	☐	☐	☐	☐	
Do you have a tracheostomy?	**Yes / No**	☐	☐	☐	☐	
Has your voice been okay?	**Yes / No**	☐	☐	☐	☐	
Have you had trouble saying some words?	**Yes / No**	☐	☐	☐	☐	
Have people had trouble understanding you?	**Yes / No**	☐	☐	☐	☐	
Have you had trouble talking on the telephone?	**Yes / No**	☐	☐	☐	☐	
Have you been hearing okay?	**Yes / No**	☐	☐	☐	☐	
Have your neck/shoulders been feeling okay?	**Yes / No**	☐	☐	☐	☐	
Have you been able to do the things you want to do?	**Yes / No**	☐	☐	☐	☐	

This past 'two weeks'…		This past 'two weeks', have you been happy with that help? Not at all *Never*	A little bit *Sometimes*	A lot *Most the time*	Always *All the time*	Comments:
Have you had help from an escort/carer/support person?	**Yes / No**	☐	☐	☐	☐	
Have you had help from anyone else?	**Yes / No**	☐	☐	☐	☐	*Do you need more help?* **Yes / No** *Who is the right person to help you?* ……
This past 'two weeks'…		**This past 'two weeks', how much has this been worrying you?** Not at all *Never*	A little bit *Sometimes*	A lot *Most the time*	Always *All the time*	**What's been worrying you?** (and other comments)
Have you had worries about money?	**Yes / No**	☐	☐	☐	☐	*Do you need any help sorting out your 'Centrelink' payments?* **Yes / No**
Have you had worries about your family?	**Yes / No**	☐	☐	☐	☐	
Have the doctors told your family about your cancer/cancer story?	**Yes / No**	☐	☐	☐	☐	
Do your family understand your sickness/know the right story about your sickness?	**Yes / No**	☐	☐	☐	☐	
Have you had enough information about what's been happening with your health?	**Yes / No**	☐	☐	☐	☐	*What do you want to know more about?*

These past 'two weeks'…		**These past 'two weeks', how much has this been worrying you?**				**What's been worrying you?** (and other comments)
		Not at all *Never*	**A little bit** *Sometimes*	**A lot** *Most the time*	**Always** *All the time*	
Have you had worries about health tests? *(e.g., needles, biopsies, scans etc.)*	**Yes / No**	☐	☐	☐	☐	
Have you had any problems with the nurses/doctors/health-care workers?	**Yes / No**	☐	☐	☐	☐	
Have you had any problems getting to appointments at the hospital/health clinic?	**Yes / No**	☐	☐	☐	☐	
Have you had any other worries at the hospital/health clinic?	**Yes / No**	☐	☐	☐	☐	
Have you had any worries at the place where you are staying?	**Yes / No**	☐	☐	☐	☐	
Have you had worries about treatment? *(e.g., surgery/radiotherapy/chemotherapy)*	**Yes / No**	☐	☐	☐	☐	
Do you need more information about treatment?	**Yes / No**	☐	☐	☐	☐	
Have you had worries about your health getting worse?	**Yes / No**	☐	☐	☐	☐	
Have you had worries about changes to how your face/neck look?	**Yes / No**	☐	☐	☐	☐	
Has anything else been worrying you?	**Yes / No**	☐	☐	☐	☐	

These past 'two weeks', how much...		**Not at all** *Never*	**A little bit** *Sometimes*	**A lot** *Most the time*	**Always** *All the time*	**How has this changed?** (and other comments)
Have you been feeling strong in your spirit?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling happy?	**Yes / No**	☐	☐	☐	☐	
Have you been thinking clearly?	**Yes / No**	☐	☐	☐	☐	
These past 'two weeks', how much...		**Not at all** *Never*	**A little bit** *Sometimes*	**A lot** *Most the time*	**Always** *All the time*	**Why have you been feeling that way?** (and other comments)
Have you been feeling frustrated?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling annoyed?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling angry?	**Yes / No**	☐	☐	☐	☐	
Have you been feeling down/ sad?	**Yes / No**	☐	☐	☐	☐	
This past 'two weeks'...		**These past 'two weeks', how much has this been worrying you?** **Not at all** *Never*	**A little bit** *Sometimes*	**A lot** *Most the time*	**Always** *All the time*	*Who can you talk to?* .....
Did you have anyone to talk with about your worries and feelings?	**Yes / No**	☐	☐	☐	☐	*Do you want to talk with a social worker/the Chaplin/Aboriginal Liaison Officer/someone else about your worries and feelings?* **Yes / No**

This past 'two weeks'…		**This past 'two weeks' how much did this worry you?** **Not at all** *Never* / **A little bit** *Sometimes* / **A lot** *Most the time* / **Always** *All the time*				
Have you had any other problems because of the cancer treatment?	**Yes / No**	☐	☐	☐	☐	*What other problems have you had?*
This past 'two weeks'…		**This past 'two weeks', how much have you been drinking/ smoking/ chewing?** **Not at all** *Never* / **A little bit** *Sometimes* / **A lot** *Most the time* / **Always** *All the time*				**Why have you been drinking/ smoking/ chewing?** (and other comments)
Have you been drinking alcohol?	**Yes / No**	☐	☐	☐	☐	
Have you been chewing/ smoking tobacco/other stuff?	**Yes / No**	☐	☐	☐	☐	
Have you tried to quit?	**Yes / No**	*What did you do to try to quit?*				*Do you want help to try to quit?* **Yes / No**

Thinking of all the things we just talked about, what 3 things were the most important/biggest problems for you?

…… …… ……

Other comments:

4.3.3 Pilot trial: Criterion and construct validity of UHRQL-HN

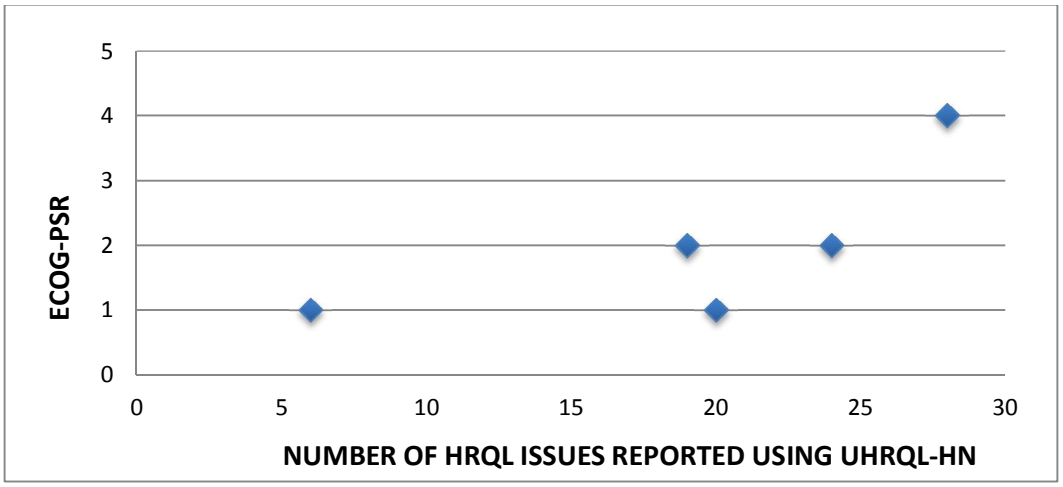
Below, Table 6 outlines the demographics of participantôs in this pilot trial and tabulates how many non-reponse items were recorded. Encountering some missing data is common with patient-reported HRQL assessments and where missing data was present the mean of the best- and worst-case scenario answers was recorded to determine the overall UHRQL-HN score (220). No obvious pattern in terms of non-response was observed during this trial.

Table 6 – Participant demographics and HRQL assessment results from UHRQL-HN pilot trial

T STAGE	N STAGE	M STAGE	OVERALL STAGE	PRIMARY SITE	TREATMENT	TIME SINCE TREATMENT	ECOG-PSR	NUMBER OF REPORTED HRQL ISSUES	OVERALL UHRQL-HN SCORE	MISSING ITEMS
T3	N2b	M1	IVb	ORAL CAVITY (FLOOR OF MOUTH)	PALLIATIVE SURGERY	PRE-TREATMENT	4	28	65	4
T2	N0	M0	II	ORAL CAVITY (TONGUE)	PRIMARY SURGERY + ADJUVANT CHEMO-RADIOTHERAPY	PRE-TREATMENT (RECURRENCE)	2	24	74	4
T3	N0	M0	III	LARYNX (GLOTTIS)	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	9 YEARS	2	19	74	2
T4	N2a	M0	IVb	HYPOPHARYNX (POSTERIOR PHARYNGEAL WALL)	PRIMARY CHEMO-RADIOTHERAPY	6 YEARS	1	20	82	1
T1	N0	M0	I	ORAL CAVITY (FLOOR OF MOUTH)	PRIMARY SURGERY + ADJUVANT RADIOTHERAPY	1 MONTH	1	6	99	5

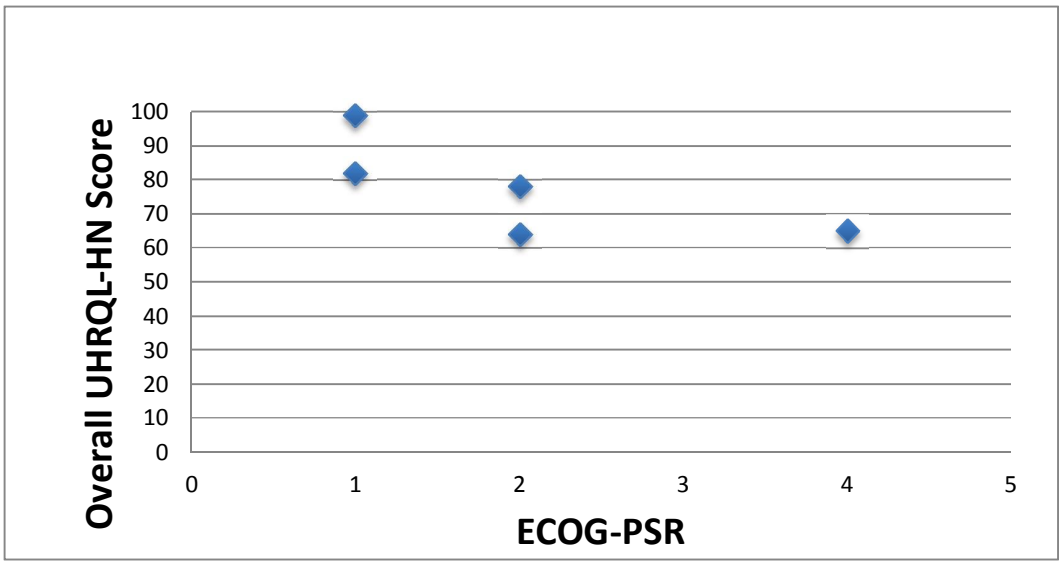
Though the number of participants in the pilot trial was small, individualôs assessment results showed expected clinical correlations with ECOG-PSR, TNM staging, tumour type, treatment and time since treatment. Below, Figure 15 illustrates that the higher the patientôs ECOG-PSR was at the time of UHRQL-HN assessment (indicating poorer functional status), the greater the number of patient-reported HRQL issues recorded.

Figure 15 – Results from pilot trial: Number of patient-reported HRQL issues recorded using the UHRQL-HN assessment vs. ECOG-PSR of patient at time of assessment



Similiarly, the overall UHRQL-HN score of each patient appeared to be inversely correlated to their ECOG-PSR, indicating poorer functional status relates to poorer recorded HRQL scores.

Figure 16 - Overall UHRQL-HN score vs. ECOG-PSR at time of assessment



Below, Figure 17 to Figure 23 charts each individual participantôs responses to the UHRQL-HN questions. The lower the bars on the chart, the lower the self-reported HRQL of the patient with ó3ô corresponding to the best possible response (ónever/not at allô indicating the HRQL issue does not upset or change the patientôs mood/spirit) and ó0ô corresponding to the worst possible response (indicating that the HRQL issue upset or changed the patientôs mood/spirit óalways/all the timeô). Where bars are coloured darker and no numbers are present above, this indicates that the no response was recorded for that particular question.

Figure 17 – 1-month post surgery for T1N0M0 floor of mouth SCC, ECOG-PSR 1

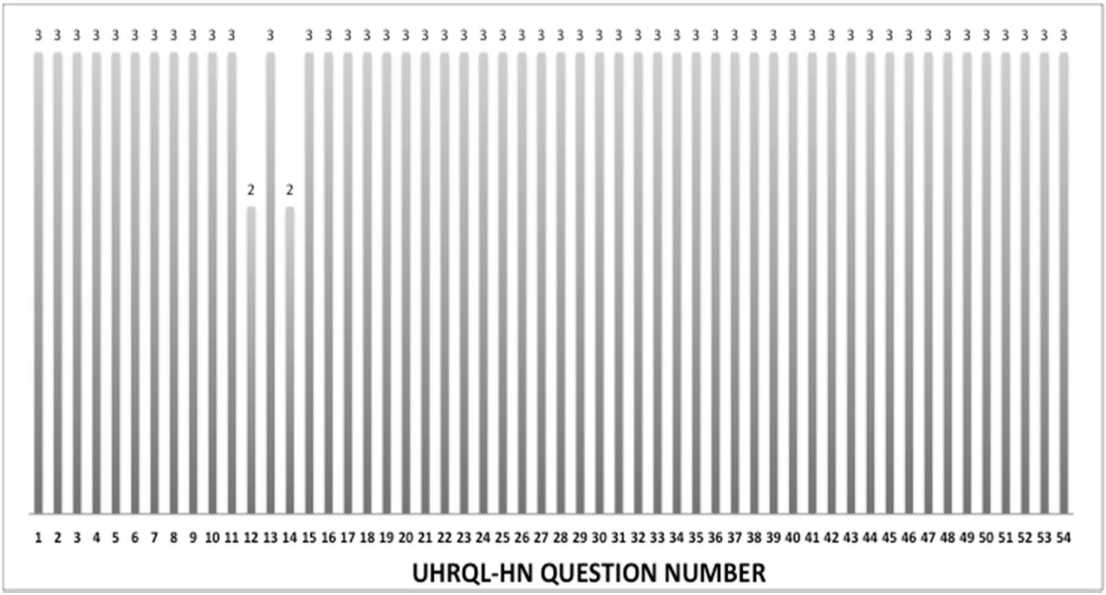

3 3 3

Figure 18 - Pre-treatment for T3N2bMX floor of mouth SCC, ECOG-PSR 4

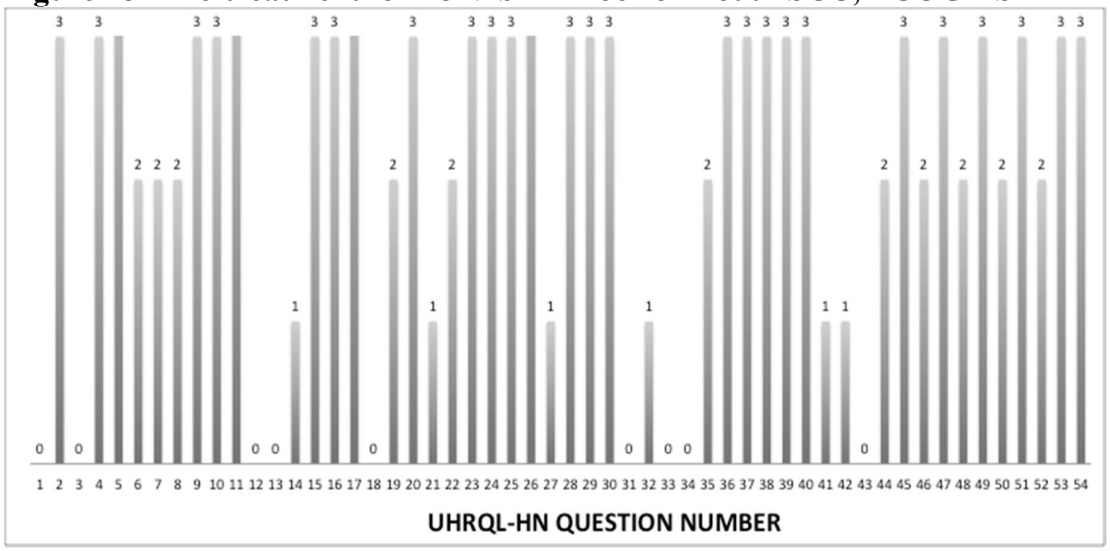


Figure 19 - 6 years post chemo-radiotherapy for T4N2aM0 posterior pharyngeal wall SCC, ECOG-PSR 1

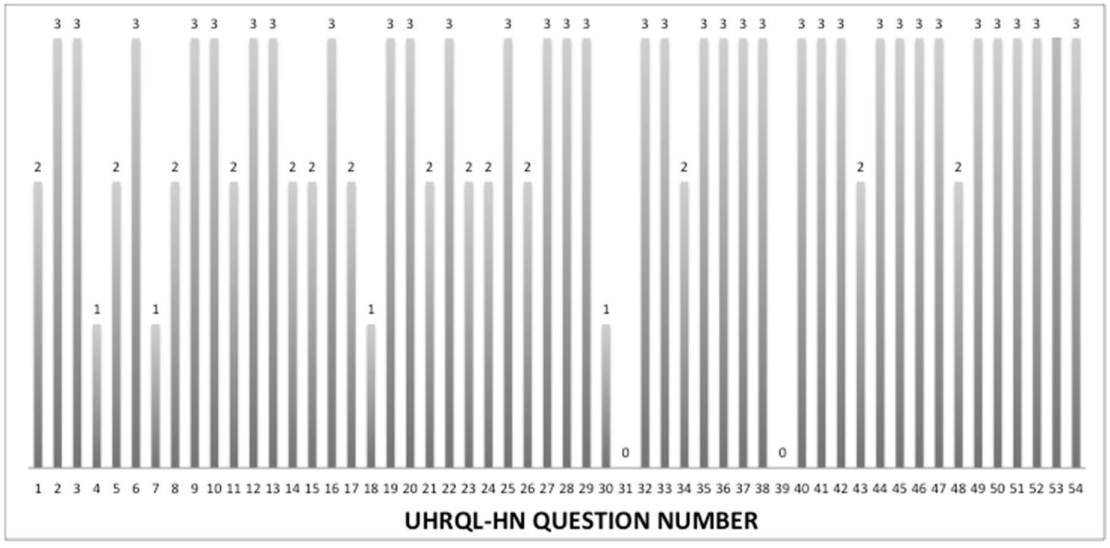


Figure 20 – Nine years post total laryngectomy and adjuvant radiotherapy for T3N0M0 glottic SCC, ECOG-PSR 2

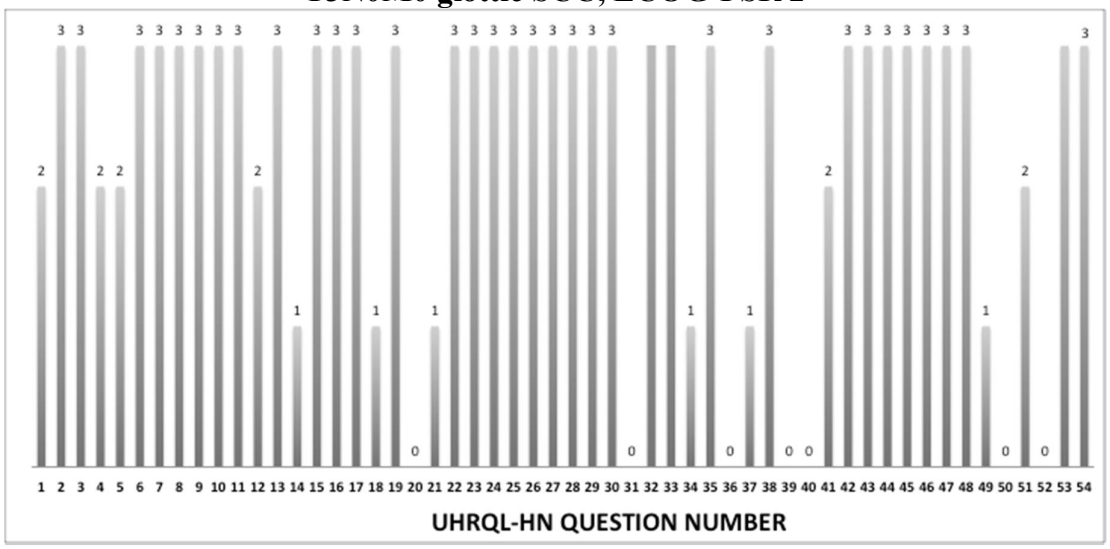
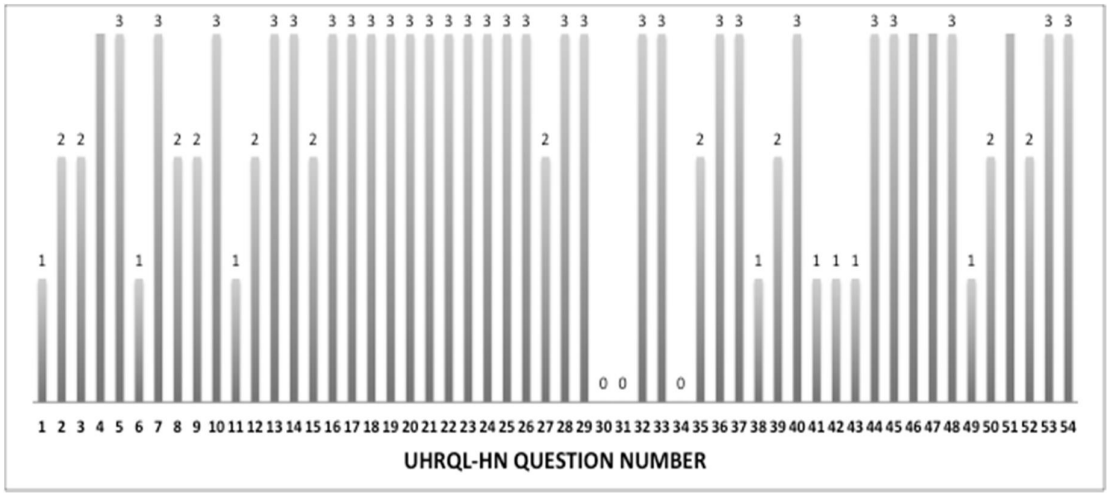


Figure 21 - Pre-treatment for recurrent T2N0M0 lateral tongue SCC, ECOG-PSR 2



Construct validity was investigated by examining the instrumentôs ability to detect clinical changes by comparing individualôs answers at before and after clinical intervention. Figure 22 and Figure 23 demonstrate changes in UHRQL-HN scores at different stages of clinical intervention for the same patient as Figure 21. For example, these figures indicate that pre-treatment the patient reported experiencing pain that was upsetting the patient a lot/most of the time and that the medication that was supposed to be controlling this pain was not working properly. This and taking the medication were both upsetting the patient a little bit/sometimes. However, post-surgery and then post-chemoradiotherapy up to 3 months, the patient reported that the pain was well controlled by medication and that pain and the medication to control pain was not upsetting him at all. Clearly demonstrable differences in responses due to clinical intervention were also found in this patient when assessed after surgery whilst awaiting adjuvant chemo-radiotherapy, and two weeks after completing chemo-radiotherapy and in the other patient in this trial who completed the assessment both before and after surgery for HNC.

Figure 22 - 2 weeks post-treatment (surgery plus chemo-radiotherapy) for recurrent T2N0M0 lateral tongue SCC

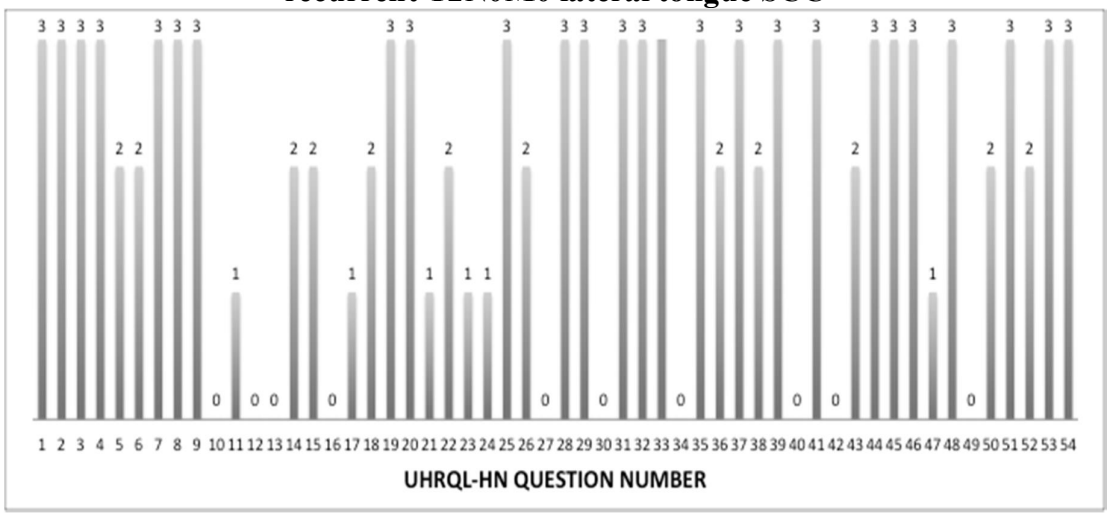
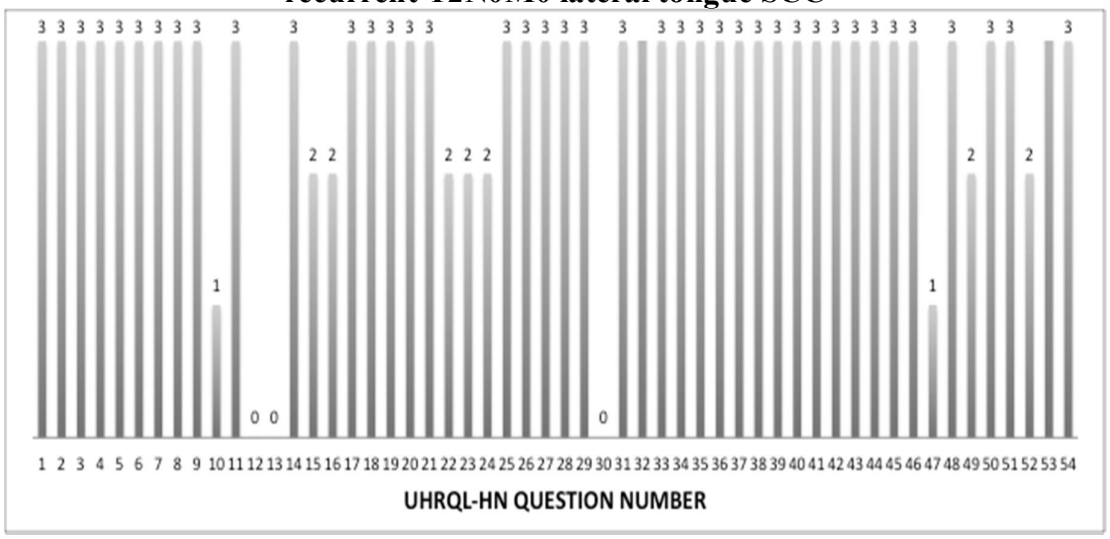


Figure 23 - 3 months post-treatment (surgery plus chemo-radiotherapy) for recurrent T2N0M0 lateral tongue SCC



4.3.4 Expert opinions: Face and content validity of UHRQL-HN

Key informants reported that UHRQL-HN showed good face and content validity in terms of concept, content, utility and measurement properties. 92% (n = 11) of key informants who completed an online survey reported that they thought the content of the assessment addressed things related to Aboriginal people with experience of HNCôs concept of HRQL (one person neither agreed nor disagreed) whilst 100% (n = 12) reported that the content addressed things related to other people with experience of HNCôs concept of HRQL. 100% (n =12) reported that they thought the content of the assessment would be relevant and acceptable for Aboriginal, rural, remote, palliative and other patients with experience of HNC and that the assessment asked things that were relevant for clinical practice.

67% (n = 8) thought that every item was relevant to clinic practice, whilst 25% (n = 3) thought that the assessment contained some things that werenôt relevant to clinical practice and one person neither agreed nor disagreed. 100% reported the assessment may be useful for clinical practice and 92% (n = 11) reported it may be useful for evidence-based research, whilst one person neither agreed nor disagreed.

92% (n = 11) thought the assessmentôs response scale would be easy for patients to understand whilst one person neither agreed nor disagreed. 42% (n =5) thought that the data yield from using this assessment would be better than other HNC-specific HRQL instruments, 58% (n = 7) neither agreed nor disagreed, whilst 100% (n =12) disagreed that the data yield would be worse.

83% of respondents said they would be comfortable administering UHRQL-HN assessment with Aboriginal patients with experience of

HNC, whilst one respondent felt they did not have enough experience to do this and another said they would like to observe someone else doing so first. 100% of respondents said they would be comfortable administering the assessment to other HNC patients including palliative patients. Only one person neither agreed nor disagreed about being comfortable administering the assessment with HNC patients from rural or remote areas.

Pilot trialling of this tool and data from other key informants gathered during the development stages of this instrument indicated that many Aboriginal patients with experience of HNC want to spend more time discussing HRQL issues with health care professionals. However, the main concern for some health care professionals was the length of the assessment in relation to limited clinical consultation time and the potential burden of a lengthy assessment for very ill patients. Further trialling and refinement of this instrument may produce a shorter form version suitable for routine use in clinical practice.

Table 7 - UHRQL-HN in relation to use with Aboriginal patients and other patients - Results of face and content validity survey with key informants

Question posed to key informants (n = 12)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I think that the UHRQL-HN assessment addresses things that are related to the **concept of HRQL from the perspective of Aboriginal patients** with experience of HNC				7	5
I think that the UHRQL-HN assessment addresses things that are related to the **concept of HRQL from the perspective of other patients** with experience of HNC				7	5
I think the **questions** in the UHRQL-HN assessment would be **acceptable** for use with **Aboriginal patients** with experience of HNC				8	4
I think the questions in the UHRQL-HN assessment would be **acceptable** for use with **other patients** with experience of HNC				8	4
I think the **questions** in the UHRQL-HN assessment would be **relevant** for use with **Aboriginal patients** with experience of HNC				9	3
I think the questions in the UHRQL-HN assessment would be **relevant** for use with **other patients** with experience of HNC				8	4
I think the **methods for administering** the UHRQL-HN assessment would be **acceptable** for use with **Aboriginal patients** with experience of HNC				9	3
I think the **methods for administering** the UHRQL-HN assessment would be **acceptable** for use with **other patients** with experience of HNC				9	3
I would be **comfortable administering** the UHRQL-HN assessment with **Aboriginal patients** with experience of HNC			1	8	3
I would be **comfortable administering** the UHRQL-HN assessment with **other patients** with experience of HNC				10	2

Table 8 - UHRQL-HN in relation to use with patients from rural or remote areas and palliative patients - Results of face and content validity survey with key informants

Question posed to key informants (n = 12)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I think the **questions** in the UHRQL-HN assessment would be **acceptable** for use with **rural and remote patients** with experience of HNC (regardless of				10	4
I think the **questions** in the UHRQL-HN assessment would be **relevant** for use with **rural and remote patients** with experience of HNC (regardless of ethnicity/culture)				8	4
I think the **methods for administering** the UHRQL-HN assessment would be **acceptable** for use with **rural and remote patients** with experience of HNC				10	2
I would be **comfortable administering** the UHRQL-HN assessment with rural and remote patients with experience of HNC (regardless of ethnicity/culture)				9	3
I think the **questions** in the UHRQL-HN assessment would be **acceptable** for use with **palliative patients** with experience of HNC				8	4
I think the **questions** in the UHRQL-HN assessment would be **relevant** for use with **palliative patients** with experience of HNC				9	3
I think the **methods for administering** the UHRQL-HN assessment would be **acceptable** for use with **palliative patients** with experience of HNC				9	3
I would be **comfortable administering** the UHRQL-HN assessment with **palliative patients** with experience of HNC				10	2

Table 9 - UHRQL-HN in relation to use in clinical practice and evidence-based research - Results of face and content validity survey with key informants

Question posed to key informants (n = 12)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I think the **questions** in the UHRQL-HN assessment would be **easy for patients to understand**				6	6
I think the **response scale** in the UHRQL-HN assessment would be **easy for patients to understand**				6	6
I think the UHRQL-HN assessment may be **useful for clinical purposes**				10	2
I think the UHRQL-HN assessment may be **useful for evidence-based research**			1	7	4
I think that the UHRQL-HN assessment asks things that are **relevant to clinical practice**				8	4
I think that the UHRQL-HN assessment asks things that are **not relevant to clinical practice**	5	3	1	2	1
Compared with other HRQL surveys, I think that the **data collected using the UHRQL-HN assessment would be better**			7	5	
Compared with other HRQL surveys, I think that the **data collected using the UHRQL-HN assessment would be comparable**		1	6	3	2
Compared with other HRQL surveys, I think that the **data collected using the UHRQL-HN assessment would be worse**	3	4	6		

4.4 Conclusions

UHRQL-HN was designed with both Aboriginal patients with experience of HNC and the health care professionals who provide services to them, to deliver a pragmatic and culturally safe approach for assessing the impact of HNC and treatment on patientsô HRQL. UHRQL-HN is designed to meet the needs of both patients and clinicians, serving dual purposes; as a patient concerns inventory to help identify and address individual patientsô health-related needs and as a PROM for clinical research. In addition to identifying patientsô HRQL concerns, routine clinical assessment utilising UHRQL-HN can help to identify patientsô unmet supportive care needs so that appropriate and timely referrals to other services (such as pain management, physiotherapy, counselling, welfare, tobacco, alcohol or substance rehabilitation etc.) can be made.

UHRQL-HN shows promise as a useful and clinically relevant tool, with good face and content validity, cultural acceptability, utility and relevance for both HNC patients and clinicians. Preliminary data indicates promising criterion and construct validity and further trialling and validation of UHRQL-HN is recommended, with a view to refining this instrument and implementing it into routine clinical practice at tertiary health care facilities in SA and the NT. As UHRQL-HN is based on principals of universality and cultural competency, it is possible that this instrument may be extended for use amongst other populations of patients with experience of HNC with culturally diverse needs. Furthermore, this instrument may be trialled and adapted to assess the impact of other illnesses and treatments on HRQL amongst culturally diverse groups.

CHAPTER FIVE:

Summary and conclusions

Chapter 5. Summary and conclusions

A systematic review of literature published prior to 2013 was undertaken to explore original data from Aboriginal patients using PROMs or otherwise self-reporting on their experiences of cancer or cancer services in Australia. HRQL issues were identified from this data utilising the Australian Psycho-Oncology Co-operative Research Groupôs definition of HRQL.

A cohort of 69 Aboriginal patients from South and Central Australia who were treated for HNC at the RAH between 1997 and 2011, were identified through the RAH HNC database. Between September 2009 and January 2012, 18 semi-structured interviews were carried out with 12 of these patients; based around the English versions of two global-standard, HNC-specific, HRQL instruments. Qualitative data from these interviews was examined and analysed alongside phenomenological, observational data about non-participation and qualitative data from key informants who have worked with or cared for Aboriginal people with experience of HNC. Barriers to active and meaningful participation in standard HRQL assessment were identified utilising *Herdman's* Universalist approach to assessing the cultural equivalence of HRQL questionnaires as a framework for thematic analysis.

Cultural discrepancies adversely affected the reliability and validity of standard, HNC-specific HRQL instruments that are currently utilised in Australia, to accurately and reliably assess the impact of HNC or its treatment on Aboriginal peopleôs HRQL. Therefore, the need for a culturally appropriate, community-informed HRQL assessment for Aboriginal people with experience of HNC was identified.

The findings from the systematic review of literature and the trialling of standard HRQL instruments with Aboriginal patients with experience of HNC and interviews with key informants, informed the development of a novel, community-informed PROM (UHRQL-HN) and pragmatic method that utilises mixed-methods to assist Aboriginal people with experience of HNC to self-report on the impact of HNC and its treatment on their HRQL. This instrument is designed to meet the needs of both patients and clinicians, serving dual purposes as a patient concerns inventory to help identify and address individual patientsô health-related needs and as a PROM for clinical outcomes research.

To evaluate this PROMôs overall functionality, face and content validity data was utilised to examine the instrument concept, items, semantics and operability, whilst criterion and construct validity data was utilised to investigate the instrumentôs psychometric properties. UHRQL-HNôs face and content validity was investigated in terms of functional usability, patient acceptance of the assessment methods and data yield by trialling and refining it with five Aboriginal patients during various stages of their experiences with HNC in SA and CA. To further assess face and content validity, 12 health care professionals who regularly work with Aboriginal people with HNC completed a standardised survey with a five-point Likert scale and free text response options. Criteria validity was investigated by comparing data collected from individual patients to a clinical assessment of each patientsôperformance status (ECOG-PSR) at the time of HRQL assessment. Construct validity was investigated by examining the instrumentôs ability to detect clinical changes by comparing responses from the same patient before and after clinical interventions.

This novel instrument and method for assessing the impact of HNC and treatment on patientsô HRQL shows promise as a clinically relevant tool for helping to improve communication between Aboriginal patients with

experience of HNC and health care professionals, so that patientsô HRQL concerns can be identified and addressed.

The findings from this study can help the RAH and the wider health community to gain better understandings of the physical and cultural needs of Aboriginal patients during their journey with HNC in SA and CA. This information can be utilised to provide Aboriginal patients with experience of HNC and their support networks, with better advice regarding treatment options and how their illness and choice of treatment may affect their symptoms, functioning and HRQL.

This instrument and method was designed with participants and key informants to be culturally safe for Aboriginal patients with experience of HNC and to accommodate the diversity within the participant group. It is not designed to be limited for use with Aboriginal patients in SA or CA only and may also be trialled and utilised with other patients with experience of HNC. The development of this instrument and method included input from participants and key informants in rural and remote areas and palliative care so this instrument may be utilised and further adapted to meet the needs of other patients and health professionals working in these areas. Furthermore, the methods utilised and proposed in this study may be utilised as a guide or basis for engaging other Indigenous communities and/or minority groups with distinctive needs, in HRQL assessment practices elsewhere in Australia or overseas.

Wider trialling and ongoing validation studies are recommended so that UHRQL-HN may be incorporated into clinical practice as a useful and pragmatic tool for assisting patients to self-report on the impact of HNC and treatment on HRQL.

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Table 10 – Examples of qualitative data from UHRQL-HN assessment: Pain management

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Have you had any pain?	"IT'S BEEN GETTING WORSE… OH GOD, A FEW WEEKS NOW."	NO PAIN NOW BECAUSE ON MEDICATION AND IT'S GETTING BETTER SINCE THE SURGERY: "NUP...NOT NOW"		NO PAIN AT THE MOMENT
Where is the pain?	WORSENING PAIN IN NECK AREA			
Have you taken any medicine for pain?	BOTHERED BY SIDE-EFFECTS FROM PAIN-KILLERS INCLUDING CONSTIPATION AND THROWING UP (ESPECIALLY AFTER A FEW BEERS). "THAT'S WHAT I PUT IT DOWN TO BECAUSE IT WAS NOTHING ELSE."	"YEAH, NOW I AM YEAH.. I JUST HAD A COUPLE (OF TEETH) PULLED OUT. I THINK IT'S STOPPED BLEEDING NOW IT TOOK A WHILE BECAUSE ASPIRIN'S IN MY MEDICATION. SEEMS TO HAVE SETTLED."	NO PAIN AT THE MOMENT AS TAKING PAIN MEDICINE.	"I'VE GOT PANADOL IF I NEED IT." DOESN'T HAVE TO TAKE IT VERY MUCH AT THE MOMENT.

Table 11 – Examples of qualitative data from UHRQL-HN assessment: Voice and speech concerns

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Has your voice been okay?	"MY VOICE IS ALRIGHT. IT'S JUST CAN'T TALK CLEARER, CLEARLY ANYMORE SINCE I HAD THAT OPERATION. THE THING IS (MY CHILD) BECAUSE IF I CAN'T TALK (MY CHILD) GONNA BE WONDERING WHAT'S WRONG. WHEN I WAS DOWN HERE BEFORE I WENT HOME I WAS THERE EVERYDAY, MORNING AND EVENING I'D TALK TO (MY CHILD). (MY CHILD) KNOWS MY NUMBER. WHENEVER (MY CHILD) GETS NEAR A PHONE (MY CHILD) RINGS IT. '"	"I THINK SO. ONCE AGAIN IT'S UP TO THIS SWALLOW THING, YOU KNOW? I'M ALWAYS COUGHING."		"NOT BAD I SUPPOSE."
Have you had trouble saying some words?	"I SLUR SOME WORDS BUT I'VE GOTTEN USED TO THIS IN THE LAST TWO YEARS AND IT'S NOT A BIG PROBLEM BECAUSE I CAN COMMUNICATE WELL AND ONLY HAVE TO SLOW DOWN AND REPEAT MYSELF OCCASIONALLY TO BE UNDERSTOOD."			
Have people had trouble understanding you?	"SOMETIME I HAVE TO REPEAT MYSELF, YOU KNOW? NOT VERY OFTEN."		SOMETIMES PEOPLE HAVE TROUBLE UNDERSTANDING	"OH YEAH, NOW AND AGAIN YEAH."
Have you had trouble talking on the telephone?			"I JUST RANG TELSTRA AND I GOT ONE OF THOSE MACHINES, YOU KNOW? I KEPT SAYING THE WORDS BUT IT COULDN'T UNDERSTAND ME UNTIL IT GOT TRANSFERRED TO AN OPERATOR. I WAS TRYING TO PAY A BILL."	SINCE THIS TREATMENT: "I DON'T LIKE TO TALK ON THE PHONE. (I AVOID IT) WHEN I CAN."

Table 12 – Examples of qualitative data from UHRQL-HN assessment: Eating

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Have you been feeling hungry?	"THE LAST FEW WEEKS (I'VE HAD A LACK OF APPETITE). I CAN EAT, IT ALL DEPENDS ON WHAT IT IS. SOMETIMES I MIGHT START EATING AND THEN ALL OF A SUDDEN DON'T FEEL HUNGRY. I WISH I COULD EAT MORE… MY WEIGHT IS GOING DOWN. "	NO APPETITE NOW AS ON PEG FEEDS: "I DON'T HAVE ANY (APPETITE). THEY JUST KEEP PUMPING IT IN, MM… I JUST PUMP (WATER) IN 'CAUSE I DON'T SEEM TO GET THIRSTY."	STILL NO APPETITE BUT PUTTING WEIGHT BACK ON NOW.	
Have you been able to eat the foods you like?	"NOT ALL OF IT."	NO EATING ANYTHING AS CAN'T EVEN SWALLOW WATER: "I'D SOONER BE EATING SOMETHING AND SWALLOWING."	NIL BY MOUTH.	
Have you been chewing okay?	"I CAN ONLY CHEW ON ONE SIDE BUT. BUT I HAD THIS TONGUE BUSINESS. IT'S TOO UNCOMFORTABLE AND HARD TO CHEW ON THE OTHER SIDE 'CAUSE IT KEEPS CATCHING THE SIDE OF MY MOUTH, OH SORRY, MY TONGUE. I CAN GET BY, JUST CHEW ON ONE SIDE. JUST MAKES IT TERRIBLE. I CAN'T SORT OF BITE ANYTHING STRAIGHT. LIKE BITE STRAIGHT INTO AN APPLE. SO I'VE GOT TO LIKE FEED IT IN THROUGH THE SIDE. I'VE GOT TO CUT REAL SMALL PIECES OFF."	"THEY PULLED A COUPLE (OF TEETH) OUT… I CAN'T CHEW. NOTHING TO CHEW."	NIL BY MOUTH THEREFORE NOT CHEWING.	
Have you been swallowing okay?	"SOME FOODS, I DUNNO, IT ALL DEPENDS ON HOW DRY IT IS AND ALL THAT SORT OF STUFF, YOU KNOW?"	CAN'T EVEN SWALLOW OWN SALIVA WHICH CAUSES COUGHING: "THAT'S THE MAIN THING THAT I'M WORRIED ABOUT ALL THE TIME IS THE SWALLOWING… IT'S REALLY LIMITED WHAT GETS THROUGH THERE. A REALLY SMALL AMOUNT MIGHT GET THROUGH… HOPEFULLY I DO (GET BETTER SOON). I DON'T WANT TO GO ON LIKE THIS ALL THE TIME."		"JUST WATER A LITTLE BIT, SOMETIMES, NOW AND AGAIN I TRY…I'VE GOT TO SEE THE SPEECH THERAPIST TOMORROW. THEY TOLD ME IT'D BE A PROBLEM BUT I THOUGHT IT WOULD'VE COME GOOD BY NOW. THERE'S STILL ALL THIS GUNK IN THERE."
Do you have a PEG/NET feeding tube?	"WELL I DON'T EVEN KNOW WHEN I'LL BE ABLE TO TALK OR EAT ANYTHING NOW AND AGAIN NOW. THEY FOUND THEY THINK I'VE GOT TO BE FED WITH A TUBE. I HAD ONE BEFORE WHEN I HAD THE SAME THING. I DIDN'T LIKE THAT. THAT (PEG) TUBE THERE, I WAS IN HOSPITAL FOR MONTHS OVER THAT."	NO TROUBLE WITH PEG IN SITU: "THEY JUST KEEP PUMPING IT IN, MM. I'D SOONER BE EATING SOMETHING AND SWALLOWING THOUGH."	PEG IN SITU	PEG IN SITU

Table 13 – Examples of qualitative data from UHRQL-HN assessment: Financial wellbeing

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Have you had worries about money?	"MONEY'S ALWAYS A BIG ONE, EVEN WHEN YOU'RE NOT SICK...'CAUSE THE BILL'S KEEP COMING IN. THEY'VE GOT TO BE PAID...I'D LIKE TO SEE WHEN, LIKE I'LL BE ON NO PAY SOON 'CAUSE I WON'T HAVE ANY SICK LEAVE BEFORE THIS TREATMENT'S FINISHED. YEAH, I'M WORKING NOW, I'M S'POSE TO BE... I WORK TWO JOB - ONE IN THE MORNING AND ONE IN THE AFTERNOON. AND ONE OF THEM I'VE GOT PLENTY OF SICK LEAVE... BUT THE OTHER LOT IS GOING TO RUN OUT VERY SHORTLY...(I HAVE TROUBLE LOOKING AFTER MY FAMILY) NOT BECAUSE I'VE BEEN ILL BUT BECAUSE I DON'T HAVE ENOUGH MONEY HALF THE TIME… LATELY I DON'T HAVE TO WORRY ABOUT IT 'CAUSE, YEAH, HE'S TAKEN ALL THAT WORRY AWAY FROM ME. ONLY GOT ONE LITTLE ONE I LOOK AFTER AND THAT'S NOT A PROBLEM. "	"I'M ALWAYS WORRIED ABOUT MONEY… BEING DOWN HERE IS CAUSING ME (PROBLEMS WITH MONEY) 'CAUSE I'M NOT WORKING SO THERE'S NO MONEY COMING IN…ONE MOB (OF SICK PAY) RUN OUT AND THE OTHER ONE'LL BE RUNNING OUT THIS WEEK."	"I'M STRUGGLING TO PAY THE BILLS. MY BOSS HAS BEEN GOOD ABOUT IT ALL. I DON'T KNOW IF I WILL END UP GOING BACK TO WORK AFTER ALL THIS, BUT MY BOSS SAYS I CAN COME BACK TO WORK WHENEVER I WANT, WHEN I'M FEELING BETTER. (MY BOSS) CAME TO VISIT ME WHEN I WAS IN ADELAIDE HAVING TREATMENT, ACTUALLY. (MY BOSS) WAS THERE FOR WORK AND (MY BOSS) DROPPED IN TO SEE HOW I WAS GOING."	"OH YEAH MAJORLY! I'VE GOT A PENSION BUT IT'S NOT ENOUGH."
Do you need any help sorting out your Centrelink payments?	"WELL I DOUBT YOU COULD GET SICKNESS BENEFIT SUPPORT BECAUSE I'VE STILL GOT ONE - STILL GOT A INCOME COMING IN… WELL THAT WAY I MIGHT FIND OUT I S'POSE. WE'LL SEE WHAT HAPPENS."	"AT THE MOMENT A LADY AT KANGGAWODLI'S JUST STARTED THE BALL ROLLING ABOUT CENTRELINK STUFF AND ALL."	"THE WOMAN AT KANGGAWODLI HELPED ME OUT A LOT GETTING THE PAPERWORK FOR CENTRELINK AND ALL THAT. IT'S NOT MUCH MONEY BUT AT LEAST THAT'S SORTED NOW."	

Table 14 – Examples of qualitative data from UHRQL-HN assessment: Social wellbeing and support

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Have you had help from an escort/carer/support person?	"SEE, FIRST WHEN I WANTED TO GO BACK, I WANTED TO GO BACK FOR EASTER. 'CAUSE LIKE THE HOSPITAL FLEW ME DOWN AND THEY PAID THE (AIRFARE) SEE, AND THEY WOULDN'T LET ME GO BACK FOR EASTER UNLESS I PAID ME OWN WAY. AND I SAID 'WELL I GOT NO MONEY'. SO I STAYED HERE FOR EASTER. THEN THIS. THIS COME UP ABOUT ALL THE SURGERY ON SUCH AND SUCH A DATE. I SAID 'GOD, I CAN'T STAY HERE THAT LONG.' SO I HAD A BIT OF A BATTLE. THEY WOULDN'T. THEY BAILED UP FIRST AND THEN ONE OF THE THINGS THEY CAME UP WITH WHICH WAS THE SILLY PART, 'OH, WE CAN'T FLY YOU BACK THERE AND BRING YOU BACK BUT WE CAN FLY SOMEONE DOWN THERE AND PUT 'EM, PUT THEM UP FOR, PUT THEM IN ACCOMODATION FOR THE WHOLE TIME YOU'RE DOWN THERE'... I SAID 'I DON'T NEED ANYONE DOWN HERE ALL THE TIME.' I SAID ' WHERE AM I GOING TO FIND SOMEONE THAT'S GONNA COME DOWN HERE FOR A WEEK, FEW WEEK? THEY ALL WORK TOO, YOU KNOW?' THEY SAID, 'WELL, THAT'S THE POLICY.' I SAID, 'WOULDN'T IT BE CHEAPER JUST TO FLY ME HOME AND FLY ME BACK AGAIN? YOU'RE GONNA FLY SOMEONE ELSE DOWN HERE AND BACK AND FOR THE WHOLE TIME THEY'RE DOWN HERE PUT 'EM UP FOR (JUST TO HOLD YOUR HAND) SO IN THE FINISH, THEY'VE GOT THE ABORIGINAL LIAISON MOB AND THEY OPENED THE CASE UP AND SOMEONE SAW A BIT OF WISDOM AND SAID, 'OH YEAH, THAT'S ALRIGHT.'...CAUSE GOD KNOWS HOW LONG IT WILL BE BEFORE I GO BACK. I THINK IT MIGHT BE ABOUT ANOTHER SIX WEEKS 'CAUSE I'VE GOTTA GO, GOTTA HAVE, AH, RADIOTHERAPY AFTER."			
Have you had help from anyone else?	FEELS CLOSE WITH FAMILY AND GETS SUPPORT FROM FAMILY & FRIENDS: "MY (CHILD) WILL WHEN I'M HOME… (CHILD) AND (GRANDCHILDREN), TWO (GRANDCHILDREN), ARE STAYING WITH ME AND NOW THAT'S GOOD. WHICH IS GOOD...SOMETIMES UP (THERE AT HOME I GET HELP FROM) FRIENDS. DOWN HERE IT'S MORE SO WITH THE FRIEND THAT I COME DOWN AND STAY WITH. THEY CAN'T DO ENOUGH."	FRIENDS THAT LIVE LOCALLY: "THEY COME EVERY COUPLE OF DAYS AND SEE ME. PICK ME UP, TAKE ME TO SHOP OR WHATEVER…(I FEEL) VERY CLOSE (WITH THEM)." FEELS CLOSE WITH FAMILY BUT THEY ARE NOT IN TOWN: "OH, WELL THEY'RE NOT HERE. THERE'S NOT MUCH THEY CAN DO FROM THERE. EVERYDAY THEY GIVE ME A CALL."	"(THE ABORIGINAL CANCER CARE COORDINATOR) WAS REALLY GOOD DOWN THERE. SHE HELPED ME A LOT. MY FAMILY HELP ME BUT I DON'T NEED MUCH HELP NOW."	FAMILY HELPS BUT CAN MOSTLY LOOK AFTER SELF.
Have you been feeling homesick?	"I JUST GOT HOME, GOT BACK FROM HOME TODAY SO I WAS. BEFORE THIS I SAID TO THEM WHILE I'M WAITING FOR SURGERY I WANT TO GO HOME AND SEE THEM, YOU KNOIW? FOR A WEEK OR WHATEVER IT WAS. IT WAS MAINLY THE SITTING AROUND AND WAITING."	"I WISH I WEREN'T HERE SORT OF THING. I WISH I WAS HOME."	"I WAS FEELING HOMESICK BUT I'M BACK HOME NOW. (THE ABORIGINAL CANCER CARE CO-ORDINATOR) ORGANISED FOR MY (CHILD) TO BRING MY (OTHER CHILD) TO VISIT ME IN ADELAIDE. IT WAS OKAY IN THE END (WITH PATS)."	"I ONLY JUST GOT HERE YESTERDAY."
Have you had any worries at the place where you are staying?	"I DON'T LIKE BEING A BLOODY DRAG ON MY MATE DOWN HERE. LIKE (MY FRIEND) DONE, (MY FRIEND) SAID, IT'S GREAT TO HAVE ME BUT IT DOESN'T MAKE ME FEEL TOO GOOD, YOU KNOW? JUST LIKE I TOLD (MY FRIEND), 'I DON'T WANT TO SPONGE OFF YOU ALL THE TIME."	"I'M AT KANGGAWODLI AND THEY'RE VERY GOOD THERE."		NO PROBLEMS WITH ACCOMODATION AT HOME. HAPPY STAYING AT KANGAWODLI WHEN VISITING ADELAIDE

Table 15 - Examples of qualitative data from UHRQL-HN assessment: Health information needs

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY
Have you had enough information about what's been happening with your health?	"I'VE FOUND THERE'S A LACK OF INFORMATION ALL THE TIME. I'D GET VERY LITTLE. NO ONE'S TALKING."	"I S'POSE, YEAH. IT'S BETTER THAN IT WAS, YOU KNOW?... IT'S NOT BAD."	
What do you want to know more about?	"MAYBE SHARE A BIT MORE INFORMATION AROUND A BIT QUICKER. THE MAIN THING IS YOU DON'T KNOW WHAT'S GOING ON AND WHEN YOU ASK SOMEONE, THEY DON'T KNOW THEY'VE GOT TO FIND OUT FROM SOMEONE ELSE."	"ALL I'VE GOT TO DO IS FIND OUT WHAT TIMES I'VE GOT TO COME IN FOR THIS RADIOLOGY I KNOW IT'S MONDAY, SO IT'S MAINLY I'VE GOT TO FIND OUT WHAT TIME. SO I'LL PROBABLY GET IT AFTER THIS, WHEN I FINISH HERE THEY SAID I SHOULD GO AND ASK DOWN AT RADIOLOGY AND THEY'LL GIVE ME A PRINT OUT OR WHATEVER."	"I WANT TO KNOW WHAT THE APPOINTMENTS IN ADELAIDE ARE FOR."
Do you need more information about treatment?	"IT'S JUST THE LACK OF INFO. I'VE FOUND THERS'S A LACK OF INFORMATION ALL THE TIME. LIKE ALL THE TIME I WAS DOWN HERE I'D GET VERY LITTLE. I'D GO HOME AND MY MATES WOULD SAY, 'WELL , WHAT DID THEY SAY?' I'D SAY, 'HUH, DON'T ASK ME.'. I SAID, 'NO ONE'S TALKING.'... THEN YOU TALK TO SOMEONE THERE AND IT'S LIKE THERE'S VERY LITTLE COMMUNICATION BETWEEN THEM ALL TOO... LAST TIME I WAS DOWN HERE I DON'T KNOW HOW MANY DIFFERENT PERSONS I SAW... THEY KEEP ASKING ME THE SAME QUESTIONS. LIKE, 'YOUR DATE OF BIRTH?', 'WHERE DO YOU LIVE?' AND ALL THAT. 'I THINK YOU'VE GOT IT ALL THERE'. AND 'WHAT MEDICATION YOU ARE ON?'. THAT'S ALL THERE TOO. YOU GET SICK OF THE SAME THINGS ALL THE TIME."	"THE SAME OLD THING THAT COULD BE DONE DIFFERENT I'VE FOUND IS THE INFORMATION AND ALL THAT STUFF. I FOUND THAT THE ONLY ONE THAT'S GIVEN ME REAL GOOD INFORMATION IS WHEN I'VE GONE TO SEE (THE MEDICAL ONCOLOGIST) YESTERDAY. VERY GOOD (INFORMATION). THE OTHERS SORT OF GAVE YOU A BRIEF OUTLINE IF ANYTHING... I STILL DON'T KNOW TOO MUCH ABOUT THE RADIOTHERAPY PART THERE...YEAH, ALL THE SIDE EFFECTS... THAT'S WHAT I WAS THINKING (THAT THEY MIGHT TELL ME EVERYTHING TOMMOROW WHEN I BEGIN RADIOTHERAPY)." SAYS WASN'T TOLD MUCH ABOUT WHAT TO EXPECT FROM SURGERY: "THEY DIDN'T TELL ME MUCH AFTERWARDS EITHER. WHAT REALLY HAPPENED. WHAT THEY REALLY DID. THEY DON'T EVEN (EXPLAIN)."	"THEY STILL HAVEN'T TOLD ME WHAT THOSE APPOINTMENTS IN ADELAIDE ARE FOR. I KNOW I HAVE TO GO BACK DOWN THERE AND SEE THE DENTIST AND SPEECH PATHOLOGIST AND THE SURGEONS BUT THEY DIDN'T TELL ME WHAT FOR. I HAVEN'T BEEN TOLD ANYTHING."

Table 16 - Examples of qualitative data from UHRQL-HN assessment: Emotional wellbeing

QUESTION:	PRE-TREATMENT	POST- SURGERY AWAITING ADJUVANT CHEMO-RADIOTHERAPY	2 WEEKS POST-RADIOTHERAPY	3 MONTHS POST-RADIOTHERAPY COMPLETION
Have you been feeling happy?		A LITTLE BIT	"A LITTLE BIT."	"I'M HAPPY AS I CAN BE I SUPPOSE, CONSIDERING EVERYTHING."
Have you been feeling down/ sad?	"ESPECIALLY WHEN I CAN'T FIND OUT WHAT'S HAPPENING OR WHAT'S GOING ON, YOU KNOW?"	"OH, A LITTLE. I WISH I WEREN'T HERE SORT OF THING. I WISH I WAS HOME."	SOMETIMES FEELS SAD AND DEPRESSED	"NOT REALLY, NO. SOMETIMES YEAH, NATURALLY. IT'S STILL THE SAME THING WITH THE SWALLOWING - I WANT TO EAT SOMETHING."
Have you been feeling frustrated?	FRUSTRATED BY LACK OF INFORMATION ABOUT HEALTH & TREATMENT: "THAT WAS WHAT WAS REALLY SO FRUSTRATING. AND IT GETS FRUSTRATING WHEN YOU DON'T KNOW, ESPECIALLY WHEN YOU GO, PEOPLE ASK YOU, 'WHAT DID THEY SAY?'. 'OH DON'T ASK.'"	BECAUSE OF SWALLOWING PROBLEMS		JUST A LITTLE BIT FRUSTRATED ABOUT SITUATION IN GENERAL
Have you been feeling annoyed?	"BIT IRRITABLE. IRRITABLE SOMETIMES."		ANNOYED AT LACK OF INFORMATION. ANNOYED AT MUCOSITIS & NOT BEING ABLE TO EAT/DRINK	
Have you had worries about your health getting worse?	"I'M THINKING A LOT ABOUT DYING. NOT THAT IT DOES MUCH GOOD."	WORRIES ABOUT HEALTH GETTING WORSE ALL THE TIME AND SOMETIMES WORRIES ABOUT DYING: "OH, THERE'S ALWAYS THAT…EVERYONE DOES (WORRY ABOUT DYING) I SUPPOSE."	"I SOMETIMES WORRY THINGS WILL GET WORSE."	
Have you had worries about treatment? *(e.g., surgery/radiotherapy/chemotherapy)*	"NOT REALLY, NOT REALLY. I'M STARTING TO GET A BIT NERVOUS NOW WITH THE SURGERY COMING UP. I DON'T WANT THEM TO CUT ANY MORE OF MY TONGUE OUT."	A LITTLE WORRIED ABOUT THE POTENTIAL SIDE EFFECTS OF TREATMENT AND THINGS: "OH, A LITTLE (NERVOUS)."		