

Health-related Quality of Life After Head and Neck  
Cancer:  
Aboriginal Patients' Experiences in South and Central  
Australia

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This thesis is presented for the Degree of

Doctor of Philosophy,

School of Medicine

The University of Adelaide

July 2014

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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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## 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.

## Acknowledgements

I would like to acknowledge and respect the Kaurna people, the traditional custodians, whose ancestral lands I live and work within. I acknowledge the deep feelings of attachment and relationship of Aboriginal people to this country and pay my respect to Elders past, present and future.

My heartfelt thanks, gratitude and respect go to all the patients, their families and support workers who agreed to be part of this project and most generously shared their time and their stories with me.

Many thanks and deep felt gratitude to the Northern Community Health Foundation Incorporated (NCHF) and The University of Adelaide for providing funding for me to complete this research through a PhD Divisional Scholarship. Additional resources and expenses were provided by the NCHF and the RAH Department of Otolaryngology and I am extremely grateful for their ongoing support and encouragement throughout this project.

For providing me with this amazing opportunity through their steadfast guidance and encouragement, and for sharing their precious time, wisdom and advice, I sincerely thank my supervisors Professor P.J. Wormald, Associate Professor Suren Krishnan, Dr. Sid Selva-Nayagam and Mr. Guy Rees.

For sharing their invaluable time, wisdom, insights and experience to help steer this project, many thanks to the staff at the Royal Adelaide Hospital (RAH) (including the RAH HNC Multidisciplinary Care Team, the HNC Ward (Q5), the Palliative Care Team, the RAH Aboriginal Liaison Unit and the RAH Aboriginal Cancer Care Coordinators), Staff at Alice

Springs Hospital (ASH) (including the ASH Aboriginal Liaison Unit, the Department of Medical Oncology and the Department of Otolaryngology), staff from Kanggawodli Caring House Ambulatory and Primary Health Care Facility, Program of Experience in Palliative Care and Territory Palliative Care, and the Royal Darwin Hospital (RDH) (including the Department of Otolaryngology and the RDH Aboriginal Liaison Unit), the Aboriginal Health Council of SA, Carmel McNamara from the Cancer Council SA, Dr. Deborah Prior from the Cancer Council QLD, Paul Eckert and Inawantji Scales from the School of Languages, and the University of Adelaide's Indigenous Mobile Language Team.

Special thanks to ASH Aboriginal Liaison Unit for their assistance with contacting participants, cultural brokerage and interpreting services in Central Australia and to Mr. Andrew Foreman for generously offering to review this manuscript. Your feedback, support and encouragement are invaluable.

Lastly, thank you to my family, friends and teammates for your support and understanding whilst tolerating my disposition and absences at times throughout these past few years.

I hope that you are pleased with the outcomes of this project and I apologise if I have not met your expectations or caused offence at any time. I thank you all for your ongoing support and patience in seeing this project to fruition.

## **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 Strait 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 of 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 ó Head and neck - version 1

QLD = Queensland

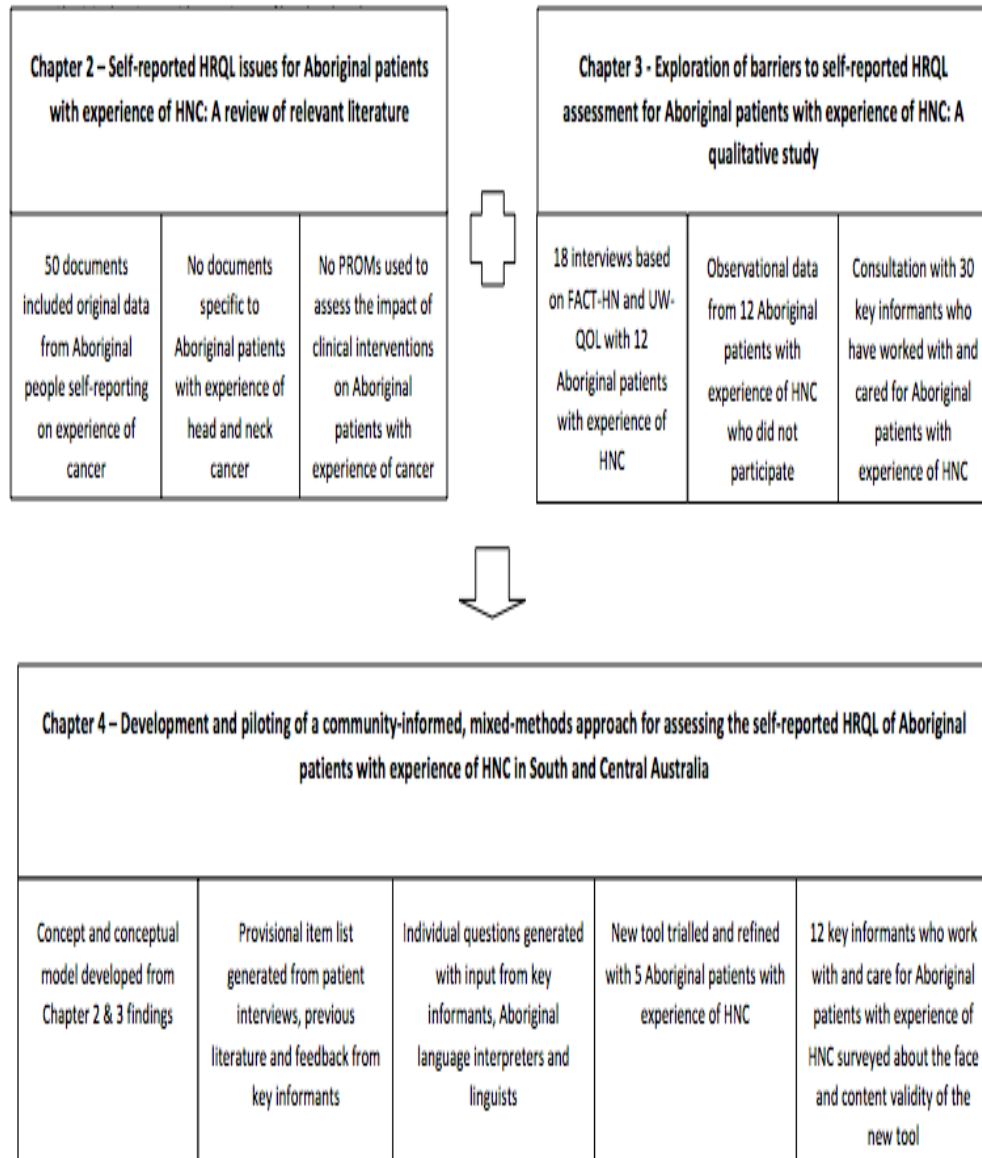
WA = Western Australia

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 5 – Conclusions and future directions**