# Exploring Wellbeing from Indigenous Perspectives

## Alana Gall

BHS (NutMed), MRSIAS

Thesis submitted for the degree of

# **Doctor of Philosophy**

Wellbeing and Preventable Chronic Diseases Division

Menzies School of Health Research

Charles Darwin University, Darwin, Australia

December 2021



### **Declaration**

I hereby declare that the work herein, now submitted as a thesis for the degree of Doctor of Philosophy at Charles Darwin University, is the result of my own investigations, and all references to the ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree and is not being currently submitted in candidature for any other degree.

I give consent for this copy of my thesis, when deposited in the University Library, being made available for loan, photocopying and online via the University's Open Access repository eSpace if accepted for the award of the higher degree by research.

Alana Gall

PhD Candidate, Menzies School of Health Research

December 2021

## Statement of financial assistance

The What Matters study of which Alana Gall's PhD sat under, is funded by a National Health and Medical Research Council (NHMRC) Project grant (#1125434). This study was also supported by the NHMRC funded Centre of Research Excellence in Targeted Approaches To Improve Cancer Services for Indigenous Australian Australians (TACTICS; #1153027). Alana Gall was supported by a NHMRC Postgraduate Scholarship (APP1168150) and a TACTICS Postgraduate Scholarship top-up.

#### **Abstract**

Wellbeing is a broad multi-dimensional concept encompassing an individual's perception of their position in life, as well as the context, culture and value systems in which they live, and their goals, expectations, standards and concerns [1]. Existing indicators of wellbeing are largely based on Western biomedical models and understandings of health.

There is growing recognition that additional domains and indicators of wellbeing are required to more fully consider and reflect Indigenous paradigms. Many Indigenous populations conceptualise good health to be more than the absence of disease or illness for the individual, and commonly embrace a holistic and collectivist worldview of health and wellbeing. Concepts and understandings of wellbeing for Indigenous peoples must also be considered in the enduring context of colonisation, which includes intergenerational trauma, racism, socioeconomic disadvantage and poorer health outcomes. These issues raise the question of how to measure wellbeing for Indigenous populations and the effectiveness and cost-effectiveness of interventions using existing wellbeing measurements.

This thesis reports on the dimensions and understandings of wellbeing from the perspectives of Indigenous peoples in Australia, Canada, Aotearoa (New Zealand) and the United States. Further, the sociodemographic, socioeconomic and health conditions associated with lower self-rated wellbeing among a cohort of Aboriginal and Torres Strait Islander adults are presented, along with an exploration of change in wellbeing over the first wave of the COVID-19 pandemic in Australia. Lastly, an evaluation was undertaken of the suitability of the 'think aloud' method and cognitive validation of a set of wellbeing

statements developed for inclusion in a new wellbeing measure for Aboriginal and Torres Strait Islander adults.

The main research findings were:

- Wellbeing for Indigenous peoples in Australia, Canada, Aotearoa (New Zealand)
  and the United States is cyclic in nature and encompasses holistic and collectivist
  concepts that include the physical, mental, emotional and spiritual aspects of the
  self, and are connected to the wellbeing of the family, community/Tribe and
  Country/land.
- Health-related quality of life is lower among Aboriginal and Torres Strait Islander adults compared to other Australians. Several factors were associated with Aboriginal and Torres Strait Islander adults having lower wellbeing and health related quality of life, both generally and in association with the COVID-19 pandemic in Australia.
- The 'think aloud' method was shown to be an acceptable method for use in research by Aboriginal and Torres Strait Islander adults.

These findings have implications for numerous aspects of health and healthcare. The findings of what is important to the wellbeing of Indigenous peoples, and what things may impact on their wellbeing, needs to be considered when developing individual health care plans, informing services, programs and policies, that include or impact on Aboriginal and Torres Strait Islander peoples.

#### Reference

1. The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. (1995). *Social Science & Medicine*. *41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

## Table of Contents

Declarat	tion	iii
Stateme	ent of financial assistance	iv
Abstract	İ	v
Acknow	ledgements	xii
Forewor	<sup>-</sup> d	xv
List of P	ublications	. xvii
List of F	igures	xix
	ables	
Abbrevia	ations	xxi
Chapter	1 Introduction	
1.1	Chapter Overview	24
1.2	Aboriginal and Torres Strait Islander research approach	25
1.3	Indigenous peoples	31
1.3.1	Indigenous peoples globally	31
1.3.2	Aboriginal and Torres Strait Islander peoples	32
1.4	Wellbeing	34
1.4.1	Understanding wellbeing	34
1.4.2	Indigenous concepts of wellbeing	35
1.4.3	Measuring wellbeing	37
1.4.4	Measuring wellbeing for Aboriginal and Torres Strait Islander peoples	38
1.5	Thesis outline	42
1.5.1	Overall aims	42

1.5.2	Chapter summaries4	3
1.5.3	Ethics guidelines and principles4	4
1.6	References	ŀ5
Chapter	2 Aspects of wellbeing important to Aboriginal and Torres Strait Islander	
peoples		5
2.1	Preface	6
2.2	Statement of Authorship	57
2.3	Author Contributions	57
2.4	References	57
2.5	Published Article One	58
2.6	Published Article Two	'9
Chapter	3 Aspects of wellbeing important to Indigenous peoples in Canada, Aotearo	а
(New Ze	ealand) and the United States9	)2
3.1	Preface	)3
3.2	Statement of Authorship	)4
3.3	Author Contributions	)4
3.4	Published Article Three	)5
Chapter	4 Factors associated with wellbeing for Aboriginal and Torres Strait Islander	
peoples	12	26
4.1	Preface	27
4.2	Statement of Authorship	28
4.3	Author Contributions	28
4.4	Published Article Four12	29

Chapter	The impact of COVID-19 on wellbeing and health-related quality of	life for
Aborigir	nal and Torres Strait Islander peoples	137
5.1	Preface	138
5.2	Statement of Authorship	138
5.3	Author Contributions	138
5.4	Published Article Five	140
Chaptei	Cognitive assessment of wellbeing statements using the "think alou	ud"
method	, and the acceptability of this method	148
6.1	Preface	149
6.2	Statement of Authorship	149
6.3	Author Contributions	149
6.4	Background	150
6.5	Methods	151
6.5.1	Design	151
6.5.2	Procedure	152
6.6	Analysis	155
6.7	Results	157
6.7.1	Participant characteristics	157
6.7.2	Errors (Statements)	158
6.7.3	Participant experience of "think aloud" method	171
6.8	Discussion	175
6.8.1	Limitations	178
6.8.2	Acknowledgements	179
6.9	References	179

Chapter	7 Final Discussion and Conclusions	184
7.1	Chapter overview	185
7.2	Summary of main findings	185
7.2.1	Aspects of wellbeing important to Aboriginal and Torres Strait Islander people	es
		186
7.2.2	Aspects of wellbeing important to Indigenous peoples in Canada, Aotearoa	
(New	Zealand) and the United States	188
7.2.3	Factors associated with wellbeing for Aboriginal and Torres Strait Islander	
peopl	es	190
	The impact of COVID-19 on wellbeing and health-related quality of life for	
Abori	ginal and Torres Strait Islander peoples	191
7.2.5	Cognitive assessment of wellbeing statements using the "think aloud" metho	d,
and th	ne acceptability of this method	
7.3	Limitations	194
7.4	Future research	195
7.5	Concluding remarks	197
7.6	References	199
Chapter	8 Appendices	205
8.1	Appendix A	206
8.2	Appendix B	218
8.3	Appendix C	219
8.4	Appendix D	221
9 Add	ditional Related Publications	227

9.1	Using Web Conferencing to Engage Aboriginal and Torres Strait Islander	
Young	g People in Research: A Feasibility Study	228
9.1.1	Preface	228
9.1.2	Statement of Authorship	229
9.1.3	Author Contributions	229
9.1.4	Published Article Six	230

## Acknowledgements

mina tunapri waranta takamuna
milaythina Turrbal & Jagara
mina tunapri ningimpi + nungumpi nara-mapali
nayri nina-tu pulingina waranta
milaythin-nanya

I would like to acknowledge that we stand on the Country of the Turrbal and Jagara people.

I also acknowledge and pay respect to the Ancestors – Elders and community, past, present and emerging.

Thank you for having us on your Country

I will tread softly.

mina kani Alana Gall.

mina Pakana luna

milaythina-mana lutruwita

My name is Alana Gall

I am a Pakana/Tasmanian Aboriginal woman

My Country is *lutruwita*/Tasmania.

When deciding to embark on my PhD I did not make the decision lightly, however I thought that with hard work and focus that everything should be fine... ah yes, famous last words! Of course, my PhD, like so many before me (and others to come), was fraught with delays, set-backs, major errors, personal crises/changes and even a pandemic; all things out of my control (which trust me, is not fun for a perfectionist!). Despite all this, my PhD continued, and I was determined I was going to finish in three years max. I had a personal goal that I would be a Doctor by the age of 40, which I turned 40 just before handing this in (so technically still 40 when conferred). This would NOT have been possible without the unwavering support of my supervisory panel, mentors, family and friends. They helped with all the issues that popped up, taught me so many new things, and gave me autonomy when I needed it most.

First, I would like to give a whole-hearted thank you to my primary supervisor, Professor Gail Garvey, who I \*literally\* would not have been at this point without. She supported me to get my undergraduate degree, was my primary supervisor for my Masters, and now brought me through the thick of my PhD until completion. Her dedication to the education and success of Aboriginal and Torres Strait Islander people, either working for her or her students, is admirable. I count myself lucky to be one of the people she has taken under her wing, both as an employee and a student, to learn and grow under her guidance.

Next, I would like to thank my other three supervisors; Professor Kirsten Howard, Dr Kate Anderson and Dr Abbey Diaz. Firstly, Kirsten, who, before my PhD, I hadn't worked with before. While she was very busy in her role as a Professor, she was able to find the time to support me when I really needed her. Her high level of understanding about Health Economics was imperative to the completion of this PhD. Then there are Kate and Abbey... I have worked with both of them for years, so they have supported me and my career long before my PhD even started. I cannot thank them enough for their tireless help, both professionally and personally over the years. They are both exceptional in their own fields and I have learnt so much from them both. I know I would not have been able to complete this PhD without their unwavering support. Next I would like to thank Associate Professor Lisa Whop and Dr Tamara Butler. They both have been amazing mentors throughout my PhD, offering insights into all aspects of my PhD, and giving me advice when I needed it most. I would also like to acknowledge the Aboriginal and Torres Strait Islander people who participated in all the studies throughout my PhD. Thank you for allowing me to have insight into the aspects of your lives that were needed to make this work possible.

Lastly, I would like to thank my family and friends for their support and understanding throughout this PhD. As anyone who has done a PhD knows, they require quite a lot more of your time, plus they can be quite taxing on your mental health at times

(or just simply make you exhausted). All my family and friends have supported me by being very understanding of this, not taking personally that I have been MIA for three years! I would also like to give a special thanks to my partner Hari and daughter Zyana, both of whom I have relied on heavily throughout this PhD for support, especially keeping me motivated and allowing me to vent. Also, Hari, for all the times you have taken on more of the workload around the home, or picked something up on your way home from work to cheer me up when I'd had a terrible day... I really appreciate that, and it did not go unnoticed.

nayri nina-tu

Alana

#### **Foreword**

In the current thesis the term 'Indigenous' is used when more than one Indigenous group is being referred to in text (refer to individual publication chapters for specific terminology in each). When referring to the Indigenous peoples of Australia, we use the terminology 'Aboriginal and Torres Strait Islander' to refer to the varying communities in Australia as a collective. When referring to the First Nations, Métis and Inuit groups in Canada, we use the term 'Indigenous peoples in Canada' as a collective. In Aotearoa (New Zealand) we use the term Maori. Lastly, when referring to the American Indians, Alaska Natives and Native Hawaiians in the United States, we use the term 'Indigenous peoples in the United States' to refer to the varying Tribes/communities as a collective.

The current thesis was somewhat impacted by the COVID-19 pandemic in Australia from 2020 onwards. This resulted in changes to the proposed PhD that could not be avoided. We originally planned to collaborate in person with our colleagues in Canada and Aotearoa (New Zealand), however due to travel restrictions this was not possible. Instead, we developed a plan to do a systematic literature review of the aspects of wellbeing that are important to the Indigenous peoples in Canada, Aotearoa (New Zealand) and the United States. The resultant review forms Chapter Three of this thesis.

I acknowledge the importance of reflectively considering and describing my own background, perspective and values that I bring to this work. I am a Pakana woman from lutruwita (Tasmanian Aboriginal woman), with a background in Nutritional Medicine and qualitative research. I have worked in Aboriginal and Torres Strait Islander health research, community engagement and research translation for over 10 years. During this time, I have engaged with Aboriginal and Torres Strait Islander people nationally, as well

as with Indigenous researchers internationally. I am a deeply spiritual person, practicing both my traditional spiritual ways and the Christian ones. I am an Aboriginal woman with a white mother, so have learned to live in both of these worlds, appreciating and understanding both.



#### List of Publications

#### Chapter 2

Garvey, G., Anderson, K., **Gall, A.,** Butler, TL., Cunningham, J., Whop, LJ., Dickson, M., Ratcliffe, J., Cass, A., Tong, A., Arley, B. & Howard, K. (2021). What Matters 2 Adults (WM2Adults): Understanding the Foundations of Aboriginal and Torres Strait Islander Wellbeing. *International Journal of Environmental Research and Public Health*, *18*(12), 1693. https://doi.org/10.3390/ijerph18126193

Garvey, G., Anderson, K., **Gall, A.,** Butler, TL., Whop, LJ., Arley, B., Cunningham, J., Dickson, M., Cass, A., Ratcliffe, J., Tong, A. & Howard, K. (2021). The Fabric of Aboriginal and Torres Strait Islander Wellbeing: a conceptual model. *International Journal of Environmental Research and Public Health*, *18*(15), 7745.

#### Chapter 3

Gall, A., Anderson, K., Howard, K., Diaz, A., King, A., Willing, E., Connolly, M., Lindsay, D. & Garvey, G. (2021). Wellbeing of Indigenous Peoples in Canada, Aotearoa (New Zealand) and the United States: A Systematic Review. *International Journal of Environmental Research and Public Health.18*(11), 5832.

https://doi.org/10.3390/ijerph18115832

https://doi.org/10.3390/ijerph18157745

#### Chapter 4

**Gall, A.,** Diaz, A., Garvey, G., Anderson, K., Lindsay, D. & Howard, K. (2021). An exploration of the sociodemographic and health conditions associated with self-rated wellbeing for Aboriginal and Torres Strait Islander adults. *BMC Research Notes.* 14, Article 386. <a href="https://doi.org/10.1186/s13104-021-05794-3">https://doi.org/10.1186/s13104-021-05794-3</a>

#### Chapter 5

**Gall, A.,** Diaz, A., Garvey, G., Anderson, K. & Howard, K (2021). Self-reported wellbeing and health-related quality of life in Aboriginal and Torres Strait Islander people during the COVID-19 pandemic. *Australian and New Zealand Journal of Public Health*, online. <a href="http://doi.org/10.1111/1753-6405.13199">http://doi.org/10.1111/1753-6405.13199</a>

#### **Additional Related Publications**

Anderson, K., **Gall, A.,** Butler, T., Arley, B., Howard, K., Cass, A. & Garvey, G. (2020). Using Web Conferencing to Engage Aboriginal and Torres Strait Islander Young People in Research: A Feasibility Study. *BMC Medical Research Methodology, 21*, 172. https://doi.org/10.1186/s12874-021-01366-y

## **List of Figures**

#### Chapter 1:

Figure 1: Example use of the Yerin Dilly Bag Model

Figure 2: The Yarning research process

Figure 3: Definition of wellbeing as proposed by Dodge and colleagues

#### Chapter 5:

Figure 1: Abridged Timeline of the COVID-19 Pandemic in Australia

#### Chapter 6:

Figure 1: Example Statement

Figure 2: Example Field Notes

Figure 3: Error coding definitions used to score the transcripts

#### Chapter 7:

Figure 1: Fabric of Aboriginal and Torres Strait Islander wellbeing

## **List of Tables**

#### Chapter 6:

Table 1: Participant characteristics (N=17)

Table 2: Frequency and type of error identified in the statements in the draft WM2Adults tool listed by participant

Table 3: Frequency and type of error identified in the 49 draft statements (n=17)

#### Chapter 7:

Table 1: Summary of themes and sub-themes of wellbeing identified in Chapter Three systematic literature review, by country

## **Abbreviations**

AQoL-4D Australian Quality of Life (4 Dimension) measure

COVID-19 disease associated with novel coronavirus SARS-COV-2

HREC Human Research Ethics Committee

HRQoL Health related quality of life

NHMRC National Health and Medical Research Council

QoL Quality of Life

TACTICS Targeted Approaches To Improve Cancer Services

VAS Visual Analogue Scale



# Chapter 1 Introduction



#### 1.1 Chapter Overview

Globally, there is increasing interest in understanding and measuring wellbeing across different populations, cultures, and contexts. Current thinking suggests that while there are some universal aspects of wellbeing, there are key differences in the experience, causes and correlates of wellbeing between cultures [1]. In recognition of these differences, measures of wellbeing and quality-of-life have been, and are being, developed for specific cultural groups and contexts [2-5]. Despite the rapid developments in this field, only limited progress has been made in understanding and measuring wellbeing for Indigenous people [6]. Existing indicators of wellbeing are predominantly based on Western biomedical models and understandings of health [6]. Instruments used to measure wellbeing of Indigenous peoples should be culturally appropriate and safe, and include dimensions that are informed by their own values and preferences [6]. In order to make progress in this area, there is a pressing need for a comprehensive understanding of the domains and indicators of wellbeing that reflect Indigenous ways of being, knowing and doing [7, 8]. This chapter examines wellbeing from the perspectives of Aboriginal and Torres Strait Islander peoples and Indigenous peoples more broadly.

This thesis is an integral part of a larger Australian project, the What Matters 2Adults Study, that aims to develop a wellbeing measure for Aboriginal and Torres Strait Islander adults, underpinned by their values and preferences [9]. Before reviewing the academic literature, Section 1.2 outlines the definitions, principles and concepts that have underpinned the work reported here, including those that guide research with Aboriginal and Torres Strait Islander peoples. Wellbeing is a complex concept; understanding wellbeing for Aboriginal and Torres Strait Islander peoples requires an understanding of the broader social, cultural and historical context. To this end, relevant demographics and historical context are discussed in Section 1.3 to enable a socially and historically contextualised understanding of wellbeing for Aboriginal and Torres Strait