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

Aboriginal Patients' 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.

In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Date:………………………

Signature: é é é é é é é é é é é é
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-HN’s 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 patients’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 professionals’ 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 patients’ 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 – 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 – 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 1 – Introduction and background

Chapter 2 – Self-reported HRQL issues for Aboriginal patients with experience of HNC: A review of relevant literature

50 documents included original data from Aboriginal people self-reporting on experience of cancer

No documents specific to Aboriginal patients with experience of head and neck cancer

No PROMs used to assess the impact of clinical interventions on Aboriginal patients with experience of cancer

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

18 interviews based on FACT-HN and UIW-QOL with 12 Aboriginal patients with experience of HNC

Observational data from 12 Aboriginal patients with experience of HNC who did not participate

Consultation with 10 key informants who have worked with and cared for Aboriginal patients with experience of HNC

Chapter 4 – Development 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

Concept and conceptual model developed from Chapter 2 & 3 findings

Provisional item list generated from patient interviews, previous literature and feedback from key informants

Individual questions generated with input from key informants, Aboriginal language interpreters and linguists

New tool trialled and refined with 5 Aboriginal patients with experience of HNC

12 key informants who work with and care for Aboriginal patients with experience of HNC surveyed about the face and content validity of the new tool

Chapter 5 – Conclusions and future directions